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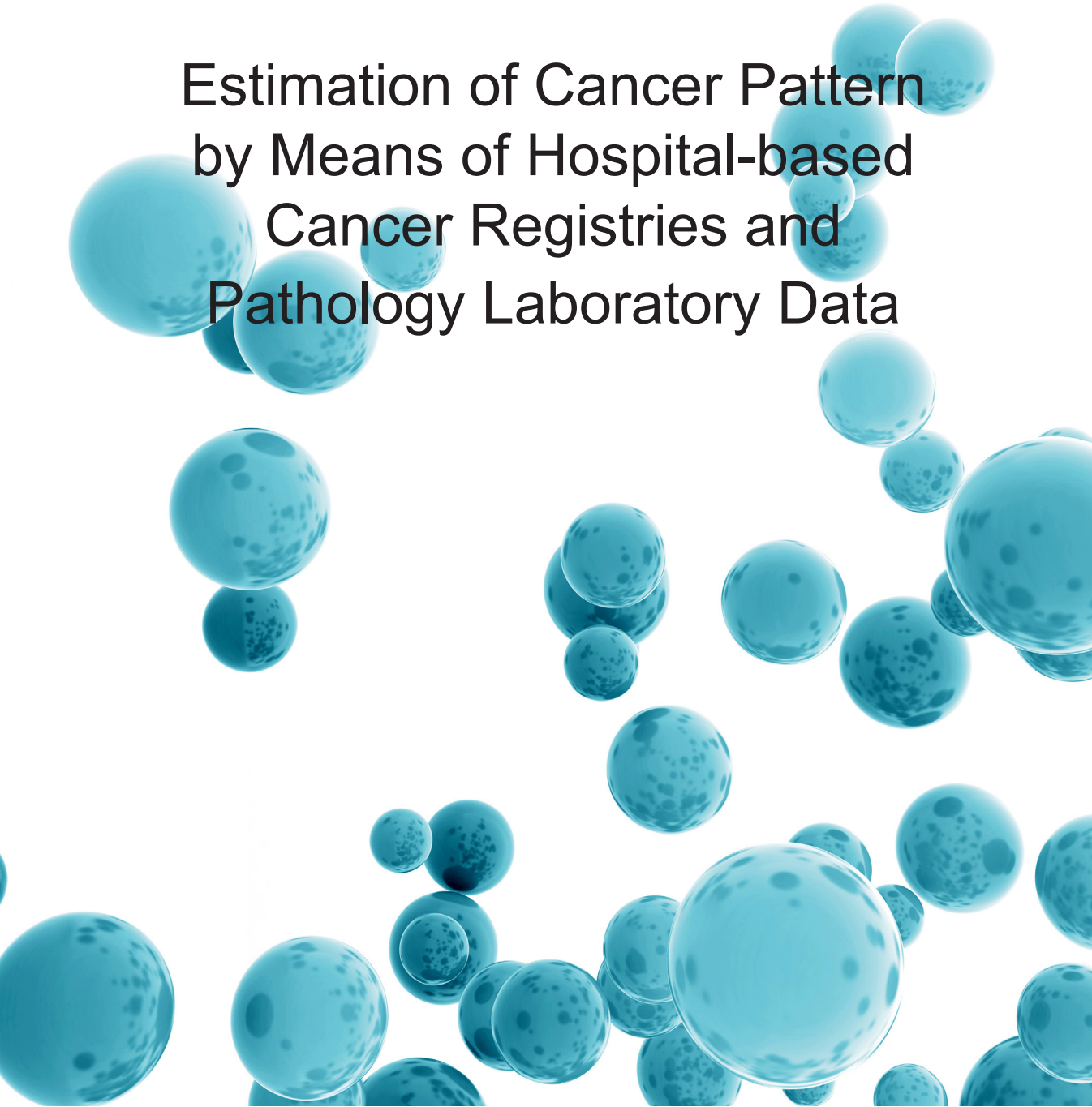
MURALI DHAR

Estimation of Cancer Pattern by Means of Hospital-based Cancer Registries and Pathology Laboratory Data



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ACADEMIC DISSERTATION
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ACADEMIC DISSERTATION
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DEDICATION


To my parents, for showing the right path.

CONTENTS

Abbreviations

AIDS	: Acquired Immuno-Deficiency Syndrome
ASHA	: Accredited Social Health Activist
ATLAS	: A project undertaken by NCRP (ICMR), India
CDT	: Cancer Directed Treatment
CHC	: Community Health Centre
COU	: Coordinating Unit
CRS	: Civil Registration System
DLHS	: District Level Household and facility Survey
DPPH	: Doctoral Program in Public Health
FRU	: First Referral Unit
GOI	: Government of India
HBCR	: Hospital-based Cancer Registry
HIS	: Health Information System
HIV	: Human Immunodeficiency Virus
HMIS	: Health Management Information System
HMN	: Health Metrics Network
IARC	: International Agency for Research on Cancer
ICD	: International Classification of Diseases
ICD10	: International Classification of Diseases and related health problems, Tenth revision
ICD9	: International statistical Classification of Diseases, injuries and causes of death, Ninth revision
ICDO	: International Classification of Diseases for Oncology
ICMR	: Indian Council of Medical Research
ICPD	: International Conference on Population and Development

ICRETT : International Cancer Technology Transfer

IIPS : International Institute for Population Sciences

IMR : Infant Mortality Rate

INPTSOUT : Set of patients who are actually from IN side the HBCR area, but do not get registered in HBCR

JSY : Janani Suraksha Yojana

LASI : Longitudinal Aging Study in India

LMICs : Low and Middle Income Countries

MCH : Maternal and Child Health

MCIR : Minimum Cancer Incidence Rate

MIC : Methyl Iso-Cyanide

MMR : Maternal Mortality Ratio

MOHFW : Ministry of Health and Family Welfare

NCD : Non-Communicable Diseases

NCRP : National Cancer Registry Programme

NFHS : National Family Health Survey

NHL : Non-Hodgkins Lymphoma

NHM : National Health Mission

NOS : Not Otherwise Stated

NRHM : National Rural Health Mission

OUTPTSIN : Set of patients who are actually from OUTside the HBCR area but registered in the HBCR

PBCR : Population-based Cancer Registry

PHC : Public Health Centre

pi : Proportion (%) of leading sites of cancer according to PBCR

pi' : Proportion (%) of leading sites of cancer according to HBCR

PIN : Postal Index Number

PRC : Population Research Centre

RCH : Reproductive and Child Health

RI : Reporting Institution

RTI : Reproductive Tract Infection

SAGE : Study of global AGEing and adult health

SRS : Sample Registration System

STI : Sexually Transmitted Infection

TMH : Tata Memorial Hospital

UICC : International Union Against Cancer

UID : Unique Identification Number

UN : United Nations

UT : Union Territory (A type of administrative division in the country. Unlike the states, which have their own elected governments, UTs are ruled directly by the Union Government, hence the name.

WAAD : Weighted Average of Absolute Differences

WARD : Weighted Average of Relative Differences

WHO : World Health Organization

WHS : World Health Survey

List of tables

5.1.1a	Proportion (%) of selected leading cancer sites according to HBCR and PBCR and absolute and relative differences between the two, Mumbai, 1999-2000
5.1.1b	Proportion (%) of selected leading cancer sites according to HBCR and PBCR and absolute and relative differences between the two, Bangalore, 1999-2000
5.1.1c	Proportion (%) of selected leading cancer sites according to HBCR and PBCR and absolute and relative differences between the two, Chennai, 1999-2000
5.1.2a	Proportion (%) of selected leading cancer sites according to ATLAS (2001-2002) and PBCR (2003-2004) and absolute and relative differences between the two, Dibrugarh
5.1.2b	Proportion (%) of selected leading cancer sites according to ATLAS (2001-2002) and PBCR (2003-2004) and absolute and relative differences between the two, Imphal West
5.1.2c	Proportion (%) of selected leading cancer sites according to ATLAS (2001-2002) and PBCR (2003-2004) and absolute and relative differences between the two, Aizawl
5.2.1	Absolute and relative differences between HBCR and PBCR for the leading sites common in the three study populations with their weighted averages (WAAD and WARD)

List of figures

Abstract

Cancer registration is one of the necessary ingredients of any cancer control programme. The requirement of cancer registration would be that it has to be population-based with diagnostic, clinical and treatment details of all the cases. Even in developed countries, there is the possibility of clinical data being incomplete for a considerable proportion of the cancer cases. In the setup of developing countries, the registries suffer from the lacunae of not being able to cover the whole population of the country and non-availability of reliable clinical and treatment details for the majority of cases. Therefore, the principle of two different registries, namely; population-based cancer registries (PBCRs) and hospital-based cancer registries (HBCRs), evolved and are in place. Another concept that has come up recently is that of the cancer atlas (ATLAS) which collected data from all the pathology centres and tabulated it according to their place of residence. Therefore, in the scenario of developing countries, there is a need to explore the potential population-based uses of HBCR and ATLAS data and to test their validity. The overall aim of the study was to explore the feasibility of using HBCR and ATLAS data in the evaluation of cancer patterns in India.

With respect to the place of residence, there are two sets of patients that account for qualitative and quantitative differences between HBCR and PBCR. They are INPTSOUT (Set of patients who are actually from INside the HBCR area, but do not get registered in HBCR) and OUTPTSIN (the set of patients who are actually from OUTside the HBCR area but get registered in the HBCR). Thus, PBCR data = HBCR data - OUTPTSIN + INPTSOUT. Any population-based interpretation of HBCR data makes basic assumption that INPTSOUT and OUTPTSIN are quantitatively equal and qualitatively similar.

As far as ATLAS is considered, data were obtained from all the sources of microscopic diagnosis of cancer, who gave their consent for the participation in the project. Utilizing the data on place of residence, the cases were divided to arrive at the number of incident cancer cases by district of residence. Subsequently, these numbers were divided by the population of the district to obtain 'minimum cancer incidence rate' (MCIR) for that district.

To compare the pattern of cancer according to HBCR and PBCR, three places with both types of registries were selected. Similarly, another three places for which PBCR and ATLAS both reported pattern of cancer were also selected. Ten leading sites by sex based on PBCR data were selected for each of the registries separately. Proportion of leading sites of cancer according to PBCR and that according to

HBCR or ATLAS were obtained from published reports and compared by calculating absolute and relative differences. To compare the differences between HBCR/ATLAS and PBCR across the registries, we calculated the weighted average of the absolute values of differences (WAAD) and relative differences (WARD). These indicators were used also to compare HBCR data minus OUTPTSIN (i.e., RHBCR) with PBCR. In addition, trend in consistency was examined by plotting a scatter diagram between PBCR and HBCR proportions for different time periods. Present study utilized the data from consolidated reports of the national Cancer Registry Programme in India for PBCR, HBCR and ATLAS during 1984-2006, and the report of Tata Memorial Hospital in 2000.

Present study found that there was gross over/under representation of different sites of cancer in the data from HBCRs or ATLAS in India. Therefore, any assessment of risk of even leading sites of cancer based on HBCR or ATLAS data may be biased. By and large, easily accessible sites like mouth, tongue and hypo-pharynx were overrepresented in HBCR data, whereas, the sites not so easy to diagnose, like stomach, lung, prostate and brain were underrepresented. Among female specific sites, cancer of the breast and ovary were underrepresented whereas that of the uterine cervix was overrepresented. Reduction of HBCR data to RHBCR did not improve the consistency with PBCR. Differences of HBCR with PBCR were not consistent over a period of time for most of the leading sites. The differences in ATLAS were on the lines of that in HBCR data. It was to be expected, because ATLAS data are conceptually similar to a multi-centric HBCR data.

Since cancer registry is the backbone of cancer control, an erroneous assessment of cancer burden and pattern can have long term negative implications on the health resources of a country, especially in a limited resource country. HBCRs are valuable institutions having vital role in patient care assessment and conduct of epidemiological and survival studies with different environmental, clinical and treatment features. Population-based interpretation of HBCR or ATLAS data on occurrence of cancer, however, may not be valid due to the diversity in the availability of health services and prevalence of etiological factors.

It may be concluded that estimates on cancer occurrence or risk of cancer based on HBCR data or use of ATLAS as an alternative to PBCRs cannot be taken as granted. This attracts the attention of policy planners and administrators towards opening up more PBCRs, especially in rural areas and the areas considerably distant from existing PBCRs.

Tiivistelmä

Syöpärekisterit ovat syöväntorjuntaohjelmien keskeinen osa, ja niitten käyttöalueet ja hyödyllisyys on hyvin dokumentoitu. Periaatteessa syöpärekisteröinti edellyttää yksityiskohtaiset tiedot kasvaimen toteamistavasta, kliinisestä luonteesta ja hoidosta, sekä tiedot siitä väestöstä, jonka rekisteri kattaa. Kehitysmaissa väestöpohjaisissa syöpärekistereissä on puutteita sekä väestökattavuudessa että potilastiedoissa. On siten tarve korvata syöpärekisteritiedot (PRCR) sairaalan (HBCR) tai patologian laboratorion (ATLAS) tiedoilla.

Väestöpohjaisten rekisterien ja niitten vaihtoehtojen erot ovat sekä määrällisiä että laadullisia. Intiassa on lukuisia syöpärekistereitä, joissa ovat kaikki kolme tyyppiä edustettuna. Kolmella alueella oli sekä HBCR että PBCR ja samoin kolmella sekä ATLAS että PBCR.

Tutkimuksen tavoitteena oli selvittää antavatko väestöpohjaisen rekisterin korvaavat HBCR ja ATLAS oikean kuvan syöpäongelmasta, kun rajaudutaan syövän primaaripaikkajakaumaan. Syövän primaaripaikka on suuressa määrin esim. resurssisuunnittelun perusta.

Jokaisesta kuudesta rekisteriparista valittiin kymmenen yleisintä syöpää (syövän primaaripaikkaa) vertailun kohteeksi. Ensin laskettiin kunkin syövän osuus kaikista syövistä. Korvaavan rekisterin ja väestöpohjaisen rekisterin antamien osuuksien erotusten perusteella avioitiin primaaripaikkakohtaista ja rekisterityyppikohtaista yhtäpitävyyttä. Mumbain rekistereitten avulla oli lisäksi mahdollista arvioida, paraniko yhtäpitävyys yli ajan tai jos HBCR-rekisteristä poistettiin ulkopaikkakuntalaiset.

Tulokset osoittivat, että HBCR tai ATLAS-rekistereitten tiedot johtivat suureen primaaripaikoittaiseen yli- tai alirekisteröintiin. Korvaavissa rekistereissä olivat yliedustettuna helposti todettavat suun ja nielun alueen syövät. Aliedustettuna olivat vastaavasti vaikeasti todettavat maha- keuhko- eturauhasen ja aivosyövät.

Ulkopaikkakuntalaisten poistaminen ei parantanut yhtäpitävyyttä eikä se systemaattisesti parantunut ajan myötä.

Koska syöpärekisteri antaa pohjan syöväntorjunnalle, syöpätaakan virheellisellä arvioinnilla on pitkän tähtäyksen seuraukset terveydenhuollolle yleensä ja erityisesti voimavarojen allokoinnille. Sen takia sairaalarekistereitä tulisi käyttää vain potilaitten hoidon arvioinnissa tai tehtäessä epidemiologisia potilaslähtöisiä ja eloonjäämistutkimuksia.

Primaaripaikkaerojen perusteella esitetään johtopäätöksenä, että HBCR tai ATLAS-rekisterit eivät anna luotettavaa kuvaa syövän esiintymisestä tai vaarasta. Tekijä suosittaa väestöpohjaisten PBCR rekistereitten perustamista erityisesti kehitysmaitten maaseudulle ja alueille joitten läheisyydestä PBCR puuttuu.

1 INTRODUCTION

Cancer registration is one of the necessary ingredients of any cancer control programme with well-established and documented utilisation (Muir and Demaret, 1985; Jensen and Storm, 1991; Nandakumar and Luthra, 2001). This has been described in detail in chapter 2. Ideally, one may desire to have a cancer registration system that fulfills all the objectives of a cancer registration. The requirement of such a system would be that it has to be population-based, and that there should be an adequately advanced health information system that is able to provide diagnostic, clinical and treatment details of all the cases. Practically however, such a system is not feasible in the setup of developing countries, because most of them, including India, lack a formal and efficient health information system (HIS). Even in developed countries, clinical data may be incomplete for a considerable proportion of the PBCR cases. For example, Schloeffel et al. (1989) integrated the HBCR data with PBCR to describe the epidemiological and clinical characteristics of laryngeal cancers in South Australia. Therefore, the principle of two different registries, namely; population-based cancer registries (PBCRs) and hospital-based cancer registries (HBCRs), got evolved and are in place. PBCR data, being able to facilitate the calculation of rates, are useful in assessing the pattern of cancer and trends therein at the community level. On the other hand, HBCR data, being able to provide clinical and treatment details, are useful in studying the magnitude and patterns of patient care in a particular hospital. PBCRs in the developed countries have been catering to their objectives effectively and accurately, at least to a reasonable extent, mostly due to small populations, advanced information systems and availability of financial resources. Therefore, the required role of HBCRs is limited in developed countries. Maybe this is the reason that there are only rare attempts at generalising the HBCR data at the population level.

In the situation of developing countries however, population-based cancer registration suffers, among other things, from two major lacunae due to the problems illustrated in detail elsewhere (Olweny, 1985; WHO, 1979); one, not being able to cover the whole population of the country and two, non-availability of reliable clinical and treatment details for the majority of cases of the PBCR. Hence PBCRs in the developing countries cover only a small part of the population. The cancer patterns observed in these small populations may not be generalised validly to the whole population, although there are a few attempts to generalise for estimating the cancer burden in the country (Murthy et al., 1990, Yeole, 1997, D'Souza et al., 2013). Moreover, the study of diagnostic, clinical extent and treatment details in all patients is not possible because the same are not available for the majority of PBCR cases. Under the circumstances, any attempt to utilise HBCR data for studying the pattern of cancer and trends therein at the population level would be of great help. In fact, there are many potential uses of HBCR data, some of which are even documented (Boyle and Parkin, 1991; NCRP, 2001a) but not tested for their validity and practical viability in the setup of developing countries.

Another concept that came up during the last decade is that of an atlas of cancer by collecting the data from all the pathology centres and tabulating according to their place of residence. However, accuracy of data on address and duration of residence in that place is a major concern. This method assumes that the proportion of cases who do not reach any of the pathology centres is very small, and therefore those cases that are captured with their residence within a geographic area are representative of the same area. There are examples of use of this concept in India at the national (NCRP, 2004) as well as state (NCDIR, Undated) level; a comprehensive validity of this concept, however, has been missing. The assumption involved in the validity of this concept is hardly tenable, especially in developing countries.

Therefore, in the scenario of developing countries, there is a need to explore the potential uses of HBCR data and to test their validity in the light of potential biases. Regarding the concept of atlas, there is a need for the comprehensive test of validity in developing countries where the proportion of cases not reaching any diagnostic centres is expected to be substantial.

1.1 Organization of the thesis

The present thesis has been organised into seven chapters. The second chapter deals with the literature review divided into two sections: The first one describes HIS in general and its status and sources of health information in India in particular; the second one highlights the current status of cancer registration in India. This section also highlights cancer control and potential uses of HBCR data in the context of developing countries. The aims and objectives of the study have been listed in the third chapter. Chapter four describes sources of data utilised for the study and statistical methods applied. Results of the application of methods developed have been presented in Chapter five. Chapter six contains the discussion of the results and the related concepts along with their applicability in India and in the rest of the developing countries. Conclusions and recommendations for further studies have also been presented in this chapter. Finally, all the aspects of this thesis have been summarised in chapter seven.

2 REVIEW OF LITERATURE

This chapter has been divided broadly into two sections. The first section defines and describes the health information system (HIS) in general and the same in India in particular. The second section deals with the cancer registration describing terms and concepts and scope of cancer registration and related epidemiological aspects in India.

2.1 Health information system

HIS may be defined as a set of components and procedures that work together in an organised manner to generate the information which may improve health care management decisions at all levels of the health system. The ultimate objective of any HIS is not to accumulate data or information but to convert the same into intelligence that can be used to improve, monitor and evaluate the health-related actions. It is therefore essential that one is clear about the concepts of data, information and intelligence that are important stages of any HIS. Data are discrete observation on some characteristics of the subjects in the study population. In general, one cannot interpret much from data unless these are converted into information. Information is determined by putting the data into some sort of summary or index measure with scientific meaning. Information gives meaningful facts about the population. However, it is not of much use for the policy planners/administrators, who are seldom subject experts. What they need is

intelligence obtained by integrating information with the existing theoretical/scientific/social beliefs about the parameter under study (Park, 2015).

Health information systems may also be defined as any system that captures, stores and manages data, transforms it into information followed by intelligence and transmits the same related to the health of individuals or the activities of organisations that work within the health sector (PHIN, 2011). Therefore, HIS should attempt to collect, process, report and use health information and knowledge to influence policy and decision making, programme action and research. Sound decision making at all levels of a health system requires reliable health information that are disaggregated by sex, age and socioeconomic characteristics, etc. At the policy level, intelligence derived from research contribute to more efficient resource allocation, and at the service provision level, information about the quality and effectiveness of services can contribute to better outcomes. Furthermore, capacity building is also required to ensure that policy makers at all levels have the ability to use and interpret health data, whether it originates from routine data collection, health surveys or special operational research. It is also important that staff working at the periphery of the health system understand the significance of local data for local program management, and that their needs for strengthened capacity for critical health statistical analysis are met. The use of data collected locally at lower levels of the health system is a key step for improving overall data quality.

In fact, the main improvement required in HIS planning is to provide all the possible information needed to make an effective policy for the betterment of the population. An information system is mostly inadequate due to shortfalls in the supply of desired information. The information needs should be specified by the group of users consisting of planners, administrators and researchers, private and public agencies related to the work within the particular segment. The means for data collection to supply the needed information should consider all the available tools according to the nature of the information. The administrative record and

registers related to the existing infrastructure, sample surveys, censuses, case studies and experimental studies designed to test different hypotheses, exploratory studies in applicable fields are the examples of instruments. The selection of particular tools is crucial to minimise different types of errors that may creep into the huge network of data bases. Currently, the validity of the data set depends on the monitoring of the respondents at the gross-root level. Most of the biases are due to inefficiency on the part of enumerators, as they may collect all the required data sitting at one place in their allotted area without visiting the home of any individuals. For instance, in the Indian census, the government employs mostly primary school teachers as enumerators who may not be adequately trained to elicidate the data.

