



Lisbon, Portugal - Site of the 1999 meeting of the International Association of Cancer Registries

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- ❖ Dr David Roder (Regional Representative for Oceania)
- ❖ Dr Dee West (Regional Representative for North America)

Many of you have been occupied this year with preparing your data and the background materials for Volume VIII of *Cancer Incidence in Five Continents*. The official deadline was 31 July, but data for the period (1993-97) are not ready for many registries and some will not be able to send their material until 2001. Nonetheless, there are now over one hundred datasets from registries throughout the world being processed at the International Agency for Research on Cancer (IARC).

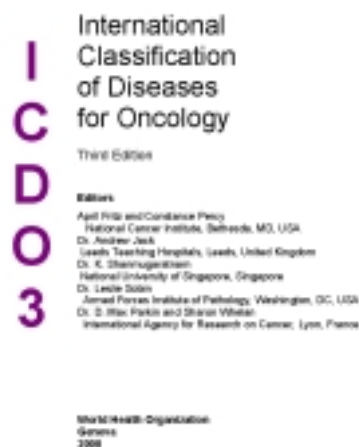
Another major collaborative project between the Association and IARC has reached a successful conclusion.

Editorial

Sharon L. Whelan

One of our activities this year has been the election of new IACR Officers by the Voting registry members. For the incoming Officers see Elections below. On behalf of the Association, I would like to welcome the new members of the IACR Executive, and to thank the outgoing officers mentioned here for all the work and help they gave to the Association during their period of office:

- ❖ Dr John Young (who remains in office as ex-officio President for the next four years)
- ❖ Dr Hans Storm (as General Secretary)
- ❖ Dr Mokhtar Hamdi-Chérif (Regional Representative for Africa)
- ❖ Dr Nandakumar (Regional Representative for Asia)
- ❖ Dr Vera Pompe-Kirn (Regional Representative for Europe)



The third edition of ICD-O is at the printers, and will be published in November 2000 – just in time for implementation in January 2001 for the registries which want to change now. CanReg 4 (the latest version of the computer software developed for cancer registration in developing countries) will incorporate ICD-O-3 and will be ready at the end of this year.

Meetings

Lisbon

The 21st annual conference of the IACR was held in Lisbon, Portugal on 29 September – 2 October 2000. Matti Hakama from Finland opened with the Calum Muir Memorial Lecture on *Screening Related to Cancer Registries*, and the session covered evaluation of screening for lung, colorectal, prostate, breast and cervix cancer.

Nigel Gray from Australia (via Milan, Italy in 1999) gave the keynote address on *Tobacco and Young People*: ‘Smoking is a habit sustained by addiction but initiated by social pressures... efforts to discourage experimentation remain an important public health priority’.

Genetic epidemiology is a term which has come to the forefront of cancer research in recent years, and Timothy Rebbeck from the USA summarized the role of genes in cancer aetiology, emphasizing the importance of gene-environment interaction. A focus of his presentation was the interaction of different classes of genes with one another and with environmental factors to produce the patterns of cancer seen in the general population.

Max Parkin (IARC, France) reminded us that the purpose behind quality control is to ensure that the data from registries are comparable – with each other and over time, so that comparisons of incidence, survival etc. reflect reality. The methodology to do this was reviewed, with emphasis on capture-recapture and death certificate methods which have been the focus of recent research.

The usefulness of cancer mapping to show geographical variation and hot-spots for specific tumours was illustrated by Susan Devesa (USA) using the 1950-94 atlas of cancer mortality in the United States. The patterns of cancer displayed serve to target analytical research into the causes and control of cancer. Susan Devesa continued

with an introduction to the session on trends, discussing the importance of graphic design and particularly the choice of axis to display temporal trends in disease rates.

A selection of oral and poster presentations of a high level accompanied each topic in the scientific programme, and the 240 participants from 54 countries formed an enthusiastic audience. Just as they participated with enthusiasm in discovering Portuguese hospitality, food and folklore – and the extraordinary beauty of the city of Lisbon. Special thanks to our hosts Edward Limbert and Ana da Costa Miranda and all their fellow workers for a very special meeting.

Next meetings

IACR 2001, late September, Havana, Cuba
IACR 2002, 26-28 June, Tampere, Finland

Elections

Elections for new officers have been held and the new officers will hold office for four years.

President: Dr Hans Storm,
Denmark
General Secretary: Professor David
Forman, UK

Regional Representatives for

Africa Dr Henry Wabinga
(Kampala, Uganda);
Asia Dr Divina Esteban
(Manila, Philippines);
Europe & Near East Dr Tiiu Aareleid
(Tallinn, Estonia);
North America Dr Brenda Edwards
(Bethesda, USA);
Oceania Dr Tim Threlfall
(Western Australia)

Dr Max Parkin, IARC remains as Deputy Secretary – an office held in permanence by the Chief of the Unit of Descriptive Epidemiology of the Agency. Regional

Representatives to remain in office for a further two years are Dr Edwin Carrascal (Latin America), Dr Eric Holowaty (North America), Dr Leo Schouten (Europe) and Dr Vanchai Vatanasapt (Asia).

The IACR officers take part in the annual meeting of the Executive, held just before the annual scientific meeting, to discuss the activities and aims of the Association. Each Regional Representative is expected to prepare a report on cancer registration activities in his/her region, but it is often difficult to obtain this information and members should remember that their Representative will always be grateful for news on what is happening in their registries/regions.

During the year all Officers assess the membership applications received, to decide on the appropriate (Voting or Associate) membership status to be given. The criteria are:

Full voting membership for well established population-based registries or associations of such registries which collect data on all sites of cancer and have good coverage of an accurately enumerated defined population and can provide valid incidence rates.

Non-voting (associate) membership for organisations and cancer registries which for one reason or another do not cover all cases of cancer in the population, e.g. newly established, not population-based, or site-specific.

Associate members can always apply to be upgraded to Voting membership. Any member (Voting or Associate) has the right to submit data for collaborative projects between the Association and the IARC.

Individual membership is available to any person/organisation wishing to be on the mailing list, to keep abreast of Association activities.

World Health Organization

Hans Storm

Meeting of the WHO Regional Office for Europe

This year's meeting was the first under the new Regional Director – Dr Marc Danzon, who took office in February 2000. He emphasized the role of the WHO in providing leadership in health and helping member states to implement their own health policies in line with the framework set out in Health 2001. It is hoped that better cooperation with the EU can be achieved.

A call was made for a central databank for Europe. Interestingly, a special call for a regular and informal dialogue with NGO's was made. The European office wishes to develop and maintain partnerships for health, acknowledging that the means of WHO are limited and that a lot of expertise is unused by WHO at present. As a first step all NGO organisations were called to a special meeting with the Director and the temporary staff for NGO collaboration. The IACR may expect to be called to a meeting on the data, and expertise, available in epidemiology and public health. In a statement to the session (below) the IACR described the databases available for cancer, and its willingness to collaborate with WHO, as well as asking WHO to support the research activities of the registries by influencing governments to avoid legislation on confidentiality that prohibits cancer registration.

Also a plea was made to support the development of cancer registries in areas not covered by registration.

