Published in final edited form as:

Cancer Epidemiol. 2011 August ; 35(4): 334–341. doi:10.1016/j.canep.2011.03.006.

Assessment of follow-up, and the completeness and accuracy of cancer case ascertainment in three areas of India

Aleyamma Mathew^{1,8}, Carrie R. Daniel², Leah M. Ferrucci², Tulika Seth³, Susan S. Devesa², Preethi S. George¹, Hemali Shetty⁴, Niveditha Devasenapathy⁵, Susan Yurgalevitch⁶, Tanuja Rastogi⁷, Dorairaj Prabhakaran^{5,8}, Prakash C. Gupta^{4,8}, Nilanjan Chatterjee², and Rashmi Sinha²

¹Regional Cancer Center, Trivandrum, Kerala, India

²National Cancer Institute, National Institutes of Health, Department of Health and Human Services, Rockville, MD, USA

³All India Institute of Medical Sciences, New Delhi, India

⁴Healis Sekhsaria Institute for Public Health, Navi Mumbai, India

⁵Centre for Chronic Disease Control, New Delhi, India

⁶Westat, Rockville, MD, USA

⁷United Nations World Food Program, Rome, Italy

⁸Principal Investigator of the respective centers

Abstract

Background—A prospective study of diet and cancer has not been conducted in India; consequently, little is known regarding follow-up rates or the completeness and accuracy of cancer case ascertainment.

Methods—We assessed follow-up in the India Health Study (IHS; 4,671 participants aged 35–69 residing in New Delhi, Mumbai, or Trivandrum). We evaluated the impact of medical care access and relocation, re-contacted the IHS participants to estimate follow-up rates, and conducted separate studies of cancer cases to evaluate registry coverage (604 cases in Trivandrum) and the accuracy of self- and proxy-reporting (1600 cases in New Delhi and Trivandrum).

Results—Over 97% of people reported seeing a doctor and 85% had lived in their current residence for over six years. The 2-year follow-up rate was 91% for Trivandrum and 53% for New Delhi. No cancer cases were missed among public institutions participating in the surveillance program in Trivandrum during 2003–04; but there are likely to be unmatched cases (ranging from 5 to 13% of total cases) from private hospitals in the Trivandrum registry, as there are no mandatory reporting requirements. Vital status was obtained for 36% of cancer cases in New Delhi as compared to 78% in Trivandrum after a period of 4 years.

© 2011 Elsevier Ltd. All rights reserved.

Corresponding author and reprint requests: Dr. Aleyamma Mathew, Regional Cancer Center, Trivandrum- 695 011, Kerala, India. amathew@rcctvm.org.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Conclusions—A prospective cohort study of cancer may be feasible in some centers in India with active follow-up to supplement registry data. Inclusion of cancers diagnosed at private institutions, unique identifiers for individuals, and computerized medical information would likely improve cancer registries.

Keywords

Cancer; end-point; follow-up; registry; prospective cohort; India

Introduction

India is experiencing both an economic transition and changing patterns of non-communicable disease, with rapid increases in diabetes, hypertension, cancer, and cardiovascular disease [1–3]. In higher-income societies, over one-third of cancers are believed to be attributable to potentially modifiable diet and lifestyle-related exposures, such as low physical activity and obesity [4]. Despite the striking prevalence of diet-related chronic conditions in Asian-Indians, diet and cancer risk is largely unexplored in India [5–12].

Existing cohorts in India have primarily focused on lifestyle factors, such as tobacco use, with cause-specific mortality outcomes assessed by reported cause of death or verbal autopsy and, in some cases, confirmed by death registry information [13–14]. Although regional and religious heterogeneity in demographic, lifestyle, and dietary exposures within India would provide unique opportunities for epidemiologic research, a large prospective study evaluating diet and cancer has not been conducted in India [15]. Additionally, bias resulting from differential recall of past diet and lifestyle in retrospective designs is a critical concern in nutritional epidemiologic studies; thus, establishing a prospective cohort in India capturing cancer and chronic disease outcomes would facilitate new investigations of modifiable aspects of diet and lifestyle.

Many challenges need to be evaluated before a large prospective cohort study can be established across different regions of India. Achieving high follow-up rates and accurate outcome assessment without systematic bias are likely to be major obstacles for prospective studies in India. Thus, we conducted the India Health Study (IHS) between February 2007 and July 2008 in New Delhi, Mumbai, and Trivandrum to assess the feasibility of establishing a potential cohort with detailed exposure assessment and follow-up for cancer endpoints. As IHS was a short-term pilot study, we used indirect methods to assess the completeness of incident cancer case ascertainment and estimate follow-up rates. We evaluated potential loss due to: (1) lack of access to medical care; (2) relocation out of the registry/study area, and (3) the coverage/quality of the cancer registry system. Furthermore, in a prospective cohort study where there is incomplete coverage by the cancer registries, participants or their proxies can provide the medical information. Therefore, we estimated: 1) the fraction of IHS participants who would provide contact information in the event they moved; 2) the two year follow-up rate; and 3) in a separate study of verified cases, we assessed the percent of cases or their proxies who could accurately provide information regarding diagnosis and thereby, the vital status of patients in the cancer registry after a period of four years.

