



Happy New Year !



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Editorial

Sharon L. Whelan

At the end of the year 2000 the Association can look back on a year of accomplishments, with a very successful meeting in Khon Kaen, the publication of ICD-O-3 and the advent of a number of new population-based cancer registries – some covering populations for which there has never been any information on cancer patterns before. We can also look back on problems, notably the recurring difficulty with confidentiality which this year has confronted the UK registries.

Next year we look forward to the IACR meeting in Cuba. Please note that the dates originally posted for this meeting have been changed, and it will be held on 3-5 October 2001 in Havana.

Congratulations to the Cancer Registry of Slovenia, which celebrated 50 years of achievement in March this year (described below).

Very best wishes to all of you from the Secretariat in Lyon and the Executive Officers for a happy, successful and peaceful 2001.

REMEMBER.....

Check the Association website for news of activities, members.....

<http://www-dep.iarc.fr/iacr.htm>

Cancer Registry of Slovenia Celebrates its 50th Anniversary

Vera Pompe-Kirn

The Cancer Registry of Slovenia was founded in 1950 at the Institute of Oncology in Ljubljana, Slovenia. At that time, it was one of very few population-based registries in Europe. Its primary tasks were collecting and processing data on cancer incidence and survival for the population of Slovenia, which was then one of the republics of Yugoslavia. Data were also actively analysed and published from the very beginning. The first analysis of data was published in 1951 as an article in *Zdravstveni vestnik*, followed by regular annual reports ever since. The data from Slovenia have been reported in all seven volumes of *Cancer Incidence in Five Continents* as well as in many other international publications and studies.

On the occasion of the 50th anniversary of the Cancer Registry of Slovenia, a small celebration was held in March at the Institute of Oncology in Ljubljana. Visitors and guests from all major hospitals and health institutions in Slovenia were present, among them the founder and first head of the Registry Professor Dr Božena Ravnihar, the director of the institute of Oncology Professor Dr Zvonimir Rudolf and present head of the Registry Professor Dr Vera Pompe-Kirn. Special guests were Dr D.M. Parkin, Deputy Secretary of IACR, and head of the Department of

Descriptive Epidemiology at IARC and Professor D. Forman, head of the North and Yorkshire Cancer Registry, UK and now General Secretary of IACR. They contributed to the spirit of the meeting with lectures on the role of population-based cancer registries in monitoring the trends of cancer incidence and survival as well as in quality control of cancer treatment.

As the Cancer Registry of Slovenia has actively evolved through this half a century, keeping up to date in the fields of oncology, epidemiology, biostatistics and computer technology, there is no doubt that the next 50 years will be even more successful. Good luck!

Meetings

Khon Kaen

The annual scientific meeting of the IACR took place in Khon Kaen, Thailand on 8-10 November. The programme opened with special lectures on Cervix cancer prevention: new approaches (R. Sankaranarayanan) and Implementation of VIA/cryotherapy in a rural area of Thailand (Pisake Lumbiganon), and further papers in the session addressed the early detection and control of cervical cancer in low resource areas.

Mary McBride gave the keynote lecture on Epidemiology of power-frequency magnetic and electric fields and cancer, stressing the importance of the contribution to be made by cancer registries. Recent work, particularly using pooled analyses, should help to evaluate the relationship there may be with exposure.

Three important cancers in the Asia-Pacific region were the subject of separate sessions. Skin cancer and the challenge of control was introduced by Adele Green, with the experience of Queensland. Chien-Jen Chen presented the epidemiology and aetiology of liver cancer, with particular reference to the results of the mass

hepatitis B vaccination programme in Taiwan. Yu-Tang Gao looked at risk factors for lung cancer in female populations with relatively high incidence and low smoking prevalence.

Dee W. West developed the theme of genetic and environmental influences in cancer causation by comparing cancer incidence among Asians residing in Asia with those living in the US. The wealth of descriptive data now available internationally should continue to provide important clues to aetiology and control.

The topic of Mind and cancer, presented by Christoffer Johansen, included data from recent studies on stress, personality traits and depression and examined differences between case-control studies and cohort studies in psychosocial cancer research.

A special poster session describing cancer registration in 18 Asian countries was moderated by Vanchai Vatanasapt and Max Parkin. The posters will be printed as a special supplement in the Asian Pacific Journal of Cancer Prevention.

Nearly 280 participants enjoyed the scientific programme, the delicious Thai food, Thai music and traditional dance, karaoke and Loi Krathong. We thank all the local organisers who put so much hard work into producing such a superb meeting.

On behalf of the Association, the Secretariat would also like to thank the US Centers for Disease Control, the US National Cancer Institute and the Descriptive Epidemiology Unit (IARC) for their generous support. This contributed greatly to the success of the meeting.

Cuba

The meeting in Havana will be held on 3-5 October 2001. The themes are:

- Quality Control of Cancer Registry data

- Geographical and Time Variations in Cancer
- Incidence and Mortality
- Survival and Survivorship
- Evaluation of Cancer Control Programmes
- Prostate Cancer
- Oral and Larynx Cancer

Finland

The dates for the 2002 meeting in Tampere have been fixed for 25-27 June.

ICD-O-3

ICD-O-3 is now available at WHO at a price of US \$54. Orders can be made to bookorders@who.int.

As a non-governmental organization in official relations with WHO, the IACR is entitled to a discount of 40%. If you wish to take advantage of this discount you must order through the IACR Secretariat, with payment of US \$32.40 per copy by cheque in favour of the International Association of Cancer Registries, or by bank transfer to the Swiss Bank Corporation, WHO Branch, CH-1211 Geneva 27 – Account No. D3-102.338.1.

Regional Reports for 1998-1999

Africa

Henry Wabinga, Regional Representative for Africa

Population based cancer registration has been going on in Africa for a long time in just two centres, the Kampala Cancer Registry in Uganda founded in 1953 and the Bulawayo Cancer Registry of Zimbabwe founded in 1963. There are many other forms of cancer registration being carried out in specialized centres such as pathology, radiotherapy and oncology units, which have also provided clues to cancer patterns in the continent, e.g. liver cancer in Mozambique (Prates 1943)

and nasopharyngeal cancer in Kenya (Clifford 1961). However these hospital-based registries do not provide adequate data for epidemiological studies. In recent years there has been a determined attempt to establish population based registries in Africa to try and determine the burden of cancer particularly in this era of the AIDS epidemic and increased use of tobacco. Below is a summary of active population-based cancer registries in Africa.

Uganda

The Kampala Cancer Registry, established in 1953 and located in the Department of Pathology, Makerere University, Faculty of Medicine, was revamped in 1988 after a relative decline due to instability in Uganda. Currently the registry has a director, Dr Wabinga, a registrar and assistant registrar. The registry is partly funded by the International Agency for Research on Cancer (IARC). The personnel have been generously supported by UICC for workshops on cancer registration. The registry had its first data published in the first edition of Cancer Incidence in Five Continents (CI5). Data from the registry appeared again in Volume VII and data on childhood cancer were published in International Incidence of Childhood Cancer, Vol. II. Because of these achievements the registry has attracted other collaborators and is currently studying cancer survival in an African setting.

Zimbabwe

There are two population-based registries in Zimbabwe. The National Cancer Registry was established in 1985 and is located in the Department of Nursing Sciences Building, Parirenyatwa Hospital. The day-to-day running of the registry is the responsibility of the registrar, Mr Chokunonga, under the guidance of

the Medical Director. There are also a secretary and two other data collection officers. The registry produces annual reports and a number of articles (e.g. on HIV related cancer) have been published; results were included in volume VII of CI5.

The Cancer Registry of Bulawayo was founded in 1963 and functioned for 15 years. It is now recommencing activities

Algeria

There are several cancer registries functioning in Algeria; the Cancer Registry of Sétif headed by Dr Mokhtar Hamdi Cherif (former African Representative of IACR) has data published in Vol. VII of CI5. More recent registries include Alger, Batna, Constantine, Oran and Sidi-bel-Abbes. Several of these have submitted data for Volume VIII.

Gambia

A National Cancer Registry was established in the Gambia as part of the Gambia Hepatitis Intervention Study Project funded by IARC, MRC and the Gambian Government in 1986. The first results have been published in Br. J. Cancer. As for other cancer registries, there are many setbacks such as shortage of funds and lack of trained local manpower which compromise the running of the registry.

