

Improving Cancer Information in Latin America and the Caribbean

Meeting and Course Report

Regional Meeting of Cancer Registries and Cancer Program Managers

(Brasilia, Brazil, 13–14 October 2009)

Train the Trainers Course: Cancer Registration and Data Quality Control in Population-Based Cancer Registries

(Brasilia, Brazil, 14–16 October 2009)

I. Regional Meeting of Cancer Registries and Cancer Program Managers

The Regional meeting was jointly organized by PAHO (Regional Office and Country Office in Brazil); the Ministry of Health of Brazil, and National Institute of Cancer in Brazil (*Instituto Nacional de Câncer / INCA*) and International Agency for Research in Cancer (IARC).

The **purpose** of the meeting was to review progress, identify challenges and opportunities for improving information on cancer in Latin America and to plan future collaborative activities within the Region.

The following **specific objectives** were drafted:

1. Learn about advances in PAHO-IARC agreement for collaboration and joint mid-term plan.
2. Discuss progress to date, challenges and opportunities for implementing the PAHO-IARC collaboration and mid term plan.
3. Showcase available tools and resources to can support countries in their cancer registration and using information for cancer programs.
4. Disseminate best practice and results of successful experiences on cancer registration across the Americas.
5. Foster the current PAHO-IARC partnership and seek potential stakeholders in support of cancer register activities on the national, subregional and Regional levels.

The expected **results** of the meeting were the following:

1. Assessment of progress, challenges and opportunities in regard to the information on cancer at Regional, subregional and national levels.
2. Better understanding of the needs for cancer registry improvement in the Region, and the resources available within PAHO and IARC to address these needs.
3. Identification of strategies, resources, training, and other opportunities to assist countries to improve information on cancer, especially in those areas with delayed progress.
4. Deepened understanding and commitment among PAHO, IARC and countries and partners towards improving cancer information and implementation of mid-term plans. (See the [Agenda](#)).

Participants from Latin America and Caribbean countries included teams composed of representatives from the Ministry of Health and cancer registries from 15 countries: Argentina, Barbados, Belize, the Cayman Islands, Colombia, Costa Rica, Cuba, the Dominican Republic, Ecuador, Guatemala, Jamaica, Mexico, Nicaragua, Peru, and Uruguay. (See the [List of Participants](#).)

Session 1: Global and Regional Mandates & Collaborative Efforts; Information on Cancer in the Region of the Americas: Progress to Date, Challenges and Opportunities

Since 2000, WHO has approved several resolutions that can be used in the case of cancer prevention. In 2005, a specific resolution on cancer was approved (Resolution 58.22). In 2006, the countries in the Region of the Americas endorsed the PAHO Regional Strategy and Action Plan for the Prevention and Control of Chronic Disease. This strategy served as a basis for the Cancer Action Plan for the Americas that was discussed and completed by the relevant stakeholders in June 2008. The cancer plan includes the following four lines of action:

- 1. Policy and advocacy:** Advocate for cancer control as a public health priority; to assist countries with national cancer control plans.
- 2. Monitoring and surveillance:** Improve country capacity for cancer program monitoring and cancer registries.
- 3. Cancer prevention and health promotion:** Disseminate information and promote education on cancer prevention, early detection.
- 4. Cancer management:** Improve access, quality and use of standardized guidelines for cancer screening, diagnosis, treatment and palliative.

Regarding capacity-building for cancer epidemiology and registration, PAHO includes in the Action plan the adaptation and promotion of the IARC summer course in Cancer Epidemiology for Latin America and the Caribbean (LAC); adaptation and promotion of the training course on “Fundamentals of Registry Operations” from the US Centers for Disease Control and Prevention (CDC). The goal set by Cancer Action Plan is that by 2015, at least 10 countries will have improved the quality and accuracy of their population-based cancer registry.

Since the early 1980s, PAHO has hosted a mortality database for the Region of the Americas. Since 1996, the PAHO Basic Data initiative has been collecting information on the incidence and prevalence of such cancers as lung, breast, and cervical cancer, with different levels of quality and updating.

The quality of the mortality data in Latin America was addressed, and the need for further and more detailed analysis of data was emphasized. Examples were presented on the rates for gastric cancer in the Region and in Ecuador. PAHO has a new project called the Observatory that will provide the opportunity for expanding the variables within mortality and will include data from different PAHO programs.

