

# Cancer Registry ABSTRACT

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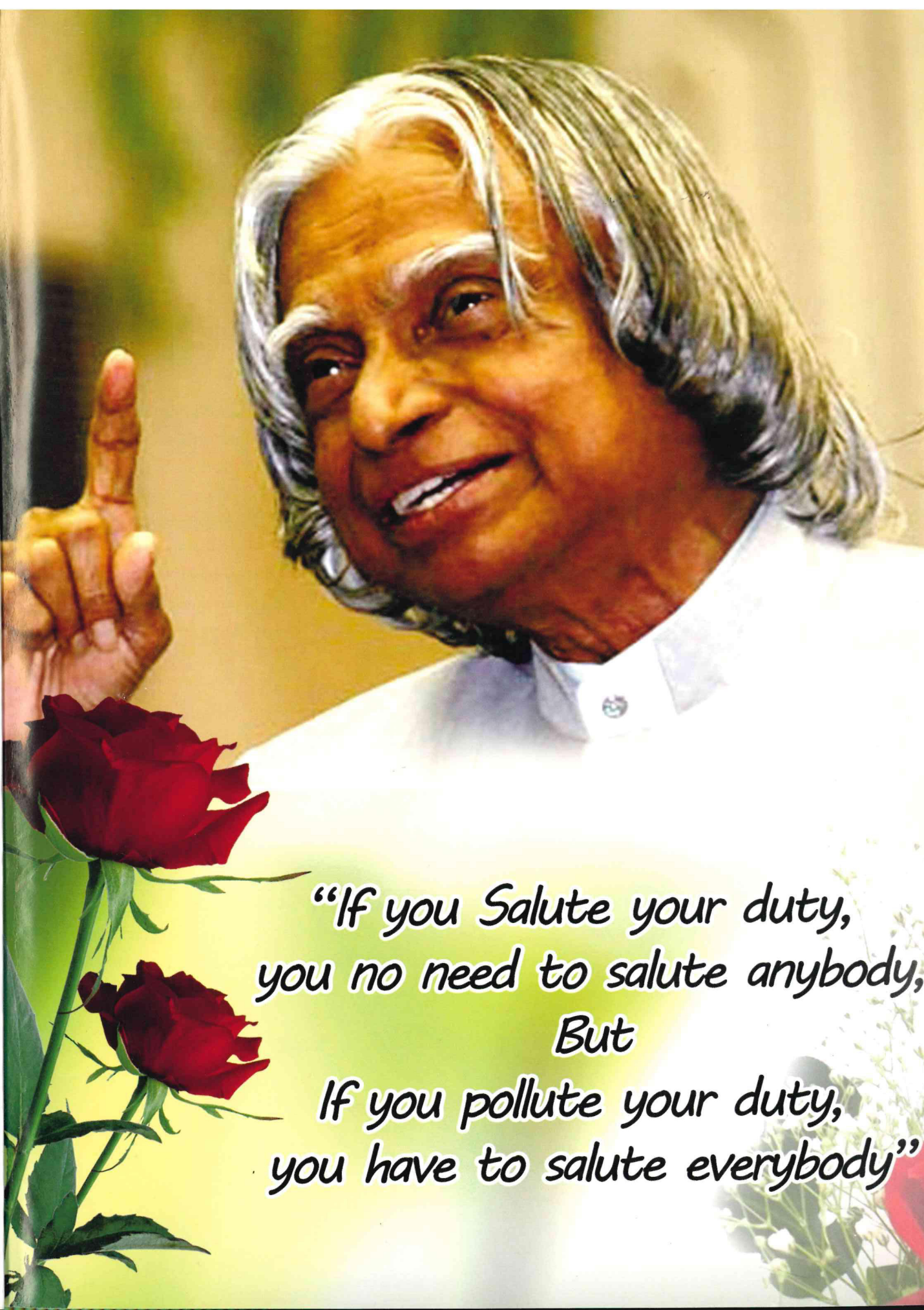
## CRAB

**NATIONAL CENTRE FOR DISEASE INFORMATICS AND RESEARCH  
NATIONAL CANCER REGISTRY PROGRAMME**

*Indian Council of Medical Research*

*Map showing network of centres that are transmitting data*





*"If you Salute your duty,  
you no need to salute anybody,  
But  
If you pollute your duty,  
you have to salute everybody"*

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**Dr. Soumya Swaminathan, MD**  
**Director General,**  
**Indian Council of Medical Research,**  
**Secretary, Department of Health Research**

Dr. Soumya Swaminathan, MD, has taken over as Director General, ICMR & Secretary, Department of Health Research (Ministry of Health & Family Welfare) **DHR** on 17<sup>th</sup> August 2015.

**Dr. Swaminathan is the second woman head of ICMR in 100 years history.**

**Dr. Swaminathan replaces Dr. V M Katoch who retired in March 2015.**

Her vast experience in health research and research administration **will henceforth guide the NCDIR and NCRP.** Prior to this assignment, Dr. Swaminathan was Director, National Institute for Research in Tuberculosis (NIRT) in Chennai since 2012.

Dr. Swaminathan is a medical graduate (MBBS) from AFMC, Pune and MD in Pediatrics from AIIMS, New Delhi. She received fellowship in Neonatology and Pediatric Pulmonology at the Children's Hospital of Los Angeles, University of Southern California, USA and a Research Fellowship in the Department of Paediatric Respiratory Diseases, University of Leicester, UK. She joined the Tuberculosis Research Centre, Chennai in 1992 and has spent the past 23 years in health research. Her research interests include pediatric and adult tuberculosis, epidemiology and pathogenesis, the role of nutrition and HIV-associated TB. She also served for 2 years as coordinator, Neglected Tropical Diseases at TDR.

She holds many professional memberships such as International Union Against Tuberculosis and Lung diseases (Chair, HIV Section 2009-2011); Member, International Scientific Advisory Expert Group for the All-Party Parliamentary Group on Global Tuberculosis (APPG TB), UK; and Member, Third World Organization of Women Scientists. She also serves as a Member, UNAIDS Expert Panel and Member, Scientific and Technical Advisory Group, WHO Stop TB department. In addition, she serves on many national committees of the health ministry, DBT, DST and national institutes like AIIMS and Indian Institute of Science.

Dr. Swaminathan has the distinction of being awarded the President's Gold Medal at the undergraduate level for the best all round outgoing student of the year 1980, the ICMR **Kshanika Oration Award** in 2008, Tamil Nadu Science and Technology award in 2012 and is a Fellow of three of India's science academies.

A new road map is on cards with focus on strengthening research administration.

**NCDIR - NCRP heartily welcomes  
 Dr. Soumya Swaminathan**

.....

**Excerpts from an interview with Nature India on 22/08/2015:**

My vision for ICMR is to make it a dynamic,

cutting edge research organization, responding to urgent public health needs of the country and providing sound, evidence-based advice to the ministry on programmes and policy issues. We will develop a roadmap for ICMR for the next 5 years.

Projects that have fulfilled or outlived their mandate will be closed and a process of internal review and re-prioritization will be undertaken. There is a need for long-term projects to understand the epidemiology, prevention and treatment of diseases affecting the Indian population. I will focus on leveraging the strengths of our existing institutions, building capacity where it is lacking, rewarding excellence, increasing networking and enhancing collaboration with national and international science agencies.

Further, there is a need to establish a mechanism for supporting the translation of early leads into products and then performing a rigorous evaluation of indigenously developed diagnostics and devices that would help make health care more affordable. ICMR will ensure that while the rights of patients and study participants are protected, the approval process does not become a barrier to conducting clinical trials. As the political environment in the country wants to bring affordable health care to its citizens, I do not anticipate any hurdles for these activities.

### **The main challenges expected:**

The challenge now is to focus on key research priorities that will have an impact on public health in the short to medium term. ICMR needs to focus on health outcomes and impact at the population level, rather than mere outputs in the form of publications and patents. We have a high burden of diseases like TB, malaria, dengue and chikungunya, emerging and re-emerging viral diseases. Having conquered polio, India could aim to eliminate measles in the next few years. A "mission mode" of operation may be needed to achieve some of these objectives. Another immediate challenge is to expand capacity to undertake high quality research in our medical schools and universities.

### **Research supported by ICMR:**

We will aim at translating the knowledge that has already been generated into products, tools and strategies and then implementing it in partnership with the health ministry. I would like ICMR to concentrate more on "implementation science", focusing on our major public health problems for which it will be essential for ICMR to collaborate both with academia and industry.

### **Change in the administrative structure of ICMR?**

ICMR needs better infrastructure, more autonomy and much greater levels of funding. Research administration will need strengthening too, with greater transparency and timeliness in the way grants are reviewed and funded. We will follow up the earlier review committee's recommendations<sup>1</sup> for reform. We will use e-governance to help speed up many processes.

### **References:**

1. Jayaraman, K. Under scrutiny, India's medical research council faces review. *Nat. Med.* 19, 386 (2013)  
doi:10.1038/nm0413-386a  
<http://dx.doi.org/10.1038/nm0413-386a>



**Dr. Vishwa Mohan Katoch**

Dr Vishwa Mohan Katoch, officially retired from Government service as Director General, ICMR, Secretary, Department of Health Research (DHR) in March, 2015. Our association with Dr. Katoch started in 2008 when he was appointed as DG, ICMR and his highly productive guidance lasted for 6 years.

As DG, ICMR, the NCRP had spectacular progress from less than 10 Population Cancer Registries to evolve into a massive 29 PBCRS, 29 HBCRS and several cancer related research activities.

Dr Katoch was instrumental in evolving and developing the unique National Centre for Disease Informatics-NCDIR. And bring under its research banner some of the most difficult diseases like CVD, Stroke, Diabetes and Cancer under the newly formed NCDIR.

As DG, ICMR, the NCDIR received active administrative support and could make remarkable head way in developing e-transmission methods necessary for health research activities.

Substantial scientific progress has been achieved under his leadership by NCDIR. Not only in increasing the number of cancer registration centres, but also expanding connected registry activity like Pattern Of Care and Survival of several forms of cancers in different parts of the country which would herald in developing a uniform pattern of disease management in India.

## NATIONAL CENTRE FOR DISEASE INFORMATICS AND RESEARCH (Indian Council of Medical Research), Bangalore

Dr. A. Nandakumar MD. Director NCDIR

### Highlights of Activities

1. The First Report of **Development of an Atlas of Cancer in Punjab State** for the years 2012-2013 completed. The First report for the combined years 2012 and 2013 for districts and centres gives an idea of the prevailing patterns of cancer by district in Punjab State. Under this project, a cost-effective design and plan using advances in modern electronic information technology, was conceived, to collate and process relevant data on cancer.  
<http://icmr.nic.in/icmrnews/PUNJAB%20PCA%20-%20Chapter%20Complete.pdf>
2. The **Patterns of Care and Survival Studies** in Cancer Breast, Cervix and Head & Neck Cancers for the year 2006-2008 is under publication. The main findings are:
  - In locally advanced cervical cancer significant survival benefit was observed when treated with a combination of radiation with cisplatin than radiation alone- The same observation was seen in patients with locally advanced cancers of the oro and hypopharynx.
  - In cancer of the breast a high proportion of early stage patients had mastectomy with poorer survival compared to breast conserving surgery which is the usual practice.
3. Development of Software Applications Programme with specific modules is a primary mandate of the NCDIR and as part of Translational Research is a major activity of the centre. An overview of the applications is given immediately after this section.
4. The report of North East Cancer Atlas (other than areas where PBCRs exist) has been prepared.
5. **Population Based Cancer Registry at Patiala** –The data for 2011-2012 has been finalised. Data has been published by PBCR Patiala in form of a report.
6. **Population Based Cancer Registry at Hyderabad** – Two visits have been made by NCDIR staff in February 2014 and May 2015 to closely monitor the functioning of PBCR Hyderabad. In the second visit NCDIR staff was also accompanied by a team of senior staff from older PBCRs to advise the new registry on its working and to provide solutions.
7. **Review – PBCRs** As per the PBCR Review system formulated by NCDIR, with the purpose of improvement in various issues of PBCR i.e. coverage, timely data submission, data quality etc. A detailed study of each registry has been carried out and a document has been prepared.
8. **Making cancer a Notifiable Disease-National Document** – A draft document on the above has been prepared by NCDIR and has been sent to ICMR headquarters in August 2014 for further approval.
9. Paper on retinoblastoma published.
10. Visited Kerala State to select Model Rural Health Research Units and had meeting with the Secretary (Health),

Dept. of Health and Family Welfare,  
Government of Kerala on 4 August  
2014.

11. To verify the completeness of data obtained through Punjab cancer atlas we have conducted a cross-sectional survey of almost 1,00,000 individuals (around 25000 families) in four districts of Malwa region in Punjab.

Those are, Muksar, Batinda, Mansa, and Barnala. During the same study we have planned to get the estimate of magnitude of other three NCDs, i.e., diabetes, CVD, and stroke.

### Network of NCDIR-NCRP:

#### Cancer

Projects	Centres Registered	Centres Registered & Transmitting Data	oneyear's complete data	≥ 500 cases	≤ 500 cases
Population Based Cancer Registries	29	29	29		
Hospital Based Cancer Registries including RCCs	29	29	29		
Patterns of Care and Survival Studies (inclu. HBCRs and RCCs)	32	32	32		
Cancer Atlas in North East Region	15	15	15		
Punjab Cancer Atlas	154	58	34		
Haryana Cancer Atlas	96	0	0		
Centres using HBCR Data Management Software	80	57	20	33	25
Pathology Software Module	151	34		4	30
Radiotherapy Software Module	25	3		1	2
<b>Total</b>	<b>611</b>	<b>257</b>	<b>159</b>	<b>38</b>	<b>57</b>

\*Sources of registration of PBCRs

#### Diabetes, CVD and Stroke

	Network	Centres Registered	Data Sets
1	A National Model to Monitor the Magnitude of Non-Communicable Diseases (Diabetes, CVD, Stroke, Cancer) in India with an intention to examine the Possibility of Developing Population Based Diabetes, CVD, Stroke and Cancer Registries Involving Medical Colleges Through Primary Health Care Setup	106	0
2	Dev. of Stroke Registry in India	55	0
	<b>Total</b>	<b>161</b>	<b>0</b>

The following two pages provide the state-wise numbers of registered centres who are transmitting data in the form of a table and location of the centres in a map.

## STATE WISE COLLABORATING CENTRES

Sl. No.	State	PBCR	HBCR (incl. RCCs)	POCSS	HBCRDM Registered	PCA - Registered & Transmitting	NE Atlas	Total
1	Jammu & Kashmir		2	3				5
2	Himachal Pradesh		1					1
3	Punjab	1		2		52		55
4	Chandigarh (UT)		1	1		2		4
5	Uttarakhand				1			1
6	Haryana		1	2	4	1		8
7	Delhi (UT)	1	1	2	4	4		12
8	Rajasthan		1	1	2	1		5
9	Uttar Pradesh		2	1	2			5
10	Bihar		1	1	3			5
11	Sikkim	1						1
12	Arunachal Pradesh	2					2	4
13	Nagaland	1			1		2	4
14	Manipur	1	1	1			1	4
15	Mizoram	1	1	1				3
16	Tripura	1	1	1			2	5
17	Meghalaya	1					3	4
18	Assam	3	2	3	3		6	17
19	West Bengal	1	1		3		1	6
20	Jharkhand							0
21	Odisha		1	1	5			7
22	Chhattisgarh		1	1				2
23	Madhya Pradesh	1	2	1	2			6
24	Gujarat	2	1	2				5
25	Daman & Diu (UT)							0
26	Dadra & Nagar Haveli (UT)							0
27	Maharashtra	7	2	3	3			15
28	Telangana	1	1	1	1			4
29	Andhra Pradesh				2			2
30	Karnataka	1	1	5	25			32
31	Goa							0
32	Lakshadweep (UT)							0
33	Kerala	2	1	2	10			15
34	Tamil Nadu	1	2	3	6			12
35	Puducherry (UT)		1					1
36	Andaman & Nicobar Islands (UT)							0
<b>Total</b>		<b>29</b>	<b>29</b>	<b>38</b>	<b>77</b>	<b>60</b>	<b>17</b>	<b>250</b>

PBCR = Population Based Cancer Registries

HBCR = Hospital Based Cancer Registries

POCSS = Patterns of Care and Survival Studies

HBCRDM = HBCR Data Management Software

PCA = Dev. of an Atlas of Cancer in Punjab State

NE Atlas = Dev. of an Atlas of Cancer in North East Region

Apart from the above, 96 centres have registered under the project on Dev. of an Atlas of Cancer in Haryana, 137 centres have registered for Pathology Software Module, 17 centres have registered for Radiotherapy software Module, 55 centres have registered under Dev. of Stroke Registry in India and 106 centres have registered under National Model to Monitor the Magnitude of Non-Communicable Diseases (Diabetes, CVD, Stroke, Cancer) in India with an intention to examine the Possibility of Developing Population Based Diabetes, CVD, Stroke and Cancer Registries Involving Medical Colleges Through Primary Health Care Setup.

**Registries contributing to Cancer Incidence in Five Continents Vol. X**

1. Africa – 8 registries
2. Central and South America – 25 registries
3. North America – 66 registries
4. Asia – 63 registries
5. Europe – 118 registries
6. Oceania – 10 registries
7. Total – 290 registries

**Eds: Ed. D. Forman, F. Bray, D. H. Brewster, C. Gombe Mbalawa, B. Kohler, M. Pineros, E. Steliarova-Foucher, R. Swaminathan and J. Ferlay; IARC Scientific Publications No: 164**

**Indian Cancer Registries in Cancer Incidence in Five Continents Vol. X**

Place of Registry	Year	No. of cases		AAR	
		M	F	M	F
Bangalore	2005-2007	8356	10208	113.5	137.7
Barshi – Paranda, Bhum	2003-2007	602	638	48.1	54.6
Bhopal	2004-2007	2511	2426	110.2	109.2
Chennai	2003-2007	11580	12481	114.9	123.8
Dindigul, Ambilikkai	2003-2007	2580	3378	54.6	68.6
Karunagappally	2003-2007	1220	996	116.6	80.4
Mizoram	2003-2007	3101	2466	197.1	159.1
Mumbai	2003-2007	24661	26116	97.9	105.5
New Delhi	2003-2007	31038	28895	119.7	118.4
Poona	2003-2007	6218	6914	83.3	89.9
Sikkim State	2003-2007	910	837	96.7	108.3
Trivandrum	2003-2007	2108	2151	132.3	114.9

## Registries reporting incidence data to Cancer Incidence in 5 continents

Place	Volumes-(I-X)									
	I	II	III	IV	V	VI	VII	VIII	IX	X
Aurangabad										
Ahmedabad						*		*		
Bangalore					*	*	*	*		**
Barshi Rural							*			**
Bhopal										**
Chennai					*	*	*	*	*	**
Delhi								*	*	**
Kollam #							*	*	*	**
Mizoram										**
Mumbai		*	*	*	*	*	*	*	*	**
Nagpur					*			*	*	
Pune				*	*			*	*	**
Sikkim										**
Trivandrum							*	*	*	**
* Data published      ** Data accepted										

# -Till Vol. IX only the Karunagappally Taluk's population cancer incidence data was published. In Vol. X the entire Kollam district's population is covered.

The Dindigul Cancer Registry (Non ICMR) reports also have appeared in Cancer Incidence in 5 Continents, Vol. X

## Software Development at NCDIR

### Hospital Based Cancer Registry (HBCR) – Pattern of Care and Survival Studies (POCSS) Data Entry

Many of our Hospital Based Cancer Registries are involved in the project of Patterns of Care and Survival studies and the newly added Regional Cancer Centres are contributing data to both HBCR and POCSS. To make it simpler and user friendly, it is better to have combined software for HBCR and POCSS data entry. When a patient is registered for HBCR with the site of Ca Breast, Ca Cervix and Head & Neck cancer the same patient is getting registered for POCSS also. Here a single patient is saved only once. Initially the HBCR staff can finish the data entry and POCSS staff can complete the detailed information on treatment and followups.

Internet based software is developed and deployed in [www.hbcrindi.org](http://www.hbcrindi.org) website. RCCs and centres contributing data to both HBCR and POCSS have been given login id and password to access the software.

#### · HBCR-HIV Data Entry

All India Institute of Medical Sciences, New Delhi wanted to capture patients having cancer and HIV for their research purpose. In this regard the online HBCR data entry software had been modified for their data entry with special user id and password. Using this credential the registry can capture information on HIV. Export option is provided to get their data online.

#### · Onset Young Diabetes Registry data entry software.

Web based data capture software was developed for Onset Young Diabetes Registry as per the requirements given to NCDIR-NCRP from the technical coordinating unit of YDR, AIIMS, New Delhi.

#### · Independent modules –

- o Pathology Data Entry with outputs/reports
- o Radiotherapy Data Entry
- o Surgical Oncology Data Entry
- o Medical Oncology Data Entry

The software modules for Pathology, Radiotherapy, Medical and Surgical Oncology were developed to record details on cancer patients attending various departments in a hospital. These modules are available online through the NCRP portal. ([www.ncrpindia.org](http://www.ncrpindia.org)). Each of the above modules are cancer site specific and has been structured in three levels for data entry- Basic, Basic+ and Advanced, with option to feed information on patient's clinical history, diagnosis and treatment. These modules are independent, and have the facility to form linkages among the departments. Thus the data collected can be organized to create a hospital based cancer registry. The patient records can be recorded in a paperless manner with option to print copies. Administrative reports and tables for research are additional features.

Centres can register for the above modules online through [www.ncrpindia.org](http://www.ncrpindia.org) or [www.ncdirindia.org](http://www.ncdirindia.org). Based on their request user id and password are generated and sent to centres for their routine use. As on now 140 centres have registered and given access to pathology software. 13 of them are using for their routine work. 24 centres had registered for radiotherapy and is used by a single centre for the routine work. Few centres have registered for medical oncology and surgical oncology, but yet to start using.

**E-Monitoring**

- a. Online Data status for RCCs and budget estimation
- b. Online Data Status - HBCRs, POCSS, Pathology, Radiotherapy etc.
- c. Online registration for independent modules
- d. Coreform stock
- e. HBCR File Maintenance
- f. QC Management
- g. Data Entry Operators daily data entry count

**Ongoing Software development**

- a. Dynamic data entry
- b. JIPMER - RT Module

**Admin Software**

Application for NCDIR-Payroll for permanent staff

This application is used to maintain the payroll of the NCDIR staff. Using this application salary can be generated every month for all the employees, pay bills, Salary Bills, Salary Slip, etc. Bank letter can be generated to credit salary to the employees account automatically. Administrator can generate each employee's month wise yearly salary statement with earnings and deductions. Options are there to generate monthly NPS statement. DA arrears and NPS arrears statement can be generated whenever it is required. Each employee has the option to print salary slip using their credentials.

This software has been functioning since July 2014.

**File Movement for Administrative Department**

File movement application is used to track the

current location of the physical file and its status. When the file moves from one user to another, a notification is executed to the person receiving the file from the person who sent the file. Through this application it is easy to find the pending file and its location. Daily email will be sent to administrator regarding the pending files.

This software has been functioning since July 2014.

**Annual Maintenance****Contract(AMC) Management**

This module is used to maintain AMC details. Whenever a new AMC is placed it should be entered into the software. Notification will be displayed for the AMCs nearing to expiry nearly 4 months before on the home page of the Administrator.

**Application for Biometrics****Attendance Report Generation**

Application is developed for the employees attendance register with in and out timing. Monthly/Periodical report can be generated for administrative purpose.

Developed application module to maintain Inward and Outward formation which is in the form of mails, posts etc.(To undergo testing)

Payroll for Project Staff maintain payment information of all project staff (ongoing)

**Population Based Cancer Registry****PBCRDM 2.1.1: New version of PBCRDM 2.1**

PBCRDM 2.1 had separate database tables for data entry and processing section. This required the user to transfer data from data entry to the processing section every now and then. An improvement in the software was done to merge both the sections and eliminate this step.

The hard copy of incidence proforma underwent changes to include 11 new fields.

The new version PBCRDM 2.1.1 was created for registries and with the above changes in database, forms and reports. This version has been deployed at Bangalore, Sikkim and Bhopal PBCR for testing and suggestions so that the same can be deployed at the remaining 21 PBCRs using the offline version.

**Data Entry Programme (www.pbcrintia.org):** PBCRs having good internet speed have shown interest in using a web based application for the data entry and processing of their data. Hence a data entry Programme with basic quality checks was developed on [www.pbcrintia.org](http://www.pbcrintia.org).

- ü Incidence Data Entry access has been given to Kamrup Urban, Hyderabad, Barshi Expanded and Malabar PBCRs.
- ü Mortality Data Entry complete access has been given to Kamrup Urban, Hyderabad, Barshi Expanded and Malabar PBCRs.

**Dynamic table generation (www.pbcrintia.org):** PBCRs needed to generate their own tables from the data submitted by them. Thus the Dynamic table generation was developed on [www.Pbcrintia.org](http://www.Pbcrintia.org). The data of yester years without any confidential information have been uploaded online. Once requested by a registry the finalized data is uploaded for the registries to access their tables. Access is given to Mumbai, Mizoram, Barshi Rural, Sikkim and Kollam PBCRs.

**Book Report Generator:** While preparing the book report on 'Three year report of Population Based Cancer registries 2009-2011', it was felt that a programme should be developed to generate the tables of all the PBCRs in the published format to reduce manual work in future. Thus an application to dynamically generate book report for use in the NCDIR Intranet has been developed.

#### Other software development:

- **Stroke Registry:** A Data Entry form with basic checks and search options developed in a web based application.
- **Punjab Cancer Atlas Survey:** This is a survey on verification of completeness of data obtained through Punjab Cancer Atlas through a survey with the additional objective of knowing the magnitude of diabetes, CVD and stroke in the Malwa region of Punjab. A data entry software in the intranet version is developed for use at NCDIR to capture all the data collected under this survey which covers three districts, Mansa, Bhatinda, Muktsar and Barnala in Punjab.

#### Publications:

##### By National Centre for Disease Informatics and Research-NCRP, Bangalore:

1. Ramnath Takiar, Sathish Kumar Krishnan, Varsha Premchandbhai Shah. A Model Approach to Calculate Cancer Prevalence from 5 Years Survival Data for Selected Cancer Sites in India – Part II, Asian Pac J Cancer Prev, 2014, 15 (14), 5681-5684
2. Ramnath Takiar, Sathish Kumar. Pattern of Reproductive Cancers in India. Asian Pac J Cancer Prev 2014,, 15 (2), 599-603
3. Rangamani S, Satish Kumar K, Manoharan N, Julka PK, Rath GK, et al., Paediatric Retinoblastoma in India: evidence from the National Cancer Registry Programme (Accepted for publication in the Asian Pacific Journal of Cancer Prevention)
4. T. Rahman, K Ahmed, Jagannath D Sharma, A Das. Solitary fibrous tumor of the orbit: A rare entity. Indian Journal of Cancer 2014 (in press)

**By the Network of Cancer Registries under NCRP:**Ø **Delhi – PBCR**

1. Evaluation of the Surveillance System for Tobacco-Related Cancers in Delhi, India.

Ø **Ahmedabad – PBCR**

## Cancer Registry Report

1. Rural Cancer Registry for the Year 2011; April, 2014
2. Population Based Cancer Registry - Ahmedabad Urban Agglomeration Area for the year 2011; April, 2014

Ø **Guwahati – HBCR**

1. Manigreeva Krishnatreya, Gayatri Gogoi, Jagannath D Sharma, Amal C Katak. Pattern of cancers in select ethnic groups of Assam: A retrospective study. *International Research Journal of Social Sciences*. 2014, Volume 3, issue 4 (In press).
2. Munlima Hazarika, Manigreeva Krishnatreya, Cidananda Bhuyan, Bhargab Jyoti Saikia, Amal Chandra Katak, Pintu Nandy, Monalisha Hazarika, Partha Sarathi Roy. Overview of Childhood Cancers at a Regional Cancer Centre in North-East India. *Asian Pacific Journal of Cancer Prevention*, 2014, 15: 7817- 19.
3. Tashnin Rahman, Jagannath D Sharma, M Krishnatreya, A C Katak. Basaloid squamous carcinoma of skin associated with xeroderma pigmentosum in an eight year old child: A rare entity. *Indian Journal of Dermatology*. 2014 (in press)
4. T.Rahman, K Ahmed, Jagannath D Sharma, A Das. Solitary fibrous tumor of the orbit: A rare entity. *Indian Journal of Cancer* 2014

### **Paediatric Retinoblastoma in India: Evidence from the National Cancer Registry Programme**

Sukanya Rangamani, Krishnan SathishKumar, N Manoharan, Pramod Kumar Julka, Goura Kishor Rath, Viswanathan Shanta, Rajaraman Swaminathan, Ranganathan Rama, Karabi Datta, Syamsundar Mandal, Shravani Koyande, Vinay Deshmane, B Ganesh, Shripad D Banavali, Rajendra A Badwe, C Ramesh, Lingappa Appaji, Ambakumar Nandakumar

**Abstract**

**Background:** Globally, retinoblastoma is the most common primary intraocular malignancy occurring in children. This paper documents the recent incidence rates of retinoblastoma by age and sex groups from the Population Based Cancer Registries (PBCRs) of Bangalore, Mumbai, Chennai, Delhi and Kolkata using the data from the National Cancer Registry Programme.

**Materials and Methods:** Relative proportions, sex ratio, method of diagnosis, and incidence rates (crude and age standardized) for each PBCR and pooled rates of the five PBCRs were calculated for the years 2005/06 to 2009/10. Standard errors and 95% confidence limits of ASIRs by sex group in each PBCR were calculated using the Poisson distribution. Standardised rate ratios of ASIR by sex group and rate ratios at risk were also calculated.

**Results:** The maximum retinoblastoma cases were in the 0-4 age group, accounting for 78% (females) and 81% (males) of pooled cases from five PBCRs. The pooled crude incidence rate in the 0-14 age group was 3.5 and the pooled ASIR was 4.4 per million. The pooled ASIR in the 0-4, 5-9 and 10-14 age group were 9.6, 2.0 and 0.1 respectively. The M/F ratio in Chennai (1.9) and Bangalore PBCRs (2.0) was much higher than the other PBCRs. Among the PBCRs, the highest incidence rate in 0-4 age group was found in males in Chennai (21.7 per million), and females in Kolkata (18.9 per million). There was a distinct variation in incidence rates in the PBCRs in different geographic regions of India.

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### Dr. Krishnan Nair Remembers!

"At this time it is essential to remember the sustained efforts of the members who contributed to the formation and functions of the National Cancer Registry Programme Registries in 1982. Dr. T. Hirayama and Dr. C S Meur guided us. Dr. Usha K Luthra, Dr. D J Jussawallah, Dr. Krishna Bhargava, Dr. N C Mishra, Dr. B D Gupta, Dr. V Shanta, Dr. S Krishnamoorthy, Dr. L D Sanghvi and from ICMR Dr. A K Prabhakar, Dr. Kishore Chowdary, Dr. D K Jain and Dr. Ravi Rangachary contributed substantially."

Dr. M Krishnan Nair was the Founder, Director, Regional Cancer Centre, Thiruvananthapuram. The first HBCR of ICMR-NCRP in Kerala was established in RCC, TVM in 1982 under Dr. M Krishnan Nair as PI.

