REVIEW

Cancer Registration in India - Current Scenario and Future Perspectives

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Abstract

Cancer registration, an important component of cancer surveillance, is essential to a unified, scientific and public health approach to cancer prevention and control. India has one of the highest cancer incidence and mortality rates in the world. A good surveillance system in the form of cancer registries is important for planning and evaluating cancer-control activities. Cancer registration in India was initiated in 1964 and expanded since 1982, through initiation of the National Cancer Registry Program (NCRP) by the Indian Council of Medical Research. NCRP currently has twenty-six population based registries and seven hospital based registries. Yet, Indian cancer registries, mostly in urban areas, cover less than 15% of the population. Other potential concerns about some Indian registries include accuracy and detail of information on cancer diagnosis, and timeliness in updating the registry databases. It is also important that necessary data collection related quality assurance measures be undertaken rigorously by the registries to ensure reliable and valid information availability. This paper reviews the current status of cancer registration in India and discusses some of the important pitfalls and issues related to cancer registration. Cancer registration in India should be complemented with a nationwide effort to foster systematic investigations of cancer patterns and trends by states, regions and sub populations and allow a continuous cycle of measurement, communication and action.

Keywords: Registries - cancer - India - incidence - public health

Introduction

Despite advances in diagnosis and treatment, cancer continues to be a leading cause of mortality, accounting for about 13% of all deaths worldwide (8.2 million deaths) and 0.68 million deaths in 2012 in India (Globocan, 2012). Projection studies suggest that global cancer burden will rise more rapidly with population growth, aging and changes in lifestyle changes associated with economic development (Shin et al., 2012). It is anticipated that there will be more than 20 million new cancer cases worldwide by 2025, with 80% of the burden falling on low-and middle-income countries (LMICs) (Bray et al., 2015). Cancers in LMICs are also more likely to be diagnosed at a later stage and, therefore, be less responsive to treatment (IARC GICR, 2011).

Cancer control strategies address three aims: reduction in cancer incidence, reduction in cancer mortality, and improvement in quality of life of cancer patients (Bryant et al., 2012). A strategy to address these goals should include proper collection of cancer data while providing training, support and infrastructure to local networks of cancer registries and conduct advocacy for them (Bryant et al., 2012). Cancer registration is an important component of cancer surveillance and is essential to a unified, scientific and public health approach to cancer prevention and control (NPCR, 2015). Cancer registration, defined as the process of continuing systematic collection of data on occurrence and characteristics of reportable neoplasms, provides accurate data on incidence and survival from cancer (NPCR, 2015). The information is crucial for national and provincial governments to assess cancer burden in the community, plan health service resources, evaluate impact of cancer control strategies and conduct research on nature and causation of cancer (Jensen et al., 1991).

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Cancer Scenario in India

A recent cancer-map atlas released by the Indian Council of Medical Research (ICMR), showed parts of India having world's highest incidence rates of gall bladder, mouth, and lower pharynx cancers (Figure 1) (Mudur, 2005) with pockets of high incidence rates of stomach and thyroid cancer in southern India. According to the three year (2009 - 2011) consolidated report of all population-based cancer registries (PBCR) under the National Cancer Registry Program (NCRP), the age-adjusted incidence rates for all cancers per 100,000 population ranged from 43.7 in Barshi to 273.4 in Mizoram for males, and 51.6 in rural Ahmedabad to 227.8 in Mizoram for females (NCRP, 2013).

Cancer mortality is another key measure of the cancer burden, Recent estimates suggest that in 2010, about 555,000 people died of cancer in India. Some 71% of the deaths occurred in people aged between 30 and 69 years. The three most common fatal cancers in men included oral (22.9%), stomach (12.6%), and lung cancers (11.4%), while cervical (17.1%), stomach (14.1%), and breast cancers (10.2%) were more common in women (Dikshit et al., 2012).

It is projected that total number of new cases in males will increase from 0.59 in 2012 to 0.93 million by the year 2026. In females new cases of cancer is projected to increase from 0.60 to 0.94 million (D'Souza et al., 2013). Another NCRP, ICMR- Bangalore report on time trends in cancer incidence rates in India (2010 to 2020) stated that total cancer cases are likely to go up from 979,78 in 2010 to 1,148,757 in 2020 (Takiar et al., 2010). In 2011, nearly 1,193,000 new cancer cases were estimated with higher incidence rates among females (603,500) than males (589,800). A study of six cancer registries in India revealed that the estimated 0.44 million deaths due to cancer during the year 2011 is likely to increase to 0.7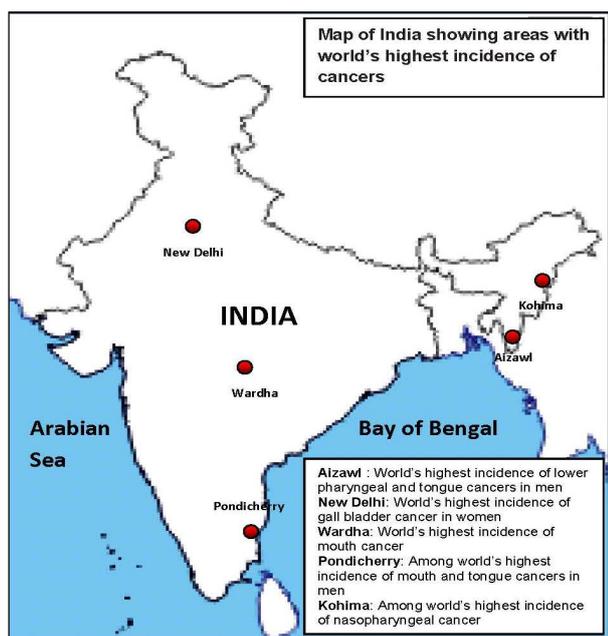0 million by year 2026. The pooled mortality rates (compiling pooled age sex specific cancer mortality rates taking weighted average) were assumed to represent the country's mortality rates (D'Souza et al., 2013).

