

Editorial

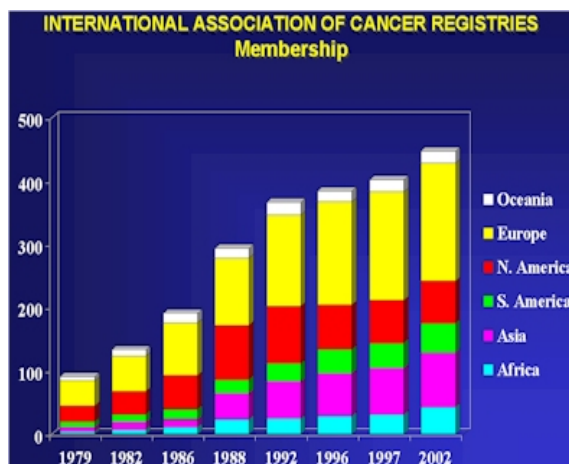
Sharon L. Whelan

On the eve of the 2002 annual scientific meeting in Tampere, Finland the Association has expanded to 451 members. Founded in 1966, the constitution and by-laws were approved at a meeting held in Houston, Texas during the Xth UICC International Cancer Congress. The first President was Dr Einar Pedersen from Norway, followed by Dr John Waterhouse (UK), Dr Pelayo Correa (USA), Dr K. Shanmugaratnam (Singapore), Dr David Thomas (USA), Dr Calum Muir (UK), Dr John Young (USA) and our present President, Dr Hans Storm from Denmark.

The number of members in the Association has grown steadily year by year. In 1975, ten years after its founding, the IACR mailing list comprised 66 members. Today there are over 450.

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Meetings

The 2001 annual scientific meeting of the IACR took place in Havana, Cuba on 3-5 October. Participants will remember with pleasure Hotel Palco, with its goldfish and free-flying exotic birds, Cuban music and dancing, mojitos and sunshine. In the scientific programme Holly Howe from the North American Association of Central Cancer Registries (NAACCR) discussed quality in the cancer registry, and how to achieve it. Rolando Herrero (Costa Rica) addressed the epidemiology of cervix cancer, Timothy Key (UK) that of prostate cancer and Paulo Boffetta (IARC) the epidemiology of head and neck cancer.

The host of the meeting, Leticia Fernandez from the National Institute of Oncology in Havana, looked at cancer control strategies for lung, breast, cervix, prostate, colorectal and oral cavity cancers. Michel Coleman (UK) presented the various approaches to estimating population-based cancer survival and examined variations in survival by region, socio-economic status and other variables. Pelayo Correa (USA) looked at recent international trends in cancer incidence, and the role of cancer registries in their detection.

There were an additional 33 oral presentations, and 93 posters, which played their traditional prominent role in the proceedings.

Details about the 2003 meeting in Hawaii will be up on the website soon (<http://www.iacr.com.fr/>).

Regional Reports for 2000-2001

Africa

Henry Wabinga

Regional Representative for Africa

East Africa

Uganda

The Kampala Cancer Registry (KCR) is one of the oldest population-based cancer registries in Africa, reactivated in 1988 after about 20 years of inactivity. It is currently registering about 1000 cancer cases annually from a population of around one million. The registry is carrying out a survival study on a cohort of 2550 cases diagnosed between 1993 and 1997.

Mbarara Cancer Registry is a new population-based cancer registry covering a population of about one million people in the Mbarara district of south-western Uganda. A pilot study was carried out to determine the patterns of cancer in this community and results indicate that there are differences compared to the Kampala Cancer Registry. The registrar from Kampala has trained a staff member to use the CanReg software.

Kenya

The Eldoret Cancer Registry was established two years ago in the Department of Pathology of Moi University, and has produced preliminary data for Vasin Gishu district in Western Kenya. The registry is receiving support from IARC.

A population-based registry has been set up in the Kenya Medical Research Institute (DEMRI), in order to determine the cancer burden in the population of Nairobi.

A training seminar on cancer registration was given by IARC in 2001, and the registry receives financial support from the US National Cancer Institute (NCI) to support the registry.

Tanzania

There is a new cancer registry in Tanzania, in the Ocean Road Cancer Institute. Initially, this is functioning as a hospital based registry. The cancer registrar attended the course in cancer registration at Nairobi in 2001, and the Director took part in the 2002 IARC Summer School on Cancer Registration and Applications in Epidemiology.

The registrar from the Kilimanjaro Cancer Registry, which started operating in 1998, also attended the Nairobi training course. The registry database now contains population-based data for four districts around the town of Moshi, from 1998-2001.

South Africa

Malawi

Case-finding in the Malawi Cancer Registry continues to improve since the registry was reactivated. The new Director was trained in the 2001 IARC Summer School.

Zimbabwe

The Harare registry continues to act as a source for training in cancer registration with support from IARC. The registry is currently involved in monitoring temporal trends in HIV-related cancers and also cancer survival in Africa. During the year 2001 the cancer registrar received an IACR Calum Muir Fellowship to analyse the incidence of childhood cancer at IARC.

Bulawayo Cancer Registry

The Bulawayo Cancer Registry was reactivated after a long spell, thanks to renewal of support from the US NCI.

Swaziland

A collaborative research agreement was established with funds from the the US NCI in 2001, to determine cancer occurrence in Swaziland.

South Africa

The PROMEC cancer registry, established by the SA Medical Research Council within the framework of their Programme on Mycotoxins and Environmental Carcinogens in Tygerberg, initially started in 1955 as a centre for collecting data on oesophageal cancer, and is now collecting data on all cancers occurring in the population of

four districts of the Transkei region (E. Cape Province) since 1981.

West Africa

Congo

The Brazzaville Cancer Registry continues to operate with support from IARC.

Burkina Faso

The Cancer Registry covers the population of Ouagadougou and has been operating for the last 3 years.

Cameroon

Plans are under way to restart this registry.

Cote d'Ivoire

The registry continues to cover the population of Abidjan.

Gambia

During 2001 two staff members of the registry took part in a course organised by IARC in Ibadan, Nigeria. The registry is one of the three in Africa investigating cancer survival.

Gabon

The registry is being re-started, based in the department of oncology and radiotherapy, and plans to operate as a population based registry for the area of the capital, Libreville.

Ghana

There has been support to start a population-based cancer registry and WHO, IAEA and the Ministry of Health provided initial funding which has enabled training of the director.

Guinea

The registry in Conakry was started in 1990 and is doing well. First results were published in Int. J. Cancer 70: 39-45 (1997). The registry has been instrumental in setting up the regional training centre for the Alliance for Cervical Cancer Prevention programme.

Mali

One of the longest established in W. Africa, the registry is taking part in the Alliance for Cervical Cancer Prevention programme.

Niger

The cancer registry has been running since 1992, and is taking part in the Alliance for Cervical Cancer Prevention programme.

Nigeria

The Ibadan registry hosted the IARC training of cancer registrars in the region in February 2001. Students came from 12 centres in Nigeria where population-based registration has started or is planned, and from The Gambia.

North Africa

Algeria

There are several cancer registries functioning in Algeria, the oldest of which is Sétif. More recent registries include Algiers, Batna, Constantine, Oran and Sidi-bel-Abbes.

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.

South America

Edwin Carrascal

Regional Representative for Latin America

Argentina

The registry of Bahia Blanca continues to function. The Concordia registry is extending registration to the whole province of Entre Rios, and the Jujuy Province histology registry has been expanded to become population-based.

Bolivia

Cancer incidence for 1998-1999 has been analysed for the population of La Paz and El Alto. A hospital-based cancer registry is being expanded to cover the population of the province of Sucre.

Colombia

The Cali Cancer Registry (CCR) is carrying out a study on cancer by socio-economic status in Cali, sponsored by a grant from The Health Office of Valle Department. The ongoing project Risk Factors for Epstein-Barr virus-associated gastric cancer in Cali, in which CCR is involved, has obtained a new grant from Japanese Agencies, through Kagoshima University, which co-directs the study.

The National Cancer Institute continues to support development of cancer registration in some strategic zones of the country geography. Cancer Registries from Pasto, Bucaramanga, Medellin, Barranquilla and Cartagena have been consolidated and now form the Cancer Registry Network of Colombia.

CCR helps in regular training of cancer registry personnel from these registries. A brochure that contains information on CCR activities and incidence and trends in Cali was issued by CCR and distributed to physicians and Health Services.

