
COMMENTARY

Establishment of an Asian Cancer Registry Network - Problems and Perspectives

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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, regional and national levels. Comparability of data is essential for interpretation and this in turn depends on standardization of methodology and the 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 Association of Cancer Registries (IACR) and individual country-based or region-based associations already active in Asia. Building on an analysis of the present status in Asia, as well as experience of the European Network of Cancer Registries (ENCR) and the North American Association of Central Cancer Registries (NAACCR), potential problems and possible solutions are here reviewed, with coverage of both organizational and financial constraints. An argument is presented here that there is a rationale for some form of an Asian Network of Cancer Registries, supported by the International Agency for Research on Cancer (IARC) and the UICC-Asian Regional Office, working alongside the IACR and existing national organizations and research institutes.

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

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Introduction

We are dependent on our cancer registries for accurate information on incidences and mortality rates, as well as trends over time. These are essential data for evidence-based cancer control programs. Due in large part to the efforts of the International Association of Cancer Registries (IACR) and the support of the International Agency for Research on Cancer (IARC), there are many cancer registries in Asia already producing data, although the indices of quality are very variable. The major division is into hospital- and population-based, but the former may also vary from simple Pathology Department surveys to coordinated efforts to registry of all cases diagnosed in an institution.

It should always be borne in mind that the history of registration is in fact generally a history of highly motivated individuals persuading those around them to help set up a registry. In the vast majority of cases, it is only very late in the game that registration becomes government policy, especially in Asia, although efforts to create national population-based registration naturally rely on official support.

At the 22nd Annual Scientific Meeting of the International Association of Cancer Registries, held in Khon Kaen, Thailand, a poster session was dedicated to a review of the current situation with respect to cancer registration on the Asian continent. All of the contributors were asked to prepare also an "extended abstract" which would include a rather structured account of cancer registration activities in the country, subsequently published as an APJCP Supplement (Parkin and Vatanasapt, 2001). Thus, the 18 countries which participated were each asked to outline:

- A summary of their history of cancer registration;
- The present status of registration (with map, if regional coverage) and the size of population covered;
- Any national policy for registration with cancer registry associations, if any;
- Incidence data: a summary of the national profile and of regional variations;
- Studies of survival, epidemiology, prevention, screening and medical care
- Significant publications: reports, peer-reviewed articles
- Contact details and Internet websites

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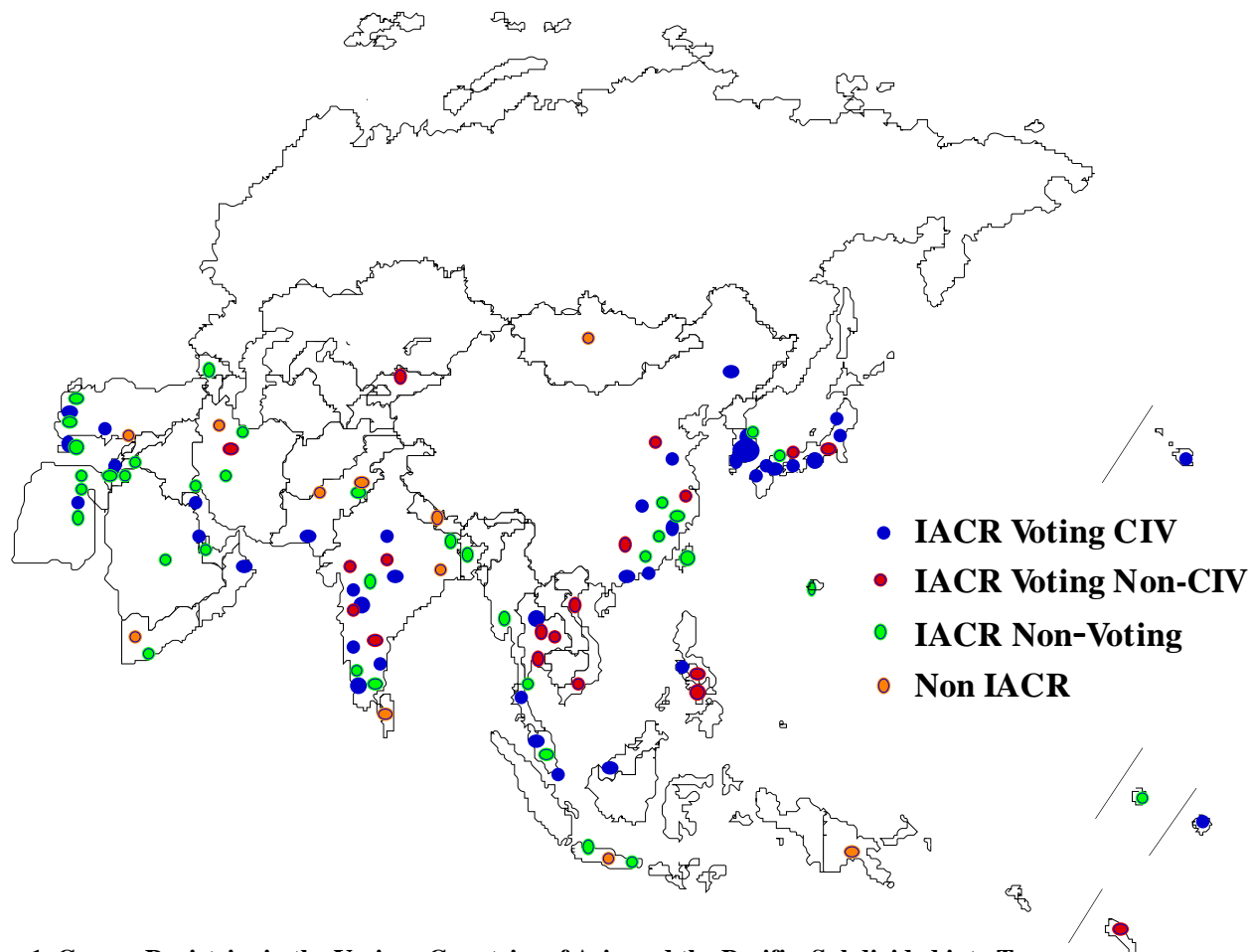


