

CANCER REGISTRATION IN INDIA

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The cancer registration is a mechanism to collect and classify information on all cancer cases in order to produce statistics on the occurrence of cancer and to provide a framework for assessing and controlling the impact of cancer on the community. The population based cancer registries collect and process data relating to a defined geographical area while the hospital based cancer registries relate to data available with a specific hospital.

Population based cancer registries record all the new cancer cases occurring in a defined population (generally a geographic area), with epidemiological and public health aspects in mind. The hospital based cancer registries record information on cancer patients attending a particular hospital, with focus on clinical care and hospital administration. If all the health care facilities in a defined geographic area collect the data on cancer cases as per standardized proforma, the pooling of data (with elimination of duplicates) would result into a population based cancer registry. In areas with no population based cancer registry, the information from hospital based cancer registries or from special patient series (as pathological record), help in assessing the public health requirements, and the impact of control measures.

To be useful, a population based cancer registry must collect information on all the cancers cases; should be able to distinguish the residents of the defined geographic area from persons residing outside; should have access to all the sources diagnosing or treating cancer in that area; should have enough identification parameters to detect multiple registration in different hospitals; should have population figures by sex and five years age groups; and should be large enough to provide meaningful figure (most registries cover a population between one to five million).

Need for data on continuous basis

Although the data on cancer occurrence can also be collected through one-time community surveys, the availability of data on a continuous basis has its special importance. The uniformly collected long-term data helps in understanding the trends in cancer occurrence. Their variation according to demographic or life style characteristics of the population, and also in relation to diagnostic facilities available in the specific region, helps in generation of hypothesis in aetiology of various cancers.

Methodology of cancer registration

In many developed countries, such as Finland, Denmark & some states in USA, notification of cancer cases is compulsory for every hospital. Such a legislation facilitates the collection of data for population based cancer registries. However, in most developing countries including India, the provision of information is on voluntary basis. Exact methodology of data collection would necessarily depend upon the local circumstances. The hospitals in areas with compulsory notification and the hospital cancer registries, abstract the information from the patient records on a specified proforma and send it to the registry (passive method). However, where trained staff for abstracting the records is not available with the individual hospitals or notification is not mandatory, the workers from registry scan through the patient records in different hospitals, clarify incomplete or contradictory information, and abstract data (active method). The cancer registration in India is through active method of data collection, with collection of data from hospital records as well as through interview of patients. In rural areas of India, where the facilities for diagnosis of cancer are sub-optimum, the active methodology of data collection from hospitals, has been supplemented with periodic population surveys on cancer occurrence. During these surveys, the information is collected on cancer occurrence, the registration number of health care agency attended (which may be within or outside the defined geographic area of interest), as well as the outcome.

Information to be collected by cancer registries

The information to be collected by cancer registries depends upon the objectives and requirements of the registry. Items depicting management modalities are necessary for hospital based registries in order to study the survival according to different treatment modalities, but may not be necessary for population based cancer registries interested in calculation of incidence rates. Logistic possibility of collection of the data should be kept in mind before inclusion in the proforma. The process of cancer registration and basic and optional items of data collection for cancer registries have been suggested in various publications as¹⁻⁵. The basic information for cancer registries includes data on personal identification, some demographic characteristics, date & most valid basis of diagnosis, site and morphology of tumor, primary site, and source of information.

A population based cancer registry is a mechanism of recording all the cancer cases diagnosed by health services. As such if an area does not have adequate facilities for diagnosis, even a complete registration may not reflect the actual magnitude of cancer occurrence in that community. As the facilities for diagnosis and treatment in the area increase, the registered incidence of the cancer may also increase. It is important that registries keep a track of facilities for diagnosis in the area. Similarly, a knowledge of classification practices and procedures is also important for rational interpretation of changes in incidence rates. International Classification of Diseases (ICD) by World Health Organization provides a specific code for different diseases. As the etiology of cancers of different sites may be different, cancer of each site has been provided with a different number. An ICD-O classification for oncology, is a special part of the ICD, and provides a code for histologic classification, to include sub-sites of different organs. This classification also provides a mechanism for morphological classification and thus, providing information on their behaviour.