Ecuador

The National Tumour Registry from Quito, Ecuador (NTRQ) has supported the creation of new cancer registries in several places in the country, representative of highland and coastal zones: the cities of Cuenca, Loja and Machala and provinces of Manabi and Tungurahua. Data from these registries have been incorporated into the 12th annual report on cancer data.

A first meeting of cancer registries in Ecuador took place on 24-28 July 2002. The aim was to standardize methods for cancer registration and quality control, and to encourage the use of the data.

Based on NTRQ current needs, new software is now in use, which facilitates data processing, validation and analysis. NTRQ has served as a tool for monitoring the Cervical Cancer Screening Programme in Quito. Some epidemiological analysis on cancer incidence of major sites. The registry plans to participate in the follow-up of cancer cases based on information from death certificates, to improve the survival data.

A message from the registry: 'We do believe that it is necessary to strength the relationships between Latin America Cancer Registries'.

Peru

The Lima cancer registry hosted a training course for staff of Latin American cancer registries in October 2000.

North America

Eric Holowaty

Regional Representative for North America

Canada

National cancer statistics continue to be generated and disseminated annually, largely as a result of the national patient-based Canadian Cancer Registry, administered by Statistics Canada. April 2002 marked the 25th anniversary of the Canadian Council of Cancer Registries. The Council represents the successful collaboration of ten provinces, three northern territories and Statistics Canada in the standardisation of cancer registration across Canada and the creation of the Canadian Cancer Registry. The national publication Canadian Cancer Statistics can be viewed at www.cancer.ca. Canadian 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) and through the North American Association of Central Cancer Registries web site (www.naacrr.org).

A national project for describing and explaining cancer occurrence patterns in young Canadian adults (ages 20-44) is underway. Funded by Health Canada, this descriptive study focuses on regional differences and temporal trends. Other recent national initiatives include the publication of standardised estimates of 5-year relative survival for 1992 cases. Several Canadian registries are joining the large multinational comparative survival project CONCORD. An important quality assurance initiative, involving four provinces and funded partly by Statistics Canada, compares various strategies for estimating the completeness of case ascertainment. Steps are underway to develop a detailed protocol for staging cancer cases across Canada's registries through a collaborative effort between the CCR Data Quality Committee, CAPCA and CCOCS.

Canadian registries hosted the 2002 NAACCR 2002 Conference in Toronto, Canada in June. The conference theme was "Achieving Equity in Cancer Control". In addition to a number of technical workshops, the conference featured a pre-meeting Symposium on Informatics and Cancer Registries. Further information is available from the NAACCR web-site www.naacrr.org

Health care reform continues to shape cancer care in Canada. Canada's lead agencies in cancer control, the

National Cancer Institute of Canada (NCIC), the Canadian Cancer Society (CCS), Health Canada and the Canadian Association of Provincial Cancer Agencies (CAPCA), have formed a partnership to plan a national cancer control strategy. National priorities for activities in five areas have been proposed: standards and guidelines; primary prevention; rebalancing focus of cancer care; human resources; and research. A draft report of the governance model is available on the CSCC website: http://healthforum.ic.gc.ca_8080/~cancer In addition, the CSCC is facilitating coordinated strategic approaches to research, prevention and patient advocacy.

The Canadian Coalition on Cancer Surveillance (CCOCS)(www.hcsc.gc.ca/lhpb/lcdc/bc/CCOcS/ifldeX.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 items, including more detailed information about radiotherapy. New Federal privacy legislation, and the emergence of new provincial health information privacy statutes, are causing data custodians to be increasingly uncomfortable about permitting research employing personal information where prior subject consent has not been obtained. Data custodians may be ill suited to perform an objective assessment of the risks and benefits associated with such research. Some statutes are now recognising the pivotal role of research ethics bodies in performing such an assessment.

Caribbean (English-speaking)

The Pan American Health Organisation, in cooperation with national health ministries, continues to develop and implement an integrated approach to cancer control. Coordinated by Dr. Beverley Barnett, Caribbean nations are identifying targets for cancer control, based on the current economic, and the emerging epidemiological, situation in each country. It is apparent that cancer registries are a necessary prerequisite to assessing the impact of cancer control programmes.

The situation regarding cancer registries in the Caribbean has not changed significantly over the past two years. Several countries (Bermuda, Guyana, 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. In early November 2001, at a PAHO non-communicable disease meeting, a technical group was formed to oversee the implementation of cancer registries across the Caribbean Region, starting with a requirements analysis. It is anticipated that IARC/IACR and other expert groups will be invited to participate in this process.

Brenda Edwards
Regional Representative for North America

United States of America

The USA national cancer registration system is structured and funded by inter-dependent programmes operating within the federal, state and private sectors. These organisations 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 organisations, ensuring that the needs of cancer patients and the 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, the Commission on Cancer of the American College of Surgeons, the North American Association of Central Cancer Registries (NAACCR), the National Cancer Registrars' Association, the Department of Defence, the National Cancer Institute (NCI) and the Centers for Disease Control and Prevention (CDC), including the National Center for Health Statistics.

The North American Association of Central Cancer Registries (NAACCR) is the umbrella organisation of professionals involved with population-based registries in the USA and Canada. NCI and CDC continue to provide significant funding for resources to maintain an office of Executive Director and associated staff and to facilitate collaboration between members.

Activities include the release, in April 2001, of Cancer in North America, which provides incidence data from 61 of 68 USA and Canadian registries. Aggregate USA incidence rates for 1994-1998 were based on data from registries meeting established standards; the pooled data came from registries representing more than half of the total USA population. Goals identified in 2000 included implementation of ICD-O-3, standard-setting for use of geographical information systems, improving the process of standards implementation, confidentiality issues in internal registry operations, the impact of changing USA definitions of race, and review of the rationale for USA multiple primary rules.

With support from a contract with NCI that offers technical assistance for cancer surveillance, NAACCR is expanding activities in a variety of areas: developing 'best practice' models for cancer registry operations, creating research data file(s) for use by a broader base of analysts under controlled conditions – to include a process for request and release of the data; developing a model for record consolidation, and establishing a Mentor Fellowship Program.

With support from CDC, the Education Committee is working to develop materials for training in cancer registry operations.

CDC and NCI continue to coordinate cancer surveillance activities. A major focus of activities for 2001 was defining a comprehensive national cancer surveillance system. Notable activities of the respective programmes include:

- Support from the CDC National Program of Cancer Registries (NPCR) for cancer reporting in 45 states, the District of Columbia and three territories for data years from 1995. This has enabled the majority to meet national data standards established by NAACCR.

- In 2002, NPCR registries began reporting cancer data to the NPCR-Cancer Surveillance System – designed to receive, assess, analyse and disseminate data from NPCR states.

- NPCR continues to develop, distribute (without charge) and support Registry Plus (tools for the collection and management of cancer registry data) and EDITS software. Registry Plus Online Help supports major standards and coding from the NCI Surveillance, Epidemiology and End Results Program (SEER), NAACCR, the American College of Surgeons and WHO in a cross-referenced searchable system. The EDITS system of programs is used nationwide to improve the quality of cancer registry data by providing a standard mechanism for testing the consistence and correctness of cancer reports.

- The SEER Program continues to develop systems for statistical analyses of data (SEER*STAT), web-based inquiry and analysis applications, and has launched long-term development of information systems for centralised data management.

- The SEER Program has implemented procedures to do web-based quality control reliability studies of coding. The software developed permits individuals from around the country to access the cases that are to be coded, to abstract and code each case – and upon completion of the exercise obtain their score. Immediate tabulation of the scores by registry and other variables is provided to NCI. These studies permit the identification of specific coding problems as well as quantitative measures of the consistency with which SEER data are collected.

In collaboration with CDC, a national database is being developed to help identify geographical areas where there are opportunities for cancer control, and to allocate resources for cancer prevention and control. The database provides for use of sophisticated statistical concepts as tools for decision-making by planners with limited knowledge of analytical techniques.

- The SEER Program is integrating measures of socio-economic status and urbanisation into cancer surveillance, specifically in relation to analysing trends and levels of cancer incidence, mortality and survival.

ICD-O-3 was implemented from 1 January 2001, and training materials were disseminated and workshops conducted to help in the process.

The Commission on Cancer with the USA American College of Surgeons is the accrediting body for hospital-based cancer care in the USA. They have re-organised to improve registry-based cancer reporting systems for clinical cancer care. Data collecting and coding system requirements (ROADS) are being revised for implementation in 2003, and

their National Cancer DataBase has been re-designed. The College has facilitated an NCCCS-initiated project through the American Joint Committee on Cancer (AJCC), a Collaborative Staging Group, to develop agreement on the uniform collection and reporting of stage by population- and facility-based organisations. This should substantially improve cancer reporting in the USA. The AJCC collaborated with the UICC TNM Committee on the sixth edition of the Cancer Staging Manual.