Statement of the International Association of Cancer Registries to the 50th Session of the WHO Regional Committee for Europe

The International Association of Cancer Registries (IACR) was founded in 1966. Its aim is to improve quality of data on the occurrence of cancer and comparability between registries, by standardizing methods of registration, definitions and coding. The Association disseminates information on cancer incidence, prevalence, mortality and survival which permits the planning, and evaluation of cancer prevention and therapy, and epidemiological research into the causes of cancer.

The Association has been a non-governmental organization in official relations with the World Health Organization (WHO) since January 1979. Over 250 member registries make expertise in this area of public health available to WHO in all regions.

With progressive ageing of populations in the European Region, cancer is becoming an increasingly important public health problem. Cancer is the leading cause of premature death in age below 65 years in the Region. Research into the causes, prevention and treatment of cancer should be a priority in all regions. It is with great concern noted that only few countries in the area have formulated and funded clear cancer control activities. We wish to draw the attention of the WHO and the member states to the availability of statistical cancer data for the entire world (GLOBOCAN) easily accessible on the web-site of our Association and data, including survival after cancer, from the European Network of cancer registries (EUCAN) at the address <http://www-dep.iarc.fr> (International Agency for Research on Cancer, WHO, Lyon). The WHO is urged to promote the establishment of cancer registries in those areas where reliable cancer statistics are not yet available, and to further strengthen the action on the non-communicable diseases, including cancer.

A major activity of cancer registries is to carry out research into the causes of cancer, with the aim of preventing the disease. In order to do this work at all, and to do it accurately and efficiently, data must be compiled on individuals, with the possibility of linking this information with that on exposure to possible risk factors in the same persons. WHO is urged to assist registration, regionally and worldwide, by influencing governments to maintain the research potential of cancer registries, in particular by advising against legislation designed to prevent the storage and use of health-related information on named individuals. Cancer registries are expected to operate within clearly defined codes of confidentiality – the Association even providing a model code for their use – which preclude any breach of civil liberties or untoward use of confidential information.

The members of the Association are willing to share with WHO and its individual members their expertise and experience in registration of individuals with cancer, and in the use of registry data in the service of the public, and for research purposes. According to the constitution of the IACR, it is the purpose of the Association to facilitate exchange of information and the organization of projects on a regional basis, and to cooperate with and seek the support of other organizations in fostering activities of mutual interest. We wish to develop and strengthen the collaboration with the WHO regional office and member states to develop common progress in the fight against cancer, against tobacco and other known causes of cancer, to reach the goal “Health for All”. We welcome that this goal is emphasized in the WHO-regional plans for the coming years. The Association also welcomes the planned organisational changes with a view to the use of our membership’s expertise in the work of WHO in the region.

Problems in Switzerland

The Association of Swiss Cancer Registries (ASCR) is obliged to consider its dissolution

**Christine Bouchardy,
President of the ASCR**

Eight population based cancer registries are now active in Switzerland. They cover a population of 3.7 million, 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, aetiological, 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 ASCR for more than 20 years. Already from the start, the objectives were the management of a pooled dataset, the use of these data for a comprehensive description of nationwide figures on the burden of cancer, the development of cancer registration and epidemiological research.

In Switzerland, as in other countries, cancer epidemiology has an ever growing need for information, results and skills, in particular for the evaluation of the effectiveness of national programmes against cancer, the epidemiological surveillance of the population, and the evaluation of healthcare output. In addition to the increasing number of cancer cases occurring in the ageing Swiss population, there is a growing demand on the cancer registries to increase the information collected and to provide useful and interpretable statistics for public health authorities, health insurance, medical communities, and researchers.

With the help of international experts (JWW Coebergh, C Hill, DM Parkin, R Zanetti), the ASCR conducted an evaluation of its objectives, means and internal functioning three years ago. 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 peripheral registration (Rapport du Comité d'évaluation et de restructuration, 1999; SIAC evaluation report, 1999; Additional funding for the Swiss cancer registry network and population epidemiology, 2000).

Because of the uncertainties related to its structural attachment and its lack of financial means, the ASCR cannot fulfil the assigned objectives any more, 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 re-organization process undertaken by the ASCR, the Association is obliged to consider its dissolution. Wishing to operate a last attempt to avoid this, it elects a President *ad interim* (as of 1 January 2001) until 30 June 2001, with the task to find structural and financial solutions to avoid this dissolution.

As cancer registries have proven to be an essential part of any rational cancer control programme, the Swiss cancer registries deeply hope that such solutions will be found. With the present information on the situation of the Swiss cancer registries' network, the ASCR is looking forward to receiving any suggestions from national and international professionals or institutions.

Collaborative Project in Europe

Automated Childhood Cancer Information System

Eva Kramárová

The Automated Childhood Cancer Information System (ACCIS) is a system of collection, presentation, dissemination and interpretation of indicators of the childhood cancer burden in Europe. Over 100 population-based cancer registries in 35 European countries are collaborating in this project.

When completed, ACCIS will provide data on childhood cancer incidence, mortality and survival, using a specially designed computer program. Aggregated statistics will be made available on the Internet and the results will also be interpreted in scientific publications. Our colleagues with an interest in collaboration are welcome to contact the secretariat of the project at IARC (Kramarova@iarc.fr).

At present, data collection is underway and the registries are sending their childhood cancer data sets to IARC for validation. The ACCIS database is being constructed. The target coverage is defined by the period (1970s until now), age at diagnosis (0-19) and geography (Europe).

An international Scientific Committee, with expertise in childhood cancer registration and population-based cancer survival analysis, supervises the project methodologically. Financially, ACCIS is supported by the European Commission and IARC.

ACCIS will greatly facilitate access of the public, press and health professionals to up-to-date information on childhood cancer in Europe and will contribute to the increase of awareness of cancer registries by use of their data. Accumulation of large numbers of childhood cancer cases will help in the

setting up and accomplishment of powerful international studies on all aspects of the fight against cancer in childhood.

ACCIS has its own home page at <http://www-dep.iarc.fr/accis.htm>, where the project is presented in more detail.

Obituaries

Virginia Sangalang

Virginia Sangalang was born on 1 January 1952 and died on 8 February 2000.

A Bachelor of Arts, with a Mathematics major, Virgie was employed at the Rizal Medical Center, Philippines since 1977. She was assigned to the DOH-Rizal Cancer Registry in 1983 where she was responsible for the in-put procedures of the registry.

At work, Virgie was dedicated, working hard without complaining, even under less than ideal working conditions. She maintained an unruffled composure even under pressure and could always be depended on to meet her deadlines. Although she was very shy, she was eager to learn and became an important asset to the registry.

In December 1999, these qualities were finally recognized by the Rizal Medical Center and she was given the "Employee of the Year (Administrative)" award.

At home, Virgie lived with her married brother and his family and helped in raising her nephews and nieces.

Virgie was a sincere and generous person, and we shall miss her presence greatly. But she will be with us for many years to come in another way. Her picture was chosen for the front cover of *Cancer Registration: Principles and Methods* (IARC, 1991). It is used all over the world, and will be for a long time to come. Virgie's

gentle presence will be there before workers in many lands who are striving to overcome the terrible toll of cancer.

