

NATIONAL CENTRE FOR DISEASE INFORMATICS AND RESEARCH
NATIONAL CANCER REGISTRY PROGRAMME
Indian Council of Medical Research

**Three-Year Report of
Population Based Cancer Registries
2009-2011**

Incidence and Distribution of Cancer

(Report of 25 PBCRs in India)

Bangalore, India

February 2013

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(Indian Council of Medical Research)

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Population Based Cancer Registries provided individual core data. Quality control checks, tabulations and statistical analysis were done at the NCDIR-NCRP, Bangalore.

The publications of NCDIR-NCRP are intended to contribute to the dissemination of authentic information on cancer incidence by age (five-year age groups), sex and site (ICD-10).

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colleagues Mr Vinay Urs K S, Mr Anish John, Ms Akanksha Tiwari, Mr Sathish Kumar K
and Mr C Somasekhar were the core members involved in preparation of the report.*

OBITUARIES

*NCRP regrets the loss of the following eminent persons since
the last NCRP report was printed:*

Dr Balakrishna Yeole (1939-2011)

Director and Co-Principal Investigator, Mumbai PBCR, Indian Cancer Society, Mumbai

Dr K.A. Dinshaw (1943-2011)

Former Director, Tata Memorial Centre, Mumbai

Dr Arun P. Kurkure (1951-2012)

Principal Investigator, Mumbai PBCR and Honorary Secretary & Managing Trustee,
Indian Cancer Society, Mumbai.

FOREWORD



This consolidated report of twenty five Population Based Cancer Registries (PBCRs) covers three years data from 2009-2011. When compared to the previous report of 2006-2008, this covers the data from four new registries namely, Wardha in Maharashtra and three new North Eastern states of Tripura, Nagaland and Meghalaya.

This is the first time that the gap between the calendar year and the reporting year has been brought down to only a year. This is a milestone that has been achieved with the advent of Information Technology in the field of Cancer Registration initiated by the National Cancer Registry Programme (NCRP). Since the data of 2011 has been included, the incidence rates and patterns of cancer are more recent hence designing, planning and evaluation of the cancer control activity in the country could be more effective.

Also noteworthy is the inclusion of new chapter on Childhood Cancer. This throws light on the quality of the data presented by each registry and also assesses the burden of cancer on the 0-14 age group which was not done before for a PBCR.

The staff at the Coordinating Unit of NCRP and at the Population Based Cancer Registries have done a commendable job by processing and analysing the data in time to be able to complete this report. Scientists and Administrators could use this report as a basis to initiate newer activities pertaining to screening, control and studies on cancer patterns in geographical areas that have presented themselves with higher cancer incidence rates.



Dr V.M. Katoch

Secretary, Department of Health Research &
Director General, ICMR

“I am among those who think that science has great beauty. A scientist in his laboratory is not only a technician: he is also a child placed before natural phenomena which impress him like a fairy tale.”

Marie Curie (1867 - 1934)

* * *

“In science the credit goes to the man who convinces the world, not the man to whom the idea first occurs.”

*Sir Francis Darwin (1848 - 1925),
Eugenics Review, April 1914*

* * *

“The practice of medicine is an art, not a trade; a calling, not a business; a calling in which your heart will be exercised equally with your head.”

William Osler

* * *

“We must not forget that when radium was discovered no one knew that it would prove useful in hospitals. The work was one of pure science. And this is a proof that scientific work must not be considered from the point of view of the direct usefulness of it. It must be done for itself, for the beauty of science, and then there is always the chance that a scientific discovery may become like the radium a benefit for humanity.”

*Marie Curie (1867 - 1934),
Lecture at Vassar College, May 14, 1921*

* * *

“That which today calls itself science gives us more and more information, and indigestible glut of information, and less and less understanding.”