HIS is known to be deficient in low and middle-income countries. In view of this, the WHO launched the Health Metrics Network (HMN) in 2005 to help countries and other partners improve global health by strengthening the systems that generate health-related information for evidence-based decision making (WHO, 2008). It is the first global health partnership focusing on two core requirements of HIS strengthening. First is the need to enhance entire health information and statistical systems rather than focusing upon specific diseases, and the second is to concentrate efforts on strengthening country leadership for health information production and use. HMN has been designed to ensure the coordination and aligning of the partners around an agreed-upon framework for the development and strengthening of HIS. The goal of HMN is to increase the availability, accessibility, quality and use of health information vital for decision making at national and global levels. The framework consists of two parts: one, components and standards of HIS, and two, strengthening HIS.

The first part of HMN specifies six components of HIS and standards and criteria for assessment of the same. These components are HIS resources, indicators, data sources, data management, information products and dissemination and use. The second part describes the guiding principles, processes and tools that taken

together outline a roadmap for strengthening HISs. Thus, HMN may be considered as an important development for evaluating and strengthening HISs in developing countries.

2.1.1 Health information system in India

India does not have a formally organised health information system. However, there are many scattered and unorganised sources of health information, resulting into many lacunae with HIS in India. The most prominent are; 1) irrelevance of the information collected, 2) poor quality of data, 3) non-availability of data in the public domain and 4) inadequate utilisation of the data for research leading to intelligence.

Raban et al. (2009) studied the essential health information available for India in the public domain on the internet. They identified 26 sources on the internet that yielded a usable essential health information system for India. These sources of health information, however, have wide variation with respect to periodicity, geographical level and availability in the public domain. The major weakness reported by Raban et al. are; lack of information on non-communicable diseases and injuries, primary data on causes of death, and the private health sector and district level information. They hoped that recent initiatives will help enhance the health information system and stressed for a systematic approach to develop a streamlined system addressing the critical gaps.

Pandey et al. (2010) reported issues of data availability and quality in the HIS in India. They pointed out many gaps and lacunae in the existing system. Most prominent of them was a discrepancy between the type of information provided and

that required by the health care planners. This points out the lack of coordination at different levels of a health care setting resulting in wastage of resources. They observed the non-existence of nationwide morbidity and epidemiological studies and paucity of cause of death statistics.

The main defect in the setup of developing countries is the lack of any information relating to treatments rendered by private practitioners, mainly in small towns where hospital services are not adequate. The reliability of morbidity data for the rural areas too, depends upon the utilisation of the services rendered by the PHCs and the sub-centers. In other words, if the utilisation rate is poor, many of the morbidity cases treated through quacks, allopathic/non-allopathic practitioners or those not treated remain unreported. The morbidity is then, as is well known, underreported in the present setup. Further, information is also needed to ascertain the proportion of expenditure by diverse socio-economic groups on medicine mainly by the weaker section. The morbidity statistics coming out of the administrative records and reports are deficient in many ways like coverage error, ascertainment errors, varying reliability and lack of comparability between the data sets generated by the states.

The constitution vests the responsibility of health to both central and state governments. The centre has the primary responsibility for provisions listed in the union list ((i) international health relations and port quarantine, (ii) administration of central institutes, (iii) promotion of research, and (iv) census, collection and publication of statistical data) and concurrent list (vital statistics including registration of births and deaths, prevention of food adulteration, drug control and labour welfare). On the other hand, states have responsibility for sanitation and medical care, public health, hospital and dispensaries (GOI, 2015). Therefore, central and state agencies are the main source of health information. Sources of health information and related issues have been grouped into two categories - direct and indirect sources. Direct sources constitute the official statistics and sample surveys.

Indirect sources encompass the Sample Registration System, Civil Registration System and Census (Pandey et al., 2010).

Typical sources of health information are quite conventional and well known, documented and reviewed for their merits and demerits. Also, these sources are into existence since middle of last century or before. Prominent among them are the Census, civil registration system (CRS) and sample registration system (SRS). Table 2.1 highlights the important socio-demographic characteristics (as obtained from Census and SRS) of India and mother states of the three registry areas under study.

There are some additional non-conventional sources of health information in India that came into existence during last few decades. Prominent among them is the National Cancer Registry Programme of India established by the Indian Council of Medical Research in 1980. This has been discussed in detail in section 2.2. There are many other non-conventional and more comprehensive sources of health information in India which have contributed to health care and facility planning in India over the last two decades. Data have been collected at the micro level, facilitating micro level analysis on the one hand, and on the other hand, collected data have been transformed into reports to provide information at the macro level. Intelligence from the policy point of view was generated directly from the reports, and availability of raw data in the public domain also results in a lot of research leading to a potential intelligence generation. Let me highlight in detail here these sources, their coverage and different dimensions of data availability.

Table 2.1: Important socio-demographic characteristics of India and three states (Maharashtra, Karnataka and Tamil Nadu).

Characteristics	**India**	**Maharashtra**	**Karnataka**	**Tamil Nadu**
Population				
Total	1,210,569,573	112,374,333	61,095,297	72,147,030
Male	623,121,843	58,243,056	30,966,657	36,137,975
Female	587,447,730	54,131,277	30,128,640	36,009,055
Rural	833,463,448	61,556,074	37,469,335	37,229,590
Urban	377,106,125	50,818,259	23,625,962	34,917,440
Children (<15 Years) (%)	28.4	26.5	25.1	23.0
Senior Citizen (60+ Years) (%)	8.3	9.8	8.8	10.9
Dependency Ratio (per 1000)				
Total	652	578	556	516
Young (<15 years)	510	422	408	358
Old (60+ years)	142	157	148	158
Sex Ratio (females/1,000 males)	943	929	973	996
Growth rate (per 1,000 persons)	17.7	16.0	15.6	15.6
Urbanization (%)	31.1	45.2	38.7	48.4
Density (per square kilometre)	382	365	319	555
Mean age at marriage of ever married persons (years)				
Males	23.0	23.6	25.2	25.8
Females	19.1	19.2	19.5	20.3
Literacy Rate (%)				
Total	73.0	82.3	75.4	80.1
Male	80.9	88.4	82.5	86.8
Female	64.6	75.9	68.1	73.4
Crude birth rate (/1,000persons)	21.4	16.5	18.3	15.6
Crude death rate (per 1,000 persons)	7.0	6.2	7.0	7.3
Total fertility rate	2.3	1.8	1.9	1.7
Life expectancy at birth (years)	67.5	71.3	68.5	70.2
IMR (per 1,000 live births)	40	24	31	21
Maternal mortality ratio (per 100,000 live births)	167	68	133	79
Maternal mortality rate (per 1,000 women 15-49 years)	11.7	4.1	7.5	4.5

Sources: Census (2011) and RGI (2014a).

2.1.2 Non-conventional sources of health information

2.1.2.1 National Cancer Registry Programme (NCRP)

Described in detail in Section 2.2. The information generated out of this programme are published in the form of reports. However, raw data are **not available** in the public domain.

2.1.2.2 National Family Health Survey (NFHS)

Until the early 1990s, there were only traditional and typical sources of demographic data like, census, CRS, SRS, etc., available mostly at the macro level. These data were quite useful in highlighting the issues related to population growth, high fertility and high mortality, especially, infant and child mortality. The focus as well as areas of intervention for the policy planners were, however, under the transition from traditional issues stated above to health in general to reproductive and child health (RCH), adult health and ageing in particular. Thus, a requirement of comprehensive data on population and health at the macro as well as the micro level was felt to be lacking. NFHS was the first step initiated by the Ministry of Health and Family Welfare (MOHFW), Government of India (GOI) in 1992 towards filling this information gap. NFHSs are the nationwide surveys with a nationally representative sample of households. The four NFHSs conducted so far have been

established as a major landmark in the generation of vast data at the national and state levels. The important objective of these surveys was to provide nation and state level estimates of fertility, family planning, infant and child mortality, reproductive and child health, nutrition of children and women, the quality of health and family welfare services and socioeconomic conditions. The information generated from the data of NFHSs help administrators and policy makers in planning and implementing programs pertaining to population, health and nutrition. The International Institute for Population Sciences (IIPS), Mumbai has been the nodal agency designated by MOHFW for conducting these surveys (IIPS, 2007).

The first round of NFHS was conducted during 1992-93 with the main objective of strengthening the survey research capabilities of the Population Research Centres (PRCs) functioning in the country. This survey was based on nationally representative samples of 88,562 households and 89,777 ever married women in the age group of 13-49 years covering 24 states and the National Capital Territory of Delhi.

The second round of NFHS was conducted during 1998-99 covering a nationally representative sample of more than 91,000 ever married women aged 15-49 years spread across all 26 states of the country. In addition to national and state level estimates as in the first round, this round also provided regional level estimates for five states, namely, Bihar, Jammu & Kashmir, Madhya Pradesh, Rajasthan and Uttar Pradesh, estimates for three metropolitan cities, namely, Chennai, Kolkata and Mumbai and estimates of slum areas in Mumbai. This survey was conducted in the backdrop of International Conference on Population and Development (ICPD) held in Cairo in 1994 highlighting the need for focus on RCH. Hence, this round of NFHS was seen as an important step in strengthening the database for implementation of RCH approach of development. Accordingly, in addition to population and health aspects covered in first round, this round collected data on

the quality of health and family welfare services, reproductive health problems, status of women and domestic violence. Important inclusions in this round were;

- Height and weight measurements of ever married women,
- Measurement of hemoglobin level of ever married women and their children aged under 3 years,
- Measurement of lead content in the blood of children aged less than 3 years in Mumbai and Delhi, and
- Measurement for the iodine content of household cooking salt.

The third round was conducted during 2005-06 covering nationally representative samples of 124,385 women aged 15-49 and 74,369 men aged 15-54 spread over all 29 states. Of these, 102,946 (51.6%) persons were also tested for HIV. Estimates of HIV prevalence were provided for older men and women at the national level, for Uttar Pradesh and five states known for high prevalence, namely, Andhra Pradesh, Karnataka, Maharashtra, Manipur and Tamil Nadu. In addition, this round provided routine estimates of population and health indicators for slum and non-slum populations of eight cities, namely, Chennai, Delhi, Hyderabad, Indore, Kolkata, Meerut, Mumbai and Nagpur. Two major components of this round were blood testing for HIV prevalence and interviewing ever married as well as never married women. Other important inclusions in this round were;

- Perinatal mortality,
- Male involvement in the use of health and family welfare services,
- Adolescent reproductive health,
- High risk sexual behaviour,
- Family life education,
- Safe injections, and
- Knowledge about tuberculosis.

The fourth round of NFHS is in the process of being conducted in 2 phases. The first phase covering 17 States and Union Territories (UTs) of the country with a reference period of 2015-16 has been completed and state and district level fact sheets already published. The second phase of this round is in the stage of data collection with a possible reference period of 2016-17. For the first time in this round, sampling was performed to provide district level estimates and inadvertently causing redundancy of continuation of district level household and facility survey (DLHS), discussed in next section. Content-wise, important inclusions in this round are;

- Malaria prevention,
- Migration in the context of HIV,
- Abortion (induced and spontaneous both),
- Violence during pregnancy, and
- Blood pressure and blood glucose levels.

The information generated out of these surveys has been published in the form of reports, and the raw data are available in the public domain for research purposes. Reports can be accessed at http://rchiips.org/NFHS/index.shtml, and raw data can be obtained for research purposes from http://www.iipsindia.ac.in/.

2.1.2.3 District Level Household and facility Survey (DLHS)

India, being a signatory to the Alma Ata Declaration of 1978, was committed to attaining 'Health for All' by 2000 through the Primary Health Care (PHC) approach (WHO, 1978). The country started establishing PHCs during the 1950s, and many changes and expansions took place during rest of that century. Initially,

the emphasis was on the expansion of health care establishment. Subsequently, however, it was shifted to the consolidation of existing health infrastructures rather than expansion. The thrust was on qualitative improvement in the health services by strengthening physical services like provision of essential equipment, supply of drugs and consumables, buildings and staff quarters and filling medical and paramedical posts. The National Health Policy stressed the provision of preventive, promotive and rehabilitative health services to the people, thereby shifting from medical care to health care. The provision of primary health care services is the foundation of the rural health information system and is an integral part of the national health care system. The health care system in India can be divided into the following four categories (Bhat, 1995);

- Public sector: government run hospitals, dispensaries and health centres,
- Organized by non-governmental organizations (NGOs),
- Organized private sector: private hospitals, nursing homes, dispensaries, and
- Unorganized private sector: faith healers, etc.

There is evidence that of the above four, the government is the dominant source of health care in the important domains like, immunisation, antenatal care, family planning and infectious disease control (GOI, 1998; World Bank, 1996). These basic facts about health care in India prompted the MOHFW (GOI) to implement a Reproductive and Child Health (RCH) programme with the objective of providing reproductive and child health services through existing government health care establishments. The programme also aimed to strengthen health infrastructure in terms of trained staff, equipment and supplies to enhance the facilities to provide good quality RCH services. For the effective implementation, monitoring and evaluation of this programme, the need for data on RCH services and facilities at the micro (district) level was felt. To fulfill this need, GOI decided

in 1998-99 to undertake a facility survey at the district level in all the 25 states and 7 UTs with the financial assistance provided by the World Bank.

As described above, DLHS started initially as Reproductive and Child Health (RCH) survey in 1998 by Department of Family Welfare, MOHFW, GOI. It was repeated in 2003, and the two surveys were known as RCH Phase I and Phase II respectively. During 2007-08, the third phase was conducted, and the three surveys were renamed (informally) retrospectively as DLHS-1, DLHS-2 and DLHS-3. Recently, during 2012-13, DLHS-4 has been conducted and has been decided to be the last phase of DLHS, as the same has been found to be somewhat contained in NFHS in its latest form.

The first phase of DLHS was conducted in 221 districts from 25 states and 7 UTs (IIPS, Undated). The second phase covered the remaining 370 districts from all the states (no UTs, as UTs were covered completely in first phase) (IIPS, 2005). These surveys were conducted with the objective to assess;

- Percent of facilities having critical inputs as per the norms stipulated by RCH,
- Utilisation of the facilities for providing RCH services,
- Utilisation of CHCs and FRUs as referral units,
- Utilisation of Indian system of medicine for RCH services, and
- Quality assessment of services at each health facility level.

The third round of DLHS was conducted in the backdrop of the National Rural Health Mission (NRHM) launched by GOI in 2005. The main goal of NRHM was to reduce the infant mortality rate (IMR) and maternal mortality rate (MMR) by promoting newborn care, immunisation, antenatal care, institutional delivery and postpartum care in the rural population of the country with a special focus on the states with poor health outcomes and inadequate public health infrastructures and

manpower. The primary focus of the mission was to improve access for rural people, especially women and children, to equitable primary health care. Therefore, DLHS-3 was designed to collect data at the district level on different aspects of health care utilisation for RCH and accessibility of health facilities, to assess the effectiveness of accredited social health activist (ASHA) and Janany Suraksha Yojana (JSY) in promoting RCH care, to assess the health facility capacity and preparedness in terms of infrastructure. This survey covered 720,320 households from 601 districts across 34 states/UTs. From these households, 643,944 ever married women aged 15-49 years and 166,260 unmarried women aged 15-24 years were interviewed (IIPS, 2010a, 2010b).

The fourth round of DLHS was conducted in 2012-13 covering 640 districts across 36 states/UTs. The aim of this survey was to provide maternal and child health (MCH) care indicators and the prevalence of morbidity for a wide range of common, communicable, non-communicable and lifestyle diseases covering the following aspects;

- Household basic amenities,
- Prevalence of morbidity,
- Coverage of antenatal and immunisation services,
- Proportion of institutional/safe deliveries,
- JSY beneficiaries,
- Economic burden of delivery,
- Contraceptive prevalence rate,
- ASHA's involvement,
- Unmet need for family planning,
- Awareness about RTI/STI and HIV/AIDS,
- Infrastructure, manpower, equipment, drugs, services of public health facilities, and

- Linkage between health facility and MCH indicators.

The information generated out of these surveys have been published in the form of reports, and the raw data are available in the public domain for research purposes. Reports can be accessed at http://rchiips.org/ and the raw data can be obtained for research purposes from http://www.iipsindia.ac.in/.

2.1.2.4 Study of global AGEing and adult health (SAGE)

Ageing of the population may be defined as an upward shift in the average age of the individuals in a population which may happen in one of three ways: 1. increase in the proportion of older persons (aged 60+ years); 2. decrease in the proportion of younger persons (aged <15 years); 3. both. Ageing of the population is one of the important demographic characteristics observed in twentieth century in all the developed and most of the developing countries. It is expected to continue as a challenge throughout the twenty-first century, especially in developing countries including India.

Population ageing is quite apparent in India with both the causes of population ageing being active. Antinatal policies in India have resulted in a reduction in the proportion of children and the control of infectious diseases and improvement in health care have resulted in an increase in life expectancy, leading to the increase in proportion of elderly. The proportion of elderly in India has increased from 6.5% in 1981 to 9% in the 2011 (Census of India, 2011), and it is expected to grow further to 11% by 2025 and to 19% by 2050. On the other hand,

the proportion of children (37.5% in 1950) is expected to decrease to 19% by 2050 (UN, 2011).

Older persons in low resource settings like India face many problems like insufficient income, ill health, absence of social security, loss of a productive role. Population projections clearly indicate that ageing may continue to pose a considerable challenge in India, and large resources may be needed to support, care and treat older persons. There were a variety of secondary data on older people in India available, however, evidence based on the health, economic status, quality of life and wellbeing of older adults was by and large neglected until recently. This gap in evidence-based policy was addressed by the World Health Organization (WHO) in 2007 by initiating SAGE in India as a part of a study focusing six of 70 countries that participated in the World Health Survey (WHS) conducted in 2003. The other five countries where SAGE was initiated are China, Ghana, Mexico, the Russian Federation and South Africa. It was initiated with the goal of i) promoting a better understanding of the effects of ageing on wellbeing, ii) examining the health status of individuals aged 50+ years as well as changes, trends and patterns that occur over time, and iii) improving the capacity of researchers to analyze the effects of social, economic, health care and policy changes on current and future health. To achieve these goals, the following are the stipulated objectives of SAGE (WHO, 2013).

- To obtain reliable, valid and comparable data on levels of health in a range of key domains for adult populations who are 50 years and older in nationally representative samples.
- To examine patterns and dynamics of age-related changes in health and wellbeing, using longitudinal follow-up of survey respondents as they age, and to investigate socioeconomic consequences of these health changes.
- To supplement and cross-validate self-reported measures of health and the anchoring vignette approach to improving comparability self-

reported measures, through measured performance tests for selected health domains.

- To collect data on health examinations and biomarkers to improve the reliability of data on morbidity and risk factors, and to monitor the effect of interventions.

The World Health Survey (WHS) conducted in 2003, considered as Wave 0 by SAGE, was conducted in six states, namely, Assam, Karnataka, Maharashtra, Rajasthan, Uttar Pradesh and West Bengal, selected randomly from six regions, namely, north-eastern, southern, western, northern, central and eastern respectively. The overall sample size was 10,279 households with a focus on one adult (aged 18+ years) in each household. A systematic random sampling method was used to ensure the representation of different

- Regions
- Gender
- Levels of development (based on infant mortality rate, female literacy, proportion of safe deliveries and per capita income)
- Place of residence (urban/rural)
- Age groups.

Wave 1 of SAGE was conducted in 2007 in all the six states included in the WHS with a sample size of 9,626 households and 11,230 individuals interviewed. This sample included 1,045 men and 3,625 women aged 18-49 years and 3,304 men and 3,256 women aged 50+ years. Wave 2 of this survey is underway. Data collection was done during the year 2015, and data editing for errors and analysis is in process.

The information generated out of these surveys has been published in the form of reports, and the raw data are available in the public domain for research purposes. The report of Wave 1 can be accessed at apps.who.int/**health**info/systems/**survey**data/index.php/catalog/65/ download/2011 and the raw data can be obtained for research purposes from http://www.iipsindia.ac.in/.

2.1.2.5 Longitudinal Ageing Study in India (LASI)

The rationale for this project is by and large contained in the write-up for SAGE. Population aging is a natural phenomenon that all countries face, but global averages may always mask the existing heterogeneity across and within regions. Like demographic transition, countries are in different stages of age transition with the proportion of the older population increasing as a result of improvement in health care and fertility control. Most of the developed world is already in the last stage of aging, and therefore their wellbeing related issues have been thoroughly studied and taken care of. In many of the developing countries including India however, transition to the older population has started somewhat recently, and therefore little is known about the economic, social and public health implications of aging. To fill this gap, LASI was started as a partnership between the International Institute for Population Sciences, the Harvard School of Public Health and the RAND Corporation. The pilot form of LASI has already been completed in 2010 with the plan of covering a longitudinal and fully representative group of the Indian population aged 45 years and older. The process of the main course of the LASI survey is currently underway. The long-term goal of LASI is to explore the social, economic and health experiences of older people throughout India as they grow from late adulthood to senior citizen (IIPS, 2010).

The information generated out of the pilot form of this survey has been published in the form of reports, and the raw data are available in the public domain for research purposes. The report of the pilot study of this survey will be available on the website of LASI to be created in due course, and the raw data can be obtained from http://www.iipsindia.ac.in/.

