

## MEETING REPORT

# Asian Cancer Registry Forum 2014 - Regional Cooperation for Cancer Registration: Priorities and Challenges

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### Abstract

In February 6-7th, the Thai National Cancer Institute, the International Agency for Research on Cancer and its Mumbai Hub for Cancer Registration, together with the International Association of Cancer Registries and the APOCP/APJCP, jointly organized an Asian cancer registry forum to discuss regional cooperation for cancer registration. Held in the Grande Mercure Fortune Hotel, Bangkok, the meeting brought together leading scientists in cancer registration from South-East and North-East Asia as well as Australia, India and Iran and IARC itself, with coverage of various priorities and challenges of cancer registries regarding cancer control policy, operational parameters, assessment of survival and contributions to screening, for example. The current situation was highlighted and future directions and possible expansion of activities were discussed, with especial attention to the necessity for networks to help improve cancer registration across Asia and Africa.

**Keywords:** Cancer registration - cancer control policy - regional networks

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### Introduction

After welcome addresses and introductory remarks by the Director General, Department of Medical Services, Ministry of Public Health, Thailand, the Director of the National Cancer Institute, Freddie Bray as IARC delegate and Malcolm Moore as APOCP/APJCP delegate, the ASIAN Cancer Registry Forum 2014 February 6-7, 2014, with the core aim of fostering regional cooperation in cancer registration in the region, got off to the start of a full program of talks. Attended by 112 participants and 9 speakers from a total of 14 countries, the Forum allowed leading cancer registry personnel to cover major aspects of cancer burden assessment in the Asian Pacific.

### The Changing Profile and Trends of Cancer in Asia

Freddie Bray, International Agency for Research on Cancer, France

Of the 55 million deaths in 2011, 36 million deaths were due to NCDs. Cancer is now the single leading cause of death, with almost eight million deaths occurring in 2011. According to GLOBOCAN, an estimated 14.1 million new cases of cancer occurred in 2012, with the global burden set to rise to 19 million new cases by 2025 due to population demographic changes; the increase will be proportionally greater in the least developed countries.

In 2012, 43% of the incidence and 52% of the mortality burden from cancer globally occurred in the vast region of Southern, Eastern and South-East Asia comprising of 25 countries and 3.8 billion people. Almost two-thirds of this cancer burden occurred in East Asia, with South Korea and Japan having the highest rates overall, and cancer rates lowest in the Southern Asian countries of Sri Lanka, Nepal and Bhutan.

Cancers of the lung, stomach, breast, liver and colorectum are the top 5 cancers in the region, with diverse country-specific differences. As an example, among men, lung cancer is the most common cancer in China, Indonesia, Nepal and the Philippines, whereas stomach cancer leads in Iran, Afghanistan, South Korea and Japan; liver cancer is the most common form in Cambodia, Mongolia, Thailand and Vietnam, whereas cancer of the oral cavity is most important in India, Pakistan and Sri Lanka. While breast cancer ranks as the leading cancer in women in most countries in the region, there are several countries where lung (China), cervical (Nepal, Bhutan) or liver (Mongolia, Laos) are estimated as the most common neoplasm in 2012.

With continuing increases in human development, a cancer transition is underway with declines in infection-related cancers of the cervix and stomach being superseded by female breast and other cancers more associated with a western lifestyle, and accompanying behavioral changes in reproduction, diet, and level of physical activity, as seen



**Figure. Group Photograph of the Assembled Faculty and Delegates from South-East Asia**

increasingly in many countries across the Asian region.

### **Cancer Registries and Cancer Control Policy: An Integrated Approach**

Young-Joo Won, National Cancer Center, Korea

Cancer registries help to establish and maintain cancer incidence reporting systems, serve as a resource for the investigation of cancer and its causes, and provide information for planning and evaluating cancer control programs. The aim of this presentation was to review the value of cancer registries and cancer control policies in the Asian region.

A literature search was performed of recent cancer registry developments in the Asia region and the ways they contribute to cancer control policies and vice versa, and how cancer control policies support or help cancer registries function continuously was determined.

Cancer registries have many important roles. Their main role is to act as a research base for information required by governments to plan and implement cancer control programs. Therefore, some countries provide a nationwide infrastructure to support cancer registries with valuable cancer control policies.

