

CANCER REGISTRY ABSTRACT - CRAB

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Special cancer registries

R. Swaminathan

The road to cancer registration has long been laid in India. The earliest hospital cancer registry had existed in the Cancer Institute (WIA), Chennai, since 1955 and the population based cancer registry in Mumbai since 1963, well before the advent of the International Agency for Research on Cancer, a WHO research body on cancer. The National Cancer Registry Program has spread its wings to include 20 PBCRs and 5 HBCRs in its fold, as on date. There are at least 4 PBCRs outside its network covering rural areas predominantly, which addresses the problem of paucity of rural PBCRs to a large extent.

The collective output of this cancer registration program so far has been enormous: in human resources development, providing leads to cancer control and research. Descriptive epidemiological studies have led to hypotheses generation. Many hypotheses have been tested by rigid scientific short-term hospital based studies and valid conclusions drawn. A few have been pursued to follow molecular epidemiological investigations. Otherwise, HBCRs in general have dished out mundane statistics over a long time now.

The time is ripe to mature into the realm of "Special Cancer Registries" that necessarily collect high-resolution data on a systematic and continuous basis suiting the objective. The theme has borne fruit with HBCRs (both inside and outside NCRP), having recently embarked on special surveillance project examining the patterns of care and survival of cervix, breast and head and neck cancer patients. This would strengthen the HBCR operations that include active follow up and give a new perspective to the study of outcome of common cancers and prognostic factors.

The PBCRs have strived hard to produce reliable cancer incidence figures from their respective regions, albeit problems, to fulfill the main objective. This has paved way for an estimate of the burden of cancer in the country, however conservative it may seem. Varied cancer patterns in different areas added pep to epidemiological investigations. Efforts are underway for an in-depth study of the trend of cancer incidence over time in all registries. This notwithstanding, some PBCRs have gone further and conducted survival studies on common cancers thus portraying an average outcome of the disease in their regions. Other PBCRs should take cue and follow suit.

Otherwise, population based epidemiological studies on a regular basis have been hard to come by for obvious reasons. Some striking differences in survival were forthcoming in inter-registries and intra-registry comparisons. However, the lack of pertinent data on potential covariates (SE status, tumour stage, treatment access, completeness and compliance) has exposed the limitations of these population based studies. Here again, the concept of forming "Special Population Based Cancer Registries" within the existing PBCR framework will go a long way to narrow down our focus, provide the needed infrastructure, foster wider collaboration with local partners, ensure completeness of details and encourage population based epidemiological studies. Such special cancer registries have been used to evaluate cancer control programs in the past in India.

Some special cancer registries that can readily be taken up are "Childhood Cancer Registry" and "Gynaec Cancer Registry". These special cancer registries often provide educational opportunities for those interested in particular type of cancer and offer support to those who may suffer from it. Let us remain optimistic that the discussions augur well to support the starting

of special cancer registries especially by older PBCRs in NCRP network in the days to come

Kudos to Prof. Matti Hakama!
Dr. C.Ramesh, KIMIO, Bangalore

Prof. Matti Hakama needs no introduction as he himself is one of the senior most family members of NCRP. I am doing this for the sake of the newcomers and newborns in NCRP.

Prof. Hakama (or Matti as he insists to be called), is an Epidemiologist of international eminence, a fascinating teacher (who is fascinated by India/Indians), a great humanist and a philosopher guide. His assignment as a WHO consultant to the National Cancer Registry Programme, India, made a beginning of an "era" of transition in the field of cancer epidemiology in India. He is a man of



few words and great wisdom, a fatherly responsible person for his students and a perfectionist with rigorous scientific thinking. He

was instrumental in conceiving the Indo-Finnish Bilateral Programme for NCRP personnel which had trained 19 so far, 14 of whom have already been awarded Doctoral Degrees in Epidemiology from Tampere School of Public Health. This has been a major landmark contribution by a foreign consultant in the field of cancer epidemiology in India.

As a first batch student in 1990, I found Matti's teaching methodology to be very unique with extremely high quality thinking and expectation. His coffee sessions every week-end at the department (he calls it "Business") served as a concession to be followed by rigorous scrutiny of one's work (he fondly calls it "Squeezing"). His grasp of the socio-cultural, anthropological information about India and adaptability is amazing: The long ride on a Bajaj Scooter, sipping of tender coconut and enjoying Indian spicy food in "typical" Indian restaurants, all demonstrate his simplicity.

These are only a few astray thoughts of mine and my friends trained by him, who are greatly indebted to him for all his support, encouragement, guidance and warm affection bestowed on us.



NCRP personal experience

*Matti Hakama University
of Tampere, Finland*

CRAB asked me to write a diary. In fact, for the first time I kept diary during my visit in India in February-March 2007. It is in Finnish, in chronological order and personal. May be, CRAB will have a translation later on. And supplemented with memorable experiences like travel in jeep with Mrs Jayant from Bombay (that time) to Barshi and back. This time the purpose is to have a story without rather than with the epithet of chrono.

In India there is a cancer control programme, one of the first in the world, first published in 1975. Cancer Registry had a central position in the programme. Dr Usha Luthra of Indian Council of Medical Research and Dr Calum Muir of International Agency for Research on Cancer collaborated in the early years. Also Dr Muir

had experience on the developing countries.

The population based cancer registries in India face many problems unknown in the western countries. The need for active registration and follow-up, avoidance of duplicate registrations when there are no personal identity numbers, and no support by death registration are just examples. Considering the inherent problems in India the establishing of the cancer registry network is indeed a success story.

It may appear as a luxury to promote cancer registration when there are immediate clinical needs and most of the patients remain without cancer directed treatment. However, the first prerequisite to control the problem is to know its magnitude. More effective is to say that 550,000 of the annual cancer patients in present day India never receive cancer directed treatment than to take it as a given fact that many patients remain without treatment. The quantities and their projections to the total Indian population and to the future were the first part of the success story. Also many of the Indian students in Tampere were

covering these issues in their doctoral theses: Dr Prabhakar, the first, Dr Budukh, the last for the time being, and Dr Yeole in between.

The other main objective of cancer registry is epidemiological research on causes of cancer. In many of the Indian registries there are unique opportunities because of the different environmental exposures, and because of the technical easiness to have access on controls from the attendants in darmashala or non cancer patients in out-patient corner. Collaboration with ICMR and between the cancer registries was very fruitful especially in the early years. Several primary sites and a variety of exposures were covered. E.g. many of the Tampere theses were reports on these studies including risk factors of oesophagus (Dr Ramesh), stomach (Dr Ravichandran), breast (Dr Gajalakshmi and Dr Reddy), prostate (Dr Sunny) cancer, or a category of cancers (Dr George, childhood cancer). Specific use of cancer registry was the evaluation of the carcinogenic effects of the Bhopal gas accident (Dr Dikshit). Cancer registries influenced indirectly other research programmes, as the

natural history of cervix cancer (Dr Murthy) and causes of papilloma virus infections (Dr Varghese). In spite of many beautiful pieces of research, the potentials and the materials collected were probably not utilised to the extent this unique source of data on cancer causation deserves.