Mali

The Cancer Registry of Mali, based in Bamako, was started in 1986 under the leadership of Professor Bayo. It is located in the Department of Pathology of the National Institute of Research in Public Health. There is a Cancer Registrar who goes around the district of Bamako collecting data. The registration process itself is carried out using CanReg. Data from the registry are published in Vol. VII of CI5 and Vol. II of the International Incidence of Childhood Cancer.

Kenya

A new population based cancer registry was started in Eldoret in the Department of Pathology and Haematology, Moi University College of Health Science with Dr Nathan Buziba as its director. Dr Buziba followed the IARC course on Cancer Registration and Applications to Epidemiology in 1999. Recently the data of this registry were reviewed and although the incidence rates are low, they show interesting patterns. The registrar requires training.

South Africa

The Cancer registry in South Africa, directed by Dr Freddy Sitas, is still pathology based. The National Cancer Registry which is a cooperative venture between the Department of Health, the South African Institute for Medical Research and the Cancer Association of South Africa, collects data on pathologically diagnosed cases in all the 90 pathology laboratories in the country.

Currently the registry faces problems with quality of the data collected, particularly concerning race/population, as there are many cases of unknown race being recorded. This is due to the current stand by government on discrimination in the country.

Guinea

The registry in Conakry was started in 1990 and is doing well. First results are published in Int. J. Cancer 70: 39-45 (1997).

Malawi

The registry in Blantyre is now under the leadership of Dr Dzamalala Charles. Data covering the years 1994-1998 have been accepted for publication in Tropical Medicine and International Health.

Tanzania

A population-based registry was set up in 1998 in Moshi, and is equipped

with a computer and CanReg. The registry has a S. African trained nurse working as registrar.

Dar-es-Salaam has a pathology based cancer registry headed by Professor Kitinya, but continuous efforts to set up a population-based system have not worked to date.

Sudan

There is no population based registration in the country, although there are hospital (the Radiation and Isotopes Centre) and pathology (Sudan Cancer Registry) registries.

Mauritius

There is a population-based cancer registry directed by Dr Shyam Manraj. The manager, Mr Burhoo, took part in the 1999 IARC Course on Cancer Registration and Applications to Epidemiology. Regular reports are produced.

Egypt

There are efforts to set up population-based registries in Egypt as part of the Middle East Cancer Consortium, supported by the US National Cancer Institute.

Tunisia

There are now three registries which cover the whole country, and the aim is to achieve good-quality national population-based cancer registration.

Niger

The cancer registry has been running since 1992.

Burkina Faso

A population-based registry was started in Ouagadougou in 1997.

Nigeria

There are several cancer registries being set up in the country. The Ibadan Cancer Registry, initiated in 1960 and located in the Department of Pathology,

University College Hospital, is being re-activated.

Congo, Brazzaville

The population-based registry is located in the Department of Oncology of the main hospital. Results are available from 1996, with a break for the worst period of the civil war.

Namibia

The National Cancer Registry is run by the Cancer Society.

Swaziland

The pathology-based cancer registry expanded in 1988 to become population based with national coverage.

Training

The Mali Cancer Registry hosted a course for Cancer Registrars from francophone West Africa in March 2000. It was funded by the Association pour la Recherche sur le Cancer (ARC) in France. Thirteen students from Burkina Faso, Congo (Brazzaville), Côte d'Ivoire, Guinea, Mali and Niger took part. The faculty consisted of Dr Antoine Buemi (Haut Rhin, France), Mr Eric Lucas and Ms Sharon Whelan (IARC).

IARC and MRC/ SAIMR/ CANSA/ WITS Cancer Epidemiology Research are organising a course on the practical application of the principles and methods of cancer epidemiology and control in Johannesburg, S. Africa in February 2001, and IARC is organising a course for cancer registrars in Nigeria at the same period. A further course for cancer registrars will be held in Nairobi later in 2001.

North America

Canada and Caribbean

Eric Holowaty, Regional Representative for North America

Health care reform continues to shape cancer care in Canada. Canada's lead agencies in cancer control, namely the National Cancer Institute of Canada (NCIC), the Canadian Cancer Society (CCS), Health Canada and the Canadian Association of Provincial Cancer Agencies, have formed a partnership to plan a national cancer control strategy. National priorities for cancer control are being identified, with clear goals, targets, actions, roles and responsibilities. Working groups have been established for prevention, screening, diagnosis, treatment, supportive care, palliative care and paediatric care, as well as cross-cutting working groups for research, surveillance, human resources planning and genetics. Each of these working groups has formulated recommendations that are available for viewing at the CSCC web site, www.hc-sc.gc.ca/hppb/csc/csc.html. In February 2001, a stakeholder conference will be held in Ottawa, in order to reach agreement on these national priorities, as well as identify the necessary infrastructure, mechanisms to link research to policy and practice, and mechanisms for addressing emerging issues and maintaining effective partnerships.

The Canadian Coalition on Cancer Surveillance (CCOCS) (www.hc-sc.gc.ca/hpb/lcdc/bc/ccocs/index.html) continues to play an important role in the evolution of cancer registries into comprehensive cancer surveillance systems. National consensus has been reached on an expanded set of standardized data elements, including more detailed information about

treatment and stage. A systematic review of legislation, regulations, policies and guidelines in relation to cancer surveillance has been completed and can be viewed on the Coalition's web site. A public communications strategy is now being planned, to better inform legislators and the general public about their role of cancer surveillance and research in cancer control, and safeguards taken to protect confidentiality of patient information. Health Canada has now taken the lead in developing a nationwide cancer progress report, with a planned release in the spring of 2002. Finally, the Coalition is undertaking a survey of all radiotherapy treatment facilities in Canada in order to establish a standardized baseline of radiotherapy information.

National cancer statistics continue to be generated and disseminated on an annual basis, largely as a result of the national patient-based cancer registry, called the Canadian Cancer Registry, which is administered by Statistics Canada. Each April, about 30,000 copies of the publication Canadian Cancer Statistics are released (can be viewed at www.cancer.ca). The data are also available in an interactive electronic format, through Health Canada's Disease Surveillance On-line web page (www.hc-sc.gc.ca/hpb/lcdc/webmap) or through the North American Association of Central Cancer Registries web site (www.naacr.org). New vehicles for disseminating data are also being considered, including the SEER*Stat System from the U.S. National Cancer Institute, and the EURO-CIM System from the European Network of Cancer Registries.

A national project has recently been initiated for describing and explaining cancer occurrence patterns for young adults in Canada, particularly in terms of regional differences and temporal trends. Other recent national initiatives include the development of a standard

protocol for the estimation of survival, and an important quality assurance initiative, involving four provinces, in comparing various strategies for estimating the completeness of case ascertainment. Through the CCR's Data Quality Committee, an initiative is being mounted to better describe the methods of registration, and data definitions actually employed, in all of the provincial and territorial cancer registries.

There are now 10 provincial and 3 territorial registries in Canada. The newest, in the Nunavut Northern Territory, covers a small population of only 27,000, over a vast territory of 2 million square kilometres. It is being undertaken as a prelude to development of a new data dictionary incorporating the core data elements defined by CCOCS.

Concerning the English-speaking Caribbean Region, the Pan American Health Organization, in cooperation with national health ministries, continues to develop and implement an integrated approach to cancer control. With expertise available from PAHO and WHO, and coordinated by Dr Beverley Barnett, nations are identifying targets based on the current economic, and the emerging epidemiological, situation in each country.

The situation regarding cancer registries in the Caribbean has not changed significantly from last year. Several countries (Bermuda, Granada, Trinidad and Tobago) currently operate central cancer registries, using the IARC software system CanReg. Cuba and Puerto Rico also operate central registries. Of the 24 countries constituting the English-speaking Caribbean, the majority are interested in implementing cancer registries in accordance with PAHO's recent published guidelines on The Establishment and Maintenance of Cancer Registries in Caribbean Countries. With plans to convene IACR 2001 in Cuba, it will be appropriate for

the IACR to host a special symposium or workshop on the Operation and Use of Cancer Registries in the Caribbean Region, perhaps in partnership with the PAHO/WHO Office of the Caribbean Region.