Disability adjusted life year (DALY), with its two components - years of life lost (YLL) due to premature mortality and years of life lost due to disability (YLD), is a sophisticated epidemiological measure of morbidity, mortality and disability from cancer. It provides a composite index of disease burden. A study compiling data from six PBCRs in India provided estimates of total number of DALYs attributable to cancer as 4,598,976 during 2001, increasing to 6,904,358 by 2016. Premature mortality is the major contributor to disease burden with YLL component of DALY around 70.0% (Murthy et al., 2010).

Evolution of Cancer Registries Internationally

The earliest registry that attempted to cover defined populations using reporting from multiple sources was set up in Hamburg in 1926 (Wagner, 1991). PBCRs with an epidemiological and ecological perspective began in USA in 1935 with establishment of the Connecticut tumor registry in 1941. The Danish registry was then set up in 1942 (Winkelmann, 1999), Growth in cancer registration has been since then mostly unplanned and haphazard, either guided by national policies or funded and founded through local government, state/city health departments, and nongovernmental organizations like anticancer societies and universities (Parkin, 2006). Today, cancer registries cover only approximately 21% of the world population with an uneven spread around continents (Figure 2) (Parkin, 2006). Some registries cover entire national populations (Singapore, Gulf states) while some of the larger populous countries have few registries which are not always situated in the most densely populated areas and cover only a non random sample of population (Parkin, 2006).

History of Cancer Registration in India

Until 1964, information on cancer cases in India was available only from adhoc surveys (Yeole, 2015). Continuous systematic collection of data, their analysis and publication by registries is important for evaluating disease trends over time and generating hypotheses about disease etiologies (Jensen, 1991). The first cancer registry in India was established in June 1963 in Mumbai as a Unit
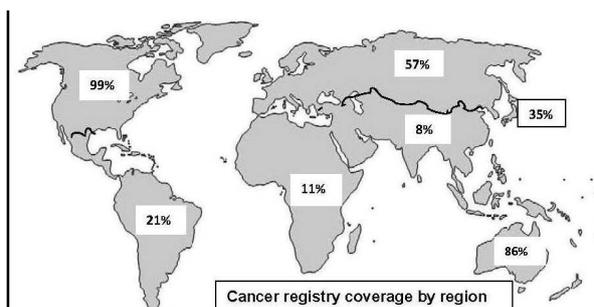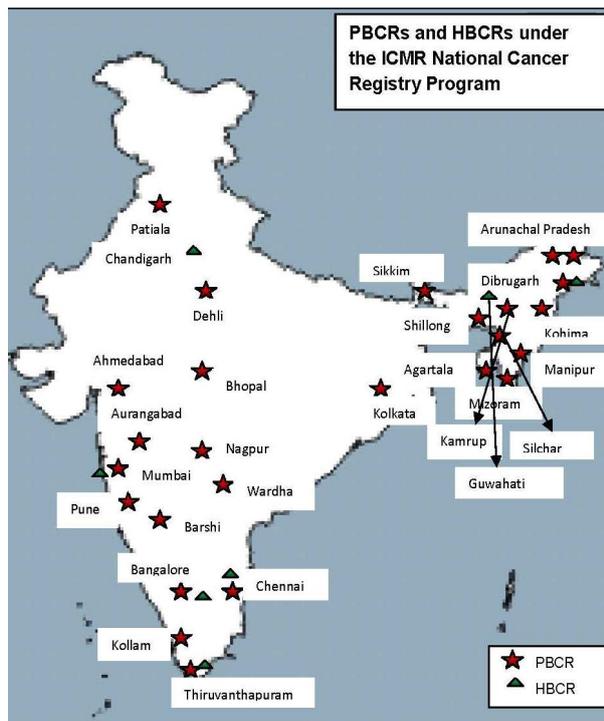

Figure 1. Map of India Showing Areas with World's Highest Incidence of Cancers (Mudur, 2005)

Figure 2. Cancer Registry Coverage by Region (All Registries in Picture are Members of IARC since 2006)

Figure 3. Showing the Distribution of PBCRs and HBCRs in India [NPCR, 2015]

of the Indian Cancer Society with an aim to obtain reliable incidence and mortality data on cancer from a precisely defined urban population (Yeole, 2015). Availability of cancer incidence data on a continuous basis started with initiation of PBCRs at Mumbai in 1964, Pune in 1973, Aurangabad in 1978, and Ahmedabad and Nagpur in 1980 (Chaudhry et al., 2015). However, the main thrust for cancer registration in India began in 1982, through initiation of the NCRP by ICMR. The NCRP began with three PBCRs (pre-existing Mumbai registry and new registries at Bangalore and Chennai), and three hospital based registries (HBCRs) (Chandigarh, Dibrugarh and Trivandrum). Further expansion of the NCRP occurred with the initiation of urban PBCRs at Bhopal and Delhi in 1987; rural PBCRs at Barshi (Maharashtra) in 1987; and HBCRs at the main hospital of PBCRs in Bangalore, Mumbai and Chennai in 1986. Currently there are twenty-six PBCRs and seven HBCRs under the NCRP network (Figure 3) (NCRP, 2015). States and union territories in India and the number of cancer registries covering respective populations are shown in Table 1 (NCRP, 2013; NCRP, 2015; Census of India 2011).

The NCRP was commenced with the following objectives (NCRP 2015): i). To generate reliable data on the magnitude and patterns of cancer incidence,