In the IARC publication CI5, the geographic coverage for LAC is about 4%. This coverage needs to be improved to better understand the burden of this disease in this Region and the diversity of populations and risk factors between and within countries, as well as to identify risk factors in carcinogenesis, better target populations at risk via cancer control programs, and evaluate public

policies and cancer control activities. More support is needed to enhance and improve cancer registration in LAC.

There are 78 cancer registries from LAC that are members of the International Association of Cancer Registries, but it is difficult to identify how many cancer registries are active at this moment, since only 11 submitted data on cancer incidence to the IARC database in the period from 1998 to 2002.

To provide some clarity on the situation of population-based cancer registries (PBCR) in the Region, the IARC representative presented the results of a study conducted in 2009, where answers showed numerous basic constraints experienced by LAC cancer registries:

- ➔ 81% considered economic difficulties/instability.
- ➔ 30% reported that their funds came from provincial resources.
- ➔ 50% reported mixed funding sources.

Further on, other problems were reported:

- ➔ Acceptance as an organizational entity.
- ➔ Understanding and use of results by health authorities and health professionals.
- ➔ Problems in the data capture.
- ➔ Lack of trained human resources.
- ➔ Lack of computerization.

All in all, 100% think that it would be useful to have an Association of Cancer Registries for LAC.

The discussion addressed the issues of data quality and correction (PAHO applies correction to mortality based on non-defined case and sub registry), as well as models to improve cancer registries as part of any information system on cancer. Regarding data quality, the comparison of country data and Regional data was stressed, and the need for validation of data by country should precede any official publishing at international level. The methodologies used by PAHO and IARC for compiling estimates should be available.

Regarding cancer registries, two different models were discussed. The first would be to have several cancer registries in the country and to see which of them will remain functioning in a sustainable way, which means waiting for “natural selection.” This second would be to apply the planning model that would recommend having one good cancer registry in the country, with a defined population, or two or three in bigger counties, while providing technical and financial support to ensure that data are good quality, updated, and capable of forecasting trends over time. There is a need for clear recommendations regarding the organization of cancer registries (some include: a population size no larger than one million, ensuring official support from health authorities, using information for the cancer program, communication channels for reports and analysis, etc).

Session 2 Health Systems, Policies & Plans: Use of Registry Information for Cancer Control Planning & Management

The Ministry of Health (MoH) of Brazil described its structure regarding the surveillance system and health information system for chronic noncommunicable diseases (CNCDs), its relationship with

INCA, and the regulation created to provide financial support for population-based cancer registries in Brazil as well as the evaluation process established to allow cancer registries to perform well through continual support. INCA described the current situation of the Brazilian cancer registries, data availability, and the existing flow of cancer data. Presently, 30 % of the territory of Brazil is covered by cancer registries.

Barbados presented its experience with an overall national CNCD policy, the structure that supports it, and the importance of data sources from disease registries. A chronic disease research center was commissioned by the MoH of Barbados to organize population-based registries. As of now, the principles for population-based registries have been applied on stroke, and the plan is to include some types of cancer in spring 2010. It was stressed that there are no data in CI5 from the English-speaking Caribbean on cancer incidence, although population-based cancer registries do exist in Guyana, Jamaica, Montserrat, and Trinidad and Tobago. In the discussion, various constraints were identified, such as limited financial support and a lack of trained personnel.

The MoH of Chile described the current situation in Chile, where there are four population-based cancer registries: Antofagasta, (1998), Valdivia, (De Los Rios, 1989), Bio-Bio (2004), and Concepcion (2006), and their work is supported and coordinated by the MoH and data used for overall assessment of the epidemiological situation in the country. There is also a national pediatric population-based cancer registry, created in 2006. The current coverage for the Chilean population is 17.5%.

An example of a national cancer registry from Latin America was the PBCR from Costa Rica, which has been collecting data since 1976. Incidence data for 2005 shows 8,525 new cancer cases. Now the national cancer registry is looking into using more technology to produce data trends, support data collection, check for consistencies, ensure data quality, and avoid duplication.