Quality assurance in registry functioning

Each registry is expected to carry out certain consistency checks and quality control measures to ensure the reliability of the data⁶. Such

exercises cover the completeness as well as accuracy of the information. The International Agency for Research on Cancer, Lyon, France, periodically publishes the data collected by various population based cancer registries, in a standardized fashion, the latest being the seventh volume of *The Cancer Incidence in Five Continents*⁷. This organization also serves as the secretariat office of the International Association of Cancer Registries, which is a membership organization for cancer registries.

Incidence rates

A major activity of the cancer registries is the calculation of incidence rates. Incidence rate is defined as the number of new cases of disease, which occur in a defined population of disease free individuals, over a specified period of time. The incidence rate of cancer is generally expressed for 100,000 population over one year (or a block of few years). The International Agency for Research on Cancer, in its publication on *The Cancer Incidence in Five Continents*, provides such rates for a period of five years. The cancer registries calculate incidence rates for every 5 year age category for each sex (age & sex specific incidence rates). The incidence rate when expressed for all ages is called crude incidence rate, and provides a direct estimate of the probability or risk of the illness for the concerned population.

It is well known that cancer does not occur with uniform rate in different age groups. Thus, for comparison of incidence rate in different areas or for the same area over a long period, it is necessary to adjust the rates for variations in the proportion of population in different age groups. The generally adopted procedure is that of direct standardization, which applies the age & sex specific incidence rates of the area under consideration, to world standard population, to derive the number of cancer cases expected to occur in the standard population. Such age standardized (or adjusted) incidence rates are useful in international or secular comparisons.

It is speculated that the intensity of efforts on diagnosis of cancer may not be as rigorous in extreme of ages, as compared to middle years. Thus, truncated incidence rates are some times used for comparison, which are actually the age standardized incidence rates for ages 35 to 64 years of age.

Uses of data on cancer occurrence

The data from cancer registries can be used for cancer control as well as for research purposes. The data from population based cancer registries, is useful in defining the magnitude and commonly affected sites of cancer. This helps in planning the quantum and type of preparedness for health services for combating the disease. The changes in incidence rates also provide a parameter for evaluation of the impact of intervention programs or socio-cultural changes. Changes in proportion of stages of disease at which the patients first contact health services (from population or hospital based cancer registries) may also be a useful parameter for such changes. The data from hospital based cancer registries helps in assessing the survival of cancer patients in relation to anatomical site, clinical stage, different treatment modalities, etc. The database may provide clues for generation of hypothesis regarding etiology and to carry out research studies.

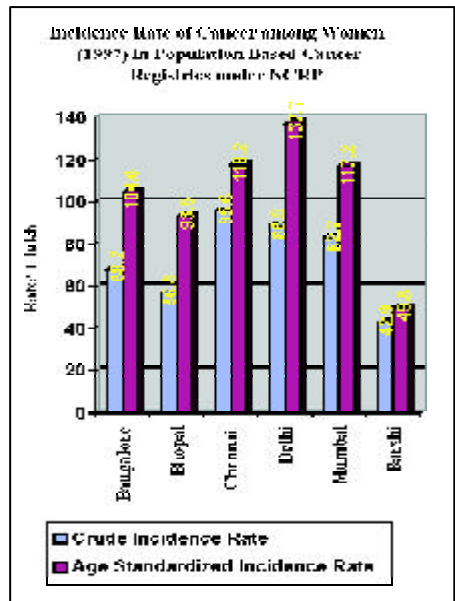
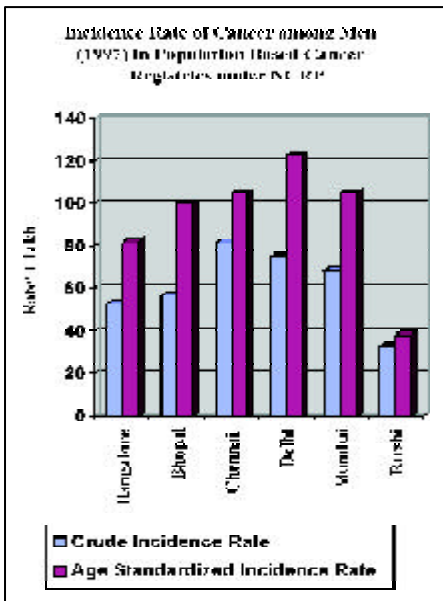
Cancer registration in India