Material and Methods

India Health Study

The main IHS was conducted in three regions of India: New Delhi in the north (All India Institute of Medical Sciences), Mumbai in the west (Healis-Sekhsaria Institute for Public

Health), and Trivandrum in the south [Regional Cancer Center (RCC)] during 2007–2008. Centers were selected in areas with established cancer registries. Eligible participants were aged 35 to 69 years, resided in the study area for a minimum period of 1 year, had no prior history of cancer, and were capable of providing informed consent. Of the 4,671 eligible individuals (Delhi 1,143; Mumbai 826; Trivandrum 2,702), 4,177 enrolled in the study (Delhi 942, Mumbai 804, Trivandrum 2,431). Trained field staff conducted interviews using questionnaires querying information on socio-demographics, medical and residential history, diet, and lifestyle.

Human ethics committees from each study center and the Special Studies Institutional Review Board of the United States National Cancer Institute reviewed and approved the study protocol prior to study commencement. Due to the nature of the international collaboration, the Indian Health Ministry Screening Committee for projects involving foreign assistance and/or collaboration, which is part of the Indian Council of Medical Research reporting to the Government of India, also reviewed and approved the study. We obtained written informed consent from all participants.

Access to medical care

Cohort members who never used the medical care system would not be diagnosed or reported during follow-up regardless of the accuracy of the case ascertainment method. Therefore, we assessed the proportion of IHS participants who would be unlikely to seek standard medical care in the event of illness or symptoms. The IHS medical history questionnaire contained questions on: type of health practice sought for different conditions (injury, chronic illness, or a mild health ailment), and when and why participants last visited a doctor. Complete demographic and medical histories were available for 3,367 participants.

Movement pattern

A successful cohort study requires a stable population; thus, in the residential history questionnaire from the IHS, we queried the number of years participants had lived in their neighborhood, as well as when and why they had moved to their current residence. This information was complete for 4,020 participants.

Cancer registry coverage

Potential concerns for a cohort that relies solely on cancer registries include obtaining accurate and detailed information on diagnosis, comprehensive and unbiased coverage of all incident cases in the registry population, and minimal delay incorporating information into a database. In India, incident cancer case information is collected through an ‘active’ system. Registry personnel visit public hospitals, nursing homes, clinical laboratories, and pathology laboratories within the registry area. Private sector institutions are visited if they allow access. However, many cases treated within the institutions not under active surveillance may still be captured by the cancer registries if they are also treated at one of the major cancer referral centers. Death information is collected from the Vital Statistics Division of the Municipal Death Register [16].

Using the resources available to us within the regions, we assessed the quality of cancer registry coverage in two ways. First, we evaluated whether cases from public institutions participating in the Trivandrum Cancer Registry (TCR) surveillance, as well as cases from private institutions not previously visited by the TCR, were captured by the registry database. Second, we linked known cases from the major cancer referral centers in Trivandrum and New Delhi to the cancer registry databases in each region. The New Delhi cancer registries were unable to participate in the first component, and Mumbai was evaluating the quality of their registry separately.

For the first component, we evaluated cancer registry coverage of cases from both public and private institutions. Of the 60 hospitals/clinics and 5 pathology laboratories in the Trivandrum area, only 37 hospitals/clinics and 3 pathology laboratories are normally actively covered by the TCR personnel [17]. Institutions not actively covered by TCR personnel are either private hospitals who do not participate in the TCR activities or institutions from which no cases were reported to the TCR in the past 15 years. From February 2007 to April 2007, study personnel abstracted information on 300 cancer cases (12% of the TCR) randomly selected from cases diagnosed between 2003–2004 from four public institutions currently participating in the TCR [Medical College in-patient records (n=200) and radiotherapy (n=50); Sree Chitra Thirunal Institute (n=25); General Hospital (n=20); and Chest Disease Hospital (n=5)]. These numbers were determined based on the proportion of total cases reported to the TCR from each institution. We also obtained records for all cancer cases (n=304) diagnosed during the same period at four major private hospitals in Trivandrum [Sree Uthradam Thirunal Hospital (n=158); Kerala Institute of Medical Sciences (n=58); Cosmopolitan Hospital (n=54); G.G. Hospital (n=34)] that previously had not provided access.

For the second component we evaluated whether the cancer registries were capturing all cases seen at the major referral centers in New Delhi and Trivandrum. These cases were also utilized in the self- and proxy-report evaluation described below. In New Delhi, we obtained case records from the Institute of Rotary Cancer Hospital (IRCH), as it contributes the largest number of cases (18.4%) to the New Delhi cancer registry (DCR) [18]. We initially abstracted information on 600 cases diagnosed between 2002 and 2004 with a goal to obtain 400 cancer cases with complete information. However, we found a large proportion of the registered cases in the IRCH had missing information, and thus abstracted an additional 200 cases (total of 800). In Trivandrum, the Regional Cancer Center (RCC) contributes more than 70% of cancer cases to the TCR. We retrieved information for 1,000 cases from the RCC with a goal of obtaining the vital status of 600 complete cases diagnosed between 2003 and 2005. We then attempted to link these 800 cases from the IRCH to the DCR and the 1000 cases from the RCC to the TCR.