United States of America

Brenda Edwards, Regional Representative for North America

The USA national cancer registration system is structured and funded by interdependent programs operating within the federal, state and private sectors. These organizations continue to meet semi-annually under the aegis of the National Coordinating Council for Cancer Surveillance (NCCCS). The mission of the NCCCS is "to coordinate cancer surveillance activities within the USA through communication and collaboration among major national cancer organizations, ensuring that the needs of cancer patients and communities in which they live are fully served; that scarce resources are maximally used; and that the burden of cancer in the USA is accurately measured and ultimately reduced." Current participants include the American Cancer Society (ACS), the Commission on Cancer of the American College of Surgeons (COC-ACoS), the North American Association of Central Cancer Registries (NAACCR), the National Cancer Registrars Association (NCRA), the Department of Defense (DOD), the National Cancer Institute (NCI), and the Centers for Disease Control and Prevention (CDC), including the National Center for Health Statistics. Substantial growth in the collective and independent infrastructure and programmatic direction for cancer surveillance in the USA has occurred during the past year. Selected activities are highlighted in this report.

The North American Association of Central Cancer Registries (NAACCR) is the umbrella organization of professionals involved with population-based registries in the USA and Canada. During 1999-2000, substantial funding from the CDC and the NCI has provided resources that helped create and sustain an office of the Executive Director and associated staff to facilitate the committee-based work provided by NAACCR members.

- In April 2000, Cancer In North America (CINA) was released, providing incidence data from 62 of 68 USA and Canadian registries. Aggregate USA incidence rates for 1993-1997 were based on data from registries meeting established standards; the pooled data came from registries representing almost half of the total USA population. A recent E-Toolkit workshop was held to assist participating members in the 2001 electronic submission of data using standard formats and application of editing programs. Other committees have been working toward revised measures of assessing completeness of reporting, quality of data items, and improved reporting of socio-demographic information. The Registry Operations Committee is developing material on procedure guidelines for cancer registries; a report was released by the Data Use and Confidentiality Subcommittee and they are preparing to release subsequent material focused on best practices pertinent to information technology.
- The Education Committee is working with other committee chairs to assess and meet the educational requirements required to effectively disseminate technical information and promote improved data reporting. The use of web-based technology for training and information dissemination is a more

recent direction.

In early 2000, the National Cancer Institute (NCI) and the Centers for Disease Control and Prevention (CDC) signed a memorandum of understanding (MOU) to codify the importance of continued coordination of cancer surveillance among USA federal agencies. The MOU covers a broad range of cancer surveillance activities, much of which builds upon population-based cancer registries. Notable activities of their respective programs include the following:

- The NCI Surveillance, Epidemiology and End Results (SEER) Program launched an expansion to include additional high quality registries within their programme that currently covers 14% of the USA population. The expansion targets coverage of registries with large non-Mexican-American populations, rural African-Americans, and American Indians, areas with high poverty, and states with high cancer mortality.
- The SEER Program continues to develop and improve systems for statistical analyses of data (SEER*STAT), web-based inquiry and analysis applications, has launched long-term development of information systems for management of centralized data management, and continues to utilize linkage with other USA health information data systems to enhance cancer surveillance within the USA.
- Implementation of ICD-O-3 for coding USA cancer cases begins in 2001 and work is in progress to facilitate implementation. A workgroup has been established under the aegis of the NAACCR to assure coordination and use by registrars and hospital-based information technology application systems.
- The CDC National Program of Cancer Registries (NPCR) began a second 5-year period of funding to

enhance cancer reporting in 45 state programs and to plan for cancer registries in 4 other areas. Based on the most recent data (1997) reported by these registries, 29 of 38 NPCR registries met NAACCR certification, which is a substantial improvement over previous years. The NPCR funding has supported data collection from 1995 forward. Specific NPCR projects in progress involve the management of cancer control inquiries, uses of electronic data exchange protocols for cancer registry programs, and special studies of prostate cancer, case follow-up, linkages with other registries and data systems, and geographic information systems.

- The NPCR new initiative, Cancer Surveillance System (CSS), was piloted during 2000 with 30 registries providing data to the CDC. This system was developed to receive, assess, enhance, aggregate, and disseminate data from the NPCR states. The initial focus will be on providing feedback to registries to improve the quality and usefulness of the data. Future plans involve work with partners to develop a coordinated nationwide approach to cancer surveillance and control.

The Commission on Cancer within the USA American College of Surgeons is the accrediting body for hospital-based cancer care in the USA. During the past year they have re-organized to address improved registry-based cancer reporting systems for clinical cancer care. In addition, they are revising their data collecting and coding system requirements (ROADS) for implementation in 2003. Also, they have facilitated a NCCCS-initiated project, the Collaborative Staging Group, to develop agreement on the collection and reporting of stage of cancer by the respective population-based and clinic-based organizations. Implementation for 2002 cases should

bring substantial improvement in cancer reporting within the USA.

Reporting of USA cancer data is a major responsibility of many federal and private organizations. As part of a coordinated effort, the NCI, ACS, CDC, and now the NAACCR are working to prepare their annual report to the nation on the USA cancer burden as measured by incidence, mortality, risk, and patterns of care.

Asia

Divina B. Esteban,
Regional Representative for Asia

India

The Madras Metropolitan Tumour Registry (MMTR) carried out a multicentric study to estimate completeness of cancer registration in Chennai and the results indicate that no cancer cases or deaths were missed by the registry. Information on all deaths occurring in Chennai, irrespective of cause, is collected in the MMTR. This is being recommended for implementation in all population-based cancer registries in India.

The XVth Asia-Pacific Cancer Conference (APCC) with the theme 'Today's Research, Tomorrow's Treatment' was hosted by the Cancer Institute (WIA), Chennai, in December 1999 with Dr V. Shanta as the President of the Asia and Pacific Federation of Organizations for Cancer Research and Control (APFOCC) and APCC. Dr C.K. Gajalakshmi and Dr S. Tominaga, Director Aichi Medical Centre, Nagoya, Japan organized a pre-congress workshop on 'Cancer Epidemiology and Prevention'.

One-day training workshops for birth and death clerks and for burial ground Caretaker and Sanitary Inspector of the Vital Statistics Department of the Corporation of Chennai were organized

in March and July 1999 to improve the quality of death data registered.

A training programme was organized for Medical Officers in Tamil Nadu on "Cancer Awareness and Early Detection" under WHO Biennium 1998-1999 on 30 September - 1 October 1999.

A population-based cancer survival study (Phase II) on common cancers in MMTR in collaboration with IARC is in progress.

The Bombay Cancer Registry assists in the follow-up of cohort study of tobacco-related cancer.

The Trivandrum Cancer Registry continues to provide valuable information related to the various research projects in the Kerala population, particularly to the oral cancer screening trial and the tobacco-related cohort study (Biennial report 1998-1999).

Iran, Islamic Republic of

There are three population-based cancer registries in Iran: the Mazanderan registry, Fars registry and Tehran.

Kyrgyzstan

The Kyrgyz Research Institute of Oncology and Radiology is currently organizing a pilot project 'Integral Network of Regional Cancer Registries in Kyrgyzstan' with regional population-based cancer registries in six provinces (oblasts) of Kyrgyzstan. The establishment of the network is aimed to ensure an optimum planning of oncology service activities from data collection, processing and utilization of data at the regional, national and international levels. Oosh Oblast oncological clinic has started preparatory work for the establishment of a population-based cancer registry.

Pakistan

The Government of Sindh established the Karachi Cancer Registry

(KCR) in January 1995 in collaboration with the Unit of Descriptive Epidemiology, IARC. The registry has completed five years' data collection. Analysis of the first three years of registration has been completed. The data were published early this year with the help of IARC. The registry participates in researches on lung cancer and tobacco-related cancers as well as survival studies on breast cancer, lymphomas and leukaemias.

The Pakistan Association of Cancer Registries, started in November 1999, has worked with the Cancer Society of Pakistan and the Karachi Cancer Registry in the urban regions of Sindh to promote cancer registration and awareness in cancer control.

Bahrain

The Bahrain Cancer Registry hosted a regional course for cancer registry personnel in November 1999. 32 participants included the governmental and private sectors in Bahrain, Oman, Kuwait, Qatar, Saudi Arabia, and the United Arab Emirates. This was organized by Dr Jamal Al Sayyad, in collaboration with IARC and supported by WHO, EMRO. Faculty were Andy Cooke and Sharon Whelan (IARC).