For a clinician, the description of patient and disease characteristics are of immediate interest. The hospital based cancer registries have provided such data. One of the main potentials of both population based and hospital based cancer registries is in running of studies on outcome of a cancer patient, on survival or otherwise. This area has a multitude of applications with practical relevance. The prerequisite, however, is a valid methodology as was the case in the cancer registration itself. Dr Ganesh and Dr Matthew developed survival methodology in case of frequent losses to follow-up, a severe source of bias in India as well as in many other developing countries. The survival studies in India cannot apply directly and without testing the methods applied in populations with complete follow-up based on the high level infrastructure. Dr Swaminathan is

making a further progress in this focal field of research by identifying the conditions for different approaches.

Probably only few believed that the component of cancer registration and epidemiology would be most expansive, energetic, and successful one, when the first cancer control plan was published. A real success story. This was due to relevance for the society, the scientific potential, and especially due to all the staff including good team spirit. However, without devoted leading persons the outcome would probably not have been so excellent. Especially, I would like to remember the early epidemiologists Dr Luthra, Dr Sanghvi, Dr Gangadharan and Dr Muir as well as the directors of the cancer centers hosting the registries. But I would like also to see the future. Any activity is veaning unless new ideas emerge.

Very basic is training of new fresh generations of cancer registry experts, epidemiologists and other registry staff. The Indian activities, of which I know best those in Mumbai, Bangalore, Trivandrum and Chennai, are of primary importance.

Another first priority issue is to

define the own Indian cancer registration methodologies, own research problems and own priorities. Active registration estimating the incidence and adjusting for losses to follow-up in estimating the survival are good examples of methodological problems addressed from the Indian perspective. The cancer registration as a framework for cancer control at large, as in Barshi, or means to identify healthy controls are examples of innovative solutions of the problems.

The objective of cancer control is to improve health, either by postponing death or improving the quality of life. Quality of life is a critical issue in a country that can afford cancer related treatment only for 20% of the patients. Future research, including what data will be registered, should probably focus more on the quality of life aspects such as pain and its treatment. This is the more important as the neglect of quality of life in the registration of the western populations is likely to continue and will be less crucial. Therefore, one cannot have the developed countries as a positive example.

Further, clinical trials run by western pharmaceutical industry are insinuating also in India. It is likely that such research better serves the interests of high technology driven and expensive health services than those lacking of basic resources. In such circumstances own research profile is essential.

It is fair to admit that research on quality of life and on other subjects relevant in the developing world is regarded sometimes second class research. And cancer registries in these countries are sometimes blamed to be of questionable quality. The problems sometimes stem from the choosing of the criteria rather than from the issue of substance.

Cancer Registry quality indicators are well developed and can be found e.g. in the Cancer in Five Continents series. As examples, it is not useful to measure the quality based on to cases registered by Death Certificate Only in a country without proper death certification. And it is illogical to aim at high percentage of histologically verified cases as a quality indicator of registration in a country that does not have

resources for treatment. In a developing country cases clinically verified are sometimes terminal patients with advanced disease and, hence, the clinical judgement is valid. Close to 100% histological verification in a western country is obtained with the risk of the adverse effect of overdiagnosis.

These examples demonstrate the need for criteria and ranking that are less designed from the point of view of developed countries.

The own profile in the research prioritising is even more important. As mentioned above, the objective of research within cancer control is health. Therefore, high quality research should be the one that fits to the objective, that results in improvement of health.

Research judged as high quality by the western criteria, as impact or citation, has sometimes the problem of not being relevant for health. Fortunately, research relevant for Indian health has a potential, as a by product or consequence, to be of first class research also by these criteria internal for (western) science. Also in science itself, it is important to see the potential to

change the criteria rather than adjust the scientific profile to fit the present criteria.

Over the years, I have seen substantial progress of multiple etiology in the field of NCRP, some causes of the progress were outlined above. **If I were to predict, the future seems bright.**

**Some Tips to Start/Sustain
Registration of Cancer Cases for
PBCR from Private Institutions**

*J. Murugaiyan, T.S. Sambandam,
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Cancer Registration

Population based cancer registration by active method is a challenge. It is usually not much of a problem to register cancer cases from government hospitals if there is a local Administrative Order issued by a competent authority that permits data collection on eligible cases. But such an order may not be binding on the institutions in private sector. The sources of registration for a PBCR in private sector comprise hospitals, nursing homes, consultants, pathology laboratories, imaging centres and

hospices. It requires unstinting cooperation from all quarters to make cancer registration as complete as possible.

Why should you worry too much to collect data from private medical institutions? What will be the impact if we don't?

The Chennai PBCR data indicates that incident cancer cases registered exclusively from private medical institutions have risen from 8% in 1984-88 to 25% in 1999-2003. Also, the cancer pattern among cases registered from private institutions is different from those registered from government hospitals (Table 1). If proper attention is not paid to register cases from private institutions, we will end up not only with lesser number of cancer cases but also portray a different cancer pattern in the region that may provide wrong leads towards cancer control.

FAQs from private institutions to cancer registrars and the possible responses

Why should I give data of MY cancer cases to YOU?

This question might have stemmed from rivalry, diffidence, uncertainty or anything. The myth

of the terms like "I", "MY" and "YOU", in the question above has to be dispelled first. It must be stressed that the data sought does not belong to any "Individual" but to "everyone" contributing. The base institution where the registry is located is just a custodian of it for proper use and to ensure utmost confidentiality. Hence, the question posed should be transformed as below:

Why should any institution give data of its cancer cases to the PBCR?

The data required for a PBCR is an integral part of the "national level" data collection and has been in process since 1982. Since cancer is not a notifiable disease, the registry has undertaken the data collection by active method. If data is not provided, the resultant overall figures of cancer incidence will be unreliable. If the institution not providing the data happens to cater to a certain specialty in medicine, the emerging overall cancer pattern in the region will be erroneous.

What is the need for data collection from any institution, which records only very few cancer cases per year?

It is well known that "collection of tiny droplets transforms into an ocean". If there are many such institutions that record very few cancer cases and if data are not collected from them, the number of cancer cases missed will be enormous which would result in erroneous statistics on cancer.

Why to collect data from institutions, which routinely refer their cancer cases to specific cancer centres for further management?

This is one "trap" which a cancer registrar should beware of! It should be impressed upon the institutions that there is no guarantee that all referred cases land up in designated places. The cases may choose a different hospital or not prefer any further treatment. Information on such cases can only be obtained from institutions registering the case initially.

We don't have all the data required by NCRP!

This will be the common refrain when we approach most of them

for the first time. It is important to realize that in the days to come, it might be a luxury to get all the data listed out in NCRP PBCR proforma even from institutions already providing data. What about increased computerization of hospitals, confidentiality concerns, insurance baitors, working against "full data scrutiny" by cancer registrars to get all the information? The solution lies in "seeking" for the barest minimum data needed for a PBCR and classifying the data as "mandatory" or "optional"? A glimpse of "Box 1" will make even a hard-bargainer to relent and provide data.

