COMMENTARY

Overview of Existing Networks - Is there a Rationale for an Asian Cancer Registry Network?

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Abstract

Cancer registration is the base for our understanding of the burden of neoplastic disease in our populations at the local level. Comparability of data is essential for interpretation and this in turn depends on standardization of methodology and diagnostic and other criteria applied. If this is to be achieved across Asia, some form of international organization is clearly necessary. The question therefore should be whether the existing arrangement is adequate, and if this is not the case how a network in Asia might be established with due consideration of aims and attainable objectives. The present commentary focuses on the contributions made by the International Agency for Research on Cancer (IARC), the International Association of Cancer Registries (IACR), the European Network of Cancer Registries (ENCR), the North American Association of Central Cancer Registries (NAACCR) and individual country-based or region-based associations already active in Asia. An argument is presented here that there is a rationale for an Asian Network of Cancer Registries, working alongside and learning from the existing international organizations to promote effective cancer registration and disease prevention in Asia.

Key Words: International organizations - cancer registration - Asia - networking

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Introduction

We are totally dependent on our cancer registries for accurate information on incidences and mortality rates, as well as trends over time. Due in large part to the efforts of the International Association for Cancer Registries (IACR) and the support of the International Agency for Research on Cancer (IARC), there are cancer registries producing data of sufficient accuracy for inclusion in the Cancer Incidence in Five Continents publication in many of the countries of the world, although the indices of data quality are very variable. However, there are clearly areas of major weakness, like Central and Western Asia, as well as South America and Africa. The need to set up registries providing comparable data was the reason for the special poster presentations on 'Cancer Registration in Asia in the year 2000: Past, Present and Future'(Parkin and Vatanasapt, 2002) and 'Cancer Registration in Africa', respectively included in the 22nd and 27th annual meetings of the IACR. These were very much due to the personal efforts of Dr Max Parkin. However, neither of the next two annual IACR meetings will be in Asia, and therefore it is to be hoped that the APOCP General Asssembly Conference in Bangkok next year, or a Satellite meeting, will allow delegates from cancer registries from our region to gather and present recent findings and perhaps produce another supplement for the APJCP. It is fortunate that due to coordination between organizing committees, interested parties should now be able to attend both the APOCP meeting, now scheduled for November 3-6th and the IARC Brazil meeting, to be held from the 8-10th of the same month.

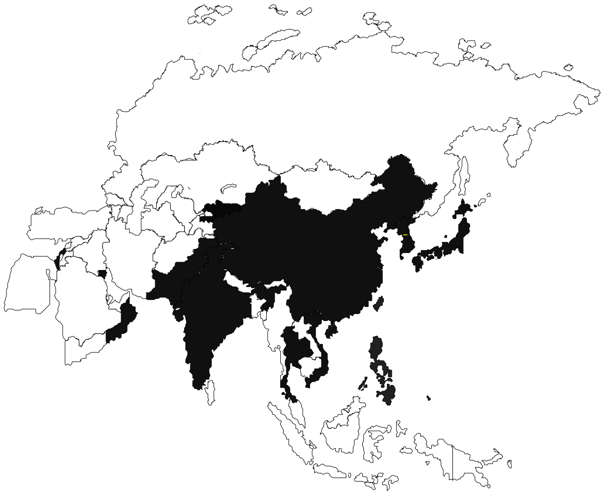

Figure 1. Asian Countries Contributing to Cancer Incidence in Five Continents (in Black)

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There are a number of regional organizations which have been established to co-ordinate and assist with promoting uniform data standards and training courses for cancer registration. In Asia we have the Japanese Association of Cancer Registries (http://home.att.ne.jp/grape/jacr/), the Chinese National Center for Cancer Registries listed as Regional Cancer Registry Organizations in the IARC website, as well as other country wide bodies. There is also a Gulf Center for Cancer Registration but the website does not appear to be active (http://www.gccr.org/main.html).

