Cancer Registry ABstract

CRAB

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IN THIS ISSUE

This issue is edited by Mr. P. Gangadharan, Cancer Registry, Amrita Hospital, Kochi

All are welcome to submit articles, news, comments to CRAB

India's cancer registry programme (NCRP) has been ongoing since 1982.

After 31 years of work, the National Cancer Registry system has expanded the coverage of population and reached more than 9 crores of people in India - still less than 10% of the total population of the country. Large variations in the incidence and pattern of cancer are recorded which give directions for further studies and research.

Such information have to be used not only for research studies but to evolve better cancer control and care facilities in the country. The studies reported so far from the individual registries both PBCR and HBCR are substantial when we recognize the number of informative studies reported in national and international journals by the Indian registries. Further, population based data on cancer from several Indian registries confirming to world standards have been published by IARC – WHO.

Is there any chance for us to translate this gathered information into public action for control of the disease or it can go deeper in the study of biology and mechanism of carcinogenesis in India. Well equipped research laboratories have to assimilate this information and translate the results to prevent, early detect and offer advice on optimal treatment for individual cancer types.

Thus the registry organization's link with the control programmes of the country is essential.

Specifically there is a need to enhance the quality of collected data and to extract more specific information on the cancer cases as well as on the victims.

Enhancing the quality of information recorded is very essential. Two studies in this issue deal with mortality data collection, their drawbacks encountered at present and the necessity to improve the data collection. It may be recalled that the mortality information collection was traditionally engaged for recording the socio-demographic details rather than the cause of death. It was basically fashioned for the advantage of the informer – as a legal documentation only. We are using it for the research and have stumbled on the drawbacks. Incomplete recording of cancer, mistaken records of personal details of age have been highlighted. The results of verbal autopsy when analyzed may reflect the identification of cause of death and reveal the drawbacks. Death reporting should insist on identifying the immediate cause and the underlying cause of death.

Another important fact which requires more scrutiny and effort is the area of recorded information. These are more reflected in the hospital based data. There was a time when we used to read about head and neck cancer or oral cancer. It is now apparent from the studies that the factors involved in the disease process varied from one anatomic location to another location in the mouth itself.

This calls for more specific documentation and collection process with regard to the site of cancer and type of cancer. As the registry records depend only the recorded information in the case note there will be difficulties to rectify this. A Tongue cancer should be identified as anterior or posterior tongue; Esophagus should be classified as upper, middle and lower, Stomach to be classified as cardiac, body and proximal end, Colon cancer to

be specifically mentioned as caecum, ascending, hepatic flexure, transverse, splenic flexure, descending colon. Terminal colon should be identified as rectosigmoid, sigmoid or anal canal.

To obtain such specific information for a population registry there should be appropriate hospital based information available. Such information when systematically computed and compared would lead to more specific studies. Thus strengthening of HBCRs is an essential process for obtaining quality information for a PBCR and a more useful information for public health action.

Optimal quality of registry functioning would need involvement and support from health administration as well as the public acceptance of the programme. These have been highlighted in the presentations in this issue.

Finally, for interpretation of the data, norms should be developed for this at least when the registry data is presented by registries themselves. Eg., the hospital based frequencies interpreted as population incidence rate will not stand scientific acceptance. Patient treatment services in a hospital are not based on a random selection of patients or cases. The drawbacks in this regard are well known.

P. Gangadharan

The National Cancer Registry Project has, from its inception in January 1982, contributed much to our understanding of cancer in India. Registries suggest many things. Generally built to be data gathering systems, they can help us convert the information into knowledge and that into an understanding of cancer association and causality. In India, with its rich diversity of peoples, environments, geography and climate, can contribute much to cancer epidemiology.

Prof. V. Ramalingaswami - - - - - NCRP Annual Report 1983

NATIONAL CENTRE FOR DISEASE INFORMATICS AND RESEARCH

Indian Council of Medical Research

Dr. A. NANDAKUMAR MD, MPH
DIRECTOR - IN - CHARGE, NCDIR

MAIN OBJECTIVES

The main broad and overall objective of the centre is to sustain and develop a national research data-base on cancer, diabetes, CVD and stroke through recent advances in electronic information technology with a national collaborative network, so as to undertake aetiological, epidemiological, clinical and control research in these areas.

PROGRESS AND EMPOWERMENT OF CANCER REGISTRATION AND REGISTRY PERSONNEL

P. Gangadharan & NCRP Sources

The NCRP Cancer Registry operations in India made considerable progress in cancer registration and facilitated several empowerment opportunities for the staff which benefitted the whole programme itself during the past 31 years of its operations. The continuity and progress of the operations and outcome are due to involvement of several committed leaders, workers and the support received from the DGs and the ICMR.

Programme uplift

The ICMR started the Cancer Registry operations in 1982 named as the National Cancer Registry Project indicating a limited existence. In appreciation of the essentialities of the work and successful implementation, it was promoted in 1988 as the National Cancer Registry Programme.

In 1982, there were three hospital based and three population based registries. In 2013, there are 29 population registries and 7 hospital registries (Table 1) Along with this several other programmes are ongoing to enable optimal functioning of the registry operations. A number of international collaborative studies have taken place in this regard.

In 2011, the NCRP became the National Centre for Disease Informatics and Research (NCDIR) which encompassed studies of several NCD's. This progression took place as a result of the successful functioning of NCRP for more than 30 years.

Staff Empowerment

The involved registry staff have, over time, specialized in their respective work areas and dedicated themselves for expansion and organization of registries in newer areas.

Along with the progress in programmes, empowerment of staff and development of technology have taken place. Several staff who were exposed to registry work utilized the opportunities to proceed to higher studies both within the country and outside also.

After their creditable achievements several of them have retained their position and continue in the activities of the Registry. Some of them left the Registry programme and are now serving in other global programmes with high credit.

Those who continue to serve the NCRP after their academic achievements:

1. Dr A. Nandakumar from Population Based Cancer Registry, KMIO, Bangalore, did 1 year IARC fellowship in Australia and MPH from University of Washington in Seattle, U.S.A.
2. Dr C Ramesh, Bangalore Cancer Registry received Phd. Degree from Tampere University, Finland.
3. Dr B Ganesh, TMH Cancer Registry, received Phd. Degree from Tampere University, Finland.
4. Dr (Ms) R. Akhtar, Dibrugarh Registry received Phd. Degree from Guwahati University, Assam

5. Dr R. Swaminathan from Chennai Registry received Phd. Degree from Tampere University, Finland.
6. Dr R. Swaminathan received a Second Phd. Degree from Madras University.
7. Dr R Rama of Chennai Registry received Phd. Degree from Madras University.
8. Dr Aleyamma Mathew, Trivandrum Registry received Phd. Degree from Tampere University, Finland.
9. Dr Aleyamma Mathew, received a Second Phd. Degree from M G University, Kottayam.
10. Dr P Jayalekshmi, Kollam Registry received Phd. Degree from Kerala University.
11. Mrs. Swapna Koyande, Mumbai Registry has got enrolled for Phd. Programme of Tampere University, Finland.

Late Dr. B B Yeole who was the Co-PI of Mumbai Registry for over 30 years had received Phd. from Tampere University, Finland while he was in service.

Dr R. Ramachandra Reddy Banglore Registry (Retired 2011) received Phd from Tampere University while in service of NCRP.

Many staff members are involved in teaching in several Universities concurrent with their involvement in registry operations.

Registries expand to newer areas

Another welcome progress is the expansion of registration areas by the registries which now cover large population groups in the country.

The Ahmedabad Urban Registry initiated the Ahmedabad Rural Registry.

The Mumbai Registry initiated registries at Pune, Nagpur and Aurangabad before it joined the NCRP.

The Chennai Registry expanded their registry activities to Dindigul first and presently cover the entire State of Tamil Nadu, the first PBCR covering an entire state in the country.

The Tata Memorial hospital started the cancer registry (PBCR) at Barshi in 1987 jointly with the Nagis Dutt Memorial Cancer Hospital, Barshi. This registry in rural Maharashtra is the first rural cancer registry in India.

The RCC Trivandrum initially had only the hospital registry. Later it developed the Taluk and District Cancer Registries.

Another significant addition by RCC, Trivandrum was the Special Purpose Registry organized in Karunagappally and now expanded to form the Kollam District Registry – first district wide cancer registry of Kerala under NCRP. Karunagappally registry is the second rural cancer registry in the country.

The Population based cancer registries in Bangalore and Chennai organized their Hospital based registries in KMIO, Bangalore and Adyar Cancer Centre respectively.

The Atlas Project- Prelude to North-East Cancer Registries

The Atlas project of NCRP (2001) identified several places in North East India with high minimum cancer incidence rate which led to the formation of new Cancer Registries in North East region.

The Cancer Atlas programme was executed with the co operation from Pathologists and Laboratories in several centres in India. The data was captured through E-transmission and

processing was done by NCRP. Several workshops and meetings were organized across the country for the Atlas Project. Dr Max Parkin from IARC graced the meeting and gave important scientific insight for the programme. The outcome quickly helped to identify very potential areas to initiate population registries.

It was noted that such an outcome came through a very minimal cost compared to the expenditure for population covering registries.

Progress of NCRP registries:

Punjab Studies:

Atlas of Cancer in Punjab, Hospital Registry at Chandigarh and Population based Cancer Registry at Patiala, all were started in 2011.

The National Cancer Registry Programme has been expanding the registry operations to different areas of the country since the past 30 years. Currently, all states and UTs except Jharkhand, Goa, Daman, Diu, Dadra and Nagar Haveli, Lakshadweep, Andaman & Nicobar Islands are covered by the registry operations. The data accrued has exhibited vide variations in the total cancer burden as well as highly contrasting site distribution in different population groups. The NCRP annual reports of PBCR & HBCR highlight these.

The progress of NCRP recorded during 2009 onwards is significant. The total population covered by registry operations currently is above 9,13,10,000 (more than 9 crores) and annually around 73000 cancers are recorded as incident cases. Along with this very vide variations are observed in sites affected with cancer among people living in different parts of the Country.

Regional differences in cancer incidence:

The age adjusted incidence rate for all cancer in men varied from 273.4 in Aizwal to 43.7 in Barshi Expanded area and among women it varied from 227.8 in Aizwal to 51.6 in Ahmedabad Rural women. Further, regional differences in incidence of certain cancers have been noted. For example, the stomach cancer incidence among males in Aizwal was 64.2/100,000, and in females it was 31.2. But the lowest incidence among males for stomach cancer was in Ahmedabad Rural – 1.1/100,000 and among women also the Ahmedabad Rural area and Barshi expanded have recorded the lowest stomach cancer incidence rates of 0.8 & 0.5. Almost all forms of cancers show such regional variations which indicate the importance and essentiality of epidemiologic and etiologic studies on cancer in India.

Research Studies by NCRP

The Patterns of Care & Survival Studies (POCSS) initiated in 2009 is an evidence based important study of presentation, management and survival rates. 18 centres from different parts of India are participating in POCSS. The cancers involved in this study are Head & Neck Cancer, Cervix Cancer and Breast Cancer.

Studies on the relation between H pylori and stomach cancer are planned now.

Regular review of Translational Research Programme and Annual Review Meetings of registry operations are held without break.

International Collaborations of NCRP:

Cancer Incidence in five continents (CI 5 - IARC-WHO)

The NCRP Registries have submitted data to the successive volumes of IARC publications of Cancer Incidence in five continents (CI 5). Thus Vol. X. of CI 5 is being processed now. Table 2, shows the Indian contribution to CI 5. Data submission to CI 5 by the Mumbai and Pune Registries had started from Volumes 2. NCRP

registries submitted data from Vol.V onwards and in Vol. X there will be data from eleven Indian registries. For seven registry data, the minimum requirement set by CI 5 could not be satisfied, and in seven registries the data submission did not take place.

Eighteen Indian PBCRs under NCDIR-NCRP network submitted the data to Cancer Incidence in Five Continents- Vol X. The data of 11 PBCRs were accepted and 7 were rejected. One important thing to note here is that the mortality data of none of the Indian PBCRs were considered.

The PBCRs that have got acceptance for CI 5 Vol. X are Bangalore (2005-2007), Barshi Rural (2003-2007), Bhopal (2004-2007), Chennai (2003-2007), Delhi (2003-2007), Mumbai (2003-2007), Mizoram State (2003-2007), Sikkim State (2003-2007), Kollam (Karunagapally) (2003-2007), Pune (2003-2007) and Thiruvananthapuram (2005-2007).

Out of the list of PBCRs above, NCDIR-NCRP formatted the data of 10 PBCRs as per CI5-Vol X guidelines. The data were subjected to checks and clarifications were sought from these PBCRs. The data was submitted by NCDIR-NCRP on CI 5 portal and 5 out of these 10 were accepted for publication.

The data of the PBCRs that were found inadequate were from Manipur State, Dibrugarh District, Kamrup Urban District, Kolkata, Ahmedabad Rural, Aurangabad and Nagpur. The data of Manipur State and Dibrugarh District showed high MV % and DCO as well as low M/I ratio. The data from both Kamrup Urban District and Kolkata showed fluctuating rates and low M/I ratio. Ahmedabad Rural PBCR had high MV %, Low M/I ratio and seemed to be using urban case finding methodology for a rural setup. The data from Aurangabad and Nagpur PBCR were also not accepted and they were submitted by the respective registries.

International Incidence of Childhood Cancer (IICC–IARC-WHO) Vol 3

Registries have contributed data to International Incidence of Childhood Cancer (IICC) (See Table of contributors). Eleven registries have submitted data to the IICC study. The Third edition of IICC required data on cancer cases of patients aged 0 to 19 years.

Data Submission Status of Indian PBCRs - 1990 onwards for the age group 0-19.

NCDIR-NCRP has formatted, sought clarifications on the data and submitted the data to IICC-3 study. The list of PBCRs for which the data has been submitted on IICC-3 portal are Bangalore (1990-2007), Bhopal (1990-2008), Dibrugarh District (2003-2008), Kamrup Urban District (2003-2008), Sikkim State (2003-2008), Ahmedabad Rural (2004-2008), Kolkata (2006-2007), Kollam (2006-2008) and Thiruvananthapuram (2005-2008).

The data from Mizoram State (2003-2008) has also been submitted except for the Introductory Text and Questionnaire which is pending from the registry. We are awaiting the receipt of corrections in the data for the 15-19 age group from Manipur State (2005-2008).

NCDIR-NCRP formatted and provided the data to Delhi registry (1990-2007) for reporting.

Concord 2 - UK

The Indian registries have collaborated with the CONCORD Programme - the International studies on cancer survival organized by Dr. Michel Colman of the London School of Hygiene and Tropical Medicine, London.

CONCORD 2 is intended to bring global surveillance of cancer survival using information received from 60 countries world wide.

The Sikkim Registry and Kollam Registry from India have submitted data so far.

1. Sikkim – submitted survival data for 5 cancer sites – 833 cancer cases were submitted with follow up information.
2. Kollam - submitted survival data for 10 cancer sites in which 2812 cases were followed and reported to CONCORD.