Oman

Since 1996, the Oman National Cancer Registry functions as a population-based cancer registry, covering the sultanate of Oman. Technical support to improve coverage and data management is provided by IARC.

China

Shanghai Cancer Registry is the oldest population-based registry in China. Among recent publications are: Cancer Incidence Trends in Urban Shanghai, 1972-1994: An Update; Colorectal Cancer Incidence Trends by Subsite in Urban Shanghai, 1972-1994;

Rising Incidence of Prostate Cancer in Shanghai, China.

The Tianjin registry hosted the Chinese Cancer Registry Meeting in 1999.

The Cancer Registry of Qidong is collaborating in studies of survival and follow-up of a cohort of subjects tested for HbsAg.

Other cancer registries in China include those in Beijing, Harbin, Chongqing, Wuhan and Guanzhou. To date 11 registries from China have submitted data for Vol. VIII of *Cancer Incidence in Five Continents*.

In the Ninth Five-Year Project of China on Cancer Registration methods of monitoring cancer incidence, mortality and risk factors nationwide were studied. A total of 14 areas participated in this project.

A new approach in estimating the national cancer mortality rates has been explored, making use of data from the national surveillance of cancer mortality in 1973-1974 and Tianjin Cancer Registry data for 1993-1997.

Survival studies for common cancers have been carried out (Tianjin, Shanghai, Qidong and Changle)

Publications:

The Handbook of Cancer Registration in China, third edition (in press)

Cancer Incidence and Mortality in 11 Areas of China (in press)

Cancer Risk Factors in China, Vol. 1 (in press)

Taiwan

The Taiwan Cancer Registry has completed 1993-1997 data. Analyses and observed trends are published in annual reports or in medical journals. The registry provides a database regarding cancer for various research efforts.

Japan

There are 34 population-based cancer registries in Japan as of July 2000, covering a total of 47 prefectures.

The Japanese Association of Cancer Registries (JACR) held its 9th meeting in Yokohama in September 2000.

A symposium on 'Protection of privacy in the cancer registry and epidemiological studies' was held in Tokyo, in March 2000; a training course on population-based cancer registration was held in Tokyo in February 2000.

Annual estimates of cancer incidence in Japan are published, the latest for the year 1995.

Indonesia

There are 12 pathology laboratories collecting data on cancer but there is only one population-based cancer registry, that of Semarang. The registries have been involved in various epidemiological studies on cancer.

Philippines

There are currently four population-based cancer registries in the Philippines.

The DOH-Rizal Cancer Registry is carrying out long-term follow-up, in collaboration with IARC, of a breast cancer screening project in the Philippines, ensuring careful staging and follow-up of breast cancer cases. It also collaborates with IARC in survival studies of the more common cancers. Data from a first analysis of survival were published in 'Survival from cancer in developing countries' (Sankaranarayanan *et al*, IARC Scientific Publications No. 145)

The PCS-Manila Cancer Registry plays an active role in the follow-up of the breast cancer screening project. The registry also undertook a ten-year survival study on the more common cancers in the Philippines.

RAFI-EJ Aboitiz Cebu Cancer Registry was established in 1987. Data for 1983-1992 have been completed and are now being analysed, with technical assistance from IARC.

Davao Cancer Registry was started in 1991 but was temporarily

discontinued due to logistic problems. In 1998, with support from the Andres Soriano Cancer Foundation, Davao Doctors Medical Centre, and the PCS-Davao Division, it was re-started. Data for 1993-1997 have been completed and are still being analysed.

Viet Nam

There are two population-based cancer registries in Vietnam, Ho Chi Minh City and Hanoi Cancer Registry, both supported by IARC. The results from the Ho Chi Minh City registry were published, as was a separate analysis of childhood cancer. An estimate of cancer incidence in the two cities for the period of 1995-1996 has been made based on the data of the two registries.

Both registries are involved in case-control studies of soft tissue sarcoma and NHL in relation to exposure to herbicides in Viet Nam. The Hanoi registry is also involved in the case control study of stomach cancer in South-East Asia.

Greater Mekong

Vanchai Vatanasapt, Regional Representative for Asia

Thailand

Cancer in Thailand Vol. II (1992-1994), S. Deerasamee *et al.*, was published as IARC Technical Report No. 34 (Lyon, 1999). The book presents data on cancer incidence from five population-based cancer registries (Bangkok, Chiang Mai, Lampang, Khon Kaen and Songkhla) in different regions of Thailand.

Cambodia

The Ministry of Health plans to set up a population-based cancer registry for the city of Phnom Penh.

Laos

A cancer registry was established in 1999, covering the population of Vientiane.

Europe

Tiiu Aareleid and Leo Schouten, Regional Representatives for Europe

Northern Europe

In Estonia, the legislative confidentiality problems for cancer registration are currently being solved; a new Decree of the Minister of Social Affairs on cancer registration and the Estonian Cancer Registry is being prepared and will come into force probably by the end of 2000; the Decree will include regulations on personal data protection and confidentiality, as well as detailed rules for data release. The Registry belongs to the Ministry of Social Affairs and is administered by the Estonian Cancer Centre, Tallinn. Funding is provided from the state budget through the Ministry. Updating of the computer software and hardware is an urgent necessity (the present framework was established in 1994 but does not meet the Registry's needs on data processing and data protection today). However, the current funding does not cover the costs of this reorganisation and additional sources are being sought. Regular annual reports on cancer incidence have been published since 1999. The second issue covered the year 1997 and included time trends in incidence for 1968-1997.

At the Finnish Cancer Registry, the various activities related to cancer registration and epidemiological cancer research have continued smoothly, without any major changes or problems. The annual statistics for the years 1996 and 1997 were published in one volume at the beginning of the year 2000. The ICD-O has finally been adopted for coding of primary site and histology.

Research activities have continued both in the Registry itself and in collaboration with researchers in various institutes in Finland and abroad. Collaboration between the five Nordic cancer registries (Denmark, Finland, Iceland, Norway and Sweden) continues within the Association of the Nordic Cancer Registries (ANCR). Recently, analytical epidemiological research has been conducted, e.g. for visual impairment, use of hormone replacement therapy in menopause, silicon breast implants and various infectious agents (using material from serum banks). The large Finnish Twin Registry has been utilised in several studies. The number of studies related to genetic epidemiology is increasing.

A special feature of the Finnish Cancer Registry is research with the aim of evaluating the two nationwide screening programmes (for cancers of the uterine cervix and breast) and conducting a randomised screening trial for prostate cancer (based on serum PSA determination) as a part of the large European screening trial. Biostatistical research is also an important area of research at the Finnish Registry. Prediction of future incidence and mortality trends and the methodology of survival analysis have been the main targets.

The National Cancer Registry of Ireland published a report on 1996 data in October 1999 and on 1997 data in October 2000. The report next year will cover the five years since the establishment of the Registry. Hopefully, it will be the last conventional report and will be followed by shorter, more focussed reports on specific topics. With the Northern Ireland Cancer Registry, the first all-Ireland report on cancer incidence and mortality is in progress, to be published in February 2001. The shortage of cancer epidemiologists in Ireland is being addressed by providing two three-year all-Ireland fellowships in cancer epidemiology, based partly at the

registries and partly at the National Cancer Institute in Washington, DC. The Registry's research programme is now building up (details on the website at www.ncrirl.org), although nothing has been actually published as yet and partners for collaborative international activities are being sought for. The Registry has to encounter legal problems with regard to right to collect data without patient consent. Although it presents a very serious matter to the registry, the authorities have not regarded it with due attention so far.

In the Latvian Cancer Registry, a monograph on cancer mortality trends is in preparation. The annual incidence statistics are published regularly, the fourth issue covering 1997–1998. The Registry staff often present information about cancer occurrence at seminars and meetings organised by GPs, oncologists, gynaecologists etc. Currently, the Registry is involved in the study on familial cancer, supported by the Scientific Board of the Latvian Academy of Sciences.

The Lithuanian Cancer Registry has been operating as a separate department of the Lithuanian Oncology Centre since 1990. Regular annual reports on cancer incidence have been published (in Lithuanian) since 1992. Registration is based on compulsory reporting of new cancer cases. The Registry receives about 14,000 notifications per year. Death certificates are traced regularly at the Department of Statistics. The IACR recommendations are followed, to meet the international standards on cancer registration.