2.1.2.6 Health management information system (HMIS)

Contrary to the general perception in the country, India does possess a HMIS launched by GOI in 2008. However, it is not exhaustive in nature. It was established and therefore devoted to a particular health programme. HMIS is a digital initiative launched in the backdrop of the National Rural Health Mission (NRHM) launched in 2005. NRHM was launched with the aim of bringing about improvement in the health status of people living in the rural area of the country. The mission aimed to provide universal access to equitable, affordable and equal health care that is accountable and at the same time responsive to the needs of the people. Later on, the scope of NRHM was expanded to also include urban areas, and therefore currently it is known as the National Health Mission (NHM). For effective working, monitoring, evaluation and guiding the NRHM, accurate, relevant and up-to-date information was felt to be an essential requirement of any level of health service providers for initiating action on the gaps in the system based on evidence- based information. To fill this need, MOHFW established a dedicated HMIS portal for all public health related information. The portal captures data to be collected as per standard formats on a web-based system at the district level so that the primary data can be easily aggregated, and the information can flow quickly to the state headquarters and the ministry (HMIS, 2016).

2.1.3 Needs pertaining to HIS in India

India is a vast country with not only socio-cultural and linguistic diversity, but also diversity in overall health, availability of health care and utilisation. There are few states with poor health outcomes and poor health care availability and utilisation. On the other hand, there are also states with a level of health status approaching that of the developed countries (IIPS, 2007; Hazaika, 2013; WHO, 2013). After reasonable improvement in population and fertility control, the focus has recently shifted to maternal and child health. The concept of equitable distribution is one of the key features of recent health policies in the country (Balarajan et al., 2011; Ghosh, 2014), and this concept takes care of the existing differentials in health care availability and utilisation.

Regarding types of health issues, some states still show high maternal, infant and child mortality rates, indicating the continuance of maternal and child health related issues. On the other hand, some states have transitioned into the era of NCDs (IIPS, 2007; WHO, 2013). As far as maternal and child health issues are concerned, programmes like NHM are already in place. The need of the hour is to prepare an adequate response to NCDs that have emerged as new public health challenges as a result of control of MCH issues and infectious diseases.

As described earlier, the first stage in any HIS is data collection. Broadly, there are two main reasons for data collection; one, for monitoring and evaluation of health programmes and two, for research purposes. HMIS is good initiative in the direction of first use of data. However, its scope is limited to NHM. Therefore, the role of HMIS should be expanded to include all the health programmes.

As far as utilisation of data for research and intelligence generation is concerned, availability and awareness are the important issues. Sometimes data may be available in the public domain, but there may not be enough awareness about the same in the research community. For example, data obtained from large-scale surveys conducted at IIPS are available in the public domain for research purposes. However, its thorough awareness may be somewhat limited to those directly or indirectly connected to IIPS. On the other hand, data on a particular health aspect may be available in the country, but not in the public domain. For example, large data sets have been collected by NCRP over the last 3-4 decades. However, the same is not available in the public domain. Therefore, all the health-related data need to be integrated into one system with its thorough awareness in the research community and availability in the public domain. This can easily be achieved by making mandatory the sharing of the data collected by spending public funding on a central system designated for the purpose. The HMIS, being a GOI initiative, has the potential to take the lead in this direction.

2.2 Cancer registration in India

2.2.1 Terms and concepts related to cancer registration

Cancer registration is a continuous process of the systematic collection of data on the occurrence and characteristics of reportable neoplasms (Maclennan et al., 1978), and a cancer registry is an office or system performing cancer registration. The definition of `reportable neoplasms' may vary from registry to registry. Some of the registries in developed countries register even benign and/or in-situ cancers. In

India however, cancer registration is restricted to the reporting of only invasive cancers (NCRP, 1987).

There are two types of cancer registries; population-based cancer registries (PBCRs) and hospital-based cancer registries (HBCRs). PBCRs collect data on all the cancer patients in a pre-defined geographic area. On the other hand, HBCRs collect data on all the cancer patients visiting a particular hospital for diagnosis and/or treatment. Therefore, PBCR data are useful in epidemiological investigations, whereas HBCR data are useful to the management, clinicians and patients of the corresponding hospital. Given these, the emphasis by the registries is also divided in the two types of registries. In the PBCR setup , the main emphasis is on the recording of each and every case of that area once and only once, whereas in the HBCR setup, the main emphasis is on the collection of maximum and most accurate information on diagnostic, clinical and treatment details.

As far as the process of cancer registration is concerned, there are two methods; active and passive. In the active method, registry personnel visit all the potential sources of cancer patients and collect data,whereas in the passive method, a cancer case identified is reported under a mandatory rule to the registry covering that area. Thus, the passive method of registration is always easier, cheaper and therefore preferable. The choice of registration method, however, is not in the hands of the registry administrator; rather it depends on the system. Registries in most of the developed countries have a passive method of cancer registration, because either notification of cancer is mandatory in those countries (Wagner, 1991) or an effective health information system is in place. For example, a cancer case diagnosed anywhere in Finland is supposed to be reported (under a mandatory rule) to the Finnish Cancer Registry operated by the Finnish Cancer Society. In most, if not all, of the developing countries including India however, there is no legislation on cancer notification. Most of the developing countries also lack a health information system, and therefore the method of cancer registration is active. The tracing of all the

potential sources of cancer cases and making regular visits to all the sources makes cancer registration quite resource intensive. Most of the developing countries have a huge population in relation to natural and other resources. This is another factor adding to the difficulties in population-based cancer registration. Therefore, most, if not all, of the developing countries lack a national population-based cancer registry. At the same time, these countries, especially India, have relatively more socio-cultural and religious diversities, making the generalisation of the results from small population to the whole national population difficult.

2.2.2 Status of cancer registration in India

Although cancer is known in Indian history from Vedic times, no data on cancer were available in India until 1963 when a limited period cancer survey was undertaken in the Mainpuri district of Uttar Pradesh by the Indian Cancer Society, Mumbai. Following the survey, the Indian Cancer Society established a population-based cancer registry in Mumbai in the same year (Jussawalla and Deshpande, 1966). Subsequently, with the idea of getting a picture of cancer pattern in whole of Maharashtra, three satellite registries of the Mumbai registry were established; at Pune in 1972 (Jussawalla et al., 1979), at Aurangabad in 1978 (Jussawalla et al., 1984) and at Nagpur in 1980 (Jussawalla et al., 1987). Probably taking a clue from the Indian Cancer Society, the Gujarat Cancer Research Institute also established a population-based cancer registry for Ahmedabad city in 1980 (Patel, 1986).

Despite only a few decades of cancer registration history in India and reliable data for Mumbai, Pune, Aurangabad, Nagpur and Ahmedabad respectively from 1964, 1972, 1978, 1980 and 1983, there were no data at the national level or data that can be extrapolated at the national level until the early 1980s. Realising the growing

problem of cancer due to the control of communicable diseases and the resultant increase in life expectancy and the lack of information on the magnitude and pattern of cancer in India, the Indian Council of Medical Research (ICMR), a premier medical research institution in India, initiated a national network of cancer registration, namely the National Cancer Registry Programme (NCRP), in 1980 with the following objectives (NCRP, 1987):

- To generate authentic data on the magnitude and pattern of cancer problem.

- To undertake epidemiological investigations and institute control measures.

- To promote human resource development in cancer registration and epidemiology.

Under the network of NCRP, three population-based cancer registries (PBCRs) -one each at Mumbai, Bangalore and Chennai - and three hospital-based cancer registries (HBCRs) - one each at Chandigarh, Dibrugarh and Trivandrum - were established in 1982. Subsequently, in 1984 three more HBCRs were added - one each at Mumbai, Bangalore and Chennai - where PBCRs were functioning. Later on, three more PBCRs were also established - one at Institute Rotary Cancer Hospital, All India Institute of Medical Sciences, New Delhi in 1986, another special purpose registry at Gandhi Medical College, Bhopal in 1986 following the MIC gas disaster, and the third one in 1987 at Barshi in the Solapur district of Maharashtra, the first rural cancer registry in India.

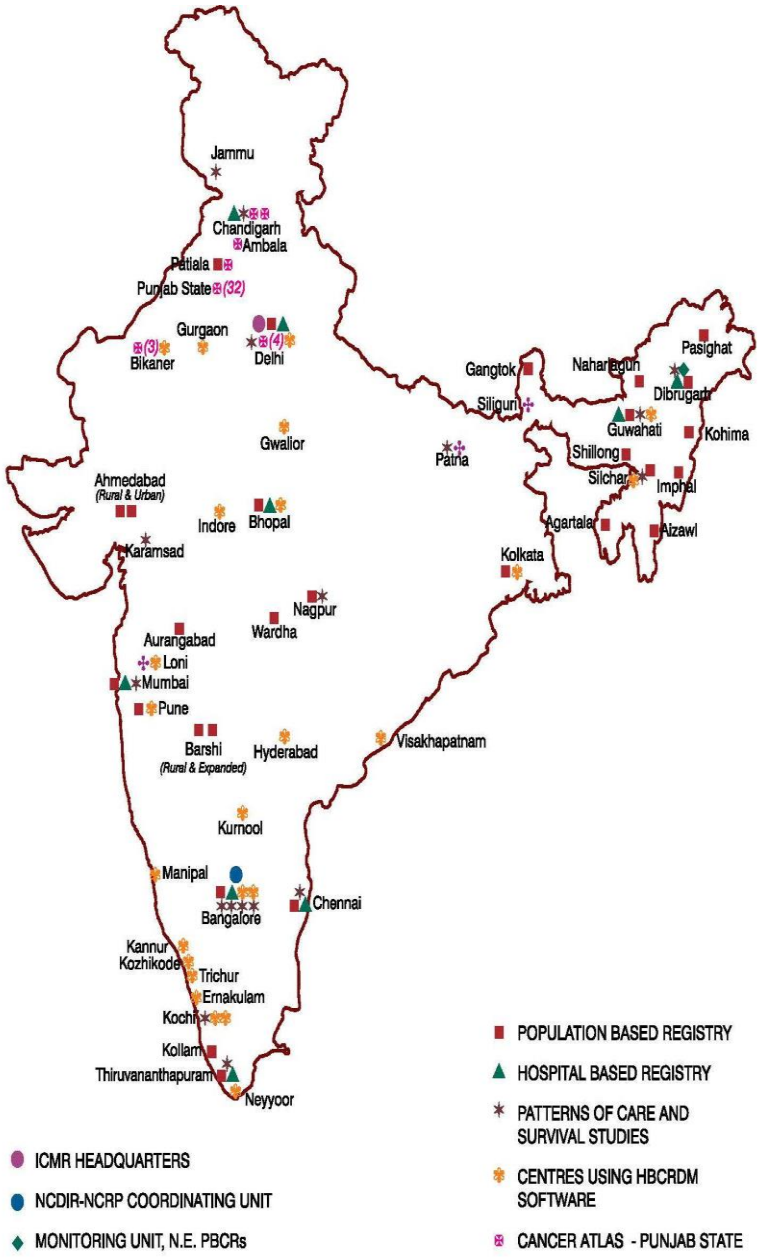
Later on, the population-based cancer registration in the country was expanded to the north-eastern region of the country by establishing six population-based cancer registries in the region. Three PBCRs were established in the state of

Assam - one each at Guwahati, Dibrugarh and Silchar and other three at Sikkim, Imphal and Mizoram.

Although NCRP is the main source of data on cancer morbidity and mortality in India, there are quite a few registries (in addition to Pune, Nagpur, Aurangabad and Ahmedabad stated earlier) in different parts of the country functioning outside the network of NCRP. The Regional Cancer Centre, Thiruvananthapuram, initiated a Rural Cancer Registry in Karunagapally in the Kottayam district of Kerala in 1990. Another rural registry has been functional in Ambillikai since 1996 operated by the Cancer Institute, Chennai. The Regional Cancer Centre, Thiruvananthapuram also established a population-based cancer registry in 1994 covering the population of Thiruvananthapuram. The Chitaranjan National Cancer Institute, Kolkata, initiated the Kolkata Cancer Registry in 1997. Although, these registries started outside the network of NCRP, most of these and many more registries over the years have been included in the network of NCRP. As of now, there are 26 PBCRs and 6 HBCRs under the network of NCRP. These PBCRs are spread over 16 States and one Union Territory and cover about 7.5% of the total population of the country (NCRP, 2013).

Figure 2.1 depicts the location of cancer registration activities in India within the network of NCRP as well as outside it with the distinction of hospital/population-based registries. The figure also shows the administrative, coordinating and monitoring units involved with NCRP as well as the centeres participating in the projects undertaken by NCRP, namely, 'Atlas' and 'Patterns of care' and those using data management software (HBCRDM) developed by NCRP.

Figure 2.1: Map* of India showing cancer registration and related activities in the country



*Not according to scale.

2.2.3 Coding of cancer sites

There are two coding systems published by the World Health Organization (WHO) adopted for the coding of cancer sites in Indian registries: 1. according to the International Statistical Classification of Diseases, injuries and causes of death (ICD) and 2. according to International Classification of Diseases for Oncology (ICDO). ICD is a classification system with the provision for coding of all the diseases, injuries and causes of death, whereas ICDO is an expansion of Chapter 2 `Neoplasm' of ICD. Coding in the ICD system is based on topography (i.e., primary site) consisting of a four-character code for each site of cancer, whereas in ICDO, it is based on the topography and morphology of the disease with a four-character topography code and a 6-digit morphology code (first 4 digits for morphology, 5th digit for behaviour code and the 6th digit for grade or differentiation).

Thus, ICDO is a detailed coding system as compared to ICD, and therefore information gathered in ICD codes are contained in ICDO codes. Still, primary site coding is done according to both systems in the Indian NCRP because it facilitates repeat collection of data on the site of cancer, which is one of the important information items collected by the cancer registries. Moreover, such double coding facilitates consistency checking between the codes according to two systems and helps in improving the quality of data on sites of cancer by minimising coding and data entry errors. As far as routine reporting is concerned, it is done according to ICD to facilitate intra and inter registry comparisons at the national and international levels.

Different versions of ICD and editions of ICDO have been used in the Indian NCRP for coding over the past two to three decades. When registries under NCRP started data collection during the early 1980s, the ninth revision of ICD (WHO, 1977) and the 1st edition of ICDO (WHO, 1976) were used. Recently however, all the registries have switched over to the 10th revision of ICD (WHO, 1992-1994) and 3rd edition of ICDO (WHO, 2000). As far as reporting of NCRP data is concerned, data for the period up to 1998 have been reported according to the 9th revision of ICD and from 1999 onwards according to the 10th revision.

2.2.4 Quality control of data

The process of quality controls in the NCRP starts with the individual registries carrying out simple checks and continues to the coordinating unit where extensive checks are carried out. A quite exhaustive list of range checks, consistency checks and so-called 'unlikely' checks have been developed during the late 1980s and 1990s. These checks are extensively used to control the quality of data.

Range checks are applied on almost all the variables that are numerically coded. These checks look for the validity of the individual codes and vary from the simplest range check for code for sex to the complex checks for the code for the site according to ICD and for morphology according to ICDO.

Consistency checks have been developed to check for the impossible, illogical or unusual combinations of codes for one or more variables. For example, if the sex code is 2 (female sex), then the primary site code should not be any of the codes meant for male genital organs. Similarly, if the sex code is 1 (male sex), then the primary site code should not be any of the codes meant for female genital organs. Another example is that the date of the start of treatment should not precede the date of diagnosis.

Unlikely checks are based on the IARC publication (Parkin et al., 1994) on 'Comparability and Quality Control in Cancer Registration'. This publication gives a detailed listing of more than 50 histological families with a corresponding list of sites in which these histologies are unlikely to occur.

Duplicates and multiple registrations of the same patient is a major issue because there is no overall personal identity number and no consistent name of patient in India. Extensive checks are carried out at the individual registry level and again at the Coordinating Unit. In the case of HBCRs, it is not a major issue unless very high in number, which is unlikely. However as stated earlier, simple duplicates checks are carried out by matching different combinations of name, age, sex and site.

In the case of multiple primaries, separate forms are filled for each of the primaries. Thus, each of the primary cancers is considered as a case. Therefore, the total number is actually not the total number of patients, but it is the total number of cancers.

2.2.5 Analysis and dissemination of information in NCRP

There are two stages of analysis and dissemination of NCRP routine data; one at the individual registry level and the other at the level of coordinating unit (COU). Individual registries generally publish their own reports every year, whereas COU publishes consolidated reports of all the HBCRs under the network of NCRP at a gap of 2 to 4 years. The technical contents of the two types of reports are similar, except that one deals with one individual registry, whereas the other one deals with all the registries under the network. The first few chapters of the reports dealing with the magnitude and leading sites of cancer in the registry hospital are based on the

entire data. The remaining chapters, however, dealing with the clinical extent of disease, method of diagnosis and treatment status and modalities, are based on the cleaned data following the exclusion criteria.

Exclusion criteria: The patients registered at the HBCR hospitals can be classified broadly into two groups: 1., those who already had cancer directed treatment (CDT) and 2. those who did not have any cancer directed treatment before coming to the HBCR hospital. The first group of patients came to the registry hospital mostly after getting diagnosed and treated in other hospitals, either for follow-up or for advanced treatment. The second group consists of those patients who came to the registry or reporting institution (RI) with a suspicion of cancer, got diagnosed at RI and those patients who got diagnosed with cancer and came to the RI for cancer treatment. The first group, viz, cancer patients who had received any form of CDT before reporting to the registry hospital, was excluded from the analysis.

Regarding place of residence, data on the place of permanent residence is collected in the form of a postal index number (PIN) code. Permanent residence is defined as the place where a patient has stayed for at least the past one year. Although PIN of place of permanent residence is regularly collected by the HBCRs and reported to COU, it has not been analysed at the COU level. Even at individual registries level, there are only sporadic attempts in making any use of the data on place of permanent residence. For example, there is an attempt by the HBCR Mumbai to project the cancer pattern in Maharashtra utilising their registry data (TMH, 2004).

2.2.6 Epidemiological studies and human resource development in NCRP

The second objective of the NCRP was to undertake epidemiological studies utilising NCRP data and other resources available with the PBCRs and HBCRs. The third objective, which was somewhat parallel to the second one in achievement, was to create a human resource in the cancer registration and epidemiology (NCRP, 1987). In order to meet the second objective, the third was required to be achieved at least substantially. Therefore, efforts to create human resource development somewhat preceded the occurrence of epidemiological studies. It was in 1989, when the Indo-Finland collaboration program was established with the objective of personnel associated with cancer registration and epidemiology in India receiving training in Epidemiology in Finland with financial assistance from the Finnish side. This was the seed sown for the development of experts in cancer epidemiology in India that has blossomed into a big tree during more than two and a half of the last decades. In addition to Indo-Finland collaboration, there have been many other programs and fellowships playing a role in the development of human resources in India, most prominently of them being the Summer School Program of IARC and ICRETT fellowship of UICC. A vast pool of human resources thus generated has been engaged in cancer registration and research as well as cancer control activities in different regions of the country. In addition, they have also been instrumental in expansion of cancer research activities and have contributed to training other staff in the different cancer registries.

Although there may not have been optimum utilisation of raw data potentially due to non-availability of the same in the public domain, there have been many epidemiological studies utilising the HIS-related infrastructure available with individual registry institutions. Some prominent examples of them are case-control

studies looking into etiological factors of many cancers and survival studies dealing with the prognosis and associated factors of many cancers. A detailed and exhaustive review of these studies is beyond the purview of this study, however. We discuss them in brief in the following sections just to highlight the achievement of the second objective of NCRP. In addition to the analytical studies, there have been many descriptive epidemiological studies utilising information from published reports of NCRP dealing with methodological developments, projection of national burden, pattern, trend and geographic variation in the occurrence of cancer (Murthy et al., 1990; Krishnamurthy and Dhar, 1992; Yeole, 1997; Yeole and Kurkure 2003, Yeole et al., 2006; Dhar et al., 2008; Takiar and Nandakumar, 2011; Swaminathan et al., 2011).

2.2.6.1 Case-control studies

Case control studies are an important tool in the assessment of etiological factors for NCDs in general and cancer in particular due to relatively rare occurrence and common exposure factors. These studies are especially useful in the setup of developing countries where the conduct of long duration cohort studies is really difficult due to inadequate HIS and scarce financial resources. There were rare examples of case control studies in India prior to the establishment of the NCRP. Following the NCRP establishment, however, there has been boom in case control studies dealing with the assessment of cancer etiological factors in India. A series of case control studies has been conducted as a PhD thesis research under the DPPH program with Indo-Finnish collaboration. Different cancer sites covered in these researches were esophageal cancer (Ramesh, 1993), gastric cancer (Ravichandran, 1997), contralateral breast cancer (Gajalakshmi, 1997), childhood hematological

malignancies (George, 1997), breast cancer (Reddy, 2004) and prostate cancer (Sunny, 2005).

In addition to the above academic dissertations published by the University of Tampere, there have been many case control studies conducted under the auspices of the NCRP and published in reputed journals. A few of them, for example, are as follow:

- Four case-control studies in Mumbai dealing with stomach cancer (Rao et al., 2002), colorectal cancer (Ganesh et al., 2009), lung cancer (Ganesh et al., 2011) and prostate cancer (Ganesh et al., 2011a).

- Two case-control studies in Bangalore dealing with ovarian cancer (Nandakumar et al., 1995) and esophageal cancer (Nndakumar et al., 1996).

- A case control study in Chennai dealing with stomach cancer (Gajalakshmi and Shantha, 1996).

- A case-control study in Delhi dealing with gallbladder cancer (Tyagi et al., 2008).

2.2.6.2 Survival studies

Knowledge of survival is essential in the community level management of a disease. Its knowledge over a period of time helps in monitoring and improving the levels of prognostic factors in the population. In addition, survival duration also

helps in deriving various indices of the burden of disease, like, disability adjusted life years, healthy life expectancy, etc. Conducting of population-based study of cancer survival is a difficult task in developing countries due to the non-existence of health information systems and the resultant poor follow-up of patients. Therefore, there have been only a limited number of population-based survival studies in India. First population-based cancer survival study for a selected site of cancer emerged in mid-1990s (Nandakumar et al., 1995) as a result of the initiative taken by IARC, Lyon, France for a multi-national collaborative study on cancer survival in developing countries in 1994 (Sankaranarayanan et al., 1998). Later on, there have been few more population-based cancer survival studies in India mostly with the support from international agencies (Swaminathan et al., 2009, Sankaranarayanan and Swaminathan, 2011).