Reporting of USA cancer data is a major responsibility of many federal and private organisations. As part of a coordinated effort, the NCI, ACS, CDC and NAACCR work to prepare an 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

Cambodia

Registration began in 2001 in Phnom Penh, following an initiative of the Preventive Medicine Department of the Ministry of Health.

Japan

There were 34 population-based cancer registries in Japan as of July 2000, covering 33 of a total 47 prefectures. All population-based cancer registries in Japan have become members of the Japanese Association of Cancer Registries (JACR) which was founded in 1992. Dr. Akira Oshima of the Osaka Cancer Registry is the current chairman

The 9th Annual Meeting of the JACR was held in September 2000 at Yokohama, Japan on the theme of 'Monitoring of Environmental Pollution by Population-based Cancer Registries'. The 10th Annual Meeting was scheduled in September 2001 in Osaka, Japan but was postponed.

A bill on privacy protection 'prohibiting the processing of personal data without informed consent' was decided by the Cabinet in March 2001 and has been carried over to the next emergency session of the Diet after the election of the House of Councillors. Through the efforts of many people concerned in public health and epidemiology, an exemption has been made for public health research.

Korea

The Kanghwa Cancer Registry, which started in 1982, collects information on cancer patients from medical records, medical insurance records, pathology and endoscopy records, and burial and cremation records in Kanghwa County, as well as medical records from hospitals in the Seoul and Incheon areas. The data on causes of death from the National Statistics Office is an important source of information, particularly for patients who died after 1992.

Research studies in which the Kanghwa Cancer Registry is involved include research on the relationship between pesticides and herbicides and cancer in the geriatric

population and on incidence in the Kanghwa region. The registry also participates in the research conducted by the National Cancer Center.

In 2001 three population-based cancer registries in Korea applied for membership of the International Association of Cancer Registries, Daegu, Incheon and Daejeon. The first two were accepted as voting members while the third was accepted as an associate member.

Data from four registries (Busan, Daegu, Kangwha County and Seoul) will appear in Cancer Incidence in Five Continents, Vol. VIII.

Laos

Cancer registration began in 2001 in Vientiane, following a request of the Ministry of Health, supported by IARC.

Philippines

There are four population-based cancer registries in the Philippines; two are in Luzon, one in the Visayas and one in Davao City. The first three registries are members of the IACR.

The DOH-Rizal Cancer Registry undertakes long-term follow-up for the Breast Cancer Screening Project of the Philippines in collaboration with the International Agency for Research on Cancer. It also participated in the field trial for ICD-O 3.

The Philippine Cancer Society – Manila Cancer Registry undertook a 10-year survival study for 1987 incident cases of cancer. It also conducted a study on reducing the percentage of DCO cases by improved follow back of death notifications for liver cancer. It also participated in the field trial for ICDO-3.

'Cancer in the Philippines' Volume 3 which includes the data of the Manila and Rizal cancer registries from 1988-1997 is being prepared for publication.

The Metro Cebu Population-Based Cancer Registry, established in 1987, completed data collection and analysis of cancer cases for 1983-1992, with technical assistance from IARC.

The Davao Cancer Registry was started in 1991 but was temporarily discontinued. In 1998, with support from the Andres Soriano Cancer Foundation, Davao Doctors Medical Center and the PCS-Davao Division, it completed data collection for 1993-1997. In 2001, management of the registry was transferred from non-governmental organisations to the Davao Regional Health Office, under the Department of Health.

Singapore

The Singapore Cancer Registry continues to comprehensive population-based cancer registration of the whole Republic of Singapore. The registry data have been used mainly to determine incidence levels and relative risks of cancer in Singapore by sex, ethnic group and migrant status. The

information has formed the basis of epidemiological and clinical studies on specific cancers.

In addition to collaborating in many research projects, recent reports of the Registry include:

- (a) Trends in Cancer Incidence in Singapore, 1968-1992
- (b) Cancer Incidence in Singapore, 1993-1997

The Registry also collaborates with IARC on studies of survival analysis.

Pakistan

The Karachi Cancer Registry (KCR), established in 1995 by the Government of Sindh, in collaboration with IARC, completed six years of data collection for Karachi South (1995-2000) and three years of data collection for the entire Karachi Division (1998-2000), which may be considered the largest incidence data set from any part of the country in the last five decades. A publication 'Cancer Epidemiology in Karachi 1995-1999' is now available.

To facilitate data collection and improve quality control of registered data, a branch of the Karachi Cancer Registry was opened at the Pathology Department of the Aga Khan University Hospital, the largest referral centre for cancer diagnoses in Pakistan, on a one-year trial basis.

The Registry participates in research projects in collaboration with the IARC Unit of Environmental Epidemiology. The first case-control study on tobacco-related cancers (lung cancer) has been completed and accepted for publication. The second case control study on oral cancer and urinary bladder cancer has also been completed. The Registry is participating in its first multicentric study on lung and larynx cancers.

Thailand

Five population-based registries (Lampang, Chiang Mai, Khon Kaen, Bangkok and Songkhla) collaborated on the preparation of a monograph on cancer in Thailand. The Khon Kaen registry database is being linked to a cohort of over 24 000 individuals (as of June 2001) to investigate the causes of liver cancer.

The cancer registry of Songkhla hosted a regional training course for ICD-O-3 and CanReg version 4 in April 2002.

Europe

Tiiu Aareleid
Regional Representative for Europe

Northern Europe

Association of Nordic Cancer Registries

The Association of Nordic Cancer Registries (ANCR) held its annual symposium and board meeting in September 2001 in Helsinki. The Association coordinates collaboration

of the cancer registries in Denmark, Finland, Iceland, Norway and Sweden. Dr. Frøydis Langmark was elected the new Chairman of the ANCR. The Nordic Summer School on Cancer Epidemiology, phase I was organised in Copenhagen, Denmark, and phase II in Norway. A *Cancer Atlas of Northern Europe* has been published. The Atlas covers cancer incidence and mortality in the Nordic and Baltic countries and in Germany, Poland, Belarus and the western part of Russia. Besides the traditional collaboration in cancer registration, members of the ANCR have focused their joint research efforts on survival comparisons, explaining the differences in patients' survival and predicting cancer incidence in the Nordic countries.

Denmark

The Danish Cancer Registry continued moving towards automatic data capture, based on the revised Hospital Discharge System, the National Pathology Registry and improved access to death certificates. As part of modernisation, the Registry will image scan the notifications, including microfilmed and coded forms on 'active' cancer patients. Registry-based research is carried out at the Danish Cancer Society. Joint activities between the Registry and the Society on quality control, publication and interpretation of the incidence data, and evaluation and audit aimed at following up and supporting the National Cancer Plan, are proceeding. The Plan was developed and is supervised by the National Board of Health. Cancer prevention, especially tobacco control, is integrated into the Plan, as is routine statistical assessment of the situation, using the registry data.

Survival and care studies are carried out on the Nordic and European bases. Differences in survival exist between Denmark (lower) and the other Nordic countries. Incidence was published for 1997 and mortality for 1998. Data from the registry have been used in international studies on cancer. A software for regional incidence and mortality analyses and producing graphical features (maps, trends etc.) was developed in collaboration with the other Nordic countries.

A full report on the registry's operations is available at www.cancer.dk/ancr. The data from the Danish Registry can be found at www.sst.dk and at www.cancer.dk.

Finland

Administrative changes occurred in the Finnish Cancer Registry. Following the retirement of Dr Lyly Teppo, the new Director of the Registry is Professor Timo Hakulinen. Dr Risto Sankila was appointed Chief Medical Officer. The cancer incidence statistics for 1998 and 1999 are available at www.cancerregistry.fi.

Iceland

The Icelandic Cancer Registry's staff has spent much time and effort on negotiations with two bio-technological companies (deCODE, UVS) regarding access to the registry data. Contracts were signed in June 2001, stating that the companies will be allowed the same access as independent scientists, i.e. project-based-access, where the projects have to be accepted by the Scientific Ethical Committee and

the Data Protection Authorities. Data from two different studies may not be linked, and linkage with the planned Health Sector Database of deCODE will not be allowed. The companies will pay for access to the registry data on a yearly basis, whereas independent scientists will have them free of charge.

Professor Hrafn Tulinius has retired from his position as Director of the Registry. Jon Gunnlaugur Jonasson, the Chief Physician of the registry, and Laufey Tryggvadottir, the Managing Director replace him.