# EDITORIAL

*Note: Dr. Manjith Singh Bal was the designated editor for the current volume of CRAB. Due to his retirement from Patiala Medical College, the work of editing the CRAB Vol 20 was entrusted to Mr. P Gangadharan.*

**P. Gangadharan**

HOD Cancer Registry, Amrita Institute of Medical Sciences Kochi  
Member, Scientific Advisory Committee, NCDIR  
Member, Research Area Panel on Cancer, NCDIR  
Member, Steering – Monitoring Committee, NCRP

**NCRP Progress:**

**Growth from a 3+3 to 29+29 in 29+3 years is the development summary matrix of NCRP.**

Besides these, the several critical studies organized in the national level on management and outcome of certain cancers, indigenous development of recording and e-transmission process of cancer and their pattern seen in different parts of the country along with quality checks and summarization is an exceptional outcome of the NCRP programme by its dedicated team which worked under the guidance of the Director-in-charge of NCDIR Dr. A. Nandakumar. More work effort is envisaged with the development of activities of the newly joined HBCRs.

The standardization of information collection and processing implemented will be highly beneficial for undertaking deeper studies in epidemiology, survival studies and etiology of the disease. The currently

developed process has to be meticulously followed and expanded which will then be the master tool for a cancer surveillance mechanism and which can evolve into the National Surveillance System for Cancer (NSSC) of India.

The spectrum and variations of the burden and pattern of cancer seen in our country is a subject matter which required deep collaborative multi-regional studies. Answers should be sought for

1. The excess of Gall bladder cancers among females and in northern states compared to southern states
2. Higher incidence of thyroid cancers in Kerala and in women compared to very low incidence in central India and in men

3. Low incidence rates of stomach cancers in Gujarat compared to the high rates seen in Aizawl
4. In certain places why the lung cancer incidence in women is equal to that seen in men

The current issue of CRAB depicts varied life style practices of the people in different parts of the country, the habits, work, living environment, food preservation practices and occupational exposures. This issue also shows the registry workers hard work the terrain to reach the work spots and the varying efforts required to obtain the required information for the registries.

There is a special write up regarding making cancer a Notifiable disease. A beginning has been made in certain states. This has to develop and produce evidence for scientific studies which would require adequate quality and quantity of information thus reported.

In almost all Low and Middle Income Countries, the PBCR would essentially depend on an active registration process in which information collection is made through visiting various sources from where information on cancer and cancer patients can be obtained and recorded. Such sources mainly are hospitals, path laboratories and official mortality records. A standardized system of maintenance and processing of information from the above sources is essential to provide quality information for the study of burden and pattern of cancer in the community. This can be achieved only through organizing standardized Hospital Based Cancer Registry.

Such hospital based data and information recorded by a hospital registry mode would contribute immensely for quality enhanced cancer registry data collection and output. Unfortunately the information collection,

storage and retrieval are practiced in many institutions including medical colleges even without the standardized discipline of an HBCR Methodology. The effort now for organizing and standardizing HBCRs taken up by NCRP in several centres would provide more quality information on cancer in India and provide immense opportunities for the study of Pattern of Care and Survival which would evolve into optimal care of the cancer patient.

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## GUEST EDITORIAL



Dr. Prakash C. Gupta .MSC.PhD  
 Member, Scientific Advisory Committee, NCDIR  
 Member, Research Area Panel on Cancer NCDIR  
 Member, Steering – Monitoring Committee, NCRP

## Areca Nut use and Oral cancer and pre cancer in India

*Prakash C. Gupta<sup>1</sup> and Cecily S. Ray<sup>11</sup> Healis Sekhsaria Institute for Public Health, Navi Mumbai*

**Increasing Incidence of Mouth Cancer:** A recent report of the National Cancer Registry Program in India showed that highly significant increases in incidence rates of mouth cancer in men had occurred in several population based cancer registries during the period of data availability up to 2010 [NCDIR-NCRP, 2013]: Bhopal, Mumbai, Delhi, Dibrugarh and Ahmedabad

(Rural)(Table 1). In addition, a recent analysis of mouth cancer data from the Ahmedabad urban population based registry also found a steep increase in mouth cancer incidence in men from 1995 to 2010; there, incidence rates age standardised and adjusted to world population increased from 9.6 in 1985 to 25.4 in 2010 with the increase being steeper in younger age groups [Gupta et al., 2014].

**Table 1: Mouth cancer incidence in men in two time periods in selected old and new population based cancer registries in India.**

Registry	Year 1	Incidence Rate	Year 2	Incidence Rate
Bhopal, Madhya Pradesh	1988	5.9	2010	11.2
Delhi	1988	3.0	2010	7.1
Mumbai, Maharashtra	1998	5.5	2010	8.3
Ahmedabad Rural, Gujarat	2004	6.5	2010	12.7
Dibrugarh, Assam, Assam	2003	5.7	2010	10.2

**Association with Areca Nut Consumption:**

All these registries showing increases in mouth cancer incidence in men are located in states with a high prevalence of consumption of

tobacco products containing areca nut, mostly *gutka* and *mawa* according to the report of the Global Adults Tobacco Survey [IIPS &

MOHFW, 2010]. Areca nut consumption has nearly doubled in India during 1991-2001 to 2009-10, from 2.5 to 5.2 lakh tons and is growing about 5% each year [Kammardi et al., 2012], owing to intense marketing efforts of the industries manufacturing packaged products.

The traditional way of consuming areca nut in India was with betel leaf (called betel quid or *pan*) and tobacco began to be added since its introduction in India by the Portuguese in the 1600s [Reddy and Gupta, 2004]. Areca nut consumption today is mostly in dry flavoured packaged form (pan masala, gutka, mawa, kharra) and has become the most common way of consuming areca nut since the mid-1970s. In 2010 in India, these were used by 13.1% of men and 2.9% of women, while betel quid was used by 7.5% of men and 4.9% of women in India as a whole. Areca nut products are typically chewed and then held just inside the cheek (buccal mucosa). Oral submucous fibrosis is typically found in the buccal mucosa area adjacent to where the areca nut quid is generally held.

Consumed with or without betel leaf, areca nut is most commonly consumed with tobacco, a known human carcinogen. While use of betel quid with tobacco has been linked with oral cancer in the medical literature for nearly a century, the added tobacco has been viewed as the main culprit [IARC, 2004]. In the past decade or more, mouth cancer has been diagnosed with increasing frequency in users <35 years of age who mainly use packaged areca nut [Chaudhry, 1999, Gupta, 1999]. This has brought the potential carcinogenicity of areca nut under the scanner. A thorough review of epidemiological studies on areca nut and cancer and experiments in animals by the International Agency for Research on Cancer published in 2004 concluded that areca nut by itself is a carcinogen to humans, as it has been linked with oral cancer [IARC, 2004]. The direct relationship of areca nut use with oral pre-cancer is even more remarkable.

**Oral Pre-cancers:** Four case control studies are available on oral submucous fibrosis (OSF) that provides odds ratios for different areca nut products. These studies were based in Gujarat [Sinor et al., 1990], Kerala ([Jacob et al., 2004], Karnataka [Bathi et al., 2009] and Uttar Pradesh [Mehrotra et al., 2013]. All four studies showed significantly elevated odds ratios for OSF for areca nut use in its various forms. The most interesting finding of these studies was that users of areca nut without betel leaf, as in *mawa*, *pan masala* or *gutka* had much higher ORs than those who used betel quid in three studies [Sinor et al., 1990; Bathi et al., 2009; Mehrotra, et al., 2013].

In the study from Uttar Pradesh, a significant dose response relationship for frequency of use per day for betel quid with tobacco was found for categories 1-6 and >6 times per day whereas for pan masala, categories were 1-2 and > 2 times used per day [Mehrotra et al., 2013]. In an earlier case series study of OSF patients in Hyderabad, pan masala and or gutka chewers presented with OSF just after 2-3 years whereas betel quid chewers developed OSF after 6-10 years. This study concluded that chewing of pan masala and or gutka can cause OSF faster than betel quid due to the absence of betel leaf and the higher consumption by weight of areca nut [Babu et al., 1996].

Leukoplakia has also been found associated with areca nut use. A case control study from Kerala [Jacob et al., 2004], reported an odds ratio of 4.0 for leukoplakia for chewers of pan without tobacco and an odds ratio of 12.8 (95% CI: 1.6-101.2) for chewers of areca nut by itself (which may include lime). The trends for both frequency and duration were significant ( $p < 0.0001$ ). An intervention study also in Kerala, aimed at reducing tobacco consumption (mainly as betel quid with tobacco), showed a substantial reduction in leukoplakia incidence among chewers after 5 years (by around 50% in men and over 25% in women), compared to the non-intervention

group [Gupta et al., 1986]. The reduction strengthened further after 10 years, the intervention to control incidence ratio being 0.63 among men and 0.45 among women chewers [Gupta et al., 1992].

**Oral Cancer:** Eight recent case control studies on oral cancer showed significantly elevated odds ratios for oral cancer for betel quid chewers with tobacco, regardless of gender. One study was conducted in Madhya Pradesh [Dikshit and Kanhere, 2000], two were in Maharashtra [Jussawala and Deshpande, 1971; Wasnik et al., 1998], and the rest, in South Indian States - Karnataka, Kerala, and Tamil Nadu [Nandakumar et al., 1990; Balaram et al., 2002; Znaor et al., 2003; Muwonge et al., 2008; Mahapatra, et al., 2015]. Six of these studies showed elevated odds ratios for chewing of betel quid without tobacco as well, significant in the four largest studies. The odds ratios for betel quid with tobacco tended to be higher than those for betel quid without tobacco and odds ratios were higher for women than for men. One study in Kerala also reported an elevated and significant odds ratio for women who chewed areca nut without tobacco [Muwonge et al., 2008].

In a cohort study in Karunagapally, Kerala, incidence of oral cancer among 144,417 individuals aged 30-80 years (women 54%), followed up between first interview during 1990-7 and until the end of 2005, significantly elevated relative risks were found for the use of betel quid, mainly with tobacco: for women 5.5 (95%CI: 3.3 -9.0) and for men 2.4 (95% CI: 1.7-3.3) [Jayalekshmi et al., 2009; Jayalekshmi et al., 2011].

In a cohort study on cancer mortality in Trivandrum, Kerala with 164 072 rural participants aged 34 years and above (60.2% women) followed up between 1996 and 2005 for a mean duration of 6.5 years, chewers without tobacco (generally betel quid) had an adjusted hazard ratio of 1.47 (95% CI: 0.98-2.19) for death due to tobacco-related

cancers including oral cancer; those who chewed with tobacco had a hazard ratio of 1.27 (95% CI: 1.07-1.52) [Ramadas et al., 2010].

The Mumbai Cohort Study on mortality that analysed for oral cancer among urban users of areca nut containing substances has had relative risks that were elevated but not significant [Gupta et al., 2005; Pednekar et al., 2011]. In another analysis of incidence of cancer among 87,222 men aged 35 years and older, after an average 7.4 years of follow-up the relative risk for oral cancer for smokeless tobacco use combined was significant (RR 1.48, 95%CI: 1.03-2.13) [Pednekar, 2011].

**Conclusion:** In view of the clear elevated risk for oral cancer posed by the use of areca nut and its products, their control, such as through bans, is justified to contain the adverse effects of this substance on the population and improve public health.

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### Methods for Appreciation of Risk Levels

- **A statistically significant excess risk among habitués,**
  - **Case Control studies, Retrospective studies, Cohort studies**
  - **Odd's Ratio, Relative Risk, Hazard Ratio, Attributable Risk**
- **A dose effect relationship**
- **Withdrawal reducing the risk**
- **Similar results from various population groups & over time**
- **Biological Plausibility Including Laboratory Evidence.**
- **Clear Definitions of Study factors essential**

## Message from Dr. Amal Chandra Kataki



Director, BBCC, Guwahati  
 Member, Scientific Advisory Committee, NCDIRZ  
 Member, Research Area Panel on Cancer, NCDIR  
 Member, Steering – Monitoring Committee, NCRP

The history of Population Based Cancer Registry in India started with the establishment of first Population Based Cancer Registry (PBCR) in Mumbai in 1963 as a unit of Indian Cancer Society. The National Cancer Registry Programme of Indian Council of Medical Research established in 1981 with 3 PBCR and 3 HBCRs heralded epidemiological research on cancer in the country. Since then, the programme has made significant stride and the numbers of PBCRs also increased to 29 at present. Unfortunately, less than 10% of Indian population is covered by these existing registries. Many of the large Indian states are still unrepresented. Therefore the national coverage of Population Based Cancer Registries under National Cancer Registry Programme of India should be expanded. However, prior to such expansion, human resource generation should be given due consideration. This can be achieved by creating four regional hubs under the National Centre for Disease Informatics and Research, Bangalore. Also, active participation of oncologists in the registry programme should be encouraged.

Making cancer a notifiable disease in the country will provide comprehensive information on cancer. All out efforts should be made to make it mandatory for all diagnostic and treatment centers in the country to provide data to the National Cancer Registry Programme. A robust task force comprising of epidemiologists, researchers, clinicians and policy makers will go a long way to address all outstanding issues. The recommendation of the

task force should be submitted to the Government as well to statutory regulatory bodies to pass necessary administrative orders for its implementation. This will fulfill the unfinished agenda of NCRP.

The results of Pattern of Care and Survival Studies of head & neck, breast and cervical cancers should be published and necessary guidelines drafted by a consensus meeting on the treatment guidelines for uniform implementation across the country. Pattern of Care and Survival Studies should be expanded to involve childhood malignancies and other region specific common cancers of the country. 70% of the country's population lives in rural India where the incidence of cancer is half of the urban populations. Unfortunately, mortality due to cancer in rural population is double than the urban population. This is largely due to the fact that 90% of the cancer treatment facilities are concentrated in urban India. Government of India should ensure uniform distribution of cancer treatment facilities in the country. The concept of rural comprehensive cancer centers (RCCC) is relevant in the country. The mandate of NPCDCS scheme of the Government of India should be widened to fulfill the aspirations of the people of the country.

Population Based Cancer Survival Studies of common cancers should be undertaken by the existing registries, which will actually reflect the ongoing cancer control efforts in the country. The leads gained from National Cancer Registry Programme should be utilized for cancer control. Translational research on cancer will pave the way for a meaningful outcome.



Dr. G K Rath  
Chairperson  
Scientific Advisory Committee,  
Research Area Panel on cancer,  
Steering Committee NCRP



Dr. A Nandakumar  
  
Scientist G  
Director-in-charge  
NCDIR



Dr. D K Shukla  
Scientist G  
Head, Division of NCD  
ICMR

## 50 years of Mumbai Cancer Registry

A scientific meeting to commemorate 50 years of Mumbai Cancer Registry was held in Pune recently. This was organized by Dr. Purvish Parik, Hon. Secretary, Indian Cancer Society. Mumbai Cancer Registry, a unit of Indian Cancer Society, a first population based cancer registry celebrated its 50 years by organizing a conference for Oncologist in collaboration with Association of Maharashtra Medical Oncologists (AMMO) on 8<sup>th</sup> and 9<sup>th</sup> August 2015 at Maharashtra Chamber of Commerce Industries and Agriculture, Pune. Dr. Purvish Parikh, an NMC Member of Indian Cancer Society and a well known Medical Oncologist and Hematologist had taken lead to arrange this event. This conference provided a platform to the registry staff to present their work. They presented the trends in cancer which was followed by a brief discussion held for the management of that particular site in the year 2020. A special session was held for "Pathologists and Sources from Pune" for appealing them to share the information with Cancer Registry in more systematic way and to include ICD codes/TNM codes. Pathologists have shown their interest to share their database with the Cancer Registries to help fight against cancer.



Dr. D.J. Jussawalla



Dr. William Haenzel



Mr. V A Deshpande



Dr. B B Yeole

Mr. V A Deshpande was the first Biostatistician and Cancer Registry chief of Mumbai Cancer Registry when it was started in 1962. Before this we never had a systematic cancer registry. Financial and technical support for the Bombay Cancer Registry was from National Cancer Institute, United States. Guidance: Dr. William Haenzel. Technical support: Mr. William Lourie. Mr. Deshpande was in-charge of the registry till 1974. During this time Dr. Yeole joined the Mumbai Cancer Registry and continued the work till 2011. Apart from Mr. Deshpande, we also had Mr. M V Natekar to help in the registry operations. Upon the sad untimely demise of Dr. Yeole, Ms. Shravani Koyande took charge of the Mumbai Cancer Registry and associated registries of Aurangabad, Pune and Nagpur.

## 50 years of Mumbai Cancer Registry



Dr. Arun Kurkure



Mrs. Kalpana Kulkarni,  
Pune Cancer Registry



Dr. Purvish Parik  
addressing audience



Dr. Krishna Kamble,  
Nagpur Cancer Registry



Prof. Ram Shinde, the honorary chief guest addressing the audience during the conference



Mrs. Rashnemi Vagal, Mumbai Cancer Registry



Mrs. Shravani Koyande, Co. PI, Mumbai Cancer Registry



Prof. Ram Shinde, Chief Guest, being honored by Dr. Purvish Parikh



Mrs. Shweta Jadhav, Mumbai Cancer Registry



## Significance of Cancer Registries in Cancer Control

Dr. R A Badwe, Director, Tata Memorial Centre, Mumbai, Member, Scientific Advisory Committee, NCDIR,

Dr. B Ganesh, Prof. and Head, Dept. of Medical records, Biostatistics & Epidemiology, Tata Memorial Centre, Mumbai

**Introduction:** Cancer is regarded universally as a dreaded disease and is one of the leading causes of death globally. The burden of cancer is still increasing worldwide despite advances made for diagnosis and treatment. Epidemiological studies have shown that many cancers may be avoidable. 80–90% of human cancers may be attributed to environmental and lifestyle factors such as tobacco, alcohol and dietary habits [1]. Cancer control aims to reduce the incidence and mortality of cancer and to improve the quality of life of cancer patients through the systematic implementation of evidence-based interventions in prevention, early diagnosis, treatment, and palliative care. In this context a robust cancer registry system is an essential element for successful implementation and functioning of any national cancer control program. The main objective of such registries is to improve efforts towards cancer control by providing information not only on magnitude of cancer problem and patterns of cancer in various segments of population, to study the various epidemiological and etiological factors

related thereon but also as a guide for planning and evaluation of health services.

**Definition:** Cancer registration is the process of continuing, systematic collection of data on cancer, occurrence and characteristics of reportable neoplasms with the purpose of helping to assess and control the impact of malignancies on the community [2]. Cancer registry has been defined as an organization for collection, storage, analysis and interpretation of data on persons with cancers. Cancer registry is an essential part of any rational programme of cancer control activity [3].

**Brief history of cancer registration:** The first serious efforts to estimate the number of new and existing cancer cases in a given population were made at the turn of the century in various European countries. In Germany, an attempt was made in 1900 to register all cancer patients who were under medical treatment. Questionnaires were sent to every physician in the country to record the prevalence of cancer on 15 October 1900 (Anon., 1901). The same approach was adopted between 1902 and 1908

in Denmark, Hungary, Iceland, the Netherlands, Portugal, Spain and Sweden. These efforts were not very successful, mainly due to poor collaboration by the physicians. Similar surveys were conducted in the United States of America. The first population-based cancer registry was set up in Hamburg (Germany) in 1926. Three nurses visited hospitals and medical practitioners in the city at regular intervals. They recorded the names of new cancer patients and transferred data to a central index in the health department. This index was compared once a week with official death certificates. Other population-based cancer registries were set up in subsequent decades, so that by 1955, almost twenty had been established in various countries.

At present 290 population-based cancer registry reports have been published by the International Agency for Research on Cancer in its publication *Cancer Incidence in Five Continents Vol. X*. These reports cover about 5% of the world's population, but the proportion is much greater in developed countries than in developing ones. Moreover, in developing countries, registries are more likely to cover urban areas, where access to diagnostic and treatment services are better [3].

#### **Types of registries:**

##### **Hospital-based cancer registry (HBCR):**

HBCR record information on all cancer patients observed in a particular hospital. Their main aim is to monitor and plan patient care at an institutional level. However, the hospital based data are of limited value for epidemiology, because it is not possible to define the population from which cases arise.

##### **Population-based cancer registries (PBCR):**

PBCR seek to collect data on all new cases of cancer which occur in a well defined population. As a result, and in contrast to hospital-based cancer registries, they can

provide information on the occurrence of cancer in a defined population and, therefore, they are of special value for epidemiology and public health.

**Special Purpose Registries:** Special purpose registries focus on a special cancer type or a population exposed to a special factor either through a natural positioning or through occupational exposures. Lymphoma registries, paediatric cancer registries are examples of special purpose registries and special group registries. Similarly, we had Radium Dial Painter's registry which focus on occupational exposure to radiation. We have in India, the Bhopal Cancer Registry focus on exposure to Methyl Isocyanate subsequent to the Bhopal disaster. There is also an ongoing Karunagappally Cancer Registry which focuses on cancer causing potential among the population exposed to high natural radiation present in the area.

**Basic Role of Cancer Registries:** It is well recognized that, as Muir et al [4] noted: "the cancer registry is an essential part of any rational program of cancer control benefiting both the individual and the society in which he lives". But it was Armstrong [5] who, in 1992, reviewed the potential range of activities that registries might undertake in the context, what they are actually doing (by means of survey of members of the International Association of cancer registries) and then provided a blueprint for an "expanded role" for registries, over and above their core functions of providing routine statistics on cancer occurrence and outcome. Thus the basic roles of registries can be summarized as follows [6]:

- To assess the magnitude & pattern of cancer burden and its trends
- To provide basis of research on cancer causes and prevention.
- To provide information on prevalence and trends in risk factors.
- To monitor the effects of early detection/screening, treatment & palliative care.

**Significance of Cancer registries in cancer control:**

The word "control" in context to cancer does not imply disease eradication, but rather control over its causes and consequences. This requires extensive resources. "In order to make the best use of resources, it is important to identify both effective strategies and strategies that are largely ineffective" [7]. The cost of various cancer control strategies differs in different countries, because of different levels of existing infrastructure and differences in local strategy implementation. Therefore, cancer registry is an essential part of any rational programme of cancer control. Its data can be used in a wide variety of areas of cancer control ranging from etiological research, through primary and secondary prevention to health-care planning and patient care.

**(a) Planning of cancer control programmes:**

Accurate information on cancer occurrence is important in fixing priorities and targeting cancer control activities. Population-based cancer registries are in a unique position to provide this information. The annual numbers of incident cases provide an indication of the resources needed for primary treatment, and the number of prevalent cases describes how many people are in need of regular long-term follow-up. The ranking of the cancer sites is quite different for incidence and prevalence. This is due to differences in survival. Cancers with a good survival have high prevalence even if their incidence is low, whereas those with poor survival have lower prevalence even if their incidence is higher. Up-to-date cancer statistics provide information on the present burden of cancer to the health care system in a population [3]. To develop long-term programmes for cancer control, it is necessary to predict what the needs will be in the future. In other words, it is necessary to have reliable estimates of the numbers of incident and prevalent cases that will occur in coming

years. Cancer registries are an important source of data upon which such predictions are based. The various statistics that obtained from cancer registry data is as follows [8]:

- Cancer incidence and mortality rates in a country: The cancer registries are rich source for yielding information on the magnitude on cancer in different population groups i.e. incidence rates and mortality rates of cancer at various sites for the geographical areas. In addition, the pooled rates for all registries can provide country statistics.
- Pattern of Cancers in the country: Lung, esophagus, stomach, oral and pharyngeal cancers are the predominant cancers in men. In women, cancers of the breast and cervix are the predominant sites. The age and sex related distributions are being obtained from cancer registry data.
- Person-years of life lost (PYLL): This index provide dimension additional to mortality, differentially weighting lives lost according to the age at death. This concept has lead to development of indices such as Disability adjusted life years (lost) (*DALYs*) and Quality adjusted life years (lost) (*QALYs*), which quantify in addition to information on death, the morbidity that is suffered between onset of disease, and death or recovery [9].

**(b) Evaluation of Primary prevention programmes:**

Cancer registries can play an important role in monitoring and evaluating the effectiveness of primary prevention measures. The trends in cancer incidence can be related to changes over time in exposure to risk factors. Occasionally, when implementation has been confined to one area, comparisons of the changes in the intervention area versus 'control' areas may be possible [10]. However, such comparisons and interpretations take considerable time to effect a change in exposure to be reflected in cancer incidence.

**(c) Evaluation of Screening and early detection programmes:** Cancer registries play an important role in the evaluation and monitoring of screening programmes aimed at detecting pre-invasive conditions. Cancer registration data have been used in routine-data-based studies to examine trends in disease rates in relation to screening frequencies within a population and to compare disease rates between different populations with the coverage offered by their screening programmes. In addition, Cancer registries can also contribute to the ascertainment of cancer occurrence in intervention trials and cohort studies designed to assess the value of screening programmes, and as an unbiased source of cases for case-control studies [11].

**(d) Evaluation of Tertiary prevention programmes:** Survival statistics can be produced by population-based cancer registries that follow up their cases, either actively or passively. Although survival analysis of data from population-based registries cannot evaluate specific treatments, it provides a useful evaluation of cancer care in the area covered by the registry, since all cancer cases will be included regardless of the type of treatment they may have received.

**(e) Computation of Survival time trends:** Time trends in survival are useful to assess the extent to which advances in treatment have had an effect in the population. However, survival time trends based on data obtained from population based registries may have certain caveats. Firstly; improvements in survival may be due, at least in part, to better ascertainment and recording of incident cases. Secondly, if there has been a trend towards earlier diagnosis (e.g., through introduction of a screening programme), survival may improve but the gain may be due entirely to increased lead time, with no change in mortality rate. These time trends may also be used to compare the effectiveness of cancer treatment across populations [12].

**(f) Epidemiological investigations:** The magnitude and patterns of cancer obtained from the various PBCRs in India helped in determining clues to the cause of cancer. A number of research investigations mainly epidemiologic studies have been undertaken based on the cancer registry data.

**(g) Planning for patient care:** Data from Hospital-based cancer registries contribute to patient care by providing readily accessible information on the patients with cancer, the treatment they received and its results. The data may also be used for clinical research and, to a certain extent, for epidemiological study purposes. The data items collected by a hospital registry tend to be more extensive than those collected by a population registry. Thus this data can be used for planning human resource and infrastructure requirements for cancer control [13].

**Conclusion:** Traditionally, It has been accepted that the cancer registry has more of a 'back room' than a 'front line' role in cancer control, its particular responsibilities are focused on description of cancer patterns, care and outcome in monitoring these variables in relation to control activities, and in providing a research database often to utilize for research studies. However, with ever growing burden of the disease and changing times, the significance of cancer registries has changed from simply providing statistical data on incidence, mortality, stage distribution, treatment patterns, and survival to conducting studies into the important causes of cancer in the local situation, and for providing epidemiological expertise and information about the prevalence of exposure to these factors in the population. Thus, today cancer registry has become the centre of all cancer control activities and plays a crucial role in formulating cancer control plans, as well as in monitoring their success.

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Mr. D N Rao  
 Statistician, Cancer registry ( 1971 - 2004 )  
 HOD Cancer registry ( 1982 - 2004 )  
 TATA Memorial Hospital

## TATA Memorial Hospital, Mumbai



## Data collection procedures for case finding and abstracting for HBCR and PBCR-NCRP

P. Gangadharan

- 1. Study the NCRP Coding Manuals – HBCR and PBCR.**
2. Distinguish between reportable and non reportable cases.  
(Guidance ICD/ICD-O Codes)
3. Receive administrative sanction from the identified sources to conduct registry operations
4. Locate and List sources of cancer patients/records, visit the sources regularly.
5. Study record storage system in the hospital. Do all cancer patient records of the hospital are received in one department or is it department wise record storage?
6. Check whether the hospital attendance of a patient can be identified through a hospital preserved record storage or whether the case record is given to the patient with an advice to bring it for the next visit only
7. Note whether the place and duration of residence is in the PBCR covering area and verify whether the registration date / diagnosis date is tallying with 'Reference date of registry'
8. From the patient records identify the cases to be reported to NCRP. Study and understand the notes and record the information in the 'Abstract Form' of NCRP.
9. Identify 'Consult only' 'Path review only' cases – separate these for HBCR but include in PBCR if a resident case.
10. From the Medical Record of patient prepare a case abstract as required by NCRP to record the following:
  - a. Record patient identification, name, address, duration of stay etc
  - b. Note the correct Date of First Diagnosis for the present cancer.
  - c. Record the Method of Diagnosis and Primary Site, Primary Histology, Secondary Site, Secondary Histology.
  - d. For coding follow ICD , ICD -O, Site and Morphology codes, 5<sup>th</sup> digit, 3,6,9 for inclusion.
  - e. Record Stage of Disease (TNM, EOD) etc.
  - f. Prepare abstracts for cases when the final diagnosis noted in the case record or death certificate is mentioned as 'cancer' even in the absence of any further description of histology or other investigational results or treatment.
  - g. Minimize case recording as 'unknown primaries'. When the final diagnosis is not clearly recorded seek the advice of treating doctor / pathologist / radiologist.
  - h. Mention the sub site of cancer cases where appropriate. (Only some examples are shown below).
    - Eg: Tongue Cancer?  
Ant. 2/3<sup>rd</sup>?Post 1/3<sup>rd</sup>
    - Esophageal Cancer ?  
U1/3<sup>rd</sup>,M1/3<sup>rd</sup>,L1/3<sup>rd</sup>
    - Intestinal Cancers-Caecum, Ascending colon, Hepatic flexure, Transverse colon, Splenic flexure, descending

- colon, Recto-sigmoid etc –  
Identify these.
- Ca Uterus? Ca Cervix uteri  
? Corpus uteri
- I. Summarize treatment received.  
Differentiate between first  
course of therapy and  
subsequent treatment given  
during follow up or for  
recurrence, completeness/inco  
mpleteness of treatment to be  
identified.
- j. Distinguish between Definitive  
treatment & Palliative  
Treatment (See code manual).
- k. Recognize when and how to  
prepare more than one abstract  
(more than one tumor or B/L  
tumor).
- 11. Institute annual follow – up of cases  
recorded by the registry.
  - a. Record post treatment quality of  
life, date of death
  - b. Record follow up treatment  
received after six months of  
initial diagnosis received at RI.  
Identify whether it was for  
primary or for secondary  
disease
- 12. For PBCR, Record Residence and  
duration of stay in PBCR area. Cover  
all the reporting sources periodically –  
hospitals, laboratories, vital statistics  
department etc. serving the  
population. Some of the sources may  
be outside the PBCR area. For PBCR,  
'consult only cases' and 'pathology  
review only' cases are included in  
PBCR if the residence is in the PBCR  
area.
- 13. Try to hold scientific discussions with  
the cooperating centre staff regarding  
registry operations to encourage the  
involvement and cooperation;  
encourage them with an outcome feed  
back
- 14. Persuade Health Administration to  
issue orders to make cancer as a  
'Notifiable Disease'

**By a cancer control programme we envisage the following**

- **Less number of people should die of cancer**
  - **This can happen only if**
  - a. **Less number of people develop the disease and**
  - b. **More people are cured of the disease and live with good  
quality of life.**



*Epidemiology and Cancer Registry training programme of IARC held in Singapore 1970 Attendees from India Ms. Kasturi Jayant, Mr. V.A Deshpande, Mr. Gangadharan & Mr. P.C Gupta Faculty included Dr. Shanmugha Ratnam, Dr. Calum Muir & Abraham Lilienfeld*

*Life is to be understood backwards, but it is lived forwards: Soren Kierkegaard, Danish Philosopher, 1813-55*

important and essential tool for the study of cancer. An editorial of International Journal of Epidemiology is presented here. This is only the first para of the editorial.