On the other hand, there have also been a few hospital-based survival studies. However, these studies serve limited purposes, because, even if the patient admitted to the HBCR hospital has a good survival, survival from the public health point of view is poor because most of the Indian patients are not hospitalised due to cancer and hence do not receive cancer treatment.

There are many reasons for only sporadic survival studies in India described in detail somewhere else (Dhar et al., 2010). These include time and finances required to conduct the study, the problem of loss to follow-up and also the time gap between the year of diagnosis of patients and the availability of results on the survival. In view of these difficulties, Dhar et al. (2008) proposed an indirect method for study of cancer survival utilising the current data on cancer incidence and morbidity. In addition, there have been a few methodological studies in India dealing with the biases in survival estimated due to substantial losses to follow-up (Ganesh, 1995; Mathew, 1996; Swaminathan, 2012). The time gap problem was realised even in the developed world, also prompting Brenner and Gefellar (1996) to come out with a new method called 'period analysis' to overcome the same. This method is based on

the concept of period monitoring of the subjects instead of the usual practice of cohort monitoring.

2.2.7 Data on cancer mortality

Collection of data on cancer mortality is inherent in population-based cancer registration in India. Thus, we have had data on cancer mortality for the PBCR areas for a few decades now. The coverage and accuracy of these data, however, are questionable. The mortality/incidence (M/I) ratio is one of the indicators of completeness of cancer mortality data. It is expected to be very close to 100%, unless there is a very high cure rate, which is not expected due to diagnosis of a majority of patients with regionally spread or advanced cancers. According to a report based on the data for the period from 2006-2008, the M/I ratio for Indian PBCRs ranged from a low of about 10% for Delhi to a high of 82% for Barshi Rural (NCRP, 2010).

Another source of data on cancer mortality in India is the report of the Office of the Registrar General of India on medical certification of causes of death (MCCD). MCCD started in India in 1969 under the provisions of Registration of Births and Deaths Act, however, with varying efficiency across the states and over the time period. The necessary data are collected in a form prescribed by the WHO (Form 4 for Hospital deaths and Form 4A for Non-institutional deaths) by the medical professionals attending to the deceased at the time of terminal illness. These data are then sent to the respective Registrars of Births and Deaths for subsequent transmission to the Chief Registrar Office for tabulation and dissemination. Deaths are listed as per the National List of Causes of Death which is based on the tenth revision of ICD10. The main issue with the MCCD data is the coverage of deaths for certification. According to the latest report (RGI, 2014), only 20% of the deaths

were medically certified. Thus, any conclusion about different causes of death including cancer based on MCCD data will have underlying assumption that these 20% of deaths are representative of all the deaths. This assumption seems hardly tenable.

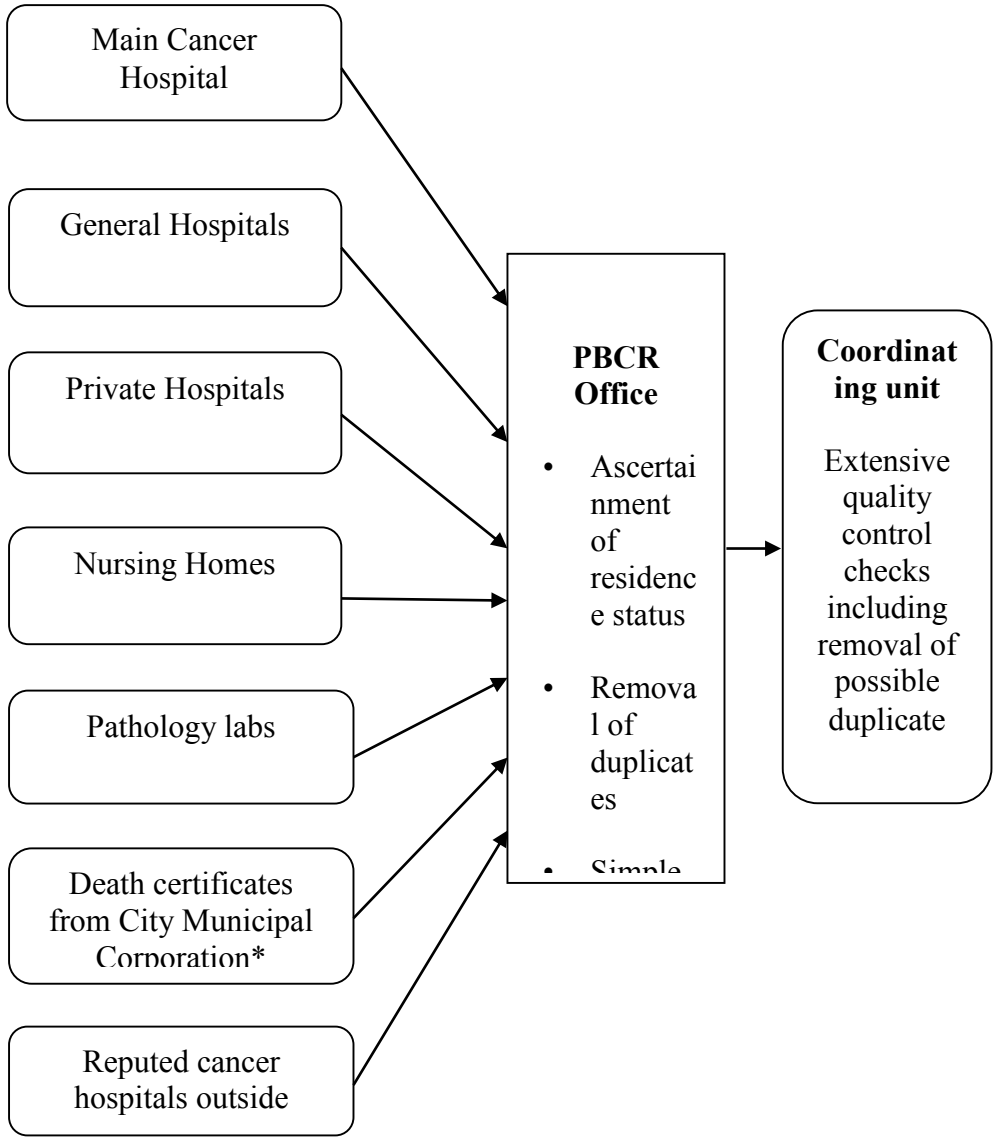
In view of the scarcity of reliable data on cancer deaths in India, Dikshit et al. (2012) conducted a nationally representative survey. This was nested within the Million Death Study (MDS) which was already in progress as one of the few nationally representative studies of causes of death in the developing world (Jha et al., 2006). They reported over 556,000 cancer deaths, of which about 70% were in the age group 30-69 years. Common fatal cancers were reported to be oral, stomach and lung in men and cervix, stomach and breast in women. Tobacco-related cancers accounted for about 42% of deaths in men and 18% in women.

2.2.8 Process of data collection in Indian PBCRs

As described earlier, the process of cancer registration in India is active and therefore, cancer registry personnel visit all the potential sources of cancer patients or their records and collect data on a standard proforma. The first step in the process of data collection after establishing a PBCR is to identify and list all potential sources of cancer cases in as well as outside the registry area. This list needs to be updated regularly, and it may include a cancer hospital, if any, general hospitals, private hospital, nursing homes, pathology labs and corporation in the registry area. From outside the registry area, one may include in the list those reputed cancer hospitals where the patients from the registry area may potentially go for diagnosis and/or treatment. Staff members of the registry personally visit the potential sources regularly to interview all identified cancer patients and also those under investigation.

As a result of such data collection from different sources, one and the same patient is sometimes found to be registered from multiple sources. Care is taken to see that multiple entries for the same patient are not made in the records. This is done by matching different combinations of the fields, like, name, age, sex, ICDO and ICD9/10 codes etc. On the other hand, in some instances, complete or maximum possible information is obtained by combining the data from two or more sources. Another important thing to ensure about a case is its residential status. Proforma has a question on the duration of stay in the present place of residence. Using this information, all the patients with a duration of stay less than one year are considered as non-resident in the registry area and therefore removed from the data set. After ascertaining the removal of duplicates and non-residents, the whole data set is subjected to standard quality control checks and then transmitted to the Coordinating Unit (CU). The CU then subjects the data set received from the registry to more extensive quality control checks and finalises the same for analysis and reporting. The whole process of data collection in Indian PBCRs described above, has also been depicted diagrammatically in Figure 2.2

Figure 2.2: Diagrammatic presentation of data collection process in Indian PBCRs



*There is possibility of finding some cancer cases from death certificates showing cancer as cause of death and not found from any of other sources.

2.2.9 Difficulties in operating a PBCR

As defined earlier, a PBCR needs to register each and every case (satisfying the specific case definition) arising in a defined geographic area. To do this, unlike developed countries, most (if not all) of the developing countries do not have an advanced health information system (HIS) and unique identification number (UID) that identifies each and every individual of the country by a unique number. The lack of an efficient HIS affects the coverage of a PBCR. On the other hand, the lack of UID, makes ruling out the duplicate registrations on the same patient difficult, thereby affecting the quality of data. In developing countries, the method of data collection is active. As a result, we have to depend on the following sources to attempt registering all the cases of a PBCR.

- HBCR in the PBCR area, if any.
- General hospitals.
- Private hospitals.
- Nursing homes.
- Cancer centres.
- General practitioners.
- Screening programmes.
- Death certificates (Corporation, cremation canters, burial grounds records, etc.).
- Pathology labs.

A PBCR has to maintain an up-to-date list of all the above sources, and registry personnel should visit them at a regular interval. This requires huge resources

in terms of money and time, which makes the functioning of a registry at the national level next to impossible and delays the publication of reports pertaining to a particular year. Another problem with the PBCR data, mostly due to the reasons explained above, is that clinical and treatment details are not available for a substantial number of cases. Hence, there is always a thrust for the alternative options.

2.2.10 Alternative options

There are two potential alternative options to evaluate cancer patterns at the population level. The first is the utilisation of HBCR data that has been available for many decades, and the second is the atlas of cancer, a concept that came-up recently.

2.2.10.1 Hospital-based cancer registries (HBCRs)

Unlike PBCRs, HBCRs register data on the patients coming to particular hospital irrespective of their place of residence. Being hospital-based, HBCRs are able to provide relatively better data of diagnostic, clinical and treatment details. Therefore, typical uses of HBCRs are related to patient care in a hospital. Established and documented uses of the HBCR are as follows (Maclennan et al., 1978; Young, 1991; NCRP, 2001a).

- To assess patient care
- Participate in clinical research to evaluate therapy

- Provide an idea of pattern of cancer in the area
- Help to plan hospital facilities

HBCRs are useful mainly in clinical research relating to the first two uses listed above. We may term these as the direct uses of HBCR. According to a survey conducted by Howard et al. (2010), the use of HBCR data to evaluate the quality of cancer care and patient outcomes was not routine. Their conclusion was based mainly on the findings pertaining to less utilisation of HBCR data for cancer care and patient outcome research. They also studied the relationship of HBCR data use to geographic and logistical factors and concluded that increasing the availability of trained registrants, specialised cancer registry software and maximising completeness of data, could potentially increase their usefulness as tools to improve cancer care.

However, this thesis analyses the validity of the third use, may be termed as indirect uses of HBCR, by data from the Indian NCRP in areas covered by both PBCR and HBCR. If the validity of the third use is questionable, the assessing of patient care at the population level may also be questionable.

2.2.10.2 Atlas of cancer in India

In view of the above difficulties with PBCR, the thrust has been on finding an alternative to PBCR and the concept of an 'Atlas of cancer' is one of them. It was observed in PBCR data that 85-90% of cancers had a microscopic diagnosis. This meant theoretically that if we are able to include all the potential sources of microscopic diagnosis in our programme, we can be reasonably sure of capturing 85 to 90% of cancer cases in the country. This was the technical basis for starting the

WHO funded project titled 'Development of an atlas of cancer in India' (NCRP, 2004, Nandakumar et al., 2005). The objectives of this project were

- To obtain an overview of cancer patients in different parts of the country.

- To calculate estimates of cancer incidence wherever feasible.

Data were obtained from all the sources of microscopic diagnosis of cancer, who gave their consent for participation in the project. Quality control exercises, mainly elimination of duplicates, were carried out. Utilising the data on place of residence, the cases were divided to arrive at the number of incident cancer cases by district of residence. Subsequently, these numbers were divided by the population of the district to obtain the 'minimum cancer incidence rate' (MCIR) for that state. The results of the project were presented diagrammatically, also showing the MCIR for different districts of the country.

2.2.10.3 Pros and cons of two alternatives

The main objectives of HBCRs is to assess the pattern of care in a hospital and help the hospital authorities in the management by providing data on clinical, diagnostic and treatment details. The study of cancer patterns in the catchment area is the potential (secondary) objective of HBCRs, whereas, it is the sole objective of ATLAS. Therefore, HBCRs are justified irrespective of the result of this study, whereas, ATLAS is justified only if it is capable of providing valid information on the pattern of cancer.

3 AIM AND OBJECTIVES

The overall aim of the study was to explore the feasibility to use hospital-based cancer registries (HBCR) and data from pathology laboratories (ATLAS) in the evaluation of the cancer pattern in India in particular and in the context of developing countries in general.

To achieve the above, specific objectives of the study were to compare

1. Consistency in the proportion by primary site of cancers in HBCR and PBCR in three areas of India with both types of registration.
2. Consistency in the proportion by primary site of cancers in ATLAS and PBCR in three areas in north eastern part of India with both types of data.
3. Comparison of quantum of inconsistency HBCR and PBCR across areas with both types of registration.
4. Changes in consistency over calendar time in the Mumbai HBCR and PBCR.
5. Effect on consistency of removal of patients with place of residence outside Mumbai from HBCR.

4 METHODS AND MATERIALS

4.1 Methods

Understanding HBCR data

The basic problem in population-based interpretation of HBCR data, is simply the fact that HBCR data, being hospital-based, do not represent a defined population. It is, however, believed that HBCR data do depict the cancer pattern in the surrounding catchment areas (NCRP, 2001). Now the question comes as to what is that surrounding area to which HBCR data may be projected. Let us define it as the district or urban part of the same in which the HBCR is located and call it the HBCR *area*. For example, the representativeness of HBCRs in Bangalore, Mumbai and Chennai may be projected to the areas represented by the corresponding PBCRs. Let us now understand the difference between the two sets of data; one from PBCR, that is gold standard to represent the area under consideration, and the other one from HBCR, which is under question.

With respect to the place of residence, there are two sets of patients that account for all the differences between HBCR and PBCR.

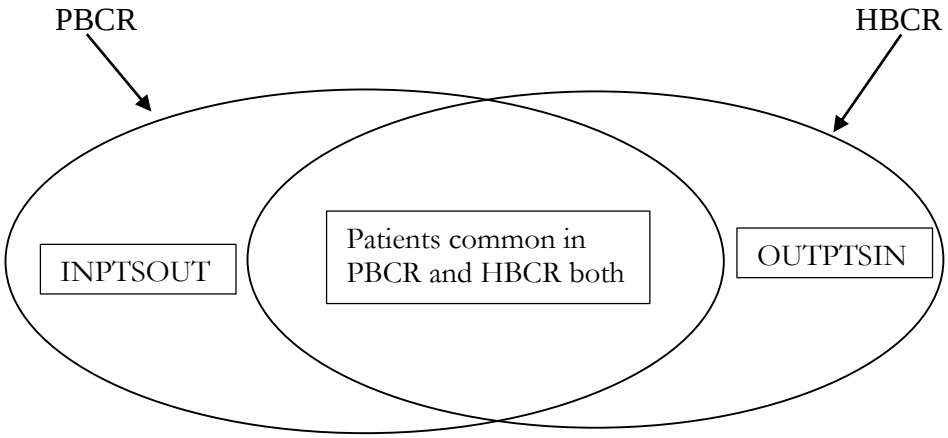
INPTSOUT: Set of patients who are actually from INside the HBCR area, but do not get registered in HBCR.

OUTPTSIN: Set of patients who are actually from OUTside the HBCR area but get registered in the HBCR.

Thus, PBCR data = HBCR data - OUTPTSIN +INPTSOUT.

This relation between PBCR and HBCR has also been illustrated diagrammatically in Figure 4.1.

Figure 4.1: Diagrammatic illustration of relationship between PBCR and HBCR data



It is the qualitative and quantitative differences between OUTPTSIN and INPTSOUT that makes HBCR different from PBCR. Any population-based interpretation of HBCR data makes the basic assumption that INPTSOUT and OUTPTSIN are quantitatively equal and qualitatively similar.

It is possible for a HBCR to exclude the cases of OUTPTSIN. However, as far as INPTSOUT is concerned, HBCRs cannot do much without the help of a sister PBCR or a survey. A sister PBCR refers to a PBCR in the same place as the HBCR.

In such cases, the corresponding HBCR is the source for the majority of PBCR cases. In fact, if the HBCR area has a sister PBCR, then all these exercises will be meaningless. The usefulness of all these methodologies has relevance only if a HBCR area does not have a sister PBCR. So, to validate any population-based interpretation of HBCR data in practical situations, the only option left will be a survey.

Thus, there are two sets of data possible with the HBCRs that can be looked into for their validity in population-based interpretation.

1. HBCR data (consisting of all the patients registered at the parent hospital)

2. HBCR data – OUTPTSIN (excluding the patients from outside the registry area), i.e., the patients resident in the registry area only. Let us name this data set as RHBCR.

The utility of HBCR, if found valid, lies in the application of either HBCR or RHBCR data, as these are either readily available or easily obtainable, because the data on place of residence is always collected and recorded by all the registries. There is no point, however, in any consideration of INPTSOUT data, because this remains always unknown for a HBCR.

Theoretically, the second one seems to be closer to the PBCR in terms of population-based interpretation, because it is free of one of the two sources of bias (i.e., OUTPTSIN). However, we cannot be sure of this, because all depends on the direction of bias caused by the two sets of patients. It may be possible in some situations that the two biases act in opposite direction, neutralising the effect on each other. In that case, the first data set may give a better approximation to the PBCR. In view of this, there is need to test the applicability of the two data sets separately for their usefulness as an alternative to PBCR data.

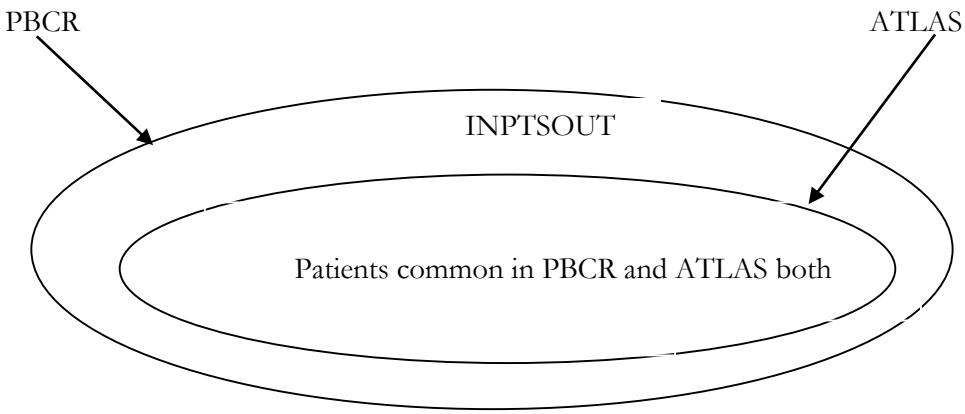
These applications of HBCR data have not been attempted, at least in the setup of developing countries. This is mostly due to the perceived understanding about the involvement of theoretical biases in the interpretation of HBCR data. What actually matters, however, is the quantitative and qualitative impact of the theoretical biases on the results. Actually, something subject to theoretical bias need not necessarily be biased in reality. Methods used to assess the applicability of HBCR data as an alternative to PBCR are described in the subsequent sections

Understanding ATLAS data

The basic problem in utilising ATLAS data is simply the fact that, as stated in chapter 2, it provides only a minimum cancer incidence rate (MCIR) with no idea of the error (underestimation) involved in it. It is, however, a general perception of some that ATLAS data gives a reasonably good idea of the cancer pattern in the population. This perception has been vindicated by the repeated use of the ATLAS concept by NCRP. The relation between ATLAS and PBCR may be expressed as following, and the same has also been illustrated diagrammatically in Figure 4.2.

PBCR data = ATLAS data + INPTSOUT

Figure 4.2: Diagrammatic illustration of relationship between PBCR and ATLAS data



It is the quantitative magnitude of INPTSOUT and its qualitative differences from ATLAS data that makes the uses of ATLAS data questionable. Any interpretation of ATLAS data in assessing the risk of cancer is based on the basic assumption that INPTSOUT is negligible. Assessment of pattern and trend using ATLAS is based on the assumption that proportionate INPTSOUT is similar across different sites of cancer and over a time period. The validity of these assumptions is among the purposes of this thesis.

Unlike HBCR, no refinement of ATLAS data is possible, as the data on INPTSOUT remained unknown.

4.1.1 Comparison of primary site proportions in HBCR and ATLAS with PBCR

Ten leading sites based on PBCR data, as listed in tables 4.1a, 4.1b and 4.1c, were selected for each of the three registries separately within each sex category.

The proportion (%) of leading sites of cancer according to PBCR (pi) and that according to HBCR (pi') were obtained from published reports and compared. For comparison, absolute and relative differences were calculated as following.

Absolute difference for i^{th} site

$$ADi = pi' - pi$$

Relative difference for i^{th} site

$$RDi = (pi' - pi) / pi$$

Similarly, for ATLAS and PBCR comparison , ten leading sites based on PBCR data, as listed in tables 4.2a, 4.2b and 4.2c, were also selected for each of the three registries separately within each sex category. Intra-registry comparison between ATLAS and PBCR were performed applying above methods.