Self- and proxy-report in New Delhi and Trivandrum

To determine whether a future cohort could supplement end-point data with self-reports, we evaluated whether the cases or their proxies could accurately recall the details of their cancer diagnosis. We could not get a complete list of patients' names from the cancer registries, as by law the registries are not permitted to reveal patient identity for other purposes.

Therefore, we restricted our study to the cases from the major cancer referral centers (IRCH in New Delhi and RCC in Trivandrum) that retained written informed consent to re-contact patients. We contacted cancer patients or their families from the IRCH (January–October 2007) and the RCC (October 2007–March 2008) by letter, telephone, and/or home visit. In-person interviews were conducted at the patient's/proxy's home or during scheduled clinic appointments. We collected information on demographics, medical history based on verbal autopsy methodology [13–14], doctor visits, types and duration of treatment, and whether the patients kept copies of their medical reports. Given the potential for differential recall by cancer site, we targeted cancers of the colorectum (15%), esophagus/ pharynx (5%), liver/ biliary tract (5%), lung (13%), non-Hodgkins lymphoma (NHL) / Hodgkins disease (HD) / multiple myeloma (MM) (5%), oral cavity (7%), stomach (5%), thyroid (10%), prostate (13%), female breast (13%), cervix (7%), and other female cancers (2%).

Quality indices of the cancer registries within the study centers

Using information from internal registry reports, we evaluated registry quality using the International Agency for Research on Cancer (IARC) indices [19–20]: proportion of cancer

cases with microscopic confirmation; the percent of cases reported by death certificate only (DCO); the fraction with basis of diagnosis as clinical; and the mortality to incidence ratio. When mortality data are known to be complete, the mortality-to-incidence ratio may be used to assess the completeness of cancer cases ascertained by the registry. We compared these indices with those from the Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI) in the United States [21].

Follow-up of the main IHS participants

The main IHS residential history questionnaire asked for additional contact information in the event participants moved to estimate the proportion of cohort members who could be contacted for active follow-up. After the main IHS visits, we conducted a follow-up survey (home visits or telephone interview) with a median follow-up of 24 months in New Delhi and 15 months in Trivandrum. We calculated the projected 2-year follow-up rates for Trivandrum assuming an exponential negative growth rate:

$$\text{Number followed-up} = \text{number at baseline} * \exp(-\text{loss to follow-up rate} * \text{time})$$

As follow-up rates may vary with risk factors and which can bias a cohort study, we also determined the follow-up rates by factors such as gender, religion, income, and residence status. In the follow-up survey, we collected information on self-reported disease status (e.g. cancer, cardiovascular disease, diabetes, hypertension, tuberculosis, and asthma). In this current study, we did not re-contact Mumbai participants to assess follow-up rates as the main Mumbai Cohort Study was already collecting information to estimate rates within this population [22–23].

Results

Access to medical care

Less than 3% of the people had never been to a doctor, and 95% had seen a doctor at least once in the last year in New Delhi (Table 1). In Mumbai, 30% of participants refused to provide information on when they last visited a doctor, as compared to <1% in New Delhi. For the treatment of a chronic illness, 99% of participants in New Delhi and urban Trivandrum would go to a hospital, compared to 82% of participants in rural Trivandrum and 77% in Mumbai. Health practices did not differ significantly between men and women (data not shown).

Movement pattern

In all three regions, 50% of IHS participants had lived in their neighborhood for over 18 years (data not shown), and over 85% had lived in their current residence for more than four years (Table 2). In both urban and rural Trivandrum, over 10% of participants had moved within the last 3 years; participants with higher education were more likely to move. Women were more likely to move after marriage in New Delhi and Mumbai (79% and 64%, respectively) compared to women in Trivandrum (22%).

Cancer registry coverage

Each of the cancer cases (n=300) from the four public institutions in Trivandrum, normally included in the TCR surveillance, were matched to the registry database. However, out of the 304 cases obtained from the private institutions not previously visited by the TCR, we found 106 (35%) unmatched cases. These 106 cases would theoretically account for approximately 5% of the total cancer incidence reported to the TCR during 2003–2004 (106 out of the 2,313 total cases). However, if the cases from the four private hospitals had not

been seen at one of major referral centers covered by the TCR, 13% (304 out of 2,313) could have been missed.

From the major referral institution in New Delhi, none of the 800 IRCH case records we abstracted could be matched to the DCR. The DCR had a substantial backlog and records for patients treated at the IRCH during 2002–2004 were not in the registry at the end of 2007. In Trivandrum, we successfully linked all of the 1,000 RCC case records to the TCR.

Self- and proxy-report in New Delhi and Trivandrum

From the IRCH in New Delhi, we obtained relatively complete diagnosis records for 443 cases (55.4% of the 800 cases records pulled from the IRCH). Of these, only 158 (35.7%) cancer cases or their families were successfully contacted and interviewed (8.6% self-reports; 27.1% proxy reports). Cases or their families could not be contacted for several reasons: 95 (21.4%) incorrect address; 112 (25.3%) moved; 45 (10.2%) refused; 20 (4.5%) not home; and 13 (2.9%) no information was available. All cases contacted correctly identified the anatomical site of their cancer, but only 63% of proxies knew this information.