Birth Cohort Studies: Past, Present and Future; Debbie A Lawlor, Anne-Marie Nybo Andersen and G David Batty; Int. J. Epid. 2009, Vol. 38; 897-902

- “There is considerable interest in the suggestion that exposures acting in early life, together with those accumulating in adulthood, and even between generations, have long-term consequences for health in adulthood. Potential early-life factors that might impact on adult health, include those acting during (or before) the period of fetal development (such as endocrine disruptors, maternal diet, smoking or alcohol), those in infancy (such as breast – or bottle feeding, exposure to moulds and damp) and those acting in childhood and adolescence (such as environmental toxins, diet and levels of physical activity, passive exposure to tobacco smoke and own initiation of smoking and alcohol consumption). Nearly all domains of later health experience, including cardiovascular disease, various cancers, respiratory disease, cognitive decline and psychological health, have been associated with early-life exposures of one kind or another.....”

## **Merging data from Hospital Information System to Data Management Server of Hospital Based Cancer Registry**

Mr. Kamal Kumar Deka<sup>1</sup>, Mr. Pintu Nandy<sup>2</sup>, Mr. Manjit Sarma<sup>2</sup>, Dr.  
Manigreeva Krishnatreya<sup>3</sup>

<sup>1</sup>Population Based Cancer Registry, Kamrup-Urban, Indian Council of Medical Research

<sup>2</sup>Hospital Based Cancer Registry-Guwahati, Indian Council of Medical Research

<sup>3</sup>Dr. B Borooah Cancer Institute, Guwahati

One of the objectives of Hospital Based Cancer Registry is to contribute data to different Population Based Cancer Registries (PBCR). The role of Hospital Based Cancer Registries (HBCR) under the network of National Cancer Registry Programme (NCRP) in this regard remains crucial in providing timely and quality data to the PBCR. The cancer registry data entry at a regional cancer centers involves large volume of data entry at Hospital Cancer Registry Data Management system. For the year 2014, more than 9000 core proforma data entry at the HBCR of Dr. B Borooah Cancer Institute is expected. Furthermore, the same identifying and demographic information of cancer patients is entered at the registration domain of Hospital Information System (HIS) in a hospital and also at the HBCRDM. However, HBCR data is stored in SQL express 2005 and HIS data of Dr. B Borooah Cancer Institute is stored in MS Access 2007 database. This essentially means duplication of data entry at two different platforms! The stumbling block of integrating these data was because of different servers used for HBCRDM and HIS.

We have devised a strategy where, the identifying patient information and demographic data collected at the time of patient registration at HIS has been tailored (Figure 1A-C) according to the Serial no 1- 19 of HBCR core proforma or at the HBCRDM 1.0. As a result it will not only avoid duplication of data entry but also, reduce the time of data entry at HBCRDM 1.0.

**Figure 1A to C** It shows registration domain of Hospital Information System at Dr.B B Cancer Institute.

The following methodology was adopted for the merger (Figure 2):

First, HBCRDM and HIS data are transferred to MS Excel spreadsheet. Next, HIS data validation check and manipulation is done at Excel, followed by merging of HIS and HBCR data at Excel. The merged data is then saved as csv format, and finally the csv file is transferred through SQL server DTS wizard to HBCRDM.

HBCRDM transfer to MS Excel spreadsheet

HIS data transfer to MS Excel spreadsheet

HIS data validation check and data editing at Excel spreadsheet

Merging HIS and HBCRDM data at Excel spreadsheet

Merged data saved as csv file & csv file transferred through SQL server DTS wizard to HBCRDM

**Figure 2:** Flow chart showing the process of data merging

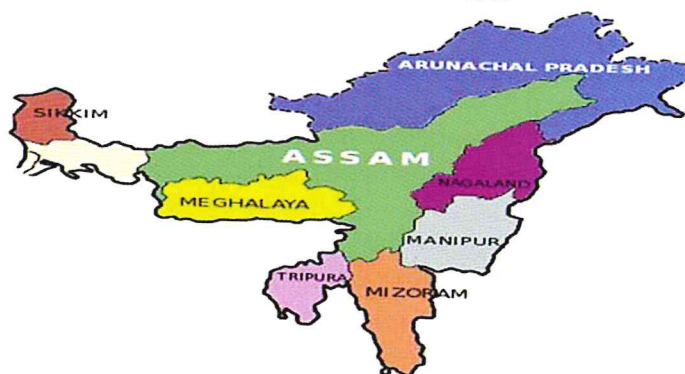
Before the merger, the column at the HBCRDM1.0 database for partial saving option is enabled. Once the merger is done, the data entry then proceeds from diagnostic details and clinical information of patients (Serial no 20-38). It is done at a later stage once all these information are available from hospital case sheets and other sources including pathological laboratory, which are duly filled in the HBCR core proforma. Now, an average data entry operator can complete the entry of more than 100 core proforma at HBCRDM 1.0 in 6 working hours a day. Additionally with the helper software (see CRAB 2014), more than 150 core proforma can be completed at HBCRDM 1.0. This will help in timely and relatively quicker data submission by HBCR-Guwahati to NCRP, and hence to different North East PBCRs under NCRP by Dr. B Borooah Cancer Institute (a regional cancer center) where the HBCR is located.

### **Cancer registry in North East India and its contribution towards cancer control**

Dr. Amal Chandra Kataki; Director, Dr B Borooah Cancer Institute;  
Dr. Manigreeva Krishnatreya, Cancer Registry, Epidemiology and  
Biostatistics, Dr B Borooah Cancer Institute

There is a marked increase in the burden of cancer in this part of the world due to increase in the life expectancy, urbanization, changing food habits and life styles. Cancer registry has been the backbone in determining the burden of cancer in India. In India, there are about 25 lakh cancer patients at any given point of time and around 9 lakh new cancer cases detected every year, out of which around 6 lakh patients dies. Still most part of the country does not appear in the national cancer map due to the lack of Population Based Cancer Registries. However, National Cancer Registry Programme under the Indian Council of Medical Research has now 29 Population Based Cancer Registries (PBCR) under its network of cancer registries, and it is increasing the national coverage. Cancer registration in the North East India began in 1982 with the establishment of a Hospital Based Cancer Registry at Assam Medical College, Dibrugarh. The geographical area of NE India is 262,230 Square km and comprises of 8 states (Map).

**Map:** The map showing the different states of North East India



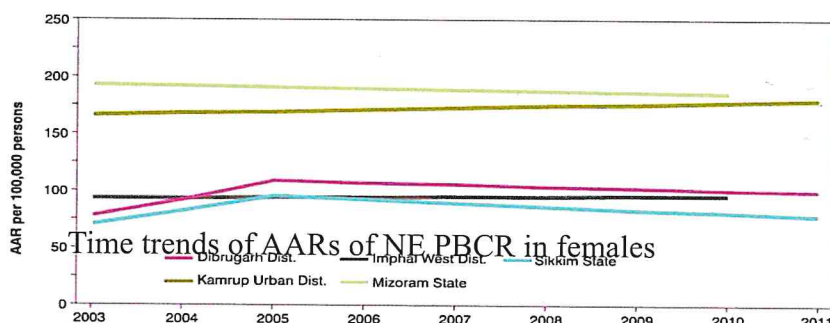
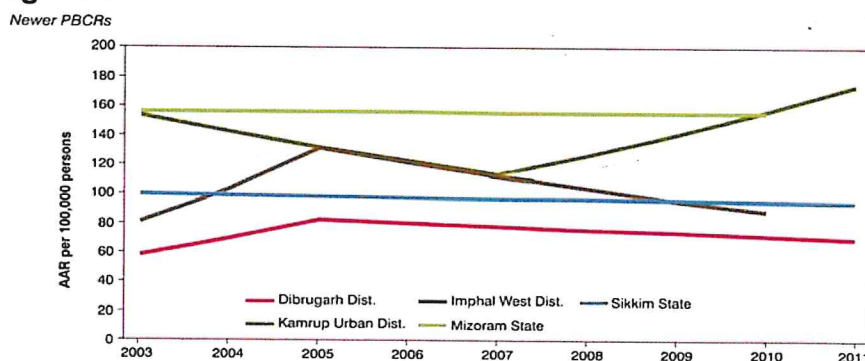
North East India's population is approximately 4.5 crores which represent roughly 3.1% of the total Indian population as shown on table 1 [1]. Almost 82% live in rural areas

**Table 1: Showing the population distribution of states of North East India**

State	Total			Rural			Urban		
	Persons	Males	Females	Persons	Males	Females	Persons	Males	Females
Sikkim	610577	323070	287507	456999	242797	214202	153578	80273	73305
Arunachal	1383727	713912	669815	1066358	546011	520347	317369	167901	149468
Nagaland	1978502	1024649	953853	1407536	725472	682064	570966	299177	271789
Manipur	2855794	1438586	1417208	2021640	1026884	994756	834154	411702	422452
Mizoram	1097206	555339	541867	525435	269135	256300	571771	286204	285567
Tripura	3673917	1874376	1799541	2712464	1387173	1325291	961453	487203	474250
Meghalaya	2966889	1491832	1475057	2371439	1194260	1177179	595450	297572	297878
Assam	31205576	15939443	15266133	26807034	13678989	13128045	4398542	2260454	2138088
<b>Total</b>	<b>45772188</b>	<b>23361207</b>	<b>22410981</b>	<b>37368905</b>	<b>19070721</b>	<b>18298184</b>	<b>8403283</b>	<b>4290486</b>	<b>4112797</b>

Population Based Cancer Registry was first established in the North East India in the year 2003 as a continuation of the “Cancer Atlas” Project, which was started in the year 2001. The older PBCRs of NE India, as these registries are commonly referred are; Kamrup-Urban, Dibrugarh, Mizoram, Manipur, Cachar and Sikkim. Now, there are 11 PBCRs and 2 Hospital Based Cancer Registries. In addition there are pattern of care and survival studies at Dr. B Borooah cancer Institute and Cachar Cancer Hospital. The coverage of North East cancer registries is 42% of the population of the region [2]. Except for Assam, rest of the PBCRs covers entire state population. In the state of Assam, there are three population based cancer registries covering the population of Kamrup-urban, Dibrugarh and Cachar Districts.

Because of the presence of Population Based Cancer Registry we now have data on the incidence of cancer in this region. The cancer incidence of the North East India is relatively high in comparison to the average national scenario. This high incidence of cancer is particularly notable in the states of Mizoram, Meghalaya and in the urban registry of Kamrup in Assam. In the NE India, approximately every year 70-170 males per 100000 population and 50-150 females per 100000 populations are affected with cancer. In India, among males the age adjusted incidence rates (AAR) of all sites is lead by six NE population based cancer registries and among all sites in females, three NE PBCRs tops the list. The leading sites of cancer in NE India for males are esophagus, hypopharynx, lung and stomach, and in females the leading sites of cancer are breast, esophagus, uterine cervix, and gall bladder. Interestingly cancers of the esophagus, lung and stomach have surpassed cancers like uterine cervix, breast and ovary in some of the NE cancer registries. National comparison shows the AAR of cancer sites like nasopharynx, hypopharynx, esophagus, stomach, gall bladder, larynx, lung, prostate and lymphomas amongst males of the North East leads the chart. In female, cancers of the tongue, mouth, nasopharynx, hypopharynx, esophagus, stomach, colon, gall bladder, lung, cervix uteri and ovary tops the AAR nationally. On international comparison, age adjusted incidence rate of pharyngeal cancers in females of Kamrup-urban and males of East Khasi Hills is highest in the world and similarly the AAR of esophagus cancer amongst both males and females of East Khasi Hills are highest in the world. The age adjusted incidence of gall bladder cancer in females of Kamrup-urban is second to the highest in the world; the highest incidence is seen in Chile, South America [3]. The age adjusted incidence rates of all cancers in the different registries of North East India has not shown a significant rise till 2011, as shown in figure 2 & 3[4].

**Figure 2:** Time trends of AARs of NE PBCR in males**Figure 3:**

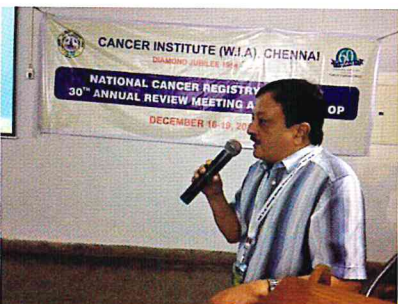
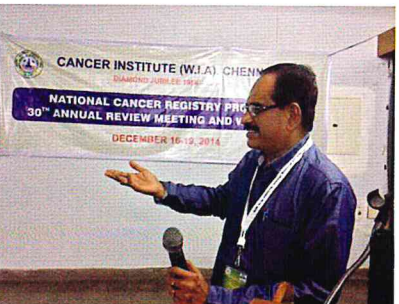
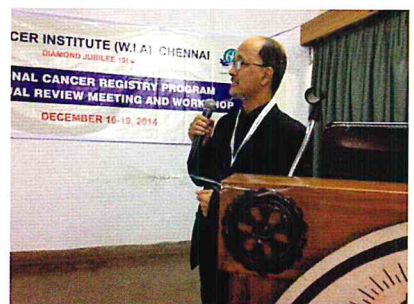
In the North East of India, tobacco related cancers accounts for almost 31-69% of cancers in males and 20-43% of all cancers in females. Besides generating data on the incidences, prevalence and time trends on cancer, NCRP data has also provided the leads for cancer control program including the urgent need for tobacco control measures in the population of North East India. The leading sites of cancer in NE India, like stomach, esophagus, lung, gall bladder, and in female's uterine cervix are fatal cancers. So, cancer control and reducing overall cancer mortality will surely pose a challenge to health planners.

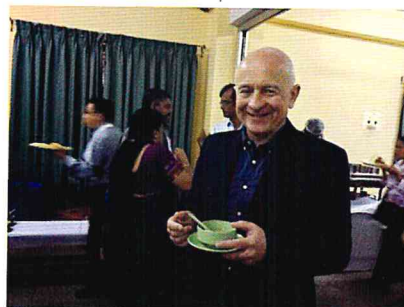
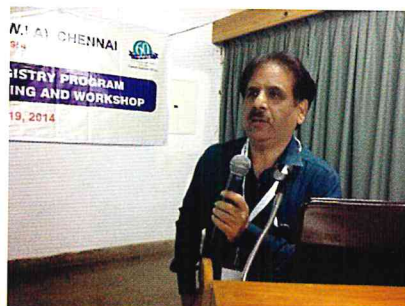
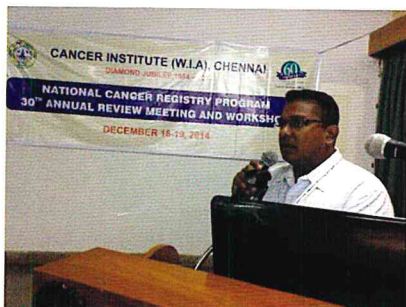
Cancer registration in the North East India poses unique challenges to the registry staff compared to the rest of India. Despite the difficult geographical reach and access of the coverage of hilly states of the North East India, efforts by registry staff in generating cancer data from these states are praiseworthy. So far, cancer registration in the North East India is a success story of its own.

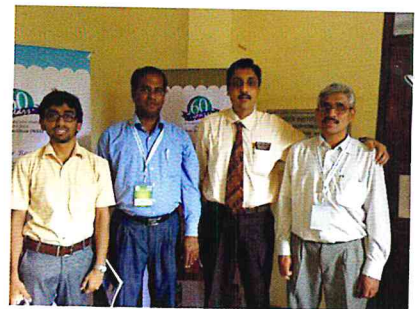
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## ARM Meeting, Cancer Institute (WIA), Chennai 2014









## Population Based Cancer Registry, Ahmedabad Urban Agglomeration Area & Rural Ahmedabad district

Gujarat Cancer And Research Institute, Ahmedabad

Principal Investigator : Dr. Rakesh K Vyas  
Co. Principal Investigators : Dr. Janmesh Shah, Dr. Geeta M Joshi,

The Population Based Cancer Registry (PBCR) – Ahmedabad Urban Agglomeration Area has been functioning since the year 2007 under the network of National Cancer Registry Programme (NCRP), ICMR. The main objective is to assess the magnitude and types of cancers in Ahmedabad city and to calculate estimate of cancer incidence in Ahmedabad urban area.

Based on 2001 census, the registry covers the population of 42,20,048 with 14,080 per km<sup>2</sup> population density. The two major risk factors for cancer are tobacco (smoking or chewing) and alcohol. In Ahmedabad Urban, the tobacco habits are more prevalent and more than half of the cancers in males are tobacco related cancers. The proportion of tobacco related cancers in females is nearly twenty percent in Ahmedabad Urban. PBCR Ahmedabad Urban has the highest incidence rate of tongue and mouth cancers in males as compared to other registries in India. It signifies the urgent need for tobacco control and other preventing measures in the city.

**Cancer Care:** Ahmedabad city is accelerating towards urbanization and modernization due to the fast growing economy of the city. Apart from The Gujarat Cancer and Research Institute (GCRI), the city has many private hospitals dedicated to comprehensive cancer care. They facilitate complete care including diagnostic, surgical, radiation and medical therapy under one roof.

**Sources:** Besides the base Institute i.e. GCRI, PBCR Ahmedabad Urban covers more than two hundred sources. There are 61 collaborating hospitals (Municipal hospitals, Government hospitals, Corporate hospitals

and Trust hospitals). The cancer information is also obtained from 25 pathology laboratories located in the city. The Birth & Death Registration Department of Ahmedabad Municipal Corporation is also one of the important sources covered by the registry.

**Cancer Incidence and Mortality:** As per the last published report of PBCR-Ahmedabad Urban for the year 2011, a total of 4390 incident cases were registered. Out of them, 2519 (57.38%) were males and 1871 (42.62%) were females. During the year 2011, a total of 1421 cancer deaths were recorded in which 862 were males and 559 were females. The Age Adjusted Mortality Rate in males and females were 44.7 and 28.1 respectively.

**Major Difficulties for data collection:** Some private practitioners are non-cooperative in giving information of cancer patients for various reasons. We have requested the Principal Secretary, Health and Family Welfare, Government of Gujarat to issue an administrative order but till date we don't have any fruitful outcome.

We succeeded to get all mortality data of Ahmedabad Urban for the year 2012 and 2013 from Birth and Death Department of Ahmedabad Municipal Corporation but the data are in PDF format and in Vernacular language. Causes of death are also lacking in most of the cases. It would adversely affect the mortality rates obtained.

From pathology laboratories, we couldn't get socio demographic information. Only diagnostic information is available. We have made efforts and we are able to get patient's details from one of the pathology laboratories having good records.

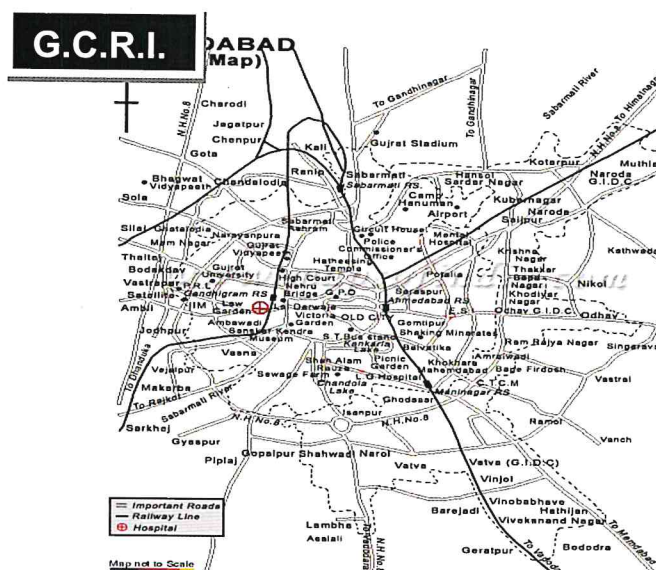
During home visit for follow up or to get missing information, the patients or their relatives felt that the Institute has sympathy and care for them. They behaved in friendly and cooperative nature and the registry staff gets detailed information. Any new cancer incident or mortality is also given by them which help registry operation.

**Leading cancer sites (AAR) among males and females:** The following tables shows the leading sites of cancers among males and females of PBCR-Ahmedabad Urban for the year 2011

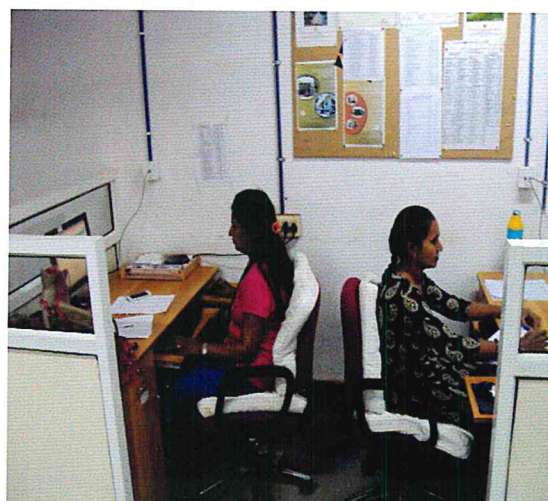
Site	Cases	%	CR*	AAR*	TR*
Mouth	500	19.85	18.90	21.65	50.70
Tongue	283	11.23	10.70	12.86	28.50
Lung	219	8.69	8.30	12.88	21.40
Esophagus	137	5.44	5.20	7.29	13.90
Prostate	98	3.89	6.74	3.70	4.40
Hypopharynx	90	3.57	3.40	5.23	8.30
Larynx	85	3.37	3.20	5.03	7.90
All sites	<b>2519</b>	<b>100</b>	<b>95.00</b>	<b>127.60</b>	<b>226.80</b>

Site	Cases	%	CR*	AAR*	TR*
Breast	588	31.43	25.20	27.67	64.90
Cervix	172	9.19	7.40	8.49	19.90
Ovary	89	4.76	3.80	4.23	9.70
Mouth	83	4.44	3.60	3.83	8.10
Esophagus	80	4.28	3.40	4.08	7.70
Tongue	75	4.01	3.20	3.73	8.60
GB	63	3.37	2.70	3.16	7.30
All sites	<b>1871</b>	<b>100</b>	<b>80.30</b>	<b>91.40</b>	<b>188.20</b>

**Source** Last published report of PBCR – Ahmedabad Urban for the year 2011



## Registry Operation: PBCR Ahmedabad Urban Project staff



**Rural Cancer Registry – Ahmedabad district (NCRP – ICMR):** Rural Cancer Registry – Ahmedabad district has been functioning since 2004 under the network of NCRP, ICMR. The main objective is to assess the magnitude and types of cancers in Rural Ahmedabad and to obtain estimate of cancer incidence in Ahmedabad district – rural area.

Based on 2001 census, the population of Ahmedabad district (excluding Ahmedabad city) was 1.56 million and the population density - 733 per km<sup>2</sup>. The two major risk factors for cancer are tobacco (smoking or chewing) and alcohol. In Ahmedabad rural area, the tobacco habits are more prevalent and more than 60% of the cancers in males are tobacco related cancers. The proportion of tobacco related cancers in females is more than twenty percent in Ahmedabad rural area. It signifies the urgent need for tobacco control and other preventing measures in Ahmedabad rural area.

**Cancer Care:** A good health infrastructure set up by government (CHCs, PHCs etc.) is available within the District. A number of private/trust hospitals and private practitioners are also present in all the towns and other places throughout the District. Proximity to the Ahmedabad city is also a big advantage as many private hospitals facilitate

comprehensive cancer care including diagnostic, surgical, radiation and medical therapy under one roof.

**Sources:** Besides the base Institute i.e. GCRI, Rural registry – Ahmedabad covers more than 275 sources. There are 61 collaborating hospitals (Municipal hospitals, Government hospitals, corporate hospitals and Trust hospitals). The cancer information is also obtained from 36 pathology laboratories located in the city. The vital statistics department, Ahmedabad Jilla Panchayat and the Birth & Death department of Ahmedabad Municipal Corporation are also the important sources of cancer cases for both cancer incident and mortality.

**Cancer Incidence and Mortality:** As per the last published report of Rural Cancer Registry – Ahmedabad district of the year 2011, a total of 919 incident cases were registered. Out of them, 557 (60.60%) were males and 362(39.40%) were females. During the year 2011, a total of 234 cancer deaths were recorded in which 151 (64.53%) were males and 83 (35.47%) were females.

**Major Difficulties for data collection:** From pathology laboratories, we couldn't get socio demographic information. Only diagnostic information is available.

**Seven leading cancer sites (AAR) among Males & Females:**\* Rate per lac population

## Male

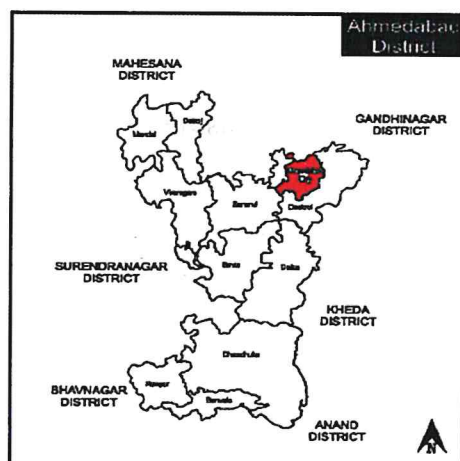
Site	Cases	%	CR*	AAR*	TR*
Mouth	99	17.77	11.20	13.49	35.40
Lung	78	14.00	8.80	12.16	27.30
Tongue	72	12.93	8.10	10.11	22.70
Hypopharynx	32	5.75	3.60	5.19	10.90
Larynx	22	3.95	2.50	3.70	6.80
Esophagus	21	3.77	2.4	3.46	7.6
NHL	20	3.59	2.3	3.20	7.0
All sites	557	100	63.00	83.20	171.30

## Female

Site	Cases	%	CR*	AAR*	TR*
Breast	83	22.93	10.50	12.04	28.60
Cervix	67	18.51	8.40	9.18	21.60
Tongue	21	5.80	2.60	2.91	7.70
Mouth	16	4.42	2.00	2.31	5.70
Ovary	14	3.87	1.80	2.05	5.80
Esophagus	13	3.59	1.6	1.96	4.3
Myel. Leuk	13	3.59	1.6	1.59	2.1
All sites	362	100	45.60	51.10	112.30

**Source:**Last published report of Rural Cancer Registry – Ahmedabad district for the year 2011

**A map of the area covered by the registry operation:**The registry area covered by Rural Cancer Registry – Ahmedabad district is shown in the map given below.



\* The Ahmedabad city taluk highlighted with red color is excluded from Ahmedabad Rural Cancer Registry Area

**National Collaboration:** Hospital Based Cancer Registries (HBCRs) and Patterns of Care and Survival Studies on Cancer Breast, Cancer Cervix and Head and Neck Cancers (POCSS) at Regional Cancer Centre (The Gujarat Cancer & Research Institute)

The National Cancer Registry Programme (NCRP), National Centre for Disease Informatics and Research (NCDIR), Indian Council of Medical Research (ICMR), Bangalore has sanctioned this project in April 2014.

The broad objectives of the project is to assess quality of patient care and cancer services in the covered area and to describe length and quality of survival in relation to anatomical site, clinical stage, types of treatment and to undertake epidemiological research. The necessary infrastructure is developed and staff are recruited. Work for the year 2014-15 is in progress. The HBCR and POCS core forms are filled and the data are submitted to NCRP, NCDIR, Bangalore through online software.

## The Barshi Registry— The 1st Population Based Rural Cancer Registry in India

*Dr. B M Nene, Ms. Kasturi Jayant*

### Alibaug Study 1969 (K.J)

Even after setting up several Population Based Cancer Registries in India, the evidence accrued was always debated as most of the experiences were derived from urban populations whereas over 70% of India's population is rural. There are several impediments for organizing a cancer registry in a rural population. They are lack of modern diagnostic and treatment facilities, lack of awareness about cancer, population preference for locally available indigenous treatment, lack of affordability for availing modern treatment option and absence of medically certified death records. Rural population in India comprises around 75-80% of India's population.

In the rural Alibaug work we could train local volunteers for cancer awareness propagation among the rural population and more importantly we could systematically conduct several rural cancer detection camps. This created a special effect on the village people and they heartily co-operated with us. More than that, we could extend our services and gain the confidence building programme to function in the rural population. Our experience of conducting a house to house survey in 1969-70 to identify proven and suspected cancer cases in a rural population in Alibaug gave several leads to undertake a population based rural cancer registry.

I was invited by ICMR to set up the first rural cancer registry in 1987.

Ms. K. Jayant

### Barshi Registry 1987

The Nargis Dutt Memorial Cancer Hospital (NDMCH) at Barshi (Maharashtra), established by Dr. B. M. Nene in 1981 was technologically supported by Tata Memorial Center. The rural population in the vicinity of Barshi was the obvious choice for setting up the first rural cancer registry. The innovative methodology adopted for cancer registration supplemented the usual registry methodology (of active registration) by regular interaction with the community to educate the men and women on warning signals for cancer, raise cancer awareness, motivate and empower suspected individuals to seek medical attention. Cancer detection clinics were regularly held in villages. Most of the cases were registered at NDMCH and village clinics. About 11% of the cases were recovered from other sources near Barshi and 10% of the cases were from urban sources situated well outside the Registry area. For every death of a resident occurring in the village or elsewhere, a verbal autopsy was conducted. A cross-check with the hospital records of the deceased at the treating hospital, if any, was also done. The reliability indices showed the registry is of an acceptable standard. The Age Adjusted Rates for overall cancer incidence was lower than in urban registries. However, incidence of cervical cancer in women was high. Initially, the three leading cancer sites in males were Hypopharynx, Esophagus and Penis (although in recent years, mouth is becoming a leading site of cancer). Smoking dependent cancers are not common.

The registry methodology has enhanced cancer awareness in the population and drained cervical cancer cases at an early stage. Improved five-year survival among cervical cancer patients is also observed. It needs to be emphasized that in the Barshi rural cancer registry, cancer control is

an important aspect of the registry programme.

The community rapport created by the registry, human resources and infra structure developed at NDMCH have attracted international attention and large scale funding of studies on cancer prevention and control of cervical cancer in this rural area. It is heartening to note that in recent years other epidemiologic studies have also been undertaken.

Incorporating the Barshi registry incidence rates in the estimation of national cancer burden has brought in some realism to the estimates of cancer in India. This estimate would further improve as rural cancer registries are being set up in different parts of India.

The hard working social Investigators and their commitment to the programme were the major support and main stay for the functioning of cancer registry operations at Barshi. I could function along with them in several field visits. The registry system covered the populations of Barshi, Paranda and Bhum. Initially we received a strange distribution of cancer sites affecting the population. Among males, the three leading cancer sites were Hypopharynx, Esophagus and Penis. In females, Cervix cancer leads the list.

Local resources utilized were the records of Barshi Cancer Hospital, about 11% of the cases only were recovered from other sources. About 10% of the cases were from outside urban hospitals situated in Sholapur, Mumbai etc. Deaths recorded had to be followed to the addresses for a better appreciation of cause of death.

Looking back I am happy that

1. The process is continuing
2. Services to the people are available
3. Scientific contribution made on cancer epidemiology in rural India.