The administrative reform which started in Lithuania in 1998, foresees new administrative units. The health care system in Lithuania is undertaking the final changes towards an insurance-based system. These changes require from the Registry that new connections with the primary and secondary health care centres, university hospitals and

GPs be established. It is hoped that the completeness and quality of cancer registration did not deteriorate during the recent transition. The Registry will continue passive follow-up of the cancer patients and survival of cancer patients in Lithuania in 1990-1995 will be analysed. The publication of incidence and mortality data for the period 1993-1997 is planned.

The Norwegian Cancer Registry has 80 employees, 15 medical doctors and 5 statisticians. The total yearly budget is US\$4 million. All new cancer cases have been coded according to ICD-O-2 since 1993. The registration of all new cases is complete to the end of 1998 and results will be published early next year. The Cancer Registry takes an active part in the associations of ANCR, ENCR and IACR. The registry is involved in many research projects as described in the yearly reports. Many of the projects are based on international collaboration with institutes and organisations.

The Swedish Cancer Registry has been coding all new cancer cases according to ICD-O-2 since 1993. The registration of all new cases is completed to the end of 1998 and was published in June 2000. The National Board of Health and Welfare publish the statistics on the Internet (<http://www.sos.se>) since year 2000.

Two new Acts were passed in 1998 - the Health Data Registers Act (1998:543) and the Personal Data Act (1998:204). These Acts will be fully implemented in October 2001 and will affect the Swedish Cancer Registry, hopefully in a positive way.

Issues of privacy, confidentiality and data protection remain a major concern in Scotland and the rest of the UK. Recent confidentiality guidelines, issued by the General Medical Council (which licences medical practitioners in the UK), have been interpreted as posing a serious threat to public health

surveillance systems in the UK (see also the report from the United Kingdom).

The Scottish Cancer Registry published a report on trends in cancer survival for the years 1971-1995. The report can be retrieved from the internet.

In parallel to the development of a Scottish Cancer Plan by the Scottish Executive Health Department, the Scottish Cancer Intelligence Unit are coordinating a "Cancer Scenarios" project with the aim of projecting cancer incidence and mortality, and, with the assistance of clinicians, assessing the scope for interventions designed to reduce the future burden and consequences of cancer.

The British Oncological Association organises a conference in Edinburgh (11-14 March 2001) entitled "European Conference on Cancer Strategies & Outcomes". The conference is mainly concerned with the organisation and delivery of cancer services, and outcomes for cancer patients. The EURO CARE study features prominently in the programme (see <http://www.euro-cancer.org>).

The United Kingdom Association of Cancer Registries unites registries from England, Wales, Scotland, Northern Ireland and the Republic of Ireland. UKACR has been involved in a wide variety of initiatives during 2000 aimed at improving the quality and comparability of cancer registration in the UK. This has included organising training for registry personnel and agreeing and implementing standard procedures for the coding and classification of tumours and procedures. A major initiative aimed at improving the timeliness of the national cancer registration data was undertaken during 2000 funded by the Department of Health. By the end of September 2000 all registries in England and Wales had submitted incidence data for 1997 to the Office for National Statistics. This represents a considerable achievement by the registries and means that timely

data are available to monitor incidence and survival trends at national level.

During September 2000 the NHS Cancer Plan was published. It outlined an ambitious programme for improving cancer services in England and included a strong statement of support for the role of cancer registries and a commitment to securing the future of registries.

Unfortunately, just before the Cancer Plan was published the General Medical Council, the body responsible for regulating medical practice, issued new guidance on confidentiality. This guidance stated that information could only be transferred to cancer registries if individual patient consent was obtained. Currently all UK registries operate on the basis of implicit consent. For reasons with which you will all be familiar the UK registries believe that it is impossible to maintain population coverage if individual consent is required and have vigorously lobbied for this guidance to be overturned and for the Department of Health to honour their commitment to cancer registries by enacting appropriate legislation to make cancer a statutorily notifiable disease. There has so far been no official response from the Department of Health and some hospitals throughout the UK have already stopped supplying data to their regional registry. This represents a crisis for cancer registration in the UK and indeed for other public health surveillance systems and for the many research projects which use registry data. Unless rapid action is taken to remedy the situation the UK cancer registration scheme which has been built up over the last 40 or more years will be irretrievably damaged. This threat has regrettably overshadowed the real advances in the quality and timeliness of cancer registration in the UK which have been achieved over the last few years. Among others, Hans Storm has written on behalf of IACR, and Max Parkin from

IARC, in support of the UK cancer registries.

The Finnish, Estonian, Latvian and Lithuanian cancer registries and research institutes participated in the Cohort Study of the Chernobyl Cleanup Workers in collaboration with the National Cancer Institute, USA. The project's objective is to reconstruct radiation doses, and it has reached the final stage. The international workshop on cancer in the NIS populations after the Chernobyl disaster was held in Tallinn, at the Institute of Experimental and Clinical Medicine, 15–20 May 2000, with participants from Belarus, Estonia, Latvia, Lithuania, the Ukraine, Russia and the IARC. In the framework of the Workshop, a training course on survival analysis was set up (faculty: T. Hakulinen, T. Luostarinen and B. Söderman from the Finnish Cancer Registry).

Information for this report was received from: L. Teppo, H. Comber, A. Strengrevics, J. Kurtinaitis, A. Andersen, L. Barlow, D. Brewster and M. Roche.

Eastern Europe

In Armenia, no population-based cancer registry has been established. A hospital-based registry, operating at the Cancer Research Centre, Yerevan, reports financial and staff problems.

In the Bulgarian National Cancer Registry, a new information system and software "Oncology 2000" have been introduced; the software meets the requirements of the National Cancer Registry and of the 13 regional cancer centres of Bulgaria. In December 1999, a training course was set up, to introduce the new program. Bulgaria hosted the ENCR course on cancer registration in January 2000. The annual incidence report for 1997 is in press. The datafile has been provided for the CI5 Vol. VIII, and is being prepared for

the new version of EUROCIM and ACCIS. The Registry's staff has participated in national and international conferences.

In the Czech National Cancer Registry, the situation has stabilized. The Registry is a part of the National Health Information System. Data are collected and corrected in the framework of the lower territorial units. The Institute of Health Information and Statistics of the Czech Republic (IHIS) fund the Registry's central unit. The Ministry of Health (MH) assigns annual contributions to cover the operating costs of the Registry, except for the central unit. The Council, involving experts, regional administrators and specialists working at the MH and IHIS, provides the conceptual and methodical steering of the Registry.

Since 2000, a new notification form has been introduced. It includes the data, supplemented according to the requirements of the Oncological Medical Society; some issues which previously had not been uniquely interpreted by physicians, were reformulated. The implementation of the new notification form was preceded by the distribution of new instruction manuals and the regional administrators organized instruction courses for physicians. The highly qualified Registry personnel provided teaching on applying the new software. The Registry had adjusted itself to changes in the territorial structure of the country. The fifth revision of the TNM classification has been translated and published; it will take effect from 1.1.2001. The incidence data for 1997 are in print. Every year, one day of the Days of Oncology in Brno deals with the problems of the Registry. Several publications, based on the data from the Registry, have been issued. The Registry's central unit has provided information to physicians, newspapers and pharmaceutical companies. Problems reported include legislative anchoring of the Registry in accordance

with the new laws, and receiving sufficient funding to cover the activities of the territorial units.

The Georgian Cancer Registry received consultation from the ENCR (Dr R. Sankila) in 2000. Future developments in the health information sector were discussed and potential national collaborators identified. The Ministry of Health of the Georgian SSR founded the Registry in 1950 for administrative purposes and for descriptive epidemiology. Due to the political instability in the last years of Georgia being a part of the Soviet Union (1989–1991), and the civil war in the early years of the independence, the cancer registration activities were practically discontinued, and the data collected in 1950–1989 got lost during the turmoil in the early 1990s. Since 1992, partial data are available in the Georgian National Cancer Registry; the coverage and completeness of the data are unknown, however. The lack of proper population data makes it impossible to produce age-standardised rates. No separate reporting systems from pathological laboratories have been established and no quality checks for data have been used. The Registry is situated at the National Cancer Centre in Tbilisi and is closely linked to the hospital archives. The hardware is common with the Centre, and it fulfils the minimum criteria for the registration needs. Currently, remarkable interest in and capacity for cancer registration in Georgia can be observed. Dr Sankila has proposed starting a proper regional registration system in the Tbilisi area. After an initiation period (possibly several years), the system should be expanded gradually, to cover the whole country.