Electronic Data Transfer, Processing and Reporting

A significant progress in NCRP operations is the development of software by NCRP for all registry operations. Consequently all registries are e connected with NCRP. This has helped to scrutinize and standardize the data analysis and presentation. The entire programme - developing and processing is done by NCRP. More than 18 centres contribute data for Patterns of Care and Survival Studies alone.

The effort to transfer and process data manually by the registries used to take a long duration. The Atlas project was initiated using electronic data entry from several centres across the country. The data was received by NCRP office and could be processed fast due to this e- processing. This also reduced the cost as well as time for reporting. Such a progress has been a major step forward in registry operations.

With continued and dedicated effort in this area the NCRP staff could indigenously develop the HBCRDM software for hospital based data transfer and PBCR DM 2.1 for population based registry data. The NCRP office developed several checks, cleaning, processing, and reporting the data received in short time. Currently there are 29 centres using the soft wares (list appended) supplied by NCRP. 155 data sets of various programmes of NCRP are mailed from these 29 centres. Similar methodology is adopted for Punjab Cancer Atlas, HBCR Chandigarh and PBCR Patiala.

NATIONAL AND INTERNATIONAL RECOGNITION OF REGISTRY PERSONNEL

Dr. Gautam Majumdar

Dr. Gautam Majumdar, Principal Investigator, PBCR, Tripura has been chosen as a member of the Standing Committee on Radiotherapy Development Programme (vide Order No. Z-15011/1/ 2008-NCD (DGHS) dated 24th July, 2013) of the Government of India, Ministry of Health and Family Welfare (Cancer Research Section).

Mr. Atul Shrivasthava

Mr. Atul Shrivasthava, Research Officer and Co PI, Bhopal cancer registry has been nominated as advisor to the WHO collaborating centre on family of International Classification ICD – 10 and ICF in India and Central Bureau of Health Intelligence (CBHI), Ministry of Health and Family Welfare, Government of India.

Dr. R. Swaminathan

Dr. R. Swaminathan, Chennai Registries was nominated as one of the editors for the flagship IARC Scientific Publication series titled "Cancer incidence in five continents, Volume 10" (to be published as IARC Scientific Publications No. 165 in 2014) representing the International Association of Cancer Registries. He is the first Indian to get this prestigious nomination.

Dr. R. Swaminathan was elected as the Regional Representative for Asia to represent in the Executive Board of the International Association of Cancer Registries (IACR), Lyon, France. His tenure will be for four years starting from 2010.

NATIONAL CENTRE FOR DISEASE INFORMATICS AND RESEARCH

NATIONAL CANCER REGISTRY PROGRAMME *(Indian Council of Medical Research)*, Bangalore

Table 1

State wise collaborating centres as on 15-Oct-2013

Sl. No.	State	PBCR	HBCR	POCSS	HBCRDM Registered & Transmitting	PCA - Registered & Transmitting	Total data sets
1	Jammu & Kashmir			1	1		2
2	Himachal Pradesh				1		1
3	Punjab	1				52	53
4	Chandigarh (UT)		1	1	1	2	5
5	Uttarakhand				1		1
6	Haryana				1	1	2
7	Delhi (UT)	1		2	2	4	9
8	Rajasthan				1	1	2
9	Uttar Pradesh				1		1
10	Bihar			1			1
11	Sikkim	1					1
12	Arunachal Pradesh	2					2
13	Nagaland	1					1
14	Manipur	1					1
15	Mizoram	1					1
16	Tripura	1					1
17	Meghalaya	1					1
18	Assam	3	2	3	2		10
19	West Bengal	1			2		3
20	Jharkhand						0
21	Orissa				1		1
22	Chhattisgarh				1		1
23	Madhya Pradesh	1	1		2		4
24	Gujarat	2		1			3
25	Daman & Diu (UT)						0
26	Dadra & Nagar Haveli (UT)						0
27	Maharashtra	7		2	2		11
28	Andhra Pradesh	1			5		6
29	Karnataka	1	1	4	6		12
30	Goa						0
31	Lakshadweep (UT)						0
32	Kerala	2	1	2	7		12
33	Tamil Nadu	1	1	1	3		6
34	Puducherry (UT)				1		1
35	Andaman & Nicobar Islands (UT)						0
Total		**29**	**7**	**18**	**41**	**60**	**155**

PBCR = Population Based Cancer Registries
HBCR = Hospital Based Cancer Registries
POCSS = Patterns of Care and Survival Studies
HBCRDM = Hospital Based Cancer Registries Data Management Software
PCA = Development of an Atlas of Cancer in Punjab State

Table 2: Registries reporting incidence data to Cancer Incidence in 5 continents

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

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

NCRP Programme – Information Accrual - Summarised

Number of PBCRs	29
Hospital Cancer Registries	7
Patterns of Care & Survival	18
HBCR DM-Utilization	41
PUNJAB Cancer Atlas	60
Total Data Set	**155**

PBCRs

Number of PBCRs	29
Total Population Covered by PBCRs	9,13,13222
Annual Cases Reported by PBCRs	**73138**

HBCRs

Number of HBCR	7
Annual cases reported by HBCR	**58,012**

POCSS

Patterns of Care & Survival Studies	18 centres
Total Cases Enrolled	**63860**

HBCRDM

Hospital Based Cancer Data	41 Centers
Total Cases Received as on 13-11-2013	**76,589**

Patterns of Care and Survival Studies Data Status (2006-2011)

Site	Total Cases	Treated only at RI	
		#	%
Cancer Breast (C50)	23236	14018	60.3
Cancer Cervix (C53)	14071	10153	72.2
Head & Neck Cancers	26553	20845	78.5
Total	**63860**	**45016**	**70.5**

Head & Neck Cancers	Total Cases	Treated only at RI	
		#	%
Tongue (C01-02)	6287	4947	78.7
Mouth (C03-06)	9115	7155	78.5
Nasopharynx (C11)	777	622	80.1
Other Pharynx (C09-10,C12-14)	6756	5248	77.7
Larynx (C32)	3618	2873	79.4
Total	**26553**	**20845**	**78.5**

Dr Ramnath Takiar MSc. Phd.

Dr. Ramnath Takiar took Voluntary Retirement in June 2013 after 4 years service in NCRP

As we focus on the health status of India's population in the twenty first century, let us remember that "tall oaks from small acorns grow". The way this Cancer Registry Project has taken off from small beginnings provides much hope for rational, well-planned efforts towards changing the traditional image of cancer. Much credit goes to the Project's individual staff – peripheral and central – for India's contribution in this field.

Prof. V. Ramalingaswami
NCRP Annual Report 1983

LEADERS AND GUIDES OF NCRP


Dr. V. Ramalingaswami


Dr. D.J. Jussawalla


Dr. P.N. Wahi


Dr. Usha Lutra


Dr. S. Krishnamurthy


Dr. V. Shanta


Dr. L.D. Sanghavi


Dr. Kirshna Bhargava


Dr. M. Krishnan Nair


Dr. P.S.S. Sundar Rao


Dr. Radhakrishna


Dr. Takeshi Hirayama


Dr. Calum Muir


Dr. Matti Hakama


Dr. V.M. Katoch

STRATEGIES APPLIED TO IMPROVE FOLLOW UP IN RURAL SETTING

Amit Das – Tumour Registry, Cachar – Assam

Importance of follow up in cancer

After cancer treatment, crucial part remains for patient's regular follow up. This is due to three important issues, which are as follows –

1. To surveil any treatment related complications in the body.
2. To ensure that primary site is disease free or existence of any recurrence disease or any other types of second primary/multiple primaries develop within the body.
3. To detect if disease spreads to any distant organ.

And, due to above mentioned factors the specialist always suggests regular follow up of patient to ensure better survival. Continuous follow up can improve and prevent the early complications of patients. After 5 years of successive continuous follow up we generally accept that the patient is disease free, however in many cases recurrence or second primary occurred even after 20 years. Regular follow up can improve the survival status of the patient and guide us to provide optimal care to patients.

Problems of regular follow up in rural cancer registries special reference to Cachar Cancer Hospital & Research Centre:

Cachar Cancer Hospital & Research Centre is a charitable, philanthropic organization run by Cachar Cancer Hospital Society with the intention to provide cancer directed treatment to its entire stakeholder of whole Barak Valley (Cachar, Karimganj & Hailakandi district) and its

neighbouring districts. The hospital registered yearly more than 1500 cancer patients. And among them 30 - 35% patients completes their whole course of treatment and rest are in the group of incomplete treatment or no treatment. Among the completed treatment, the major problems of regular follow up are as follows–

1. Insufficient knowledge about regular follow up and hence patient thinks that tumour is removed and now they are disease free.
2. Road communication is considered as one of the major problem. Our follow up team went for home visit and came with conclusion that lots of patients are coming from very remote areas where there is no proper transportation and the road is basically kaccha. Due to this some patients are not coming for their regular follow up.
3. Poor economic status of patient is one of the barriers for regular follow up. Almost 60% of our patients monthly income is under rupees 3000/month
4. Lots of schemes are offered by mobile phones and patients frequently change their sim card, which is one of the major barriers of follow up.
5. Negligence is another cause for irregular follow up or no follow up.

6. Some patients thought that after treatment if they visit to cancer hospital then there may be a chance to hear any bad news like cancer is still in the body or neighbour will be able to know that he/she had cancer earlier. Due to these and superstitions some people missed their regular follow up.
7. Some patients went to other hospitals and continued their follow up there.
8. Patients coming from neighbouring state generally missed their follow up after completion of their treatment at Cachar Cancer Hospital and do follow up at other hospitals in their states.

These are the basic problems that Cachar Cancer Hospital is facing for regular follow up.

Strategies taken by the Cachar Cancer Hospital & Research Centre for improving follow up and Tumour Registry:

Cachar Cancer Hospital & Research Centre started the department of Tumour Registry in the year 2008 and linked it with the National Cancer Registry Program under ICMR in the year 2009. Cachar cancer hospital had and took participation in Cancer ATLAS project and POCSS project. Cachar Cancer Hospital made their special effort to develop a good registration card with full socio-economic detail in 2009 and in this context one registry staff was sent to Dr. B.B.C.I, Guwahati to see the registry operations. In 2010, three registry staff were sent to Cancer Institute (WIA), Chennai for 3 weeks and they spent one week in NCRP (ICMR) for training on data abstraction, basic statistics and epidemiology. In the year 2009 – 10, registry started functioning actively for patients follow up and started phone calls to their patients, started sending letters and accordingly home visit was planned. The response over telephone/mobile was too poor and in this context phone verification started from the year 2011 along with six (6) address detail of patients for effective home visit. In the year 2013, the department of tumour registry started to collect complete home mapping of patients which will help the registry staff to locate patients quickly.

Currently, Cachar Cancer Hospital has more than 80% follow up for Head & Neck, Breast and Cervical cancer.

ERROR IN REPORTING OF AGE AT MORTALITY OF CANCER PATIENTS IN TRIVANDRUM

Dr. Aleyamma Mathew, Dr. Preethi Sara George, Dr. Kalavathy MC,
PBCR Thiruvananthapuram Taluk, RCC-Thiruvananthapuram

Background

Age is an important factor for assessing the prognosis of cancer patients as well as for effective cancer control programmes. From the population based cancer registry (PBCR) data in India, it was observed that even for prognostically better cancers, there is not much difference in the age at diagnosis and age at mortality. This clearly shows that there is an error in reporting age at death. Mortality data collection procedure from the vital statistics offices for the various PBCRs in India is

almost similar in all parts of the country. Hence same kind of error reporting may exist in all the PBCRs. In order to assess the magnitude of error in reporting of age at mortality of cancer patients in India, we used Thiruvananthapuram cancer registry incidence and mortality database.

Materials and Methods

Incidence and mortality data from the period 2006 to 2011 of PBCR, Trivandrum Taluk was used for the present illustration. The PBCR, Trivandrum Taluk was established in 2006 under the National Cancer Registry Programme (NCRP) of Indian Council of Medical Research (ICMR) with the objectives of assessing the magnitude and pattern of cancer incidence and mortality rates as well as estimating relative survival of various cancers among the population in the Taluk.

Data on all deaths were collected from the death registers maintained at the vital statistics office of the Trivandrum Corporation and ten panchayats viz. Kadinamkulam, Mangalapuram, Pothencode, Andoorkonam, Kazhakkoottam, Sreekaryam, Kalliyoor, Venganoor, Kudappanakunnu, Vattiyoorkavu in the registry area. Demographic details such as age, gender and addresses of all subjects deceased during the year 2006 to 2011 whose permanent address is within the registry area were collected using the PBCR mortality form from the registers and death certificates maintained in the respective divisional offices.

The major sources for the incidence data were the Regional Cancer Centre, Trivandrum and Medical College Hospital (Radiotherapy out-patient department, Medical Records Library for inpatients, Sree Avittam Thirunal Women & Children Hospital and Pathology department). Cancer patient data is also collected from more than 60 private hospitals in Thiruvananthapuram. Address linkage of data obtained from Pathology laboratories were made. Duplicate registrations were eliminated and care was taken to see that multiple entries of the same patient were not made in the records. After eliminating duplicates, data on cancer incidence and mortality, were computerized.

In order to assess the magnitude of error in reporting of age at death, we have taken the ages of the same patients from the mortality as well as incidence data of the PBCR, Trivandrum. Initially average age (SD) at incidence and mortality of all cancers and leading cancers were estimated. Further, the proportion of variation in reporting (over and under reported) of age at death compared to the age at incidence by gender for all cancers and leading cancers was assessed. Also, the magnitude of difference in under reporting of age at death by gender for all cancers and leading cancers was assessed.

Results

During the 6-year period, mortality data matched to the incidence data were available for a total of 1971 males and 1369 females. Table 1 provides mean and standard deviation of age at incidence and mortality (reported) of all cancers and common cancers by gender. From Table 1, it was observed that the average age at incidence and mortality (reported) was almost similar. The average age at incidence and mortality (reported) for female breast cancers is 54 and 56 years, for cervix uteri cancers 59.2 and 59.8 years, for corpus uteri cancers 59 and 61 years and ovarian cancer 56 and 57 year respectively. Similarly for all other cancers such as oral cavity, pharynx, esophagus, lung etc. there was not much difference in the average age at diagnosis and mortality (reported) (Table 1).

Table 2 provides the proportion of variation (over and under) in reporting of age at mortality

compared to the age at incidence. Only for a negligible proportion of cases, age at death, was over reported. However, in 66% of all cancers in males age at death was under reported and among these, under reporting of age was more than 3 years in 12% of cases. Similarly, 65.0% of age at death was under reported for all cancers in females and among these, under reporting was more than 3 years in 22% of cases (Table 2).

When we analyzed the leading cancer sites, for almost all cancer sites, age was under reported in more than 90% of cases. For female breast cancer patients, under reporting of age at death was more than 3 years in 40% of cases. For cervix, corpus uteri and ovarian cancers, under reporting of age at death was more than 3 years in 27% of cases (Table 2).

