

# Let's face the F ACTS



**GLOBAL INITIATIVE** FOR CANCER REGISTRY DEVELOPMENT

INITIATIVE MONDIALE POUR LE DEVELOPPEMENT DES REGISTRES DU CANCER

ernational Agency for Research on Cancer. 2012



The threat to human and economic development posed by the growing burden of cancer in low- and middle-income countries is widely

recognized. Cancer is now one of the leading causes of morbidity and mortality worldwide, with an estimated 12.7 million new cases and 7.6 million cancer-related deaths in 2008.

With more than 7 million of these new cases and 4.8 million of the deaths, developing countries bear more than half of this burden, but are the least equipped to cope with this situation. Also, in developing countries, cancer is more likely to be diagnosed at a later stage and, therefore, to be less responsive to treatment.

This situation will become worse in the future due to the expected increase in the global population and as a result of ageing: it is predicted that by 2030 the number of new cancer cases will increase to more than 21 million, and cancer-related deaths to 13 million. Without evidence-based cancer planning and control interventions, 60–70% of the global cancer burden will occur in developing countries.



Sources: Global Status Report on Noncommunicable Diseases 2010 (WHO) and GLOBOCAN 2008 (IARC)

These global figures are made possible by the work of population-based cancer registries, which provide the means of estimating the burden of cancer in different communities.

Cervical cancer is an example of the burden disproportionately borne by developing countries. The map below shows the major disparities in the occurrence of this largely preventable disease.

Cervical cancer: estimated annual new cases



Estimated age-standardized incidence rate per 100 000 Source: GLOBOCAN 2008, IARC

Survival estimates are another indicator that population-based cancer registries can produce to help inform cancer control. The bar chart below shows that, after accounting for differences in age, almost 80% of women in Korea are alive 5 years after diagnosis of cervical cancer, but less than 20% in Uganda are; this is because women in Uganda are much more likely to be diagnosed at a late stage of cervical cancer than women in Korea.



# Figures

The United Nations (UN), its specialized health agencies, and major non-governmental organizations emphasize the critical importance

of improved monitoring of cancer incidence and survival as well as mortality at national and regional levels to generate evidence to develop effective cancer prevention and control strategies. This was reasserted in 2011 through the Political Declaration unanimously adopted at the UN high-level meeting on noncommunicable diseases (NCDs), and in 2012 by the 65th World Health Assembly approving the development of a global monitoring framework for the prevention and control of NCDs.

In times of limited economic resources, it is crucial to maximize the population impact of money spent. Investing in the collection of basic cancer information should not be considered a luxury for a population but as a cost-effective investment that will make it possible to determine where the real needs are and to spend the money where it matters most.

"Population-based cancer registry data is an essential foundation of national cancer control planning – if you don't know your cancer burden, how can scarce resources be targeted at the most appropriate solutions for cancer?" Dr Eduardo Cazap (Argentina), Past President, UICC

One example of the important role played by a cancer registry in a public health intervention is in Taiwan: after the implementation of the nationwide hepatitis B vaccination programme, the Taiwan Cancer Registry was able to demonstrate the programme's success in reducing the incidence of liver cancer.

Currently, the existence of cancer registration shows large disparities between high-income and low- and middle-income countries (LMICs): the percentage of the

population covered by cancer registries in the reference publication Cancer Incidence in Five Continents (CI5), Vol. IX (2007) is 83% in North America and 32% in Europe, but only 6% in Latin America, 4% in Asia, and 1% in Africa.

% of population covered by cancer registries in CI5 Vol IX



There is a pressing need to expand the coverage of population-based cancer registries in order to obtain more complete and reliable data to guide requisite cancer control interventions. The complex problems facing cancer registries in LMICs must be addressed in a systemic way. Such problems include limited staff availability and qualifications, inadequate information technology support, difficult transportation to reach hospitals to retrieve data, lack of diagnostic facilities, lack of pathologists and consequent long reporting delays compounded by poor verification of data, no formal death certification, and – paramount – lack of support from ministries of health. The formal support of health authorities is critical to ensure the sustainability of cancer registries and their role in developing and evaluating cancer control strategies.



