

# ASIAN PACIFIC JOURNAL OF CANCER PREVENTION

The Official Publication of the Asian Pacific Organization for  
Cancer Prevention and the UICC Asia Regional Office for Cancer Control  
An Official Journal of the International Association of Cancer Registries



Volume 10, IACR Supplement,  
October 2010



**International Association of Cancer Registries**  
**- A History Sharon L Whelan**



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**Cancer Registration**

**Education**

**Epidemiology**

**Screening and Intervention**

**Toxicological Pathology**

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# ASIAN PACIFIC JOURNAL OF CANCER PREVENTION

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Sharon L Whelan**

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# IACR - SUPPLEMENT

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## IACR - SUPPLEMENT

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# The International Association of Cancer Registries: a History

**Sharon L Whelan**

### Origins

In September 1946 experts on cancer statistics, meeting at the Danish Cancer Registry, came to the conclusion that a proper system of data collection on cancer was required. At the time cancer registries had been established in Hamburg (Germany), Connecticut and New York (USA), Denmark, Belgium, Saskatchewan (Canada) and England and Wales. Variations in death rates from different cancers according to occupation or social class, differences in the occurrence of

cervix and corpus uteri cancer between races and between parous and nulliparous women and increasing numbers of deaths from lung cancer in many countries, had been demonstrated by prevalence data, mortality statistics and clinical observation. And numbers of deaths caused by different cancers were not the same in different countries and parts of countries. The international group concluded that the information available was inadequate, and prepared a formal recommendation to the Interim Commission of the World Health Organization (WHO) through the Danish



**Figure 1. IACR Members Present at the Entebbe 2005 (Courtesy of Li Ling)**

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and the British governments that:

1. Great benefit would follow the collection of data about cancer patients from as many different countries as possible.

2. Such data should be recorded on an agreed plan so as to be comparable.

3. Each nation should have a central registry to arrange for the recording and collection of such data.

4. There should be an international body whose duty it should be to correlate the data and statistics obtained in each country.

The recommendations were taken up by WHO and gave the impetus to build on the work of the pioneer registries to create an international forum. The WHO Subcommittee on the Registration of Cases of Cancer as well as their Statistical Presentation was based on the Copenhagen meeting recommendations and held a first meeting in Paris in 1950. The UICC set up a Committee on Cancer Incidence in 1964, which produced a Technical Report in 1966 - the first volume of Cancer Incidence in Five Continents (Doll et al, 1966).

New cancer registries developed during the 1950s and 1960s and in 1966, during the IXth UICC International Congress in Tokyo, Japan, some 60 scientists met at the invitation of Professor Mitsuo Segi (Miyagi, Japan) to hold an informal discussion on cancer registration. Dr Sidney Cutler of the US National Cancer Institute proposed the founding of an International Association of Cancer Registries (IACR), with the aim of improving the quality of data on cancer incidence and comparability between registries by standardizing methods of

registration, definitions and coding. Dr Einar Pedersen, Director of the Norwegian Cancer Registry, reporting on the outcome, said: 'After some discussion – at times rather heated – a small group was formed to explore the implications of Dr Cutler's proposal, and after some hours of discussion this group came out with recommendations strongly in favour of his proposal.'

A committee of seven members, with William Haenszel of the US National Cancer Institute as chairman, was appointed to draft a Constitution and By-laws, and in 1967 the IACR was formally announced through selected journals and by mail - 'a professional society, whose members are interested in the development and application of cancer registration and morbidity survey techniques to studies of defined population groups'. It was stated, furthermore, that 'the Association welcomes to membership the professional staff of organizations concerned with the collection and analysis of data on cancer incidence and/or the end-results of cancer treatment in defined population groups'.

Dr Cutler defined the purposes of the Association as to:

- provide a continuing, organized framework for maintaining an inventory of population-based cancer registry resources throughout the world;
- facilitate exchange of both scientific and technical information among cancer registries and uniformity of definitions;
- facilitate the organization of projects and studies that may be proposed and supported by various organizations such as UICC, WHO and IARC;
- facilitate the organization of scientific

sessions based on cancer registry data, at meetings sponsored by various organizations such as UICC, WHO and IARC.

(Reported at IACR meeting in Montecatini, 18-19 October 1974)

The only formal meeting of the Organizing Committee was held in Lausanne, Switzerland in 1968, in connection with the UICC Congress on Thyroid Cancer. The Committee then decided that their task was complete and initiated the first election of officers of the Association. Dr Einar Pedersen was elected as President and Dr Sidney Cutler as General Secretary. The draft Constitution and By-laws were approved at the first meeting of the Association, held in Houston, Texas in May 1970 - a one-day meeting devoted to topics such as the relationship of the Association with various international organizations (WHO, UICC, IARC), international classification of diseases, collection and publication of data from cancer registries and methodological problems.

## **Organisation**

### *Constitution and By-laws*

The IACR has a Constitution and By-laws (Annex 1), and is governed by an Executive Committee comprising mainly elected officers – a President, a General Secretary and Regional Representatives from Africa, Asia, Central and South America, Europe, North America and Oceania. It is non-political and non-profit. The membership fees, instituted in 1990, are used to support IACR activities, including funding members to attend meetings and courses organised by the

Association. The membership fee is voluntary for members in low and medium income countries.

In 1974 the Association entered into a formal Agreement with the International Agency for Research on Cancer (IARC) in Lyon, France. Via a formal contract the Agency provides a Secretariat for the Association and a scientist to act as Executive Secretary (called Deputy Secretary until 2004) to the Executive of the Association. This contractual agreement has been regularly renewed, and has been in almost continuous operation since 1974. The Constitution and By-laws were amended in 1989 to include the office of Executive Secretary. The duties of the Executive Secretary, as specified by the constitution, were expanded in 2004, to include the role of Treasurer. However, in 2006, IARC suddenly intimated that staff members were prohibited from handling monies of a different organisation; a separate post of Treasurer was therefore created, and the constitution amended accordingly.

Members of the Executive are elected for a term of four years by ballot of the Voting members. Originally registries granted Voting membership designated two individuals who had the right to vote when ballots are taken, a policy which posed many problems (departure from the registry by the persons designated). In 1989 it was decided that the logical solution was for each voting member to have one vote – i.e. the registry became the member, rather than named individuals.

### *The Executive Board*

The General Secretary is responsible for supervising the elections of IACR officers. The Executive Board designates

a Nominating Committee, comprising three IACR members not likely/wishing to be elected. Their list of nominations is circulated to all voting members and further suggestions invited; a minimum of five voting members is required to support additional nominations. 90 days later the ballot paper is sent to voting members, to be returned to the secretariat in Lyon. While officers remain for four years, elections have been held every two years since 1996 in order to ensure continuity in the Executive Board. The one exception to the four-year term is the General Secretary, who may choose to stand for a second four years, if he/she so wishes. The outgoing President remains on the Executive for a further four years as immediate past President. Annex 2 shows the serving members through the years.

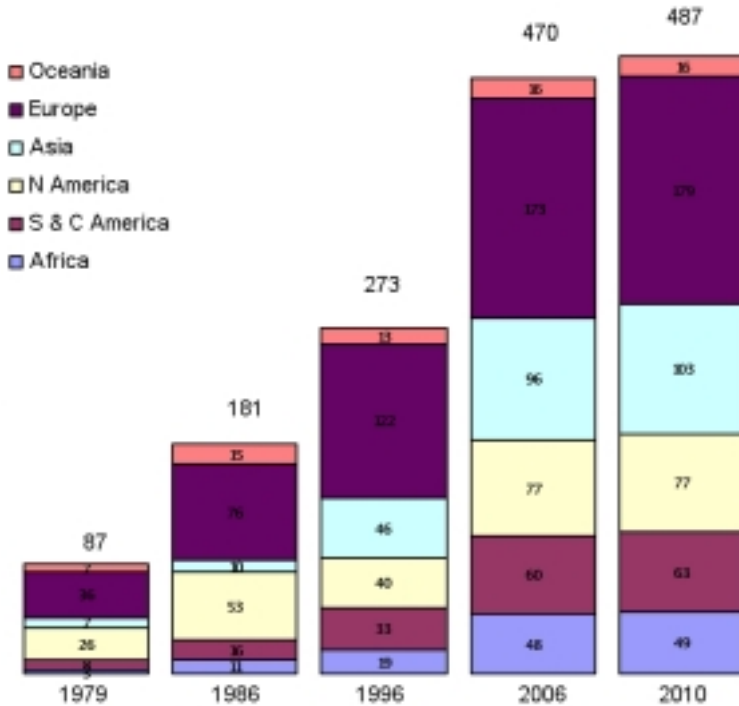
The office of Executive (then Deputy) Secretary was formally included in the Constitution in 1989.

The first elections were organized in 1968. Officers meet during the Association's scientific meetings – the Executive met first in 1970 in Houston, Texas. The second Executive meeting was an informal gathering in Dusseldorf, Germany in 1973, during a Symposium on Cancer Registration, but several regional representatives were absent and no formal decisions were taken. In 1974, at the Montecatini meeting, it was suggested that IACR meetings spend approximately one third of the time on IACR business, the remaining two thirds being devoted to methodological problems in cancer registration. This pattern evolved rather rapidly into the present format, with the main meeting addressing more scientific than registration topics and a relatively short business meeting to discuss the results

of the Executive Board meeting. The Executive has met annually since 1982 (a formal recommendation to this effect was made in 1988). The meetings are held on the day before the scientific meeting (in 1989 the Deputy Secretary reported that the Executive met for 'a long afternoon' – these days the meeting takes a long day) and the outcome is reported to the members during the business meeting. If any officer is unable to attend he/she is asked to send a report on activities/issues of concern in their area: proxies are not accepted.

### *Membership*

The criteria for membership have changed little over time. There are two categories for cancer registries, Voting and Associate. Voting membership is given to well-established population-based cancer registries or associations of cancer registries that collect data on all sites of cancer, have good coverage of an accurately enumerated defined population and can provide valid incidence rates. Associate membership is for registries that, for any reason, do not achieve a reasonable level of coverage of all cancer diagnoses (newly-established, site-specific, covering areas where the medical infrastructure is inadequate...). In practice the only distinction between the categories is that voting members can vote in elections of officers, and on issues requiring a formal ballot such as changes to the Constitution. The President, General Secretary and Regional Representative(s) for the area concerned assess membership applications (the application forms are available on the IACR website <http://www.iacr.com.fr/>) and decide on the category to be allocated (Associate members can be upgraded if they show improvement – conversely



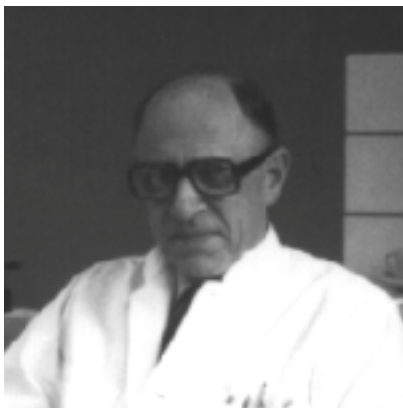
**Figure 2. The IARC Membership Across the Globe** (excluding Individual, Corporate and Honorary Members)

Voting members can be downgraded, but this is rare). In 1989 it was decided that paediatric registries would be accepted as members on the same conditions as registries collecting data on all sites for all ages.

A further category, individual membership, is given to newly-established registries or to individuals who are interested in the activities of the Association. Corporate non-voting membership was created in 1998 for corporate organizations.

The first membership list was created for the 1974 meeting in Montecatini, Italy. The Executive Secretary asked at the time whether he should actively canvass for further members, and if so what his terms

of reference should be. The IACR never did actively look for new members (although incentives for registries to join have arisen over the years – only IACR members can have their data published in *Cancer Incidence in Five Continents* and the *International Incidence of Childhood Cancer*). But the Association has grown: in 1979 there were 87 members; by 1996 there were 273 members in 99 countries – according to Dr Calum Muir ‘We are large enough to mount collaborative studies and small enough to know nearly everybody’ – an assessment which holds true today in spite of the increasing size of the organization. In 2010 there are 487 (voting and associate) member registries in 129 countries (see Figure 2).



**Figure 3. Dr Johannes Clemmesen**

Twenty-one % of the world's population is now covered by registration, with a rather uneven spread among the continents (Parkin, 2008).

There is not always full agreement when applications for membership are considered by the elected officers – the status assigned is decided by majority vote. It is rare in the history of the Association that substantial disagreement has arisen, but on occasion political issues have come under discussion. In 1989 the application of the Cancer Registry of South Africa was being assessed, and this resulted in a considerable amount of correspondence concerning the issue as to whether the IACR should manifest its protest against the then government policy of apartheid by refusing membership. Finally, the Executive Committee agreed to South Africa's membership, but with the provision that no meeting of the organization be held in South Africa unless government policies changed.

In October 1979 Dr Calum Muir, as Executive (then called Deputy) Secretary, suggested that it would be appropriate for the Association to recognize outstanding contributions to cancer registration by

appointing an Honorary President. The then President of the IACR, Professor Pelayo Correa, proposed rather that individuals who have contributed in an exceptional way to the development of cancer registration be especially honoured by being awarded Honorary Membership of the Association. This further category of membership was initiated in 1980, and in that year was awarded to:

- Dr Sidney Cutler (USA) (who proposed the founding of the Association and served as General Secretary from 1971-1978)
- Dr Johannes Clemmesen (Danish Cancer Registry) (see Figure 3)
- Sir Richard Doll (UICC Committee on Cancer Registration; responsible for Vols 1 and II of Cancer Incidence in Five Continents)
- Dr William Haenszel (USA)
- Dr Einar Pedersen (Norwegian Cancer Registry, 1st IACR President)
- Dr Mitsuo Segi (Miyagi Cancer Registry)

Any IACR member is free to nominate a candidate for Honorary membership, the decision being taken by the Executive. The criteria are: 'Individual Honorary Membership of the Association may be awarded to persons who have made distinguished contributions to the development of cancer registration and studies of cancer in defined populations'. At one point the question of making Honorary membership more exclusive was raised – should the criteria be changed to make the contribution to cancer registration requirement international rather than national? It was agreed to leave the criteria as they stood.

One further (although never stated in

the Constitution) criterion is that awardees should be retired, or have retired from cancer registration activities. This has been adhered to with a few exceptions – one of them notable. Mrs Constance (Connie) Percy, a staff member of the US National Cancer Institute, and an expert on classification and coding of cancer, had been an active member of the Association almost from its beginning, and was said never to have missed any of its annual meetings. Connie was awarded Honorary Membership in 1993 – at the age of 79 and eight years before she retired from her post in the NCI (USA).

In 2008 the Executive recommended that the selection be formalized and supported by a number of criteria – close connection to the work of the Association, recognized contribution to cancer research, or pioneer in their own country – and close to the end of their career. Proposals can come from the membership and be submitted to the President, General Secretary and Executive Secretary.

A full list of Honorary Members is attached as Annex 3.