4.1.2 Comparison of differences among registries

To compare the differences between HBCR and PBCR across the registries, we looked at the differences in the case of individual major sites. However, for overall comparison among the registries, a composite index, combining the differences across the registries, was required. For this purpose, a list of sites common in 10 leading sites in all the three registries was selected (9 in males and 7 in females). For overall objective comparison between the registries, weighted average of the absolute values of differences (WAAD) and relative differences (WARD) were calculated as following.

$$WAAD = (\Sigma |ADi| * pi)/(\Sigma pi)$$

$$WARD = (\Sigma |RDi| * pi)/(\Sigma pi)$$

Similarly, differences between ATLAS and PBCR were also compared across the registries by calculating WAAD and WARD using above formulae.

4.1.3 Trend in consistency between HBCR and PBCR

To examine the trend in consistency in the leading sites between HBCR and PBCR, the differences between the two proportions were examined over a period of time. For this purpose, we tabulated the proportions according to two types of registries and the differences between the two over five time periods under study. In addition, we plotted a scatter diagram by taking HBCR proportions on X-axis and PBCR proportions on the other. In case of perfect consistency in the differences over the period of time, the scatter plot is expected to depict a diagonal line pattern (exactly 45° from each of the axes) with the all the dots falling on the line. Deviation of the dots from diagonal towards the X-axis indicates higher HBCR proportions compared to PBCR proportions. On the other hand, deviation towards the Y-axis indicates the smaller HBCR proportions compared to PBCR proportions. The dots have been connected to show the trend in consistency with a circle indicating the first time period and an arrow indicating the last time period. Reduction or increase in the absolute differences of the dots from the diagonal line over the time period under study indicates respectively improvement or deterioration of the consistency between HBCR and PBCR.

4.1.4 Comparison of RHBCR with HBCR and PBCR

The proportion of leading cancer sites, according to HBCR after taking off OUTPTSIN (let us call this dataset as RHBCR) (pi"), were obtained from the published report available for Mumbai. The proportions obtained from RHBCR

were compared with those from HBCR and PBCR by working out the absolute and relative differences as described earlier under section 4.1.1.

Subsequently, the absolute and relative differences between PBCR vs. HBCR were compared with those between HBCR vs. RHBCR and PBCR vs. RHBCR by calculating the weighted averages described earlier under section 4.1.2.

Finally, to compare the consistency of HBCR and RHBCR proportions with PBCR proportions, we plotted a scatter diagram by taking differences in HBCR proportions on the X-axis and that in RHBCR proportions on the Y-axis. The dots above the diagonal line indicate higher inconsistency in RHBCR resulting in deterioration, and below the line indicate lower inconsistency in RHBCR, resulting in improvement by reducing the HBCR data to RHBCR. Cumulative distances above and below the diagonal line provide a measure of overall inconsistency respectively in RHBCR and PBCR.

4.2 Materials for the present study

HBCR vs. PBCR

India had five hospital-based cancer registries functioning under the network of the National Cancer Registry Programme (NCRP) of the Indian Council of Medical Research started many years ago. These registries have gathered data over a period of more than 25 years now. The five HBCRs are located at Mumbai (Tata Memorial Hospital), Bangalore (Kidwai Memorial Institute of Oncology), Chennai (Cancer Institute), Thiruvananthapuram (Regional Cancer Centre) and Dibrugarh (Assam Medical College). Table 4.1 gives the average annual number of cancer cases

registered by these HBCRs over a period from 1984-2006. The registries have been presented in NCRP reports in the order based on the number of cancers registered by each registry. Of the above five HBCRs, three are accompanied by long-standing PBCRs, and these are also three decades old now. Since the objective of the study was to compare the data from HBCRs to the same from PBCRs in India, three registries/areas with HBCR and PBCR both, namely, Mumbai, Bangalore and Chennai were selected.

Table 4.1: Average annual number of cancer patients registered by different HBCRs in India during 1984-2006

HBCR	Calendar years				
	1984-1993	1994-1998	1999-2000	2001-2003	2004-2006
Mumbai	14,019	15,346	15,658	16,066	17,356
Bangalore	6,730	6,896	6,825	7,812	7,378
Chennai	5,327	5,799	6,667	7,761	8,704
Thiruvanantha-puram	5,141	7,125	7,553	8,281	7,986
Dibrugarh	1,205	829	767	837	948

The NCRP publishes consolidated reports from time to time separately for HBCRs and PBCRs. Unfortunately, however, there is a rare case of consolidated reports of two types of registries being for the same time period. The present study

utilised the data from consolidated reports of HBCR and PBCR for the following years.

HBCR reports

I- For the calendar period 1984-1993 (NCRP, 2001a)

II- For the calendar period 1994-1998 (NCRP, 2002a)

III- For the calendar period 1999-2000 (NCRP, 2005a)

IV- For the calendar period 2001-2003 (NCRP, 2007)

V- For the calendar period 2004-2006 (NCRP, 2009)

PBCR reports

I- For the calendar period 1990-1996 (NCRP, 2001)

II- For the calendar period 1997-1998 (NCRP, 2002)

III- For the calendar period 1999-2000 (NCRP, 2005)

IV- For the calendar period 2001-2004 (NCRP, 2006)

V- For the calendar period 2006-2008 (NCRP, 2010)

It may be observed from the above that 1999-2000 is the only period for which consolidated reports for both types of registries (i.e., HBCR and PBCR) are available. Therefore, this was the time period considered for all the comparisons other than the trend between HBCR and PBCR as well as for the comparison of

differences among the registries. Selection of primary sites of cancer was done as stated in section 4.1.1.

In addition, in order to compare the HBCR data after taking off the patients from outside the registry area, the data on place of residence by site and sex was required. For this purpose, the annual report of HBCR Mumbai (TMH, 2004), was utilised.

Tables 4.2a, 4.2b and 4.2c present the basic data on number, proportion expressed as percentages and the rates expressed per 100,000 person years for the selected leading sites in the three registries under consideration for the time period 1999-2000.

ATLAS vs. PBCR

The first all India report of ATLAS presented MCIR for the biennial period 2001-2002 (NCRP, 2004). Based on the results of the ATLAS project, six PBCRs were started in the northeastern part of the country. The first consolidated report of these PBCRs dealt with the data for the years 2003-2004 (NCRP, 2006a). Three PBCRs, namely, Dibrugarh, Imphal West and Aizawl, were also found to be available in the ATLAS report. Therefore, these three populations were selected for the comparison between ATLAS and PBCR.

Tables 4.3a, 4.3b and 4.3c present data on proportion (%) and age-adjusted cancer incidence rates (per 100,000 person years) according to PBCR and ATLAS for ten leading sites.

Table 4.2a: Number (No.), proportion (%) and rate (per 100,000 person years) of ten leading sites of cancer according to HBCR and PBCR, Mumbai, 1999-2000

ICD-10	Site	HBCR		PBCR		
		No.	%	No.	%	Rate
Males						
C01-02	Tongue	1,236	7.0	399	4.5	3.1
C03-06	Mouth	1,986	11.3	525	5.9	4.1
C12-13	Hypopharynx	935	5.3	345	3.9	2.7
C15	Oesophagus	998	5.7	527	5.9	4.1
C16	Stomach	504	2.9	381	4.3	3.0
C32	Larynx	937	5.3	524	5.9	4.1
C33-34	Lung	1,253	7.1	804	9.1	6.2
C61	Prostate	*	*	506	5.7	3.9
C70-72	Brain, NOS	370	2.1	402	4.5	3.1
C82-85,96	NHL	950	5.4	452	5.1	3.5
Females						
C03-06	Mouth	656	4.8	295	3.4	2.8
C15	Oesophagus	505	3.7	361	4.2	3.4
C23-24	Gallbladder	381	2.8	201	2.3	1.9
C33-34	Lung	298	2.2	239	2.8	2.3
C50	Breast	3,617	26.4	2,238	25.7	21.3
C53	Cervix uteri	2,643	19.3	1,244	14.3	11.9
C54	Corpus uteri	281	2.1	214	2.5	2.1
C56	Ovary	777	5.7	579	6.7	5.5
C70-72	Brain, NOS	204	1.5	279	3.2	2.7
C82-85,96	NHL	359	2.6	247	2.8	2.4

*Not within ten in HBCRs, therefore, figures not available.

Table 4.2b: Number (No.), proportion (%) and rate (per 100,000 person years) of ten leading sites of cancer according to HBCR and PBCR, Bangalore, 1999-2000

ICD-10	Site	HBCR		PBCR		
		No.	%	No.	%	Rate
Males						
C01-02	Tongue	346	5.7	120	3.4	2.1
C12-13	Hypopharynx	554	9.1	156	4.5	2.7
C15	Oesophagus	587	9.6	298	8.5	5.1
C16	Stomach	427	7.0	330	9.4	5.7
C22	Liver	*	*	130	3.7	2.2
C32	Larynx	192	3.1	145	4.2	2.5
C33-34	Lung	432	7.1	267	7.6	4.6
C61	Prostate	*	*	201	5.8	3.4
C70-72	Brain, NOS	252	4.1	139	4.0	2.4
C82-85,96	NHL	250	4.1	141	4.0	2.4
Females						
C03-06	Mouth	833	11.0	196	4.8	3.7
C15	Oesophagus	467	6.2	224	5.5	4.3
C16	Stomach	172	2.3	171	4.2	3.2
C50	Breast	1,001	13.3	902	22.1	17.2
C53	Cervix	2,490	33.0	765	18.7	14.5
C54	Corpus uteri	75	1.0	132	3.2	2.5
C56	Ovary	328	4.3	205	5.0	3.9
C70-72	Brain, NOS	121	1.6	97	2.4	1.8
C73	Thyroid	212	2.8	120	2.9	2.3
C82-85,96	NHL	127	1.7	97	2.4	1.8

*Not within ten in HBCRs, therefore, figures not available.

Table 4.2c: Number (No.), proportion (%) and rate (per 100,000 person years) of ten leading sites of cancer according to HBCR and PBCR, Chennai, 1999-2000

ICD-10	Site	HBCR		PBCR		
		No.	%	No.	%	Rate
Males						
C01-02	Tongue	450	7.3	185	4.7	4.3
C03-06	Mouth	544	8.8	201	5.1	4.7
C12-13	Hypopharynx	420	6.8	188	4.8	4.4
C15	Oesophagus	478	7.7	330	8.3	7.7
C16	Stomach	562	9.1	452	11.4	10.6
C32	Larynx	238	3.8	169	4.3	4.0
C33-34	Lung	378	6.1	364	9.2	8.5
C61	Prostate	*	*	142	3.6	3.3
C70-72	Brain, NOS	43	0.7	132	3.3	3.1
C82-85,96	NHL	269	4.3	177	4.5	4.1
Females						
C03-06	Mouth	441	6.2	177	4.2	4.4
C15	Oesophagus	263	3.7	195	4.7	4.8
C16	Stomach	223	3.1	192	4.6	4.7
C33-34	Lung	84	1.2	81	1.9	2.0
C50	Breast	1,412	19.8	941	22.5	23.2
C53	Cervix uteri	2,499	35.0	1,053	25.2	25.9
C56	Ovary	248	3.5	216	5.2	5.3
C70-72	Brain, NOS	21	0.3	81	1.9	2.0
C73	Thyroid	135	1.9	82	2.0	2.0
C82-85,96	NHL	96	1.3	87	2.1	2.1

*Not within ten in HBCRs, therefore, figures not available.

Table 4.3a: Number (No.), proportion (%) and rate (per 100,000 person years) of ten leading sites of cancer according to ATLAS (2001-2002) and PBCR (2003-2004), Dibrugarh

ICD-10	Site	ATLAS		PBCR		
		No.	%	No.	%	Rate
MALES						
C15	Oesophagus	32	15.9	134	17.5	10.6
C12-13	Hypopharynx	40	19.9	90	11.8	7.1
C16	Stomach	7	3.5	60	8.0	4.8
C03-06	Mouth	19	9.5	53	6.9	4.2
C33-34	Lung	6	3.0	42	5.5	3.3
C01-02	Tongue	14	7.0	41	5.4	3.2
C32	Larynx	9	4.5	26	3.4	2.1
C23-24	Gall bladder	1	0.5	20	2.6	1.6
C18	Colon	3	1.5	16	2.1	1.3
C19-20	Rectum	6	3.0	10	1.3	0.8
FEMALES						
C50	Breast	5	6.5	105	18.8	8.8
C53	Cervix uteri	17	22.1	66	11.8	5.5
C15	Oesophagus	12	15.6	61	10.9	5.1
C23-24	Gall bladder	1	1.3	45	8.1	3.8
C56	Ovary	4	5.2	34	6.1	2.9
C16	Stomach	1	1.3	30	5.2	2.4
C03-06	Mouth	5	6.5	29	5.2	2.4
C33-34	Lung	1	1.3	21	3.8	1.8
C18	Colon	2	2.6	11	2.0	0.9
C12-13	Hypopharynx	0	0.0	7	1.3	0.6

Table 4.3b: Number (No.), proportion (%) and rate (per 100,000 person years) of ten leading sites of cancer according to ATLAS (2001-2002) and PBCR (2003-2004), Aizawl

ICD-10	Site	ATLAS		PBCR		
		No.	%	No.	%	Rate
MALES						
C16	Stomach	79	20.5	122	19.7	34.1
C15	Oesophagus	49	12.7	94	15.2	26.3
C33-34	Lung	28	7.3	75	12.1	21.0
C12-13	Hypopharynx	26	6.7	53	8.6	14.8
C19-20	Rectum	8	2.1	15	2.4	4.2
C22	Liver	11	2.9	15	2.4	4.2
C32	Larynx	9	2.3	12	1.9	3.4
C92-94	Myeloid Leuk.	5	1.3	11	1.8	3.1
C11	Nasopharynx	15	3.9	10	1.6	2.8
C01-02	Tongue	17	4.4	9	1.5	2.5
FEMALES						
C33-34	Lung	31	9.0	85	16.1	24.9
C53	Cervix Uteri	62	18.0	83	15.7	24.3
C16	Stomach	38	11.1	67	12.7	19.6
C50	Breast	53	15.4	65	12.3	19.0
C56	Ovary	15	4.4	17	3.2	5.0
C15	Oesophagus	12	3.5	16	3.0	4.7
C23-24	Gallbladder	5	1.5	14	2.7	4.1
C22	Liver	11	3.2	13	2.5	3.8
C19-20	Rectum	8	2.3	12	2.3	3.5
C25	Pancreas	3	0.9	2	0.4	0.6

Table 4.3c: Number (No.), proportion (%) and rate (per 100,000 person years) of ten leading sites of cancer according to ATLAS (2001-2002) and PBCR (2003-2004), Imphal West

ICD-10	Site	ATLAS		PBCR		
		No.	%	No.	%	Rate
MALES						
C33-34	Lung	49	23.6	65	20.5	14.1
C16	Stomach	21	10.1	26	8.2	5.6
C15	Oesophagus	8	3.9	23	7.3	5.0
C11	Nasopharynx	19	9.1	18	5.7	3.9
C82-85,96	NHL	9	4.3	16	5.1	3.5
C18	Colon	7	3.4	13	4.1	2.8
C92-94	Myeloid Leuk.	7	3.4	11	3.5	2.4
C44	Other Skin	0	0.0	7	2.2	1.5
C22	Liver	3	1.4	5	1.6	1.1
C67	Bladder	4	1.9	5	1.6	1.1
FEMALES						
C33-34	Lung	36	13.4	61	16.2	13.1
C53	Cervix Uteri	33	12.3	55	14.6	11.8
C50	Breast	52	19.4	54	14.3	11.6
C23-24	Gallbladder	13	4.9	20	5.3	4.3
C73	Thyroid	15	5.6	20	5.3	4.3
C16	Stomach	18	6.7	16	4.2	3.4
C56	Ovary	15	5.6	14	3.7	3.0
C15	Oesophagus	4	1.5	12	3.2	2.6
C44	Other Skin	1	0.4	5	1.3	1.1
C82-85,96	NHL	7	2.6	4	1.1	0.9

5 RESULTS

5.1 Comparison of proportions

5.1.1 Comparison between HBCR and PBCR

Mumbai *(Tables 5.1.1a)*

Males: Lung, accounting for nearly one tenth of cancers in males, was the leading site of cancer, followed by oesophagus, mouth and larynx, about 6% each. In absolute terms, the leading sites were overrepresented in HBCR by up to 5% units and underrepresented by up to 4% units. Mouth was the most overrepresented in HBCR followed by tongue and hypopharynx. Underrepresentation was highest for prostate followed by brain and lung. The pattern of relative difference was similar to that of absolute differences. However, the highest positive relative difference was observed to be 92% for mouth cancer and negative relative difference -74% for prostate cancer.

Females: Breast, accounting for about a quarter of the patients, was the leading site of cancer followed by uterine cervix (14%) and ovary (7%). The absolute difference was within 2% units except in the case of uterine cervix (5% units). However, the relative difference was highest for brain (-53%), followed by mouth (41%) and uterine cervix (35%). Thus, the highest overrepresentation was of mouth and uterine cervix and underrepresentation of brain in HBCR data.

Bangalore *(Tables 5.1.1b)*

Males: Stomach was the leading site of cancer, accounting for nearly one tenth of the cancer patients, closely followed by oesophagus (9%). The next leading sites were lung (8%) and prostate (6%). Absolute differences were within two percent units except for prostate (-5% units) and hypopharynx (+5% units). The relative difference was highest for hypopharynx (+102%), followed by prostate (-79%), liver (-51%) and stomach (-26%). Thus, hypopharynx was overrepresented in HBCR data and prostate, liver and stomach were underrepresented.

Females: Breast (22%) was the leading site, followed by uterine cervix (19%) and oesophagus (6%). Oesophagus was closely followed by ovary and mouth, each accounting for 5% of cancers in females. The absolute difference was highest for uterine cervix (14% units), followed by breast (9% units) and mouth (6% units). For other sites, the absolute difference was within 2% units. The relative difference was highest for mouth (129%), followed by uterine cervix (77%) and corpus uteri (-69%).

Chennai *(Tables 5.1.1c)*

Males: Stomach (11%) was the leading site, followed by lung (9%), oesophagus (8%) and mouth (5%). Absolute differences were within 4% units, being highest for mouth and followed by lung (negative) and tongue and brain (negative). The relative difference was highest for brain (-79%), followed by mouth (73%) and prostate (-67%).

Females: The leading site was uterine cervix, responsible for a quarter of cancer patients. It was followed by breast (23%) and ovary (5%). The absolute difference was highest for uterine cervix (10% units). For other sites, the absolute

difference was within 3% units. The relative difference was within 50%, with the exception of brain (-84%). Next, it was highest for mouth, followed by uterine cervix, lung (negative) and ovary (negative)

Table 5.1.1a: Proportion (%) of selected leading cancer sites according to HBCR and PBCR and absolute and relative differences between the two, Mumbai, 1999-2000

ICD-10	Site	Proportion (%)		Difference	
		PBCR	HBCR	Absolute	Relative
Males					
C01-02	Tongue	4.5	7.0	2.5	55.6
C03-06	Mouth	5.9	11.3	5.4	91.5
C12-13	Hypopharynx	3.9	5.3	1.4	35.9
C15	Oesophagus	5.9	5.7	-0.2	-3.4
C16	Stomach	4.3	2.9	-1.4	-32.6
C32	Larynx	5.9	5.3	-0.6	-10.2
C33-34	Lung	9.1	7.1	-2.0	-22.0
C61	Prostate	5.7	1.5	-4.2	-73.7
C70-72	Brain, NOS	4.5	2.1	-2.4	-53.3
C82-85,96	NHL	5.1	5.4	0.3	5.9
Females					
C03-06	Mouth	3.4	4.8	1.4	41.2
C15	Oesophagus	4.2	3.7	-0.5	-11.9
C23-24	Gallbladder	2.3	2.8	0.5	21.7
C33-34	Lung	2.8	2.2	-0.6	-21.4
C50	Breast	25.7	26.4	0.7	2.7
C53	Cervix uteri	14.3	19.3	5.0	35.0
C54	Corpus uteri	2.5	2.1	-0.4	-16.0
C56	Ovary	6.7	5.7	-1.0	-14.9
C70-72	Brain, NOS	3.2	1.5	-1.7	-53.1
C82-85,96	NHL	2.8	2.6	-0.2	-7.1

Table 5.1.1b: Proportion (%) of selected leading cancer sites according to HBCR and PBCR and absolute and relative differences between the two, Bangalore, 1999-2000

ICD-10	Site	Proportion (%)		Difference	
		PBCR	HBCR	Absolute	Relative
Males					
C01-02	Tongue	3.4	5.7	2.3	67.6
C12-13	Hypopharynx	4.5	9.1	4.6	102.2
C15	Oesophagus	8.5	9.6	1.1	12.9
C16	Stomach	9.4	7.0	-2.4	-25.5
C22	Liver	3.7	1.8	-1.9	-51.4
C32	Larynx	4.2	3.1	-1.1	-26.2
C33-34	Lung	7.6	7.1	-0.5	-6.6
C61	Prostate	5.8	1.2	-4.6	-79.3
C70-72	Brain, NOS	4.0	4.1	0.1	2.5
C82-85,96	NHL	4.0	4.1	0.1	2.5
Females					
C03-06	Mouth	4.8	11.0	6.2	129.2
C15	Oesophagus	5.5	6.2	0.7	12.7
C16	Stomach	4.2	2.3	-1.9	-45.2
C50	Breast	22.1	13.3	-8.8	-39.8
C53	Cervix	18.7	33.0	14.3	76.5
C54	Corpus uteri	3.2	1.0	-2.2	-68.8
C56	Ovary	5.0	4.3	-0.7	-14.0
C70-72	Brain, NOS	2.4	1.6	-0.8	-33.3
C73	Thyroid	2.9	2.8	-0.1	-3.4
C82-85,96	NHL	2.4	1.7	-0.7	-29.2

Table 5.1.1c: Proportion (%) of selected leading cancer sites according to HBCR and PBCR and absolute and relative differences between the two, Chennai, 1999-2000

ICD-10	Site	Proportion (%)		Difference	
		PBCR	HBCR	Absolute	Relative
Males					
C01-02	Tongue	4.7	7.3	2.6	55.3
C03-06	Mouth	5.1	8.8	3.7	72.5
C12-13	Hypopharynx	4.8	6.8	2.0	41.7
C15	Oesophagus	8.3	7.7	-0.6	-7.2
C16	Stomach	11.4	9.1	-2.3	-20.2
C32	Larynx	4.3	3.8	-0.5	-11.6
C33-34	Lung	9.2	6.1	-3.1	-33.7
C61	Prostate	3.6	1.2	-2.4	-66.7
C70-72	Brain, NOS	3.3	0.7	-2.6	-78.8
C82-85,96	NHL	4.5	4.3	-0.2	-4.4
Females					
C03-06	Mouth	4.2	6.2	2.0	47.6
C15	Oesophagus	4.7	3.7	-1.0	-21.3
C16	Stomach	4.6	3.1	-1.5	-32.6
C33-34	Lung	1.9	1.2	-0.7	-36.8
C50	Breast	22.5	19.8	-2.7	-12.0
C53	Cervix uteri	25.2	35.0	9.8	38.9
C56	Ovary	5.2	3.5	-1.7	-32.7
C70-72	Brain, NOS	1.9	0.3	-1.6	-84.2
C73	Thyroid	2.0	1.9	-0.1	-5.0
C82-85,96	NHL	2.1	2.2	0.1	4.8

5.1.2 Comparison between ATLAS and PBCR

Dibrugarh *(Tables 5.1.2a)*

Males: Oesophagus (18%) was the leading site of cancer, followed by hypopharynx (12%), stomach, mouth and lung. In absolute terms, ten leading sites were over-or underrepresented in ATLAS by up to 8% units. Hypopharynx, mouth and tonsil were the sites overrepresented, whereas stomach, lung and gall bladder were underrepresented. Relative differences were from 50 to 100% for most of the sites within the top ten.