Edward Abbey

Three-Year Report of Population Based Cancer Registries 2009-2011*

Executive Summary

This report of 25[#] Population Based Cancer Registries (PBCR) includes the data of four new PBCRs (Meghalaya, Nagaland, Tripura and Wardha) that have commenced working and included under the NCRP network since the last report for the years 2006-2008 was published. Three other PBCRs at Patiala, Naharlagun and Pasighat have just commenced collating data and therefore, only a description of their working is included in this report.

McLennan has defined cancer registration as a process of continuing systematic collection of data on the occurrence and characteristics of reportable neoplasms (McLennan *et al*, 1978). Cancer registration is a means to a purpose and not a purpose in itself. The cancer registry is central to any rational programme on cancer control (Muir, C.S., 1985). It is the forerunner of studies in descriptive epidemiology of cancer, which in turn generates specific scientific hypotheses. It is necessary in all settings, more so in the setting of a developing country like India. Cancer Registration and Epidemiologic principles lay the foundation and are the very intelligence for evidence based scientific cancer research, be that of determining risk factors, assessing control measures or evaluating patterns of clinical care.

The basic thrust of a PBCR is cancer in the community. PBCRs provide information on cancer incidence and mortality in a defined population for a particular time period. They also provide information on variation in incidence or mortality over time and with follow up, population based cancer survival rates. To initiate, establish and sustain population based cancer registries as per international norms requires meticulous planning, cooperation of medical institutions in the area, dedicated and committed personnel and adequate funding.

The 25 PBCRs that comprise the basis of this report cover 7.45% of the population of India, with partial or complete representation of 16 States and one Union Territory. Eleven of the PBCRs are in urban localities and 2 in wholly rural regions. The remaining 11 correspond to both urban and rural parts by virtue of being state or district registries. Though the geographic area and population covered are small compared to the vastness of India and its population, they give a fair idea of the cancer problem in the country.

*# Refer to Note on Page 80

Highlights

Cancer incidence rate is generally expressed as age adjusted or age standardized rate (AAR) (according to world standard population) per 100,000 persons. As in the previous report (NCRP: 2006-08), Aizawl district in Mizoram state shows the highest AAR in both males and females. In males, Aizawl district is followed by East Khasi Hills district of Meghalaya state and in females by Kamrup Urban district. The incidence rates by each PBCR are given in Chapter 1 and Chapter 2 describes the leading sites of cancer in the different PBCRs.

Among males, cancers of lung, mouth, oesophagus and stomach are the leading sites across all the registries. Lung cancer is the leading site in Bangalore, Chennai, Delhi, Kolkata, Tripura, Kollam and Thiruvananthapuram. All the PBCRs in Gujarat and Maharashtra states and Bhopal PBCR have mouth cancer as the leading site of cancer. Cancer of the oesophagus is the leading site in the registries in the states of Assam and Meghalaya. Stomach cancer is the leading site in Sikkim and Mizoram while cancer of the nasopharynx is the leading site in Nagaland. Among females, cancer of the breast and cervix are the leading sites of cancer in 18 of 25 PBCRs. Cancer of the gallbladder and cancer of the oesophagus followed cancer of breast as the leading site in Dibrugrah and Kamrup respectively. Lung was the leading site in Manipur and Mizoram. Cancer of the oesophagus led the list of cancers in Meghalaya. Cancer of the thyroid followed cancer of breast in the two PBCRs at Kollam and Thiruvananthapuram in Kerala state.

Chapter 3 gives the proportion of cancers associated with the use of tobacco. East Khasi Hills district of Meghalaya had the highest relative proportion with 69.3% and 43.0% for males and females respectively. Chapter 4 deals with different types of cancers in childhood. The proportion of cancers in childhood relative to cancers of all ages in both sexes varied from 1.1% in Meghalaya to 4.4% in Delhi.

Chapter 7 provides a comparison of cancer incidence and patterns in 25 PBCRs along with 5 sub areas (districts or combination of districts) within the states of Manipur, Mizoram and Meghalaya.