Divina Esteban

Antonio Zubiri Vidal

Antonio Zubiri Vidal was born on 29 June 1917 in Castellón de la Plana. He died on 13 September 2000.

Distinguished both as physician and politician, Antonio Zubiri started his medical studies at the University of Zaragoza in 1933, and his political life in 1936 as Head of the Spanish University Union of Zaragoza.

He was at the head of the Provincial Government of Zaragoza for 18 consecutive years from 1954 –1970, and during this period became renowned not just for the excellence of his work but for consistent kindness and fair treatment of all, a democratic commitment particularly noteworthy in an authoritarian era in Spain.

Antonio Zubiri combined his political duties with his scientific career skilfully, to the point of becoming one of the foremost dermatologists in Zaragoza and Aragon. He never abandoned his position as Director of the Dermatological Service of the Provincial Health Authority.

Moreover in 1960 he initiated the population-based cancer registry of Zaragoza, the first in Spain. The Spanish Association Against Cancer found in him one of its strongest guardians.

He was a member of the Royal Academy of Medicine of Zaragoza from 1957, and in 1975 was named Honorary President of the Spanish Academy of Dermatology. Five years later he was awarded in Madrid the title of Medical Specialist in Dermatological and Venerological Medicine. In 1993 the Official College of Doctors of Zaragoza designated him Most Distinguished Professional. He was given many awards

and distinctions in recognition of his life's work in the service of others, not only in his quality of doctor but also in his capacity of politician.

When Antonio Zubiri learnt of his diagnosis, he published an article entitled: 'I have cancer' with the aim of helping and encouraging those sharing the same disease.

Antonio Zubiri leaves a widow and eight children.

John A.H. Waterhouse



Born in Birmingham in 1918 John went from King Edward's School to Cambridge returning to take his PhD at the University of Birmingham. After four years as research student and fellow, he was appointed in 1947 Senior Lecturer in the newly established Department of Medical Statistics becoming Reader in Medical Statistics six years later. His early work was widespread, including twin studies, field trials on the acceptability of the contraceptive pill and a pioneer study on the incidence of hypothermia among the elderly. Throughout his career he was involved in advising colleagues and in clinical trials. He liked young people and enjoyed trying to inspire, through his lectures, each new intake of medical students.

He was one of the first cancer researchers in the UK to realise that the National Health

Service Central Register, started in the UK after the introduction of the NHS, could be used to obtain national follow-up data for cohort studies. He initiated cohort studies of chrome platers, rubber workers and cadmium workers; all of which continue to be the source of new information into occupational cancer risks. These studies have stood the test of time because of their simple elegant design. They were all entry cohorts (eg the study of rubber workers comprised 36,000 male workers first employed in the period 1946-60 who were employed for at least twelve months). Also, they included data on complete work histories: this was at a time when statistical software was not available to make full use of such work histories! Other studies made use of the Birmingham Cancer Registry and his work on scrotal cancer in workers exposed to mineral oils is a fine example of his approach to epidemiology: use the simplest possible experimental design to study the question in hand.

From the late 1950's John was involved in the development of standards for and the recognition of Cancer Registries. Birmingham (now the West Midlands) Cancer Registry, established in 1957, collected both epidemiological and clinical information and was soon involved in co-operation at international level.

One of the founders of descriptive epidemiology as we know it today, his pioneering work made an immense contribution to our understanding of the geography of cancer. As an editor of the first five volumes of *Cancer Incidence in Five Continents* (a noteworthy achievement in itself) he laid an enduring foundation for the development of cancer registration and the use of the data collected. As a founder member, and second President, of the International Association of Cancer Registries he was active in promoting the development of cancer registration and epidemiology internationally.

Jean Powell

Regional Reports for 1998-1999

Africa

Mokhtar Hamdi-Cherif,
Regional Representative for Africa

The considerable effort which has gone into fostering the development of population-based cancer registration in Africa is now bearing fruit. Population based registration is developing in many areas in Africa. There are at least 50 population-based cancer registries functioning in Africa at the present time, with many new registries in the year 1999.

In Algeria, eight cancer registries (four of them new), using Canreg-3, have now published data: Algiers in the Centre; Oran, Tlemcen and Sidi Bel Abbes in the West, and Constantine, Annaba, Batna and Setif in the East.

In Tunisia, there are two new registries, North Tunisia and South Tunisia, Sfax. The Sousse cancer registry in Central Tunisia has been functioning for a number of years. There is a plan to coordinate the three regional registries to achieve national coverage.

Nine cancer registries published data in the *International Incidence of Childhood Cancer, Vol. II*: Setif (Algeria), Alexandria (Egypt), Ibadan (Nigeria), Kampala (Uganda), Malawi, Mali, Namibia, South Africa, and Zimbabwe.

Five cancer registries published data in *Cancer Incidence in Five Continents, Vol. VII*: Setif (Algeria), Bamako (Mali), Kyadondo (Uganda), Harare (Zimbabwe), and Ile de la Réunion (France).

Recent results are available for the cancer registries of Côte d'Ivoire, Niger, Nigeria, Gabon, Congo, Gambia, Malawi, Namibia, Niger, Rwanda, Uganda, Guinea and Zimbabwe. New Registries have been

established in Eldoret (Kenya) and Butare, Rwanda, and Botswana. Data from Bulawayo, Harare, Butare and Conakry have been published in scientific journals.

A small minority of African cancer registries is published in Volume VII of *Cancer Incidence in Five Continents (CI5)* due to the circumstances in which they have to work, with poor medical infrastructure, and difficulties in data collection. The data available on cancer patterns in Africa are sparse and it was decided to produce a monograph on the epidemiology of cancer in contemporary Africa, drawing upon several sources, not only the accurate incidence data which appear in CI5. The publication will include results from the published incidence and relative frequency data from the literature and a comprehensive review of cancer occurrence for selected sites and for the different regions in Africa. Data from over 20 cancer registries are being analysed. The book will be published in 2001.

Two courses on cancer registration and CanReg 3 were held in the Unit of Descriptive Epidemiology at IARC. They concerned the directors of the registries of Niamey, Oran, Batna, Rwanda, Congo, Kenya, Swaziland and Tunisia.

The majority of cancer registries in Africa use CanReg 3.

A meeting on Cancer Registration was held in Algiers on 1 July 1999, in which all the Algerian cancer registries participated.

The first meeting of the African Association of Cancer Registries, planned for November 1998 in Bamako, was cancelled because of finance, the travel especially being very expensive.

The 1999 Calum Muir Fellowship was awarded to Leslie Banda from the Malawi Cancer Registry.

The Association de Recherche sur le Cancer (ARC) (France) has awarded 30 000

FF (\$5000) to IARC and FRANCIM (the Association of French Cancer Registries), to promote six sub-Saharan francophone cancer registries. Measures to improve the quality of the registries include provision of equipment and training for the cancer registries of Burkina Faso, Mali, Guinea, Mali, Congo (Brazzaville) and Côte d'Ivoire.