Figure 1. Cancer Registries in the Various Countries of Asia and the Pacific, Subdivided into Types

Table 1. Numbers of Middle Eastern Countries and Registries in the Series of Nine Volumes of CIV

Volume	I	II	III	IV	V	VI	VII	VIII	IX
Countries	4	4	5	6	8	10	12	15	18
Registries	4	5	7	11	17	23	26	43	48
Hawaii, USA	1	1	1	1	1	1	1	1	1
Israel*	1	1	1	1	1	1	1	1	1
Singapore*	1		1	1	1	1	1	1	1
Japan	1	2	3	4	4	6	6	6	7
India		1	1	2	5	4	6	9	7
China				2	3	4	4	10	6
Taiwan*								1	
Kuwait*					1	1	1	1	1
Philippines					1	2	1	2	1
Kyrgyzstan						1			
Thailand					2	2	3	3	
French Polynesia							1	1	1
Korea*							1	4	9
Viet Nam							1	1	
Oman								1	1
Pakistan								1	1
Bahrain									1
Cyprus									1
Egypt									1
Malaysia									2
Turkey									2

*: National cancer registry

In preparation for the possible setting up of an official, Asia + Pacific Network of Cancer Registries the present review was compiled focusing on the same points.

An overview of the registries already active in Asia, to our knowledge, is given in Figure 1, with division into hospital- and population-based, the latter being further divided into those deemed to have or lack sufficient accuracy for inclusion in the Cancer Incidence in Five Continents (CIV) publication of the International Agency for Research on Cancer. In the last issue, stricter application of criteria than was previously the case resulted in a number of cancer registries no longer being included in CIV, despite an increase overall over the numbers in previous volumes (see Table 1). The registries were in fact graded into A, B and C grades (along with the D grade not included) on the basis of percentages of microscopically verified and death only certified, many of the Asian registries being included in B, with a few examples in C.

Region and Country Profiles

Western Asia

There are two supra-national organizations operating in Western Asia. The first is the Middle East Cancer Consortium (MECC), established through an official agreement of the

Ministries of Health of Cyprus, Egypt, Israel, Jordan, and the Palestinian Authority. The agreement was signed in Geneva in May 1996 and financial support is provided by the American National Cancer Institute, National Institutes of Health (<http://mecc.cancer.gov/>). Turkey officially joined the Consortium in June 2004.

The objective of the MECC is to reduce the incidence and impact of cancer in the Middle East through solicitation and support of collaborative research. Since its inception, the major activities have been the Cancer Registry Project (CRP) and the Small Grants Programme. Cancer incidence data for four of the members are available on the website. Included in the CRP are training for registrars and assistance with software and data standards.

There is also a Gulf Center for Cancer Registration but the website does not appear to be active (<http://www.gccr.org/main.html>). However, a comparison of lung cancer rates in the different countries of the Gulf region was published relatively recently (Al-Hamdan et al., 2006).

Turkey. There are now two population-based registries from Turkey reporting to CIV, in Izmir and Antalya, and a number of others are also in operation, in Adana, Turkish Cyprus and Bursa, for example. The Cancer Control Department in the Ministry of Health has overall responsibility. There are 1 Individual and 6 Associate IARC members.

The first population-based data were published from Izmir in 2001 (Fidaner et al., 2001). A number of groups are conducting hospital-based incidence surveys, for example of lung cancer (Goksel et al., 2002; Elci and Akpinar-Elci, 2007), types of gastric adenocarcinomas (Bor et al., 2007), breast cancer (Kilciksiz et al., 2007; Kosgil and Baykal 2007) and mesotheliomas (Metintas et al., 2002).

Cyprus. The country has an two registries one in the Turkish part and the other in the Greek part, now reporting to CIV. There have been no separate recent publications.

Syria. The Ministry of Health houses the Syrian National Cancer Registry, an IACR Associate member, but the status is . A semi-population-based report on neoplastic diseases in Aleppo appeared in 2002 (Mzayek et al., 2002).

Lebanon. There once existed a cancer registry in the Lebanon, and incidence rates were published in 2004 (Shamseddine et al., 2004), but there is no IACR member and the present status is unclear.

Israel. Israel has long had very active registration, reporting to CIV from the very beginning of the series in 1967. The Israel National Cancer Registry is an IACR Voting member and is active in research, for example into differences in incidence between the various ethnic groups in the country and time trends (Barchana et al., 2004; Lerner-Geva et al., 2006; Lubina et al., 2006; Menczer et al., 2006; Rozen et al., 2007a; 2007b; Tarabeia et al., 2007).

Jordan. Cancer registration was started in 1996 by the Jordanian Cancer Registry (JCR) at the Ministry of Health. This single population-based cancer registry collects information on cancer patients treated in 83 hospitals from different health sectors (government, private, military, university), in addition to 13 laboratories and various clinics throughout the country (Qasem, 2001). It is an Associate member of IACR. A population-based comparison of incidence rates with those in Israel appeared in 2003 (Freedman et al., 2003). Childhood cancer has been another focus of the registry (Al-Sheyyab et al., 2003), along with skin cancer (Olmari et al., 2006).

Egypt. One of the Egyptian registries is now reporting to CIV, and there are 1 Individual and 5 Associate Egyptian members of IACR. There are data in the literature for cancer burden (Omar et al., 2007) and changes over time have been a focus of attention for liver (Lehman et al., 2007) and non-Hodgkin's lymphoma (Abdel-Fattah and Yassine, 2007).

Saudi-Arabia. The National Cancer Registry (NCR) in Saudi Arabia is a population-based registry developed in 1992. It was established under the jurisdiction of the Ministry of Health at the King Faisal Specialist Hospital and Research Center (KFS&RC) and commenced reporting cancer cases in 1994 (Al Hamdan et al., 2001). Data on overall incidence have been published (Al-Hamdan et al., 2006), with emphasis on increase in both incidence and mortality (Ibrahim et al., 2008), as well as intra-country variation in oral cancer (Brown et al., 2006) and breast cancer survival (Ravichandran et al., 2005).