Table 1. Locations of Cancer Registries in India

State/Union Territory	Estimated population	No. of cancer registries	No. of population served/per registry	Registry type
Andaman & Nicobar Islands	379, 944	-	0	-
Andhra Pradesh	84, 580, 777	-	0	-
Arunachal Pradesh	1, 383, 727	2	691,864	PBCR
Assam	31, 205, 576	5	6, 241, 115	3 PBCRs & 2 HBCRs
Bihar	104, 099, 452	-	0	-
Chandigarh	1, 054, 686	1	1, 054, 686	HBCR
Chattisgarh	25, 545, 198	-	0	-
Dadra & Nagar Haveli	342, 853	-	0	-
Daman & Diu	242, 911	-	0	-
Delhi	16, 753, 235	1	16, 753, 235	PBCR
Goa	1, 457, 723	-	0	-
Gujarat	60, 439, 692	1	60, 439, 692	PBCR
Haryana	25, 351, 462	-	0	-
Himachal Pradesh	6, 864, 602	-	0	-
Jammu & Kashmir	12, 541, 302	-	0	-
Jharkhand	32, 988, 134	-	0	-
Karnataka	61, 095, 297	2	30, 547, 649	1 PBCR & 1 HBCR
Kerala	33, 406, 061	3	11, 135, 354	2 PBCRs & 1 HBCR
Lakhswadeep	64, 429	-	0	-
Madhya Pradesh	72, 606, 809	1	72, 606, 809	PBCR
Maharashtra	112, 374,333	7	16, 053, 476	6 PBCRs & 1 HBCR
Manipur	2, 570, 390	1	2, 570, 390	PBCR
Meghalaya	2, 966, 899	1	2, 966, 899	PBCR
Mizoram	1, 097, 206	1	1, 097, 206	PBCR
Nagaland	1, 980, 602	1	1, 980, 602	PBCR
Odisha	41, 974, 218	-	0	-
Puducherry	1, 244, 464	-	0	-
Punjab	27, 743, 338	1	27, 743, 338	PBCR
Rajasthan	68, 548, 437	-	0	-
Sikkim	610, 577	1	610, 577	PBCR
Tamil Nadu	72, 147, 030	2	36, 073, 515	1 PBCR & 1 HBCR
Tripura	3, 673, 917	1	3, 673, 917	PBCR
Uttar Pradesh	199, 812, 341	-	0	-
Uttarkhand	10, 086, 292	-	0	-
West Bengal	91, 276, 115	1	91, 276, 115	PBCR

morbidity and mortality stratified by age, gender, geographical location, anatomical site, histological type and other socio-demographic parameters; *ii*). To undertake epidemiological studies based on registry data; *iii*). To help design, plan, monitor and evaluate cancer control activities; and *iv*). To help develop human resource and training programs in cancer registration and epidemiology.

Data collection

Cancer is not a notifiable disease in India. Cancer cases are primarily registered through active methods (NCRP, 2001; NCRP, 2006; NCRP, 2015). Registry staffs visit hospital departments (pathology, radiology, radiotherapy, in-patient wards, private wards and outpatient clinics) to elicit cancer information from patient records (NCRP, 2015). Cancer information is also recorded from pathology laboratories and death certificates stored in municipal corporation units. Institutional staffs scrutinize records in various departments to retrieve desired information on reported cancer cases in a "common core proforma" which is standardized for all cancer registries in India. Every attempt is made to record information of all cancer patients in the registration area. All cancers are coded as per the International Classification of Diseases for Oncology (ICD-O) with a behavior code-3 (the latter codes for tumor malignancy behavior). Data collected include personal identifiers, demographic variables, date of diagnosis, the most valid basis of diagnosis, tumor site and morphology, extent of disease and treatment(s) given up to six months after diagnosis (NCRP, 2015) which are then entered into a customized computerized database.

Quality assurance

Each registry ensures quality control measures and an overall database audit for data reliability and completeness of coverage through routine exercises based on "Comparability and Quality Control in Cancer Registration" published by the International Agency for Research on Cancer (IARC 1994). A comprehensive account of various sources of registration is obtained to minimize duplicate registrations and to identify number of cases whose residential status is unknown. Notifications per case are recorded which gives an idea of diagnostic workup and mechanics of reporting. A regular re-abstracting audit of 10% random sample of cases is performed by supervisory staff to assess disagreements and errors which are subsequently discussed and resolved at NCRP workshops. Database reliability is programmed code validation checks and consistency checks (such as method of diagnosis, primary and secondary histology, ICD-9 conversion codes, and histology combinations), to compare values of data items against others. Validity of diagnostic information is assessed using quality indicators (i.e., microscopic verification (MV %), percent of cases reported by death certificate only (DCO), clinical diagnosis and mortality to incidence ratio) (NCRP, 2015).

Registry personnel

The most important element of any cancer registry is a dedicated leadership committed to the registry's success. All cancer registries in India are headed by a principal investigator, who is typically medically qualified, has good knowledge of oncology and has a background in epidemiology and/or public health. The registries have access to pathologists, clinical oncologists, epidemiologists, biostatisticians and public health specialists. Technical staff includes record personnel for case finding, abstracting and coding patient information, and data processing programmers to plan and implement data storage and retrieval (NCRP, 2015).

Rural registry

About 68% of Indian population lives in rural areas (World Bank, 2015). Ensuring satisfactory case finding in rural areas can be challenging. Major obstacles for cancer registration in rural India include population's lack of cancer awareness, low socio-economic status, and need to travel long distances to access healthcare services which are often minimal. The first rural cancer registry was set up in 1987 at Barshi (population 0.4 million in 1987) in western Maharashtra. Apart from using active case-finding methods as in urban registries, the Barshi cancer registry used a method of regular interaction with the community, positively impacting efforts to educate them about warning signals for cancer, raise cancer awareness and motivate suspected individuals to seek medical attention which facilitate optimal cancer registration (Jayant et al., 2010).

Population-based cancer registries (PBCR) *vs.* Hospital-based cancer registries (HBCR)

PBCRs are considered to be the "gold standard" for providing information on cancer incidence and patterns in the population being served (NCRP, 2013). Under NCRP, the criteria used to determine residence status in the geographic area is a minimum period of one year before the time of cancer diagnosis. PBCRs in India provide reliable data on magnitude, patterns and trends of cancer over time and also serve to assess impact of cancer control activities. Though only a small proportion of the population is covered by PBCR registries, they are reported to provide a fairly accurate estimate of the cancer burden in the country (NCRP, 2013). Figure 4a shows an example of statistics generated by PBCRs in India. The age-adjusted incidence rates for cancer of all sites were highest in Delhi between years 1990 - 1996. Cancer of all-sites affected females more than males. (NCRP, 2013). These annual reports generated by the NCRP also describe the incidence of different cancers, and their geographic distribution, thus suggesting severity of the problem and determining priority areas for cancer control.