Of the 1,000 case records from the RCC in Trivandrum, 783 (78.3%) cases or their families were contacted through home visits (n=627) or outpatient RCC clinical visits (n=156). We obtained information from 351 (35.2%) patients and 432 (43.2%) proxies (Table 3). Proxy reports were more common for male (66%) compared to female (34%) cases. All cases, including proxies, correctly reported a cancer diagnosis, but anatomical site was incorrectly reported by 8% of cases and 22% of proxies. Common inaccuracies included: cervix uteri or ovary as uterus; tongue as tonsil; thyroid as throat; pancreas or esophagus as stomach; and multiple myeloma as bone. Almost all patients (99%) and 81% of the relatives of deceased cases kept medical records (laboratory or physician reports) at home and permitted study staff to review them to confirm diagnosis. If records were not kept at home, the majority of cases knew where they were located and gave the study staff permission to retrieve them.

Quality indices of the cancer registries within the study centers

Based on information from the cancer registries, we found that microscopic verification of cases in the Indian cancer registries was lower than the SEER standard, and 12.7% of males and 15.2% of female cancer cases in the DCR were diagnosed by clinical examination only (Table 4). The proportions reported by DCO were higher in Trivandrum and Mumbai than SEER. The mortality-to-incidence ratio ranged from less than 10% in New Delhi to over 50% in Mumbai. We also found that the time-delay for registry data was more than 3 years in New Delhi, 3 years in Mumbai, and less than 2 years in Trivandrum (Table 3) [17–18].

Follow-up of the main IHS participants

The majority of IHS participants in Trivandrum, (urban 94%, rural 96%) provided contact information in the event of a move, contrasting with approximately half from New Delhi (51%) and Mumbai (54%). After a median follow-up time of 24-months, we obtained the status of 422 (52.8%) New Delhi participants via telephone (Figure 1). During the observed follow-up, one participant had a heart attack, 13 participants were diagnosed with diabetes, and 25 participants were diagnosed with hypertension (Figure 1). After a median follow-up time of 15-months, we successfully contacted 2,285 (94.0%) of participants in Trivandrum (88.8% home visits, 11.2% telephone). The estimated 2-year follow up rate was 91%. The difference between the follow-up rates across various demographic factors, such as gender, religion, income, and residence status, was less than 10%. Outcomes during follow-up are given in Figure 2.

Discussion

We evaluated the accuracy and completeness of follow-up and cancer case ascertainment needed for a prospective cohort study in India. We found that among the IHS population, there would be minimal loss of cancer cases due to lack of access to health care or relocation; however, not all cancer diagnosis and treatment centers report to cancer registries. We found that we could use information provided by cancer cases or proxies in Trivandrum, but only with medical record verification. The projected 2-year (calculated from 15-months follow-up) rates in Trivandrum were substantially better than the 2-year rates we observed in New Delhi. Additional information for future contact was provided by 95% of Trivandrum participants, as compared to only half from the other centers.

Most IHS participants lived in or near major urban areas where medical care, including modern diagnostics centers, is widely available. Among the IHS population, we observed that cases were unlikely to be missed due to lack of access to conventional medical care. Data from the National Family Health Survey also supports this, as less than one percent of people in our study regions did not report conventional medical services [24].

Inclusion of incident cancers in registry data should be close to 100% [19–20], but this was not achieved by any of the registries we evaluated. The TCR estimates their coverage at approximately 85% (75% main cancer referral centers, 10% DCO) [25] with overall age-adjusted incidence rates of 102 per 10⁵ men and 91 per 10⁵ women in the urban areas; and 188 per 10⁵ men and 159 per 10⁵ women in the rural areas for 2007 (personal communications). Considerably lower rates in the urban areas are counter-intuitive and may indicate underreporting of cancer cases in these areas. Prior research based on a survey of over 50,000 individuals from a defined region of Mumbai (1991–1995) revealed that the coverage of cancer cases in the Mumbai registry was 78% [26]. Such a study was beyond the scope of the IHS, but this issue needs to be evaluated in each of the registry catchment areas.

Furthermore, cancer registries in India without consistent coverage may result in differential cancer incidence reporting that needs further evaluation. In Trivandrum, we found that the TCR had complete information on cancer diagnosis from public institutions that registry personnel had previously visited. However, one-third of the cases from four private hospitals were not found in the TCR. Cases from private hospitals may have higher income and differ with regard to other factors, such as diet and occupational exposures. Thus, the exclusion of such private hospitals may introduce a systematic bias by socioeconomic status and other important risk factors. This issue is likely to be present in other Indian registries as well. The Indian National Family Health survey found that over 70% of residents of New Delhi and Mumbai, and 50% of the residents of Kerala (Trivandrum is the capital) sought care in the private medical sector [24].

Quality indicators (i.e., microscopic verification, DCO, etc) are normally used by cancer registries in India to evaluate reliability and completeness [27]. Compared to the standards of the SEER registry in the U.S., all three of the Indian registries were of lower quality. In New Delhi, a substantial percentage of the cases were diagnosed clinically, possibly because the patients came to seek medical attention with late-stage disease. The mortality-to-incidence ratio ranged from less than 10% in New Delhi to over 50% in Mumbai. Although a lower number generally indicates better quality, stringent requirements for the death registry as compared to the incidence registry in Mumbai may elevate their ratio. The large range observed may indicate true regional differences in cancer incidence and survival patterns or reflect inaccuracies in the incidence and/or mortality measures.