Convened by the International Agency for Research on Cancer (IARC) and backed by several international, regional, and major national organizations, the Global Initiative for Cancer

Registry Development in Low- and Middle-Income Countries (GICR) aims to place cancer and its surveillance firmly on the emerging global NCD agenda: developing the capacity to produce reliable, highquality information on the burden of cancer so that effective policies for cancer control can be developed, implemented and evaluated.

GICR is implemented through "hubs" – IARC regional resource centres capable of providing developmental support towards and for populationbased cancer registries. Through this network of regional hubs GICR offers assistance to national authorities in planning and strengthening cancer registration, and to individual cancer registries through methodological, technical, educational support and collaborative research.

Although the development of cancer registries in LMICs can be addressed through a multi-partner approach, such as the one advocated by GICR, sustainability of their function depends on the commitment of governments, and in particular health authorities. National authorities are responsible for their citizens' health: producing reliable data on which to base cancer control should be understood to be not only a life-saving but also a cost-effective approach.

The success of GICR will lead to an increase in the number and quality of population-based cancer registries, and ultimately to national cancer control interventions guided by reliable data. This means saving lives and improving the situations of cancer patients and their families.



# HUBS

GICR was launched at the World Cancer Leaders' Summit in November 2011. Initial achievements include:

Establishment of three regional hubs: the regional hub for South, South–East, and East Asia based at Tata Memorial Centre in Mumbai (India) is operational since 2011; the regional hub for Western Asia and Northern Africa based at Izmir Cancer Registry (Turkey), and the regional network hub for sub-Saharan Africa, in collaboration with the African Cancer Registry Network, are planned to become operational in the second half of 2012.

Negotiations for the setup of the regional hub for Latin America and the Caribbean, foreseen to become operational in 2013.

### **TECHNICAL SUPPORT**

Expert visits by Mumbai hub staff to three Asian countries; *ad hoc* and general support in the use of the free, open source cancer registration software CanReg5 to users all over the world through direct contact, electronic communication and social media.

# RESEARCH

Collaborative Research Agreements with registries in three Asian countries; articles in major peer-reviewed journals on regional aspects of cancer; mapping and surveys to update the understanding of cancer registration needs in LMICs.

### TRAINING

Regional training course in cancer epidemiology at the Mumbai hub; collaboration with other major organizations for regional training courses to French-speaking African countries and to Latin American countries. Online training in CanReg5 through a series of webinars.

# ADVOCACY

Development of advocacy material and activities at major national and international meetings, and with national authorities. Establishment of a "Community of Practice" – a virtual forum for cancer registry professionals to discuss issues related to their work.

A steadily increasing number of individuals and institutions endorse and contribute their expertise to GICR. We would be delighted to count on you as well – please visit **http://gicr.iarc.fr** to join.

### Your support to GICR is important.

GICR estimates a minimum required investment of 5 million US dollars over 5 years to make a difference in national and regional capacity to generate information for cancer control purposes. To date, several cancer-related organizations have provided seed funding to support initial GICR activities, but fund-raising efforts are continuing, to allow the GICR to develop to its full potential.

By investing in the collection of cancer information, you are indirectly investing in evidence-based prevention, treatment, and supportive care strategies. We ask supporting partners to commit for a minimum of 3 years, so that solid foundations can be established.

Some examples of how you can get involved:

- support one or more regional hubs
- support one or more cancer registries
- support collaborative initiatives, data sharing and joint analyses
- support training activities and the development of tailored training material to improve the technical and managerial capacity of cancer data professionals
- support the development of the open source, population-based cancer registration software CanReg to
  offer additional tools for cancer registries
- support the production and dissemination of local, regional and global data for their ful use by national and international stakeholders
- support awareness programmes to sensitize national authorities and international stakeholders on the fundamental role played by cancer registries in cancer control



The Global Initiative for Cancer Registry Development in Low- and Middle-Income Countries is supported by:

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Learn more at http://gicr.iarc.fr Contact us at gicr@iarc.fr



International Agency for Research on Cancer

GLOBAL INITIATIVE FOR CANCER REGISTRY DEVELOPMENT INITIATIVE MONDIALE POUR LE DEVELOPPEMENT DES REGISTRES DU CANCER INICIATIVA MUNDIAL PARA EL DESARROLLO DE REGISTROS DE CÁNCER