Ms. K. Jayant



**Mrs. Kasturi Jayant**

Mrs. Kasturi Jayant joined as Statistician at the Human Variation Unit in the Indian Cancer Research Centre (ICRC) in 1953. Her basic training was in Statistics and she became associated with several work fields of ICRC. Dr L D Sanghvi was the chief of Human Variations Unit. The land mark study on oral cancer and tobacco habit was published in British Journal of Cancer in 1955 which was highly appreciated by the scientific community. Several epidemiologic studies have been reported by Mrs. Jayant. Most of studies or topics covered were unique and attempted for the first time in our country.

Mrs. Jayant gave innovative lead for the cancer control work in the rural area of Alibag in early 1970s and later on she was instrumental in organizing the first rural cancer registry of India at Barshi in 1987.

She continues to lead the Barshi Expanded Registry covering Osmanabad and Beed Districts along with Dr B M Nene, Director, Nargis Dutt Memorial Cancer Hospital in collaboration with NCRP.

She is a Life Member of Indian Association of Cancer Research, Human Genetics Society and Action on Tobacco.

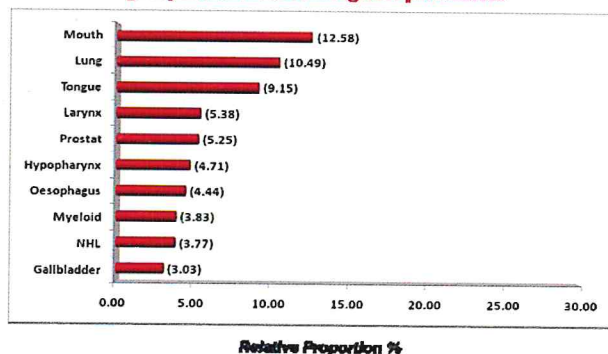
Indian Council of Medical Research awarded her the Sandoz Oration Award for research in cancer.

She is an honorary member of International Association of Cancer Registries.

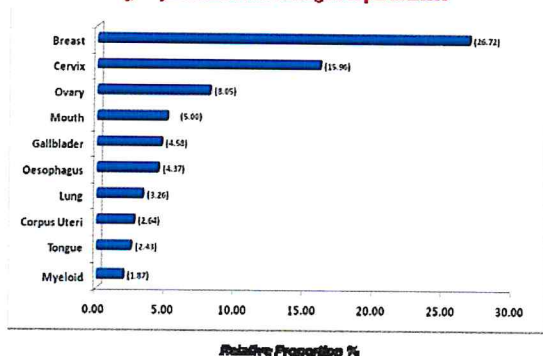
records. Any further matches discovered in this fashion are updated. Cancers with no other details, other than those available on the death certificate, are registered as "Death Certificate Only". Significant improvement in mortality statistics has been found by using this methodology.

In the last two decades of its functioning the registry has observed a very high incidence of tobacco related cancers among males with cancer of lung, tongue, mouth, hypopharynx, and esophagus as the leading sites. As per the Cancer Incidence in Five Continents the incidences of Tongue and Mouth cancers among males of Bhopal are highest in the world. High prevalence of tobacco chewing in the population underlines the increasing incidence of Mouth cancer in the city of Bhopal and is a cause of concern for the cancer control activities in the region. The Government of Madhya Pradesh ban on tobacco chewing has been a significant move towards the cause.

**Ten Leading Sites of Cancer among Males 2009-2010**  
Age Adjusted Incidence Rates give in parentheses



**Ten Leading Sites of Cancer among Females 2009-2010**  
Age Adjusted Incidence Rates give in parentheses



Among females cancer of breast, genital system and esophagus are the leading sites. These malignancies accounts for more than 55% of the total cancer burden. Cancer of the breast has shown a rising trend whereas a significant decreasing trend has been observed for cervical cancers.

During the years 1991-2010 the AAR for Tongue cancer varied from 8.8/100,000 to 9.5/100,000, whereas for mouth cancer the AAR varied from 7.8/100,000 to 12.8/100,000. Statistically no significant change was observed in the incidence rates of Tongue cancer whereas a statistically significant increasing trend was observed in the incidence of Mouth cancers (APC:2.97 %,  $p < 0.05$ ) with a shift towards younger ages. Similar shift towards younger age was also observed for Tongue cancer.

In the year 1988 Cervix was the leading site of cancer contributing 24.6% of the total cancers among females, followed by Breast 21.2% and Ovary 5.3%. By the year 2010 the pattern of these sites of cancer changed significantly with cancer of the Breast becoming the leading cause of cancer contributing 26.7% of all cancers followed by cervix 16.0% and ovary 8.0%. The time trend analysis indicated a significant increasing trend for cancer of Breast (APC:1.7%  $p < 0.05$ ) and Ovary (APC:2.3%  $p < 0.05$ ) where as a decreasing trend was observed for cancer of Cervix (APC: -1.3%  $p < 0.05$ ). The trends have resulted in a significant change in the load and pattern of these cancers among population of Bhopal. The observed changes in the load and pattern of these cancers will help in redefining the cancer control activities in the region.

#### Team at Task

Dr. Sunil Surange	Research Officer
Mrs. Alka Goley	Social Investigator
Mrs. Sushma Shrivastava	Social Investigator
Mrs. Shubhra Trivedi	Social Investigator
Mrs Ragini Nair	Typist

Mr. Atul Shrivasthava, Research Officer and Co-Principal Investigator has been nominated as advisor to the WHO collaborating centre on

## Population Based Cancer Registry of Bhopal, Gandhi Medical College, Bhopal

Principal Investigator : Dr. Reeni Malik  
Co. Principal Investigator : Mr. Atul Srivastava

Under the network of National Cancer Registry Programme a Population Based Cancer Registry Bhopal was established in the year 1985. The registry is placed in the Department of Pathology, Gandhi Medical College, Bhopal. The main objective of the registry is to generate a reliable data on magnitude and pattern of cancer morbidity and mortality among the population of Bhopal urban agglomerate. The collection and compilation of data began from 1<sup>st</sup> January 1986.

Bhopal is situated at an altitude of 505 meters above the sea level at 23.07°North and 77.12° East with a total area of 284.90 sq km, Bhopal is the capital of the state of Madhya Pradesh (India) and the administrative headquarters of Bhopal district and Bhopal division. Bhopal is known as the "City of Lakes" for its various natural as well as artificial lakes and is also one of the greenest cities in India. The city has a humid subtropical climate, with cool, dry winters, a hot summer and a humid monsoon season. According to the 2011 census the population of the Bhopal city is 1,795,648, with 939,560 males and 856,088 females. The urban / metropolitan Bhopal population extends beyond Bhopal city, and the metro population was 1,883,381 in 2011. The total effective literacy rate was 85.24%, with male and female literacy respectively at 89.2% and 80.1%. Out of Bhopal's total population, 1.25 million were Hindus (71%), 0.5 million or 500,000 were Muslims (27%), and rest were Jains, Christians, Buddhists, Sikhs and others. As per GATS India Report 2009-201 the prevalence of smokeless tobacco usage

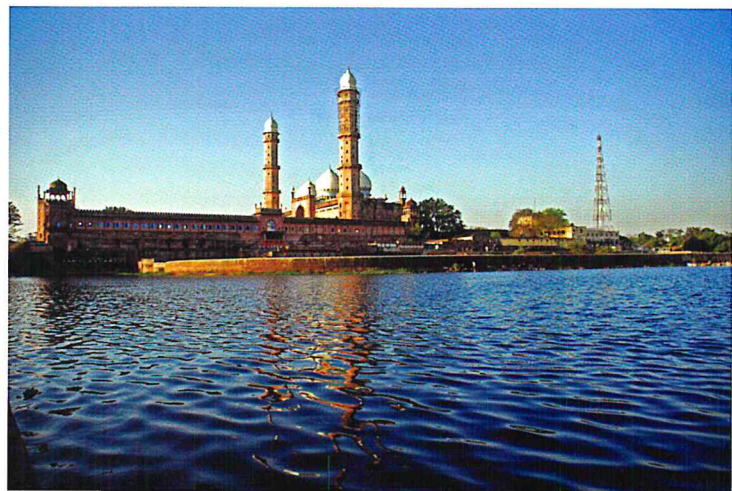
among males in the state is very high and so does in the city of Bhopal.

Registration of cancer cases is done by active method of registration. Information on cancer patients is obtained from 62 sources which include 7 comprehensive cancer care units' government hospitals, private hospitals, nursing homes and diagnostic centres. Due to growing population and increasing number of cancer care facilities in Bhopal, the manual data collection required a lot of manpower. The manual process resulted in a delayed data finalization. To reduce the manpower requirement and overcome the delay in data finalization, the registry started exploring the use of electronic medical records at various sources of registration. These records were transferred to the registry databases which were then processed for registration using dedicated computer software. Ensuring totality in electronic medical records and software based processing of records has resulted in enhancing completeness of data, improving the quality of registration with timeliness in data finalization.

Cancer mortality data was assumed to be incomplete due to incorrect certification of cause of death. Keeping this in mind, efforts have been made to improve this aspect of data. Burial ground and crematorium records of Bhopal were examined and all deaths irrespective of the cause of death mentioned were noted. These are then matched with the cancer morbidity data available in PBCR. The deaths which match are then updated. The deaths which mentioned cancer as cause of death but could not be matched were traced back by house visits and scrutiny of medical

family of International Classification ICD – 10 and ICF in India and Central Bureau of Health Intelligence (CBHI), Ministry of Health and Family Welfare, Government of India.

### Views of Bhopal City:

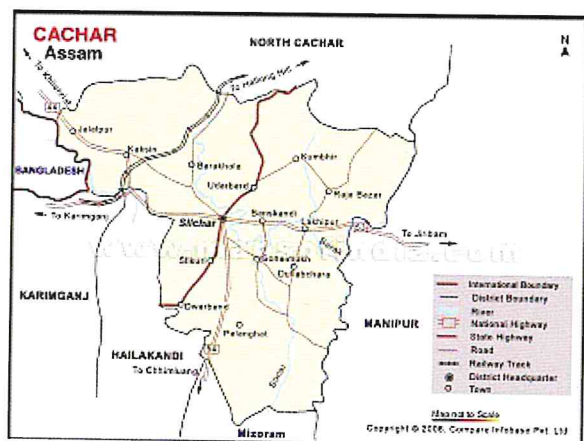


## Population Based Cancer Registry–Cachar District

Principal Investigator : Dr. Sekhar Chakravarti  
Co. Principal Investigator : Dr. R P Banik

The PBCR Cachar district of Assam started functioning from 2007. It is one of the six old cancer registries of North East India. The registry is located in the city of Silchar, the head quarters of the district of Cachar, Assam. The PBCR area is a mix of rural and urban population. The total population is over seventeen lakh out of which the rural population is about 80% of the total population.

**A Map of Cachar District**  
(Area covered by the registry operation)



The general life style of the people is similar to the plains of the country. Rice is the staple food and majority is non vegetarian. Chewing of “betel quid or Pan “comprising of betel leaf, dried betel nut, lime and homemade dried tobacco leaf powder is a very common socio cultural habit. Offering a “Pan Khili” or “Betel quid” to the guests and invitee at home or in any social gathering is a tradition here.

There is a Government Medical College, a Cancer Hospital, many diagnostic centers and nursing homes in the city of Silchar with adequate facilities for radiological and pathological diagnosis of cancer. Cancer treatment is being done in the Cancer Hospital and in Medical College.

**The number major sources in the registry area is as follows**

- Hospital - 4nos
- Private Laboratory –10nos
- Nursing homes- 8nos

Vital Statistics Department - Office of the birth & death registration of Silchar, Cachar and Silchar Municipal Board.

**Cancer cases in the registry area 2011-2012**  
Male: 1566 Female: 1206 Total: 2772

### Seven Leading sites of cancer (2011-2012)

MALE	AAR	FEMALE	AAR
Esophagus	13.11	Breast	11.94
Lung	10.46	Cervix	10.75
Hypopharynx	10.4	GB	9.21
Tongue	6.94	Esophagus	6.96
Mouth	5.45	Mouth	3.57
Stomach	4.85	Lung	3.42
Larynx	4.75	Ovary	3.30

**Proportion of Tobacco related cancer (2011-2012)**

Population	Number of cases	Percentage
<b>Male</b>	820	52.36%
<b>Female</b>	301	24.96%

**Some major difficulties in obtaining data in our area are as follows**

- Many variables are not available in the records of some sources.
- Some cases cannot be traced as they are diagnosed and treated in cancer centres outside the states.
- Some patients do not want to share information.
- Due to incomplete death certification and less number of death registration in rural females, collection of reliable mortality data remains a major challenge.

**37<sup>th</sup> ANNUAL MEETING OF IACR****2nd time in India**

The 37<sup>th</sup> Annual Meeting of International Association of Cancer Registries (IACR – IARC) will be held from 7<sup>th</sup> to 10<sup>th</sup> October 2015 at Taj Mahal Palace, Mumbai – Hosted by Tata Memorial Centre – Dr. R A Badwe, FRCS, Director, Programme Co-ordinator, Dr. Rajesh Dixit, M Sc, Ph D, Prof of Epidemiology, Tata Memorial Centre, Mumbai.

The 18<sup>th</sup> Annual Meeting of IACR was held at Ashok Hotel, Bangalore in 1994, hosted by Kidwai Memorial Institute of Oncology, Bangalore and National Cancer Registry Programme – ICMR.

Organizer & Co-ordinator was Dr. A. Nandakumar, MD .

**31<sup>st</sup> ANNUAL REVIEW MEETING of NCRP - ICMR**

The 31<sup>st</sup> Annual Review Meeting of NCRP – ICMR will be held on 5<sup>th</sup> and 6<sup>th</sup> October 2015 at Tata Memorial Centre, Parel, Mumbai - 12.

Local Co-ordinator: Dr. B. Ganesh, M Sc, Ph D.

## Delhi PBCR - Dr. B.R.A. Institute Rotary Cancer Hospital, All India Institute of Medical Sciences, New Delhi

Principal Investigator: Dr. P. K. Julka

Co. Principal Investigators: Mr. N. Manoharan, Dr. G. K. Rath

The population based cancer registry at Dr. B. R. Ambedkar Institute Rotary Cancer Hospital (IRCH), All India Institute of Medical Sciences (AIIMS), New Delhi was established in January 1986 with the aim of obtaining reliable morbidity and mortality cancer data among the Delhi residents.

Delhi is a densely populated urban metropolis situated between the Himalayas and the Aravalli range in the heart of Indian sub-continent. It lies between 28 25' and 28 53' North latitude and 76 50' and 73 20' East longitude. It is surrounded on the north, west and south by Haryana and the east by the Uttar Pradesh. The Delhi State for the purpose of census was divided into 4 tracts viz.:-

- Delhi Municipal Corporation (Urban)
- New Delhi Municipal Committee
- Delhi Cantonment and
- 29 Census towns

According to 2011 census the population in Delhi UT Urban is 16,787,941 (Males: 89,87,326; Females: 78,00,615). The sex ratio in Delhi is 868 females per 1000 males. The density of population is 11320 persons per sq. km. The total area of National Capitol Territory of Delhi is 1483 Sq. kms. The rural and urban areas are 591.91 sq. kms and 891.09 sq. kms respectively.

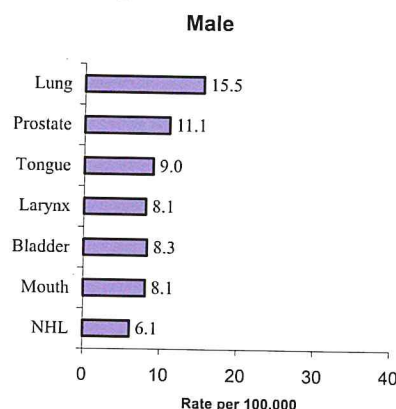
The registry covers only urban area of Delhi. The registry collects morbidity and mortality data on cancer patients from 162 major Govt. Hospital centers and Institutions, more than

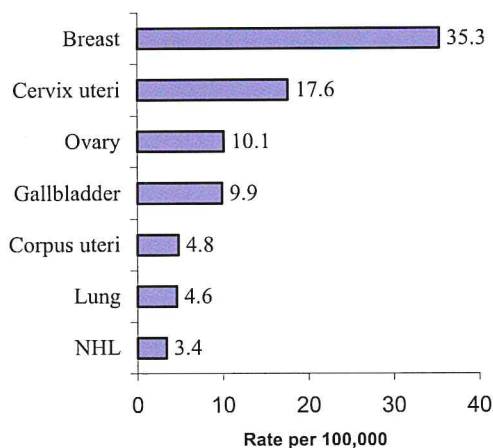
250 private hospitals and nursing homes, and the Dept. of Vital Statistics of the Delhi Municipal Corporation, New Delhi Municipal Committee and the Cantonment Board. When the registry was established in 1986 it had only 25 major sources for data collection. Currently it has a number of excellent facilities for cancer diagnosis in both government and private set up. A number of new hospital / centers have come up over the years and so the number of sources also increased for data collection

A total of 17,175 cancer cases were registered in 2010. Out of these, males were 8993 (52.4%) and females 8182 (47.6%). AIIMS/IRCH and Rajiv Gandhi Cancer Hospital are contributing nearly 18% and 16% cases respectively. Safdarjung Hospital and Delhi State Cancer Institute are contributing 10% each and the remaining 46% of cases were contributed by the rest of the sources.

The world age-adjusted (AAR) for all sites among the males and females are 141.5 and 132.6 per 100,000 persons respectively for 2010.

### 7 leading sites of cancer males and females - 2010



**Female**

Since the inception of the Delhi PBCR, carcinoma of lung remains the leading site of cancer among males. Prostate cancer which was the seventh leading site of cancer in 1988 becomes the second leading site. It also tops second among the Indian registries preceded by Kamrup Urban District. Cancer of mouth which was not among the leading site of cancer in 1988 became sixth leading site of cancer in Delhi. The incidence of urinary bladder cancer in Delhi is the highest among the Indian registries reported.

Breast cancer which was second commonest cancer among females in 1988 became the leading site of cancer replacing cancer of the cervix. Cancer of corpus uteri which was not among the leading site of cancer in Delhi in 1988 becomes the fourth leading site of cancer. It was also the third highest among the Indian registries. Gallbladder cancer which is common in Delhi was the third highest among Indian registries. Cancer of the lung which was not among the ten leading site in 1988 became the sixth leading site among female cancers.

In males, a statistically significant increase in AAR was observed for cancer of lung, prostate, tongue, bladder, mouth and NHL over the years (1988-2010) and in females a statistically significant increasing trend was observed for cancers of breast, ovary, gallbladder, corpus uteri, lung and NHL and a decreasing trend was observed for cervix uteri. It may be noted that stomach and esophageal cancers have low

incidence rate compared to the North East experience.

The major difficulty faced by the staff is that as Delhi is vast area it consumes lot of time in traveling (reaching different sources). Another difficulty faced by the staff is that in some major hospital disease indexing and coding has not been done in due time and the staff are forced to scrutinize the entire files of the Medical Records department for cancer data collection.

The registry has now started HBCR and POCSS with the financial assistance of NCRP, NCDIR, ICMR, Bangalore and data collection is under process.

In females, breast (35.3), cervix uteri (17.6), ovary (10.1), gall bladder (9.9), corpus uteri (4.8), lung (4.6) and NHL (3.4) are the first seven leading sites of cancer.

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### Staff of Delhi PBCR

1. Dr. P.K. Julka M.D.	- Head
2. Mr. N.Manoharan M.Sc., P.G.D.C.A.	- Scientist – III
3. Mr. Ashok Kumar Singh M.S.W	- Supervising MSSO
4. Mr. Shambu Prasad Bhadola M.A.	- MSSO (Gr.I)
5. Ms. Indu Gaur M.S.W.	- MSSO (Gr.I)
6. Mr. S.K.Rai M.S.W.	- MSSO (Gr.II)
7. Ms. Sudha Saxena M.A.	- MSSO (Gr.II)
8. Mr. C.P.Singh M.S.W.	- MSSO (Gr.II)
9. Mr. Anand Sharma M.S.W.	- MSSO (Gr.II)
10. Ms. Rosemary Gangte.M.S.W., M. Phil(PSW)	- MSSO (Gr.II)
11. Mr. Aditya Kumar M.J.M.C	- Receptionist
12. Mr. Sanjiv Kumar Pandey	- Data Entry Operator
11. Ms. Garima Negi	- LDC



### Staff – Delhi Registry



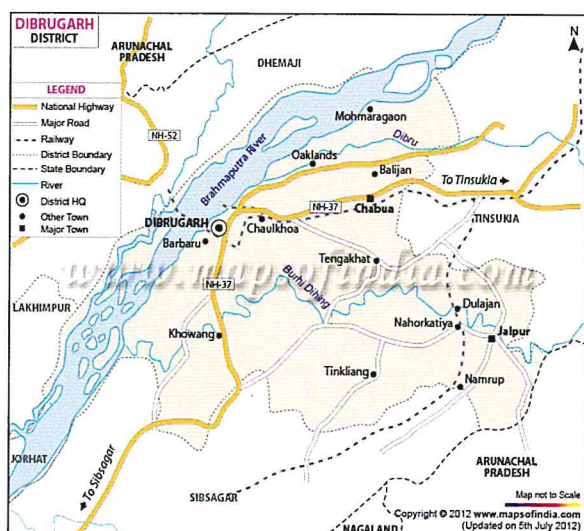
## PBCR, Dibrugarh

Principal Investigator: Dr. M. S. Ali

Co. Principal Investigators: Dr. S. Bhuyan, Dr. C Hazarika

The PBCR covering the district of Dibrugarh situated in the eastern corner of the state of Assam was initiated as a part of North-East Regional Cancer Registries (NERCR) by NCRP of ICMR in 2003. Dibrugarh is predominantly a rural district comprising 81.6% rural and 18.4% urban population. There are 7 towns and 1348 villages in the district. The map showing the geographical boundary and demographic profile as per 2011 census report of the district are given in Fig 1 and Table 1.

**Fig 1: PBCR area, Dibrugarh district, (3381 sq Km)**



**Table1: Demographic profile: PBCR area**

Area covered : Dibrugarh District : 3381 sq.km	
Population ( 2011 census)	Male : 6,76,434
	Female : 6,49,901
	Total : 13,26,335
Male : Female	0.96:1
Literacy Rate	Male : 72.6%
	Female : 60.5%
	Total : 66.7%
Urban Population (18.38%)	2,43,730
No. of Towns	7
Rural Population (81.62%)	10,82,605
No. of villages	1348
Density	392 / sq.km

**Sources of Registration:** Apart from Assam Medical College Hospital (AMCH), there are many sources of registration both within and outside the registry area. These include, one Govt. Railway Hospital, OIL Hospital, Fertilizer Corporation Ltd. Hospital, Tata Referral Hospital, 32 nursing Homes, 35 Pathology Laboratories and Imaging Centres and 15 Birth and Death Registration centres (VSD) located at different PHCs and CHCs of the district. Currently there are 87 data collection sources.

**Table 2: Number and proportion of cancer cases registered during 2012-13 from major sources:**

Major Source	#	%
AMCH	1126	59.3
Private Hospital/ N. Homes	144	7.6
Laboratories	209	11.0
Outstation Sources	179	9.4
VSD (DCO)	240	12.6
<b>Total</b>	<b>1898</b>	<b>100.0</b>

AMCH has adequate facilities for diagnosis and treatment of cancer but being only a tertiary Govt. general hospital lacks comprehensive treatment infrastructure for certain types of cancer. With the increase in literacy level as well as spread of health awareness among the population, increasing number of cancer patients have been going to advanced cancer centres outside Dibrugarh/Assam; and in the absence of central referral mechanism in the District Health Department, it was not possible to know the whereabouts of those patients. However, the registry gets feedback from some of the outstation sources and Cancer Atlas Website but still a sizeable proportion of cancer cases remained untraced. These have been the sole reasons for consistently high proportion of DCOs in Dibrugarh registry. The travel agents, airport authority or the railway stations do not maintain records of cancer patients who seek travel concessions.

Moreover, it has been observed that the number of cancer cases registered from Nursing Homes and Laboratories have been gradually declining over the recent years. The Social Investigators are not allowed to visit the wards or to make contacts with the patients registered exclusively from private hospitals and nursing homes. The registry has provided abridged forms to all diagnostic centres containing salient identification items including site and histology / cytology/ imaging report. The patient's attendants are supposed to fill in the identification part and the laboratory technician the technical part. Due to ignorance on the part of the attendants in many instances the identification parts remained incomplete. These are some of the formidable perennial problems the PBCR, Dibrugarh has been facing.

**Life style of the population:** Dibrugarh is predominantly a rural district where 81.6% populations are rural and 18.4% urban. Tea and oil are two major industries of the district. The landscape of the district is dotted with 140 lush green tea plantations having workforce (workers and their dependents) consisting 28% of the total population.

A study conducted on tobacco and alcohol use in the tea garden populations of Dibrugarh district (GK Medhi et al, 2006) revealed that the prevalence of alcohol consumption among the youths in tea gardens was 33.2%, the prevalence of non-smoked (chewing and/ or khaini/Chadha) tobacco was 52.5%. However, the prevalence of smoking was only 2.2%. Most of the tobacco users used non-smoked tobacco because of cheaper rates and easily available and considered by some to be less harmful. The literacy rates in tea-garden population (42%) is comparatively very low than the general population which was 67%. The prevalence of these habits in the community may also be compounded by wide spread illiteracy. The prevalence of alcohol use was significantly higher ( $p < 0.05$ ) among respondents in whom both parents were illiterate (34.8%) than in the respondents in whom at least one parent was literate (25.4%). Likewise in whom both the parents were illiterate, the prevalence of tobacco use was 55% higher when one parent was literate (48%).

Alcohol and tobacco use are influenced by cultural practices and religious faiths. Alcohol use is woven into religious rituals and the cultural fabric of not only among tea garden community but also among other ethnic communities of the district. Tea drinking is a very common habit among the population. Pattern of tea drinking and temperature at which tea is drunk is significantly associated with the occurrence of esophageal cancer (R. Malekzadeh et al, 2009). Moreover, khar a locally made alkaline additive is also very common dietary practice in the district. The frequent consumption of khar has also been found to be a potent risk factor of esophageal cancer (Ali, M.S et al, 2001). These are some of the common prevalent practices in the district which may account for high incidence of the cancers of the esophagus, hypopharynx, mouth and lung in the population.

**Cancers by Gender, PBCR, Dibrugarh 2012-2013:** Seven leading cancers by site and sex are given in table 2A and 2B. Cancer of esophagus, hypopharynx and stomach has been the top three cancers among males during 2012-2013 followed by mouth, lung, tongue and colon. It may be mentioned here that mouth was the third leading site till 2010 which was replaced by stomach since 2011.

In female breast has been the commonest site of cancer in the individual years since 2004 followed by esophagus in the earlier years 2004 through 2010. However, from 2011 onwards gallbladder became the second leading site of cancer among females followed by esophagus, ovary, cervix uteri, stomach and mouth. The AAR of cancer cervix in Dibrugarh registry is the lowest among all the PBCRs under NCRP. Overall, the incidence of esophageal cancer in PBCR, Dibrugarh was the highest in the population constituting almost one-fourth of all cancers in the population.

Table 3A shows the number of incident cancer cases by sex during the years 2012-2013. Table 3B shows the numbers of incident cancer cases by sex-ratio during the year 2010-2013. The sex-ratio has been gradually narrowed down over the years and in 2013 it was nearly even. The trends may apparently mean that cancer incidence among females was gradually increasing. It may also be interpreted other way that increasing number of male cancer patients have opted for better treatment in advanced cancer centres outside the registry area which as per our observation, is more likely.

The latter likelihood is reflected in Table 3C which shows the number and proportion of DCOs by sex during 2010-2013. All throughout the male proportions have been more than twice the female proportions which implied that higher number of male cancer patients went to unknown sources outside the registry area for treatment. They returned and died at their residence and registered as DCOs.

### Number, Relative Proportion (%) and AAR of Common Cancers of Dibrugarh District by Sex: 2012-2013

Table 3A: Male			
Site	No.	%	AAR
Esophagus	148	15.0	15.9
Hypopharynx	116	11.7	12.4
Stomach	85	8.6	9.1
Mouth	69	7.0	6.9
Lung etc.	54	5.5	5.9
Tongue	47	4.8	4.9
Colon	38	3.8	3.9
<b>All Sites</b>	<b>990</b>	<b>100.0</b>	<b>102.5</b>

Table 3B: Female			
Site	No.	%	AAR
Breast	163	18.0	15.4
Gallbladder etc.	104	11.5	10.9
Esophagus	85	9.4	9.4
Ovary etc.	76	8.4	6.8
Cervix uteri	58	6.4	5.7
Stomach	54	6.0	5.3
Mouth	36	4.0	4.0
<b>All Sites</b>	<b>908</b>	<b>100.0</b>	<b>91.1</b>

**Table 4A: No. of Incidence Cases of Male & Female,  
Dibrugarh District: 2012-2013**

Year	Male	Female	Total
2012	501	425	926
2013	489	483	972
2012-2013	990	908	1898

**Table 4B: Cancer incidence by sex-ratio in PBCR,  
Dibrugarh: 2010-2013**

Year	Male	Female	Sex-ratio	Total
2010	478	331	1:0.69	809
2011	497	336	1:0.76	873
2012	501	425	1:0.85	926
2013	489	483	1:0.99	972

**Table 4C: Number and proportion of DCOs by sex,  
2010-2013, PBCR, Dibrugarh**

Year	Male		Female		Total DCOs
	#	%	#	%	#
2010	71	73.20	26	26.80	97
2011	106	71.62	42	28.38	148
2012	71	70.30	30	29.70	101
2013	87	62.59	52	37.41	139
Total	335	69.1	150	30.9	485

#### References:

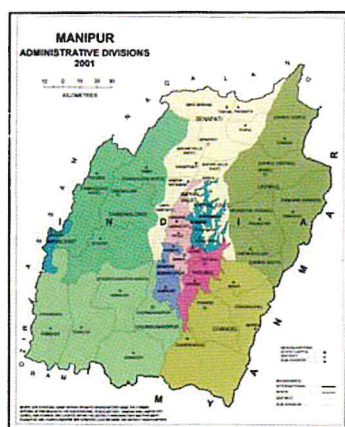
1. Medhi GK, Hazarika NC et al: Tobacco and alcohol use among the youth of the agricultural tea industry in Assam, India. *Southeast Asian J Trop Med Public Health* 2006; 37,581-586
2. Malekzadeh R, Bofetta P et al Tea drinking habits and oesophageal cancer in a high risk area in northern Iran: population based case-control study: *BMJ* 2009; 338

## Population Based Cancer Registry, Manipur State - Regional Institute of Medical sciences, Imphal

Principal Investigator : Dr. Kaushik Debnath  
Co. Principal Investigators : Dr. Punyabati Devi, Dr. L. Rajesh Singh  
Research Officer : Dr. H Satyajyoti Singh

**Introduction:** The Population Based Cancer Registry (PBCR), RIMS Imphal is functioning in the department of Pathology, Regional Institute of Medical Sciences (RIMS) since January 2003. It is one of the Cancer Registries in Northeastern India functioning under National Cancer Registry Programme (NCRP) of the Indian Council of Medical Research (ICMR). Initially, it covered only the most populated district of Imphal West with an area of 519 Sq.Km and an estimated population 4,39,532. Since January 2005, the study has been extended to whole state of Manipur with total area of 22,327 Sq.Km and total population of 28,55,794 (2011 census) of which 14,38,586 are male and 14,17,208 are female. Nearly 90% of the total land area is covered by hills and the plain area occupies the centre of the mainland.

The following table shows the distribution of cancer incidence of rural and urban population in different districts of Manipur during the year 2014.