International Agency for Research on Cancer (IARC)

The Descriptive Epidemiology Unit in the IARC (http://www.iarc.fr) houses the European Network of Cancer Registries secretariat and is responsible for the Agencies contribution to world-wide cancer registration. However, the Unit is much smaller now than when Dr Max Parkin was the Chief and after two years with a new Director of IARC no decision has been made (to my knowledge) as to his replacement. Dr Paula Pisani, as Acting-Chief, has already commenced preparations for publication of the next volume in the Cancer Incidence in Five Continents series.

The Agency in the past has produced a number of scientific publications covering various aspects of cancer registration but the last was published in 2003 and the English version of 'Cancer Registration: Principles and Methods' is out of print and IARC Press no longer exists. How the IARC will continue to provide the lead in this area remains to be seen. In the past, with few exceptions, it has not actively pursued the path of publishing in different languages to reach a world audience.

In line with the importance of cancer registration for the international research community, there is a module in the yearly IARC Summer School which covers all relevant aspects of data collection, coding and analysis:

sources of information, case-finding and methods of data abstraction
classification of tumours and coding according to ICD and ICD-O
quality control, measures of comparability, standard definitions according to IACR
data analysis and reporting

Training in the implementation of all registry functions by means of the IARC CANREG4 software is also part of this module.

It is unclear whether the international courses on Cancer Epidemiology Principles and Methods (for example held in Trivandrum, India in 2003 and Tonga in the Pacific in 2004) will continue, since none was staged in 2005 and none are scheduled in the IACR website. Indeed, since the new Director of the Agency took over the post there has been a marked drop in international courses on any subject other than the Summer School (7 in 2003, 3 in the first 6 months of 2004 and none in 2005 or scheduled for the future). Again we may not be able to count on major support for cancer registry development from Lyon in the near future although the pages of the APJCP will always be open to Dr Peter Boyle should he wish to provide information on concrete measures which might be implemented in the future.

International Association for Cancer Registries (IACR)

The International Association of Cancer Registries (IACR) (http://www.iacr.com.fr) was founded in 1966, as a professional society dedicated to fostering the aims and activities of cancer registries worldwide. It primarily serves population-based registries, collecting information on the occurrence and outcome of cancer in defined population groups. The Association is a non-governmental organization which has had official relations with the World Health Organization since 1979. To ensure the comparative value of the statistics which cancer registries produce, a number of software packages have been produced by the IACR, in collaboration with the International Agency for Research on Cancer, these being available free to members of the Association.The encouragement of comparative studies is one of the objectives of IACR and to aid this process it has developed classifications (successive editions of the International Classification of Diseases for Oncology, published by WHO), as well as guidelines for registry practices, as exemplified by documents recently published in the APJCP (IARC, 2005a; 2005b), as well as the European Journal of Cancer Prevention.

In addition to the yearly scientific meeting, located in different continents each year so that as many members as possible can participate, news on the activities of the association has been circulated to the membership in Newsletters, but the last of these was in 2003, to my knowledge.

European Network of Cancer Registries (ENCR)

The ENCR was established in 1989 within the framework of the 'Europe Against Cancer' programme of the European Commission, with the following objectives:

to improve the quality, comparability and availability of cancer incidence data
to create a basis for monitoring cancer incidence and mortality in the European Union
to provide regular information on the burden of cancer in Europe
to promote the use of cancer registries in cancer control, health-care planning and research

The ENCR Secretariat is housed at the IARC and has an active website (http://www.encr.com.fr/). The network was supported by the European Commission until 31 March 2004 but applications submitted in 2003 to continue the Network from 2004 onwards were rejected, resulting in ENCR activities being reduced and loss of staff. This is illustrative of the difficulties faced by cancer registration even in the developed world, although further applications submitted in 2004 to the new EC Public Health Programme apparently have been favourably reviewed and funding is being received from other sources.

