Cancer Registry and Epidemiological Study Working Group Report

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International Agency for Research on Cancer: The International Agency for Research on Cancer serves as a global reference for cancer information. The Cancer Information Section of the International Agency for Research on Cancer publishes the world’s largest information database on cancer incidence and supports cancer registries by providing administrative facilities and training, etc. Many Asian countries have published cancer registries, but Indonesia and Bangladesh have yet to do so.

International Association of Cancer Registries: The International Association of Cancer Registries is a non-governmental organization that promotes information exchange between cancer registries internationally. It supports cancer registries by means of fellowship funds and computer programs.

Cooperative Studies: Asian cooperative studies using cancer registration data are essential for combating cancer in the region. For a cooperative study, countries first need to exchange cancer data and then conduct a comparative study using non-individualized data. The third step is collection of individualized, anonymous data, which would improve comparability.

Collaborative Epidemiological Studies: The Asia Cohort Consortium, which includes investigators from various countries, is a complicated collaboration. Good epidemiological research collaboration requires researchers’ comprehension of the significance of multinational collaborative studies, good coordination, adequate funding and balanced collaboration.

Conclusions: Asia faces various problems in relation to cancer registry, including inadequate quality, weak infrastructure, insufficient coverage, etc. Epidemiological studies are hampered by differences in expertise and resources, limited understanding of epidemiology, etc. To alleviate those problems, an organization for Asian cooperation on cancer registration should be established. Adequate funding of registries and activities is essential. Collaborative and comparative epidemiological studies based on data from cancer registries are needed.

Key words: cancer registries – epidemiological studies – collaboration – network

The Cancer Registry and Epidemiological Study Working Group comprised almost 50 members from 19 countries. Its discussions focused on the registry systems and collaborative work necessary for attacking the problem of cancer in the Asia-Pacific region.

INTERNATIONAL AGENCY FOR RESEARCH ON CANCER

The International Agency for Research on Cancer (IARC)’s mission is cancer research for cancer prevention. It also serves as a global reference for cancer information, including geographical variations, incidence and trends over time. The IARC also provides education and training for low-resource countries. The Cancer Information Section (CIS) includes three groups: biostatistics, data analysis and descriptive epidemiological production. One of the core activities of the CIS is to issue the cancer incidence in five continents series, which is the world’s largest database of information on cancer incidence and has been invaluable for conducting cancer research, establishing cancer control programs and determining healthcare policies around the world. The CIS also supports cancer registries by providing administrative
facilities, conducting site visits, providing individual and group training, etc. In 2009, Asian Workshops were held in Vietnam and Bhutan.

Various Asian countries have published cancer registries over recent years. Data from 77 registries in 18 countries were submitted for inclusion in the IARC’s Cancer Incidence in Five Continents Vol. IX, and 44 (55%) of those registries in 15 countries were accepted. (1) Sixty per cent of the world’s population lives in Asia, and 6 of the 10 most populated countries are in Asia, consisting of China, India, Indonesia, Pakistan, Bangladesh and Japan. Unfortunately, there has still been no cancer registry data from two of those Asian countries, Indonesia and Bangladesh (Table 1).

GLOBOCAN 2002 estimated 4.8 million cases of cancer and 3.4 million deaths in Asia, representing almost 45 and 50%, respectively, of the world’s cases. (2) GLOBOCAN data are being updated, and the objective is to provide estimates of cancer incidence, mortality and prevalence for 28 major cancers. Estimated data for 2008 showed that the number of cancer cases in Asia had increased by ~10% since 2002, but deaths increased only slightly.

INTERNATIONAL ASSOCIATION OF CANCER REGISTRIES

The International Association of Cancer Registries (IACR) is a non-governmental organization that was founded in 1966 to foster the exchange of information between cancer registries internationally, aimed at improving the quality of data and comparability between registries. The number of member countries has been increasing, especially Asian nations. In 2009, members from 26 countries covered ~20% of the world’s population. The IACR is affiliated with two scientific journals, the European Journal of Cancer Prevention and the Asian Pacific Journal of Cancer Prevention. The IACR standards have been presented in a number of publications, aimed at improving the quality of data and comparability between registries. The IACR provides support to cancer registries by means of fellowship funds (the Calum Muir Memorial Fellowship and the Constance Percy Memorial Fund) and also computer programs. Many Asian countries have cancer registries, but some do not, including North Korea, Cambodia and Laos. Meetings to set up an Asian Network of Cancer Registries were held in Korea in 2008 and Thailand in 2009. Then a survey was conducted regarding the establishment of an Asian Network of Cancer Registries, and 22 responses were obtained from 109 Asian registries (Fig. 1). Seven main objectives of networking were favored for the organization, including training for standardization of networking, planning and execution of collaborative research, evaluation of cancer control and treatment outcomes, meetings and discussions, etc. Regarding the name, half of the respondents preferred ‘Asian Association of Cancer Registries’, whereas the other half preferred ‘Asian Network of Cancer Registries’.