Females: Breast, accounting for nearly one fifth of the cancers, was the leading site followed by cervix (12%), oesophagus (11%), gallbladder (8%), ovary, mouth and stomach. Uterine cervical cancer was overrepresented in ATLAS by 10% units, other sites overrepresented being oesophagus and mouth. Underrepresentation was highest for breast (12% units), followed by gallbladder, stomach and lung. In relative terms, over/under representations were quite high (60 to 90%) for cervix, gallbladder, stomach, lung and breast.

Imphal West *(Tables 5.1.2b)*

Males: The leading site of cancer was lung which accounted for one out of five cancers. Common sites were stomach (8%), oesophagus (7%), and nasopharynx (7%). Hypopharynx, oesophagus and colon were underrepresented in ATLAS, and other sites were overrepresented. The absolute quantum of over/underrepresentation was up to 3% units. Relative overrepresentation was

highest for larynx (91%), followed by nasopharynx (60%), and underrepresentation was highest for hypopharynx (84%) followed by oesophagus (47%).

Females: Lung (16%) was the leading site of cancer followed by cervix (15%), breast (14%) gallbladder and thyroid. Stomach, breast, ovary and thyroid were overrepresented in the ATLAS, and the remaining sites were underrepresented. Absolute figures showed the highest overrepresentation of breast cancers (5% units) and underrepresentation of lung cancers (3% units). In relative terms, overrepresentation was highest for stomach (60%), followed by ovary (51%), and underrepresentation was highest for myloid leukaemia (75%), followed by mouth (59%).

Aizawl *(Tables 5.1.2c)*

Males: Stomach, accounting for one fifth of all cancers, was the leading site followed by oesophagus (15%), lung (12%) and hypopharynx (9%). In ATLAS, the proportion of lung cancer was underrepresented by about 5% units, and the rest of the ten leading sites were over/underrepresented by within 3%. In relative terms, NHL was overrepresented by 148% (5.2 against 2.2%), and pancreas was underrepresented by 74% (0.5 against 1.9%). The rest of the sites within the ten showed relative over/underrepresentation of less than 50%.

Females: Lung and cervix (16% each) were the leading sites of cancer, followed by stomach (13%) and breast (12%). In ATLAS, the sites of lung, stomach and gallbladder were underrepresented, and the rest of leading ten were overrepresented. The inconsistency was highest for lung (-7%). For the rest of the sites, the

over/under representation was within 3%. Relative differences were within 50%, being highest (-44%) for lung and gallbladder.

Table 5.1.2a: Proportion (%) of selected leading cancer sites according to PBCR (2003-2004) and ATLAS (2001-2002) and absolute and relative differences between the two, Dibrugarh

ICD-10	Site	Proportion (%)		Difference	
		PBCR	ATLAS	Absolute	Relative
Males					
C01-02	Tongue	5.4	7.0	1.6	29.6
C03-06	Mouth	6.9	9.5	2.6	37.7
C09	Tonsil	2.9	6.0	3.1	106.9
C12-13	Hypopharynx	11.8	19.9	8.1	68.6
C15	Oesophagus	17.5	15.9	-1.6	-9.1
C16	Stomach	8.0	3.5	-4.5	-56.3
C18	Colon	2.1	1.5	-0.6	-28.6
C23-24	Gallbladder	2.6	0.5	-2.1	-80.8
C32	Larynx	3.4	4.5	1.1	32.4
C33-34	Lung	5.5	3.0	-2.5	-45.5
Females					
C03-06	Mouth	5.2	6.5	1.3	25.0
C15	Oesophagus	10.9	15.6	4.7	43.1
C16	Stomach	5.2	1.3	-3.9	-75.0
C18	Colon	2.0	2.6	0.6	30.0
C23-24	Gallbladder	8.1	1.3	-6.8	-84.0
C33-34	Lung	3.8	1.3	-2.5	-65.8
C50	Breast	18.8	6.5	-12.3	-65.4
C53	Cervix	11.8	22.1	10.3	87.3
C56	Ovary	6.1	5.2	-0.9	-14.8
C92-94	Myeloid Leuk.	2.0	1.3	-0.7	-35.0

Table 5.1.2b: Proportion (%) of selected leading cancer sites according to PBCR (2003-2004) and ATLAS (2001-2002) and absolute and relative differences between the two, Imphal West

ICD-10	Site	Proportion (%)		Difference	
		PBCR	ATLAS	Absolute	Relative
Males					
C01-02	Tongue	2.8	3.4	0.6	21.4
C11	Nasopharynx	5.7	9.1	3.4	59.6
C12-13	Hypopharynx	3.2	0.5	-2.7	-84.4
C15	Oesophagus	7.3	3.9	-3.4	-46.6
C16	Stomach	8.2	10.1	1.9	23.2
C18	Colon	4.1	3.4	-0.7	-17.1
C32	Larynx	3.5	6.7	3.2	91.4
C33-34	Lung	20.5	23.6	3.1	15.1
C82-	NHL	5.1	4.3	-0.8	-15.7
C92-94	Myeloid Leuk.	3.5	3.4	-0.1	-2.9
Females					
C03-06	Mouth	2.7	1.1	-1.6	-59.3
C15	Oesophagus	3.2	1.5	-1.7	-53.1
C16	Stomach	4.2	6.7	2.5	59.5
C23-24	Gallbladder	5.3	4.9	-0.4	-7.5
C33-34	Lung	16.2	13.4	-2.8	-17.3
C50	Breast	14.3	19.4	5.1	35.7
C53	Cervix	14.6	12.3	-2.3	-15.8
C56	Ovary	3.7	5.6	1.9	51.4
C73	Thyroid	5.3	5.6	0.3	5.7
C92-94	Myeloid Leuk.	3.2	0.8	-2.4	-75.0

Table 5.1.2c: Proportion (%) of selected leading cancer sites according to PBCR (2003-2004) and ATLAS (2001-2002) and absolute and relative differences between the two, Aizawl

ICD-10	Site	Proportion (%)		Difference	
		PBCR	ATLAS	Absolute	Relative
Males					
C03-06	Mouth	2.3	2.9	0.6	26.1
C09	Tonsil	1.9	2.9	1.0	52.6
C12-13	Hypopharynx	8.6	6.7	-1.9	-22.1
C15	Oesophagus	15.2	12.7	-2.5	-16.4
C16	Stomach	19.7	20.5	0.8	4.1
C19-20	Rectum	2.4	2.1	-0.3	-12.5
C22	Liver	2.4	2.9	0.5	20.8
C25	Pancreas	1.9	0.5	-1.4	-73.7
C33-34	Lung	12.1	7.3	-4.8	-39.7
C82-85,96	NHL	2.1	5.2	3.1	147.6
Females					
C11	Nasopharynx	2.1	2.6	0.5	23.8
C15	Oesophagus	3.0	3.5	0.5	16.7
C16	Stomach	12.7	11.1	-1.6	-12.6
C19-20	Rectum	2.3	2.3	0.0	0.0
C22	Liver	2.5	3.2	0.7	28.0
C23-24	Gallbladder	2.7	1.5	-1.2	-44.4
C33-34	Lung	16.1	9.0	-7.1	-44.1
C50	Breast	12.3	15.4	3.1	25.2
C53	Cervix	15.7	18.0	2.3	14.6
C56	Ovary	3.2	4.4	1.2	37.5

5.2 Comparison of differences among registries

For comparing the differences between HBCR and PBCR across registries, the primary sites common in the top ten in all the three registries were selected. This selection yielded 9 sites in males and 7 sites in females. Likewise, based on similar criteria, 9 sites in males and 7 in females were also selected for comparison of differences between ATLAS and PBCR across the registries. WAAD and WARD of these 9 and 7 sites were calculated and compared across the registries.

Comparison of differences between HBCR & PBCR among the registries (Tables 5.2.1)

In males, the maximum absolute difference was highest in Bangalore (4.6% units) and lowest in Chennai (3.1%). The maximum relative difference was observed to be highest in Bangalore (102%) and lowest in Mumbai (74%). Similarly, in females the maximum absolute and relative differences were found to be highest in Bangalore (14.3% units and 129% respectively) and lowest in Mumbai (5% units and 53% respectively). For the purpose of objective comparison, the weighted average of the absolute values (ignoring signs) of the absolute and relative differences was worked out. Averages of both absolute and relative differences were similar in all the registries in males. However, there was considerable difference in females, the highest for Bangalore (WAAD = 8.3 and WARD = 52.9) and lowest for Mumbai (WAAD = 1.8 and WARD = 17.4).

Comparison of differences between ATLAS & PBCR among the registries (Tables 5.2.2)

There were substantial inconsistencies among registries in misreporting of the leading sites. The weighted average of inconsistencies between ATLAS and PBCR was highest for Dibrugarh in both sexes. On average, a particular leading site within the top ten in males was over/under reported by a highest absolute difference of 3.4% units in Dibrugarh, followed by 2.6% units in Imphal and 2.1% units in Aizawl. In females, corresponding figures were respectively 7.6, 2.9 and 3.3% units. Relative differences also were highest in Dibrugarh, followed by Imphal and Aizawl in both sexes. The weighted average of the relative differences was 41% for Dibrugarh, 37% for Imphal and 24% for Aizawl in males and 64%, 27% and 26% respectively in females. Like HBCR, there was also larger inter registry variation in inconsistency in females in ATLAS.

Comparison of inconsistencies between HBCR and ALAS

Overall, WAAD and WARD were larger in ATLAS than in HBCR. Even inter registry variation was larger in ATLAS, but only slightly worse than HBCR.

Table 5.2.1: Absolute and relative differences between HBCR and PBCR for the leading sites common in the three study populations with their weighted averages (WAAD and WARD), 1999-2000

ICD-10	Site	Absolute difference (% units)			Relative difference (%)		
		Mumbai	Bangalore	Chennai	Mumbai	Bangalore	Chennai
Males							
C01-02	Tongue	2.5	2.3	2.6	55.6	67.6	55.3
C12-13	Hypopharynx	1.4	4.6	2.0	35.9	102.2	41.7
C15	Oesophagus	-0.2	1.1	-0.6	-3.4	12.9	-7.2
C16	Stomach	-1.4	-2.4	-2.3	-32.6	-25.5	-20.2
C32	Larynx	-0.6	-1.1	-0.5	-10.2	-26.2	-11.6
C33-34	Lung	-2.0	-0.5	-3.1	-22.0	-6.6	-33.7
C61	Prostate	-4.2	-4.6	-2.4	-73.7	-79.3	-66.7
C70-72	Brain, NOS	-2.4	0.1	-2.6	-53.3	2.5	-78.8
C82-85,96	NHL	0.3	0.1	-0.2	5.9	2.5	-4.4
Weighted average*		1.7	1.9	1.9	30.7	32.7	30.1
Females							
C03-06	Mouth	1.4	6.2	2.0	41.2	129.2	47.6
C15	Oesophagus	-0.5	0.7	-1.0	-11.9	12.7	-21.3
C50	Breast	0.7	-8.8	-2.7	2.7	-39.8	-12.0
C53	Cervix uteri	5.0	14.3	9.8	35.0	76.5	38.9
C56	Ovary	-1.0	-0.7	-1.7	-14.9	-14.0	-32.7
C70-72	Brain, NOS	-1.7	-0.8	-1.6	-53.1	-33.3	-84.2
C82-85,96	NHL	-0.2	-0.7	0.1	-7.1	-29.2	4.8
Weighted average*		1.8	8.3	5.1	17.4	52.9	28.7

*Weighted average of absolute differences (WAAD) and of relative differences (WARD)

Table 5.2.2: Absolute and relative differences between ATLAS (2001-2002) and PBCR (2003-2004) for the leading sites common in the three study populations with their weighted averages (WAAD and WARD)

ICD-10	Site	Absolute difference (% units)			Relative difference (%)		
		Dibru-garh	Imphal	Aizawl	Dibru-garh	Imphal	Aizawl
Males							
C01-02	Tongue	1.6	0.6	2.9	29.6	21.4	193.3
C03-06	Mouth	2.6	3.4	0.6	37.7	178.9	26.1
C09	Tonsil	3.1	-0.6	1.0	106.9	-37.5	52.6
C12-13	Hypopharynx	8.1	-2.7	-1.9	68.6	-84.4	-22.1
C15	Oesophagus	-1.6	-3.4	-2.5	-9.1	-46.6	-16.4
C16	Stomach	-4.5	1.9	0.8	-56.3	23.2	4.1
C18	Colon	-0.6	-0.7	-0.6	-28.6	-17.1	-37.5
C32	Larynx	1.1	3.2	0.4	32.4	91.4	21.1
C33-34	Lung	-2.5	3.1	-4.8	-45.5	15.1	-39.7
Weighted average*		3.4	2.6	2.1	40.5	36.9	23.9
Females							
C15	Oesophagus	4.7	-1.7	0.5	43.1	-53.1	16.7
C16	Stomach	-3.9	2.5	-1.6	-75.0	59.5	-12.6
C23-24	Gallbladder	-6.8	-0.4	-1.2	-84.0	-7.5	-44.4
C33-34	Lung	-2.5	-2.8	-7.1	-65.8	-17.3	-44.1
C50	Breast	-12.3	5.1	3.1	-65.4	35.7	25.2
C53	Cervix	10.3	-2.3	2.3	87.3	-15.8	14.6
C56	Ovary	-0.9	1.9	1.2	-14.8	51.4	37.5
Weighted average*		7.6	2.9	3.3	64.0	27.2	25.9

*Weighted average of absolute differences (WAAD) and of relative differences (WARD)

5.3 Trend in consistency between HBCR and PBCR

The trend in consistency between HBCR and PBCR was studied for Mumbai. For this purpose, four leading sites of cancer in males, namely mouth, stomach, larynx and lung, were selected for comparing the proportions observed in PBCR and HBCR for different time periods. Similarly, four leading sites in females, namely, mouth, breast, cervix and ovary, were also selected. Consistency between HBCR and PBCR over a period of time is going to be affected by the changes in proportions according to the two types of registries. Therefore, before looking at the trend in consistency, we also examined the trend in the proportions according to HBCR and PBCR. Tables 5.3.1a & b present the number and proportion according to HBCR, and the same and crude incidence rate according to PBCR for five time periods and four leading sites in males and females. Figures 5.3.1a & b show the consistency between HBCR and PBCR proportions for different time periods in the form of scatter diagram.

Mouth cancers: There was consistent increase in the proportion of mouth cancers in males in HBCR (from 10 to 13%) as well as PBCR (from 5 to 8%). However, the relative increase was less in HBCR (30%) compared to PBCR (60%). This was also evident in the crude incidence rates. The scatter diagram also showed consistency between the trends according to HBCR and PBCR. As a result, the difference between HBCR and PBCR was similar for the five time periods under study. In females, however, there was a slight increase in the HBCR proportions between latest two time periods under study (from 4.7 to 5.0%), whereas there was slight decline (from 3.4 to 3.1%) in PBCR, resulting into the widening of differences over

time. This was also evident in scatter diagram. All the dots being below the diagonal line indicated over-registration of mouth cancers in HBCR.

Stomach cancers in males: There was an increasing trend in HBCR proportions, but a declining trend in PBCR proportions as well as rates. The proportions increased in HBCR from 2.5 to 3.1 percent and decreased in PBCR from 5.3 to 4.2 percent. Thus, there was a clear trend in both types of registries, however, in the opposite direction resulting in the narrowing of differences from 3 to 1 percentage units during five time periods. This can also be visualised in the scatter diagram. The scatter diagram showed the dots above the diagonal line, indicating under registration of stomach cancers in HBCRs. However, over the study period, the dots seemed to approach the line, indicating improvement in consistency.

Laryngeal cancers in males: There appears to be a decline in the proportion or rate of these cancers, but only recently. HBCR proportions, however, showed a clear declining trend throughout the study period. As a result, there was no consistency in the differences between HBCR and PBCR over five time periods. This may also be visualised in the scatter diagram, which shows the dots almost parallel to the X-axis, indicating no change in PBCR proportions. Like stomach cancers, most of the dots in the figure were above the diagonal line, depicting under registration of these cancers in HBCRs. As far as the trend in consistency between HBCR and PBCR is concerned, there was improvement during the latter part of the 1990s. However, later on, deterioration of consistency in the opposite direction was noted.

Lung cancers in males: The HBCR proportion registered an almost regular increasing trend. On the other hand, PBCR proportions and rates declined regularly until the 4th time period under study. Recently, however, there was an increase in both. The scatter diagram also showed a negative correlation, because at the changes between the 1st and 2nd and between the 4th and 5th time periods separately, we find that the changes in HBCR and PBCR are in the opposite direction. It is also evident in the scatter diagram showing a negative correlation pattern. As a result, there was an indication of a narrowing of differences, indicating improvement of consistency between HBCR and PBCR proportions over the time period. However, this was not consistent.

Female breast cancers: There appeared to be consistency in the trends in proportions according to HBCR and PBCR. Both showed an increasing trend in the occurrence of breast cancer. Resultant positive correlation is also evident in the scatter diagram. Most of the dots are close to the diagonal line, indicating similarity between HBCR and PBCR proportions. Therefore, the differences in the proportions according to HBCR and PBCR were small. Regarding the trend in consistency, it improved during the middle of the study period, but deteriorated later on.

Uterine cervical cancers: There appeared to be consistency in the trends in proportions according to HBCR and PBCR. Both showed a decreasing trend in the occurrence of uterine cervical cancer. A resultant near perfect positive correlation is also evident in scatter diagram. The quantum of decrease, however, is bigger in HBCR compared to PBCR. Overrepresentation of this cancer in HBCRs is apparent in the scatter diagram from all the dots being below diagonal line. This resulted in inconsistent differences in proportions according to two types of registries, narrowing over the study period, indicating improvement in consistency.

Ovarian cancers: The proportion of this cancer appears to fluctuate in both types of the registries, indicating no clear trend. The scatter diagram also showed no consistency in the proportion according to two types of registries. As far as the quantum of proportion is concerned, all the dots in the scatter diagram are way above the diagonal line, indicating under registration in HBCRs. Thus, the differences in proportions according to two types of registries were not consistent over the study period, indicating no trend in consistency between proportions according to HBCR and PBCR.

Summary of trend in consistency: The purpose of this section was to find out if the HBCR and PBCR data may become more comparable over the study period or in the future. This was to be expected because cancer services in the country may increase in quantity and quality and may also become more evenly distributed over time. This could result in a decline in the relative quantum of OUTPTSIN and INPTSOUT, accounting for differences between HBCR and PBCR. The quantum of OUTPTSIN may decline because outside patients may find the required cancer care facilities in their registry area, and therefore may not come to the HBCR hospital. Similarly, the quantum of INPTSOUT may also decline because the patients in the registry area may find the required cancer care facilities in the HBCR hospital itself and therefore may not go outside the registry area for the same. Results of this study, however, showed many types of trends in consistency over time, even though the study was confined to only one study area (Mumbai). Cancer of uterine cervix in women and stomach in men showed improvement in consistency over time, however attributed to different technical possibilities. In the case of uterine cervix, it improved, because the overestimate by HBCR was reduced, and the true trend was relatively stable. However, in the case of stomach cancer in men, it improved

because the underestimate by HBCR as well as the true risk both reduced. On the other hand, mouth cancer in males and females both showed stability in consistency over time, however attributed again to different technical possibilities. In the case of mouth cancer in men, the trend was the same in both HBCR and PBCR. In women, there was no trend in HBCR or in PBCR. Laryngeal and lung cancers both showed initial improvement and deterioration later on, however attributed to different technical possibilities. In the case of laryngeal cancer, the PBCR proportion increased and then decreased, and the HBCR proportion consistently decreased. In the case of lung cancer, HBCR and PBCR proportions both initially decreased and then increased. Female breast and ovarian cancers did not show any trend in consistency. In view of the above, we cannot expect that the consistency in cancer pattern according to HBCR and PBCR would improve with time.

