RESEARCH ARTICLE

Evaluation of Delhi Population Based Cancer Registry and Trends of Tobacco Related Cancers

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Abstract

Background: Tobacco use is the single most important preventable risk factor for cancer. Surveillance of tobacco-related cancers (TRC) is critical for monitoring trends and evaluating tobacco control programmes. We analysed the trends of TRC and evaluated the population-based cancer registry (PBCR) in Delhi for simplicity, comparability, validity, timeliness and representativeness. Materials and Methods: We interviewed key informants, observed registry processes and analysed the PBCR dataset for the period 1988-2009 using the 2009 TRC definition of the International Agency for Research on Cancer. We calculated the percentages of morphologically verified cancers, death certificate-only (DCO) cases, missing values of key variables and the time between cancer diagnosis and registration or publication for the year 2009. Results: The number of new cancer cases increased from 5,854 to 15,244 (160%) during 1988-2009. TRC constituted 58% of all cancers among men and 47% among women in 2009. The age-adjusted incidence rates of TRC per 100,000 population increased from 64.2 to 97.3 among men, and from 66.2 to 69.2 among women during 1988-2009. Data on all cancer cases presenting at all major government and private health facilities are actively collected by the PBCR staff using standard paper-based forms. Data abstraction and coding is conducted manually following ICD-10 classifications. Eighty per cent of cases were morphologically verified and 1% were identified by death certificate only. Less than 1% of key variables had missing values. The median time to registration and publishing was 13 and 32 months, respectively. Conclusions: The burden of TRC in Delhi is high and increasing. The Delhi PBCR is well organized and generates high-quality, representative data. However, data could be published earlier if paper-based data are replaced by electronic data abstraction.

Keywords: Surveillance - tobacco-related cancers - evaluation - Delhi

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Introduction

Tobacco use kills an estimated 6 million people each year (WHO report, 2013) and is the leading preventable cause of disease and premature deaths globally. The Global Adult Tobacco Survey, India in 2009 showed that nearly 35% of adults use tobacco (GATS India, 2009-10). Tobacco-related diseases account for an estimated 0.8-0.9 million deaths each year in India, including a large number of deaths due to cancer (Reddy et al., 2004). In India, tobacco-related cancers (TRC) represent 42% and 18% of cancer deaths among men and women, respectively (Dikshit et al., 2012). To monitor trends in incidence over time, it is critical to conduct surveillance for TRC. Surveillance is also necessary for assessing the effectiveness of tobacco control programmes and policies, allocating resources and identifying research priorities.

In India, monitoring of new cancer cases, including monitoring for TRC, is conducted since 1981 by the National Cancer Registry Programme (NCRP) through 7 hospital-based cancer registries (HBCRs) and 28 population-based cancer registries (PBCRs). The PBCR collects a complete summary of the patient's history, diagnosis, treatment, and status for every cancer patient in the defined geographical area such as district, state or country and on the other hand the HBCR records all cases in a given hospital. The objectives of NCRP is to develop a national research data-base on cancer with a national collaborative network, so as to undertake etiological, epidemiological, clinical studies and help the National Cancer Control Program of our country in planning, monitoring and evaluation of cancer control activities. The NCRP periodically publishes PBCR and HBCR cancer statistics and it is also available on the website. The PBCR report 2009-2011 of NCRP for 25 PBCR's for proportion of tobacco-related cancers (as per International Agency for Research on Cancer (IARC) 1987 definition) shows that East Khasi Hills District of Meghalaya had

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the highest relative proportion of cancers associated with the use of tobacco for males and females at 69.3% and 43.0% respectively when compared to all sites of cancers. The lowest proportion of tobacco related cancers was among females in Thiruvananthapuram with 10.3% of cancers being associated with the use of tobacco. In male's mouth cancer, oesophagus cancer and lung cancer were the leading site among the tobacco related cancers and in female's mouth cancer, oesophageal cancer and lung cancer were the leading sites.

The PBCR in the capital city Delhi was established by the Indian Council of Medical Research (ICMR) in January 1986, at the All India Institute of Medical Sciences (AIIMS), with the objective of generating reliable data on the magnitude, trends and patterns of cancers in Delhi. It collects data on more than 50 cancers, including 10 TRCs. Until 2005, it was partially funded by the NCRP; however, since 2006, it is funded entirely by AIIMS. The Delhi PBCR covers only the urban area of Delhi consisting of 1113.65 km^2 with a population of 16.3 million.