DESIGNING COOPERATIVE STUDIES

A major element in the overall strategy for combating cancer in Asia-Pacific countries in the future is the effective design and execution of cooperative studies using cancer registration data and international comparisons with Asian countries. The rationale is that society, the mass media and health authorities pay more attention to cancer incidence and trend data when they are compared with other countries, rather than only within their own country. Moreover, the results contribute to improved cancer control planning in the participating countries.

Prior to a cooperative study, countries need to exchange data regarding cancer in each of their countries. In Japan, the incidence of hepatocellular carcinoma (HCC) has been decreasing because of reduced hepatitis C virus (HCV) infection rates due to improved hygiene and prevention of

<table>
<thead>
<tr>
<th>Table 1. Cancer Registries in Asia</th>
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<tbody>
<tr>
<td>Eastern (6)</td>
</tr>
<tr>
<td>China: 43 + (A)</td>
</tr>
<tr>
<td>Japan: 35 + (A)</td>
</tr>
<tr>
<td>South Korea: 8 + N</td>
</tr>
<tr>
<td>North Korea:</td>
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<tr>
<td>Mongolia: N</td>
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<tr>
<td>Taiwan: N</td>
</tr>
<tr>
<td>Philippines: 4</td>
</tr>
<tr>
<td>Singapore: N</td>
</tr>
<tr>
<td>Timore</td>
</tr>
<tr>
<td>Thailand: 19 + (A)</td>
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<tr>
<td>Vietnam: 6</td>
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</tbody>
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Bold: Countries where registries are in operation.

Survey: establishment of Asian Network of Cancer Registry

- 22 responses from the 109 registries in Asia
- ‘Asian Association of Cancer Registries’ vs. ‘Asian Network of Cancer Registries’
- 17 people agreed to be the country steering committee members
- Such networking should address:
  1. Training for standardized networking of cancer registries
  2. Planning collaborative research work and executing them
  3. Evaluation of cancer control, treatment outcome
  4. Serve as a training tool in oncology in Asia
  5. Exchange-related research workers
  6. Meetings and discussions
  7. Conduct statistical and epidemiological training and studies

Figure 1. Survey: Establishment of Asian Network of Cancer Registry.
blood-borne infection (3). Information in this regard may be helpful to countries where HCV-related HCC is endemic, such as Mongolia, Myanmar and Taiwan.

Another example is lung cancer. Many Asian countries have high smoking rates in males. Male smoking rates in Japan have been decreasing, and the incidence of lung cancer has been decreasing since 1993, and also reduced incidence of squamous cell carcinoma because of a change from non-filter to filter cigarettes. The incidence rate of squamous cell carcinoma has been decreasing since 1994, whereas the incidence rate of adenocarcinoma increased until 1998, after which it plateaued. It took nearly 30 years for the decrease in non-filtered cigarettes to translate into a decrease in squamous cell carcinoma. Although it takes a long time, anti-smoking policies reduce the incidence of lung cancer. Evidence of this has been presented in Western countries, and it is important to advance such policies in Asia, as well, in order to reduce lung cancer.

A study group financially supported by a Grant-in-Aid for Comprehensive Cancer Control from Japanese Ministry of Health, Labor and Welfare conducted a collaborative study using a population-based cancer registry in East Asia (4). They have reported a 5-year relative survival rate of stomach cancer patients diagnosed between 1997 and 1999. The survival rates were higher in Japan, and even in Korea and Taiwan, than in Europe and the USA. The breast cancer 5-year survival rate was very high in Japan, Korea and Taiwan, and almost the same as in the EU and USA, whereas the survival rate of breast cancer was low in the Philippines, and hence improvement is needed there. The highest cervical cancer 5-year survival rate was seen in Korea, whereas several regions in Japan were not so high. Elucidation of the reasons for the lower rates in Japan is needed. Again, the Philippines had the lowest 5-year survival rate for cervical cancer, as well.

The next stage for cooperative studies is to collect individualized, anonymous data, which would make it possible to elucidate the factors that cause differences between populations, such as age, clinical stage at diagnosis, treatment procedures, etc. Individualized, anonymous data would also improve the comparability of survival data among the participating regions.

In conclusion, designing cooperative studies using cancer registry data involves a first stage in which information is exchanged among the participating countries to facilitate cancer control planning, a second stage consisting of a comparative study using non-individualized data and a third stage using individualized data (Fig. 2). Good human relationships among researchers are also very important, and the APCC represents a good platform for nurturing such good relationships.