The discussion supported a need for strategic planning at the country level and the role of international organizations in supporting such planning. Cancer registries are important tools when adequate policy on cancer is a priority. For these purposes, sustainability, data quality, and timelines are all crucial factors that can be dealt with only if registries are considered to be part of the health information system. Examples presented in the panel—as well as those confirmed by Cuba, Colombia, and Peru—showed that, regardless of size, countries whose health authorities recognize the importance of cancer registries are capable of addressing not only the issues related to “registry survival” but also data quality, expansion of variables, research and analysis, and the introduction of new technologies. Also noted was the need to clarify the opinion that when the MoH is providing support for a cancer registry, it has to be a national one. This is where international organizations can make an important contribution, by clarifying the criteria to be set for cancer registries, the technical capacity needed for maintaining the registry, and the selection of geographic areas for registries based on criteria related to public health and technical capacity.

A report was made by the IARC representative on the constraints that cancer registries face if left alone or when counting on donor support alone, which supported the points made above.

Session 3: Setting Up and Maintaining a Cancer Registry

Ecuador presented its experience with the central registry in Quito and six other cancer registries in different regions of the country. The Quito registry has celebrated its 25 years of continuous work.

At present, the Society for the Fight against Cancer (*Sociedad de Lucha contra el Cáncer / SOLCA*) is providing support for the work of this registry, which in turn receives regular resources from the national health system. The lessons learned from Quito included the point that, to create a PBCR, it is necessary to have an organized healthcare system with adequate resources, as well collaboration with information sources that will enable the PBCR to produce reliable data. Another remark underlined the need to promote the communication of incidence data and to make it available to policy-makers, academics, and researchers. An example was given on the use of incidence data for planning the cervical screening program in Quito. The success of the Ecuadorian cancer registries in terms of sustainability is based in the institutionalization of the PBCR, which supports permanent staff, periodic training, and recognition of data inclusion in the IARC database and the CI5 publication.

The discussion outlined experiences from Mexico, with 80 cancer registries showing different levels of quality and years of operation; the current decentralization in Peru; the positive experience of Uruguay; and the need to support efforts in Paraguay and Bolivia, where more than the pure enthusiasm of professionals is needed to bear fruit. The problems about weak health information systems in these countries were noted. Ecuador, e.g. the registry representative from Guayaquil, asked about training plans for Latin America and asked for support.

Session 4: Available Tools and Resources to Support Country Cancer Programs

Regarding technological support, IARC presented the tools available to support cancer registries: summer school, Regional training courses, advisory missions, and the Canreg5 software. The IARC course on cancer registries can be found at: <http://www.iarc.fr/en/education-training/training-courses.php>. CANREG 5 is an open-source software program, with application for Apache DerbyDB databases (by default) and in according with computer environments like Windows (2000, XP, Vista, 7), Mac OSX (10.4, 10.5, 10.6), Linux (all major distributions), FreeBSD, etc. CanReg5 was designed with an emphasis on user-friendliness and will be available in several languages. Built into CanReg5 are several quality control mechanisms.

The GLOBOCAN project presents estimates of the incidence and prevalence of, and mortality from, 27 cancers for all countries in the world in 2002. Data are available from cancer registries that cover either entire national populations, or samples of such populations from selected regions. This Internet application has limited tabulation and graphic facilities. The complete facilities such as grouping of cancer sites and populations, as well as predictions of cancer burden, are available using the GLOBOCAN 2002 software on CD-ROM.

The PBCR from Cali, Colombia—the oldest in the Region—has recently created a dynamic web tool called SiSCan, aimed at faster and more interactive data reception from web sources. The features of this web tool were presented, along with preliminary results of its use on the population of Cali.

Among the training opportunities available, PAHO/WHO presented advances in the project for an online learning course that has been prepared to support the [WHO framework for strengthening management capacity](#). The course is aimed at low- and middle-income countries with a strong political will to improve the cancer control situation, with duly appointed cancer control program managers at national or provincial level and adequate access to web and videoconferencing. It consists of 8 training modules over a space of 2 months. Each module includes 4-hour interactive

sessions, plus 1-2 hours of tasks to be carried out in learner's own working environment. This project-based learning methodology is applied with a focus on both individual and team competencies. Experts are invited to facilitate this training on a voluntary basis. It encourages a web-based learning network to extend beyond the duration of the course. It supports the country cancer control program manager and team responsibilities (planning, organizing, staffing, leading, evaluating), team-level competences (task orientation and team relationships), as well as individual teamwork and self management competencies.'