Norway

The Registry has changed its name to 'Kreftregisteret' (institute of population-based cancer research) and has a new logo. *Cancer in Norway 1998* and two reports on the evaluation of screening programmes were published. Research activity is high, with many papers published in international journals. In October 2001, the registry celebrated its 50th anniversary.

Sweden

The Registry has been coding all new cancer cases according to ICD-O-2 since 1993. Data to 1999 were published in June 2001. Since the year 2000, the National Board of Health and Welfare publishes the statistics only on the Internet (www.sos.se). Two Acts adopted in 1998, the Health Data Registries Acts, will hopefully be positive for the registry.

UK, England and Wales

During 2001, the main preoccupation of the United Kingdom Association of Cancer Registries (UKACR) was the threat posed to the national cancer registration scheme by the publication of new guidance on confidentiality at the end of 2000. The Guidance, published by the General Medical Council (GMC), stated that identifiable information could only be passed to cancer registries with individual patient consent. This led to immediate problems with the flow of data to cancer registries and it was clear that the national system, which has been in existence for more than 40 years, was in danger of collapse. Many colleagues both within the cancer registry field and within the broader public health and research community in the UK and beyond raised serious concerns about the potential loss of reliable population based cancer data in the UK. As a consequence, the GMC issued a statement acknowledging the need for further time to allow these issues to be resolved without damaging the cancer registration system.

It is ironic that the threat to the national cancer registration scheme coincided with the publication of the National Cancer Plan, which contains a commitment from the government that by 2010 cancer survival rates in the UK will equal the best in Europe. It will, of course, only be possible to monitor progress towards this target if the national cancer registration scheme is protected by appropriate legislation.

There is still considerable uncertainty over the future of the cancer registration in the UK and the continuing support of international colleagues is much appreciated.

UK, Scotland

Issues of privacy, confidentiality and data protection are still a major cause for concern in the Cancer Registry of Scotland. Unlike England and Wales, there has so far been no legislation to give (even temporary) protection to cancer registration and other important public health surveillance systems. Instead, the Scottish Executive Health Department has established the Confidentiality and Security Advisory Group for Scotland (CSAGS) which has produced a consultation paper and, on the basis of the comments received, will make its recommendations to the Scottish Executive.

Two recent Scottish Executive publications may be of interest to others involved in cancer control activities: (1) *Cancer Scenarios: An Aid to Planning Cancer Services in Scotland in the Next Decade*. This provides projections of cancer incidence and mortality, calculated by age-period-cohort modelling. Many clinicians contributed to the commentary. It is available at www.scotland.gov.uk/library3/health/csatp-00.asp (2) *Cancer in Scotland: Action for Change*. This represents Scotland's cancer plan or strategy and is on www.scotland.gov.uk/library3/health/csac-0.asp. The data are available at: www.show.scot.nhs.uk/isd/cancer/cancer.htm

Estonia

In February 2001, the Minister of Social Affairs issued a revised Decree on Cancer Registration and Running the Estonian Cancer Registry. The Decree brought access to the registry data into accordance with the Act of Personal Data Protection. On the other hand, due to limited resources and lack of use of the registry data for planning and evaluation of the health care services, officials of the Ministry of Social Affairs even discussed the possibility of closing down the registry and other medical registries as being too specific and too expensive. There is an idea that a computerised overall health database could substitute for the disease registries and guarantee adequate data on, for example, cancer incidence and survival. The registry's future is also jeopardised by the fact that the National Cancer Control Programme, developed by the Working Group and presented to the Government in Spring 2000, was not approved and did not receive funding. The present crisis is also related to rapid health care reorganisation and, in particular, to the disintegration of the present Cancer Centres and cancer care services provided by the general hospitals.

The Registry was founded in 1978 and has retrospective data to 1968. The use of its data for research purposes has been intensive. The Registry contributes to various international projects, e.g. Cancer Incidence in Five Continents, EUROCIM, ACCIS, EURO CARE (including the high-resolution study) and EUROPREVAL. A copy of the registry database is provided annually to the Department of Epidemiology and Biostatistics at the Institute of Experimental and Clinical Medicine, Tallinn, for research purposes. The President of the IACR Dr Hans Storm and the Chairman of the ENCR Dr Jan Willem Coebergh sent letters to the Minister of Social Affairs of Estonia early in

2001 to express their support for the registry, but have not received a reply. Also, the IACR, IARC and ENCR issued a Diploma of International Recognition to the Estonian Cancer Registry in March 2001.

Latvia

The Latvian Cancer Registry continues its routine activities. There are increasing problems with completeness of notification, particularly from general practitioners. The registry has asked the Health Department to issue a new, revised decree about obligatory notification of all new cancer cases (including autopsy findings). The cancer incidence statistics for 1999–2000 will be published in 2002. The first issue of *Mortality from Cancer in Latvia* covering the period 1980–1999 is under preparation. The Registry participates in multiple collaborative projects. In 2001, the Registry contributed to organising the 18th International Conference on Human Tumor Markers (Riga, June 17–20) and the 4th World Latvian Physicians' Congress (Riga, June 20–22).

Lithuania

The Lithuanian Cancer Registry has operated as a separate department of the Lithuanian Oncology Centre since 1990. Regular annual reports on cancer incidence have been published (in Lithuanian) since 1992. The Registry has succeeded to collect all the data, covering the periods 1978–82, 1983–87, 1988–92, 1993–97. The last two periods will appear in Volume VIII of *Cancer Incidence in Five Continents*.

In September 2000, as a result of administrative reform, Lithuania introduced a new administrative division, consisting of 44 districts (rayons) and 11 cities with 60 municipalities. These changes required a new coding system and finding ways to keep monitoring trends from the former to the new administrative areas. The health care system in Lithuania is finalising a change to an insurance-based system. The Lithuanian Oncology Centre is trying to build a new network, connected to the university and the local hospitals and general practitioners. The Registry must also comply with the new system. Measures have been taken to avoid a loss in completeness and quality of cancer registration during the transition. The Registry will continue passive follow-up of cancer patients and it is intended to analyse the survival of cancer patients in Lithuania in 1996–1997. Some occupational studies, including workers in the asbestos-cement industry, the nuclear industry and the Chernobyl clean-up workers, are in progress.

Information received from A. Anderson, L. Barlow, D. Brewster, T. Hakulinen, J. Kurtinaitis, K. Moller-Hansen, M. Roche, H. Storm, A. Stengrevics, L. Tryggvadottir

Eastern Europe

Armenia

The Cancer Research Centre in Yerevan published cancer incidence data for 1970–1998 in 2000. Approximate crude incidence rates were presented, due to a suggestion of a discrepancy between the official and the 'real' population data. The last census was held in 1983 when Armenia was a part of the USSR. In 2001, the Centre also published results of research projects *Spreading of Carcinogens and Mutagens in the Environment of Armenia and Possible Ways of Cancer Prevention* and *Chromosomal Aberrations in Lymphocytes of Persons Exposed to Earthquakes in Armenia*.

Bulgaria

The Bulgarian National Cancer Registry participated in accreditation of the Bulgarian National Cancer Institute in July 2001. The Registry's staff attended an international course on survival analysis and national seminars and conferences on cancer epidemiology. A significant contribution was made to National Breast Cancer Week in April 2001. Cancer incidence statistics are published regularly.

Czech Republic

An Act on Health Care was passed in Summer 2001. The Act includes the legislative anchoring of health registries and brings their functioning into accordance with the Act on Personal Data Protection which was passed in 2000, whereby the cancer registry is taken as a model. The total concept of health registries is at present being defined. After a year of intensive work, the program SVOD (System for Visualisation of Oncological Data) was demonstrated in the Days for Oncology in Brno. The system was developed by the University Oncological Centre of Masaryk University in collaboration with other organisations. Its presentation was based on examples of breast cancer data prepared by the Registry. At present, an extension of the SVOD to other common diagnoses is in progress. Improved software for checking the data in the registry database has been completed in the past month. Data are published regularly.

Georgia

The National Association of Cancer Control in Georgia created a Web site in 2001, available at <http://www.nacc.org.ge>. The objectives of the Association include the establishment of a National Network of Cancer Registries.