For lung cancers, under reporting of more than 2 years in age was observed in 20% males and 37.7% females. Similarly for esophageal cancers, under reporting of more than 2 years was in 27.4% males and 31.3% females, the same for oral cancers in 57.6% males and 32.6% in females, for prostate cancers, in 64.4% and for rectal cancers, in 54% males and 59% in females (Table 2).

Discussion

Age is an important factor for the occurrence and survival of various cancers. The present paper highlighted the error which may occur in reporting of age at death in various cancer registries in India. In order to assess the magnitude of the error, Thiruvananthapuram cancer registry data was used.

During the 6-year period (2006-2011), mortality data matched to the incidence data were available for a total of 1971 males and 1369 females. In the present analysis, it was observed that the average age at incidence and mortality was almost similar. The difference between the average age at death and incidence is an indirect indicator of survival. The very minimal difference between the average at death and incidence observed in the present analysis, clearly indicated error in reporting of age at death. In the present analysis, it was observed that more than 65% of cancers whose age at death was under reported and this under reporting of age was more than 3 years in 12% of males and 22% of females.

When we analyzed specific cancer sites, it was observed that the average age at incidence and mortality for female breast cancers is 54 and 56 years, for cervix uteri cancers 59.2 and 59.8 years, for corpus uteri cancers 59 and 61 years and ovarian cancer 56 and 57 year respectively. These cancers are prognostically better cancer sites. Even for these cancer sites, as there is not much difference in the age at diagnosis and death. The smaller difference in the age at diagnosis and age at mortality is clearly showing an under reporting of age at mortality. Similarly for all other cancers such as oral cavity, pharynx, esophagus, lung etc. not much difference in the average age at diagnosis and mortality.

The error in reporting of age at death can be minimized using the variables age at diagnosis, date of diagnosis and date of death for matched cases. i.e. correction can be made for cases where information is available in both incidence and mortality database, using computer based programmes.

In conclusion, there is a need to record correct age at mortality either by verifying identity proofs such as 'adhar card' or any other authorized identity of the deceased. Also, steps are to be taken to correct the age at mortality of cancer cases which are matched to incidence data. The correct age at mortality would be quite helpful for planning cancer control programmes.

Table 1. Average age at incidence and mortality of all cancers and common cancers PBCR, Thiruvananthapuram (2006-2011)

Cancers	Gender	Incidence		Mortality	
		Mean (yr)	S.D.(yr)	Mean (yr)	S.D. (yr)
All cancers	Male (n=1971)	61.46	13.599	60.88	13.632
All cancers	Female (n=1369)	59.30	14.970	58.47	15.008
Breast	Female (n= 228)	54.33	11.894	56.14	12.011
Cervix uteri	Female (n= 86)	59.21	11.742	59.80	11.569
Corpus uteri	Female (n=30)	59.23	11.437	60.52	10.908
Ovary	Female (n=69)	55.75	9.841	57.47	10.210
Lungs	Male (n=284)	61.01	11.443	61.50	11.371
	Female (n=84)	60.02	11.321	61.01	11.671
Esophagus	Male (n=80)	60.82	9.286	61.68	9.212
	Female (n=17)	69.12	11.884	70.47	12.011
Pharynx	Male (n=85)	60.19	9.634	61.44	10.004
	Female (n=4)	62.75	13.200	63.5	13.820
Oral cavity	Male (n=141)	59.69	11.667	61.63	12.443
	Female (n=43)	62.79	12.293	63.47	12.923
Prostate	Male (n=51)	70.22	9.292	70.55	10.011
Lymphoma	Male (n=68)	57.19	13.653	56.79	13.689
	Female (n=38)	58.95	15.579	58.76	15.759
Leukaemia	Male (n=65)	45.28	23.524	47.11	23.539
	Female (n=58)	42.41	23.710	41.77	23.187
Liver	Male (n=86)	61.01	13.898	61.24	14.083
	Female (n=18)	56.06	16.261	58.25	17.067
Rectum	Male (n=44)	62.43	10.836	63.36	10.598
	Female (n=19)	57.68	12.248	58.53	12.103
Stomach	Male (n= 86)	60.56	10.999	60.67	10.777
	Female (n=21)	51.19	12.266	53	13.012
Thyroid	Male (n=12)	63.25	15.052	63.08	14.042
	Female (n=19)	61.21	14.262	62.42	13.070
Others	Male (n=799)	62.60	13.537	62.80	13.504
	Female (n=592)	61.82	14.584	62.35	14.347

Table 2. Percentage of error in reporting of age at mortality compared to age at incidence, PBCR, Thiruvananthapuram (2006-2011)

Cancers	Gender	Reporting of Age at death compared to age at incidence (%)			Year difference in under reporting of age at death (%)				
		correct	over	under	1	2	3	4	>5
All cancers	Male (n=1971)	34.0	0.3	65.7 (n=1294)	66.5	21.8	7.6	2.8	1.4
	Female (n=1358)	34.8	0.2	65.0 (n=882)	50.4	27.4	12.7	6.0	3.5
Breast	Female (n=228)	8.3	0.4	91.2 (n=207)	29.3	30.8	23.6	7.7	8.7
Cervix uteri	Female (n=86)	5.8	--	94.2 (n=81)	32.1	40.7	17.3	7.4	2.5
Corpus uteri	Female (n=30)	--	3.3	96.7 (n=29)	31.0	41.4	13.8	13.8	--
Ovary	Female (n=69)	--	1.4	98.6 (n=68)	48.5	23.5	17.6	7.4	2.9
Lung	Male (n=284)	13.4	--	86.6 (n=245)	80.1	16.7	1.6	1.2	0.4
	Female (n=84)	8.3	--	91.7 (n=77)	62.3	20.8	15.6	1.3	--
Esophagus	Male (n=80)	7.5	1.3	91.3 (n=73)	72.6	23.3	1.4	--	2.7
	Female (n=17)	5.9	--	94.1 (n=15)	68.8	31.3	--	--	
Pharynx	Male (n=85)	5.9	--	94.1 (n=79)	63.8	25.0	6.3	3.8	1.3
	Female (n=4)	--	--	100 (n=4)	100	--	--	--	--
Oral cavity	Male (n=141)	7.8	--	92.2 (n=130)	42.3	39.2	11.5	3.1	3.8
	Female (n=43)	--	--	100 (n=43)	67.4	20.9	4.7	4.7	2.3
Prostate	Male (n=51)	9.8	2.0	88.2 (n=44)	35.6	42.2	6.7	13.3	2.2
Lymphoma	Male (n=68)	8.8	--	91.2 (n=62)	69.4	19.4	6.5	1.6	3.2
	Female (n=38)	10.5	--	89.5 (n=34)	67.6	20.6	2.9	5.9	2.9
Leukaemia	Male (n=65)	20	--	80 (n=52)	69.2	15.4	7.7	5.8	1.9
	Female (n=58)	17.2	--	82.8 (n=48)	70.8	22.9	--	6.3	--
Liver	Male (n=86)	31.4	--	68.6 (n=58)	89.8	8.5	--	1.7	--
	Female (n=18)	22.2	--	77.8 (n=14)	85.7	14.3	--	--	--
Rectum	Male (n=44)	11.4	--	88.6 (n=38)	46.2	20.5	25.6	5.1	2.6
	Female (n=19)	10.5	--	89.5 (n=17)	41.2	41.2	5.9	5.9	5.0
Stomach	Male (n=86)	10.5	1.2	88.4 (n=76)	81.6	15.8	2.6	--	--
	Female (n=21)	28.6	--	71.4 (n=14)	73.3	13.3	13.3	--	--
Thyroid	Male (n=12)	8.3	--	91.7 (n=11)	45.5	18.2	27.3	9.1	--
	Female (n=19)	10.5	--	89.5 (n=17)	41.2	41.2	5.9	--	11.8
Others	Male (n=799)	66.3	0.3	33.4 (n=266)	66.5	27.6	6.3	--	--
	Female (n=592)	69.4	--	30.6 (n=181)	41.5	41.5	4.9	--	--

EXPERIENCE USING NEDES 2.0 AND PBCRDM 2.1 AT PBCR-GUWAHATI

Mrs. Arpita Sharma, Computer Programmer, PBCR-Guwahati

Introduction:

Computer based health information system has become a necessity now. The management of patient information & care requires objectives pertaining to record keeping, record retrieval and record sharing. For greater accuracy, quality data in large quantity must be precisely calibrated to assist in decision making. With the help of application software in the field of Hospital, Clinics etc. and ready availability of records make management of patient care easy & less time consuming.

North East Data Entry Software 2.0 (NEDES 2.0) was designed & developed by coordinating unit NCRP/ICMR & was used for entering & processing cancer data. The software was specially designed for newer PBCRs of North East. It was an updated version of North East offline data entry software version 1.0.

NEDES 2.0 was a stand alone and single user system & was first installed at PBCR-Guwahati in mid year 2006. The software was implemented to facilitate entering both incidence & mortality data; few advanced features were incorporated for user like provision for adding new sources of registration, user details and database repairing & data was exported into comma separated format (csv text file) after completion of data entry to coordinating unit NCRP.

Population Based Cancer Registry Data Management: Advantages of (PBCRDM 2.1) in data management and processing. A new version of software namely PBCRDM 2.1 was installed in October, 2010 at PBCR –Guwahati after new proforma was introduced to North East PBCR in 2010 and Local Area Network (LAN) connection was set up at PBCR –Guwahati in July, 2010. PBCRDM 2.1 is used for entering and managing Cancer data (both incidence & mortality) of "Population Based Cancer Registries". The highlights of the software are that it is an all in one comprehensive package that can be used to simulate all the activities of a registry.

The software contains two sections namely, **Data Entry and Processing.**

Data Entry & Data Editing: This caters to recording, running checks, reporting and exporting of data. Incidence and mortality data entry and editing are simple data entry forms with drop down lists of variables and use of other fields such that mandatory, recommended & optional fields facilitate in completeness of data. During data entry, each record is evaluated for all possible checks for range, unlikely values, family, date checks etc. Alerts for errors and potential duplicates are displayed so that user can either take an immediate action or is marked suspected at the time of saving of record. Retrieving of records for editing / updating is also convenient and flexible with multiple search option techniques. One more feature has been incorporated in this software ie. is a check box to 'enable data entry with added features', which helps to identify

duplicates during data entry itself. Here the search engine will automatically search for the record based on combinations of patient name, sex, age, PST, ICD 10, while the current data entry is going on. With this feature mortality record can be automatically generated against the incidence record if date of death is mentioned/ updated in incidence proforma. So it helps in automatic creation of mortality record against incidence.

Data linkage between incidence & mortality can be done at entry level by assigning mortality registration number in the incidence proforma and vice versa so that matches can be identified prior to entry. There are references available in the form of dictionaries for ICD10, Topography and Morphology. A HELP file is available for users to understand the features of the software better.

Data processing: PBCRDM is well equipped with powerful processing tools; processing section helps users to execute quality checks, duplicate checks, matching or data linkage between mortality and incidence can be marked and reporting on a set of chosen data. Subsequently several actions can be taken on the data so that the finalized clean data can be produced.

Data once is entered / updated in entry section, incidence and mortality data have to transfer from data entry section to processing section & user has to set year of processing before data transfer and records belonging to the processing year will get transferred & it is further used for batch quality check, duplicate checking and matching. User has to select a year of processing from set up menu available in menu bar and then transfer the data for necessary checks & in set up menu user can easily create new user account, new sources of registration, pin code and user can edit & delete data as well.

Data checking: entered data of incidence as well as mortality can be checked with the help of inbuilt check program which generates list of records with inconsistencies and regular checking of records lead to minimize the scope of errors.

'Check Data Quality' option of Incidence QC/Mortality QC will allow user to Perform Quality Checks on incidence / mortality data. This window will enable the user to execute quality checks like Range, Consistency, Unlikely and Family on the incidence data. This will initiate a batch processing of the incidence data pertaining to a specific year of the user's choice. Only those records that have been newly entered and have not been processed earlier will be eligible for the check. Records once processed become eligible for a subsequent round of checks only if they have been modified by the user during data entry.

'Quality checks listing at data entry & processing' of Data Entry menu can be generated in two ways; view errors at data entry or view or rectify errors reported during quality check with respect to DFD year. Data updation/ modification/deletion can be possible at the same point of time.

PBCR-Guwahati tries to eliminate redundant data as much possible before going for data entry that has been collected through multiple sources by our Social Investigators. We follow three methodologies for finding duplicate records.

1. First we select **'Search'** option from the simple data entry incidence proforma and then we choose search criteria from the list

assigned. We pick name of the patient or hospital registration number of patient (if any) for search criteria. If matched duplicate record found in database then we try to update the additional information if available for that particular record and then delete the duplicate one.

2. Secondly we keep radio button 'Enable data entry with added features' ON during data entry so that it could mark current duplicate entry at once to omit.

This process of finding duplicate record through search option may not always help us to obtain actual numbers of duplicates; as well as 'Enable data entry with added features' is also limited in case there is any kind of spelling or phonetics fault in name of the patient.

3. In that case we follow third methodology by which a record could be retrieved from 'Duplicate incidence menu' in menu bar through 'Find duplicates using level checks 'or 'other checks' options.

Duplicate verification of incidence and mortality data is the most powerful application of the software. The software scrutinizes the data for duplicate registration with multiple predefined checks which includes fixed combinations the identifying variables such as name of patient, father, mother and relative; sex; site of tumuor (ICD-10); hospital registration number, PIN code. The application is also provided with a flexible option wherein the user can define the combinations of various identifying variables with/without fixing the length of variable. After the scrutiny of records, list of potential duplicate cases are generated and these records are displayed in a vertical grid such that the records can be listed adjacent to each other. In the vertical grid, records can be edited/ updated and deleted with tagging of registration number of the duplicate case in retained record. Deletion can be done after tagging of record.

Incidence/mortality duplicate checking is the process of finding incidence/mortality duplicates records based on different checking criteria. Duplicate checking may be performed within same year or across years. This window provides user with the option to execute checks based on criteria which are pre defined. These checks are defined into check levels, check numbers within each check level. User has to select one check at a time to execute search engine. The user can select the sex, site and range of year for incidence data against which records will be searched for duplicates. Records of any one year can be compared.

Matching is a process of matching the mortality record with the incidence for current year or previous year. Matching of mortality cases with incidence case is also done using predefined and flexible options available in PBCRDM which is similar to the incidence data duplicate checking. The listed records can be modified /updated and marked with tagging of the registration number of matched mortality case. The Matches menu in the window provides user to execute checks based on predefined checks divided into five levels. The user can select the range of year for incidence data against which the mortality records will be matched. Records of any one year of mortality can be compared. Only one level and one check/criterion per level can be used to search for matches at a time. The checks are demarcated clearly by gender.