Why do you require patients' full postal address?

Competing interests or genuine suspicion about data

confidentiality or any other might be the reasons for this reluctance. One will be hard-pressed to convince Mr.X or Ms.Y who are willing to provide data on cancer and NOT on the person having cancer. It must be reiterated that the patient identity information is sought only as a "means" to identify their cases that might also be registered from other institutions and to "weed" out the duplicate cases so as to count them only "once" in the incident case series. If the data providers are unconvinced, Box 1 provides an option for recording only PIN codes or merely residence area without full address.

What is the benefit that the institution will get by providing data on cancer cases to the PBCR?

First of all, one can derive a sense of satisfaction of having been of aid in estimating the "true" cancer incidence and pattern in the

region. Feedback in the form of descriptive statistics on the cancer cases collected from the institution can be obtained from the PBCR. Information on the overall cancers collected from the region can also be provided for use in lectures/seminars. Access to regional, national and international reports on cancer incidence soon after their publication is guaranteed. If the institution caters to only cancer cases, all assistance can be obtained from the PBCR to start a hospital cancer registry to foster research programmes in that institution.

What about institutions giving the fullest cooperation to PBCR?

The institutions SHOULD be honoured by giving a "memento" signed by the Principal Investigator of PBCR as a token of appreciation.



Box 1: MINIMUM REQUIRED INFORMATION FOR PBCR		
Information required	Mandatory	Optional
I. Patient related		
1. Name of patient (in full)	✓	
2. Age at diagnosis/Sex	✓	
3. Residence area or PINcode	✓	
4. Full postal address/contact details		✓
5. Relative name & relationship		✓
II. Disease related		
1. Date of cancer diagnosis/visit to hospital	✓	
2. Basis of diagnosis (Histology/Cytology/Imaging/ Clinical only/Others (specify).....	✓	
3. Primary site of cancer	✓	
4. Histology (if known)	✓	
5. Tumour stage or extent of disease (Localized/Direct extension/Regional nodes/Dist. Met./Others (specify)		✓
III. Others		
1. Treatment given (Surg/RT/Chemo/Others)		✓
2. Date and cause of death (if known)		✓

Note: Please ensure with source institutions that the information is provided for permanent residents of the registry area

Flowchart: Criteria to choose an institution as a source of registration for PBCR

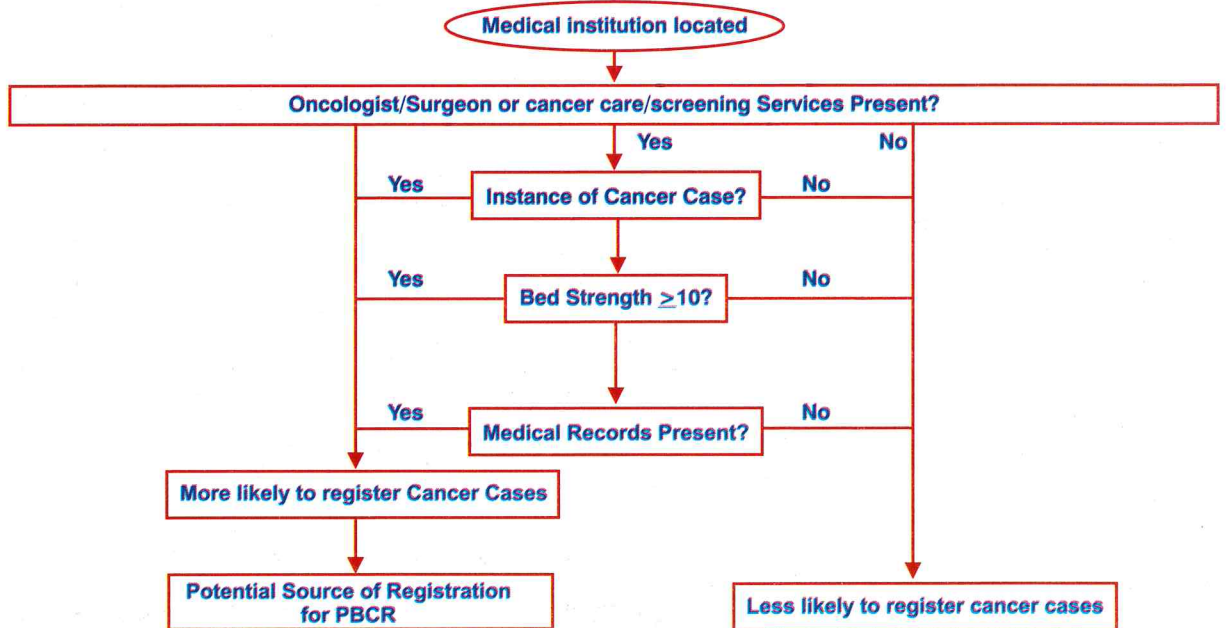


Table 1: Common cancers in Chennai by source of registration of cases, 1999-2004

MALE		FEMALE	
GOVERNMENT HOSPITALS	PRIVATE HOSPITALS	GOVERNMENT HOSPITALS	PRIVATE HOSPITALS
STOMACH	LUNG	CERVIX	BREAST
ORAL CAVITY	PROSTATE	BREAST	CERVIX
LUNG	COLORECTUM	ORAL CAVITY	OVARY
PHARYNX	STOMACH	STOMACH	COLORECTUM
OESOPHAGUS	LYMPHOMA	OESOPHAGUS	LYMPHOMA

Box 2: General tips to some specific problems faced

Problem faced	Possible solutions
If the reception at the entry level of the source hospital itself is not encouraging	<ul style="list-style-type: none"> ◆ Adhere to dress code; Greeting ◆ Possess visiting card, identity badge and bonafide certificate ◆ Keep the key staff of source institutions in good humour
Inability to meet the Head of the institution	<ul style="list-style-type: none"> ◆ No time constraint; repeated attempts ◆ Try your luck with subordinates ◆ Identify a mutual contact to facilitate an appointment
No medical records maintained; all given to the patient; cancer details not available	<ul style="list-style-type: none"> ◆ Encourage the hospital to retain a copy of the discharge summary
Hospital medical record not informative	<ul style="list-style-type: none"> ◆ Devise a printed cancer register with broad category headings for minimum data for PBCR (Box 1) ◆ Long size note book or printed forms ◆ Patient ID details to be filled by receptionist/nurse ◆ Cancer details to be filled by the concerned doctor Periodic monitoring by cancer registrar
Death registers lacking details on cause of death	<ul style="list-style-type: none"> ◆ Include cause of death in cancer register
Errors found in data provided: Cancer site coding, sex, address, PIN code, etc.	<ul style="list-style-type: none"> ◆ Errors to be rectified without annoying source personnel. It should not be conceived as a fault finding exercise
Locating new potential source institutions for data collection on cancer cases	<ul style="list-style-type: none"> ◆ Perusal of any directory of hospitals in the region (Yellow pages, etc.)
Data collection from source institutions located in remote places (outside city/state)	<ul style="list-style-type: none"> ◆ Explore possibility of electronic transfer of minimum required data
Head of the institution has given permission but junior level staff uncooperative	<ul style="list-style-type: none"> ◆ Share their work to an appreciable extent