Yemen. Yemen has one population-based cancer registry in Aden, which is also an Associate member of IACR. There is also cancer registration in the National Oncology Center and other locations in the country but their status is unclear. A number of papers have appeared in the literature on the distribution of malignancies (Al-Thobhani et al., 2001), and incidences of oral (Sawair et al., 2007), colorectal (Basaleem and Al-Sakkaf, 2004), breast (Abdul-Hamid et al., 2001) and thyroid (Al-Hureibi, 2004) cancers.

Oman. The Cancer Registry in Oman was established in 1985 as a hospital based cancer registry. It has been functioning under the Directorate General of Health Affairs as a population based registry since 1996 (al-Lawati et al., 2001). It is an IACR Voting member. First data were published in 1999 (al-Lawati et al., 1999).

United Arab Emirates. UAE has no cancer registry membership of IACR and there is no evidence of activity in the literature, other than a report on prostate cancer epidemiology (Ghafoor et al., 2003), and a possible survey of cancer patterns in one hospital (El-Halal et al., 1997).

Qatar. Only hospital-based data are available and there is no member of IACR. From recent results, lung cancer is

the most frequent cancer diagnosed in men and breast cancer in women (Bener et al., 2008).

Bahrain. The registry is now reporting to CIV and is an Associate member of IACR. Cancer incidence data are also available in the literature (Alsayyad and Hamadeh, 2007).

Kuwait. With a population-based registry reporting to CIV for 25 years and a Voting member in IACR, Kuwait has a well-established system. Data are provided by both Kuwaiti and non-Kuwaiti populations. The only published data are for lung cancer in comparison with other Gulf countries (Al-Hamdan et al., 2006).

Iraq. There is no IACR member in the country and the only data available are hospital-based for Basrah in 2005 (Habib et al., 2007).

Armenia. There is no IACR member in the country and there are no recent data available in the literature except for the comparison of incidence and mortality data with other Commonwealth of Independent States after the break up of the USSR (Davydov and Aksel, 2007).

Georgia. There is no IACR member in the country and there are no recent data available in the literature.

Azerbaijan. There is no IACR member in the country. Vital statistics data were used to calculate annual crude cancer incidence and mortality rates for selected cancers and regions in Azerbaijan for the years 1980-2000 (Andruchow et al., 2006). The country was also included in the comparison of incidence and mortality data with other Commonwealth of Independent States after the break up of the USSR (Davydov and Aksel, 2007).

Iran. Although results of a survey were published by Habibi in 1965 (and again in 1975), cancer registration activity actually dates to 1968 when the first program was launched as a collaborative research agreement between the International Agency for Research on Cancer (IARC) and the Institute for Health Studies affiliated to the Tehran University School of Public Health, in order to study the high incidence of esophageal cancer in the province of Mazandran. By 1971, this registry expanded its activity to cover whole area of Caspian littoral (from North of Khorasan province to North of East-Azerbaijan province) (Mahboubi et al., 1973). Activity ceased in early 1980 but restarted in 1991. Another population based cancer registry was established in Fars province in 1976, and expanded its activity to neighboring provinces (Bakhtaran and Khozestan provinces). In 1993, the Cancer Institute affiliated to Tehran University of Medical Sciences with a grant from Ministry of Health and Medical Education initiated a cancer registry program which resulted in series of activities in different regions including a collaborative research agreement with IARC (Mosavi-Jarrahi et al., 2001).

Registry data have been published for Iran as a whole (Sadjadi et al., 2005), for Ardabil (Sadjadi et al., 2003), East Azerbaijan (Somi et al., 2006; 2008), Tehran (Larijani et al., 2004), and Semnan (Babaei et al., 2005; 2006). Attention has been focused on breast (Mousavi et al., 2006), prostate (Sadjadi et al., 2007), thyroid (Haghpanah et al., 2006) and colorectal (Azadeh et al., 2008) cancers, as well as Karposi's sarcomas (Mousavi et al., 2007). Registry research has also been conducted into methodology (Fallah and Kharazmi, 2007; 2008).

Turkmenistan. There are no data available.

Uzbekistan. There are no recent data available.

Kazakhstan. There is no IACR member in the country and there are no recent data available in the literature except for the comparison of incidence and mortality data with other Commonwealth of Independent States after the break up of the USSR (Davydov and Aksel, 2007).

Kyrgyzstan. There is a Voting IACR member in the country and a series of papers have appeared in the literature from the Iginov group on ethnic variation in cancer in females (Iginov, 2004; Iginov et al., 2002a), the breast (Iginov et al., 2005), the ovary (Iginov and Umaralieva, 2008) and the oesophagus and lung (Iginov et al., 2002b).

Tadjikistan. There are no data available.

South Asia

To our knowledge there are no supranational organizations operating in the South Asian subcontinent.

Pakistan. The 'Karachi Cancer Registry' (KCR), the first population-based cancer registry in Pakistan was established by the Government of Sindh in January 1995, in collaboration with the IARC (Bhurgri, 2001). Now there are also registries in the Shaukat Khanum Memorial Cancer Hospital and Research Center as well as Rawalpindi. There are one Voting and 2 Associate IACR members, and Karachi has been reporting to CIV since 2002. The first population-based data for the country were published in 2000 (Bhurgri et al., 2000). Subsequently data have been reported for Karachi (Bhurgri et al., 2002a), Quetta (Bhurgri et al., 2002d), Larkana (Bhurgri et al., 2006c), Hyderabad (Bhurgri et al., 2005), Punjab (Aziz et al., 2003) and Dir province (Zeb et al., 2008). Reports on quality control (Bhurgri et al., 2002b) and comparison of pathology and population-based data (Bhurgri et al., 2002c, have appeared, along with implications of registry data for the national plan (Bhurgri, 2004; Nishtar et al., 2004; Akhtar, 2007).

