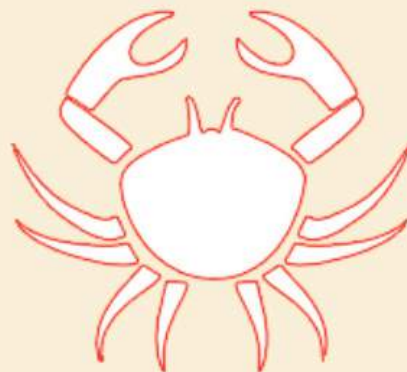




# Cancer Registry **AB**stract **CRAB**

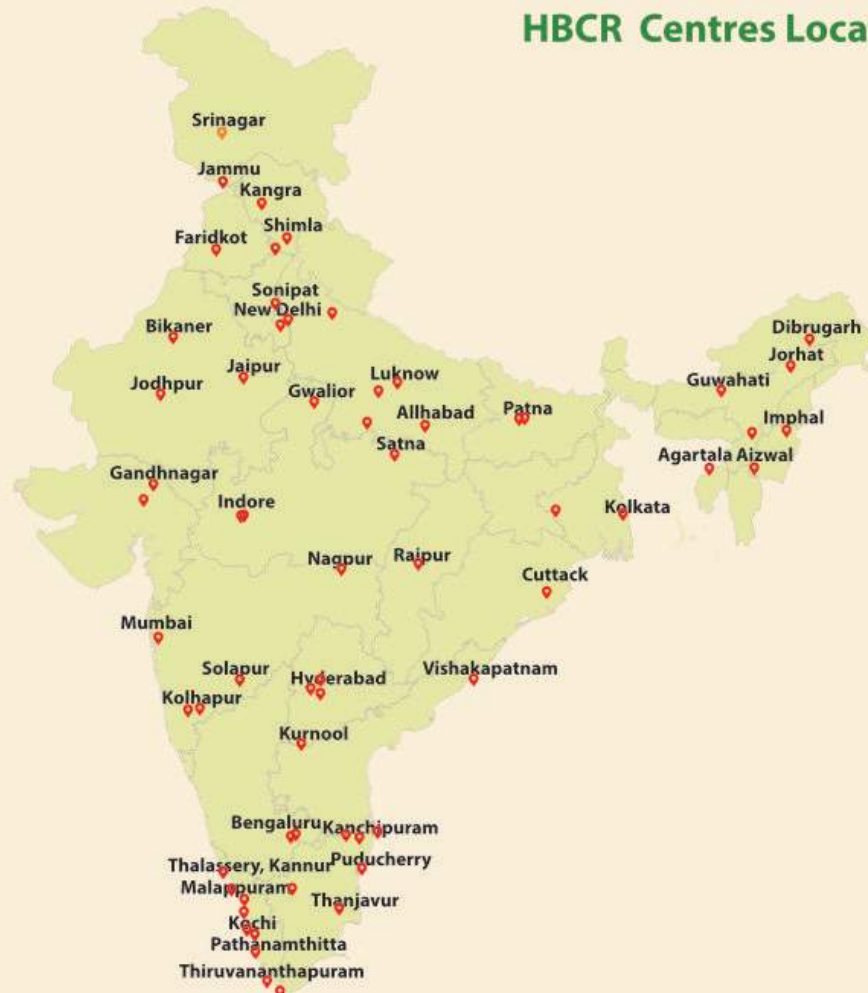


**The Newsletter of NCRP**  
**Vol. XXII No.1 November 2017**

## PBCR Centres Located in India



## HBCR Centres Located in India



# Cancer Registry ABSTRACT CRAB

The News Letter of NCRP

Vol.22.No1. November 2017

## National Centre for Disease Informatics and Research Centre National Cancer Registry Programme

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## Message

**Dr. Soumya Swaminathan, MD,**  
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### MESSAGE

Incidence data on Cancer and patterns of cancer in India provided by the National Cancer Registry Programme (NCRP) serves as a benchmark for disease surveillance of a major non-communicable disease using information technology in India. The data is being used for policy planning, programmatic interventions and to strengthen health systems, and thus setting a good example of evidence to policy translation. The progress and achievements of the National Cancer Registry Programme (NCRP) coordinated by the ICMR-National Centre for Disease Informatics and Research, Bengaluru lies in the strength of the network of NCRP spanning over 700 centres across India.

I am glad that the Cancer Registry Abstract (CRAB) newsletter of the NCRP has brought out this issue on the theme of 'Best practices in the functioning of the NCRP, India', along with the activity updates, photographs from the Registries. These articles have brought out the significant achievements and challenges in cancer registration, use of registry data to answer research questions and to support and aid responses within the health system. This is reflective of the sincerity and enthusiasm of the registry partners and the members to contribute to the CRAB. I appreciate their collective efforts and activities towards public health goals and congratulate them for their untiring efforts in pursuing scientific rigor and excellence in cancer registration.

These articles will surely aid in disseminating the value of cancer registration, and the need for strengthening capacity in health research and disease surveillance across the corners of India.

Best wishes to the NCRP network, and to the release the CRAB -2017 issue on the occasion of the XXXIII Annual Review Meeting of the NCRP.

  
 (Soumya Swaminathan)



## Message

**Dr. Prashant Mathur**

Director

ICMR - National Centre for Disease Informatics and Research,  
Bangalore

The Cancer Registry Abstract (CRAB) – Newsletter is an important part of the National Cancer Registry Programme (NCRP) showcasing the remarkable work and progress of the registry partners across the span of India from Arunachal Pradesh to Ahmedabad, and Jammu & Kashmir to Thiruvananthapuram, covering more than 800 sources of registration. The compilation of CRAB has been steered by the registry members over these years in true spirit of collaboration of the NCRP network. The CRAB is an opportunity to illustrate the success stories in cancer registration, challenges of registry coverage, and the scientific endeavours of the team members and of the NCRP.

It's a great privilege to bring out the XXII Volume of CRAB - 2017 based on the theme of 'Best practices in the functioning of the NCRP, India', on the occasion of the XXIII Annual Review Meeting of the NCRP. The articles are based on the three sub themes of 'best practices in cancer registration', 'use of registry data for research', and 'registry data for health action'. These articles have described the foundations laid down and structures that support cancer registration activities by each team in their respective registry, and bridges built to reach out to scientific professionals, programme managers, policy makers, and the public. It is commendable that the registry team are engaging with state officials in cancer screening, prevention and control activities. This issue has not only brought out the list of publications, abstracts, and contribution of registry data to studies, but also published articles answering research questions based on registry data. All of these shall contribute to furthering the scientific contribution of NCRP.

I sincerely thank all the members of the Research Area Panel on Cancer and senior faculty who have written for the CRAB tracing the NCRP journey and mapping its future course. I appreciate and congratulate all Principal Investigators, co-Principal Investigators, and the registry team members in their overwhelming response. Most of the articles, reports, updates and photographs have been published. ICMR- NCDIR team have also provided their technical and editorial inputs so that interpretation of data is in accordance to NCRP standards.

I am pleased that CRAB 2017 features articles covering the entire spectrum of cancer registration activities, achievements and learnings of the NCRP network. I sincerely hope and wish that it is widely read, and circulated to all registry staff, experts and stakeholders.

Heartily welcome to the Annual Review Meeting (ARM) of the NCRP, from 28<sup>th</sup> to 30<sup>th</sup> November 2017 at the prestigious Amrita Institute of Medical Sciences, Kochi !





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## Obituary



**M.N. Bandyopadhyay**  
**(1955-2017)**

Dr. Manas Nath Bandopadhyay, gentleman par excellence joined the family of the National Cancer Registry Programme at the time of commencement of the WHO project on Development of an Atlas of Cancer in India. He was not only one of the earlier entrants to the project but also one of the major contributors to the project in particular and subsequently to the NCRP as a whole. Besides data from his own institute – then called The Cancer Centre Welfare Home, Thakurpukur he took responsibility in ensuring that all other major centres in Kolkata contributed to this exercise. These efforts of Dr. Bandopadhyay eventually culminated in reviving and setting up of the Population based Cancer Registry in Kolkata.

Once the PBCRs in the North East were started he ensured that information on cancer cases from any of PBCRs in the north east were promptly dispatched to the respective registries with a copy to NCDIR. His meticulousness in abstracting cases from the demographic, diagnostic and clinical standpoint was unparalleled. He was one of the very few clinicians who genuinely appreciated the potential of cancer registries in cancer research from both epidemiological and clinical standpoints and actually contributed whole heartedly to the NCRP.

Despite his failing health in recent times he was full of eagerness and enthusiasm in participating in the meetings of the NCRP and provided valuable clinical inputs for the Patterns of Care and Survival Studies. His absence will be sorely felt by the entire NCRP family in general and by all members of the monitoring and scientific advisory committees in particular. The NCRP family would like to convey through this tribute, heartfelt condolences to his wife, son and daughter, his close aides and last but not the least the faculty of PBCR Kolkata who were so very deeply attached and indebted to him for all the guidance and training that he gave to them in the true spirit of a Karma Yogi.

**A. Nandakumar**

# Articles

# Time Trend in New Patient Registration in a Comprehensive Cancer Institute in Eastern India

**Manas Nath Bandyopadhyay, MD, DMRT (1955-2017)**

(This article is re-printed from CRAB 2006)

## Introduction

Cancer Centre Welfare Home & Research Institute (CCWHRI) at Thakurpukur, Kolkata was established in 1976 as a 25 bedded shelter for cancer patients who came to Kolkata for treatment in different city hospitals but did not have a place to stay. It was established by a philanthropic society registered in 1973 with about 40 members that included some oncologists. Since then, with help and donations from various sources, it has become one of the most important comprehensive Cancer Institutes in eastern India. It is still managed by the same voluntary society. This Institute is now a 260-bedded hospital with facilities of all modern treatment for cancer. The annual new patient registration is more than 7,000. This Institute receives patients from Kolkata, other districts in the state of West Bengal, from the neighboring states of West Bengal and from neighboring countries like Bangladesh, Nepal and Bhutan. The present communication analyze the time trend in new patient registration and their geographical distribution.

## Material and Methods

Data were mostly obtained from the Annual Reports of the Institute. Hence, the years as mentioned in this communication are the financial years (1<sup>st</sup> April of one year to 31<sup>st</sup> March of the next). Although the hospital was established in 1976, the out patient services were started only during 1980-81. Hence data on registration is reported from this period onwards. Some of the detailed data of the earlier periods (upto 1983-84) were obtained directly from case records by the present author after he joined this Institute in 1982.

The geographical areas from where the patients attend this Institute have been designated as Greater Kolkata (KOL), Other Districts of West Bengal (WBD), Other States of India (IND) and Neighboring Countries (NBC). Distribution (%) of newly registered cases of each year according to the above 4 designated geographical areas is presented. In the present communication, data on geographical distribution of the patients have been given only from the year 1984-85 as older data (1980-81 to 1983-84) could not be properly retrieved.

## Results

Table 1 shows the data on new patient registration and the proportion of diagnosed cancer cases between the years 1980-81 and 2004-05. It is seen that the number of new patients registered in this Institute has increased from 595 to more than 7,000 in about 11 years (from the year 1980-81 to 1991-92). The figures in the subsequent years remained stable between 7,000 to 8,000 cases (Figure 1). The relative proportion of diagnosed malignant cases out of all newly registered cases was comparatively high (70-80%) in the initial 9 years. The figures settled at around 60% from the 10<sup>th</sup> year (1989-90) onwards. A time trend analysis was done and the nature of data fitted to a logarithmic trend [ $y = -6.5435 \ln(x) + 83.943$ ] with a negative gradient (Figure 2). The proportion of patients coming from other districts of West Bengal (WBD) and other states of India (IND) remained almost constant at around 50% and 10% respectively throughout the entire period. However, the proportion of patients coming from Greater Kolkata (KOL) showed a declining trend from 44% to around 14% in about two decades (1984-85 to 2004-05). It is also seen that the proportion of patients

coming from neighboring countries (NBC) showed a gradual rise from a negligible 0.1% to more than 20% during the same period (Table 2 & Figure 3).

Figure 4 shows the magnitudes of the decline of KOL and the increase of NBC, the yearly absolute figures for these two geographical zones have been calculated based on registration figures and the proportion of geographical distribution. Fitted trend lines of both KOL & NBC in polynomial ( $n=2$ ) have shown that there is a definite fall in the absolute numbers of patients coming to this Institute from Greater Kolkata over the last two decades. It is also seen that there has been a remarkable rise of the same for the people coming from the neighboring countries.

## Discussion

The increase in number of new registration every year has been substantial in this Institute for the first 11 years. The numbers have kept pace with infrastructural development of the Institute like better diagnostic and therapeutic facilities, increasing number of beds (from 25 to 260), increasing numbers of medical and paramedical staff etc. However, after the 12th year, there has not been substantial increase in the numbers although developments in the hospital continue till date. It seems that the number of new registration has reached a saturation point. This finding is more significant as it is a fact that recent developments in the therapeutic and diagnostic facilities in this Institute have been very significantly resource intensive. The fall in the absolute numbers of freshly registered cases from Greater Kolkata could be contributory to this phenomenon. In a previous communication (Dey et al.2004), it has been shown that there is a referral bias of this center for radiation therapy. Compared to PBCR Kolkata, the HBCR of this Institute shows a preponderance of patients with diseases that are primarily treated by radiation therapy. Thus the cause of the fall in absolute numbers of patients coming from Greater Kolkata may be due to improvement of radiation therapy facilities in the existing oncological units of Kolkata. Proportionately more people in

Greater Kolkata are perhaps availing these facilities. The static pattern of time trend for patients coming from other districts of West Bengal and other states of India and the increasing load of patients from neighboring countries (notably Bangladesh) is perhaps a reflection of the fact that this Institute is the most affordable comprehensive cancer care Institute in this part of the country. People coming from outside perhaps prefer this Institute because they have to spend less time in diagnosis and treatment. This Institute continues to be basically philanthropic in nature and hence the cost of diagnosis and treatment also remains more affordable to the common people.

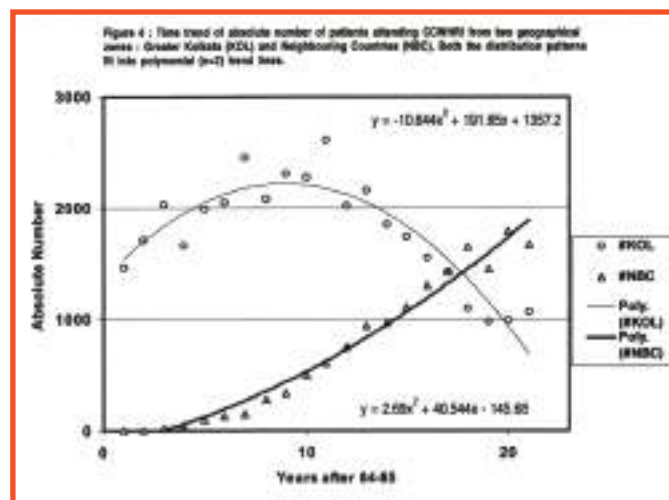
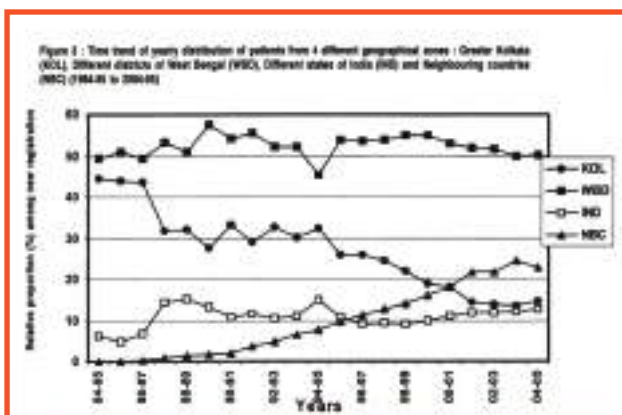
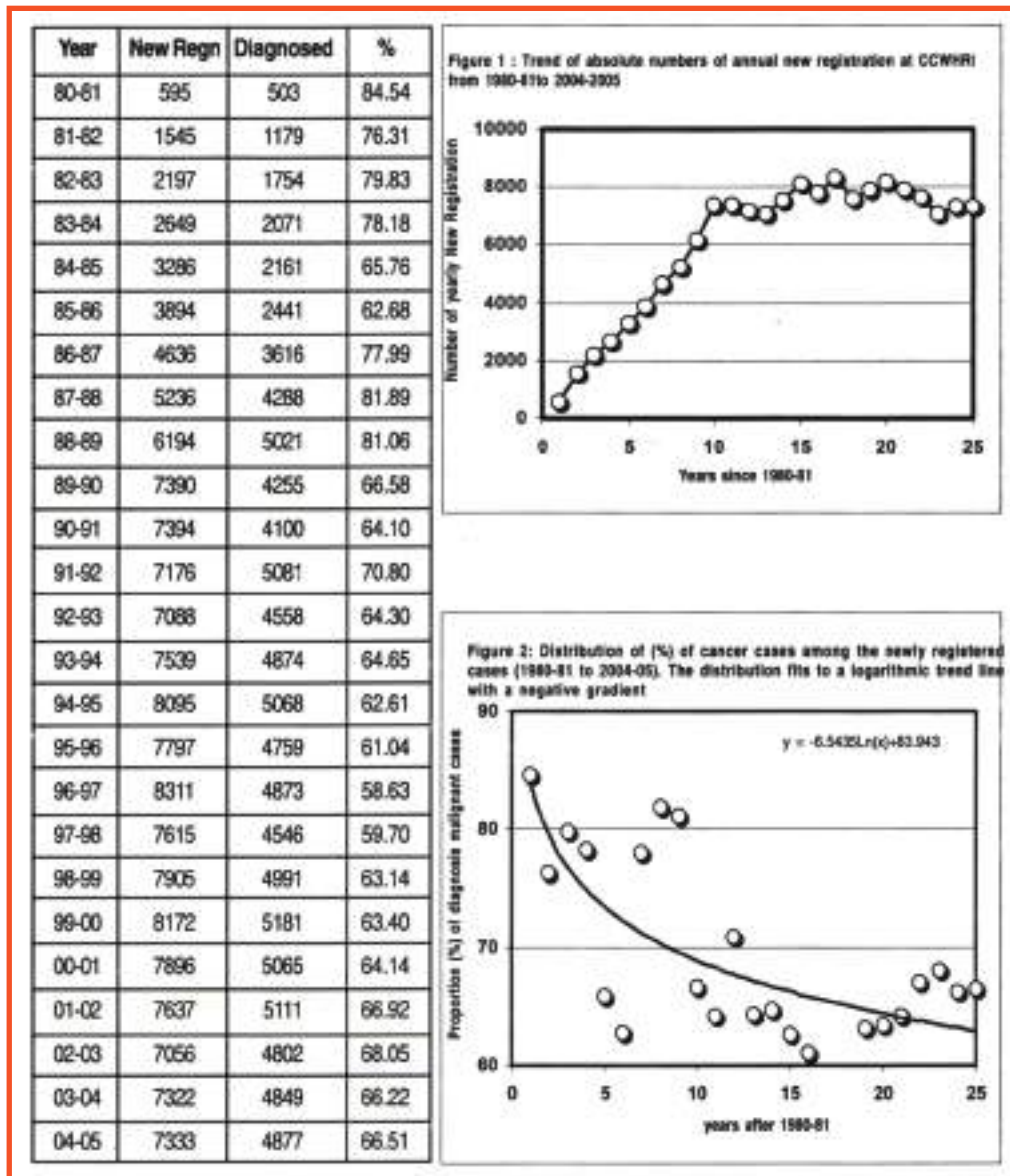
## Conclusion

This Institute is a unique model in its conception and functioning. By analyzing the time trend pattern of the patients, the positive and negative aspects of the model can be interpreted. With such interpretations, one can plan to modify and improve the system so that the institute continues to serve the people of a developing country in the most cost-effective way.

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**Table 1: Number of New Patients and the Number & Proportion of Cancer Patients (1980-81 To 2004-05) at CCWHRI**



**Table 3: Number (#) and Proportion (%) of Patients from 4 Geographical Zones: Greater Kolkata (Kol), Different Districts of West Bengal (Wbd), Different States of India (Ind) and Neighboring Countries (Nbc) (1984 - 85 To 2004 - 05).**

Year	KOL		WBD		IND		NBC		Total
	#	%	#	%	#	%	#	%	
84-85	1463	44.5	1619	49.3	201	6.1	3	0.1	3286
85-86	1714	44	1985	51	191	4.9	4	0.1	3894
86-87	2026	43.7	2284	49.23	311	6.7	15	0.3	4636
87-88	1663	31.76	2781	53.11	748	14.28	44	0.85	5236
88-89	1990	32.12	3160	51.02	949	15.33	95	1.53	6194
89-90	2047	27.7	4242	57.4	975	13.2	126	1.7	7390
90-91	2453	33.16	4007	54.2	781	10.57	153	2.07	7394
91-92	2081	29	3990	55.6	832	11.6	273	3.8	7176
92-93	2310	32.6	3701	52.2	744	10.5	333	4.7	7088
93-94	2277	30.2	3928	52.1	837	11.1	497	6.6	7539
94-95	2615	32.3	3675	45.4	1198	14.8	607	7.5	8095
95-96	2021	25.92	4192	53.76	835	10.71	749	9.61	7797
96-97	2163	26.03	4452	53.57	759	9.13	937	11.27	8311
97-98	1856	24.37	4087	53.67	703	9.23	969	12.73	7615
98-99	1739	22	4348	55	711	9	1107	14	7905
99-00	1553	19	4495	55	817	10	1307	16	8172
00-01	1422	18	4185	53	868	11	1421	18	7896
2-Jan	1102	14.43	3969	51.97	910	11.92	1656	21.68	7637
3-Feb	981	13.9	3646	51.67	970	13.75	1459	20.68	7056
4-Mar	986	13.47	3654	49.9	894	12.21	1788	24.42	7322
5-Apr	1069	14.58	3670	50.05	924	12.6	1670	22.77	7333

**Down the memory lane - XXI Annual Review Meeting November, 2005 at Cancer Centre Welfare Home and Research Institute, Kolkata**





## National Cancer Registry Programme: Journey and Achievements

### G.K.Rath

Professor and Head,  
Department of Radiation Oncology and Chief, Institute Rotary Cancer Hospital,  
All India Institute of Medical Sciences, New Delhi.



With the control of communicable diseases, non-communicable diseases like cancer has become a major public health problem in India. According to GLOBOCAN 2012,<sup>1</sup> the estimated incidence of cancer in India was 14.5 lakhs and death of 7.36 lacs. However, the estimate for the year 2020 was 17.3 lacs and 8.8 lacs respectively. Cancer control aims to reduce the incidence, morbidity and mortality of cancer and to improve the quality of life of cancer patients through the systematic implementation of evidence-based intervention, early diagnosis, treatment and palliative care.<sup>2</sup> In the context of cancer control programme, cancer surveillance via the population based cancer registry plays a crucial role in formulating cancer control plans as well as monitoring their success. Worldwide, cancer registries have been shown to be critical for the determination of cancer burden, conduct of research and in the planning and implementation of cancer control measures. Cancer registries are veritable tools for collecting accurate and complete information of cancer incidence, prevalence, and mortality in a given geographical location and can be used to conduct research, plan and implement cancer control, allocate resources for treatment and prevention and other public health planning<sup>2</sup>.

Until 1962, information on cancer occurrence in India was available only from surveys. The Mumbai Cancer Registry was the first registry to be established in June 1963 as a unit of the Indian Cancer Society, with the aim of obtaining reliable morbidity data on cancer, from a precisely defined urban population (Greater Mumbai). Subsequently PBCRs were established in Pune (1973),

Aurangabad (1978), Nagpur and Ahmedabad (1980). However the boost for cancer registration started in the early eighties through the initiation of the National Cancer Registry Programme (NCRP) by Indian Council of Medical Research. In December 1981, ICMR commenced the National Cancer Registry Programme across the country with a network of three Population Based Cancer Registries (PBCR) in Bangalore, Chennai and Mumbai and three Hospital Based Cancer Registries (HBCR) in Chandigarh, Dibrugarh and Thiruvananthapuram with the following main objectives:

1. To generate reliable data on the magnitude and patterns of cancer
2. Undertake epidemiological studies based on results of registry data
3. Help in designing, planning, monitoring and evaluation of cancer control activities under the National Cancer Control Programme (NCCP)
4. Develop training programmes in cancer registration and epidemiology

The NCRP further expanded with the initiation of urban population based registries at Bhopal and Delhi in 1987 and with a rural population based registry at Barshi in 1987.

After realizing the success of NCRP, a new institution National Centre for Disease Informatics and Research

(NCDIR) was established in Bangalore in March 2011 by ICMR with an additional mandate to cover other non-communicable diseases with more or less similar etiological factors like cardiovascular diseases (CVD), Diabetes and Stroke but mainly focusing on cancer.

The NCRP network has gradually expanded over the years and at present there are 29 PBCRs and 29 HBCRs (including RCCs) under its network. Apart from cancer registries the other thrust areas of NCRP are Patterns of Care and Survival Studies (POCSS) on cancer breast, cervix and head and neck cancer, Punjab Cancer Atlas, Haryana Cancer Atlas and development of software application programmes. Currently 38 centers (including 5 HBCR) are collaborating in the POCSS. A total of 154 centers for Punjab Atlas and 97 centers for Haryana Atlas are collaborating and transmitting the data to ICMR. The software modules developed by NCDIR for documentation of details of pathology<sup>3</sup> and radiotherapy<sup>4</sup> which are being used by 154 centers is an invaluable tool for collection of high quality data from various centers across the country.

Though the cancer registries covers only 10% (approx.) of the population in India, over the years NCRP evolved in such a way that the results of the registry and NCRP reports give an insight into the cancer pattern in different parts of the country. The Cancer Atlas project launched by NCRP in 2001 was the first to provide important leads about significantly higher incidence of cancer in the north eastern parts of India. These findings were later confirmed by the establishment of PBCRs in north eastern states.

There is a wide demographic variation in the incidence of cancer in different parts of our country. Aizwal District in Mizoram state has the highest incidence in India with an age adjusted incidence rate (AAR) of 270.7 per 100,000, while the lowest rate was noted in Barshi (40.9)<sup>5</sup>. These findings reflect the impact of environmental and cultural factors on the incidence of cancer. The PBCRs in North East have also shown some of the highest incidence rates for some anatomical sites in the world. Incidence of tongue and nasopharyngeal cancer are the highest

reported in East Khasi Hills District among males in the world.

In most of the urban registries viz. Delhi, Mumbai, Chennai and Kolkata and other metropolitan cities breast cancer is the most common cancer. However, in Arunachal Pradesh, Barshi, Mizoram, Tripura and Nagaland; cervical cancer is the most common among women. The incidence of stomach cancer is very high in Papumpare district in Arunachal Pradesh and Mizoram State. Cancer of the gallbladder figures as one of the most common cancer among the top three cancer in some registries such as Delhi, Kamrup Urban district, Dibrugarh and Cachar district.

The data collected by the registries which have been in operational for more than 25 years (Bangalore, Bhopal, Chennai, Delhi, Mumbai and Barshi Rural) has been utilized to analyse the time trends in cancer incidence in their respective registration area. Among men a significant increase in lung, prostate was observed in all the urban registries. Among females in urban areas a significant increase in breast, ovary and corpus uteri was observed whereas cancer of cervix has shown a decline. The data generated by the registries was used to project the burden of cancer in India. The projected burden of cancer in both sexes in 2020 will be approximately 1.74 million

Though the NCRP generates high quality data with the existing registries, the coverage of the sample of population is insufficient. There is no cancer registry present in highly populated states like Bihar, Uttar Pradesh, and Rajasthan. Hence, NCRP should take initiative to establish registries in these states also so that the coverage of population can be wider. Such additional registries may reveal data similar to the outcome from North East states.

Site specific and region specific etiological studies are essential in order to have effective cancer control activities. The NCRP should take lead and take initiative to conduct more studies of translational research nature.

In conclusion the National Cancer Registry Programme is an essential and integral part of any cancer control activity playing a critical role in determining priorities for planning, conducting, monitoring and preventive and curative programmes.

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## National Cancer Registry Programme: Scope and Way Forward

### Amal Chandra Kataki

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The battle against cancer is multi-dimensional and involves clinicians, basic researchers, and epidemiologists as foot soldiers, and it is unanimously accepted as a global and national priority. The role of cancer registries in this continuing war on cancer is crucial. According to the International Agency for Research on Cancer (IARC), the cancer registry is an organization for the systematic collection, storage, analysis, interpretation and reporting of data on subjects with cancer. In India, the National Cancer Registry Programme (NCRP) under the Indian Council of Medical Research is providing the necessary data to the policy makers and public health specialists to formulate the cancer policy of the country. The NCRP was started in the year 1981 and since then, it has seen phenomenal rise in its network of cancer registries across the country, both Hospital Based and Population Based. Also, the Pattern of Care and Survival Studies of head & neck, breast and cervical cancer under the NCRP has provided vital evidences for improving the standard of cancer care in India, where resources are limited and burden of cancer is high.

The present network of cancer registries in India covers less than 10% population of the country. Making cancer a notifiable disease in the country can certainly add to better population coverage. It is also a matter of concern that registry coverage in some of the bigger states like Madhya Pradesh, Rajasthan, Bihar, Uttar Pradesh, and Andhra Pradesh under the NCRP network is much lower than expectation. Geographic variations of cancer exist in the country due to its large size, different food habits etc. Therefore, researchers from particular geographic

areas should devote on epidemiological study to find out the risk factor for cancer peculiar to that part of the country. Cancer registries in India should now focus to improve the aetiologic research to identify the various causes of cancer, over and above the incidence and mortality statistics. Cancer registries should have access to available data on risk factors including environmental exposures, personal habits including tobacco usage, and familial links. As the data collection for PBCR in the country is an active one, the different sources of cancer registration must be taken aboard in this whole exercise. Periodic meetings and valedictory functions must be held by individual PBCR acknowledging the role of these laboratories, clinics, diagnostic centers, and hospitals. Now that the Aadhaar card has been made mandatory in the country, this should be linked with the registration network of NCRP. It will help in patient follow-up for population-based survival studies.

National Cancer Registry Programme should also have a component for cancer control by integrating public awareness and screening programme for common cancers. For difficult to cure cancers where burden is high, like lung, stomach, gall bladder, and esophagus cancers, step should be taken for early diagnosis. There must be a mechanism for transport and treatment support for patients who are detected with potentially malignant lesions or early cancers. Otherwise, it will bring disrepute to the screening programme.

Presently, data of only selected Population Based Cancer Registries (PBCR) are accepted for publication

in the Cancer Incidence in five continents (CIV) report published by the IARC under the World Health Organization. All the PBCRs under the network of NCRP should strive hard to generate high quality incidence data so that it can be published in the CIV report. This will strengthen the framework of cancer incidence and proper surveillance of cancer in the country. Similarly, cancer registries should participate in population-based relative survival studies. Information obtained from population-based survival is vital to measure the overall effectiveness of cancer care in a given population.

National Cancer Registry Programme should actively engage with the oncologists of the country at national, regional or local levels by periodic workshops and meetings. NCRP should take steps to promote their work at the annual meetings of the major professional societies in the country viz, Associations of Surgeons, Physicians, and Oncologists. Renowned oncologists can be invited to the Annual Review Meetings as guest speakers on topic of importance based on cancer registry findings. Epidemiologists and staff of cancer registries should closely work with clinicians or oncologists in the context of developing research networks. This approach will help cancer registries to orientate their research on clinicians and patient's actual needs and to discuss within the network about the clinical implication of this research outcome.

Impact of some of the national schemes on health initiated by the Government of India may be evaluated by NCRP in future. It is hoped that providing free LPG

connections to poor people who otherwise burnt wood for cooking will reduce the exposure of harmful carcinogens and may lower the incidence of lung cancer, especially in women. NCRP should take up with the Government for strict pollution control norms, which is posing as a major threat not only for cancer, but for other non-communicable diseases as well. The initiative of the Government of India to start sizeable number of newer cancer centers in the next 2-3 years will reduce the huge burden of patients in existing centres and improve access to cancer care. All these new centers should be linked under the network of NCRP.

In future, results from genome wide association studies will be available in India. Therefore, the scope of linkage of cancer registries with bio banks should be explored. The interaction between genetic and environmental factors is probably the key for understanding not only carcinogenesis but also drug effectiveness and resistance.

The contribution made by senior scientists in the field of cancer epidemiology and registry should be duly acknowledged at the Annual Review Meetings of NCRP. National Cancer Registry Programme has been playing a pivotal role in the fight against cancer in the country. Cancer registries under the network of NCRP will continue to evolve, adapt to recent developments and future challenges in cancer research.

## Action Developments in Cancer Registration

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Cancer registration had its beginning in 1728 with a cancer census in London which was not successful but it led to the systematic methods for cancer registration by 1937 only. Inadequacies in case identification and reporting were overcome progressively and even today such developments are taking place which are the outcome of constant review of registry information – methodology and outcome accrued from different settings analysed and applied for cancer control which focuses on prevention, treatment and survival of cancer patients.

In India, the first cancer registry covering the population of Greater Bombay was by the Indian Cancer Society in 1962 under Dr. Jussawallah. The ICMR registry programme was started in 1982 and systematic progress have taken place for cancer registry operations. This was the outcome of constant annual reviews and regular discussions with all participants of the programme. Here, we can say that the developments evolved from experiences. Dr. A Nandakumar was guiding the NCRP activities and its development during its formative years for almost three decades. In NCRP we follow several regulatory norms for recording, reporting, information analysis etc which were developed on the basis of the experiences and directions of WHO, IARC, SEER, AJCC etc. Regular review meetings of NCRP developed such norms and implementation is constantly safeguarded. In 1982, the ICMR initiated the NCRP with three HBCRs and three PBCRs. These have now, ie, after 35 years increased to 29 PBCRs and several HBCRs use the HBCR DM software for cancer registry operations developed by the NCRP.

The NCRP has its own procedure manuals for hospital registry as well as for population registry operations. However the manuals mainly focus on information coding. We recall here the significant contribution and leadership by Indian scientists – Dr. P N Wahi, Dr. Usha Luthra and Dr. L D Sanghvi.

Annually the registry outcome reviews were presented and discussed and future operations were decided in the meetings. Along with this a workshop for registry workers was also held. Guidance of international consultants like Dr. Calum Muir and Dr. Thakeshi Hirayama were sought in the initial years and along with them Dr. Sunder Rao and Dr. Radhakrishna took active participation. In registry operations, information processing is now successfully developed and implemented by the NCRP scientists in the NCDIR headquarters - particularly the consistency checks, age and site of cancers, duplicate entries by name checking and other inconsistencies reported by the registries are identified and repaired. This is a major part of the tedious work undertaken by the registry staff guided by NCRP. An important and often a strenuous work is the information collection from appropriate medical records and sources. In a general hospital setting, we often face an unsystematic record maintenance both in recording and also preservation of records so that retrieval of information becomes problematic. However, in a cancer hospital setting there is one entry for all new patients and this enhances uniformity of information collection, filing of reports and its availability from the case papers uniformly. These problems are much more

complex for a PBCR which collects case details from several hospitals, pathology laboratories covering the area and Vital Statistics Department records. Here it may be mentioned that the WHO death certification mode is used for only a small proportion of deaths. It has been observed that some of the hospitals are deficient in death reporting quality. Making cancer as a notifiable disease is essential for complete reporting of cancer cases and other diseases in a population. The NCDIR's active involvement is essential for improving the system.

## Incredible India

The available information on population cancer incidence in India reveals the complex nature of distribution of cancers which have to be studied for identification of associated habit prevalence and other socio-demographic features in the population. Examples of such incidence variations which have been recorded in the NCRP reports are following. The AAR of certain cancers reported by registries are in Table 1.

**Table 1: Age Adjusted Incidence Rates of certain cancers; Source NCRP reports**

### 1. AAR of Stomach

Papumpure district : Male: 50.2 Female: 29.2

Wardha : Male: 1.7 Female: 1.4

### 2. AAR of GB cancer

Kamrup Urban District : Male: 8.8 Female: 17.1

Pune : Male: 1.1 Female: 1.3

### 3. AAR of Esophagus cancer

East Khasi Hills : Male: 71.2 Female: 33.0

Barshi Expanded : Male: 2.7 Female: 1.1

### 4. AAR of Thyroid cancer (females)

Trivandrum Female: 13.3

Barshi expanded Female: 0.6

### 5. AAR of Lung cancer

Mizoram : Male: 32.6 Female: 29.3

Sikkim : Male: 6.7 Female: 7.8

Trivandrum : Male: 16.8 Female: 4.5

Such wide variations observed in incidence rates, sex ratios provide unique opportunities for intense studies - can this be due to a life style factor? Is it due a local factor? Is there a biological susceptibility in these sites? How is the lung cancer rate in female equal to or more than male lung cancer cases who are traditionally believed to be tobacco smokers?

## Life Is To Be Understood Backwards But It Is Lived Forwards (Soren Kierkegaard 1813 – 55)

Important information required for further studies is on site-sex-age distribution of cancer in populations. Such information analysed would also help for elucidating risk factors. Here, the meticulous information collection on cancer cases is needed. Examples are given below.

1. In PBCRs we get information on tongue cancer – ICD - 01-03 – this includes all Tongue Cancers – anterior two thirds and posterior one thirds. Both may differ in proportion between centres and may have different associated risk factors. Further, disease spread may differ along with treatment and survival rates. These have to be brought out by appropriate scientific studies.

2. Most often studies address 'Colorectal cancer'. The ICD codes are Colon C18, Rectum C20. Are the etiological, epidemiological factors same for such a combined terminology? Studies should be more specific regarding the anatomical location of the tumour. Here, the associated factors and survival may differ.

3. A similar overall term used is "H&N cancer". Several sites are included in this group. But sometimes we are unable to separately assess risk factors, treatment and outcome when the terminology used does not indicate specific sites. Thus the combined H&N cancer terminology should not be practiced.

The life practices are directed by socio-cultural racial groups. Dr. Ali points out (CRAB XIX) that the North East region comprises more than 120 ethnic groups with distinct cultures and life styles. These may have different risk factors and risk levels.

### **Knowing Is Not Enough, We Must Apply; Willing Is Not Enough, We Must Do (Goethe)**

In 1983, the NCRP reported 15578 cancer cases (PBCR+HBCR) but in 2016 report of ICMR-NCRP the total no of cases reported was 3, 27,753 (PBCR+HBCR). Such a massive increase in cancer registration and sources were the result of continuous interest, hard work and involvement of several registries and their staff located in different parts of the country together with the encouraging guidance, discipline and support provided by the NCRP. The NCRP has now developed with expanded activities and is known as NCDIR.

Research expertise for registry operations was attained through higher training of several registry workers in our country as well as abroad. These provided several opportunities for the registry staff to get involved in active registration methods in India. Similarly the registries have been actively involved in expanding the activities (CRAB Vol. XVIII). Convincing advancements in cancer registration activities, techniques and outcome are evident from the number of cancer registries which presented their data in the IARC publication - Cancer Incidence in Five Continents Vol. II to Vol X. There was an increase from one registry report in vol. II to 12 registries presented in vol. X. More have to be attained in this regard. Similarly another international data presentation is by the CONCORD. Here also the Indian registries have utilized the opportunity to present the data which have been accepted by the International study group. Convincing work of NCRP registries initiated several governments to make cancer as a notifiable disease.

Another important development was the beginning of multi-centric studies by NCRP which were started from 2001 - 16 years back. The NCRP- ICMR organized the Cancer Atlas Project which received intense cooperation from several centres across the country and the Atlas of cancer was the outcome of a highly committed work force. The information collection, transmission and analysis were on-line. Such an outcome was the motivation for the NCRP to organize several cancer

registries in different population groups after the cancer occurrence variations became apparent. Similar multi-centric studies on Pattern of Care and Survival of cancers of H&N, Breast and Cervix have received much acceptance. More have to be done in this regard.

A very important and significant factor which helped the advancement of cancer registries is the hard working enthusiastic workforce in the NCRP-NCDIR head quarters. The critical support for information collection processing and analysing developed by the NCDIR staff was instrumental for all the advancements of the NCRP programme. Registries have become confident about the work undertaken after receiving the NCDIR approval of the data. Meticulous programming innovated right from the information collection; abstracting and analysis had become the large effort which forced the registry operation to optimize the outcome. The problems and situations encountered for registry operations have been repeatedly presented in previous issues of CRAB by the registry workers themselves.

### **God's Own Country Kerala**

The national census has shown that the expectation of life at birth is the highest in Kerala comparing other states – Kerala 74.9 years in 2014 and the average life expectancy of India was 67.9 years. This indicates that among other things there would a good proportion of elderly people and hence the incidence rate higher than in other states. The two PBCRs reported in the state are one in rural and another in urban area. There are only slight differences in incidence rates between the two. Further, the ranking of sites affected are almost similar. A third registry covering areas in northern Kerala will be available soon. The incidence of thyroid cancer in Kerala women is noteworthy. It is the highest rate among southern states and second to national rates. The high rate of thyroid cancer in female compared to that in males in Kerala is parallel to the higher rate of GB cancer in women than in men seen in northern state of the country. The reason is to be studied. Further, the only Special Purpose Registry in India – Natural radiation exposure and cancer occurrence is also located in Kollam



District (Dr. P Jayalakshmi, CRAB Vol: XX)

Information collection process yields very uncomfortable situations at times. Cancer registries have observed certain anomalies mentioned in CRAB XVIII. This presented the disparities in age recording and reporting between the age at death and age at diagnosis. Analysing the death records it was seen that age recorded for many cancer patients showed that they had expired before their visit to the hospital! (Dr. Aliyamma Mathew, CRAB Vol. XVIII)

Lastly we must critically look how much the registry gathered information have been helpful in guiding the cancer control efforts of the nation. It is essential that we pursue intense study of causative factors and factors that optimize the survival in the presence of multi lingual, multi racial variations in life practices in India.

The NCRP activities for future have been envisaged by the NCDIR chief Dr. Prashant Mathur as follows:

1. Strengthening data collection in terms of its completeness and time lines
2. Improving the existing scope for cancer registries
3. To leverage the information generated by NCRP for strengthening research for cancer prevention and control
4. Setting up of a cancer surveillance system

The Research Area Panel in Cancer (RAP-C) under the NCDIR has proposed some essential areas of work execution. In this connection, Late Dr. Bandyopadhyay has observed the 'the activities of RAPC should remain flexible. The data yielded by the registry programme should be a major guideline. The RAPC endeavour will be recognized as a milestone in the history of medical research in India.

## NCDIR and Data

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From its inception in early 80s till date, NCRP, and now NCDIR, has been collecting, analysing, evaluating and utilizing data on cancer in our country. A process which started as manual collection and entry, has evolved into an electronic methodology with a real time entry of data at source of registration as well as data processing at the central repository. This transformation has largely been facilitated by the rapid progress in information technology in our country. World Health Organization assisted ICMR research project on 'Development of Cancer Atlas for India' was a real catalyst and in fact, "a game changer" in this regard. The collection of data has been useful in projecting cancer incidence in various parts of our country and compare them with the international picture. The accumulated data has resulted in several translational research projects involving aetiology, presentation pattern, prognosis as well as comparison/effect of treatment methods and clinical course of several cancers in different parts of our country.

Data is a very vital component of this programme. It is amply demonstrated by the establishment of a national institute, the NCDIR (upgradation of the previous NCRP), which is endowed with the responsibility of collection, cleaning, storage, security, analysis and utilization of data. This institute has continuously been developing/reinventing several formulae, programmes, and methodologies to succeed in the above activities. There is great interest and constant research to further each aspect of this data activity.

Right through the years of the existence of NCRP, there has been a successful implementation of the programme

by active, enthusiastic, voluntary participation of centres from different parts of the country and a constant expansion of the programme to represent maximum areas of urban as well as rural areas of our country. Data collected from medical records of patients is used for the national purpose of estimating cancer burden in India. This has resulted in an enormous amount of data at NCDIR, which has to be used to benefit common man. When such large amounts of personal data are elicited and stored, legitimate questions regarding security and ethical utility are bound to be raised. The interest shown by several research organizations to access data for further research is also indicative of the enormous value of this data.