Cancer registration has been in legislative deadlock for a long time in Hungary. It was "temporarily" halted by the Act on Personal Data Protection in 1992. A new Act which includes a separate paragraph on the National

Cancer Registry, was passed by Parliament in 1997. Thereafter, the fight went on for two more years until the Decree of the Minister of Health on organisation of data collection and handling was issued. Basically, registration has been running again since 1.8.1999. The main data sources are the hospitals and outpatient clinics. Among the problems highlighted, there is concern about the quality of the data.

The Territorial Cancer Registry of Bihor County, Romania has been functioning since 1981. The county is situated in the North-Western part of the country. Reporting on cancer cases is compulsory, based on the Health Minister's Act No 219/1980. There have been no breaks in the registration process but its quality varies over time. Current quality control methods are relatively inefficient. The financial sources are not clearly established; at present, funding is received from the Oradea University Oncological Centre through the County Clinical Hospital. The Registry publishes the annual journal "Territorial Cancer Registry, Bihor County", presenting the basic data on cancer incidence in the county. The Journal includes results from epidemiological studies. The Registry data are actively used for research and teaching (including students' diploma papers). The priorities of the Registry include introducing ICD-O, establishing a reliable source of finance and closer communication with other cancer registries in the country (particularly, with the National Cancer Registry) and confidentiality assurance. A change in legislation, regarding cancer patients' management, reporting on cancer cases and functioning of the cancer registries, is a necessity.

In the Russian Federation, the territorial Cancer Registry of St. Petersburg is responsible for elaborating a model for cancer registration in the North-Western part of the country. The Registry was founded in 1993 and is the

first population-based cancer registry in the Russian Federation. At present, regional registries are being set up in Murmansk, Archangelsk and Karelia. A workshop on cancer registration activities is planned for autumn 2001. The Registry has already published the annual incidence report (in Russian) for 1999. Problems reported include those related to insufficient funding, but also the fact that the Registry staff have to work on tasks other than cancer registration.

The National Cancer Registry of Slovakia has finally become independent. The Registry is located in the National Institute of Oncology in Bratislava and has its own budget, financed by the Ministry of Health. The annual reports are published regularly; the 1997 issue is in press. Due to the changes in the administrative division of the country since 1997 (8 counties instead of the former 4, and 79 districts instead of 43) and the lack of the relevant population data, the calculating of incidence rates was somewhat delayed. In early 2000, the Ministry of Health issued the innovated regulation on the cancer registration. The new notification form has been also introduced; however, the changes are insignificant compared to the previous form.

The data collection in the framework of the EURO CARE High Resolution Studies is being carried out. The Registry's staff actively participates in research: in 2000, seven papers were published in local and international journals. Numerous analyses performed are related to the National Program of Health Promotion. Considerable progress was the publication of two textbooks on epidemiology for medical faculties and for the postgraduate training of physicians.

The Ukrainian Cancer Registry (UCR) completed its part of the European Commission INCO-Copernicus programme and delivered

the reports. Participation in the project contributes to the furnishing of the oblast cancer registries with proper computers, conducting workshops and developing relevant software. The last "blank spot" on the map of the UCR has been filled up: the unified information technology of UCR has been introduced in the Zaporozhskaya oblast. The cancer registry of the Poltavskaya oblast resumed its activities after two years of work standstill. It means that the Ukraine has all the prerequisites for obtaining a complete overview of cancer incidence for 2000, with all the new cases personalised in the centralised database of the UCR.

The Annual Bulletin of Cancer Statistics in the Ukraine for 1998 was published in October 2000. Incidence statistics were provided for 21 oblasts and Kiev City (there were no data in 1998 for the Kirovogradskaya, Zaporozhskaya, Poltavskaya oblasts, the Crimea Autonomous Republic and Sevastopol City). The 5-year survival rates for ten main cancer sites were provided on the basis of the pooled data of eight oblasts which have incident cases registered in 1994 and earlier. The UCR has planned to provide data for CI5 Vol. VIII. In November 1999, a workshop of the oblast registries was organized. The issues of data quality, elimination of duplicates and conducting in-time follow-up of patients were discussed. The Registry is facing problems in receiving complete and reliable data from the Crimea Autonomous Republic and Sevastopol City, because of problems with staff and computers. Insufficient manning of the oblast registries and lack of finance render it difficult to conduct regular training and to print annual statistics and scientific publications.

The cancer registries from Denmark, Estonia, Finland, Iceland, Sweden (South Sweden), Slovakia, Slovenia, Poland (Cracow and Warsaw) and the UK (Scotland, England) participated in

the EURO CARE-2 project; the special issue of the European Cancer Journal on survival in childhood cancer is in press. Norway and the Czech Republic joined the EURO CARE-3 and EUROPREVAL projects in 2000. There are some new participants from the UK registries (Trent, Wales, Childhood Cancer Research Group).

Information received from: Dr A.K. Nersesyan, Dr S. Danon, Dr M. Jechova, Dr Z. Peter, Dr V. Pacurar, Professor V. Merabishvili, Professor I. Plesko, Dr L. Goulak, Dr R. Sankila, Ms. E. Taussig

Southern Europe

In Albania, the National Cancer Registry covers about 80% of the population. The Registry is run by the Institute of Oncology, Tirana, and its data are used mainly for descriptive epidemiological studies. Problems include lack of experience and relevant literature on cancer registration techniques, but also insufficient computer support for data processing.

Last year, the staff of the Cancer Registry of Crete (CRC), Greece had three publications in medical journals reporting the incidence of cancer on Crete for 1994. Interested readers can ask for copies of these papers by e-mail using the address: socmed@edu.uch.gr The director of CRC was asked by the Central Council of Health (Oncology Committee) to submit a paper with proposals for the re-organisation of Cancer Registration in Greece. This was the second time that such a paper was invited. In both occasions there were no further developments. There are plans for CRC to have a one-day conference on Crete, on Cancer Epidemiology and Cancer Registration, during November 2001, within our local Annual Postgraduate Congress of Medical Oncology. The CRC hopes to announce final details in January 2001.

The Malta National Cancer Registry is part of the Department of Health Information. The last annual report presents cancer incidence and mortality rates in Maltese Islands in 1996 and 1997, but also the accumulated data for the period from 1993 to 1997. It includes updated comparisons of the age-standardised incidence rates between the Maltese population (1993–1997) and the populations of the countries of the European Union (1995) for selected cancer sites. The source of the mortality information is the National Death Registry, functioning within the Department of Health Information. For the first time the Report includes the survival rates for selected cancers. The data for the cancer cases diagnosed in 1993–1997 were used to analyse survival. The Report will be available soon on the website of the Department of Health Information in the Health Division, Malta; the current Internet address is: <http://www.magnet.mt/services/health/dhi1.htm>. In 2000, the Registry joined the EUROCARE-3 and EUROPREVAL projects. As a part of the Department, the Registry is involved in the preparation of the White Papers on Data Protection Act and Computer Misuse Act that are scheduled to pass through parliament in the near future.

The Cancer Registry of Slovenia celebrated its 50th anniversary on 9 March 2000. Dr D.M. Parkin and Professor D. Forman attended the special workshop where Professor V. Pompe-Kirn presented an overview of the history and activities of the Registry. The festive annual report for 1997 includes maps on cancer incidence and graphs on cancer patients' survival. The staff has actively presented epidemiological data at different symposia, conferences and congresses in Slovenia. The research is mainly focused on cancer incidence projections, APC-models, and second primary cancers; two papers on the trends of smoking behaviour and lung

cancer incidence were published. The Registry's equipment has been modernised, but there are problems related to the staff: the salaries of Cancer Registrars are much lower than those for other Registered Nurses employed in hospitals.

In Spain new cancer registries are being set up in regions such as La Rioja, Cantabria, Girona and Guadalajara. The annual meeting of the Ascension Group (Latin Language Group of Cancer Registries) was organised in San Sebastian (June 2000). Most of the registries have been working hard to send the data for C15 on time. There is no professional Association of Cancer Registries in Spain and some of the Registries work together on projects.