HBCRs provide information on the magnitude of cancer and patterns of patient care in a given hospital. However in India, most HBCRs are located in regional cancer centers, and may reflect patterns of cancer in the population of that region. HBCRs help in assessing cancer patient care in a given hospital and provide important information for assessing hospital cancer control programs. Patient compliance and follow up, which can only be assessed in HBCRs, help in monitoring and evaluating patient care in the hospital. Details of diagnostic and treatment information gathered by a

HBCR is generally more thorough compared to a PBCR. Also, the comprehensive epidemiology and clinical data collected by HBCRs constitute a rich source of material for conducting etiological research. An example of data generated by HBCRs is shown in Figure 4b. Radiotherapy seems to be the commonest mode of cancer treatment across all hospital-based registries. (NCRP, 2013).

## Use of Cancer Registry Data in India

Incidence data

One of the most important activities of cancer registries in India is calculation and reporting of incidence rates (Chaudhury et al., 2015). Recent data reported from the Mumbai registry in 2006 showed that the crude all-cancer incidence rate per 1000 population was 96.2 for females and 72.9 for males. Time trend incidence analysis from 1982 to 2006 from the Mumbai registry revealed an increasing incidence of cancers of: liver, gallbladder, prostate, kidney, brain, lymphomas, leukemias among males; and cancers involving: gallbladder, breast, uterus, ovary, kidney, lymphomas, leukemias and multiple myelomas among females. Lung cancer was the most common cancer in males followed by cancers of prostate, liver and larynx, whereas in females, breast had highest incidence followed by cancers of cervix, ovary and lungs (Yeole, 2015).

Cancer registry and research

Cancer registry databases are important resources for studies in descriptive epidemiology, which in turn generate scientific hypotheses. For example, reported results from most Indian cancer registries show cervical cancer to be the most common cancer among women (NCRP, 2006). This data initiated several epidemiological studies looking into risk factors associated with cervical cancer, which identified several major risk factors for cervical cancer in India such as: early age at marriage, early age at first coitus, early age at first child birth, sexual promiscuity (among both women and their spouses), sex with uncircumcised men, multi-parity, low socioeconomic status and poor genital hygiene (Agarwal et al., 1993; Biswas et al., 1997; Munoz et al., 2002; Natphopsuk et al., 2012; Thulaseedharan et al., 2013; Sreedevi et al, 2015). It is estimated that by 2020, India, will have about 218,500 (19.0% of all sites cancers) incident head and neck cancer cases (Takier et al., 2010). Research studies have demonstrated important risk factors for oral cancers which include chewing tobacco as a betel quid (produced by chewing a combination of betel leaf, slacked lime, areca nut and tobacco with or without other condiments), smoking bidi (a local hand-rolled cigarette of dried temburni leaf containing coarse tobacco) and drinking locally brewed crude alcoholic drinks. Consuming betel quid even without tobacco has also been found to have a high risk for oral cancer (Gupta et al., 2014; Kadashetti et al., 2015; Mahapatra et al., 2015). Chewing betel nut and other related products have been associated with oral submucous fibrosis (OSF) for long (Chattopadhyay, 1987). OSF is a potentially malignant condition (Warnakulasurya et al., 2007). Although mechanistic details of occurrence of cancer in OSF are still being unearthed, there is enough information available to understand the molecular pathology of cancer in OSF (Chattopadhyay and Ray, 2015).

An assessment of 732 consecutive cases of oral squamous cell carcinoma were analyzed at a dental college-hospital in Calcutta between January 1967 and December 1987, reported incidence of oral cancer to be 47.7 per 100,000 with a mean age of 52.1 years demonstrating early onset of such cancers. Buccal mucosa was the most common site involved, followed by gingiva and mandibular alveolar ridge (Chattopadhyay, 1989). A recent study from Ahmedabad also demonstrated increased age specific incidence rates of mouth cancer among men over a 25-year period (Gupta et al., 2014). Two other case control studies demonstrated 'Kolakhar', a locally made unique alkaline food additive, papad, very hot spicy food, chiles, chewing quid containing fermented betel-nut (processed underground) with or without tobacco, bidi smoking and a combination of these habits to be important risk factors associated with high incidence of esophageal cancer in Assam (Phukan et al., 2001; Phukan et al., 2001).
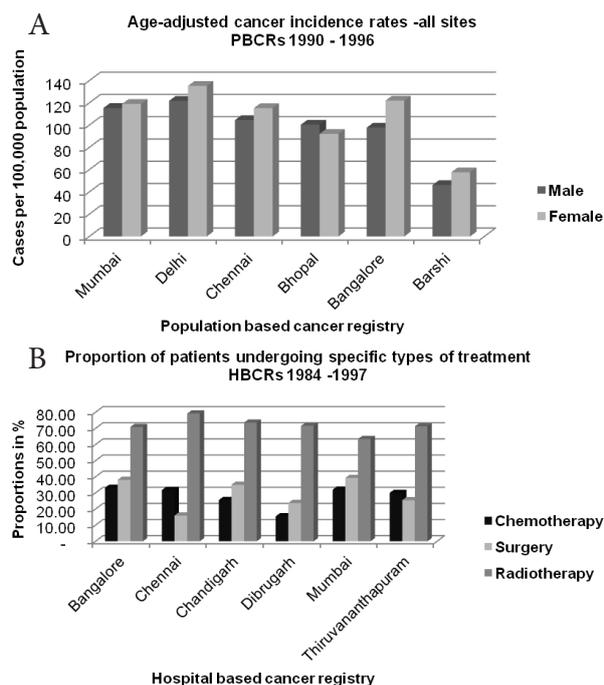
Figure 4. Indian Cancer Statistics. A) Generated by PBCRs. B) Generated by HBCRs

Cancer registry and cancer control

Cancer surveillance is central to any rational cancer control program. The World Health Organization recommends that cancer-control activities are best planned and delivered through national cancer control plans, using cancer registries as core component of the control strategy (WHO, 2002). A robust and well-researched cancer registry database can help health planners assess true community needs, calculate level of services needed and invest appropriate level of resources for prevention, early detection, treatment and care. Population-based survival studies are important resources for assessment of effectiveness of cancer control strategies in that region.