To address the concerns of data confidentiality, data security and data sharing, the Institutional Ethics Committee of NCDIR was endowed with the responsibility to form guidelines taking cues from ICMR and other international guidelines. NCDIR has developed the 'ICMR-NCDIR Policy on Data processing and disclosure', which has been approved by the IEC and RAP - Cancer of NCDIR. These guidelines will help data security at the centre and beneficial utilization of data for common benefits keeping in mind the confidentiality of the patient as well as the contributing institutions. Guidelines have been evolved on data confidentiality, data security, and data sharing.

I hope this will be of great help in furthering the activities of NCDIR in establishing disease databases on cancer and other NCDs in this country using electronic information technology and support ICMR in its national efforts in disease control.

## National Cancer Registry Programme (ICMR): Strengths, Weaknesses, Opportunities, Threats (SWOT) Analysis

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### Strengths

1. Only disease data base in the country that collects data in a systematic way as per international standards and quoted. The PBCRs provide actual incidence rates and trends in incidence rates over time. Thereby, near authentic estimates of the burden of cancer (year on year) in the country can be calculated.
2. Sustained programme for over 35 years;
3. Has a permanent centre with established infrastructure and expertise that administratively and technically guides the collaborating centres.
4. Progress in terms of Descriptive Epidemiological Research has been substantial. Shown vast differences in incidence rates of overall and specific organ sites of cancer across different states/regions of the country. Such marked variations are hardly seen in any other country in the world.
5. In terms of leads towards furthering cancer research, NCRP has provided the following:

#### A. Towards Aetiological – Risk factor Research Studies

- a) Identified geographic areas for anatomic site specific research e.g., cancer stomach in the South and North East; gallbladder cancer in the North, etc.
- b) identified variation in incidence rates of organ sites of tobacco related cancers vis-à-vis geographic areas;

#### B. Towards Cancer Control

- a) identified different organ sites for priority towards cancer control, e.g., oesophageal cancer in Meghalaya and Arunachal Pradesh
- b) Since NCRP constantly gives figures on the magnitude and trends over time in cancer according to age, gender and anatomic site there is an opportunity for evidence based cancer control activities through specific indicators.

#### C. Towards Patient Care

- a) Identified deficiencies in cancer patient care in the Indian setting in terms of standardised recording of clinical information, compliance to treatment and follow-up;
- b) Identified proportion of patients presenting at late stage and trends there-of;
- c) The results on the Patterns of Care and Survival Studies (on cancers of the cervix, breast and head & neck) have substantial implications towards testing through clinical trials modifying treatment regimens to suit Indian conditions. It has laid a framework towards clinical evaluation and multi-centric trials.
- d) Measures burden of disease in the cancer centre or hospital.
- e) Provides an idea of cancer diagnostic and treatment measures in a given centre.

6. Information Technology Application Programmes. The software team at NCDIR has picked up domain knowledge on all aspects of assessing cancer burden and care and in-house robust data applications, checking-mining and analytical tools have been developed.

### Weaknesses

1. The PBCRs do not cover all the regions/states of the country (especially the rural areas in main states) although it's a national programme.
2. Completeness of incident data coverage especially in the metro PBCRs has become increasingly incomplete with the commencement of multiple cancer diagnostic/treatment facilities.
3. Mortality Data is incomplete and there are limitations in getting the exact cause of death.
4. The PBCRs have not provided Clinical Stage based incidence and survival even on major important cancers (like cancers of breast, cervix, head & neck) within a PBCR area.
5. There has been limited progress in Analytic Epidemiological studies.

### Opportunities – including possible future research studies

1. The NCRP data-base provides unprecedented opportunities for research, whether that is on cancer causation, patient care evaluation or control measures.
2. With advent of electronic information technology and a team in place there is an excellent opportunity to strengthen and refine the flow of digital scientifically and clinically evaluable cancer data across more and more centres.
3. The HBCR data-base and the patterns of care study have set a platform for standardising diagnostic and treatment information.
4. The leads/hypothesis that have arisen out of the first results of the patterns of studies need to be tested with

randomized clinical trials.

5. The regional cancer centres (with HBCRs) have a rich source of clinical and laboratory data. This should be utilized. Some broad areas include conducting hospital based case control studies with laboratory component, health services research on various aspects of patient care and setting up of systems of referral.
6. The e-mortality software should be successfully implemented in all PBCR areas. The evidence of this should be reflected in the MI ratio and in the Population Based Survival studies.
7. Regional cancer centres that have housed both PBCR and HBCR should be upgraded to Departments of Epidemiology and/or Clinical Research.

### Threats

1. The staff of the PBCR registries especially in the metros needs to put in additional efforts to ensure completeness of coverage in the registry areas. Support by NCDIR in terms of additional funds and evaluation with recommendation by an expert team is essential. The back bone of the NCRP is the PBCR incidence data and particularly that of the metro registries and if this is flawed in terms of incompleteness or illogical incidence rates over succeeding years then there is a major threat of the data not conveying the true picture. Once outputs become suspect it would be very difficult to get this back to base.
2. Likewise all HBCRs and RCCs should and must participate in the patterns of care studies and provide nearly complete follow-up information. Otherwise these centres' data will become irrelevant.
3. For the NCDIR only core permanent staff is in place. In fact the sanctioned strength of these core staff is only about one-third of that which was requested for NCRP activities ALONE. Therefore, additional staff will be required for sustaining the NCRP activities itself and all the types of staff need to get practical training by three monthly rotational posting in cancer registries on a continuous basis.

# Best Practices in Cancer Registration

## SWOC Analysis of Functioning of Population Based Cancer Registry - Ahmedabad

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### Introduction

In February 1972 with joint efforts of Government of Gujarat & Gujarat Cancer Society under a tripartite agreement, the formation of an autonomous institution was crystallized. This has metamorphosed over the years into the present edifice of one of the most modern 650 bedded Comprehensive Cancer Care Centre of the country known as The Gujarat Cancer & Research Institute (G.C.& R.I.).

The Gujarat Cancer & Research Institute (GCRI), a Regional Cancer Centre (RCC) is one of the largest comprehensive cancer treatment centres in India and recently it has been upgraded as State Cancer Institute by Government of India. GCRI is equipped with all the latest diagnostic and interventional equipment to achieve best quality patient care. The Institute is also recognized by International Union against Cancer (UICC), Geneva, as a Comprehensive Cancer Centre.

### The functioning of PBCR Ahmedabad

GCRI has been maintaining Rural Cancer Registry – Ahmedabad district and Population Based Cancer Registry – Ahmedabad Urban Agglomeration area since the year 2004 and 2007 respectively under the network of National Cancer Registry Programme (NCRP) - National Centre for Disease Informatics and Research (NCDIR) - Indian Council of Medical Research (ICMR), Bengaluru.

The method of data collection is active. Ahmedabad PBCR has identified more than 200 sources (government/private/trust hospitals, nursing homes,

### Gujarat Cancer & Research Institute (GCRI)



Onco-specialists, pathology laboratories, imaging centres, Death registration Units etc.) for cancer data collection. The registry personnel visit these sources regularly and they actively pursue and collect information on cancer cases reported.

### Why SWOC Analysis?

SWOC analysis is an evaluation method by which the registry team will identify the internal and external factors that will affect the future performance of the registry. The registry's strengths and weaknesses are the internal factors. Opportunities and Challenges deal with factors external to the registry (environmental factors).

GCRI is running registries since 2004, and more than 12 years have passed. It is time to analyze the strengths and weaknesses of the registry, and work towards opportunities, and overcome challenges.

## STRENGTHS

### 1. GCRI- Major source of registry

As mentioned earlier, GCRI is a State Cancer Institute and is one of the major sources contributing around 60-70% of the cancer patients for Ahmedabad cancer Registry. Moreover, Medical Records Department and Registry work is managed by Community Oncology Department, so all the relevant information of the patients can be managed easily.

### 2. Well exposed and experienced staff with mature registry

Ahmedabad has Population Based Cancer Registry in rural and urban area since 2004 and 2007 respectively. The registry has matured with experienced and well settled staff, who properly understand their roles and responsibilities.

### 3. Well integrated HMIS and registry software

GCRI has its own Hospital Management Information System (HMIS) and Hospital Based Cancer Registry (HBCR) as well. Due to good communication and coordination with NCDIR technical staff, an integrated system has been developed which reduces duplication of work.

### 4. Government Administrative order

After constant efforts for more than 10 years, GCRI is finally successful in getting an administrative order from the State government which is helpful in convincing the sources to provide cancer related data.

### 5. Good support from institute administration and authorities

Ahmedabad Cancer Registry is fortunate to have institutional support for the proper functioning of the cancer registry. The Institute has a positive approach towards any constructive change to strengthen the

registry work.

### 6. Accessibility of Mortality data from Ahmedabad Municipal Corporation

The Ahmedabad- Municipal Corporation is providing good support and all-cause Mortality data of the Municipal Corporation is easily accessible to the registry personnel.

### 7. Easily accessible location and availability of public transport

GCRI is located in the centre of the city with excellent availability of public transport. This helps not only the patients to reach GCRI, but it also helps field workers to reach different areas of the registry sources.

### 8. Population density

Ahmedabad, being the major city of the state, is a densely populated area that helps field workers to get maximum registry data sources and cancer patients with less number of field activities.

## WEAKNESS

### 1. Incomplete coverage

In spite of the State Government Administrative order, many private clinicians refuse to provide data on various unexplained grounds, which is a hurdle in achieving completeness of data.

### 2. Less data in digital form

Though NCDIR is providing their software for free to the sources of cancer registry, they are not using the software for various reasons. The hospitals have their own software, many hospitals want customized versions, and other hospitals don't want to share the information by using this software.

Ahmedabad Cancer Registry has more than 200

sources, yet majority of sources do not provide data in digital form. So data has to be collected by abstracting the case file, which is time consuming with chances of human errors.

### **3. Lack of Mortality data in rural setup**

Unlike the urban area where mortality data is obtained from the Municipal Corporation, it is very difficult to get mortality data in the rural cancer registry. In rural areas, house to house visits are being carried out to complete the mortality record.

### **4. No advisory committee as per direction of NCDIR**

As per the direction of the NCDIR, there should be an active advisory committee of various registry stakeholders. Ahmedabad cancer registry does not have an advisory committee due to lack of interest in registry work of the sources.

## **OPPORTUNITIES**

### **1. Complete data coverage**

Ahmedabad Cancer Registry needs to work to improve the data coverage. Major hospitals and well known clinics are covered, and there is a scope to convince many private clinicians who are refusing to provide data.

### **2. To get data from various Government Schemes**

In Gujarat, cancer patients are provided benefits from various State Government schemes like Mukhyamantri Amrutam Yojana, Vatsalya Yojana etc. There are chances of getting valuable patient information from the central record keeping department of these schemes. This also gives a chance to include cancer patients residing in Ahmedabad but who are taking treatment in other places.

### **3. Acquiring Laboratory data with detailed information**

Data from laboratories in Ahmedabad do not have adequate information like detailed address that is mandatory for the cancer registry. Therefore data from the laboratories cannot be included in cancer registry, leading to loss of few cancer cases.

### **4. To include unreported cancer cases going for alternative medicines**

In many rural areas of India, still many people prefer alternative mode of treatment modalities like Homeopathy, Ayurveda and Naturopathy etc. Even today a large portion of rural Indian community is seeking treatment from quacks or not taking treatment at all. Cancer registries are missing such cases particularly of patients from lower socioeconomic background.

### **5. Using registry data for policy making**

Main purpose of a cancer registry is to generate data for future policy decisions on cancer control. At state level there is a scope to include registry data in their policy making decisions.

### **6. Improvement in Mortality data**

As mentioned earlier, mortality data from the urban area of Ahmedabad is available but still there is a scope of improvement in getting mortality data in rural areas.

### **7. IDSP like surveillance programme for Non Communicable Disease (NCD)**

The Integrated Disease Surveillance Programme (IDSP) data on communicable diseases are collected and monitored regularly by the higher level officials. If IDSP like programme is implemented for Non Communicable Diseases including Cancer, more precise number of cancer cases can be obtained.

## **CHALLENGES**

### **1. Declare cancer as a notifiable disease**



Making cancer a notifiable disease can definitely increase the coverage of cancer registry. But it is a herculean task to make cancer a notifiable disease. It involves strong political will, proper representation from registry people and other procedural hurdles.

## **2. To be aware about cancer registry**

Even in this era, clinicians and private hospitals are unaware of cancer registry and its importance. It is a challenge to make them understand the need for cancer registry and its role in cancer control.

## **3. Lack of data from outside Ahmedabad area**

Many patients who are actually residents of Ahmedabad district but take treatment from hospitals outside the Ahmedabad registry region. Registry field staff are collecting data from nearby hospitals outside Ahmedabad to cover such cases, but it is difficult and challenging to collect data from distant hospitals.

## **4. Urban Rural demarcation**

There is a discrepancy in urban rural demarcation since there is exclusion of 2 Talukas from Ahmedabad district. Constant efforts are being made to get exact details about the urban and rural area. Due to proximity to the corporation area of Ahmedabad, rural area is going through rapid urbanization. Thus, rural area of Ahmedabad is not necessarily rural.

## **5. Motivation of sources**

It is a challenge to motivate sources to provide timely and complete data regularly. They are afraid of confidentiality of data and few doctors do not want to reveal the actual number of patients they treat.

## **6. Motivation of registry staff**

Constant motivation of field workers is needed to get complete and quality data. It is a challenge to keep them motivated because there is too much of travelling, uncertainty of waiting time at sources and salary is not at par with institute's regular employees.

# An Experience on Population Based Cancer Registry (PBCR) Data Entry and Management

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## Introduction

Data management system is perhaps most useful for providing a centralized view of data that can be accessed by multiple users in a controlled manner. The database management system provides users and programmers a systematic way to enter, update and manage data in a database.

Cancer registry includes incidence cases and cancer deaths. The registration of cancer cases in cancer registry comprises collection of data on all newly diagnosed cancer cases and mortality due to cancer. The primary objective of cancer data entry and management is to provide information on cancer incidence, mortality, pattern, leading sites, time trends and cancer survival rates.

National Cancer Registry Programme (NCRP), ICMR, Bangalore in September 2010, provided the "Population Based Cancer Registry data management (PBCRDM2.1)" software for entering and managing data (both incidence and mortality) of "Population Based Cancer Registries". The PBCRDM2.1 provides the following.

- Simple and easy to handle.
- Can search cases by name, age, sex years etc.
- Various types of checks can be performed.
- Negotiates error ICD coding.
- Duplicate cancer cases (both incidence and mortality) can be eliminated by cross checking.

- Incidence mortality matching can be done with ease.
- Proved dictionary for Topography, Morphology and ICD-10.

## Incidence data entry

Incidence data entry consists of four parts:

- 1) Identifying information
- 2) Basic demographic parameters
- 3) Diagnostic details
- 4) Essential clinical data

The user can perform several operations on incidence and mortality cases like to add, modify, search and delete a record.

## Transfer data to Processing Section

This process is used for transferring incidence and mortality data from data entry to processing section. Data once entered in entry section will be available for quality check, duplicate check and matching.

## Quality check

Quality checks involve various types of checks like Range, Consistency, unlikely and family checks. This will initiate a batch processing of the incidence and mortality data pertaining to a specific year of the user's choice. Only those records that have been entered and not processed earlier will be eligible for subsequent

round of checks, only if they have been modified by the user during data entry.

### **Duplicate check**

Duplicate checking is process of finding any duplicate record on incidence and mortality based on different criteria. Duplicate checking may be performed within same year or across years. Two types of duplicate checking may be performed, one is level checking and another using other checks. Level checks provides user the option to execute check based on criteria which are predefined. Other checks provide user the option to execute checks.

### **Matches**

This process involves matching the mortality record with the incidence. There are two types of matching that may be performed, one is using level checks and another using other checks. Level checks provide user the option to execute checks based on predefined checks divided into different levels. Other checks provide user the option to execute check based on user defined criteria. The user can build a query on his/her own. The user can select the range of year for incidence data against which the mortality can be performed.

### **Export Data**

Once the duplicate checks and matching is done the user can export the incidence and mortality data to CSV (comma separated value) format. It is a text file, this file can be opened in an excel sheet and the data that is entered under data entry section can be exported. Thus, the exported data in CSV format are sent to the coordinating unit in Bangalore for the report preparation.

### **All-Cause mortality**

To improve the cancer mortality data, the PBCR Cachar, has developed a software in which all death cases except cancer can be recorded. After entering

the mortality cases all those record are exported in Microsoft Access file and the file is sent to NCDIR so that those records can be matched with the incidence records.

### **Report Preparation**

Reports can be generated from the processed data and it will help the user to use them as a ready reference while rectifying all data at the data entry. The report can be exported to various formats like doc, rpt, pdf, xls.

### **Data backup**

A data backup is the result of copying or archiving files and folders for the purpose of being able to restore them in case of data loss. There can be multiple causes of data loss ranging from computer viruses to hardware failure to file corruption. Backup procedure should be thoroughly tested to ensure the archived files remain uncorrupted and can be restored.

Health research must be aware of confidentiality and ethical requirements when working with research files. This is especially important when data contain personal identifiers and medical information.

### **Conclusion**

This software simplifies the cancer registry process by case finding and abstracting outcomes. It also focuses on simple and easy handling of software and also improves data quality by automated tools like quality checks, consistency and reduces risk of errors.

## A Critical Review of Data Collection of Population Based Cancer Registry (PBCR) - Cachar

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### Introduction

Cancer registries collect data elements that include demographics, diagnoses, tumour histology, treatment, and outcome information. Data collection enables a person or organization to answer relevant questions, evaluate outcomes and make predictions about future probabilities and trends. Accurate data collection is essential to maintaining the integrity of research, making informed business decisions and ensuring quality assurance. There are basically two types of cancer registries namely, Hospital Based Cancer Registry (HBCR) and Population Based Cancer Registry (PBCR). The PBCR seeks to collect data on all new cases of cancer occurring in a well-defined population. The population represents residents of a particular geographical region and at present there are 29 PBCRs in India.

### PBCR-Cachar

PBCR-Cachar district is one of the six old cancer registries of north eastern India. It has expanded from PBCR-Silchar town to PBCR-Cachar district in the year 2007. Since then it has been collecting data on cancer cases in the district of Cachar in a systematic and scientific manner. The office of the Population Based Cancer Registry is located in the Department of Pathology, Silchar Medical College, Silchar. The team includes seven registry staff comprising of one Senior Research Fellow (SRF), one Statistician, one Programmer, three Social Investigators and one Data Entry Operator. These three social investigators are engaged in the process of data collection covering approximately seventeen lakh population through 51 centres.

The Social Investigators visit the sources of registration on a regular basis to collect data on cancer patients as per the core proforma from the record of the sources. Data will be collected from both the primary and secondary sources.

**Primary source of data:** Silchar Medical College and Hospital (SMCH) is the only primary source of data from where the data are collected from the patients by direct interview.

**Secondary sources of data:** Cachar Cancer Hospital, (CCHRC) diagnostic centres, private laboratories, private practitioners etc. are the secondary sources of registration. Data are collected from the secondary sources by abstraction of records.

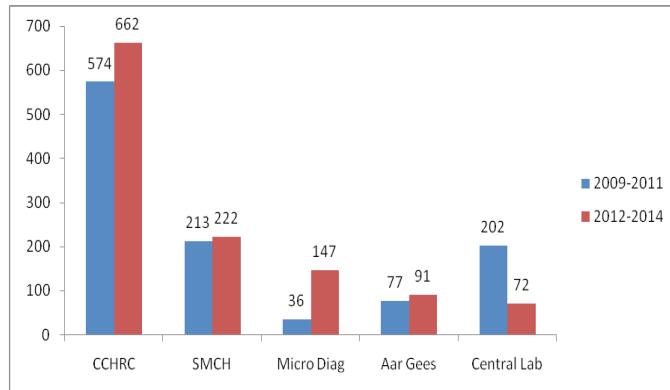
**Mortality data:** Mortality data are collected from secondary sources like the Joint Directors' Office and newspapers. Mortality data are also collected from primary sources through direct telephonic interviews and home visits.

### Process of Data Collection

The Social Investigators visit the sources of registration on regular basis in order to collect data on cancer patients as per the core proforma. Social Investigators do not simply wait for cancer information to be handed over from the sources mentioned above. Instead, they become actively involved in case finding activities so that the cancer information they receive is as complete as possible. Apart from the data collection the registry staff always try to maintain an established relationship network among the different registries as well as with various sources. As the process of data collection is a

continuous process, regular monitoring is mandatory.

### Comparison of the average data received from the



### major sources of registration, Cachar District (2009-2011 & 2012-2014).

**CCHRC** - Cachar Cancer Hospital and Research Centre

**SMCH** - Silchar Medical College and Hospital

Micro Diag - Micro Diagnostic Laboratory

Aar Gees - Aar Gees Medicare

Central Lab - Central Laboratory

### Problems of Data Collection

1. Lack of motivation among the field staff in maintaining data for the cancer registry staff.
2. Inadequacy in maintenance of proper records by the source staff leads to missing variables thus, hampering the quality of the data.
3. In order to maintain patient's privacy (confidentiality), patients cannot be directly contacted in other institutions apart from Silchar Medical College and Hospital.
4. In a cancer hospital setting, more time is required to collect majority of the variables as per the core proforma which hinders the real time data entry.
5. Lack of information provided by the patients at the source of registration on their address creates problems for further follow up.

### Initiatives by PBCR-Cachar District

To ensure the quality of cancer data, cancer registries may create and adopt their own innovative data collection systems. PBCR Cachar district is taking the following initiatives

1. Comparison of the number of incidence cases per year at each sources collected by the social investigators to find out the trends,
2. Regular meetings with the staff working at the different sources of registration so that they can be motivated to keep proper records of the cancer patients,
3. Performance of the social investigators are checked on monthly basis so that the data collection goes on effectively,
4. Annual meetings are conducted with the head of the institutions of different sources so that problems of data collection can be minimised.
5. Finding an entry point to build up rapport with the staff of different registries as well as various sources

### Conclusion

The 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 like etiological research, primary and secondary prevention, health-care planning and patient care. Most of the cancer registries possess the potential for developing and supporting important research programmes by making use of the information they collect. Cancer data collection is a time and labour intensive effort, but the great value of its product that is the cancer statistics, makes all of the hard work worthwhile. Furthermore, ethical issues should be taken care of while collecting data from any Institution. The Social Investigators must be aware of the confidentiality and ethical requirements when working with cancer data. This is especially important when data contain personal identifiers and medical information.

## Delhi PBCR-Practices, Coverage and Challenges

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The registration of cancer cases began with several unsuccessful attempts at cancer surveys in the United Kingdom in 1728, Germany in 1900 and Netherlands and Spain in 1902 and 1908. After several attempts at population based cancer registration in Germany in 1926, USA, Denmark, England and Canada in 1940s, the need for the establishment of cancer registries throughout the world was recommended to World Health Organization (WHO) by leading experts in the field of cancer control. A few years later, the WHO established a subcommittee mandated to proffer recommendations for the establishment of cancer registries.

The specialized arm of the WHO that deals with cancer, the International Agency for Research on Cancer (IARC) was formed in 1965 and the following year, the International Association of Cancer Registries (IACR) was founded. The IARC and IACR through their activities promoted the development of cancer registration in many developing countries.

In India, the Mumbai Cancer Registry was established in June 1963 as a unit of the Indian Cancer Society, with the aim of obtaining reliable morbidity data on cancer, from a precisely defined urban population (Greater Mumbai). Subsequently PBCRs were established in Pune (1973), Aurangabad (1978), Nagpur and Ahmedabad (1980).

In December 1981, ICMR commenced the National Cancer Registry Programme (NCRP) across the country with a network of three PBCRs in Bangalore, Chennai and Mumbai and three HBCRs in Chandigarh, Dibrugarh and Thiruvananthapuram with the following main

### Objectives

1. To generate reliable data on the magnitude and patterns of cancer
2. Undertake epidemiological studies based on results of registry data
3. Help in designing, planning, monitoring and evaluation of cancer control activities under the National Cancer Control Programme (NCCP)
4. Develop training programmes in cancer registration and epidemiology.

The PBCRs have gradually expanded over the years and as of now there are 29 PBCRs and 29 HBCRs under the NCRP network.

Under the NCRP network, the Delhi PBCR was established at Dr. B.R. Ambedkar Institute Rotary Cancer Hospital (IRCH), All India Institute of Medical Sciences (AIIMS), New Delhi 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.:-

- (i) Delhi Municipal Corporation (Urban)
- (ii) New Delhi Municipal Committee

(iii) Delhi Cantonment and

(iv) 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 Capital Territory of Delhi is 1483 Sq. kms. The rural and urban composition of Delhi is 326.44 sq. kms and 1156.56 sq. kms respectively.

The registry covers only urban area of Delhi consisting of 1156.56 sq. Kms. 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. Since the Delhi is the capital of India, it has excellent facilities for cancer diagnosis in both the government and private set up. Number of new hospital/centers have come up over the years and so the number of sources also increased for data collection.

The Medical Social Service Officers (MSSO) visit various hospitals and nursing homes and interview the patients

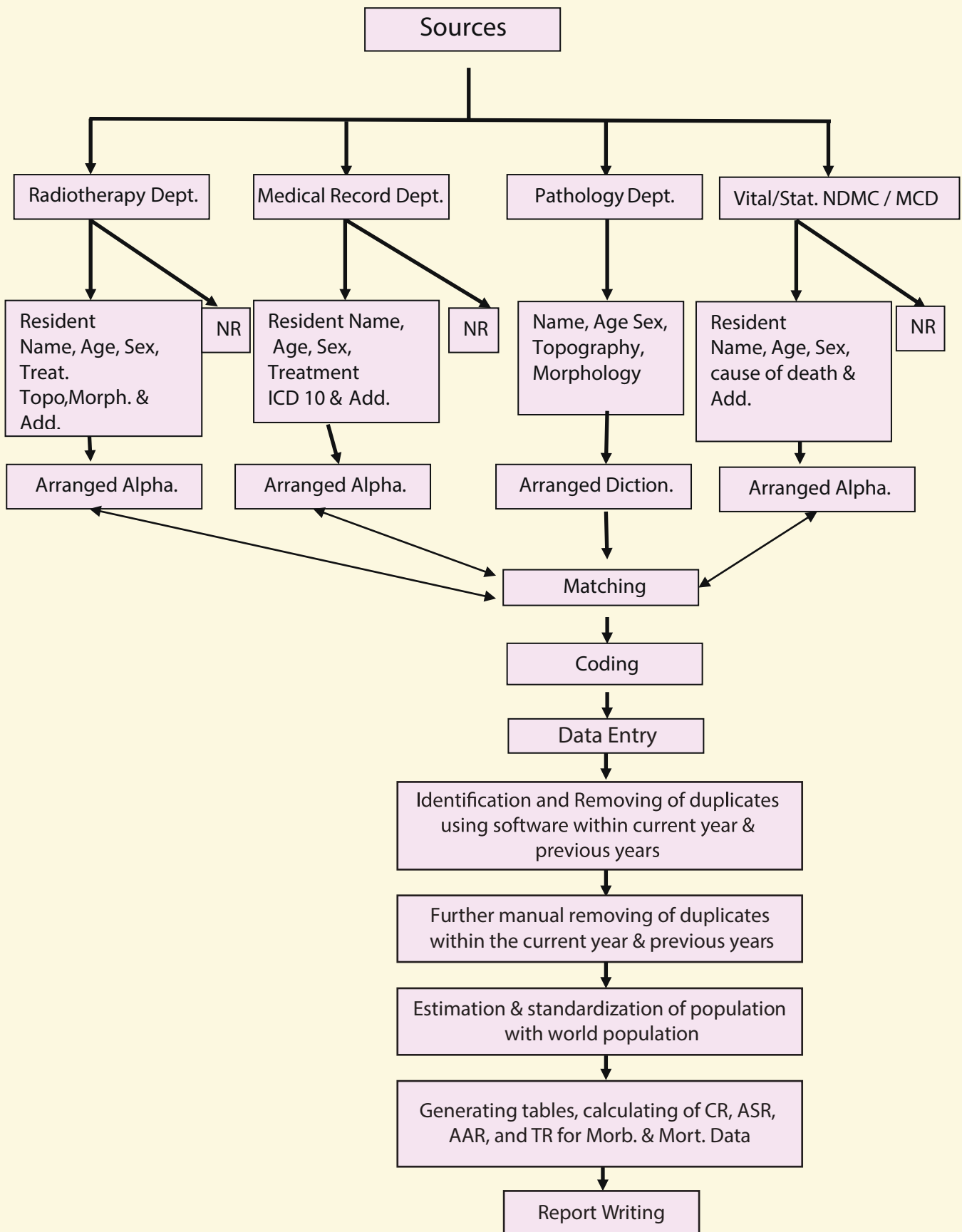
who are either undergoing cancer treatment or being investigated for cancer at radiotherapy department. They also examine the case records maintained by various departments of these hospitals viz. Pathology, Hematology, Radiology etc. All the information collected is cross-checked for completeness of the data. Sometimes same patient may register his/her name in more than one hospital for treatment. So care has been taken to exclude duplicates and ensure that each patient is included only once in the records. MSSO's also personally visit the offices of New Delhi Municipal Committee and Municipal Corporation of Delhi and collect information about deaths from death certificates that state the cause of death as cancer or tumours. These death records are then matched with the morbidity records. Cases not matching with the records are registered as Death certificates only cases (DCO's) in that corresponding year. Figure 1 depicts the working of the Delhi Cancer Registry.

Since the inception of registry (1986) to 2012, Delhi PBCR registered a total of 2,62,710 cancer cases with 1,33,641 males and 1,29,069 females with an approximately equal sex ratio. The change in the incidence of top ten cancer sites observed in both the genders are provided in Table 1 and Table 2.

**Table 1: TEN LEADING SITES OF CANCER IN 1988 AND 2012, MALES**

RANK	1988			2012		
	ICD10	SITE	%	ICD.10	SITE	%
1	C33-34	Lung	8.35	C33-34	Lung	10.48
2	C32	Larynx	6.55	C03-06	Mouth	6.93
3	C82-85,C96	NHL	4.58	C61	Prostate	6.74
4	C15	Oesophagus	4.38	C01-02	Tongue	6.49
5	C70-72	Brain	4.17	C32	Larynx	5.65
6	C01-02	Tongue	4.14	C82-85,96	NHL	4.49
7	C61	Prostate	3.97	C67	Bladder	4.44
8	C67	Bladder	3.73	C15	Oesophagus	4.03
9	C92-94	Myel. Leuk.	3.63	C23-24	Gallbladder	3.56
10	C91	Lymp. Leuk.	3.46	C91	Lymp. Leuk.	3.49

Fig 1. Flow chart showing working of Delhi PBCR





**Table 2: TEN LEADING SITES OF CANCER IN 1988 AND 2012, FEMALES**

RANK	1988			2012		
	ICD10	SITE	%	ICD.10	SITE	%
1	C53	Cervix	20.50	C50	Breast	28.59
2	C50	Breast	20.06	C53	Cervix	10.83
3	C56	Ovary	5.95	C23-24	Gallbladder	7.87
4	C15	Oesophagus	2.92	C56	Ovary	7.17
5	C23-24	Gallbladder	2.86	C54	Corpus uteri	3.51
6	C92-94	Myel. Leuk.	2.06	C82-85,C96	NHL	3.09
7	C70-72	Brain	2.03	C33-34	Lung	3.07
8	C82-85,C96	NHL	1.90	C15	Oesophagus	2.31
9	C16	Stomach	1.89	C03-06	Mouth	2.22
10	C33-34	Lung	1.89	C01-02	Lymp.Leuk	2.1

In males lung cancer remains the most common cancer in 1988 and 2012, but with increase in numbers which was 8.4% in 1988 and increased to 10.5% in 2012. Mouth, which was the second most common cancer in 2012 was not among the top ten leading sites of cancer in 1988. Prostate (4.0%) which was the seventh most common cancer in 1988 has been increased over the years and it has become third most common cancer with 6.7% of cases in 2012.

In females, cervix cancer was the top most cancer in 1988, was replaced by breast in 2012, with cancer cervix becoming the second most common cancer. The distribution of breast cancer which was 20% in 1988 has increased to 28.6% in 2012. Corpus uteri which was not among the first ten leading site in 1988, has become the fifth most common cancer in 2012. Mouth and tongue were not among the ten leading sites in 1988, but are ninth and tenth most common cancers in 2012 respectively.

The following are the some of the challenges faced by the registry in collection and maintenance of the data along with some possible solutions to these challenges.

### 1. Age unknown

Information on age or date of birth is particularly important for cancer registry for accurate estimation of age-specific incidence rates. In some sources, the age is not recorded properly or missing in the case file it is very important to note the phone number and to call the patient/patient's relative, wherever telephone number/mobile number is given.

### 2. Unknown duration of stay

A major problem faced by any registry is unknown duration of stay. The information on duration of stay can be collected only through interviewing the patients. All sources (hospitals) never record the duration of stay in their case files and it is not possible to interview the patients in all the sources. But the duration of stay can be identified through phone by interviewing the patients wherever phone number is available.

### **3. Missing histopathology/cytopathology (microscopic confirmation) and unspecified histology cases**

In all case files pathology reports may not be available. So there is no microscopic confirmation. Another problem faced by registry is unspecified histology/non availability of clear histology. When sources are providing only soft copies of the data due to either non availability of hard copy of the files or destruction of files due to space constraint for maintaining the files, the histology information is missing as the sources never enter the histology of cancer cases in their data base.

### **4. Unspecified sub-site**

In most of the histology reports or case files the sub-site is not mentioned.

### **5. Lack of manpower and increase in number of sources**

When the registry was established, it covered an urban area of 550 sq. kms of Delhi with 25 hospitals/sources and over the years the urban limit has been expanded and at present it is covering an area of 1156 sq. kms of Delhi with more than 170 sources with the same manpower. Moreover the manpower is reducing due to retirement of field staff and being a Government organization it takes a lot of time to fill these vacancies and for creation of new posts. So data collection has become a time-consuming process and there is a lot of delay in our data collection and reporting. In order to overcome this problem, we are taking initiative to convince the big sources to start HBCR in their centers and for small centers we have been requesting them to use the Pathology and Radiotherapy modules developed by NCDIR, Bangalore. The NCRP also should take initiative to provide some financial assistance to these centers for equipments and extra manpower etc.

### **6. Lack of coding or wrong International Classification of Diseases (ICD) coding of cancer**

In some sources there is no practice of disease coding in the medical record section and whereas in some sources, cases were coded wrongly- where benign cases are coded as malignant and vice versa. So it is better to scrutinize the medical record files for correct data. But it is laborious and time-consuming process while going through all the files in medical records and death certificates in the vital statistics division of Municipal Corporation.

### **7. Non-cooperation from New Delhi Municipal Committee (NDMC)**

Due to confidentiality we are unable to collect data from NDMC and in turn it results in very less Death Certificates Only (DCOs). Now we are trying our best to collect mortality data from NDMC.

### **8. Quality and maintenance of death certificates**

Earlier in Municipal Corporation of Delhi (MCD) all birth and death certificates were kept together and it was a time-consuming process to scrutinize all the certificates to record cancer deaths. In recent years the death certification process is being computerized and we are in a position to get soft copies of the all-cause mortality which is around 1 lac per year which is being matched with our incidence data using the software developed by NCDIR.

### **9. Matching and duplicate elimination**

This is another major problem encountered by the registry. The patients used to register their names in hospital in abbreviated form and in full form in some other place. So it is very difficult to eliminate duplicates. Now this has been resolved up to some extent by using the NCRP software.

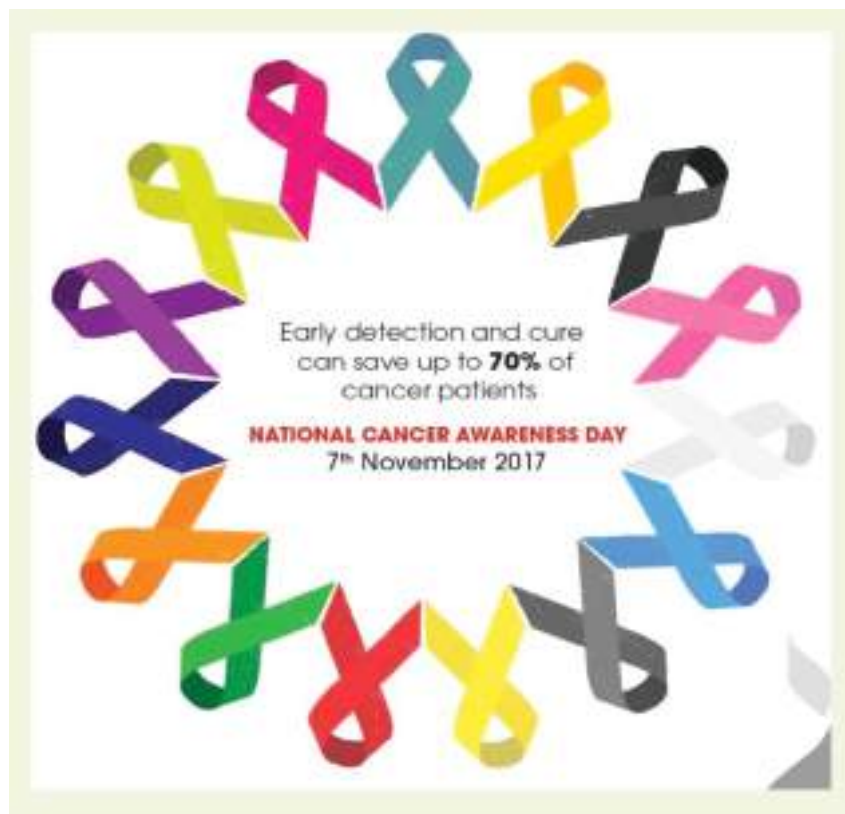
In conclusion, for successful implementation of cancer registration, it requires cooperation of many stakeholders in the health and non-health care sectors,

whose cooperation must be assiduously cultivated. These include both private and government hospitals, pathology labs, medical records and vital statistics division of municipal corporations. Engaging heads of institutions, head of medical records at regular interval is crucial for cancer registries. Also in order to ensure complete coverage, it is essential to periodically check for any establishment of new hospitals or cancer treating centers for cancer data collection/registration.

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End



## Present and Future Prospects of PBCR - Dibrugarh

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### Introduction

Cancer registration is the process of continuing, systematic collection of data on the cancer occurrence and characteristics of reported neoplasms with the purpose of helping to assess and control the impact of malignancies on the community. Broadly, there are two types of cancer registries viz. Population Based and Hospital Based Cancer Registries. Population Based Cancer Registry is an registry which performs cancer registration by systematic collection, storage, analysis, interpretation and reporting of all newly diagnosed cases of cancer in a defined population, usually in a well-defined geographical region occurring in a defined time period & relates this to the 'population at risk'. Such information is the primary resource for planning, evaluating health services for the prevention, diagnosis, treatment and epidemiologic research. On the other hand a Hospital Based Cancer Registry (HBCR) records all cases in a given hospital emphasizing on clinical care and hospital administration without any relation to the background population.

Realizing the need for setting up of demographic cancer registries in different states of North East (N.E) region, ICMR initiated NERCR (North Eastern Regional Cancer Registry) under NCRP in 2003. Accordingly, six PBCRs were set up in four out of the eight states of N.E Region. Dibrugarh PBCR was one of them. At present a network of 33 PBCRs are functioning under the National Centre Registry Programme (NCRP) of Indian Council of Medical Research (ICMR).

The PBCR covering the district of Dibrugarh situated in the eastern corner of the state of Assam covering an area of 3381 sq.km 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. As per 2011 census Dibrugarh district has a total population of 13,26,335 (Male: 6,76,434 & Female: 6,49,901).

PBCR Dibrugarh collects cancer data from several sources situated within and outside of Dibrugarh district. At present it has access to nearly 100 sources of registration. Broadly the sources can be classified as AMCH, other hospitals & nursing homes, pathological laboratories, imaging centres, cancer centres outside Dibrugarh and Birth & Death registration centres. All the information collected from these sources are kept strictly confidential and used only for research purpose. Cancer is not a notifiable disease in India as in most developed countries. Hence registration of cases is not voluntary and is done by active method in that Social Investigators personally visit the different sources and collect data on cancer cases either by interviewing the patients, attendants or from the medical records. As cancer data are collected from different sources, the same patient may sometimes be registered at two or more sources. Care has been taken not to have multiple entries of the same patient. After collecting the core information of incident cancer cases from all the collaborating and outstation sources, the cases are finally re-checked from the diagnostic point of view. Suspected cases are deleted from subsequent

analysis. The proved cancer cases are further checked for the residential status and duration of stay. Only patients who have been living in the registry area for at least one year prior to the first diagnosis of cancer are registered. This is done to avoid registering of cases from floating population. Only invasive cancers are reported. In-situ and borderline cases are filed separately for future follow-up. The third edition of the International Classification of Disease for Oncology (ICD-O) is used to code morphology and topography. The 10<sup>th</sup> revision of ICD10 (International Classification of Disease) is also used for cancer coding.

Data on mortality are collected from the death registers and certificates maintained in the birth and death registers in the PHC's, CHC's of the district as well as in the Municipality Board Dibrugarh and Medical Record Department of AMCH. Cancer deaths, first identified on the basis of 'Death Certificate Notification (DCN)' only are matched with the current and previous year's death records. Death records at MRD and Nursing Homes are scrutinized for more information on causes of death. Cases with no additional information other than that available in the death certificate are registered as "Death Certificate Only" DCO. Data on cancer incidence and mortality formatted in the prescribed proforma developed by NCRP are entered in the computer. Checks are then undertaken for identifying data entry errors. Variety of range and consistency checks for all variables developed by the registry and the check program developed by NCRP are carried out to detect the inconsistencies in the combination of age, site and histology. The completed data are then sent to NCRP. Report based on these data are published regularly both locally and centrally.

### **Some Important Projects**

Since inception several research projects under PBCR Dibrugarh has been completed successfully. Among them "Understanding the role of Tobacco" and "Understanding the role of Pesticide" are worth mentioning. A project entitled "Pattern of Survival and Quality of Life of Oesophageal and Stomach Cancer patients of N.E. Region of India" in collaboration with

RMRC Dibrugarh is going on under PBCR Dibrugarh. We are thankful to NCDIR for the recently granted study "Population based cancer survival on cancers of Breast, Cervix and Head & Neck". Population based cancer survival provides an idea of the effectiveness of the overall cancer control strategy in the registry area. It gives a baseline on impact of cancer and its treatment on the population and help plan health services facilities for improvement of survival. Monitoring the survival over a period of time will give evidence on whether a particular prevention programme is working.

### **Expansion of PBCR Dibrugarh**

PBCR Dibrugarh is going to expand its coverage to the districts of Jorhat, Golaghat, Sibsagar, Tinsukia, Lakhimpur and Dhemaji. It would help to determine the incidence, trends and patterns of cancer in entire 'Upper Assam division'. After analyzing the data the high risk population would be identified and the data acquired would be used for planning, prevention and therapeutic measures at the hospital and state levels. The expansion is taking place at the right time from the point of view of health infrastructure development. The reporting institution (Assam Medical College & Hospital) is undergoing a massive revamp in infrastructure. Government has undertaken several new infrastructure projects in AMCH. Super-specialty block, 100 bedded cancer hospital are few such important projects. AMCH already has a state of the art blood bank. After completion of these projects AMCH will be the only hospital in entire 'upper Assam' to have such facilities of treatment. We can expect a surge in flow of cancer patients from the 'upper Assam' belt to AMCH is near future.

### **Future Project Prospects**

An increasing trend of colorectal cancer is observed in the region along with very high prevalence of gallbladder cancer. Lymphoma cases are also on the rise though it does not occupy a position among the ten leading sites. An ICMR sponsored project on Lymphoma subtyping is going on in the Department of Pathology and if we take a parallel survival study on the patients

it would help us to understand the behavior pattern of the disease and drug response. We think it is the right time to take up a survival study on the two sites. The laboratories in the dept. of Pathology are very well equipped. It also has Molecular Pathology Lab (IHC) with flow cytometry. The available infrastructure and manpower can be utilized in diverse cancer related projects.