## **Finances**

### *Membership fee*

The Executive Board agreed to establish a membership fee during their meeting in Maastricht in 1989. There was proviso that fees could be waived for developing countries or registries without access to hard currency, and that the funds would be used to fund meetings of the Executive Board. The remaining funds would be used primarily to pay for the travel of persons attending IACR meetings, with the highest priority going to persons from developing countries.

The fees were initially established as:

Voting member	US\$100
Associate members	US\$ 50
Individual members	US\$25
Honorary members	No fee

It was during this meeting that it was decided to continue to exclude site-specific registries from Voting membership, but to accept paediatric registries that fulfilled the usual criteria.

To be a member of IACR, the members are expected to pay the membership fee. Payment is compulsory for all registries in the 'high income' countries; for registries outside this category payment is voluntary and they continue to enjoy membership rights according to their membership. Honorary Members and new members for the year in which they join IACR are exempt. Periodically a list of non-paying members is drawn up and registries are asked to pay or to explain if there is a problem. In 2001 the Executive decided to remove non-payers in developed countries from membership.

It was agreed, in 1998, that companies, e.g. pharmaceutical, should be offered Corporate Membership (annual cost US\$500); they could then receive a copy of the membership list, that would be updated annually on payment of dues. Such members would also be encouraged to donate funds to the Calum Muir Memorial Fund. Requests from other sources, such as medical journals, would be given the option of Corporate membership or simply buying the list for US\$500. Corporate members can be offered a reduced fee for stands at meetings.

## *IACR expenditures*

### IACR annual meeting

The annual meeting is funded from:

- a. Registration fees
- b. Contribution of the host country (e.g., sponsorship of the local government)
- c. IACR membership contributions
- d. CDC grant
- e. NCI grant (SEER)
- f. Constance Percy memorial fund

The expenditures include:

- a. Conference facilities
- b. Meals and coffee breaks
- c. Simultaneous translation
- d. Printing material
- e. Bookkeeping
- f. Keynote speakers travel/per diem.

### Courses

The courses are funded from:

- a. IACR funds
- b. Contribution from NCI
- c. Host country
- d. UICC
- e. Other (ENCR, NCI/Foreign Affairs Office,...)

The expenditures include:

- a. Premises (might be provided by the organisers)
- b. Coffee breaks and lunches for faculty and participants
- c. Travel and per diem of faculty

### Other travel and support expenses

Several types of travel are funded by IACR:

- a. Registry staff visiting another registry or institution for the purpose of training (from the Calum Muir fund)
- b. Travel expenses of the IACR auditor
- c. Consultant traveling to a registry.

## *Auditing of accounts*

The IACR accounts have been audited annually since 2004. The auditor is nominated by the General Secretary of IACR after the approval of the Executive Board.

## *The IACR logo*

It was Ole Jensen who proposed the current “green ball” logo in 1988. He wrote to the Executive secretary: ‘I am giving some further thought to the layout of the letterhead and front page of the IACR Newsletter. The Danish Cancer Society’s Information Unit has promised to provide professional assistance’.

The design department of the Danish Cancer Society prepared a camera ready copy of the IACR logo – which is meant to symbolize the world, and to be printed in green (shade also provided). Of course at the time (February 1989) this involved printing 5000 copies of the letterheads and 2500 copies of the Newsletter front page for the following 2 years: objections were raised due to cost, but Fabian Corral (Quito, Ecuador) - was adamant that the green ball be chosen and it was adopted during the Maastricht meeting in 1989.

## **Relationships with Other Organizations**

### *International Agency for Research on Cancer*

When the Association was set up in the 1960s there was considerable debate about where it should be located, with strong argument from Dr Sydney Cutler that it should be in the US. The International Agency for Research on Cancer (IARC) was established in May 1965, through a



**Figure 4. The IARC**

resolution of the XVIIIth World Health Assembly, as an extension of the World Health Organization. The Agency's headquarters' building was provided by France, the country that initiated the organization of IARC, and is located in Lyon, France (see Figure 4). The stated mission of the new international organization was the identification of causes of cancer, so that preventive measures could be adopted against them.

In 1974 Dr Einar Pedersen reported:

‘A review of developments through 1971 inevitably led to the conclusion that we had not been making the kind of progress which had been envisaged. It seemed to me, and to other members of the Association, that we were faced with a real problem and that a solution had to be found. Having considered the situation for some

time I began to feel that if we wanted the Association to become active and to fulfil its potential role in the international study of cancer, the desirable solution might be to establish close liaison with a suitable international institution. After discussions between the General Secretary and myself, and subsequently with the consent of the Regional Representatives, IARC in Lyon was approached in 1972. It was immediately recognized that close cooperation would serve the interests of both parties, and starting from this basis a formal agreement was worked out which was signed in April 1973.’

This formal contract (renewed regularly since 1973) specified that IARC would provide a secretariat and other supporting services. The agreement provides for a permanent Executive (previously Deputy) Secretary, who would be the person in charge of descriptive epidemiology at IARC. When this department was abolished (in 2006) the constitution was amended to stipulate that the IARC nominee would require approval by the IACR Executive Board.

Calum Muir fulfilled this role until 1986 and was subsequently elected President of the Association in 1992 (a position he held until his death in June 1995). Max Parkin took over in 1986 until his own departure from IARC in October 2004, when he too was elected President of the Association. Thereafter the role was held sequentially by Sharon Whelan (2004-5), Paula Pisani (2005-6), Eva Steliarova-Foucher (2006-8) and Maria Paula Curado (January 2008-2010). David Forman took over in May 2010.

The Association is administratively and financially independent of IARC. IARC must ensure the allocation of an adequate

amount of staff time for the good functioning of the Association. The benefits of being located inside IACR have been of great assistance to the development of the Association, with provision of personnel, office facilities and miscellaneous services (postage, telephones, etc.).

### *World Health Organization*

The Association was accepted as a non-governmental organization (NGO) in official relations with the World Health Organization (WHO) at the World Health Assembly in January 1979. The Association's status is reviewed every three years by WHO, on the basis of a report prepared by the Executive secretary, describing the Association's activities in relation to the work and aims of WHO. To date the review of the work of IACR has been favourable, and the relevance of its activities to WHO commended. The Executive decided to publish the triennial review of WHO on the internet in 2001.

WHO invites the IACR to send an IACR member with the status of observer to the World Health Assembly and to WHO's regional meetings. IACR generally sends a representative to any meeting of particular relevance to its own activities (often delegating the task to a person working in a cancer registry located close to the meeting venue).

In 1998, at the IACR meeting in Melbourne, Dr Hans Storm suggested that IACR prepare position papers to be tabled at WHO regional meetings, and he subsequently wrote a statement to serve as a basis for IACR representatives at meetings of WHO, designed to present the Association and its role in the problem of cancer. The original version described IACR as follows: 'According to the

constitution of the IACR it is the purpose of the organization 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. The IACR hereby wishes to stress the need for close collaboration between its members and national agencies, as well as on a regional basis between countries, in order to join forces in the common combat against cancer. WHO should consider strengthening cancer research with the aim of controlling the disease and to take advantage of the collaboration offered by the IACR and its national members to reach the noble goals set forth in the Alma Ata declaration 1978.'

IACR members participated actively in WHO meetings prior to the implementation of Hans Storm's 'position paper' proposal. Dr Thomas B. Maramba represented IACR at the 37th Session of the WHO Regional Committee for the Western Pacific Region in Manila in 1986 and presented a statement on behalf of Association which included a report on the Annual Meeting in Budapest (The Cancer Registry in the Service of the Community):

'A number of examples were presented, in which data from the cancer registry formed the basis for action by health authorities, such as the number and sites of high voltage radiotherapy units, introduction of screening programmes for specific sites of cancer, and anti-smoking legislation. In one instance, there were fears of an 'epidemic of liver cancer' in the Niagara Region. More precise data from the cancer registry demonstrated that such fears had no basis'.

In addition to the annual World Health

Assemblies members have generally attended one or two WHO meetings each year, for example, in November 2001 WHO held a meeting of the Intergovernmental Negotiating Body on the WHO Framework Convention on Tobacco Control in Geneva. IACR was represented and a document presented to the meeting. In 2002 a representative attended the Ministerial Round Table on Diet, Physical activity and Health, which took place during the WHO Regional Committee for the Western Pacific in Kyoto.

In 2005 on the occasion of the World Health Assembly a resolution was passed that WHO:

‘URGES the Member States .. to develop and strengthen the health system infrastructure, particularly related to human resources for health, in order to build adequate capacity for effective implementation of cancer prevention and control programmes, including a cancer registry system;

REQUESTS the Director-General .. to advise Member States, especially developing countries, on development or maintenance of a national cancer registry containing the type, location of the cancer and its geographical distribution’ (WHO 2005).’

The IACR collaborates with WHO on disease classification and the global burden of disease. WHO nominates a liaison officer, who is invited to the IACR scientific meetings – as are representatives from the WHO Non-Communicable Disease programme in the areas where the meetings are held.

*UICC (International Union Against Cancer)*

UICC and IACR have a long history of

collaboration. UICC published the first two volumes of Cancer Incidence in Five Continents, many UICC Member Institutions are associated with cancer registries and cancer registry personnel are trained through UICC fellowship programmes. Sessions on cancer registry data are regularly included in the organizations’s World Cancer Congress programmes.

In 2008 the President of UICC, David Hill, was invited to the annual Executive meeting to raise awareness regarding the World Cancer Declaration 2008, which had been adopted at the UICC’s World Cancer Congress in Geneva in that year. Priority actions fall into three key areas: health policy, cancer prevention and detection, and cancer treatment. They include several that coincide with the interests of IACR, in particular the implementation of strategies that have been proven to bridge existing cancer surveillance gaps. It was agreed that the Association would be interested in working to support the aims of the Declaration.

In May 2009, Roberto Zanetti introduced the concept of a UICC-IACR Partnership, based on the World Cancer Declaration, with the aims of measuring the world cancer burden, setting up national cancer control plans and using cancer registry data to measure, plan and evaluate action. Cooperation would involve increasing registration coverage, with priority given to areas where such coverage is absent or insufficient; supporting the training of registry personnel and dissemination of data.

The UICC Board of Directors has adopted the proposal. The UICC-IACR partnership was discussed recently at the first meeting of an Advisory Group set up

by the Director of IARC (including UICC and IACR representatives) to reinvigorate cancer registration in low- and middle-income countries.

### *European Network of Cancer Registries*

A European Network of Cancer Registries (ENCR) was launched in 1989 at the IACR meeting in Maastricht (Netherlands) with the support of the 'Europe Against Cancer' programme of the European Union (EU). The overall objective of the project is to improve the availability and comparability of cancer incidence data, with the aim of creating a basis for monitoring cancer occurrence in the EU, to increase the use of cancer registry data and to make the European data widely and promptly available. The Network also generates regular information on the burden of cancer in Europe, on cancer incidence and mortality patterns and on the variations within and between states. A number of ENCR recommendations for data collection and coding have been developed, to improve quality and comparability of data.

Other activities include surveys of cancer registration methods in Europe, training in cancer registration methods, fellowships and consultancies, audits and publications. The European Cancer Incidence and Mortality Database (EUROCIM), created as one of the activities of the Network, consists of cancer incidence (from IACR members) and mortality (from the WHO database) together with software to analyse and display the data. The ENCR website provides further details (<http://www.encl.com.fr/>). Since early 2009, the EURO COURSE project (EUROpe against Cancer: Optimisation of the Use of

Registries for Scientific Excellence in Research), supported by the Seventh Framework Programme of the European Commission, allowed intensification of collaboration between the registries. The first milestone is the creation of a common portal for exchange of data. Around 50 member registries are actively involved in the numerous working groups striving to improve various aspects of cancer registration. EURO COURSE will culminate with the Cancer Control Summit, planned for Autumn 2011.

EURO COURSE is the current major project of the ENCR and further information may be found at the web-site <http://www.eurocourse.org/>. The core activities of the Network are supported by IACR. Complementary funding is sought from the European Commission. All cancer registries established in Europe may become members of the ENCR. IACR is permanently represented on the Steering Committee.

## **Meetings and Courses**

### *Annual Scientific Meeting and Annual General Meeting*

These two meetings have been held regularly since 1970, and annually since 1982. The choice of location is based on geography, moving around the world so that all members have the opportunity to attend at intervals that are not too far apart. Sometimes there is a need to boost cancer registration in an area, and this type of factor would be taken into consideration when looking at invitations received.

The very first meeting took place in 1970, in Houston - a one-day meeting devoted to topics such as the international classification of diseases, collection and

publication of data from cancer registries and methodological problems. Until the early 1990s the local organisers arranged the scientific programme without reference to the IACR Executive. From that time the Executive has designated one or two members, usually Executive officer(s), to act on the programme committees.

The list of venues of the meeting and the corresponding year is as follows:

1970	Houston, Texas, USA
1973	Dusseldorf, Germany
1974	Montecatini, Italy
1978	Buenos Aires, Argentina
1980	Oslo, Norway
1982	Seattle, USA
1983	Heidelberg, Germany
1984	Fukuoka, Japan
1985	Connecticut, USA
1986	Budapest, Hungary
1987	Copenhagen, Denmark
1988	Melbourne, Australia
1989	Maastricht, Netherlands
1990	Hamburg, Germany
1991	Quito, Ecuador
1992	Ottawa, Canada
1993	Bratislava, Slovakia
1994	Bangalore, India
1995	Rio de Janeiro, Brazil
1996	Edinburgh, United Kingdom
1997	Grand Bassam, Cote d'Ivoire
1998	Atlanta, USA
1999	Lisbon, Portugal
2000	Khon Kaen, Thailand
2001	Havana, Cuba
2002	Tampere, Finland
2003	Hawaii, USA
2004	Beijing, China
2005	Entebbe, Uganda
2006	Goiania, Brazil
2007	Ljubljana, Slovenia

2008	Sydney, Australia
2009	New Orleans, USA
2010	Yokohama, Japan

At the Executive Board meeting in Maastricht (1989) it was agreed that annual (scientific) meetings were probably too frequent, no meeting would be held in 1991 and future meetings should be biennial - a decision rescinded the following year during the Maastricht Executive meeting.

Through the years the emphasis of the annual scientific meetings moved steadily from methodology (although to this day there is always a place in the programme for registration techniques) to epidemiology, using the results of the cancer registries to investigate the causes of cancer, and to plan and evaluate cancer services for cancer control. For example, the 2000 meeting in Khon Kaen, Thailand included approaches to cervix cancer prevention, magnetic and electric fields and cancer, ethnicity and cancer and the epidemiology of important cancers in Asia. In 2001 in Cuba, topics included the epidemiology of cervix, prostate and head and neck cancer, and geographical and time variations in cancer incidence and mortality. A list of programme topics is given in Annex 4.

Responsibility for the annual scientific meeting is conferred on a host registry, selected a few years in advance. The host is responsible for organisation and finance, although expected to liaise closely (usually through the programme committee) with the IACR Executive on the scientific programme. The meeting is financed by registration fees, and by any sponsorship that can be found locally. The Association contributes not only through sponsoring attendance of members (when possible

from the geographical area of the meeting), but through grants and awards obtained for the purpose.