GENERAL UPKEEP OF THE REGISTRY

To have an e-mail ID for the registry to facilitate quick electronic exchange of information, seasonal greetings and any specific requests from/to stakeholders. If the base institution has a website, to get a slot for hosting registry related material

In-house training

Information interchange: Cancer registrars should be updated on the consolidated findings of the data processed; Other personnel should be briefed about the data collection mechanisms

A coding board should be conducted periodically to resolve queries on disease coding among all the registry staff

Specific lectures on clinical aspects (like anatomy, stage of disease, diagnosis and treatment) by local experts to be organized for registry staff

Equipping the cancer registrars with adequate computer operating skills to optimize data entry and thereby the data processing

Organizing seminars and workshops for the PBCR stakeholders (staff of source

hospitals) should be conducted by the registry to promote exchange of information, and their participation in registry program.

To try and get slots for lectures on "Functions of Cancer Registries" in CME programs involving specialties to serve as a gentle reminder of registry activities

To register in conferences involving health records personnel and get a chance for a presentation to spread the message of cancer registry activity and their role in it

To bring out small brochures highlighting the salient features of cancer incidence data apart from the regular reports for wider dissemination.

The need for routine collection of all-cause mortality data for PBCR: A debate

*Participated by Dr. B. B. Yeole,
Dr. R. Dixit, Mrs. R. Rama and
Mr. A. Shrivatsava
Moderated by Dr. R. Swaminathan*

The method of all-cause mortality data collection was proposed by Chennai PBCR and was recommended in the NCRP workshop to be followed by

PBCRs in 1997. So far, only the Chennai, Bhopal and Bangalore PBCRs are following it. With many new entrants into the NCRP network, a review of this method will be useful.

Why all the trouble to collect all cause mortality data?

The main reason was the appalling figures for the number of deaths of cancer cases published by PBCRs under NCRP with the exception of Mumbai PBCR until 1991. Furthermore, active follow up of incident cancers was considered a difficult proposition.

Was there any indication that all-cause mortality data collection will be useful?

A study on 4,000 all-cause deaths in Chennai resulted in matching more deaths with cancer cases than before.

What was in store for all-cause mortality data collection?

The challenge of abstracting about 20 - 25 folds more deaths every year, with no additional financial support.

Questions for the debate?

Question 1: Have the twin objectives (Box 3) been achieved to full satisfaction?

A. Enhancement of M/I ratio

Atul: There has been a 2-3 fold increase in the number of deaths of cancer cases which should result in the rise in M/I ratio.

Yeole: But M/I ratio due to cancer should NOT include deaths not certified as cancer in the numerator!

Swami: CI5 Vol IX did not include deaths whose codes for "cause of death" was not cancer in the M/I ratio calculation.

Rama: In that case, criteria may be evolved by NCRP to classify matched deaths (of cancer cases) without specific medical cause of death in the certificate as "probably due to cancer" and include it in the M/I ratio calculations.

Rajesh: Even so, the M/I ratio such derived cannot be used as an indicator of data quality of the registry, which is the objective of computing it. Cancer incidence figures of good quality are sufficient to know the burden in a population and to generate

Box 3: An overview of the objectives, advantages, achievements and limitations of this method			
Objectives of all-cause mortality	Advantages perceived	Achievement so far	Limitations encountered
1. Optimizing cancer mortality statistics	<ul style="list-style-type: none"> • Single source of death information • Unambiguous vital status 	<ul style="list-style-type: none"> • Availability of deaths of cancer cases has doubled: from <1,000 to about 2,000 every year 	<ul style="list-style-type: none"> • Incompleteness of death registration • Incompleteness of details • Changes in death regn system • Faulty certification of death
2. An alternative to active follow up	<ul style="list-style-type: none"> • Reduces the laborious task of field work • Exact date of death available 	<ul style="list-style-type: none"> • M/I ratio figures comparable with those of active follow up of selected cancers 	<ul style="list-style-type: none"> • Outstation deaths not reported • Deaths after migration within registry area- difficult to match

hypothesis regarding etiological factors in causation of cancer.

Swami: It seems that there should be no undue worry at the low M/I ratio encountered by our registries given the fact that strengthening the general mortality registration does not solely depend on registry efforts.

B. To emerge as an alternative to active follow up?

Rama: The increase in the number of deaths itself suggests that this method has emerged as an alternative to active follow up.

Yeole: Can this method then replace the active follow up?

Rajesh: No, it is an alternative where active follow up is not possible.

Atul: This can augment active follow up by reducing the number of cases needing it.

Swami: The Chennai experience suggests that there were 18-40% deaths identified ONLY by active follow up for different cancers.

Rama: A vast majority among these were "missed" to be matched with all-cause mortality database due to insufficient identity details.

Rajesh: Active follow up is needed for doing survival analysis as a separate study and not for routine cancer registration.

Swami: It seems that for doing a meaningful cancer survival analysis, active follow up is indispensable. However, the new method ensures the availability of more deaths with correct date of death.

Rajesh: But at what cost?

Question 2. Is it really possible to carry this on without any extra-budgetary support for personnel or any other requirement?

Yeole: It is not possible to do with the existing registry staff. We require at least 3-4 extra staff dedicated for the purpose.

Rama: The load of work will increase with the size of the population covered by the registries. It is 30 times more in Chennai.

Atul: It will be even harder if the data has to be abstracted manually. Access to computerized mortality data will be beneficial.

Swami: Mortality data computerized by vital statistics division is not usually complete in details on identity and/or cause of death.

Rama: Even if data is electronically available, the several fold increase in the

volume of work towards matching will remain the same.

Rajesh: With no definite and uniform algorithm for matching with non-cancer deaths, the possibility of false positives in matching assumes great significance.

Yeole: All cause mortality data collection may not be needed by all registries. For small registries, active follow up of all incident cancers may still be the best viable option like in Barshi.

Atul: All cause mortality data collection should be undertaken only when general mortality registration in the registry area is complete.

Swami: All our experiences have so far been based on two urban registries only. It is yet to be tried in bigger urban or rural registries. Hence, generalizing the perceived advantages seems to be questionable.

Question 3. What is the impact of all-cause mortality data collection on the other functions of PBCR, say, cancer cases data collection, processing, analysis and reporting?

Yeole: The delay in submitting the data will be unavoidable if this work is carried out with existing registry staff.

Atul: Extra hands and E-special software for matching may be a way out for faster processing and reducing the delay.