## Vision

We have a vision to develop PBCR Dibrugarh as a hub of cancer registration in entire upper Assam. To make this vision come true apart from the resources and infrastructures we would also need help from society. And to get that help we must make society aware of this dreaded disease. We have put our best foot forward in that direction and included 'Cancer awareness programme' as a routine activity of PBCR Dibrugarh.

In order to mobilize the awareness on the objectives and function of PBCR, five awareness camps have been organized during 2016-17 at different strategic PHCs of the district. Moreover efforts have been continuously made to optimize the case finding through sustained liaison with all concerned. With the passage of time some of the difficulties have already been eased but some are still there.

In order to increase the reach of registry other non-conventional sources like ASHA workers, NGOs and personnel from health sectors were roped in. Some other potential sources are also being approached. ASHA workers are now active sources of registry. After involving a few ASHA workers under five PHCs: Lahoal, Khowang, Naharani, Namrup mini PHC and Barbaruah in Dibrugarh district we received nearly 50 new cancer cases from them in 2016. That accounts for more than 5% of total incident data. We could not invite all the ASHA workers of the respective areas due to unavailability of enough space in the auditoriums of the PHCs. Only 1/3<sup>rd</sup> of the total ASHA workers could be sensitized during the awareness camps. More awareness camps would be organized during Nov 2017 to Feb 2018. Hopefully this will further improve

our coverage. The involvement of ASHA workers may help us further with respect to diagnosis and care of other non-communicable diseases like diabetes, hypertension etc. provided they are properly equipped and trained to use instruments like BP monitor, glucometer, portable haemoglobin analyzer etc. We are also planning to approach the competent authority to access the information on any cancer patient treated under the Govt. initiated scheme "AtalAmrit Yojna."

During the field surveys conducted in view of the expansion, different district showed different level of awareness among the health workers on importance of cancer registration. Hence we are planning to arrange meetings with the concerned officials and health workers to increase the awareness on the objectives and function of PBCR and importance of cancer registration. In the next level of the programme, we would like to target the college going population (18+ age group) to spread the awareness among the mass. The most important factor that made us to target the college going population because this is the age when youths develop affinity towards alcohol, pan masala, gutkha, tobacco and other intoxicated carcinogens. Then we are planning to include the students doing their Bachelor or Master degrees and actively involved in the clubs and other social welfare societies' as volunteers. They would help us by providing information of any suspected cancer patient in the locality. The Social Investigator would further investigate the case and include it in the database if found positive.

Looking to the future the problems of non-registration of cancer needs to be addressed. Until cancer is declared as a notifiable disease in Assam, we'll have to try unconventional methods and sources for data collection.

**Staff of PBCR Dibrugarh with Principal investigator**



**Cancer Awareness Programmes at various PHCs**



## Challenges in Data Abstraction and Quality Indices

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### (A) Patient confidentiality a legal aspect

The objective of a cancer registry is to make complete and individual data accessible for medical, research and statistical purpose. To draw a conclusion with validity, data must be complete, accurate and as reliable as possible. Accuracy and completeness can be accomplished only when the patient and physician are at trade-off that the data required is necessary enough for the aim and objective of the registry and the data will be safe guarded. Safe guards for the data need to ensure that the data are sufficiently secured against unauthorized access on the network and that they are used for the purpose with which the registry is initiated.

### Preservation of confidentiality

Principal Investigator holds the responsibility for the maintenance of confidentiality of the data and it should be stated by legislation or by the concerned Government administrative order. To maintain the patient confidentiality, it is the responsibility of all the staff within the registry and, at the time of employment, it is recommended that the staff sign a special declaration that no information on the data in the cancer registry would be disclosed. It is highly recommended that cancer registries review certain confidentiality measures at regular intervals.

### Practical aspects of confidentiality in cancer registration:

**(a) Collection of patient's information:** Information

about the cancer patients usually is derived from source hospitals such as the treating physician, hospital record room, discharge office, pathology, and cytology, radiologist and vital statistics department. These reports generally consist of the name of the patient, unique identification and other information and it is mandatory that the collected content is not disclosed to parties other than the concerned source hospital and registry.

### (b) Transmission of information from source to registry

Information may be transmitted through mail, magnetic media computer terminal, or telephone.

**Magnetic media:** It is recommended to maintain track record of all magnetic tapes, CD's or other data media leaving and received by the registry.

**Computer:** Information can be exchanged through computer and a registry can send its information for storage on an external computer. Stringent step should be taken up to monitor the use of user id and password (which should not be written in any format), the time of the authorized entry, and an attendance should be maintained in a log book. Passwords should be changed at regular intervals.

**Telephones:** To complete the missing information from the source hospitals, telephones are used to obtain the information. Confidential information should not be disclosed on telephone unless the caller



is an authorized employee of the hospital.

Social workers request the concerned staff of the source hospitals to call the patients to find out any missing information that was not captured during Data Abstraction. The patient replies to the queries confidently as the call has come from the source hospital where he is getting treated, thus confidentiality is maintained.

### **Social worker counseling the patient - PBCR, Hyderabad**

**Access to Storage of data:** It is suggested that a list of persons authorized to access data is maintained in a



written format.

**Disposal of dead files:** Many registries safeguard paper files for a period of two years after a registered patient is known to have expired. The original documents are to be microfilmed before they are destroyed.

**Cessation of Registry activity:** Cancer registry should frame a policy, in case the registry ceases its activities. The records in the registry should be microfilmed and stored for a minimum of 35 years, by an appropriate body, which should follow the same confidentiality rules as the cancer registry when in operation.

## **Conclusion**

Regardless of the potential challenges to maintain the confidentiality of data in developing countries, evidence from the years of cancer data management in Hyderabad suggests that rigid measures can ensure confidentiality. The use of multiple measures to ensure confidentiality is mandatory in surveillance data management.

### **(B) All- Cause Mortality Data**

Information on the underlying cause of death of cancer patients is of interest as it enables us to estimate net survival. The PopulationBased Cancer Registry Hyderabad receives the all-cause mortality data from the Greater Hyderabad Metropolitan Corporation and sends the same to NCRP for each calendar year. NCRP reviews the official cause of death on the basis of mortality data. Official cause of death is useful while estimating cancer specific survival. Submission of all-cause mortality data to NCRP completes the data submission for each calendar year.

### **Quantitative methods for completeness of Registration**

**1. Independent Case Ascertainment:** Registry database is compared with sets of cancer cases that have been compiled independent of the cancer registry. Case finding procedure is a useful method of evaluating completeness.

**Estimation of Missing Numbers:** The record linkage between cancer registry database and independent case series provides estimate of the missing numbers that are missed by the registry.

### **2. Capture – Recapture Methods**

This method concentrates on the same cancer cases that are received from multiple sources. In this process, the source hospitals are integrated into

hospitals, laboratory and death certificate which are independent of each other. The objective is that if we know how many cases are registered by one source, pair of sources or all three sources, we can project on how many cases that are registered by none. The use of Capture –Recapture analysis of completeness requires successful linkage of multiple sources.

### 3. Death Certificate Methods

This method highly depends on the availability of high quality (complete information and accuracy) certification of cause of death within the geographical limits covered by the registry.

Data quality indicators for PBCR survival: Unlike incidence data, estimating cancer survival requires best quality follow up information. This can be accomplished, if all-cause mortality data is available as data source for the registry and the linkage procedures (Unique Identification Number) is in place. In low and middle income countries, registration of vital event is unavailable to the cancer registries, many of them have employed active follow-up methods. Lack of follow up leads to high percentage of DCOs due to which they are excluded from analysis. With the not so structured health statistics data system and unavailable mortality data, PBCRs provides the only information on the status of cancer in the country. Successful reporting of PBCR results require evaluation of the data to allow a valid comparison of cancer rates and risks, between population and subgroups over time.

#### Procedure to get all-cause mortality data

For each calendar year, PBCR staff approach the Commissioner of the Greater Hyderabad Municipal Corporation (GHMC) for the mortality data. The concerned government officials of GHMC study the file and send the mortality data to PBCR Hyderabad. It takes more than 8 months for the registry to receive the mortality data from GHMC. This whole process is the reason for the delay in submission of each year's mortality data to NCRP.

### Quality Control for PBCR

**(i) Mortality to Incidence Ratio (M:I)** :The M:I is the number of deaths registered at the Vital Statistics system to the number of new cases of specific cancer registered in the same period in the registry. Mortality data of good quality is required for the application of this method. This method cannot be applicable where there is no accurate death registration system or when the cause of death is missing or inaccurate

**(ii) Stability of incidence data over time:** Registry checks on the number of cases registered in each year. If the defined population is not changed, this method identifies the potential defects in case finding.

### C) Administrative problems in Source Hospitals

Access to pathology labs, Medical Records room, and to the department of Information Technology in the source hospitals is not possible during the office hours of the hospitals. Staff of the registry approach through the management of hospitals for data abstraction which is a time consuming process. Delay in data abstraction from the source hospitals leads to delay in internal quality check, consistency check as each record has to pass through a methodology for submission of the complete record to the registry database.

Limitation in computer systems, space and time provided by hospitals to our staff in collection of data can delay the data abstraction, hence we work at odd times, or on Sundays for data abstraction.

### (D) Timely Submission of the Data

Rapid reporting of the data is required from the registries on regular basis. A win-win situation must be identified between data timeliness and extent to which the data collection is complete. The timeliness depends on the acceleration with which the registry can collect, process through the internal quality check, and submit complete and accurate data.

Some patients move from one hospital to another hospital for opinion and treatment, hence there can be duplication of data, and the same patient may have multiple access numbers instead of one single identity number. In order to get first date of diagnosis and all relevant data for completing the PBCR or HBCR forms, we may have to search multiple files of the same patient. This can cause delay in data abstraction and in getting the accurate information, as all the files will not contain required data for data abstraction.

Sometimes we have to approach the treating doctor for diagnosis details of the patient as they may sometimes write multiple diagnoses for the same patient. We have to wait for the consultant to give us his valuable time for clarification of the same. All these things cause delay in timely submission of data to NCRP

**Internal Consistency:** A new patient record should be processed through data checks for duplicates and edits for case validity, internal consistency and inter record consistency before they are duly linked with the central data base. Such data checks needs to be linked to the central registry data base after the necessary changes have been made.

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## Improving Mortality Data in Population based Cancer Registry Manipur

Ph. Madhubala <sup>1</sup>

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### Mortality Data Collection: The Biggest Challenge so far

Collection of mortality data has been a big challenge in our registry area as the death registration system and certification has been extremely poor in our state. Records of death and their causes 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. So chances of getting death certificate only (DCO) cases are also dim.

We have been actively following up the incident cases from our records by matching up with the obituaries published in local newspapers and media, through phone calls and home visits etc.

However due to frequent change of SIM cards and poor network connectivity at remote places, the outcome of the method is not as satisfactory as expected.

Home visits also have lots of limitations. We have only three social investigators to cover the whole of the state. Their primary task is collection of incidence data from more than 30 primary sources within our registry area. Besides the prevailing law and order situation

arising out of insurgency problem, geographically nearly 90% of the total land area is hilly with difficult terrain. So travelling to cover far off places is not an easy task. Tracing their home by the address given in our records is again not easy because in most of the cases, it is incomplete, as we have very limited idea about the place.

### Engaging ASHAs effectively to accomplish the task

In order to overcome these limitations we started reaching out to our people through Accredited Social Health Activists (ASHAs). They are community health workers instituted by the Government of India's Ministry of Health and Family Welfare (MoHFW) as part of National Rural Health Mission (NRHM) programme which began in the year 2005 with the aim of having "an ASHA in every village" in India. ASHAs are local woman trained to act as health educators and promoters in their communities.

ASHAs must primarily be female residents of that particular village that they have been selected to serve who are likely to remain in that village for the foreseeable future. Married, widowed or divorced woman are preferred over women who are yet to marry since Indian cultural norms dictate that upon marriage, a woman leaves her maiden village to shift to her husband's village. They are generally between the age group of 25 to 45 years and are mainly educated upto 10<sup>th</sup> standard only.

Because of those above mentioned characteristics of ASHA, we believe that they can definitely play an important role in communicating with the locales. On a trial basis, we started covering three Primary Health Centres (PHCs) namely Phayeng, Khumbong and Yaingangpokpi. On an average every PHCs has about 20 to 30 villages, each being represented by an ASHA. For smooth functioning, 15 to 20 ASHAs form a group with their elected leaders under the overall supervision of the Chief Medical Officer (CMOs) of those PHCs. They regularly meet every month on a particular day at their local PHC. We also visit the PHCs on that day of the meeting and make acquaintance with the ASHAs.

one village after another along with the concerned ASHA. ASHAs belong to the same locality and during their course of ongoing health promotion activities they come to know of every household even better than they had known before. Locating the residence and further identifying the patient from our records becomes quite easy. We can actually talk to the patient or their family members and know more about their actual conditions. Thus we can collect mortality data we and also improve and update our incidence data by filling up missing information. So involvement of ASHA workers in collecting mortality data has really been effective and commendable for centres like us. These significant improvements will be evident in the coming reports.

Then we take an area or village wise prints out of our incidence records, and subsequently start covering

**PBCR staff attending one of the meetings of ASHAs along with CMOs at Phayeng PHC**



**PBCR staff meets CMO and ASHA group leader at CHC Wangoi**



**PBCR staff at Khumbong PHC**



**Staffs of PBCR & PHC Yaingangpokpi**



## Experiences and Practices at PBCR - Pasighat

**Kaling Jerang**, Principal Investigator, Sr. Pathologist,

**G. Jongkey**, Co - Investigator

BP General Hospital, Pasighat

### Introduction

Arunachal Pradesh, - the 29<sup>th</sup> State of India has mesmerizing scenic beauty and is geographically the large state of the entire North Eastern India, spread over an area of 83,743 km<sup>2</sup>. It borders the states of Assam in the South and Nagaland in the east and southeast. The state also shares international boundaries triangularly with Bhutan, China and Myanmar respectively. Arunachal Pradesh falls in the outer Himalayas and Patkai ranges and is endowed with wide topographical variations, vegetation and wild life. With mountainous topography and humid subtropical climate, the eastern part of Arunachal Pradesh covers ten (10) districts namely East Siang, Upper Siang, Changlang, Lohit, Lower Dibang Valley,

Tirap, Anjaw, Namsai and the newly created districts of Siang and Longding with a total population of 6,22,817 ( 3,25,156 males; 2,97,659 females) according to 2011 census. These ten districts cover an area of 41,668 sq Kms with an average population density of 17 per sq.km. These districts are mainly named after the four major rivers viz., Siang, Lohit, Dibang, and Noa Dihing and these river valleys dissect the precipitous terrain of Arunachal Pradesh and makes the link road facilities to the districts unfeasible. The interstate boundaries shared are with Assam and Nagaland. Assam being the highest referral centres because of availability of better medical facilities and good transportation and network, it adds to extensive travel for data collection which is very challenging.

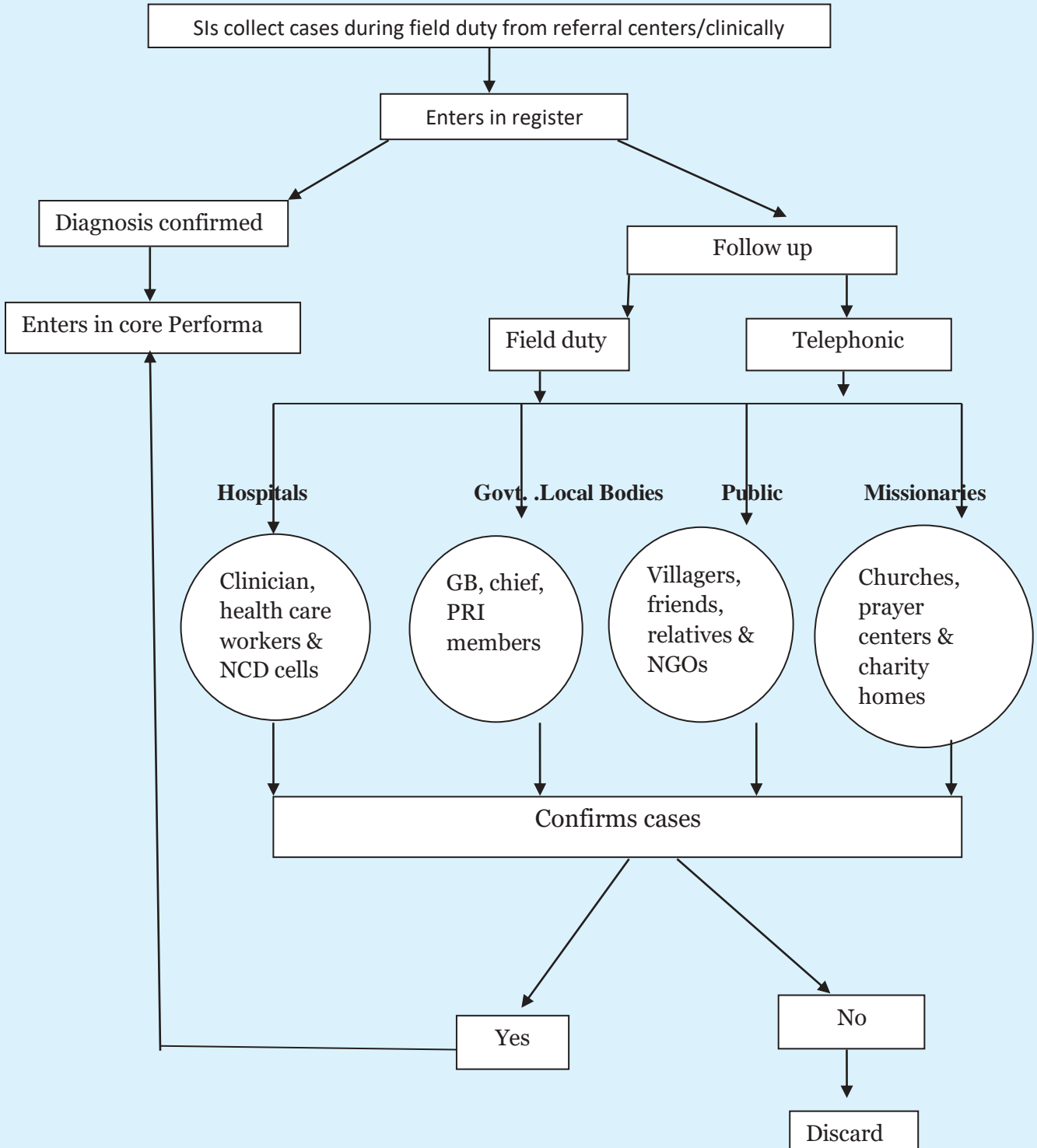


**Our Practices**

With high dependency on active data collection and field duty, we are experimenting and improving on various avenues to collect reliable data. We have added

four aspects very vital for inclusive data collection. Flow chart - 1 has been shown to give clarity of the aspects we have incorporated in our data collection.

**Flow Chart - 1**



In the chart, the encircled groups are the key informants that help us in completing data collection. These include:

1) In Hospital level, we keep constant touch with the clinicians, health care workers and Non-communicable disease (NCD) cells.

2) Govt. local bodies and Panchayat Raj Institution (PRI) members provide relevant information of their respective villages. It is not possible to visit the GBs (Goan Burah- local village head), Village Chiefs, ASMs (Ancal Samiti member) and GPMs (Gram Panchayat member) individually. So we contact them over phone twice in a year and meet some, when it is necessary. But some reliable members take initiative to contact us whenever there is any case known to them.

3) Villagers and NGOs are also great source of information. Friends, relatives and villagers of patients also share information and NGOs in Tirap District are also sensitized about PBCR and shares information of their respective project areas.

4) Christian missionary centers especially in the districts of Tirap, Longding and Changlang have been providing cases of terminally ill patient where the number of Christians is the maximum in the state.

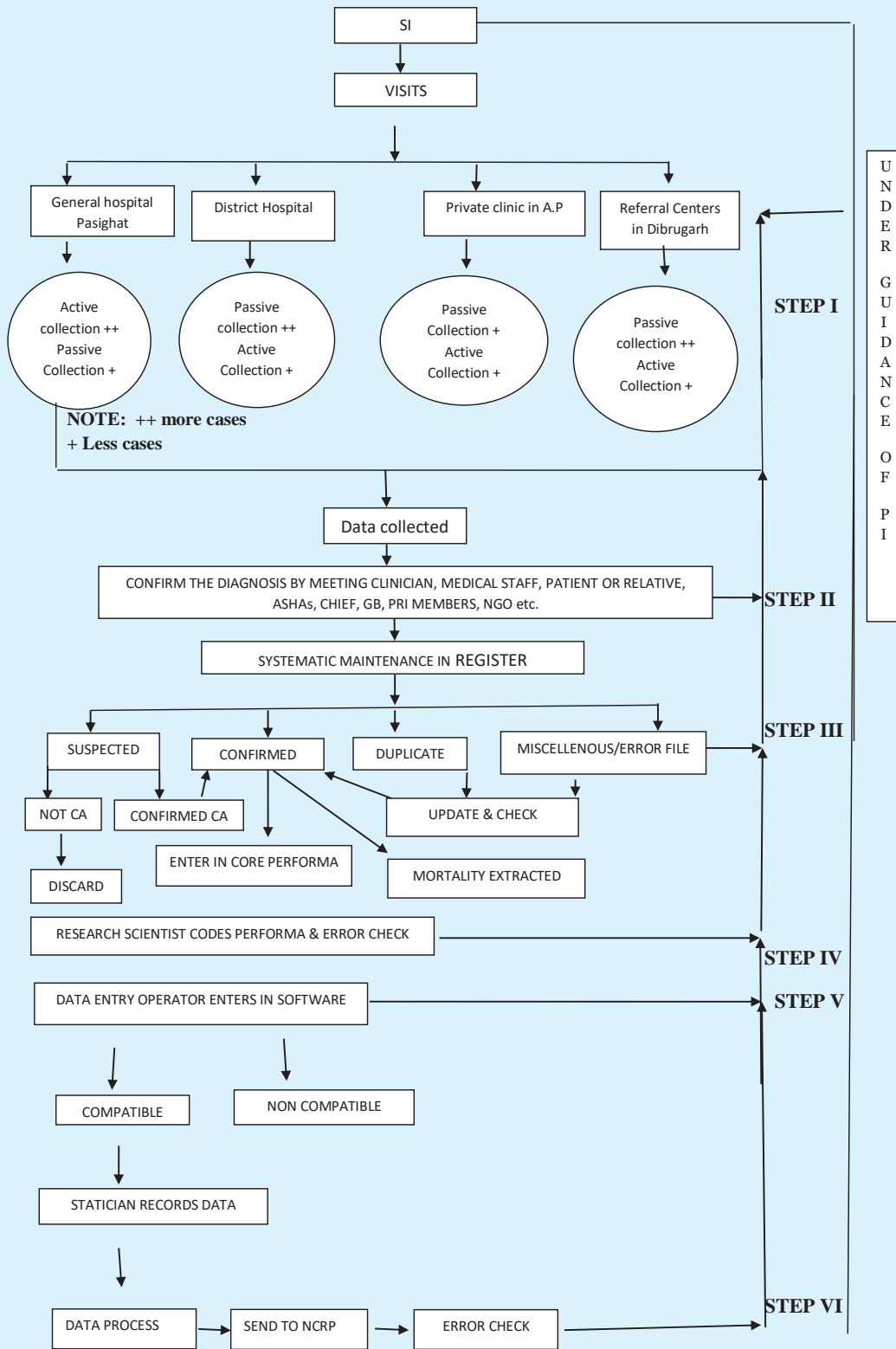
Effective communication with these four factors helps us in covering and maintaining quality data which adds to larger framework of our data which is explained in 6 steps in Flow chart - 2

Challenges	Strategies
<ul style="list-style-type: none"> <li>• Inadequate health care facilities within the state</li> <li>• No oncologists</li> <li>• Reluctance to share information and data by the patient parties and various institutions</li> <li>• Highly dependent on passive data collection</li> <li>• Duplicacy and incomplete data</li> <li>• Telephone may not be always available</li> <li>• Erratic electricity supply and internet failure</li> </ul>	<ul style="list-style-type: none"> <li>• Sensitizing as many clinicians, health workers, NGOs, PRIs and religious leaders and keep in constant touch with them</li> <li>• Coordination with NCD cells in districts</li> <li>• Contact phone numbers are taken for follow up of cases and maintain separate year-wise call back registers for easy follow-up</li> <li>• Build good rapport with patients and their relatives and meet concern clinician for further information</li> <li>• Systematic maintenance of file for follow-up of cases</li> <li>• Work during off hours as per availability of electricity and internet</li> <li>• Data is also maintained in excel file for office record</li> </ul>



Flow chart of data collection to ensure maximum and quality coverage in eastern Arunachal Pradesh

Flow Chart - 2



## Our Achievements

1. The basic in data extraction is proper registration which is not followed in many hospitals. Therefore, it is essential to persuade the concerned health centers for proper record maintenance and also to incorporate Registry requirements. As such, we are able to influence the staffs for proper maintenance of registers and extraction of the details required by us from the patients.
2. Awareness among the mass about cancer and factors that triggers, it is being sensitized with the help of health care workers, NGOs, PRI members, chief and GBs.
3. The State Govt. has declared cancer as 'Notifiable disease' since August 2015.
4. Acknowledging the increasing cancer burden in the state as a result of data coming out of the Cancer Registries, the state government has started a Tertiary Cancer Center at Tomo Riba Institute of Health and Medical Sciences, Naharlagun from April 2017 with the installation of a Tele Coblat External Beam Therapy unit.
5. Additionally, the state Government has started

the Chief Minister's Free Cancer Treatment scheme in collaboration with Tata Memorial Hospital Mumbai, under which cancer patients from the state get the commonly used chemo drugs for free, with a ceiling of Rs 10 Lakhs per patient per year.

### PBCR, Pasighat Staff

Dr. Kaling Jerang	:- Principal Investigator, Sr.Pathologist, BP General HospitalPasighat
Dr. G. Jongkey	:-Co-Principal Investigator
Dr. Kapang Yirang	:- Research Scientist
Mrs Moti Megu	:- Statistician
Ms, T.Miti Boko	:- Social Worker
Ms, Chanyam Lowang	:- Social Worker
Mr. Tayi Mize	:- Programmer
Mr. Kabom Perme	:- Data Entry Operator

### Field work at Tezu with Doctor.



**Sisters of Charity Home Tirap District**



**PRI Members & SHG Members of Bordumsa, Changlang District**



**Goan Burah- local village head with PBCR Staff.**



## District Cancer Registry, Thiruvananthapuram: Achievements and Challenges in Maintaining Data Quality

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**Preethi Sara George,**      **Paul Sebastian**  
**Kalavathy MC,**  
 Regional Cancer Centre, Thiruvananthapuram

### Introduction

Cancer registry covering Thiruvananthapuram Taluk has been included under the network of National Cancer Registry Programme (NCRP) of Indian Council of Medical Research (ICMR), Govt. of India since 2006. As Thiruvananthapuram being the state capital, a lot of requests are received regarding the cancer statistics of the district. On the basis of the revised project proposal, the Taluk registry has been expanded as District registry and has been included under the network of NCRP since 2012. The data collection system is active as the staff visit various hospitals, pathology laboratories in the district to collect data. NCDIR provided funding support for 14 cancer registrars for data abstraction and coding. These staff were trained through continued in-service training in cancer registration and they reviewed medical records from 75 potential data sources and 7 pathology laboratories at regular intervals and abstracted data on incident cancer cases.

### Achievements in maintaining quality data

To obtain a good coverage of cancer registration in Thiruvananthapuram, a meeting of health authorities of the sources of registration in the district was convened by Shri. Rajeev Sadanandan, IAS, Additional

Chief Secretary (ACS), Health & Family Welfare Department, Government of Kerala in November 2011. In continuation of this meeting, two administrative letters were provided by the ACS to all health authorities (sources of registration) in the district, requesting them to provide cancer patient information to the cancer registry, Thiruvananthapuram, functioning at RCC (D.O.No.398/HS/2011 dated 28-12-2011 & D.O No. 64/ACS/2016/ H&FWD dated 19-07-2016, Govt. of Kerala). Since then, information on cancer patients from all hospitals and pathology laboratories are being obtained with good co-operation.

As regards the mortality data, e-copy of death data of all cause from Thiruvananthapuram Corporation (urban), 72 vital statistics offices (rural) and the 4 municipalities (urban) were obtained since 2012. In Kerala, almost all deaths are registered in the vital statistics offices but information on cause of death is lacking. Because of this limitation, special efforts of matching incident cases with all-cause mortality data were made to improve the quality of mortality rates.

Strict quality control measures are maintained in the registry, coverage of the registry has been made as complete as possible. Data quality was measured through microscopic diagnosis (MD), death certificate

**Table 1. Quality Indicators and Completeness in Case-ascertainment (%) (2012-2014)**

#### District Cancer Registry, Thiruvananthapuram

Year	Incidence	MD	DCO	UP	FR	Case-ascertainment
2012	4848	81.4	9.2	0.6	37.4	20
2013	5157	81.1	8.6	0.5	36.6	15
2014	5641	82.2	8.7	0.4	34.8	13

only (DCO), fatality ratio (FR) (%) and the proportion of unknown primary (UP) sites. Further the case-ascertainment was measured using capture-re-capture method (Table 1).

### Availability of a Vehicle

In order to assess the follow-up and density mapping of cancer in Thiruvananthapuram using Geographic Information System (GIS), the New India Assurance Company Ltd. donated a vehicle (Maruti Suzuki EECO, 5 seater, KL-01- BY 5477) along with 10 Global Positioning System (GPS) instruments to the cancer registry. Mr. John Philip, Deputy General Manager, New India Assurance Company Ltd. handed over the vehicle to Dr. Paul Sebastian, Director, RCC.

#### Donation of Vehicle by the New India Assurance Company Ltd. to the Registry



### Meeting with Sources of Registration

A meeting was convened by the ACS, Health & Family Welfare Department, Government of Kerala, on 3<sup>rd</sup> August 2017, by inviting all health authorities in Thiruvananthapuram. A total of 55 health authorities participated in this meeting. The purpose of this meeting was to obtain continued co-operation and acknowledging all the contributors who provided data to the cancer registry. Dr. Paul Sebastian, Director, RCC, welcomed the invitees, Sri Rajeev Sadanandan, IAS, ACS, Health, Govt. of Kerala, presided, Dr. GK Rath, Chairman, Steering Committee, NCRP(ICMR) was the Guest of Honour and Dr. Prashant Mathur, Director of NCDIR was the Chief Guest, of the meeting. They addressed collaborators regarding the importance of their contribution of data for operating a good quality

cancer registry.

### Report publication

We published the Three-year (2012-2014) report of the Thiruvananthapuram Registry. This is the 1<sup>st</sup> report of the PBCR, Thiruvananthapuram district. This report was released by Sri Rajeev Sadanandan, IAS, ACS, Health, Govt. of Kerala and handed over to Dr. Prasanth Mathur, Director, NCDIR. Dr. Aleyamma Mathew, Professor of Cancer Epidemiology & Biostatistics, RCC presented highlights of the report. We provided the report to all who attended the meeting and our cancer registrars handed over the report to the respective hospitals who did not participate in the meeting.

#### Release of the PBCR, Thiruvananthapuram (2012-2014) Report



### State Cancer Registry- Proposal

We handed over a proposal for initiating the need for setting up a "State Cancer Registry" in Kerala to the ACS, Health, and Govt. of Kerala in the above meeting. The main aim of this programme is to provide high-quality cancer incidence and mortality data annually to the government so that effective policies for cancer control can be developed, implemented and evaluated. Further, the following news was published in The Times of India (Kochi) Sep 16 2017.

"State cancer registry plan gains momentum: The Kerala government plans to expedite its state cancer registry initiative for a better picture of the incidence and mortality rates. All hospitals in the state, treating cancer patients will come under a state cancer grid

for collecting the data and maintaining the registry, Additional Chief Secretary (Health) Rajeev Sadanandan said. The RCC had mooted the idea of a state registry in a proposal to the Health department for better understanding of the geographical distribution of the disease. At the moment, the RCC registry is used for state-wide projection of cancer incidence. We need a state-wide registry to get a better picture”.

### **Handing over the “Kerala Cancer Registry” Proposal by the RCC to the Govt. of Kerala**



### **Challenges**

Cancer incidence varies markedly because of the population heterogeneity in demographics and risk factors among states and also within each state in India. “Registry coverage with high-quality data remains well below 10% in Africa, Asia, and Latin America, and there is an urgent need to support the initiation, expansion, and development of registries in many low- and middle-income countries,” stresses Dr Roberto Zanetti, President of IACR, an organisation with member registries across all continents, and a close partner of IARC (Bray et al., 2014).

In India, a central coordination of cancer registration with large population is very essential. The existing online transmission of HBCR data from various parts of country to the NCDIR has many limitations. i) Unavailability in utilising cancer patient information for state cancer control activities ii) due to the heavy workload of health professionals many hospitals do not get enough time to do the HBCR data abstraction : iii) limitations in utilising the HBCR data for their own

services and research due to online data submission: iv) incompleteness in the coverage of area. Hence the presently existing PBCRs in India and the present online transmission of HBCR data from the various hospitals in all over the country may not help in obtaining completeness in the coverage of a national registry.

Other major challenges in a registry are in the recording of accurate information on place of residence (address) and pin code within the defined geographical area. Contact address of patients is usually incomplete, many patients may be unwilling to give specific and detailed address due to lack of understanding of the need for such information and in many instances, health facilities do not have organized, stored, and accessible medical records of their own. Multiple registrations (patient visit) in different hospitals (duplicates) are to be eliminated. Such problems can be solved to a great extent by the local cancer registry staff as they know the area, eliminating duplicates under a registry correctly and whether the patient should be included in the registry or not.

Next challenge is making cancer as a notifiable disease. In the present scenario, changing the cancer registry data collection system from active to passive by simply making cancer as a notifiable disease alone will not help in setting a nation-wide/ state-wide cancer registry. A Government regulation (an administrative order) for all facilities including private sector to report cancer cases in making cancer a registrable disease (thus empowering ‘cancer registrars’ access to institutional records) in contrast to being a notifiable disease (report the disease to government authorities as required by law) would increase the authority of cancer registrars and reduce the challenges encountered at health institutions.

Considering all the above challenges, one possible suggestion for a complete nation-wide cancer registration is to set-up a state registry initially. For this, i) identify a well experienced centre who is providing good quality data, as a state nodal centre ii) pool the available PBCR data from the respective state in

the state nodal centre in addition to the national submission of data iii) provide the data (obtained from various sources) by the national registry to the state-nodal centre and iv) expand the area of existing PBCRs in the various parts of the country to a large population in their respective state.

In Kerala, presently, RCC has an HBCR including more than 15,000 new cancer patient information annually functioning since 1982, two PBCRs covering the entire districts of Thiruvananthapuram and Kollam functioning under the NCDIR. These two PBCRs cover nearly 18% of the total population in Kerala. There are 30 staff having more than 10 years' experience in cancer registry operations. For setting up a "Kerala Cancer Registry", the existing registry staff can be utilised to a great extent.

In conclusion, setting-up a nation-wide cancer registry can be achieved step by step by expanding the existing registries to the respective state-wide registry. An offline HBCR program of NCDIR would help the state for setting up state-wide cancer registry and then to the national registry.

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End



## The Impact of Collecting and Streamlining Accurate Demographic Data at Reporting Institution/ Health Care Setting

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Vydehi Institute of Medical Sciences and Research Centre is situated in the technology capital of India, Whitefield, and Bangalore. It is one of the leading medical institutes providing education and health care services. A comprehensive range of general and super specialty medical services are provided. It is a 1680 bedded hospital offering 24 hours, seven days a week services. Departments like Emergency Medicine, Critical Care Unit, Blood bank, Central Diagnostic labs and Ambulance services work round the clock to attend to the growing needs of patients.

The department of Oncology was established in the year 2007, with full-fledged departments of Surgical, Radiation and Medical Oncology. The Hospital Based Cancer Registry was established in December 2012, but actual extraction of data for the year 2012 started from January 2013.

Vydehi Institute of Oncology is situated in the premises of the medical college. It is a 300 bedded dedicated institute having all the important specialties of Oncology namely Radiation, Surgical, Medical and Preventive and Palliative Oncology. The centre is well supported by the multispecialty units of the Medical College Hospital.

In February 2017, the Oncology Centre was renamed as Vydehi Oncology Institute & Centre of Excellence (VOICE) and a new radiation zone, a dedicated Oncology OPD-DKA block, state of the art paediatric oncology wing and a hybrid world class operation theatre complex were established.

Demographics are characteristics of a population. Patient's information collected during the registration

process on patient's demographic data such as name, age, gender, education, marital status, primary language/ ethnicity, residential address, telephone numbers and socioeconomic status become a part of the patient's medical record.

The cancer registry associated with hospitals like ours extracts the data of all cancer patients attending the centre in a pre-devised format and sends data to the technical wing of NCRP.

The first part of the core proforma namely the socio demographic details of the patients are entered at the time of registration. The second part namely diagnostic and treatment details are extracted later from the case records. The completed forms are scrutinized and coded as per International Classification of Diseases for Oncology- 3<sup>rd</sup> Edition and International Classification of Diseases for Oncology- 10<sup>th</sup> Edition, by a senior staff. Inputs from Surgical, Medical and Radiation Oncology faculty wherever necessary are taken.

The data from completed proformas are entered online and submitted to the technical wing of NCRP. The data is checked for validity and consistency by a software programme provided by NCRP.

The department has made an effort to have a separate MRD for oncology cases which are taken care of by dedicated MRD Clerk. Follow-up of patients is periodically done by personal telephone calls.

However, hospital faces challenges associated with collecting accurate data and using these data for quality improvement and reduction of disparities. One transposition of a patient's first or last name could



result in widely different versions and may give an entirely different experience of the healthcare system. This kind of error can cause delay in the process of cashless treatment approval provided by a Government scheme, funding or insurance, which in turn can lead to treatment delay or make them defaulters. Aadhaar card which is fast becoming a single identity for various cash benefits extended to general public, can overcome these issues.

Data describing the age, education, address, telephone numbers and socioeconomic characteristics are frequently inaccurate, incomplete and lack in detail. Sometimes, they are not collected at all. This may be due to the nature of the information itself. Information about an individual's socioeconomic status may be considered to be of sensitive nature, both by those collecting it and the individuals to whom it pertains.

Socioeconomic status gauges a person's relative economic and social position based on factors such as their education, income and occupation. Common indicators include postal code, because where a person resides is associated with income level. In a healthcare setting, insurance coverage can be a socioeconomic indicator. Accuracy increases dramatically when individuals are allowed to self-identify their economic status, rather than staff recording the information by observation or assumption.

Improvements in methods of communication have resulted in more and more of the population having telephones (including mobile phone). Recording the correct telephone numbers is essential for any clarifications, to follow-up the patient (to know the disease status) and also time and manpower saving, cost-effective and hence it is more economical. The purpose of collection explained to the patient during the time of registration improves response rate and also reduction of wrong phone numbers. Weekly follow-up of patients through phone calls has also helped in reduction of drop-out percentage. One peculiar issue faced by people who are associated with demographic data collection and follow up is that patients frequently

change their cell phone numbers, lose their phones, numbers given are that of friends or neighbours, thus contacting them is difficult. We feel making Aadhaar card details a must during registration of the patient might address this issue since the unique number is linked with a definite mobile number the patient is likely to maintain.

Communication gaps between medical members (or providers) and patients are often a source of medical errors and may lead to excessive testing. They can also result in delay of necessary care. Therefore streamlining data collection can help identify areas where trained and professional interpreter (or translator) services are needed.

Patients are more likely to share personal information when asked by respectful, knowledgeable staff and the hospital is better able to serve its patients when this information is collected for everyone in a consistent manner.

These data are essential for research (to find a common variable), analysis and implementation of initiatives that could reduce health care disparities. Therefore, it has to be ensured that the data collected should meet these needs. Similar to diagnosis and procedure coding, these data developed during the initial assessment or registration have many uses.

Through analyzing the data collected, it helps identify areas where specific groups are receiving less preventive care, especially screening. Therefore focus should be made on improving/ streamlining registration and information systems to capture more comprehensive demographic information about patients.

Stratifying average length of stay, admissions and re-admissions by patient demographics can help identify any trends associated with specific patient groups, which can be addressed to improve quality of care. Streamlined data collection helps in reduction of duplicates and helps to track inpatient and outpatient performance as well.

## Best Practices in Cancer Registration

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The data collection for Population Based Cancer Registries (PBCR) in India is an active one. The network of Hospital Based Cancer Registries (HBCR) under the National Cancer Registry Programme serves as major sources of cancer information for different PBCRs. In collecting cancer data from various sources like, laboratories, and private clinics and hospitals, the clinical data in most of time is incomplete or inadequate. Thus, this renders the PBCR data with missing information about site specificity, specific histology, staging information, and about the outcomes (survival). So, high quality data collection at HBCR is of great help for facilitating high quality PBCR data for generating useful incidence and mortality statistics, at least in the Indian context. The precise demographic and clinical data collected by HBCR can provide clues for epidemiological studies by PBCRs.

For undertaking population-based cancer survival studies the importance of registration of full date of birth has been highlighted [1]. In this regard, HBCR-Guwahati has been collecting full date of birth of cancer patients as and when available since May 2015. Accurate survival estimates are essential for monitoring cancer survival trends, for health care planning and for resource allocation. So, five to 10 years from now or in the near future, PBCRs receiving cancer data from HBCR-Guwahati can undertake population-based relative survival studies with better accuracy.

HBCR-Guwahati has linked cancer registry data with that of the Department of Cancer Epidemiology and Biostatistics at Dr. Bhubaneswar Borooah Cancer Institute (BBCI) to obtain information on tobacco consumption and family history of cancer. Thus, this

practice has now made it possible to analyze cancer registry data with that of tobacco and familial history of cancer patients.

For follow-up information on vital statuses, HBCR-Guwahati is employing mostly telephonic follow-up and clinical case sheet based follow-up. Despite these methods, many patients are lost to follow-up. Now, the administrative (death certification) and other health records of patients (insurance and official/departmental claims) are obtained from the Medical Records Section of BBCI to update the registry records. This has improved our follow-up for the ongoing pattern of care and survival studies.

Every year, HBCR-Guwahati sends the data of cancer patients registered from different PBCRs of the North East India on a timely manner without any delay. This helps these PBCRs to generate timely and reliable incidence data.

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# Bridging Quantitative Feasibility Impact-A Brief Discussion of Registry Works and Achievements

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## Background

The colourful kingdom, princely rule came to close due to the merger of the state with India on 15<sup>th</sup> October 1949. Then the princely state became a part of C state. The same democracy process continued up to 1971 and Tripura was granted statehood by an Act of Parliament on January 1972.

Cancer Hospital Agartala was established after eight years of statehood on 21.04.1980 with OPD service. Then in the year 1985 IPD service started with 50 bed capacity. The hospital was recognized as Regional Cancer Centre in March 2008.

Cancer Hospital Agartala had participated in the North East Cancer Atlas Programme of NCRP in January 2006 which later started a PBCR in the year 2009 after successful journey of five years of the Atlas Programme. a new programme of HBCR was started in the year 2015 with the aim of strategy constitution and region specific data creation in case of H&N, Cervix and Breast, cancers linked with an organized screening program.

## Preface

The primary purpose of this programme is to identify the most feasible technical solution for better patient care and follow up. As stated above, the orientation of a hospital based cancer registry is towards administrative and patient purposes and to provide information to assist public health officials for the planning and evaluation of cancer prevention and control programs.

Purposes of registries: Hospital Based Cancer Registries framework have the best possibility of improving patient's quality of life.

- Improvement of patient care
- Administrative information
- Clinical research
- Cancer prevention
- Cancer rates and trends' determination
- Early detection
- Pattern of care and outcomes
- Survival analysis
- Evaluation of control

## The registration process

The Regional Cancer Centre Registration process is little different from other general hospital registration. We have collected data directly from the out patient department in two ways, one is confirmed cases, another is non-confirmed. Microscopically diagnosed cases are registered as confirmed and suspected, clinical, biochemical and radiological diagnosed cases are registered as non-confirmed.