The utility of data from a PBCR depends largely on the completeness and accuracy of the information collected. Periodic comprehensive evaluation of a PBCR helps to ascertain the validity of data and is considered vital for quality control. Therefore, we evaluated the Delhi PBCR with the specific objectives of describing its structure and functioning, and assessing selected attributes such as simplicity, flexibility, comparability, validity, timeliness and representativeness. We also studied trends in the incidence of TRC in Delhi using the latest available TRC definition of IARC.

Materials and Methods

We used internationally established quantitative and semi-quantitative methods for describing and evaluating the surveillance system, as recommended by the Centers for Disease Control and Prevention (CDC), USA, and Parkin and Bray (Bray et al., 2009; Parkin et al., 2009).

The Delhi PBCR has a total of 14 staff, including scientists, medical social service officers, a data entry operator and a clerk. To understand the functioning of the registry, we interviewed key informants, including officials from the Delhi PBCR, source hospitals and laboratories. We also reviewed key documents, including published annual reports, guidelines, operation manuals, forms, published data, and publications of the ICMR. To observe and assess selected attributes of the Delhi PBCR, such as simplicity, acceptability and flexibility, we visited five large hospitals where cancer data abstraction was ongoing at the time of the study - Safdarjung Hospital, Lady Hardinge Medical College & Hospital, Dharamshila Hospital, Lok Nayak Jai Prakash Narayan Hospital and Ram Manohar Lohia Hospital.

We defined TRC as any case of cancer registered between 1 January 1988 and 31 December 2009 in a resident of the Union Territory of Delhi in any of the following sites: oral cavity, oropharynx, nasopharynx, hypopharynx, oesophagus, stomach, colorectum, liver, pancreas, nasal cavity and nasal sinuses, larynx, lung, uterine cervix, ovary, urinary bladder, kidney, ureter, bone marrow (myeloid leukaemia), in accordance with the recommendations provided by the IARC in 2009 (Cogliano et al., 2011). We used the cleaned dataset of the Delhi PBCR for TRC. The population for urban Delhi for the years 1988 to 2009 was estimated by the exponential method using the 1981, 1991 and 2001 Census figures (Census India, 2011). We calculated the crude incidence rates, age-specific rates and age-adjusted rates per 100 000 population, and analysed trends by age, gender, and type of cancer among TRC cases from 1998 to 2009 in Delhi. We calculated 95% confidence intervals (CIs) using the EpiInfo version 7 software.

We assessed the simplicity of the system by the organogram of the Delhi PBCR, forms for data collection, process of data abstraction from source hospitals and ease of flow of data. We assessed flexibility by the capacity of the registry to adapt to changing systems with minimal additional time, personnel and funding. We assessed comparability by the extent to which coding and classification procedures at the registry adhered to agreed international guidelines.

We examined the quality of data by (i) calculating the percentage of cases that were morphologically verified (MV) by histopathology and death certificate only (DCO) for a 3-year period (2007-2009), (ii) the proportion of missing values for selected variables-age, sex, religion, date of diagnosis and method of diagnosis-for two time periods: 1988-1989 and 2008-2009, and (iii) assessing the internal consistency check methods applied to the data (Parkin et al., 1994).

For assessing timeliness, we used two indicators (i)"time until registration" defined as the median interval in months from the month of diagnosis to the month of registration in the PBCR and (ii)"process time" defined as the median interval in months from the month of registration in the PBCR Delhi to the month when the annual report was published. If the month was missing in the date, we used July as the month of registration/ publication. We calculated the timeliness of the registry based on data abstracted from the first 100 and the last 100 records of 2009, arranged alphabetically.

We assessed completeness by semi-quantitative approaches such as historical trends, stability of incidence rates over time (1988-2009), comparison of incidence rates in different populations (comparison with data in other PBCRs-Chennai and Mumbai), and shape of the curve for age-specific rates (tobacco-related sites combined 1988-2009).

We assessed representativeness based on knowledge of the characteristics of the population (e.g. age, gender, geographical location), by the type of facilities participating (e.g. public, private) and the geographical location of facilities.

We analysed the trends of TRC for the years 1988 to 2009 using the SPSS software version 16 and Microsoft Excel. Chi-square test for linear trends and bivariate analysis were done using the EpiInfo software version 7.

Ethics approval

We undertook this study using data that had already been collected by the Delhi PBCR. We did not collect

any additional information as part of this evaluation. We obtained institutional approval for conducting this evaluation.