Studies from Bangalore reported 5 year relative survival from breast cancer to be 46.8%, while another study from Mumbai reported 41.6% relative survival for prostate cancer (Nandakumar et al., 1995; Yeole et al., 2001). Data from cancer registries should also be presented each year to state health departments to identify most prevalent cancers. Another approach can be to compare cancer incidence rates in areas with or without preventive programs, or with different intensities of intervention (Weir et al., 2003). Data presented as maps may help focus target areas for cancer control interventions and monitor the impact of interventions. The Taiwan cancer registry reported a fourfold decrease in incidence of hepatocellular carcinoma between 1980 and 1994 following introduction of Hepatitis B vaccination in 1980. Such knowledge of cancer trends over time can be used for projection of future incidence rates, case loads, and needs for treatment facilities (Chang et al., 1997).

Pitfalls and Issues

Some major concerns associated with cancer registry data discussed below include accuracy and detail of information about diagnosis, comprehensive and unbiased coverage of all incident cases in the registry population, and delay in incorporating information into the database.

Cancer coverage
Inclusion of incident cancers in registry data should be close to 100% and PBCRs should endeavor to register every case within its defined population (Mathew et al., 2011). In countries with low and medium Human Development Index (HDI), notably in sub-Saharan Africa and south Asia, both vital registries and PBCR registries are not high quality programs which reflect shortage of human and financial resources, rather than lack of awareness of need (Bray et al., 2015). With 15% population coverage (Murthy et al., 2010), Indian cancer registries are unevenly distributed relative to population distribution and may not be representative of the national cancer experience. Some of the most populous states such as Uttar Pradesh (population 19, 981, 477), Uttarkhand (population 10,086,292), Odisha (population 41,947,398), Andhra Pradesh (population 84,580,777), Bihar (population 31,675,607), and Rajasthan (population 68,548,437) do not have cancer registries (NCRP, 2015). Even the limited data that is gathered from specified towns and cities do not have adequate population coverage within their defined area. The Trivandrum cancer registry estimates their coverage between approximately 80% (urban) and 85% (rural) (Mathew et al., 2011). The estimate of coverage of cancer cases is 71.8% in Bangalore and 78% in Mumbai (NCRP, 2000).

In India, cancer case information is collected through an 'active' system. Many cancer cases are treated in private sector hospitals that are not under active cancer surveillance. Cases from private hospitals may belong to higher income groups and may differ from others in factors such as diet and occupational exposures. The Indian National Family Health survey found that over 70% of residents of New Delhi and Mumbai, and over 50% of residents of Kerala sought care in the private medical sector. Hence exclusion of cases admitted to private hospitals may result in under-counting of cancer cases attenuating the true population estimates (Mathew et al., 2011).

Accurate diagnosis
Accurate information on cancer diagnosis ensures quality and reliability of registry data. Evaluation of registry data at New Delhi, Mumbai and Trivandrum using IARC quality indicators (MV%, DCO%, clinical diagnosis only and the mortality to incidence ratio) showed that all three Indian registries were of lower quality compared to Surveillance Epidemiology and End Results (SEER) registries standards in the United States (US) (Mathew et al., 2011). Microscopic verification, considered to be the ''gold standard'' in diagnosis and typing of tumors, was available only in 85.7 % of cases compared to 94.5% in SEER (Ries, 2003) and 93% in England and Wales (Dickinson et al., 2001). In New Delhi, substantial percentages (14%) of cases were based on clinical diagnosis compared to only 0.7% in SEER. The mortality-to-incidence ratio ranged from less than 10% in New Delhi to over 50% in Mumbai. The large range may likely reflect inaccuracies in incidence and/or mortality measures in the two cities (Mathew et al., 2011). Cases registered on the basis of DCOs, which provide an extent of the missing cases in routine registration practices, were close to 7% in Mumbai and Trivandrum compared to 1.0% in SEER. The proportion of DCOs reported by Bangalore cancer registry was even higher at 9% (Gajalakshmi et al., 2001).

Timeliness
Cancer registries should provide complete and reliable cancer incidence information with the least possible delay; however case reports typically arrive at most registries several months after diagnosis. For example, cases are reported anywhere from 12 to 30 months after diagnosis in US registries (NPCR, 2015), from 12 to 18 months in English registries (UK, 2015), and within 30 months of diagnosis in Chinese registries (Chen et al., 2013). In the US, data from individual state registries participating under the NPCR-CDC are available 12 to 30 months after close of the year in which cancer is diagnosed. Annual publication of cancer data and public use cancer data sets from SEER program are available approximately 28 months after the close of the year of cancer diagnosis. The North American Association of Central Cancer Registries (NAACCR) also ensures availability of their cancer data within 23 months of diagnosis (NPCR, 2015). Cancer registries in England are required by their Department of Health to provide data to their Office of National Statistics within 18 months of the end of the registration year which was reduced to 12 months in 2010 to improve timeliness in data publication (UK, 2015). The National Central Cancer Registry in China (NCCR) rule says that every registry should upload cancer registry data within 30 months of diagnosis (Chen et al., 2013). In India however, time for availability registry data was approximately three years in Mumbai and less than two years in Trivandrum. A study

demonstrated that in New Delhi, 800 cancer case records from a private hospital could not be matched with records at the Delhi cancer registry (DCR) due to a backlog at the Registry. Furthermore, no records for cases treated at the private hospital during 2002-2004 were found in the registry up to the end of 2007 (Mathew et al., 2011).

Though the original function of cancer registries was to calculate incidence rates, not all cancer registries in India utilize their data to publish a timely estimate of cancer incidence for their respective areas. Currently, while the NPCR-CDC and SEER have cancer information dating as recent as 2010 - 2011, many cancer registries in India have their annual reports published before 2011 (NCRP, 2013). There are marked variations even within registries leading to miscalculation of disease characteristics, especially with data coming from specialized and non-specialized medical institutions (Parkin et al., 2015). Internationally, many cancer registries have also expanded far beyond calculating incidence rates to include studies of cancer cause and prevention and provide information for cancer-control program planning and evaluation. However, in India, most cancer registries are still an under-used resource in this respect.