In accordance with WHO recommendations to promote health in the African region we asked the WHO Regional Office for Africa to participate actively in the promotion and development of Cancer Registries in sub-Saharan Africa, and to support of the African Association of Cancer Registries.

Canada

Eric Holowaty, Regional Representative for North America

Health care reform and demographic changes continue to shape cancer care in Canada. With cancer incidence expected to double by the year 2010, Canada's lead agencies in cancer control, namely, the National Cancer Institute of Canada (NCIC), the Canadian Cancer Society, Health Canada, and the newly created Canadian Association of Provincial Cancer Agencies, are now meeting to formulate a nationwide cancer control strategy. A new national framework will define common goals, priorities, standards and indicators. Canada's cancer registries will provide the cornerstone for an expanded surveillance system that will monitor and report on our progress towards these goals. Last August, the Canadian Council of Cancer Registries had a special retreat focusing on the emerging demands for a more comprehensive and standardized cancer surveillance system across our nation.

The new Canadian Coalition on Cancer Surveillance (CCOCS) continues to play a seminal role in the evolution of cancer registries in Canada. With financial support

largely from Health Canada and NCIC, the CCOCS is now implementing a five-year business plan to test and develop vital components of a comprehensive surveillance system:

1. Consensus has been reached on an expanded set of standardized data elements, including more detailed information about primary treatment and stage.
2. With assistance from Statistics Canada and the Canadian Institute for Health Information, a comprehensive quality management program will be initiated, beginning with a redevelopment of national standards and careful piloting of case ascertainment studies.
3. A framework and protocols for estimating the costs of cancer control.
4. A standardized dataset of information about cancer risk factors and screening behaviours.
5. A data model and pilot studies to demonstrate the feasibility and utility of networking existing administrative databases and health information systems, including cancer registries, perhaps in collaboration with the new National Health Surveillance System
6. A systematic review, undertaken by a legal/privacy expert, of legislation, regulations and policies relating to the collection, use and dissemination of data products and services.

While national cancer statistics have been generated in Canada since 1969, the national patient-based cancer registry, called the Canadian Cancer Registry, only begins with 1992 registrations. As a result of this centralized system, Canada can efficiently report on the burden of cancer. For example, based on recent projections, we expect that about 130,000 Canadians will be diagnosed with cancer this year and approximately 60,000 will die from it. As reported last year, we are now seeing a steady fall in the rate of all causes cancer mortality, following many decades of a steady increase. This

recent decrease in the risk of dying of cancer is most notable among men, and is mostly attributable to recent declines in cancers of the lung, colorectum and stomach. Among women, this decline in overall cancer mortality is more recent, or has not yet been seen in all provinces of Canada, largely because the risk of lung cancer in Canadian women has not yet begun to fall.

All provincial and territorial registries, and the CCR, are full members in the North American Association of Central Cancer Registries (NAACCR). There are substantial advantages for members, including access to standards, software, publications and, most important, new ideas for operating and using our registries. NAACCR's recent call for data, for both 1996 and 1997 incident cases, by December 1999, will be a challenging target for all Canadian registries - only last month the CCR finally released data for the 1995 incidence year.

As reported last year, there is significant variation in the size of individual registries in Canada, ranging from approximately 65 new cases per year in our smallest territory, to approximately 50,000 cases per year in our largest province. Organizational size limits research and development projects within many of our registries. However, several of our registries are now moving towards automated record linkage with population-wide health administration files and mortality files. Further, with increasing automation in our hospitals and laboratories, many registries are receiving a growing proportion of their reports electronically, particularly hospitalization abstracts and confirmatory pathology reports.

Cancer Registries in the Caribbean

*Eric Holowaty and Beverley Barnett
(WHO/PAHO Caribbean Office)*

New strategies are being formulated by the World Health Organization and the Pan

American Health Organization, in cooperation with national health ministries, to develop and implement an integrated approach to cancer prevention, early detection, curative treatment and palliative care. The focus of these strategies is the "cancer priority ladder": tobacco control, curable cancers, healthy eating, effective pain control, referral guidelines, clinical care guidelines, nurse education, a national cancer network, clinical evaluation, and clinical and basic research. With expertise available from PAHO and WHO, nations are adapting this framework and identifying targets based on the current economic, and the emerging epidemiological situation in each country.

Cancer registries, just as cancer control programs, are at different stages across the nations of the Caribbean Region. Those that currently operate central cancer registries (Bermuda, Grenada, Trinidad and Tobago) are mostly using the software system CanReg. Cuba and Puerto Rico also operate central registries, but their software systems were unknown at the time of this report. Installation and training for CanReg has recently been provided in Barbados, St. Kitts and Nevis, Dominica, St. Vincent and Grenadines, and the Bahamas, although none has yet implemented a central registry. Cayman Islands and Guyana have also recently requested CanReg training.

Dr Beverley Barnett, at the PAHO/WHO Office of Caribbean Program Coordination, recently surveyed all Health Ministries in the Caribbean Region regarding cancer registry status. As of September 1999, she had received responses back from 15 of 24 countries surveyed, each expressing a high degree of interest. However, it is unclear what barriers remain for successful implementation. Dr. Barnett is interested in working with the International Association of Cancer Registries in order to complete requirements analysis and to provide technical and other assistance in support of the successful development and implementation of central registries across

the Caribbean Region. Interestingly, PAHO recently (October 1998) published a written guide on the Establishment and Maintenance of Cancer Registries in Caribbean Countries.

With preliminary plans for IACR to convene in Cuba in 2001, it may be appropriate for the IACR to host a special symposium or workshop on the operation and use of cancer registries in the Caribbean at that time.

Central and South America

Edwin Carrascal (Colombia), Regional Representative for South America

In spite of requests for information, the only news came from Ecuador.

Ecuador

The national Cancer Registry in Quito (NTRQ) produced its 11th annual report on Cancer in Quito in 1999. The NTRQ continues to encourage the creation of new population-based cancer registries in Ecuador, and a registry is being set up in Guayaquil, the largest city in the country. Technical advice and training are provided by NTRQ.

The Director, Fabian Corral, attended the XXII Latin American Congress of Pathology in Lima, Peru, where he gave a presentation on *Epidemiology of Gastric Cancer in Ecuador*. The registry coordinator, Patricia Cueva, attended the IARC Course on Cancer Prevention and Control in Costa Rica.

Colombia

The Cali Cancer Registry (CCR) implemented CanReg3 in August 1998. The program is now in full use and this has greatly facilitated the work of the registry. In addition, three new Pentium PCs have been acquired.

The registry held a workshop on Cancer Registration in April 1999 in Cali, sponsored by the National Cancer Institute of Colombia (NCIC). The meeting was the first step in the creation of new cancer registries in Colombia, based on initiatives from the NCIC and advice from CCR. A cancer registry started activities in Pasto in 1998, and the aim is to create further new cancer registries in areas with differing characteristics: Cartagena on the Atlantic North coast, Bucaramanga in the West and Medellin in the centre of the country. The Cartagena Cancer Registry was formally established in August 1999, with a local workshop in which CCR staff participated. Registries in Bucaramanga and Medellin should commence in 2000.