However, other countries need mid- or long-term planning and systematic strategies for cancer control policies, including cancer registries, based on their socioeconomic and political situations. Cancer registries help us understand the burden of neoplastic diseases in populations at the local, regional, and national levels. In addition, cancer registries should be designed, organized, and directed in the context of cancer control policies and programs.

### **Measuring Cancer Survival in Asia**

Swaminathan Rajaraman, Cancer Institute, Chennai, India

Cancer survival is a positive sounding measure to describe the outcome of cancer diagnosis and success of treatment. Besides incident cancers, data acquisition on cancer mortality is a routine activity integrated into any population-based registry operations. However, where the quality of death registration and certification systems are weak, mortality data is often enhanced in

registries by undertaking special efforts and monitoring. Thus, cancer survival data in low and middle income countries may not be routinely possible and would require concerted efforts to obtain follow up data on vital status of patient including mortality through active methods. Loss to follow up, at varying lengths of time since cancer diagnosis, is conspicuous from the published literature on cancer survival estimation from less developed countries. This necessitates recognition of qualitative differences among censored cases and application of loss- adjusted approaches in survival estimation.

The multinational cancer survival study by IARC (SurvCan project) generated a database of >541,000 cases from 21 cancer registries in 8 countries of Asia on 1-56 cancer types period varying 1990-2001. Variable methods of follow up for vital status of patients were attempted and standard methods of survival estimation were undertaken. In China, Republic of Korea and Singapore, 5-year age-standardized relative survival ranged 76-82% for breast, 63-79% for cervix and 44-60% for large bowel cancers. These figures were slightly lesser for India, Pakistan, Philippines and Thailand. For localized cancers of the breast, large bowel, larynx, ovary, urinary bladder and for regional diseases at all sites, higher survival rates were observed in countries with more rather than less developed health services. Inter- and intra-country variations in survival implied variable levels of development of health services and inequitable access. Systematic evaluation of bias by intrinsic methods also explained other possible reasons for differential cancer survival statistics between these registries.

The long-term global strategy would be to prevent cancer where possible while ensuring universal access to effective treatment for those who develop the disease.

### **Use of Cancer Registries in Cancer Screening in Australia**

David Roder, University of South Australia, Australia

Cancer registries have been used in Australia to assess need for screening and to plan and evaluate screening services for cancers of the cervix, breast and large bowel. Assessments have used combined data from the research literature and cancer registries to assess likely costs, comparative effectiveness and cost-effectiveness

of screening options.

Registry data are being used with population cohort data to develop risk prediction models to prioritize and customize screening and associated clinical management to individual person needs. Registry data have furthermore been used to monitor interval cancer rates, small-cancer detection rates, nodal status and other markers of screening performance. Safety monitoring has compared screening outcomes of new screening policies with outcomes of prior policies to assess comparative safety and effectiveness. Registry data have been used in observational studies of screening effects on cancer incidence and mortality and to investigate risks of progression of pre-invasive abnormalities and likelihood of over-diagnosis under Australian screening conditions. Information for women on likely benefits and negative effects of breast and other screening are reliant in part on registry data.

Through data linkage, cancer registry data are being used with Pap Test registry data to evaluate the impact of HPV vaccination on rates of pre-invasive conditions and invasive disease. Increasingly, data linkage with privacy protection is being used to link data from population-based cancer registries, structured pathology reporting, imaging reports, hospital co-morbidity and treatment data, radiotherapy databases, clinical cancer registries, screening registries and large population-based cohorts to achieve a holistic view of screening coverage and effects of screening on the screening-assessment-treatment pathway, for the population as a whole and high-risk subgroups. Health insurance data are being sort to assess use of systemic therapies and broader effects on care utilization. R&D is underway to improve cancer registry technology as part of a broader cancer information management system.

### **Singapore Cancer Registry - the Operational Challenges**

Chow Khuan Yew, National Registry of Disease Office, Singapore

A video presentation by Dr Yew was viewed.