District (Codes)	Rural		Urban		Total	
	#	%	#	%	#	%
Senapati (1401)	96	8.4	0	0.0	96	6.3
Tamenglong (1402)	32	2.8	0	0.0	32	2.1
Churachandpur (1403)	134	11.8	0	0.0	134	8.9
Bishnupur (1404)	143	12.5	2	0.5	145	9.6
Thoubal (1405)	232	20.4	0	0.0	232	15.3
Imphal West (1406)	205	18.0	278	74.5	483	31.9
Imphal East (1407)	178	15.6	92	24.7	270	17.8
Ukhrul (1408)	75	6.6	0	0.0	75	5.0
Chandel (1409)	45	3.9	1	0.3	46	3.0
<b>MANIPUR</b>	<b>1140</b>	<b>100.0</b>	<b>373</b>	<b>100.0</b>	<b>1513</b>	<b>100</b>

**Life Style Peculiarities which may be associated with cancer occurrence:** The most common site of malignancy among both males and females during the last 10 years is carcinoma of lung. Among many contributory factors, a particular type of hut in which majority of the population lived decades back might have played some role. This hut is an unitary structure having mud-plastered wall, thatched roof and fitted with a single door for both entry and exit. Very few of these huts had provision for cross ventilation. Over and above, due to lack of electricity, they used kerosene lamp as source of light, fire woods and dried husk of paddy for cooking, resulting in trapped smoke inside the room for most of the time.

**Traditional Manipuri Thatched hut****Hut during the winter**

**Dietary Habits:** Manipur is inhabited by various ethnic groups and their diverse food comprise both fermented and non fermented items. Different types of fermented foods are prepared and consumed by different ethnic groups of this region, which includes various preparations made out of vegetables, bamboo, soyabeans, meat, fish, cereal and alcoholic beverage. The fermented food particularly bamboo shoot (soibum, soijin and soidon), soyabeans (hawaizar) and fish (Ngari) are very popular to all the households in Manipur and have been consuming on regular basis in different recipies since time immemorial.

**Traditional method of preparing smoke dried Fish**

**Fermented Fish (Ngari)****Fermented Soyabeans (Hawaizar)**

Other than the fermented foods, majority of the population consume smoked dry fish and meat. The content of toxic hydrocarbon compounds in such items is very high which are well known carcinogenic agent. Chewing betel nuts with or without tobacco is also common here. The dietary habits seem to contribute to some extent for the increase incidence of cancer of aerodigestive tract (e.g: Nasopharynx, Esophagus, Stomach, Liver, Gall Bladder, Colon and Rectum). Thus there is ample scope for carrying out scientific study and research in establishing affects (if any) of dietary habit in cancer progression.

**Facilities Available for Diagnosis and Treatment:** For the diagnosis of cancer, FNAC (Fine Needle Aspiration Cytology) and HPE (Histopathological Examination) are widely available in both government and private sectors. So the numbers of microscopically diagnosed cases are very high (above 90%). Facilities for X-ray, CT scan, MRI, Ultrasonography are also available in most of the major hospitals and diagnostic centres. Biochemical tumour markers study for different site/organs are available in Babina Diagnostic Centre and RIMS, Imphal. Regional Institute of Medical Sciences (RIMS), Imphal is the only centre where cancers are being treated. Radiotherapy department is well established and has the following facilities for treatment:

1. Cobalt-60 Theratron 780-C 3 megavolt (Canada)
2. High Dose Rate (HDR) Microselectron of Nucletron Co.(Ir.192 Source–Brachytherapy Unit)
3. Simulix – XP Nucletron (Conventional Simulator with image intensifier)
4. Equinox Theratron (Telecobalt with Energy equivalent to 6 MV)
5. Treatment Planning System Oncentra (Nucletron Co.)
6. Mould Room

There are functional units of Medical and Surgical Oncology in the departments of Medicine and Surgery respectively.

**Sources Covered:** The registry collects information from 28 sources of which 10 are hospitals and 18 are clinical laboratory or diagnostic centres.

**Major Primary Contributing Sources during the year 2014**

<b>Name of Major Contributing Sources within Registry Area</b>	<b>#</b>	<b>%</b>
Regional Institute of Medical Sciences (RIMS), Imphal	906	59.9
Babina Diagnostic Centre (BDC), Imphal	513	33.9
Shija Hospital and Research Institute (SHRI), Langol	45	3.0
Imphal Hospital and Research Centre (IHRC), Imphal	49	3.2
<b>Total</b>	<b>1513</b>	<b>100.0</b>

There are altogether 51 secondary sources outside our registry area of which 30 are hospitals and remaining 21 are clinical lab. Or diagnostic centres.

**Major secondary contributing sources outside our registry area during 2014**

<b>Major Secondary Contributing Sources Outside Registry Area</b>	<b>#</b>	<b>%</b>
Tata Memorial Hospital (TMH), Mumbai	31	33.0
Ayursundara Medical Centre, Mumbai	10	10.6
Dr. B Barooah Cancer Institute (BBCI), Guwahati	8	8.5
Saharia Path Lab. Guwahati	8	8.5
All India Institute of Medical Sciences (AIIMS), New Delhi	7	7.4
<b>Total</b>	<b>64</b>	<b>100.0</b>

The total number of cases registered during the year 2014 was 1513, out of which 671 cases were male and 842 cases were female.

**Number, Proportion, CIR, AAR and TR of Leading Sites of Cancer, Manipur: 2014**

<b>MALE</b>							
<b>Sl. No.</b>	<b>ICD 10</b>	<b>Site</b>	<b>No.</b>	<b>%</b>	<b>CIR</b>	<b>AAR</b>	<b>TR</b>
1	C33-34	Lung	99	14.8	6.3	11.4	8.7
2	C15	Esophagus	55	8.2	3.5	5.8	9.2
3	C11	Nasopharynx	40	6.0	2.5	3.9	9.0
4	C16	Stomach	38	5.7	2.4	4.3	5.8
5	C82-85,C96	NHL	37	5.5	2.4	3.1	5.9
6	C32	Larynx	28	4.2	1.8	3.2	4.9
7	C92-94	Myeloid Leuk	27	4.0	1.7	2.2	3.1
<b>Others</b>			<b>250</b>	<b>37.3</b>	<b>15.9</b>	<b>25.4</b>	<b>37.9</b>
<b>All Sites</b>			<b>671</b>	<b>100.0</b>	<b>42.7</b>	<b>69.0</b>	<b>99.6</b>

FEMALE							
Sl.No.	ICD 10	Site	No.	%	CIR	AAR	TR
1	C50	Breast	139	16.5	9.0	10.8	26.5
2	C33-34	Lung	103	12.2	6.6	10.5	11.6
3	C73	Thyroid	83	9.9	5.3	6.0	10.9
4	C53	Cervix Uteri	68	8.1	4.4	5.5	13.6
5	C23-24	Gall Bladder	42	5.0	2.7	3.1	7.6
	C56	Ovary etc.			2.7	3.7	8.7
6	C16	Stomach	37	4.4	2.4	3.2	6.0
7	C82-85,C96	NHL	36	4.3	2.3	3.0	6.0
<b>Others</b>			<b>206</b>	<b>24.5</b>	<b>13.3</b>	<b>17.2</b>	<b>33.2</b>
<b>All Sites</b>			<b>842</b>	<b>100.0</b>	<b>54.3</b>	<b>70.4</b>	<b>135.5</b>

CIR = Crude Incidence Rate per 100,000 persons, AAR = Age Adjusted Rate (Age Standardized Rate) per 100,000 persons,  
TR = Truncated Rate (AAR for the age groups 35-64 years per 100,000 persons)

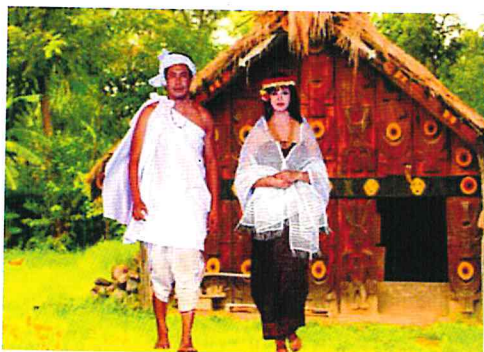
**Difficulties Encountered & Methods used to solve them:** Besides the prevailing law and order problems, difficulties in registration of cancer cases and records of death in Manipur, our staff also encounters other forms of difficulties and some of them are as follows.

- Information obtained from various pathological laboratories, Radiological or private X-ray clinics often do not give full details of the patient like complete residential address etc. So every effort has to be made to trace these patients to the source namely, referring doctor/hospital/ nursing home/ medical records etc. Even after approaching them, we find incomplete information and at times the name of the referring doctor is missing. For that we personally persuade them to kindly record the complete residential address and if possible contact numbers of the patients and concerned doctors.
- We often fail to find the primary site of cancer and laterality of paired sites from the case files. Thus it takes time for further investigations. In such case, we keep in touch with the concerned doctor and enquire from time to time for the final diagnosis. Despite all these efforts, some of the cases remain unsolved.
- Co-operation given by all the concerned personal in private hospitals and laboratories are appreciable except one or two who wants incentives only in the form of cash. For that our Principal Investigator has been kind enough to approach them personally and do the needful like making them understand the basic purpose, aims & objectives of our work.
- Death registration system and certification has been extremely poor in our state. In paper, registration of birth and death is compulsory but not in practice. Even the records of Vital Statistics Department, birth & death records (especially death) of the Municipal councils are not maintained properly. Death certification is done only at hospital and according to our unique custom, as far as possible patients with chronic illness or who are in terminal stages are allowed to die at home where the local quacks take the charge of declaration of death. Hence, there is less chance of authentic certification except for few cases of insurance claims.

Every weekend all the staff of our registry sits together and the work is assessed and the difficulties and problems faced by the various personals are also discussed.

### Some of the Ethnic groups in Manipur in their traditional dresses

**Meitei couple in traditional dress**



**Rongmei - Naga Couple**



**Vaiphei – Kuki couple**



**Baite - Mizo Couple**



## Kamrup Urban District Cancer Registry - PBCR

Principal Investigator: Dr. Jagannath Dev Sharma, PBCR & HBCR  
Dr. A. C. Kataki, Director, Dr. B. Borooah Cancer Institute,  
Dr. Debanjana Barman, Medical Research Officer

Indian Council of Medical Research (ICMR) launched National Cancer Registry Programme (NCRP) in 1982 to measure the burden and pattern of cancer in India. No data on cancer was available till 2001 from NE-region when the "Development of an Atlas of Cancer in India" a WHO-sponsored ICMR project started in the Department of Pathology of Dr. B. Borooah Cancer Institute (BBCI). The relatively high frequency of microscopically diagnosed cancer cases observed was the reason for commencing Population Based Cancer Registry (PBCR) in Kamrup Urban District in 2003.

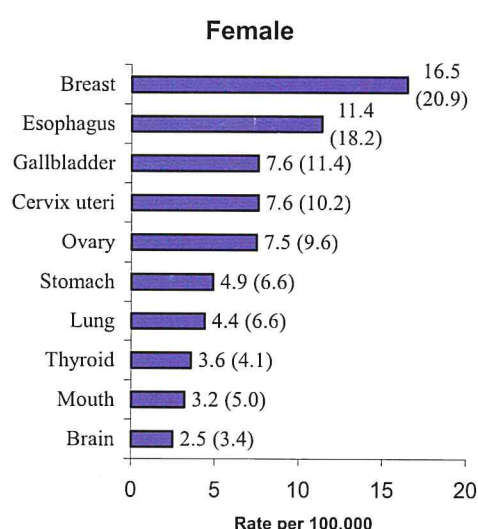
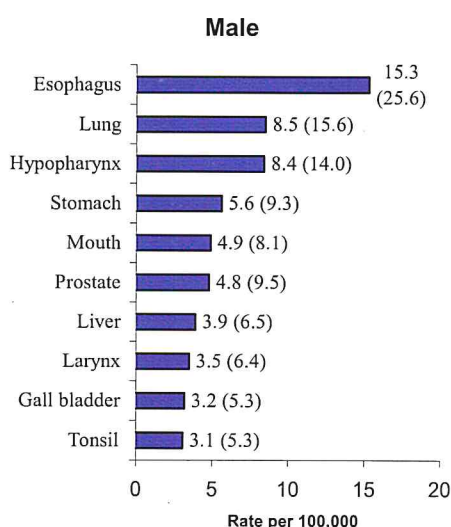
**Registry Area - Map:** Kamrup District is the most populous district in the state of Assam. According to the 2011 census, the Kamrup District is divided into Kamrup district and Kamrup Metro. , both of which have urban and rural components. The registry area comprises of the urban components of Kamrup district and Kamrup Metro. PBCR Guwahati, covers the whole of

Kamrup-Urban with a population of 12,21,489 of which 626128 are males and 595361 are females for 2012. Kamrup Urban District (KUD) is 267.1 sq. km. It is situated in 26.11 north latitude and 96.46 east longitude approximately 200 meter (656 feet) above sea level (ref.: New Horizon in Geography - Great World Atlas, Publisher McMillan, London). Many areas have both rural as well as urban components and the registry staff has been quite vigilant in obtaining accurate residential area, to be included in registry.

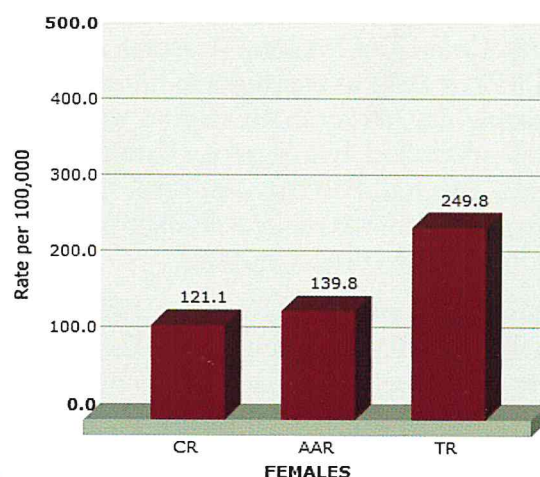
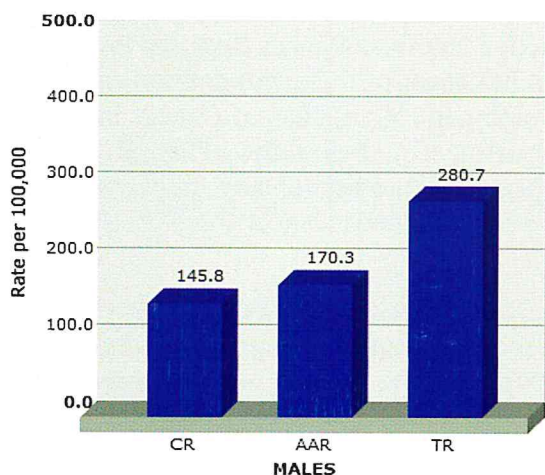


Annual number of cases for the year 2012, Total incident cases: 1634 (Male: 913 and Female: 721), Total mortality cases: 449 (Male: 284 and Female: 165), M/I ratios: Total 27.5 (Male: 31.1 and Female: 22.9)

### Seven leading sites of cancer among males and females - 2012



Average Annual Crude, Age Adjusted and Truncated Incidence Rates  
All Sites of Cancer (ICD-10) : C00-C97



**Effect of lifestyle on cancer:** Cancer is a complex group of diseases which can occur in all living cells in the body and different cancer types have different natural history. Epidemiological studies have shown that 70-90% of all cancers have their roots in the environmental and lifestyle. Only 5-10% of all cancer cases can be attributed to genetic defects. The lifestyle factors include cigarette smoking, diet (fried foods, red meat), alcohol, sun exposure, environmental pollutants, infections, stress, obesity, and physical inactivity. Appropriate changes in lifestyle can reduce the mortality and morbidity from a good proportion of cancer.

Guwahati is in the process of rapid urbanization and accordingly lifestyle has been changing over the last two decades. Cancer and other NCDs are considered associated with lifestyle, occupations and sedentary nature. To keep pace with the fast changing competitive world traditional Assamese foods are being replaced by easily available fast foods.

In Kamrup Urban District (KUD), 9 out of 10 leading sites and 6 out of 10 are tobacco related cancer (TRC) and head and neck cancers respectively. About 40% of all cancers are tobacco related in KUD. TRC of KUD comprised 49.1% of cancers in males and 25.7% of cancers in females. Tobacco use is by smoking, chewing and use of snuff - kept in the oral cavity and by reverse smoking. Smoked tobacco mainly consists of cigarettes and bidis, chewing tobacco as a betel quid (a combination of betel leaf, slacked lime, areca nut and tobacco with or without other condiments). Smoking bidi and drinking locally brewed crude alcoholic drinks are factors related to the occurrence of cancer.

The most important risk factors for developing head and neck cancer are tobacco use and alcohol consumption, which have a synergistic effect. Besides tobacco consumption, lower

intake of fresh foods, green vegetables and high cooking temperature are responsible for cancer of mouth and pharynx.

**Facilities available in the registry area for cancer diagnosis and treatment:** Dr. B. Borooah Cancer Institute (BBCI), a Regional Cancer Centre (RCC) is a major source of registration contributing more than 50% of registry data. It is fully equipped with all the facilities for cancer diagnosis and treatment. Besides BBCI, there are 40 hospitals and 31 diagnostic centers. Another source, North East cancer hospital and research institute has radiotherapy facilities. An oncology unit at GMCH will be soon operating having all the required facilities. All the other corporate hospitals have adequate infrastructure to deal with chemotherapy treatment.

#### Sources covered

- Dr. B. Borooah Cancer Institute (RCC) is one of the major source of registration
- Other than BBCI there are 40 hospitals and 31 diagnostic centres
- One Pain and Palliative centre
- A state referral board
- Birth and death registration centre- 18 nos

#### Activities of Registry

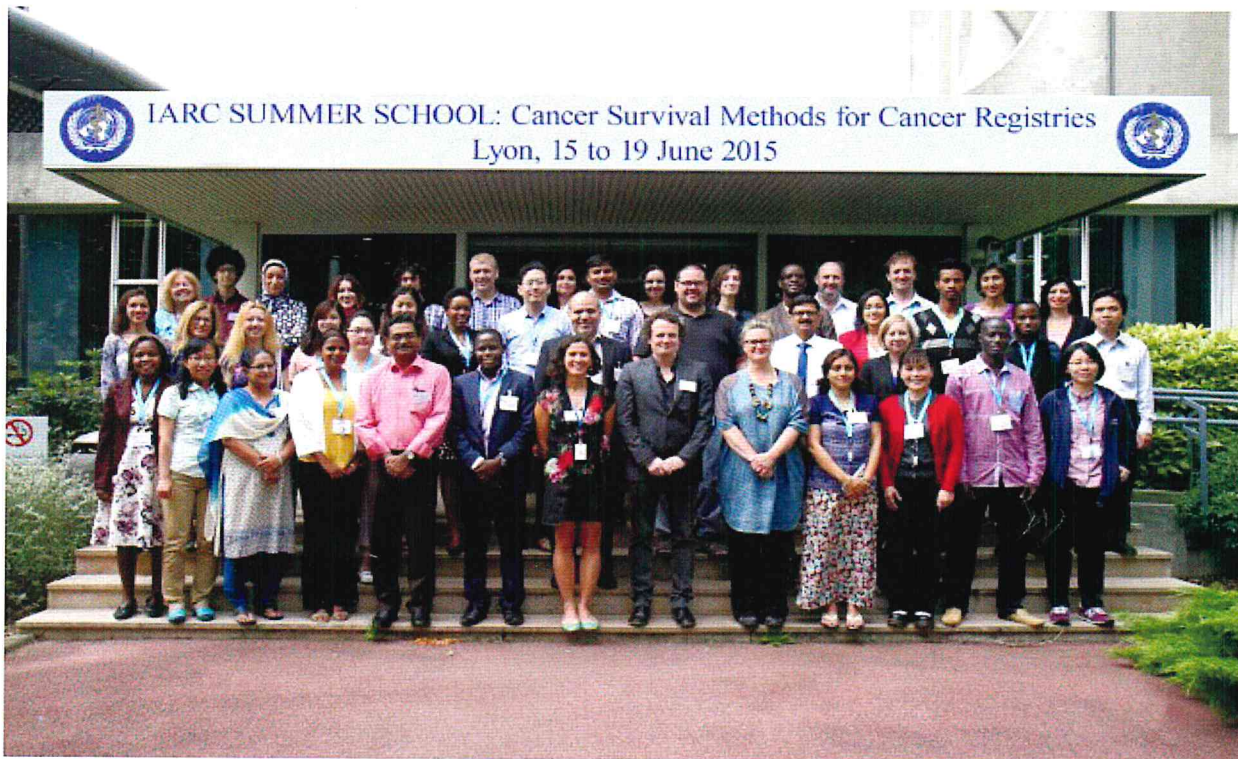
1. Organized "Regional workshop of North East Cancer Registry" at Dr. B. Borooah Cancer Institute on 30<sup>th</sup>, 31<sup>st</sup> Oct and 1<sup>st</sup> Nov, 2014.
2. Dr. Debanjana Barman, Medical research Officer, PBCR Guwahati, attended summer school on "Cancer Survival Methods for Cancer Registries" from 15<sup>th</sup>-19<sup>th</sup> June, 2015 at IARC, Lyon, France.
3. Summer Training on Cancer Registry, Epidemiology and Biostatistics was conducted at Dr. B. Borooah cancer institute from 1<sup>st</sup> July to 14<sup>th</sup> July, 2015.

**Difficulties encountered at data collection:**

Cancer is not notifiable in India so data collection is an active one. The number of cancer cases collected from various SOR varies from time to time so our social investigators have to be very vigilant in getting the adequate information from all the sources. Follow up of

cases from various sources has become a mandate. Lack of computerization in many sources especially in the birth and death registration centres where records are registered manually increases the chance of error and consumes a lot of precious time and energy.

**At IARC summer school, Lyon, 15<sup>th</sup> June to 19<sup>th</sup> June, 2015**



**Summer Training on Cancer Registry, Epidemiology & Biostatistics at BBCI from 1<sup>st</sup> July to 14<sup>th</sup> July, 2015**



## Population Based Cancer Registry, Kolkata

Principal Investigator: Prof. Dr. Jayadeep Biswas

Co Principal Investigator: Dr. M N Bandyapadhaya, Dr. Karabi Datta

PBCR Kolkata is an urban PBCR and funded by NCRP / NCDIR. PBCR Kolkata covers urban population (14.38 million in 2014 ,overall literacy rate of 87.14% and Sex ratio 899 females for every 1000 males) of metropolitan city of Kolkata. Majority are non vegetarians. 60%to 70% of the population has tobacco habits of which smoking tobacco is predominant among males and chewing tobacco more among females.

There are several Cancer hospitals, Government General Hospitals, Private hospitals and Pathology Laboratories. There are all diagnostic and treatment facilities. Many centres have Cancer Detection facilities including CNCI.

Latest data on 4580 cases - incidence & mortality data of 2012 have been submitted to NCRP. Among males the five leading sites are Lung, Prostrate, Mouth, Larynx, Urinary Bladder and among females, the five leading sites are Breast, Cervix, Ovary, Gall bladder and Lung.

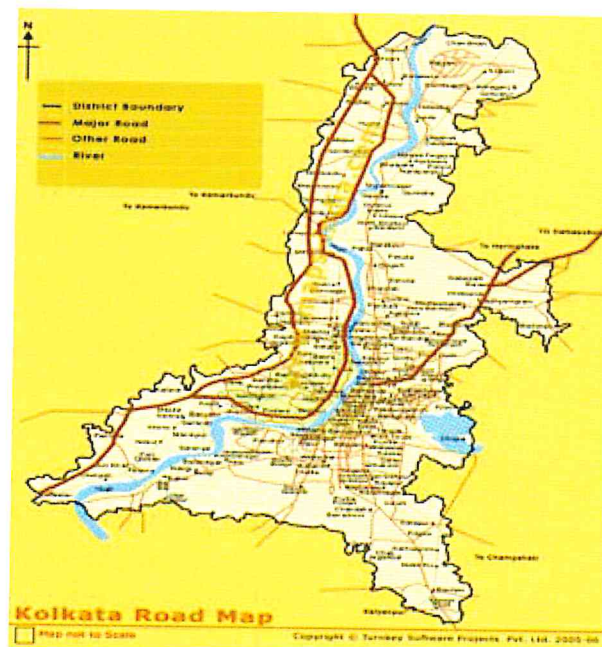
There are 52 sources of which Major cancer hospitals contributed 39.4%, Government General Hospitals 27.5%, Private General Hospitals 19.6%, Diagnostic centres 5% of Incidence data. Vital Statistics Dept of Kolkata Municipal Corporation contributed Mortality data.

**Problems encountered in Source centres:** Tata Medical centre is now one of the major Private cancer hospitals catering to a large

number of Kolkata patients since 2011. Inspite of several attempts, it was not possible to retrieve data from this possible source centres. This problem needs immediate solution. In some hospitals and diagnostic centres clarity of address is not adequately clear.

**Very interesting experiences during the registry operations:** Two of our registry staff locatd a 5 year old boy suffering from Acute Lymphoblastic Leukaemia diagnosed by a diagnostic centre near our centre. His relatives were raising fund for treatment and were confused. The registry staff persuaded his parents to attend our Medical Oncology Dept. The boy received full treatment at free of cost and now he is attending school.

### Map of Kolkata



A **Meeting & Workshop** on Cancer Registry was held in CNCI on 20.11.2014. Participants were people of source centres at different levels. The Workshop was conducted by Dr. Meesha Chaturvedi and Ms. Roseline from NCRP/ICMR. Participation and feedback were very good.

**Inauguration of NCRP workshop**



**Participants of NCRP workshop**



**Award Ceremony - NCRP workshop**



**Expansion of activities of Registry:** Cancer prevention programmes and Cancer Awareness camps are held regularly in different rural areas and urban slums by CNCI. Regular screening of patients is done on all working days in Cancer Detection Outdoor of CNCI. Special emphasis is placed on Oral Cancer, Cervical cancer & Breast cancer. Comprehensive screening is done including Pap test, FNAC and Biopsy if required.

**Latest publication:**

Association of Breast Cancer with Sleep Pattern - A Pilot CaseControl Study in a Regional Cancer Centre in South Asia; **Karabi Datta** Asoke Roy, Durgaprasad Nandalla Das Subhas GuhaDipanwita Ghosh, Samar Sikdar Jaydip Biswas  
Asian Pacific Journal of Cancer Prevention, Vol 15, 2014

## Observations from a Rural Registry – District Cancer Registry, Kollam, Kerala

P. Jayalekshmi<sup>1</sup>, Harikrishnan, Jyothisree, Sandhya, Paul Sebastian<sup>2</sup>

(Dr. Paul Sebastian, Principal Investigator DCR & Director, RCC, Thiruvananthapuram

Dr. P. Jayalekshmi, Co Principal Investigator & Officer-in-Charge, DCR Kollam.)

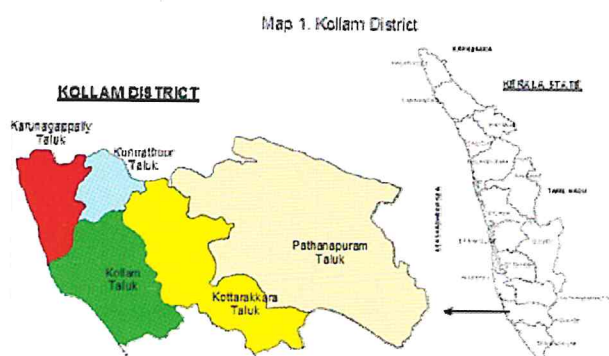
**Introduction:** District Cancer Registry, Kollam (PBCR) is an extension of Natural Background Radiation Cancer Registry (NBRR), Karunagappally which was started in 1990 by the Regional Cancer Centre, Thiruvananthapuram. The NBRR registry was initiated as a Special Purpose Registry to study the cancer occurrence and health exposure effect due to natural radiation present in the sea coast of Karunagappally Taluk. This registry is the first PBCR in Kerala and the second rural registry in India. The Cancer Atlas project of NCRP ICMR showed a minimum higher incidence of cancer in Kollam District. This prompted ICMR to extend the registration area to cover the total Kollam District from 2006 onwards. There are no dedicated cancer treatment centres or Medical College or hospital with radiotherapy facilities in this area. People have to travel a long distance to reach cancer treatment centres which are located in metropolitan cities.

The registry covers the whole Kollam District with an area of 24,913 Sq.Km. The area is bounded by the district of Alappuzha in the north, Tamil Nadu in the east, Thiruvananthapuram district in south and Arabian Sea covers the west coast. This district is well known for its rich deposits of rare earth sands, china clay and graphite and it is the foremost centre of cashew industry in the country. The Kollam district constitutes 70 panchayaths, 1 corporation and 3 municipalities with a population of 26,35,375 (census 2011). There are 1,113 females for every 1,000 males. 93.8% of the population is literate with male literacy rate 95.8% and female literacy is 92.0%.

**Socio demographic life style factors:** The registry area constitutes 55% rural and 45% urban population (2011 census). The life style habits varied among different population groups. There are three major religions in the registry area. They are Hindus, Christians and Muslims. Tobacco alcohol habit was highly prevalent among the population. The results of the studies (Cohort study) in Karunagappally taluk and Kollam conducted during 1990-97 and 2009-12 indicated that the habit of smoking reduced from 50.5% (90-97) to 33.6% during 2009-12 periods (1,2). Females are habituated to chewing tobacco and that also reduced from 15.1% to 3% during 2009-12. The habits of tobacco and alcohol use exist, the illegal sale and accessibility of tobacco products are often reported in Medias even after the strict ban of Govt. of Kerala.

The studies have shown that the high incidence of lung cancer among males in the registry area is related to bidi smoking (3). The habit of bidi

### Demographic Profile of Kollam



smoking increases the risk of hypopharyngeal and laryngeal cancers also (4). Tobacco chewing increased the risk of oral cavity cancer in males and females (5). The alcohol habit along with tobacco is also found to be a strong risk factor of laryngeal and pharyngeal cancers and oral cavity cancers among men (5). The food habits varied among religions. Majority of the people are non vegetarians and fish is the common item consumed among non-vegetarian food (1). Breast cancer among females have a strong association with the habit of using Chicken meat in daily diet and also in females having history of lesser number of children (6). Marital and reproductive indicators varied among religions. Age at marriage is 22 years for Hindus, 20 years for Muslims and 22 years for Christians in the current age group of 20-24 among women (1).

#### Radiation emitting black sands of Kerala coast Karunagappally Taluk



#### Fish Processing-



#### Net weaving



#### Coir makeing



#### Cashew processing



**Sources of Registration, DCR:** The major sources of registration are given in table 1.

**Table 1: Major sources of registration and number of cases registered in 2011– 2012**

Sources of registration	No. of cases	%
Regional Cancer Centre	2211	33.2
Medical Colleges with Oncology Units	2137	32.1
Other Hospitals	2020	30.0
DCO Only	291	4.4
Total	6659	100.0

There are more than 200 sources for data collection and some are far away from this registry area and are located in Thiruvananthapuram, Cochin and Aleppey Districts. Trained field investigators visits each source and collect information on cancer cases. Survival information, residential status and other data collected by personal interviews, phone contacts and home visit. The patients from the private hospitals often avoided for interview. Cancer cases were also identified from Palliative Care Centers. The unit of RCC in Neendakara is a major source of registry where patients from all over the district came for supportive care and review clinics. The data collection in hilly area of the registry mainly Pathanapuram and Kottarakkara Taluk is very tedious.