Given the limitations of the existing cancer registries, we evaluated whether case or proxy interviews would be useful for ascertaining diagnoses and found substantial differences between New Delhi and Trivandrum. Four years after treatment at the RCC in Trivandrum, we successfully contacted nearly 80% of the cancer patients or proxies, whereas in New Delhi we contacted only one-third from the IRCH. Deficiencies in these rates may reflect patients' or families' experiences with treatment or incorrect contact information collected at the time of registration. It is also likely that our inability to reach New Delhi cases may also be due, at least in part, to the large numbers of patients treated at the IRCH who come from outside the catchment area. According to IARC's Cancer Incidence in Five Continents [19], 40% of patients treated in the DCR catchment area are non-residents. In Trivandrum, although we were successful in making contact with patients and families, only 45% of the cancer cases provided the information themselves. Many cancer patients in India seek treatment with advanced disease and five-year survival rates are surprisingly low, particularly for prostate cancer in men, and breast and cervical cancers in women [33–36]. Of the patients and proxies in Trivandrum who provided cancer diagnosis information, about 8% of cases and 27% of proxies incorrectly reported the primary cancer site, indicating that medical record verification is necessary.

High follow-up rates and the ability to recontact participants over time are another essential to element to a successful cohort. Although we limited IHS recruitment to people likely to remain in the study areas (35 years or older, lived in area for over 1 year), the projected 2-year follow-up rate was 91% for Trivandrum, but only 53% for New Delhi. The Mumbai Cohort Study, which was established to investigate the role of tobacco use with all cause and cause-specific mortality [28–29], found that after 5.5 years of follow-up, 17% of the baseline population had migrated out of the immediate study area and 9% had died. Based on the information we collected in Trivandrum and that provided by the Mumbai Cohort Study, follow-up rates were close to those of other ongoing cohorts [30–32]. We also observed dramatic regional differences in the willingness of IHS participants to provide contact information in the event of a move (over 95% in Trivandrum compared to less than 50% at other centers). The cooperative nature of the Trivandrum participants may be due to the size, as well as the social and political structure of their communities. The state of Kerala has a strong healthcare system and the highest literacy rates in India. Utilizing interviewers connected with the RCC, the area's major cancer center, may have engendered more trust in these participants. Additional protocols and procedures would need to be established if a cohort study were to be conducted in New Delhi.

Although we have identified weaknesses with respect to follow-up of participants, as well as completeness and accuracy of cancer case ascertainment, a prospective study of cancer risk may still be possible in India. In the last few years the use of mobile phones has become common among people of all socioeconomic backgrounds and may be a tool for efficient follow-up. It may also be possible to expand cancer screening programs within India [37–38] to a full cohort of participants and their family members. A successful approach to developing a cohort in Bangladesh has been to set up health clinics in high arsenic areas to facilitate biennial contact with study subjects [39–40]. Improved data collection is ongoing as many hospitals are changing to electronic records that can be transmitted to the registries in an efficient and timely manner. The incomplete reporting from private hospitals to the TCR has already benefitted through contact with our study staff as these hospitals have consented to participate in the registry program. The difficulty in linking the participant's information with the registry may also improve in the near future once the voter identification program is fully implemented.

Over the course of this study to assess the feasibility of a prospective cancer cohort within India, we have begun to address numerous questions regarding the follow-up potential, and

the accuracy and completeness of cancer case ascertainment within India. We encountered different levels of impediments relevant to all three of these issues, some of which could be overcome with the successful completion and implementation of planned improvements.

Acknowledgments

We are indebted to the participants in the IHS for their patience and outstanding cooperation even during the busy times of their day. We are sincerely grateful to the patients and their families for providing us with the relevant information on the diagnosis and treatment of this devastating disease.

The authors would like to thank all the cancer registry, field, data-entry, and office staff at the three centers for their dedicated work to make this study possible. Our special thanks go to Mangesh Pednekar and Binukumar for their continued support. We would also like to express our gratitude to Mary McAdams of Information Management Systems, Inc., and Kerry Grace Morrissey, Judy Walsh, and Viji Narayana of Westat for data management.

Abbreviations

DCO	death certificate only
IARC	International Agency for Research on Cancer
IHS	India Health Study
IRCH	Institute of Rotary Cancer Hospital
RCC	Regional Cancer Center
SEER	Surveillance, Epidemiology, and End Results
TCR	Trivandrum Cancer Registry
DCR	Delhi Cancer Registry