The special feature of the software is that it creates DCOs for the unmatched mortality cases. Thus after matching process is over; one can transfer the unmatched cases as DCOs to the incidence data. Miscellaneous menu in the window allows the user to create the incidence records for the DCO cases of cancer mortality. The user can create the incidence cases in two ways

* Create record one by one

* Create records in bulk

At present we are not allowed to create DCOs at our end. Once DCO has been created for respective year it is difficult to modify / update incidence cases against DCO. So after going through various checks at our level we send our data to NCRP and the staff of NCRP performs a series of checks and send the check reports to us for verification & updation. We follow necessary instructions sent by NCRP and modified report is sent back to NCRP. After completion of final compilation NCRP create DCOs for us. Data can be exported to CSV format or excel format. Backup of data can be taken at any point of time. In case of any loss of data, data can be easily restored from the back up file. In data entry menu Incidence/Mortality Export data option is available where user can choose any of two radio buttons for fixed field export and User defined export. The Annexure Tables are prepared after that.

Report generation: Reports are generated based on the results of data processing for quality, duplicates and mortality. The reports will help the user to use them as a ready reference while analyzing the data at the end of data entry. Reports are as follows, records with missing values, unknown sites, unknown variables, range, consistency, family and unlikely errors; Probable duplicates & sequence check repots and matches reports; deleted record list; matched death records list etc. Quality statistics like missing variable statistics, unknown variable statistics, and cases per SORs can be displayed.

Advantages of PBCRDM over NEDES:

1. PBCRDM is a multiuser & user friendly system whereas NEDES is a single user system.
2. Maintaining & managing cancer data become simpler in PBCRDM and thus data entry/ modification are faster, complete and error free.
3. All types of incidence /mortality checks can be performed at an instance & daily basis. Thus regular checking of records helps in timely corrections of errors.
4. Duplicate data can be marked and eliminated on daily basis and Enable data entry with advance features' option of PBCRDM, made easy to carry out duplicate data entry. For any registry, the manual elimination of duplicate cases is tedious and time consuming, the use of PBCRDM helps in faster & precise processing of data for duplicate checking.
5. Automatic mortality record creation is possible when DOD is available in incidence proforma in PBCRDM.
6. Mortality & Morbidity data can be matched to minimize DCOs in PBCRDM whereas those options were not available in NEDES.
7. Ease of searching information & report generation with the help of PBCRDM.

8. PBCRDM provides user to access dictionary for topography, morphology and ICDO-10 which is not possible in NEDES.

At present PBCR Guwahati is engaged in Real-time Data entry and following are the areas where PBCR Guwahati has improved in quality data submission.

Advantages of Real-time Data Entry:

1. Immediate identification of errors at the time of data entry. User can't skip unfilled mandatory portion of the proforma.
2. Data accuracy & quality improves.
3. No backlogs, no delay; if data is incomplete then it will show results for rectification.
4. Data handling is easy & safe. To ensure data protection, the software can be only accessed by authorized user as it is protected by password.
5. Once data is entered user can perform quality checks, range checks, family checks & consistency checks immediately at the end of the day.
6. Duplicate incidence/mortality can be listed & eliminated at time of data entry with the help of Enable data entry with advance features .
7. Contribution & cooperation from different sources can be listed out on daily basis.
8. Every day up to date reports can be generated and performance appraisal of staff can be made.
9. Number of missing, unknown variables, unknown primary site can be listed daily basis so that quality of information can be improved.
10. Generating tables is not tedious.

Key observations:

PBCR GUWAHATI has been utilizing the PBCRDM 2.1 software since October, 2010. This software was first installed on 18th October 2010. Our registry has been using the software for entering and processing of records for the year 2010, 2011, 2012 and 2013 (going on). The key observations made by our registry after the use of software are given as follows.

Real time data entry has resulted in the improvement in availability of Demographic details; improvement in Microscopic diagnosis as

Percentage of Quality indicators	Year				
	2008	2009	2010	2011	2012
Complete Demographic details	53.98%	63.12%	72.4%	90.3%	93.1%
Microscopic diagnosis	74.6%	77.7%	78.0%	79.2%	84.9%
Clinical details	68.9%	69.4%	69.7%	73.5%	85.6%
Treatment details	56.2%	70.0%	66.0%	70.8%	71.6%
Unknown primary	5.8%	5.6%	5.1%	4.9%	5.0%
DCOs	9.4%	11.0%	8.9%	6.8%	6.2%
M/I % ratios	19.1%	26.1%	24%	26.6%	28.0%

well as in the areas of Clinical & Treatment details. The proportion of DCOs from unmatched mortality has been diminished. Our registry staff is engaged in collecting all cause mortality data from 2008 onwards and matching of all cause mortality data has resulted in improvement of mortality registration. And accordingly, time taken for submission of data has reduced significantly from one year to few months.

We are very much grateful to coordinating unit NCRP /ICMR for carrying out such a wonderful & user friendly software for PBCR family across the county that helps management of patient information easy and less time consuming. Hearty congratulations to them.

Acknowledgement: My sincere thanks to Dr. A.C. Kataki, Director, Dr. B. Borooah Cancer Institute, for his support & valuable supervision for smooth functioning of our registry. I am grateful to our Principal Investigator, Dr. J.D. Sharma for his constant guidance & motivation to make our registry running. I thank my colleagues for their constant effort to make real time data entry a success.

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WORK ORGANISATION IN KOLLAM DISTRICT CANCER REGISTRY

Dr. P. Jayalakshmi, PBCR, Kollam

Karunagappally Taluk in Kollam District has a Special purpose Cancer Registry initiated in 1990 to study the cancer problem in relation to natural background radiation present in the seacoast of Karunagappally taluk. From initiation of the registry, we had actively involved in cancer control and palliative care services. To organize and regularize the activities, Cancer Care Centre, Kollam was started in the year 2000 with fund support from the Health and Family Welfare Department, Govt. of Kerala. For the Kollam District PBCR work this centre (CCC) became a potential support for information collection and, through the services it offered, the public support for our work increased. The following activities were undertaken to maximize all cases registered by the PBCR. As per the recommendations of the ARM of NCRP the administrative work up to make "Cancer as a notifiable disease in Kerala" was started by RCC, Thiruvananthapuram.

1. Advisory Committee (Administrative committee of Cancer Care Centre Kollam) was constituted from 2006 onwards for facilitating continued support of all the institutions contributing cancer data and supporting cancer control activities. Kollam PBCR is also actively involved in the Cancer Care Centre Kollam.
2. Meetings were convened in 2011 covering all Staff members of Medical records and Vital

Statistics Department in Trivandrum and Kollam district

3. Administrative Directors / Medical Directors / Senior Faculty members including Municipal Chairman / Block / Grama Panchayath Presidents / Secretaries attended the meetings which were conducted minimum 3 times in a year to review and discuss the activities of registry and of Cancer Care Centre.
4. Kollam PBCR staff promoted cancer control activities jointly with hospitals in Govt. and Private sectors. In all major programs of NRHM and Health and Family Welfare Department, Government of Kerala, we were involved and conducted cancer awareness, anti tobacco and cancer detection programs. This received full co-operation of DMO, NRHM and the Public in Kollam.
5. Weekly detection clinics were regularly conducted in Taluk Head Quarters Referral Hospital, Karunagappally.
6. Monthly report was given to DMO, Kollam regarding the detected and reported cases of Kollam PBCR.
7. Data checking was routinely conducted as suggested from NCRP.

Such activities enhanced the administrative and public support for the entire programme and more importantly the completeness of information collection and public co-operation with programme.

CHILDHOOD CANCERS VIS-A-VIS UNLIKELY ERROR DETERMINANT IN THE DATA MANAGEMENT SOFTWARE: AN IMPORTANT FEATURE OF HBCRDM 1.0.

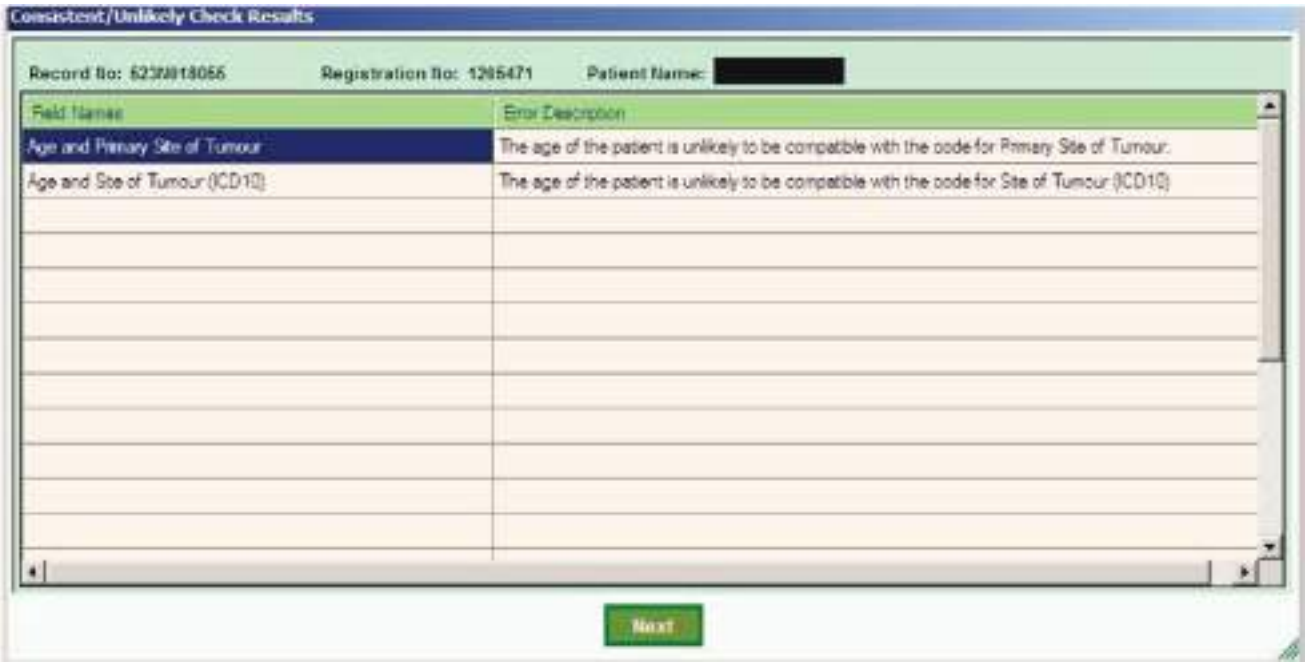
Dr. Manigreeva Krishnatreya, Dr. Jagannath Dev Sharma - HBCR Guwahati

Though cancer is a disease afflicting mostly the elderly people, there are certain cancers which are known to affect children and young adults. The proportion of childhood cancer in India ranges from 1.6-4.8% with variation by place of residence.[1] The role of cancer registrar or personnel working in registries whether it is a hospital based (HBCR) or population based registry (PBCR), is of paramount importance in identifying childhood cancers and abstracting the data in core proforma. The cancer registrar should be well versed with basic knowledge of common childhood cancers like retinoblastoma, leukemia, bone tumors, lymphomas and CNS tumors. Leukemia is the most common childhood cancer in India and in the developed world with relative proportion varying between 25 and 40% of all childhood cancers. CNS tumors are the second most common childhood cancer (22-25%) and lymphomas are the third (10%).[2,3]

There are situations when unlikely cancers are seen in certain age group like retinoblastoma in 6-years- old (ICD-10: 69.2 ICD-O-3: 9510/3/) and sometimes cancers seen in adults are observed in the pediatric age group like basaloid squamous carcinoma of the cheek skin in an 8 –year-old child

(ICD-10:44.3; ICD-O-3: 8083/3/).[4] These are marked as unlikely errors. One of the key features in cancer registry data management software (HBCRDM1.0) developed by National Cancer Registry Programme is the ability to detect unlikely errors at the time of data entry [Figure 1]. The unlikely error for age, ICD-10, and histomorphology that are detected at the time of data entry can guide the cancer registrar for further verification of the age, site and pathology of the tumor. In HBCR the medical social workers or cancer registrar have a direct interface with the patient, so physical verification of any patient of 0-14 years is possible and should be undertaken as a routine practice at the time of patient registration. In spite of that, unlikely error occurs at the time of data entry, and in such a situation the cancer registrar of HBCR can go back and relook into the records of the patient, whether be it clinical records, pathology records or even the medical records to ascertain the age and rectify if necessary. However, for PBCR - personnel who collect cancer data from different sources may not have access to physical verification of age of the patient. Erroneous entry of age at sources of registration may lead to unlikely error during the data entry at data management software of PBCR. In such a situation the cancer registrar of PBCR can verify the age by passive methods like telephonic interaction with the parents/guardian, though it is easier said than done because of ethical constraints and sentimental issues related to it. Another way of confirming the age, site and histomorphology of the patient by PBCR personnel is by checking with the concerned or primary physician. The cooperation by primary physician remains an important factor in the quality of data for PBCR's especially in case of childhood cancers.

The role of cancer registrar in ascertaining the burden of childhood cancer is very important, given the fact that most data on cancer in our population is collected by active method. Necessary check and correction of unlikely errors of site of the tumor and/or histomorphology in



cancers of 0-14 years old is equally important in determining the actual burden of childhood cancers in our population.

References:

1. Arora R S, Eden T, Kapoor G. Epidemiology of childhood cancer in India. Indian J Cancer 2009; 46:264-73
2. Stiller C (Ed.) Childhood cancer in Britain: Incidence survival, mortality. Oxford; Oxford University Press: 2007
3. Gurney JG, Bondy ML. Epidemiology of childhood cancer. In: Pizzo PA, Poplack DG, Editors. Priciples and Practice of Pediatric Oncology, 5th edition. Philadelphia; Lippincott Williams and Wilkins: 2006. P. 2-14.
4. Rahman T, Sharma JD, Krishnatreya M, Kataki AC. Basaloid squamous carcinoma of the skin associated with xeroderma pigmentosum in an 8 year old child: A rare entity. Indian J Dermatol (In press).

Legends:

Figure 1: It shows the detection of unlikely error of age of the patient with site of tumor at the time of data entry at HBCRDM1.0.

CANCER MORTALITY IN KAMRUP URBAN DISTRICT

Dr. Debanjana Barman, Medical Research Officer, PBCR - Guwahati

Introduction:

Globally cancer mortality poses a major threat to humanity. Worldwide, cancer is the third cause of death with more than 12 million new cases and 7.6 million cancer deaths estimated to have occurred in 2007. It is projected that in years to come it will increase.

Cancer incidence and mortality are key measures of the cancer burden in a country providing an important basis for implementing public health preventive measures. Information on cancer patterns determines the priorities for cancer control in different countries. Cancer incidence data provide important information on the risk of different cancers which is important in the planning and evaluation of prevention and early detection programmes. Cancer surveillance can be best achieved by improvements in the quality of mortality data. Mortality statistics is an important tool for undertaking epidemiological studies of cancer. International comparison of mortality data has been productive in outlining new directions for undertaking epidemiological studies. Cancer recorded as the underlying cause of death in death certificate and cancer recorded in population based cancer registries are often compared to assess the quality of registry findings (M/I ratio).

Based on the increasing trends of cancer incidence during the last few decades many projects were set up by National Cancer Registry Programme to study the pattern and magnitude of cancer in

different places in India. Registries also represent important sources for identification of cancer survivors.