Follow - up and survival data

Reliable information on cancer survival is important for cancer control activities. Survival estimates of unselected groups of cancer patients from PBCRs can serve as an important index for evaluating cancer diagnosis and treatment and the effectiveness of overall cancer services in a given region. In India, only six of the twenty six PBCRs have undertaken survival studies (Sankaranarayanan, 1999; Sankaranarayanan, 2010). In many developed countries, passive follow up of cancer patients is carried out by using personal identifying information of cancer patients, matching them with mortality databases. However, in India, unique citizen identifiers such as personal identification numbers do not exist (Sankaranarayanan, 2010). Medical certification of deaths is often deficient and identity particulars of deceased individuals are often inaccurate. Under such circumstances, passive follow up is unlikely to yield valid estimates of survival among cancer patients. Only four PBCRs from India (Mumbai, Bangalore, Barshi and Chennai), have contributed survival data to the IARC by employing active follow-up method (Swaminathan et al., 2008).

Other data gaps and inconsistencies

In India, currently there are only two time points where cancer data is collected: at diagnosis (incidence) and at death (mortality). With advances in prevention, screening and treatment, many cancer patients live longer, either free of disease or with recurrent disease, yet there is minimal national follow-up data to monitor information such as: quality-of-life after treatment, intermediate and long-term toxicities, and effects of new treatments and technologies. Indian PBCRs do not collect information such as: Tumour Node and Metastasis (TNM) (or equivalent) stage at diagnosis, or treatment data. Data on TNM (or equivalent) stage, as well as recurrences, would add significant value to existing data on incidence and mortality for monitoring service needs and outcomes across populations.

Future Perspectives

Population coverage

Further expansion of Indian cancer registry network in a planned manner, to cover more areas, would be a key initial step in development of a stronger infrastructure for cancer surveillance, prevention, control and research. The current NCRP database comes from cancer cases in selected urban areas and only one rural cancer registry raising questions about validity of the national estimates. Even hospitals and clinics in urban areas are perpetually overcrowded, and setting up a cancer registry requires frequent clarifications from practitioners for incomplete and contradictory information in patient records. The quality of information is also often poor, based on clinical information only. Increasing the number of PBCRs in India may be an important measure to have representative cancer data that account for underlying inter-regional and urban-rural demographic and epidemiological differences. Such expansion and enhancement of cancer registration will require proper administrative and financial plans for registries' success. The area covered should also have well developed diagnostic and treatment centers that attract patients. Close integration with community health care workers (such as the Accredited Social Health Activists (ASHAs) or Anganwadi workers) may also be helpful in facilitating rural cancer registration.

Population enumeration

Accuracy of cancer incidence rates reported by registries depends not only on completeness of coverage of cancer cases, but also on the "accuracy of population at risk" data. The populations of developing countries are usually more mobile - rural people often migrate to urban areas for better job opportunities and living standards, while other communities move because of social and political upheavals. These migrations are often unrecorded, invalidating census data. Hence development and expansion of registries must also ensure that they have valid estimates of the population covered with their subgroups (such as gender, ethicn groups and age distribution) to ensure an appropriate denominator for calculating proportions and rates.

Expansion of dataset to include bio-sample laboratory variables

The expanding role of registries in monitoring etiological factors demands datasets that include many more variables than those that are traditionally collected. Sometimes this can be achieved through linkage with other databases, in-depth study of sample cases and collecting biological specimens. Undertaking research studies supported by a laboratory component - integration of population based epidemiology and molecular biology -- may provide new opportunities for cancer etiological studies. This would, however, increase the need for rapid identification of cases and enable prompt collection of blood and tissue specimens after diagnosis. Availability

of comprehensive data of good quality will allow better data usage, especially for cancer epidemiologists', clinical oncologists', public health practitioners' and for training programs.

Standardization of methodology and definitions

Comparability of data with other regions is essential for interpretation and this in turn, depends on standardization of methodology, diagnostic criteria and other criteria applied. To achieve this objective, the Thai National Cancer Institute, the IARC and its Mumbai Hub of cancer registration together with the International Association of Cancer Registries jointly organized the Asian Cancer Registry Forum in February, 2014, which highlighted the necessity of cancer registry networks to improve cancer registration across Asia (Moore et al., 2014). Research needs to be conducted to actually explain differences observed in incidence rates between countries and among registries in a convincing way so that they offer practical application. An Asian Network, as currently being pursued by the Mumbai IARC Hub, could clearly be beneficial in this respect, particularly in those countries within the region that are trying to establish more effective registry systems.

Active follow-up

In India, active follow-up of cancer patients is not usually integrated with PBCR practices (Swaminathan et al., 2008). Active follow-up information on cancer patients should be collected from each reporting hospital and public registry. These could be in the form of annual follow up surveys of registered cancer cases through patients' respective doctors. Such "medical follow-ups" will not only assess quality and duration of survival, but will also reveal the number of patients who cannot be traced or whose vital status is unknown. Attempts should be made to document patients' disease and functional status during follow-up.

Staff and training

Unlike in developed countries, where cancer registries have adequate and appropriately trained personnel, most Indian registries are obliged to rely upon medical or nursing records, or operation books, a method which is generally insufficient in terms of the collected quantity and quality of information. Hence, adequate staffing with specific training on cancer registration will be key to collecting and maintaining good quality cancer data and timeliness in reporting cancer statistics. Formal training courses, workshops and use of standard protocols will help avoid individualized practices by registries. Regional offices of WHO and IARC may be consulted in this regard. The Mumbai IARC Hub is expected to play an important role in addressing this issue as training and directed support to registries is a core element of its activities.

Conclusion

Completeness of ascertainment of cancer cases remains the principal test of cancer registries in India; beside accuracy in recording, classification and coding of diagnosis. Complete ascertainment is crucial for providing accurate incidence rates, unbiased survival, and other statistics. It is critical that the cancer registries in India checks on its accuracy through regular audit and administrative excellence. Advances in cancer registration in India should be complemented with a nationwide effort to foster systematic investigations of cancer patterns and trends by states, regions and sub populations and allow a continuous loop of measurement, communication and action.