References

- Shetty PS. Nutrition transition in India. *Public Health Nutr.* 2002 Feb; 5(1A):175–182. [PubMed: 12027282]
- Rastogi T, Devesa S, Mangtani P, Mathew A, Cooper N, Kao R, et al. Cancer incidence rates among South Asians in four geographic regions: India, Singapore, UK and US. *Int J Epidemiol.* 2008 Feb; 37(1):147–160. [PubMed: 18094016]
- Sinha R, Anderson DE, McDonald SS, Greenwald P. Cancer risk and diet in India. *J Postgrad Med.* 2003 Jul-Sep;49(3):222–228. [PubMed: 14597785]
- Wiseman M. The second World Cancer Research Fund/American Institute for Cancer Research expert report. Food, nutrition, physical activity, and the prevention of cancer: A global perspective. *Proc Nutr Soc.* 2008 Aug; 67(3):253–256. [PubMed: 18452640]
- Ramachandran A, Mary S, Yamuna A, Murugesan N, Snehalatha C. High prevalence of diabetes and cardiovascular risk factors associated with urbanization in India. *Diabetes Care.* 2008 May; 31(5):893–898. [PubMed: 18310309]
- Patel JV, Vyas A, Cruickshank JK, Prabhakaran D, Hughes E, Reddy KS, et al. Impact of migration on coronary heart disease risk factors: Comparison of Gujaratis in Britain and their contemporaries in villages of origin in India. *Atherosclerosis.* 2006 Apr; 185(2):297–306. [PubMed: 16005463]
- Singh RB, Rastogi SS, Niaz MA, Postiglione A. Association of central obesity and insulin resistance with high prevalence of diabetes and cardiovascular disease in an elderly population with low fat intake and lower than normal prevalence of obesity: the Indian paradox. *Coronary Artery Dis.* 1998; 9(9):559–565.
- Singh RB, Niaz MA, Thakur AS, Janus ED, Moshiri M. Social class and coronary artery disease in a urban population of North India in the Indian lifestyle and heart study. *Int J Cardiol.* 1998 Apr 1; 64(2):195–203. [PubMed: 9688439]

9. Singh RB, Ghosh S, Niaz AM, Gupta S, Bishnoi I, Sharma JP, et al. Epidemiologic-Study of Diet and Coronary Risk-Factors in Relation to Central Obesity and Insulin Levels in Rural and Urban Populations of North-India. *Int J Cardiol.* 1995 Jan 6; 47(3):245–255. [PubMed: 7721501]
10. Heald AH, Sharma R, Anderson SG, Vyas A, Siddals K, Patel J, et al. Dietary intake and the insulin-like growth factor system: effects of migration in two related populations in India and Britain with markedly different dietary intake. *Public Health Nutr.* 2005 Sep; 8(6):620–627. [PubMed: 16236191]
11. Rastogi T, Reddy KS, Vaz M, Spiegelman D, Prabhakaran D, Willett WC, et al. Diet and risk of ischemic heart disease in India. *Am J Clin Nutr.* 2004 Apr; 79(4):582–592. [PubMed: 15051601]
12. Chambers JC, Eda S, Bassett P, Karim Y, Thompson SG, Gallimore JR, et al. C-reactive protein, insulin resistance, central obesity, and coronary heart disease risk in Indian Asians from the United Kingdom compared with European whites. *Circulation.* 2001 Jul 10; 104(2):145–150. [PubMed: 11447077]
13. Gajalakshmi V, Peto R. Commentary: Verbal autopsy procedure for adult deaths. *Int J Epidemiol.* 2006 Jun; 35(3):748–750. [PubMed: 16751580]
14. Jha P, Gajalakshmi V, Gupta PC, Kumar R, Mony P, Dhingra N, et al. Prospective study of one million deaths in India: Rationale, design, and validation results. *PLoS Med.* 2006 Feb; 3(2):191–200.
15. Rastogi T, Hildesheim A, Sinha R. Opportunities for cancer epidemiology in developing countries. *Nat Rev Cancer.* 2004 Nov; 4(11):909–917. [PubMed: 15516963]
16. Kumar, A.; Raut, DK.; Gupta, P.; Singh, SU. Mortality statistics in India 2006. New Delhi: Government of India, Central Bureau of Health Intelligence, Ministry of Health and Welfare; 2007 Mar.
17. Trivandrum Cancer Registry Report: 2005–2006.
18. National Cancer Registry Program. Consolidated Report of Population Based Cancer Registries 2001–2004. Bangalore: ICMR; 2006.
19. Curado, M.; Edwards, B.; Shin, H.; Storm, H.; Ferlay, J.; Heanue, M., et al., editors. Cancer Incidence in Five Continents. Vol. No. 9.. Lyon: IARC Scientific Publications; 2007.
20. Curado MP, Voti L, Sortino-Rachou AM. Cancer registration data and quality indicators in low and middle income countries: their interpretation and potential use for the improvement of cancer care. *Cancer Causes and Control.* 2009 Jul; 20(5):751–756. [PubMed: 19112603]
21. Ries, L.; Eisner, M.; Kosary, C.; Hankey, B.; Miller, B.; Clegg, L., et al. SEER Cancer Statistics Review, 1975–2000. Bethesda, MD: National Cancer Institute; 2003.
22. Pednekar MS, Gupta PC, Hebert JR, Hakama M. Joint effects of tobacco use and body mass on all-cause mortality in Mumbai, India: results from a population-based cohort study. *Am J Epidemiol.* 2008 Feb 1; 167(3):330–340. [PubMed: 17989059]
23. Pednekar MS, Hakama M, Hebert JR, Gupta PC. Association of body mass index with all-cause and cause-specific mortality: findings from a prospective cohort study in Mumbai (Bombay), India. *Int J Epidemiol.* 2008 Jun; 37(3):524–535. [PubMed: 18276634]
24. International IIfPSIam. National Family History Survey (NFHS-3), India, 2005-06. Mumbai: IIPS; 2009.
25. 2005–2006. TCR. 2007. 2007
26. National Cancer Registry Program. Report of population based cancer survey at Bangalore C, Mumbai. Indian Council of Medical Research; 2000.
27. Yeole BB. An Assessment of Improvement in Reliability and Completeness of Mumbai Cancer Registry Data from 1964–1997. *Asian Pac J Cancer Prev.* 2001; 2(3):225–232. [PubMed: 12718635]
28. Pednekar MS, Hebert JR, Gupta PC. Tobacco use, body mass and cancer mortality in Mumbai Cohort Study. *Cancer Epidemiol.* 2009 Dec; 33(6):424–430. [PubMed: 19854693]
29. Pednekar MS, Gupta R, Gupta PC. Association of blood pressure and cardiovascular mortality in India: Mumbai cohort study. *Am J Hypertens.* 2009 Oct; 22(10):1076–1084. [PubMed: 19629050]
30. Bergmann MM, Bussas U, Boeing H. Follow-up procedures in EPIC-Germany - Data quality aspects. *Annals of Nutrition and Metabolism.* 1999 Jul-Aug; 43(4):225–234. [PubMed: 10592371]