INCA and the MoH-Brazil presented a methodology to monitor the quality of data produced by the cancer registry through the monitoring indicators as a percentage of microscopic verification, death certificates, and mortality incidence ratio, as well as by age group.

The discussion included praise for the tools as advanced versions of existing IARC tools. Particular interest was shown for the managerial course to be piloted in the Region. There was an expressed need for a course on coding.

The proposal for organizing training on how to improve cancer information in the Region, in both Spanish and English, was strongly supported. There is enough experience and competence in the Region to be able to organize such training with support from IARC and PAHO, as regards program, selection of teachers, place, and time for the course.

For the English-speaking Caribbean, the first training course was proposed as a satellite of the annual Chronic Disease Research Conference, to take place in Port-of-Spain, Trinidad and Tobago, at the end of April 2010.

For the Spanish-speaking countries, the place and host for the 2010 course is yet to be decided.

Session 5 Networks, Partnerships and Potential Stakeholders to Support Cancer Registry Activities

EPICAN was presented as one of the main networks to support improvement of information on cancer in the Spanish-speaking countries of the Region. It was established by the Iberian American Program for the Development of Science and Technology, with the aim of creating a platform for scientific and technical exchange related to epidemiological information systems on cancer among the Spanish-speaking LAC countries. The basic principles for its work include professional exchange among counties, the organization of conferences and courses, publications, participation in international events, and knowledge dissemination through the Internet.

In 2009, EPICAN prepared two documents: a manual containing guidelines for setting up population-based cancer registries (*Guía para la elaboración del manual de procedimientos para los registros poblacionales de cáncer*) and guidelines for external review of population-based cancer registries (*Guía para la revisión externa de registros poblacionales de cáncer*).

The International Union for Cancer Control (*Unión Internacional de Control del Cáncer / UICC*) presented its long and vast cooperation with cancer registries based on the World Cancer Declaration. It was the first publisher of *Cancer Incidence in Five Continents* (Vols 1-2). The UICC supports cancer registry work in different ways. Many UICC Member Institutions include hosting/helping a cancer registry; and a large number of staff from cancer registries have received

training through UICC fellowship programs. Sessions on cancer registry data are regularly included in World Cancer Congress (WCC) scientific programs (Washington 2006; Geneva 2008; Shenzhen 2010). The UICC publishes the *International Journal of Cancer*. Points emphasized included the availability of fellowships to support training for cancer registries, either individually or as a group, and that they can be facilitated in collaboration with WHO, and IARC. There was a presentation on the history of fellowships and grants available for low- and middle-income countries.

The discussion emphasized opportunities within UICC, such as special fellowships for cancer registries, or for joint projects and training courses. Suggestions were made for PAHO and IARC to follow up on this.

Furthermore, the program followed up on the revision of the [PAHO-IARC five-year collaboration plan](#), previously drafted by a small working group in Quito in April 2009.

Next on the agenda came the process of drafting the policy statement on cancer registration, to support cancer program planning and management, by the Ministry of Health and partners: the [Brasilia Statement on Improving Cancer Information](#).

II. Train the Trainers Course on Cancer Registration and Data Quality Control in Population-Based Cancer Registries

The aim of this course was to identify expertise in population-based cancer registries in LAC countries in order to support the creation of future reference centers in the Region that will provide technical support to PBCRs as part of the PAHO-IARC collaboration.

Program included the following topics: how to establish a cancer registry in a developing country, basic variables for cancer registries, introduction of data quality, procedures used in CI%, and methods used to evaluate data quality (see annex 6 agenda)

The methodology used was based on presentations followed by group work. For the latter, discussion questions were prepared and conclusions reported in the plenary.

At the end of the meeting, the following conclusions were prepared by the course participants to reinforce the Brasilia statement.

- The Brasilia statement approved on 14 October 2009 is considered of ultimate importance, and its accomplishment will improve information on cancer and strengthen cancer programs.
- The participants also consider that it would be very useful that the agreements arising from this meeting be sent to the World Health Organization to serve as a basis for a Framework Convention on Cancer Information and Cancer Control—a strategy of proven effectiveness in many of our countries when used for tobacco control.
- We might also consider inviting the other countries of the world, as the existence of a national law of this kind will help preexisting cancer programs.

Both the meeting and the course were evaluated by participants. Please see the [evaluation](#) that lists positive and negative comments, salient points, and suggestions.