Papers have also been published on oral (Bhurgri, 2005; Bhurgri et al., 2003b; 2006a), oesophageal (Bhurgri et al., 2003a; 2004a; Badar et al., 2005a), lung (Bhurgri et al., 2006b), ovarian (Sarwar et al., 2006), breast (Bhurgri et

al., 2007a), endometrial (Bhurgri et al., 2007a), cervical (Badar et al., 2007; Bhurgri et al., 2007b), ocular (Bhurgri et al., 2003c), and childhood (Jamal et al., 2006) cancers. There has also been coverage of non Hodgkin lymphoma (Mushtaq et al., 2007) and retinoblastoma (Bhurgri et al., 2004b), as well as occupation associations (Zeb et al., 2006) and survival from neoplasms of the liver (Yusuf et al., 2007) and breast (Badar et al., 2005b).

India. The first population based cancer registry, THE Bombay Cancer Registry, was established by the Indian Cancer Society in Mumbai (formerly Bombay) in 1963. This was followed by the setting up of three satellite registries in the State of Maharashtra at Pune (in 1972), Aurangabad (in 1978) and Nagpur (in 1983). Realising cancer as a significant health problem and the need to implement cancer control activity in the country, the National Cancer Registry Programme (NCRP) was launched by the Indian Council of Medical Research of Government of India, with two new population based cancer registries founded in Chennai (formerly Madras) and Bangalore in 1981. Subsequently, new population based cancer registries were commissioned in Bhopal (in 1984) and New Delhi (in 1986) and a rural registry in Barshi, Maharashtra (1987) (Gajalakshmi et al., 2001). The first published data appeared towards the end of the 20th century for Mumbai, formerly Bombay (Yeole and Jussawalla, 1992; Yeole, 2002), for Chennai, formerly Madras (Shanta et al., 1994; Gajalakshmi et al., 1998; Rajkumar et al., 2000), and for Kolkata, formerly Calcutta (Sen et al., 2002). Mumbai has contributed to CIV since Vol II and a total of 7 registries are now included. There are 10 Voting, 5 Associate and 6 Individual IACR members.

Papers have appeared on reliability of data (Yeole, 2001; Yeole and Jussawalla, 1988), social inequalities (Kurkure and Yeole, 2006) geographical comparisons (Nandakumar et al., 2005; Jayalakshmi et al., 2006; Hislop et al., 2007; Marimuthu, 2008), time trends (Tyagi et al., 2001), with a recent series of papers covering Mumbai, Chennai, Bangalore, Delhi and Bhopal for head and neck, gastrointestinal, female cancers, prostate and brain (Yeole et al., 1989; 2007; Yeole, 2007; 2008a; 2008b; 2008c; 2008d, respectively), childhood cancers (Swaminathan et al., 2008), geriatric cancers (Yeole, 2008e), mortality and survival (Yeole et al., 2000; 2004; Yeole and Kumar, 2004; Yeole, 2006; 2008e), ethnic variation (Yeole et al., 2001; 2006) and lifetime risk (Satyanarayana and Asthana, 2008). Attention has been concentrated on oral (Sunny et al., 2004b; Elango et al., 2006), oesophagus (Cherian et al., 2007; Tony et al., 2007), stomach (Sunny et al., 2004a; Harikumar et al., 2005), breast (Yeole and Kurkure, 2003; Ghumare and Cunningham, 2007), cervix (Murthy et al., 2005), prostate (Sunny et al., 2004c) and brain (Ghosh et al., 2004) cancers, as well as retinoblastomas (Yeole and Advani, 2002).

Nepal. There is no IACR member in the country and the only data so far available are hospital-based, published with the cooperation of an Indian group (Binu et al., 2007).

Bhutan. There is no IACR member in the country and there are no data available.

Bangladesh. The country has one individual member of the IACR and now appears to be focusing attention on cancer registration, with the relatively appearance of two papers on cancer prevalence (Talukder et al., 2007a; 2007b).

South-East Asia

To our knowledge there are no regional organizations yet in place, although the Thai Cancer Institute has been active in providing cancer registry training for various other countries within South and South-East Asia.

Myanmar. There is a cancer registry in the University hospital which is an Associate member of the IACR, but no data have been published in the available literature.

Thailand. Cancer registration in Thailand was started in 1971 by the National Cancer Institute, but the first population-based cancer registry commenced in 1986 in Chiang Mai, followed by Khon Kaen in 1988, Songkhla and Bangkok in 1990 and Lampang in 1993. With the cooperation of the registries, the National Cancer Institute in Bangkok, and the International Agency for Research on Cancer (IARC), the first volume of Cancer in Thailand was published in 1993 and updates have regularly been produced since then (Deerasamee et al., 2001). There are 5 Voting, 1 Associate and 3 Individual (1 Honorary) IACR members and Thai registries have been contributing to CIV since Volume VI. Trends over time for all major cancers (Sriplung et al., 2006), as well colorectal and stomach cancer (Suwanrungruang et al., 2006) have been published along with findings for childhood cancer (Wiangnon et al., 2003).

Malaysia. The National Cancer Registry of Malaysia was established in 1987 and officially launched in 1988. Centrally based at the Epidemiology Unit, Ministry of Health progress was not as expected and after a National Cancer Control Program Conference in 1993, it was decided to focus instead on regional cancer registries. The state of Penang initiated the first in 1994, followed by Sarawak in 1995, then Sabah and Kelantan, and by the end of 1999 all states had their own state cancer registry, although varying in quality (Rosemawati and Sallehudin, 2001). Penang and Sarawak are now reporting to CIV and there are two Malaysian members of IACR, one Voting and one Associate.

The first report of Penang data appeared in 1994 (Chan et al., 1994) and cancer incidence data were more recently covered by Lim (2002). Papers have also been published on lung (Liam et al., 2006), cervical (Cheah et al., 1999), and nasopharyngeal (Devi et al., 2004) cancers, as well as lymphomas (Ariffin et al., 2007).

Singapore. The Singapore Cancer Registry (SCR) was founded in 1968 as a population-based registry covering the

entire national population. The existence of unique national registration numbers greatly helps in identifying duplicate registrations and record linkages and DCOs are now at 1%, with microscopic confirmation at around 90% (Chia et al., 2001b). There is a very strong research presence because of the Singapore National University link, with emphases on inter-ethnic variation, for example for in breast neoplasia (Lim et al., 2007), lung cancer type (Seow et al., 1998; Fernandes et al., 2006), survival overall (Chia et al., 2001a) and change in survival of colorectal cancer patients (Wong and Eu, 2007).