Rama: Even then, the time taken manually for synthesizing the tasks of different persons and their outcome will still result in considerable delay in submitting data.

Rajesh: Duplicate matching by computers will not be perfect and manual scrutiny is inevitable.

Swami: Will any other PBCR operations get affected?

Rama: With no extra hands, frequency of visits to hospitals by registry staff for data collection on cancer cases may come down.

Atul: Case finding efforts may take a beating with hardly any time left for subtle clarifications needed for enhanced data quality.

Swami: It seems that only a negative impact can be expected even on other PBCR functions by

adopting the new method of all-cause mortality data collection in present conditions.

Closing remarks by participants

Yeole: For the success of this new method, the NCRP should provide extra budget for each registry depending on total mortality cases registered in respective geographical area. Till then, I feel that "choice be left with individual registries".

Rajesh: In India, to improve cancer mortality statistics is a challenging job; it cannot be done with routine staff of registry at the cost of affecting the quality of cancer incidence data. Under present circumstances, the new method is "Useless, but continuation depends on additional requirements being fully met".

Rama: This method had yielded fruitful results in Chennai registry albeit problems. I consider it "Useful, but continuation depends on the additional requirements being fully met".

Atul: Extra budgetary allocation and electronic data availability are mandatory. Then, the method is "Useful, but continuation depends on the

additional requirements being fully met".

CONCLUSION

Swami: The twin objectives with which this method was mooted have not been "fully" achieved. "There is more than meets the eye". As such, long-term sustenance of this method hinges on additional inputs from NCRP and respective registries.



Trivandrum paperless cancer registry The first of its kind in the country

Dr. Aleyamma Mathew, Regional Cancer Centre, Trivandrum

Cancer registry helps to assess the magnitude and nature of the cancer problem, distribution of stage at diagnosis, pattern of treatment management, survival and to monitor time trend in incidence/mortality by cancer site. To carry out these functions, the medical records and other source documents have to be properly recorded and coded. Increasing standardization of

methods and definitions has marked the development of cancer registration system over the last quarter of century. The data obtained from the cancer registries are used in a wide variety of areas for cancer control activities. The operation of a cancer registry requires understanding of several aspects of the disease including recent advancements. Rigid quality control measures are required. The quality of data collected should be of high standard and as complete as possible.

The Hospital-Based Cancer Registry (HBCR), Regional Cancer Centre (RCC), Trivandrum started in 1982 under the network of National Cancer Registry Programme (NCRP) of the Indian Council of Medical Research (ICMR), currently collects information on cancer patients attending the RCC, Trivandrum. Now it records approximately 9,500 new cancer cases annually. The registry has made significant achievements in data abstraction. The data abstraction and retrieval has been made online via intranet since 2002. Since then, no hardcopy documentation is used. This is the first paperless cancer registry in the country.

The details of the procedure employed are described below:

Data Abstraction Procedure

An in-house web based software "rccintranet.org" for the NCRP HBCR core-proforma is developed for data abstraction.

The core-proforma consist of:

- (a) Demographic details (names of patient, father and spouse, addresses permanent and local, age, gender, religion, mother tongue, marital status and, education),
- (b) Diagnostic details [date of first diagnosis, date first seen, diagnostic status at registration at RCC, method of diagnosis, primary site and primary histology, secondary site and secondary histology (if present), ICD-10, sequence, and laterality]
- (c) Extent of disease [clinical extent of disease before treatment at RCC (SEER manual 1977), staging system, TNM and composite stage],
- (d) Treatment details [cancer directed treatment received

prior to registration at RCC (if any), type of prior treatment, intention to treat at RCC, date of commencement of treatment at RCC, treatment status and type of treatment received at RCC],

- (e) Performance status (WHO) (before treatment at RCC and at first follow-up or at 6 months whichever is earlier),
- (f) Disease status at first follow-up or at 6 months whichever is earlier,

The demographic details are collected and entered into the computer at the time of new patient registration at RCC using the above software. The second part is entered using the above software after retrieving case-sheets from the RCC medical records. (See Appendix I in HBCR Annual Report 2005, RCC Thiruvananthapuram, published in August 2007 for a full list of variables)

All variables in the core-proforma except various dates are directly selected from a selection box in the hypertext mark-up language (HTML) form. The selection box contains all the codes along with their descriptions for each variable. This helps to avoid

mistakes beyond the range of values for each variable. The selection box corresponding to the variables topography and morphology contains the third edition of International Classification of Diseases for Oncology (ICD-O-3) and the International Classification of Diseases (ICD-10). In the selection box corresponding to primary histology, only the codes with fifth digit behavior code for neoplasm '3' are displayed in order to avoid the selection of other behavior codes. Similarly for secondary histology, only the codes with fifth digit behavior code for neoplasm '6' are displayed.

Data Processing

The database is subjected to a series of consistency checks (comparing the values of certain variables against others) to ensure whether valid codes have been entered using in-house software. The lists of various consistency checks are provided in Appendix II of HBCR Annual Report 2005 of RCC, Thiruvananthapuram, published in August 2007. The data are edited based on the error list of cases obtained using the above check program.

Advantages of Paperless Registry

1. Improvement in data quality

Using the in-house program, checking of most of the data is carried out through online, and this has helped in a significant improvement in the quality of data. No range checking is required as the selection box contains only the required codes and their description for each variable.

2. Reduced time delay

Before the above process of computerization, there used to be a three-year delay for completing data abstraction and now the delay is less than one year (The HBCR data abstraction for the year 2007 has already started since 1st of October 2007).

3. Cost effectiveness

i) *Requirement of less human resource* Before computerization, six full time staff were abstracting the data in a hard copy and one-person used to key the data into computer, whereas presently, only three staff are carrying out data abstraction. The other important point, which needs a mention here is that during the

recent years, the load of patient registration has increased approximately by 25% as compared to the period before the computerization. This increased workload has also been taken-up by the above three staff meant for data abstraction. The above three registry personnel are also documenting through the above web based program additional information on treatment and follow-up (variables other than in the core proforma).

ii) With the web-based program no physical storage space is required.

iii) Similarly, cost towards printing is also not required now.

iv) Report generation is carried-out in a two-weeks time period using one staff only, an exhaustive report being prepared (HBCR, Trivandrum report). Earlier, it used to take three months time period and also three staff used to work for report preparation. Also no such detailed report was generated previously due to the difficulties in data retrieval and lack of time.

v) *Application of data-*
Documentation of case-records

in electronic form has helped clinicians and other researchers to obtain the necessary information much faster. HBCR data now serves for evaluating the performance of hospital administration, services and medical audit more efficiently. The two population-based cancer registries located in Thiruvananthapuram and Kollam districts have utilized the electronic HBCR data.