Hungary

Dr Zoltan Peter retired from his position as Director of the Hungarian Cancer Registry. The new Director since July 2001 is Dr. Istvan Gaudi, while Dr. Peter remains the Medical Advisor of the Registry. A legal basis for cancer registration was established by an Act and Methodical Directions, issued by the Minister of Health in 1999. Thus, a new registration system started in August 1999. The main innovation was that nearly all the hospitals, outpatient departments and GPs were supplied with computers and computerised data on cancer cases (including morphology) could be retrieved from these databases. The registry

receives the data on disks quarterly. The major concern is the quality of the data.

The national Hungarian Childhood Cancer Registry was established in 1971. A network of ten regional centres, working in close collaboration carries out registration. The registry has joined the ACCIS study, initiated by IARC. In order to provide good quality data, the Registry's procedures were modernised. The old computer programmes have been replaced by a new system which is compatible with the IARC requirements, including modern coding systems (ICD-O-2). Hard work has been done during this period to check the data against the original patient documentation. By the deadline, the registry was able to produce population-based data on leukaemia incidence in Hungary for 1971–2000, and on solid tumours for 1988–2000. The data for the years 1975–1987 will be provided shortly. The Registry collaborates with the Neurosurgery and Ophthalmology Centres, which provide specific care for patients with CNS tumours and retinoblastoma. The registry staff participated in the Conference 'Chernobyl 15 Years Ago' at the Hungarian Academy of Sciences and presented the data on childhood leukaemia incidence in 1980–2000. A paper on childhood cancer incidence in Hungary in 1988–1997 was published in the Hungarian Medical Journal.

Poland

The President of the Association of Cancer Registries in Poland (ACRP), Dr Jerzy Tyczynski, recently succeeded Dr Risto Sankila as the Scientific Co-ordinator of the ENCR. Currently, the Polish National Cancer Registry with a network of 16 regional registries covers the entire population of the country. The creation of an Internet-based network and introduction of a new notification form are in progress. The completeness of reporting on cancer cases is gradually improving. In 2002–2003, the introduction of ICD-O-3 is envisaged.

The Holycross Cancer Registry (Kielce) which operates as a separate department of the Holycross Cancer Centre has provided a detailed report on activities. It covers a population of 1,350,000 people. The Ministry of Health funds the Registry. All doctors and medical centres are obliged to report all cancer cases on a special notification form, including the information advised by IARC, by administrative order. Although reporting is obligatory, it is often neglected and therefore the reports received have to be completed and checked against the data from the Statistical Office, local civil departments and hospital data by the registry staff. The registry maintains two basic files: a computerised file containing the patient's serial number, sex, surname, name, date of birth, date of first cancer diagnosis, code and year of death (if applicable); and a file, containing the first and follow-up information about the cancer cases. The diagnosis is coded to ICD-9 and ICD-O is used for coding topography and morphology. The Registry prepares annual reports on cancer incidence and mortality for the local government, and provides incidence data to the National Cancer Registry of Poland. Research activities have continued both within the registry and in collaboration with researchers in various institutes. Dr. Carmen Martinez Garcia, the Director of the Granada Cancer Registry (Spain) made a consultant visit to

the Registry in September 2000. The Registry participates in the ACCIS project and contributed to the elaboration of ICD-O-3.

Romania

The Romanian National Cancer Registry was established in 1981. Each of the 41 districts of the country and 6 municipalities of Bucharest have their own territorial cancer registries. Data from these are centralised at the Health Statistics and Medical Documentation Centre of the Ministry of Health, Bucharest. Cancer registration is compulsory in Romania and carried out in accordance with Order No 219, issued by the Ministry in 1980. Although the Order was an important progress in the 1980s, it does not meet today's needs and a new legislative basis is required. It also should clearly state the source of funding for the activities of the registry.

The Territorial Cancer Registry of Bihor County published a new issue of the annual journal in 2001, under the patronage of the Faculty of Medicine and Pharmacy of the University of Oradea. The issue describes the activities of the Cancer Registry Network in Romania, and particularly, the activities of the Registry in Bihor County. Dr Risto Sankila, then Scientific Co-ordinator of the ENCR, made a consultant visit to the Registry in October 2000. His report is published in the Journal. In summary, Dr Sankila advised that over 40 cancer registries existing in the country is not cost-effective, and that approximately 6–8 regional registries would be optimal. The CanReg software could be used and strict follow-up of the data flow and quality control should be accompanied by active feedback to hospitals and clinicians. The European Union's PHARE Program might be a source for funding a pilot phase.

Russian Federation

A symposium *New Computer Technologies in Cancer Statistics* was held in St. Petersburg on 10–11 October 2001. The Symposium was organised by the Cancer Registry of St Petersburg and the N.N. Petrov Research Institute of Oncology. The focus was on population-based cancer registration and its economic aspects. The territorial Cancer Registry of St. Petersburg is responsible for elaborating a model for cancer registration in the north-western part of Russia.

Slovakia

The National Cancer Registry of Slovakia has its own budget and is responsible only to the Ministry of Health. Annual reports are published regularly. A new directive of the Ministry of Health was issued in 2000, emphasizing the obligatory notification of cancer cases together with the introduction of a new, slightly changed notification form. This had a positive influence on the completeness and quality of notification. The Registry supported and initiated the publication of the Slovak translation of the most recent TNM version and the ICD-O-2. Members of the staff participated in the publication of monographs and papers on cancer epidemiology. A comprehensive contribution was made to a Textbook of Epidemiology for Medical Students. The registry staff also contributes to lectures and courses, set up for the postgraduate education of physicians and paramedical

personnel. The Registry participates in projects such as ACCIS, EUROCIM, ECLIS, C15, EUROCLUS, and EUROCARE (including the high-resolution study). There is a fruitful collaboration with the League against Cancer in Slovakia, particularly in anti-smoking campaigns, and preparing textbooks on oncology.

Ukraine

The Ukrainian Cancer Registry today covers almost the whole country (50 million). A network of computerised territorial and hospital-based cancer registries has been created. Data are exchanged with the State Chernobyl Registry, which contributes to validity and completeness in both databases. Special software for analysing the survival and treatment effectiveness has been introduced.

Information received from S. Danon, L. Goulak, S. Gózd, Z. Jakab, M. Jechova, V. Merabishvile, AK Nersesyan, R. Mezyk, V. Pacurar, Z. Peter, I Plesko, V. Roman, V. Tkeshelashvili, U. Wojciechowska

Leo Schouten

Regional Representative for Europe

Southern Europe

Albania

The National Cancer Registry started in 1986 and is located in the Institute of Oncology of Tirana (the Capital of Albania). The cancer registry is population-based and covers about 80% of the Albanian population. The data are mainly used for descriptive epidemiological studies. Problems in obtaining relevant literature on cancer registration techniques and sufficient computer support for data processing have been solved with the help of IACR and the Canadian foundation Terry Fox.

At the beginning of 2002 the cancer registry began to use CanReg 3.

Croatia

The Croatian National Cancer Registry has a new director, Dr Ariana Znaor. She succeeded Dr Strnad, who has become director of the Croatian National Institute of Public Health. The Croatian Cancer Registry is working on the introduction of notifications in electronic form and is constructing a website for the registry. Cancer registry reports are published regularly.

Malta

The Malta National Cancer Registry's report for 1998 and 1999 includes information on extent of disease at diagnosis for selected common cancers. The registry is part of the Department of Health Information services. This department also houses a number of other national registries including the Mortality Registry, the Congenital Anomalies Registry and the Maternity Registry.

Slovenia

The registry published a comprehensive annual report for 1998. It includes maps on cancer incidence and graphs on survival. The staff present epidemiological data at symposia, conferences and congresses in Slovenia. Special attention has been given to the analysis of cervical cancer incidence and mortality because a pilot study on an organised cervical screening programme is being carried out. Research has been mainly focused on cancer incidence projections, APC-models, and second primary cancers. A paper on trends of available reproductive risk factors for the female population of Slovenia and breast cancer incidence has been published. International collaboration continues (EUROCARE, EUROPREVAL, CI5, ACCIS, Second primary cancers).

The Registry's equipment has been modernised, but there are still problems related to staff: the salaries of cancer registrars are much lower than those for other registered nurses employed in hospitals. Therefore, a special course for these nurses is foreseen to provide them with a formal certificate in recognition of the additional knowledge needed for efficient work in the registry.

Turkey

The Izmir Cancer Registry (ICR) has been functioning since 1992 and covers Izmir province, on the west Mediterranean coast of Turkey.

ICR staff collect data by actively from all of the hospitals and oncology centres in the province. The ICR staff has prepared a Turkish version of Canreg-3. Several publications, based on the data from the Registry, have been issued.

The IARC International Course on Cancer Epidemiology was held in Izmir at April 2002 in collaboration with the ICR.