Indonesia. A first step toward population based cancer registration was taken by the Department of Pathology Diponegoro University in Semarang in 1970 and semi-population based cancer incidence data have been available since 1985, allowing comparisons across the country (Sarjadi, 2001). Indonesia has one Associate and one Individual member of IACR. One focus has been on gastrointestinal malignancies (Soeripto et al., 2003) and the very low incidence of gastric cancer (Tokudome et al., 2005), as well as rise in oral tumours (Budhy et al., 2001). There is now a major new effort in Jakarta by the Dharmas National Cancer Center to set up a partial population-based registry.

Papua New Guinea. There are no IACR members in PNG and the recent literature is limited to a report on the rising incidence of breast cancer (Halder et al., 2001) but the Ministry of Health is trying to establish a registry.

Pacific Islands. There are IACR members from Fiji (Associate), New Caledonia (one Individual, one Voting), Guam (Associate), Hawaii (Voting) and Vanuatu (Individual). Hawaii has been reporting to CIV since the beginning of the series and French Polynesia since Vol VII. Recent published data include a paper on cancer disparities among indigenous Polynesian populations (Dachs et al., 2008), reports from French Polynesia for all cancers (Gleize et al., 2000), from New Caledonia on thyroid cancer (Truong et al., 2007) and pleural mesothelioma (Baumann, 2007), and on cancer incidence (Haddock and Naval, 2002) an ethnic variation in cancer mortality in Guam (Haddock et al., 2006). There is of course major research capacity in Hawaii.

The Philippines. The Department of Health-Rizal Cancer Registry (DOH-RCR), the first population-based cancer registry in the Philippines, was launched in 1974 as an activity of the Community Cancer Control Program of Rizal. The Philippine Cancer Society-Manila Cancer Registry (PCS-MCR) began a cooperative effort with the DOH-RCR in 1984 and currently the two registries cover 131 hospitals. First data for the Philippines were published in peer-reviewed literature in 1998, for the years 1980-1992 (Laudico et al., 1998). 1978-82 data were included in CIV in 1987 (Esteban et al., 2001) and contributions have continued ever since. A third population-based registry in the Philippines, the Cebu

Cancer Registry (CCR), was founded in February 1988 as an activity of the the RAFI-Eduardo J. Aboitiz Cancer Center (EJACC). All three of these registries are voting members of the IACR. A fourth population-based cancer registry, the Davao Cancer Registry (DCR) was initially started in 1991 and then again in 1998, with support from the Andres Soriano Cancer Foundation.

Viet Nam. The first population based cancer registry was established in Hanoi in 1988 by the National Cancer Institute and a second was founded by the Oncology Center of Ho Chi Minh City (HCMC) in 1990 (Anh, 2001). Both are Voting members of IACR and Hanoi registry contributed to CIV VII and VIII, but not IX. First data from Hanoi were published in 1993 (Anh et al., 1993) and for adults and children in HCMC in 1998 and 2000, respectively (Nguyen et al., 1998; 2000). A series of papers have also appeared from the Ngoan group on populational based mortality and survival (Ngoan, 2006a; 2006b; Ngoan et al., 2002; 2007a; 2007b), differences between the north and south of the country (Ngoan et al., 2001), and shifts in lung cancer incidence over time (Ngoan, 2006c).

North-East Asia

To our knowledge there are no regional organizations as yet although there has been some movement towards setting up an Asian Cancer Information Network in Japan (Moore and Tajima, 2005; 2006b).

China. At the end of 1970's, a national survey of cancer mortality for the period of 1973-1975 was organized by the Chinese Ministry of Public Health. After 1977, many new cancer hospitals and cancer institutes were established nationwide (Wang, 2001). The Shanghai and Hong Kong Cancer Registries were established in the 1960's, and have been reporting to CIV since Vol IV (Foo et al., 2001). The Taiwan Cancer Registry was founded in 1979 (You et al., 2001). Now six registries are reporting to CIV and there are 13 Voting and 10 non-Voting Chinese members of IACR. First data for Shanghai were published by Jin et al in 1993. Cancer incidence data across the country (Yang et al., 2005) and in Shanghai (Jin et al., 1999), Qidong (Chen et al., 2006; 2007) and Tianjin (Song et al., 2008) have subsequently appeared. mortality Beijing (Wang et al., 1995).

Research has also been conducted on sources of information (Yang et al 2003), trend in cancer mortality overall (Cui et al., 2007) and in the stomach (Wang et al., 2007), and incidence of oesophagus and/or stomach (Wang et al., 2005; He et al., 2005; 2006; 2008; Su et al., 2007; Sun et al., 2007; Tse et al., 2007; Yee et al., 2007), colorectal (Ji et al., 1998), cervical (Chen et al., 2004), liver (Hao et al., 2003), breast in Shanghai (Jin et al., 1993) and Hong Kong (Leung et al., 2003) and nasopharyngeal (Hsu et al., 2006; Jia et al., 2006; Luo et al., 2007) cancers.

Mongolia. In 1971, cancer registration was intro-

duced on a national basis, using a system modeled upon that developed in the Soviet Union and featuring notification of all newly diagnosed cancer cases by oncology clinics located in the provincial hospitals. The National Registry, located in the National Oncological Centre in Ulaan Baatar, is responsible for identifying duplicate notifications (from different districts), and compiling national level statistics (Munkhtaivan et al., 2001). There are no data published in peer-review journals and there is no IACR member.

Korea. Cancer registration was started in Korea in 1980 with financial support of the World Health Organization (Ahn, 2001). Subsequently, the Ministry of Health and Welfare compelled all the university and training hospitals to join the Korean Central cancer Registry program. Now there is a very comprehensive nationwide program (Ahn, 2007; Shin 2008), with nine registries reporting to CIV and 10 IACR members, 8 Voting and 2 Associate. First population-based data were published in 1995 (Kim et al., 2005).