## Total patient registered in RCC, Agartala as below

Registration	2014	2015	2016
Confirmed cases	1892	1989	2132
Suspected cases registered	230	270	289
Total Patients	2122	2259	2421

## Data collection

The data collection process is systematic in that defining the objective, managing the data, and communicating the findings occur within established frameworks and in accordance with existing guidelines. The frameworks and guidelines provide more constructive idea for the programme. Thus, some of the data items collected by hospital registries will be different from those collected by a PBCR. The hospital based cancer registry serves and is organized to assist the patient and patient parties. Data are primarily stored in physical files and maintained for further evaluation. Social worker and registry staffs manage register, patient index and tumour record file.

## Improvement of patient care

Hospital based cancer registry's social workers are an integral and fundamental part of the registry and their work goes a long way to contribute to patient care. Their responsibility is to assist patients so that they can focus on their treatments. In the Regional Cancer Centre the Social Workers give supportive care and assist patients to identify and receive appropriate information, thus enabling increased compliance with treatment and preventing unnecessary hospital admissions. Social workers in hospital also provide counselling for anxiety and depression by explaining the diagnoses to friends and family for improving their quality of life. Social workers also inform the patient and the family about schemes under which they can get free medicines and get various pathological tests done through BPL card and RSBY facility. They educate patients and families to facilitate in the understanding of illness, locate resources, and identify options for available supports.

Social workers also provide an extra layer of support to the palliative patients by reducing hospital burden and help them experience the best possible quality of life by focusing on the whole body, mind and spirit.

## Problems and achievements

We have made full-fledged use of registry personnel to help recover those patients who are not willing to come for treatment in earlier stage. In the first year we had less knowledge of HBCR data collection since we were not trained about patient's data collection and keep up. One learns from their mistakes and we did the same. Gradually we started to identify our mistakes, find the missing links with the help of our PI & Co-PI doctors and senior staff of the PBCR for better service in the project and hospital services.

Our problems have become fewer when it comes to data collection. Sometimes we get patients from outside of the country like Bangladesh, Myanmar. It is difficult to follow up such patients because of lack of communication.

Another issue is that of uploading the data in real time, as we have entered data in retrospective manner from the time that the programme started. We are unable to do so but we intend to achieve real time data entry by the end of this year. It is recommended that every Hospital Based Cancer Registry reports its data annually to ICMR-NCDIR.

## Conclusion

Social workers help with a wide variety of issues and are a wealth of knowledge when it comes to the help of patients and their care given during treatment. Improving the quality of care requires useful measures of quality. Patient registration to follow up in order to improve quality of patient service is the main purpose of HBCR, Agartala.

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# REGISTRY DATA FOR HEALTH ACTION

# Enhancing Cancer Awareness and Early Detection in the Population of Solapur District of Maharashtra for Cancer Control

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1 Registry in - charge, 2 Co-Investigator

PBCR-Barshi, Nargis Dutt Memorial Cancer Hospital, Barshi

## Background - Cancer control

The objectives of National Cancer Registry Programme (NCRP), started in 1982 were to determine the patterns of cancer and mortality due to cancer. It was also felt that this would create a database for National Cancer Control Programme (NCCP) to assist in planning and monitoring and in addition it would have a positive impact on human resource development. When National Cancer Control Programme (NCCP) was launched in 1985, the mandate was to reduce the frequency and impact of cancer. It was aimed at primary and secondary prevention of cancers (for example, prevention of tobacco related cancers, early detection of carcinoma of uterine cervix and breast) and adequate treatment, rehabilitation and pain relief of affected victims. It is essential to have an ongoing registry to evaluate these objectives. Any control programme needs to be monitored to measure its effectiveness. The best way to evaluate and monitor such a programme is to start an ongoing Cancer Registry to provide data.

## Main Objectives

1. Cancer Awareness 2. Early Detection 3. Motivation for Cancer Treatment 4. Improve the Survival of patients

## Area Covered

Entire Solapur District (11 Tehsils including Barshi) of Maharashtra and total population as per censuses 2011 is 4,317,756 (male-2,227,852, female -2,089,904)

## Methodology

1. The district is subdivided into areas covered by the number of Primary Health Centres (Total PHC-77). It is intended to recruit some social workers and we should conduct Programme through ASHA workers. Each Social worker or ASHA worker will be responsible for certain PHC areas and ASHA workers will be responsible for their allotted population of 1000.
2. ASHA workers will do the household survey in the prescribed format and will collect information of symptomatic cases and refer them for detection at clinics.
3. The household survey will be monitored by the Nargis Dutt Memorial Cancer Hospital's Social workers and ASHA supervisors. We will pay some remuneration to ASHA workers and their supervisors from the budget.
4. We will conduct Awareness training programme (workshop) for ASHA workers at Tehsil headquarters.
5. Health education programme & cancer awareness programme will be arranged for PHC Health workers and Aanganwadi workers at PHC headquarters.
6. Every PHC will have a detection clinic. The symptomatic patient will be examined at the detection clinic. This clinic will function four to six days in every month.
7. Detection will be mainly for Cervix and Breast Cancer

in females and Oral Cancer in both males and females.

8. The suspected cases will be referred to Nargis Dutt Memorial Cancer Hospital, Barshi where the final diagnosis will be established and if required, treatment will be given to those diagnosed.

9. It is planned to hold workshops for Aanganwadi workers, PHC staff to enable them to spot early cancers during their routine home visits.

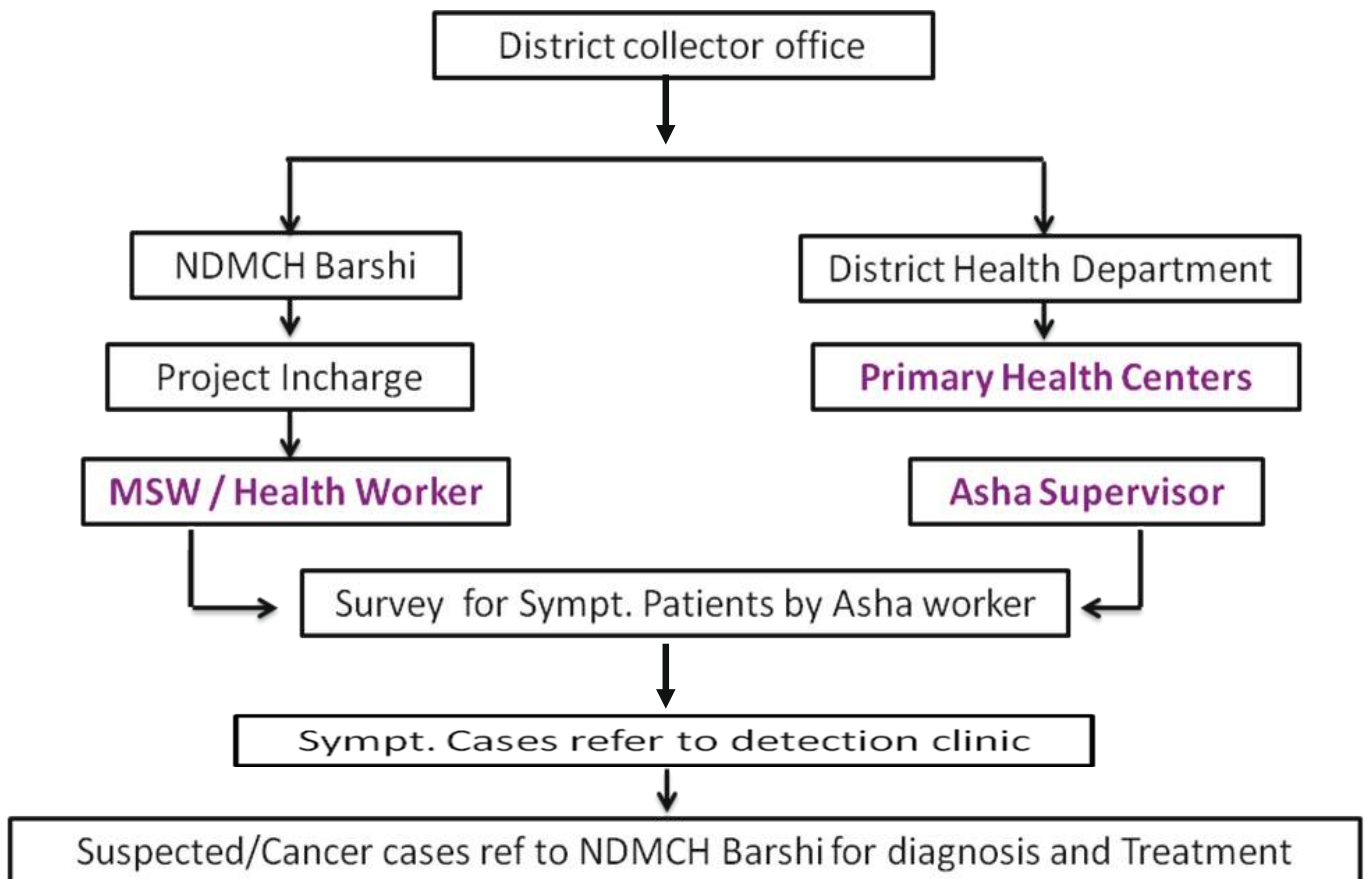
10. The patients and their attendants will be provided return bus ticket, food and free stay from the budget.

cases at the clinic and we will provide free treatment for them under RGJAY Scheme.

**Conclusion**

1. This Programme will assist the National Cancer Control Programme in planning and monitoring of Cancer prevention, early detection, cancer treatment and its control.

2. It will have a positive impact on human resource development to create cancer awareness in the community.



Treatment of Cancer Patients-Comprehensive cancer treatment will be given to all cancer patients from the project area at Nargis Dutt Memorial Cancer Hospital, Barshi under District Cancer Control Programme (DCCP) or Rajivgandhi Jeevodayee Arogya Yojana (RGJAY). Free Cancer treatment will be provided to the cancer patients who attend the clinic from the project area at NDMCH. There are also possibilities to attend known

3. This will improve the survival of cancer patients with quality life.

4. Huge number of population will be screened.

5. Creating awareness against cancer risk factors such as tobacco, alcohol, poor hygiene etc.

6. This will help to generate positive impacts on physical, mental, and social health.

7. It will save significant number of lives (Note –above project was funded by District Planning committee Solapur. Maharashtra state government programme started from June 2016)

**Provisional Result**  
**Provisional Progress Work Report (2016-17)**

Details	Work done
Total No. of Tehsil covered	10
Total No of villages covered For cancer awareness	1061
Total No. of PHC and RH	65
Total No. of Household survey done (by ASHA workers)	408108
Total Population covered	2040540
Total No. of ASHA workers contribution for survey	1836(2200)
Total No. of Training workshops for ASHA workers	17
Total No. of Cancer detection camps	65
Total No. of Screened patients	17145
Total No. of Cytology (Pap smear)	6604
Total No. of patient calls to Hospital for diagnosis and investigations	687
Total No. of Patients Attended at Hospital	490
Total No. of Known Cancer Cases Attended	312
Total New Cancer Cases Diagnosed (Clinical + Microscopic)	150
Total No. of Patients given preventive treatment	350



## Home Based Palliative Care Activity – A Successful Application in Tripura in Collaboration with Population Based Cancer Registry

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### Background

Tripura, is one of the small states of North Eastern Region with area of 10,491.69 sq.km covering 8 districts and has a population of 36,71,032 (Census 2011). Tripura Cancer Atlas was established by the NCRP in January, 2006, which expanded as Population Based Cancer Registry in the year 2009 and started collecting incidence and mortality data. Follow up is an important activity of the registry to estimate survival of cancers which is influenced by severity of the disease, efficacy of treatment, environmental effect and host factors like age, habit etc. Monitoring the survival over a period of time gives evidence on effectiveness of a particular preventive programme. Factors like ignorance, socio-economic constrains, poor death registration system, incomplete/incorrect certification of cause of death and inadequate medical records influence the quality of data collected.

PBCR Tripura, being located at Regional Cancer Centre, Agartala extended cooperation for identification of patients in establishing home based palliative care activity in Tripura in the later part of 2011. Home Based Palliative Care Services are designed to meet the needs of the patient in advanced stage of cancer at home with symptoms and distress. Services are intended to improve symptoms and quality of life, enable patients to stay at home and avoid unnecessary hospital admission. Through this follow-up activity of home based palliative care, the Population Based Cancer Registry was benefitted.

### Introduction

Palliative Care is defined by WHO as “An approach that improves the quality of life of patients and their families facing the problem(s) associated with life threatening illness through the prevention and relief of suffering by means of earlier identification and impeccable assessment and treatment of pain and other problems – physical, psychosocial and spiritual”.

The primary intent in the care of a dying patient is to relieve distressing symptoms and maximise the quality of life of patients.

The goal of palliative care is to achieve the best possible quality of life (Q.O.L.) for patients and their families and friends.

### Palliative care

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intents neither to hasten nor postpone death
- Integrates the psychological, emotional, spiritual and social aspects of care for the patients, the family and close carers (care givers).
- Offers a support system to help patient to live

actively as possible

- Uses a team approach to address the needs of patients and their care givers

It becomes evident that home & hospital inpatient palliative care services significantly improved patient outcome in the domain of pain, symptom control & anxiety and reduced needless hospital admissions. It is advised to offer home based palliative care to all patients with life threatening disease as early as possible.

One of the important outcomes in care of advanced stage cancer patients is the choice of dying at their preferred place, and majority of the patients preferred to die at home. Palliative home care services provide the patients good symptom control and improvement in quality of life.

With the active support and financial assistance of Pallium India, a Kerala based Non-Governmental Organisation, Home based palliative care programme was launched on 7<sup>th</sup> November, 2011. Initially the programme was for two years, and was extended for one more year. Finally, National Health Mission, Tripura took the responsibility and funded for palliative care throughout the state. Initially one palliative team was made available with proper training of doctors and nurses (care giver). In the year 2015, 10 teams comprising of Doctors, Nurses, Pharmacists and Social Workers were identified and trained for the purpose of home based palliative care.

## Objectives

To know the impact of home based palliative care service on symptom control in cancer patients identified by the registry, hospital admission burden and to assess survival pattern of cancer patient.

## Materials

The PBCR data for the year 2009 to 2014 are taken into account for understanding trends of cancer patients in

Tripura. Hospital records for the registered patients for the year 2012 & 2013, records of palliative care home visit and number of palliative patients, deaths records for the year 2012 & 2013 of Regional Cancer Centre, Agartala are also studied.

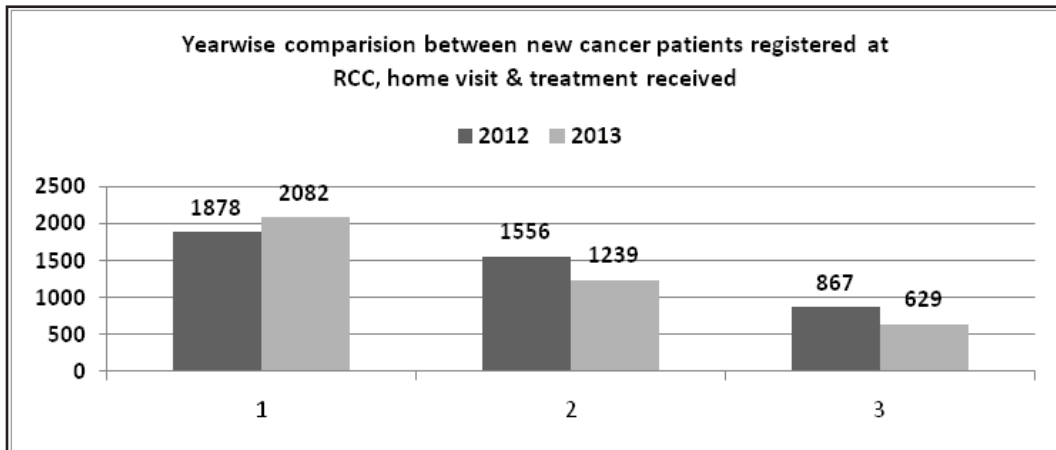
## Method

Study was done retrospectively with the available data of registered cancer patient under Population Based Cancer Registry, Tripura. Cancer patients who required home based palliative care were identified first, and then patients and their families were assessed at home and hospital. During the process, assessment of pain plays an important role. Pain is assessed through different rating system. Here Numerical Rating Scale (NRS) is used where zero means no pain and 10 means severe pain. Patient with score of 0-4 scale was considered as having mild pain, 4-7 was considered as moderate pain and 7-10 as severe pain. Appropriate prescribed measures were taken for symptom control of the patient. The family members or local care givers were trained by the palliative team for action like dressing, back care, oral hygiene etc. Where oral route was not possible, a subcutaneous line was given and family members were empowered to administer the same at home. Home care team also liaised with the local care givers for this purpose. Psychological support was provided for both patient and family through counselling which was initiated in the hospital and continued at home. Initially, one palliative team with trained doctors, nurses and other staff and one vehicle was employed for the purpose.

## Result

A total of 3960 new cancer cases were registered under Home Based Palliative Care Service during the year 2012 & 2013, out of which 1596 patients were visited with a total of 2795 home visits done during the year 2012 – 2013 (Fig-1).

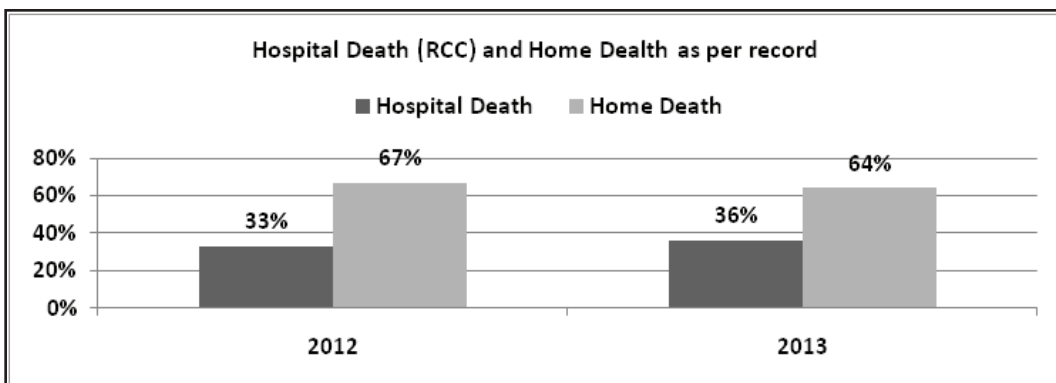
**Fig-1**



(1) No. of new cancer patients registered at RCC. (2) No. of Palliative care home visits. (3) No. of patients received treatment for Palliative Care.

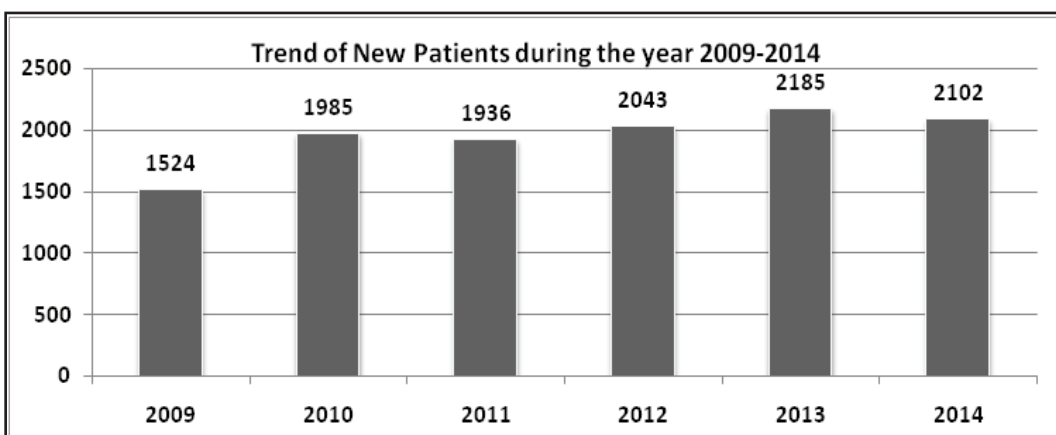
During this period a total of 1874 patient died due to cancer out of which 1228 number of patients died at home. Percentage of home and hospital death is shown in Fig-2.

**Fig-2**



Numbers of patients registered under PBCR, Tripura during the period 2009-2014 are shown in Fig-3 below.

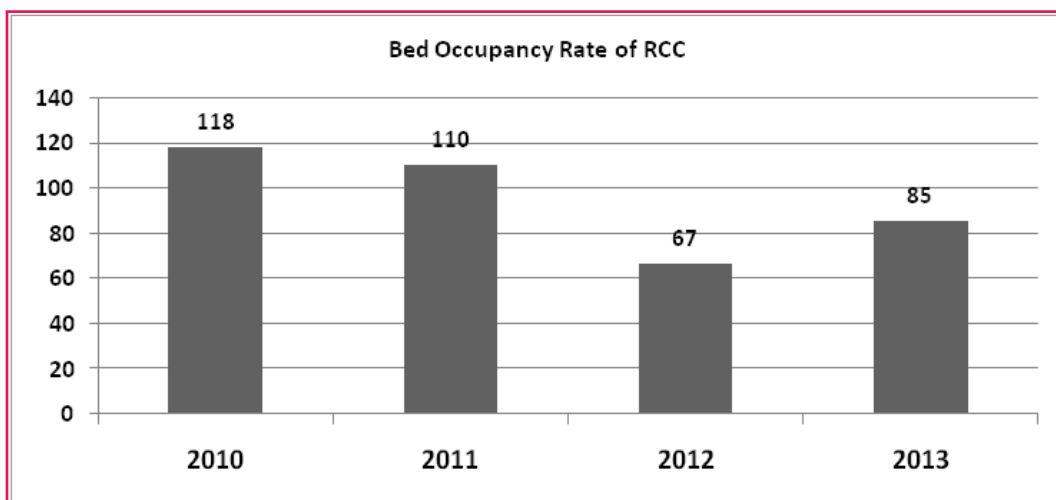
**Fig-3**



Availability of hospital bed is an administrative & social problem in our country. In Tripura, there is only one cancer hospital which is trying to provide tertiary cancer care with only 100 beds. Due to several factors most of the cancer patients in Tripura are diagnosed in advanced stage and thus treatment for all patients at cancer hospital becomes difficult. Any effort to reduce tertiary hospital burden will give opportunity of proper treatment to the admitted patients in a referral hospital like RCC.

Hospital bed occupancy rate of Regional Cancer Centre, Agartala as seen from the available hospital records shows that "Bed Occupancy Rate" of RCC was 67 & 85 during the year 2012 & 2013 respectively, in comparison to 118 & 110 during the year 2010 & 2011 respectively which is shown below in Fig-4.

**Fig-4**



**Fig -5**

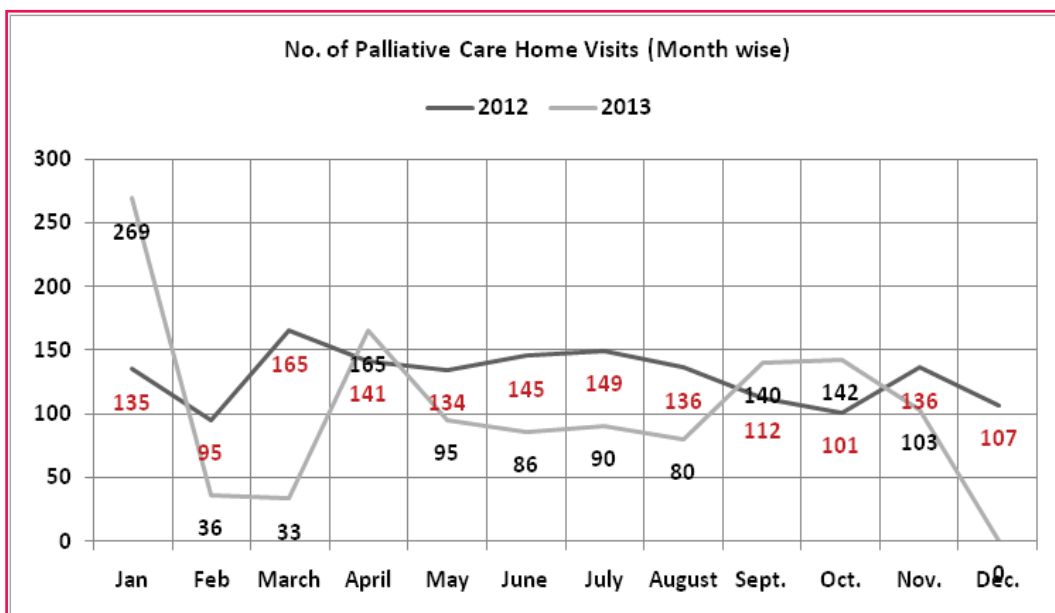


Fig-5 above shows month-wise number of palliative care home visits for the year 2012 & 2013. The graph shows maximum of 165 and minimum of 95 home visits done during the month of March and February respectively in the year 2012. It also shows maximum 269 visits during the month of January and minimum of 33 visits in the month of March in the year 2013. No home visits were done during December, 2013.

Fig-6

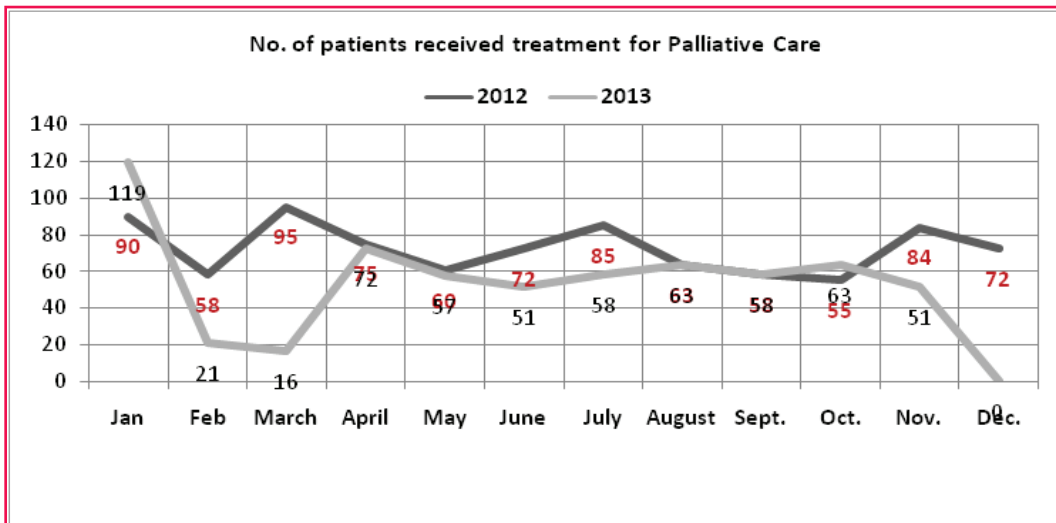
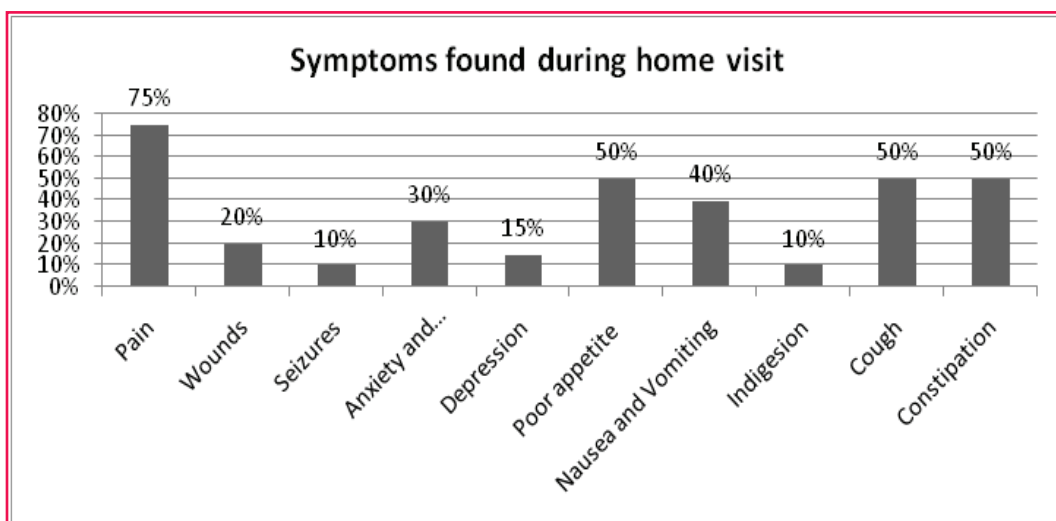


Fig-6 above shows number of patients received treatment for palliative care during the year 2012 & 2013. Maximum of 95 & 119 patients were benefitted during the month March, 2012 & January, 2013 respectively.

Patients were relieved from symptoms after visit by the palliative team. More than 70% of people with advance cancer experienced pain and was assessed by the Medical Officer for appropriate management with recommended analgesic like morphine. A total amount of 4100 mg and 9000 mg of morphine was used for cancer patients during the period of 2012 & 2013 respectively. Cough (50%), constipation (50%), loss of appetite (50%), nausea & vomiting (40%), anxiety (30%), depression (15%), seizures (10%) were other symptoms commonly detected by the palliative care team (Fig-7).

Fig-7



Follow-up of these patients was done for their symptom management mostly through telephonic call or directly visiting the patient and thus continuity of care, early reporting of symptoms was facilitated. A good rapport with the care givers was also established.

The visits helped family members to get over the fear of contagion of cancer, social stigma and their overall attitude towards the patient. Free medicine was provided by the palliative care team.

## Discussion

PBCR collects cancer incidence data primarily from different health institutions where diagnosis facilities are there. PBCR also collected data from home visit of long standing home bound or bed ridden patients. With these available data from the PBCR, palliative care team started their programme of home visits for the purpose of identification and palliative care, and continued follow-up programme, which also enriched the PBCR.

It is estimated nationally that 350 per lakh population are home bound and bed ridden who need care. In Tripura, one small survey conducted by the registry staff of PBCR in the year 2012 roughly identified 7000 bed ridden and home bound patients in the state out of which approximately 3000 were cancer patients.

Formulation of palliative care policy for the state is under consideration of the government and manpower training, drugs, and infrastructural availability will enrich the programme.

## Conclusion

India has 2.5 million people with cancer at any given time. There are one million new patients diagnosed with cancer every year. With recent advances in treatment, some of the cancers have a chronic course of disease. About 75-80% of these are diagnosed at an advanced stage. Patient with "incurable cancer" may now survive longer with palliative oncology

interventions. Due to all these reasons, palliative care is ideally required to be incorporated into comprehensive cancer care programs. Specialist home-based palliative care improved symptom control, health-related communication and psychological support. It promoted increased number of home-based deaths, appropriate and early hospice referral, and averted needless hospitalization. Thus, collaboration between PBCR and Home Based Palliative Care benefits each other mutually.

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## Thiruvananthapuram District Cancer Registry: Findings to Health Action

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Regional Cancer Centre, Thiruvananthapuram

### Introduction

Cancer registry statistics in Thiruvananthapuram district have shown that the crude incidence rates are 173 and 166 per 100,000 males and females respectively in 2014. About 50% of cancers among males and 60% among females occur in 35-64 year age group. The cancer incidence rates are 219 and 239 per 100,000 males and females respectively in this age group. Among females in the 35-64 year age group 43% of the cancers occur in breast, cervix uteri and oral cavity. Among males, about 26% of the cancers occur in lung and oral cavity. Other tobacco related cancers such as pharynx, larynx, oesophagus and urinary bladder account 14% among males and 2% among females in the district. These cancers are directly attributable to the use of tobacco (chewing, smoking) and alcohol consumption. The incidence rates of these cancers in 35-64 years are 60 and 9 per 100,000 for males and females respectively in Thiruvananthapuram district.

Considering the magnitude of the cancer problem in Thiruvananthapuram district, we translated the registry findings to health action by conducting cancer awareness and detection programmes. The detection programmes were focused mainly on breast, cervix and oral cavity in the age group of 35-64 years. The programmes were conducted by involving other governmental, non-governmental (NGO) and voluntary organisations. An overview and summary statistics the various programmes conducted during the past two years are provided in the subsequent sessions.

### Dissemination Efforts through Cancer Awareness

Cancer awareness programmes are primarily done by providing awareness to the community starting from the medical fraternity to common people. Nine Gram Panchayats in the district allotted funds for cancer awareness and detection programmes in their Panchayat area. Initially a one day training programme was arranged for medical officers and staff nurses of the Primary Health Centres (PHC) in the respective Panchayat area. The training module included information about common cancers among males and females, risk factors, early warning signals for these cancers, and steps for primary and secondary prevention. After this, an orientation programme was arranged for the Accredited Social Health Activists (ASHA) workers for conducting house to house visit and inviting symptomatic people to attend the prefixed cancer detection clinic in the PHC/Sub centre within the Panchayats. Self-explanatory leaflets on common cancers and self-breast examination were also distributed by these ASHA workers. In the period 2015-2017, 32 Medical Officers, 13 Staff Nurses, 22 Health Inspectors, 35 Junior Health Nurses and around 400 ASHA workers were trained in Thiruvananthapuram district.

Cancer awareness programmes were conducted in schools and colleges. Such programmes were conducted in 11 schools and 5 colleges, and about 1500 students participated. Awareness programmes were conducted for lay public also. A total of 101 programmes were conducted, in which around 11,000 people participated. NGOs also played an active role in

organising such awareness programmes.

## **Dissemination Efforts through Cancer Screening Programmes**

### **a) Hospital-based cervical cancer screening programmes**

We have been conducting, twice a week Pap smear screening clinic in Women & Children Hospital (W&C), Tycaudu, Trivandrum, an apex health care Government institution for women in the district since 2006. This hospital is 6 kms from RCC. All women reporting to the Gynaecology outpatient department are being referred for the routine Pap smear by the attending Gynaecologist. Gynaecology patients from other major Government hospitals in the district and nearby districts are also referred to clinic. The entire infrastructure that is needed like a separate room, assisting manpower, autoclaving facilities, conveyance to RCC with the samples etc. are provided by the W&C hospital. Women referred for Pap smear are being interviewed based on a questionnaire for collecting details on socio-demographic and reproductive factors. The women are then subjected for Pap smear after obtaining a written consent. Initially a per-speculum examination of the cervix is done using spot light. The method used for screening is traditional Pap smear. Each woman is given a unique ID number and this number is noted in the patient's details, Pap smear and also in the ID card given to the patient. The following week results of the Pap smear were issued to patients. The collected samples were taken to RCC Epidemiology division where the data was recorded. Samples were processed in the Pathology division of RCC and slides were reported there.

A similar Pap-smear clinic has been conducted by the RCC once in a month in the government hospital, Peroorkkada, Thiruvananthapuram, which is 7 kms from RCC. This hospital also provided the entire infrastructure for conducting Pap-smear clinic. All the samples were taken to RCC for processing and reading and reporting of the slides. The reports were distributed back to the women regularly.

Based on the above programmes we published a paper entitled "Squamous Cell Abnormalities and Risk Factors on 10,979 Pap-Smears in a Tertiary Care Hospital in Trivandrum, South India". The study aimed at assessing squamous abnormalities using Pap-smear and risk factors among women who visited the above W & C, tertiary care hospital for gynaecological problems during 2010-2015. Among these, atypical squamous cells of unspecified significance were 2.9%, low grade squamous intra-epithelial lesions, high-grade squamous intra-epithelial lesions (HSIL)/cancers were 1.6%. The odds ratio (OR) for developing HSIL/cancers among women with higher education was 0.20 (CI: 0.07-0.58) compared to women with no education. Women with age at marriage >30 years had OR of 0.23 (CI: 0.08-0.66) for developing HSIL/cancer compared to women with age at marriage <20 years. Women with unhealthy cervix had OR of 3.16 (CI: 1.80-5.54) for having HSIL/cancer compared to women with normal cervix. In conclusion, Pap-smear clinics would help to detect women in pre-malignant conditions and also has a greater role in the diagnosis of inflammatory lesions (Kalavathy et al., 2016)".

During the past two years (2015-2017), we screened a total of 2816 women and detected 112 women with Atypical Squamous Cells of Undetermined Significance (ASCUS), 11 women with LSIL (Low grade Squamous Intraepithelial Lesion) and 24 with HSIL (High-grade Squamous Intraepithelial Lesion).

### **b) Community-based screening programme**

Cancer screening programmes were conducted in 9 Grama Panchayats in the district. In these places initially an awareness programme on common cancers, their causes and early detection methods was conducted for the local PHC doctor, Health Inspectors, Junior health inspectors and other paramedical staff with special emphasis to the ASHA workers. The Panchayat area is divided into 3 or 4 zones and date and venue for cancer detection clinics are announced when we conduct the awareness classes. ASHA workers are the key persons in motivating the general public by doing



house to house survey. They also take the responsibility of bringing, men with smoking or chewing habits, and any other specific complaints, and also women with complaints in the breast, discharge PV, itching vulva, and irregular bleeding to the clinic. On the day of clinic, RCC team visit the place and examine the people. All women attending the clinic are subjected for physical examination of breasts by a Medical Officer. Women are interviewed for collecting basic socioeconomic details and Pap smear is collected. A unique ID number is provided here also. Males and females are being screened for common cancers like Oral cavity, Breast, and Uterine cervix. Women with any suspicious lump in the breast are advised Mammogram and FNAC as the case may be. Women with suspicious breast cancer are referred to RCC and are being investigated there. During 2016-2017, a total of 44 programmes were conducted in Trivandrum, 1992 women and 602 men were screened, 5 breast and 4 oral cancers were diagnosed, and 822 Pap smears collected, 6 cervical pre-cancers and 2 cervical cancers were detected. Other than the Thiruvananthapuram district we conducted a total of 5, 4, 16 and 9 cancer detection programmes in Idukki, Kottayam, Kollam and Pathanamthitta districts respectively, screened 2213 people, detected 6 breast, 5 oral, 7 cervical pre-cancers and 2 cervical cancers.

### **Follow Up Strategy for Suspicious Cases**

Women with precancerous changes of cervix are requested to come for a repeat Pap smear (both in hospital and outreach programmes). If the repeat smear shows ASCUS, patient will be advised to repeat smear after six months. There is an active follow-up system which invites these women after 6 months. Women with LSIL in repeat smear are directed for a colposcopy and biopsy if indicated. If the biopsy report also favours LSIL, then she is referred for LEEP excision etc. If the repeat Pap smear is showing HSIL changes, then the patient is referred for immediate colposcopy and biopsy and further steps are decided after biopsy. Such women are referred to Gynaecologic oncologist.

People presenting with suspicious swelling anywhere in the body are subjected for Fine Needle Aspiration Cytology (FNAC) either from the clinic site or in RCC. If the FNAC result comes out as positive for malignancy, then the patient are referred for further investigation and treatment. Serum markers like PSA (Prostate Specific Antigen) for Prostate malignancy, CEA (Carcino Embryonic Antigen) for large intestinal malignancies, Ca 125 for ovarian malignancies, etc. are also advised and results are reviewed the next week. Ultra sound scanning of abdomen, pelvis, prostate, breast and thyroid etc. are also being carried out for when there is an indication. Women falling in the category of high risk for breast cancer are advised mammogram. Women with suspicious lumps in the breast are subjected for FNAC, Ultrasound or Mammogram as the case may be. FNAC slides are reported by experienced Cytotechnologist and Pathologist in RCC. Thiruvananthapuram Corporation provided financial support for cancer related investigations and treatment for patients with poor financial background under their cancer patient support scheme.

### **Reference**

Kalavathy MC, Mathew A, Sujathan K, Saritha VN, Krishna JKM, Jayasree K (2016). Squamous Cell Abnormalities and Risk Factors on 10,979 Pap-Smears in a Tertiary Care Hospital in Trivandrum, South India. *International Journal of Science and Research (IJSR)* ISSN (Online): 2319-7064.

## A Novel Concept of Community Involved Cancer Registry Model Through Local Self Government Level by a Tertiary Cancer Centre in Northern Kerala

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### Introduction

Cancer is emerging as a leading cause of mortality and morbidity in India. It is an important public health problem with 8 to 9 lakh cases occurring every year. At any point of time, it is estimated that there are nearly 25 lakh cases in the country and every year about 4 lakh deaths occur due to cancer. Breast cancer, cervical cancer and oral cancer are the three most common cancers in India in terms of incidence and mortality. Cancers namely those of oral and lungs in males, and cervix and breast in females account for over 50% of all cancer deaths in India. Together, they account for about 34% of more than 1 million individuals being diagnosed with cancer each year in India.

There is no authenticated 100% cancer data on incidence/mortality of any particular defined region available through screening populations. Though the conventional methods of data collection of a Cancer Registry, sources like Government/Private hospitals, Medical colleges, Laboratories, Palliative Centres & Department of Vital statistics & economics are considered the gold standard, there may be limitations in its completeness.

During the development of Malabar PBCR, the difficulties faced through conventional methods like poor documentation, preservation of files of medical records in hospitals and lacking documentation of correct site of cancer, has made PBCR team to think of an alternative method of data collection at other points using community involvement. These include the involvement of Local self-government bodies for

awareness and using their mechanisms to collect data of cancer cases by house to house visits, incidence/mortality data on co-morbidities and life style related factors on food/addictions etc.

### Main aims are

1. To create community participatory avenues at local self-government level for cancer registration on a long term basis with the support of a tertiary cancer centre.
2. To develop a replicable and adoptable role model in every local self-government level to achieve 100% cancer notification on incidence/ mortality cases from 2014.
3. To create awareness and education on cancer among public representatives and house visitors so that fight against cancer may get another dimension at the grass root level.

### This initiative was implemented with following objectives

1. To empower every local self-government in the registration of cancer incidence/mortality.
2. To facilitate a model for the policy stakeholders so as to adopt it successfully.
3. To reduce manpower of field staff from tertiary cancer centre.

4. To utilize the feasible software & social media for sharing of data & views.

This project was implemented at the local self-government level with the technical support of Department of Cancer Registry & Epidemiology and Division of Health & Information Technology of Malabar Cancer Centre (MCC).

In order to set up a community involved cancer registry for recording information on cancer cases (incidence/mortality, co-morbidity & lifestyle) of a particular block/panchayat/district, a software was developed by the Health Information & Technology division. Software was installed at nodal points. House to house visits were made using a prescribed proforma. User manual was provided by the MCC defining each variable in the questionnaire. Health Inspectors were given training in general cancer registration & questionnaire with user manuals at local self-government level of the project for fruitful data collection. The concerned officer of the local self-government was responsible for the implementation of the project. They played a leadership role in formation of the resource centers. Potential resource centers were Primary Health Care/Community Health Care (PHC/CHC), Taluk Hospital, and Palliative care centers. A project co-ordination team was created, comprising of Medical officer as the implementation officer, Accredited Social Health Activist (ASHA) workers, Palliative Nurse, Anganwadi and health care workers. A validated questionnaire in English and Malayalam was provided by the MCC. A WhatsApp group was created with the Director, MCC, Cancer registry head, Presidents of Block Panchayat, Medical officers, and all team members, and the progress was regularly updated. Utilization of social media to provide a platform for various discussions, clarifications, monitoring & upgradation of the project was facilitated.

The data on the project was generated at the community level and the same was analyzed in MCC. Data entry was done by Health Inspectors after verification by the implementing officers

and sent to Principal Investigators for approval. All discrepancies in data entry were resolved by communicating with the implementing officer when needed. This finalized database was secure and was used for statistical analysis using SPSS software.

An approval from the Institutional Review Board was obtained for conducting this project. While names of patients will be referred to compare data across registers, the data abstraction form will not contain the name or any other personal identifiers. Since the source data is routinely collected for programme purposes as per national guidelines by the local self-government and involves patient/bystander interaction, informed consent is deemed unnecessary. The protocol including the chart abstraction form was submitted to the Ethical committee of MCC and an ethical clearance was obtained.