In Turkey, the Izmir Cancer Incidence Project (ICIP) is the first pilot project to establish population-based cancer registration system in the country. This was assigned between the Turkish Ministry of Health, Ege University and Turkish-American Health Centre in Massachusetts. Collaboration with WHO, IARC and IACR was established in 1992, and with the ENCR in 1998. In 1993, the Izmir Cancer Registry Centre (KIDEM) was founded. The Registry is responsible for collecting the cancer data in Izmir on behalf of the Turkish Ministry of Health. Registration is now complete and the data for 1993–1994 have been processed for publication. The international recommendations (WHO, IARC, IACR, ENCR) are followed.

The Cancer Registry of Vojvodina, Yugoslavia reports the same problems as in previous years: the necessity for modernisation of the Registry's equipment, the deficiency of staff and very low salaries. The data from the Registry have been presented in different symposia, conferences and congresses in Yugoslavia and abroad. The research is mainly focused on analyses of incidence and mortality. The

staff has participated in the courses held in Lyon and Sofia; support from the IACR is acknowledged.

Information received from: Dr F. Jorgoni, Dr I. Vlachonikolis Dr M. Dalmas, Professor V. Pompe-Kirn, Dr I. Izarzugaza, Dr G. Aydemir, Professor M. Miladinov-Mikov

Western Europe

The Austrian Cancer Registry was established in 1969 within Statistics Austria. Apart from the national register there are four regional registries in Austria (Tyrol, Salzburg, Carinthia and Vorarlberg).

A project, carried out together with the Tyrol cancer registry, to implement the pathology reports has been successfully completed. Preparatory work was done to enable automatic transfer of data from hospitals. So far, the registration forms are sent by the hospitals to the Austrian Cancer Registry. A quality check will be carried out at the end of this year and the beginning of next year to identify whether data from the hospitals can be received on diskette. Furthermore preparatory work has been done to carry out a survival analysis. The study will be based on the incident cases registered at the Austrian Cancer Registry and official death records collected at Statistics Austria. The data cover a period from 1983 to 1997. In order to carry out a survival analysis, the incidence data were merged with the official death records. This was necessary because not all deaths of cancer patients are reported to the Austrian Cancer Registry (for example, a cancer patient dying of a heart attack). Data on 1997 cancer incidence were published in the Health Statistics Yearbook 1998 (Gesundheitsstatistisches Jahrbuch 1998), edited by

Statistics Austria, Vienna 2000 [in German].

Dr M. Haelterman

The National Cancer Registry of Belgium established a new, highly automated, cancer registration scheme in 1996 with considerable additional financial support from the Flemish Government. Only in Flanders (northern part of Belgium) did several additional information sources contribute to the existing National Cancer Registry. Data for 1996 show a remarkable increase of incident cases (22%) in Flanders. The quality of the collected parameters also increased. The coverage of the provincial cancer registry in Antwerp (A.K.R.) will be complete by 2001. In this cancer registry data nurses are collecting data from pathology laboratories and from medical files in the hospitals (Dutch model). Data (national, regional and provincial) can be retrieved from the websites: www.kankerregister.org and www.registreducancer.org

On behalf of the ENCR Dr J.W. Coebergh made a visit to the National Cancer Registry in November 1999.

The National Cancer registry provides data on breast cancer for the provinces of Limburg and Liège to the CONCERT project. This project intends to study differences in care of cancer patients in the EU region Rhine-Meuse (in collaboration with the Maastricht Cancer Registry and the hospital-based cancer registry of the Aachen region).

The encryption procedure has been studied on the data set of 1996; a publication has been submitted: E. Van Eucken *et al.* "Evaluation of the encryption procedure and record linkage in the Belgian National Cancer Registry" (submitted to Arch. Public Health).

The provincial cancer registry of Limburg (a pathology based cancer registry) published "Incidence of cancer in the Belgian Province of Limburg 1996-1998" (authors: F.Buntinx *et al.*).

By 2000 population-based cancer registries were established in all states of Germany. This was made a requirement to the states by a federal law on cancer registration. Most states have founded a registry that (will) cover(s) the total population, four states, however, have created registries that cover only a proportion of the population. With respect to confidentiality, seven regional registries have a double structure with a separate office that encrypts the identifying information (Vertrauensstelle), before the information is handed over to the cancer registry itself. Almost all states require a form of informed consent, encryption of names or information to the patient about the notification to the registry. Only the state of Saarland allows the pathologists and doctors to notify the cancer registry without these restraints. It is proposed to evaluate the cancer registries in about five years.

The cancer registries in the states cooperate with the Robert Koch institute in Berlin (the so called Dachdokumentation Krebs). This institutes collects and compares the incidence data from the German states.

The Netherlands Cancer Registry published in 2000 its ninth annual report (incidence year 1996) and a special report on lung cancer and mesothelioma. Also a report was published for the general public with the title 'Facts and fairytales about cancer'. This publication and the lung cancer report received large attention from the press. The Netherlands Cancer Registry probably will use the new ICD-O-3 classification for topography and morphology.

The Netherlands Cancer Registry is revising its bylaws and will develop a publicity campaign to inform cancer patients about the existence of the cancer registry. The president of the official privacy court has acknowledged that (written) informed consent will make cancer registration impossible. When

cancer patients are informed about the existence of the registry (e.g. by leaflets) and are able to object against registration this would be acceptable to the Privacy Court.

Eight population based cancer registries are now active in Switzerland. They cover a population of 3.7 millions, i.e. about half of the Swiss population. Cancer registries are independent units, producing their own statistics and research at a cantonal level. Some of them have become efficient research centres where descriptive, etiological, surveillance and evaluation studies are regularly performed. Central coordination for collecting standardized data at the inter-regional level has been the major goal of the Association of Swiss Cancer Registries (ASCR) for more than 20 years. Already from the start, the objectives were the management of a pooled data set, the use of these data for a comprehensive description of nationwide figures for the burden of cancer, the development of cancer registration and epidemiological research.

With the help of international experts (J.W.W. Coebergh, C. Hill, M. Parkin, R. Zanetti), the ASCR conducted 3 years ago an evaluation of its objectives, means and internal functioning. The ASCR was also evaluated by other international experts (including P. Kleihues and H. Storm) in the context of the Swiss Institute for Applied Cancer Research (SIAC) into which the ASCR is integrated. These evaluations established that cancer epidemiology remains marginalized in Switzerland and that the present subsidy is far from sufficient to give the necessary stability to the coordinating structure and the peripheral registration.

Because of the uncertainties related to its structural attachment and its lack of financial means, the ASCR cannot fulfil the assigned objectives anymore, in particular the maintenance of the registration network and the

development of cancer epidemiology. Under these conditions and taking into account the unfruitful attempts of the evaluation and reorganization process undertaken by the ASCR, the Association is obliged to consider its dissolution. Wishing to operate a last attempt to avoid this, it will elect Professor J. Torhorst as President ad interim (as of January 1, 2001) until June 30, 2001, with the task to find structural and financial solutions to avoid this dissolution.

Information was received from Dr E. Urbas, Dr M. Haelterman, Dr H. Ziegler and Dr C. Bouchardy.

European Network of Cancer Registries (ENCR)

The IACR is represented on the board of the ENCR by David Brewster (Edinburgh, UK).

Activities of the ENCR:

- The ENCR cancer registration course was held in Sofia, Bulgaria on 18-23 January 2000, and was attended by 32 participants from 11 countries, mainly from Eastern Europe. Dr Shemuel Danon, Head of the National Cancer Registry of Bulgaria, was responsible for the local organisation. Another cancer registration course was organised on 19-23 September 2000 in Warsaw, Poland under the local responsibility of Dr Jerzy Tyczynski, Polish Cancer Registry. This course was attended by 18 participants.
- A statistical analysis course (focused on the analysis of time trends) was held on 8-10 December 1999 at IARC, Lyon. It was attended by 30 participants. The faculty consisted of Roger Black, Freddie Bray, Antonio Decarli, Timo Hakulinen and Michael Hills.
- The cycle of statistical courses continued with a course on survival analysis methods. This was held at IARC on 5-8 December 2000. The faculty were Dr Timo Hakulinen

(Course President), Paul Dickman, Arduino Verdecchia and Andy Sloggett.