Table 5.3.1a: Number, proportion and crude incidence rate of selected sites of cancer for the five time periods according to HBCR and PBCR Mumbai, Males

Site and indicator	Time - period*				
	I	II	III	IV	V
Mouth cancers					
PBCR Number	229	230	263	352	417
PBCR Proportion (%)	5.5	5.3	5.9	7.7	7.9
PBCR Rate (per 100 000)	4.0	3.7	4.1	5.2	5.6
HBCR Number	777	957	993	1096	1244
HBCR Proportion (%)	9.9	11.1	11.3	12.2	12.8
Difference in proportions (% units)	-	-5.8	-5.4	-4.5	-4.9
Stomach cancers					
PBCR Number	218	208	191	186	220
PBCR Proportion (%)	5.3	4.8	4.3	4.1	4.2
PBCR Rate (per 100 000)	3.8	3.4	3.0	2.7	2.9
HBCR Number	199	245	252	279	297
HBCR Proportion (%)	2.5	2.8	2.9	3.1	3.1
Difference in proportions (% units)	2.8	2.0	1.4	1.0	1.1
Laryngeal cancers					
PBCR Number	232	246	262	264	254
PBCR Proportion (%)	5.6	5.7	5.9	5.8	4.8
PBCR Rate (per 100 000)	4.1	4.0	4.1	3.9	3.4
HBCR Number	494	484	469	411	371
HBCR Proportion (%)	6.3	5.6	5.3	4.6	3.8
Difference in proportions (% units)	-	0.1	0.6	1.2	1.0
Lung cancers					
PBCR Number	389	392	402	375	468
PBCR Proportion (%)	9.4	9.1	9.1	8.2	8.9
PBCR Rate (per 100 000)	6.9	6.3	6.2	5.5	6.3
HBCR Number	542	632	627	683	763
HBCR Proportion (%)	6.9	7.3	7.1	7.6	7.9
Difference in proportions (% units)	2.5	1.8	2.0	0.6	1.0

*PBCR I:1996-1996, II:1997-1998, III:1999-2000, IV:2001-2004, V:2006-2008
HBCR I:1984-1993, II:1994-1998, III:1999-2000, IV:2001-2003, V:2004-2006

Table 5.3.1b: Number, proportion and crude incidence rate of selected sites of cancer for the five time periods according to HBCR and PBCR Mumbai, Females

Site and indicator	Time - period*				
	I	II	III	IV	V
Mouth cancers					
PBCR Number	131	140	148	155	179
PBCR Proportion (%)	3.4	3.3	3.4	3.4	3.1
PBCR Rate (per 100 000)	2.8	2.8	2.8	2.8	3.0
HBCR Number	292	342	328	351	380
HBCR Proportion (%)	4.7	5.1	4.8	5.0	5.0
Difference in proportions (% units)	-1.3	-1.8	-1.4	-1.6	-1.9
Breast cancers					
PBCR Number	955	1062	1119	1263	1753
PBCR Proportion (%)	24.7	25.0	25.7	27.5	30.1
PBCR Rate (per 100 000)	20.2	21.1	21.3	23.0	29.2
HBCR Number	1416	1770	1809	1913	2106
HBCR Proportion (%)	23.0	26.2	26.4	27.2	27.5
Difference in proportions (% units)	1.7	-1.2	-0.7	0.3	2.6
Uterine cervical cancers					
PBCR Number	589	620	622	597	753
PBCR Proportion (%)	15.2	14.6	14.3	13.0	12.9
PBCR Rate (per 100 000)	12.4	12.3	11.9	10.9	12.5
HBCR Number	1703	1480	1322	1182	1183
HBCR Proportion (%)	27.7	21.9	19.3	16.8	15.5
Difference in proportions (% units)	-	-7.3	-5.0	-3.8	-2.6
Ovarian cancers					
PBCR Number	249	307	290	334	380
PBCR Proportion (%)	6.4	7.2	6.7	7.3	6.5
PBCR Rate (per 100 000)	5.3	6.1	5.5	6.1	6.3
HBCR Number	264	359	389	379	412
HBCR Proportion (%)	4.3	5.3	5.7	5.4	5.4
Difference in proportions (% units)	2.1	1.9	1.0	1.9	1.1

*PBCR I:1996-1996, II:1997-1998, III:1999-2000, IV:2001-2004, V:2006-2008
HBCR I:1984-1993, II:1994-1998, III:1999-2000, IV:2001-2003, V:2004-2006

Figure 5.3.1a: Consistency of proportions observed in PBCRs with that observed in HBCRs: Mumbai, Males

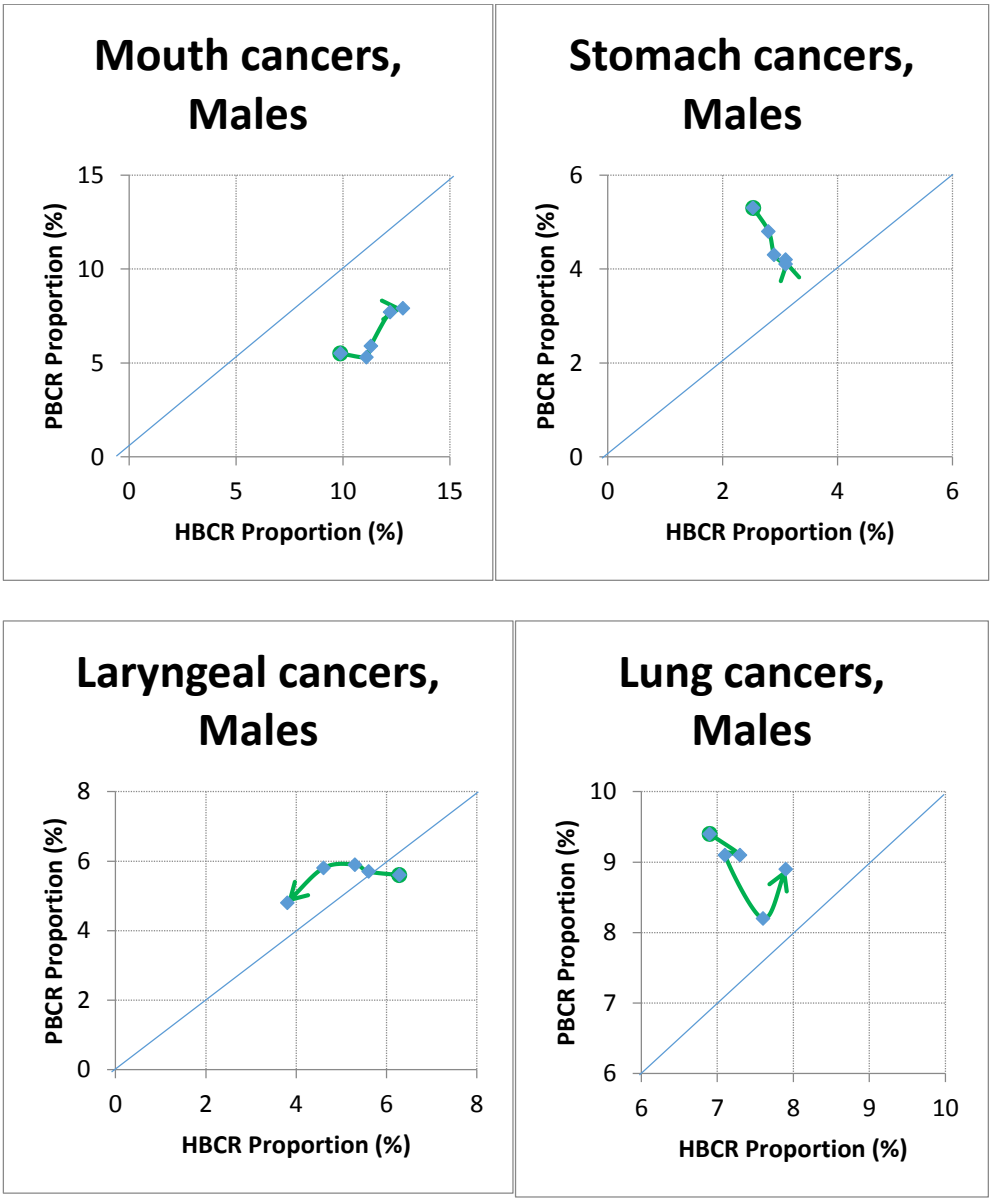
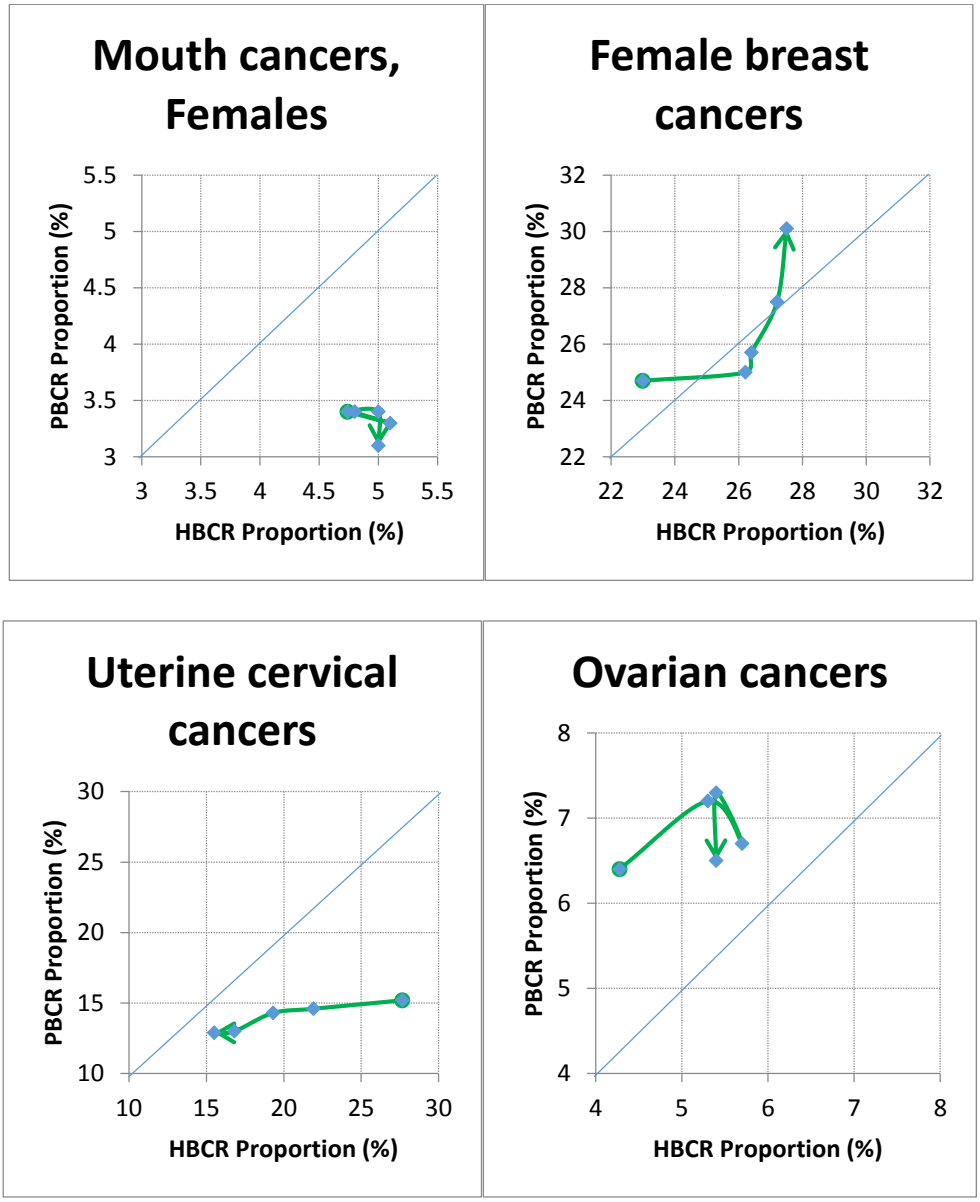


Figure 5.3.1b: Consistency of proportions observed in PBCRs with that observed in HBCRs: Mumbai, Females



5.4 Comparison of RHBCR with HBCR and PBCR

RHBCR vs. HBCR: There were substantial differentials between the proportions obtained from the two sets of data. The difference varied up to 4.6 % units in absolute terms and as high as 91% in relative terms in males. In females, the difference was slightly on the lower side, nonetheless, it is there, with an absolute difference up to 2 and relative difference up to 64%. The differences were higher for hypopharynx, larynx, gallbladder and female breast. (Table 5.4.1)

RHBCR vs. PBCR: This comparison also showed quite substantial differences in both sexes. In males, the absolute difference was highest for mouth (4.1% units), followed by hypopharynx (-3.2), prostate (-2.8) and stomach (-2.5). The relative difference was also quite high for these sites. In females, the absolute difference was highest for cervix uteri (5.5), followed by breast (2.7). However, in relative terms, it was not so high for the common sites like breast and cervix. It was highest for gallbladder, mouth and brain NOS. (Table 5.4.2)

Table 5.4.1: Proportion (%) of selected leading cancer sites according to RHBCR and HBCR and absolute and relative differences between the two, Mumbai, 2000

ICD-10	Site	Proportion (%)		Difference	
		HBCR	RHBCR	Absolute (% units)	Relative (%)
Males					
C01-02	Tongue	7.0	7.8	0.8	11.8
C03-06	Mouth	11.3	10.0	-1.3	-11.7
C12-13	Hypopharynx	5.3	0.7	-4.6	-86.5
C15	Oesophagus	5.7	6.4	0.7	12.1
C16	Stomach	2.9	1.8	-1.1	-38.1
C32	Larynx	5.3	8.3	3.0	55.8
C33-34	Lung	7.1	7.2	0.1	1.1
C61	Prostate	1.5	2.9	1.4	91.4
C70-72	Brain, NOS	2.1	3.4	1.3	60.7
C82-85,96	NHL	5.4	5.8	0.4	7.7
Females					
C03-06	Mouth	4.8	5.2	0.4	9.0
C15	Oesophagus	3.7	4.3	0.6	17.5
C23-24	Gallbladder	2.8	1.0	-1.8	-63.6
C33-34	Lung	2.2	2.6	0.4	20.4
C50	Breast	26.4	28.4	2.0	7.6
C53	Cervix uteri	19.3	19.8	0.5	2.8
C54	Corpus uteri	2.1	2.4	0.3	16.5
C56	Ovary	5.7	5.6	-0.1	-1.1
C70-72	Brain, NOS	1.5	1.6	0.1	4.2
C82-85,96	NHL	2.6	2.9	0.3	9.7

Table 5.4.2: Proportion (%) of selected leading cancer sites according to RHBCR and PBCR and absolute and relative differences between the two, Mumbai, 2000

ICD-10	Site	Proportion (%)		Difference	
		PBCR	RHBCR	Absolute (% units)	Relative (%)
Males					
C01-02	Tongue	4.5	7.8	3.3	73.9
C03-06	Mouth	5.9	10.0	4.1	69.1
C12-13	Hypopharynx	3.9	0.7	-3.2	-81.6
C15	Oesophagus	5.9	6.4	0.5	8.3
C16	Stomach	4.3	1.8	-2.5	-58.3
C32	Larynx	5.9	8.3	2.4	39.9
C33-34	Lung	9.1	7.2	-1.9	-21.1
C61	Prostate	5.7	2.9	-2.8	-49.6
C70-72	Brain, NOS	4.5	3.4	-1.1	-25.0
C82-85,96	NHL	5.1	5.8	0.7	14.0
Females					
C03-06	Mouth	3.4	5.2	1.8	53.9
C15	Oesophagus	4.2	4.3	0.1	3.5
C23-24	Gallbladder	2.3	1.0	-1.3	-55.7
C33-34	Lung	2.8	2.6	-0.2	-5.4
C50	Breast	25.7	28.4	2.7	10.5
C53	Cervix uteri	14.3	19.8	5.5	38.7
C54	Corpus uteri	2.5	2.4	-0.1	-2.2
C56	Ovary	6.7	5.6	-1.1	-15.8
C70-72	Brain, NOS	3.2	1.6	-1.6	-51.2
C82-85,96	NHL	2.8	2.9	0.1	1.9

5.5 Evaluation of changes from HBCR to RHBCR

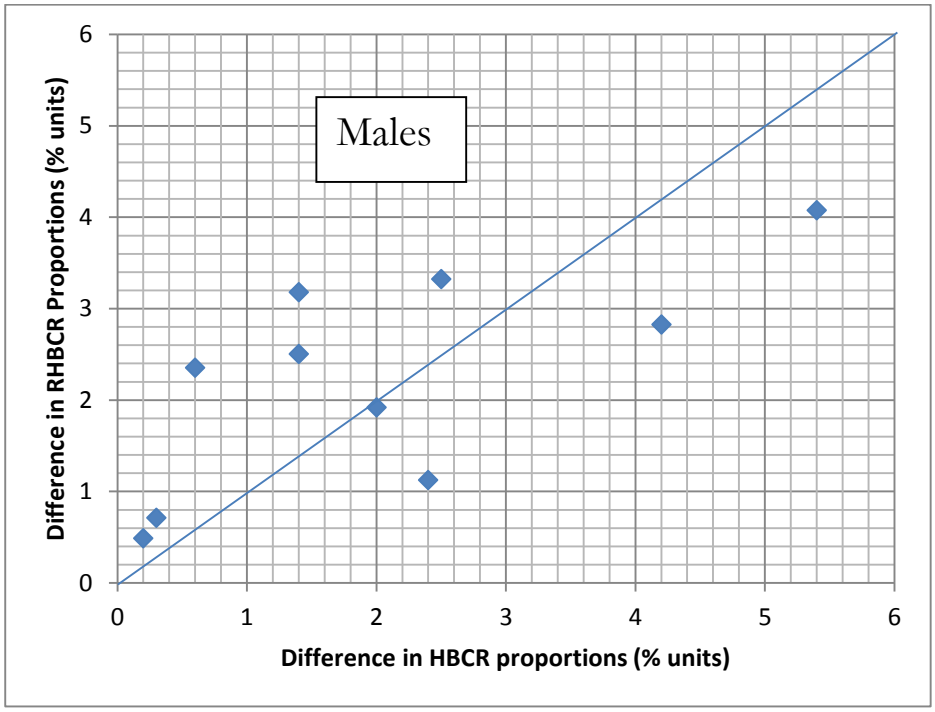
Reduction of HBCR data to RHBCR did not bring uniform changes in over or underrepresentation of a particular site in HBCR data. For some of the sites, the quantum of over/underrepresentation reduced. For example, the overrepresentation of mouth was reduced from 92% to 69%. Similarly, the underrepresentation of prostate cancer reduced from 74% to 50%. In females, the underrepresentation of lung and corpus uteri also reduced respectively from 21 and 16% to respectively 5 and 2%. At the same time, however, there were examples of the differences being widened. For example, larynx cancer in males which was underrepresented in HBCR by 10% was overrepresented by 40% in RHBCR. In the case of mouth cancer in females, the overrepresentation increased from 41% to 54%. Gallbladder cancer in females, overrepresented in HBCR by 22%, was underrepresented in RHBCR by 56%. Looking at the weighted averages, WAAD increased from 2.1 to 2.2 in males and from 1.7 to 2.5 in females. Similarly, WARD also increased from 37 to 41 in males and from 18 to 21 in females. Unexpectedly, the overall inconsistency in RHBCR was larger than that in HBCR, indicating deterioration of consistency when HBCR data was reduced to RHBCR (Table 5.5.1). Looking at the scatter diagram, the distances of dots above the diagonal line appeared to be slightly larger than those below, indicating deterioration of consistency in RHBCR (Figure 5.5.1).

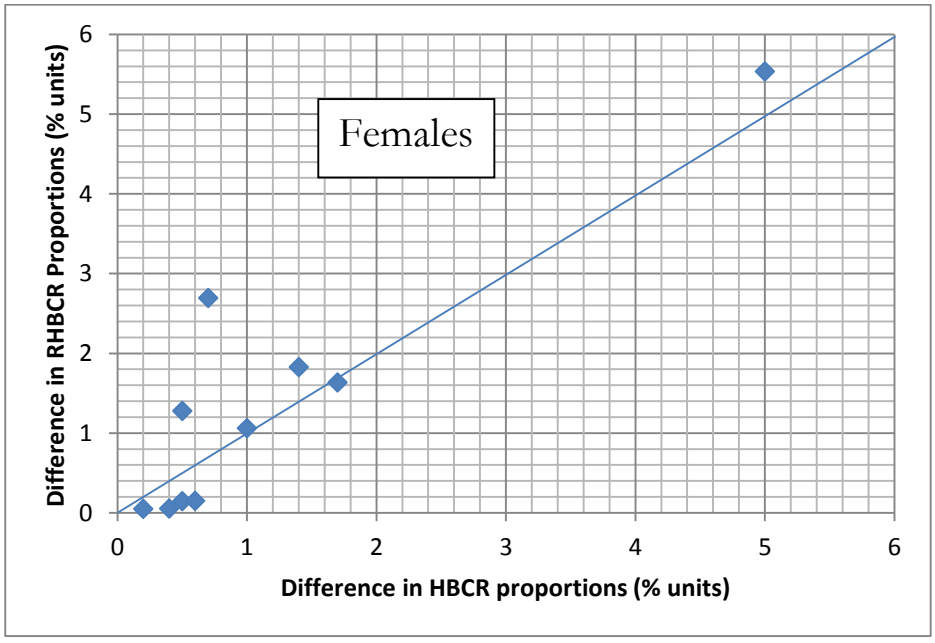
Table 5.5.1: Absolute and relative differences in proportions between PBCR vs. HBCR and HBCR vs. RHBCR along with their weighted average (WAAD and WARD), Mumbai, 2000

ICD-10	Site	Absolute differences (% units)		Relative differences (%)	
		PBCR vs. HBCR	PBCR vs. RHBCR	PBCR vs. HBCR	PBCR vs. RHBCR
Males					
C01-02	Tongue	2.5	3.3	55.6	73.9
C03-06	Mouth	5.4	4.1	91.5	69.1
C12-13	Hypopharynx	1.4	-3.2	35.9	-81.6
C15	Oesophagus	-0.2	0.5	-3.4	8.3
C16	Stomach	-1.4	-2.5	-32.6	-58.3
C32	Larynx	-0.6	2.4	-10.2	39.9
C33-34	Lung	-2.0	-1.9	-22.0	-21.1
C61	Prostate	-4.2	-2.8	-73.7	-49.6
C70-72	Brain, NOS	-2.4	-1.1	-53.3	-25.0
C82-85,96	NHL	0.3	0.7	5.9	14.0
Weighted average*		2.1	2.2	37.2	41.1
Females					
C03-06	Mouth	1.4	1.8	41.2	53.9
C15	Oesophagus	-0.5	0.1	-11.9	3.5
C23-24	Gallbladder	0.5	-1.3	21.7	-55.7
C33-34	Lung	-0.6	-0.2	-21.4	-5.4
C50	Breast	0.7	2.7	2.7	10.5
C53	Cervix uteri	5.0	5.5	35.0	38.7
C54	Corpus uteri	-0.4	-0.1	-16.0	-2.2
C56	Ovary	-1.0	-1.1	-14.9	-15.8
C70-72	Brain, NOS	-1.7	-1.6	-53.1	-51.2
C82-85,96	NHL	-0.2	0.1	-7.1	1.9
Weighted average*		1.7	2.5	17.7	21.3

*Weight average of absolute differences (WAAD) and of relative differences (WARD)

Figure 5.5.1: Correlation between the differences in HBCR and RHBCR proportions with PBCR proportions for ten leading sites, Mumbai, 2000





6 DISCUSSION

There are many uses of HBCR data. Well accepted uses are: to assess patient care, to participate in clinical research to evaluate therapy, and to help plan hospital facilities. In addition, there are some potential uses that require validation. These uses are based on the generalisation of relative frequencies (proportion of a particular site relative to all sites) at the population level. There are examples of generalisation of hospital data at the population level in India (Dhar and Nandakumar, 1994, TMH, 2004, NCRP, 2004) as well as abroad (Jedy-Agba, et al., 2012, Higashi et al., 2013, Okobia, 2013).