In the past consultancies were provided for ENCR members who wished to discuss particular areas of their registry operation with an expert in the field but the last of these was held in 2001. Structured reviews to evaluate registry performance, and to identify positive and negative aspects of a registry's procedures and outputs, taking account of available resources, were also on offer but the latest was in 2003. The last of a series of cancer fact sheets was in 2003. All had involvement of Dr Max Parkin who is no longer at IARC. Newsflashes were also suspended in 2003 but have now been revived and in the report made available in March of last year is of direct interest to the present discussion. In response to a survey carried out in 2004, the activities registries in Europe considered most important to fund by any membership fee were:

1) training courses
2) working froups on standards
3) collection & processing of data for databases
4) consultancy & structured reviews
5) advocacy with respect to access to data
6) fellowships
7) collaborative research
8) website
9) common applications
10) publications

Clearly it would be of advantage to conduct an equivalent survey of registries in Asia to determine the level of interest in a Network and what might be its responsibilities. Courses in cancer registration methods have in fact been held by the ENCR with a standardised content, the core curriculum being:

history, purposes and use of cancer registration
natural history of cancer and general pathology
data sources, definitions and collection
classification and coding of collected data
quality control and completeness of cancer registration
computers/computer systems/automation of cancer registration
statistical analysis and presentation of results
legal aspects and confidentiality

These 1-week courses were once organized almost yearly in different European countries, but the last was again in 2003. Various other courses run to cover aspects of methods of statistical analysis also now have the same status.

North American Association of Central Cancer Registries (NAACCR)

The NAACCR (http://www.naaccr.org) is a professional organization that develops and promotes uniform data standards for cancer registration; provides education and training; certifies population-based registries; aggregates and publishes data from central cancer registries; and promotes the use of cancer surveillance data and systems for cancer control and epidemiologic research, public health programs, and patient care to reduce the burden of cancer in North America.

The activities of the NAACCR are too numerous to list here. Suffice it to say that their annual meetings and continued efforts in all areas of cancer registration are exceedingly worthy of emulation on our part (a visit to the website is heartily recommended).

Asian Network of Cancer Registries?

We now come to the question of whether there is a rationale for a new network specifically serving the interests of cancer registration in Asia. My own feeling is clear - it is an urgent responsibility if we are to contribute to cancer prevention across the region. As stressed by Yang et al (2005), there are great difficulties in guaranteeing comparability even within individual countries. Thus they found marked variation in practice between registries in China, with respect to data collection, data management and coding, as well as administrative aspects and sources of financial support. Their survey suggested that lack of qualified personnel, insufficient funding support and lack of stability in the population are major problems in carrying out registration work under the prevailing conditions. In the last issue of the APJCP a review was published on major varaibility in cancer incidence rates across registries in Japan (Moore et al., 2005). Networking within the country is essential to determine to what extent this is due to differences in cancer registration practices, now in the capable hands of Dr Tomotaka Sobue.The experience gained here in Japan or by Dr Hai-RimShins group in Korea, Drs Yao and Gao in China, Dr Pattrawin in Thailand and all those active elsewhere in Asia should be shared and passed on.

Education and training need to be practical and provided in forms that actually allow realisation of aims. Political and moral considerations need to be addressed. There are two major inter-related points which deserve stress. One is confidentiality, public interest, financing and statutory requirements, and the other is the roles of the cancer registry. As argued by Coleman et al (2003), surveys of public opinion, initiation of public debate, and legislation to protect both citizens' rights and medical research that is demonstrably in the public interest, are high priorities. If we can not convince the populace and the medical community of the necessity for accurate incidence data for cancer and other chronic diseases, then obtaining the funding and legal backing commensurate with effective cancer registration will continue to be a problem.

To provide ammunition for the argument in favour, research needs to be conducted to actually explain differences observed in incidence rates between countries and among registries in a convincing way so that they offer practical application (Moore et al., 2005). An Asian Network could play a major role in this endeavour In this context, more stress on the role of cancer registries in providing evidence of adequacy or inadequacy in care is also needed, perhaps featuring active collaboration with cancer treatment centres (Evans et al., 2002).

In conclusion, whatever the particular aim, it would clearly be beneficial for Asian cancer registries to have an international organization devoted to providing training and research opportunities, especially for those countries within the region which are now trying to establish more effective registry systems. The question of financial support, last but not least, may depend on the ability to generate research findings, and this should be a stimulus to specific collaborative research. Should we build on the start made in September of last year (Moore and Tajima, 2005)?

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