Cancer mortality data collection in Kamrup Urban District

Sources: Data on all cancer deaths occurring within the KUD area are obtained from the Birth and Death Registration Centre (BDRC) which is under the municipal corporation and from death register of Dr. B. Borooah Cancer Institute (BBCI). There are 18 BDRC's in KUD.

Registration of mortality data: The staff of BDRC visit burial grounds and crematoriums at an interval of 10 to 15 days and collect death records available in the death register. Information of the deceased like identity , demographic details , date and cause of death are noted. The relatives of the deceased are asked to fill up two forms before issuing death registration certificate. Form 2 – for socio demographic details. Form 4 – for recording institutional death. Form 4 a—for recording non institutional death. In case of institutional death the underlying cause of death are certified by a medical practitioner and death certificate is issued. The social investigators of the registry visit BDRC to collect mortality information. They also abstract information from BBCI death register.

"Death Certificate Only (DCO)": Death information are matched and compared with incident cases of current and previous year. Information of the matched cases are updated in the incidence database. Cases registered from 'Death Certificate Only' (DCO) are the unmatched cases for which no other information other than certificate mentioning cancer could be obtained and are obtained after active follow up of the unmatched deaths which are classified as death certificates notification (DCN). In an area with accurate death certificate system and registration DCO% should be minimum of about approximately 2-3%. Mortality data supplement the incidence database and thus assist in survival studies.

Collection of all cause mortality: As per instructions from NCRP, the registry staff collect of all death cases from BDRC register irrespective of the cause of death. This was started from August 2011 and from mortality records of 2008 onwards. All the death records are then matched with the incident data available in the registry. When matched the date of death is entered in the incident database thus updating the recorded information. This methodology has significantly reduced the number of 'Death Certificate Only' (DCO) cases.

Compilation of cancer mortality data: Mortality cases are matched with morbidity data recorded since the inception of the registry to prevent duplicate registrations. The information is entered in mortality proforma with ICD-10 coding and duplicate checks and other consistency checks are done both manually and by computer. The new software PBCRDM 2.1 has been installed in PBCR Guwahati. A special feature incorporated in it 'Enable Data Entry with Added Features' which has an added advantage that it can create mortality record on its own provided the date of death is present in the proforma. By this the mortality record of the particular incident case need not be entered into the computer again.

Measures to improve the death registration system: The staff of PBCR Guwahati have made persistent effort for a greater coverage of mortality information for which new methodologies have been adopted.

1. Record all deaths regardless of the cause of death from all of the BDRC registers. This has helped to minimize the "DCO" cases.
2. Efforts are made to record the complete information of cancer cases.
3. Steps are taken to create an awareness among the staff for proper death record keeping. Yearly workshops are organized to motivate the staff of BDRC. PBCR Guwahati organized workshops to highlight the importance of data collection in the registry area. This was attended by staff of BDRC.
4. A new methodology has been adopted by our registry in case of institutional deaths of the DCO's cases. Those cases are searched in the respective hospitals by a trace back method. The social investigators revisits those centres to abstract all available information and thus new incidence record are created against those mortality cases. This is an attempt to reduce DCO's.
5. Computerization of BDRC saves time and help in maintaining qualitative data and quick generation of various reports.

Setbacks: In spite of all the measures adopted by the registry to improvise the registration system the mortality data collection has some limitations. The factors responsible for it are inadequate record keeping, diagnostic details in some BDRC's. Absence of specific cause of death also limits the quality of data collection. Records registered manually increases the chances of error and lack of computerization in the BDRC consume a lot of precious time and energy.

Non availability of death certificates at source of information may lead to under registration. The other factors responsible for it may be deaths occurring outside the registry area and not registered in BDRC or cases may migrate outside the registry area.

M/I% ratio and its importance:-

Mortality statistics are widely used to calculate the mortality /incidence ratio (M/I ratio) which is a reliability index for completeness of coverage. Cancer mortality data has an overall impact on cancer control activity and assists for obtaining survival rates.

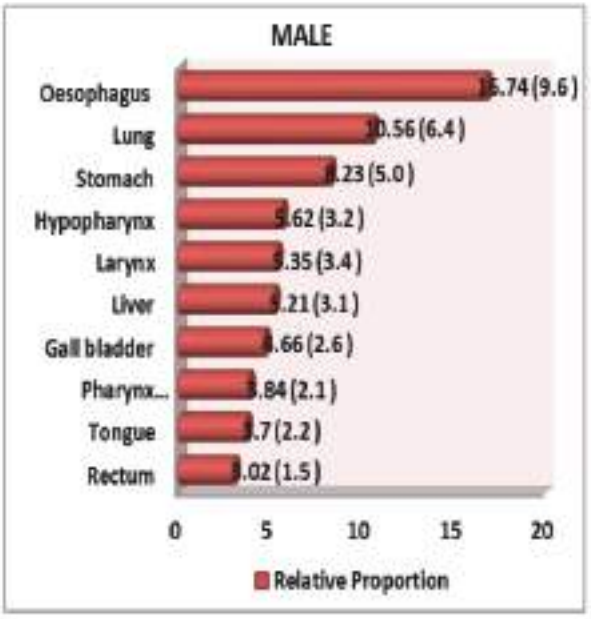
Table 1: M/I Ratios (%) during two time periods

	2006-2008		2009-2011	
	Male	Female	Male	Female
M/I%	23.1	15.1	30.43	19.6

From Table 1 it is seen that the M/I ratios of both male and female have increased over the. This indicates that the there has been better coverage.

In Fig 1, the leading causes of death during 2009-2011 are shown. In males esophagus tops the list for cancer death followed by lung, stomach and hypopharynx. In females gallbladder is the leading cause of cancer death followed by esophagus, ovary and breast cancers.

Fig:1 Relative Proportion of cancer deaths for ten leading sites
Age Adjusted Mortality Rates given in Parentheses(KUD)- **2009 – 2011**



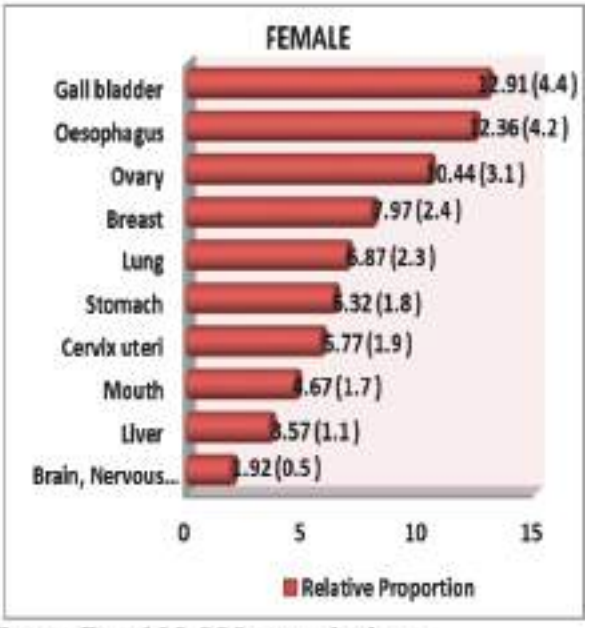
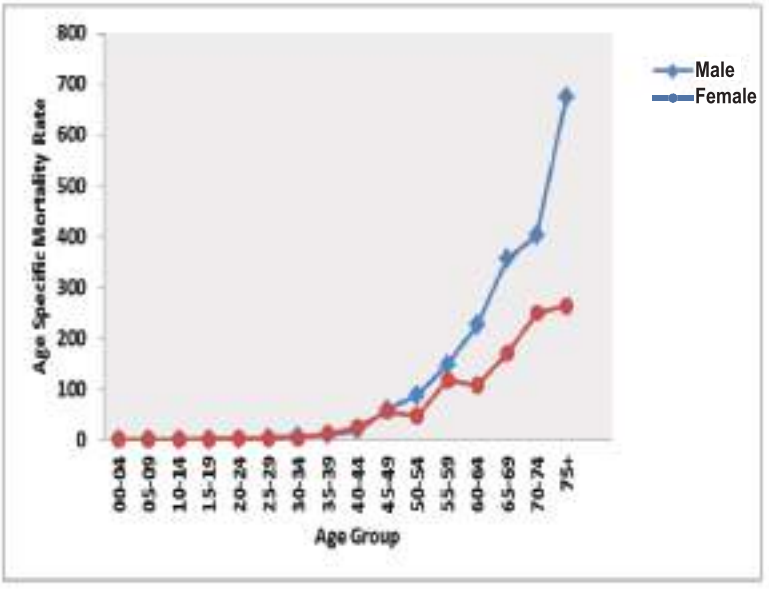


Table2: Average Annual Age Specific Mortality Rates Per 100,000 populations (KUD)

2009-2011		
Age	Male	Female
00-04	-	-
05-09	-	-
10-14	-	-
15-19	-	0.6
20-24	-	1.8
25-29	3.0	2.0
30-34	6.8	4.0
35-39	9.6	11.0
40-44	8.7	23.8
45-49	9.2	55.4
50-54	86.6	46.6
55-59	47.4	117.3
60-64	225.3	106.8
65-69	355.1	169.9
70-74	401.9	248.2
75+	673.4	263.0

Fig:2: Age specific mortality for all cancer 2009-2011



From table 2 and fig 2 the age-specific mortality rates were found to follow the general pattern of increase with age. . There has been increase in the death rates from the age group 50-54 onwards for both male and female. But age-specific death rates for females were found to be generally lower than for males. There has been a sharp rise in the death rates in males above 70 years which may be due to cancer of the esophagus, stomach, prostate and lung. Death from cancer of the esophagus tops the list in female followed by deaths from cancer of the breast, gallbladder and cervix in the older age group.

Conclusion:

Information on cancer pattern and magnitude is an important basis for cancer control. Cancer mortality assessment is a vital part of it. .Mortality statistics are influenced by the accuracy of information on death certificate. Actual cause of death should be reported. Cancer registry is an important base for cancer mortality evaluation and provides comprehensive information on cancer occurrence and means to cancer control.

Reference:

1. Mortality data in population based cancer registry, Chennai – R. Rama, R. Swaminathan, M. Kavitha ; CRAB vol XII 2005
2. Alternate methodology for reporting of cancer mortality in India: An experience of Bhopal cancer registry- Atul Shrivastava and Shushma Shrivastava; CRAB vol XII 2005
3. Role of cancer registries in determining cancer mortality in Asia- B.B.Yeole, Mumbai cancer registry, Indian Cancer Society, Mumbai, India
4. Cancer Incidence and Mortality in Nagpur city 2000-2004
5. PBCR reports NCRP:2003-2004, 2006-2008

Acknowledgement: Dr. A.C. Kataki, Director, BBCI; Dr. A. Nandakumar Director- in- charge NCRP - ICMR; Dr. J. D.Sharma, PI (PBCR & HBCR-NCRP-ICMR), all staffs of PBCR-Guwahati.

PBCR GUWAHATI Organized a Cancer Mortality Workshop on 6th January 2012

Participants were Medical Records Professional, Staff of 18 Birth & Death Registration Centres, Staff of PBCR– HBCR & Medical Record Department

SIGNIFICANCE OF M/I RATIO

It is axiomatic that if the number of deaths from cancer exceeds the number registered then registration is incomplete, unless the incidence of that site of cancer is declining at a very rapid rate. For this reason contributing registries were asked to provide information on the number of deaths from cancer by age, sex and site, for their registration area, during the period covered.

[Calum Muir & John Waterhouse: Comparability & Quality of Data Reliability of Registration. Chapter 7, Cancer Incidence in Five Continents Vol V]

ARM 2013

ARM 2012

PIONEERING CENTRES IN CANCER TREATMENT & RESEARCH

TATA MEMORIAL HOSPITAL, Mumbai

1941

2013

CANCER INSTITUTE - WIA, Chennai

2013

1954

ARM 2012 PHOTOS









28th CANCER
REGISTRY
MEETING &
WORKSHOP


28th CANCER
REGISTRY
MEETING &
WORKSHOP
National Cancer Registry
Programme (ICMR),
Govt. of India








Dr. Babu Mathew (Left) who suggested the name CRAB

Life Time Achievement Awards Prsented to Dr. M. Krishnan Nair & Mr. P. Gangadharan

AGARTHALA

Population Based Cancer Registry, Agartala was started in 2009. Earlier cancer data collection was done under Cancer Atlas Project of NCRP. Till date cancer is not a notifiable disease in the country including Tripura. Following an active case registration method, Social Investigators collect data from various incidence and mortality sources spread throughout the state. Currently 149 sources (19 major and 130 minor) are covered by the registry.

Table 1: Tripura PBCR - Cases Registered

Year	Male	Female	Total
2009	893	631	1524
2010	1051	785	1836
2011	1132	755	1887

Ranking of cancers according to site is in Table II .The leading cancers among males and females in Tripura differ from the experience of neighbouring north east PBCRs.

Table II- Ranks of 10 leading sites of cancer in North Eastern Region 2010

Males

Site	Trip	Dib	KU	IW	Miz	Sik	Cac	MS	Meg	Nag
Lung	1	5	2	1	3	4	2	1	4	6
Esophagus	2	1	1	3	2	2	1	4	1	3
Hypopharynx	3	2	3	9	4	.	3	8	2	4
Larynx	4	10	8	4	7	7	5	7	6	.
Stomach	5	4	4	.	1	1	8	2	3	2
Tongue	6	7	5	10	9	.	4	9	7	7
Tonsil	7	-	6	.	.	.	9	.	.	.
Mouth	8	3	7	.	.	10	7	.	5	8
Liver	9	6	.	7	5	3	10	5	9	.
Gall Bladder	10	9	9	.	.	.	6	10	.	.

Females

Site	Trip	Dib	KU	IW	Miz	Sik	Cac	MS	Meg	Nag
Cervix Uteri	1	4	3	3	3	2	2	3	3	1
Breast	2	1	1	1	4	1	1	2	2	3
Gall Bladder	3	2	4	4	9	3	3	6	6	.
Stomach	4	6	6	7	2	4	8	7	5	2
Esophagus	5	3	2	.	5	6	4	10	1	.
Ovary	6	5	5	6	7	8	5	5	9	5
Tongue	7	.	10	.	.	.	7	.	8	.
Lung	8	.	7	2	1	5	6	1	7	.
Mouth	9	7	8	.	.	.	9	.	4	.
Rectum	10	8	.	.	8	.	.	.	.	.

Trip – Tripura, Dib – Dibrugarh, KU – Kamrup Urban, IW – Imphal West, Miz – Mizoram, Sik – Sikkim, Cac – Cachar, MS – Manipur State, Meg – Meghalaya, Nag – Nagpur

Such observations would lead us to undertake epidemiological studies. Survival and Mortality observations help in Home care Palliative Services. Social Investigators of PBCR, Agartala are engaged for the purpose of follow-up of cancer cases and thus collects mortality data by home visits. This helps to identify bed ridden cancer cases in the locality and helps the Home Based Palliative Care Team to extend their service. Social Investigators in PBCR, Tripura take part in various national programmes for prevention and control of cancer, diabetes, cardiovascular disease and stroke. Social Investigators of PBCR, Tripura are also involved in public education against evil effects of tobacco in NTCP Project.