Colciencias, the Colombian System for Science and Technology, provided funds for projects on *Helicobacter pylori: pathology and prevalence in gastric biopsy material in Colombia* and *Wilms' tumour: pathoepidemiology in Colombia*. Initiation of the projects was delayed because of financial problems in Colciencias, but work started in 1999 in representative parts of the country. CCR members conduct the studies.

HTLV-1 associated lymphoid neoplasia in Cali and *Epstein-Barr associated gastric carcinoma worldwide* were the objects of studies sponsored by Japan Agencies through Kagoshima University. The report of the first was finished in March 1999, and the second, including data from several collaborative centres, at the end of 1999.

The CCR Director presented *Epidemiology of Gastric Cancer in Colombia*, and a proposal to standardize pathology reports on gastrectomy specimens for cancer in Latin America, at the XXII Latin American Congress of Pathology in Lima, Peru in October 1999.

Asia

A. Nandakumar,
Regional Representative for Asia

India

The National Cancer Registry Programme (NCRP), under the Indian Council of Medical Research, partly funds and coordinates the network of population- and hospital-based cancer registries through its Coordinating Unit. A workshop was held in August 1999 at the rural registry of Barshi. The main subjects discussed were ICD-O-2 coding, quality control exercises, design and statistical techniques for epidemiological studies, planning a research project, oncological terms and clinical staging in breast and cervical cancers. The Coordinating Unit of NCRP is coordinating a multi-centric case-control study on 'Vasectomy and Cancer of the Prostate' and a case-control study on cancer of the gallbladder in Delhi.

In Ahmedabad the PBCR covers an area of 255 sq km. with an estimated population of 3.75 million and registers some 3500 cases, of which 2300 confirmed as cancer, a year. It has over 50 sources of data all over the city, although many cases are referred to the registry base the Gujarat Cancer Research Institute, as radiation therapy is available only in this institute.

A Rural Cancer Registry covering Panchmahal District was sanctioned by the ICMR in 1994. The district covers 8866 sq km and a population of 3.27 million. It is a socio-economically backward area with a substantial (42%) tribal population. The primary objective is to estimate cancer incidence in the rural and tribal communities. It will also evaluate the district cancer control project. There are over 150 data sources.

Another rural population is that covered by Ambillikai, established in 1995. The

population of 359,674 live in 384 villages spread over 2058 sq km in Palani and Oddanchathram taluks of Dindigul District, Tamil Nadu, in South India. In males, mouth cancer was the most frequent cancer (ASR 11.5), while in females cervical cancer accounted for more than half the cancers (ASR 65.4 – second highest incidence of cervical cancer in the world). More than four-fifths of cervical cancer cases were diagnosed in stages IIB and IIIB; a third of the patients either did not have or did not complete treatment. The observed cancer patterns in this population establish that measures directed at prevention and early detection (linked with treatment) of cervix and head and neck cancers are of paramount importance for cancer control in this and other rural populations of India.

In Bangalore, a new active follow-up procedure through visits to homes of patients was undertaken for selected sites of cancer and results on survival have since been published. The registry has carried out several exercises to examine coverage and quality, including circulating a specially-designed form emphasizing residential address and duration of stay in Bangalore to the principal data sources, and collecting all general deaths from all death units in Bangalore to match with incident cases. It has also been involved in multi-centric projects – a survey of tobacco and cancer, and a case-control study of prostate cancer.

In the first rural registry in India, Barshi, established in 1987, a survey of tobacco use in the population has been under way since 1994; information on the literacy level of the population interviewed has also been collected.

The Calcutta registry's annual report for 1997 was published in 1999. In Chennai, Madras the PBCR is the only urban registry to abstract data from the Vital Statistics Division on all deaths irrespective of indicated cause of death on the death certificate and match them against the morbidity database. The registries of

Chennai and of long-established Bombay are involved in a number of descriptive and analytical studies. The PBCR in Delhi, which has a high incidence of gallbladder cancer, is conducting case-control studies on cancers of the gallbladder and prostate. There is a PBCR in Trivandrum, and a registry has been established at Karunagappally, 100 km from Trivandrum to study a population exposed to high levels of natural radiation.

Iran

The registry in Iran is essentially hospital-based. A collaborative research project with a main focus on genetic epidemiology, and more specifically breast cancer, is being carried out with IARC. The project includes analyses on breast histopathology, immunochemistry and ethnic and patient pedigrees.

Israel

The Israel Cancer Registry receives more than 100,000 records, relating to 15,000 new cases and 20,000 known cases, every year. The registry was founded in 1960, in part to exploit the unique possibility of studying the incidence of cancer in a population made up largely of migrants from different parts of the world and their descendants who, although united by religion, represent a wide diversity of lifestyles. Another peculiar opportunity is offered by the co-existence in the Israeli population of Jews and Moslems with their own specific lifestyles.

Every record arriving in the Registry is checked against the National Population Registry for accuracy of the demographic data. There is a computer system of logical checks. A 10% sample of the records processed by each Registry clerk is checked by another clerk for agreement between the data keyed in and the original record. The whole team discusses specific cases of disagreement. When periodic summation of records received reveals a drop in the reporting rate from a particular source the

matter is investigated with the reporting institute.

Jordan

The Ministry of Health established the National Cancer Registry of the Hashemite Kingdom of Jordan (population 4.3 million), in 1996. It collects data from 38 sources using both passive and active methods. Data are managed by the CanReg3 software. In 1996 2833 cancer cases were registered.

Kuwait

The Cancer Registry covers a population of some 1,700,000, of whom 37% are children aged below 15 years. Kuwait nationals constitute about 40% of the population, and expatriates from more than 50 countries 60%. The registry is a department of the Kuwait Cancer Control Centre, which is the only specialized cancer treatment hospital in the country. Notification of cancer is compulsory through a Ministerial Decree. Registration is reasonably comprehensive as almost all cases not initially diagnosed or treated in the Centre (including those who receive initial treatment abroad) are referred to the Centre for further treatment or follow-up.

Oman

Oman Cancer Registry, established as a hospital-based registry in 1985, started population-based coverage of the 2.3 million (1.7 Omanis and 0.6 million expatriates) population in the Sultanate of Oman in 1996, by case-finding in all the regional hospitals and tertiary care centres in the country. Annual reports were published in 1996, 1997 and 1998. A total of 915 cases (817 Omanis and 98 expatriates) were registered during 1998.

Pakistan

The Karachi Cancer Registry, established in 1995, is the first population-based registry in Pakistan. Muslims form 97% of the population, and Hindus, Christians and

Parses account for the remaining 3%. Registration is active and the personnel visit the hospitals, laboratories and clinics to collect data, including interviewing the patients. Residents of Karachi South are identified in the death-registry offices.

Completed forms are checked and coded in the registry office. There are generally three or more sources of case-finding/reporting per case, so a careful check is performed to avoid duplicates. The registry uses CanReg for data management and analysis.

In addition to the traditional methods of estimating data completeness, including an annual re-abstracting and re-coding exercise. Counselling clinics and free-of-charge drugs/laboratory facilities have been set up to help patients who might avoid the health-care system for financial reasons. A telephone helpline for patients is now available with student volunteers dealing with patients' problems, with the help of supervisors.