Results

Description of the surveillance system

Cancer cases occurring in the population are captured by more than 180 government and 250 private health facilities. Approximately 82% of the cancer cases are reported from 10 hospitals and 96% from 20 hospitals. Staff of the Delhi PBCR visit these health facilities periodically and, using standard forms, they abstract data on new cancer cases among Delhi residents from the medical and pathology records. Selected patients are interviewed at the radiotherapy departments or surgical outpatient departments (OPDs) of major hospitals. To abstract data on cancer deaths, the staff also visits the New Delhi Municipal Committee and Municipal Corporation of Delhi. Soft copies of the reports are collected every year. Cases that do not match with the records are registered as DCOs. Data processing includes removal of duplicate entries by eyeballing, matching records from multiple sources, and coding as per the standard ICD-10 codes. Hard copies of the coded data files are then sent to the Bengaluru NCRP office where data are entered in the PBCR data management software. The registry data undergo further quality checks, which are built into the software, including "un-duplication" of cancer cases using the national database. The list of cases with possible errors/duplications is then sent back to the Delhi PBCR for verification with the original records and the corrections received are updated in the registry database. The cleaned dataset is then used for basic data analyses, including crude rates, age-specific rates and age-standardized rates of incidence data by the NCRP. The Delhi PBCR undertakes further analyses and prepares regular reports, which are then posted on national websites. Data are also shared with international partners, chiefly IARC, and made available on the global cancer website or GLOBOCAN (Figure 1).

Trends

A total of 210 108 incident cases of cancer (107 585 men, 102 523 women) were registered in the Delhi PBCR during 1988-2009. The number of new cases increased from 5854 in 1988 to 15 244 in 2009 over two decades, a 160% increase. (Chi-square for linear trend in men was 551.736 [P<0.00001] and in women it was 168.201 [P<0.00001].) Of the total number of cancer cases, 104 544 TRC were registered during 1988-2009 in Delhi. TRC constituted 58% and 47% of cases among men and women, respectively, in 2009. The age-adjusted incidence rates for all TRC for the years 1988-2009 was 1643 and 1375 per 100 000 population in men and women, respectively. The site-wise age-adjusted incidence rates and age group-wise age-specific incidence rates of TRC in men and women for 1988-2009 in Delhi are shown in Tables 1 and 2.

The incidence of TRC increased steadily among men, from 64.2 to 97.3 per 100 000 during 1988-2009; among women, it changed little, from 66.2 to 69.2 per 100 000 population (Figure 2). Among men, the lung is the leading site of cancer, with an age-adjusted incidence of 11.2 in 1988, which increased to 17.2 per 100 000 population in 2009. During 1988-2009, the rates of cancer of the tongue increased from 5.1 to 10.9, larynx from 8 to 9.8, urinary bladder from 5.7 to 9.2 and mouth from 3.1 to

Table 1. Age-adjusted Incidence Rates of Tobacco-related Cancers Per 100 000 Population by Site, 1988-2009, Delhi