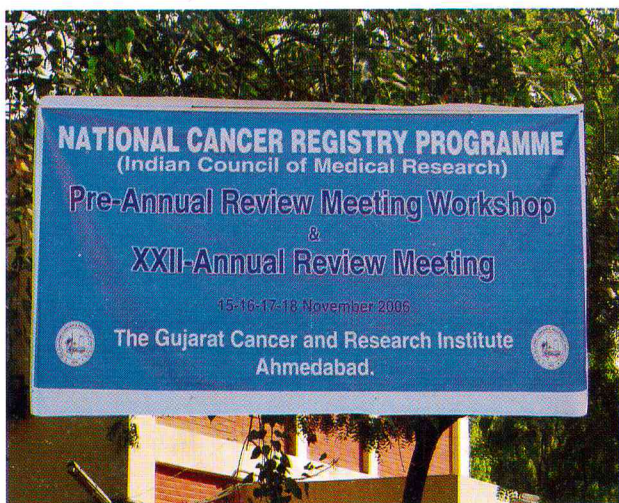
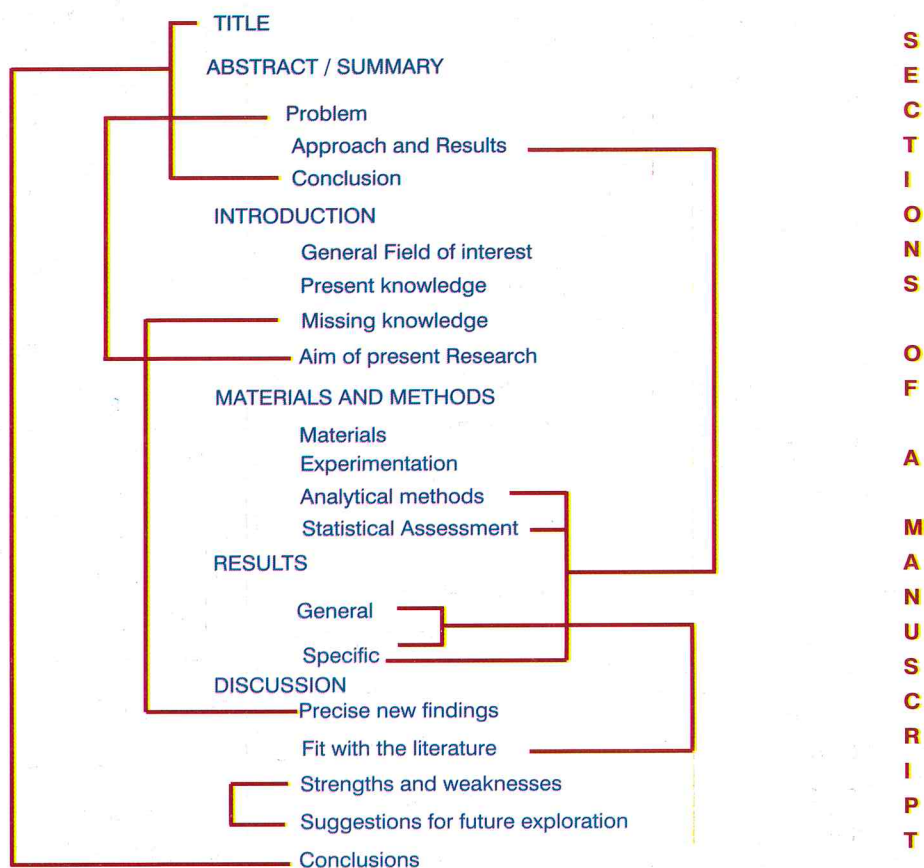
Currently we are in the process of making all the consistency checking listed in Appendix II as online. This would further help us to reduce the error, which may occur while data abstraction, and we hope that 20% of the data abstraction time would further be reduced.

In conclusion, with increasing computerization, work of the cancer registries has been revolutionized. Electronic storage and processing of data collected has greatly enhanced the quality of data. Based on our experience, it is suggested that other cancer registries also can employ the above procedure of paperless registry system.

A QUICK- GUIDE FORMAT FOR SCIENTIFIC PUBLICATIONS

Courtesy Mr. P. Gangadharan

Source Asia Pacific Organization for Cancer Prevention Handbook



News Items

The Ahmedabad Cancer Registry organized the XXII Annual Review Meeting (ARM) and Pre-ARM workshop at The Gujarat Cancer & Research Institute (M.P. Shah Cancer Hospital), Ahmedabad, on behalf of the National Cancer Registry Program of Indian Council of Medical Research, New Delhi, during November 12-15, 2006. The workshop had 99 participants and there were 112 registered delegates for the ARM.



The NCRP Workshop on "Cancer Registration Using Data Sets for Research, Analysis and Publications" was held at the Regional Medical Research Centre for North East, Dibrugarh, Assam, during 10th June and 13th June 2007.



FACULTY

Dr.A.Nandakumar, Dr.T.Ramnath and Dr.Meesha Chaturvedi of Coordinating Unit of NCRP, Bangalore Dr.J.Mahanta and Dr.R.K.Phukan of RMRC-NE, Monitoring Unit of NERPBCR, Dibrugarh, Dr.P.S.S. Sundar Rao, then Steering Committee Member, NCRP, Dr. P. Gangadharan, Monitoring Committee Member of NCRP,

Kochi, Dr.B.B.Yeole, Indian Cancer Society, Mumbai and Mr.A.Srivastava, Bhopal Cancer Registry, Bhopal.

TOPICS COVERED

Introduction to statistical tools in cancer registration, Calculation of various incidence rates, Writing a research paper and Introduction to computer software SPSS & EPIINFO.

PARTICIPANTS

Total number of 15 from PBCRs in Dibrugarh (4), Guwahati (2), Silchar (1), Sikkim (1), Mizoram (2) and Imphal (2), Assam Medical College (1), Monitoring Unit of NERPBCR (2).

Courses organized by Tata Memorial Hospital, Mumbai

1. International Course in Clinical Epidemiology Date : 5-9 March 2007 Venue: TMH, Mumbai

Subject area

Clinical trials, vaccination trial, intervention trial, screening, survival, Cochrane database and meta analysis.



FACULTY

Dr.M.Hakama, Tampere, Dr.R. Sankarnarayanan and Dr.C.Sauvaget, France, Dr.R.Swaminathan, Chennai, Dr.R.Dikshit and Dr.B.Ganesh, Mumbai.

Participants 26 (Medical doctors:19, Statisticians:5, Basic sciences:2)

2. Course in Molecular Cancer Epidemiology 18-21 September 2007. Venue: TMH, Mumbai

Subject area

Study design options in Molecular Epidemiology, Analysis of data, Storage of biological samples, Markers of exposure, markers of effect, markers of susceptibility.

FACULTY

Dr.P.Boffetta, France, Dr.R.Dikshit and Dr. R. Mulherker, Mumbai

Participants 22



Conferences/Training courses ahead

UICC World Cancer Congress, "Towards True Cancer Control", Aug 27-31, 2008, Geneva, Switzerland. Travel grants available (secretariat08@uicc.org) Abstract submission deadline Feb 29, 2008.