Saudi Arabia

The National Cancer Registry of Saudi Arabia was established in 1992 under the Ministry of Health and covers the entire population of the country (14.2 million). During the years 1994-96 8791 male and 7503 female cases were registered, and reports are produced regularly.

Yemen

A population-based cancer registry covering the population of Aden city and suburbs was initiated in 1999.

Europe, South and East

Vera Pompe-Kirn,

Regional Representative for Europe

Reports on cancer incidence were published for 1996 in *Bulgaria*, the Czech

Republic, *Estonia*, *Poland* (all registries together), and *Slovenia*, for 1995/1996 in *Latvia*, for 1995 in *Malta*, and *Slovakia*, and for 1994 in *Croatia*. The quality of reports is improving everywhere. In the Czech Republic, an Atlas of Cancer Incidence 1978-1994 was published in 1998. In Poland, an Atlas of Cancer Incidence and Mortality within Katowice district in the years 1985-1993 was published in 1999 (dedicated to the memory of Prof. Jerzy Staszewski).

In 1998 the Italian Association of cancer registries (13 Italian population-based regional cancer registries, and three special cancer registries) published a booklet *Fatti e cifre dei tumori in Italia* containing incidence, prevalence, survival and mortality data.

In *Lithuania* no report was issued, but analyses on trends in incidence have been done (see: Kurtinaitis J. Winkelmann R. Cancer incidence in Lithuania, 1988-92. IACR Newsletter 01/1999, and the abstract No. 63 from the IACR Lisbon meeting, Cancer Incidence in Lithuania 1993-1997), and ICD-O was introduced for data coding. Three participants from Ukraine presented data during the Lisbon meeting.

Cancer registration techniques in the New Independent States of the former Soviet Union (IARC Technical Report No.35) was published in 1998. The report analyses the cancer registration techniques in the context of the underlying health care system and discusses to what extent cancer registration in the NIS is comparable to that in Western countries.

The Cancer Registry of Crete, Greece, was established in October 1992 in the Department of Social Medicine at the University of Crete. In 1998 the registry organised sessions in the European School of Oncology course on Cancer Control in the European Mediterranean, Balkans and Middle East Countries.

In *Hungary*, the legislation problems were finally solved after a ministerial decree came into force on 1 August 1999 (Official Gazette, 16 July 1999).

In *Latvia*, health officials wish to join the well-established Cancer Registry to an ill-defined Medical Statistical Centre. In Bulgaria, the ENCR consultation (Dr Risto Sankila) proved to be very useful and important for the future work. The Bulgarian National Cancer registry was also selected by ENCR to organize an international course in population-based cancer registration for senior level cancer registry staff at the end of January 2000. Slovakia is establishing an electronic communication network with periphery, while in the Czech Republic a new cancer registration form and connected methodology have been created.

An Association of Cancer Registries in Poland was established and registered at court in Warsaw in May 1999. The Association covers 24 regional registries in Poland as well as the Polish National Cancer Registry. The First General Assembly of the Association took place in Warsaw on 14 September 1999. During the Assembly the programme of activities was discussed and established, and the board of directors elected for the next two years. The activities of the association the first few months were focused on three points: (a) implementation of ICD-10 in all regional registries, (b) changing the structure of cancer registration in Poland to fit it to the new administrative divisions of the country, and (c) development of a new software for the registries. The Association can be contacted via its President: Dr Jerzy E. Tyczynski, Polish Cancer Registry, 5 Roentgen St., 02-781 Warsaw, Poland, tel./fax: (48)-(22)-643-92-34, e-mail: tyczynskij@coi.waw.pl.

In *Portugal* there are three population-based cancer registries: Zona Centro, Zona Sul and Zona Norte. Dr P. Pinheiro is carrying out analyses on Cancer in Portugal at IARC.

In *Romania*, a National Registry for Cancer Patients was organised according to the Order 219/1980 of the Health Minister, and compulsory reporting was introduced in 1981. Different districts have been staffed unequally with oncologists and pathologists. So, there were rather great differences in the quality of notifications and registries between districts. Nowadays the situation is improving, but it is still unsatisfactory due to the insufficient health budget (decreased number of qualified personnel). For personnel working in the regional as well as in the central unit in Bucharest cancer registration is not the only work they have to do. Nevertheless, in 1999, the Bihor county territorial cancer registry published an annual report on cancer incidence in this county.

In *Spain* there are at the moment 10 population-based cancer registries, covering almost 25% of the Spanish population. They run their own activities in order to accomplish the objectives for which the registries were founded. Cancer incidence and mortality in Spain for 1990 based on data from nine Spanish registries have been analysed and published in English and Spanish (IARC Technical Report No. 36, Lyon, 2000). A commentary on the results includes a comprehensive review of epidemiological studies of cancer in Spain. Because there is no professional association, the persons involved in the registries used to meet in forums such as congresses, conferences, multicentric studies, et cetera. The Latin Language Group of Registries celebrated its 2000 Annual Meeting in the Basque Country - San Sebastian in the North of Spain.

Both registries from *Yugoslavia*, the registry in Vojvodina, and the registry in Beograd have reported war-related problems (staff and equipment shortage). In Albania, methods recommended by IACR and ENCR are being introduced. No problems have been reported from Cyprus.

Two registries from Switzerland and five from Central Europe (Estonia, Krakow and Warsaw from Poland, Slovakia and Slovenia) are collaborating in the EUROCCARE 3 and in the EUROPREVAL study. A special issue of the Eur J Cancer on the EUROCCARE II study: Survival of Adult Cancer Patients in Europe diagnosed from 1978-1989 was published in December 1998 and the book EUROCCARE II (IARC Scientific Publication No. 151) was published in 1999.

The ECLIS study is continuing. It includes registries from six regions in Belarus, Bulgaria, the Czech Republic, Estonia, Hungary, Latvia, Lithuania, Norway, Romania, four regions in Russia, Slovakia, Slovenia, and six registries from Switzerland. A new paper describing the incidence of Non-Hodgkin's lymphoma has been published (Eur J Cancer, 35, 1235-1237, 1999).

Information received from: Dr F. Jorgoni, Prof N. Piliptsevich, Dr R. Sankila, Dr R. Winkelmann, Dr S. Danon, Dr. M. Strnad, Dr M. Boyiadzis, Dr V. Mazankova, Dr T. Aareleid, Dr V. Kumar, Dr I. Vlachonikolis, Dr Z. Peter, Dr A. Stengrevics, Dr J. Kurtinaitis, Dr M. Dalmas, Dr J. E. Tyczynski, Dr V. Romanov, Prof. I. Pleško, Dr A. Vukicevic, Dr M. Mikov, and Dr I. Izarzugaza.

Europe, North and West

Leo Schouten, Regional Representative for Europe

The national cancer registry of *Austria* has moved from being manually operated to become a computer-based registry. Since the reporting year 1997, a computer programme has been used to process the cancer registration forms. Data from the Tyrol (regional) cancer registry are received on diskette. A special routine of the computer programme enables automatic transfer of the

received data. A quality check will now be carried out to assess whether the data of the three other regional registries in Austria (Salzburg, Carinthia, and Vorarlberg) can be transmitted in the same way. So far, the registration forms are sent to the Austrian Cancer Registry and processed manually into the database. A project, carried out together with the Tyrol cancer registry, to implement processing of the pathology reports has been started. A poster with the progress report of this project was presented at the IACR Lisbon meeting.