Research has been conducted into trends in incidence (Shin et al., 2008), survival rates (Jung et al., 2007; Yang and Bae, 2007; Kim et al., 2008) and influence of income (Kim et al., 2008). Papers have also been published focusing on lung (Hwang et al., 2007), colon (Kim et al., 2000), cervical (Chung et al., 2006; Jo et al., 2007) and ovarian cancers (Chung et al., 2007).

Japan. The first survey of cancer incidence in Miyagi prefecture was conducted in 1951-1953 by Segi and his colleagues. Population-based cancer registries were first established in Hiroshima city in 1957 and in Nagasaki city in 1958 for studying the long-term effects of atomic bomb radiation. In 1959 the Miyagi Tumor Registry was started and cancer registration schemes as part of prefectural cancer control programs were first provided in 1962 by the Health Departments of Aichi Prefecture and of Osaka Prefecture. Subsequently, this type of cancer registry has gradually spread throughout in Japan (Oshima et al., 2001). Japanese registries have been reporting to CIV since the inception and there are now data from 7 included. Japan has 10 Voting and 3 non-Voting members of IACR.

In 1975, the Research Group for Population-based Cancer Registration in Japan was organized (Research Group for Population-based Cancer Registration in Japan, 2000) and as of 2007, there were population-based cancer registries in 35 of Japan's 47 prefectures and in one city. The Japanese Association of Cancer Registries (JACR) was organized in 1992 (Okamoto, 2008). To improve completeness of incidence data in Japan, hospital-based cancer registries at designated cancer-care hospitals is now underway (Sobue, 2008).

The first population-based data were published in 1979 (Fujimoto et al., 1979). Cancer incidence has been detailed for the country (Tsukuma et al., 2005; Tabata et al., 2008) and for individual registries, like Aichi (Ito et al., 2004) and

Miyagi (Nishino et al., 2004). Papers have appeared on variability in cancer incidence rates across registries (Murata et al., 2008; Moore et al., 2005b), data quality (Ajiki et al., 1998; Mori et al., 2005), projected cancer prevalence (Tabata et al., 2008) mortality and survival (Kaneko et al., 2003; Nomura et al., 2006). Cancer in Hiroshima and Nagasaki atomic bomb survivors has been reported (Mabuchi et al., 1994) and research into childhood cancer (Ajiki et al., 1994), pancreas (Seino et al., 2006), and trends in lung (Soda et al., 2000; Sobue et al., 1999a; 1999b; Yoshimi et al., 2003; Toyoda et al., 2008), esophageal adenocarcinoma (Shibata et al., 2008), stomach (Kaneko and Yoshimura, 2001; Liu et al., 2006; Japanese Gastric Cancer Association Registration Committee et al., 2006), colon (Moore et al., 2005a), liver (Tanaka et al., 2008), breast (Minami et al., 1996; Nagata et al., 1997), cervix (Minami et al., 1996), cancers, melanomas (Tanaka et al., 1999) and mesotheliomas (Kanazawa et al., 2006) has been conducted.

International Agency for Research on Cancer (IARC)

The Descriptive Epidemiology Production Group in the IARC (<http://www.iarc.fr>) houses the secretariats for both the International Association of Cancer Registries and the European Network of Cancer Registries and is responsible for the Agencies contribution to world-wide cancer registration. It has now been joined by a Data Analysis and Interpretation group. In particular these are involved in producing the Cancer Incidence in Five Continents (CIV) series, as well as the Globocan estimates of incidence and mortality burden. The new version of CIV IX was published in 2007 (Curado et al., 2007) and has been made freely available at www.dep.iarc.fr and the hard copy can be ordered at www.who.int/bookorders.

The Agency has always been very active at helping setting up new regional registries across the globe. It has also published a number of other scientific publications covering various aspects of cancer registration, and a new version of the book 'Cancer Registration Principles and Methods' is under preparation.

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 for:

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

The emphasis is on participants from low and middle income countries and training in the implementation of all registry functions by means of the IARC CanReg4 software is also part of this module. It is updating the CanReg5

software with a new version CanReg5-5 open source now being tested by the MECC countries. IARC has in fact been active across the globe in holding regional courses, for example in cooperation with the Korean National Cancer Center in Seoul and also in Brazil in 2008. Further courses are planned for 2009 in Latin America, Africa and China.

International Association for Cancer Registries

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. With a secretariat located in the IARC, it primarily serves population-based registries, collecting information on the occurrence and outcome of cancer in defined population groups. The Association is an NGO 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. Encouragement of comparative studies is one of the objectives of IACR and to aid this process it has developed classifications (in editions of the International Classification of Diseases for Oncology, WHO), as well as guidelines, as exemplified by documents recently published in the APJCP (IARC, 2005a; 2005b), as well as the European Journal of Cancer Prevention.

The Association has Voting, Associate and Individual membership categories (decided on the level of activity achieved by the registry), only the first being entitled to vote when any ballots are taken. Corporate non-voting membership is also available. The Executive Board consists of the President, the general Secretary, the Executive Secretary and the Regional Representatives, of which there are two from Asia and one from Oceania. Fees, which may be waived at the discretion of the Executive Board, are US\$145 for Voting and Associate, \$50 for Individual and \$500 for Corporate members, and include access to a canreg 4 manual.

In addition to being invited to attend the yearly scientific meeting, with some possibility of applying for financial assistance, members benefit from news updates. Two Fellowship Programs are in place, the Calum Muir Memorial Fellowship and the Constance Percy Memorial Fund for which donations are welcomed, primarily to support travel to meetings. The website provides access to CanReg4 and IARCcrg Tools, with direct links to Cancer Mondial and European Network of Cancer Registries (ENCR) Home. The membership list is available for each of the continents and information on publications available from members is provided under Reports from Registries.

European Network of Cancer Registries

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**

All population-based cancer registries in Europe are automatically members of the ENCR (lists available for each country through clicking on a map). There is no information available on the website regarding membership fees. Financial support from Cancéropôle Rhone-Alpes has apparently been funding all the activities in 2007 and 2008. 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.