Training Visits by Staff

Mr. Priyatosh Dhar, Statistician and Mr. Bikash Gan Chowdhury, Data Entry Operator of PBCR, Tripura had training in cancer registration at the Department of Biostatistics and Cancer Registry, Cancer Institute (WIA), Chennai. Both completed the training-cum-workshop during August 5-17, 2013. The training comprised one-to-one interaction with senior staff, exercises, discussions and assignments on hospital and population based cancer registration, understanding of the methodology for active follow up of treated cases using online telephone directory, disease coding using ICD-O and ICD-10, electronic data processing and on-site visits to source hospitals in government and private sectors. Hands-on experience in the use of EPI-INFO software to generate frequency tables for consistency checks is also obtained. Availability of EPI-INFO or such software will be helpful for the registry.


Investigators busy abstracting cases and recording deaths


Investigators working in rural areas

AHMEDABAD

A. Rural Cancer Registry – Ahmedabad District

B. Population Based Cancer Registry – Ahmedabad Urban Agglomeration Area

Conference/Meeting/Seminar/ Workshop attended

Dr. Parimal Jivarajani attended 3rd National Conference of Asia Oceania Research Organisation&Neoplasia, AOGIN INDIA 2012 at Chennai 02 -04 November, 2012 as Delegate.

Dr. Parimal Jivarajani attended INDOX Meeting at Jaipur 24-25 November 2012 as Delegate.

Dr. Parimal Jivarajani attended HPV meeting at Pune 4-7 February 2013 as Delegate.

Dr. Parimal Jivarajani attended INDO-US joint workshop on HIV database and cancer registry match at Pune 12-13 February 2013 as Delegate.

Publications

Cancer Registry Reports

1. Population based cancer registry – Gandhinagar district report for the year 2010
2. Population based cancer registry – Gandhinagar district report for the year 2011
3. Cancer Incidence and Mortality – Patan district report for the year 2011

Studies Published

1. Jivarajani Parimal J, Shah Prachi K, Solanki Jayesh B, Patel Himanshu V, Pandya Vishruti B. Magnitude of Head and Neck Cancer in Patan District, Gujarat. Gujarat Cancer Society Research Journal. Volume 15, Number 1, April 2012.
2. Jivarajani Parimal J, Solanki Jayesh B, Pandya Vishruti B, Patel Himanshu V, Shah Prachi K. Pattern of Head and Neck Cancers in Regional Cancer Centre, Gujarat. Gujarat Cancer Society Research Journal. Volume 15, Number 1, April 2012.

ACTION TAKEN FOR MAKING CANCER AS A NOTIFIABLE DISEASE

Ahmedabad Cancer Registry has taken action as per below on the recommendations of XXVIII ARM:-

a. The Gujarat Cancer and Research Institute (GCRI) wrote a letter to the Gujarat State Government to make cancer a notifiable disease on 16/01/2013.

b. There was a personal meeting with Dr. Amit Begda, Registrar, Birth and Death, Ahmedabad Municipal Corporation on 4/10/2013 for all cause mortality. He gave instruction to all 64 wards to give complete information on form no. 2 to the Gujarat Cancer and Research Institute.

c. There was a personal meeting with Dr. Panchal, additional director, Statistics, Government of Gujarat on 11/10/2013 for obtaining all cause mortality data. He assured to look into the matter.

d. The GCRI had arranged a meeting of Ahmedabad Cancer Registry Advisory Committee on 15/10/2013. Minutes of the meeting is attached herewith.

Abstracted Minutes

The Ahmedabad Cancer Registry Advisory Committee met on 15/10/2013 to discuss the Cancer Registry activities with Dr Rakesh Vyas, In Charge Director, G C R I.

The meeting discussed the problems facing the Ahmedabad Cancer Registry. Dr Geetha Joshi, Deputy Director, G C R I, opined that for better and useful information on Cancer in Gujarat, Cancer should be made a notifiable disease. The meeting expressed concern about confidentiality, co-operation from Radiologists and Radio Therapists working outside GCRI.

WEST ARUNACHAL PRADESH - NAHARLAGUN

Dr Sopai Tawsik, Senior Pathologist (SG) and Principal Investigator, West Arunachal PBCR Arunachal, State Hospital, Naharlagan have undergone the International Cancer Technology transfer fellowship awarded by Union for International Cancer Control (UICC) from 16th Sept to 16th Oct 2013 under Dr Anna Gavin, Director N Ireland Cancer Registry Centre for Public Health, Queens University Belfast UK on Cancer Registration and Epidemiology.

The Faculty

BANGALORE

Training Programmes conducted by the Registry:

1. One week training programme in Practical aspects of functioning of HBCR for two batches of Social Investigators from Oncology Centre of Vydehi Institute of Medical Science and Research, Bangalore was conducted during January and April 2013.
2. One week training Programme in functioning of HBCR was conducted for three social Investigators form Nizam Institute of Medical Sciences, Hyderabad during February 2013.

Projects Undertaken/Collaborated by the department involving Registry Staff:

1. Dr. C. Ramesh – Principal Investigator and Mr. Vijay CR, Co – Principal Investigator for the project "Barriers Related to Screening, Diagnosis and treatment or Oral Cancers in the Resource Limited Setting" in collaboration with Research Triangle Institute of U.S.A.
2. Dr. C. Ramesh – Principal Investigator from KMIO, for the project "Demographic profile of Lung cancer in India" in collaboration with Thoracic Oncology Disease Management Group, Convener, Dr. C.S.Pramesh, Tata Memorial Centre, Mumbai.

3. Dr. C. Ramesh – Co Principal Investigator for the Research Project "Correlation of Clinical target volume in Head & Neck Cancer to Pathological Tumor margins and nodal disease and analysis of Predictive variables for microscopic disease (Proposal submitted to ICMR and clearance awaited).
4. Dr. C. Ramesh – Principal Investigator for the project "Lifelong Vegetarianism and Risk of Colorectal Cancer in India. Case Control Sturdy : Project of Indox Case Control Consortium (Ongoing Project)
5. B.R. GopalaKrishnappa: To identify the risk factors of stomach cancer incidence : Ph.D. work registered under Rajiv Gandhi University of Health Sciences.

Meeting Attended by Registry Staff:

The following staff from KMIO attended the 28th ARM of NCRP held at Regional Cancer Centre, Trivandrum, 6-7th December, 2012

1. Dr.M.Vijayakumr, Director and Principal Investigator
2. Dr.C.Ramesh, Prof.&Head, Co-principal Investigator.
3. Mr.C.R. Vijay, Asst.prof.
4. Mr.D.J.Jayaram, Sr.Investigator (HBCR)
5. Mr.B.R. Gopalakrishnappa, Field Supervisor (PBCR)
6. Mr.P.Manjunath, Asst.Social Scientist (PBCR)

Note: Staff at Sl.No. 3-6 attended Pre ARM workshop also.

Lecturers delivered:

Dr. C. Ramesh, Prof.& Head,

1. Has been a Resource person for the Orientation Course on Family of International Classification for Medical Personnel involved in the field of Insurance and also for Para medical personnel of various Hospitals, covering Chapter II Neoplasm of ICD10. This training programme is conducted 2-3 times every year by Central Bureau of Health Intelligence, Govt. of India at Bangalore.
2. "Statistics as a Profession" – keynote address in the UGC sponsored National Conference on Research in Science for Beginners at MES College, Bangalore on 30-9-2013
3. "Statistical Issues in Research Studies" – Lecture delivered in the Refresher Course in Statistical Methods for Behavioural Research – NIMHANS, Bangalore, 29-31, August 2013
4. "Epidemiology of Cancer" Lecture delivered in the One day Seminar on Health Awareness , Organized by Dept. of Sericulture /Life Science, Bangalore University, 13th June 2013
5. Analytical Studies – Lecture delivered in the Workshop on research Methodology Organized by Dept. of Epidemiology, NIMHANS, Bangalore 13th December 2012
6. "Statistical Issues in Clinical Trials" Lecture delivered at Apollo Hospital, Bangalore, 30th November 2012.

7. "Epidemiology of Cervical Cancer – Clues to Prevention" Lecture delivered in the First Annual Conference of Association of Gynecological Oncologists of India (Karnataka Chapter) at RGUHS, Bangalore held on 17-18 November 2012.
8. "Hospital Cancer Registry – Principles and Methods" Lecture delivered at Oncology Centre of Vydehi Medical College, Bangalore, 10th October 2012.
9. "Epidemiology of Ovarian Cancers – the Indian Scenario" lecture delivered in the One day CME on Management of Ovarian Cancer Organized by BIOCON, at KMIO, Bangalore, 18th August 2012.

Mr.D.J. Jayaram, Sr. Investigator.

Delivered a talk on "Sample size determination and sampling design" in the Pre ARM Workshop at NCRP held on 4-5th December 2012 at RCC, Trivandrum.

Training Received by the Staff of the Registry:

Mr.C.R. Vijay, Asst.Professor and Mr.K.Venkatesh, Statistical Assistant attended a training programme on R software in Dept.of Biostatistics, Manipal Institute of Health Sciences, Manipal

Papers Published:

1. Rahul Bhagat, Shilpa Chadaga, CS Premalatha,G. Ramesh, C. Ramesh, VR Pallavi, Lakshmi Krishnamoorthy "Aberrant promoter methylation of the RASSF 1A and APC genes in epithelial ovarian carcinoma development", Cell Oncol 35:473-479, 2012
2. Gopalakrishnappa BR[1], Vijay C R [2], Ramesh C[3], Bapsy P P[4], Uday Kumar M[5], Vijayakumar M[6], Supe SS[7]. "Trends in Oesophagus and Stomach Cancer incidence in Bangalore, India". The Gulf Journal of Oncology, 2013:13:42-50
3. Gopalakrishnappa BR[1], Supe SS[7], Bapsy P P [4], Uday Kumar M[5]. "An Overview of risk factors for stomach cancer 1: Genetic Susceptibility". Bio nano frontier. 2013:6(1): 164-168
4. Rahul Bhagat, C.S. Premalatha, V.Shilpa, V.R. Pallivi, G.Ramesh, Vijay C.R. & Lakshmi Krishnamoorthy. "Altered Expression of [2]- Catenin, E-Cadherin, and E-Cadherin promoter methylation in epithelial ovarian carcinoma": International Society of Oncology and BioMarkers (ISOBM) 2013.

Superannuation:

Mr.C. Shivanna and Mr.A.V.Srinivasa Gowda who worked as Asst.Social Scientist (more than 25 years) since the inception HBCR at KMIO, attained superannuation November 2012 and July 2013 respectively. The department acknowledges their contribution to the Registry.

BARSHI

The first rural cancer registry was set up in 1987 in Barshi in the state of Maharashtra in Western India. The registry is functioning well, Rural Cancer Registry Barshi Data for the year 2003-2007 has been accepted for Cancer Incidence in Five Continent Volumes – X. This is a big achievement for the Registry.

Mr. Panse N.S. Registry Manager attended Verbal Autopsy Training workshop as a faculty member Sponsored by the 'Centre for Global Health Research, Toronto' for RGI (Birth and Death Registration) Karnataka at Bangalore on Feb-2013.

On 15th March 2013 Centre for Disease Control and prevention USA (CDC) visitors Dr. Mrs. Mona Saraiya & Dr. Florence K.L. visited Barshi Registry. They were very much impressed with the registry work and methodology. They observed the day to day registry functions and of primary health centres from expanded registry area and observed the working of PHC, visited one of the Primary Health Centre (Usuf Wadgaon-Kej-Beed) from Expanded Registry area and observed the working of PHC, Tahsil - Health Officer, Medical Officer of PHC and All PHC staff attended the programme. The PHC had organized a felicitating programme for the visitors at PHC. After completion of visit they expressed their comments as follows,

"We are very much impressed with the quality and amount of work that is being done by the Barshi Cancer Registry. You not only do the case registration activities but you are also involved in cancer control activity. We look forward to working with you to estimate the cost of starting and maintaining cancer registry as an example that other countries can use."

Dr. Mrs. Mona Saraiya & Dr. Florence K.L.
CDC - USA
with Mr. Panse N.S., Dr. Khan

BHOPAL

The Bhopal gas disaster in 1982 prompted the ICMR to establish the cancer registry in Bhopal in 1985. The major objective was to study the health effects of MIC gas exposure on the people. The total population of Bhopal city was covered by the cancer registry. The Bhopal PBCR is placed in the department of pathology, Gandhi Medical College (GMC). The GMC along with the 1000 bedded associated hospital is the premier medical teaching institute of the state of Madhya Pradesh. It provided comprehensive cancer care to the patients in the city.

Organization of cancer registry:

The registry staff were trained by visits to Thiruvananthapuram and Mumbai registries. Registration of cancer was started from 1st of January 1986. The registry staff regularly attended the ARM workshops of NCRP held annually and are continuously updated in cancer registration.

Initially in Bhopal the only cancer care centre was the GMC and its associated hospitals; hence cases were registered for PBCR from these hospitals. A small proportion of cases were seen in some of the nursing homes and private diagnostic centres. From the beginning cooperation from these centres were sought. Cancer patients from Bhopal also visited advanced centres like TMH and information was collected from such centres situated even outside the state. Currently more cancer care centres are established in the city and this reduced the number of cases referred outside Bhopal, but increased the number of sources of registration within the city.

Information collection from sources:

The frequency of visit to each source of registration in the city by the investigators depended on the number of cases registered in these centres. To assure the completeness of requisite information of the cancer cases a small registration form containing the mandatory information has been compiled in a booklet and placed at the reception desk of the source. Thus information on all patients visiting this centre was obtained.

Digital data transfer from sources:

As the number of sources of registration increased it became difficult for registry to obtain data in time. Hence digital transfer of data from sources to the registry was implemented after testing at two sources of registration. However, the quality and completeness of data transferred digitally was also compared manually. There was no significant difference in the two data sets. Regular visits were made to these sources for augmenting the available information. Digital transfer of such information reduced the number of visits.

Meetings to ensure cooperation:

Cooperation of the sources of registration was ensured by regular meetings. Often treating doctors, administrative staff and personnel of the medical records attended such meetings and their suggestions were discussed. Yearly workshops, training programmes are also organized for persons handling the medical records. These have significantly improved the the registry information.

Death registration and information collection on deaths:

The death registration system at Bhopal is far from adequate resulting in under registration of cancer mortality. To overcome this, information on all deaths taking place in the city are collected from Municipal and crematorium records. Matching these with the recorded morbidity data is undertaken. Cases with no details other than those available on death certificate are registered as DCOs. Overtime, the MI ratio has improved to 35.2% in 2010 from 14.5% in 1997.