In 1995 the Executive agreed that the chief keynote address at IACR meetings should become the Calum Muir Memorial Lecture.

The IACR has applied to the US CDC since 1998 for financial support to the meetings, and this has been granted annually and very generously since. The US NCI also provides a conference grant. These and other organisations provide ad hoc funding, for example seven participants in the 1997 Grand Bassam meeting were financed by CDC and the National Cancer Registrars Association of the USA; the US National Institute of Aging sponsored a symposium on Cancer in an Aging World in the programme of the 1993 Bratislava meeting. IACR funds, fed by the membership fees, are used to support travel and subsistence of the executive board members from low to medium resource countries, the new honorary members and selected participants from cancer registries, preference being given to members from the region where the annual meeting takes place.

The annual general meeting of the Association (business meeting) is traditionally held on the final afternoon. It provides the opportunity for the Executive to report back to the membership on the work they have undertaken on their behalf over the preceding year, and includes a financial report. The membership may be asked to vote on substantive issues affecting the Association – constitutional changes, for example. No quorum of members has been fixed, but the meetings are usually well attended by those present for the scientific proceedings.

No discussion of the IACR meetings could exclude the poster sessions – always considered to be an integral and important part of the scientific programme. It has been a tradition for many years for prizes to be awarded and the posters are assessed and judged by two IACR members (traditionally Hans Storm and a ‘volunteer’ identified by him). Poster evaluation criteria include structure, readability and clear scientific conclusions. In addition to the ‘Finest poster’ award, ‘Teamleaders’ (authors or co-authors of more than five papers in the conference) are given the Eric Holowaty award (so named because Eric had been notoriously prolific over the years). The Mike Quinn award, instituted in 1996, is presented for use of the most unnecessary use of 3-dimensional graphics in a scientific meeting.

Finally, the Executive agreed during the Khon Kaen meeting that the organizers of the preceding year’s meeting should be acknowledged each year with a special certificate and a small gift during the current year’s meeting, and be invited as the Association’s guest to the meeting the following year.

#### *Other meetings and courses*

Courses/workshops and/or cancer related meetings are often held in association with the annual meetings, to facilitate attendance at both. In 2006 the Executive Board agreed that the offer of courses in conjunction with the annual meeting should be formalized as an IACR activity. The decision arose from discussion during the Board meeting of the possibility that IACR produce an international certification of registrars (an issue which had recurred over the years). It was agreed that such a project would involve too much

work for the Association, but the Executive recognized that opportunities for training of registry managers is insufficient. The provision of annual courses would help, and the IACR website should provide a bibliography of methodological references and key-publications on cancer registration techniques and data analysis.

From time to time, the Association has sponsored meetings and courses of more local interest than the Annual scientific meeting and its satellite events. In 1975 a joint IACR/IARC meeting was held in Lyon, France to examine 'The Role of Cancer Registries in the Detection of Environmental Cancer Hazards'. The meeting marked the bicentenary of the publication by Percival Pott of the relationship between soot and cancers of the scrotum and skin in chimney sweeps. The workshop brought together workers in environmental health and from cancer registries to discuss how they could pool their resources and most efficiently assess the occupational cancer risk. In the same year the WHO Regional Office for the Western Pacific welcomed the collaboration of IACR in a seminar on cancer registration in the area.

An IARC course on cancer epidemiology (in French) was held in October 1997, just prior to the IACR annual meeting in Grand Bassam, and the African Association of Cancer Registries met during the meeting. A regional meeting of African Cancer Registries was held in Accra, Ghana during a meeting of the African Organization for Research and Training in Cancer (AORTIC) in October 2003. With financial support from the Association, the opportunity was taken to re-activate the African Association of Cancer Registries and to seek ways of

finding funds for the establishment of new registries in areas where there were none. The African registries met again in Cape Town, South Africa in December 2006 during a meeting held as part of the International Atomic Energy Agency's Nobel Peace Prize 'Special Event' on Cancer Control in Africa – a meeting focused on the growing burden of cancer in Africa.

Moving to another part of the world, a meeting of cancer registrars from Pacific Island countries was held in Noumea in July 1998. 13 registrars were trained in the use of CanReg3, EPIINFO6 and ICD-O. New CanReg3 databases were created for the Federated States of Micronesia, Papua New Guinea, Palau, Kiribati, Solomon Islands, Cook Islands, Tonga and Samoa. Transfer of existing data from CanReg2 or other software was completed for Fiji, Vanuatu and Guam and plans made to update the French Polynesian data system to CanReg3.

Thanks to a separate donation, IACR supported a course in Quito, Ecuador for cancer registry personnel from eight Central and South American countries to learn how to use ICD-O-3 and the then latest version of the IARC software for cancer registries, CanReg4 in November 2002.

The following workshops/meetings have been held in conjunction with the annual IACR meetings:

1991 Quito, Ecuador- Seminar/ Workshop on Cancer Registration in Latin America organized by IARC, IACR, UICC and the Asociación Brasileira de Registros de Cancer (in Spanish)

1993 Bratislava, Slovakia -

Meeting of European Network of Cancer Registries - Meeting of European Childhood ENCR meeting - Meeting of ECLIS study group

1994 Bangalore, India - Meeting of collaborators in project on population-based survival in developing countries

1995 Rio de Janeiro, Brazil - Seminar on cancer registry jointly supported by IACR, IARC, PAHO and UICC

1996 Edinburgh, UK - Meeting of European Network of Cancer Registries - Meeting of European Childhood Leukaemia Study Group - Workshop on cancer survival

1997 Grand Bassam, Cote d'Ivoire - IARC course on cancer epidemiology (in French) - Symposium in French: Aspects Therapeutiques des infections associées aux cancers - Meeting of African Association of Cancer Registries

1998 Atlanta, USA - Genetics Workshop - Meeting of North American Association of Central Cancer Registries (NAACCR)

1999 Lisbon, Portugal - Meeting of European Network of Cancer Registries - Meeting of European Childhood Leukaemia Study Group

2000 Khon Kaen, Thailand - Seminar on the Cohort Study in Cancer Research - Meeting of Research Group for Population-Based Cancer Registration in Japan (in Japanese) - Meeting of Asian cancer registries

2002 Tampere, Finland - Meeting of European Network of Cancer Registries - Developments in methodology for survival analysis - Developments in methodology for prediction of incidence and mortality

2003 Hawaii, USA - NAACCR Annual Conference

2004 Beijing, China - 16th Asian

regional meeting to promote cancer registries in Asia

2005 Entebbe, Uganda - Course on Analysis and presentation of cancer registry data (for directors of cancer registries in Africa) - Meeting organized by the WHO Regional Office for Africa to prepare a strategic document on cancer control in Africa

2007 Ljubljana, Slovenia - Roundtable discussions on computerized sources of information in cancer registration - Cancer mapping and spatial statistics in cancer epidemiology - Meeting of the European Network of Cancer Registries

2008 Goiania, Brazil - Course on population-based survival analysis - Workshop on data quality and international comparisons - Workshop on prediction of cancer incidence

2008 Sydney, Australia - Record linkage workshop

2009 New Orleans, USA - Data Quality and Relevance for International Comparison of Cancer Rates - Predictions of Cancer Incidence - Survival Analysis for Cancer Registry Personnel

2010 Yokohama, Japan - Cancer survival: practical use of cancer registry data in cancer control

## Scientific Publications and Collaborative Studies

The major activities of the Association are focused on the original aims – producing technical material to improve the quality and comparability of cancer registry data, and collaborating in the production of publications to make the data readily available at an international level. The Cancer Incidence in Five Continents (CIS) series, a unique source of data on cancer

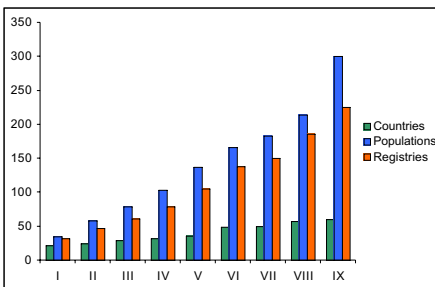
**Table 1. Coverage in the Nine Volumes of Cancer Incidence in Five Continents**

	Year	Registries	Populations	Countries	Period (approx.)
I	1966	32	35	29	1960-62
II	1970	47	58	24	1963-66
III	1976	61	79	29	1968-72
IV	1982	79	103	32	1973-77
V	1987	105	137	36	1978-82
VI	1992	138	166	49	1983-87
VII	1997	150	183	50	1988-92
VIII	2002	186	214	57	1993-97
IX	2008	225	300	60	1998-02

incidence around the world, and the International Incidence of Childhood Cancer publications, are a product of the collaboration between IACR and IARC.

*Cancer Incidence in Five Continents (Table I, Figures 5 and 6)*

From Volume III IARC and IACR agreed that successive volumes would be produced by IARC staff, the interests of the data contributors being represented by a nominee of the President of IACR. This nominee was expected to contribute actively to the editorial work. The IACR representative for Volume III was Dr Pelayo Correa (Cali/New Orleans). Professor K. Shanmugaratnam (Singapore)

**Figure 6. Coverage in Nine Volumes of Cancer Incidence in Five Continents****Figure 5. CI V Covers**

represented the Association for Volume IV, and Dr Tom Mack (California, USA) for Volume V. Since Volume VI there have been two IACR editors – Calum Muir (UK) and Yu-Tang Gao (China) for Volume VI, Luc Raymond (Switzerland) and John Young (USA) for Volume VII, Lyly Teppo (Finland) and David Thomas (USA) for Volume VIII and Brenda Edwards (USA) and Hans Storm (Denmark) for Volume IX.

Volume V data were published in the form of diagrams – histograms, pie charts and line-graphs - to allow an easier appreciation of the range and pattern of incidence internationally, and highlight the interesting variations for the different cancer sites (Whelan et al, 1990).

Volume VI included a diskette providing the data electronically, and by the time Volume VII was published it was no longer necessary to provide diagrams depicting cancer patterns. The electronic database of the volumes (Ferlay, 1997) contains the data with software designed to allow the extraction and further analysis of data. Sites, subtypes and cancer registries can be grouped as desired and summary rates calculated and sorted to produce reports. The software includes facilities for performing statistical comparisons between registries, together with standard graphical

representations.

In 2005 an electronic database presented all the published data from Volumes I through VIII, and corrected data from registries with at least three time periods on a CD-ROM (Parkin et al, 2005).

The data published in the first six volumes of Cancer Incidence in Five Continents covered some 30 years. The data had already provided a wealth of information on geographical variation in cancer risk by personal characteristics such as age, sex and racial or ethnic group. Time, the third element in the classic triad of epidemiological descriptors was the central interest of the book (Coleman et al, 1993). The analyses covered 60 populations in 29 countries for cancer incidence and 36 national datasets for cancer mortality.

### *International Incidence of Childhood Cancer*

Cancer occurs rarely in children, but it is the second most common cause of death

in the age-range 0-14. The spectrum of cancer types affecting children is, however, different from that of adults, most likely due to differences in aetiology. Although the CI5 series includes data on children, many of the typical childhood tumours go unnoticed because they are not well described by the ICD topographic categories.

It was the International Incidence of Childhood Cancer (IICC), published by IARC in collaboration with IACR in 1988 (Parkin et al, 1988), which provided the first comprehensive and systematic data on childhood cancer occurrence worldwide (see Figure 7). The monograph quickly became a universal source of reference. This success was a clear invitation to establish a monograph series specifically devoted to childhood cancer incidence and the second volume (Parkin et al, 1998) was published in 1998 and included data for the 1980s from some 130 cancer registries.

The third monograph of the series is now being prepared by IARC in collaboration with IACR. The new publication will bring availability of international data on childhood cancer incidence up to date. The two previous volumes covered roughly the 1970s and 1980s. For the third volume registries are invited to submit data for age-groups 0-14 or 0-19, for the period 1990 to 2008. Charles Stiller (UK) and Glynn Wessels (South Africa) are the IACR editors.

### **Other Scientific Collaborative Studies**

Volume II of CI5 (Doll et al, 1970) included an analysis of histological types of cancers of the ovary, testis, bladder, thyroid and leukaemia.

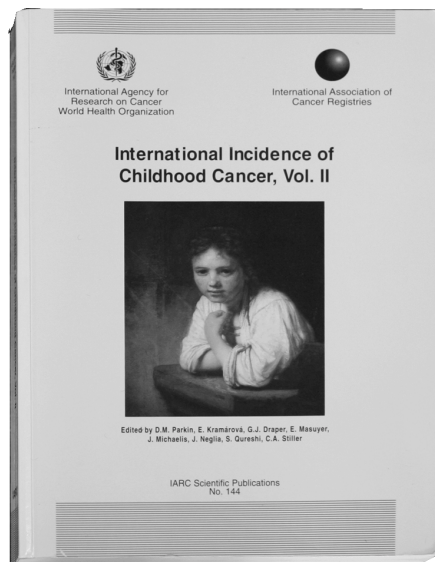
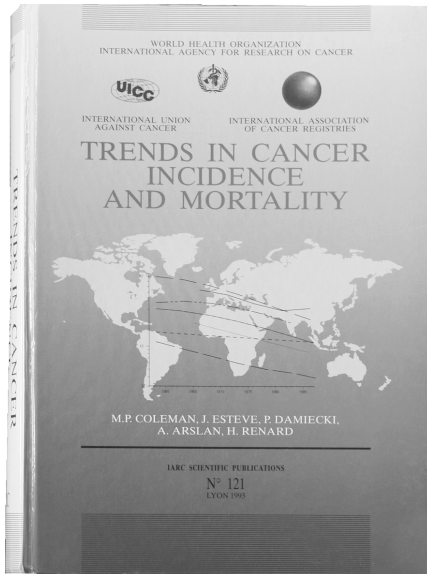


Figure 7 Childhood Cover



**Figure 8. Trends in Cancer Incidence and Mortality**

In 1974, at the Montecatini meeting, it was reported that data had been received from 12 registries for a collaborative study on adenocarcinoma of cervix and vagina. At the same meeting it was decided to ask members to undertake a review of cases of primary liver cancer, following publication of a dramatic series of cases of benign hepatoma of the liver in young women with a history of contraceptive pill taking (a diagnosis which would not normally be registered). A proposal for a study on influenza and childhood cancer had been circulated to members for discussion at the meeting.

In 1978 the Executive Board reported on these studies and on a further study of nose, nasal cavities, middle ear and accessory sinuses – then nearing completion. It was decided to investigate the role of UV radiation in the anatomical distribution of cutaneous malignant

melanoma, as well as data on less exposed sites, such as eye, and on non-exposed sites, i.e. those occurring within internal organs.

Thirty-eight contributing registries to Volume IV of CI5 took part in a study coordinated by the IACR editor, Professor K. Shanmugaratnam, on the distribution of histological types of urinary bladder, thyroid and Hodgkin's disease. 'It had been hoped that registries would tabulate these histological diagnoses, both as they appear in the cancer registry and after review of all or a sample of the histological material; unfortunately only 13 registries were able to take part in the latter part of the study' (IARC, 1983). It was reported (Shanmugaratnam & Powell, 1982) that the variations in terminology and diagnostic criteria used by pathologists might be of such magnitude 'that analyses based on histological data obtained from the files of cancer registries would be of limited value'.