31. Smith-Warner SA, Spiegelman D, Ritz J, Albanes D, Beeson WL, Bernstein L, et al. Methods for pooling results of epidemiologic studies: the Pooling Project of Prospective Studies of Diet and Cancer. *Am J Epidemiol*. 2006 Jun 1; 163(11):1053–1064. [PubMed: 16624970]
32. Boeing H, Korfmann A, Bergmann MM. Recruitment procedures of EPIC-Germany. *Annals of Nutrition and Metabolism*. 1999 Jul-Aug;43(4):205–215. [PubMed: 10592369]
33. Hebert JR, Ghumare SS, Gupta PC. Stage at diagnosis and relative differences in breast and prostate cancer incidence in India: comparison with the United States. *Asian Pac J Cancer Prev*. 2006 Oct-Dec;7(4):547–555. [PubMed: 17250425]
34. Ali R, Mathew A, Rajan B. Effects of Socio-economic and Demographic Factors in Delayed Reporting and Late-stage Presentation among Patients with Breast Cancer in a Major Cancer Hospital in South India. *Asia Pac J Can Prev*. 2008; 9(4):703–707.
35. Kaku M, Mathew A, Rajan B. Impact of Socio-economic Factors in Delayed Reporting and Late-stage Presentation among Patients with Cervix Cancer in a Major Cancer Hospital in South India. *Asia Pac J Can Prev*. 2008; 9(4):589–594.
36. Yeole BB, Ramanakumar AV, Sankaranarayanan R. Survival from oral cancer in Mumbai (Bombay), India. *Cancer Causes Control*. 2003 Dec; 14(10):945–952. [PubMed: 14750533]
37. Sankaranarayanan R, Nene BM, Shastri SS, Jayant K, Muwonge R, Budukh AM, et al. HPV Screening for Cervical Cancer in Rural India. *New England Journal of Medicine*. 2009; 360(14): 1385–1394. [PubMed: 19339719]
38. Sankaranarayanan R, Chatterji R, Shastri SS, Wesley RS, Basu P, Mahe C, et al. Accuracy of human papillomavirus testing in primary screening of cervical neoplasia: results from a multicenter study in India. *Int J Cancer*. 2004 Nov 1; 112(2):341–347. [PubMed: 15352050]
39. Parvez F, Chen Y, Brandt-Rauf PW, Slavkovich V, Islam T, Ahmed A, et al. A prospective study of respiratory symptoms associated with chronic arsenic exposure in Bangladesh: findings from the Health Effects of Arsenic Longitudinal Study (HEALS). *Thorax*. 2010 Jun; 65(6):528–533. [PubMed: 20522851]
40. Ahsan H, Chen Y, Parvez F, Argos M, Hussain AI, Momotaj H, et al. Health Effects of Arsenic Longitudinal Study (HEALS): description of a multidisciplinary epidemiologic investigation. *J Expo Sci Environ Epidemiol*. 2006 Mar; 16(2):191–205. [PubMed: 16160703]

Figure 1.
Follow-up of the India Health Study in New Delhi

Figure 2.
Follow-up of the India Health Study in Trivandrum

Table 1

Health practices of the India Health Study participants in New Delhi, Mumbai, and Trivandrum