<http://www.uicc-congress08.org/>

International Association of Cancer Registries (IACR) 30th Annual Meeting, Sydney, Australia. Limited travel grants available. Ideal for NCRP project personnel.

www.iacr.com.fr/sydney/sydney.htm

IARC Summer School in Cancer

Epidemiology 2008, Lyon, France, Jun 2-27, 2008. Cancer registrars are most suitable to attend. For more details contact cor@iarc.fr

[Http://www.iarc.fr/ENG/Training_Courses/index.php](http://www.iarc.fr/ENG/Training_Courses/index.php)



Events (workshops/meetings/Programs organized,)

Name of the event, place, month/year	Profile of participants, number of participants, any other information
<p>Bhopal Cancer Registry Cancer Awareness Workshop, Nov 2006 Tobacco awareness Workshop, April 2007</p>	<p>Medical Students of Gandhi Medical College, Bhopal 110 participants Students of Class Xth & XIth : 120 students</p>
<p>Thiruvananthapuram registries Workshop on Cancer Control Programme at RCC, Trivandrum, 9th August, 2007 Cooperative Program in Bio-Statistics, RCC, Sep-Oct 2007</p>	<p>Trivandrum Corporation ward Councilors (n= 81), Trivandrum Corporation Mayor inaugurated the programme <i>Five MSc. Bio-statistics students under the Mahatma Gandhi University, Kottayam, completed two-month project work under the guidance of Dr.A.Mathew</i></p>
<p>Chennai Registries Cooperative Program in Statistics, Cancer Institute (WIA), Chennai</p>	<p>Eight M.Sc. Statistics students from Loyola College, Madras University, Chennai and Bharathidasan University, Trichy, utilized the data from PBCR and HBCR for their dissertation under the co-guidance of Dr.Swaminathan and Mrs.Rama</p>
<p>Imphal Cancer Registry Cancer awareness cum screening of cancers among women particularly of breast and cervix in collaboration with Medical unit of Army, based at Sendra in Bishnupur district, on 24th and 25th June 2007.</p>	

Meetings / Conferences / workshops attended

Name of the meeting/workshop Conference, place, month/Year	Name of delegate and nature of participation	Title of presentation
Bhopal Cancer Registry 28 th Annual Meeting of IACR Goiania, Brazil, November 2006	Atul Shrivastava Oral presentation	Registration of Cancer Mortality in Pursuit to Improve the Quality of Data; An Experience of Bhopal Cancer Registry in India- A Model for Developing Countries
29 th Annual Meeting of IACR, Lublanijana Slovenia 17 th 20 th September 2007	Atul Shrivastava, Oral & Poster Presentation	How use of information technology and electronic data transfer has led to early finalization of annual report of national cancer registry programme in India. Trends in tobacco related cancers in the population based cancer registry of Bhopal
All India Workshop for Medical Persons on ICD-10 organized by CBHI Dec' 2006 & Apr' 2007 at Bhopal	Atul Shrivastava As faculty	Introduction to ICD-10 & Coding of neoplasms
All India workshop for Medical Record Officer on Health Statistics organized by CBHI, June 2007 at Bhopal	Atul Shrivastava As faculty	Introduction to ICD-10 & Coding of Neoplasms Vital Statistics
Dibrugarh Cancer Registry A workshop on "Cancer Registration: Using data sets for Research Analysis and Publication" 10-13 June, 2007 Dibrugarh	Dr. M.S.Ali, Dr.(Ms) R.Akhtar, Sri S. K. Bhuyan, Sri. R. Dutta,	Incidence and Pattern of Cancer in urban and rural population of Dibrugarh district.
Imphal Cancer Registry Meeting of the 'North East Cancer Atlas' in February 2007, Kolkata Workshop on 'Cancer Registration Using Data sets for research, analysis and publication', Dibrugarh 11 th Scientific Session of the Medical Society RIMS, Imphal	Dr.Y.Mohen Singh Dr.Y.Mohen Singh Dr.O.Bijaya Devi Dr.H.Satyajyoti	Population Based Cancer Registration in RIMS

Meetings/Conferences/workshops attended

Name of the meeting/workshop Conference, place, month/Year	Name of delegate and nature of participation	Title of presentation
Mumbai PBCR APOCP/UICC APO conference on breast cancer research in Asia, Bangkok during 1 st and 2 nd November 2006	Dr.B.B.Yeole	Breast Cancer Research in India
UICC organized General Assembly Conference, Bangkok, November 2006	Dr.B.B.Yeole	Role of Cancer Registries in improvement on cancer mortality in Asia
Golden Jubilee Conference on "Emerging population issues in the Asia Pacific Regions: Challenges for the first 21 st century" of International Institute for Population Sciences, Mumbai, Dec 2006	Dr.B.B.Yeole	Trends in cancer incidence in Greater Bombay- An Epidemiological Assessment
International Study on Heart disease and Lung Cancer after radiotherapy for breast cancer meeting by CTSU and Epidemiological Unit, London, Jan 2007	Dr.B.B.Yeole	Cancer Epidemiology
Conference on "Research Methodology" by TMC, Mumbai, January 2007	Dr.B.B.Yeole	Invitee
Evident based management conference on "Tobacco Control and Lung Cancer", Mumbai, Feb 2007	Dr.B.B.Yeole	Invitee
International Course on "Clinical Epidemiology", Mumbai, March 2007	Dr.B.B.Yeole	Invitee
Sikkim Cancer Registry Meeting of the 'North East Cancer Atlas' in February 2007, Kolkata	Dr.Yogesh Verma	
Workshop on 'Cancer Registration Using Data sets for research, analysis and publication', Dibrugarh	Dr.Yogesh Verma	
Thiruvananthapuram registries Trivandrum Breast cancer conference February 2007	Dr.Aleyamma Mathew	1. Pattern of anthropometric factors between urban and rural women in south India and the risk of breast cancer: a case-control study 2. Physical activity level between urban and rural women in south India and the risk of breast cancer: a case-control study.
Trivandrum Breast cancer conference February 2007	Dr.M.C.Kalavathy	Battle against breast cancer utilizing trained female community volunteers in rural areas of Kerala
UGC Sponsored refresher course in Bio-statistics, University of Kerala, Trivandrum, October 2007.	Dr.Aleyamma Mathew	Statistical methods in Epidemiology

Meetings / Conferences / workshops attended

Name of the meeting/workshop Conference, place, month/Year	Name of delegate and nature of participation	Title of presentation
Chennai Registries 23 rd Annual Meeting of ISMS, Coimbatore, Nov 2006	Dr.R.Swaminathan	Cancer Survival in Developing Countries: An overview
National Workshop on Research Methodology, Kannur, 2006	Dr.R.Swaminathan	1. Epidemiological designs 2. Case control studies 3. Clinical trials
Editorial meeting of IARC Clinical on Cancer Survival in Developing Countries, France, Dec 2006 Jan 2007	Dr.R.Swaminathan	Completing the analysis and preparation of draft version
International Course in Clinical Epidemiology, TMH, Mumbai, 2007	Dr.R.Swaminathan	Cancer survival analysis
INCTR Breast Cancer Strategy Meeting, Brussels, Belgium, June 2007	Mrs.R.Rama	Breast cancer project Status Report and Data processing
IARC Summer School on Cancer Epidemiology, France, Jun-Jul 2007	Ms.P.Shanthi	Coursework Hands-on training using STATA
Department of Statistics, University of Madras, November, 2006.	Dr.R.Swaminathan	Recent advances in cancer survival analysis