In a more recent collaboration, IACR in association with the Clinical Trial Service Unit, UK, is sponsoring the Collaborative Group on Observational Studies of Breast Cancer Survivors (COBS). The aim of the project is to bring together information from cancer registries and elsewhere on the long-term side effects of treatment in breast cancer survivors.

## **Cancer Classification**

IARC, as the technical agency of WHO for cancer, is responsible for classification. IACR members collaborate actively in revisions of the International Classification of Diseases (the Neoplasms chapter and the Rules) and the International Classification of Diseases for Oncology and the Association made a major contribution to development of ICD-10 and ICD-O.

### *ICD-9 and ICD-O-1*

WHO asked IARC to make recommendations about the content and structure of the neoplasms chapter for ICD-9 in 1968. In the early years of IACR activities the WHO ICD Unit asked members to send any suggestions for addition, regrouping or deletion from the ICD A List – 150 causes for tabulation of mortality and morbidity – often used for mortality and hospital data, which was being updated in 1974 – and ideas for the creation of any other list which they felt might be useful. Members were also asked to assist in preparing a precise list of obsolete and unused terms which could be removed from the index for ICD-9.

At the IACR meeting in Montecatini in 1974 it was agreed that a major aim of the Association should be to attempt to achieve uniformity of definitions, notably the variation between different centres in histopathological nomenclature and interpretation. Over the years the increasing use of cancer registry data for research, and notably the publication of the CI5 series, revealed substantial differences. Until Volume V data for these publications were submitted in a paper tabular format (numbers of cases by five-year age-group, sex and ICD topography). Volume V was complicated by the acceptance of case-by-case data, coded either to ICD-9 or to ICD-O, as well as data in the traditional tabular format. This brought home the fact that many registries used their own 'modifications' to the basic ICD system of classification.

WHO agreed to include a code for the morphology of neoplasms in ICD-9 – an expansion to the five figures of MOTNAC (Manual of Tumor Nomenclature and Coding of the American Cancer Society,

1968), in turn based on SNOP (the Systematised Nomenclature of Pathology) (CAP, 1965) to take into account concepts current in Europe and elsewhere as well as in the United States. The result was the first edition of ICD-O (ICD-O-1) (WHO, 1976), published in 1976, adopted rapidly by cancer registries worldwide and greatly facilitating comparison of the incidence of cancer by histological type.

Following the publication of ICD-O-1, with clearly defined axes of anatomical location, histology and behaviour, international conformity to standard classification systems and coding rules increased steadily. For data published in Volume IV of CI5 (1973–77), just over one-third of the registries used MOTNAC (ACS, 1951; 1968), one-third had started to use ICD-O, 12% used SNOP (CAP, 1951) and 10% did not record histology (one registry used four distinct classifications in addition to ICD-O) (Powell, 1982).

Seventy-five % of contributors to Volume V used ICD-O to code histology, and this figure rose to over 90% for Volumes VI and VII. Only six of the 186 contributors to Volume VIII did not code their histological data to ICD-O (Whelan, 2002).

### *ICD-10, ICD-O-2 and ICD-O-3*

The first draft proposal for neoplasms in ICD-10, sent out by WHO in 1984, was circulated together with a questionnaire prepared by Connie Percy to some 160 registries in September of that year. The results were examined during a working party held at IARC to discuss ICD-10 and ICD-O. Recommendations were made to WHO on the structure and content of the chapter in light of the comments received. The conclusions were guided by the

considerations that cancer registries wanted:

- to see as little change as possible;
- malignant neoplasms of lymphatic and haematopoietic tissue to remain in the cancer section;
- further space for certain benign and in-situ neoplasms including recognition of carcinoma in-situ of cervix uteri at the 3-digit level;
- the lymphomas and leukaemias to be revised to reflect current concepts;
- that if changes were made and the content of a rubric altered then, wherever possible, a new number should be used leaving the previous one vacant;
- space for expansion.

In addition to contributing to the overall content of the chapter on Neoplasms, Association members were active in reacting to two issues, expansion versus conservative revision and neoplasms associated with HIV being located outside the Neoplasms section.

At the end of the 1980s the Deputy Secretary wrote to members:

‘I would like to take this opportunity to thank those among you – and you were numerous – who took the trouble to reply, often at length, to our questionnaires concerning the revision of the Neoplasms chapter in the 10th Revision of the ICD.

You will remember that our latest circular, sent to you at the beginning of this year, asked for your vote on which of two proposals should be put forward to WHO for the Neoplasms chapter. The first proposal was the more conservative revision presented to WHO in April 1985, in which we had endeavoured to make as little change as possible in order to facilitate

conversion. However following a Working Party in December 1985, it became evident that a number of workers in the field of cancer felt that more advantage should be taken of the potential for expansion provided by the new overall organization adopted by WHO (i.e. the creation of an alpha-numeric structure giving much more space at the 3-character level). Accordingly a second proposal was prepared which, while making every effort to ensure that conversion could be properly effected between ICD-9 and ICD-10, did include a number of ‘new’ 3-character rubrics.

Seventy-eight% of the registries which replied to this questionnaire stated that they would prefer the more radical version. Most of you preferred it for the same reasons: a more logical order; space for further expansion; the fact that this version bore a greater resemblance to ICD-O concepts, and the greater detail provided. It was therefore this version that I presented to the WHO Heads of Classification Centres in Tokyo this April, and which has been accepted.’

One hundred and seven members responded to an IACR circular asking for their opinion on the creation by WHO of a rubric for ‘HIV with malignant neoplasms’ located outside the neoplasms chapter in ICD-10. 89 of them were against, and this view was presented to WHO at the Revision Conference held in October 1989 by Dr Franco Berrino for IACR and by Dr Calum Muir for IARC. The plea to keep all mention of neoplasms within the chapter on cancer was rejected, but revised wording of the rubric was accepted:

‘Human immunodeficiency virus (HIV) disease causing malignant neoplasms’.

In 1989 work was also on-going for the

production of the second edition of ICD-O (World Health Organisation, 1990), to correspond to the new ICD-10 topographic classification. When the IACR Secretariat sent out the first draft proposal for the neoplasms chapter in September 1984 it had been hoped to produce a revised ICD-O at the same time as ICD-10.

However the considerable changes in certain areas of histopathology (notably the T- and B-cell neoplasms and the then recent concepts in the classification of lympho-haematopoietic malignancies) made it imperative to issue an update as soon as possible, and (with the permission of WHO) ICD-O-2 was published in 1990, two years before ICD-10.

When ICD-O-2 appeared the introduction contained the statement: 'It is not planned to publish another edition of ICD-O for many years, probably until the Eleventh Revision of ICD is published. However the understanding of lymphomas and leukaemias developed rapidly in the 1990s, and the third edition (ICD-O-3) (World Health Organisation, 2000), was developed to provide revised morphology codes, particularly for the lymphomas and leukaemias. The codes incorporate the WHO classification (Harris et al, 1999), which superseded the REAL (Revised European-American Lymphoma) classification (Harris et al, 1994) for lymphomas and the FAB (French-American-British) classification (Bennett et al, 1976) for leukaemias.

For ICD-O-3, many IACR members also completed a lengthy questionnaire on terms being used in different countries. Replies were amalgamated with the material prepared by groups such as the

European Network of Cancer Registries and the US SEER Program. Seventy-five member registries took part in field testing of the new edition, coding 400 cancer diagnoses with a field trial edition (Percy & Van Holten, 1988) and sending results with a commentary on problems encountered.

The cover of ICD-O-3 is purple – a tribute to Connie Percy who loved the colour, and was usually dressed in it.

In 2003 IACR recommended that the myeloproliferative and myelodysplastic diseases which appear in the D categories of ICD-10 (polycythaemia vera, myelodysplastic syndromes and other neoplasms of uncertain or unknown behaviour of lymphoid, haematopoietic and related tissue) be reported in tables of incidence, singly or together, with these code numbers. There were no plans at the time to revise ICD-10 to put these diseases into the malignant categories, where they belong.

It was recognized that some of the changes agreed would cause 'blips' in data, e.g. borderline ovarian cancer, myelodysplastic syndrome and refractory anaemia. A thorough evaluation of the differences the changes made to patterns and trends was then conducted using the US SEER data.

### *Childhood cancer classification (ICCC)*

The classification of childhood cancer is based on tumour morphology rather than, as for adults, the site of the tumour. The first classification was produced by Birch and Marsden in 1987. In 1996 an update (Kramárová et al, 1996) was produced in the light of ICD-O-2 and ICD-10.

The 1996 classification, produced by IARC and IACR in collaboration with the

International Society of Paediatric Oncology (SIOP), contains the program 'Child-check', software designed for the conversion of ICD-O coded data to the ICCC. A third edition (ICCC-3) took into account the major changes in coding and classification of neoplasms, notably for leukaemias and lymphomas – important groups of cancer types that occur in childhood cancer – in ICD-O-3. ICC-3 also proposed finer classification for selected subgroups of tumours, to reflect the recent development of diagnostic methods and their integration in routine data (Steliarova-Foucher et al, 2005)

### *Multiple primaries*

A survey conducted among contributors to Volume IV of CI5 found that 90% counted each independent primary separately if in different organs; 60% counted tumours in the same organ, e.g. colon, separately and 60% counted bilateral breast cancers separately (Muir & Waterhouse, 1982).

The members of IACR participated in a lengthy discussion over a standard 'international' definition of multiple primary tumours, for use in studies which compare results from different registries. Although registries vary considerably in the precise definition used, for international purposes a simple definition was adopted in 1995 into which most local systems could be 'collapsed' for comparative purposes. These were published in *Cancer Registration: Principles and Methods* and in the introduction to ICD-O-2 (p xxxviii).

With the introduction of ICD-10, there was a considerable increase in the number of 3-character topographic codes. Some sites, e.g. base of tongue (coded to the fourth digit in ICD-9 and ICD-O-1), were

assigned unique 3-character codes in ICD-10 and ICD-O-2. The IACR recommended combining some of the sites concerned to ensure comparability over time, and IACR members were circulated in October 1992 asking which 'groups' of topographic codes from ICD-O-2 should be considered as a single 'site' for the purpose of defining multiple cancers at the international level. Some sites, e.g. base of tongue, previously identified only at the 4th digit level in ICD-9 and ICD-O-1, were assigned unique 3-character codes in ICD-10 and ICD-O-2. In December 1993 members were asked for their views on the draft proposal. The revised rules for multiple primaries (as well as basis of diagnosis) were published in the introduction to ICD-O-3.

## **Technical Publications**

Cancer registries have worked closely with IACR and IARC over the years to improve the quality and comparability of data on cancer incidence. Work on the production of CI5 and IICC revealed many inconsistencies in registration practices between the members and a major result of IACR activities has been the production of a number of books, reports, recommendations and electronic publications to help registries.

### *The Role of the Registry in Cancer Control*

One of the first collaborative publications between IARC and IACR (although not yet with the IACR logo) was the book *The Role of the Registry in Cancer Control* (Parkin et al, 1985). The series of papers derives from discussions that followed the 1983 annual meeting in Heidelberg, with the theme 'The Benefits of Cancer Registration to the Cancer

Patient and Society'. Some of the contributions are revised versions of presentations given at the Heidelberg meeting, and a few were specially commissioned to explore certain subject areas in great depth. The publication concentrates on the use of cancer registration data both in the search for epidemiological risk factors and in the provision of screening and early detection, therapy and rehabilitation following treatment.

### *Cancer Registration: Principles and Methods*

A first manual on cancer registration methodology was produced by WHO in 1976 – designed for hospital based registries. Cancer Registration and its Techniques (MacLennan et al, 1978), published by IARC, incorporated the material from the WHO manual with additions and changes appropriate for

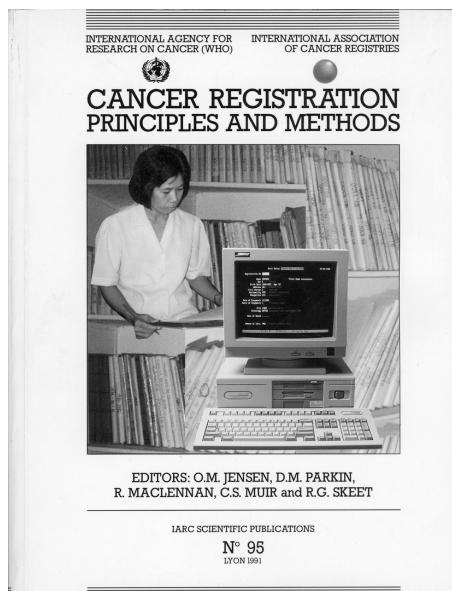
population-based registries. Its successor, Cancer Registration: Principles and Methods (Jensen et al, 1991) (see Figure 9), reflected the transformation effected by the advent of widespread use of the computer. The manual is aimed primarily at registry directors and research staff and describes the steps involved in planning and operating a population-based cancer registry. Work on a new edition is underway and will comprise both an update and an expansion of the previous incarnation, particularly in relation to the numerous advances and increased utilisation of statistical methods by cancer registries in the field of descriptive epidemiology. The publication, as previously, will be a joint IACR and IARC effort.

### *Training Manual for Cancer Registry Clerks*

A further manual (Esteban et al, 1995) provides a training guide and day-to-day reference for personnel working in population-based cancer registries. Prior to this publication, the only formal courses for cancer registry personnel were held in the USA, and the training manuals available were oriented towards the health care system of that country. It is suitable for use by anyone starting to work in cancer registry, especially those without medical training, and is designed with particular reference to the needs of cancer registries in developing countries. The loose-leaf format permits local modification and updating. The IACR is planning to revise the publication.

### *Automated Data Collection in Cancer Registration*

Automated data collection in the cancer registry has been studied regularly within



**Figure 9. Principles and Methods**

IACR in recent years. A first introduction to the issues involved in automating cancer registry procedures is the result of a meeting organized jointly by the European Network of Cancer Registries (ENCR) and the Veneto Cancer Registry (Black et al, 1998). It discusses general issues of automated systems, such as: data capture, transfer and security, computerized record linkage, summary of information required for cancer registration from multiple sources, quality control problems, automated diagnostic coding and conversion, and dedicated computer networks. The publication contains a set of recommendations for the registries.

In 2008 the IACR Executive reviewed the project set up by a group to provide leadership in the field of automated cancer registration, coordinate the evaluation of current methods and establish consensus standards. Progress is monitored by monthly telephone conferences. A survey has been set up to find out what types of electronic registration are used in registries. Similar surveys, for example the Australian cancer registries and the EURO CIM project, are being carried out and efforts will be coordinated. Registries will be surveyed in order to ascertain how automatic cancer registration is incorporated into their registries.

The group intends to set up a technical group to represent IACR and assist registries in understanding automatic registration.