- Working groups: the proposed condensed TNM system (distributed in 1999) is being tested in a small field trial. Recommendations by the Working Group on Basis of Diagnosis were distributed to the cancer registries in 1999. Advice on the registration and coding of non-melanoma skin cancer and on confidentiality are being finalized. New working groups have been set up on 'Audits of cancer registries' (Chairman David Brewster) and 'Method of Detection (Chairman Leo Schouten).
- To follow up the automated cancer registration which led to IARC Technical Report No. 32, published in 1998, a small group representing registries which are entirely or partly automated (Veneto, Northern Ireland, Thames and Ontario) has been set up, chaired by Lorenzo Simonato, University of Padova, Italy. The main aim of the project is to make existing systems comparable and reduce the proportion of cases requiring manual checking. Sample files of automated incident cases are currently being tested in different systems. A workshop on the topic was held on 27 October 2000 in Venice. A report with guidelines for the registries will be prepared, including a model for a case resolution algorithm.
- The monograph on 'Evaluation and Monitoring of Screening Programmes', which follows up the Workshop on the topic held in Luxembourg in February 1999, is currently being finalised.

(Information from June 2000 ENCR Newsflash)

News of ENCR activities, courses, fellowships, publications, databases etc.

are on the website: <http://www-dep.iarc.fr/encr.htm>

Islands Cancer Registry and Vanuatu for the next report.

Oceania

Tim Threlfall,
Regional Representative for Oceania

It has been difficult to contact registries in several areas and this report is based on recent information from Australia, and older information from New Zealand

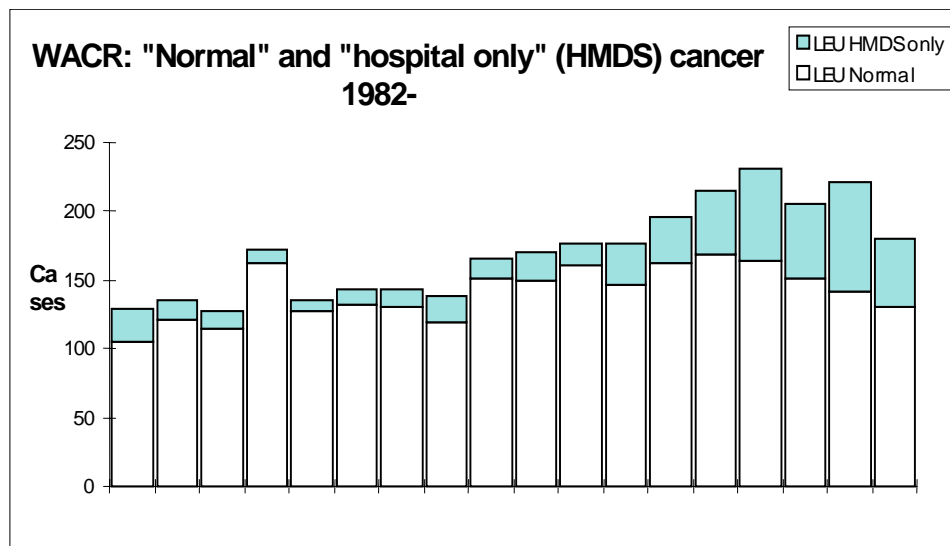
Notably, it is hoped that there will be information from French Polynesia, Guam, Fiji, New Caledonia, the Pacific

Australia

The National Cancer Statistics Clearing House has for many years prepared reports on cancer incidence and mortality in Australia. It receives identified data from individual Registries, and produces national reports on incidence. Mortality reports are based on data from the Australian Bureau of Statistics.

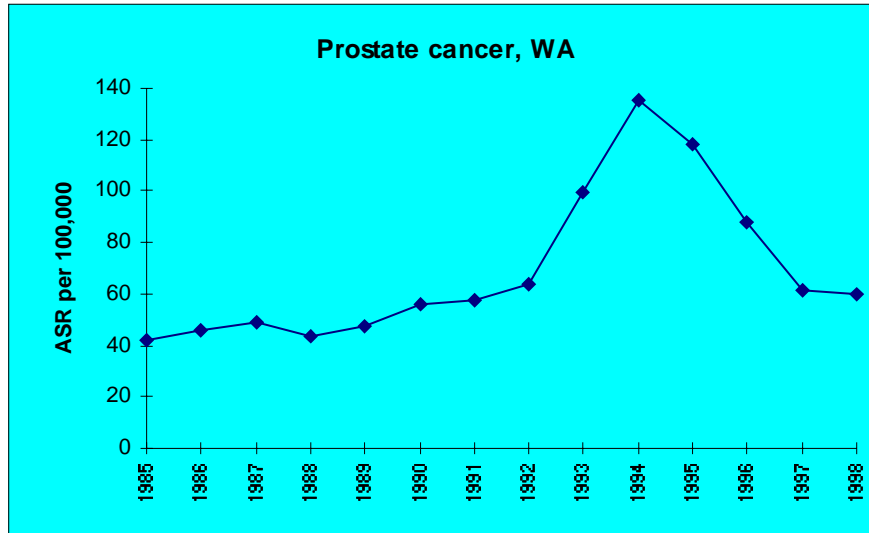
Notification systems: no hospital notification in Western Australia. Effect - lowest incidence for non-pathologically diagnosed diseases such as leukaemia.

Figure 1. Changes in apparent numbers of incident cancer cases, Western Australia, 1982-1999*, based on addition of hospital-only (HMDS) cancer notifications, by year of diagnosis: leukaemia



Changes in medical practice:

Prostate cancer - huge changes in reported incidence, no change in mortality.



Recent publications:

Australian Institute of Health and Welfare (AIHW) and Australasian Association of Cancer Registries (AACR) 2000 (in press). Cancer in Australia 1997: Incidence and mortality data for 1997.

Australian Institute of Health and Welfare (AIHW) 2000. Cervical Screening in Australia 1997–1998. AIHW cat. no. CAN 9. Canberra: Australian Institute of Health and Welfare (Cancer Series number 14).

Australian Institute of Health and Welfare (AIHW) 2000. BreastScreen Achievement Report 1997–1998. AIHW cat. no. CAN 8. Canberra: Australian Institute of Health and Welfare (Cancer Series number 13).

Major Issues

Ethical approval: – differing rules in States and Territories

Current project: production of public-information brochures for Cancer Registries

(required by Government but no funding available).

Extent of disease: – OK for NSW, New Zealand; trial proposed in Western Australia

State and Territory information, 1997: Australia

States and Territories	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	New Zealand
Total population (1997)	6,272,784	4,605,210	3,397,071	1,797,870	1,479,680	473,478	308,011	186,907	
Per cent of Australian population	33.8	24.8	18.3	9.7	8.0	2.6	1.7	1.0	
Per cent of population older than age 65	12.7	12.6	11.2	10.4	14.1	12.9	7.5	3.3	
No. new cancers (1997)	27,287	20,296	14,832	6,422	7,226	2,090	982	413	15,453
First year of population registration	1972	1982	1982	1982	1977	1978	1972	1981	
Year of legislation	1972	1982	1982	1981	1977	1992	1994	1991	1993
Funding source	Pvte-Govt	Pvte-Govt	Govt	Govt	Govt	Pvte-Govt	Govt	Govt	Govt
ICD site coding	ICDO-2	ICD-9	ICD-9	ICD-O-2	ICD-9	ICD-9	ICD-9	ICD-9	ICD-9
Morphology coding	ICD-O-2	ICD-O-2	ICD-O-2	ICD-O-2	SNOMED-II	ICD-O-2	SNOMED-II	SNOMED-II	ICD-O?
Reporting sources									
Public hospitals	Yes	Yes	Yes	No*	Yes	Yes	Yes	Yes	
Private hospitals	Yes	Yes	Yes	No*	Yes	Yes	Yes	No	
Repatriation hospitals	Yes	Yes	Yes	No*	Yes	Yes	Yes	No	
Pathology laboratories	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Radiotherapy units	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	
Nursing homes	Yes	No	Yes	No	No	No*	Yes	No	
Registrar of Births, Deaths and Marriages	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Doctors	No*	No*	No*	No*	No*	No*	No*	No*	No