References

Agarwal SS, Sehgal A, Sardana S, Kumar A, Luthra UK (1993). Role of male behavior in cervical carcinogenesis among women with one lifetime sexual partner. *Cancer*, **72**, 1666-9.

Biswas LN, Manna B, Maiti PK, Sengupta S (1997). Sexual risk factors for cervical cancer among rural Indian women: A case-control study. *Int J Epidemiol*, **26**, 491-5.

Bray F, Znaor A, Cueva P, et al (2015). Planning and developing population-based cancer registration in low- and middle-income settings. IARC Technical Publication No. 43. IARC, Lyon.

Bryant H, Shin HR, Forman D, et al (2012). Managing population health to prevent and detect cancer and non-communicable diseases. *Asian Pac J Cancer Prev*, **13(4 Suppl)**, 13-22.

Census of India. Census Info India (2011). Final Population Tables. WWW page. URL: http://censusindia.gov. in/2011census/censusinfodashboard/. Last accessed February 24, 2016

Chang MH, Chen CJ, Lai MS, et al (1997). Universal hepatitis B vaccination in Taiwan and the incidence of hepatocellular carcinoma in children Taiwan Childhood Hepatoma Study Group in children. *N Engl J Med*, **336**, 1855-9.

Chattopadhyay A (1987). Paan masala and betel nut may lead to oral cancer. *Science Reporter*, **24**, 669.

Chattopadhyay A (1989). Epidemiologic study of oral cancer in eastern India. *Indian J Dermatol*, **34**, 59-65.

Chattopadhyay A, Ray JG (2016). Molecular pathology of malignant transformation of oral submucous fibrosis. *J Environ Pathol Toxicol Oncol*. 2016**.**

Chaudhry K, Luthra UK (2015). Cancer registration in India. WWW page. URL: www.mohfw.nic.in/WriteReadData/l892s/Cancer%20Registration%20In%20India.pdf. Last accessed February 24, 2016

Chen W, Zheng R, Zhang S, et al (2013). The incidences and mortalities of major cancers in China, 2009. *Chin J Cancer*, **32**, 106-12.

Dickinson HO, Salotti JA, Birch PJ, et al (2001). How complete and accurate are cancer registrations notified by the National Health Service Central Register for England and Wales? *J Epidemiol Community Health*, **55**, 414-22.

Dikshit R, Gupta PC, Ramasundarahettige C, et al (2012). Cancer mortality in India: a nationally representative survey. *Lancet*, **379**, 1807-16.

D'Souza ND, Murthy NS, Aras RY (2013). Projection of burden of cancer mortality for India, 2011-2026. *Asian Pac J Cancer Prev*, **14**, 4387-92.

D'Souza ND, Murthy NS, Aras RY (2013). Projection of cancer incident cases for India - till 2026. *Asian Pac J Cancer Prev*, **14**, 4379-86.

Gajalakshmi V, Swaminathan R, Shanta V (2001). An independent survey to assess completeness of registration: population based cancer registry, Chennai, India. *Asian Pac J Cancer Prev*, **2**, 179-83.

Globocan (2012). Estimated cancer incidence, mortality and

prevalence worldwide in 2012. WWW page. URL: http://globocan.iarc.fr/Default.aspx. Last accessed February 24, 2016

Gupta B, Johnson NW (2014). Systematic review and meta-analysis of association of smokeless tobacco and of betel quid without tobacco with incidence of oral cancer in South Asia and the Pacific. *PLoS One*, **9**, 113385.

Gupta PC, Ray CS, Murti PR, et al (2014). Rising incidence of oral cancer in Ahmedabad city. *Indian J Cancer*, **51**, 67-72

IARC. Comparability and Quality Control in Cancer Registration (2015). WWW page. URL: http://www.iarc.fr/en/publications/list/sp/techreports.php. Last accessed February 24, 2016

IARC. Global Initiative for Cancer Registry Development in Low- and Middle-Income Countries (2011). WWW page. URL: http://gicr.iarc.fr/. Last accessed February 24, 2016

IARC Globocan (2012). Estimated cancer incidence, mortality and prevalence worldwide in 2012. WWW page. URL: http://globocan.iarc.fr/Pages/fact_sheets_cancer.aspx. Last accessed February 24, 2016

Jayant K, Nene BM, Badwe RA, et al (2010). Rural cancer registry at Barshi, Maharashtra and its impact on cancer control. *Natl Med J India*, **23**, 274-7.

Jensen OM, Whelan S (1991). Planning a cancer registry. Cancer registration: principles and Methods. WWW page. URL: www.iarc.fr/en/publications/pdfs-online/epi/sp95/sp95-chap4.pdf. Last accessed February 24, 2016

Kadashetti V, Chaudhary M, Patil S, et al (2015). Analysis of various risk factors affecting potentially malignant disorders and oral cancer patients of Central India. *J Cancer Res Ther*, **11**, 280-6.

Mahapatra S, Kamath R, Shetty BK, Binu VS (2015). Risk of oral cancer associated with gutka and other tobacco products: a hospital-based case-control study. *J Cancer Res Ther*, **11**, 199-203.

Mathew A, Daniel CR, Ferrucci LM, et al (2011). Assessment of follow-up and the completeness and accuracy of cancer case ascertainment in three areas of India. *Cancer Epidemiol*, **35**, 334-41.

Moore MA, Sangrajrang S, Bray F (2014). Asian Cancer Registry Forum 2014 - regional cooperation for cancer registration: priorities and challenges. *Asian Pac J Cancer Prev*, **5**, 1891-4.

Mudur G (2005). India has some of the highest cancer rates in the world. *BMJ*, **330**, 215.

Munoz N, Franceschi S, Bosetti C, et al (2002). Role of parity and human papillomavirus in cervical cancer: the IARC multicentric case-control study. *Lancet*, **359**, 1093-101.

Murthy NS, Nandakumar BS, Pruthvish S, George PS, Mathew A (2010). Disability adjusted life years for cancer patients in India. *Asian Pac J Cancer Prev*, **11**, 633-40.