Meetings / Conferences / workshops attended		
Name of the meeting/ workshop Conference, place, month/Year	**Name of person and nature of participation**	**Title/Topic of presented**
34th Annual Meeting of IACR at Cork Ireland 17-19 September 2012	Atul Shrivastava Oral presentation	Trends of Cancer in Bhopal India (1988-2005)
Workshop on ICD-10 held at Medical College, Pune, Goa & Nagpur, organized by CBHI February & March 2013	Atul Shrivastava As faculty	Workshops on Awareness on ICD-10
All India Workshop for Medical Persons on ICD-10 organized by CBHI December 2012 &April 2013 at Bhopal	Atul Shrivastava As faculty	Introduction to ICD-10 Basic Guide Lines Coding of neoplasm
All India workshop for Medical Record Officer on Health Statistics, organized by CBHI, June 2013 at Bhopal	Atul Shrivastava As faculty	Introduction to ICD-10 & its Implementation in Medical Department
Tobacco Awareness Workshop, October 2013	Atul Shrivastava As faculty	Sultania Higher Secondary School attended by 200 Students of Class X, XI & XII
Meeting of Indian Association of Pathologists M.P Chapter January 2012 at Bhopal	Atul Shrivastava	Trends of Cancer In Bhopal

Implementation of PBCRDM:

For timely submission of registry data and to overcome the disparities the NCRP developed the software PBCRDM. This was tested at Bhopal PBCR.

Events of the registry:

Meeting of staff of sources of registration held on 25th of April 2013 & 11th of October 2013.

Workshop on cancer registration organized for persons handling the medical records of all sources of registration was held on 26th of April 2013

A Hospital Based Cancer Registry has also been established at Gandhi Medical College Bhopal. The registry started working from 1st of January 2011.

CHENNAI

Workshop organized

A workshop on Cancer Registration was organized by the Department of Biostatistics and Cancer Registry at the institute during August 5-10, 2013 as part of Tamil Nadu Cancer Registry Project operations towards evaluation and training of staff members.

Courses organized

An in-house certificate course on Research Methodology and Biostatistics was organized by the Department of Biostatistics and Cancer Registry at the institute during June 15-20, 2013 as per Tamil Nadu Dr. MGR Medical University syllabus. A total of 35 delegates comprising oncology post-graduates, PhD students, research fellows, senior faculty and staff participated. Dr. R. Rama, Ms. P. Shanthi, Dr. R. Swaminathan from the department and Dr. P. Venkatesan from ICMR National Institute for Research in Tuberculosis, Chennai, served as faculty.

Training programs

Mr. Priyatosh Dhar and Mr. Bikash Gan Choudhury from Tripura Cancer Registry, Tripura, participated in a training program on Cancer Registration, Principles and Methods, organized by the Department of Biostatistics and Cancer Registry at the institute during August 5-17, 2013. The program comprised exercises, discussions, hands-on experience and on-site visits pertaining to cancer registration.

A delegation comprising 24 students of diploma course in medical record science and 3 faculty members from Sri Shakthi Amma Institute of Allied Health Sciences, Vellore, visited the department on May 10, 2013 for observation training on medical record aspects. This comprised lectures, discussions and demonstration of active follow up of cancer patients using online telephone directory.

International visits

Dr.R.Swaminathan visited the International Agency for Research on Cancer (IARC), Lyon, France, during February 19-25, 2013 to participate in the Childhood Leukemia Meeting organized by Environment and Radiation Section; final review of data sets from Asia for the IARC flagship publication titled "Cancer Incidence in Five Continents, Volume X" and during June 24-27, 2013 to develop the research protocol for SurvCan-3, a global survival study.

Dr.R.Swaminathan was a faculty member in the international course on Cancer Survival: Principles, Methods and Applications held in London School of Hygiene and Tropical Medicine, London, UK and delivered an invited lecture titled Cancer survival estimation in low or medium income countries (LMIC) on June 28, 2013.

National visit

Dr.R.Swaminathan visited the Regional Cancer Centre, Agartala, Tripura, during May 27-29, 2013 in connection with the multi-centric molecular epidemiological study on gastric cancer funded by DBT and delivered lectures on descriptive epidemiological measures and role of cancer registries in cancer control.

University Examiner

Dr. R. Swaminathan was the external examiner for conducting PhD viva-voce in Statistics for Kannur University at Kannur, Kerala, on May 3, 2013.

International Fellowship

Mr. T.S. Sambandam, Senior Investigator, MMTR, was awarded the IARC Fellowship to participate in the IARC Summer School in Cancer Epidemiology at IARC, Lyon, France between June 17 and July 5, 2013.

Publications

Thulaseedharan JV, Malila N, Hakama M, Esmy PO, Cherian M, Swaminathan R, et al. Effect of screening on the risk estimates of socio demographic factors on cervical cancer - a large cohort study from rural India. Asian Pac J Cancer Prev 2013; 14(1): 589-94. PubMed PMID: 22534800

Swaminathan R, Shanta V, Balasubramanian S, Sampath P. Technical Report 2009-2010: Madras Metropolitan Tumour Registry. National Cancer Registry Program, Cancer Institute (WIA), Chennai, 2013

Swaminathan R, Rama R, Shanta V. Technical Report 2009-2010: Chennai Hospital Cancer Registry, National Cancer Registry Program, Cancer Institute (WIA), Chennai, 2013

GUWAHATI

Publications:

1. D Barmon, A Sarma, JD Sharma, AC Kataki, C Bhuyan.Primary Non-Hodgkin's Lymphoma of the Uterine Cervix: Report of Three Cases with Immunohistochemical Study.Journal of Cancer Research Updates 2012;1 (1)
2. D Barmon, AC Kataki, L Imchen, JD Sharma.Extra mammary Paget's disease of the vulva .Journal of Mid-life Health 3 2012;(2), 100
3. D Barmon, AC Kataki, JD Sharma, J Bordoloi. Aggressive angiomyxoma of the vulva.Journal of Mid-life Health 2012;3 (1), 47
4. D Barmon, AC Kataki, JD Sharma, D Gharpholia. A Case of Cervical Tuberculosis Mimicking Cervical Carcinoma. The Journal of Obstetrics and Gynecology of India, 1-3
5. Mishi Kaushal,[1] Ashwani K. Mishra,[1] Jagannath Sharma,[2] Eric Zomawia,[3] Amal Kataki,[2] Sujala Kapur,[1] and Sunita Saxena[1]* Genomic Alterations in Breast Cancer Patients in Betel Quid and Non Betel Quid Chewers.PLoS One. 2012; 7(8): e43789. Published online 2012 August 24. doi: 10.1371/journal.pone.0043789
6. Jagannath D Sharma. Population based cancer incidence in Kampur urban, India: Report on cancer National Medical Journal of Inbdia. Ref : Manuscript No.3453/329/2011 (Accepted on August 2012)

7. Anupam Sarma,R J Das,Jagannath D Sharma, A C Kataki:Spindle cell carcinoma of the Head and Neck:A clinicopathological and Immunohistochemical study of 40 cases .Journal of Cancer Therapy, 2012,3,1055-59.

8. T.Rahman, K Ahmed, Jagannath D Sharma, A Das. Solitary fibrous tumor of the orbit: A rare entity. Indian Journal of Cancer 2013 Jan-March issue (in press)

9. Rahman T, Bhattacharjee K, Sarma JD, Dey D, Kuri G. Primary dermatofibrosarcoma protuberans of orbit-a rare entity. Orbit. 2013 Apr;32(2):127-9.

10. Tashnin Rahman, Jagannath D Sharma, M Krishnatreya, A C Kataki. Basaloid squamous carcinoma of skin associated with xeroderma pigmentosum in an eight year old child: A rare entity. Indian Journal Of Dermatology (Accepted on January;2013)

11. M Krishnatreya, T Rahman, Jagannath D Sharma, A C Kataki. Synchronous sporadic medullary carcinoma of the thyroid and small cell carcinoma of lung: A rare entity. Clinical Cancer Investigation Journal 2013;Apr-June .Vol 2,issue 2.

12. 'Primary Laryngeal Tuberculosis mimicking as a supraglottic carcinoma:A rare ntity.'Monigreeva K,K Das,A Sarma,Jagannath D Sharma. International Journal of case reports and images.Vol,No,2013.

13. Nested Multiplex PCR Based Detection of Human Papilloma Virus in Cervical Carcinoma Patients of North –East India.D Das,A Rai, ACKataki,D Barman,P Deka,J D Sharma,A Sarma,A Kalita.Asian Pacific Journal of Cancer Prevention,Vol14,2013.

KOLKATA

PBCR Kolkata activities (2012 – 2013):

a. Interdepartmental meetings were held at regular intervals

b. Co-PIs and staff personally met officials of different New source centres ie, Tata Medical Centre, D. S. Research centre etc and requested cooperation

c. Dr. Karabi Datta attended Indian Public Health Conference – 2013 (IPHACON – 2013) on 2nd – 3rd February, 2013 at Science City in Kolkata and presented a poster, "CANCER REGISTRY IS THE ONLY WAY TO ASSESS THE MAGNITUDE AND PATTERN OF CANCER IN KOLKATA"

KOLLAM

In the CRAB Vol XV-2010 we described the circumstances which led to the formation of the population registry of Kollam District – as an expansion of the Karunagappally Taluk registry which was in Kollam District. As mentioned, there were several public expressions regarding an increased occurrence of cancer among Karunagappally population due to the exposure to natural radiation present in the area. Several instances of such public concern regarding high occurrence of cancer in different localities are increasingly voiced now. This is a welcome sign and requires well planned studies.

The Karunagappally Cancer Registry was started in 1990 as a special purpose registry to evaluate whether the occurrence of cancer was due to exposure to natural radiation emitted by the radiation bearing monazite sands present in Karunagappally.

Outcome from NCRP-ICMR Atlas of Cancer project spotted Kollam district as a productive area to organize a PBCR covering the Kollam District population and Karunagappally registry was entrusted with this work. The Kollam district registry was initiated in 2006. The population of Kollam District was around 27 lakhs (Estimate-2009)

The unique features of Kollam district are

1. There are no medical colleges or hospitals with radiotherapy facilities in the district.
2. The district extends from the sea cost in the west to hilly plantation areas in the east.
3. A large proportion of the population living on the western areas of the district are fishermen, cashew nut workers and coir workers.
4. The literacy rate in the population of the district is high, more than 80%.
5. There is good transport & communication network.
6. The district is divided into 5 taluks - Karunagappally, Kollam, Kunnathur, Kottarakkara and Pathanapuram.

PBCR Kollam pursued an active registration system for case finding and recording. Identifying and recording of cancer cases had to cover a large number of sources – Pathology laboratories, Major hospitals, District hospitals and Vital Statistics departments of all the Panchayaths in the district.

Apart from these, cancer cases were located from the records of RCC, Govt. Medical colleges at Thiruvananthapuram, Alappuzha and Amrita Hospital Kochi. Some of the Cancer deaths recorded in the vital statistics department needed house visits of the deceased to obtain the required details of the deceased.

The All cancer incidence rates for Kollam district was marginally different from that recorded in the Thriuvananthapuram Taluk registry. In Table 1. The 5 leading sites of cancer in Kollam district are given

Table I Incidence (AAR) Rates of Five Leading Cancers in Kollam 2009-2010

Males		Females	
Lung	19.5	Breast	25.8
Stomach	6.5	Thyroid	7.3
Mouth	6.0	Cervix	6.8
Liver	5.8	Ovary	5.0
Prostate	5.7	Mouth	3.4

The Age Adjusted Incidence Rates of all cancer among Males was 118.5 and among females it was 91.6 /100000.

Cancer Patient Services in the Area

We organized several community programmes in the area covering cashew factory workers and other industrial workers including public of the registry area which helped us to get co-operation from the public and local administration.

The services rendered mainly with the support of registry are Palliative care, Cancer Education and Cancer Detection Camps, Review clinics of treated cancer patients and other Rehabilitative supports. All these helped us to receive Public Co-operation in all our work.

Expansion of registry operations into etiological and epidemiological studies:

The observations of the Kollam & Karunagappally registries have led to seven projects which are now ongoing in the Kollam District.

These are

1. Cancer Incidence studies in High Background Radiation area Karunagappally - Health Research Foundation Japan 2001- 2012.
2. Sociodemographic and Cancer studies in Kollam Corporation and other coastal areas – Dept. of Atomic Energy. Govt. of India 2009 -2012.
3. Concord 2 programme for survival Analysis of 10 cancer sites - London School of Hygiene and Tropical Medicine 2012.

The study initially concentrated on the Cancer Risk estimates in relation to radiation and the findings lead to the following indepth studies based on the established cohort.

1. Thyroid nodularities in high background radiation area.
2. Molecular signature of Thyroid cancers in relation to natural radiation in Karunagappally.
3. Prevalence of Atherosclerosis and Cataract among the residents in High background Radiation area Karunagappally Kollam District Kerala.
4. Non Cancer mortality studies.

Publications

Association of tobacco use and alcohol use with Laryngeal and Hypopharngeal cancer in men in Karunagappally, Kerala, India --Karunagappally cohort study Padmavathy Amma Jayalekshmi1,2, Athira Nandakumar3, Suminori Akiba,*3 Paleth Gangadharan4, Chihaya Koriyama3. (PLOS ONE, www.plosone.org, August 2013, Volume 8, Issue 8, e73716)

Acknowledgements

Kollam PBCR was supported financially & technically by NCRP- ICMR. We could accomplish the above activities due to the hard working registry staff and medical record staff of RCC, Co-operation from several hospitals and laboratories, Department of health Government of Kerala, Panchayath Administration and Community Services.

MUMBAI

Mumbai Cancer Registry established in the year 1963 is the first population based cancer registry in India and functioning from 1st Jan 1964 onwards. This registry initiated by the Indian Cancer Society received fund support form NCI (US) and from the Department of Science and Technology, GOI. The registry is celebrating 50 successful years of contribution towards the cancer research, prevention and cancer control activities. The Mumbai cancer registry was the first functioning registry to merge with National Cancer Registry Programme in 1982 and has been consistently active in all NCRP functions.

Three other population based registries at Pune, Aurangabad and Nagpur all in Maharashtra were also organized by the Mumbai cancer registry and Indian Cancer Society. These registries also merged with the National Cancer Registry Programme of ICMR and all the four registries are now functioning with the NCRP.

Up till now the Mumbai cancer registry has published more than 100 research articles in national and International journals. More than 45 Monographs have been published by the registry based on cancer database. More than 70 papers have been presented in scientific conferences at national and international cancer conferences.

Late Dr. B. B.Yeole, Director of Cancer Registry received his PhD (Epidemiology) and Dr. Lizzy Sunny PhD (Epidemiology) a former employee of the cancer registry had received their doctorates from Tampere School of Public Health. They both used the cancer registry data of Mumbai registry for their thesis work. Dr. Yeole managed the registry operations for 35 years.

More than 40 staff members have received trainings in national level workshops arranged by NCRP and TMH. More than 5 staff members have attended the Course on Cancer Registration and Epidemiology arranged by International Agency for Research on Cancer, Lyon, France.

Present Co-Principal Investigator of Cancer Registry, Mrs. Shravani Koyande has been selected for the International Post Graduate Programme of Epidemiology organized by Tampere School of Public Health, Tampere, Finland and registered for doctorate programme in Epidemiology in year 2010.

Population cancer registry data from Mumbai and Poona Cancer Registries have been accepted by IARC for the Scientific Publication, Cancer Incidence in 5 continents, Vol. X.