Site	Total			Men			Women		
	No.	Rate	95% CI	No.	Rate	95% CI	No.	Rate	95% CI
Total	104544	1518.7	(1509.5-15278.9)	59658	1642.7	(1629.5-1655.8)	44886	1374.7	(1362-1387.4)
Lip	494	7.1	(6.5-7.7)	380	9.9	(8.9-10.9)	114	3.8	(3.1-4.5)
Tongue	7387	109.5	(107.0-112.0)	5867	157.8	(153.8-161.8)	1520	50.2	(47.7-52.8)
Mouth	5914	85.4	(83.2-87.6)	4327	111.7	(108.4-115.0)	1587	52.8	(50.2-55.4)
Salivary gland	1152	14.8	(14.0-15.7)	707	17.1	(15.8-18.4)	445	12	(10.9-13.1)
Tonsil	2097	31.2	(29.9-32.6)	1779	47.7	(45.5-50.0)	318	10.8	(9.6-11.9)
Oropharynx	931	14.4	(13.5-15.3)	808	22.7	(21.1-24.2)	123	4.3	(3.5-5.0)
Nasopharynx	782	9.8	(9.1-10.5)	565	13	(11.9-14.0)	217	5.8	(5.1-6.6)
Hypopharynx	2398	37.8	(36.3-39.3)	2030	59.3	(56.8-61.9)	368	11.6	(10.4-12.8)
Oesophagus	6991	109.5	(106.9-112.0)	4449	127.6	(123.9-131.4)	2542	87.4	(84.0-90.8)
Stomach	4409	64.9	(63.0-66.8)	2942	80.8	(77.9-83.7)	1467	45.5	(43.2-47.8)
Colon	3850	55.4	(53.7-57.2)	2362	61.9	(59.4-64.4)	1488	47.5	(45.1-49.9)
Rectum	3168	43.5	(42.0-45.1)	1960	50.1	(47.8-52.3)	1208	35.7	(33.7-37.7)
Liver	3139	46.6	(45.0-48.3)	2083	57.3	(54.9-59.8)	1056	33.7	(31.7-35.7)
Pancreas	2613	40.7	(39.1-42.2)	1640	46.7	(44.5-49.0)	973	33.3	(31.2-35.4)
Nasal cavity & nasal sinuses	506	6.5	(5.9-7.0)	309	7.1	(6.3-7.9)	197	5.7	(4.9-6.5)
Larynx	7670	120.2	(117.5-122.9)	6809	195.3	(190.6-199.9)	861	28.5	(26.6-30.4)
Lung	12937	207.8	(204.2-211.4)	10536	311.7	(305.8-317.7)	2401	81.6	(78.4-84.9)
Kidney	3112	43	(41.5-44.5)	2133	55.6	(53.2-58.0)	979	27.8	(26.1-29.6)
Ureter	39	0.6	(0.4-0.8)	23	0.7	(0.4-1.0)	16	0.5	(0.2-0.7)
Urinary bladder	5930	98.1	(95.6-100.6)	4868	148.7	(144.6-152.9)	1062	37.2	(35.0-39.4)
Bone marrow (myeloid leukaemia)	5134	54.9	(53.4-56.4)	3081	59.8	(57.7-62.0)	2053	48.8	(46.7-51.0)
Uterine cervix							16835	503.1	(495.5-510.7)
Ovary							7056	207.1	(202.2-211.9)

Table 2. Age-Specific Incidence Rates of Tobacco-Related Cancers Per 100 000 Population by Age Group and Sex, 1988–2009, Delhi

Age (years)	No.	Total		Males			Females		
		Rate	95% CI	No.	Rate	95% CI	No.	Rate	95% CI
<39	16470	179.7	(177.0–182.5)	7673	154.3	(150.9–157.8)	8797	210	(205.6–214.3)
40–49	20460	1877.2	(1851.5–1902.9)	9990	1580.5	(1549.5–1611.5)	10470	2286.9	(2243.1–2330.7)
50–59	26779	4248.3	(4197.4–4299.2)	15814	4516	(4445.6–4586.4)	10965	3836.5	(3764.6–3908.3)
60–69	25422	6762.7	(6679.5–6845.8)	15795	7830.5	(7708.4–7952.6)	9627	5530.1	(5419.6–5640.5)
>70	15413	7910.8	(7785.9–8035.7)	10386	9695.6	(9509.2–9882.1)	5027	5724.1	(5565.9–5882.3)

Table 3. Percentage of Missing Variables for Tobacco-related Cancers, Delhi Population-based Cancer Registry, 1988 Versus 2009

Demographic features	1988		2009	
	No.	%	No.	%
Age	44	1.5	48	0.6
Sex	0	0	0	0
Religion	34	1.2	7	0.1
Incidence (date of diagnosis)	368	12.8	78	0
Method of diagnosis	0	0	4	0.1
Total TRC Cases	2886		7592	