Study results was communicated through the reports and presentations to the local self-government at the local meetings. The first project of community involved cancer registry was launched in Nileschwaram block panchayat in Kasaragod district in 2016 under name of "ATHIJEEVANAM". The first report was released dated 16/04/2017, at a public function by the Health Minister, MP, MLA, Director, MCC. This project was well appreciated by the Government.

### **Expected outcome**

- Creation of community participatory avenues at local self-government level for cancer registration & control on a long term basis with the support of a tertiary cancer centre.
- Developing a replicable and adoptable model in every local self-government level to achieve a near 100% cancer notification of incidence/ mortality cases in the state.
- This data could facilitate further epidemiological studies, in turn helping the local self-government

in the fight against cancer over a period of time.

- Expected to improve cancer awareness among public and healthcare workers.

This model may enable patient follow-up through their lifetime, facilitate better outcome & survival data, and maintain data standardization, consistency & quality involving the Local self-government.

End

## Risk factors related to specific sites of Cancer

Risk Factors	Cancer sites
Tobacco	Oral, Lung, Pharynx, Oesophagus, Bladder, Hypopharynx, Stomach etc
Infection	Cervix, Liver, Stomach, Nasopharynx, Lymphoma, Kaposi Sarcoma etc
Alcohol	Breast, Colorectal, Oesophagus, Stomach, Liver, Pancreas etc
Dietary Factors (high fat) and obesity	Breast, Colorectal, Ovary, Prostate, Endometrium, Liver Pancreas etc
Environmental Pollutants and Contaminants	Lung, Skin, Larynx, Nasal Cavity, Leukaemia, Liver, Kidney, Prostate, Bladder etc

## Level of Evidence for Dietary Risk Factors

Level of evidence	Decrease risk	Increase risk
Convincing	Physical activity	Overweight and obesity Alcohol Chinese-style salted fish Some mycotoxins (aflatoxin)
Probable	Fruit and vegetables Physical activity	Preserved meat and red meat Salt preserved foods & salt Very hot food and drinks
Insufficient	Fibre, soya, fish, n-3 fatty acids, carotenoids, vitamins B <sub>2</sub> , B <sub>6</sub> , folate, B <sub>12</sub> , C, D, E, calcium, zinc, selenium, non-nutrient plant constituents	Animal fats, heterocyclic amines, polycyclic aromatic hydrocarbons, nitrosamines

## Descriptive Study of Oral Cancer from Vidarbha Region: Initiatives to Reduce the Incidences

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HBCR, Rashtrasant Tukdoji Regional Cancer Hospital, Nagpur (MH)

### Introduction

Rashtrasant Tukdoji Regional Cancer Hospital (RST RCH) is a recognized 'Tertiary Care Centre' for cancer treatment and 'Regional Cancer Hospital' by Ministry of Health & Family Welfare, Govt. of India. It is situated at the heart of the country, in the 'city of oranges', Nagpur. RST RCH serves patients from the catchment area of around 500 kilometers in perimeter viz. Vidarbha, Marathawada, Madhya Pradesh, Andhra Pradesh, Telangana, and Chhattisgarh. The hospital is equipped with latest treatment modalities in Head & Neck Surgical Oncology, Surgical Oncology, Radiation Oncology, Medical Oncology, Gynec Oncology, Pain and Palliation. RST RCH is serving more than 5000 new patients and 35000 old patients each year.

The Hospital Based Cancer Registry (HBCR) project was started at RST RCH in the year 2012 under the network of Indian Council of Medical Research (ICMR). Presently, the staff working with HBCR include a research scientist, a statistician, three social workers and 3 data entry operators.

Mostly patients are from low economic strata and to serve such a huge numbers within an affordable cost, the Rashtrasant Tukdoji Regional Cancer Hospital runs various Government schemes as listed:

- 1) Prime Minister Fund
- 2) HMCPF (Health Minister's Cancer Patient Fund)
- 3) Chief Minister Fund
- 4) Mahatma Jyotiba Phule Jan Arogya Yojana (cashless

facility to BPL patients, scheme run by Govt. of Maharashtra)

- 5) 50% concession for poor and needy persons under charity

The hospital also conducts two courses like Maharashtra State Board of Technical Education (MSBTE), Mumbai and Nursing Training centre

### Scenario of Oral Cancer prevalence in Vidarbha

Cancer is one the threatening cause of death in adults. The prevalence of oral cancer in India especially in Vidarbha region is high due to use of tobacco and tobacco related products such as Kharra, Jarda Masala, Smoking bidi and cigarettes. The cases of oral cancers reported in Vidarbha are extremely alarming as widespread population of Vidarbha region is mostly addicted to use of tobacco and tobacco related products. We have noted that young age is no more a barrier to oral cancer. It is evident that even school going children are falling prey to this deadly monster of tobacco consumption. Nowadays, we are observing an increase of oral cancer in younger age group of 25 to 40 years, which constitutes the productive age group of the society. The World Health Organization (WHO) has denoted Nagpur, as a world capital for oral cancer.

According to the data from the regional cancer registry of RSTRCH, more than one third of the cancer patients registered for the year 2014 suffered from Oral Cancer. Oral Cancer is among the leading cancers in Vidarbha and also accounts for 42% of Vidarbha's cancer burden.

Although, India's National Cancer Control Programme was launched in 1975- 1976, large scale implementation of cancer prevention and control strategies are yet to occur and public expenditures on cancer prevention remain low. The National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) strongly supports the prevention, early diagnosis and treatment policies. Sadly, Nagpur district doesn't have the NPCDCS programme for an effective data collection of cancer prevalence, thus affecting the government to take any steps on corrective measures.

### **Awareness among the Masses**

RST RCH felt urgent need for creating awareness among the masses about the wide spread incidences of different types of cancer. The focus is on preventable oral cancers which are related to tobacco use. The problem lies with, unrestricted availability of tobacco related products in cities and villages in Vidarbha. It is evident that even school going children are habitual tobacco users and most of them are developing 'Oral Sub mucous Fibrosis' by the age of 15 years. Oral sub mucous fibrosis is an alarming sign to the tobacco user to quit the habit.

### **Health Talks**

RST RCH aims at creating awareness about hazards of using tobacco related products through various activities. It includes, health talks at schools, colleges, institutions, associations and various organizations against the use of tobacco related products, self-examination of breast, and also identifying early signs and symptoms suggestive of cervical cancer.

### **Celebrating various cancer days**

RST RCH celebrates special cancer days, months for mass awareness about particular type of cancer viz. World Head & Neck Cancer Day, World No Tobacco Day, National Breast Cancer Awareness Month. Various reputed speakers from concerned specialty are invited

for health talk. They organize poster competitions, exhibitions depicting preventive measures and hazards of particular type of cancer. The street plays are organized by college students for the common people. On such special occasions, the RST RCH also organizes rally or form long human chain with posters and slogans for mass awareness.

### **Cancer Screening Camps**

RST RCH conducts cancer screening camps across Vidarbha region in collaboration with government agencies, Public Health department in coordination of Deputy Director (Public Health Department), District Civil Surgeon, and District Health Officer at Primary Health Centre, Rural Hospital, Sub District Hospital and District Hospital. The ASHA workers and MPW's are involved in successful screening of patients by motivating suspected cases to get screened at the camp by expert team of RST RCH. RST RCH team goes with all preparation required for PAP smear collection, oral scraping and if possible Fine Needle Aspiration Cytology (FNAC). Biopsies. All the samples collected are reported to the concerned medical officer and ASHA worker if report comes positive, the suspected cases are called at the RST RCH for further screening and diagnosis. All attempts are made to minimize financial burden of patients referred through camps. Patient's lodging; boarding and food arrangements are made by RST RCH during his/her stay.

RST RCH has adopted a village named 'Patansawangi' recently and has arranged multiple cancer screening camps in this and adjoining small villages. The suspected cases shall be taken under complete care right from his transportation, food, diagnostic expenses, treatment and further follow up.

### **Orientation of Medical Officers, Nurses, ASHA Workers and MPW**

To enhance the grass root level screening at Primary Health Centre, Rural and Sub District Hospital, the RST RCH has started orientation of Medical Officers, Nurses,

ASHA(Accredited Social Health Activists) workers and MPW about basic screening of patients and how to suspect a case of cancer. They are made to orient about oral cavity cancer, breast cancer, and cervical cancer.

In addition to it, the RST RCH is planning to start a fellowship program for a 1 month duration for Medical officers working in a government set up. The medical officers shall be provided hands on training on taking FNAC, scrape cytology, Biopsies, and Pap smear. They will be rotated in each department including Medical Oncology.

As these programs are running successfully, the RST RCH has received a request from State Public Health Department to provide hands on training to General Physician and Sister in- charges, ICU staff of district hospital on Medical Oncology. The aim behind this request is to start chemotherapy services at each district hospital under the guidance of RST RCH so that patients can avail chemotherapy at his/her own district hospital.

The RST RCH emphasizes on reaching to the key unit of Health department, who visit each house of the village i.e. ASHA worker. In future, the RST RCH is planning to strengthen the awareness and screening through ASHA workers. The ASHA workers shall be trained at each district headquarters, they are provided with all study materials, training on suspecting a case of cancer and a survey form. The survey report will be collected and each family will be brought under line listing so as each suspected patient of cancer can be traced and

his/her follow up for diagnosis, treatment can be taken.

### Orientation of Allied Medical Specialties

The RST RCH conducts orientation training of fellow colleagues of allied medical specialties such as Ayurveda, Homeopathy and Dental Surgeons. As a general practitioner, patients report to them for underlying symptoms of cancer, so the general practitioners are oriented about identification on a suspected case of cancer and further referral of such patients to the cancer hospital at the earliest.

### Nurturing Future Doctors, Nurses and Social Workers

The RST RCH is nurturing the students of all medical sciences and allied medical specialties on orientation of cancers. The post graduate students of ENT, Dentistry are enrolled for a month long fellowship program in Head & Neck cancer Department under supervision of consultant surgeon. The students of Ayurveda, Homeopathy, Nursing and Social Work are regularly invited for attending orientation sessions, CME's on different types of cancer. The RST RCH feels early orientation about cancer in budding stage will help them to fasten the process of identifying and referring suspected cancer patient to cancer hospital, as after few years, these students will start their carrier as Doctor, Nurse and Social Worker.

## Summary of Reports of Tobacco Related Cancers at RST RCH for the Year 2012, 2013 & 2014.

### Oral Cancer In Males And Females

**Table 1: Tobacco Related Cancer Patients at RST for the Year 2012**

Total malignant patients=2870, Male=1386, Female=1484

Sites Of Tobacco Related Cancer		Males		Females		Total	
		No	%	No	%	No	%
Oral Cavity	Lip	11	0.8	1	0.1	12	0.42
	Tongue	116	8.4	36	2.4	152	5.30
	Mouth	261	18.8	101	6.8	362	12.61
	Lung	123	8.9	41	2.8	164	5.71
Tobacco related Cancer		804	58	305	20.6	1109	38.6

**Table 2: Tobacco Related Cancer Patients at RST for the Year 2013**

Total malignant patients=2989, Male=1503, Female=1486

Sites of Tobacco Related Cancer		Males		Females		Total	
		No	%	No	%	No	%
Oral Cavity	Lip	16	1.1	8	0.5	24	0.80
	Tongue	161	10.7	56	3.8	217	7.26
	Mouth	336	22.4	118	7.9	454	15.19
	Lung	123	8.2	42	2.8	165	5.52
Tobacco related Cancer		892	59	316	21	1208	40.41

**Table 3: Tobacco Related Cancer Patients at RST for the Year 2014**

Total malignant patients=3086, Male=1532, Female=1554

ICD 10	Site Name(TRC)	Males		Female		Total	
		No	%	No	%	No	%
Oral Cavity	Lip	7	0.46	2	0.13	9	0.29
	Tongue	173	11.29	50	3.22	223	7.23
	Mouth	419	27.35	126	8.11	545	17.66
	Lung etc.	136	8.88	37	2.38	173	5.61
Tobacco related Cancer		989	64.56	316	20.33	1305	42.29

### Leading Sites of Cancer in Vidarbha

Oral Cancers (32.2) were the leading sites of cancer among males and females in Vidarbha. Among females, cancer of Breast (15.56%) was the leading site followed by cancer of cervix. Ref. (Cervical cancer is the only one definitively caused by tobacco use, according to the 2004 Surgeon General's Report on the Health Consequences of Smoking). However, breast and colorectal cancers have also been associated with tobacco use in some evaluations.

Type of Cancer/Year	2012	%	2013	%	2014	%
Oral(Male & Female)	632	22.02	776	25.96	769	24.90
Breast	359	12.51	439	14.69	426	13.80
Cervix	370	12.89	326	10.91	343	11.11



## Delivering High Quality Cancer Care in Public Sector Health Institute for Accessible and Affordable Cancer Care

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The Regional Cancer Centre (RCC), Raipur is located in Dr. Bhimrao Ambedkar Memorial Hospital run by the Pt. Jawaharlal Nehru Medical College. RCC, Raipur has been part of 'Hospital Based Cancer Registry' (HBCR) since 2011 with grant from National Cancer Registry Programme of ICMR. We started uploading on-line data from year 2012. We became part of patterns of care and survival studies (POCSS) in year 2014. We recruited registry staff comprising of social workers and data entry operators who are contributing in reliable data generation in the year 2015. HBCR staff is appointed for data collection, verification and coding according to ICD-10 but they also assist patients for accessing and pursuing treatment and help consultants in proper management of treatment by offering assistance in various situations, apart from their sole work of data collection.

In RCC, Raipur we are offering high quality treatment for cancer patients through our department of Radiotherapy, department of Onco-surgery, department of Pathology, Radiation physics and Pain and palliative care. We serve cancer patients from all the corners of the state of Chhattisgarh and nearby regions of neighboring states. Most of our patients belong to socially and economically backward background. In RCC they are able to access treatment under one roof depending on the stage and type of cancer. Our pathology department provides reports of blood tests, cytology, histopathology, IHC in minimum time required. It decreases burden of residential stay on patients who complete their course of chemotherapy on OPD basis. Earlier we were dependant on the pathology department of medical college for reports of

biopsy. Now our own pathology department provides all the crucial details required for better management of disease.

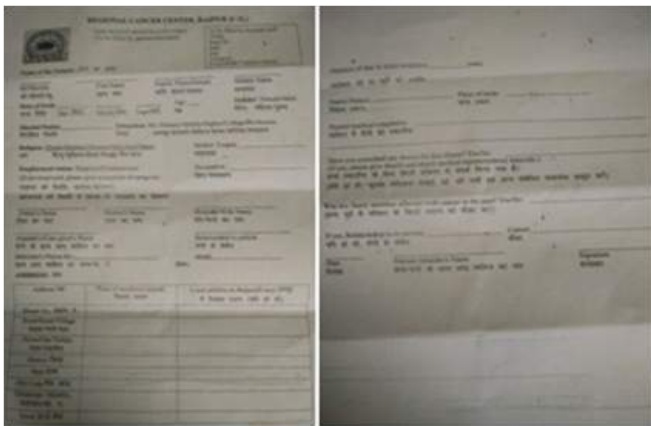
In radiotherapy department we have one cobalt machine, two linear accelerator machine, one HDR brachytherapy machine, one CT stimulator machine for planning and treatment of different types of cancer. Chemotherapy is also given to patients depending on clinical stage of patient with complete adherence to universal protocol. Choice of treatment is done according to need of the patient but we also try to ensure that information of treatment planned is provided to patient and care givers for inform and conscious choices for clinical decisions. During treatment of cancer through chemotherapy and radiotherapy, patients are referred to pain clinic for pain management. We are authorized to provide morphine tablets to patients suffering from pain. In palliative patients when no role of active treatment is identified they are also handled by palliative and pain clinic to lessen the suffering of patients due to pain.

Since initiation of POCSS project in RCC, Raipur we have made several changes in our data collection techniques. We encourage care givers to fill one form to get first hand information on the day of registration (fig.1 Adapted from WIA). This provides us data related to patient identity, demographic and epidemiological data. We are also collecting Aadhaar card number of all the patients essential for inter-institute linkage, tacking and prevention of duplication of data. The remaining data as per ICMR core proforma are abstracted from the medical records. We have also modified our case

sheet and folder of file which records and illustrates important details in one glance. In case ticket we have separate column which records and highlights multiple morbidity of patient. It also records performance status of patients on the day of registration which helps us to monitor recovery of patient in follow up visits.

Folders of our file are also divided in four types as H&N, Breast, Cervix and other cancers. All the folders record and provide glance at topography and morphology code, TNM and stage of respective patient, report of hormonal tests and tumor markers (fig. 2). In follow up our consultants also record disease status on the file. This helps to manage patient treatment during rush hour as PD status patients are attended with priority. We also record on file if patient belongs to particularly vulnerable tribal group (PVTG's). PVTG's are provided free treatment at all stages with priority.

**Figure 1**



On radiation card we also record important details and parameters such as specific tissue diagnosis and stage, including relevant biomarkers, initial treatment plan and proposed duration, isocentric verification on treatment machine, assessment during radiotherapy according to CTC version 3.0 for expected common and rare toxicities during treatment and their management. It facilitates better communication with our technical staff and helps them to perform precisely. It also helps us to identify if any problems persist and corrective action can be taken immediately which may also include modification or change in treatment plan.

We are able to offer free treatment to more than 95%

of our patients due to wide health insurance coverage by central government as well as state government insurance scheme. We are also providing form with estimates for accessing benefits of Sanjivani scheme which is Chief Minister financial assistance scheme for patients suffering from chronic diseases. With this financial aid we are able to provide chemotherapy and hormonal treatment with required drugs which are not supplied by the state government.

Along with this our HBCR registry staff contributes for putting patient at the centre of treatment. They do counseling of patients regarding effects and side effects of cancer treatment planned, for addiction withdrawal and maintaining hygiene, advise for healthy diet along with other do's and don'ts during treatment. It has played vital role in increases pursuance of treatment by the patient. HBCR staff also follow-ups over phone for drop out patients. We do age-wise and disease-wise categorization of drop out patients and make phone calls to families of children and old patients with priority.

**Figure 2**

Earlier we have noted increase of 6-8% rise in registration of cancer patients. In year 2016 we have registered 4831 patients which is 23% increase compared to previous years 3929 patients' registration. It is culmination of our better inter-departmental collaboration over past few years and increase in all the facilities required for treatment of cancer under one roof. With all our collaborative efforts we have been

able to motivate patients from all strata of society to trust and access health facility at public sector health institute. It has definitely lessened financial burden of many families.

Our HBCR staff has also conducted two studies on the basis of data gathered, one on incidence of buccal

mucosa cancers in the young patients aged below 25 years and another on incidence of lung cancer in smoking and non smoking patients. Still we are conducting the study and will try to publish it in coming year with acknowledgement to NCDIR.

End

### Common symptoms or signs of Cancer



# RESEARCH BASED ON REGISTRY DATA

## Impact of Cancer Registry Data in Research Activities and Health Policy

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In Assam, the incidence of cancer has been known to be high. But till 2001 there was a paucity of scientific data in this regard. In the year 2001-02, from the Cancer Atlas project under ICMR an overall estimate of incidence, pattern and associated risk factors of cancer in the country was obtained for the first time in a scientific manner. Understanding the magnitude of the problem, ICMR in 2003, decided to establish six "Population based Cancer Registries" in North East India. PBCR-Silchar Town was one of them. In 2007, the PBCR-Silchar Town was expanded to PBCR- Cachar district covering the entire population of Cachar district of Assam. Since beginning the PBCR- Cachar district has been systematically collecting data on cancer in Cachar district. The registry data are published by the PBCR annually and NCDIR at periodical intervals. From the available data of the registry, it has been possible to get an overall estimate of the magnitude of the problem of cancer in the district of Cachar as well as the state of Assam. In the PBCR-Cachar district, the five most common sites of cancers are Esophagus, Hypo-pharynx, Lung, Mouth, and Larynx in male and Breast, Uterine cervix, gall bladder, Esophagus and Ovary in the female. About 46.2% cancers in male and 20.6% cancer in the female are associated with tobacco use. The Age Adjusted Rate of cancer in the district is 125.4 in male and 95.2 in female (2012-14 data). The data generated by the registry have a great impact in research activities in various fields of cancer. It also significantly influences the process of formulation of the action plan by the health authorities of the state.

### Research Activities

Realizing the role of tobacco use in the causation of cancer in north east India and the wide spread use

of pesticide in the cultivation fields of the region, the following multicenter research projects were undertaken under ICMR during the period of 2005 to 2011.

1. Cancer in North East India - Understanding the role of tobacco
2. Cancer in North East India- Understanding the role of pesticides

The PBCR Cachar district actively participated in the above mentioned projects along with other registries of North East India, IOP New Delhi, ICPO New Delhi, NIOH Ahmedabad and RMRC, Dibrugarh. As cancer of esophagus and stomach are prevalent in this region, a research project entitled "Pattern of survival and quality of life of the patients of cancer esophagus and stomach in North East India" was undertaken by RMRC, Dibrugarh in which PBCR- Cachar is one of the participants. The project has started in the year 2013. Recently ICMR has sanctioned research projects on survival studies of common cancers of this region. The PBCR- Cachar is going to start work in these survival studies soon. At Silchar Medical College it has been observed that the post graduate students of various clinical disciplines have been taking up more and more research topics on common cancers of this geographical region for their mandatory thesis work and regularly taking help of the PBCR data for this purpose. During last three years about 12 thesis topics on cancer stomach, breast, uterine cervix and oral cavity were selected by the post graduate students. Few examples of these research topics during the period from 2014-16 are mentioned below:

3. Study of expression of E-Cadherin and Vimentin in oral squamous cell carcinoma at Silchar Medical

College Hospital.

4. Study of Ki-67 expression in invasive ductal carcinoma and its correlation with Nottingham modification of Bloom- Richardson grading system.
5. Histo-pathological study of gastric carcinoma with special reference to Her2/Neu and Ki-67 expression
6. Study of neo-adjuvant therapy in cancer of breast patients treated at Silchar Medical College, Silchar
7. A clinic- pathological study and surgical management of carcinoma stomach at Silchar Medical College, Silchar
8. A clinic-pathological study of squamous cell carcinoma of the lower gingivobuccal complex with special reference to its management with surgery and irradiation and irradiation alone.

The Multi-disciplinary Research Unit (MRU) under Department of Health Research, has been established at Silchar Medical College, Silchar. It has started functioning from the year 2015. The PBCR- Cachar data is helping the researchers of the MRU to select some of their research projects on common cancers of this region. The PBCR-Cachar district and the MRU are located on the same campus of Silchar Medical College, Silchar, Assam. It is hoped that in coming years the PBCR-Cachar and the MRU at Silchar Medical College, Silchar shall work hand in hand to bring out the best possible translational outcomes of the PBCR data.

## Health Policy

The PBCR data are also helping the health authorities of the state in the formulation of strategies for prevention, control and setting up treatment and diagnostic facilities. The Registry data have shown that in Assam about 50 percent cancers in male and about 23 percent cancers in females is associated with tobacco consumption in all forms. In 2014, an Act has been passed in Assam Legislative Assembly prohibiting manufacture, trade and consumption of all kinds of smokeless tobacco in the state. It is hoped that in future similar steps will also be taken in case of smoking tobacco. This initiative will go a long way in

prevention and control of cancer in Assam as a whole.

As it has been already established from the registry data that cancer is a major health concern in Assam, the government has taken many steps for providing affordable diagnostic and treatment facilities for the cancer patients. It has been a regular observation by the registry that many patients from Assam go to cancer hospitals outside the state to avail quality treatment. In a bid to offer quality and also affordable treatment to the patients of the state, this year a 200 bedded state-of-the-art cancer hospital has started functioning at Guwahati Medical College, Guwahati. Recently the government of Assam has signed a MOU with Tata Trust, Mumbai for establishing a cancer grid in the state. Under this plan, state-of-the-art Oncology unit will be established in all existing and upcoming medical colleges of the state. The government of Assam will provide infrastructure and manpower while Tata Trust will assist in training personnel for cancer care and provide necessary technology. Under this partnership the trust will not only work in the curative aspect of the disease but will also help to create awareness among the people, guiding at risk population to get screened and following up with diagnosed patients to ensure that they receive the required treatment. The Cancer Hospital at Guwahati Medical College, Guwahati and Dr. B. Borooah Cancer hospital shall continue to act as the tertiary cancer care centre in the state while the proposed Oncology centers at the medical colleges shall provide cancer care in the periphery. With these efforts, it will be possible to bring cancer care and detection facilities to the community level in the state.

Cancer registration is a continuous activity. The PBCR will continue to provide information about the incidence, pattern and trend with time of the disease in the community. These inputs shall be of immense value in making the future action plan to reduce the menace of the disease in the state. Utilizing the PBCR data as a platform, more research work can be undertaken in the future, in different aspects of cancer relevant to the PBCR area and the state of Assam.

## Changing Common Cancer Incidence Pattern Among Young Adults in Chennai – A Case for Investment in Primary Prevention

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### Background

Cancer registries are the nucleus of cancer control aimed at reducing morbidity and mortality through record-based surveillance. A snapshot will reveal the burden and its impact on the society.

### Objective

This is a descriptive epidemiological study on cancer incidence trend among young adults (YA) in the age group of 15-39 years between the period 1982-86 and 2012-2014 in Madras Metropolitan Tumour Registry (MMTR), a population Based Cancer Registry, Chennai, Tamil Nadu.

### Methods

Case-finding was carried out predominantly by active methods from a variety of data sources including cancer and other hospitals, pathology labs, imaging centres, other support services and vital statistics division in and around Chennai city.

### Results

The average annual new cancer burden in Chennai for all ages combined during 2012-14 was 5,990, of which, the young adult age-group comprised 10.5% (Males-4.7%; Females-5.9%). The corresponding figures for YA during 1982-86 were 16.6% (Men-6.0%; Women-10.6%). Contrasting trend in CIR (Cancer Incidence Rate) between YA men and women was observed: CIR among YA men has risen from 19.1 per 100,000 in 1982-86 to 27.3 per 100,000 in 2012-14 while the corresponding figures for women were 25.8 and 33.0 respectively (Fig. 1). A sub-group analysis of YA

as 15-29 years and 30-39 years revealed the following: Among YA men, the average annual increase was 1.5% among those aged 15-29 and 2.3% among those aged 30-39 (Fig. 2).

**Fig.1: Changing common cancer pattern in young adult men and women Chennai, 1982-86 vs. 2012-14**

Age Group (15-39)				
	Male			Female
Lymphoma	3.0	1982-86	Cervix	9.8
Stomach	1.8		Breast	4.2
Leukemias	1.6		Ovary	1.6
Brain & Ns	1.6		Stomach	1.1
Mouth	0.9		Leukemias	0.9
All Sites	19.1		All Sites	25.8
<hr/>				
Mouth	3.6	2012-14	Breast	9.8
Tongue	3.5		Cervix	2.7
Leukemias	3.2		Ovary	2.6
Lymphomas	2.6		Lymphomas	2.5
Brain & Ns	2.3		Leukemias	2.4
All Sites	27.3		All Sites	33.0

**Fig. 2: Changing common cancer pattern in sub-groups of young adult men Chennai, 1982-86 vs. 2012-14**

Age Group (15-39) Male				
Lymphoma	3.1	1982-86	Stomach	4.0
Leukemias	1.7		Lymphoma	3.0
Brain & Ns	1.3		Brain & Ns	2.4
Bone	0.9		Mouth	2.3
Connective & STS	0.8		Leukemias	1.5
All Sites	13.1		All Sites	31.0
<hr/>				
Leukemias	2.7	2012-14	Mouth	9.9
Tongue	2.2		Tongue	9.8
Mouth	2.2		Leukemias	3.6
Lymphomas	2.0		Brain & Ns	3.1
Brain & Ns	1.6		Stomach	2.8
All Sites	19.0		All Sites	52.8

Among YA women, no change was forthcoming in 15-29 years while the decrease in CIR was 1% per annum among 30-39 years (Fig. 3). The common cancer pattern showed variation both among YA men and women (Table 1). This is explained by the changing common cancer pattern in sub-groups of YA men (Fig. 2) and women (Fig. 3) viz. 15-29 years and 30-39 years of age. The commonest cancer in both age groups among YA men and women were different in 2012-14 compared to 1982-86. The CIR of lymphoma and

leukemia together had either remained the same or shown minimal increase among both sub-groups of YA men in the two time periods. But it is the emergence of mouth and tongue cancers within the top 5 in and the rise in their CIR among both sub-groups of YA men in 2012-14 compared to 1982-86 that is very significant: 10.7% in 15-29 years and 14.9% in 30-39 years of age. On the other hand, mouth cancer that was ranked within top 5 among YA women in 1982-86 was not found within top 5 in 2012-14 among YA women and in any sub-group (Fig. 3).

**Fig. 3: Changing common cancer pattern in sub-groups of young adult women Chennai, 1982-86 vs. 2012-14**

Age Group (15-29) Female		Age Group (30-39) Female		
Cervix	2.5	1982-86	Cervix	37.2
Breast	1.8		Breast	15.2
Lymphomas	1.3		Ovary	4.4
Ovary	1.2		Stomach	3.7
Leukemias	1.1		Mouth	2.6
All Sites	14.9		All Sites	84.9
<hr/>				
Leukemias	2.2	2012-14	Breast	21.9
Ovary	1.9		Cervix	6.4
Breast	1.8		Ovary	4.3
Lymphomas	1.5		Leukemias	2.7
Thyroid	1.3		Thyroid	2.7
All Sites	14.9		All Sites	60.4

**Table 1: Common cancer pattern of young adult (15-39 years) Chennai, 1982-1986 vs. 2012-14**

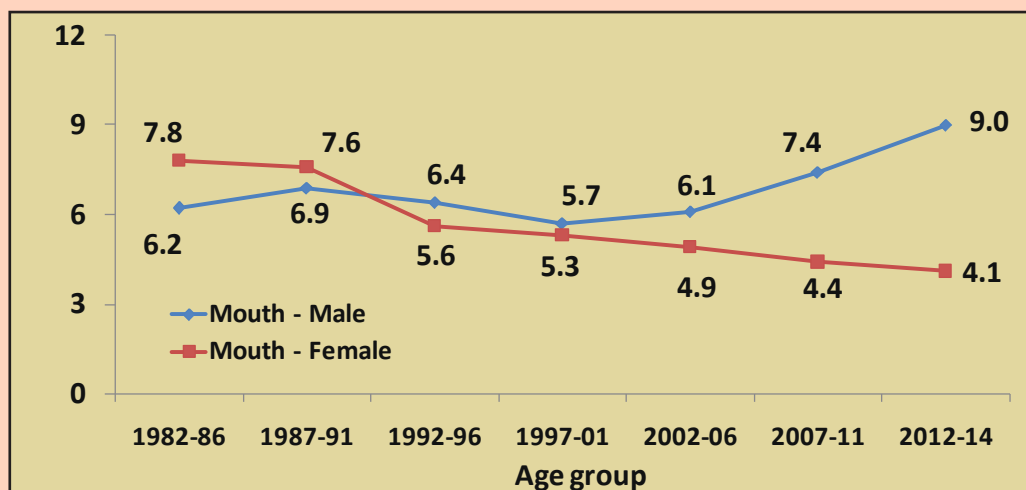
MMTR, Period: 1982-86 Cases: 2169			Male : 779 Female: 1390		
P Site	Male		Female		
	CIR	ASR	P Site	CIR	ASR
Lymphomas	3.0	3.0	Cervix	13.1	13.9
Stomach	1.8	1.8	Breast	5.9	6.2
Leukaemias	1.6	1.6	Ovary	2.2	2.3
Brain N. S	1.6	1.6	Stomach	1.5	1.5
Mouth	0.9	0.9	Lymphomas	1.3	1.3
All sites	19.1	19.0	All sites	36.2	37.8



MMTR, Period: 2012-2014		Male : 847			
Cases: 1902		Female: 1055			
P Site	Male		Female		
	CIR	ASR	P Site	CIR	ASR
Mouth	3.6	3.0	Breast	9.8	8.1
Toungue	3.5	2.9	Ovary	2.9	2.8
Leukemias	3.3	3.2	Cervix	2.7	2.2
Lymphomas	2.6	2.7	Lymphomas	2.5	1.5
Brain	2.3	2.0	Leukemias	2.3	2.3
All sites	27.3	24.0	All sites	33.0	29.4

Mouth cancer incidence in Chennai, for all ages together, has shown opposite trends among men and women. Mouth cancer incidence, that was higher in women than men until year 1991, has shown a steady decline among women till date. There was not much of a change among men until 2003 before showing a sharp rise in recent period (Fig. 4). The rise in CIR among YA men (Fig. 5) and the fall in CIR among YA women (Fig. 5) in 2012-14 compared to 1982-86 were particularly significant.

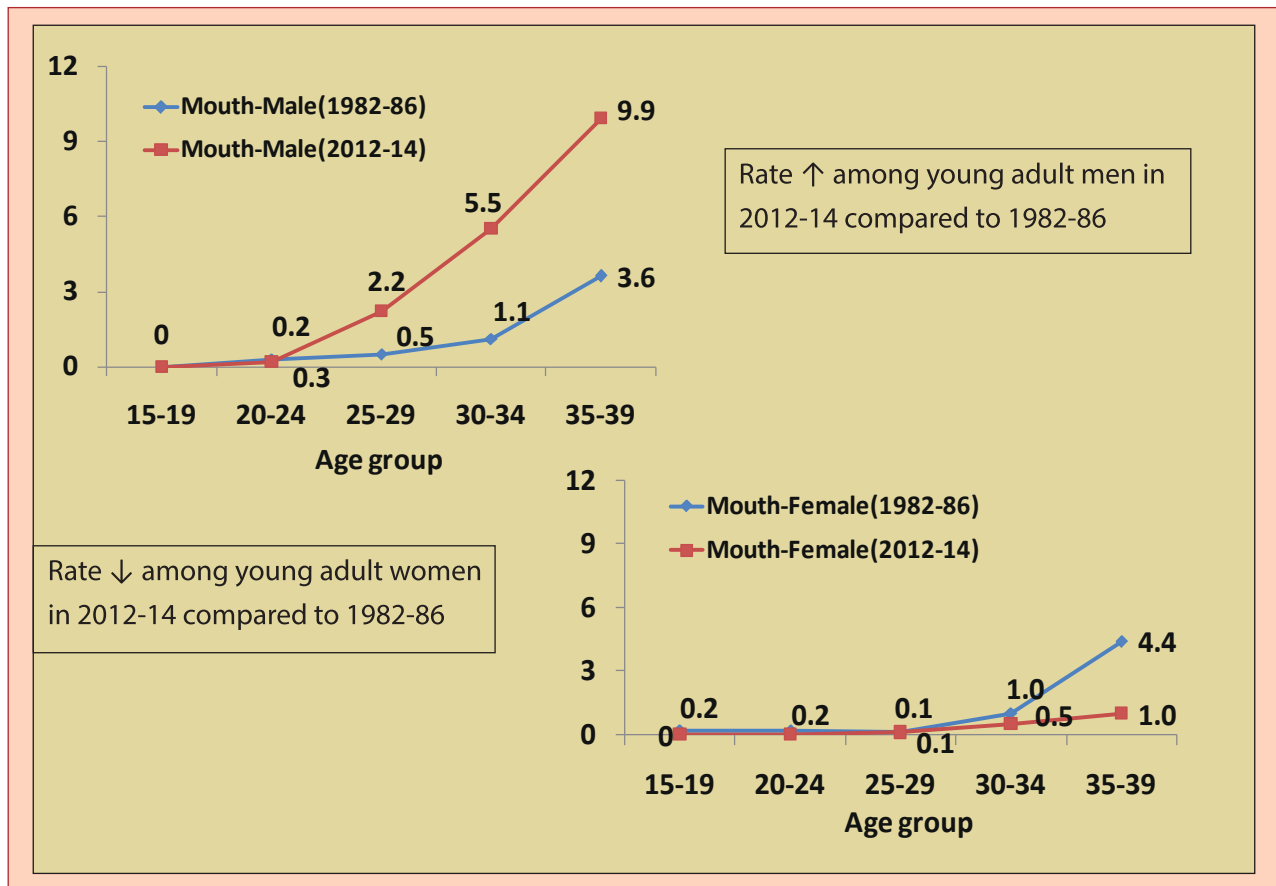
**Fig. 4: Trend of CIR by sex of mouth cancer, All ages together, Chennai, 1982-2014**



Mouth cancer (all ages together)

- CIR of mouth cancer among women was higher than men until 1991
- Trend in men: Incidence rate static till 2003 but ↑ in recent years
- Trend in women: Incidence rate is decreasing over the years
- Average annual percent change: 1% ↑ in men; 1.5% ↓ in women

**Fig. 5: Trend of age-specific rate of mouth cancer among young adult men Chennai, 1982-1986 vs. 2012-14**



## Discussion

There has been an improvement in education status both among men and women in recent census. Also, recent NFHS statistics shows that smoking prevalence has come down among adult men while that of tobacco chewing has increased in Tamil Nadu. Among women, there has been a steep decline in smokeless tobacco use while smoking remains negligible with only a marginal increase. Hence, it is clear that, smokeless tobacco use has come down with improved education among women but not among men. This could partly be due to a general social acceptance of chewing habit than smoking. It is also felt that there has been a singular emphasis on smoking cessation but a lackadaisical approach to smokeless tobacco use by anti-tobacco activists. Furthermore, a differential risk of cancer occurrence among men without formal education (10.5) compared to those with more than 12 years of education (1.6) was observed.

All these call for a definite investment on primary prevention of cancer like tobacco control. Anti-tobacco activists must take cognizance of the emerging threat of smokeless tobacco use catching up with even young adults especially men. It will be very useful to revisit the strategy on tobacco control through continuous public awareness campaigns by identifying specific high-risk groups of general public as well as incorporating ways of reaching out to all especially those under-privileged. COPTA is already there, but its implementation in letter and spirit is the need of the hour. Continuous monitoring of these services through surveillance measures like prevalence surveys, down-staging of oral cancers in hospital cancer registries should be part of the operations.

## Conclusion

MMTR data on mouth cancer incidence has provided valuable leads for revisiting tobacco cessation strategies, especially targeting YA men in the region.

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## Population Based Study of Breast Cancer Cases Below 40 Years – A Comparative Study

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### Introduction

Breast cancer is the second most common cancer in the world and, by far, the most frequent cancer among women with an estimated 1.67 million new cancer cases diagnosed in 2012 (25% of all cancers). It is the most common cancer in women both in more and less developed regions with slightly more cases in less developed (883,000 cases) than in more developed (794,000) regions. Incidence rates vary nearly four-fold across the world regions, with rates ranging from 27 per 100,000 in Middle Africa and Eastern Asia to 92 in Northern America.

Breast cancer ranks as the fifth cause of death from cancer overall (522,000 deaths) and while it is the most frequent cause of cancer death in women in less developed regions (324,000 deaths, 14.3% of total), it is now the second cause of cancer death in more developed regions (198,000 deaths, 15.4%) after lung cancer. The range in mortality rates between world regions is less than that for incidence because of the more favorable survival of breast cancer in (high-incidence) developed regions, with rates ranging from 6 per 100,000 in Eastern Asia to 20 per 100,000 in Western Africa.

Breast cancer incidence increases with age, with the vast majority of women diagnosed after the age of 40 years. Breast cancer risk factors, clinical outcomes, and tumor biology are somewhat different in the subgroup of women below 40, suggesting that breast cancer in young women represents a distinct entity. The definition of a 'young woman' in the field of breast

oncology varies, with most articles referring to women under either age 35 or 40 years as 'young'. In this article women below 40 years are referred as young.

Delayed childbirth (first child after age 30 years) is known to be a risk factor for breast cancer in women older than 35. Conversely, early childbearing seems to be a risk factor for developing breast cancer before the age of 35. This discrepancy could possibly be explained by the transient increase in breast cancer risk that occurs around 2 to 7 years following a pregnancy, but more information is needed about this association.

The characteristics of tumors that arise in women under the age of 35 differ from those that arise in premenopausal women who are older than 35. Women younger than 35 have a lower rate of ductal carcinoma in situ, likely due to detection bias (women in this age range do not typically have screening mammograms). Tumors in women younger than 35 are more likely to be of a higher histological grade and to be classified as estrogen receptor (ER) and progesterone receptor negative. In addition, young women are more likely to have local recurrences, to be diagnosed at a more advanced stage, and to have an inferior 5 year survival compared to their older premenopausal counterparts.

These differences in breast cancer risk factors, tumor characteristics, and clinical outcomes suggest that breast cancer arising in young women may be a distinct clinical entity. A study by Anders and colleagues looked at tumor gene expression between two age specific cohorts (young,  $\leq 45$  years; and older,  $\geq 65$  years), and identified 367 gene sets that could differentiate tumors

in young women from tumors in older women. This suggests that breast cancer in young women may be distinct with a unique underlying biology.

### Data of different PBCRs

Breast cancer in females was found to be one of the most common sites that occupied a position in the list of 10 leading cancers during 2012-2014 among all the PBCRs in India. Baring a few almost all the registries have reported breast cancer as the top leading site in their individual listing. Delhi reported the highest with AAR 41.0 and Naharlagun excluding Papumpare reported lowest with AAR 4.4, but still it managed to occupy the 6<sup>th</sup> position in their individual list of 10 leading sites. In North East region of India Aizwal district reported highest AAR of 28, followed by Kamrup urban (27.2), Kolkata (25.5), Mizoram State ( 19.9), Pasighat (17.4), Imphal west (16.2), Mizoram state excluding Aizwal dist (14.2), Dibrugarh (13.9), Cachar (12.8), Sikkim state (11.1), Manipur state (9.7), Nagaland (9.1), East Khasi Hills (8.9), Manipur state excluding Imphal west (8), Tripura state (6.9), Meghalaya (6.7), Naharlagun excluding Papumpare (4.4). In Dibrugarh district it occupied the top rank among the leading sites of cancer within the female population. It was interesting to find that in the older registries in N.E, breast cancer

within female populations are reported as top leading site of cancer but in the comparatively newer registries in the region breast cancer appeared to be getting momentum to move above in the graph. It reflects an alarming trend of ever increasing rate of breast cancer in the N.E region.

After analyzing the data available for the registries during the period 2005-2014, with respect to Breast cancer in young populations ( age <40 years ), it was observed that excluding Meghalaya, more than 20% of all the breast cancer cases reported in the N.E registries were from younger population ( age <40 years). The proportion ranged from 17.9(Meghalaya) to 34.2(Naharlagun) among the N.E registries. Dibrugarh reported 25.7% breast cancer cases in age group < 40 years.

### Female breast cancer cases (age<40) PBCR Dibrugarh 2005-2014

During this period a total of 649 female breast cancer cases have been registered in PBCR, Dibrugarh, out of which 167 (25.7%) cases were below the age 40. Maximum cases (n=101) were within the age group of 35-39

**Table 1. Year-wise Number and Proportion of Breast Cancer cases in age group 0-39 Females**

Year	No of Cases(0-39)	No of cases all age group	%
2005	10	49	20.4
2006	10	42	23.8
2007	7	68	10.3
2008	17	59	28.8
2009	17	56	30.4
2010	10	52	19.2
2011	25	65	38.5
2012	17	73	23.3
2013	25	92	27.2
2014	29	93	31.2
Total	167	649	25.7

**Table 2. Demographic Profile of Female Breast Cancer Cases (age < 40)**

Variables		N=167	%
Locality	Urban	59	35.3
	Rural	108	64.7
Religion	Hindu	151	90.4
	Muslim	10	6.0
	Others	6	3.6
Mother tongue	Assamese	120	71.9
	Bengali	15	9.0
	Others	32	19.2
Community	Ahoms	19	11.4
	Tea-tribe	16	9.6
	Others	106	63.5
	Unknown	26	15.6
Education Level	Illiterate	24	14.4
	Literate	17	10.2
	Prim+Mid+Sec	117	70.0
	College & above	8	4.8

The proportion of female breast cancer cases within the age group (0-39) to all female breast cancer varies from 10.3% (2007) to 38.5% (2011) (refer table 1).