There is a Steering Committee of elected (five representatives) and nominated (one each by IARC, IACR, Group pour l'Epidemiologie et l'Enregistrement du Cancer dans les Pays de Langue latine and the Association of Nordic Cancer Registries) members, with up to two additional co-opted individuals. The ENCR Secretariat is housed at the IARC and has an active website (<http://www.encl.com.fr/>).

The ENCR produces updates, for example concerning the yearly scientific meeting and of steering committee decisions. It also provides Fellowships to attend courses, for example, although there is no information available on recent activity. The website allows for study proposals for research collaboration. 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. 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 groups 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

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 some time ago (around 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.naacr.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 exceedingly numerous and the web-site is very well organized, allowing direct access to population-based data for all of the member registries. When first organized, the focus was on achieving a consensus on cancer registration standards among the many standard setters in the United States and Canada. They include the American College of Surgeons, the National Cancer Institute, and the Canadian Cancer Registry at Statistics Canada. Today nearly all registries throughout the United States and Canada have adopted the NAACCR consensus standards, which are updated annually. Maintaining current standards to meet the needs of the NAACCR community is an ongoing and major NAACCR activity.

Since it is also critical to develop and maintain the skills and knowledge of cancer reporters the NAACCR has development and release of training workshops, resource materials, and continuing education opportunities as a second major focus. The program includes Webinars and In-Person Workshops. Forthcoming examples are:

Regional Training Programs on Registry Operations or Abstracting

Data Toolkit Workshop

Cancer Surveillance Institute I:

Principles and Public Health Applications

Cancer Surveillance Institute II:

Methods and Statistics

Cancer Registry Operations Workshops

There are also Annual Conference Workshops and a Scholarships & Grants Program. The NAACCR Research Program web page serves as a clearinghouse of information for researchers. It includes information on how to access individual member registries' data, and also includes contact information, a description of their infrastructure, and capacity for data availability for various types of research protocols and topics (e.g., rapid case ascertainment studies, record linkage studies or studies involving patient contact). The information about member registries will be updated annually in December. In addition, the page includes information on how to access the NAACCR CINA Deluxe file.

Annually, NAACCR compiles a bibliography of all research studies, reports, manuscripts, and monographs that have been conducted using the NAACCR incidence data file, developed from the submissions of member registries. Completed reports are publicly available online. Papers published in the scientific literature may only be available by using the citation and accessing it directly from the journal.

Cancer reporting is mandated through state or provincial laws. NAACCR registries from each state or province voluntarily submit their non-identified data annually for evaluation and publication to NAACCR. After NAACCR receives the data, members of the Data Use and Research Committee (DURC) compile the data for publication in Cancer in North America (CINA). An online interactive query system called CINA+ Online is available, and statistics and descriptive reports can be generated from the data.

The Data Quality Assessments web page contains information about Registry Certification, the NAACCR Call for Data, information for vendors involved in the Call for Data, and Data Quality Reports from NAACCR projects.

The Data Analysis Tools web page contains programs and documentation to assist with data analysis including the Great Circle Distance Calculator, NHIA v2 Algorithm, Poverty and Census Tract Linkage Program, and the Record Uniqueness Program (EXE - Moderate-Sized Files) (Zipped SAS Macro - Large Files).

NAACCR participates with other organizations in scientific endeavors and providing cancer information to the public. Most notably is the annual report to the nation on the status of cancer for which member incidence data are used for sections of the report.

NAACCR Membership has a number of categories.

Full memberships: These are available for central registries that are or have the potential to become population-based. Full membership benefits include:

Having data published in CINA.
 Voting privileges for election of NAACCR officers.
 Voting privileges at the annual business meeting.
 Can run for election as a representative.
 Listed in the Membership Directory on the Web site.
 Reduced rates to attend the annual meeting.
 Can serve on NAACCR committees.
 Receive all published reports from NAACCR.
 Recognized with certificates if serving on a committee.
 Can participate in the NAACCR Member Award Recognition Program.

Sustaining memberships: These are available for either a for-profit or a not-for-profit association that is interested in promoting the purposes of the Association. Benefits are as for other members but without voting or candidature rights.

Sponsoring Member: A NAACCR Sponsoring Member Organization is a national professional or governmental organization primarily involved in any of the following areas: cancer epidemiology, patient care, cancer control, cancer registration, professional education, research, or biostatistics. These organizations participate in NAACCR's Sponsoring Member Organization quarterly meetings and provide input on NAACCR's activities within the cancer surveillance field. Benefits are as for full members and the sponsors are:

Sponsors with Distinction

- American Cancer Society
- American College of Surgeons
- American Joint Committee on Cancer

Sponsors

- Canadian Association of Provincial Cancer Agencies
- Canadian Partnership Against Cancer
- Centers for Disease Control & Prevention
- National Cancer Institute
- National Cancer Registrars Association
- Public Health Agency of Canada
- SNOMED Terminology Solutions (College of American Pathologists)

Individual Members: These are individuals who are not currently working in a member organization but who have demonstrated career and professional commitments and interests that are consistent with or complementary to those of NAACCR. Benefits are similar to those of Full Members.

Proposed Asian Network of Cancer Registries

By analogy with ENCR and the NAACCR there is clearly a rationale for a new network specifically serving the interests of cancer registration in Asia. From our survey we can conclude that the present registry coverage is minimal in 19 (36%) of the total of 52 countries here included in Asia and the Pacific (17% have only rudimentary registration and over 65% have no CIV involvement). The indices of data quality used by IARC point to major variation across countries (see Table 2). As stressed by Yang et al (2005), there are also great difficulties in guaranteeing comparability even within individual countries, like China.