In *Belgium* the national cancer registry is being re-established. From the reporting year 1996 onwards, data will be collected from several sources: e.g. the health insurance companies, the main oncological hospitals, pathology laboratories, two regional cancer registries (Antwerp and Limburg) and some specialised cancer registries. Computer software has been developed to process the data. The Belgian Cancer Registry will become a highly automated cancer registry.

The network of *French cancer registries* (FRANCIM) consists of 15 member registries, including seven specialised registries. The President in 1999 was Prof. J. Faivre and the Secretary Dr P. Grosclaude. FRANCIM was created in 1985, but became a true association only in 1997. The objectives are quality and comparability of data, and epidemiological research.

Following an ENCR study in 1995, data about cancer incidence and mortality in France between 1975 and 1995 were published in a book by FRANCIM, in close collaboration with the French Government. Most French Cancer Registries are involved in EURO CARE Program, dealing with survival, and some of them are involved in screening programme evaluation (Breast, cervix, colon...). There is now a link between the Cancer Registries and the Ministry of Health, in order to give quick answers to emerging problems such as protection of the population against new risk

factors, with objectives comparable to those of the Centers for Disease Control (CDC) in Atlanta. This connection between FRANCIM and the Ministry of Health is made through l'Institut de Veille Sanitaire (InVS).

Germany: A federal law on Cancer Registration came into force on 1 January 1995, mandating all 16 German states (Länder) to establish population based cancer registries. Since all the German states have undertaken intensive initiatives to fulfil this legal duty. The registration model proposed by the federal law is based on modern technology of data encryption and record linkage.

The German states were allowed to modify widely the federal model by state-specific regulations. This led to a wide variety of cancer registration rules, techniques and methods in the country with the consequence that the German landscape on cancer registration is still very heterogeneous. In 1998, there was still only a small fraction of all German adults monitored by a population-based cancer registry, making it impossible to work out accurate incidence rates for the whole of Germany. To provide a basis for the common activities of the different cancer registries, the "Network of German Population-Based Cancer Registries" (NGPCR) was founded in January 1996. It is associated with the federal government's overall programme for combating cancer. The speaker of the NGPCR is Dr. Joachim Schütz from the IMSD Mainz (Institute of Medical Statistics and Documentation - University of Mainz).

Each population-based cancer registry and the federal Cancer Reporting Unit at the Robert-Koch Institute in Berlin, where the data are aggregated on a national level, is represented by one member of the scientific staff. To assist in the public relations work of the registries, the NGPCR published a booklet called "Krebs in Deutschland".

In Germany, only the cancer registry of the Saarland currently fulfils international criteria of data quality and completeness as has been demonstrated by applying capture-recapture-analyses. For the last decade, expected numbers of new cancer cases for the whole of Germany were mainly estimations based on the incidence rates derived from this relatively small German region.

For some types of cancer, information on incidence is also available from the registries of Hamburg and Münster. However, most differences from Saarland could be partly due to underreporting.

The consequences of the expiration of the federal law on cancer registration at the end of 1999 can hardly be foreseen precisely at this time. Five states (Bavaria, Hessen, Lower Saxony, Rhineland-Palatinate, and Schleswig Holstein) require new laws since their current legal frameworks are based on the federal law. The task of the NGPCR in this process is to demonstrate the benefits of population-based cancer registration and to ensure the compatibility and comparability of the German registries.

The National Cancer Registry of *Ireland* published a report on 1995 data in October 1998 and 1996 data, with a summary for 1997, in October 1999. The publication of the report coincided with the signing of a memorandum of agreement between the health ministries in Ireland, Northern Ireland and the US National Cancer Institute. This agreement includes, as a high priority, collaborative studies and exchange of staff between the two Irish registries and the US (SEER Program).

A national breast screening programme began in November 1999 and the registry is involved in quality assurance for this programme. The registry will be similarly involved with the national cervical screening programme, which begins a pilot phase in 2000. After some years of negotiation, the Irish Department of Health has been

persuaded that the Registry should not just collect data, but also needs to be able to carry out research and analysis. The registry has been given funding to do this and has appointed two epidemiologists and a data analyst, who are planning the research strategy.

Cancer Registration in *the Netherlands* is going well. There are nine regional and one national cancer registry (that receives its data from the regional registries). Reports have been published on 1995 incidence (December 1998) and special reports have been published on head-neck cancers (September 1998), haematological malignancies (January 1999) and urological cancers (September 1999). Further reports, e.g. cancer in childhood, are being prepared. Also a special publication about cancer facts and fairytales is being prepared for the public.

The most newsworthy information from the *Nordic Cancer Registries* is the creation of the Icelandic Health Sector Database. In December 1998, the Icelandic Parliament passed a law about this creation, and Decode Genetics (which is an American based company) has applied for a license to do it. Currently (as of September 1999) the company is negotiating with the Icelandic Health Ministry about the execution of the project. The planned database is a collection of as yet unlimited, computerised information from patient records, intended for research and statistical purposes. The use of encryption and other methods is supposed to prevent anyone from retrieving data about individual patients from this database, but specialists have doubted the safety of those methods. The law permits record linkage with large collections of genetic and genealogical information, already available at Decode. The Icelandic Medical Association has criticised this way of putting all this sensitive information in the hands of a private company on grounds of lack of personal rights and informed consent and also because this arrangement restricts access to the computerised data for scientists

not working for the company. The data will be used for commercial purposes and it will be difficult to control record linkage between the proposed Health Sector Database and other information on individuals, that the company has access to. This puts the Icelandic Cancer Registry in a fairly complicated situation with both ethical and practical questions remaining unanswered, e.g. how to deal with requests from the company for access to data-sets that comprise a large proportion of the records in the Registry.

Lotti Barlow (Sweden) was chairman of the Association of Nordic Cancer Registries in 1999.

The *United Kingdom Association of Cancer Registries (UKACR)* unites registries from England, Wales, Scotland, Northern Ireland and Ireland. During 1999 there were a number of initiatives with major implications for cancer registries in the United Kingdom: Concerns about confidentiality, patient consent and the legal status of cancer registries in the UK have again been raised. Currently UK registries do not seek explicit patient consent but the legality of this has been questioned. Within the registry community there is concern about the potential damage to the registration system with loss of population coverage if explicit consent was introduced and many feel that it may be necessary to make cancer registration a statutory function. The Departments of Health commissioned a review of cancer registries in England and Wales in the two countries, and this was led by Professor Charles Gillis from Glasgow. The review was commissioned because of concerns over variations between registries in the quality of data and in the volume and quality of outputs. A preliminary report of the review's findings was published in September 1999 and the final report in 2000.

UKACR was active throughout 1999. A number of training events were held or planned, including training for registry staff

on coding of haematological malignancies and gynaecological cancers and workshops on survival, geographical information systems and deprivation indices. Several of the UKACR subgroups have also been very active in areas other than training, including the development of quality indicators for cancer registries.