Table 2 shows the highest proportion of cases belonged to the rural areas (64.7%). Among all cases, Assamese was the most common mother tongue and Ahoms were the single largest community represented. . The education level of most of the incident cases were Primary+ Middle+ Secondary (70.0%). The demographic profile of the incident cases didn't show any clear picture as it is a simple case of higher number of people getting the disease from the larger population of respective variables. Again though the tea-tribes were not a big community in the region, yet they were found to be the second mostly affected community.

A recent study was conducted over a period from April 2016 to Mar 2017 in the Dept. of Pathology, Assam Medical College & Hospital, Dibrugarh. During the study period, 78 cases of carcinoma breast were diagnosed which included patients in all age groups.

Out of these, 23 cases were  $\leq 40$  years of age. The most common variant was Infiltrating duct carcinoma and one was diagnosed as papillary carcinoma. From the study the following observations were made.

- Out of the 78 positive cases, 23 were  $\leq 40$  years of age, with percentage of breast cancer cases below 40 years was 29.4%.
- The commonest factor was due to illiteracy and lack of awareness of the disease.
- Immunohistochemistry for ER and PR showed positive reactions in more than 90% of cases.

Further comparative analytical epidemiological studies are required to find the leads to high proportion of incident cases of female breast cancer below age 40 in Dibrugarh district.

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## Scenario of Nasopharyngeal Carcinoma in Nagaland

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Nasopharyngeal carcinoma (NPC) is rare in most parts of the world, with a remarkable ethnical and geographical distribution. In India, high incidence of NPC has been reported from North-East India, particularly Nagaland, which has one of the highest incidences of NPC in the world. Nasopharyngeal carcinoma is the most common and leading cancer in Nagaland. It is the leading cancer in male with 15.47 AAR (PBCR Report 2010-2014) and 4<sup>th</sup> leading cancer in female with 6.5 AAR (PBCR Report 2010-2014). The PBCR includes data only from two districts of Dimapur and Kohima.

Every year about 80-90 new cases of NPC is reported from the entire state. There are more than 16 ethnic tribal groups (recognized scheduled tribes) in Nagaland and each has their own distinct culture and food habits. The high incidence could be due to viral infection, genetic factors, environmental and dietary habits.

The information of the epidemiology and trends of nasopharyngeal carcinoma of 5 years i.e. 2010-2014 in Nagaland is presented. Data used for this study comprises of the demographic and tumour identification of 460 cases of NPC in the period from 2010 to 2014 in all districts of Nagaland. Out of the 460 cases, complete data was not available for 11 patients.

The male to female ratio was noted as 2.5:1 which shows that males are more susceptible to NPC and correlates with other reports of other ethnic groups. The highest occurrence of NPC was seen in the age of 41-50 years in a unimodal distribution pattern (Fig.1),

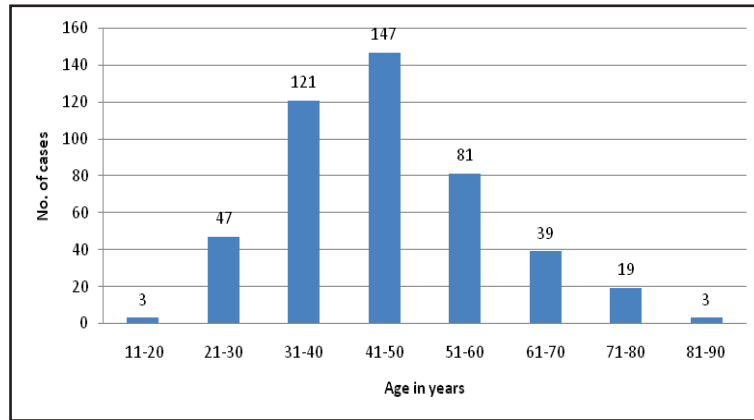
while studies from other countries reported a bimodal age distribution pattern. The mean age of the patients was observed to be  $46.5 \pm 12.7$ . The age of the youngest NPC was 16 years and the oldest was 90 years.

The most common type of NPC in Nagaland was observed to be undifferentiated Carcinoma (64.3%), followed by Squamous Cell Carcinoma (16.7%) and Non-keratinizing Carcinoma (10.8%) (Fig.2). Most of the patients were diagnosed with NPC during the late stage of the disease. We observed that 75.2% and 6.5% of the cases were diagnosed at stage III and stage IV respectively, which is a significantly high percentage of cases presenting late. (Fig.3). A distinct geographical distribution was noted with high incidence in the urban area (71%) compared to rural area (27%).

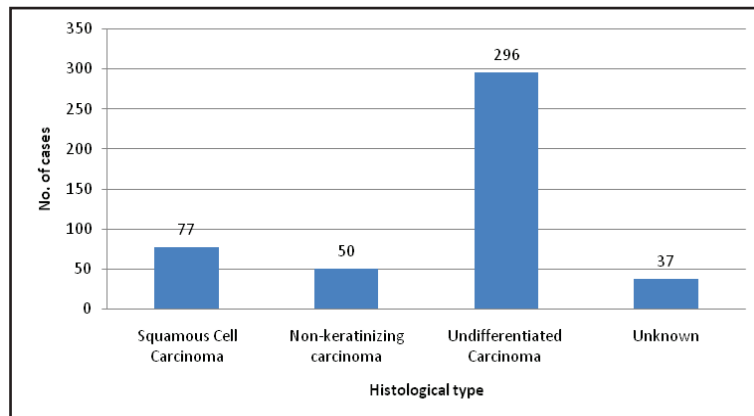
Our study concludes that malignancy of the nasopharyngeal carcinoma poses a big burden in Nagaland. NPC tend to present at younger age (less than 50 years of age). Moreover, most of the patients are being diagnosed at the late stage III and IV, leading to low survival rate. Therefore, public education and well developed screening programs for early diagnosis and management of NPC in high risk populations are urgently needed to overcome this burden.



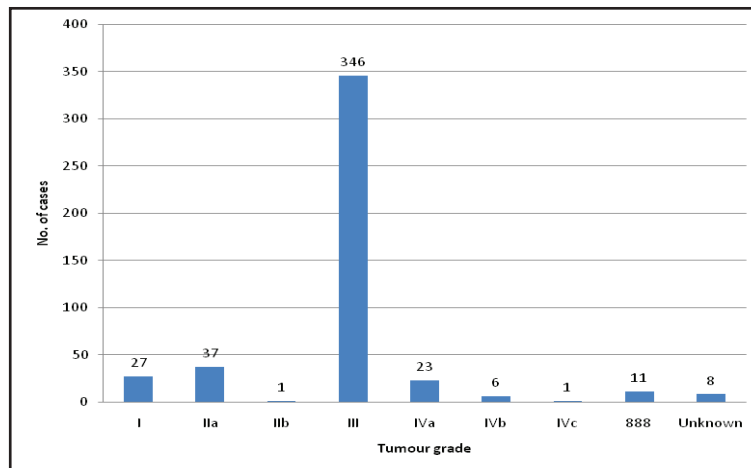
**Fig 1. Age distribution in years of studied patients**



**Fig 2. Histological classification of the NPC patients**



**Fig 3. Tumour grade of the NPC patients**



## Breast Cancer Pattern, Demographic Distribution and Treatment in Last Five Years in Tripura

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### Introduction

Breast Cancer is one of the leading causes of death worldwide specially in developing world<sup>1</sup>. It is an important public health problem in developing countries. Worldwide cancer rates have been increasing primarily due to many reasons like aging population and life style changes in the developing world.<sup>2</sup> There is rising trends of cancer of all sites. Of the different sites breast cancer incidence is also alarming among female patients. Both incidence of cancer and mortality due to it in India have been increasing.<sup>3</sup>

Most types of cancers increases rapidly with age, the rates are usually standardized for age. Age standardized incidence rate is more in developed countries though mortality rates is less in developed regions. Data of 2008 shows breast cancer incidence and mortality rate in more developed region is 66.4 and 15.3 respectively where as in less developed regions it is 27.3 and 10.8.

Tripura, a tiny state in the North-Eastern region of India has a population of 36,71,032 (2011 Census) (males 18,74,376 and females 17,99,541) in a total area of about 10,491.69 sq.km.<sup>4</sup> There is one dedicated cancer hospital in the State established in the year 1980 with only OPD facility only. Govt. Of India recognized Agartala Cancer Hospital as 27<sup>th</sup> Regional Cancer Centre of the country on 24.03.2008. R.C.C., Agartala was upgraded to 100 bedded Cancer Hospital in April, 2012. The Govt. of India has decided to upgrade this

institute further as a State Cancer Institute and funded accordingly.

Regional Cancer Centre has the facilities of Mammography, External Beam Radiotherapy (EBRT), Brachytherapy, Gamma Camera, Chemotherapy and other supportive care system. Population Based Cancer Registry (PBCR) is in operation at State Cancer Hospital, Agartala since June, 2009. The R.C.C, Agartala is the main source of registration where approximately more than 80% data of Tripura PBCR are available.

Breast cancer incidence in Tripura according to PBCR is more in female. Breast cancer is the second leading cause of death in female patients in Tripura and many of the patients usually present in advanced stage.

### Pattern & demographic distribution

Cervix, Breast and Gall bladder cancer are the three top sites of cancer among female population during the period of 2010-2014 in Tripura as per report from PBCR (Population Based Cancer Registry) of ICMR India.

As per PBCR-Tripura data of 2012-2016 there is increase in number of new cancer patients as shown in Table-1. This is due to increased awareness, detection and active participation of Regional Cancer Centre, Agartala.

**Table 1. Total Number of Cancer Cases (new)  
2012-2014**

Year	No. of Male Patients	No. of Female Patients	No. of Total Patients
2012	1177	866	2043
2013	1243	942	2185
2014	1208	894	2102

**Table 2. Number of Breast Cancer  
2012-2014**

Year	Male	Female	Total
2012	2(0.2%)	110(12.7%)	112(5.5%)
2013	6(0.5%)	129(13.7%)	135(6.2%)
2014	4(0.3%)	130(14.5%)	134(6.4%)

Proportion of breast cancer among all cancers is more in female than male as shown in Table-2. During 2012-2014 around 0.2%-0.5% males were affected with breast cancer whereas in females it is 12.7%-16.2%.

Tripura State has eight districts. As per Table-3 in District wise distribution of breast cancer, West district had more number of breast cancer patients than others due to higher population density.

**Table 3. District-wise Distribution of Breast Cancer 2012-2014**

Year	West Tripura	Sepahijala	Gomati	South Tripura	Khowai	Dhalai	North Tripura	Unakoti	Others	Total
2012	54	12	8	7	7	5	10	5	4	112
2013	42	31	13	10	8	11	11	9	0	135
2014	56	20	10	12	11	8	8	8	1	134

Tripura is a small state in the North-East region of India with mixed population. Majority of the populations are of Bengalis and different Tribes of indigenous origin. Majority are Hindus by religion, followed by Christians, Buddhists and Muslims. Table-4 depicts community wise distribution of breast cancer cases

**Table: 4 Community-wise Distribution of Breast Cancer 2012-2016**

Year	Bengali Comm.	Tribal Comm.	Muslim Comm.	Total
2012	85 (75.9%)	18(16.1%)	09(8.0%)	112
2013	96((71.1%)	28(20.7%)	11(8.1%)	135
2014	100(74.6%)	26(19.4%)	8(6.0%)	134
2015	132(76.7%)	35(20.3%)	5(3.0%)	172
2016	133(79.5%)	24(14.4%)	10(6.1%)	167

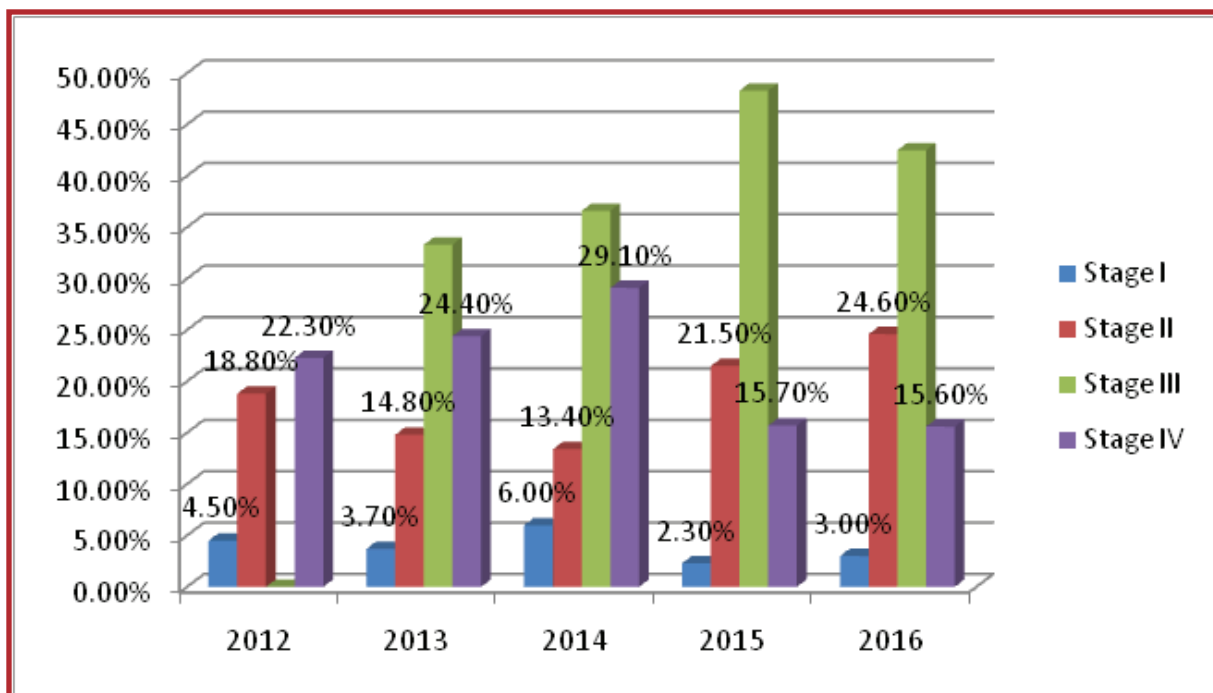
Among the breast cancer cases, major proportion belong to rural areas (>60%) as compared to urban areas of Tripura.

Majority of the patients affected are of 20-60 years age group as shown in Table-5. Very rarely case has been reported below 20 years of age. A significant percentage of patients were diagnosed at more than sixty years of age.

**Table 5. Age at Diagnosis of Breast Cancer Cases (2012-2014)**

Year	<20 yrs	20-40 yrs	1-60 Yrs	>60 yrs	Total
2012	0	40(35.7%)	55(49.1%)	17(15.2%)	112
2013	1	40(29.6%)	77(57.0%)	17(12.6%)	135
2014	0	40(29.6%)	83(61.9%)	11(8.2%)	134

Patients usually present in advanced stage of disease, usually-stage III-IV (as shown in Fig-2). Many patients are now attending hospital at an early stages (stage I-II). More radical treatment can be offered to these patients. The quality of life has also improved. Owing to lack of awareness, lack of infrastructure, publicity & low priority to public health schemes, breast cancer screening and early detection have not caught up in time in the under privileged area.

**Fig 2. Stage-wise distribution 2012-2014**

## Pattern of Care

Pattern of care given under R.C.C., Agartala is according to institutional protocols. After confirmation of the disease, either by histopathology or by FNAC, treatment is given to the patient considering the stage of the disease. As a rule, pattern of care is to be approved by the 'Tumour Board' constituted at the institute.

## Discussion

After inception of PBCR & HBCR in Regional Cancer Centre in June, 2009 & January, 2015 respectively, the picture of cancer incidence, the distribution of geographic area like district wise, and stage of disease can gradually be understood in a more scientific way. The burden of disease can be understood easily from data which will help in future planning & understanding of disease pattern. Participation of NGOs has to be encouraged side by side with govt. activities.

## Conclusion

Rising incidence of breast cancer is due to increasing life expectancy, improved control of infectious diseases, changing life style, diet, physical activity and obstetric practices and breast feeding. At present majority of the patients are diagnosed in advanced stage with poor quality of life even after treatment. Pathology report to know the hormone receptor status need to be mandatory. Aim is to detect cancer in

early stage and to provide radical treatment to cure the disease and provide healthy quality life to the sufferers. Active participation of Health Providers and health care receivers can lead to a quality life in future. Younger generation are to be encouraged to participate in cancer research activities.

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# Years of Potential Life lost due to Cancer in Kamrup Urban District of North East India

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## Abstract

Cancer is a major public health problem as well as a major cause of premature death across worldwide. Cancer is known as disease of older population but a number of cancers harm relatively young people. Focus should therefore not only be on the deadly cancers in terms of absolute death toll, but also take into account the numbers of life years lost due to the disease.

Objective: To quantify the total and years of life lost due to cancer in Kamrup urban district between 2010 and 2014.

## Materials and methods

Sex-specific data on age distribution, remaining life expectancy, deaths due to specific cancers and total numbers of deaths were obtained from the National Cancer Registry Programme, India and census of India data bases. Years of life lost (YLL) were calculated based on each individual's age at death and the remaining life expectancy at that age. Average years of life lost were calculated by dividing years of life lost by the number of cause-specific cancer deaths.

## Results

Total years of life lost due to cancer are 9305.4 years for males and 7668.6 years for females over the study period. In Kamrup Urban District, the female population had a lower YLL, but lost more years on average (higher AYLL) by cancer type, largely because of the age at onset of particular tumour type of cancer and longer

life expectancy of women. The mean AYLL amounts to 11.0 years in men and 15.0 years in women.

## Conclusion

Cancer is a major and increasing cause of premature deaths, and YLL may be a more accurate measure than number of deaths. Average years of life lost measures the burden to individual patients and may be helpful where individuals' needs are relevant, such as hospice care.

Key words: cancer, years of life lost (YLL), average years of life lost (AYLL)

## Introduction

Despite sophistication in diagnosis and advances in treatment, cancer continues to be a major public health problem as well as a major cause of premature death across worldwide [1, 2]. In 2012, there were an estimated 8.2 million deaths from cancer in the world: 4.7 million (57%) in males and 3.5 million (43%) in females. The World age-standardized mortality rate shows that there are 126 cancer deaths for every 100,000 men in the world, and 83 for every 100,000 females [3]. However, an estimated 600,000–700,000 death in India was caused by cancer in 2012 [4]. In India highest incidence and mortality rate of cancer was seen in the North-Eastern region of the country. Some of the specific types of cancer have highest incidence and mortality in these regions as compared to National (India) and Global scenario, particularly cancers of the gall bladder, stomach cancer, esophageal cancers,

mouth cancer and hypopharyngeal cancer [5, 6]. Aizwal district of North east India has the highest rate of mortality in India in men (140.6 per 100,000) and women (83.2 per 100,000). In Kamrup urban district 70 per 100,000 men and 41.2 per 100,000 women died to due to cancer [7].

The number and rates of deaths alone does not reflect the complete burden on the society, as some cancers harm people more than others. The number of years of life lost (YLL) therefore depends on the age at death and the number of deaths at each age, and may resolve some of the mismatch of disease impact derived from numbers of death alone. YLL data may be more useful in resource allocation and design of prevention programs [8, 9].

Herein we have analyzed on a population level (Kamrup Urban District) the total number of YLL to different cancer diagnoses in the year 2010-2014 as a calculation of number of deaths and the expected remaining life years at each age level. It is the first-of-its kind analysis done in this region.

## Materials and Methods

Data from Kamrup Urban District Cancer Registry for the 5-year period 2010 to 2014 were used to calculate YLL. Simple percentage mortality expresses the number of deaths from an individual tumour type divided by the total number of deaths from cancer as a percentage.

### Person Years of Life Lost (YLL) Due To Cancer

Years of potential life lost (YPLL) or potential years of life lost (PYLL), is an estimate of the average years a person would have lived if he or she had not died prematurely. It is, therefore, a measure of premature mortality. Estimates of the years of life lost due to cancer (YLL) are generated by comparing the life expectancy at five year of age interval with the number of deaths from cancer that occurred at that age group. The projected level of the expectation of life at birth for 2010-2015 for Assam state is calculated

as 63.6 years for male and 64.8 years for females (Ref 10 Source : Report of the Technical Group on Population projections, 2001-2026 : M/O Health & family Welfare). The calculation of YLL was done with the following formula for each type of cancer.

$$\sum_i^{99} (\text{No. of deaths at age } i) \times (\text{Expected remaining life years at age } i)$$

The average YLL (AYLL) was calculated by dividing the total YLL by the total number of deaths for cancer in total, and for each of the 15 most frequent cancer types for each sex separately.

## Results

### Overall Deaths

In Kamrup Urban District a total of 2259 number of deaths (male = 1474, female = 785) have occurred due to cancer in the last five years (2010-2014). On average about 452 deaths due cancer was recorded per year, out of which 295 were male deaths and 157 were female deaths. The age distribution of death among men and women is shown (Figure 1 & Figure 2). Probability of death is increasing with advancing age and higher among older age group. A total of 82.6 % (1218/1474) and 70.6% (554/785) number of deaths among men and women respectively have occurred in the population of 50 and above years of age group.

### Leading Sites of Deaths

Esophageal cancer was the leading cause of cancer deaths in both sexes, 15.6% in men and 11.6% in women during the period of 2010-2014 (Figure 3 & Figure 4). Lung cancer is the second leading cause of death among men (11.5% of all cancers) of Kamrup urban district, and among women, gallbladder cancer was thesecond leading cause of death, comprising 11.5% of total deaths due to cancer. Deaths from esophagus, stomach, lung, gallbladder, breast and ovary cancers together made up almost half of all deaths from cancer during this period.

Figure 1. Total number of cancer-caused deaths in Kamrup Urban District in 2010-2014 per 5-year age group.

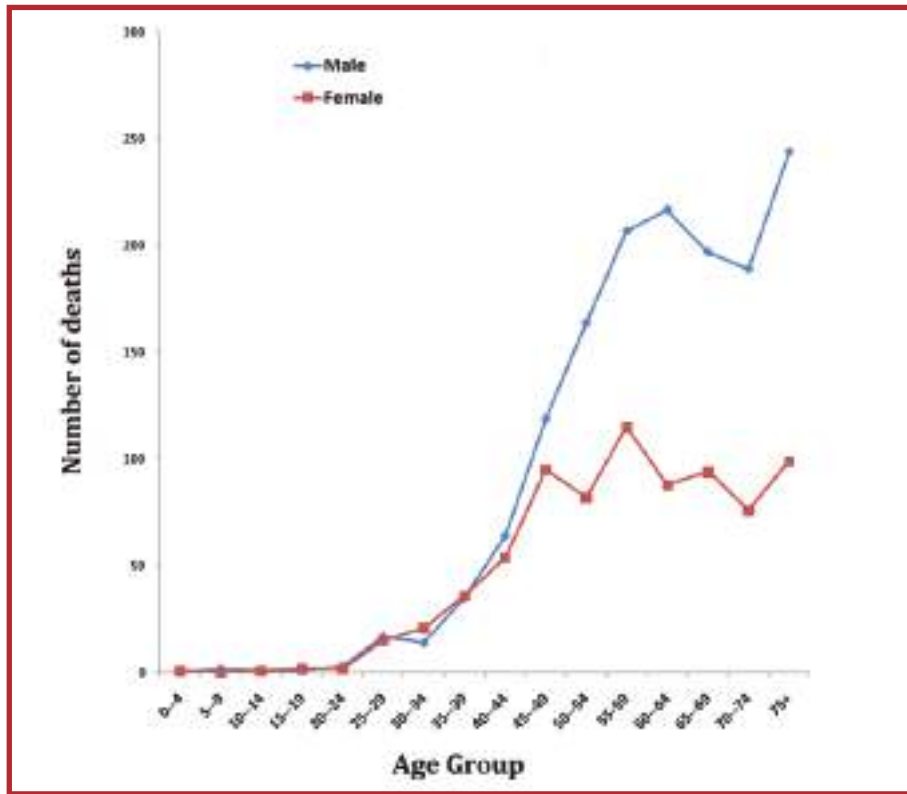


Figure 2. Total percentage of cancer-caused deaths in Kamrup urban district in 2010-2014 per 5-year age group.

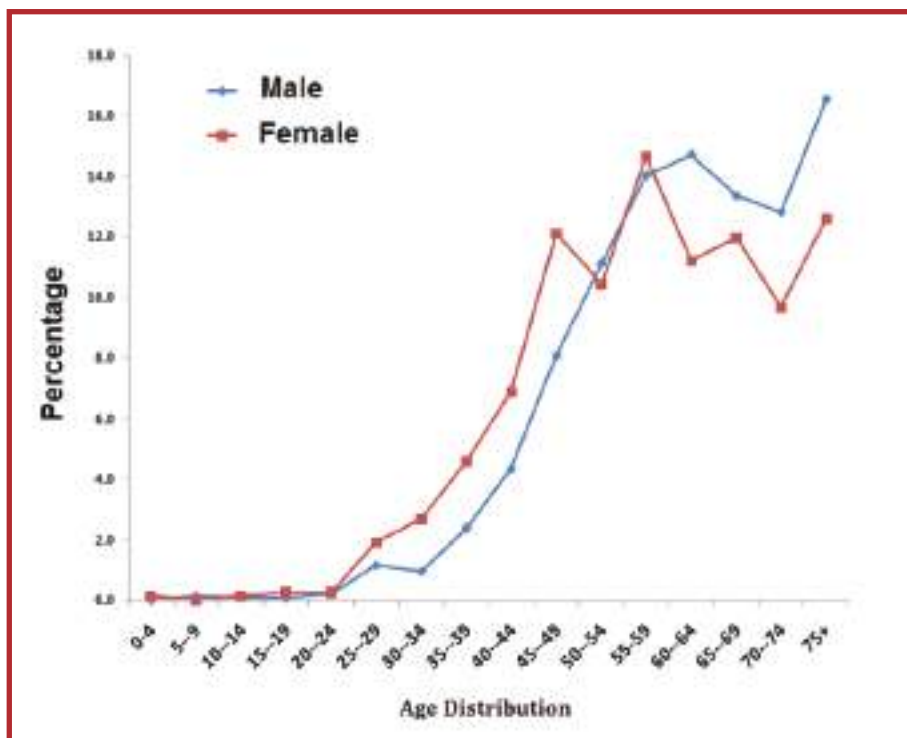




Figure 3. Leading site cancer death among men percentage wise

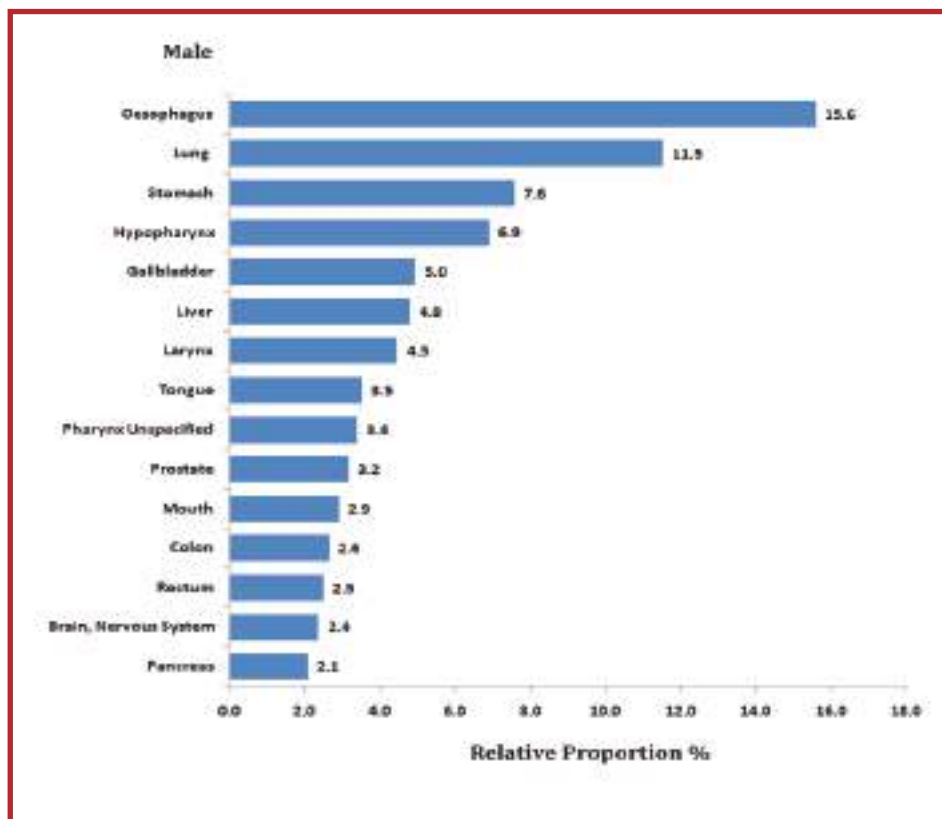
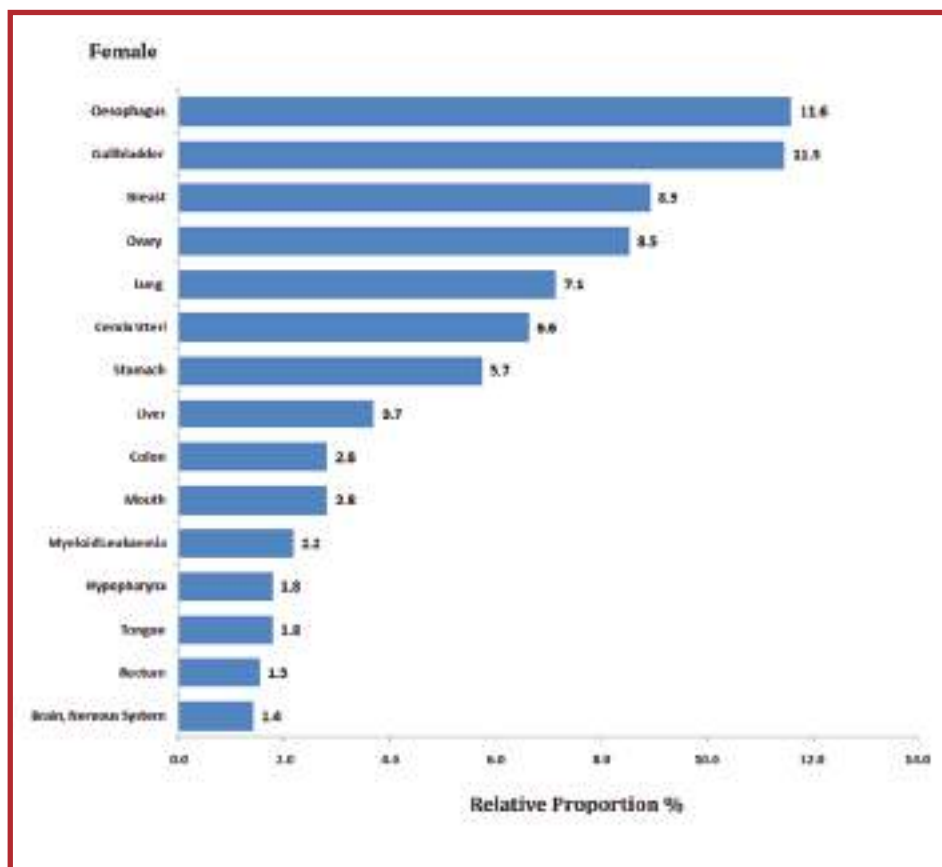


Figure 4. Leading site cancer death among women percentage wise



## Overall Years of Life Lost

The YLL for an individual cancer site can be expressed as a percentage of the total years of life lost from all cancers, so it can be directly compared with percentage mortality. Based on the total number of deaths at each age level, multiplied by the expected remaining years of life on each level, a total of 9305.4 YLL was estimated

for men and 7668.6 for women who died from cancer during 2010-2014 (Table 1a and 1b ). The greatest percentage of YLL in men was due to oesophageal cancer, contributing a total of 16.8% followed by hypopharyngeal cancer (7.8%) and lung cancer (7.4%). Among women, the greatest percentage of YLL was from breast cancer (12.1%) followed by ovarian cancer (11.3%).

**Table 1a. Years of life lost (YLL) due to cancer, 2010 - 2014 (Male)**

Male					
Sites of Cancer	Total YLL	Avg. YLL	% of all yrs. lost	% Mortality	% YLL / % mortality
Oesophagus (C15)	1567.4	11.3	16.8	15.6	1.1
Hypopharynx (C12-13)	723.4	9.8	7.8	6.9	1.1
Lung (C33-34)	691.0	8.1	7.4	11.5	0.6
Stomach (C16)	632.8	10.9	6.8	7.6	0.9
Liver (C22)	444.2	12.0	4.8	4.8	1.0
Larynx (C32)	400.8	10.5	4.3	4.5	1.0
Gallbladder (C23-24)	395.8	10.4	4.3	5.0	0.9
Brain, Nervous System (C70-72)	355.2	16.1	3.8	2.4	1.6
Rectum (C19-20)	353.4	14.7	3.8	2.5	1.5
Pharynx (C14)	306.6	11.8	3.3	3.4	1.0
Tongue (C01-02)	291.2	9.1	3.1	3.5	0.9
Mouth (C03-06)	268.0	8.9	2.9	1.5	1.9
Tonsil (C09)	263.6	12.6	2.8	2.9	1.0
Colon (C18)	238.6	11.4	2.6	1.8	1.4
Pancreas (C25)	183.8	10.2	2.0	2.6	0.8
All Sites	9305.4	11.0	100.0		

Table 1b. Years of life lost (YLL) due to cancer, 2010 - 2014 (Female)

Female					
Sites of Cancer	Total YLL	Avg. YLL	% of all years lost	% Mortality	% YLL/ % mortality
Breast (C50)	925.2	15.7	12.1	8.9	1.4
Ovary etc. (C56)	865.0	17.3	11.3	8.5	1.3
Gallbladder (C23-24)	735.2	12.5	9.6	11.5	0.8
Oesophagus (C15)	581.2	10.8	7.6	11.6	0.7
Cervix Uteri (C53)	534.2	13.7	7.0	6.6	1.1
Lung (C33-34)	516.4	13.6	6.7	7.1	0.9
Stomach (C16)	511.2	17.6	6.7	5.7	1.2
Colon (C18)	329.2	23.5	4.3	2.8	1.5
Liver (C22)	280.4	15.6	3.7	3.7	1.0
Myeloid Leukaemia (C92-94)	215.8	19.6	2.8	2.2	1.3
Brain, Nervous System (C70-72)	172.4	21.6	2.2	1.4	1.6
Hypopharynx (C12-13)	169.6	24.2	2.2	1.8	1.2
Mouth (C03-06)	148.6	12.4	1.9	2.8	0.7
Tongue (C01-02)	102.4	12.8	1.3	1.8	0.7
Tonsil (C09)	91.8	15.3	1.2	1.0	1.2
All Sites	7668.6	15.0	100		

The relative difference between the two parameters of mortality is given by the ratio % YLL/% mortality. Figures are presented only for the 15 specified sites. YLL years of life lost; AYLL Average years of life lost.

### Average Years of Life Lost

Figures for YLL can be used to produce an additional mortality statistic, the average years of life lost (AYLL). Average years of life lost is simply an average derived by dividing YLL by the actual number of deaths for each cancer site, over the defined time period. This parameter is interesting because it provides a measure

of the burden of cancer to the individual patient, rather than the population as a whole. Effectively it shows, on average, how much a patient's life is likely to be shortened by their cancer.

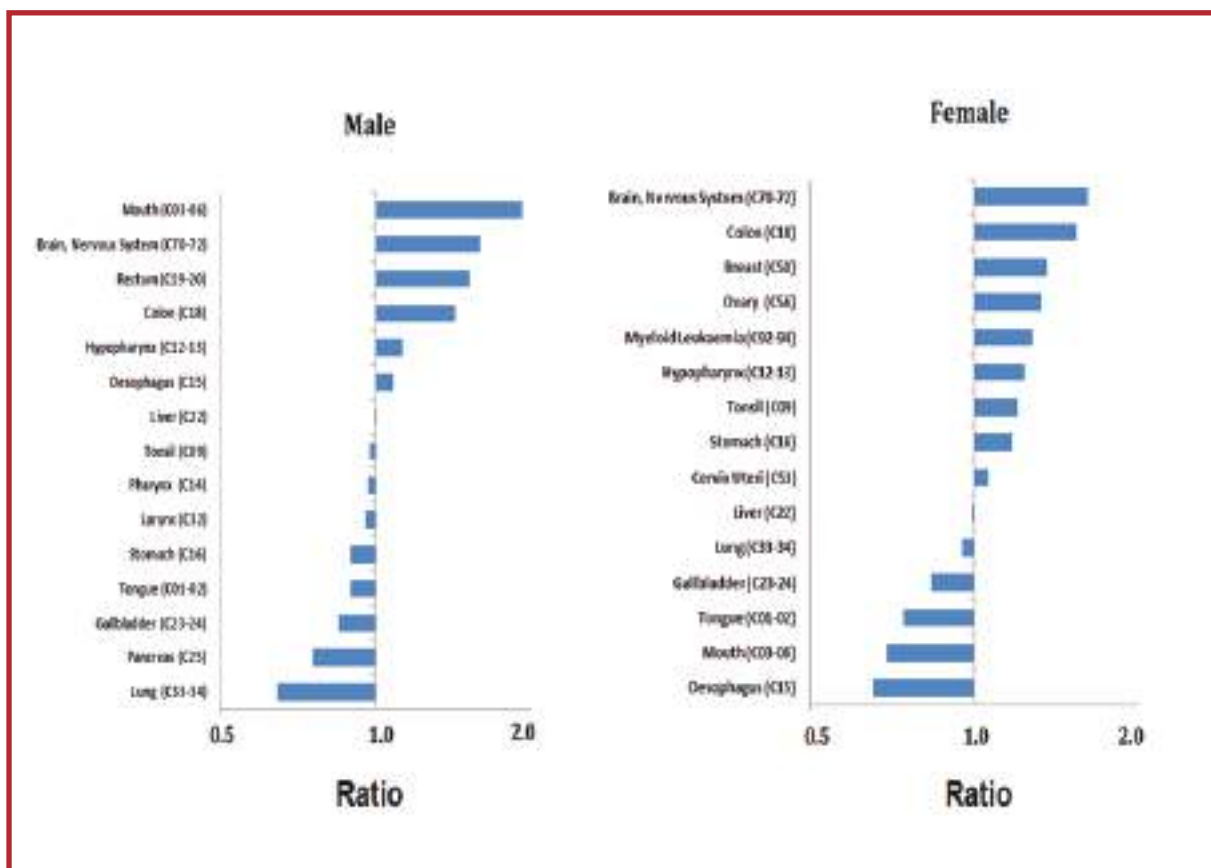
The variation in cancer burden per affected patient varies dramatically according to tumour type. The mean AYLL amounts to 11.0 years in men and 15.0 in women,

indicating the numerical average of the life shortening from cancer (Table 1a and 1b). Deaths among female-specific cancers as cervical, breast, ovarian and uterine cancers occurred in lower ages than the male-specific or predominant cancers as prostate, bladder and oesophageal cancers, contributing to a higher AYLL in females than in males. Among the top 10 sites, brain and CNS cancers in male had the highest average number of AYLL per death (16.1 years) followed by rectum (14.7 years). Among females, the highest years of life lost was due to hypopharyngeal cancer (21.6 years) followed by carcinoma of colon (23.5 years). The YLL (%)/mortality (%) ratio is close to 1 for most types of cancer, and ranged from 0.64 (lung) to 1.92 (mouth) among men (Figure 5).

at earlier diagnosis and treatment, and the effects of environmental and other causative factors such as tobacco, smoking etc.

In Kamrup Urban District, the female population had a lower YLL, but lost more years on average (higher AYLL) by cancer type, largely because of the age at onset of particular tumour type of cancer and longer life expectancy of women. Breast and cervical cancer were very important contributors to female cancer mortality. A sustainable portion of this deaths can be prevented only by improving early detection and treatment methods of breast and cervical cancer.

**Figure 5. The ratios (log scale) of YLL (%)/mortality (%) are shown for the 15 most frequent cancers**



## Discussion

Measures of mortality from all types of diseases are clearly important for public health considerations. With regards to cancer mortality, data are important to monitor the effects of screening programmes, efforts

Esophageal cancer is the sixth leading cause of cancer death worldwide [11]. A substantial number of years of life were lost or affected by esophageal cancer worldwide, with the burden resting disproportionately on less-developed countries. Geographically, the greatest burden is in Eastern Asia [12]. Oesophageal

cancer is the top most killer among men of Kamrup urban district in terms of total years life lost and mortality percentage. A total of 1567.4 and 581.2 life years have been lost due to oesophageal cancer death among men and women respectively in 2010-2014.

Among men highest average years of life lost was due to brain and nervous system cancer (16.1 AYLL), probably due to nervous system cancers occurring at early years of life. Among women on an average 24.2 life years was lost due to hypopharyngeal cancer among women. Kamrup Urban District recorded a statistically significant increasing trend in prostate cancer incidence rates over time from 2003 onwards and it is the sixth leading site among men in Kamrup urban district [13]. Despite this observed increase, the AYLL due to prostate cancer was relatively low compared to other cancer types; this could be attributed to the advanced age at diagnosis. Leukemias frequently occur amongst children and explain the very high AYLL encountered for this cancer type. Not surprisingly, all childhood cancer deaths (all cancer types) had AYLL of around 60 years, because of very similar remaining life expectancy during childhood ages.

These estimates and projections may be used to target investments to cancer control strategies for tumor sites. These are likely to result in the greatest reductions in burden of illness and will also be those that are the most cost-effective.

## Conclusions

Cancer is a major and increasing cause of premature deaths, and YLL may be a more accurate measure than number of deaths. Average years of life lost measures the burden to individual patients and may be helpful where individuals' needs are relevant, such as palliative care. The high average years of life lost illustrate the poor prognosis. Primary prevention, early detection, adequate and timely treatment are needed to change this situation. Public health efforts and research funding should be explicitly directed at preventing premature deaths.

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- High resolution microendoscopy for early detection of esophageal cancer in low-resource settings (Conference Presentation)", Proc. SPIE 9691, Endoscopic Microscopy Jain S, Saxena S, Kumar A. Epidemiology of prostate cancer in India. Meta Gene.2014;2:596–605.

## PUBLICATIONS FROM REGISTRIES

## Abstracts of published papers from PBCR & HBCR Bangalore

### 1. Assessment of Adaptive Breast Cancer Screening Policies for Improved Mortality Reduction in Low to Middle Income Countries

Baban Wagh<sup>1,2</sup>; Ramesh Chaluvaryaswamy<sup>3</sup>; Debnath Pal<sup>2</sup>

Asian Pac J Cancer Prev. 2017 Sep 27;18(9):2375-2380.

1 Department of Physics, Indian Institute of Science, Bangalore, India.

2 Department of Computational and Data Sciences, Indian Institute of Science, Bangalore, India.

3 Kidwai Memorial Institute of Oncology, Bangalore, India.

#### Abstract

Objective: To investigate adaptive breast cancer screening policies using clinical breast examination for early detection and mortality reduction in low to middle income countries like India. Methods: Using published data from the Mumbai randomized cluster control trial (1998-2006), we first estimated the mean sojourn time at 5.9 years (95% Confidence Interval: 5.3-6.5) assuming 52% sensitivity of the test. The estimated mean sojourn time was used as a "silent interval" in time varying cellular kinetics with the two stage deterministic clonal expansion model, and we found age specific sojourn times in years as follows: 35-39, 0.8; 40-44, 1.0; 45-49, 1.8; 50-54, 3.2; and 55+, 5.9. Equipped with age specific sojourn times and sensitivity, we investigate adaptive screening policies for various year age groups using different screening intervals, maintaining a constant screen count of 10 and a 6 state Markov transition model. The rationale for using a fixed number of screens was to benchmark the effect of the screening interval. Result: We found that annual screening at ages 35-39 and biennial from 41-49 would achieve a mortality reduction of 27.9%, while annual screening from 38-42 and triennial from 43-58 would achieve a

mortality reduction of 25.5%. Biennial screening from 40-60 years of age showed a mortality reduction of 23.6%, indicating inclusion of annual screening might be effective. We demonstrated a modelling framework that could be applied to the final data of randomized controlled trials, such as the ongoing Mumbai and Trivandrum trials in India, for assessing efficacy of annual screening in younger women. Conclusion: The framework could be useful to decide age groups that would yield maximal effectiveness in screening trials with selected screening intervals. Further, the framework could be adapted in other low to middle income countries for designing either screening trials or adaptive screening policies.