Table 2. Indices of Data Quality for CIV Asian Participants

Country	Cervix		Liver		Large Bowel	
	MV%	DCO#	MV%	DCO#	MV%	DCO#
China	87-99	0.4	18-68	3.0	78-97	0.9
India	81-92	5.4	53-92	23.0*	77-92	7.5
Israel	93-95	1.3	59-76	15.3	94	1.3
Japan	87-98	6.6	18-91	30.6	79-94	8.2
Korea	92-98	1.3	17-31	8.5	90-93	3.8
Kuwait	97-99	3.4	35-43	44.6	85-94	14.5
Malaysia	94-96	2.8	54-55	16.9	90-94	5.1
Oman	96	0.0	86	5.6	88	0.0
Pakistan	99	0.0	57	0.7	97	0.0
Philippines	90	3.3	26	28.2	79	5.0
Singapore	99	0.0	22-31	0.0	95-97	0.0
Thailand	94-98	1.9	23-46	22.1*	63-90	16.6
Turkey	93-97	0.7	57-88	1.8	92	2.1
Hawaii	100	0.0	62-81	6.5	97-99	0.7

MV% DCO#, microscopically verified, death certificate only% (highest value for the country selected), * unrepresentative

Table 3. Questions for Discussion with Establishment of an Asian (+ Pacific) Cancer Registry Network

Who Should be the Members? Voting/Associate? Criteria for Selection
What Should the Form of Organization be?
How Should the Steering Committee be Constituted?
Where Should the Office be Located?
Who Should be the Sponsors?
What Should the Activities be? Publications? Training Courses? Research Collaboration?
Should there be an Official Journal?

National networking is of obvious importance and in India, China, Korea, Japan and Thailand in particular, there are active responsible organizations. One question is how their expertise can best be made available elsewhere in Asia.

There are a number of obvious points which require discussion (see Table 3). The most basic perhaps is what countries are to be eligible. The APJCP has always adopted a non-political geographical definition based on the continent of Asia. The ENCR does the same for Europe and also includes countries of Central Asia. The size of Asia does present problems in terms of coordination, at least in terms of physically attending meetings. However, most business can now be conducted by email or telephone conferences. While it might be simpler in the first place to set up regional groupings, for example within East Asia, then clearly this would have to be reflected in the name chosen.

One question which has arisen in the past is whether membership should be on an individual registry or on a country basis? It appears likely that the IACR approach would most convenient to allow individual registries to maintain some independence, but views may differ. The two tier system of IACR (Voting and non-Voting) presumably has the merit of providing an incentive to improve but introduces a non-democratic element which the ENCR has

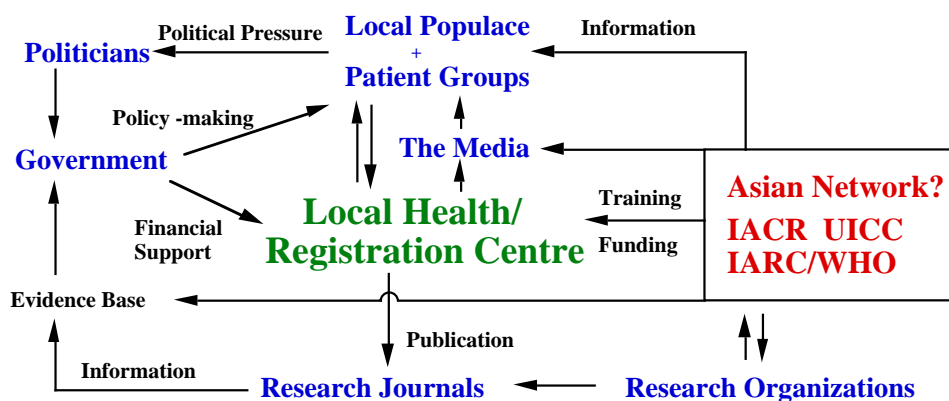


Figure 2. Concept of a Local Registration Center as a Major Research and Cancer Control Resource

apparently not adopted, although no precise definition of a population-based registry is given in their web-site.

The next question concerns what governance should be put in place and how should which officials be elected? Should there be a yearly meeting to allow elections to take place? Clearly there would have to be some form of office, if only virtual in the computer of the Secretary. Should the IARC be asked to provide this type of support. It is willing to provide some support for this initiative in collaboration with IACR. What form of sponsorship should be sought? - from governments within Asia, from WHO/IARC, from UICC or other NGOs, or from philanthropic organizations? Should there be membership fees? All of these are of essential importance with regard to viability. Should there be an official journal appointed, as is the case for IACR (in fact two, the APJCP and the European Journal of Cancer Prevention), and if so what should be its responsibilities? One possibility is that a regular literature update of papers of interest to the cancer registry community should be made, as recently published in the APJCP (Moore, for the APOCPC/UICC-ARO Cancer Registration Consortium, 2008).

Clearly it would be of advantage to conduct a survey of registries in Asia equivalent to that performed in Europe to determine the level of interest in a Network and what might be its responsibilities. Naturally, given the great variation in levels of cancer registration so far achieved, there will be differences in the priorities across countries. For example, should the main emphasis be on training or on collaborative research? For the sake of discussion we can assume that there will be consensus as to: 1) the need for accurate statistics for incidence and mortality, where conceivable; 2) provision of training where appropriate; 3) control of standards and issues of confidentiality; 4) sharing of data on an open basis. The actual activities will depend on the concept adopted of an Asian Registry Network. One argument is that the cancer registry is the major resource available to most countries in Asia that can be employed to conduct a large range of cancer control activities at the local level. Already very many of the analytical epidemiology and screening research findings being published in the region are due to the efforts of cancer registry affiliated staff. It

could well be envisaged that this be expanded (Moore and Tajima, 2006a - see Figure 2).

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. It is natural that the registry should play a role in conducting such surveys. A start has in fact been made in Khon Kaen registry in Thailand (Wiangnon et al., 2007).

To provide ammunition in support of more funding for cancer registries and any Asian Network, research needs to be conducted to actually explain differences observed in incidence rates between and within countries in a convincing way so that they offer practical application (Moore and Tajima, 2006b). The question of financial support may depend on the ability to generate better understanding, and this should be a stimulus to specific collaborative research. More stress might be given to cancer registries providing survival data, perhaps in active collaboration with cancer treatment centres (Evans et al., 2002). Research into clinical epidemiology is another high priority and such activity by cancer registries might stimulate pharmaceutical industry support (Kawahara, 2007a; 2007b).

In conclusion, whatever the particular aim, it could in many ways be beneficial for Asian cancer registries to have an international organization devoted to providing training and improving research opportunities, especially for those countries in the region which are now actively establishing more effective registry systems as part of comprehensive cancer control efforts. This should be a team effort.

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