**Mortality Information:** Registry collected mortality information from 71 Panchayaths, 3 Municipalities and Kollam Corporation. Recently electronic data transfer is available from Death Registration Unit of Economics and Statistics department of Govt. of Kerala. There are discrepancies in the data transferred. Usually the differences noticed are on cause of death reporting. Repeated visits to the respective Panchayaths are attempted often for completion of information. We often discussed the problem of mortality records with staff members. Manual abstraction of death records from certain panchayaths often resorted for rectifying the incompleteness of the electronic data. Another issue of mortality data is that it is available in Malayalam and we re-enter them in English. Death records kept in hospitals are also a source of mortality information. In order to complete the mortality registration we used all the sources above described and methods.

**Cancer Incidence rates Kollam:** Changes in cancer incidence rates among males and females in different periods is given in table 2.

**Table 2: Cancer incidence rates of Kollam 2006-2012.**

Period	Male			Female		
	No.	CR	AAR	No.	CR	AAR
2006-2008	4656	119.9	113.6	4374	103.3	89.7
2009-2010	3375	128.3	118.5	3128	108.3	91.6
2011-2012	3414	136.9	113.2	3245	116.5	92.8

**Cancer pattern among males and females in Kollam District:** Changes are observed in the distribution (AAR) of five leading cancers in men and women during 2006-2012 in Kollam district. These are shown below in table 3.

**Table 3: Following table shows the 5 Leading Cancers of Kollam**

Male – 2006-2008			Male – 2009-2010			Male – 2011-2012		
Rank	Site	AAR	Rank	Site	AAR	Rank	Site	AAR
1	Lung	18.1	1	Lung	19.5	1	Lung	21.6
2	Mouth	7.1	2	Stomach	6.5	2	Mouth	5.9
3	Stomach	6.3	3	Mouth	6.0	3	Stomach	5.5
4	Esophagus	5.4	4	Liver	5.8	4	Prostate	5.4
5	Tongue	5.0	5	Prostate	5.7	5	Rectum	5.1

Female – 2006-2008			Female– 2009-2010			Female– 2011-2012		
Rank	Site	AAR	Rank	Site	AAR	Rank	Site	AAR
1	Breast	23.2	1	Breast	25.8	1	Breast	25.1
2	Cervix	8.3	2	Thyroid	7.3	2	Thyroid	9.9
3	Thyroid	5.8	3	Cervix	6.8	3	Cervix	7.0
4	Mouth	4.4	4	Ovary	5.0	4	Ovary	5.4
5	Ovary	4.2	5	Mouth	3.4	5	Lung	3.6

Lung cancer incidence rate in Kollam is higher and it stood in the 3<sup>rd</sup> position in AAR when compared to other population registry areas just behind Aizwal and Mizoram. Thyroid cancer among women is also higher in Kollam and Thiruvananthapuram (7,15).

**Tobacco Related Cancers among males and females:** The Table 4 shows the percentage Tobacco related cancers

**Table 4: Percentage tobacco related cancers in Kollam**

Year	Male	Female
2006-2008	42.2 %	14.6 %
2009-2010	41.2 %	12.7 %
2011-2012	43.8 %	13.6 %

**Trends in breast and cervix cancer incidence 1991–2011 in Thiruvananthapuram and Karunagappally:** The trends in the incidence of breast and cervix cancer during the period 1991-2011 are given in the following table 5. These rates are published in successive volumes of cancer incidence in five continents by IARC and 2009-11 data were obtained from National Cancer Registry reports.

**Table 5: Trends in the incidence of Breast and Cervix cancer during 1991-2011.**

Source	Year of Report	Breast cancer		Cervix cancer	
		Tvm	Kply	Tvm	Kply
*CIN. 7 – 143(8)	1991-1992	18.8	15.1	15.9	15.7
CIN. 8 – 155(9)	1993-1997	19.7	15.0	10.9	15.0
CIN. 9 – 160(10)	1998-2002	24.2	16.0	9.4	10.6
CIN.10 – 164(11)	2003-2007	35.4	16.6	10.1	8.9
NCRP – 2013(7)	2009-2011	35.1	25.8	8.0	6.8

\* Cancer Incidence in Five Continents (CIN),  
Tvm – Thiruvananthapuram, Kply –  
Karunagappally

It may be observed that breast cancer incidence increased over the years and cervix cancer incidence has been decreasing. The changes might have resulted from socio demographic changes like age at marriage, age at first pregnancy, breast feeding practices apart from improvements in diagnostic facilities, maternity care, family planning etc.

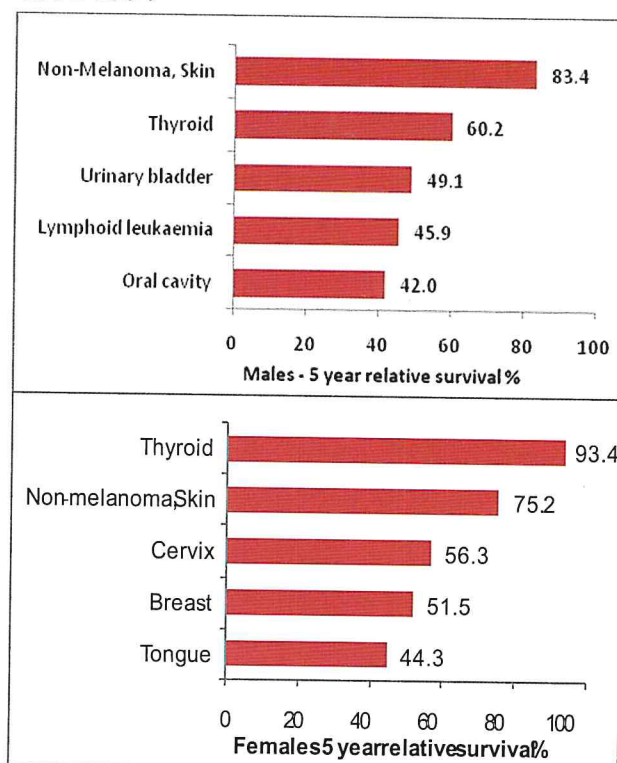
**Cancer Registry and Research Programmes:** The DCR of Kollam is an extended registry of Natural Background Radiation Registry, started in 1990 for evaluating cancer incidence and natural radiation present in Karunagappally taluk of Kollam District. Radiation and cancer epidemiologic studies are ongoing with the support of Health Research Foundation Japan. Special purpose cancer registration methodology adopted for this purpose. Besides Cancer studies, Cytogenetic studies, Dosimetric studies, Clinical studies to assess radiation effects are ongoing with the active support of Cancer Registry Staff.

Radiation and cancer studies so far do not reveal any excess cancer due to radiation. The findings of this study are of global importance (8, 12). Radiation and cancer studies are now ongoing based on cohort methodology. Surveillance of the cohort is actively undertaken and along with this mortality and migration studies are also undertaken.

**Cancer Survival studies – Collaboration with IARC, Lyon and Concord study group, London:**

#### Collaboration of registry with IARC

Registry contributed data on 22 cancer sites registered in Karunagappally taluk during 1991-97 for survival analysis with IARC. The top five cancers (ranked by survival) among males and females is given below

**Fig. 1: Top five cancers (ranked by survival), Males & Females, Karunagappally, India, 1991-1997**

**Collaboration of registry with CONCORD**

**Study Group London:** The cancer survival studies of ten cancers-Stomach, Colon, Rectum, Liver, Lung, Breast, Cervix, Ovary, Prostate, Leukaemia were undertaken with collaboration of CONCORD working group, London School of Public health. 2812 cancer cases registered during the period 1995 to 2009 were contributed for analysis. The result was published in 'Global surveillance' of cancer survival 1995-2009 (CONCORD-2)(14).

**Cancer Incidence Studies – Cancer Incidence in 5 Continents – Vol 7 – 10, IARC:**

The cancer incidence data of Karunagappally was published in the successive volumes of Cancer Incidence in 5 Continents 1991-92, 1993-97, 1998-2002, 2003-2007.

**Cancer control activities, cancer patient support service practiced in registry:**

Cancer Registry is actively involved in cancer control activities and cancer patients support services in the registry area. Along with the registry operations we initiated in 1990, cytological detection facilities and review clinics in the registry office realizing the non existence of such services in the area. Now with the funds of Govt. of Kerala and Local Administrative Development funds of Panchayaths we are running these services. Cancer Care Centre for providing these services was organized in the year 2000. The doctors from the registry area and from Medical College of Thiruvananthapuram, Cochin and Aleppey referred the patients to the centre for supportive, palliative care and cancer detection. Community cancer awareness programmes, and field cancer detection camps were convened periodically with the help of field staff all over Kollam District. Prevention and cancer detection projects of Jilla panchayath and other panchayaths also undertaken periodically. The cancer control and patient support services of the Cancer Care Centre at Neendakara attached to the registry helped to liaison with almost all major and minor hospitals in the areas. With the co-operation of civic administration we are implementing all

activities. The registry staff received co-operation from all the hospitals and offices. We are always vigilant in giving cancer patient support services and in view of the lacunae in diagnostic and therapeutic facilities available in the districts. Cancer detection campaigns in communities are regularly conducted. These resulted in the acceptance of our registry programme by the community and state administration which extended their cooperation and support.

The services offered to the population of the registry area are

1. Cancer awareness, cancer detection & palliative care training programmes.
2. Cancer detection clinics in Cancer Care Centre & Community cancer detection camps in communities.
3. Weekly pap smear clinic in Taluk Head Quarters Hospital, Karunagappally.
4. Palliative care, pain clinics, day care and home care for advanced patients.
5. Supportive clinics for treated patients and for patients in the treatment phase.
6. Review clinics- Monthly.
7. Rehabilitative services.

## Report of the services rendered 2011-2012

Cancer Control activities and dial services 1-1-2011 to 31-12-2012		
	No	Person attended
Cancer awareness and Palliative Training Programme	44	6010
Field cancer detection camps	136	15313
Pap smear screening programmes and other cytology Investigations (Taluk Hospital Karunagappally, Cancer Care Centre and Field cancer detection camps)		7456
Clinics and supportive services – patients visits	All working days	17620
Cancer detected		83
Pre cancer lesions of oral, cervix, breast and others detected		514

## Papers published: Research Publications indexed Journals-NBRR:

1. Raghu Ram K Nair, Balakrishnan Rajan, Suminori Akiba, Jayalekshmi P, Krishnan Nair M, Gangadharan P, Taeko Kogo, Hiroshige Morishima, Seiichi Nakamura and Tsutomu Sugahara. Background radiation and cancer incidence in Kerala India: Karunagappally cohort study. Health Physics Journal. Vol.96(1), page.55-66,2008.
2. Jayalekshmi P Suminori Akiba, Madhavan Krishnan Nair, Gangadharan P, Rajan B, Reghuram K Nair and Tsutomu Sugahara. Bidi smoking and lung cancer incidence among males in Karunagappally cohort, Kerala, India. International Journal of cancer – Vol.123, page.1390-1397,2008.
3. Jayalekshmi P, Sunoj C Varghese, Kalavathy MC, Krishnan Nair M, Jayaprakash V, Gangadharan P, Raghuram K Nair, Suminori Akiba. 'A nested case-control study of female breast cancer in Karunagappally Cohort in Kerala, India'. Asian Pacific Journal of Cancer Prevention, Vol.10, page.241-246, 2009.
4. Jayalekshmi PA, Gangadharan P, Akiba S, Nair RR, Tsuji M, Rajan B. Tobacco chewing and female oral cavity cancer risk in Karunagappally cohort, India. Br. J. Cancer. 100(5), page.848-852, 10 Mar 2009.
5. Sankara Narayanan R, Jayalekshmi P et.al. 'Cancer survival in Africa, Asia and Central America- A population-based study'. The Lancet Oncology. Vol.11(2), page.165-173, Feb 2010.
6. Gangadharan P, Jayalekshmi. P. Natural background radiation exposure and cancer: The Karunagappally experience. Indian Nuclear Society News Letter. Vol. 8 ( 1 & 2 ), page. 52 – 59 , Janu–June2011.
7. Jayalekshmi.P, Gangadharan P, Paul Sebastian. Cancer survival in Africa, Asia, the Caribbean and Central America Cancer survival in Karunagappally. India 1991–1997. IARC Scientific Publication No.162, Chapter 15, page.125–132. 2011.
8. Jayalekshmi PA, Gangadharan P, Akiba S, Koriyama C, Nair RR. Oral cavity cancer risk in relation to tobacco chewing and bidi smoking among men in Karunagappally, Kerala, India: Karunagappally cohort study. Cancer Sci. 102(2), page.460-467, Feb 2011.
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use and alcohol drinking with laryngeal and hypo pharyngeal cancer risks among men in Karunagappally, Kerala, India: Karunagappally cohort study. PLoSONE8(8)2013

Doi:1371.pone.0073716.

10. Jayalekshmi P, Paul Sebastian.

CONCORD Working group-Global Surveillance of cancer survival 1995-2009: Analysis of individual data for 25676887 patients from 279 population based registries in 67 countries (CONCORD-2). Lancet, 385: page.977-1010, 2015.

#### References:

1. Technical Report 1990-1999, Natural Background Radiation Cancer Registry, Karunagappally, Kerala, India.
2. Technical Report 2009-2012, Natural Background Radiation Cancer Registry, Karunagappally, Kerala, India.
3. Jayalekshmi P, Suminori Akiba, Madhavan Krishnan Nair, Gangadharan P, Rajan B, Raghuram K Nair, Tsutomu Sugahara. Bidi smoking and lung cancer incidence among males in Karunagappally cohort, Kerala, India. International Journal of Cancer – Vol.123, page.1390-1397, 2008.
4. Jayalekshmi P, Athira, Akiba.S, Gangadharan.P. Association of tobacco use and alcohol drinking with laryngeal and hypo pharyngeal cancer risks among men in Karunagappally. Kerala, India: Karunagappally cohort study. PLoSONE8(8)2013 Doi:1371.pone.0073716.-2013.
5. Jayalekshmi PA, Gangadharan P, Akiba S, Nair RR, Tsuji M, Rajan B. Tobacco chewing and female oral cavity cancer risk in Karunagappally cohort, India. Br J Cancer. 100(5), page.848-852, 10 Mar 2009.
6. Jayalekshmi P, Sunoj C Varghese, Kalavathy MC, Krishnan Nair M, Jayaprakash V, Gangadharan P, Raghuram K Nair, Suminori Akiba. A Nested case-control study of female breast cancer in Karunagappally Cohort in Kerala, India. Asian Pacific Journal of Cancer Prevention. Vol.10, page.241-246, 2009.
7. Three-year report of population based cancer registries 2009-2011, National Cancer Registry Programme-ICMR, 2013.
8. 1991-1992 – Cancer Incidence in Five Continents. Vol.7, IARC report 143.
9. 1993-1997 – Cancer Incidence in Five continents. Vol.8, IARC report 155.
10. 1998-2002 – Cancer Incidence in Five Continents. Vol.9, IARC report 160.
11. 2003-2007 – Cancer Incidence in Five Continents. Vol.10, IARC report 164.
12. Raghu Ram K Nair, Balakrishnan Rajan, Suminori Akiba, Jayalekshmi P, Krishnan Nair M, Gangadharan P, Taeko Kogo, Hiroshige Morishima, Seiichi Nakamura and Tsutomu Sugahara. Background radiation and cancer incidence in Kerala India: Karunagappally cohort study. Health Physics Journal. Vol.96(1), page.55-66, 2008.
13. Jayalekshmi.P, Gangadharan P, Paul Sebastian. Cancer survival in Africa, Asia, the Caribbean and Central America Cancer survival in Karunagappally. India 1991-1997. IARC Scientific Publication No.162, Chapter 15, page.125-132. 2011.
14. Jayalekshmi P, Paul Sebastian. CONCORD Working group-Global Surveillance of cancer survival 1995-2009: Analysis of individual data for 25676887 patients from 279 population based registries in 67 countries (CONCORD-2). Lancet, 385: page.977-1010, 2015.
15. Cancer incidence & mortality in Kollam 2011-2012, District Cancer Registry, Kollam, Kerala, India.

**DISTRICT CANCER REGISTRY, KOLLAM – 2013**

The Kollam Cancer Registry 2013 is a functional programme under the Regional Cancer Centre, Trivandrum.

Active cancer case finding method covering more than 200 sources was adopted to register the cases in the Kollam district. The registry staff interviewed the as many patients as possible and collected the essential information needed for the registry. As there are no dedicated cancer hospital in the area, registry is actively involved in conducting cancer awareness programmes and detection and also providing supportive and palliative care facilities to the residents in the registry area which enhanced the acceptability of the registry operations which helped to improve the data quality and

Males			Females		
Sites	%	AAR	Sites	%	AAR
Lung	17.6	20.2	Breast	28.0	27.2
Prostate	5.7	6.6	Thyroid	11.4	12.0
Mouth	5.7	6.5	Cervix Uteri	6.7	6.5
Larynx	5.1	5.7	Ovary	5.3	5.3
Stomach	4.8	5.5	Mouth	4.3	4.0

**Mortality data collection:** Efforts are on-going for population based survival and mortality data collection. The prevention and cancer control projects targeting the scheduled caste people were undertaken.

**Project undertaken/Collaborated by Registry:**

1. Cancer Incidence studies in High Background Radiation area, Kerala. Supported by Health Research Foundation, Japan, 2009-2015.
2. Socio-demographic and cancer studies in Kollam Corporation and other coastal area 2009-2014. Department of Atomic Energy, Govt. of India.
3. Molecular Signature of Thyroid cancers in relation to natural radiation in Karunagappally.
4. Prevention and cancer control projects of Jilla Panchayats, Kollam and Local Grama, Block Panchayats of Karunagappally Taluk.

**Conference/Workshops/Training Programmes attended**

Participants	Conference/ Meeting	Date & Venue	Paper presented / Talk delivered / Participants status
Dr. P. Jayalekshmi	Annual Review Meeting of NCRP (ICMR)	18-19 Dec. 2014, Chennai Adayar Cancer Institute	Talk: Quality of cancer registry data and completeness of coverage-DCR, Kollam
Mr. K. Harikrishnan Mr. P. Sreekandan Mrs. K. Beena Mrs. S. Soumya	Annual Review Meeting of NCRP (ICMR)	16-17 Dec. 2014, Chennai Adayar Cancer Institute	Workshop Participants

**Cancer control activities and patient support services in the registry area**

<b>Details of activities 01-01-2013 to 31-12-2013</b>	<b>No</b>	<b>Person attended</b>
Cancer awareness and Palliative Training Programmes	10	866
Field cancer detection camps	82	7937
Pap smear screening programmes and other cytology Investigations (Taluk Hospital Karunagappally, Cancer Care Centre and Field cancer detection camps)	-	2756
Clinics and supportive services – patients visits	All working days	7746
Cancer detected		19
Pre cancer lesions of oral, cervix, breast and others		230

**Papers published:** Jayalekshmi P, Athira, Akiba.S, Gangadharan.P. Association of tobacco use and alcohol drinking with laryngeal and hypo pharyngeal cancer risks among men in Karunagappally. Kerala, India: Karunagappally cohort study. PLoSONE8(8)2013 Doi:1371.pone.0073716.-2013.

**Acknowledgements:** The financial and technical support of NCRP ICMR is gratefully acknowledged. The Administrators, Principals of Medical Colleges, Directors of all hospitals, Path labs, Scan centres and Vital Statistics Divisions contributed by providing data to Social Investigators. The Medical Record staff, Hospital Cancer Registry staff and Computer division of RCC supported the registry activities.

## **Hospital Based & Population Based Cancer Registries – Rural Kerala – Malabar Cancer Centre, Thalassery**

Principal Investigator : Dr. Satheesan Balasubramaniam, Director Malabar Cancer Centre  
Co. Principal Investigators : Dr. Saina Sunil Kumar, HOD, Cancer Registry & Epidemiology  
Ms. Bindu T – Biostatistician, Cancer Registry and Epidemiology  
Mr. Ratheesan K – Biostatistician, Cancer Registry and Epidemiology



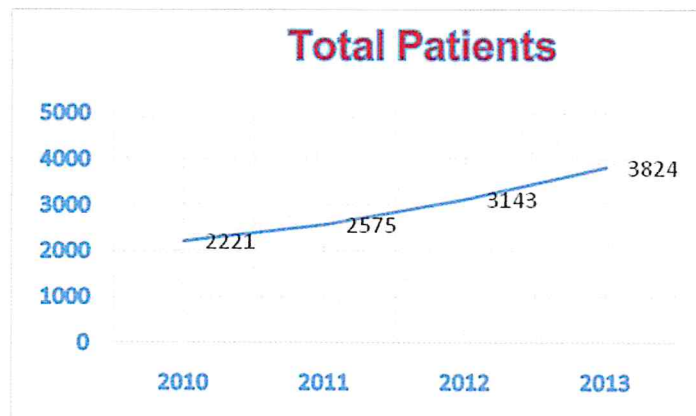
Dr. Satheesan Balasubramaniam

Malabar Cancer Centre(MCC) is an autonomous institution under Health & Family Welfare department of Govt. of Kerala, started with an aim to provide the much required oncology services to the population of Northern Kerala and neighboring areas of Karnataka and Tamil Nadu states, and Union Territory of Puducherry (Mahe).MCC is the second largest cancer centre in Kerala with 200 beds and recognized as Tertiary Cancer Centre by Government of India in 2012.The main objective of the centre is not only to provide comprehensive cancer care but also to develop as a Research and Training Centre of international standards. During the last 13 years, more than 20,000 new cancer patients had registered for cancer treatment and around 3, 00,000 patient visits made during this period. The treatment offered by MCC includes radiotherapy, chemotherapy, onco-surgery and palliative care. The MCC conducts Community Oncology activities including cancer awareness and early detection programmes. Currently it has 15 departments and 23 divisions to provide state of the art cancer treatment including Bone Marrow transplantation, Endoscopic skull base surgery, LASER cancer surgery etc. It has research and academic collaboration with School of Health Sciences, Kannur University, Centre for Electronic Materials Technology, Thrissur, P.S.Vaidhyarathnam Ayurveda College, Kottakkal, HTIC-Chennai, National Cancer Grid which are expected to bring in revolutionary changes in the management of cancer. Malabar Cancer Centre has been recognized as a Research Institute by Kerala University of Health Science.

**Department of Cancer Registry & Epidemiology:** Department of Cancer Registry and Epidemiology was established 2010 with just two staffs. Dr. Saina Sunilkumar took charge of the department along with a data entry operator and started Hospital Based Cancer Registry partially supported by NCRP- ICMR. Now it has published four HBCR annual reports for the years 2010, 2011, 2012 and 2013. Funding support of Rs. 1, 10,000 was sanctioned to MCC by NCRP-ICMR for the functioning of the project Patterns of Care & Survival Studies in Breast, Cervix & Head & Neck cancers. The Malabar Population Based Cancer Registry was launched on 1<sup>st</sup> January 2014 covering the populations of the districts of Kannur, Kasaragod & Mahe (Two States- Kerala & Pondicherry) with the help of 8 field staffs – 4 social Investigators and 4 Data Collectors.

## Consolidated 4-Year Hospital Based Cancer Registry Report

Total number of Patients registered at MCC



### 10 Leading sites of cancers- Males and Females, MCC

YEAR WISE LEADING SITES OF CANCER IN MALES							
2010		2011		2012		2013	
Lung	241	Lung	312	Lung	372	Lung	397
Mouth	106	stomach	111	Mouth	121	Mouth	157
stomach	97	Mouth	104	stomach	121	stomach	135
Larynx	63	Tongue	67	Tongue	91	Tongue	116
Tongue	61	Esophagus	61	Esophagus	86	Larynx	103
Esophagus	58	Larynx	55	Prostate	85	Esophagus	88
Prostate	52	Oropharynx	52	Larynx	66	Rectum	85
Rectum	52	Rectum	50	Rectum	64	Prostate	77
Hypopharynx	48	NHL	47	Hypopharynx	58	NHL	72
colon	38	Hypopharynx	45	NHL	57	Bladder	65

YEAR WISE LEADING SITES OF CANCER IN FEMALES							
2010		2011		2012		2013	
Breast	301	Breast	358	Breast	425	Breast	574
cervix	124	cervix	103	cervix	113	cervix	131
Mouth	81	ovary	92	ovary	109	Mouth	124
ovary	75	Mouth	83	Mouth	92	ovary	114
Corpus uteri	46	Corpus uteri	47	stomach	57	Rectum	72
Lung	40	Tongue	46	Lung	49	Lung	71
Rectum	36	Rectum	44	Tongue	49	Tongue	60
Esophagus	32	NHL	39	Corpus uteri	46	Thyroid	59
NHL	27	Lung	35	NHL	43	NHL	55
colon	27	Thyroid	34	Rectum	40	stomach	53

## MALABAR POPULATION BASED CANCER REGISTRY (MPBCR):

The MPBCR covering three districts - Kannur, Kasaragod and Mahe was launched on 1<sup>st</sup> January 2014 (Two States- Kerala & Pondicherry) partially supported by National Cancer Registry Programme (ICMR). New cancer cases (incidence and mortality) among residents of Kannur, Kasaragod and Mahe districts for a minimum of 1yr. are registered in MPBCR. This is part of national level data collection and reported to the Government of India.

**Advisory Committee:** For the smooth functioning of MPBCR, an advisory committee was formed for Kannur, Kasaragod and Mahe with the District Collector (Kannur & Kasargod) and Regional Administrator (Mahe). The other members of the advisory committee are as follows:

### Kannur & Kasaragod Districts

1. District Collector, Kannur & Kasaragod (Chairman)
2. District Medical Officer, Kannur & Kasaragod (member)
3. Deputy Director, Economics and Statistics Department, Kannur & Kasaragod (member)
4. Principal, Pariyaram Medical College (member)
5. Principal, Kannur Medical College, Anjarakkandy (member)
6. Chairman, Private Hospital Board, Kannur (member)
7. President, Kannur District Lab Owner's Association (member)
8. Legal expert (Member)
9. Director, Malabar Cancer Centre (Convenor)

### Mahe District

1. Regional Administrator of Mahe (Chairman)
2. Deputy Director, General Hospital (member)
3. Municipal commissioner (member)
4. Principal, Mahe Dental College (member)
5. Legal expert nominated by MCC (Member)
6. Director, Malabar Cancer Centre or his nominee (Convener)

**Sources and methods of Data Collection:** The MPBCR collects information on cancer cases from several sources. These include pathology reports, medical records, radiology and radiography departments and death certificates. The institutions that were covered for this are Government and Private hospitals, PHCs, CHCs, Taluk Hospitals, Nursing Homes, Medical Colleges, Laboratories, Clinics, Dental clinics, Palliative care centers, Eye hospitals, Vital Statistics Departments of Municipalities and Panchayats. We collect mortality data from Sevana Application Software of Information Kerala Mission under Local Self Government Department, Govt. of Kerala.

**Methods of data collection:** For data collection the registry staff periodically visits various sources to actively pursue and collect information on cancers reported and interview patients wherever possible. For collecting information the registry used a separate semi structured questionnaire in different languages such as English, Malayalam and Kannada. The questionnaire contains the demographic information, diagnosis details, clinical information and vital status of the cancer cases which is approved by the committee. The data collected are submitted to the Department every month. Meetings are held to discuss the problems faced during field visits, errors found in the Proforma are clarified, steps are taken to improve the performance, exercises for information abstraction & data entry are done taking turns. Meeting of the advisory committee is held once in six months. Two meetings were held so far in the three Districts separately at the District Collectors chamber.

Similarly for information completion, data collected from various institutions where cancer related treatment is given are merged in the records appropriately. The Malabar Population Based Cancer Registry has completed 1½yrs of its functioning.

Principal Investigator: Dr. W B Langstieh,  
Pasteur Institute, Shillong

[illegible]

Meghalaya is one of three states in India to have a Christian majority. About 70% of the population practices Christianity, with Presbyterians and Catholics the more common denominations. The religion of the people in Meghalaya is closely related to their ethnicity. Close to 90% of the Garo tribe and nearly 80% of the Khasi are Christian, while more than 97% of the Hajong, 98.53% of the Koch tribes are Hindu.

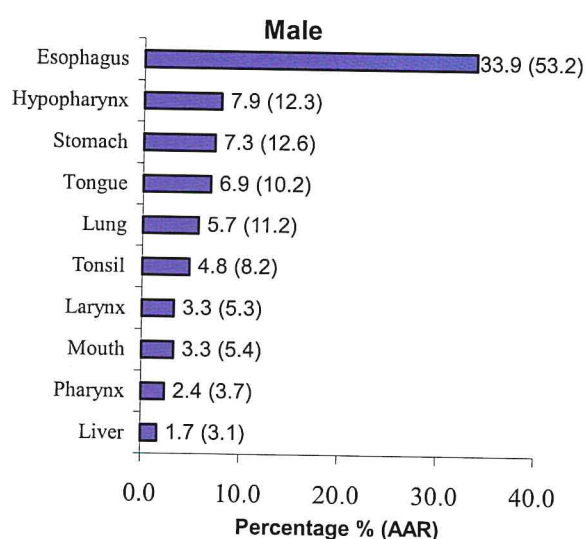
The Meghalaya tribes are mainly classified into three groups - Garos, Khasis and Pnars or Jaintias. The most noteworthy feature of tribes of Meghalaya is their parental lineage. The tribes of Meghalaya follow matrilineal lineage.

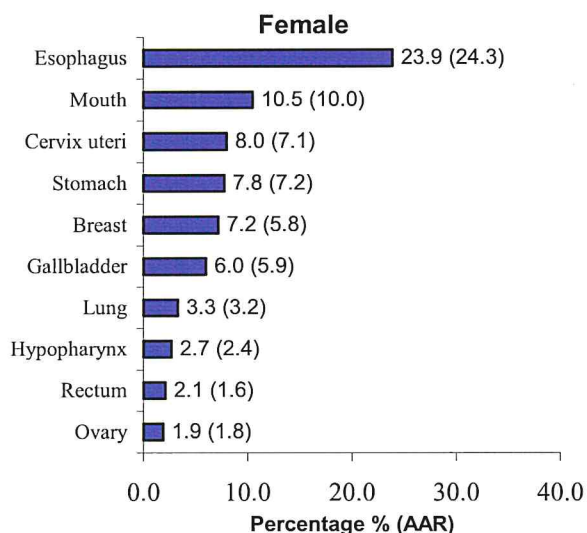
Improper dietary habits are the suspected main cause of cancer prevalence in this region. In Khasi society, chewing of raw betel nut is part of the Khasi social life, there has been a strong indication for an association with the higher incidence of esophageal Squamous Cell Carcinoma. The raw betel nut is consumed with lime paste and a portion of the betel-leaf with or without tobacco. Also, the average onset age of betel- nut chewing, tobacco smoking/chewing in this area is 12 - 14 years which is a significant factor in the high incidence of esophageal cancers. Besides, these factors alcohol drinking, smoking and a high consumption of red meat contribute to the increase in cancer incidence. (Reference: *Distinct Involvement of 9p21-24 and 13q14.1-14.3 Chromosomal regions in Raw Betel-Nut Induced Esophageal Cancers in the State of Meghalaya, India. Avdhesh K Rai, Allen J Freddy, Atanu Banerjee, Sillarine Kurkalang, Gordon MRangad Mohammad Islam, Henry B Nongrum, Dr. Hughbert Dkhar, Anupam Chatterjee; DOI: <http://dx.doi.org/10.7314/APJCP.2012.13.6.2629>*)

Several facilities have been set up in the state for early cancer detection. All main health institutions in the state are being equipped with up-to-date cancer detection with their own laboratories and radiological facilities like

histopathology, cytology, hematology, MRI, CT scan, and USG etc. Cancer treatments in the registry area available are Chemotherapy, Radiotherapy and Surgery (Cobalt treatment at Civil Hospital Shillong). Apart from the usual medical treatment facilities, traditional medical practitioners/healers also play a significant role in cancer treatment in this region.