Health practices	New Delhi	Mumbai	Trivandrum	
			Rural	Urban
	(n=801)	(n=795)	(n=778)	(n=984)
Last time visited doctor (%)				
Never	<0.5	1	<0.5	3
1 to 7 years	5	5	15	29
Within last 12 months	95	64	84	64
Other/refused	<0.5	30	1	4
Reason for last doctors' visit (%)				
Check-up	35	29	76	58
Injury/Acute illness	56	44	5	5
Chronic illness/allergies	9	20	17	32
Other/refused	<0.5	7	1	5
Treatment for injury (%)*				
Self/pharmacy/homeopathic/ayurvedic	<0.5	1	9	0
Doctor/clinic	52	26	21	2
Any hospital	95	78	80	99
Treatment for mild illness (%)*				
Self/pharmacy/homeopathic/ayurvedic	1	2	10	7
Doctor/clinic	58	77	18	2
Any hospital	97	25	85	92
Treatment for chronic illness (%)*				
Self/pharmacy/homeopathic/ayurvedic	<0.5	2	8	<0.5
Doctor/clinic	45	27	19	1
Any hospital	99	77	82	99

* Participants could select multiple responses

Table 2
Residential history of the India Health Study participants from New Delhi, Mumbai, and Trivandrum

Residential history	New Delhi		Mumbai		Rural		Urban	
	Female (n=472)	Male (n=412)	Female (n=408)	Male (n=362)	Female (n=589)	Male (n=597)	Female (n=588)	Male (n=592)
Years lived at current residence(%)								
<3 years	3.6	2.7	2.4	1.9	11.7	12.3	13.6	12.5
4–6 years	2.3	4.3	6.7	0.9	4.9	6.9	7.8	7.4
6+ years	94.1	93	90.9	97.2	83.4	80.8	78.6	80.1
Years lived at current residence[median,(10%,90%)]								
University graduate	20 (10, 35)	40 (10, 60)	23 (10, 37)	40 (22, 56)	12 (2, 32)	12 (1, 43)	13 (3, 31)	18 (3, 41)
Secondary school	19 (8, 36)	40 (10, 60)	26 (11, 45)	45 (21, 63)	18 (2, 40)	20 (3, 45)	17 (2, 38)	16 (2, 41)
Middle school or under	25 (10, 44)	35 (4, 60)	31 (14, 50)	42 (17, 61)	25 (4, 50)	22 (2, 54)	20 (2, 42)	20 (4, 54)
Primary reason for moving(%)								
Job	3.2	24	2.1	12.2	4.2	6.9	9.3	7.3
Family	17.4	71.8	15.4	34.4	36.8	44.6	45	54
Health	0.2	0	0	0.3	0.5	0.3	1	0.7
Marriage	78.8	1	64	1.4	23.9	14.8	20.2	16.2
Other	0.4	3.2	18.4	50.8	34.5	33.5	24.4	22.1

Table 3

Self- and proxy-report of cancer diagnosis in Trivandrum from case-report study

Site	Male		Site	Female	
	Direct Number (%)	Proxy Number (%)		Direct Number (%)	Proxy Number (%)
Prostate	21 (31.8)	45 (68.2)	Breast	63 (68.5)	29 (31.5)
Pharynx	8 (33.4)	16 (66.6)	Cervix uteri	30 (57.7)	22 (42.3)
Colo-rectal	24 (46.2)	28 (53.8)	Colo-rectal	29 (54.7)	24 (45.3)
Thyroid	32 (84.2)	6 (15.8)	Thyroid	44 (95.6)	2 (4.4)
Esophagus	3 (25)	9 (75)	Esophagus	4 (40)	6 (60)
Oral cavity	17 (41.5)	24 (58.5)	Oral cavity	13 (86.7)	2 (13.3)
Lung	6 (10.9)	49 (89.1)	Lung	5 (14.3)	30 (85.7)
NHL / HD / MM	15 (48.4)	16 (51.6)	NHL / HD / MM	7 (31.8)	15 (68.2)
Stomach	0	8 (100)	Stomach	0	11 (100)
Liver / biliary	2 (11.8)	15 (88.2)	Liver/ biliary	1 (8.3)	11 (91.7)
Others	10 (15.2)	56 (84.8)	Others	18 (69.2)	8 (30.8)
Total	138 (33.7)	272 (66.3)	Total	213 (66.3)	160 (33.7)

NHL: non-Hodgkin's lymphoma, HD: Hodgkin's disease, MM: multiple myeloma

Summary of coverage and quality of registries in New Delhi, Mumbai, and Trivandrum from measured and published information.

Table 4

Information from cancer registries	New Delhi	Mumbai	Trivandrum		USA SEER
			Rural	Urban	
Completeness of coverage	Not assessed	78%	85% *	80% *	97–98%
Quality indicators of registry (%) [#]					
Microscopic verification (M / F)	83.2 / 81.5	84.4 / 85.8	83.8 / 87.8	87.3 / 91.6	94.6/94.5
DCO (M/F)	1.4 / 1.1	6.8 / 6.2	8.8 / 7.0	4.5 / 4.5	1.0 / 1.0
Clinical (M/F)	12.7 / 15.2	7.4 / 7.2	2.1 / 2.4	2.5/2.3	0.7/0.7
Mortality to incidence ratio (M/F)	12.6 / 9.3	51.1 / 44.3	47.2 / 41.6	37.5 / 25.4	41.6 / 40.7
Time between diagnosis and inclusion in registry	>3 years at time of study	3 [#]	2	2	<2

* From the Trivandrum Cancer Registry report
** DCO, Death certificate only
[#] ICMR Consolidated Report of population-based registries 2001–2004