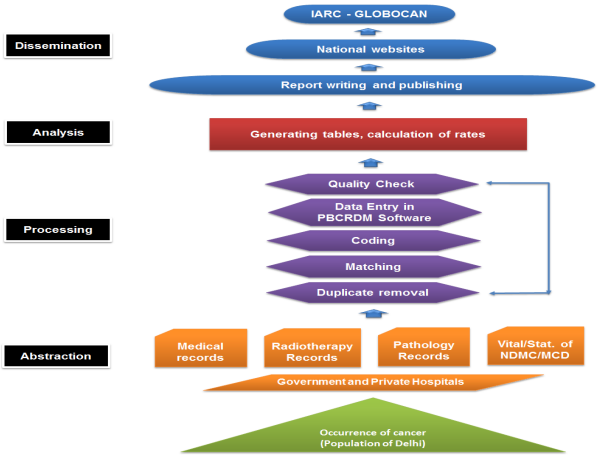

Figure 1. Data Flow

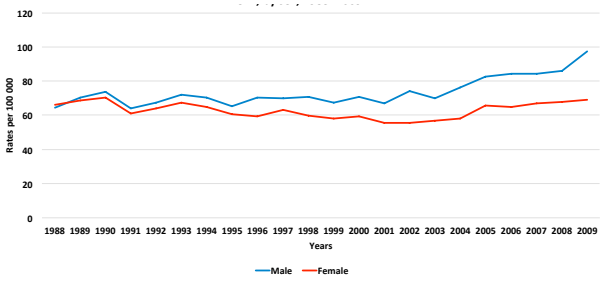

Figure 2. Age-adjusted incidence rates of tobacco-related cancers all sites combined in Delhi, by sex, 1988–2009

8.77 (Figure 3). Among women, the uterine cervix was the most common site, with an age-adjusted incidence rate of 27.8 in 1988, which decreased to 19.1 per 100 000 population in 2009. During 1988-2009, the rates of cancer of the ovary increased from 7.9 to 10.8, lung from 2.8 to 5.8, mouth from 2.4 to 3.8, while the rate of cancer of the oesophagus decreased from 4.4 to 4 (Figure 4).

Attributes of the surveillance system

Simplicity: Data collection forms used by the Delhi

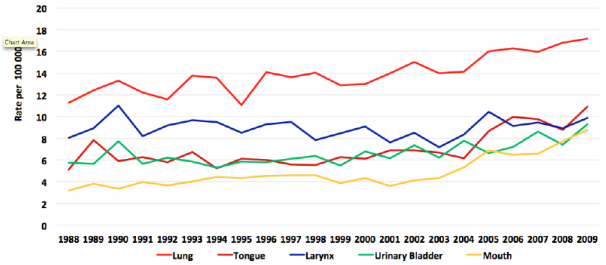

Figure 3. Age-Adjusted Incidence Rates of the Top Five Tobacco-Related Cancers among Males, Delhi, 1988–2009

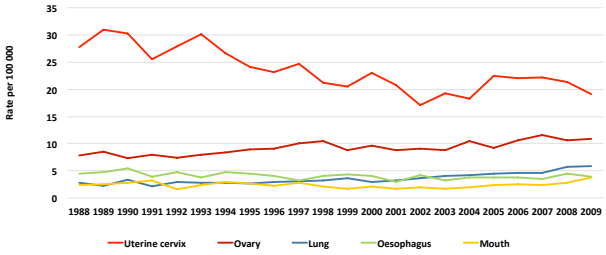

Figure 4. Age-Adjusted Incidence Rates of the Top Five Tobacco-Related Cancers among Females, Delhi, 1988–2009

PBCR are uniform, short and easy to understand; however, data collection is a labour-intensive process. In 1988, there was one staff member for 890 cases, while in 2009, the load more than doubled with one staff member for 2136 cases. Processing of the data goes through time-consuming steps; however, the staff of the Delhi PBCR is well trained in the process and the source hospitals are cooperative.

Flexibility: The Delhi PBCR has been adapting to changes in ICD codes and cancer definitions. The staff are regularly informed of and trained in the changes in coding manuals as per the World Health Organization (WHO) and IARC guidelines. New hospitals and laboratories are also regularly updated in the source list and the existing resources of the PBCR are utilized for data abstraction.

Comparability: The Delhi PBCR follows ICD-O-3 (International Classification of Disease-10) for coding all malignancies. The registration of new cases, incidence date, method of diagnosis and multiple primary tumours follow NCRP recommendations, which follow the international guidelines recommended by IARC based upon a hierarchy of the possible source.

Validity: Cancers were morphologically verified by histopathology in 80.9% of men and 79.9% of women registered during the period 2007-2009. The proportion of DCO cases was 0.8% in men and 0.5% in women. A comparison of the percentage of missing variables for TRC between 1988 and 2009 data (Table 3) shows that there is

a decline in the percentage of missing variables, such as age, religion, date of diagnosis and method of diagnosis. As per IARC norms, validity checks are carried out on all variables in the PBCRDM software at the NCRP. The PBCRDM 2.1 application has evolved tools to identify potential duplications.

Timeliness: Time until registration and Process time in the Delhi PBCR calculated for the year 2009 in Delhi PBCR was 13 months and 32 months, respectively.