The ICR is the only population-based registry in Turkey. The Cancer Control division of the Ministry of Health has launched efforts to establish nine more population-based registries in different cities in Turkey in order to cover about 20% of the population. ICR was accepted as a model for these newly established registries and the founding staff received training on cancer registration in August 2001 in Ankara with the contribution of experienced staff from the ICR. ICR prepared a national data base, a notification form and an instruction manual. for filling the notification form for the purpose of common usage at national level. CanReg3 was customised for the national system by ICR staff.

Yugoslavia

The Cancer Registry of Vojvodina has converted its entire database ICD-9 to ICD-10. The reporting system, although statutory, should be improved in quality, which is not easy in circumstances of the country, with inadequate equipment and lack of staff (especially doctors). Because of interest in the Balkan syndrome, the registry receives many requests for data.

Information received from: M. Dalmas, S. Yalçın Eser, F. Jorgoni, M. Miladinov-Mikov, V. Pompe-Kirn, A. Znaor.

Western Europe

Austria

The Austrian Cancer Registry was established in 1969 within Statistics Austria. There are also four regional registries in Austria (Tyrol, Salzburg, Carinthia and Vorarlberg).

Preliminary data on cancer incidence 1998 were published in the Health Statistics Yearbook 1999 (Jahrbuch der Gesundheitsstatistik 1998), edited by Statistics Austria, Vienna 2001 [in German].

From reporting year 2002, the site of cancer is coded to ICD-10 and histology to ICD-O-2. ICD-O-3 will be implemented when a German version becomes available.

Due to several queries from politicians about the Austrian Cancer Registry, a working group was established to improve the quality of the data. This working group consists of providers of information on cancer patients (physicians working in hospitals, pathologists), producers of cancer incidence data (Austrian Cancer Registry as well as the four regional cancer registries) and users of the data (epidemiologists and Ministry).

The goals of the working group are:

- Evaluating the cancer registration form and designing a new one taking into account international standards.
- Improving the quality and frequency of cancer notifications through involving pathology reports, facilitating the burden of the physicians in hospitals and regularly providing statistics on cancer incidence to the physicians.
- Decreasing the percentage of DCO cases as well as investigating the differences between the Austrian Cancer Registry and the regional registries. A project to decrease the DCO cases through pathology reports or tracing-back of DCO cases has already started.

The regional cancer registry of Tyrol has been certified according to EN ISO 9001:2000 in May 2001. The 1998 report has been published. The registry is involved in several research projects, e.g. an indoor radon study, evaluation of PSA screening and evaluation of treatment of ovarian cancer.

Belgium

A Flemish Cancer Registry Network has been established. In Flanders several additional information sources are used for cancer registration, and the registry has been able to increase completeness of case ascertainment and data quality. Three university oncology departments, pathology laboratories and all health insurances are integrated in the network. Also two provincial registries participate: The Antwerp cancer registry is based on active registration in all the hospitals of the province, and the LIKAR registry operates in the province of Limburg.

LIKAR publishes data regularly. Special emphasis is given to the haematological malignancies in the latest report.

In 2001 a report was published on geographical differences in cancer incidence by community. Extensive Bayesian based analytical techniques were used. Additional analyses are now being performed to explain the identified clusters of prostate and bladder cancer. Data from the registry are being used by an increasing number of groups and working parties. A separate cervical screening registry is under construction within the LIKAR framework.

France

There are 13 active population based registries according to the assessment of the Comité National des Registres, covering a population of 8.5 million, that is about 14% of the French population. These registries are independent units, producing their own statistics and research at the level of the department (French administrative area). Some are involved in screening programmes. Since 1994 the Network of French Cancer Registries (FRANCIM) has provided an opportunity for cancer registries to work together on common research projects. A pooled cancer database has been created to produce a comprehensive description of the national cancer burden and patterns (incidence, prevalence, survival). The registries cooperate with the Department of Biostatistics of the Hospices Civils de Lyon (J. Estève).

In the last few years, many official reports stated that cancer registration was marginalized in France and that funding is insufficient to provide stability for the existing registries. The creation of the Institut National de la Veille Sanitaire and the issue of a 'Cancer Plan' could provide this stability to the cancer registries despite rather slow progress and difficulties encountered due to a lack of flexibility of the French administration.

Germany

In Germany three (out of 11) registries do not cover the whole population yet (Baden-Wurtemberg, North-Rhine Westfalia, Hessen). The registries of Bavaria and Lower-Saxony will cover the whole population from the beginning of 2002 and 2003 respectively.

In December 2000 the German Childhood Cancer Registry, Mainz, celebrated its 20th anniversary. Further information about this event can be found on the website of the registry (www.kinderkrebsregister.de).

The Cancer Registry of Münster, North-Rhine Westfalia, conducted a study on the evaluation of homonym and synonym rates of encrypted vs. plain text data. The results were presented by the study group at the meeting of the IACR in Portugal 2000 and are published in German (contact: krebsregister@uni-muenster.de) As mentioned in the previous report the cancer registries in the states of Germany cooperate with the so called Dachdokumentation Krebs at the Robert Koch Institute, Berlin. One aspect of this cooperation is that the Dachdokumentation Krebs analyses the data of the registries with the objective of finding possible duplicate notifications in two (or more) individual registries. In 2001 this was done successfully and it is now the task of the Working Group of Population-based Cancer Registries in Germany to define standards for the evaluation and exchange of possible duplicate notifications.

The Saarland Cancer Registry will have a new modified "working" version of the originally established system of the former federal law on cancer registration. In principal there will be two separate units, a notification office and the "true" registry, but the separation between these two is not so extreme as originally intended. Record linkage will be done automatically on the basis of anonymized "control numbers", but doubtful cases are allowed to be re-identified for clearing. Notification will become compulsory. Principally all patients have to be informed on notification to the registry, and they have the right to withdraw. But there will be some derogation of the law, permitting reporting of patients who cannot be fully informed about their diagnosis. Pathologists are entitled to notify cases without immediately informing the patients.

The Netherlands

The Netherlands Cancer Registry is working on a report on the first ten years of cancer registration in the country (1989-1998). The regional cancer registries are working on a common information system for data-entry.

The regional cancer registry of Amsterdam (IKA) completed the follow-up of all recorded cases in the period 1988-1997 and a report is being prepared. The cancer registry of Eindhoven (IKZ) published recently a report on 45 years of cancer incidence and survival (book and CD-rom).

Information was received from W. Batzler, F. Buntinx, J. Coebergh, L. van Eijcken, P. Grosclaude, D. J. Klimont, V. Mattauch, W. Oberaigner, O. Visser and H. Ziegler.

European Network of Cancer Registries: Report to the Board of the International Association of Cancer Registries

David Brewster (Edinburgh, Scotland, UK) represents the IACR on the Steering Committee of the ENCR

New ENCR scientific co-ordinator
Dr Jerzy Tyczynski from the Polish Cancer Registry in Warsaw has recently succeeded Dr Risto Sankila as the scientific co-ordinator of ENCR. He can be contacted at tyczynski@iarc.fr.

Courses/course materials

A local course on the use of the new EUROCIM database (see below) was organised for UK registries in Sheffield, UK on 25-27 April 2001.

The first of several two day national ICD-O-3 coding courses for trainers of cancer registry personnel were held for cancer registries in northern Europe in Copenhagen, Denmark in September 2001 in London, UK in January 2002 for UK registries.

A statistical course, on the analysis of geographical studies was organised by Eero Pukkala (Helsinki, Finland) and held at IARC, Lyon on 15-18 January 2002.

A general course on cancer registration took place at IARC, Lyon on 8-12 April 2002.

The final version of the manual *Pathology of tumours for cancer registry personnel*, prepared by A Buemi from the Haut-Rhin Cancer Registry, Mulhouse, France, is now available. The manual is mainly intended for the ENCR courses, but will also be used at other IARC courses. It has been printed in English, but French and Spanish translations are also available.

Working groups

Recommendations on *Coding non-melanoma skin cancer* and *Method of detection in relation to screening* have now been distributed to registries and are available from the ENCR website (see below). Recommendations for coding Extent of disease have recently been circulated.

Confidentiality (Chairman: H. Storm, Danish Cancer Society, Copenhagen): In the light of the 1995 Directive of the European Union with respect to processing personal data, new guidelines for the cancer registries have been produced and sent to the ENCR member registries. The guidelines will provide a basis for the International Association of Cancer Registries (IACR) to prepare international guidelines

Registry reviews (Chairman: D. Brewster, Scottish Cancer Intelligence Unit, Edinburgh): This Working Group, previously called the Working Group for Auditing Cancer Registries, has now finalised the instructions and questionnaire to be used. A pilot review was carried out at the IKN Regional Cancer Registry, Groningen, Netherlands in June 2001. The main purpose of the review process (which, of course, is voluntary) is to help registries to improve their performance.