The data of the newer PBCRs that are being reported for the first time in this report are Nagaland, Meghalaya including Khasi Hills district, Tripura and Wardha. Among these new PBCRs, males in Nagaland show the highest AAR of 21/100,000 for nasopharyngeal cancer. East Khasi Hills district and Meghalaya state as a whole show the highest AAR in cancers of the oesophagus (in both males and females) and cancers of the hypopharynx and larynx in males. Since this data is being reported for the first time, it needs to be viewed with some caution as in the initial years of registry operation there could be some degree of over reporting. Nonetheless, the states of the North East have already reported high incidence rates of cancers of the upper aerodigestive tract that would include anatomical sites such as, oral cavity, pharynx, hypopharynx, nasopharynx, larynx, oesophagus and even stomach. The international comparisons of the incidence rates of these sites of cancer (Chapter 8) reveal that the PBCRs at Meghalaya (especially East

Khasi Hills district) and Mizoram (Aizawl district) and Kamrup in Assam have the highest AARs of cancers of these sites, particularly oesophagus, hypopharynx and larynx.

The details of individual registry write-up including that of Patiala, Naharlagun and Pasighat PBCRs are provided at the end of the report.

Quality of Data

The authenticity of the data depends on its quality and the completeness of coverage of cancer cases in the geographical area (quantity) and timeliness in data abstraction and is comprehensively covered in Chapter 9. This chapter along with Chapter 5 that addresses the most valid basis of diagnosis of cancer and Chapter 6 dealing with mortality data show the challenges and limitations of cancer registration in the Indian context vis-à-vis International comparisons. Every effort is made by both the individual PBCRs and the coordinators at NCDIR to ensure that the data reported is as correct and as complete as possible. In more recent years the PBCR software applications programme has greatly helped in enhancing the speed of data submission and its quality.

Use of Electronic Information Technology

Software programmes developed in-house have to a great extent contributed to improving the quality and coverage. Data that is keyed is checked as per international norms. In terms of completeness of coverage a new feature in the software monitors the data received from different sources of a particular registry and identifies paucity of data received from any given source for a desired period of time. **The full potential and thereby the benefit of the software will be felt if the registries could quickly get into doing real-time data entry. This real-time data entry in other words mean, data abstraction, collation and entry onto the computer of currently diagnosed cancer cases (say within one week).** Six PBCRs have been able to report the data of 2011. This brings down the gap between the reporting year and the calendar year to only one year for these PBCRs.

Priorities for Cancer Research and Control

The results of this report have provided a lead to set priorities for cancer research and identified target sites – both anatomic and geographic, for cancer control measures.

The upper aerodigestive tract cancers as a group (oral cavity, hypopharynx etc., larynx, oesophagus and stomach) have emerged as important sites for undertaking risk factor research and implementing early detection programme. The PBCRs in the North East have shown the highest or some of the highest incidence rates in the world of these sites of cancer and also comprise a substantial proportion of all cancers. They comprise 37.6% of all cancers in both sexes (50.5% in males and 24.7% in females) in the registries

in the North East. Investigation into the type of tobacco consumption and dietary factors (for cancers of the oesophagus and stomach) is an obvious necessity. Aside from the unmistakable need for tobacco control and possible elimination of the habit (for primary prevention), early detection and screening exercises specifically for the cancers of these anatomical sites as an entity is an immediate requirement. Such plans are vital across the North East and in other registry areas like Bangalore that has shown consistent high AARs over the years for cancer of the oesophagus in both sexes. Programmes using endoscopy and laryngoscopy should be tried out initially as pilot studies in the Indian context and then depending on the feasibility, validity and acceptability extend state/region-wise. Simultaneously, education of the public about these sites of cancer and the need for early detection including the benefits of undergoing endoscopy should be widely publicised. In patients who do come and undergo endoscopy, facilities should be created for prompt diagnosis and wherever necessary, adequate treatment.

Thus, this important feature of this report described above should be used to undertake research studies and implement cancer control measures. If done right, one would have evidence of the effectiveness of such measures over the years through the registry data.