Murthy NS, Nandakumar BS, Shivaraj AS, (2010). Cancer registration: it's relevance for health care planning in India. *Indian J Prev Soc Med*, **41**, 75-87

Nandakumar A, Anantha N, Venugopal TC, et al (1995). Survival in breast cancer: a population-based study in Bangalore, India. *Int J Cancer*, **60**, 593-6.

National Cancer Registry Programme (2001). Report of population based cancer survey at Bangalore and Mumbai. ICMR, New Delhi.

National Cancer Registry Programme. Consolidated report of population based cancer registries 1990 - 96. (2001). WWW page. URL: http://www.ncrpindia.org/Annual_Reports.aspx. Last accessed February 24, 2016

National Cancer Registry Programme, (2006).Consolidated Report of Population Based Cancer Registries 2001-2004. WWW page. URL: http://www.ncrpindia.org/Annual_

Reports.aspx. Last accessed February 24, 2016

National Cancer Registry Programme (2013). Consolidated report of hospital based cancer registries 2007 - 2011. WWW page. URL: http://www.ncrpindia.org/Annual_Reports.aspx. Last accessed February 24, 2016

National Cancer Registry Programme (2013). Three year report of population based cancer registries 2009 - 2011. WWW page. URL: http://www.ncrpindia.org/Annual_Reports.aspx. Last accessed February 24, 2016

National Cancer Registry Programme, (2015). WWW page. URL: http://ncrpindia.org. Last accessed February 24, 2016

National Program of Cancer Registries. CDC (2015). WWW page. URL: www.cdc.gov/cancer/npcr/about.htm. Last accessed February 24, 2016

Natphopsuk S, Settheetham-Ishida W, Sinawat S, et al (2012). Risk factors for cervical cancer in northeastern Thailand: detailed analyses of sexual and smoking behavior. *Asian Pac J Cancer Prev*, **13**, 5489-95.

Parkin DM (2006). The evolution of the population-based cancer registry. *Nat Rev Cancer*, **6**, 603-12.

Parkin DM, Sanghvi LD (1991). Cancer registration in developing countries. Cancer registration: principles and Methods. WWW page. URL: http://www.iarc.fr/en/publications/pdfs-online/epi/sp95/sp95-chap14.pdf. Last accessed February 24, 2016

Phukan RK, Chetia CK, Ali MS, Mahanta J (2001). Role of dietary habits in the development of esophageal cancer in Assam, the north-eastern region of India. *Nutr Cancer*, **39**, 204-9.

Phukan RK, Ali MS, Chetia CK, Mahanta J (2001). Betel nut and tobacco chewing; potential risk factors of cancer of oesophagus in Assam, India. *Br J Cancer*, **85**, 661-7.

Ries L, Eisner M., Kosary C, et al (2003). SEER Cancer Statistics Review, 1975-2000. Bethesda, MD: National Cancer Institute. WWW page. URL: http://seer.cancer.gov/archive/csr/1975_2000/. Last accessed February 24, 2016

Sankaranarayanan. R, Black RJ, Swaminathan R, Parkin DM (1998). An overview on cancer survival in developing countries. *IARC Sci Publ*, **145**, 135-73.

Sankaranarayanan R, Swaminathan R, Brenner H, et al (2010). Cancer survival in Africa, Asia, and Central America: a population-based study. *Lancet Oncol*, **11**, 165-73.

Shin HR, Carlos MC, Varghese C (2012). Cancer control in the Asia Pacific region: current status and concerns. *Jpn J Clin Oncol*, **42**, 867-81.

Sreedevi A, Javed R, Dinesh A (2015). Epidemiology of cervical cancer with special focus on India. *Int J Womens Health*, **7**, 405-14.

Summary Quality Report for Cancer Registration Statistics (2015). WWW page. URL: www.ons.gov.uk/summary-quality-report. Last accessed February 24, 2016

Swaminathan R, Rama R, Shanta V (2008). Lack of active follow-up of cancer patients in Chennai, India: implications for population-based survival estimates. *Bull World Health Organ*, **86**, 509-15.

Takiar R, Nadayil D, Nandakumar A (2010). Projections of number of cancer cases in India (2010- 2020) by cancer groups. *Asian Pac J Cancer Prev*, **11**, 1045-9.

Thulaseedharan JV, Malila N, Hakama M, et al (2013). 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*, **14**, 589-94.

Wagner G (1991). History of cancer registration. Cancer registration: principles and methods. WWW page. URL: www.iarc.fr/en/publications/pdfs-online/epi/sp95/SP95.pdf. Last accessed February 24, 2016

Warnakulasuriya S, Johnson NW, van der Waal I (2007).

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Nomenclature and classification of potentially malignant disorders of the oral mucosa. *J Oral Pathol Med*, **36**, 575-80.

Weir HK, Thun MJ, Hankey BF, et al (2003). Annual report to the nation on the status of cancer, 1975-2000, featuring the uses of surveillance data for cancer prevention and control. *J Natl Cancer Inst*, **95**, 1276-99.

Winkelmann, R (1999). Cancer Registration Techniques in the New Independent State of the Former Soviet Union Technical Report No. 35. IARC, Lyon.

World Bank Rural Population Data (2015). WWW page. URL: http://data. worldbank. org/indicator /SP.RUR. TOTL.ZS. Last accessed February 24, 2016

World Health Organisation (2002). National Cancer Control Programmes. Policies and Managerial Guidelines 2nd Edn. WHO press, Geneva.

Yeole BB, Kurkure AP (2015). Mumbai cancer registry update. WWW page. URL: http://www.indiancancersociety.org/uploads/articles_on_cancer/art-34.pdf. Last accessed February 24, 2016

Yeole BB, Sunny L (2001). Population based survival from prostate cancer in Mumbai (Bombay), India. *Indian J Cancer*, **38**, 126-32.

Yeole BB (2001). An assessment of improvement in reliability and completeness of mumbai cancer registry data from 1964-1997. *Asian Pac J Cancer Prev*, **2**, 225-32.