### 2. Gall Bladder Cancer Incidence Trend Over the Time Period in Bengaluru Population Based Cancer Registry (1982-2012)

Vijay CR, Dr Ramesh C, Dr P Sridhar, Dr Gopalakrishnappa, Dr V Lokesh.

JMSCR Volume 05 Issue 08 August 2017

#### Abstract

Background: Gall Bladder cancer has emerged as one of the frequent cancer among men and women in Bengaluru, with incidence increasing rapidly over the past two decades. Incidence has also been increasing in some of the registries across India. We conducted a study at Kidwai Cancer Institute. (KCI) to know the Gall Bladder cancer trend in Bengaluru population based cancer registry. The study is important because Gall Bladder cancer is having low screening facility and the prognosis is very poor.

Materials and Methods: Gall Bladder cancer (GBC) cases were drawn from data base of Bengaluru populationbased cancer registry located at Kidwai Memorial Institute of Oncology which is functioning



from 1982 under the network of National Cancer Registry Programme (ICMR). Age adjusted incidence rates were calculated. Time trends in age-standardized cancer incidence rates were analysed by using statistical tools like Joinpoint and Annual percentage Change over the study period, using relative change.

Results: The highest relative percentage change observed 228% in men from 1982-1990 to 1991-2000, similarly in females 266% change was observed between 1991-2000 and 2001-2012. Joinpoint regression showing from 1986 to 2012 significantly increased in GBC trend was observed in PBCR Bengaluru in segment 1 1982-1986. In Mumbai from 1982 to 1989, increasing trend- 13% annual percentage change was observed, after 1990 trend is stabilized. Similar trend was also observed in Delhi, Sikkim, Kamrup urban registries. Similarly increasing trend was observed in Females in almost all registries.

Conclusion: Gall Bladder cancer trend is significantly increasing in Bengaluru, also same trend is observed in other registries in India. The screening to diagnose at early stage is difficult and very poor prognosis is found in Gall Bladder cancer. Hence prevention is the only method to reduce the Gall Bladder cancers in India.

### 3. Epidemiology of Oral cancer-A Hospital based case control study in Bengaluru.

Vijay C R, Dr Lokesh V, Dr Ramesh C, Dr P Sridhar,  
Dr Mahanthesh A S.

JMSCR Volume 05 Issue 08 August 2017.

#### Abstract

Back Ground of the Study: Oral cancer is estimated to be the fifteenth most common cancer and it accounts an age adjusted rate (AAR) of 4.0 persons for every 100,000 population after combining both sexes in global level. In Asia, Oral and lip cancer is ranked ninth most common cancer with AAR 3.8 in both sex. In India oral cancer is found to be third leading site after combining both sex (AAR 7.2), in males it occupies 1st

position with AAR 10.1 in females 5<sup>th</sup> leading position with AAR 4.3 per 100,000 persons. In Hospital based cancer registry (HBCR) oral cancer showed increasing proportion among tobacco related cancer in both sex. Oral cancer is twice as common in men as in women. This difference may be related to the use of alcohol and tobacco in Kidwai hospital based cancer registry and the proportion of male and female oral cancer is same. This study was conducted to know the risk factors associated for oral cancer pattern.

Material and Methodology: The study was conducted in Kidwai cancer Institute located in Bengaluru, which is the capital of the state of Karnataka. It is comprehensive center for cancer research and treatment in the state and is one of the Regional cancercenters in India. To study risk factors, prospective case control study was plan Ned. The information on exposure factor was collected through direct personal interview method using structure questionnaire prepared based on old review and experts opinion. Only microscopically confirmed cases were including in the study, one case per control was matched for sex and age group was selected. 300 cases and equal number of control selected for the study. A descriptive statistics along with odds ratio estimate the effects of different variables on oral cancer.

Results: The proportion of women (55%) was higher than in men (44%). The mean age group of respondents is 54 years. About 67% of cases and 44% of controls are illiterates and 4% in study group and 14% in control groups have completed their college level education. The average income level of cases and controls is 1700 Rs/month and 3600Rs/month respectively. Among 600 respondents, 74% and 26% are tobacco users either in the form of chewing or smoking tobacco. Out of 288 respondents, majority of the cases have tobacco chewing habit (78%) compared to control group which was 22%. 66% of the cases and 33% of controls have smoking habits out of 125 respondents. Odds ratio was found to be significant 2.3 and 10.8 between cases and controls with respect to chewing and smoking habits. The odds ratio between cases and control with respect

to only smoking, alcohol and Smoking+Alcohol consumption was not found significant. Only chewing, smoking+chewing and smoking+chewing+alcohol was found

Significant (p-values 0.001, 0.033, 0.001). Majority of them had the habit of chewing tobacco stem (Kaddipudi) with lime and betel leaf. Among 64 respondents, tobacco chewing in the form of leaf (Khaini) 43(67.2%) and 21 (32.8%) with respect to case and control, the odds ratio is statistically significant.

**Conclusion:** In this study, a higher chance of oral cancer was found in those who were chewing and smoking tobacco in any form and a strong risk for oral cancer is proved from chewing with different combination. Alcohol and smoking alone has not proved the association with oral cancer, it may be due to high proportion of women respondents or combined males and female respondents for analysis.

#### 4. Demographic and Clinicopathologic Profile of Malignant Epithelial Ovarian Tumors: An Experience from a Tertiary Cancer Care Centre in Bangalore, South India.

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M. S. Ganesh<sup>3</sup>, Shashidhar V. Karpurmath<sup>2</sup>, Jahnavi Hatti<sup>4</sup>  
Int J Reprod Contracept Obstet Gynecol. 2017 Mar;  
6(3): 856-860

1 Department of Obstetrics and Gynecology,

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#### ABSTRACT

**Background:** Ovarian cancer is fast emerging as the leading cancer of the female genital tract. It is the

second most common gynecological malignancy in India, but has poor outcomes making it the leading cause of gynecologic cancer related deaths. There is a paucity of data regarding demographic details, patterns of care and outcomes of ovarian epithelial malignancies in India. This is a study to evaluate the demographic details, clinical profile and pathology details of epithelial ovarian cancer registering in a tertiary cancer center in Bangalore, Karnataka, India.

**Methods:** This is a retrospective study of the case records of patients diagnosed with epithelial

Ovarian cancer from January 2012 to December 2014.

**Results:** Malignant ovarian tumors constituted 5.6% of all malignancies in women. 84 cases were of epithelial origin constituting 64.4% of all malignant ovarian tumors. 58% of patients were from Karnataka and 25% were from West Bengal. 27% underwent suboptimal surgery outside at presentation. The median age at presentation was 51 years. Most of the patients were parous (25% were para 2 and 3). 5% patients were nulliparous. Pain abdomen (39%) and abdominal distension/ bloating (16%) were the most common symptoms. 75% of these cases presented in III-IV stage. Method of diagnosis was: primary surgery and Biopsy of mass (50%), fine needle aspiration cytology of mass or ascites/ pleural effusion (40%), and diagnostic laparoscopy in (9.5%) of the patients. The most common histological variants were serous cystadenocarcinoma (32%) and mucinous adenocarcinoma (15%).

**Conclusions:** Majority of the patients presented with vague nonspecific abdominal complaints which leads to delay in diagnosis. Most of the patients presented in advanced stage of the disease. Delay in diagnosis and improper management prior to registering in tertiary cancer centre was common. There is a need to improve awareness regarding ovarian cancer in general population and also primary care physician.

## Publications using HBCR Data:

Dr. B. Borooh Cancer Institute Guwahati

1. Krishnatreya M, Rahman T, Kataki AC, Das A, Das AK, Lahkar K. Synchronous primary cancers of the head and neck region and upper aero-digestive tract: Defining high risk patients. *Indian J Cancer* 2013; 50:322-26. PMID: 24369209
2. Krishnatreya M, Rahman T, Kataki AC, Sharma JD, Nandy P, Baishya N. Pretreatment performance status and stage at diagnosis in patients with head and neck cancers. *Asian Pac J Cancer Prev* 2014; 15:8479-82. PMID: 25339050
3. Krishnatreya M, Sharma JD, Kataki AC, Kalita M. Survival in carcinoma of unknown primary to neck nodes treated with neck dissection and radiotherapy. *Ann Med Health Sci Res* 2014; 4:S165-S6. PMID: 25184090
4. Krishnatreya M, Saikia A, Kataki AC, Sharma JD, Baruah M. Variations in the spatial distribution of gall bladder cancer: A call for collaborative action. *Ann Med Health Sci Res* 2014; 4:329-31. PMID: 25364614
5. Krishnatreya M, Kataki AC, Sharma JD, Borthakur BB, Kalita M. Epidemiology of primary small cell carcinoma of the esophagus: A retrospective study. *South Asian J Cancer* 2014;3:231-32. PMID: 25422814
6. Krishnatreya M, Kataki AC, Sharma JD, Nandy P. Brief descriptive epidemiology of primary malignant brain tumors. *Asian Pac J Cancer Prev* 2014; 15:9871-3. PMID: 25520120
7. Krishnatreya M, Kataki AC, Sharma JD, Nandy P, Talukdar A, Gogoi G et al. Descriptive epidemiology of common female cancers in the North East India: a hospital based study. *Asian Pac J Cancer Prev* 2014; 15:10735-38. PMID:25605167
8. Krishnatreya M, Kataki AC, Sharma JD, Nandy P, Rahman T, Kumar M. Educational levels and delays in start of treatment for head and neck cancers: a stage at diagnosis correlation study. *Asian Pac J Cancer Prev* 2014;16:10867-69. PMID: 25605191
9. Krishnatreya M, Kataki AC, Sharma JD. A retrospective analysis of occupational exposure to pesticides as a possible risk factor for non-melanoma skin cancers. *South Asian J Cancer*. 2015;4:47-8. PMID:25839025
10. Krishnatreya M, Nandy P, Rahman T, Kataki AC, Sharma JD, Das A et al. Characteristics of oral tongue and base of the tongue cancer - A hospital cancer registry based analysis. *Asian Pac J Cancer Prev* 2015;16:1371-4 PMID:25743801
11. Krishnatreya M, Kataki AC, Sharma JD, Nandy P, Gogoi G. Association of educational levels and survival in Indian patients with cancer of the uterine cervix. *Asian Pac J Cancer Prev* 2015;16:3121-23 PMID: 25921107
12. Sharma JD, Krishnatreya M, Das AK, Bhattacharyya M, Hazarika M, Kataki AC et al. Radiotherapy and concurrent chemo-radiotherapy in locally advanced hypo pharyngeal cancers- A hospital registry based analysis. *Asian Pac J Cancer Prev* 2015;16:4723-6. PMID:26107231
13. Krishnatreya M, Rahman T, Kataki AC, Lahkar K. Synchronous primary cancers in the head and neck region and upper aero digestive tract: Role of endoscopy. *Indian J Cancer* 2015;52:53-6 PMID: 26837973
14. Das RJ, Kataki AC, Sharma JD, Baishya N, Kalita M, Krishnatreya M. A study of head and neck cancer patients with special reference to tobacco use and educational level. *Clin Cancer Invest J* 2017;6:21-5
15. Kataki AC, Sharma JD, Krishnatreya M, Baishya N, Barmon D, Deka P, Kalita M. A survival study of uterine cervical patients in the North East India: Hospital-cancer registry based analysis. *J Cancer Res Ther* (Ahead of print)
16. Kataki AC, Sharma JD, Krishnatreya M, Baishya N, Kalita M. Patterns of tobacco use in patients with upper aero-digestive tract cancers: A hospital-based study. *J Cancer Res Ther* (Ahead of print)

## Research and publications based on Registry data

**Aleyamma Mathew**      **Jagathnath Krishna KM**  
**Preethi Sara George**      **Paul Sebastian**  
**Kalavathy MC**

PBCR and HBCR–RCC, Trivandrum

Cancer registry covering Thiruvananthapuram (Trivandrum) Taluk (1.1 million population) has been included under the network of NCRP of ICMR since 2006 with retrospective data collection since 2005. Further, the Taluk registry has been expanded as district registry (3.34 million population) and has been included it under the network of NCRP since 2012. Thus a total of 12 year Taluk data and 5-year District data are presently available. Utilising these data, we published several papers and collaborated on several research studies and projects during 2016-2017 and are provided below.

### I. Data utilisation for Publications

#### I a. Indexed Journals

**1. Mathew A, George PS, Kalavathy MC, Padmakumari G, Krishna KMJ, Sebastian P. Cancer incidence and mortality: district cancer registry, Trivandrum, south India, APJCP (2017).**

This paper provided the first results of cancer incidence and mortality [Crude (CR) and age-standardized (ASR)] rates (world-standard population) of Trivandrum district and compared with other registries under the NCRP network. During 2012-2014, registry recorded 15,649 incident cases and 5667 deaths. Proportion of microscopic diagnosis was 85% and 'Death certificate only' was 8%. Total cancer incidence (CRs) rates were 161 and 154 (ASR: 142.2 and 126) and mortality rates were 66 and 49 (ASR: 54 and 37) per 10<sup>5</sup> males and females respectively. Common cancers in males were lung (ASR:19), oral cavity (ASR:15), colo-rectum (ASR:11.2), prostate (ASR:10.2) and lymphoma (ASR:7) and in females, breast (ASR:36), thyroid (ASR:13.4),

cervix-uteri (ASR:7.3), ovary (ASR:7) and colo-rectum (ASR:7). Nationally, the highest CRs for breast, prostate, colo-rectum, corpus-uteri and urinary bladder cancers and low incidence of cervix-uteri cancer were observed in Trivandrum. Cancer incidence (CR) in Trivandrum was the highest in both genders in India (except Aizwal). This is mainly due to the highest life expectancy in Kerala.

**2. Mathew A, George PS, Krishna KMJ, Kalavathy MC and Sebastian P. Urban-rural gradients in cancer incidence and mortality among males in Trivandrum, Kerala. BAOJ Cancer Res Ther 2: 029 (2017).**

This paper assessed disparities of cancer incidence and mortality among males in urban and rural populations of Trivandrum. Crude incidence rates (per 10<sup>5</sup>) were 181 in urban and 149 in rural (ASR: 149 in urban & 122 in rural) with 21% higher incidence (CI: 1.2-1.3) and 7% mortality (CI:1.0-1.16) and lower fatality (mortality/incidence) (38.3% urban vs. 43.0% rural) in urban. Common cancers were lung (CR: 19.2, ASR: 15.4), prostate (CR: 19.0, ASR: 15.0) and colo-rectum (CR: 15.3, ASR: 12.4) in urban and lung (CR: 21.7, ASR: 17.5), colo-rectum (CR: 11.3, ASR: 9.2) and mouth (CR: 8.5, ASR: 6.8) in rural. Higher incidence of 135% were observed for prostate (95% CI: 2.0-2.8), 70% kidney (CI: 1.3-2.3), 59% urinary bladder (CI: 1.3-2.0) and 36% colo-rectum (CI: 1.2-1.6) and lower incidence (12%) of lung cancer (RR: 0.88, CI:0.8-1.0) in urban. A distinction is drawn in cancer incidence and mortality between urban and rural population in Trivandrum. Higher incidence of prostate, colo-rectal and genito-urinary cancers might be due to some changes in life-style factors.

**3. Mathew A, Kalavathy MC, George PS, Krishna KMJ, Sebastian P. Urban-rural disparities in female cancer incidence and mortality in Trivandrum, South India. *Annals of Translation Medicine and Epidemiology* (2017).**

This paper assessed the pattern of cancer incidence and mortality among females in urban and rural populations of Trivandrum. Combination of all cancer incidence rates (per 10<sup>5</sup>) were 177.2 (ASR: 137.7) in urban and 142.6 in rural (ASR: 112) and showed a higher incidence (RR: 1.23; CI: 1.2-1.3) and mortality (RR: 1.09; CI: 1.01-1.18) and lower fatality (mortality/incidence) in urban (29.2% urban vs. 33.1% rural) for 2012- 2014. Common cancers in urban were breast (CR: 55.4, ASR: 42.2), thyroid (CR: 15.1, ASR: 12.5), ovary (CR: 11.1, ASR: 8.6) and colo-rectum (CR: 10.6, ASR: 8.0), and in rural, these were breast (CR: 38.8, ASR: 29.9), thyroid (CR: 16.5, ASR: 13.7) and cervix uteri (CR: 9.4, ASR: 7.0). Striking higher incidence in urban were for corpus uteri (RR: 1.85, CI: 1.5-2.3), breast (RR: 1.41, CI: 1.3-1.5), ovary (RR: 1.40, CI: 1.2-1.7) and colo-rectum (RR: 1.35; CI: 1.1-1.6). A distinction is drawn in cancer incidence and mortality between urban and rural women in Trivandrum. Higher incidence of breast, corpus uteri and colo-rectal cancers might be due to some changes in life-style factors and improved health care access in urban population.

**4. Mathew A, George PS, James FV, Jayakumar KL, Kumar A, Arjunan A, Mathew BS. Age at diagnosis and mortality due to breast and cervix uteri cancers in Trivandrum, South India, *BAOJ Cancer Res Ther* (2017).**

This paper assessed the age at incidence and mortality of breast (BC) and cervix uteri (CC) cancers reported in the cancer registry, Trivandrum. Incidence rates (per 10<sup>5</sup>) were 51 and 9 and mortality rates were 9 and 2.4 for BC and CC respectively for 2014-2015. Mean and median age at diagnosis was similar for BC (55 years) and these were similar for CC also (60 years). The mean/median age at mortality was 4 years lower for BC (56 years). The difference between mean/median age at

diagnosis and mortality for BC was only <2 years and the same difference were almost similar for CC. 35% of both the diseases were diagnosed in stages III/IV with the lowest age at diagnosis in stage IV. Age at diagnosis of BC was much lower particularly for late stage women than that in western countries. Contrary to this, the mean/median age at diagnosis of CC was much higher than that in western countries. Due to the burden and higher young age mortality due to BC, the productive role of women years was lost largely in the society.

**5. George PS and Mathew A. Spatial distribution of cancer in Trivandrum, India Using Geographic Information System: Pilot Study. *Academic Journal of Cancer Research*, 9(3): 35-41 (2016).**

This paper assessed the density map of all cancers together and common cancers by gender in Trivandrum. Cancer registry incidence data from Trivandrum Taluk for the year 2012 and Geographic Information System (GIS) were used. From density maps CRs ranged 150-494 in 58% areas (CR >300 in 14.8% area) in males and CRs ranged 150-551 in 54.5% areas (CR >300 in 14.5% area) in females. 21.7% of all cases were in coastal, 65.5% in residential and 12.8% in forest areas. In males, common cancers were lung (CR >50 in 10% area) and prostate (CR >50 in 6.5% area) and in females, breast (CR >100 in 10% area) and thyroid (CR >50 in 5% area), 36.3% of breast cancer in residential (p= 0.021) and 20.8% of thyroid cancer in coastal areas (p=0.001). This study located high cancer incidence areas in Trivandrum Taluk and demonstrated effective use of cancer registry data and technological advancements in cancer research.

**6. Mathew A, George PS, Arjunan A, Augustine P, Kalavathy MC, G Padmakumari G, Mathew BS. Temporal Trends and Future Prediction of Breast Cancer Incidence Across Age Groups in Trivandrum, South India. *APJCP*, 17 (6), 2895-2899 (2016).**

This paper estimated trends in incidence by age from 2005-2014, to predict rates through 2020 and to assess the stage at diagnosis of BC in Trivandrum. Breast

cancer accounted for 31% (2681/8737) of all female cancers in Trivandrum. Thirty-five percent (944/2681) were <50 years of age and only 9% present with stage I disease. Average age increased from 53 to 56.4 years ( $p=0.0001$ ), CR (per  $10^5$  women) increased from 39 (ASR: 35.2) to 55.4 (ASR: 43.4), AAPC for CR was 5.0 ( $p=0.001$ ) and ASR was 3.1 ( $p=0.001$ ). Rates increased from 50 years. Predicted age-specific rate is 174 in 50-59 years, 231 in > 60 years and overall CR is 80 (ASR: 57) for 2019- 20. Breast cancer, mostly diagnosed in advanced stages, is rising rapidly in Trivandrum with large increases likely in the future; particularly among post-menopausal women. This increase might be due to aging and/or changes in lifestyle factors.

**7. Mathew A, James FV. Prostate cancer trends in developing countries. *Cancer Stud Mol Med Open J.* 3(1): e1-e2 (2016).**

This paper estimated trends in incidence of prostate cancer in Trivandrum by age from 2005-2014. Trends in incidence rates (average annual percent changes) were estimated using joinpoint regression model. Increasing trends in incidence has been observed in Trivandrum.

**I b. Proceedings**

1. Mathew A, George PS, Kalavathy MC, Krishna KMJ and Sebastian P. Public health burden of cancer among women in Kerala. 29th Kerala Science Congress 2017, p 969-976.
2. Mathew A. Cancer registry statistics for public health assessment, 2<sup>nd</sup> International Conference on Statistics for twenty first century 2016, p. 17-18.
3. George PS, Mathew A. Cut point determination methods for a continuous covariate with a time to event outcome, 2<sup>nd</sup> International Conference on Statistics for twenty first century 2016, p. 29.
4. Krishna KMJ, George PS, Mathew A. Cancer survival using mixture models, 2<sup>nd</sup> International

Conference on Statistics for twenty first century 2016, p.22.

**I c. Indexed publications of the registry staff for other studies**

1. Krishna KMJ, Mathew A, George PS. Cancer Survival Estimates Due to Non-Uniform Loss to Follow-Up and Non-Proportional Hazards, *APJCP*, 18 (6), 1493 – 1497 (2017).
2. Tomar TS, Sucheta, Rema, Mathew A, Krishna KMJ (2017): Role of laparoscopy in predicting surgical outcomes in patients undergoing interval cytoreduction surgery for advanced epithelial ovarian carcinoma: a prospective validation study, *Indian Journal of Cancer* (in press).
3. Anjanappa M, Jayadevan ER, Bhasi S, Koshy SM, George PS, Arjunan A, Raghukumar P, Mathew, BS. (2017). Radiosurgery for Arteriovenous Malformations Using Micro-Multi-leaf Collimators: Analyses of Outcome. *Indian Journal of Neurosurgery* 6 (02), 095-098.
4. Neeta S, George PS, Girija Devi PS (2017) Diagnostic utility of RNFL Thickness and Macular GCC Thickness in Primary Open Angle Glaucoma using Spectral Domain Optical Coherence Tomography in South Indian patients. *Journal of Medical Research and Clinical Research.* 5 (6). 22926-22931.
5. Nair LM, Kumar RR, Thomachan KC, Rafi M, George PS, Krishna KMJ (2017): Phase IIb trial comparing two concurrent cisplatin schedules in locally advanced head and neck cancer. *South Asian J Cancer*, 6, 64-68.
6. Jayakrishnan K, Geetha S, Krishna KMJ, Thomas G, Sebastian P (2016): Tobacco and Alcohol use and the Impact of School Based Anti-Tobacco Education for Knowledge Enhancement

Among Adolescent Students of Rural Kerala, India, *Journal of Addiction*, 1-8,

7. Rajasree O, Subha R, Rachel CK, Krishna KMJ (2016): A survey on the use of low flow anaesthesia and the choice of inhalational anaesthetic agents among anaesthesiologists of India, *Indian Journal of Anaesthesia*, 60(10), 59-64.
8. Prabha NG, Subair MK, Rajan B, Koshy AG, Sunitha V, George PS, Praveen V. (2016). Geographical variation in the clinical presentation of endomyocardial fibrosis. *Indian Heart Journal*.
9. Kalavathy MC, Mathew A, Sujathan K, Saritha VN, Krishna KMJ, Jayasree K (2016). Squamous Cell Abnormalities and Risk Factors on 10,979 Pap-Smears in a Tertiary Care Hospital in Trivandrum, South India. *International Journal of Science and Research (IJSR) ISSN (Online): 2319-7064*.
10. Arjunan A, Anjumol P, Ratheesan K, Kusumakumary P, Priyakumari T, Mathew BS, Jiji V, Mathews A, Mathew A, Krishna KMJ (2016). Cr-08 retrospective Analysis of Paediatric Craniopharyngioma: A Single Institution Experience, *Neuro-Oncology*, 18 (3), 18-23.

## II. Data utilization for projects

### II a. Epidemiological projects

#### 1. Comparative study of Genetic, Clinical and Epidemiological factors of Breast Cancer in Indian population.

Investigators: Dr. Paul Sebastian, Dr. Aleyamma Mathew, Dr. Lekshmi S, Dr. Beela Sarah Mathew, Dr. Paul Augustine, Dr. Jayasree K, Dr. Anitha Mathews, Dr. Preethi Sara George

The main aim of this study is to evaluate the risk factors and genomic basis of breast cancer in India with specific objectives are to determine Life-style, clinical, Hormonal and other factors associated with breast cancer and to identify the mutational landscape of breast cancer (exome & transcriptome with validation).

#### 2. Density Mapping and Environmental factors of Cancer in Thiruvananthapuram District using Geographic Information System (GIS)

Investigators: Dr. Preethi Sara George, Dr. Aleyamma Mathew, and Dr. Jagathnath Krishna K M.

The main objectives of this study are to assess cancer density maps in the district by gender using Geographic Information System (GIS), to examine the relationship between cancer incidence and its elevation as well as land cover in the district and to examine whether any environmental factors are associated with the cancer risk in Thiruvananthapuram district.

#### 3. Reasons for Diagnostic Delay, Treatment Refusal/ Incompleteness, and Loss to Follow-up: A Hospital-Based Cancer Registry Study in Trivandrum, India.

Investigators: Dr. Aleyamma Mathew, Dr. Paul Sebastian, Dr. Preethi Sara George, Dr. Kalavathy MC and Dr. Jagathnath Krishna K M.

The main objectives of this study are to assess the timeliness of cancer diagnosis and initiation of cancer treatment, to assess the proportion of patients who: a) received any cancer-directed therapy; b) received an incomplete course of treatment; c) who were offered treatment but do not accept it to assess the proportion of patients who completed radical treatment but are loss to follow-up, to assess the reasons for treatment refusal/incompletion and loss to follow-up including use of alternative health systems, to assess the socio-demographic factors associated with diagnostic/ treatment delays, treatment refusal/incompletion; and use of alternative health systems.

## II b. Cancer surveillance programmes

### 1. Population Based cancer survival on breast, cervix and head & neck cancers

Investigators: Dr. Aleyamma Mathew, Dr. Preethi Sara George, Dr. Kalavathy MC, Dr. Jagathnath Krishna KM and Dr. Paul Sebastian

Follow-up updation of the above cancers was started in 2017. This project is in collaboration with NCDIR of ICMR.

### 2. Pattern of care and survival studies on breast, cervix and head & neck cancers

Investigators: Dr. Paul Sebastian, Dr. Aleyamma Mathew, Dr. Beela Sara Mathew, Dr. Francis V James and Dr. Ramadas K, Dr. Preethi Sara George

Systematic data abstraction on patterns of care and survival in cancers of the uterine cervix, breast and head and neck cancer patients reporting to the RCC has been started since 2006 in collaboration with the NCRP of ICMR. More than 30,000 patient data is abstracted & follow-up information is updated regularly.

### 3. Pattern of care and survival studies (only ovarian cancers)

Investigators: Dr. Paul Sebastian, Dr. Aleyamma Mathew, Dr. Francis V James, Dr. Rema P, Dr. Preethi Sara George

Systematic data abstraction of ovarian cancers to obtain survival of this cancer started in 2017 in collaboration with the NCDIR. This programme includes a detailed cancer patient data abstraction (diagnostic, stage, treatment and follow-up details).

### 4. Attributing death to cancer: Relative survival estimation in Kerala

Investigators: Dr. Preethi Sara George, Dr. Paul

Sebastian and Dr. Aleyamma Mathew

The main objectives of this study are to estimate relative survival of all cancers in Thiruvananthapuram district and the common cancers by gender, age and residence status in the district using life-tables.

### 5. The Impact of Socioeconomic Status (SES) on Stage and Survival of Gastrointestinal Cancer: A Comparative Study of Canada and South India.

Investigators: Dr. Aleyamma Mathew, Dr. Roshni S., Dr. Chandramohan K, Dr. Preethi Sara George and Dr. Christopher Booth.

The main objectives of this study are to compare the association between SES and stage of gastrointestinal cancer at diagnosis in Trivandrum district, to compare the association between SES and survival in the district, to compare the extent to which stage of cancer at diagnosis explains any difference in survival across SES groups, to compare and contrast the relationship between SES/stage/survival in the district with data from Ontario.

### 6. The impact of Socioeconomic Status (SES) on Stage of Cancer at Diagnosis (oral cavity, breast, cervix and lung) Survival: A Comparative Study of Canada and South India

Investigators: Dr. Aleyamma Mathew, Dr. K. Ramadas, Dr. Beela Sarah Mathew, Dr. Aswin Kumar, Dr. Roshni S, Dr. Preethi Sara George and Dr. Christopher Booth

In this study we will evaluate SES, stage of disease, and survival in Canada and South India. The main objectives of this study are to compare the association between SES and stage of cancer at diagnosis in Kerala and Ontario, to compare the association between SES and survival in Kerala and Ontario and to compare the extent to which stage of cancer at diagnosis explains any difference in survival across SES groups in Kerala and Ontario.



## II c. Biostatistics projects

### 1. Modeling of recurrent and terminal events in cancer survival due to non-proportionality in follow-up and hazards

Investigators: Dr. Jagathnath Krishna K M, Dr. Aleyamma Mathew, Dr. Preethi Sara George

The proposed study aims to develop a method to reduce the bias in risk estimates of prognostics factors with different proportion of follow-up, to derive statistical test in presence of non-proportional hazards, to derive joint frailty model for estimating survival probability and to assess the properties and estimate the parameters of the joint frailty model. The derived methods will be illustrated using realistic data from the RCC, Thiruvananthapuram.

### 2. Weighted mixture cure rate modeling for cancer survival data

Investigator: Dr. Jagathnath Krishna K M

The objectives of the study are to derive weighted mixture cure rate model for cancer survival data, to estimate the parameters of the weighted mixture cure model, to compare weighted mixture cure rate model with non-mixture cure rate and survival models and to validate the weighted mixture cure rate model using cancer survival data.

### 3. Mathematical model for competing risks in cancer survival: Data mining techniques

Investigators Dr. Preethi Sara George & Dr. Aleyamma Mathew

The objectives of the proposed study are to develop an appropriate decision tree model for competing risks survival time data and validate the model using cancer patient survival data. The specific objectives are to develop a theoretical decision tree CART model for cumulative incidence function of competing risks, to

compare the performance in terms of the number and type of variables and sample size for the newly developed decision tree CART model and the extended Cox-Proportional Hazards Regression model and to validate the CART model using cancer survival data.

## II d. Clinical Projects

1. Survival outcome and morbidity profile after interval cytoreductive surgery in advanced epithelial ovarian cancers.

Investigators: Dr. Rema P, Dr. Suchetha S & Dr. Aleyamma Mathew

2. Treatment outcome in the management of intracranial hemangiopericytoma: A retrospective study

Investigators: Dr. Asha Arjunan, Dr. Ancy George, Dr. Biju Azariah M, Dr. Aleyamma Mathew, Dr. Anitha Mathews, Dr. Rajeev K. R., Dr. Jagathnath Krishna K M, Dr. Preethi Sara George

3. A prospective cross sectional study among patients to estimate the prevalence of chronic post-surgical pain (CPSP)

Investigators: Dr. Rajasree O, Dr. Rachel Cherian Koshy, Dr. Elizabeth M Iype, Dr. Kurien Cherian, Dr. Hereen Antony, Dr. Jagathnath Krishna K M

4. Audit of female ovarian germ cell tumours treated in RCC-trivandrum during 2006-2016

Investigators: Dr. Francis V James, Dr. Aswin Kumar, Dr. Susan Mathews, Dr. John Joseph, Dr. Pallavi Nair, Dr. Suchetha S, Dr. Preethi Sara George

5. Performance of colposcopic scoring by modified IFCPC terminology for diagnosing cervical intra epithelial neoplasia in a low resource setting. Investigators: Dr. Rema P, Dr. Suchetha S & Dr. Aleyamma Mathew

6. Adenoideystic carcinoma of head and neck region:  
Analysis of treatment outcomes  
CO2 laser surgery vs radiation therapy for ealy  
glottis carcinoma
- Investigators: Dr.Malu Rafi, Dr. Milan D, Dr. Kainickal  
CT, Dr. Preethi Sara George, Dr. Rejnish Kumar R, Dr.  
Tapash B, Dr. Ramadas K
- Investigators: Dr. Elizabeth Mathew Iype, Dr.  
Ramadas K, Dr. Bipin T Varghese, Dr. Anitha Francis,  
Dr. Aleyamma Mathew, Dr. Keshavarajan G.
7. Validation study of feasibility of sentinel lymph node  
sampling in early carcinoma endometrium
- Investigators: Dr.Suchetha S, Dr. Pradeep, Dr.  
Aswathy G Nair, Dr. Rema P, Dr Anila, Dr. Rari, Dr.  
Aleyamma Mathew
13. Radiation in the management of primary orbital  
lymphoma: Retrospective study
- Investigators: Dr. Aswin Kumar, Dr. Anjali VR, Dr. N  
Geetha, Dr. Jagathnath Krishna K M, Dr. Francis V  
James, Dr. Ancy George
8. Change in quality of life of patients undergoing  
different treatment protocols of advanced  
carcinoma esophagus and OG junction
- Investigators: Dr. Chandramohan K, Dr. Sajeed A, Dr.  
Arun Peter Mathew, Dr. Preethi Sara George
14. Quality of life and functional outcome in long term  
survivors of osteosarcoma
- Investigators: Dr.Geetha N, Dr. Harish S, Dr. Sreejith  
Nair, Dr. Prakash NP, Dr. Aleyamma Mathew
9. Retrospective analysis of adeno carcinoma  
rectum-A clinical audit
- Investigators: Dr. Roshni S, Dr. Preethi Sara  
George, Dr. MadhuMuralee, Dr. Lijeesh AL, Dr. CD  
Sivanandan, Dr. Sajeed A, Dr.ArunSankar, Dr. Geethi  
MH, Dr. Chitra AV, Dr. Nityanandan
15. P-glycoprotein expression in newly diagnosed  
acute myeloid leukemia in adults and its impact on  
treatment outcome
- Investigators: Dr.Geetha N, Dr. Sugeeth MT, Dr.  
Sreejith Nair, Dr. Prakash NP, Dr. Lakshmi S, Dr.  
Aleyamma Mathew
10. Pap-smear screening programme among women  
attending peripheral cancer detection campaigns  
in Thiruvananthapuram: A retrospective Analysis
- Investigators: Dr. Kalavathy MC, Dr. Aleyamma  
Mathew, Dr. Sujathan K, Dr. Jayasree K
16. The impact of gutkha ban on tobacco  
consumption behavior in Kerala
- Investigators: Dr. Jayakrishnan R, Dr. Aleyamma  
Mathew, Dr. Paul Sebastian
11. Pap-smear screening programme among women  
with gynecological problems reported in a hospital:  
A retrospective Analysis
- Investigators: Dr.Kalavathy MC, Dr. Aleyamma  
Mathew, Dr. Sujathan K, Dr. Jayasree K
17. Analysis of clinical outcomes in patients with  
atypical teratoid/ rhabdoid tumour treated at  
Regional Cancer Centre, Thiruvananthapuram: A  
retrospective analysis
- Investigators: Dr. Asha Arjunan, Dr. GouriSomanath,  
Dr. Kusumakumari P, Dr.Priyakumari T, Dr. Binitha R,  
Dr. Manjush T, Dr. Beela Sarah Mathew, Dr. Ratheesan  
K, Dr. Anitha Mathews, Dr. Aleyamma Mathew
12. Treatment outcomes of transoral microlaryngeal

18. Clinical outcome of intracystic papillary carcinoma breast: A retrospective study
- Investigators: Dr. Asha Arjunan, Dr. Shabna Abbas, Dr. Biju Azariah M, Dr. Jagathnath Krishna K M, Dr. Preethi Sara George, Dr. Rajeev K R
19. Ten year survival of patients with well differentiated thyroid cancers: A retrospective analysis
- Investigators: Dr. Elizabeth Mathew Iype, Dr. Pradeep VM, Dr. Keshavarajan G, Dr. Minolin, Dr. Aleyamma Mathew
4. Pooja B. Nair. Cure rate modeling for cancer survival (2017)
5. Reshma VR. Classification and regression tree model in predicting breast cancer survival (2017)
6. Anagha Menon VU. Determination of optimum cut point to separate high and low risk patients in cancer survival (2016)
7. Anju S. diabetes mellitus and endometrial cancer: a meta-analysis (2016)
8. Aswin R. Mixed modelling for cancer survival (2016)
9. Surya S. Biasedness in cancer survival due to non-proportional hazards (2016)

### III. Data Utilization for Human Resources

#### III a. Post graduates/ MCH/ DM students in RCC

A total of 30 (PG, MCH and DM) students in RCC were trained in biostatistics. A total of 82 lectures were given by the faculties during 2016-2017. Further, we provided assistance for carrying out research studies; starting from sample size calculation, designing the study, analysis and interpretation of data and for the preparation of research article.

#### III b. Biostatistics studies

The following 9 students from the Mahatma Gandhi University, Kottayam had undergone two-months training in Epidemiology and completed their post-graduate thesis 2016-2017.

1. Ananthakrishnan B. Medical history and family history of cancer and the risk of breast cancer: a case-control study (2017)
2. Anju Eldhose. Reproductive risk factors for breast cancer: a case-control study (2017)
3. Jayalakshmi M.R. Role of anthropometric, physical activity and dietary factors on the development of breast cancer: a case-control study (2017).

#### III c. Doctoral Students

Currently provides guidance to 8 students in Epidemiology and 2 students in Biostatistics. In 2016, one student received degree (Dr. Sona PS, Assistant Professor, Govt. college of Nursing, Medical college, Trivandrum) and in 2017 one submitted thesis (Dr. Kalavathy MC, Assistant Professor in Epidemiology, RCC).

## REPORTS FROM REGISTRY

## Report from PBCR- Bangalore

### C. Ramesh

Professor and Head, Department of Epidemiology and Biostatistics,  
Kidwai Memorial Institute of Oncology, Bengaluru (Karnataka)

1. Several training programmes were conducted to train Medical Records staff of various sources contributing data to Bangalore PBCR
2. Demonstration of software “e-Mor” developed by NCDIR was done on 10<sup>th</sup> February 2017 by NCDIR staff and a Pilot study on use of this software was conducted and the feedback shared with NCDIR

### Participation of registry staff in meetings/conferences/workshops

The following staff of the department of Epidemiology and Biostatistics participated in the 31<sup>st</sup> Annual Review Meeting held at Naga Hospital authority, Kohima from 11/11/2016 to 12/11/2016 at Nagaland

Dr. K.B. Lingegowda, Director & Principal Investigator (PBCR & HBCR)

Dr. C Ramesh, Professor and Head and Co-Principal Investigator

Sri. Vijay C R, Assistant Professor

Dr. B R Gopala krishnappa, Senior Biostatistician,PBCR

Sri. Bhadraiah, Assistant Social Scientist

Sri. MKM Gowda, Assistant Social Scientist

Smt. Kumudini Assistant Social Scientist

1. Dr. C. Ramesh delivered a talk “Cancer – An Overview”, on the occasion of World Cancer Day, 4<sup>th</sup> February at KMIO, Bangalore.
2. Dr. C. Ramesh chaired the session “Indian CNS Tumor Registry Initiative “during 9<sup>th</sup> Annual conference of Indian Society of Neuro Oncology,

on 12<sup>th</sup> March 2017 held at Bangalore

3. Dr. C. Ramesh was invited to participate for the Stakeholder Forum on Childhood Cancer Epidemiology in India, on 28<sup>th</sup> April 2017 at New Delhi.
4. Dr. C. Ramesh delivered a talk “Cancer – An Overview”, on the occasion of world cancer Day, 4<sup>th</sup> February at KMIO, Bangalore.

### Ph.D. Awarded

Dr. D.J. Jayaram was awarded Ph.D. on 11<sup>th</sup> May 2017 from School of Health Sciences, University of Tampere, Finland for his work “Microscopically confirmed pharyngeal cancer in South India – An epidemiological case-control study”. The staff of the Department convey their Hearty congratulations to him



**From left to right: the opponent Cherian Varghese, international coordinator Catarina Stahle-Nieminen, doctoral candidate Jayaram D J, and the Kustos Professor Emeritus Matti Hakama**

## Superannuation

Sri. V. Bhadrach, Assistant Social Scientist, who served the Hospital Based Cancer Registry since its inception (served more than three decades) superannuated on 31<sup>st</sup> May 2017. The staff of the department and registry acknowledges his valuable contribution to the registry.

## Other activities carried out by the registry staff

I) Department of Epidemiology and Biostatistics has submitted a proposal to Government of Karnataka to take up systematic screening activity in Karnataka with a pilot study at Kanakapura taluk. The initial plan to take up cancer awareness and screening for Oral cancers, Cancer Breast and Cancer Cervix in Kanakapura taluk with the objective of

1. To carry out a mass awareness campaign about cancer, its warning signs with a focus on the importance of early diagnosis in treatment of cancer by conducting seminar, group discussion, showing videos in panchayath level with help of health departments women and child welfare department (ASHA workers).
2. To identify individuals showing the warning signs/symptoms rising suspicion of cancer.
3. To locate and find the Number of existing cases of cancer already diagnosed so as to identify the needs to strengthen preventive, treatment and palliative care facilities.
4. Capacity building amongst the 'Accredited Social Health Activists (ASHAs)', ASHA Facilitators, 'Auxiliary Nurse Midwives (ANMs)', 'Multipurpose Health Workers (MPHWs Male)', the Nursing Students, Medical and Para Medical manpower.
5. Explaining benefits about Government health schemes like 'Vajpayee Arogya Shree', schedule caste and schedule tribes and others

The vast exercise is to be undertaken by way of conducting campaigns at village panchayath level associated with primary health center and ASHA and MPHWS (F&M) in the rural areas and in the urban areas, the same shall be carried out by the students of nursing institutes in taluk areas.

## The main Goals are

1. Generation of awareness about cancer amongst the masses.
2. To create awareness about government schemes about health concern (Vajpayee Arogya shree, SC/ST)
3. To know the pattern of cancers in Kanakapura Taluk
4. Identification of the existing patients suffering from cancer.
5. Assortments of those cancer cases who have received any financial help from any agency and those who have been left out.
6. Proportion of the number of cancer patients in the respected areas.
7. Identification of persons depicting the warning signs.
8. Detection of early cases of cancer on the basis of symptoms and their medical examination and medical aid to them.
9. Diagnose of the cause of the symptoms and medical aid to the patients who don't turn out to be the cancer patients.
10. Enhancement of the capacity of the field workers ASHAs, ASHA Facilitators, Panchayath members, ANMs, LHV's, Supervisors and the Medical Staff.
11. Assessment of the regional difference in the occurrence of cancer cases (between rural and

urban)

I) Increased awareness about risk factors

Couple of meetings was held with Deputy Commissioner and District Health Officer and other officials of Ramanagara district involved in this project. Subsequently a final proposal is sent to the government for approval.

II) Bharath Electronics Limited (BEL) has agreed to donate fully equipped Cancer Detection Bus worth Rs. 2 crore, under CSR funds to Kidwai Cancer Institute. The staff of the department are actively involved in preparing the proposal, providing technical specifications and monitoring the progress of the project. The Mobile unit will be ready for use by February 2018

III) The staff of the department have involved in conduction of 'cancer awareness programme' organized by the National Service Scheme, Schools and colleges.