### *Comparability and Quality Control in Cancer Registration*

Following Cancer Registration: Principles and Methods, this practical manual (Parkin et al, 1994) provides detailed practical advice on methods that

can be used by cancer registries to maximize the comparability and quality of their data. The three chapters address comparability, completeness and validity and the book concludes with a guide to the use of the IARC-CHECK program, provided on diskette, which contained the inter-field edits that were used to assess the validity of data submitted for Volume VI of Cancer Incidence in Five Continents. A two-part review has recently been published in the European Journal of Cancer which serves as an update of the practical aspects and techniques for addressing data quality at the cancer registry. The first installment examines the factors influencing the comparability, validity and timeliness of cancer registry data (Bray and Parkin, 2009a), with a second installment focusing on the principles and techniques available for estimating completeness, separating methods into those that are semi-quantitative - in that they give an indication of the degree of completeness relative to other registries or over time, and more quantitative techniques – those that provide a numerical evaluation of the extent to which all eligible cases have been registered (Parkin and Bray, 2009b).

### *Histological Groups for Comparative Studies*

The publication provides a description of the recognized histological subtypes of the principal cancers, together with the appropriate ICD-O morphology codes. Accompanying software allows recoding of data to the proposed histological groups, to permit comparative studies, with the aim of facilitating investigations of incidence and survival.

The groupings have been used to report

incidence of cancer by histological subtype since Volume VII of CI5.

### *Pathology of Tumours for Cancer Registry Personnel*

The manual was written in French by Antoine Buemi (Haut Rhin, France), translated by Paul Silcocks (Thames, UK) and first published in 2001 (Buemi, 2001). The 2nd edition (published on the IACR website in 2008) was updated by Antoine Buemi, translated by Paola Pisani and reviewed by Max Parkin. The aim of this ENCR/IACR manual is to explain in simple terms the genesis of tumours and the techniques used for pathological diagnosis, and to contribute to the understanding of the terminology used. It contains some 50 colour pictures of histological slides, and is intended for cancer registry personnel.

## **Software**

### *IACRCrgTools*

The first IARC/IACR CHECK Program (Parkin et al, 1994) was created to assess data submitted for Volume VI of Cancer Incidence in Five Continents (Parkin et al, 1992). It followed the initial validation process developed for Volume V of the series, when a minority of contributors sent data in the form of a case-listing (as opposed to data tabulated by site, sex and 5-year age-group). The program included the traditional data checks normally carried out in registries, such as validity of codes, sex versus site, age versus date of birth, site versus morphology, and site/histology versus age. The major part of the development work consisted of preparing an extensive check of the site/morphology combinations, in order to

reject outright errors, and to flag unlikely combinations.

The validation program for site and histology was based on ICD-O-1 and -2. In 2001 IACR, in collaboration with IARC, contacted cancer registries regarding a major review of the check program. The registries were asked for a copy plus documentation of any verification programs developed by cancer registries in order to undertake an international review of their validation procedures and incorporate useful ideas into a new program.

Successive revisions of ICD and ICD-O required conversions, and the following programs were made available to IACR members in 1994 (on diskette):

ICD-O-1 (1976) to ICD-9 (1975)  
ICD-O FT Ed (1988) to ICD-9 (1975)  
ICD-O-2 (1990) to ICD-9 (1975)  
ICD-O-1 (1976) to ICD-O-2 (1990)  
ICD-O-2 (1990) to ICD-O-1 (1976)  
ICD-O-2 (1990) to ICD-10 (1993)

The publication of ICD-O-3 required the preparation of new programs to convert and to validate data collected by cancer registries and these were provided as an IARC/IACR technical publication in 2005 (Ferlay et al). The latest release (July 2008) provides:

ICD-9 (1975) to ICD-O-2 (1990)  
ICD-9 (1975) and ICD-O-1  
morphology (1976) to ICD-O-2 (1990)  
ICD-10 (1992) and ICD-O-2 (1990)  
ICD-10 (1992) and ICD-O-2  
morphology (1990) to ICD-O-2 (1990)  
ICD-O-1 (1976) to ICD-O-2 (1990)  
ICD-O-2 (1990) to ICD-9 (1975)  
ICD-O-2 (1990) to ICD-10 (1992)

ICD-O-2 (1990) to ICD-O-3 (2000)

ICD-O-3 (2000) to ICD-10 (1992)

### *Child-check*

Child-check is a computer program designed to check individual cancer records for internal consistency, and for the conversion of cancer registry data coded according to the different editions of the ICD-O to the International Classification of Childhood Cancer (ICCC). The program helps users to improve the quality and comparability of childhood cancer data and to automate the scrutiny procedures as far as possible.

The first version of the software published in 1996 is being revisited at IARC and modernized, in order to incorporate the ICCC-3 and provide additional functions to facilitate conversion, verification, evaluation and comparison of datasets of childhood cancers.

## **CANREG**

In 1982 IARC began work on a collection of programs for a micro-computer which would provide a complete and easy-to-use system for a population-based cancer registry, and required no previous programming skills. The resulting software, CanReg, became a major collaborative activity between IARC and IACR. The program was installed in the registries of Singapore, Shanghai, Manila, Gabon and Zimbabwe in 1986, and in 1987 a version of CanReg, consisting of a single compiled program which could be used by all registries, was created. Text files were used to define data structures and program messages so that CanReg could be translated into different languages.

Allan Bieber created the original version of CanReg, and by 1988-99 the program had been installed in Algeria, Burundi, Gabon, Mali, Zimbabwe, Shanghai, Pakistan, Malaysia, Philippines (2 centres), Thailand (2 centres), Singapore, Vietnam, Bermuda, Costa Rica, Fiji, French Polynesia, New Caledonia and several smaller registries in Europe. Allan returned to his native Canada in 1989 and was replaced by Stephane Olivier. Stephane upgraded the system in 1994-95 (CanReg2), although it remained a menu-driven program based on MS-DOS, and by 1994-95 it had been installed in more than 50 sites worldwide, and translated into many languages. Andy Cooke took over responsibility in 1994, and developed the first MS-Windows based version (CanReg3), which was further upgraded to CanReg4 during 2001-2003. In 2008 140 registries in some 75 countries were using the program.

Since late 2006 Morten Ervik has been responsible for the CanReg project. The implementation of the fifth version of the program started in 2008. Based on the results of a survey among IACR members the software was redesigned and written from scratch.

Maybe the biggest change was in the autonomy it gave its users. Using open standards and built-in tools the registries could now tailor and set up the CanReg system to suit their needs, but still follow the international standards for comparability of incidence data. Also the project is run as an open source project.

Other improvements of CanReg5 were the redesigned network support, the move to a more modern relational database engine and full support for other operating systems than Windows 9x. A beta version

was released in January 2009 with several cancer registries participating in the testing.

CanReg is made available to members of the Association on request, free of charge.

## The Newsletter

The first newsletter is undated, but probably appeared in 1974 (it introduced the proposal to hold an IACR meeting in Montecatini in October 1974, on the occasion of the XIth UICC International Cancer Congress). The first page announced the creation of the newsletter, to contain information on items such as:

- on-going and projected Association studies;
- items in the literature which might be of particular interest to registries;
- news about progress with the third volume of Cancer Incidence in Five Continents;
- news from the regions;
- items of registry gossip.

The second edition appeared in late 1974 and was devoted to the IACR meeting held in Montecatini, Italy.

The original aim of four newsletters a year was never achieved – at the most they were biennial and usually annual. The printed newsletter was later replaced by the IACR website – originally hosted on the IARC website, then separated from IARC activities in 1999. A complaint recurring in nearly every Executive Board meeting was the lack of information for the newsletter from registries – however efforts were made over the years to abstract and reference all registry reports. The annual report from the regional representatives to

the Executive, reporting on significant activities in their region, is now available on the website.

## Fellowships

### *The Calum Muir Fellowship*

The Executive Board of IACR, meeting in Brazil prior to the 1995 scientific meeting in Rio, felt strongly that the Association should find some lasting way in which to commemorate Dr Calum Muir, who made such a major contribution to the development of cancer registration and the use of cancer registry data for epidemiological research during his lifetime. Calum Muir was a founder member of IACR and worked for many years as the permanent Deputy Secretary and subsequently President until his death in 1995.

It was agreed to seek funds to set up a memorial fellowship – an aim which was achieved by requesting voluntary contributions from members annually, which has permitted the accumulation of a capital sum which, with the interest from investment and (primarily) continued donations from IACR members, has enabled IACR to pay for one to two fellowships each year.

The fellowship is open to persons working in the field of cancer registration in any part of the world, particularly those who are establishing newer registries, permitting them to visit institutions away from their home base for approximately one month. It is awarded to individuals, not to registries. The project should have an element of learning related to cancer registration activities, which would benefit the cancer registry the person comes from. A maximum amount is not specified.

Fellowship selection is carried out by a committee comprising two members of the IACR Executive Board. The first fellowship was awarded in 1998, and taken up by Dr Quoc from Vietnam in 1999. By 2008 there had been a total of 13 awards to people working in cancer registries.

1999 Dr Nguyen Manh Quoc, Ho Chi Minh, Vietnam (Chennai, India to learn about population-based follow-up and to study survival methods and analyse results at IARC)

2000 Mrs Leslie Banda, Malawi (to analyse the results of the cancer registry at IARC and to attend the IACR meeting)

2001 Sory Kane, Cancer Registry of Bamako, Mali (to attend an IARC training course for registry clerks in Mali, and IARC to analyse the results of the cancer registry)

2002 Krittika Suwanrungruang, Khon Kaen, Thailand (Training in survival analysis at the Finnish Cancer Registry)

2003 Dr Gerelt-Od Luvsannorov, Ulaanbaatar, Mongolia (East Anglian Cancer Registry, UK)

Dr Chu Hoang Hanh, Hanoi, Vietnam (IARC Summer School on Cancer and Registration and Applications in Epidemiology)

2004 Shuzheng Liu, Zhengzhou City, Henan Province, China (IARC Summer School on Cancer and Registration and Applications in Epidemiology + Thames Cancer Registry)

Jumo Amero, Uganda Cancer Registry (IARC Cancer Registration Course, Yaounde, Cameroon + Thames Cancer Registry)

2005 Yogesh Verma, Gangtok, Sikkim, India (Thames Cancer Registry, North Western Cancer Registry and Welsh Cancer



**Figure 9. Calum Muir**

Intelligence Unit – UK)

Supot Kamsa-ard, Khon Kaen, Thailand (Cancer Institute, Chennai, India)

2006 Anne Korir, Nairobi Cancer Registry, Kenya (Thames Cancer Registry)

2007 Mrs Shravani Shrikant Koyande, Mumbai Cancer Registry, India (Summer School on Modern Methods in Biostatistics & Epidemiology, Institute BIOEPI, Padova, Italy)

2008 Dr Maria Aamir, National Cancer Registry, United Arab Emirates (UK Thames Cancer Registry)

2009 Mary Phoebe Amulen, Kampala, Uganda (Cancer Registration, coding and data analysis, Chennai, India)

Bouramo Coulibali and Brahim Sekou Malle, Mali (CanReg Training, Conakry, Guinea)

Zsuzsanna Jakab, Hungary (Comparative study of differences in survival of different childhood cancer diagnostic subgroups in Britain and Hungary)

*The Constance Percy Memorial Fund*

Hans Storm: 'I believe the general rule



**Figure 10. Connie Percy**

should be old timers – retired from active service, and that they have done something special for cancer registration and our organization. Mrs Constance Percy is differing from this since she continues to be in active service. Since she is probably never retiring I find it appropriate to give her Honorary Membership’.

The Constance Percy Memorial Fund was established at the request of her family when she passed away in 2004. Money donated is used to fund a travelling fellowship to each annual meeting of IACR. When the money runs out (donations are still welcome) it is proposed to continue to commemorate Connie Percy by, for example, naming an oral presentation or a Poster Award after her. As for the Calum Muir Fellowship, the fund is administered by two members of the Executive. The fund has been used for the 2005 annual meeting in Uganda (two fellowships), and for the 2009 meeting in

New Orleans (one fellowship).

## Journals

In the 1990s the IACR Executive decided that it would be beneficial to become affiliated to a scientific journal. Issues to be considered for such association included:

- IACR representation on the editorial board at executive level
- No page charges for IACR members
- Close collaboration with the editor-in-chief on selection of papers
- IACR logo and name on front cover
- policy on supplements (consisting of selected papers, particularly keynote, from the annual meetings)
- The newsletter to be included at least once, and possibly twice, a year as well as meeting announcements
- Electronic publication + link to the IACR website

By September 1994 two concrete proposals had been received, from Cancer Causes and Control (CCC), and Cancer Epidemiology, Biomarkers and Prevention (CEBP). It was agreed that CCC would become the official IACR journal, but the association proved problematic. In November 1995 the Executive asked the journal for statistics on the submission of papers to the journal, by subject type, and the outcome as percentage accepted (+/- modification) or rejected, in order to have some idea of use by the membership of CCC and current rates of success with submitted manuscripts. IACR also requested that, for papers submitted which involved analysis of data from cancer registries, at least one of the reviewers

should themselves be active in the field, and ideally a member of the Association. The senior editor of CCC came to the Executive meeting held in Edinburgh in 1996 to discuss, and it was noted in the subsequent newsletter that there had been a few teething troubles, notably with subscriptions, but it was hoped that the practical problems would be resolved. The IACR officers agreed that the journal appeared to be keeping to its commitment to publish papers based on registry material carried out, and that a reasonable proportion of the contents was devoted to descriptive epidemiology. However in 1997 the Executive decided to end the association with CCC due to lack of editorial consultation, problems with circulation and substantial price increases (without prior discussion with IACR).

In 1998 discussions were underway with CEBP, but negotiations came to a standstill in 1999 due to the journal's requirement that all members subscribe. Negotiations were commenced in that year with the Journal of Epidemiology and Biostatistics, but in 2000 it was reported that the journal did not feature in the impact factor list (and was not available in the Netherlands). By then the IACR was negotiating with the European Journal of Cancer Prevention, and the journal was accepted in 2001 (for a trial period of 3 years).

At the same time it was agreed that the Asian-Pacific Journal of Cancer Prevention become affiliated to IACR (initially for a trial period of two years). The extended abstracts from the Cancer Registries in Asia session in the 2000 meeting in Khon Kaen had already appeared in the journal.

The IACR became officially affiliated to both journals on 1 January 2002.

Each journal has an IACR member on the editorial board, to promote the publication of cancer registry articles and encourage members to submit. The IACR logo figures on the front covers and the journals have links to the IACR website on their own homepages.

In 2005 the journals published the IACR Guidelines on Confidentiality for Population-Based Cancer Registration and the International Rules for Multiple Primaries.

## **Issues**

Over the years the Association has been concerned with various issues concerning cancer registration, notably in matters related to registration completeness, coverage and comparability.

### *New world standard population*

The standard populations used for comparing data on cancer are those introduced by Sir Richard Doll in 1966, rounding off the figures first used by the late Professor M. Segi in 1960. This 'world standard population' had become almost universally accepted by epidemiologists for comparative studies, for example between different places, and over time.

Given that the age composition of this standard population is not representative of the global population, WHO proposed (and used) a standard in the WHO Statistics Annual 1994, based on the mean world population-age structure projected for the period 2000-05 (Ahmad et al, 2000).