**COLLABORATIVE EPIDEMIOLOGICAL STUDIES FOR CANCER PREVENTION**

With regard to collaborative epidemiological studies to collect evidence concerning cancer risk and protective factors in the Asian region, recent trends show that the number of studies has been increasing, meta-analysis/pooled analysis of multiple studies has become very popular, and the importance of estimating the population-attributable fraction in each country/region/world has been recognized.

Collaboration between two countries is fairly simple, consisting of securing a research grant/funding, data collection by investigators and co-investigators in each country, and data analysis and manuscript preparation. The data center, data analysis and manuscript preparation are usually in the country of the principal investigator, while the grant is usually executed in the currency of the funding host.

In the case of collaboration between multiple countries, things get more complicated. The principal investigator is in one country, with a network including co-investigators collecting data in each of the participating countries, and the data analysis and manuscript preparation are performed at a data center, usually in the country of the principal investigator. However, the location of the data center and the manuscript writer are flexible.

An even more complicated example of collaboration is the Asia Cohort Consortium, which includes investigators from various countries and who change in accordance with the topic (Fig. 3). Interesting features are that the data center is outside Asia, in the USA, and the researchers include not only Asians but also Europeans and Americans, because they get funding, by topic, from their countries. Also, there is no firm funding base for network maintenance.

The funding agency in support of epidemiological research can be a domestic organization or an international organization. In the case of a domestic organization, the study is based in that country and is usually research topic-oriented. In the case of an international organization, the study base can be anywhere, and it is a potential research platform.

For good epidemiological research collaboration in Asian countries, the following points are important: each researcher must have an understanding of the significance of
multinational collaborative studies; the leader must be a good coordinator; funding must be available for network maintenance and a multinational consortium; and the collaboration must be balanced and provide equal opportunity.

CONCLUSIONS

The problems that are faced in relation to cancer registry in Asia are various (Fig. 4). They include insufficient quality of most registries, weak infrastructure, inadequate coverage in some countries, difficulty in sustainability due to insufficient financial support and turnover of trained personnel, few opportunities for education and training, and low response rates to IACR questionnaire surveys. Similarly, problems in relation to epidemiological studies include wide variation in expertise and resources among Asian countries, and limited understanding of epidemiology in some nations, which constrains funding for epidemiological studies (Fig. 5). Other key problems are the lack of opportunity for contact between experts in Asia via collaborative activities and language barriers among Asian countries.

As solutions, from the perspective of researchers, the highest priority should be placed on information-sharing among researchers within the Asia-Pacific region. Newly developed and widely used techniques, such as those for record linkage, should be shared. In addition, there is a need to promote coordination meetings/workshops/symposia, provide training courses, establish international standards and promote collaborative studies, publication and a common database for pooled analysis, both for cancer registries and epidemiological studies. In order to do this, an organization for Asian cooperation on cancer registration should be established in the field of cancer registries. In addition, a common hub for collaborative research will be needed for epidemiological studies. More opportunities for collaborative research projects, activities and publications would improve the research skills and expertise in the region.

From the perspective of international organizations, such as the IARC and IACR, in a 2009 meeting the governing council of the IARC discussed how to provide greater support to cancer registries in developing countries. The IARC/IACR is planning to create a password-protected online system, so that questionnaires can be completed online and updated every year. The website would also allow registries to update their contact information. In October 2010, an Asian session will be held as a post-conference of the IACR annual meeting in Yokohama, Japan and Asian cooperation in cancer registration will be one of the main themes. To maintain a network of cancer registries, or an Asia Cohort Consortium, it will be necessary to maintain funding not only for topic-specific research proposals, but also for the research platform itself. To that end, funding should also be requested of other organizations.
In the future, the Asia-Pacific region must make full use of the platforms afforded by the WHO, IARC/IACR, UICC Headquarters, APFOCC and liaison societies in order to promote and achieve its goals of establishing cancer registries, accumulating cancer statistics, promoting and performing epidemiological studies and formulating regional and national cancer control programs.

With regard to concrete actions, from the perspective of researchers, there must be continued development of collaborative research projects and activities in subregions such as West Asia, Central Asia, Southeast Asia, East Asia and the Pacific. Publication of these activities should be encouraged to improve research skills and expertise in the study of Asia-Pacific populations. In that context, a steering committee for Asian cooperation for cancer registration will be assembled for the kick-off meeting in Yokohama 2010. At the same time, it will be proposed that the IARC supports the administrative work needed to maintain the network. Finally, collaborative and comparative epidemiological studies based on data from cancer registries should be promoted.

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**Conflict of interest statement**

None declared.

**Appendix**

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