At Present Dr. Purvish Parikh has taken charge as Principal Investigator of Cancer Registry Division after the sad demise of Dr. A. P. Kurkure.

Publications:

1. Increase in breast cancer incidence among older women in Mumbai : 30-year trend and prediction to 2025.Dikshit R, Yeole BB, Nagrani R, Dhillon P, Badwe R, Bray, F, Cancer Epidemiology, International Journal of Cancer Epidemiology, Detection and Prevention, (36) pp 215-220, 2012.
2. Substantial Burden of Non-AIDS Cancers in Persons with HIV in India: Early Results from a Computerized HIV and Cancer Registry Match in Pune, India Sheela Godbole[1], Nandy Karabi[2], M Gauniyal[1], P Nalavade[1], Shravani Koyande[1], A. Nandakumar[1], Joy Toyama[2], R Devkar[1], Phil Virgo[4], Kishor Bhatia[4], Ramesh Paranjape[1], Arun Risbud[1], Sam M. Mbulaiteye[5] and Ronald Mitsuyasu[2] (Sent to Journal yet not accepted)

Monographs:

1. Cancer Incidence and Mortality in Greater Mumbai 2010 (In Press)
2. Cancer Incidence and Mortality in Poona City Agglomeration (In Press)

Meetings:

1. Miss. Vaishali Thorat, Research Assistant, has attended workshop on CANREG-5 at TMH during 14-18 January 2013 and Miss. Komal Rane has attended workshop on CANREG-5 at TMH during 17-18 Jan, 2013, arranged by International Agency of Research on Cancer (IARC), Lyon France.
2. Mrs. Shravani Koyande, Executive of Cancer Registry Division and Miss Vaishali Thorat, Research Assistant, has attended a program on Survival Analysis, under the guidance of Dr.Swaminathan, Head of Chennai Cancer Registry, Adyar, Chennai during 4-7 Feb 2013.
3. Mrs. Shravani Koyande, Co-Principal Investigator of Cancer Registry Division was invited as a Faculty Member to attend the Workshop arranged by TMH and PGI at Chandigarh during 10-12 Oct 2013 on Cancer Registration and Control. She has presented Survival Analysis on Major Sites of Cancer in Greater Mumbai.

PATIALA REGISTRY AND PUNJAB CANCER ATLAS

Inaugurated by Minister of Medical Education & Research Punjab, PBCR Patiala was started at Deptt. of Pathology, GMC Patiala, in June 7, 2011with Dr. MS Bal as PI, Dr. Vijay Bodal & Dr. Ms. Harjot Kaur Bagga as Co-PI's, 3 social workers, one statistician and one data entry operator. Recognizing the PBCR work, Punjab Cancer Atlas was installed in January 2013; and two more workers were employed.

Award:-

Dr. Manjit Singh Bal Principal Investigator PBCR and PCA Patiala, was awarded by NGO Mrs.Niraml Verma Cancer Cry Care Society (REGD.) Patiala on 12-02-2013 for being star presenter to disseminate, cancer-awareness, through his lectures in almost all meetings.

Events Organized/Conducted:-

1. Punjab Health System Corporation Mohali, on 07/09/2013, organized a training about online submission of cancer data at NCRP Web Site; the training to pathologists working in various health centres and civil hospitals of Punjab, provided by Dr. Jaspreet Kaur, Mr. Vicky Harinder pal, Mr. Dalvir Singh, Ms. Swati Sharma
2. Dr. Vijay Kumar Bodal and Dr. Sarabjit Kaur (PG Student Pathology) participated in the Mega Camp for Cancer Awareness at district Hoshiarpur on 22/09/2013.
3. Dr. Manjit Singh Bal, Dr. Vijay Kumar Bodal, Dr. Jaspreet Kaur, Ms. Asha Rani, Ms. Monika, Ms. Parvinder Kaur, Ms. Amandeep Kaur, Ms. Swati Sharma, Mr. Vicky Harinderpal, Mr. Dalvir Singh actively participated in Mega Camp for Cancer Patients at Rajindra Hospital Patiala on 28-29/09/2013.

Training Imparted

Under the guidance of Dr. Manjit Singh Bal, Principal Investigator cum HOD Pathology GMC Patiala, Dr. Vijay Kumar Bodal, Dr. Jaspreet Kaur, Ms. Asha Rani, Ms. Monika, Ms. Parvinder Kaur, Ms. Amandeep Kaur, Ms. Swati Sharma, Mr. Vicky Harinderpal, Mr. Dalvir Singh attended training cum workshop on Development of an Atlas of Cancer in Punjab State at National Centre for Diseases Informatics and Research (NCDIR) Bangalore on 18-19/03/2013. Dr. Bal, Dr. Bodal (Co-Principal Investigator) and Dr. Jaspreet (Research Scientist) actively participated in the discussions, whereas, power point presentations were given by Ms. Asha, Ms. Swati and Ms. Amandeep Kaur.

Meetings

1. Dr. Manjit Singh Bal, Dr. Vijay Kumar Bodal and Dr. A. Nanda Kumar, attended the meeting with Mrs. Vini Mahajhan, Principal Secretary, Govt of Punjab on April 15, 2013 regarding Punjab Cancer Atlas.
2. Dr. Manjit Singh Bal and Dr. Vijay Kumar Bodal attended meeting with Mrs. Vini Mahajhan, Principal Secretary, and Dr. Tejbir Singh Director Research & Medical Education Punjab on Govt of Punjab May 7, 2013 regarding PBCR, Punjab Cancer Atlas and hosting of Annual Review Meeting (ARM) of NCRP at GMC Patiala.
3. Dr. A. Nanda Kumar, Dr. Manjit Singh Bal, Dr. Vijay Kumar Bodal and Mr. Vicky Harinder Pal had a meeting at Chandigarh on June 19, 2013 regarding 29th Annual Review Meeting of National Cancer Registry Program to be organised by Department of Pathology Govt. Medical College, Patiala.

In connection with Cancer Registry Organisation and Cancer Control programme of Patiala we conducted several cancer camps and the staff attended workshops and meeting at Bangalore

SIKKIM

This year the Population Based Cancer Registry Sikkim participated in the CONCORD-2 study. The CONCORD-2 study will examine global trends and geographic differences in survival for 10 cancers in adults, and childhood leukemia. It will include patients diagnosed during the period 1995-2009 or later. More than 280 cancer registries in 64 countries have signed up to participate so far.

Out of the ten sites of cancer picked up the CONCROD -2 study the PBCR Sikkim submitted the records for five cancer sites i.e Stomach, Liver, Lung, Breast, and Cervix from the year 2006 to 2011. The study is presently being supervised by Dr. Michel Coleman, Professor of Epidemiology and Vital Status, Cancer Research UK Cancer Survival Group, London School of Hygiene & Tropical Medicine Around 833 cancer cases were followed up and updated as required by the CONCORD study.

Dr. Yogesh Verma participated in the meeting "Planning Workshop for Cancer Screening Strategies" organized by ICMR and National Cancer Institute, Washington, in New Delhi on 13th and 14th of September 2013.

Entries of core proforma both for Incidence and Mortality for the year 2012 has been completed and sent to coordinating unit Bangalore. Entries of 2013 incidence cases is presently in progress. We are striving towards real time entry of 2014 data.

THIRUVANANTHAPURAM

Awards

Dr. Aleyamma Mathew

Received Second Doctorate degree ((Statistics) from the Mahatma Gandhi University in December 2012.

Dr. Preethi Sara George

Young Investigator award, 6th APOCP General Assembly meeting, Sarawak, Malaysia, 26-29th April 2012.

Received Prof. (Miss) Aleyamma George Memorial Best paper award from the Kerala Statistical Alumni Association, Kariyavattom, University of Kerala, July 2013.

Events organized

1. Pre-ARM workshop on Cancer Registries at Sree Chitra Thirunal Institute of Medical Science, 4-5 December 2012.
2. 28th Annual Review Meeting (ARM) of National Cancer Registries at Sree Chitra Thirunal Institute of Medical Science, 6-7 December 2012.

Training imparted for other staff, other hospitals

1. One day training to 21 Biostatistics students, from St. Thomas College, Pala at Regional Cancer Centre, Thiruvananthapuram, 9th April 2012.
2. Two-days training to Biostatistics students, from Veterinary college, Thrissur at Regional Cancer Centre, Thiruvananthapuram, 10-11, May 2012
3. 3-months training to two MSc Biostatistics students from St. Thomas College, Pala at Regional Cancer Centre, Thiruvananthapuram, June - August 2012.
4. Training on Cancer prevention and early detection of cancers to 724 Medical officers and other health workers in Trivandrum district at Regional Cancer Centre, Thiruvananthapuram, 10-11 August, 2012, 19th& 28th September 2012.
5. One week training on Cancer Registration and Epidemiology given to Dr. Abhishek, MD (PSM) student, Annamalai University (16/9/13 to 23/9/13).

Meetings participated by registry staff

International:

Dr. Aleyamma Mathew

Improvement of cancer registration in Thiruvananthapuram, after overcoming the barriers on 6th APOCP General Assembly meeting, Sarawak, Malaysia, 26-29th April 2012.

Cancer Registration and Cancer Control Programmes in India, 12th Annual meeting of Asia Pacific Organization for Cancer Prevention, Pattaya, Thailand, February 15-17, 2013.

Dr. Kalavathy M.C

Age distribution of Pan Chewing related oral neoplasia among the participants of a rural women cancer screening programme in Trivandrum, Kerala, India, 15th World Conference on Tobacco Or Health, March 2012, Singapore.

Dr. Preethi Sara George

Comparison of Artificial Neural Network with Logistic Regression as Classification Models for Variable Selection for Prediction of Breast Cancer Patients Outcome, 6th APOCP General Assembly meeting, Sarawak, Malaysia, 26-29th April 2012.

Papers presented:

Dr. Preethi Sara George

Comparison of decision tree model vs. regression model, National Conference on statistics for Twenty-first century-2012, University of Kerala, Kariavattom, 10-12, December, 2012.

Lectures delivered:

Dr. Aleyamma Mathew

Bias in Epidemiologic studies, Workshop on Survey methods, Medical College, Thiruvananthapuram, 28th February -2nd March 2013.

Research methods in Life & Medical Sciences, UGC-Academic staff college, University of Kerala, Workshop on Statistics to College Teachers, 8th December, 2012.

Cancer registries and Cancer statistics in India, University of Kerala, Kariavattom, National Conference on statistics for Twenty-first century-2012, 10-12, December, 2012.

Cancer in India and risk factors, St. Thomas College, Pala, International Conference on Epidemiology, 16-18 August 2012.

Application of Statistics in Various fields, Walk with a scholar programme for Statistics students, Government College, Kariavattom, 9th March 2013.

Dr. Preethi Sara George

Prognostic factors of breast cancer: Comparison of three data mining methods, International Conference on Epidemiology, 16-18 August 2012, St. Thomas College, Pala.

Data Processing and Analysis, Workshop on Survey methods, Medical College, Thiruvananthapuram, 28th February -2nd March 2013.

Honors received:

Dr. Aleyamma Mathew:

Received FAMS, National Academy of Medical Sciences, India, 2012

Dr. Kalavathy MC

Award of appreciation for effective implementation of Jilla Panchayath Cancer Control Programme in the District of Trivandrum presented by Jilla Panchayath, 2012.

Poster presentations in meetings

Dr. Aleyamma Mathew and Dr. Preethi Sara George

Comparison of age conditional probabilities and cumulative risk of developing breast and reproductive tract cancer in Thiruvananthapuram, Kerala, on 6th APOCP General Assembly meeting, Sarawak, Malaysia, 26-29th April 2012.

Fellowships received

Dr. Aleyamma Mathew

Received fellowship for attending Asia Pacific Organization of Cancer Prevention meeting held on February 15-17, 2013 Pattaya, Thailand.

Training received by the staff

Dr. Preethi Sara George

Attended a course on Bootstraping (Resampling), Jackknife and Monte Carlo Methods in Research at Department of Biostatistics, Christian Medical College, Bagayam, Vellore on August 29-31, 2013.

All Staff in the Thiruvananthapuram cancer registry attended Pre-ARM workshop on Cancer Registries at Sree Chitra Thirunal Institute of Medical Science, 4-5 December 2012.

Extension of registration areas:

National Cancer Registry Programme (Indian Council of Medical Research) has accorded approval for expansion of Thiruvananthapuram Taluk PBCR (1.1 million population), to cover the entire district (3.3 million population) from 2012 onwards and enhanced the budget.

New studies

Conducted the following three-months projects during 2012-2013.

Magnitude, Trends and Risk factors of Thyroid cancer in Kerala.

Predicting breast cancer survivability: a comparison of three data mining methods.

Assessment of prognostic factors of cervical cancer using artificial neural network comparing with regression models.

Assessment of changes in the age distribution of cancer patients in Kerala during the past 30 years.

Risk factors of Kidney cancer in Kerala using Principal Component Analysis.

Risk factors of Bladder cancer in Kerala using Discriminant Analysis.

Risk factors of Breast cancer in Kerala using Factors Analysis

Inconsistency in logistic regression model by different variable selection methods.

Papers published

Balagopal PG, George NA, Venugopal A, Aleyamma Mathew, Iqbal M Ahamed, Paul Sebastian. Tobacco related habits among first degree relatives of patients undergoing surgery for advanced head and neck malignancies in India.Asian Pac J Cancer Prev. 2012; 13(1):217-20.

Jayakrishnan R, Aleyamma Mathew, Lekshmi K, Paul Sebastian, Finne P, Uutela A. Assessment of nicotine dependence among smokers in a selected rural population in Kerala, India. Asian Pac J Cancer Prev. 2012; 13(6):2663-7.

Veena VS, Preethi Sara George, Jayasree K, Sujathan K. Cytological Analysis of Sputum: The Simplest and Preliminary Method of Lung Cancer Diagnosis-A Retrospective Analysis of 8690 Samples of Symptomatic Patients. International J of Scientific and Research Publications 2012: 2(12).

"Priority setting for cancer control and cancer services in any region needs to be based on knowledge of the cancer burden and the local mix of predominant cancer types."

Peter Boyle & Bernard Levin - WORLD CANCER REPORT 2008

SUGGESTED BOOKS FOR REGISTRY

1. Procedure Manuals – NCRP - PBCR, HBCR, Atlas of Cancer
2. ICD 10, ICD-O3
3. PIN Code Directory
4. Medical Dictionary
5. TNM Staging (UICC)
6. Manual for Cancer Registry Personnel (IARC Technical Report No. 10)
7. Cancer Registration – Principles and Methods; IARC Scientific Publications No. 95
8. Cancer Epidemiology – Principles and Methods (Eds. Isabel dos Santos Silva, IARC 1999)
9. Report on Tobacco Control in India; Ministry of Health and Family Welfare, Govt. of India
10. Bidi Smoking and Public Health; Ministry of Health and Family Welfare, Govt. of India
11. IARC Monographs on the Evaluation of Carcinogenic Risks to Humans – Vol. 83; Tobacco Smoke and Involuntary Smoking
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