In 1993, the IACR Executive wrote to WHO in vigorous protest:

'The introduction of a new standard should thus only be contemplated for very compelling reasons, and we can think of

none whatsoever for the change in the World Health Statistics Annual. It seems that the 'New' standard populations are based upon current estimates of the populations of the world and Europe; there is, however, no reason why a standard should resemble any particular population, so this can hardly be considered a valid reason for change. In addition to violating the principles of universality and continuity, the 'New' standard is also unnecessarily detailed (the extra digits complicate computation), and differs between the sexes (so that their standardized rates become non-comparable).'

That standard was withdrawn, but a new one was introduced without any consultation later. Bray et al (2002) examined the validity of the ratio of age standardized rates using the WHO and Segi standards and concluded that there was nothing to gain by changing the standard population for routine comparison of cancer data worldwide.

### *Confidentiality and ethics*

Cancer registries have been beset by problems concerning confidentiality for many years. The first attempt to examine the legal basis of cancer registration within the IACR was made in 1982 (Muir & Demaret, 1982). The survey on problems of confidentiality was prompted by the realization that in many parts of the world it is felt that legislation is needed not so much to compel the reporting of cases as to protect the person or institute reporting to the cancer registry from legal action for breach of confidentiality. 117 members were sent a two-part questionnaire, one part dealing with the legal basis of cancer

registration, the other with the identification of patients. Registries were also asked to make any comments on problems of confidentiality encountered in their registration area. 77 registries replied. At that time cancer reporting was voluntary for 47% of respondents, 35% had both voluntary and compulsory reporting (by law or administrative order or both), depending on the source of notification. Some 18% of the registration areas had compulsory reporting only. In most areas where reporting was voluntary it was found that physicians did not seem to be protected legally against proceedings for breach of confidentiality (for example, in Europe, physicians were protected only in 7 out of 13 areas).

The registries were asked about information recorded – and about storage. It transpired that the loss of information by fire, flood or computer failure was considered to be minimal or non-existent. Maximum loss would normally be one day's or one week's work, uncoded information or physical records. However in Africa, Asia, South America and 27% of European registries most information would be completely lost.

Few registries reported problems with confidentiality. Nonetheless it was reported that the cancer registry of Saarland (Germany) ceased operation for a year while the position of physicians reporting to the cancer registry in relation to confidentiality legislation was clarified and an appropriate local act passed. In France, Belgium, the Netherlands and Switzerland the absolute secrecy of the death certificate made it legally impossible for death certificates to be linked to the cancer registry data (a problem which persists in some areas to this day). And in the USA

and Europe written or oral consent often had to be obtained from the patient or next of kin or the treating physician (hostile attitudes on the part of physicians could make collaboration difficult).

Following the survey it became evident that many cancer registries would like to have an internationally accepted code of practice in relation to confidentiality.

Guidelines on Confidentiality in the Cancer Registry were produced by IARC/IACR in 1992, and 'Two opposite points of view emerged: the majority welcomed the code as a useful tool for registries, facilitating their work, but for a minority, it was considered that such a code would be harmful by drawing attention to the problem' (IARC, 1985). The code did, however, include a statement recognizing that a balance had to be struck between the right of privacy of an individual and his right, and that of his fellow citizens, to benefit from the knowledge of cancer causation, prevention and treatment that derives from cancer registration.

In 1992 the European Parliament was considering legislation to protect individual privacy through the Proposed Council Directive on the protection of individuals with regard to the processing of personal data and on the free movement of such data (COM(92) 422 final – SYN 287). The Executive Secretary contacted IACR members to express the concern that such legislation would seriously hamper, if not put an end to, the collection of accurate data on cancer incidence and other health statistics in Europe. Registry directors were encouraged to contact their European Member of Parliament about the likely effect on cancer epidemiology and other aspects of cancer control.

In the July 1999 Newsletter it was

reported that the issue of confidentiality had recently threatened cancer registration in two countries. The IACR had intervened (successfully) on both occasions, but these problems stimulated the Association to join with the European Network of Cancer Registries' initiative to prepare new guidelines.

#### *Definition of incidence date*

Rules were provided in Cancer Registration: Principles and Methods, but became outdated. There is no international agreement about the definition of incidence date and the IACR Executive decided in 2000 that it was not necessary to provide guidelines (IARC incorporates its own rules into CanReg).

#### *CTR (certification of registrars)*

The question of some international qualification for cancer registrars has been raised several times over the years. It is very difficult to develop an international standard suitable for very varying conditions. In 2005, in Uganda, the Executive decided to try and identify an organization that could define the basic principles. It was agreed that a start could be made by putting resources into one of the regions, e.g. CDC had developed a Spanish version that might be extended to Latin America. However in 2006, at the Goiania meeting, it was agreed that the issue constitute a huge piece of work which the Association could not assume – while recognizing that opportunities of training for registry managers is insufficient.

It was decided to add a section to IACR website to provide a bibliography of methodological references and key publications on cancer registration techniques and data analysis.

## Conclusion

The Association has grown in size and in the range of its activities since its inception in 1967. Thanks to its influence major progress has been made in improving the quality, comparability and availability of data on cancer incidence worldwide. It acts as a forum for discussion, exchange of ideas, experience and expertise. And it serves as an invaluable focal point for cancer registries worldwide, linking the well-funded, generously staffed cancer registries in much of the developed world to registries working in varied and often more difficult circumstances – sometimes the only ones in a country, run by one enthusiastic pathologist and one or two registrars. While it has grown in size and in influence over the years, in essence it can still be no better described than in the words of Calum Muir in a 1992 IACR Newsletter:

‘While we have many problems we have many strengths. Possibly the most important of these is the sense of belonging to an organization in which we all believe, and which contributes in a major way to the control of cancer. Last, but by no means least, we are a friendly crowd.’

## References

- Ahmad OE, Boschi-Pinto C, Lopez AD, Murray CJL, Lozano R, Inoue M (2000). Age Standardization of Rates: a New WHO Standard (GPE Discussion Paper Series; No 31), Geneva: World Health Organization.
- American Cancer Society (1951). Manual of tumor nomenclature and coding (MOTNAC). Washington, DC
- American Cancer Society (1968). Manual of tumor nomenclature and coding. New York, NY, American Cancer Society.
- Bennett JM, TWO AUTHORS, et al ( 1976). Proposals for the classification of the acute leukaemias. *Br J Hematol*, 33, 451-8.
- Birch JM, Marsden HB (1966). TITLE? *Int J Cancer*, 40, 620-4.
- Black RJ, Simonato L, Storm HH & Demaret E. (1998). IARC Technical Report No 32, Lyon, France.
- Bray F, Guilloux A, Sankila R, Parkin DM (2002). Practical implications of imposing a new World standard population. *Cancer Causes & Control*, 13, 175-82
- Bray F, Parkin DM (2009). Evaluation of data quality in the cancer registry: principles and methods. Part I: comparability, validity and timeliness. *Eur J Cancer*, 45, 747-55.
- Clemmesen J (1974) Statistical Studies in the Aetiology of Malignant Neoplasms IV. Duppl 247, *Acta Pathol Microbiol Scand*. Munksgaard, Kobenhavn.
- Coleman MP, Esteve J, Damiecki P, Arslan A, Renard H (1993). Trends in Cancer Incidence and Mortality. IARC Scientific Publications No. 121, IARC, Lyon, France.
- College of American Pathologists (1965). Systematized Nomenclature of Pathology (SNOP). Skokie, IL, USA.
- College of American Pathologists (1977). Systematized nomenclature of Pathology (SNOMED). Skokie, IL
- Curado MP, Edwards B, Shin HR, Ferlay J, Heanue M, Boyle P, Storm H (2008). Cancer Incidence Five Continents, Volume IX. IARC Scientific Publications No 160, IARC, Lyon, France.
- Doll R, Payne P, Waterhouse J (eds) (1966). Cancer Incidence in Five Continents: A Technical Report. Berlin, Springer-Verlag (for UICC).
- Doll R, Muir C, Waterhouse J (eds) (1970). Cancer Incidence in Five Continents, Volume II. Berlin, Springer-Verlag (for UICC).
- Esteban D, Whelan S, Laudico A, Parkin DM (1995). Manual for Cancer Registry Personnel (IARC Technical Report No. 10),

- International Agency for Research on Cancer, Lyon, France.
- European Cancer Incidence and Mortality Database (EUROCIM) User Manual (1995). 2nd Edition
- Ferlay J (1994). ICD Conversion Programs for Cancer IARC Technical Report No. 21, International Agency for Research on Cancer, Lyon, France.
- Ferlay J (1997). Cancer Incidence in Five Continents VII. CancerBase Series No 2, International Agency for Research on Cancer, Lyon, France.
- Ferlay J (2002). Cancer Incidence in Five Continents VIII. (CancerBase Series No 6) The International Agency for Research on Cancer, Lyon, France.
- Ferlay J, Burkhard C, Whelan S, Parkin DM (2005). Check and Conversion Programs for Cancer Registries. IARC Technical Report No 42, Lyon, France.
- Harris NL, TWO AUTHORS, et al (1994). A revised European-American classification of lymphoid neoplasms: a proposal from the International Lymphoma Study Group. *Blood*, **84**, 1361-92.
- Harris NL, TWO AUTHORS, et al (1999). World Health Organization classification of neoplastic diseases of the hematopoietic and lymphoid tissues: report of the Clinical Advisory Committee meeting, Airlie House, Virginia, November 1997. *J Clin Oncol*, **17**, 3835-49.
- Harris NL, TWO AUTHORS, et al (1999). World Health Organization classification of neoplastic diseases of the hematopoietic and lymphoid tissues: report of the Clinical Advisory Committee meeting, Airlie House, Virginia, November 1997. *Ann Oncol*, **10**, 1419-32.
- IARC (1985) Annual Report for 1985, p. 103. IARC, Lyon, France.
- IARC (1993) Annual report for 1982, p. 21. IARC, Lyon, France.
- IARC (1994) Multiple primaries. Internal Report No. 94/003, IARC, Lyon, France.
- Jensen OM, Parkin DM, MacLennan R, Muir CS, Skeet RG, eds (1991). Cancer Registration: Principles and Methods. IARC Scientific Publications No 95, IARC, Lyon, France.
- Kramárová E, Stiller CA, Ferlay J, Parkin DM, Draper GJ, Michaelis J, Neglia J, Quershi S (1996). The International Classification of Childhood Cancer. IARC Technical Report No. 29, IARC, Lyon, France.
- Lukes RJ, Craver LF, Hall TC, Rappaport H, Ruben P (1966). Report of the nomenclature committee. *Cancer Res*, **26**, 1311.
- MacLennan R, Muir CS, Steinitz R, Winkler A (1978) Cancer Registration and its Techniques. IARC Scientific Publications No 21, IARC, Lyon, France.
- Menck HR, Parkin DM, eds (1986). Directory of Computer Systems used in Cancer Registries. IARC, Lyon, France.
- Muir CS, Demaret E (1982). Some Current Problems in Cancer Registration. IARC Internal Technical Report No 82/003, IARC, Lyon, France.
- Muir C, Waterhouse J, Mack T, Powell J, Whelan S (eds) (1987). Cancer Incidence in Five Continents, Volume V (IARC Scientific Publications No. 88), IARC, Lyon, France.
- Parkin DM (2008) Cancer Registration: Its Purposes and Uses INCTR (International Network for Cancer Treatment and Research), Vol. 8, No. 1, Spring
- Parkin DM, Bray F. Evaluation of data quality in the cancer registry: principles and methods Part II. Completeness. *Eur J Cancer*. 2009;45(5):756-64.
- Parkin DM, Demaret E, Crosignani P (1983). The use of the computer in the cancer registry. *Methods Inf Med*, **22**, 150-5.
- Parkin DM, Wagner G, Muir CS, eds (1985). The Role of the Registry in Cancer Control. IARC Scientific Publications No. 66, IARC, Lyon, France.
- Parkin DM, Stiller CA, Bieber CA, Draper GJ, Terracini B & Young, JL (eds) (1988). International Incidence of Childhood Cancer. IARC Scientific Publications No 87, IARC, Lyon, France.
- Parkin DM, Muir CS, Whelan SL, Gao Y-T,

- Ferlay J, Powell J (1992). Cancer Incidence in Five Continents, Volume VI. (IARC Scientific Publications No. 120), IARC, Lyon, France.
- Parkin DM, Chen VW, Ferlay J, Galceran J, Storm HH, Whelan SL (1994). Comparability and Quality Control in Cancer Registration (IARC Technical Reports No. 19), IARC, Lyon, France.
- Parkin DM, Whelan SL, Ferlay J, Raymond L, Young J (1997). Cancer Incidence in Five Continents, Volume VII. (IARC Scientific Publications No. 143), IARC, Lyon, France.
- Parkin DM, Whelan SL, Ferlay J, Teppo L, Thomas DB (2002). Cancer Incidence in Five Continents, Volume VIII. IARC Scientific Publications No 155, IARC, Lyon, France.
- Parkin DM, Sobin L, Shanmugaratnam K, Ferlay J, Whelan SL (1997) Histological subtypes of common cancers: Diagnostic groups for comparative studies of incidence and survival. IARC Technical Report No 31, IARC, Lyon
- Parkin DM, Kramarova E, Draper GJ, Masuyer E, Michaelis J, Neglia J, Quereshi S & Stiller CA, eds (1998) International Incidence of Childhood Cancer, Volume II. IARC Scientific Publications No 144, IARC, Lyon, France.
- Parkin DM, Whelan SL, Ferlay J & Storm H (2005) Cancer Incidence in Five Continents. Volumes I-VIII. IARC CancerBase Series No 7, Lyon, France.
- Percy CL, Berg JW, Thomas LB (eds) (1968). Manual of Tumor Nomenclature and Coding, Washington, DC, American Cancer Society.
- Percy C ed (1980). Conversion of Malignant Neoplasms by Topography and Morphology from the International Classification of Diseases for Oncology to Chapter II, Malignant Neoplasms, International Classification of Diseases, 8th Revision, 1965 NIH Publication No 80-2136. Bethesda, MD, National Cancer Institute.
- Percy, CL (1983). Conversion of Neoplasm Section, 9th Revision of International Classification of Diseases 1975 to Neoplasm Section, 8th Revision of International Classification of Diseases 1965 and eighth Revision of International Classification of Diseases, Adapted for use in the United States. NIH Publication No. 83-2638.
- Percy CL, Van Holten V eds. (1988). ICD-O, International Classification of Diseases for Oncology, Field Trial Edition (developed by working party coordinated by IARC, Lyon, France).
- Percy C, Van Holten V (1992). Conversion of Neoplasms by Topography and Morphology from the International Classification of Diseases for Oncology, 2nd edition (ICD-O-2) to International Classification of Diseases for Oncology (ICD-O). National Cancer Institutes, USA.
- Percy CL ed. (1992) Conversion of Neoplasms by Topography and Morphology from the ICD-0-2 to ICD-9 and the ICD-9-CM. National Cancer Institute, Washington, USA.
- Schinz HR (1946). Kleine Internationale Krebskonferenz vom 2-6 September 1946 in Copenhagen. *Schweiz Med Wochenschr*, 76, 1194-6.
- Shanmugaratnam K, Powell J (1982). Special study on histomorphological types of cancer. In: Waterhouse JAHW, Muir, Shanmugaratnam K and Powell J. (1982) Cancer Incidence in Five Continents Vol IV IARC Scientific Publication No. 42, IARC, Lyon, France.
- Steliarova-Foucher E, Stiller C, Lacour B, Kaatsch P (2005). International Classification of Childhood Cancer, third edition. *Cancer*, 103, 1457-67.
- Wagner G (1985). Cancer Registration: Historical Aspects. In: Parkin DM, Wagner G & Muir CS., eds. The Role of the Registry in Cancer Control. (1985). IARC Scientific Publications No. 66, IARC, Lyon, France.
- Waterhouse J, Muir C, Correa P, Powell J (eds) (1976). Cancer Incidence in Five Continents, Volume III (IARC Scientific Publications No. 15), IARC, Lyon, France.