There are several other anatomical sites of cancer (as documented in previous reports) that continue to be a challenge in terms of aetiology and control. Cancers due to use of tobacco including cancers of the lung, are at the top of the list followed by cancers of the breast and cervix in women. Cancers of the gallbladder and thyroid also in women, too require special attention in terms of identifying risk factors and initiating early detection schemes. The former is seen in the north and northeast and the latter in the south and northeast of the country.



Dr A. Nandakumar
Director-in-Charge

Cancer Registration and Epidemiological principles lay the foundation and are the very intelligence for evidence based scientific cancer research, be that of determining risk factors, assessing control measures or evaluating patterns of clinical care.

The full potential and thereby the benefit of the software will be felt if the registries could quickly get into doing real-time data entry. This real-time data entry in other words mean, data abstraction, collation and entry onto the computer of currently diagnosed cancer cases (say within one week).

NATIONAL CANCER REGISTRY PROGRAMME

The Coordinating Unit of the National Cancer Registry Programme (NCRP) which is now the new permanent institute of ICMR – National Centre for Disease Informatics and Research, has been functioning at Bangalore since 1991. The NCRP itself started in 1982 with three Population Based Cancer Registries (PBCRs) and three Hospital Based Cancer Registries (HBCRs). NCRP developed a unique concept of an Atlas of Cancer in India (NCRP, 2004b) covering several regions in the country by use of internet for data collection for the year 2001-2002 thus mapping the patterns of cancer region-wise. The outcome of this activity was extensive use of information technology in subsequent activities of NCRP and the birth of newer registries and commencement of Patterns of Care and Survival Studies (POCSS). There are 27 PBCRs and 7 HBCRs as of now. Web based HBCR data entry software has been provided to hospitals which are potential HBCRs. In addition, NCRP has started Patterns of Care and Survival Studies (POCSS) in 16 Hospitals for three sites of cancer namely, Cervix, Breast and Head & Neck. The Cancer Atlas project for the state of Punjab has been initiated to collect cancer data from that region. The network of the NCRP is depicted in the map.

NCRP plans, directs, develops, supports, coordinates and evaluates a national programme of cancer surveillance (electronic or otherwise) involving the collection and analysis of reliable data on magnitude and patterns of cancer so as to answer key questions about cancer incidence and mortality in different demographic and population settings. It designs, undertakes and implements multi-registry collaborative aetiological research studies in keeping with recent advances in epidemiological research. A national standardised programme on patterns of patient care and survival in different anatomical sites of cancer has also been evolved.

Development of human resources in use of disease data base and informatics for research with focus on multi-disciplinary approach – field, clinic, laboratory using the tool of electronic information technology has been an important area of focus within NCRP and across all the centres in its network. Training programmes, workshops and meetings are held regularly to keep itself abreast with the progress made by the centres. Additionally, it has undertaken tasks in data formatting, checking and submission of data to several international studies on behalf of the registries.

With the creation of the new permanent centre, National Centre for Disease Informatics and Research, other diseases namely, diabetes, CVD and stroke have also been included. It intends to plan and facilitate programmes on patterns of patient care and survival in diabetes, CVD and stroke in the not too distant future.

Role of Information Technology in Cancer Registration and Cancer Research

NCRP has come a long way since its first report was published. Plenty of data has been handled from several projects over the years. This network of registries and hospitals has kept growing and managing enormous number of data sets has been challenging. There was a need to systematically standardise and streamline the process for which Information Technology was the obvious choice. There was thus a need to develop robust and comprehensive software applications. Automation meant reduction of human efforts and latency although much time has to be spent on developing the software. The data on cancer was already

available in electronic form and software modules were developed to generate reports using them. Gradually independent data capture and quality checks modules were developed and given away to registries.

During the initial phase the technology that was applied also underwent change so that new advancements in Information Technology can be used to full potential. Thus Microsoft Visual Basic 6.0 gave way to Microsoft Visual Studio 2005 and Microsoft Access was replaced by SQL Server. Software development using Dot.Net technology and SQL Server was commenced for both online and offline applications. The task of merging medical science, statistics and software was and is a demanding one. It requires extensive study of the existing system and appropriate planning thus involving requirements gathering, planning, designing, coding and testing. NCRP located at Bangalore, the Information Technology (IT) hub of this country tapped the available IT talent to train them in technical and cancer domain.