**Coverage:** The registry at present is covering more than 30 sources of registration out of which 11 are major contributors. Most of the sources of registration are hospitals and laboratories located in the state capital Shillong. Primary registration is done at Civil Hospital, Shillong being the center. Currently, the total number of incident cases registered for the year 2014 is 1206 with male cancers 799 and female cancers 407. On the other hand mortality registered is 563 with 366 male deaths and 197 female deaths. The graph below shows the ten leading cancer sites (Age Adjusted Rates) among males and females.





Registry's staff faces many difficulties in cancer registration. One of the main difficulties is the reluctance of patient to furnish detailed information during follow up, either by telephonic conversation or home visits. Another difficulty is in the collection of mortality data wherein the *Death report/Form 2* is not filled in all respect. For example, some of the identifying information like name, age, sex, date of death, address of the deceased, is at times missing or return in an incomplete manner in the death report. The registry staff had interesting experiences, in carrying out their routine registry's operation. One such experience is the use of the online Electoral Roll List being provided by the office of the Chief Electoral officer, Meghalaya. The staff is able to ascertain identifying facts about the cancer patient and their next of kin and hence able avoid duplicates. The following is a list of sources of registration covered by the registry.

### Hospitals

1. Civil Hospital Shillong
2. Woodland Hospital Shillong
3. Bethany Hospital Shillong
4. Super Care Hospital Shillong
5. NEIGRIHMS, Shillong
6. Nazareth Hospital Shillong
7. Ganesh Das Hospital Shillong
8. Civil Hospital Jowai
9. Civil Hospital Nongpoh
10. Civil Hospital Nongstoin
11. Dr. Norman Tunnel Hospital Jowai
12. Dr. H Gordon Roberts Hospital, Shillong
13. Dr. BCCI, Guwahati
14. Christian Medical College, Vellore
15. NE Cancer Hospital and Research Institute Jorabat

### Laboratories

1. NE Diagnostic Centre (NEDC) Shillong
2. Melari Diagnostic Laboratory Shillong
3. Clinical Pathology Shillong
4. Sendro Polyclinic Shillong
5. Shillong Diagnostic Shillong

### Vital Statistics Department

1. DMHO Shillong
2. DMHO Jowai
3. DMHO Nongpoh
4. DMHO Nongstoin
5. The Municipal Board Shillong
6. The Municipal Board Jowai

### **Cancer Registration at Civil Hospital, Shillong**



**PBCR staff**



**Living Root Bridge, Meghalaya**



## Cancer Registry Division -Mumbai–Pune–Nagpur–Aurangabad

Principal Investigator: Dr. Vinvay Deshmane

Co-Principal Investigator: Mrs. Shravani Koyande

The Mumbai Cancer Registry was established in June 1963 as a Unit of Indian Cancer Society with the aim of “Obtaining reliable incidence and mortality on cancer from a precisely defined urban population”. Later ICS has established the first satellite registry in 1972 at Pune, the second at Aurangabad in 1978 and third at Nagpur in 1980. All the above registries are now part of the National Cancer Registry Programme–NCRP-ICMR.

**Mumbai Cancer Registry:** Greater Mumbai is a densely populated urban metropolis on the west coast of India occupying an area of 603 sq.km and it is the smallest administrative district of Maharashtra State. Greater Mumbai is the industrial heart of India and has a multi-religious, multi-lingual population, representing every state in the union.

### Sources of Information:

Two major sources have been utilized for cancer data collection.

- All hospitals, nursing homes and consultants in private practice in the Registry area.
- The Vital Statistics Division of the Department of Public Health of the Mumbai Municipal Corporation.

The Mumbai Cancer Registry today covers 100 hospitals and private nursing homes in the metropolitan area. The majority of hospitals in Mumbai are maintained by

Municipal Corporation and the State Government, which are responsible for organization of medical and public health services in the city. A major source of cancer data collection is the Tata Memorial Cancer Hospital and Research Institute, a post-graduate teaching centre of the University and an autonomous unit supported by the Department of Atomic Energy, Government of India.

The pattern of diagnosis and treatment of cancer in Mumbai has undergone a major change over the last decade. With a mushrooming private sector, there are now an increasing number of private hospitals, both large and mid-sized, which are involved in cancer care. Many have the latest facilities for treatment, including IMRT and IGRT. Major cancer surgery is undertaken at all major hospitals, as well as in a number of well equipped private nursing homes in the city.

**Pune Cancer Registry:** Pune is one of the important districts of Maharashtra State which lies on a plateau between latitude 17°54' and 19°22' North, and longitude 70°24' and 75°14' East, covering the area of 344.18 sq.kms.

**Sources of Data:** Two major sources have been utilized for cancer data collection.

- 1 All hospitals, nursing homes and consultants in private practice in registry area.

- 2 The Vital Statistics Division of the Department of Public Health of the Pune Municipal Corporation.

The majority of hospitals in Pune are maintained either by the Municipal Corporation, the State Government or Public Trusts. There are three medical colleges in the area, viz., the B. J. Medical College, associated with the Sassoon General Hospital, the Armed Forces Medical College with the Command Hospital, and the B.A.M.S. College with the Seth Tarachand Hospital

The diagnosis and treatment of cancer is however, centralized in six major hospitals and nursing homes, viz., the Sassoon General Hospital, the K.E.M. Hospital, the Lata Mangeshkar Hospital, the Ruby Hall Nursing Home, the Jahangir Nursing Home, the Inlaks Hospital and the Armed Forces Command Hospital. Facilities for Cobalt 60 beam therapy are however available at Ruby Hall Nursing Home, Inlaks Budharani Hospital and the Armed Forces Command Hospital. With a growing private sector, there are now an increasing number of private hospitals, both large and mid-sized, which are involved in cancer care.

**Nagpur Cancer Registry:** Nagpur city lies on the Deccan Plateau of Indian Peninsula on plateau between latitude 21, 06 North and longitude 79, 03 East, covering the area of 236.9 sq.kms.

**Sources of Data:** Two major sources have been utilized for cancer data collection.

1. All hospitals, nursing homes and consultants in private practice in the registry area.
2. The Vital Statistics Division of the Department of Public Health of the Nagpur Municipal Corporation

The major Govt. Hospitals with indoor facilities are Government Medical College Hospital, Indira Gandhi Medical College Hospital (MAYO General Hospital) CGHS has 10 Hospitals while ESIS has 13 dispensaries and one hospital. RCC –Rashtriya Sant Tukdoji Cancer Hospital, many private hospitals like Mure Memorial, Nagarik Sahakari, Lata Mangeshkar, Matru-Seva Sangh, Janata, Radhakrishna, Orange City, etc. With a growing private sector, there are now an increasing number of private hospitals, both large and mid-sized, which are involved in cancer care.

**Aurangabad Cancer Registry:** Aurangabad city is the head quarters of Marathwada, a geographic division of Maharashtra. It covers an area of 50.48 sq.kms. Aurangabad is an important industrial town as well as popular conference center.

The main source of our data collection is Aurangabad Government Medical College and Dhoot Radiotherapy Center. Besides this private nursing home there are facilities available for diagnosis and treatment of all cancer cases as city has specialists practicing neurology, neurosurgery, medical oncologists, histopathologists and cardio-vascular surgeons in the public as well as private sector institutes

#### **Difficulties at the time of Data Collection:**

Active Data Collection methodology has been used by the Social Investigators to collect the information on cancer patients. Mumbai, Pune being the metropolis city of the Maharashtra, data collection at the private sector hospitals has become a challenge to the registry. As many times hospitals are not sharing information on the confidentiality background. Hence registry is facing the problem of incompleteness of the data.

**Data Collections and Data Entry Status of all Four Registries:**

Registry	Population Type	Data Entry Completed in last year			Data Collection	
		Male	Female	Total	Completed	Ongoing
Mumbai (2012)	Urban	6175	6443	12628	2013	2014
Pune (2012)	Urban	1509	1611	3120	2013	2014
Nagpur (2012)	Urban	1159	1192	2351	2013	2014
Aurangabad (2013)	Urban	386	378	764	2014	2015

**5 Leading Cancer sites of Registries: (No of cases given in brackets)**

Mumbai 2012		Pune 2012		Nagpur 2012		Aurangabad 2013	
Male	Female	Male	Female	Male	Female	Male	Female
Lung (587)	Breast (1890)	Mouth (128)	Breast (504)	Mouth (126)	Breast (373)	Lung (54)	Breast (105)
Mouth (564)	Cervix (511)	Lung (113)	Cervix (171)	Tongue (98)	Cervix (161)	Tongue (34)	Cervix (84)
Prostate (491)	Ovary (445)	Lymphoma (101)	Ovary (119)	Esophagus (85)	Ovary (71)	Mouth (34)	Ovary (30)
Liver (455)	Lung (274)	Prostate (99)	Mouth (67)	Lung (75)	Esophagus (60)	Leukemia (32)	Lung (18)
Tongue (309)	Cor.Uteri (223)	Tongue (86)	Lymphoma (55)	Larynx (72)	Mouth (43)	Esophagus (27)	Leukemia (16)

**Event:** Mumbai Cancer Registry is celebrating an event of 50 years of establishment with hosting a Conference at Pune namely "Cancer in Maharashtra by 2020" during 8/9 August 2015. All the staff members from Mumbai, Pune, Nagpur and Aurangabad will be presenting the cancer statistics and predictions. We are inviting all the cancer treating hospitals and nursing homes, Municipal Corporation, laboratory, pathology, and radiology centers for this conference from Pune. Cancer Registry has also formed the Scientific Advisory Committee as suggested by NCDIR.

**Publications:**

1. Mumbai Cancer Registry, Eds Dr Arun Kurkure, Ms.Shravani Koyande-Cancer Incidence of 5 Continents Vol.X.
2. Cancer Incidence and Mortality in Greater Mumbai, 2011. (Press)
2. Rural Urban differences in Breast Cancer in India. Nagrani Rajini T, Buduk Atul, Koyande Shravani. Panse NS. Mhatre S S, Badwe Rajendra. Published in IJC

## Population Based Cancer Registry and Punjab Cancer Atlas – Patiala

Principal Investigator: Dr Vijayakumar Bodal  
Co. Principal Investigator: Dr Manjit Singh Bal

**Introduction:** Population Based Cancer Registries (PBCRs) collect data on all new cases of cancer incidence and cancer deaths who are residents of a defined area for a particular time period to produce statistics on the occurrence of cancer in the population of the defined area and provide an idea of the patterns of cancer in the population. This data thus collected will describe the extent and nature of the cancer burden in the community and assist in the establishment of public health priorities and help in monitoring and assessing the effectiveness of cancer control activities.

### Working of PBCR, Patiala:

#### **Incident data collection at PBCR, Patiala:**

Social Workers visit various hospitals and nursing homes and interview the patients who are either undergoing cancer treatment or being investigated for cancer at radiotherapy department. They also examine the case record maintained by various departments of these hospitals viz. Pathology, Haematology, Radiology etc. All the information collected is cross checked for completeness of the data. Some patients may have registered in more than one hospital for treatment. So, care is taken to exclude duplicates and ensure that each patient is included only once in the data.

#### **Mortality data collection at PBCR, Patiala:**

Social workers visit the offices of Patiala

Municipal Corporation and committees, PHC's under district Patiala to collect information about deaths which reported cause of death as cancer or tumours. The death record is then matched with the morbidity records. Cases not matching with the records are registered as Death certificate only cases (DCO's) in that corresponding year. All cause mortality data is also collected for that corresponding year and is being sent to NCDIR Bangalore for further matching of the incident cancer cases belonging to district Patiala but registered by other participating centres.

### Electronic capture and processing of data:

**At PBCR Patiala:** NCDIR-NCRP has installed a software application, PBCRDM 2.1 at PBCR Patiala to capture incidence and mortality data with international standard checks on data quality at both data entry and processing stage. A de-duplicate programme lists probable duplicate registrations of the same patient from different sources (hospitals/labs/diagnostic centres). Matching of mortality with incidence is possible after finalization of data. The data is submitted to NCDIR-NCRP.

**At NCDIR-NCRP:** The cancer data of Patiala residents collected from hospitals under Punjab Cancer Atlas (project under NCDIR-NCRP) including collection under Mukhyamantri scheme, Hospital Based Cancer Registry data submitted by Rajiv

Gandhi Cancer Institute New Delhi, PGI Chandigarh, Acharya Tulsi Regional Cancer Treatment & Research Institute Bikaner and Medanta Cancer Institute Gurgaon is also added to the PBCR data. A duplicate check is run across the data thus collected to eliminate any duplicate registration. All cause deaths submitted by the PBCR is matched with the incidence data. Unmatched mortality records form part of Death Certificates Only (DCO). Generation of statistical tables are done and sent to PBCR.

**Leading sites of cancer:** The leading sites of cancer for each gender were decided on the basis of proportion relative to all sites of cancer or in other words based on crude incidence rates. Tables 2.1 & 2.2 and Figures 2.1 & 2.2 show the ten leading sites of cancer for both males and females.

In the description given below, the relative proportions (%) of leading sites are given for each leading site. Likewise, in the figures the Age Adjusted Rate (AAR) per 100,000 population are shown in parentheses for each site.

**Males:** The leading sites of cancer with relative proportions (%) in Patiala were esophagus (12.7%), prostate (8.8%), lung (6.5%), mouth (4.9%), myeloid leukaemia (4.7%) followed by others. The respective CR and AAR per 100,000 population for above sites were: esophagus (9.5 and 10.4), prostate (6.6 and 7.3), lung (4.9 and 5.4), mouth (3.7 and 4.0) and myeloid leukaemia (3.5 and 3.6).

**Females:** The leading cancer sites among females were breast (32.8%) followed by cervix uteri (11.7%), esophagus (7.5%), uterus unspecified (4.5%) and ovary (4.2%). The two leading sites breast and cervix constituted 44.5% of all cancers in females. The respective CR and AAR per 100,000 population for the above sites were: breast (32.6 and 32.5), cervix uteri (11.6 and 11.6), esophagus (7.5 and 7.6), uterus unspecified (4.5 and 4.6) and ovary (4.1 and 4.1).

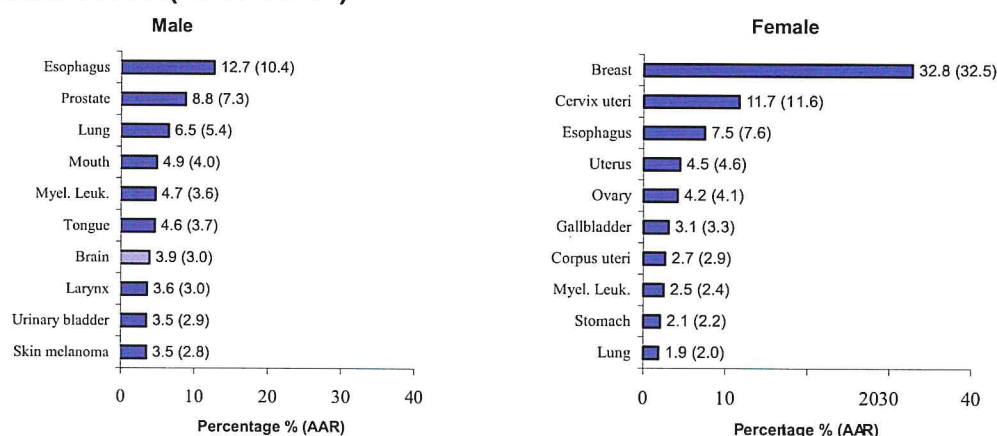
**Table 2.1: Ten Leading Sites of Cancer for Patiala PBCR (2011-2012) - Males**

Sl.No	Sites	#	%	CR	AAR	TR
1	Esophagus	193	12.7	9.5	10.4	20.3
2	Prostate	134	8.8	6.6	7.3	8.9
3	Lung	99	6.5	4.9	5.4	11.4
4	Mouth	75	4.9	3.7	4.0	8.9
5	Myeloid Leuk.	71	4.7	3.5	3.6	5.1
6	Tongue	69	4.6	3.4	3.7	9.2
7	Brain	59	3.9	2.9	3.0	5.6
8	Larynx	54	3.6	2.7	3.0	6.9
9	Urinary Bladder	53	3.5	2.6	2.9	5.2
10	Skin Melanoma	53	3.5	2.6	2.8	5.5
<b>Total</b>		<b>860</b>	<b>56.7</b>	<b>42.3</b>	<b>46.1</b>	<b>87.1</b>
<b>All Sites</b>		<b>1516</b>	<b>100.0</b>	<b>74.5</b>	<b>81.1</b>	<b>151.6</b>

Table 2.2: Ten Leading Sites of Cancer for Patiala PBCR (2011-2012) – Females

Sl.No	Sites	#	%	CR	AAR	TR
1	Breast	592	32.8	32.6	32.5	83.6
2	Cervix Uteri	211	11.7	11.6	11.6	29.6
3	Esophagus	136	7.5	7.5	7.6	15.8
4	Uterus	82	4.5	4.5	4.6	9.5
5	Ovary	75	4.2	4.1	4.1	9.4
6	Gallbladder	56	3.1	3.1	3.3	7.4
7	Corpus Uteri	49	2.7	2.7	2.9	6.8
8	Myeloid Leukd	46	2.5	2.5	2.4	4.5
9	Stomach	38	2.1	2.1	2.2	4.3
10	Lung	35	1.9	1.9	2.0	3.2
<b>Total</b>		<b>1320</b>	<b>73.1</b>	<b>72.7</b>	<b>73.1</b>	<b>1740</b>
<b>All Sites</b>		<b>1806</b>	<b>100.0</b>	<b>99.5</b>	<b>100.2</b>	<b>227.1</b>

Fig. 2.1: Ten Leading Cancers (AARs given in brackets) for Patiala PBCR(2011- 2012)



### Promotional Events & Meetings:

1. **March 29<sup>th</sup> 2014:** Workshop on Cancer Registry Awareness held at Pathankot by PBCR & PCA Patiala. Civil Surgeon of Pathankot, Doctors of IMA Pathankot, Local practitioners, PCMS Doctors, including Surgeons, Gynecologists, Radiologists, Ortho, and Pathologists attended the workshop.
2. **April 9<sup>th</sup> 2014:** Meeting with Dr. KD Singh (Principal) GMC Patiala, Dr. Bali (Civil Surgeon) Patiala, by Dr. A.Nanda Kumar (Director- In- Charge) NCRP, Bangalore, Dr. Manjit Singh Bal (PI), Dr. Vijay Kumar (Co-PI), Dr. Sathyaparkash, Dr. Misha and Dr. Jaspreet Kaur regarding cancer patients survey under the Punjab Cancer Atlas, Patiala.
3. **April 10<sup>th</sup> 2014:** Meeting with various Civil Surgeons at District Mansa, District Bathinda, District Muktsar, District Barnala regarding cancer patient's survey. Attended by Dr. Vijay Kumar (Co-PI), Dr. Sathyaparkash, Dr. Misha and Mr. Dalvir Singh (Social Worker, PCA).
4. **October 14-15<sup>th</sup>, 2014:** Meeting at National Cancer Registry Program Head Quarters,

Bangalore regarding 1<sup>st</sup> provisional Report of PBCR Patiala for the year 2011-2012. Dr. Manjit Singh Bal (PI), Dr. Jaspreet Kaur (Research Scientist), Mr. Vicky Harinderpal attended the meeting.

5. **November 12<sup>th</sup> 2014:** Participation in Mega Medical Camp for cancer patients at Rajindra Hospital, Patiala by Ms. Monika (Social Worker), Ms. Parvinder Kaur (Social Worker), Mr. Vicky Harinderpal (Data Entry Operator).
6. **November 25<sup>th</sup> 2014:** Meeting by Dr. Sathya parkash With Dr. Manjit Singh Bal(PI), Dr. Vijay Kumar (CO- PI), PBCR and PCA Staff at Rajindra Hospital, Patiala regarding two months survey for Diabities, CVD, Stroke and Cancer.
7. **December 16-19<sup>th</sup> 2014:** 30<sup>th</sup> ARM of NCRP at Chennai attented by Dr. Manjit Singh Bal (PI), Dr. Vijay Kumar Bodal(Co-PI), Dr. Jaspreet Kaur(Research Scientist), Mr. Vicky Harinderpal, Ms. Monika, Ms. Parvinder Kaur, Ms. Swati Sharma, Mr. Dalvir Singh and Presentation given by Dr. Manjit Singh Bal (PI), Dr. Jaspreet Kaur(Research Scientist).
8. **Feburary 17 28<sup>th</sup> 2015:** Interviews and Training given by Dr. Sathyaparkash, Dr. Vijay Kumar, Dr. Jaspreet Kaur, Mr. Dalvir Singh, Mr. Vicky Harinderpal at Districts Barnala, Mansa, Bathinda, Muktsar regarding Verification of completeness of data obtained through Punjab Cancer Atlas through a survey with the additional objective of knowing the magnitude of Diabetes, CVD and Stroke in the Malwa Region of Punjab.
9. **March 1-31<sup>st</sup> 2015:** Supervision and Verfication of Diabetes, CVD, Stroke and Cancer Cases in the Malwa Region of Punjab, District Barnala, Mansa, Bathinda and Muktsar done by Dr. Manjit Singh Bal, Dr. Vijay Kumar, Dr. Sathyaparkash, Dr. Jaspreet Kaur, Mr. Vicky Harinderpal, Mr. Dalvir Singh, Ms. Monika, Ms. Parvinder Kaur.

#### Sources of Data of PBCR & PCA Patiala:

1. Govt. Rajindra Hospital and Govt. Medical College Patiala.  
(Radiotherapy Department, Pathology Department & Others)
2. Mata Kaushalya Hospital, Patiala.
3. Amar Hospital, Patiala.
4. Govt. TB and Chest Hospital, Patiala.
5. Gian Sagar Hospital, Banur, Patiala.
6. Visit to Private Laboratories in various districts of Punjab.
7. Local Private Hospitals & Clinics.
8. Visit to Civil Surgeon Office in various districts of Punjab.
9. Municipal Corporations in various districts of Punjab.
10. Various Private Hospitals at Mohali (Fortis , Grecian)
11. PHCs and CHCs under Civil Surgeon in Patiala.
12. Mukh Mantri Punjab Rahat Kosh Scheme.
13. Cancer Control Cell, Chandigarh.

**PBCR Staff**

**Data Entry Operator:** Mr. Vicky Harinder Pal

**Social Workers** : Ms. Monika, Ms. Parvinder Kaur, Mr. Dalvir Singh

**PBCR, Patiala Pictures**



## CANCER ATLAS - PUNJAB

### PBCR - PATIALA



**Dr. Manjit Singh Bal**

Dr. Manjit Singh Bal was principal Investigator PBCR Patiala and Punjab Cancer Atlas (PCA). He contributed a lot to these projects. A graduate and postgraduate (Pathology) from GMC affiliated to Guru Nanak Dev University Amritsar, he worked at Amritsar, Faridkot and Patiala on various positions and retired from after more than 37 years of government job (17 years as head of Pathology at GMC Patiala).

He produced 115 postgraduates who are settled in India as well as distributed throughout the globe. He is examiner in 17 Indian Universities. He has over 100 publications in national and international reputed journals. Currently he is member of editorial boards of six international journals.

In additions to Annual Review Meeting (ARM) 2013, and APCOM 2011, we organized 10 regional, international and National Conferences at GMC Patiala under Dr. Bal's guidance. ARM held at Patiala will be

remembered by all. Dr. Bal visited US, Canada, Singapore, Australia, Bangladesh, Nepal and Pakistan to present papers in Pathology Conferences on cancer subjects.

His literary and extracurricular tastes include, 9 books authored by him in Punjabi, Hindi and English. He has a flute music CD and he produced a film on his own story. Recently, (June 2015) he was invited to Canada to participate and present his literary paper in World Punjabi Conference held in Brampton and he did. He is regularly contributing to world media, especially in Punjabi, i.e, articles, TV and Radio talks pertaining to cancer.

Currently he is working as Professor of Pathology in a private institution (MM Medical College and Hospital, Kumarhatti, Solan in Himachal Pradesh) and continuing as Co-Principal Investigator for cancer projects.

## Population Cancer Registry, Trivandrum District

**Director: Dr. Paul Sebastian**

Principal Investigator: Prof. Dr. Aleyamma Mathew

Other Investigators : Dr. Preethi Sara George,  
Smt. G Padmakumary Amma,  
Dr. M C Kalavathy

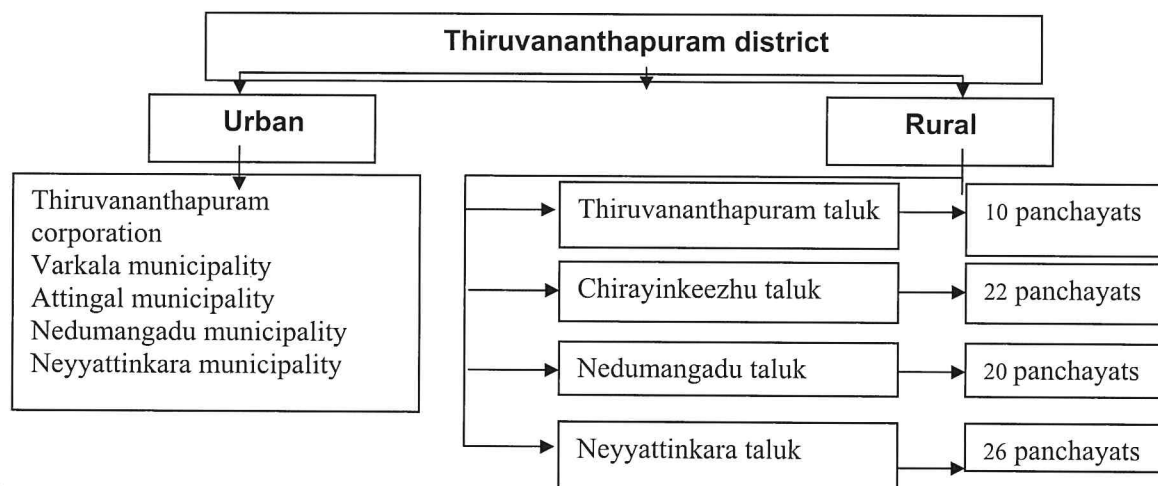
Thiruvananthapuram is the capital city of Kerala State which was formed in 1957. It is also the district head quarters.

The Population Based Cancer Registry (PBCR) covering the entire district of Thiruvananthapuram joined the network of National Cancer Registry Programme (NCRP) of Indian Council of Medical Research (ICMR) in 2012. The formation of this District Cancer Registry may be traced back to the functioning of HBCR of RCC since 1982 and the Thiruvananthapuram Taluk Registry in 1994. The Thiruvananthapuram district covers an area of 2192 Sq. kms and a population of 3307284 (2011 census) with 54% urban and 46% rural. The decadal population growth was 2.3%. It is the densest district in Kerala with 1059 people per sq kms. The average density is about 5000 persons per sq kms. Currently the district area covers 141.74 sq kms (map). The Thiruvananthapuram district is the southern most district of Kerala bordering Tamil Nadu in South and East and Arabian sea in the west. The district covers hills and high lands in the east, the sea coastal belt is known for sea fishing and beach resorts. In the urban areas 75% of the population is engaged in government / non-government sectors, trade & commerce. Coconut and paddy cultivation are the main agricultural sectors.



The administrative structure of the district is shown in Flowchart1.

**Flow chart 1. Administrative structure of Thiruvananthapuram district**



**Sources Covered for registry operations:** Based on an administrative letter provided by the Principal Secretary, Government of Kerala to all Health authorities in the District, co-operation has been obtained from all hospitals which helped to improve registry coverage since 2011. Data have been collected by an active method from more than 60 hospitals 7 pathology laboratories and other sources (Table 1). The major data sources are the RCC Thiruvananthapuram, Medical College Hospital (Radiotherapy Out Patient Department, Medical Records Library and Path department) and Avittam Thirunal Women and Children Hospital. Computerized information processing included linkage of patient data obtained from various sources, duplicate elimination etc.

Tables 1 shows the sources covered, Table 2 shows the facilities in the hospitals contributing more than 100 cases annually and Table 3 shows the incidence, mortality, Truncated rate, Cumulative life time risk, Age distribution summary and sex ratios

**Table 1: Taluk-wise distribution of Government and major private medical (allopathic) institutions in Thiruvananthapuram district**

Thiruvananthapuram		Chirayinkeezhu		Nedumangadu		Neyyattinkara	
Name	No	Name	No	Name	No	Name	No
Government							
Regional Cancer Centre	1	HQ <sup>3</sup> Hospital	1	HQ Hospital	1	HQ Hospital	1
Medical College Hospital	2	Govt. Hospital	2	Govt. Hospital	1	CHC	2
SCTIMST <sup>1</sup>	1	CHC <sup>4</sup>	2	CHC	4	Govt. Hospital	1
General Hospital	1	PHC	20	PHC	18	PHC	27
Other Govt. Hospitals	11						
PHC <sup>2</sup>	21						
<b>Total</b>	<b>37</b>		<b>25</b>		<b>24</b>		<b>31</b>
Private Hospitals	28		11		3		5
Private Laboratories	7		1		2		2

<sup>1</sup>Sree ChitraThirunal Institute of Medical Sciences; <sup>2</sup>PHC: Primary Health Center; <sup>3</sup> HQ: Head Quarters Hospital; <sup>4</sup> CHC: Community Health Center

**Table 2. Hospitals contributing more than cancer 100 cases annually**

No.	Major Hospitals	OP/IP	Surgey	Radiotherapy	Chemotherapy
<b>Private</b>					
1	Ananthapuri Hospital, Chackai, TVM	√	√	X	√
2	Cosmopolitan Hospitals (P) Ltd, Pattom,	√	√	X	√
3	Jubilee Memorial Hospital, Palayam, TVM	√	√	X	√
4	NIMS Hospital, Aralumoodu, Neyyattinkara,	√	√	X	√
5	PRS Hospital, Killippalam, TVM	√	√	X	√
6	Santhwana Hospital, NCC Road, Peroorkada,	√	√	X	√
7	SK Hospital, Edappazhinji, TVM	√	√	X	√
8	SreeGokulam Medical College, Venjar ammoodu, TVM	√	√	X	√
9	SUT Hospital, Pattom, TVM	√	√	X	√
10	SUT, Royal Hospital, Ulloor, TVM	√	√	X	√
11	Kerala Institute of Medical Sciences (KIMS), Anayara, TVM	√	√	√	√
<b>Government</b>					
1	General Hospital, TVM	√	√	X	√
2	SreeChitraThirunal Institute of Medical Sciences, TVM*	√	√	X	√
3	Medical College, TVM*	√	√	√	√
4	Regional Cancer Centre, TVM*	√	√	√	√

\* Referral hospital, TVM - Thiruvananthapuram

**Mortality Data Collection:** Computerised data on all deaths was obtained from the Thiruvananthapuram Corporation, 72 vital statistics offices and the 4 municipalities and data from death registers were obtained from the remaining 4 vital statistics offices in the district. Demographic details such as age, gender and addresses of all subjects deceased during the year 2012 whose permanent address is within the registry area were computerised using the PBCR mortality form. Data on all deaths were collected due to the limitation in the reporting of specific of cancer. Almost all deaths are registered in the vital statistics offices but information on cause of death is lacking. Because of this limitation, special efforts are made to improve the quality of mortality rates.