- Waterhouse J, Muir C, Shanmugaratnam K, Powell J (eds) (1982). *Cancer Incidence in Five Continents, Volume IV* (IARC Scientific Publications No. 42), IARC, Lyon, France.
- Whelan SL, Parkin DM, Masuyer E (1990) *Patterns of Cancer In Five Continents*. IARC Scientific Publications No 102, IARC, Lyon, France.
- Whelan SL (2002). *Classification and Coding*. In: Parkin DM, Whelan SL, Ferlay J, Teppo L, Thomas DB. *Cancer Incidence in Five Continents, Volume VIII*. IARC Scientific Publications No 155, IARC, Lyon, France, p. 35.
- WHO (1967) *International Classification of Diseases, 1965 Revision*, Geneva, World Health Organization.
- WHO (World Health Organization) (1976) *WHO Handbook for Standardized Cancer Registries (Hospital Based)*. WHO Offset Publications No. 25.
- WHO (World Health Organization) (1956) *Histological classification of neoplasms*, (WHO/HS/CANC/24.1), Geneva.
- WHO (World Health Organization) (1976) *International Classification of Diseases for Oncology (ICD-O)*, Geneva.
- WHO (World Health Organization) (1990) *International Classification of Diseases for Oncology, Second Edition (ICD-O)*, Geneva.
- WHO (World Health Organization) (1957) *Manual of the International Statistical Classification of Diseases, Injuries and Causes of Death (Based on the Recommendations of Seventh Revision Conference, 1955)*, Geneva.
- WHO (World Health Organization) (1977) *Manual of the International Statistical Classification of Diseases, Injuries and Causes of Death (Based on the Recommendations of Ninth Revision Conference, 1975)*, Geneva.
- WHO (World Health Organization) (1992) *Manual of the International Statistical Classification of Diseases, Injuries and Causes of Death (Based on the Recommendations of Seventh Revision Conference, 1990)*, Geneva.
- WHO Resolution WHA58.22 (2000). *Cancer Prevention and Control*.
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## Annexes

# Annex 1: IACR Constitution and By-laws

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## CONSTITUTION

### 1. SCOPE AND PURPOSE

The International Association of Cancer Registries is a professional society, whose members are interested in the development and application of cancer registration and morbidity survey techniques to studies of defined population groups.

The Association welcomes to membership organizations concerned with the collection and analysis of data on cancer incidence and/or the end results of cancer treatment in defined population groups.

### 2. MEMBERSHIP

The Association consists of Voting, Associate and Corporate members. Each organization for which Voting Membership is approved by the Executive Board (see 3 below) is entitled to one vote when ballots are taken.

Other organizations, for which Associate or Corporate Membership is approved by the Executive Board, are not entitled to vote.

The Executive Board is empowered to offer non-voting membership to individuals who are interested in and who have contributed to the aims of the Association.

Individual Honorary Membership of the Association may be awarded to persons

who have made distinguished contributions to the development of cancer registration and studies of cancer in defined populations.

### 3. EXECUTIVE BOARD

The Executive Board is the highest authority of the Association. It consists of the President, the General Secretary, the Executive Secretary and the Regional Representatives. The immediate past President of the Association serves as an ex-officio member of the Executive Board.

The President, the General Secretary and the Regional Representatives shall be elected by the Voting members for designated terms as provided for in the By-laws. Officers must be affiliated with and proposed by an Associate or Voting member. A Regional Representative shall be from a member organization in the Region he or she represents.

A vacancy on the Executive Board may be filled, for the remainder of the term of office, either by vote of the Voting members or by vote of the Executive Board.

In the case of death or resignation of the President within one year of the end of his/her mandate, the election of a new President will take place on the scheduled date (4 years after the previous election). If death or resignation occurs in the first three years of office, a new President shall be elected as soon as possible. The

Executive Board shall adopt general By-laws, define the duties of officers, create and discharge committees and take such other actions as required to implement the stated purposes of the Association.

If the immediate past President is not available because of death or resignation, the previous President shall continue ex-officio for a further two years.

The International Agency for Research on Cancer (IARC) provides the Association with a Secretariat. IARC provides, in agreement with the Executive Board of the Association, a professional staff member to act as Executive Secretary. A vacancy in the position of Executive Secretary may be filled by decision of the Executive Board for a maximum period of one year.

#### **4. REGIONS**

The Executive Board shall define the several Regions of the Association, realign the Regional structure of the Association from time to time as conditions warrant and may approve By-laws for a Region submitted by members of that Region and recommended for adoption by the Regional Representative.

For the purpose of regional representation, members shall be elected for:

- Africa (1)
- Europe (2)
- North America (2)
- Central and South America (1)
- Asia (2)
- Oceania (1)

The Executive Board may approve By-laws for a Region submitted by members of that Region and recommended for adoption by the Regional Representative.

The Regional Representatives will serve as primary liaison officers to provide a continuing inventory of cancer registries and to facilitate exchange of information and the organization of projects.

#### **5. ACTIVITIES**

The Executive Board shall consult the Voting members on vital questions that may affect the policies of the Association.

Any activities which fall within the sphere of interest of the Association may be authorized by the Executive Board, including arrangements for international and local scientific meetings and the issuance of publications reporting the activities of the Association. The Association will cooperate with and seek the support of other organizations concerned with cancer registration in fostering the activities of mutual interest.

No action taken by the Association shall be construed as committing an affiliated organization to a prescribed course of action.

#### **6. AMENDMENTS**

Amendments to the Constitution may be proposed by the Executive Board or in writing by at least 20 Voting members. Before becoming effective, an amendment must be ratified by a two-thirds majority of those voting in a mail ballot of Voting Members.

## **BY-LAWS**

### **TERM OF OFFICE**

Each officer except the Executive Secretary shall normally serve a term of four years. No elected officer other than the General Secretary may have two successive terms in the same position.

### **NOMINATIONS**

The Executive Board shall appoint a Nominating Committee of three staff members of organizations holding Voting membership. The Nominating Committee shall report their slate of candidates to the General Secretary for circulation to the members and notification on the website at least 60 days in advance of the distribution of mail ballots; five Voting members may nominate a candidate for any office by so informing the General Secretary in writing. If the General Secretary is a candidate for a second period of office, the slate of candidates shall be reported to the President.

### **BALLOTING AND ELECTION**

All ballots for election of officers shall be conducted by mail and supervised by the Executive Secretary, who may set reasonable deadlines for the return of ballots. Candidates receiving a plurality of the votes cast shall be declared elected.

The President and General Secretary of the Association shall be elected by the total voting membership. The Regional Representatives shall be elected by the Voting members of the Region concerned.

As required by the terms of office, elections are to be held every four years.

### **MEMBERSHIP**

The Executive Secretary shall prepare and distribute application forms for membership. The Executive Board takes decisions about membership applications, but this Board may delegate the authority to approve applications for membership to the President, the General Secretary and to the appropriate Regional Representative(s)

The Executive Board has the power to change the membership status from Associate to Voting and vice versa; it shall also have the power to withdraw membership after due consideration.

Corporate membership can be given to companies, journals or other appropriate organizations. Payment of the Corporate membership fee entitles such members to have access to the IACR mailing list.

From time to time lists of members of the Association shall be prepared and distributed by the Secretariat.

### **MEMBERSHIP FEES**

Voting and Associate members of the Association pay an annual membership fee, to be reconsidered when necessary by the Executive Board of the Association.

The fees shall be as follows:

Voting and Associate members:

145US\$ or EUR \100

Non-voting individual members:

50US\$

Corporate members: 500 US\$

Membership fees may be waived at the discretion of the Executive Board.

Members that only have access to non-convertible currency may, at the discretion of the Executive Board, pay their fees into a local currency account.

## **FINANCIAL MANAGEMENT**

The Executive Board will appoint a Treasurer to the Association who will:

- Maintain good order of the Association Finances and ensure that financial regulations are adhered to.
- Maintain an up to date account of all financial transactions.
- Advise the Executive and membership on expenditure of the budget.
- Prepare a statement of revenue and expenditure to be presented at the Annual Business Meeting for ratification.
- Be empowered to disburse Association funds for such purposes as are agreed.

All transactions over \$250 shall be agreed with the President and General Secretary.

## **CRITERIA FOR VOTING AND NON-VOTING MEMBERSHIP**

Full voting membership is accorded to well established population-based cancer registries or associations of cancer 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.

Associate non-voting membership is given to 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.

Individual membership is given to registries which have not started operating and to individuals who are interested in the activities of the Association.

Corporate non-voting membership is given to corporate organizations.

## **COMMITTEES**

Other than the restriction placed on membership for the Nominating Committee, all staff members of Voting and Associated organizations are eligible to serve as chairman or member of any Association committee.

The President shall make committee appointments after consultation with members of the Executive Board. The General Secretary and the Executive Secretary are ex-officio members of all Association committees.

## Annex 2 IACR Executive Board

Dates	President	Ex-officio President	General Secretary	Africa	Asia	
					1	2
1971	E Pedersen (Norway)	SJ Cutler (USA)		FO Torres (Mozambique)	K Akazaki (Japan)	
1974	E Pedersen (Norway)	SJ Cutler (USA)		GM Edington (Nigeria)	N Kurihara (Japan)	
1975-78	J Waterhouse (UK)	E Pedersen (Norway)	SJ Cutler (USA)	GM Edington (Nigeria)	N Kurihara (Japan)	
1979-82	P Correa (Colombia/USA)	J Waterhouse (UK)	E Saxen (Finland)	Ed 'B Attah (Nigeria)	I Fujimoto (Japan)	J Ford (Australia)
1983-86	K Shanmugaratnam (Singapore)	P Correa (Colombia/USA)	J Young (USA)	R Owor (Uganda)	T Shigematsu (Japan)	J Ford (Australia)
1989-92	D Thomas (USA)	K Shanmugaratnam (Singapore)	O Jensen <sup>2</sup> (Denmark)	TA Junaid (Nigeria)	G Giles (Australia)	A Hanai (Japan)
1992-96	C Muir <sup>3</sup> (UK)	D Thomas (USA)	A Hanai (Japan)	S Bayo (Mali)	HP Lee <sup>4</sup> (Singapore)	K Mabuchi (Japan)
1996-97	J Young (USA)	D Thomas (USA)	H Storm (Denmark)	M H-Cherif (Algeria)	A Nandakumar (India)	K Mabuchi (Japan)
1998-99	J Young (USA)	D Thomas (USA)	H Storm (Denmark)	M H-Cherif (Algeria)	A Nandakumar (India)	V Vatanasapt (Thailand)
2000-01	H Storm (Denmark)	J Young (USA)	D Forman (UK)	H Wabinga (Uganda)	D Esteban (Philippines)	V Vatanasapt (Thailand)
2002-03	H Storm (Denmark)	J Young (USA)	D Forman (UK)	H Wabinga (Uganda)	D Esteban (Philippines)	A Oshima (Japan)
2004-05	M Parkin (UK)	H Storm (Denmark)	T Hakulinen (Finland)	M Koulibaly (Guinea)	M Soda (Japan)	A Oshima (Japan)
2006-07	M Parkin (UK)	H Storm (Denmark)	T Hakulinen (Finland)	M Koulibaly (Guinea)	M Soda (Japan)	S Wiangnon (Thailand)
2008-10	B Edwards (USA)	Max Parkin (UK)	F Bray (Norway)	CG-Mbalawa (Congo)	H Tsukuma (Japan)	S Wiangnon (Thailand)

<sup>1</sup>Asia was combined with Oceania until 1996; <sup>2</sup>(d 1991); <sup>3</sup>Calum Muir died in office and was replaced by David Thomas, previous President, until the next election; <sup>4</sup>Hin Peng Lee was unable to continue in office after 1994; <sup>5</sup>Paul Jelfs moved from cancer registration during the period and so resigned his office. Graham Giles, as organiser of 2008 meeting in Sydney, agreed to replace him on the Executive until his term of office expired in 2008. Notes: - The President serves a

## Annex 2 IACR Executive Board

Europe		North America		Central and	Oceania <sup>1</sup>
1	2	1	2	South America	
PM Payne (UK)	J Staszewski (Poland)	I Martinez (USA)	G Linden (USA)	BKG de Arruda (Brazil)	
PM Payne (UK)	R Steinitz (Israel)	THC Barclay (Canada)	G Linden (USA)	BKG de Arruda (Brazil)	
B Ravnihar (Yugoslavia)	R Steinitz (Israel)	THC Barclay (Canada)	C Key (USA)	AP Mirra (Brazil)	
G Riotton (Switzerland)	J Staszewski (Poland)	A Clarke (Canada)	J Young (USA)	AP Mirra (Brazil)	
O Jensen (Denmark)	P Schaffer (France)	T Mack (USA)	G Hill (USA)	C Cuello (Colombia)	
F Berrino (Italy)	I Plesko (Slovakia)	M Swanson (Canada)	D Robson (USA)	E de Stefani (Uruguay)	
I Izarzugaza (Spain)	H Storm (Denmark)	V Chen (USA)	R Lussier (Canada)	F Corral (Ecuador)	
I Izarzugaza (Spain)	V Pompe-Kirn (Slovenia)	D West (USA)	R Lussier (Canada)	F Corral (Ecuador)	D Roder (Australia)
L Schouten (Netherlands)	V Pompe-Kirn (Slovenia)	E Holowaty (Canada)	D West (USA)	E Carrascal (Colombia)	D Roder (Australia)
L Schouten (Netherlands)	T Aareleid (Estonia)	E Holowaty (Canada)	B Edwards (USA)	E Carrascal (Colombia)	T Threlfall (Australia)
R Zanetti (Italy)	T Aareleid (Estonia)	D Deapen (USA)	B Edwards (USA)	M-P Curado (Brazil)	T Threlfall (Australia)
R Zanetti (Italy)	D Brewster (UK)	D Deapen (USA)	H Bryant (Canada)	M-P Curado (Brazil)	P Jelfs (Australia)
M Colonna (France)	D Brewster (UK)	LG-Ries (USA)	H Bryant (Canada)	E Laura (Argentina)	P Jelfs <sup>5</sup> (Australia)
M Colonna (France)	S Siesling (Netherlands)	L G-Ries (USA)	B Kohler (USA)	E Laura (Argentina)	F Baumann (New Caledonia)

further 4 years on the Executive following election of his/her successor as ex-officio President - The Executive Secretary is a non-elected office and is held by a staff member of the International Agency for Research on Cancer. The office of Treasurer was created in 2006: Egil Engen (2006-2007), Lynn Gloeckler Ries (2008-Present)