### **Current Situation and Future Direction of Cancer Registration in Thailand**

Hutch Sripilung, Thai Cancer Registry Network, Thailand

IARC has been helping Thailand to set up cancer registries since the late 1980. From four population-based cancer registries in 1989, Thailand has now more than twenty cancer registries running in all regions of the country. Registry reports and the estimates of cancer statistics for the country have been published since 1993. The series of 'Cancer in Thailand' are regularly published for the 3-year period. The last volume for such the 3-year period is CIT vol. VII which covers 2007-2009. After this volume, a summary cancer statistics for Thailand from 1988 to 2007 with the revision of the time period from three to five years so that the time period is concordant with that of the series 'Cancer Incidence in Five Continents'.

The National Cancer Institute of Thailand supports data pooling from ongoing population-based cancer registries in Thailand. There are key problems to be solved. All the cases are to be unique. Duplication of registered cases within and across registries has to be cleaned. The process can be done using the personal identification number. However, there are still some cases in the past that PIN was missing and other identification variables are going to be used. The software has now been developed and tested. We are discussing how to handle the cases found to be duplicated in two or more registries, ie. how to indicate and record those with long surviving cancer cases who migrate from one to another catchment area, how to verify and document multiple primary cancer cases registered in different registries, etc.

In addition to the cancer incidence statistics, cancer survival, mortality trends and projections of future cancer burden are to be analyzed and published. Cancer registry of Songkhla is working with the School of Public Health, University of Michigan to pilot such the analysis in various cancers. When the protocol and issues of emphasis have been settled, analysis will be employed to datasets of other registries under the agreement to produce collaborative publications and to come up with the national figures. The Thai Cancer Registry Network is welcome for collaboration with other institutions as far as the goals of the collaboration are to learn from each other and to solve the health problems of our people.

### **Regional Networks**

*South Asia* - Rajesh Dikshit

*South-East Asia* - Malcolm Moore

*Australia* - David Roder

*Africa* - Max Parkin

### **Evaluation of Quality Control in Cancer Registries**

Max Parkin, African Cancer Registry Network, UK

As the keynote lecture, Dr Parkin provided a comprehensive coverage of evaluation strategies for quality control of data in cancer registries.

### **Types of Cancer Registries and their Role in Cancer Control**

Rajesh Dikshit, Tata Memorial Centre, India

Highlighted were the contributions of pathology-, hospital- and population-based registries in the various areas of cancer control, from assessment of incidence, survival, mortality and prevalence to screening efforts and clinical epidemiology.

### **Utilizing Cancer Registry Data - a Multi-institutional Approach**

Laura Rozek, University of Michigan School of Public Health, USA

The Songkhla Cancer Registry, initiated by Dr.

Hutch Sripilung at Prince of Songkla University, has been actively collecting cancer incidence and survival data since 1988. These data are now sufficiently mature to describe incidence and survival trends for cancers as well as project future disease trends. Collaborative analyses are facilitated by bimonthly phone conferences, student exchanges between the University of Michigan and Prince of Songkla University, and preparation of manuscripts. In this talk I will describe ongoing analyses in breast, colorectal and thyroid cancers in southern Thailand. This includes evaluation of current trends in cancer by age group and gender using joinpoint analysis, conduction of Age-Period-Cohort analyses to understand the effects of time and generations on incidence cancer rates and the use of mathematical modeling to predict incidence rates thirty years into the future. Additionally, we measure patient survival based on specific cancer histology. I will then describe our approach to collect pilot data for a breast cancer case-control study in southern Thailand that takes advantage of the Songkla Cancer Registry.

## Free Papers

*Predicting lung cancer mortality from smoking prevalence data – a possibility to evaluate cancer registration* - Volker Winkler, Germany

*The role of population-based cancer registries in the cohort study* - Supanee Promthet, Thailand

*Developing standards tool and evaluation of population based cancer registry in Iran* - Kazem Zendehdel, Iran

*The role of communication in cancer registry in “Dharmais” National Cancer Hospital, Jakarta* - Evlina Suzanna, Indonesia

*Cancer as causes of death at a district in Thailand: Challenging for population-based cancer registry at district level* - Wachara Eamratsameekool, Thailand

*Cancer incidence in Thailand, 2007-2009* - Pattarawin Attasara, Thailand

## Conclusions

The forum was very much enjoyed by the participants, who were given the opportunity by the National Cancer Institute to enjoy the sights and atmosphere from a night cruise on the Chao Praya river.

It is to be hoped that the contacts established through the Forum will lead to greater cooperation for cancer control in South, South-East and North-East Asia, as well as Australasia, in the future.