

CANCER REGISTRIES

Information for Action in Latin America and the Caribbean

Facts

Cancer in Latin America and the Caribbean

The growing burden of cancer is a threat to the human and economic development in low- and middle-income countries. Data gathered by population-based cancer registries indicate that cancer is now one of the leading causes of morbidity and mortality worldwide. Contrary to the belief that cancer is a problem only in developed countries, 56% of global new cases and 64% of deaths occur in developing countries. In Latin America and the Caribbean some 900.000 new cases and 542.000 deaths are estimated to occur annually, and over 2 million people live with cancer.

In this region there is a dearth of high-quality cancer registries: only 6% of the population is covered by population-based cancer registries (*Cancer Incidence in Five Continents*, vol IX, 2007), vs 83% in North America and 32% in Europe. Further, few centers in Latin America and the Caribbean have produced quality statistics over a large period of time.



Figures

Figures for action: the role of registries in the fight against cancer

Population-based cancer registries collect and classify information on all new cancer cases in a defined population, providing data on incidence, patterns, trends and survival, which are needed by governments together with regional data on the distribution and determinants of the disease, as well as the quality of and access to health services.

Hospital-based cancer registries, beyond being an important source for population-based registries, provide information on the quality of care, diagnosis and treatment, survival, economic evaluations, and help design networks of care services.

The strategic decision about where to implement and support population-based cancer registries is still a pending issue which needs the involvement of epidemiologists and policy-makers to ensure that registries are sustainable and representative, and that quality data on a regional level can be obtained.

The case for and viability of a national network of population- and hospital-based cancer registries should be assessed by national health authorities and will depend on the organisation of the health system.

The importance of training of registry professionals and accreditation of registries should be stressed, as this ensures quality of the information and reduces staff turnover.

Incorporating cancer registries in a national cancer policy fosters maximum utilisation of available information in the development and evaluation of programs. Further, it guarantees the good functioning and sustainability of registries.

The most efficient way to tackle the cancer problem in a country is through a cancer control plan based on evidence, which takes into account a number of considerations, available resources and reliable data.

Investing in the collection of these cancer data can therefore not be considered a luxury: it is a cost-effective investment enabling to prioritize needs and spend the money where it matters to most people.

Examples of use of information

Paediatric cancer registries

Childhood cancer is not a frequent pathology but has a high social and financial cost. Regional inequities in survival reflect missed diagnostic and therapeutic opportunities.

The Hospital-based Paediatric Cancer Registry in Argentina (ROHA-INC), a network of public and private institutions, has been recording since the year 2000, new cancer patients under 15 years of age.

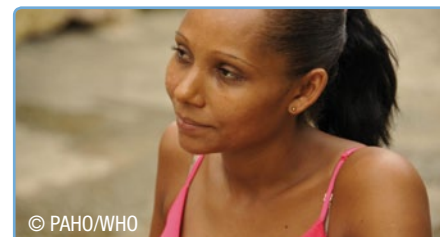
Analyses are carried out on hospital, local, provincial, regional and national levels, and on migration patterns.

Together with other institutions, it published "*Suspicion of cancer in children*", a diagnostic guide for clinical use disseminated by the National Cancer Institute to all paediatric care centers throughout the country.

The childhood cancer outcomes surveillance programme VIGANCER was established in 2009 in Colombia with the support of the UICC "My Child Matters" programme, with the aim of improving the understanding of determinants of survival. Preliminary analyses show great disparities in survival among the different insurance schemes in the Colombian health system.



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Screening

The Cancer registry in Quito, Ecuador, played a crucial role in the cervical cancer screening programme, which started in 1996. Cancer registry data enabled to define risk groups, baselines, and to evaluate the impact of the programme, which in 2005 saw a reduction in mortality and incidence of 21%.



Dearth of reliable cancer information in Latin America and the Caribbean: the role of governments

The development of cancer registries in Latin America and the Caribbean can be solved through a multi-partner approach, but its success depends on the commitment of governments, and in particular health authorities.

The creation of the Union of South American Nations (UNASUR) and the Network of National Cancer Institutes (RINC), in 2008 and 2011 respectively, are strategic opportunities to involve governments in the implementation of information systems and epidemiologic surveillance to formulate evidence-based regional cancer control public policies.

Governments should facilitate the activities of population-based cancer registries to obtain regional data, and the development of hospital-based registries to optimize resources and efficiency in care.

This support should include the sustainability of existing registries, training and accreditation of technical personnel as well as the dissemination of information produced by registries to decision-makers, the general population and academic institutions- both within and among countries.

The Cali cancer registry (Colombia), pride of Latin America: 50 years of continuity



1962: the Population-based Registry of Cali was founded within the Pathology Department of the del Valle University to ensure its sustainability and academic support.

The registry identified epidemic rates of cervical cancer in Cali, was the basis for establishing a pap-smear screening programme in the city, and documented the drastic reduction in incidence of the disease following programme implementation. Similarly, it detected epidemic rates of lung cancer and documented its decrease. The information provided by the registry helped the Colombian National Cancer Institute design targeted cancer control actions.

The Population-based Registry of Cali, now covering 2 million inhabitants, is the only one in a country in the low- and middle-income category which has contributed information for publication in each of the nine volumes of *Cancer Incidence in Five Continents (CI5)*.



A Future

A cost-effective investment with multiple benefits

Cancer registries are a long-term commitment and a stepwise implementation in strategic areas is recommended. When benefits are considered, the investment in financial terms is often less than anticipated, and is cost-effective. In Latin America there are several financing models, often merging public, academic and private sector resources.

The bottom line is that no country, no matter its financial situation, can afford not to collect quality information, because cancer control actions which are not based on sound data will ultimately be more expensive.

The importance of a legal framework

A legal framework ensures the provision of information from primary sources to registries and in turn, from registries to decision-makers. The legal framework also ensures financial sustainability by securing a line item in the national budget for cancer surveillance.

On a supranational level, the adoption in 2011 of the Political declaration on the Prevention and Control of Non-Communicable Diseases (NCD) by the United Nations General Assembly commits every State to implement it. In this framework, the development and strengthening of surveillance systems is a critical component for the development and implementation of National Cancer Control Programmes.

The Role of the Global Initiative for Cancer Registry Development in Low- and Middle-Income Countries (GICR)

GICR is convened by the International Agency for Research on Cancer (World Health Organization) and supported by major international and national organizations.

In collaboration with regional partners such as the Pan American Health Organization, RINC and Latin American excellence centers, GICR offers assistance to national authorities in planning and strengthening cancer registration through methodological, technical, educational support and collaborative research. **Do not hesitate to contact us!**

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