## Annex 3: Honorary Members of the IACR

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Dr E. Anglesio (Italy) 1985*	Mrs Constance Percy (USA) 1993*
Dr Bruce Armstrong (Australia) 2008	Dr Zoltan Peter (Hungary) 2001*
Dr Aileen Clarke (Canada) 1994	Dr Ivan Plesko (Slovakia) (2004)
Dr Tiit Aareleid (Estonia) 2007	Dr Vera Pompe-Kirn (Hawaii) 2003
Dr Johannes Clemmesen (Denmark) 1980	Miss Jean Powell (UK) 1996
Mrs Marylon Coates (Australia) 2003	Dr Mati Rahu 2007
Dr Pelayo Correa (USA) 1995	Dr Bozena Ravnihar (Slovenia) 1996*
Dr Sidney Cutler (USA) 1985*	Mr Luc Raymond (Switzerland) 1996
Sir Richard Doll (UK) 1980*	Dr David Roder (Australia) 2008
Dr Gerald Draper (UK)	Dr Erkki Saxén (Finland) 1985
Dr Yu-Tang Gao (China) 1996	Dr M. Segi (Japan) (1980)*
Dr Isaburo Fujimoto (Japan) 1993	Dr V. Shanta (India) 1996
Dr William Haenszel (USA) 1980*	Dr K. Shanmugaratnam (Singapore) (1980)
Dr Matti Hakama (Finland) 2002	Dr Ruth Steinitz (Israel) 1980*
Dr Aya Hanai (Japan) (1996)	Dr Lyly Teppo (Finland) 2002
Dr Harald Hansluwka (Switzerland) 1998	Dr David Thomas (USA) 1999
Dr Gerry B. Hill (Canada) 2000	Dr Hrafn Tulinius (Iceland) 1996
Dr Kasturi Jayant (India) (2000)	Dr Albert Tuyns (France) 1985*
Dr Lajos Juhasz (Hungary) (1998)	Dr John Waterhouse (UK) 1985*
Dr D.J. Jussawalla (India) 1993*	Ms Sharon Whelan (France) 2007
Dr Usha K. Luthra (Kuwait) 1994	Dr John Young (USA) 1994
Dr Bob MacLennan (Australia) 2008	Dr Calvin Zippin (USA) 1994
*Dr Knut Magnus (Norway) 1994	Dr Antonio Zubiri (Spain) (1996)*
Dr Nimit Martin (Thailand) (2000)	Dr Fabian Corral (Ecuador) 2009
Professor Raphael Owor (Uganda)	
Mrs Marjorie Page (UK) 2001	
Dr Antonio Pedro Mirra (Brazil) 1995	* Deceased
Dr Einar Pedersen (Norway) 1980*	

## **Annex 4: Main Topics, IACR Annual Meetings**

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### **1970 – Houston, Texas, USA**

The relationship of the Association with various international organizations (WHO, UICC, IARC)

International classification of diseases

Collection and publication of data from cancer registries

Future goals of the Association

Activities and objectives of cancer registries

Methodological problems

o Data collection and handling

o Compatibility of data

### **1973 – Dusseldorf, Germany**

(an informal meeting held during a Symposium on Cancer Registration with attendance largely restricted to European countries)

Relationships between IACR and IARC

Cancer Incidence in Five Continents

During the meeting it was suggested that the annual meeting spend approximately one third of the time on business, the remaining two thirds being devoted to methodological problems of cancer registries.

### **1974 – Montecatini, Italy**

A lecture on the future aims of the IACR. There are mixed abstracts but no programme on record.

### **1978 – Buenos Aires, Argentina**

Quality control in the cancer registry

In-put operations (sources of data)

Out-put operations (presentation of data for users)

Clinical follow-up

The central registry

Completeness of registration

### **1980 – Oslo, Norway**

Urban and rural differences and small geographical areas

Establishment of numerators and denominators for occupation and social class

Establishment of numerators for ethnic and religious groups and migrants

### **1982 – Seattle, USA**

Data collection systems

Linkage

Second primaries

Survival

Confidentiality

Use of the computer

### **1983 – Heidelberg, Germany (FRG)**

Benefits of cancer registration to the cancer patient and society

o Cancer control

o Follow-up studies and epidemiology

o Industrial cancer risk

o Planning and monitoring of curative and preventive measures

o Screening

### **1984 – Fukuoka, Japan**

Population-based cancer registries in Japan and cancer registration in various countries (USA, UK, USSR, Canada, Australasia, China, Hungary, India)

Screening

Cancer control

Aetiological studies

Quality control

### **1985 – Hartford, Connecticut, USA**

Multiple tumours

WHO/IACR collaborative activities with particular reference to WHO's Health For All 2000 programme

### **1986 – Budapest, Hungary**

The cancer registry in the service of the community from the point of view of a developing country

Historical review of selected registries

International incidence of childhood cancer

ICD-9, ICD-10 and ICD-O

Confidentiality

### **1987 – Copenhagen, Denmark**

Environmental cancer

Mapping

Radiation and cancer risk

Occupational cancer

### **1988 – Melbourne, Australia**

Diet and cancer Migrants

Alcohol and cancer

Dietary methods in epidemiological research on cancer

### **1989 – Maastricht, The Netherlands**

Cancer screening

Confidentiality

Occupational risk

Planning of health services for the cancer patient in the year 2000

### **1990 – Hamburg, Germany**

Urban life and cancer

General environmental risks

Occupational risks

Way of living and lifestyle

Methods

### **1991 – Quito, Ecuador**

Poverty and cancer

Cancer in developing countries

Infection and cancer

Diet and cancer

Cancer screening in developing countries

Gastric cancer screening

Tobacco and cancer

Control and prevention perspectives : stomach, cervix and lung cancer

### **1992 – Ottawa, Canada**

Cancer and the environment

Cancer control

Data quality and use

Cancer and youth

Cancer in special populations

Privacy and the implications for cancer registries

### **1993 - Bratislava, Slovakia**

Cancer in the ageing

Environmental pollution and cancer

The central position of the registry in prevention and control of cancer

Cancer registry and the planning of cancer control programmes

Methodological problems in cancer registration

Methodological issues of time trend analyses

### **1994 - Bangalore, India**

Cancer in women :

o Lifestyle and cancer in women

o Cancer in women : size of the problem and future trends

o Smokeless tobacco use in India with special reference to women

Cancer control

Molecular epidemiology of cancer

Smokeless tobacco and cancer

Lymphoid and haemopoietic malignancies

Tumours of upper GIT

Epidemiology of gallbladder cancer

Oesophagus cancer in Assam

Factors for improvement of stomach cancer survival in Osaka

Cancer Incidence in Five Continents – the story so far!

### **1995 - Rio de Janeiro, Brazil**

Causes and prevention of cancer in developing countries

Risk factors and possible interventions for breast, stomach, prostate and cervix cancer

Tobacco and cancer  
Diet and cancer  
Quality control  
Childhood cancer

### **1996 - Edinburgh, UK**

Survival :  
o Methodological issues  
o Understanding variations in survival  
o Time trends  
o Social class and ethnic group  
o Survival in the developing countries  
Cancer registries in aetiological research and development  
Cancer – Science and Society : the assessment of communication of risk

### **1997 - Grand Bassam, Côte d'Ivoire**

Infection and cancer  
HIV/AIDS  
Herpes viruses and oncogenesis in humans  
Helicobacter pylori  
Hepatitis viruses  
HTLV  
Papilloma virus  
Parasites  
Cancer registration

### **1998 - Atlanta, USA**

Genetics in population-based cancer research  
o Cancer registries genetics and studies of genetic susceptibility  
o Advances in cancer genetics  
o Uses of population-based cancer registries for cancer genetics research  
o Uses of population-based cancer registries for translating genetic research into prevention and control  
Confidentiality and ethics in cancer research  
Cancer registry operations, methods and issues  
Ethical and social issues in genetic-based cancer studies  
Balancing the conflict between privacy and public health research – the international cancer

registry experience

### **1999 – Lisbon, Portugal**

Screening related to cancer registries  
Tobacco and young people  
Quality control in cancer registries  
Cancer trends  
Cancer mapping  
Genetic epidemiology and cancer registries

### **2000 – Khon Kaen, Thailand**

Cervix cancer prevention : new approaches  
Electromagnetic fields and cancer  
The challenge to control skin cancer  
Liver cancer  
Ethnicity and cancer : Asian migrant data and directions for future research  
Cancer registries in Asia (poster session)  
Lung cancer in females  
Mind and cancer

### **2001 – Havana, Cuba**

Quality control of cancer registry data  
Cervix cancer  
Prostate cancer  
Head and neck cancer  
Evaluation of cancer control programs  
Latinoamerica cancer registry results  
Population survival studies  
Geographical and time variations on cancer incidence and mortality

### **2002 – Tampere, Finland**

Environmental epidemiology  
Evaluation of interventions  
Biological and genetic data banks and cancer registries  
Registry studies  
Survival analyses including quality of life  
Confidentiality and ethics

### **2003 – Honolulu, Hawaii**

Pacific Islanders and indigenous populations  
Registry operations  
Physical activity and cancer

- Survival analysis
- Diet and cancer
- Human papillomavirus, cervical cancer and vaccines
- Rare cancers
- Migrants and cancer
- Issues of data harmonization, especially concerning multiple primary and comparative data analysis

## **2004 – Beijing, China**

Promoting cancer registration in the developing countries and enhancing cancer prevention and control in the world

## **2005 – Entebbe, Uganda**

- Cancer in low resource populations
- AIDS and cancer
- Cervix cancer control in Africa and other developing countries
- Infection and cancer
- Palliative care for the cancer patient in Africa and other developing countries (including psychosocial aspects)
- Prostate cancer
- Cancer control in Africa
- Cancer registration in Africa (problems and results) (poster session with round-table discussion)

## **2006 – Goiania, Brazil**

- Occupation and environment
- Radiation
- Time trends
- Cancer geography
- Cancer registration: methods
- Population-based cancer survival
- Diet and physical activity
- The cancer problem in Latin America: round table

## **2007 – Ljubljana, Slovenia**

- At the crossroad of tradition and new technologies in cancer registration
- The use of computerised sources in the registries

- The role of cancer registries in cancer control
- Evaluation of impact of primary prevention measures
- Methodological aspects
- Evaluation of screening and early detection
- Evaluation of cancer care and survival
- Evaluation of late effects of treatment for a primary cancer
- Strategies of cancer control

## **2008 – Sydney, Australia**

- Global considerations in oesophagogastric cancer
- Cancer trends
- Screening and early detection
- Cancer registration
- Epidemiological studies
- Skin cancer epidemiology
- Cancer projections and survival
- Information in, information out
- Cancer registries and clinical practice

## **2009 – New Orleans, USA**

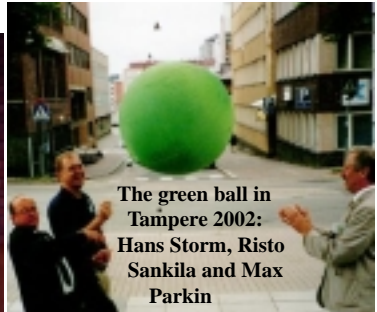
- Trends and projections
- Cancer registries and screening
- International perspectives on data quality
- Childhood cancer

## **2010 – Yokohama, Japan**

- Society and cancer registration : towards harmonization
- Cancer monitoring and control planning
- Quality of cancer care and outcome research
- Cancer registry methods
- Cancer registration for evaluation of risk factors – aetiology and prevention

## Annex 5: Photo Gallery

**1st Honorary members from left: Ruth Steinitz, William Haenszel, Richard Doll, Sidney Cutler, Ole Jensen accepting for Johannes Clemmesen, Takeshi Hirayama for Mitsuo Segi, and Knut Magnus for Einar Pedersen**



**The green ball in Tampere 2002: Hans Storm, Risto Sankila and Max Parkin**

**Ottawa meeting 1992**



**Bratislava meeting 1993**



**Meeting audience in Beijing 2004**



Latin American course in Ecuador , November 2002



The Ambillikai cancer registry with Rajkumar and some of his personnel in 2003 Photo: Sharon Whelan



Meeting audience in Finland 2002

Henry Wabinga ( Uganda ), Nguyen Quoc ( Vietnam ), Eric Chokunonga ( Zimbabwe ) in Hawaii 2003



African Association of Cancer Registries meeting in 2003 Photo: Max Parkin

## INFORMATION FOR AUTHORS

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**APJCP Editorial Offices:** located in Thailand and Korea but submission is all electronic.

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Editorials	Reviews/Mini-reviews	Research Communications
Commentaries	Letters to the Editor	

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**Text pages:** Arranged as appropriate for the type of manuscript

**References:** In **text** cited as Yellow (2000), (Brown and Pink, 2000), (Black et al., 2000): NOT NUMBERED! Earliest first, then chronologically and alphabetically In the **reference list** alphabetically then by year, all authors if up to five, three and et al for more. **Formats:** Brown A, Pink B, Black C, et al (2000). Cancer prevention in the Asian-Pacific. *Asian Pac J Cancer Prev*, **8**, 10-2. **or** Brown A, Pink B, Black C, et al (2000). Cancer prevention. In 'Neoplasia', Eds Blue Dand Red E. Asian Pacific Education Press, Bangkok pp1-10.

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**Ottawa meeting 1992**

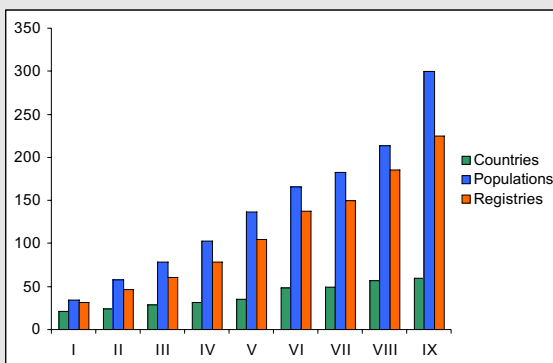
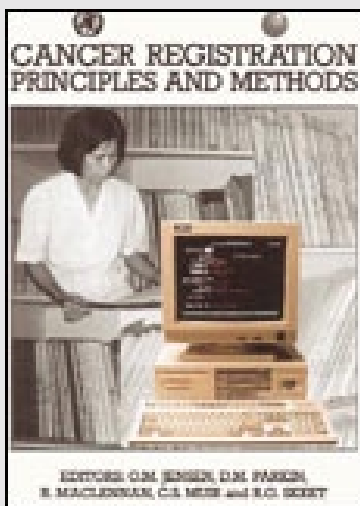


**Calum Muir**



**Hawaii meeting 2003**

## Meetings



## Publications