Bladder tumours (Chairman: C. Martinez, Granada Cancer Registry): A Working Group will be established to review the original ENCR recommendations for coding of bladder tumours, which is still a major challenge.

Completeness of registration A Working Group to look at methods of assessing completeness of registration will be established.

Automated cancer registration

Following a successful workshop on automated cancer registration held in Venice, Italy on 27 October 2000, two further meetings have taken place. Web pages and links designated to automated cancer registration will now be designed on the ENCR Internet home page, incorporating the material presented at the workshop, as well as downloads of the tumour matching test database and the tumour case consolidation test database. Standard definitions of essential data items in the summarisation process, case consolidation, etc., will be established and made available. It is intended to summarise the main results of the presentations in a journal publication.

Information for cancer control and planning

In collaboration with ENCR and the Health Monitoring Programme of the European Commission, a joint UICC/IARC workshop was held on 25 September 2001 in Paris, as a satellite meeting during the 4th UICC Cancer Management Meeting.

Cancer registries and evaluation of clinical care

A workshop for cancer registries on evaluation of clinical care was held in Veldhoven, the Netherlands, on 14-15 December 2001. The format was similar to that of the Screening Workshop held in 1999, with invited speakers and people from the European registries attending as observers. The proceedings will be published as a monograph.

Screening evaluation

The monograph, *Evaluation and Monitoring of Screening Programmes*, has now been published.

EUROCIM

A new EUROCIM version, with a time trends module and an updated dataset, was distributed to registries.

EUCAN

EUCAN was updated with estimates for 1997 and can be downloaded from the ENCR website.

Website

Further information on ENCR activities is available from the Network's website at:
<http://www-dep.iarc.fr/encr.htm>

Oceania

Tim Threlfall, Regional Representative for Oceania

The bulk of the Oceania Region's population lives in Australia, where there are population-based cancer registries in each State and Territory, and New Zealand. These registries liaise with one another through membership of the Australasian Association of Cancer Registries (AACR), which meets annually and conducts business through telephone conference throughout the year.

Other members of IACR are located in Guam (USA), New Caledonia, Vanuatu, Fiji and French Polynesia, and there is a Pacific Islands Cancer Registry administered through the South Pacific Commission in New Caledonia.

While communications within Australia and New Zealand are good and based heavily upon e-mail, the situation in the Pacific is less straightforward.

Efforts over the last two years to elicit more information about achievements and needs have been hindered by distance and, possibly, language differences.

Guam (USA)

Robert Haddock and Cynthia Naval produced the Guam Registry's first report in October 2000, comprising mortality for 1970-1999 and incidence for 1999. The data do not include information on military personnel, so are not

complete - although inclusion could complicate assessment of potential risk factors have been encountered. The report compares death rates for different ethnic groups, and compares standardized rates to those in various US areas. The report promises to be particularly useful to care and service providers, as the information is broken down by village and by ethnicity. Efforts to enhance the comparability of data should be well rewarded.

New Caledonia

Dr Yannick Rougier and Francine Baumann have supplied information based on 1998 incidence, in a registry active since 1977, now using the CanReg software. They note cancer to be increasing more rapidly in women than in men, and present time trends and data by ethnicity. Comparability may be an issue, as numbers of unknown-primary cases are low, and registration is based on pathology.

Australia

There are population-based registries in each of the States and Territories of Australia and these, together with the New Zealand Central cancer Registry, form the Australasian Association of Cancer Registries. All cancers are collected with the exception of basal and squamous cell skin. National reports, with data from all members, are now a regular event. Local concerns lead to the inclusion in these reports of standardized rates using both the Australian and the World standard populations.

Registries are independent, ultimately funded by State/Territory governments, but only Western Australia and South Australian registries remain wholly Government-operated, the remainder being administered through other bodies such as the local Cancer Fund or Cancer Foundation. Resources vary considerably, although this does not directly relate to the timeliness of reporting. Due to local concerns, data for National reports have to be held back until States and Territories have had a chance to publish their own data first.

Commonality of coding systems has yet to be achieved due to funding problems, however all areas are now able to produce or translate data coded to ICDO-2 and an ICD10 + morphology-based tabulation scheme has been agreed for future reports.

Registration sources generally include pathologists and hospitals, but Western Australia remains the only area without mandatory hospital

reporting. In-patient data are used passively to create records, but funding of a data quality study must be obtained before these cases can be safely included in routine incidence statistics. In-patient data collected thus lack basis of diagnosis and true incidence date information, but hospital data do now include a tumour morphology code.

New South Wales and New Zealand routinely collect information on extent of disease. Most areas collect melanoma thickness and breast cancer tumour size and nodal status. Moves towards an extent-of-disease system in Western Australia are hindered by disagreement between

the basic- classification supporters, and those who think full TNM staging is all that is worth collecting.

Brochures to inform the public about cancer registries have been produced by most areas in order to address concerns about privacy. These have been well received and have not resulted in any adverse publicity.

New Zealand

The current legislative basis of the New Zealand Cancer Registry was passed in 1994, however registration has been on-going since 1948. ICD-O-2 is used for coding, however a new system will use ICD-10 in the near future. The New Zealand population is about 3.8 million. New Zealand participates in the AACR, and collects extent of disease data. Certain screen-detectable cancers are “fast-tracked”, and liaison with screening programmes is increasing.

World Alliance of Cancer Research Organizations

The World Alliance of Cancer Research Organizations was created during the First Summit of World Cancer Research Organizations, held in Thailand in December 1999. The goal was to convene the world’s scientific leaders to identify and address the major issues in cancer research worldwide.

From the Constitution of the Alliance:

‘The mission of the Alliance is to accelerate progress against cancer by establishing an innovative, collective forum of leading cancer research organizations around the world for the advance of cancer research, global communication, and collaboration. The purposes of the Alliance are to share knowledge and expertise about cancer across all interested sectors in developing and developed countries; promote the advancement of cancer research; foster and expand education and training; advocate for increased funding for cancer research; expedite the application of new research discoveries to the cancer patient and the general public, support the implementation of science policies that benefit the cancer patients and the conduct of research; and harness the potential of new technology to accomplish the goals of the Alliance.’

The IACR was invited to become a Charter member of the Alliance, and the Alliance Steering Committee agreed to waive the membership fees. It was agreed during the Executive meeting in Cuba that this invitation should be accepted for an initial trial period of one year.

The Alliance website is www.aacr.org. It can be contacted by fax in the US (215) 440-9313 or via e-mail to their staff liaison wolodzko@aacr.org.

Obituaries

Lorraine Levy

Lorraine Levy was Professor of Medicine at the University of Zimbabwe Medical School. With a longstanding interest in medical oncology, and the author of several papers on lymphomas in South-Central Africa, Lorraine was active in the development of the Zimbabwe National Cancer Registry in 1985. The registry became fully population-based for the city of Harare in 1990 when she took over as chairman of the cancer registry committee.

Lorraine was very supportive of the registry and its activities, and in ensuring that it continued to receive funding from the Ministry of Health, even in difficult economic times for the country.

Lorraine Levy died at her home in Harare in October 2001.

Albert Tuyns

Dr Albert Tuyns joined the International Agency for Research on Cancer in 1967, and in 1969 started his well-known studies on oesophageal cancer in France in relation to alcohol and tobacco. He was an Honorary Member of the IACR and contributed to the development of cancer registration worldwide through his teaching and in his work with the Group for Epidemiology and Cancer Registration in the Latin Language Countries.

Albert Tuyns died on 11 November 2001.

Paul Schaffer

Professor Paul Schaffer was a Professor at the Faculty of Medicine of the University Louis Pasteur, Strasbourg and physician in CHU of Strasbourg. He founded the Laboratory of Epidemiology and Public Health in Strasbourg, and in 1975 set up the Bas-Rhin Cancer Registry – the first in France – which he directed until his death on 10 February 2002.

Paul was very involved in the two screening programmes in Bas-Rhin, a pilot breast cancer screening programme supported by Europe Against Cancer and launched in 1989 (With Professor R. Renaud), and cervical cancer screening from 1994 (with Professor P. Dellenbach).

Paul Schaffer worked closely with the International Agency for Research on Cancer and was a strong supporter of the Association and its activities.