Until 1964, information on cancer occurrence in India was available from surveys. Initiation of population based cancer registries at Bombay in 1964, at Pune in 1973, at Aurangabad in 1978, and at Ahmedabad & Nagpur in 1980, started the availability of data on cancer incidence on a continuous basis. However, the boost for cancer registration in India was in 1982, through initiation of National Cancer Registry Programme (NCRP) by Indian Council of Medical Research. The NCRP began with three population based (existing Bombay registry and new registries at Bangalore and Madras), and three hospital based registries (at Chandigarh, Dibrugarh & Trivandrum). Further, expansion of NCRP saw the initiation of urban population based cancer registries at Bhopal & Delhi in 1987; rural population based cancer registries at Barshi (Maharashtra) in 1987; and hospital based cancer registries at main hospital of PBCRs at Bangalore, Bombay & Madras in 1986. A hospital based cancer registry functioned at Chandigarh from 1982 till 1992. Coordinating unit of NCRP provides guidelines and quality control checks to the current network of six population based and five hospital based cancer registries of NCRP. The data from cancer registries helped in highlighting the magnitude

and common sites of cancer in India, and was useful in planning the National Cancer Control Programme. The network of population based cancer registries under NCRP is proposed to be expanded. Besides the above mentioned registries population based cancer registries are also functioning at Kolkatta, Thiruvananthapuram, Karunagapally (rural Kerala) and Ambillikai (rural Tamil Nadu).

Cancer in India

The crude incidence rates of cancer in 1997 as recorded by the urban population based cancer registries under NCRP, varied between 52.9 and 81.5 per 100,000 men; and between 56.8 and 95.6 per 100,000 women⁸. The age standardized incidence rates in these registries ranged from 81.8 to 122.8 per 100,000 men; and from 93.5 to 137.7 per 100,000 women. The rural registry at Barshi (Maharashtra) showed crude incidence rates of 32.6 per 100,000 men & 42.9 per 100,000 women; and age standardized rates of 38.2 per 100,000 men & 49.8 per 100,000 women. Cancer incidence in Indian men is about half to one third of the incidence recorded in USA & Europe. Incidence rates in Indian women are about half the experience of USA & European women. A global comparison shows that India has high incidence rates of cancers of oral cavity, pharynx, & cervix.



Based on the data from population based cancer registries in Bangalore, Bombay & Madras till the year 1989, the estimated number of new cancer cases⁹ for the year 1992 was 644,600. Considering no change in age specific incidence, 806,000 incident cases would have occurred during the year 2001. About half of the cases among men and one fifth of cases among women, pertain to sites mainly attributable to tobacco use. Cervical cancer is the commonest cancer among women, followed by breast cancer. The most common cancer among men is lung & bronchus in Mumbai, Delhi & Bhopal; stomach cancer in Bangalore & Chennai; and hypopharyngeal cancer in Barshi. However, all these cancers occupy important ranks in all the registries. The other important cancers sites among men are that of oral cavity, pharynx, larynx, prostate, & rectum. Cancer of uterine cervix followed by breast cancer is the most frequently encountered sites in women in all registries, except Mumbai, Delhi & Bangalore, where the two sites interchange their ranks. Other common forms of cancer among women are that of oral cavity, esophagus, ovary, & stomach. Incidence of cancer of gall bladder is very high in Delhi.