**Method of cancer patient recruitment- mortality data:** Mortality data is matched with the incidence cases and it is verified in three different manners as specific site of cancer is not obtained from the vital statistics offices. Firstly, all cancer deaths are compared with the 'cancer incidence database'. Any death, which was matched with the incidence database, the corresponding site of cancer was added to the 'cancer mortality database'. Secondly, any cancer

date of death was considered as date of diagnosis.

death collected from the vital statistics office, but not seen in the incidence database were included in both incidence and mortality database after verification through house visits. i.e. unmatched cases obtained from the mortality database were added to the incidence database as 'Death certificate only' (DCO). Their date of death was considered as date of diagnosis.

Deaths due to accidents or natural calamity were excluded if matched with cancer incidence database. Thirdly, 'non-cancer specific-mortality database' was compared with the 'cancer incidence database'. If all details except cause of death were matched with this database, such deaths were also added to the 'cancer mortality database' and their cause of death was corrected as due to the respective cancer obtained from the 'cancer incidence database'.

Microscopic confirmation, Death Certificate Only (DCO), fatality ratio (%) and proportion of Unknown primary sites are used to assess the quality of the registry. Microscopic verification was available for 82% in males and 87% in females. The proportion of DCO was 9.5% in males and 8.1% in females, fatality ratio was 37.8% and 30.2% in males and females respectively

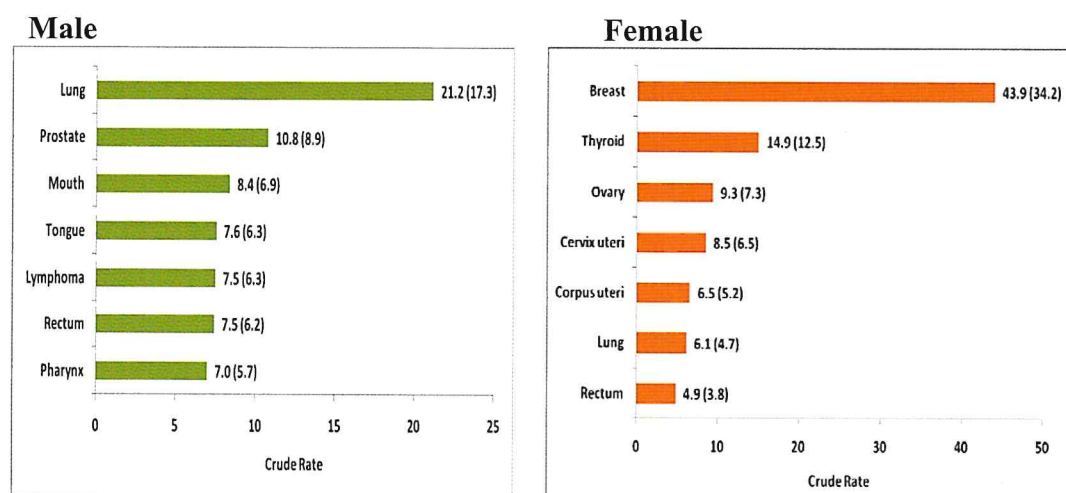
**Government Secretary's letter helped in Data Collection from Centres. This will be guidance to other registries:** To obtain a good coverage of the cancer registration system, a meeting of health authorities in the district was convened by Shri. Rajeev Sadanandan, IAS, Principal Secretary, Health & Family welfare Department, Government of Kerala along with RCC and Dr. A Nandakumar, on 30<sup>th</sup> November 2011. In continuation of this meeting, an administrative letter was provided by the Secretary to all health authorities in the district, requesting them to provide cancer patient information to the PBCR, Trivandrum functioning at RCC. Since then, cancer patient information from all major hospitals, pathology laboratories and all vital statistics offices in the district are obtained.

**The PBCR data has been included in the C15 Vol 10 of IARC:** In 1994, a PBCR was initiated to estimate cancer incidence and mortality in Thiruvananthapuram city (urban) and adjacent three community development blocks (rural population) covering a population of nearly 1 million in collaboration with the International Agency for Research on Cancer (IARC), Lyon, France for a period of 5 years and subsequently the Cancer Society of Finland for a period of 12 years provided funding support. Cancer statistics of the above urban and rural population was published in the 'Cancer Incidence in Five Continents', IARC, WHO, Volumes 7 to 10.

**Table 3: Incidence & Mortality: All Cancer Sites (TVM district 2013)**

Rates	Incidence			Mortality		
	Male	Female	Total	Male	Female	Total
Total Cases	2566	2676	5242	986	823	1809
Crude Rate (CR) per 10 <sup>5</sup> persons	162.1	154.9	158.3	62.3	47.7	54.6
Age Adjusted Rate (AAR) per 10 <sup>5</sup>	134.9	122.3	127.8	51.6	36.7	43.6
Truncated Rate (TR) (35-64 yrs) per 10 <sup>5</sup>	206.0	242.3	225.7	78.7	64.7	71.4
Cumulative Risk(CuR)(%)(0-74yrs)	15.0	12.9	13.9	6.1	4.9	5.1
Life Time Risk (LTR) (0-74 years)	7.0	8.0	7.0	16.0	24	20
Peak Age Group (years)	75+	55-59	60-64	65-69	75+	75+
Average Age (years)	60.3	55.7	57.9	61.3	60.8	61.1
Minimum age – Maximum age	1 - 96	1 - 97	1 - 97	1 - 93	3 - 97	1 - 97
Male to Female Ratio	1 : 1.04			1: 0.84		

**Fig 1. Seven Leading Cancer Sites in Males and Females - Crude incidence rates (AAR in parenthesis), Thiruvananthapuram District 2013**



### Major difficulties experienced for data collection

- Data collection from medical college hospital is a huge work- Nearly 1 lakh case sheets are to be sorted initially from medical records for identifying cancer cases from the Thiruvananthapuram district. A case sheet is provided for each patient visit and thus generally 4-6 case sheets are available for patients undergone chemotherapy. Nearly 10,000 cases sheets are abstracted annually and after computerizing the information, duplicates are eliminated. This is time consuming (6 month work of 6 persons).
- Some pathology laboratories do not have the hospital name/number/address. Hence data linkage is difficult.
- Data collection from other systems of medicine such as Ayurveda, Homoeopathy, Unani, Sidha etc. is not presently done. It was observed that many patients once registered and diagnosed as cancer, drop out from treatment and approach the above systems of medicine. Hence data may be missed.

**Expansion of activities of Registry:** Trivandrum cancer registry programme has been expanded to the status of the division of Cancer Epidemiology & Bio-statistics consisting of one Professor, one Associate Professor, two Assistant Professors. An Assistant Professor has also joined in the division recently. The division is the 1<sup>st</sup> research centre for Bio-statistics in Kerala, 9 doctoral students are doing their research in Bio-statistics and Epidemiology. Apart from providing research assistance to post-graduates in Bio-statistics; we guided 4 students last year and thus a total of 54 students during the past 7 years. During the period under-report we organized two workshops related to the topics such as Research methodology, Design and Analysis of Clinical Trials and Knowledge enhancement in scientific writing, accommodating approximately 120 participants.

**Workshops organized**

1. Research Methodology & Knowledge Enhancement in Scientific Writing in collaboration with Centre of Excellence in Ayur Informatics and Computer Aided Drug Design, University of Kerala at RCC, Trivandrum 28-29 April, 2014
2. Workshop on Design and Analysis of Clinical Trials & Knowledge Enhancement in Scientific Writing at RCC, Trivandrum 4<sup>th</sup> March, 2015

**Teaching/training programme for Medical record offices of the Rural hospitals:** A total of 4 training programmes were conducted for PHC Doctors and Health Inspectors, 3 training programmes were conducted for JPHNs and JHIs, 3 orientation programmes were conducted for ASHA workers in 2014.

**Cancer screening and awareness programmes organized by PBCR in 2014:** 92 cancer detection programmes were conducted in Trivandrum, 13,244 women and 1768 men were screened in 2014.

**Other on-going programmes**

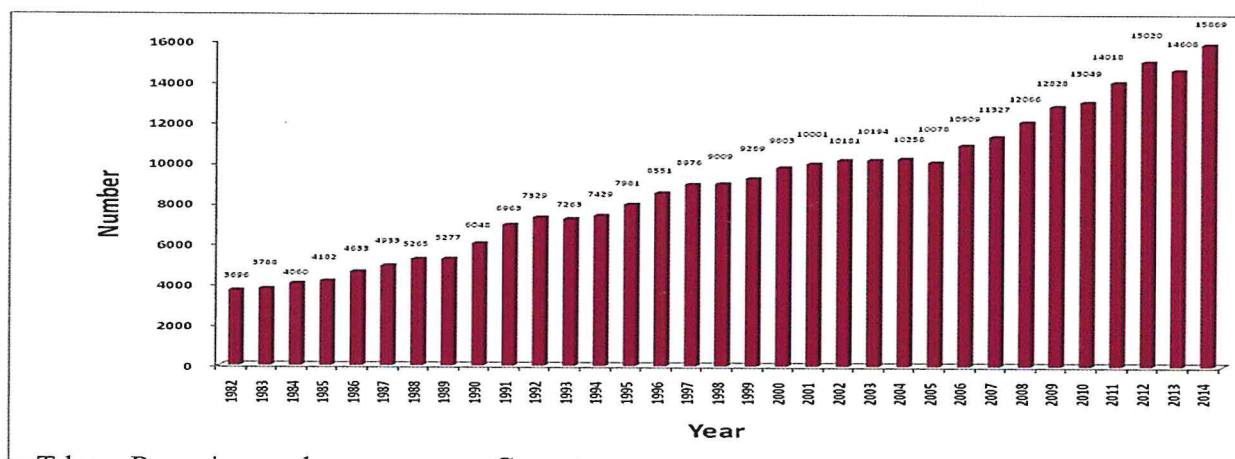
1. HBCR of RCC is in its 33<sup>rd</sup> year under the network of NCRP. Report of 2011 is available in our web-site. During the period under report (2013), a total of **15,939** cases were registered in RCC. **13,839** (87%) cases were invasive cancers
2. Pattern of Care and Survival of female breast, cervix uteri and head & neck cancers started in 2006 by the NCRP; ICMR is in its 9<sup>th</sup> year. Computerized data of case-records with updated follow-up details on a total of **7447** female breast, **2172** cervix uteri and **11,835** head & neck cancer cases are provided to NCRP for national compilation.
3. Risk estimation of bladder and kidney cancers supported by the STEC, Kerala completed a 3-year study and submitted the report. Paper on Tobacco and bladder cancer, Obesity and kidney cancer were submitted for publication

**Cancer screening awareness and detection programmes:** 4 cancer screening training programmes were conducted to PHC Doctors and Health Inspectors (305 persons attended), 3 to JPHNs and JHIs (635 persons attended), 3 orientation programmes to ASHA workers (around 1000 persons attended) **92** cancer detection programmes were conducted in Trivandrum, **13244** women and **1768** men were screened, **5** breast and **11** oral cancers were diagnosed, and **5948** Pap smears collected, **52** cervical pre-cancers and **11** cervical cancers were detected. **9** and **7** cancer detection programmes were conducted in the district of Kollam and Pathanamthitta respectively, screened **2314** people, detected **4** breast and **4** oral cancers.

**Student projects completed**

1. Assessment of completeness in Trivandrum cancer registry data: capture-re-capture method
2. Conditional logistic regression model for a 1:1 age matched case-control study on male bladder cancers
3. Burden of cancer in Trivandrum, Kerala: sensitivity analysis for disability-adjusted life years
4. Bias in breast cancer survival estimates when non-uniform loss to follow-up among prognostic factors

### Cancer Patient increases during 1982-2014, Regional Cancer Centre, Trivandrum



The Regional cancer Centre Thiruvananthapuram was established in 1982 by the Government of Kerala. Annual number of patient registration of RCC Thiruvananthapuram has been increasing since its inception. In 2014 the new patient registration was 330% more than in 1982 (Figure). Among the new registration, over 13,000 are new cancer patients which represents the second largest hospitals cancer load in the country. The first being the Tata Memorial hospital, Mumbai. However there are marked differences in the site distribution of cancers seen in these two institutions.

#### Achievements of registry staff

##### Dr. Aleyamma Mathew

1. Selected as **Professor of Cancer Epidemiology & Bio-statistics, RCC, Trivandrum**
2. **Abstract Reviewer**, 3<sup>rd</sup> National conference on Tobacco or Health 2014, Mumbai
3. **MPH thesis evaluator**, SCTIMST, Trivandrum, 2014
4. **Doctoral Thesis Evaluator**, Manipal College of Nursing, Manipal University, Karnataka, October, 2014.
5. **Expert Committee Member** for the Burden of Disease study, Organized by ICMR, New Delhi.
6. **Post-graduate thesis-Guide** for two MSc Bio-statistics students, Mahatma Gandhi University, Kerala.

7. Life-member and Selected as **Working group member** of Kerala Statistical Institute.

##### Dr. Preethi Sara George

1. **Received Post Graduate Diploma in Epidemiology – Distance Learning (PGDEPI-DL)** with Grade A+ from Indian Institute of Public Health, Delhi in the academic year 2014.
2. Recognized as **Research Guide in Biostatistics** under Mahatma Gandhi University, Kottayam.
3. **Doctoral committee member** in Mahatma Gandhi University, Kottayam.
4. **Life-Member**, Kerala Statistical Institute.
5. **Post-graduate thesis –Guide** for two MSc Bio-statistics students, MG University.

#### Conferences/workshops/Training programmes attended, Papers presented

##### Dr. Aleyamma Mathew

1. CNE on Breast Cancer on 12 April 2014 RCC, Trivandrum - Invited Talk: Global Trends in Breast cancer incidence and mortality.
2. Research Methodology & Knowledge Enhancement in Scientific Writing. 28-

29 April, 2014, RCC, Trivandrum.  
Talks: 1.Study designs in Bio-medical research, 2.Sample size in Bio-medical Research, 3.Scientific writing- An Overview, 4.Ethical considerations in the conduct of research and Publications.

3. Workshop on Research Agenda Setting on Chronic Respiratory Diseases. 1<sup>st</sup> June 2014, Health Action by People, Trivandrum - Invited Talk: Development of a disease registry with emphasis on Interstitial Lung Disease Registry
4. ICMR, Meeting 11<sup>th</sup> and 26<sup>th</sup> July, 2014, ICMR, New Delhi - Comparative study of Genetic, clinical and epidemiological factors of breast cancer in urban and rural area in India
5. ICMR, Meeting 1<sup>st</sup> August, 2014, ICMR, New Delhi - Burden of Disease study
6. Workshop on Design and Analysis of Clinical Trials & Knowledge Enhancement in Scientific Writing 4<sup>th</sup> March, 2015, RCC, Trivandrum  
Talks: 1.Overview of Clinical trials, 2.Sample size and Power of a study, 3.Statistical Analysis of Clinical trials, 4.Knowledge Enhancement in Scientific Writing

#### Dr. Preethi Sara George

1. Research Methodology & Knowledge Enhancement in Scientific Writing 28-29 April, 2014, RCC, Trivandrum - Talk: Data Processing and Analysis

#### Publications: Journal articles

1. Mathew A, George PS, Padmakumari G, Kalavathy MC, Sebastian P, Cancer Incidence in Thiruvananthapuram, Cancer Incidence in 5 Continents Vol X, IARC, Scientific Publication No. 164.
2. Carrie R. Daniel, Kavita Kapur, Mary J. McAdams, Sujata Dixit-Joshi, Niveditha Devasenapathy,

Hemali Shetty, Sriram Hariharan, **George PS**, **Mathew A** and Sinha R. Development of a field-friendly automated dietary assessment tool and nutrient database for India. British Journal of Nutrition 111, 160–171, (2014).

3. Varghese BT, Babu S, Desai KP, Bava AS, **George PS**, Elizabeth M Iype, Rajan B, Sebastian P. Prospective study of outcomes of surgically treated larynx and hypopharyngeal cancers. Indian J Cancer. 2014 Apr-Jun;51(2):104-8.

#### Conference papers

1. Arjunan A, Raju P, **George PS**, **Mathew A**, Ratheesan K, Parameswaran S. Clinical outcome of postmastectomy chest wall radiotherapy using electrons: A retrospective analysis. JI of Cancer Research & Therapeutics 10 (30), 2014.
2. Suchetha S, Rema P, Vikram S, George PS, Ahmed I. Role of lymphadenectomy and its impact on survival in endometrial carcinoma - an institutional experience. Gulf JI Oncology 2015 Jan;1(17):30-3.
3. Saritha VN, George JK, **Kalavathy MC**, Somanathan T, Rema P, Sujathan K. Liquid chromatography- mass spectrometry analysis of exfoliated cells from the squamous cell carcinoma and cervical intraepithelial neoplasia: significance in deciding candidate markers. 34<sup>th</sup> Annual convention of India Association for cancer research (IACR, 2015) 19-21 February, Jaipur.



Division of Cancer Epidemiology and Biostatistics  
Regional Cancer Centre, Thiruvananthapuram

## West Arunachal Population Based Cancer Registry

Principal Investigator: Dr. S. Tawsik, MD,  
Arunachal State Hospital, Naharlagun

**Introduction:** The West Arunachal Population Based Cancer Registry (PBCR), located in the Department of Pathology, Arunachal State Hospital, Naharlagun started functioning from 1<sup>st</sup> January'2011 under the aegis of National Cancer Registry Programme (Indian Council of Medical Research) as a part of network of over 29 PBCRs across the country covering 10 districts viz., Papumpare, Kurung Kumey, Kra Dadi, Lower Subansiri, Upper Subansiri, West Siang, Lower Siang, Tawang, West Kameng and East Kameng.



**Population:** The Total Population of Arunachal Pradesh according to 2011 census is 13, 82,611 of which 77 percent of population live in rural areas whereas only 23 percent live in urban areas. Our registry covers the population of 7, 59,794.

**Life style and food habits:** Arunachal Pradesh is a tribal state and majority of population live in rural areas in traditional houses with poor ventilation and sleep alongside fire places. Use of tobacco items among rural populace is common. Variety of peculiar food items like smoked meats,

fermented bamboo shoot and soya beans are delicacies of tribal people. One peculiar food item called "Pike Pilla" is a delicacy consumed by Apatani tribe which is prepared from preserved pork with Pilla water prepared by filtering burnt ashes of dry leaves. 'Kala Apong' meaning Black beer prepared from fermented rice along with burnt paddy husk ashes is very popular alcohol consumed by three major tribes of our registry area.

**Facilities for cancer diagnosis and treatment:** By and large Arunachal Pradesh has very poor health infrastructure facilities. Except for twin capital city of Itanagar and Naharlagun, all other districts do not have diagnostics as well as treatment facilities for cancer patient. Diagnostics facilities like USG, Endoscopy, CT scan, MRI and Pathology are available in the capital city. Arunachal State Hospital, Naharlagun and Rama Krishna Mission Hospital, Itanagar have chemotherapy facilities. Tertiary cancer centre is coming up in Arunachal State Hospital, Naharlagun very soon; building and equipments for which is ready. Only in two other districts in our registry area have services of pathologists. As of now, most of our cancer patients go outside the state for treatment.

### List of main sources of data collection

1. Arunachal State Hospital, Naharlagun
2. Ambee Lab, Itanagar
3. Rama Krishna Mission Hospital, Itanagar
4. Diagnostic centres/ Nursing Labs, Itanagar
5. BBCI, Guwahati
6. Tata Memorial Hospital, Mumbai
7. North East Cancer Hospital & Research Institute
8. All District Hospitals

### Number of Cases, Deaths and Relative proportion % (2011-2013)

	No. of Cases	%	No. of Deaths	%
<b>Males</b>	781	52.6	205	64.2
<b>Females</b>	703	47.4	114	35.8
<b>Total</b>	<b>1484</b>	<b>100</b>	<b>319</b>	<b>100</b>

### 7 Leading Sites of Cancer (2013):

Number (#), Relative Proportion (%) and AAR

#### Male

Rank	Sites	#	%	AAR
1	Stomach	70	26.82	29.38
2	Liver	59	22.60	26.81
3	Esophagus	24	9.2	12.40
4	Lung	15	5.75	7.20
5	Leukaemia	10	3.83	2.41
6	Larynx	8	3.06	3.28
7	Other Skin	8	3.06	2.93
	<b>All Sites</b>	<b>261</b>	<b>100.0</b>	<b>93.78</b>

#### Female

Rank	Sites	#	%	AAR
1	Stomach	36	17.31	19.13
2	Breast	22	10.58	7.94
3	Thyroid	21	10.10	8.56
4	Cervix	20	9.61	9.31
5	Liver	13	6.25	6.19
6	Ovary	10	4.81	4.55
7	Other Skin	10	4.81	4.02
	<b>All Sites</b>	<b>208</b>	<b>100.0</b>	<b>70.54</b>

### Expansion activities:

1. Government of Arunachal Pradesh has issued a notification to notify all cancer cases to the registries.
2. Reached out to NEIGRIHMS, Shillong and North East Cancer Hospital, Guwahati for seeking co-operation and collecting data respectively.

3. Districts tours undertaken for data collection.

### Major difficulties:

1. Poor health infrastructure.
2. Lack of proper diagnostic & treatment facilities.
3. Poor medical record keeping.
4. Communication Problem and scattered population.
5. Dependence on traditional healing in rural population.
6. Corporate Hospital attendees.
7. Lack of crematorium and traditional methods of disposal of dead bodies.
8. Frequent change of sim cards and lack of proper addresses for home visits.
9. Poor death registration.

### Preserved Pork Meat



### Kala Apong (Black Rice Beer)



**Pilla**



**Opium smokers**



1. Jigonso Tawsik: Computer Programmer
2. Habung Pampi: Social Investigator
3. Hage Ampa: Social Investigator
4. Ngilyang Otung: Statistici

**Knowing is not enough; we must apply.  
Willing is not enough; we must do - Goethe  
Jane E Ferrie - Editorial; Int. Jl. Epid. 2014:  
1671-1677**

**CANCER MADE A  
NOTIFIABLE  
DISEASE  
&  
TOBACCO USE  
BAN ORDERS**



# Cancer: A Notifiable Disease

Dr. R A Badwe, Director, Tata Memorial Centre, Mumbai,  
Dr B Ganesh, Prof. and Head, Dept. of Medical records, Biostatistics & Epidemiology,  
Dr. Arshi Khan, Research Fellow, Dept. of Medical records, Biostatistics & Epidemiology

Cancer is the second most prevalent disease in India. According to recent studies an estimated 600000-700000 deaths have been reported in India in 2012 which is indicative of low rates of early detection and poor treatment outcomes. 'Cancer' has a profound psychosocial and economic impact for people in India as it is leading to highly diminished physical, mental, capabilities, family impoverishment and inequity. Developing countries including India accounts for more than half of new cancer cases in the world, however notification of cancer is not yet mandatory. The primary purpose of notification is to effect prevention and control by better planning and utilization of resources. It is also a valuable source for incidence, prevalence, mortality and morbidity assessment of the disease. Notification of cancer will also lead to improved awareness of common etiologic agents, better understanding of common preventable causes and better utilization of health resources with better monitoring and evaluation of the effectiveness of health programs such as cancer screening and cancer treatment programs, which ultimately would help prevention and improve survival. Notification of cancer can be done by the doctor or the hospital. Akin to the integrated disease surveillance project where more than 90% of the districts report weekly data through E-mail/portal, notification of cancer can be implemented if it is incorporated into the National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular diseases and Stroke scheme. The need of the hour is cancer notification in INDIA made mandatory.

The existing cancer registries in India include Population Based Cancer Registries (PBCRs) and Hospital Based Cancer Registries (HBCRs). PBCRs now actively collect and process data relating to a defined geographical area while HBCR include data available with a specific hospital only. However the available cancer registry programme in India has many limitations. They do not include the entire country; only include data gathered from specified towns and cities. Even within these registries there is marked variation, which can lead to misestimating of disease burden and characteristics. Variation in data obtained from specialized and non-specialized medical institutions can be related to many factors. The need of the hour is uniformly implemented cancer notification system throughout the country.

Notification is reporting by a physician or other health care provider of the occurrence of specified disease to a designated health agency. List of notifiable diseases varies from country to country and also between states, urban and rural areas. The primary purpose of such notification in cancer is to achieve prevention and control of the disease in the community. It is a valuable source for information on the incidence, prevalence, mortality and morbidity of the disease. Notification of cancer will lead to improved awareness of common etiologic agents, better understanding of common preventable causes and better utilization of health resources with better monitoring and evaluation of the effectiveness of health programs such as cancer screening and cancer treatment programs which ultimately might

improve survival. Assessment of time trends is mandatory while undertaking preventive action. This is also achieved by 'notification'. Presently some of the communicable diseases are notifiable in India. Under the integrated disease surveillance project more than 90% of districts in India notify some of the communicable diseases. These include many syndromes and diseases like dengue, Japanese encephalitis, meningococcal meningitis, diphtheria, acute flaccid paralysis in <15 years and various other diseases.

#### **Advantages of Cancer Notification:**

Prompt and appropriate reporting allows for better management of cancer through:

- Monitoring of changes in the incidence
- Identification of risk factors and causes, with better utilization of resources
- Monitoring and evaluation of the effectiveness of health programs such as cancer screening and cancer treatment programs
- Monitoring of patterns of prescribing drugs
- Planning of services for better care.
- Undertaking epidemiological studies.
- Training programmes in cancer.

The notification can be used for compilation the formation of a National Cancer Registry data base which can help clinicians, health planners and researchers for better management of the patients and community cancer control.

**Possible Limitations of Notifications:** The system may suffer from under-reporting. The accuracy of diagnosis and thereby notification may depend upon the availability of facilities for histopathological diagnosis.

The lack of such facilities in many parts of rural India may work against the correct reporting.

**Conclusion:** Notification of cancer will lead to improved awareness of common preventable causes, better utilization of health resources with better monitoring and evaluation of the effectiveness of health programs such as cancer screening and cancer treatment programs.

**The following states made cancer a Notifiable disease.**

#### **Reference: CRAB Vol.18, Nov.2012**

1. Tripura-Order dated 24/09/2008 (No. F.3 (163)-CH/MS/As/2008/2655
2. West Bengal – No. HF/O/PHP/402/5C-05/2010 dated Kolkatta the 20/12/2010
3. Punjab – Department of Health and Family Welfare - Order No. 2-3-011-4HB4-3226-dated 18/10/2011-2/3/2011-4HB4
4. Kerala – Principal Secretary of Health – D O No. 398/HS/2011 dated 28/12/2011
5. Tamil Nadu – G O (Ms) No. 132 dated 17/04/2012

**Government of Karnataka**  
(Abstract only)

**No. HFW 189 CGM 2015, Karnataka Government Secretariat, Vikas Soudha,  
Bengaluru, Dated: 25/07/2015**

Whereas cancer appears to be a matter of serious concern for us at the national and regional State level in the country.

And whereas the Indian Council of Medical Research recommends that it is absolutely necessary to initiate mandatory reporting of Cancer Registry Programme to facilitate planning, guidance, monitoring and evaluation of Cancer Research and Control Programme in country.

.....And whereas, the data received on cancer in the state would be used to frame policy on prevention and control of cancer, establishing treatment facilities and cancer research and training centres in the state.

.....And whereas the pathologist should make it mandatory to receive the clinical details, physician details and other pertinent information while collecting the specimen for the purpose of notifying.

.....And whereas in the event the doctor or the medical institution fails to comply with the above mentioned rules, he would be liable for punitive action as that would be decided by the Committee thereof.

By order in the name  
of the government of Karnataka

**Atul Kumar Tiwari,**  
Principal Secretary to government,  
Health and Family Welfare Department.

**Government of Mizoram****No:J.11011/8/2012-HFW-Health & Family Welfare Department**

Notification, Dated August 27/01/2014.

.....Therefore, henceforth cancer is hereby made Notifiable for the purpose of registration and all persons concerned in hospitals (government and private), nursing homes, pathological labs, radiology centres and institutions imparting medical education and providing diagnosis, treatment and any other health care related facilities shall report diagnosed or suspected cases of cancer to the Principal Investigator, Mizoram Population Based Cancer Registry, Civil Hospital, Aizawl, Mizoram in the Proforma appended herewith and available with Mizoram Population Based Cancer Registry, within a period not exceeding one month from the date of diagnosis or the date on which suspicion arose. Identity of the patient should not be revealed by PBCR or utilized for any other purpose except for the purpose of registration and analysis of the data.

**Esther Lalruatkimi,**Secretary to the Govt. of Mizoram  
Health & Family Welfare Department**Government of Arunachal Pradesh**

Department of Health &amp; Family Welfare, A P Civil Secretariat: Itanagar

No. HFW – 05/2015

Dated Itanagar the 29<sup>th</sup> July

.....Therefore, all government as well as private hospitals/Nursing home, private diagnostic centres/laboratories are requested to report/notify all cancer cases in the core Proforma to the principal investigators of Population Based Cancer Registries (PBCR), Arunachal State Hospital, Baharlagun and General Hospital, Pasighat. All are requested to extend cooperation in the national endeavor to generate reliable data on incidence and mortality in Arunachal Pradesh.

**Indra Mallo, IAS**Secretary (Health and FW)  
Govt. of Arunachal Pradesh, Itanagar  
Dated Itanagar the 3/8/2015

## **Gutka Ban Order – Maharashtra (Excerpts from Government Order)**

The Commissioner of Food Safety, Food and Drugs Administration, Government of Maharashtra, has issued the following order on 17/07/2015. (No. FSSA/Notification/827-2015/7).

.....After going through various scientific reports and opinions it was noticed that Gutka, Pan Masala, Flavored/Scented Tobacco, Manufactured Chewing Tobacco, Flavored/Scented Supari, Kharra and similar products containing either Tobacco or Areca nut (betel nut) by whatsoever name called, cause immense damage to the health consumers and their adverse impact could also lead to alterations of the genetic makeup of future generations.....

Overwhelming scientific evidence shows that food products which have tobacco and or areca nut (Betel nut) as their basic ingredient whether or not containing the said additives and whether going by the name of Gutka, Pan Masala, Flavored/Scented Supari, Flavored/Scented Tobacco, Chewing Tobacco, Jarda, Khaini, Kharra or by any other name have extremely deleterious effects on human health and well being with consequential impact on society as well.

.....Therefore, I, the Food Safety Commissioner, Maharashtra State PROHIBIT in the interest of Public Health for a period of one year from 20<sup>th</sup> July, 2015, the manufacture, storage, distribution or sale of tobacco and Areca nut (betel nut) which is either Flavored/Scented or mixed with any of the said additives, and whether going by the name or form of Gutka, Pan Masala, Flavored/Scented Tobacco, Flavored/Scented Supari, manufactured chewing tobacco with additives, Kharra, Mawa, or otherwise by whatsoever name called whether packaged or unpackaged and or sold as one product, or through packaged as separate products, sold distributed in such a manner so as to easily facilitate mixing by the consumer for its consumption.

**Harshadeep Kamble, IAS**

Food and Safety Commission  
Food and Drug Administration  
Maharashtra State.



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