The repository of cancer data from the yester years and forms available in non-standardized format across all the registries and studies was carefully standardised with few differences. Several auxiliary modules on quality checks, duplicates, matching, reporting etc were developed for the software PBCRDM 2.1. The information is captured in a core standardised incidence and mortality form after which the data undergoes quality checks, duplicates search, matching of mortality with incidence and then generates reports. Similar application, HBCRDM 1.0 has been developed for Hospital Based Cancer Registries (HBCRs). Since the approach to software development is evolutionary, the software team is systematically and continuously working to translate in-house software development into cancer epidemiological studies so that the cancer registration in India can meet the gold standards of data quality and completeness of coverage. Several in-house online internet based applications are being developed to provide better coverage of hospitals all over the country especially for projects collecting huge data and for easy maintenance of databases, software codes and their versions. The software programmes related to HBCR, Patterns of Care and Survival Studies and Punjab Cancer Atlas are described in the companion publication of the HBCR (NCDIR-NCRP, 2013).

Apart from the quality checks on data (see Chapter 9), the uniqueness of this PBCRDM-SW is in undertaking duplicate checks and matching with mortality cases thereof. This includes phonetic checking for which regional dictionaries have been developed. In the past year a module to keep track of coverage of cases from different sources of registration of PBCRs has been put in place. An alert is given if there is a decline or variation in contribution by a particular source.

The full potential of the PBCRDM software application will be realised if PBCRs can quickly get into the mode of abstracting and entering the data on to the software of currently diagnosed cases (see Chapter 9).

Apart from developing software applications, the technical team undertakes the following activities:

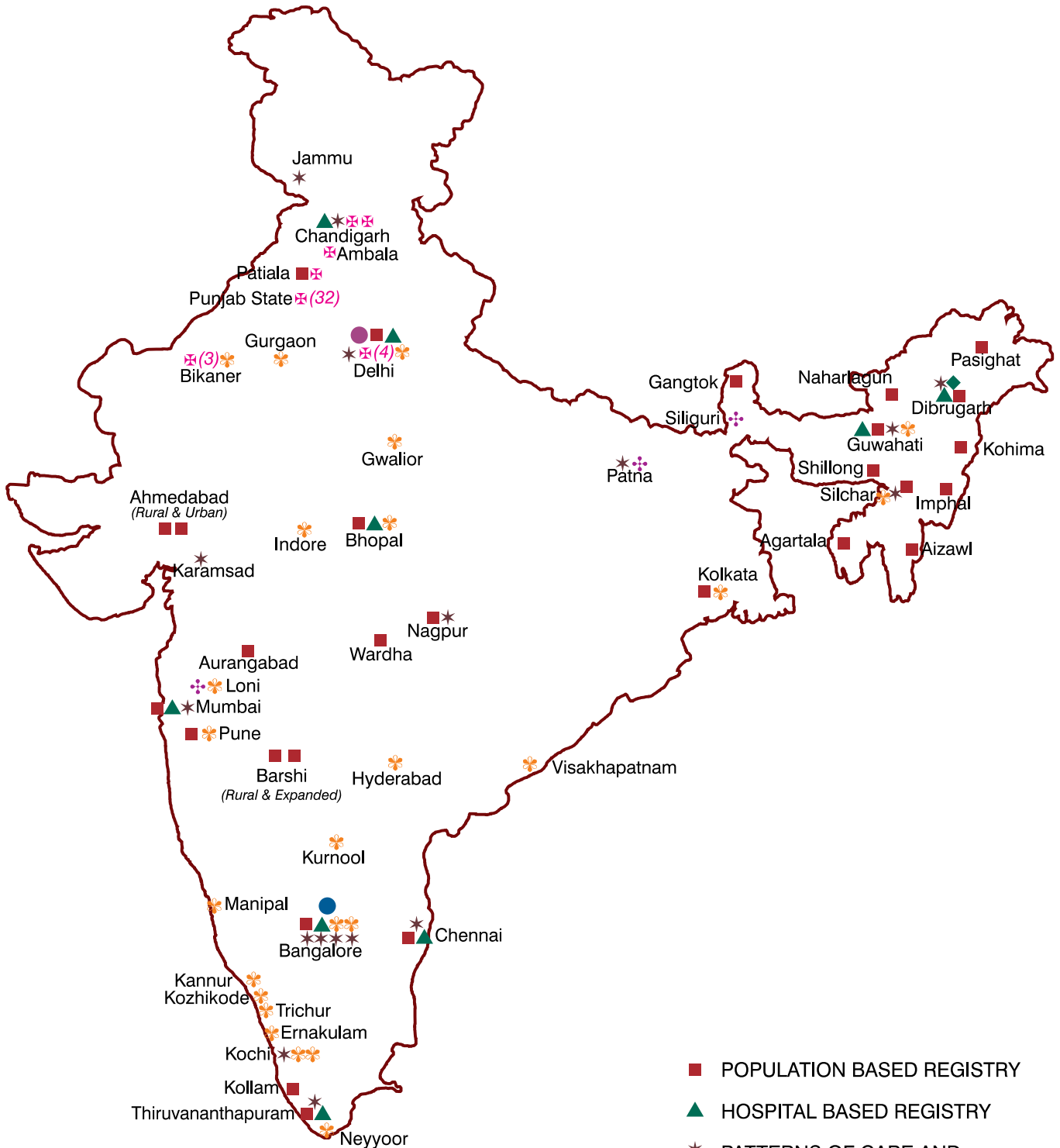
- a. Data maintenance of online and offline databases, backups, restore and recovery;
- b. Provides suggestions on system configurations and network issues;
- c. Deployment and installations, version releases, patches deployment with bug rectifications;
- d. Remote support to centres using monitoring and remote control tools.