Leading Cancers in Population Based Cancer Registries under National Cancer Registry Programme of ICMR (1997), Men

Rank	Bangalore	Bhopal	Chennai	Delhi	Mumbai	Barshi (Rural)
1	Stomach (5.0)	Lungs (7.2)	Stomach (9.6)	Lungs (7.4)	Lungs (6.4)	Hypopharynx (3.9)
2	Esophagus (4.0)	Mouth (unspecified) (4.7)	Lungs (8.3)	Larynx (5.3)	Esophagus (4.3)	Esophagus (3.5)
3	Lungs (3.7)	Tongue (4.6)	Esophagus (6.7)	Prostate (3.6)	Larynx (3.7)	Liver (3.1)
4	Hypopharynx (3.1)	Esophagus (4.5)	Tongue (4.3)	Brain (3.4)	Tongue (3.7)	Myeloid Leukemia (2.3)
5	Prostate (2.1)	Hypopharynx (3.3)	Prostate (4.0)	Tongue (3.2)	Prostate (3.5)	Penis (1.9)

Figures in parenthesis are the crude incidence rates per 100,000

Leading Cancers in Population Based Cancer Registries under National Cancer Registry Programme of ICMR (1997), Women

Rank	Bangalore	Bhopal	Chennai	Delhi	Mumbai	Barshi (Rural)
1	Breast (14)	Cervix (12.7)	Cervix (23.6)	Breast (19.8)	Breast (20.6)	Cervix (18.7)
2	Cervix (13.8)	Breast (12.3)	Breast (21.4)	Cervix (15.8)	Cervix (12.1)	Breast (7.5)
3	Esophagus (3.8)	Ovary (3.5)	Stomach (4.6)	Ovary (6.5)	Ovary (6)	Esophagus (2.1)
4	Stomach (3.1)	Esophagus (2.5)	Ovary (4.4)	Gall Bladder (5.6)	Esophagus (3.9)	Ovary (2.1)
5	Ovary (2.9)	Mouth (unspecified) (2.5)	Esophagus (4.2)	Lymphoma (2.3)	Lungs (3)	Gum (1.2)

Figures in parenthesis are the crude incidence rates per 100,000

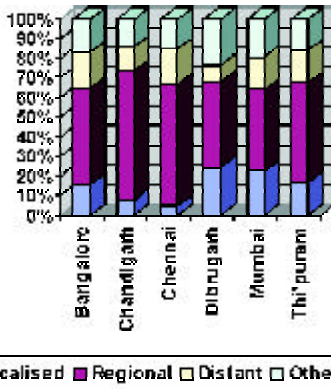
Time trend analysis for cancer of all sites considered together for the period 1990 to 1996 does not indicate any remarkable change in any of the registry in both males and females¹⁰. However, individual sites do show some changes over the period 1982 to 1996. Mumbai data suggests an increase in incidence of cancers of colon, prostate, non-Hodgkin's lymphomas, leukaemias & brain among men; decrease in cancers of oral cavity, hypopharynx, oesophagus & stomach among men; increase in cancers of breast, ovary & lungs among women; and decrease in cancers of oesophagus, stomach & cervix among women. Bangalore data suggests an increase in incidence of leukaemias; a decrease in incidence of cancers of oral cavity & stomach among men; increase in ovarian cancer among women; and decrease in cancers of oral cavity, stomach & cervix among women. Chennai data suggests an increase in incidence of cancers of prostate, leukaemias & brain among men; decrease in cancers of oral cavity among men; decrease in cancers of oral cavity & cervix among women. Delhi data suggests an increase in incidence of cancers of colon, rectum, prostate, non-Hodgkin's lymphoma, leukaemias & brain among men; increase in cancers of gall bladder, ovary & rectum among women; and decrease in cancer of cervix among women. Bhopal data suggests an increase in incidence of cancers of colon &

leukaemias among men; decrease in cancers of tongue among men; increase in lung cancer among women; and decrease of cancer of cervix among women. Rural Barshi has shown a decrease of incidence of cancer of oesophagus among men.