IV) A workshop was organized for farmers who are growing tobacco on the occasion of 'World No Tobacco day' on 31<sup>st</sup> May 2017. This was primarily intended to create cancer awareness and to motivate them to grow alternative crop to tobacco. Many experts from the field of agriculture, food scientists delivered lectures. Dr. C. Ramesh delivered a talk on this occasion on 'Burden and Economics of Tobacco Related Cancers in India'.

## The District Cancer Registry, Kollam, the 1<sup>st</sup> Population Based Rural Cancer Registry in Kerala, India - Problems and Achievements

P. Jayalekshmi, Rohith Mohan, Geetha M. L,  
Jyothisree. R, Harikrishnan. K, Paul Sebastian  
PBCR, Kollam, Kerala

### Natural Background Radiation Cancer Study - 1990

Regional Cancer Centre, Thiruvananthapuram initiated the natural background radiation studies in Karunagappally taluk in 1990. The study was initiated due to the public concern that radiation causes cancer and also scientific demand for authentic data on cancer in the radiation area. The public voiced their concern in assemblies and in parliament regarding the increased occurrence of cancer in the people who exposed to radiation by the coastal sands of Karunagappally taluk.

The methodology of the study was socio-demographic survey covering the whole taluk population, Radiation measurements of all houses and registration of all cancer cases occurring in the taluk. As part of the study almost 4 lakh people were enumerated and 1 lakh houses' radiation level was measured. Now this population study is continued as a radiation cohort study. The PBCR organized to cover the taluk is identified as a 'Special Purpose Registry'. The results so far indicated no excess incidence of cancer in relation to radiation in this area. There are in depth studies ongoing to assess the biological effects of radiation.

### Organisation of Natural Background Radiation Registry – Special Purpose Cancer Registry

'Natural Background Radiation Registry (NBRR)' was organized along with the study initiated in 1990. Cancer registry organisation in a rural area in Kerala is a formidable task. Health infrastructure and health awareness was minimal when registry started in 1990. Moreover there was no dedicated cancer

detection or treatment facility in this area. Such facilities were located in nearby major towns and in Thiruvananthapuram, capital of Kerala, which are at a distance of 100 km. Socio economic problems and the distance restricted the patients to go for either detection or treatment of cancer and follow up.

Considering the sufferings of the patients and the lack of early cancer detection services in Karunagappally taluk, we initiated review clinics in Karunagappally with the specialist of Regional Cancer Centre. We had also organised a well-equipped cytology laboratory in the registry office. The cancer awareness classes and cancer detection camps were regularly organized by close interaction with the community. The trained field investigators visited the houses and motivated the people to attend the cancer detection camps convened in registry office and in the field. The field investigators also visited the houses of the deceased and the medical details regarding the cause of death were collected. Cross checking was done in every case with hospital and registry records. The study and the interaction generated co-operation of the public and the medical community which contributed to the success of the registry to a great extent.

Special Purpose Cancer Registration methodology was adopted for registering cancer cases. This included not only the socio-demographic details but also the radiation exposures were assessed. The innovative methods suited to this rural area for registering cancer cases together with the built in program for patient services helped to stabilize the cancer registration methodology. The data quality improved over time when follow up rate was optimized. The findings of the registry are of global importance and it is the



only one registry which is ongoing in India now which provides reliable data on exposure effect due to natural radiation and cancer in human population.

The cancer registry findings has not shown any increase in cancer incidence in Karunagappally taluk. The registry work is continuing.

### Cancer Atlas Project & Initiation of District Cancer Registry Kollam-2006

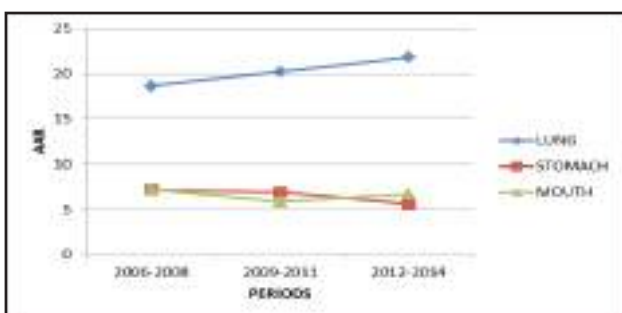
Cancer Atlas Project covering whole Kollam District started in 2001-2002 by NCRP indicated a higher incidence of cancer in Kollam district with a minimum age standardized rate for men as 106.5 (9<sup>th</sup> among all PBCRS and 90.7 for women -17<sup>th</sup> among all PBCRs). This observations prompted NCRP - ICMR to extend cancer registration to cover the whole Kollam district from the year 2006 onwards and named as 'District Cancer Registry', Kollam. Kollam DCR covers an area of 2483 Sq. Km with 2635375 (2011 census) population. District constitutes 1 corporation 68 panchayaths and four municipalities.

Initially the registry when started had only 60 sources

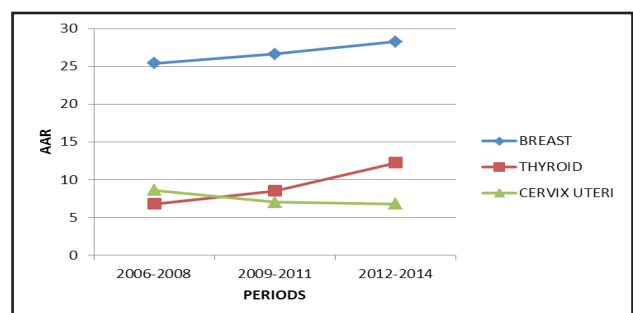
currently this have increased to more than 300 sources. The work force also had to be increased. The Kollam District Cancer registration also faced a lot of difficulties in data collection due to the special geographic and demographic features of Kollam District. The western boundary was the sea coast and eastern boundary was covered by high plantations. Field visits were very difficult in this hilly areas. The dedicated team of the registry staff and the long experience created an excellent rapport with the community in the registry areas especially among the medical services. Regular field visits attempted to approach the contact person Asha workers/palliative care nurses/village elders/ward members for collection of cancer information in the community. The incidence data reported by the registry was included in 4 volumes of the publications – 'Cancer incidence in 5 continents by IARC from 1991 to 2007 (CI5 VII-X)'

The incidence rates from 2006 to 2014 shows lung cancer occurrence is increasing & stomach and mouth cancers are decreasing among males. Lung cancer incidence stood in 5<sup>th</sup> position when compared to other population groups in India. The trends of leading sites are shown below.

**Fig1. Trends in 3 Leading Sites of Cancer among Males – Kollam 2006-2014 (Period Wise)**



**Fig 2. Trends in 3 Leading Sites of Cancer among Females - Kollam 2006-2014 (Period Wise)**

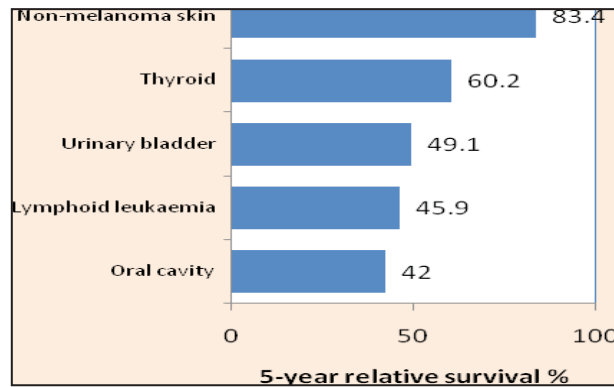


Among females, the breast cancer and thyroid cancer incidences increased over the years, cervix cancer incidence have been decreasing. High incidence of Thyroid cancer is also noted. It stood in the 3<sup>rd</sup> position when compared to other population groups.

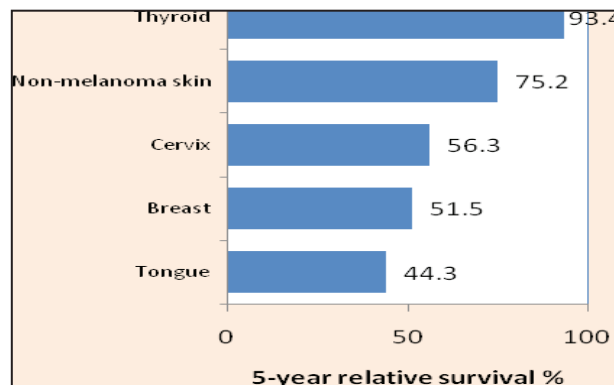
## Cancer Survival Studies

Cancer survival studies have been undertaken with the collaboration of IARC Lyon and CONCORD study group London from 1990 onwards. This gives a reliable estimate of the survival in the rural areas. The top five cancers ranked by survival during the follow up periods among the registry population are given in Fig. 3 and Fig. 4.

**Fig. 3 Top Five Cancers (Ranked by survival)  
Male, Karunagappally, India, 1991-1997**



**Fig. 4 Top Five Cancers (Ranked by survival)  
Female, Karunagappally, India, 1991-1997**



**Table 1. Top Five Cancers (Ranked by survival), Karunagappally, India (CONCORD 2)  
in Selected Sites (C50,C61,C53,C18,C20,C16,C56,C34,C22,C95)**

	1995-99	2000-04	2005-09
<b>Breast</b>	50.7	58.2	63.8
<b>Prostate</b>		33.8	55.3
<b>Cervix</b>	51.0	49.3	47.5
<b>Colon</b>		33.4	37.3
<b>Rectum</b>		41.2	30.1

The percentage survival of breast cancer among females has increased during 1991 to 2009 (51.5% to 63.8%). But the survival rate has decreased from 56.3% to 47.5% among females with uterine cervix cancers. Survival rate of prostate cancer has increased from 33.8% to 55.3% during 2005-2009 period.

## Cancer Control Activities & Cancer Patient Support Services

The patient services initiated in 1990 is continued with the support of local self-government and from 2000 onwards with the support of Health and Family Welfare Department, Govt. of Kerala. The financial support was obtained by convincing the community and stake holders about the cancer problem and the sufferings of the patients. With the fund support we had set up a viable infrastructure for cancer detection and cancer care. Registry is unique in activities in Kerala because this is the model programme of cancer detection in the community undertaken by

Grama, Block, Jilla Panchayath under the 'People's Planning Programme' from the year 2000 onwards. Public awareness classes, cancer detection camps, anti-tobacco programmes, professional re orientation in cancer control, palliative care, supportive care and home care services are rendered. Report of the services rendered during the last years given below (Table 2). Cancer control programmes undertaken targeting selected population such as scheduled caste people, coir workers, cashew workers and BPL groups helped in making awareness regarding early detection. A lot of poor people have undergone cancer detection and cancer treatment services. Resume of the services rendered are given below (Table 2).

**Table 2. Clinical activities and patient services (01/01/2006- 31/12/2016)**

Particulars	No.	Person Attended
Cancer awareness classes & Palliative care training programs	236	28002
Review clinics	60	6758
Pain clinics & Supportive clinics- Patient visits	Daily	61798
Field detection camps	713	1,15,295
Women undergone cervical cancer detection		38672
FNAC and Scrape (Cytology Investigations)		2381
Cancer cases detected		271

The studies undertaken by the registry involvement are survival studies with international collaboration of IARC LYON and CONCORD working group London School of Hygiene and Tropical Medicines U.K, Radiation epidemiologic studies supported by Government of Japan are the major ongoing work. This is the only one registry which provides authentic data on exposure natural radiation and cancer in human beings and the findings have gained global importance. There are more than 30 publications in indexed journals regarding the findings of the registry. The registry activities stabilised and continued with reporting reliable data on cancer load, optimising survival figures in the rural area. Moreover registry also provides leads for planning and control of the disease in Kollam district and we are happy in giving maximum service to the public and cancer patients especially because there is not committed oncology treatment centre in

the district.

### Acknowledgement

We are greatly acknowledged to The Director, Former Director and staff co-ordinating office NCDIR Bengaluru for the technical support rendered so far. District Medical Officer Kollam, Principal Medical Colleges, Medical Directors and staff members of Medical colleges Pathology labs, Hospitals who supported in registry activities are also acknowledged. Our special thanks to Oncologist RCC, HOD Epidemiology Division, Medical Record officer, Cancer Care Centre Staff members and all registry staff of HBCR Thiruvananthapuram and DCR Kollam. Our sincere thanks to all the funding agencies and officials of Local Area Development Department and Health and Family Welfare Department Govt. of Kerala.

## Impact of Cancer Registry in Arunachal Pradesh

### Sopai Tawsik

Principal Investigator, PBCR, Selection Grade Specialist (Pathology)

Tomo Riba Institute of Health and Medical Sciences, Naharlagun, Arunachal Pradesh

Arunachal Pradesh has joined network of cancer registries in 2011 with two 'Population Based Cancer Registries'(PBCR) one located at 'Tomo Riba Institute of Health Medical and Science' (TRIMHS) formerly known as Tomo Riba State Hospital, Naharlagun and the other at General Hospital Pasighat covering the Western and Eastern parts of the State respectively. The State is very sparsely populated with total population of 13, 83,727 as per 2011 census with 77% of population living in rural areas and 33% live in urban areas. The State is inhabited by 26 major and around 120 minor tribes with diverse culture, tradition and food habits.

Our registry covers western part of the Arunachal Pradesh comprising of 10 districts viz, Papumpare, KurungKumey, KraDadi, Lower Subansiri, Upper Subansiri, West Siang, Lower Siang, Tawang, West Kameng and East Kameng with total population of 7, 59,794. Our main sources of registration are Tomo Riba Institute of Health Medical and Sciences (TRIHMS), 'RKM Hospital Itanagar and Ambee Lab' in the capital city. Due to poor health infrastructure in other districts due to lack of diagnostic facilities we get few cases of districts. Our other main sources of registration are from hospitals outside our state e.g. BBCI Guwahati, TMH Mumbai and NEIGRIMS Shillong as many patients from our state go outside for cancer treatment.

In spite of lot of challenges our registry is trying to collect cancer data with local innovations:

1. We have made a PBCR desk at Tertiary cancer centre where one of the registry staff sits regularly and collect information of all cancer patients by direct interview.

Consultant pathologist at Ambeelab, Itanagar which is one of the major sources of registration fills the core proforma while signing off cancer reports with the help of lab staff who complete the demographic part of the proforma.

2. The in-charge of Medical Records of Rama Krishna Mission Hospital, Itanagar has been given responsibility to keep the records of all cancer cases of the hospital from whom our registry staff collects the data on fortnightly basis.
3. We mainly depend upon active follow up by telephone apart from hospital records to get mortality information as we don't have organized crematoria nor have proper Municipal set up which keep mortality records.
4. Registry staff undertake tours to districts at least twice a year to collect cancer data from district hospitals.
5. Sources outside the state like BBCI Guwahati, NEIGRIHMS Shillong, and TMH Mumbai do share cancer data to our registry every year.

In the beginning of 2017, Tertiary cancer centre (TCC) has started functioning at our hospital and free chemotherapy drugs are given to local tribal under the Chief Minister's flagship programme. 'Tertiary Cancer Centre'(TCC) will soon be upgraded to 'Tertiary Cancer Care Centre' (TCCC) for which Government of India has already given approval. Another positive development is that the Medical College is going to start functioning from 2018 in this hospital. With these developments, it is hoped that most cancer patients will get treatment

inside the state and cancer registration will be easier. In recent years health infrastructure in terms of diagnostics as well as treatment facilities has improved considerably in capital city of Itanagar and doctors trained in cancer management are also available.

Cancer registration has brought about positive impact on policy planners and people at large. Cancer Report of 2012-2014 from Arunachal Pradesh getting published for the first time is an eye opener for all:

1. Awareness level of people in general has improved significantly with more and more people coming for health checkup.
2. Health department of the Government started
3. Translational research initiatives has started coming. We had under taken one such project entitled "Risk factors of Hepatocellular Carcinoma" with Indian Council of Medical Research and more such project are in pipeline.
4. The state Government has issued a notification for compulsory registration of all cancer cases in 2015.
5. Government of Arunachal has launched free chemotherapy drugs to local populace of the state from July 2017.

### **Tomo Riba Institute of Health and Medical Science**



### **PBCR Staff - Naharlagun**



## Report from Registry - PBCR Patiala

**Working from 1st April, 2016 to 31st March, 2017**

### Introduction

Population Based Cancer Registry at Patiala started on 1<sup>st</sup> June 2011. It was inaugurated by Minister of Medical Education & Research Punjab at Deptt. Of Pathology, Govt. Medical College Patiala. Dr. Vijay Bodal as PI, Dr. MS Bal as Co-PI, Dr. Ms. Mohanvir Kaur as Co-PI and Dr. Ms. Vandana Singla as Co-PI, four social workers, one data entry operator are the PBCR team.

### 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 Patiala, Bathinda and Muktsar districts. They also examine the case record maintained by various departments of these hospitals viz. Pathology, Hematology, Radiology etc. All the information collected is cross checked for the completeness of the data. Sometime the patient may have registered his or her name in more than one hospital for treatment. So, care has been taken to exclude duplicates and to ensure that each patient is included only once in the data.

#### Mortality data collection at PBCR, Patiala

Social workers visit the offices of Civil Surgeon offices, Municipal Corporation and committees, PHC's under district's Patiala, Bathinda and Muktsar to collect information about deaths where the death certificates state the cause of death as cancer. 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, Bathinda and Muktsar but registered by other participating centres.

#### Electronic capture and processing of data: at PBCR Patiala

NCDIR-NCRP has provided Online Data Submission 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. Then data is submitted to NCDIR-NCRP.

#### At NCDIR-NCRP

The cancer data of Patiala, Bathinda and Muktsar District's residents collected from hospitals under Population Based Cancer Registry Program,(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 cancer incidence data. Unmatched mortality records form part of Death Certificates Only (DCO). Generation of statistical tables are done and sent to PBCR.

### **PBCR, Patiala 2016-2017 Promotional Events & Meetings**

- 1. May 06<sup>th</sup>-2016:** Meeting with Dr. Raja Paramjit Singh, HOD, Department of Radiotherapy at Guru Gobind Singh Medical College, Faridkot regarding collection of Cancer patient's data of District's Bathinda and Muktsar attended by Dr. Vijay Kumar Bodal(PI), Mr. Vicky Harinderpal and Mr. Dalvir Singh.
- 2. May 18<sup>th</sup> 2016:** Dissemination of Cancer Registry Reports(2012-2014), Conference hall, ICMR Headquarters New Delhi attended by Dr. Vijay Kumar Bodal (PI).
- 3. June 22<sup>th</sup> 2016:** Meeting with Dr. Monika (Monika path lab, Bathinda) , Dr. Deepali, (Deepali Path lab, Bathinda) regarding collection of cancer patient's data of Districts Bathinda and Muktsar attended by Dr. Vijay Kumar Bodal, Mr Vicky Harinder Pal and Mr. Dalvir Singh.
- 4. June 28<sup>th</sup> 2016:** Meeting with Dr. Sankalp Sancheti, Homi Babha Cancer Institute Sangrur regarding collection of cancer patient's data of districts Bathinda and Muktsar attended by Dr. Vijay Kumar Bodal, Mr Vicky Harinder Pal and Mr. Dalvir Singh.
- 5. July 18<sup>th</sup> 2016:-** Meeting with Dr.M. K Mahajan, Advance Care Institute, Bathinda and Civil Surgeon Office, Muktsar regarding collection of cancer patient's data of District's Bathinda and Muktsar attended by Dr. Vijay Kumar Bodal(PI), Mr Vicky Harinder Pal and Mr. Dalvir Singh.
- 6. October 11th- 12th 2016:** 32<sup>rd</sup> ARM of NCRP at Nagaland attended by Dr. Vijay Kumar Bodal (PI), Dr. Manjit Singh Bal (Co-PI).
- 7. October 24<sup>th</sup> 2016:** Meeting with Dr. Navtej Singh, Professor, Department of Pathology at Guru Gobind Singh Medical College, Faridkot regarding collection of Cancer patient's data of Districts Bathinda and Muktsar attended Dr. Mohanvir Kaur(Co-PI), Mr. Dalvir Singh, Ms. Gulshan and Ms. Parvinder Kaur.
- 8. February 16<sup>th</sup> 2017:** Meeting with Dr.M. K Mahajan Advance Care Institute, Bathinda regarding collection of Cancer patient's data of Districts Bathinda and Muktsar attended by Dr. Vijay Kumar Bodal(PI), Mr Vicky Harinder Pal and Mr. Dalvir Singh.
- 9. March 7<sup>th</sup> 2017:** Meeting with Dr. G. S Bhullar, Civil Surgeon, Muktsar regarding collection of Cancer patient's data of Districts Bathinda and Muktsar attended by Dr. Mohanvir Kaur (Co-PI), Mr. Vicky Harinderpal.
- 10. March 27<sup>th</sup> -28<sup>th</sup> 2017:** Audit General of Punjab, Chandigarh Mr. Rajiv Audit Officer and his team,(Indian Audit and Accounts Department office of the Pr. Accountant General (Audit), Punjab, Chandigarh) audited the PBCR, Patiala Account attended by Dr. Vijay Kumar (PI), Dr. Mohanvir Kaur (Co-PI), Dr. Vandana Singla (Co-PI), Mr. Vicky Harinderpal, Mr. Dalvir Singh, Ms. Monika, Ms. Gulshan and Ms. Parvinder Kaur.
- 11. March 30<sup>th</sup> 2017:** Meeting with Dr. Monika, (Monika Path lab, Bathinda), Dr. Deepali, (Deepali Path lab, Bathinda), Dr. Anita Mittal, (Mittal Path Lab, Bathinda), Dr. Vijay Suri, Adesh Medical College, Bathinda, Dr. M. K Mahajan, Advance Cancer Institute, Bathinda and Civil Surgeon Office, Bathinda regarding collection of Cancer patient's data of Districts Bathinda and Muktsar attended by Dr. Vandana Singla (Co-PI), Ms. Monika, Ms. Gulshan, Ms. Parvinder Kaur and Mr. Dalvir Singh.

### Sources of Data of PBCR, 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. Visit to Private Laboratories in Patiala, Bathinda and Muktsar districts of Punjab.
6. Local Private Hospitals & Clinics of Patiala, Bathinda and Muktsar Sahib Districts of Punjab.
7. Civil Surgeon Office in Patiala, Bathinda and Muktsar districts of Punjab
8. Municipal Corporations in Patiala, Bathinda and Muktsar Sahib Districts of Punjab.
9. Various Private Hospitals at Patiala, Bathinda, Muktsar, and Mohali districts of Punjab.
10. PHCs and CHCs under Civil Surgeon in Patiala, Bathinda, Muktsar, and districts of Punjab.
11. Mukh Mantri Punjab Rahat Kosh Scheme.
12. Cancer Control Cell, Chandigarh.

## Working of PBCR, Patiala Staff





## Population Based Cancer Registry, Sikkim

Prakash Pradhan<sup>1</sup>

Sangeeta Bhandari<sup>2</sup>

1 Principal Investigator, 2 Co-Investigator

Sir Thotup Namgyal Memorial Hospital. Gangtok, Sikkim

### Demographic Characteristics of Sikkim

Sikkim is mountainous and the population sparse and scattered. On the world map it is just a speck with approximate latitude of 27 degrees north and longitude of 88 degrees east but its size belies its richness of culture, customs, heritage, flora and fauna. It possesses climates right from the tropical to the tundra. It has the physical features like the rivers and the mountains that define the boundaries of the state with its neighbours. Sandwiched between Nepal in the west and Bhutan in the east, lies a small stretch of rugged land just 115 km by 65 km. On its northern border towers the plateau of Tibet whereas it shares its southern border with West Bengal.

Sikkim has an area of 7096 sq km with population of 607688 as per 2011 census. The population comprises mainly of Nepalese who form the majority followed by the Bhutias and the Lepchas, who comprise the Tribal population

### Evolution of PBCR in Sikkim

The Population Based cancer Registry (PBCR) was established in Sikkim in the year 2003 with its office at the STNM Hospital Gangtok. Since its inception, it has developed in terms of manpower development and quality of the data collected over the past 15 years.

As mentioned Cancer registry is a means to a purpose and not a purpose by itself and taking this into account the PBCR in Sikkim has been participating in all the annual review meetings since its inception and also

the data has been published in all the documents published by the National Cancer Registry Programme under the National Centre for Disease Informatics and Research. These documents being national documents are shared with the decision makers in the State government for taking up a focused interventions in the common cancers prevalent on the State.

The Registry has also published papers in International journals. The registry has also been able to contribute its data in the 'Cancer Incidence in Five Continents, Volume X of its first five years of data (2003 -2007)' which was published in 2014. PBCR Sikkim was one of the few registries from India which was able to achieve this honour because of its good quality of information which matched with International standards. The registry is working towards providing data for the next volume of Cancer Incidence in Five Continents in close coordination with the National Centre for Disease Informatics and Research.

The Sikkim PBCR has also participated in CONCORD2 programme. CONCORD is the global programme for world-wide surveillance of cancer survival, led by the London School of Hygiene & Tropical Medicine. It is supported by the Union for International Cancer Control (UICC) as a programme of strategic significance for the World Cancer Declaration. The CONCORD programme is endorsed by 39 national and international agencies, including WHO EURO, the Organization for Economic Co-operation & Development (OECD) and the World Bank. The data of PBCR Sikkim was accepted and was among the 279 PBCRs in 67 countries of the world. The paper was

published in The Lancet.

The PBCR is working towards further improving its data quality with special emphasis on completeness. The aim is to provide the National Centre for Disease information and Research, information which could be utilized by the decision makers in the Central and State Government effective direction towards cancer control and development of manpower and infrastructure

looking at the local needs .The information provided could also be a source of evidence based research in the future .

The matter regarding making cancer a notifiable disease has been taken up with the State Government and is under active consideration.

**PBCR Staff - Sir Thotup Namgyal Memorial Hospital. Gangtok, Sikkim.**



# Annual Review Meeting 2016 - Photo Gallery

**Annual Review Meeting - 2016, Kohima, Nagaland**  
**Pre-ARM workshop on November 9 & 10, 2016**



**Annual Review Meeting - November 11 & 12, 2016**  
**Hon. Governor, Nagaland at the Inaugural Ceremony**



**Scientific Sessions**



**NCRP team hosted by the Hon. Governor, Nagaland**



## Population Based Cancer Registries under NCRP

S.No	PBCR	Principal Investigator	Institution
1	Bangalore	Dr. Linge Gowda	Director, Kidwai Memorial Institute of Oncology, Bengaluru, Karnataka.
2	Barshi Rural	Dr. R A Badwe	Director, Tata Memorial Hospital, Mumbai Nargis Dutt Memorial Cancer Hospital, Barshi (Barshi Rural), Maharashtra.
3	Barshi Expanded	Dr. Bhagwan M.Nene	Chairman - Ashwini Rural Cancer Research & Relief Society. Nargis Dutt Memorial Cancer Hospital, Barshi, (Barshi Expanded), Maharashtra.
4	Bhopal	Dr. Reeni Malik	Professor & Head, Department of Pathology, Gandhi Medical College, Bhopal, Madhya Pradesh.
5	Chennai	Dr. R. Swaminathan	Asst. Director and Head, Department of Biostatistics and Cancer Registry, Cancer Institute (WIA), Chennai, Tamil Nadu.
6	Delhi	Dr. N. K. Shukla	Professor and Head, Department of Surgical Oncology, Institute Rotary Cancer Hospital, Dr. B.R. Ambedkar Institute Rotary Cancer Hospital, All India Institute of Medical Sciences, New Delhi.
7	Mumbai	Dr. Vinay Deshmane	Jt. Hon. Secretary, Indian Cancer Society, Mumbai, Maharashtra.
8	Cachar District	Dr. Sekhar Chakravarty	Vice Principal, Silchar Medical College, Silchar, Assam.
9	Dibrugarh District	Dr. Projnan Saikia	Prof & Head, Dept. of Pathology, Assam Medical College and Hospital, Dibrugarh, Assam.
10	Guwahati (Kamrup urban district)	Dr. Jagannath D. Sharma	Senior Chief Consultant, Department of Pathology, Dr. B. Borooah Cancer Institute, Guwahati, Assam.
11	Manipur	Dr. Madhubala Devi (from 29th June 2017) Dr. Kaushik Debnath (till 28th June 2017)	Prof & Head, Department of Pathology, Regional Institute of Medical Sciences, Imphal, Manipur.
12	Mizoram	Dr. Eric Zomawia	Deputy Director, Hospital & Medical Education, Civil Hospital, Aizawl, Mizoram.
13	Sikkim	Dr. Prakash Pradhan	Chief Consultant and HOD, Department of Pathology, Sir Thutob Namgyal Memorial Referral Hospital, Gangtok, Sikkim.
14	Ahmedabad Rural	Dr. Rakesh K Vyas	Director, Gujarat Cancer & Research Institute, Ahmedabad (Rural), Gujarat.
15	Ahmedabad Urban	Dr. Rakesh K Vyas	Director, Gujarat Cancer & Research Institute, Ahmedabad (Urban Agglomeration), Gujarat.

16	Aurangabad	Dr. Vinay Deshmane	Jt. Hon. Secretary, Indian Cancer Society, Mumbai, Maharashtra.
17	Kolkata	Dr. Tapas Maji	Director, Chittaranjan National Cancer Institute and Saroj Gupta Cancer Centre and Research Institute, Kolkata, West Bengal.
18	Kollam District	Dr. Paul Sebastian	Director, District Cancer Registry Kollam, Regional Cancer Centre, Thiruvananthapuram, Kerala.
19	Nagpur	Dr. Vinay Deshmane	Jt. Hon. Secretary, Indian Cancer Society, Mumbai, Maharashtra.
20	Pune		
21	Thiruvananthapuram District	Dr. Aleyamma Mathew	Professor and Head, Division of Cancer Epidemiology & Bio-statistics, Hospital Cancer Registry, Regional Cancer Centre, Thiruvananthapuram, Kerala.
22	Meghalaya	Dr. W.B.Langstieh	Pathologist, Civil Hospital, Shillong, Meghalaya.
23	Tripura	Dr. Gautam Majumdar	Medical Superintendent & Head, Cancer Hospital, Regional Cancer Centre, Agartala, Tripura.
24	Nagaland	Dr. V.Khamo	Head, Department of Pathology, Naga Hospital Authority, Kohima, Nagaland.
25	Wardha	Dr. Nitin Gangane	Director, Professor and Head, Department of Pathology, Mahatma Gandhi Institute of Medical Sciences, Sevagram, Wardha, Maharashtra.
26	Naharlagun	Dr. Sopai Tawsik	Head, Dept. of Pathology, Tomo Riba State Hospital, Naharlagun, Arunachal Pradesh.
27	Pasighat	Dr. Kaling Jerang	General Hospital, Pasighat, Arunachal Pradesh
28	Patiala District	Dr. Vijay Kumar Bodal	Associate Professor, Department of Pathology Government Medical College and Rajindra Hospital, Patiala, Punjab.
29	Hyderabad District	Dr. G. Sadashivudu	Associate Professor, Dept. of Medical Oncology Nizam's Institute of Medical Sciences, Hyderabad, Telangana.
30	GautamBudh Nagar	Dr. Smita Asthana	Scientist D, ICMR-National Institute of Cancer Prevention and Research, Noida, Uttar Pradesh.
31	Karimganj, Hailakandi, Dima Hasao	Dr. Ravi Kannan	Director, Cachar Cancer Hospital & Research Centre, Meherpur, Silchar, Cachar, Assam.
32	Allahabad	Dr. Paul Thaliath	Head, Dept.of Radiation Oncology & Addl. Director, Kamala Nehru Memorial Hospital, Allahabad, Uttar Pradesh.
33	Malabar	Satheesan Balasubramanian	Director, Malabar Cancer Centre, Thalassery, Kannur, Kerala.



### List of Hospital based cancer Registries under NCRP

S. No.	Regional Cancer Centres
1	Cancer Institute (WIA), Chennai
2	Dr. B.R. Ambedkar Institute Rotary Cancer Hospital, New Delhi
3	Dr. B. Borooah Cancer Institute, Guwahati
4	Govt. Arignar Anna Memorial Cancer Hospital & Research Institute, RCC, Kanchipuram
5	Indira Gandhi Institute of Medical Sciences, Patna
6	JIPMER, Regional Cancer Centre, Puducherry
7	Kidwai Memorial Institute of Oncology, Bangalore
8	Mizoram State Cancer Institute (Civil Hospital), Aizawl
9	PGIMER, Chandigarh
10	Regional Cancer Centre Indira Gandhi Medical College, Shimla
11	Regional Cancer Centre Kamala Nehru Memorial Hospital, Allahabad
12	Regional Cancer Centre, Agartala
13	Regional Cancer Centre, Raipur
14	Regional Cancer Centre, Thiruvananthapuram
15	RST Regional Cancer Hospital, Cancer Relief Society, Nagpur
16	Sher-I-Kashmir Institute of Medical Sciences, Srinagar
17	The Gujarat Cancer & Research Institute, Ahmedabad
18	Acharya Harihar Regional Cancer Centre, Cuttack
19	Acharya Tulsi Regional Cancer Treatment and Research Institute, Bikaner
20	Cancer Hospital & Research Institute, Gwalior
21	Chittaranjan National Cancer Institute, Kolkata
22	Government Medical College, Jammu
23	MNJ Institute of Oncology and Regional Cancer Centre, Hyderabad
24	Regional Institute of Medical Sciences, Imphal
25	Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow
26	Tata Memorial Hospital, Mumbai
27	Assam Medical College, Dibrugarh

**Institutions reporting on the HBCR Data Management software (HBCR DM)  
(funding supported by ICMR )**

S. No.	Centre Name
1	Tata Medical Center, Kolkata
2	Peerless Hospitex Hospital and Research Center Limited, Kolkata
3	Rajiv Gandhi Cancer Institute and Research Centre, New Delhi
4	Max Super Speciality Hospital, Saket, New Delhi
5	Fortis Memorial Research Institute, Gurgaon
6	Medanta Cancer Centre, Gurgaon
7	Govt. Stanley Hospital, Chennai
8	R.G. Govt. General Hospital, Chennai
9	Govt. Royapettah Hospital, Chennai
10	Institute of Obstetrics &Gynecology,Chennai
11	Bhagwan Mahaveer Cancer Hospital and Research Centre, Jaipur
12	Nizams Institute of Medical Sciences, Hyderabad
13	General Hospital, Ernakulam
14	International Cancer Centre, Neyyoor
15	Government Medical College, Thrissur
16	Kolhapur Cancer Centre, Kolhapur
17	North East Cancer Hospital & Research Institute, Guwahati
18	Cancer Research Institute - Himalayan Institute Hospital Trust, Dehradun
19	Pravara Rural Hospital & Rural Medical College, Loni
20	Amrita Institute of Medical Sciences & Research Centre, Kochi
21	Mahavir Cancer Sansthan and Research Centre, Patna
22	Malabar Cancer Centre, Kannur
23	Erode Cancer Centre, Thindal, Erode
24	Kovai Medical Centre and Hospital, Coimbatore
25	Apollo Hospital, Bhubaneswar
26	Baby Memorial Hospital Ltd., Kozhikode
27	R. K. Birla Cancer Center, Jaipur
28	Cancer Care Hospital & Research Centre - Cancer Care Clinic, Patna
29	Apollo CBCC Cancer Care (A Unit of Apollo Hospital), Gandhinager
30	Guru Gobind Singh Medical College Hospital, Faridkot
31	Govt. Medical College & Hospital , Chandigarh
32	MES Medical College, Perinthalmanna
33	Choithram Hospital and Research Centre, Indore
34	Institute of Liver of Biliary Sciences, New Delhi

### List of centres reporting on HBaCR DM (non funded)

S. No.	Centre Name
1.	St. Johns Medical Hospital, Bangalore
2.	Narayana Hrudayalaya Health City, Bangalore
3.	HCG Bangalore Institute of Oncology, Bangalore
4.	ESIC Medical College & Post Graduate Institute of Medical Sciences & Research, Bengaluru
5.	Vydehi Institute of Medical Sciences, Bangalore
6.	Sagar Hospital, Bangalore
7.	Karnataka Cancer Hospital, Bangalore
8.	Apollo Hospital, Bangalore
9.	Sapthagiri Institute Of Medical Science Research Centre, Bangalore
10.	Columbia Asia Referral Hospital - Yeshwanthpur, Bangalore
11.	Columbia Asia Hospital - Whitefield, Bangalore
12.	Victoria Hospital, Bengaluru
13.	Manipal Hospital, Bengaluru
14.	St. Marthas Hospital, Bangalore
15.	BGS Global Hospitals, Kengeri
16.	Institute of Nephro Urology, Bangalore
17.	Sri Shankara Cancer Hospital & Research Centre, Bengaluru
18.	M S Ramaiah Hospital, Bengaluru
19.	Elbit Medical Diagnostics Limited, Bangalore
20.	Apollo Gleneagles Hospitals, Kolkata
21.	Advanced Medicare and Research Institute, Kolkata
22.	Madras Cancer Care Foundation, Chennai
23.	Max Super Speciality Hospital, PPG, Delhi
24.	Max Super Speciality Hospital, Shalimar Bagh, New Delhi
25.	KokilabenDhirubhaiAmbani Hospital & Medical Research Institute, Mumbai
26.	Mandya Institute of Medical Sciences, Mandya
27.	Kurnool Medical College & Govt. General Hospital, Kurnool
28.	J.N. Medical College & Hospital, Aligarh
29.	Ravi Polyclinic Maternity and Nursing Home, Shivamogga
30.	ShirdiSaibaba Cancer Hospital & Research Centre, Manipal
31.	Father Muller Medical College Hospital, Mangalore

32.	Bharath Hospital & Institute of Oncology, Mysore
33.	Belgaum Cancer Hospital Pvt. Ltd., Belgaum
34.	Malnad Hospital & Institute of Oncology, Shimoga
35.	A.J. Hospital & Research Centre, Mangalore
36.	HCG NMR Cancer Centre, Hubli
37.	K.L.E.S, Belgaum
38.	K.S.Hegde Medical Academy, Mangalore
39.	S.S.Institute of Medical Sciences and Research Centre, Davanagere
40.	Basaveshwar Teaching & General Hospital, Gulbarga
41.	Mysore Medical College & Research Institute, Mysore
42.	Yenepoya Medical College Hospital, Mangalore
43.	Mangalore Institute of Oncology, Mangalore
44.	Chirayu Hospital, Gulbarga
45.	JSS Hospital, Mysore
46.	KMC Hospital, Mangalore
47.	SDM College of Dental Sciences and Hospital, Dharwad
48.	Cauvery Hospital, Mysore
49.	Bhanavi Hospital, Mysore
50.	Shakunatala Memorial Hospital & Research Centre, Hubli
51.	Adarsha Hospital, Udupi
52.	Mahatma Gandhi Cancer Hospital, Miraj
53.	Shri Siddhivinayak Ganapati Cancer Hospital, Miraj
54.	Sukshema Hospital PVT Ltd, Davangere
55.	The Karnataka Cancer Therapy & Research Institute, Hubli
56.	Shri Siddheshwar Cancer Hospital & Research Centre, Solapur
57.	Narayana Hrudayalaya Surgical Hospital Pvt Ltd, Mysuru
58.	CSI Holdsworth Memorial Hospital (Mission Hospital), Mysore
59.	Dr. N.B. Patil Hospital, Gadag
60.	Kerudi Healthcare Pvt. Ltd, Bagalkot
61.	SreeThirumala Hospital, Ballari
62.	Global Multispeciality Hospital, Mangalore
63.	Mcgann Teaching District Hospital, Shimoga
64.	Vijayanagara Institute of Medical Science, Ballari
65.	Sri Chamarajendra Hospital, Hassan
66.	Mahatma Gandhi Multi Speciality Hospital and Research Centre, Gadag
67.	R. L. Jalappa Hospital and Research Centre, Kolar

68.	VTSM Peripheral Cancer Center, Kalaburgi
69.	K H Patil Hospital and Research Institute, Gadag
70.	Venkatesh Hospital, Mahalingpur
71.	HCG Cancer Kalaburgi, Kalaburgi
72.	Nayana Hospital, Bhadravathi
73.	Aditya Diagnostics and Shushrutha Surgical Clinic, Shimoga
74.	The Radiant Institute / Radiant Global Solutions, Mysore
75.	GuttiMalnad Hospital, Shivamogga
76.	Sahyadri Narayana Multispeciality Hospital, Shimoga
77.	MudanurMultispeciality Hospital, Vijayapur
78.	Mallikarjuna Nursing Home, Shivamogga
79.	Max Super Speciality Hospital, Shimoga
80.	Archana Hospital and Urology Center, Mandya
81.	Pragathi Hospital, Mandya
82.	Seva Nursing Home, Mandya
83.	Sri Nidhi Hospital, Mandya
84.	Ashraya Maternity Home, Mandya
85.	Ramakrishna Nursing Home, Mandya
86.	Shimoga Diagnostic Center, Shimoga
87.	Sigma Hospital, Mysuru
88.	Nandini Nursing Home, Mandya
89.	Shilpasri Nursing Home, Mandya
90.	Arpana Hi Tech Diagnostic Center, Mandya
91.	Anusha Diagnostic Center, Mandya
92.	Mandya ENT Care Centre and Hospital, Mandya
93.	CT Scanning Centre, Mandya
94.	Kalaburgi Scanning and Diagnostic Centre, Kalaburagi
95.	City Hospital and Diagnostic Centre, Udupi
96.	St. Josephs Hospital, Chamarajanagar
97.	Matha Nursing Home, Mandya
98.	Santhathi Infertility and Maternity Center, Mandya
99.	Kasturiba Nursing Home, Mandya
100.	Sudha Nursing Home, Mandya
101.	Shanthi Nursing Home, Chamarajanagar
102.	Nanjappa Hospital, Shimoga
103.	Hassan Cancer Center, Hassan

104.	Preethi Centre for Oncology, Mysore
105.	Meherbai Tata Memorial Hospital, East Singhbhum
106.	All India Institute of Medical Sciences, Patna
107.	King George Medical University, Lucknow
108.	Royal Cancer Institute and Research Centre, Kanpur
109.	Shankar Institute of Cancer Therapy & Research, Mathura
110.	Indo-American Cancer Institute & Research Centre, Hyderabad
111.	Indore Cancer Foundation, Indore
112.	Lakeshore Hospital and Research Centre Ltd., Kochi
113.	Amala Institute of Medical Sciences, Amalanagar, Trichur
114.	Cachar Cancer Hospital and Research Centre, Silchar
115.	Gandhi Medical College, Bhopal
116.	Pramukhswami Medical College, Karamasad
117.	Rural Development Trust, Bathalapalle
118.	Batra Hospital & Medical Research Centre, New Delhi
119.	Sanchetee Hospital and Cancer Institute, Jodhpur
120.	Ashadeep Hospital, Moradabad
121.	All India Institute of Medical Sciences, Bhubaneswar
122.	Institute of Medical Science and Sum Hospital, Bhubaneswar
123.	Caritas Cancer Institute - Caritas Hospital, Kottayam
124.	Thanjavur Cancer Centre, Thanjavur
125.	Aster Medcity, Kochi
126.	Asian Institute of Medical Sciences, Faridabad
127.	S S Hospital & Research Centre, Patna
128.	Satyam Hospital and Research Centre, Jorhat
129.	BPS Government Medical College for Women, Haryana
130.	Medwin Hospital, Hyderabad
131.	Pushpagiri Institute of Medical Sciences & Research Centre, Tiruvalla
132.	Priyamvada Birla Cancer Research Institute, Satna
133.	Dr. Rajendra Prasad Govt Medical College, Kangra
134.	Kullolli Hospital, Sangli

# Welcome

to the

## XXXIII Annual Review Meeting

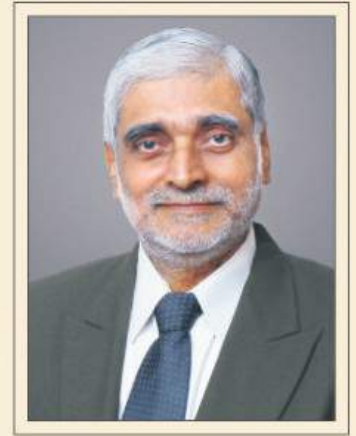
of

## National Cancer Registry Programme (NCRP),

### November 28-30, 2017

at

## Amrita Institute of Medical Sciences, Kochi





**CRAB**

**The Newsletter of NCRP**