Dhar and Nandakumar (1994) utilised HBCR data to study the urban rural differences in cancer patterns. They combined the data of HBCRs located in Bangalore, Chennai and Trivandrum, in the southern part of the country and divided the data into urban and rural by matching the pin codes of permanent addresses of the patients. They observed that the proportion of leading sites of cancer as well as the proportion of advanced and localised cancer did show some variations between urban and rural areas.

In a report from Mumbai, India (TMH, 2004), an attempt has been made to interpret the data of HBCR for different areas of Maharashtra. While ascertaining the leading sites in different regions, the report states that the observed differences in relative frequencies need further scrutiny.

Through the ATLAS project supported by WHO, the NCRP collected data from selected centres, who volunteered to collaborate in the project (NCRP, 2004). These data were used to arrive at minimum cancer incidence rates (MCIR) for the geographic divisions of the country to estimate the cancer pattern in the country.

Shin et al. (2005) came out with first Korean national population-based registry using nationwide hospital-based recording system and the regional cancer registries. They compiled the data on cancer from different sources like the Korea Central Cancer Registry database, medical record review survey, regional cancer registry databases, site specific cancer registry databases and cancer mortality data from the Korea National Statistical Office. The data was collected for research and cancer control in Korea.

Jedy-Agba et al. (2012) used the data from HBCRs in Nigeria to assess the cancer pattern and projected the generalisation to the low and middle-income countries (LMICs). In a letter to the editor in response to this study, Rajaram et al. (2013) upheld the authors' views that robust HBCRs are needed in resource poor countries for efficient study of cancer epidemiology. Retrospective analysis of histologically confirmed gynaecologic malignancies over a six-year period was performed to identify patterns and trends of cancer received at their centre.

Okobia (2013) reviewed the existing literature on cancer statistics in sub-Saharan Africa to assess the need for PBCRs to enhance cancer care and prevention. The observation of a small variation in the pattern may not be valid, even for sub-Saharan Africa. The paper concluded that cancer statistics from developing countries are inadequate due to the lack of functional PBCRs and recommended establishing PBCRs to facilitate the formulation of appropriate policies.

Higashi et al. (2013) described the national database of HBCRs as the national infrastructure to support evidence-based cancer care and cancer control policy in Japan. They advocated that the future evolution of HBCRs will lead to continuous monitoring of cancer care in Japan.

In view of the above and well-known scarcity of accurate and reliable data on the pattern of cancer in developing countries, the present study was planned to assess the validity of a population-based interpretation of HBCR and ATLAS data

in India. This was demonstrated using 3 indicators, viz, proportion of a particular site relative to all sites, rank order by site, and trend in the proportions.

6.1 Evaluation of cancer pattern at population level

To plan, monitor and evaluate the cancer control programmes, we need data on risk of occurrence of the disease. The risks are given per population (prevalence rate) or per population time (incidence rate). In order to arrive at the risks, data on the occurrence of cancer is needed to be accompanied by a corresponding valid and representative population. HBCRs, however, provide the numerator (the data on the occurrences of cancer) for an unknown denominator (population at risk), that too, with potentially under coverage. Hence, the ideal need is either a national PBCR or a number of PBCRs representing the national population to a reasonable extent.

6.2 Suitability of HBCR and ATLAS as alternatives

6.2.1 General considerations

The assumption involved in the interpretation of HBCR data at the population level is that the base population contributing to the attendance at a particular hospital remains the same over the study period. Actually, patient attendance at a hospital depends on the reputation of that hospital, the diagnostic and treatment facilities available and whether it is a Government hospital or a Private one. A hospital may receive patients from all over the country, and sometimes even from abroad as well. Most of the patients attending a particular hospital, however, may come from a certain area surrounding the hospital.

Another factor that may affect the population contributing to a hospital is the opening up of new cancer diagnostic and treatment facilities in the area. In this case, however, the new setup is likely to attract relatively early cases, and most of the advanced cases will continue to go to the established reputed hospital.

In other words, there are two assumptions involved in the interpretation of results on cancer pattern drawn out of HBCR data. First, in the case of a particular HBCR, the patients coming from the registry area to the registry hospital are representative of all the cancer patients in the same registry area. Second, the base population contributing to the attendance at a particular HBCR hospital remains similar over the study period.

Broadly, there are two reasons for the potential biases in the population-based interpretation of HBCR data.

1) Under registration due to exclusion of some of the cases from the registry area, as they may be going to other hospitals.

2) Overregistration due to inclusion of the cases from outside the registry area, as they may be coming to the registry hospital.

Since the present study was based on secondary data obtained from published reports, it was not possible to separate HBCR data based on their place of residence. However, since HBCRs do invariably collect data on the place of residence, it may be possible to divide the raw data into those from the registry area and those from outside the registry area. It may be difficult even for the HBCRs to adhere to the definition of residence, though, because the duration of stay may not be available, as this was not mandatory in HBCR proforma.

6.2.2 HBCR

Ideal requirements for planning and administration are the data from a PBCR. Establishing and sustaining a PBCR however, is not an easy job. It is a costly affair and therefore hardly affordable in developing countries. On the other hand, it is possible to establish and sustain a HBCR at a minimal additional cost. Hence, one of the aims of present study was to examine the feasibility of population-based interpretation from HBCR data that can be useful for policy planning and administration.

The data from the HBCR may potentially give some idea of the occurrence of cancer in the catchment area of the registry. However, this is subject to validation, which may not be possible. The main difficulty in the utilisation of HBCR data in cancer control is the lack of knowledge about the population from where the cancers arose. Therefore, we are unable to calculate any rate and left with only relative frequencies (proportion of individual sites relative to all sites). At best, the proportions may be sufficiently correlated with rates to give an idea on the most frequent cancers and changes in the risk over time or geography. The proportions as a substitute of rate are subject to many potential biases if the underlying assumptions are not true. Due to the biases, the interpretation of HBCR data at the population level is always questionable. At the same time, it may be appreciated that the theoretical biases may or may not affect the interpretations considerably. Therefore, it would be worth to examine the applicability of HBCR data at the population level before arriving at any conclusion. It may be noted that findings of such exercises can be only case specific and therefore cannot be generalised to other setups. The methods applied here, however, can always be used to evaluate the role of HBCR data in estimating cancer patterns in other developing countries subject to the existence of a PBCR covering the catchment area of the HBCR.

The present study has found that there is gross over/underrepresentation of different sites of cancer in the data from HBCRs in India. Therefore, any assessment of risk of even leading sites of cancer based on HBCR data may be biased. By and large, easily accessible sites like mouth, tongue and hypo-pharynx were overrepresented in HBCR data, whereas, the sites not so easy to diagnose, like stomach, lung, prostate and brain were under-represented. Among female-specific sites, cancer of the breast and ovary were underrepresented, whereas that of the uterine cervix was overrepresented. Looking at it in another way, HBCRs have overrepresentation of cancers with relatively clear signs and symptoms. On the other hand, the cancers not easy to detect have underrepresentation in HBCR data. This may be due to a majority of the patients of these cancers not being referred to the specialised cancer hospitals due to advanced stage of the disease. Availability of diagnostic and treatment facilities in different hospitals is another factor that may explain these inconsistencies. For example, a particular hospital having better diagnostic and treatment facilities may attract more cases of that cancer and vice versa.

Substantial variation was observed in the quantum of over/under registration. This may be due to the facilities available in the hospital under study changing over time. Another reason may be the change in the geographic area that is contributing the patients to the hospital. This may again be due to opening up of new or ceasing of existing diagnostic and treatment facilities within the catchment area of the HBCR. Still another reason may be the opening-up of new health care facilities in the country outside the catchment area of the HBCR that may be attracting some of the patients who would otherwise have joined to the hospital under study.

The over/underrepresentation of leading sites in HBCR data across the registries was also compared, and the differences were not uniform across the

registries. If the differences were similar, it would have been possible to correct the proportions of the HBCRs and arrive at the risk in areas with a HBCR only.

The present study also looked into the improvement of comparison between HBCR and PBCR by removing the patients from outside the registry area. However, no considerable improvement was found. In fact, deterioration of the comparison for some of the sites was observed. Thus, in summary of the findings of the study, HBCR data are to be used with caution for any population-based interpretation in India.

6.2.3 ATLAS

The NCRP undertook an Atlas of Cancer in India as a project funded by WHO and generated so-called 'minimum crude incidence rates (MCIR)', and different sites of cancer were ranked based on the MCIR. In fact, the pattern depicted by MCIR is technically the same as that based on proportions (of individual sites relative to all sites). If proportions are not similar in PBCR and ATLAS data, then the assumption of estimation of minimum incidence is not valid. Therefore, we compared the pattern depicted by proportions according to ATLAS with that observed in PBCRs published later. The earliest report published for the PBCRs in northeast region presents the data for 2003-2004. We found three registries in the northeast region appearing in both the reports. They were Dibrugarh district in Assam, Imphal West district in Manipur and Aizawl district in Mizoram. It may be observed in comparisons that there were many similarities, but at the same time there were many dissimilarities also. This may be mainly due to the proportion of non-microscopically confirmed cases being substantial, assuming that the data was subjected to perfect quality control checks and analyses.

Theoretically, the uses of ATLAS data are identical to those of PBCRs. Practically however; the validity of the uses depends upon the tenability of the assumptions involved. The uses of ATLAS data are similar to the uses of PBCR data if ATLAS is able to capture 80 to 90% of cases, i.e., MCIR reported by ATLAS is 80% to 90% of the true incidence rate. However, the uses will be valid under the assumption that the deficit in ATLAS data is proportionally distributed among different primary sites of cancer. Under these assumptions, ATLAS data may be used to find the risk of different forms of cancer and the patterns and trends therein.

Our results on comparison of consistency of ATLAS data with PBCR showed that there was no overall comparability between the two cancer patterns. There was substantial over/under representation of different primary sites in ATLAS. The differences were on the lines of that in HBCR data. It was to be expected, because ATLAS data are conceptually similar to multi-centric HBCR data. The rationale behind the idea of ATLAS was that 80% to 90% of the cancers in the existing PBCRs were microscopically diagnosed. However, this cannot be generalised to the whole country. Second, the list of all pathology centres in the country obtained may not be exhaustive. Third, all the centres contacted may not have given the consent for collaborating in the project.

6.3 Validity of population-based uses of HBCR or ATLAS

One of the general uses of PBCR useful for the policy planners and administrators is to 'provide an idea of pattern of cancer in the area'. Pattern of cancer generally refers to the following questions in planning and prioritising the allocations of resources for the control of cancer.

Q1. What is the overall burden of cancer?

Q2. What are the leading sites of cancer?

Q3. What is the trend in the overall as well as leading sites of cancer?

The present study has shown that validity is a major issue in utilising HBCR or ATLAS data in answering these questions in the Indian setup. However, the methods presented in this report may be useful in other populations within and outside the country, where the HBCR and PBCR both exist.

6.3.1 Overall burden of cancer in the country

Data on the overall as well as the site-wise burden of cancer are the basic requirements of any cancer control activity. India has few PBCRs representing a small proportion of the country's population, mostly from urban areas, although, the majority of the Indian population lives in rural areas. Therefore, there are no data available on the cancer pattern at the national level. On the other hand, HBCR data seem inappropriate to supplement limited PBCR data to all of India. Even ATLAS data may require (if possible at all) sophisticated modeling to provide any idea of the overall cancer burden in the country.

6.3.2 Leading sites of cancer

It may be noted that even if the levels of risk (incidence) was poorly estimated, we may get a picture on the rank of the leading sites if the inconsistency

in over/underrepresentation is evenly distributed through different sites of cancer. However, this was not the case. Some of the sites were underrepresented in HBCR and some others overrepresented. Therefore, there were variations even in the top 5 leading sites depicted by HBCR and ATLAS with PBCR. For example, HBCR Chennai showed stomach as leading site of cancer in males, and stomach is really the leading site of cancer in males. In Mumbai and Bangalore, HBCRs show respectively mouth and esophagus as the leading sites, whereas, the leading sites in Mumbai and Bangalore were actually lung and stomach. Similarly, in females, breast and cervix were the top two sites of cancer. However, as far as their rank between HBCR and PBCR is concerned, it was altered in Bangalore because of a higher detection rate of cervical cancer. In the other two areas, although the rank of these two sites did not change, the proportion of cervical cancer was also considerably higher and that of breast cancer was considerably lower in HBCR than in PBCR. This may be partly due to sporadic screening activities. Thus, any tally in the rank of the sites between HBCR and ATLAS with PBCR is not sufficient to support the representativeness of the PBCR area by a HBCR or ATLAS.

6.3.3 Trend in leading sites of cancer

The knowledge of trend in leading sites is important from a policy point of view. It helps in planning and evaluation of cancer prevention measures. Like assessment of leading sites, even trend can be assessed from HBCR, even if the level of incidence was poorly estimated, given that quantitative over/underrepresentation of a particular site is constant over a period of time. Consistency between HBCR and PBCR over a period of time was assessed by drawing a scatter plot between HBCR and PBCR proportions. It may be noted that calculation of correlation

coefficient and test of its statistical significance, which is technically possible, can be misleading, because, there is a possibility of a highly significant correlation,even when there is no agreement and vice versa. Furthermore, one may be tempted to test the scatter plots- However, the same is not warranted because the objective is to assess bias in the estimates rather than random error. The plot showed variations in inconsistency over a period of time, indicating that assessment of trend in leading sites using HBCR data can be misleading. For some of the sites, especially those with substantially higher proportions, small variations in inconsistency may not matter and the HBCR may depict the correct trend. However, one cannot be sure of which are the sites under this category.

6.4 Conclusions

The Cancer registry is the backbone of cancer control. An erroneous assessment of cancer burden and pattern can have long-term negative implications on the health resources of a country, especially for a limited resource country (Bhurgri, 2004). HBCRs are valuable institutions having a vital role in patient care assessment and conduct of epidemiological and survival studies with different environmental, clinical and treatment features.

Population-based interpretation of HBCR on occurrence of cancer, however, may not be valid due to various potential biases in view of the diversity in the availability of health services and the prevalence of etiological factors. Even ATLAS data appears to considerably under/over-estimate different sites of cancer with substantial inconsistency due to a large number of cases remaining uncaptured.

Therefore, it may be concluded that estimates on cancer occurrence or risk of cancer based on HBCR data or use of ATLAS as an alternative to PBCRs cannot be taken for granted. This attracts the attention of policy planners and administrators towards opening-up of more PBCRs, especially in rural areas and the areas considerably distant from existing PBCRs.

6.5 Recommendations

1) This study was based on published data which caused several limitations in analysis and interpretation. E.g. the consolidated data from PBCR, HBCR and Atlas used different periods and calendar years in the publications with a few exceptions. It is possible to identify some of the causes of differences between PBCR and HBCR or ATLAS in the cancer burden estimates with the data available at the registry, but not in public domain. Further steps of research are provided by the use of data as place of residence and extent of disease. Direct linkage of data between PBCR and HBCR or Atlas is also possible. Hence, such research is recommended.

2) Those associated with cancer control planning in the country should strengthen cancer information by opening up more PBCRs accounting for cancer etiological diversity in the country.

3) Existing HBCRs may continue and more HBCRs in the hospitals with a large number of cancer patients may be encouraged. However, their role should be clearly outlined to include their typical uses, like, to help hospital administration in the management of patients, to assess cancer care in the parent hospital and to undertake epidemiological studies pertaining to prognosis of patients with different clinical features and treated with different modalities.

7 SUMMARY

Cancer registration is one of the necessary ingredients of any cancer control programme. Its uses are well established and documented. Ideally, one may desire to have a cancer registration system that fulfills all of its objectives. The requirement of such a system would be that it has to be population-based with diagnostic, clinical and treatment details of all the cases. Practically however, such a system is not feasible in the setup of developing countries. Even in developed countries, there is the possibility of clinical data being incomplete for a considerable proportion of the PBCR cases. Therefore, the principle of two different registries, namely; population-based cancer registries (PBCRs) and hospital-based cancer registries (HBCRs), evolved and is in place. Another concept that has come up recently is that of the cancer atlas (ATLAS) which collected data from all the pathology centres and tabulated it according to their place of residence. PBCRs in the developed countries have been catering to their objectives effectively and accurately, at least to a reasonable extent, mostly due to small populations, advanced information systems and availability of financial resources. In the setup of developing countries however, PBCRs suffer from the lacunae of not being able to cover the whole population of the country and non-availability of reliable clinical and treatment details for the majority of cases. Therefore, in the scenario of developing countries, there is a need to explore the potential population-based uses of HBCR and ATLAS data and to test their validity. The overall aim of the study was to explore the feasibility of using HBCR and ATLAS data in the evaluation of cancer patterns in India.

With respect to the place of residence, there are two sets of patients that account for all the differences between HBCR and PBCR. They are INPTSOUT (Set of patients who are actually from INside the HBCR area, but do not get registered in HBCR) and OUTPTSIN (the set of patients who are actually from

OUTside the HBCR area but get registered in the HBCR). Thus, PBCR data = HBCR data - OUTPTSIN +INPTSOUT.

The qualitative and quantitative differences between OUTPTSIN and INPTSOUT make HBCR different from PBCR. Any population-based interpretation of HBCR data makes basic assumption that INPTSOUT and OUTPTSIN are quantitatively equal and qualitatively similar.

As far as ATLAS is considered, data were obtained from all the sources of microscopic diagnosis of cancer, who gave their consent for the participation in the project. Quality control exercises, mainly elimination of duplicates, were carried out. Utilizing the data on place of residence, the cases were divided to arrive at the number of incident cancer cases by district of residence. Subsequently, these numbers were divided by the population of the district to obtain 'minimum cancer incidence rate' (MCIR) for that district.

To compare the pattern of cancer according to HBCR and PBCR, three places with both types of registries were selected. Similarly, another three places for which PBCR and ATLAS both reported pattern of cancer were also selected. Ten leading sites based on PBCR data were selected for each of the six registries separately within each sex category. Proportion of leading sites of cancer according to PBCR (pi) and that according to HBCR or ATLAS (pi') were obtained from published reports and compared by calculating absolute and relative differences. To compare the differences between HBCR and PBCR across the registries, we calculated the weighted average of the absolute values of differences (WAAD) and relative differences (WARD). These indicators were used also to compare HBCR data minus OUTPTSIN (i.e., RHBCR) with PBCR. In addition, trend in consistency was examined by plotting a scatter diagram between PBCR and HBCR proportions for different time periods. The NCRP publishes consolidated reports from time to

time separately for HBCRs and PBCRs. Present study utilizes the data from consolidated reports of PBCR, HBCR and ATLAS during 1984-2006.

Present study found that there is gross over/under representation of different sites of cancer in the data from HBCRs in India. Therefore, any assessment of risk of even leading sites of cancer based on HBCR data may be biased. By and large, easily accessible sites like mouth, tongue and hypo-pharynx were overrepresented in HBCR data, whereas, the sites not so easy to diagnose, like stomach, lung, prostate and brain were underrepresented. Among female specific sites, cancer of the breast and ovary were underrepresented whereas that of the uterine cervix was overrepresented. Looking at another way, HBCRs have overrepresentation of cancers with relatively clear signs and symptoms. On the other hand, the cancers not easy to detect have underrepresentation in HBCR data. Reduction of HBCR data to RHBCR did not improve its consistency with PBCR. Differences of HBCR with PBCR were not consistent over a period of time for most of the leading sites.

The results on comparison of consistency of ATLAS data with PBCR showed that there was no overall comparability between the two in cancer pattern. There were substantial over/under representation of different primary sites in ATLAS. The differences were on the lines of that in HBCR data. It was to be expected, because ATLAS data are conceptually similar to multi-centric HBCR data.

Since cancer registry is the backbone of cancer control, an erroneous assessment of cancer burden and pattern can have long term negative implications on the health resources of a country, especially in a limited resource country. HBCRs are valuable institutions having vital role in patient care assessment and conduct of epidemiological and survival studies with different environmental, clinical and treatment features. Population-based interpretation of HBCR on occurrence of cancer however, may not be valid due to various potential biases in view of the

diversity in the availability of health services and prevalence of etiological factors. Even ATLAS data appear to considerably under/over-estimate different sites of cancer with substantial inconsistency due to the large number of cases remaining uncaptured.

It may be concluded that estimates on cancer occurrence or risk of cancer based on HBCR data or use of ATLAS as an alternative to PBCRs cannot be taken as granted. This attracts the attention of policy planners and administrators towards opening up more PBCRs, especially in rural areas and the areas considerably distant from existing PBCRs.

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