Ian (Joe) Wilson Kemp

After graduating Dr Ian Kemp worked as a GP for ten years, then took up epidemiology in his native Edinburgh under Sir John Brotherstone. He became a Fellow of the Faculty of Community Medicine and a lecturer at Edinburgh University.

Later, he was the driving force behind Scotland’s first cancer atlas – pioneering work which earned worldwide acclaim.

After a stroke in 1988, Joe took up skiing, saying ‘I would rather die at the top of a mountain than sitting in a chair

staring out of the window'. Then he took up horse-riding and Scottish country dancing.

Ian Kemp died on 12 February 2002.

Claire Walker

WHO and a Tobacco-Free Europe

The WHO Ministerial Conference for a Tobacco-free Europe took place in Warsaw on 18-19 February 2002. The organisers of the conference were WHO-Euro in Copenhagen and the Polish Ministry of Health in Warsaw. Dr Jerzy Tyczynski represented the IACR.

Participants included delegations from 48 of the 51 Member States in the WHO European Region, and representatives of government, national and international organisations.

The World Health Organization has responded to the tobacco epidemic with the Tobacco-Free Initiative. The conference was held to strengthen the political climate for an international response to the tobacco epidemic, and to facilitate support for the Framework Convention by European Member States.

Dr Gro Harlem Brundtland, Director General of WHO, delivered the opening keynote speech, noting that worldwide 48% of men and 14% of women smoke. In the European Region an average of 30% of adults are still smoking and only Sweden has achieved less than the 20% target of WHO, with only 17% of men still smoking.

Dr Brundtland called upon Governments not to take money from the industry to finance youth campaigns. She reminded the audience that voluntary restrictions do not work and called for the creation and expansion of anti-smoking organisations to combat an estimated 700 million children exposed to environmental tobacco smoke worldwide.

Mr David Byrne (Member of the European Commission responsible for health and consumer protection) stated 'when it comes to life and death issues...we need to make the political weather. We need to take our political courage and be bold... the framework convention process gives us a unique opportunity to make the political weather for a global climate of tobacco control policy. . He insisted on the need for flexibility from governments in order to achieve a total ban on advertising, and criticised Germany for blocking the EU position on advertising and the UK for negating the rights of non-smokers to clean air.

Mr Byrne intends to propose a new directive before 2005 concerning a common list of ingredients authorised for tobacco products, and to develop recommendations on indirect advertising and access of young people to tobacco. He questioned the tobacco industry's arguments on freedom of speech... 'when its own products rot the tongues and mouths of its consumers to a stony premature silence !'

New publications

IARC tools

<http://www-dep.iarc.fr/resour/software/iarctools.htm>

IARCTools is a Windows-based package (Windows95 or higher). It incorporates a set of inter-field validity checks (especially for site vs morphology), and conversions between ICD-O, and ICD-10 and the International Classification of Childhood Cancer (ICCC).

A new version of IARC tools, incorporating the third edition of the International Classification of Diseases for Oncology, is being finalized and will be available soon.

Cancer registration and quality control in cancer registration

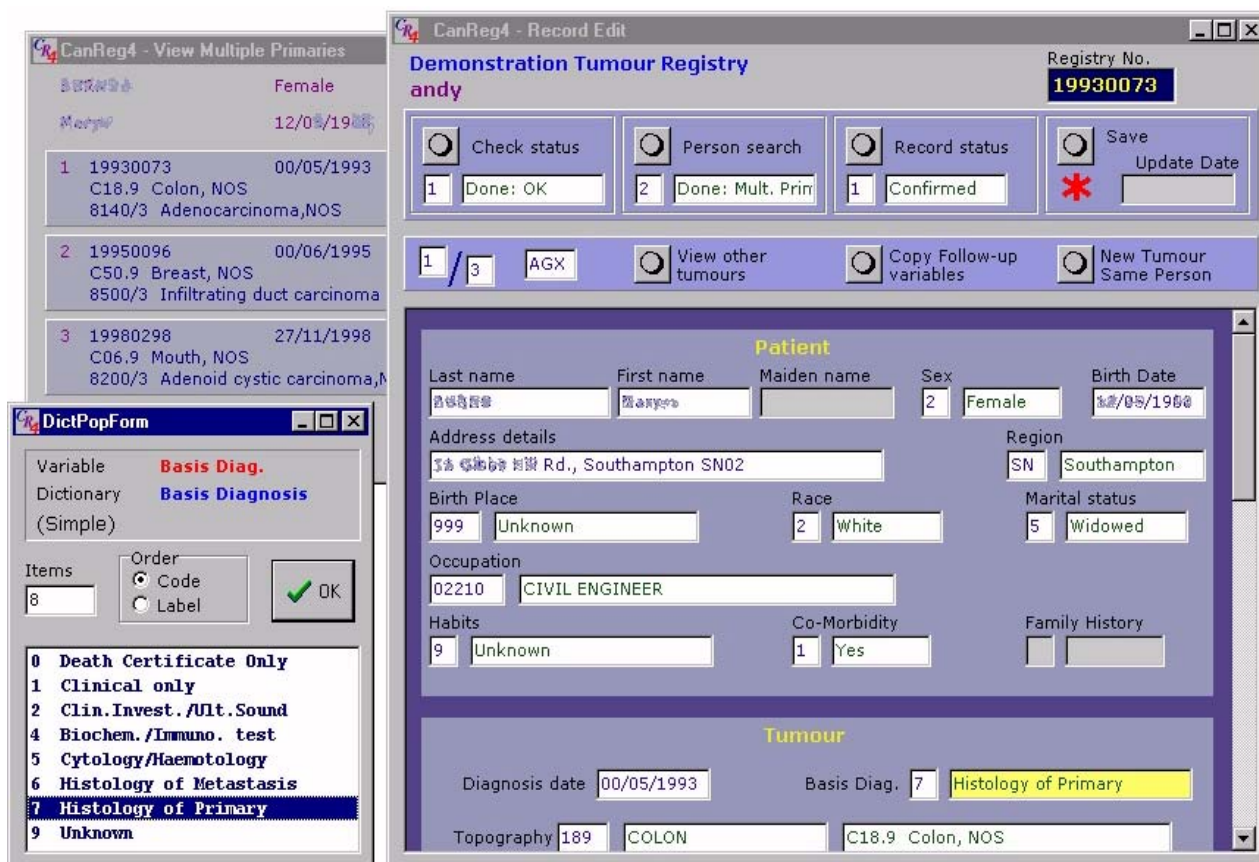
A compendium of three IARC/IACR publications for cancer registries (Manual for Cancer Registry Personnel, Cancer Registration Principles and Methods and Comparability of Quality Control) has been produced in Korean by Dr Choong Won Lee of the Daegu Cancer Registry. It is published by Gyeochuk Munwhasa and costs US\$15.

Cancer Incidence in Five Continents Volume VIII



The eighth volume in the Cancer Incidence in Five Continents series presents comprehensive data on cancer incidence for over 200 populations worldwide. The time-period covered is 1993-97, making available information on patterns and trends of cancer for over 40 years for the older-established cancer registries. The book follows the traditional format, with background chapters and descriptions of the areas and populations presented, as well as data on incidence by site and by histological type. A CD-ROM presents detailed data which can be extracted and analysed by the user.

Volume VIII will appear at the end of 2002.



Training

CanReg4

CanReg is a configurable computer program designed for cancer registration in population based registries. The previous version - "CanReg3" - was first released in late 1996 and has since been installed in more than 100 sites around the world.

The latest version, "CanReg4" is just being completed to include the checks and conversions for the recently published ICD-O-3. The Data-Entry module provides consistency checking for impossible / rare cases, search for duplicate records / multiple primaries using probability matching, and conversion to ICD-10. Easy-to-use analysis options include Frequency distributions, Reports, Incidence tables and an interface into EpiInfo6.

CanReg4 will allow for full integration into a Windows-based network environment, and extends the language-swapping capability to languages such as Chinese, Thai and Arabic.

Training courses for cancer registrars in CanReg4 and ICD-O-3 are being held throughout 2002 and into early 2003. The places and dates are:

2002

1-5 April	Hat Yai, Thailand
18-20 September	Lyon, France (for English-speaking Africa)
25-27 September	Lyon, France (for French-speaking Africa)
1-4 October	Saudi Arabia
21-25 October	Beijing, China
6-8 November	Quito, Ecuador
11-15 November	Barbados
28 November-1 December	Korea
10-13 December	Tunisia

2003

January	India
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