Awards / Honour / Fellowship

Name & Designation	Honour received or Name of the award & agency	Year
Bhopal Cancer Registry Dr. Neelkamal Kapoor PI, Bhopal Cancer Registry Bhopal	Gold Medal for excellence for Promoting Voluntary Blood Donation & Collection In Madhya Pradesh. Awarded by Government of Madhya Pradesh.	2007
Mumbai PBCR Dr.B.B.Yeole Deputy Director	Name included in Afro-Asian WHO's WHO Volume I published by Reficimento International, New Delhi, Gold Medal, Silver Trophy and certificate of felicitation by Friendship Forum of India, New Delhi	2006 2007
Thiruvananthapuram Registries Dr.Aleyamma Mathew, Additional Professor	Core-committee Chairman of MSc. Biostatistics, MGU, Kerala Research Guide in Epidemiology Kerala and MG Universities, Kerala	2005 onwards 2005 onwards
Chennai Registries Dr. V. Shanta Chairman, Cancer Institute (WIA)	Padma Bhushan, Govt. of India	2006
Dr. R. Swaminathan Head, Division of Epidemiology & Cancer Registry	Editor of IARC Monograph on Cancer Survival in Developing Countries, Volume II, IARC, France	2007
Ms. P. Shanthi Cancer Registrar	ICRETT Fellowship by UICC, Geneva	2007

PROJECTS

Name of the project & funding agency	Name of PI/ Co-PI	Start and end date
Dibrugarh Cancer Registry		
Understanding the Role of Tobacco ICMR	Dr. M.S. Ali	January 2006 - December, 2008
Understanding the Role of Pesticide ICMR	Dr. M.S. Ali	January 2006 - December, 2008
Development of an Atlas of Cancer in NE Region NCRP	Dr. M.S. Ali, Project Officer	January 2004 & continuing
Pattern of Care and Survival Studies NCRP project	Dr. T.R.Borbora Principal, AMCH	January 2007 & continuing
Ahmedabad Cancer Registry		
Rural Cancer Registry Project Ahmedabad District NCRP	Dr. Pankaj M. Shah Dr. Shilin N. Shukla Dr. Parimal Jivarajani	Year 2004 & Continuing
Patterns of care and survival studies of Cancer Cervix, Cancer Breast and Head & Neck Cancers NCRP	Dr. Pankaj M. Shah Dr. Shilin N. Shukla Dr. Parimal Jivarajani	Year 2006 & Continuing
Population Based Cancer Registry - Ahmedabad Urban Agglomeration Area - NCRP	Dr. Pankaj M. Shah Dr. Shilin N. Shukla Dr. Parimal Jivarajani	Year 2007 & Continuing
Imphal Cancer Registry		
Development of an Atlas of Cancer in NE Region NCRP	Dr.Y.Mohen Singh	Since 2001
Understanding the Role of Tobacco ICMR	Dr.Y.Mohen Singh	Since 2005
Understanding the Role of Pesticide ICMR	Dr.Y.Mohen Singh	Since 2005
Sikkim Cancer Registry		
Development of an Atlas of Cancer in NE Region NCRP	Dr.Yogesh Verma	Since 2001
Understanding the Role of Pesticide ICMR	Dr.Yogesh Verma	Since 2005
Understanding the Role of Tobacco ICMR	Dr.Yogesh Verma	Since 2005

PROJECTS

Name of the project & funding agency	Name of PI/ Co-PI	Start and end date
Thiruvananthapuram registries Pattern of Care and Survival of Breast, cervix and Head & neck ICMR	Dr. B Rajan (PI), Dr.Aleyamma Mathew (Co-PI)	Since 2006
Feasibility study for Development of a Dietary Cohort study in India NCI, USA	Dr.Aleyamma Mathew (PI)	Started in September 2006 (2 year)
Nutritional factors and risk of breast cancer: A Case-Control Study	Dr.Aleyamma Mathew (PI)	Started in 2007 (3 year)
Case-control study of Bladder and Kidney cancers - Kerala Science & Technology.	Dr.Aleyamma Mathew (PI)	Started in 2007 (3 year)
Rural Cancer Registry, Trivandrum - Finnish Cancer Society, Finland	Dr.Aleyamma Mathew (PI)	Started in 2001 (10 years)
Trivandrum Corporation Cancer Control Programme - Trivandrum Corporation	Dr.Kalavathy MC (PI)	Started in 2007 (II phase)
Chennai registries		
Development of a Manual and Software for Hospital Based and Population Based Cancer Registries WHO	Dr.R.Swaminathan	2006 - 07
A Retrospective Survey of Presentation Features of Breast Cancer and Risk factors for Treatment Outcome - INCTR, Belgium	Mrs.R.Rama	2006 - 08
Dindigul Ambilikkai Cancer Registry (DACR) - IARC	Dr.R.Swaminathan	Since 2004
Estimation of Survival Rates of Common Cancers in HBCR IARC	Dr.R.Swaminathan	2004 - 08
Population Based Hereditary Cancer Registry - CI	Dr.R.Swaminathan Co-Investigator	Since 2003
Population based screening for cancers of the cervix, breast and oral cavity in the Thiruvanniyur belt area GSK, New Delhi	Dr.R.Swaminathan	Since 2003
Pattern of Care and Survival of Breast, cervix and Head & neck ICMR	Dr.R.Swaminathan	Since 2006

PUBLICATIONS

Bhopal Cancer Registry

Incidence of Cancer Morbidity and Mortality in Bhopal Urban Agglomerate 2000-2003. Bhopal Cancer Registry, Gandhi Medical College, Bhopal, 2007.

Dikshit R, Kanhere S and Surange S. Cancer Survival in Bhopal, India: 1991-1995. In: SURVCAN-DC: Cancer Survival in Developing Countries, Vol II. IARC Non-Serial Web Publications, International Agency for Research on Cancer, Lyon, 2007. (in press)

Dibrugarh Cancer Registry

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Ahmedabad Cancer Registry

Rural Cancer Registry Ahmedabad District Annual Report 2004. National Cancer Registry Programme (ICMR), The Gujarat Cancer & Research Institute, Ahmedabad, 2006.

Mumbai PBCR

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Thiruvananthapuram Registries

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regions: India, Singapore, UK, and US. *International Journal of Epidemiology* (in press).

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CRAB features articles on cancer registration, issues of current interest and news items on events in registries and conferences ahead.

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All are welcome to submit articles, news, comments, views, rejoinders to CRAB.