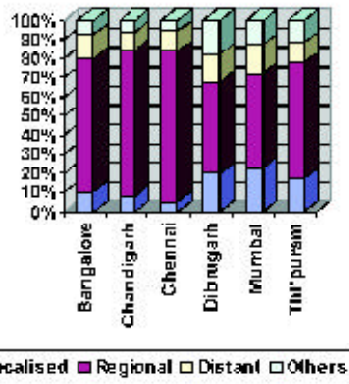
The age specific incidence rates of cancer gradually increase with age. There are no major variations in age specific incidence rates in different registries, except Barshi where the rates are consistently lower. The incidence rates in the rural registry of Barshi are of special interest, as these are likely to throw light on rural-urban differentials in cancer occurrence. Incidence rate of cancer of penis as recorded by this registry is the highest in the country. The information on cancer occurrence from rural areas is based on a small population. Availability of data from more rural population based cancer registries would help in better understanding of rural-urban differentials.

A comprehensive ten years (1984 to 1993) report of the hospital cancer registries under National Cancer Registry Programme shows that majority of cases had microscopic verification ranging from 70% to 95% among men and from 72% to 96% among women¹¹. The cases diagnosed on clinical examination alone varied from 1% to 23% among men and 2% to 26% among women. At the time of initial reporting, the disease had spread to regional tissues or metastasis had occurred in most of the cases. The proportion of patients with localized disease varied between 5.1% and 24.3% among men and between 5.6% and 22.8% among women. The proportion of patients who did not receive cancer directed treatment at the specific hospital of the registry varied from 16.1% to 45.7% among men, and from 15.1% to 39.8% among women. Among the patients treated at the reporting institutions, cancer directed treatment was received by 16.1% to 45.7% men and by 15.1% to 39.8% women. Radiotherapy was the commonest modality of treatment at all stages, surgery was used for localized cancers and chemotherapy for patients having distant spread.

Proportion of Patients according to Clinical Extent of Disease in Hospital Based Cancer Registries under NCRP, 1998-1993 (Men)



Proportion of Patients according to Clinical Extent of Disease in Hospital Based Cancer Registries under NCRP, 1998-1993 (Women)



Human resource generation

National cancer registry programme has generated invaluable human resource in cancer epidemiology and registration, through various international fellowships (including the Indo-Finnish collaboration with University of Tampere), support of tumour registration training programmes, and continuing education programmes for registry workers. This useful resource from cancer registries is actively engaged in research as well as cancer control activities in their respective regions. The scientists have been instrumental in establishment of departments of cancer epidemiology and have contributed in training of other staff of the registries.

Cancer registries and research

A number of research studies have been undertaken based on the cancer registry data and many of these have been published in national and international journals¹². A study on stomach cancer revealed that at Chennai tobacco chewing, smoking, alcohol, fried food, chutney and increased use of chillies elevated the risk and increased use of vegetables decreased the risk. At Mumbai elevated risks were observed for tobacco chewers, smokers & alcohol users. Thiruvananthapuram observed high consumption of rice, high

consumption of chilly and high temperature food, as independent risk factors. A study at Bangalore showed the need for defining the anatomical sub-site of cancer of oesophagus. Tubectomy as a method of family planning appeared to reduce the risk of ovarian cancer. A population based survey revealed that the proportion of coverage of cancer cases was 72% in Bangalore, 100% in Chennai and 78% in Mumbai.

Population based survival studies were reported for selected cancer sites, which was the first data of its kind from developing countries¹³. The five-year relative survival for female breast cancer was 46.8% in Bangalore, 49.5% in Chennai & 55.1% in Mumbai. The five-year relative survival for cervical cancer was 40.4% in Bangalore, 60.0% in Chennai & 50.7% in Mumbai.

Cancer registries and cancer control

Cancer registries under the National Cancer Registry Programme have provided high quality data on cancer occurrence. The data has been used for estimation of load of the disease for the country, establishment of management facilities, as well as for development of the objectives & strategy for the national cancer control programme. The population based survival studies by the registries have provided information on age and stage specific survival and mortality. Several cancer registry centres are involved in planning, implementation, and monitoring of district cancer control programmes in their respective regions.

Future of National Cancer Registry Programme

It is proposed to expand the network by initiation of more population based cancer registries so as to cover more areas of the country. Research studies supported by in-depth laboratory components are proposed to be undertaken. A closer coordination in planning, monitoring and evaluation of activities under the National Cancer Control Programme would help in cost-effective utilization of scarce resources.

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