Completeness: Analysis of age-adjusted incidence rates of all TRC shows that overall rates are steadily increasing in both men and women. The rates at selected cancer sites were also found to be comparable among men and women in the Delhi, Mumbai and Chennai PBCR for the year 2009. The patterns of age-specific incidence rates over time differ by age group in the tobacco-related selected sites combined (1988-2009). In men, the rates are stable but increasing with age and in women, the rates were stable in those aged less than 50 years, whereas the rates fluctuated in those aged over 50 years.

Representativeness: The Delhi PBCR covers all major public and private hospitals spread over Delhi. Time, place and person are well defined in the captured data, except for duration of stay in Delhi for the maximum number of cases. Peripheral cancer hospitals around Delhi are now also considered as sources of data.

Discussion

The incidence of TRC in Delhi has steadily and significantly increased over the past two decades. This increasing trend over the years indicates the need to further intensify and strengthen the efforts of the National Tobacco Control Programme and the National Cancer Control Programme.

The Delhi PBCR is a well-organized surveillance system with high-quality data; however, data abstraction is labour intensive due to non-uniform software and non-availability of an indexing procedure in many source hospital's medical records departments, resulting in delays. Identifying duplicate records is carried out manually; this is time consuming. In addition, transferring coded data files to Bengaluru for data entry and then back to the Delhi PBCR for verification before removing the duplicate entries is an extra process that can be simplified.

The high validity of the data is reflected by the fact that 80% of cases in the Delhi PBCR are morphologically verified. The higher the proportion of microscopically verified cases, the more accurate the confirmation of cancer, as diagnosis based on histopathological examination is more accurate than diagnosis based solely on clinical examination. The registration time in the Delhi PBCR is close to that in recommended guidelines (international standards for cancer registry require 95% of reportable cancer cases to be reported within 24 months of the end of the year of diagnosis). However, it is possible to improve process time by further simplifying the process (Havener et al., 2004).

The workload in the PBCR Delhi has increased by over 160% since the registry started but the staff size is almost the same. At present, electronic abstraction of data is done from very few source hospitals. However, the efficiency of the registry is still good despite the increased workload on the staff. The transition from a manual process to automated, electronic reporting, especially from all major source hospitals, may result in more complete, timely and accurate cancer surveillance data.

India is committed to implementing the Framework Convention on Tobacco Control (FCTC) treaty, which recommends evidence-based methods for tobacco control. India also adopted a comprehensive tobacco control law, i.e. the Cigarettes and Other Tobacco Products Act, 2003. The Ministry of Health and Family Welfare, Government of India, adopted the National Tobacco Control Programme (NTCP) under the Eleventh Five-Year Plan, 2007-12. While there is a strong policy framework and legislation for tobacco control in India, the enforcement of tobacco policies and laws is generally weak. The rising trends of TRC in our study provides evidence to advocate for stronger tobacco control measures.

As the Delhi PBCR follows international guidelines for collection, coding, classification and estimation of TRC incidence, it is comparable with that of other regional registries and other countries. The registry data have been widely used by researchers in India for estimating the national and economic burden of cancer, and making projections. In the latest IARC definition, the list of TRC sites has been expanded, with the availability of sufficient scientific evidence of the relationship of these sites with tobacco. The Delhi PBCR presently covers 10 sites given in the definition of TRC. More sites need to be covered, both for the registry as well as for the NTCP, as this will provide the latest available evidence for stronger advocacy against tobacco.

The findings of this study should be read in light of the following limitations. First, the information regarding tobacco use among incident cancer cases is not available in the registry database; however, the cancer types included in this report are those defined by IARC as having a direct causal relationship with tobacco use. Second, the residential status of the registered cases is based on reported information and not all are verified, as a limited number of patients are interviewed by the registry. This may lead to non-residents being registered as residents. While this may lead to overestimation of the incidence, it is unlikely to affect the direction of the trends.

In conclusions, We conclude that the burden of TRC in Delhi is high and increasing in both men and women. The Delhi PBCR is a well-organized surveillance system that generates representative, complete and high-quality population-based data on the incidence of cancers. However, data collection and processing is a laborious process. The efficiency of the Delhi PBCR can be further improved by replacing paper-based data abstraction by electronic data abstraction. An ongoing quality assurance system and evaluation system may be instituted in the Delhi PBCR by re-abstracting 5-10% of records every year. Additionally, comprehensive periodic evaluation of the Delhi PBCR may be considered once in five years. To reflect the true burden of TRC, the NCRP of India should adapt the latest IARC definition for TRC sites. The National Tobacco Control Programme should use the data

generated by cancer registries to advocate for stronger tobacco control policies and legislation.

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