Although NCRP has established that information technology is here to stay, the key lies in software development being a continuous process of improvisation especially in cancer epidemiology.

NATIONAL CENTRE FOR DISEASE INFORMATICS AND RESEARCH

NATIONAL CANCER REGISTRY PROGRAMME

(Indian Council of Medical Research)



- ICMR HEADQUARTERS
- NCDIR-NCRP COORDINATING UNIT
- ◆ MONITORING UNIT, N.E. PBCRs
- POPULATION BASED REGISTRY
- ▲ HOSPITAL BASED REGISTRY
- * PATTERNS OF CARE AND SURVIVAL STUDIES
- ✿ CENTRES USING HBCRDM SOFTWARE
- ✕ CANCER ATLAS - PUNJAB STATE

“Growth for the Sake of Growth is the Ideology of the Cancer Cell.”

*Edward Abbey (1927-1989)
American author and Essayist*

*Comprehending
nature !*

“The Scientific Temperament feels much more comfortable when it is breaking down a complex phenomenon into simpler parts than when it is trying to pull together a series of diverse facts into a unity of relationship. For a solution of the ultimate riddles, however, synthesis is more important than analysis... It is not an understanding of units that we now seek, but of unity.”

*An address by Edmund Sinnott quoted by Lynd, R.S.
In “Knowledge for What?,” Princeton, 1939, p 245.*

*Figuring out
Multidisciplinary
Research !*

“Cancer Control is the reduction of cancer incidence, morbidity and mortality through an orderly sequence from research on intervention and their impact in defined populations to the broad, systematic application of the research results.”

Greenwald and Cullen, 1985.

*Understanding
Translational
Research !*

“There is nothing more difficult to take in hand, more perilous to conduct or more uncertain in its success than to take the lead in the introduction of a new order of things.”

*Niccolo Machiavelli (1469-1527)
Italian Author & Statesman*

*Valuing
Information
Technology !*

Epidemiology has been described as a science that moves slowly but with great force.