The chairman of the UKACR in 1999 was Monica Roche (Oxford, UK).

In *Scotland*, cancer registration has undergone a fairly major re-organisation in recent years, moving from a system of five regional cancer registries to a single central registry. Other changes include the development of a new computer system to maximise electronic capture of potential registrations from multiple sources, extension of the minimum dataset and the introduction of outposted cancer registration officers with access to medical records. The extended dataset applies to patients diagnosed on or after 1 January 1997 and the registry hoped to undertake an assessment of data quality in 1999-2000.

On the output side, the publication *Trends in Cancer Survival in Scotland 1968 - 1990* has been updated, and in 2000 work will commence on a publication about trends in incidence of, and survival from, childhood cancer. A number of other epidemiological studies were in progress.

As in the rest of the UK, there is currently considerable emphasis on the clinical effectiveness agenda and the registry works closely with the Scottish Cancer Therapy Network to help establish prospective audit of the major cancers across Scotland.

Information was received from Jeannette Langgassner (Austria); François Ménéégoz (Isère, France); Hartwig Ziegler (Saarland, Germany); Harry Comber (Ireland); Lotti Barlow, (Sweden); Monica Roche (Oxford, UK) and David Brewster (Edinburgh, UK).

Oceania

*David Roder,
Regional Representative for Oceania*

In Australia, the National Cancer Statistics Clearing House continued its data collection from State and Territory Cancer registries on cancers diagnosed in Australian residents. National data have been published for 1982-95 and 1996 data were published in late 1999. Data on the prevalence of cancer cases have been released, together with the more customary incidence, mortality and survival statistics.

Other national reports published in Australia in 1998-99 included: 'Breast cancer in Australian women, 1982-96'; 'Breast cancer survival in Australian women, 1982-94'; and 'Breast and cervical screening in Australia, 1996-97'. In addition, national data were used in reports on National Health Priority Areas in Cancer and National Cancer Control Initiatives. Papers on these data applications were presented at the conference of the Clinical Oncological Society of Australia. Planning for a national cancer case survival analysis is underway, plus preparation of a report on the epidemiology of ductal carcinoma in situ in Australia.

During 1997-98, a national protocol for coding breast-cancer size, nodal status and ductal carcinoma in situ was developed, which has since been endorsed by the Australasian Association of Cancer Registries for implementation by State and Territorial registries. The Association is addressing the broader issue of standardized coding criteria for all registries.

There is a strong interest in Australia in the development of hospital-based and other clinical cancer registries. This is consistent with the growing emphasis that is being given to the use of registry data for local service planning, outcome monitoring and more general applications. Clinical registries

exist to varying extents in South Australia, Western Australia and Tasmania, and there is now a range of initiatives to develop networks of these registries in New South Wales and Victoria.

In 1998, the New Zealand Cancer Registry celebrated its 50th birthday. The Registry is very active, with increasing numbers of researchers making use of the database. A recent example is the application of Registry data in the National Prostate Control Study. Improvements in cancer reporting by laboratories have increased the completeness of the database.

There have been a number of coding initiatives recently addressed in New Zealand. The Registry collaborated in the IARC/IACR field trial of the ICD-O-3 classification and implemented a system of cancer staging recommended in New Zealand for national registry purposes. Also, a new Registry database is being developed, taking advantage of advances in computer technology, and an updated Registry Procedures Manual has been produced. Six Honorary Consultants in Pathology, Oncology and Epidemiology have been appointed to enhance Registry performance. The Registry is accommodating the transition in hospital coding in New Zealand from the ICD-9 to ICD-10 classification.

The New Zealand Registry continues to place special emphasis on the timeliness of data on melanoma and cancers of the prostate, breast and cervix, in order to meet service requirements. This includes the provision of data relating to breast screening.

The Waikato Registry, which covers the Waikato/Bay of Plenty population, continues to operate well, in collaboration with New Zealand's national cancer registry. There is still some doubt about the future of the Waikato Registry, due to funding uncertainties. Apart from acting as a regional data-collection utility for the New Zealand Registry, it collects additional data

on tumour stage, grade, treatment and case survival. This is considered to be an important adjunct to the national dataset for service monitoring and research.

As indicated in last year's Oceania report, a meeting was held in Noumea, New Caledonia for cancer-registry staff from Pacific Island countries in July 1998. This was organized by the South Pacific Commission, IARC and the WHO Western Pacific Office. The 22 Pacific Island countries and territories have an aggregate population of about 6.5 million. An important purpose of the meeting was to introduce a more unified registration system to facilitate data pooling across the region and to facilitate comparative analyses. Emphasis was placed on training in the use of CanReg3, EpiInfo6 and the ICD-O classification system. A standard notification form was developed, together with an operational manual for databases for Pacific Island countries. An association of Pacific Island registries was recommended and registry staff agreed to contribute data annually to the Pacific Islands Registry. This Registry has received funding support, inter alia, from the New Zealand Government for a range of specific applications. Cancer registration continued actively in the South Pacific during 1998-99.

Materials for cancer registries

GLOBOCAN2000

A new version of the GLOBOCAN software, named GLOBOCAN2000 is being developed and will be ready at the end of year 2000. It aims to provide the most up-to-date statistics on cancer incidence, mortality and prevalence from 24 cancers in all the countries of the world. In addition to the basic report and graphic options, the user may download new versions of the database directly from the web. A simplified version of GLOBOCAN2000 with limited statistic and graphic capabilities will be available on the CANCERmondial web page (<http://www-dep.iarc.fr>).

Computer software for cancer registries

Following the publication of the third edition of the International Classification of Diseases for Oncology (ICD-O-3), new programs to convert data from ICD-O-2 to ICD-O-3, and from ICD-O-3 to the International Classification of Diseases (ICD), 10th revision, have been developed. In addition, the IARC-CHECK program, which performs various validity and consistency checks, has been updated. These will be incorporated in an up-to-date version of the IARCTools package, to be distributed free of charge and downloadable from the IACR web site (<http://www-dep.iarc.fr/iacr.htm>).

Standards

A new page on the IACR website (<http://www-dep.iarc.fr/iacr.htm>) gives the IACR guidelines for registry practices and standard definitions. The first topics available are *Multiple Primaries* and *Basis of Diagnosis* and the texts can be downloaded from the site.

New IACR members in 1999

Voting

Amsterdam, Netherlands
Beijing, China
National Cancer Statistics
Clearing House, Australia
Umbria, Perugia, Italy
Washington State, USA

Associate

Amman, Jordan
Aswan, Egypt
Bahrain
Bari, Italy
Butaré, Rwanda
Constantine, Algeria
Eldoret, Kenya
Gharbia, Egypt
Gibraltar
Girona, Spain
Liguria Mesothelioma, Italy
Limburg, Belgium
Madinat Al Salam, Egypt
Menya, Egypt
Munster, Germany
Network of German Registries
Ouagadougou, Burkina Faso
Sfax, Tunisia
Sidi-bel-Abbes, Algeria
Sousse, Tunisia
Swaziland
Tirana, Albania
Tunis, Tunisia