



**FACTS
FIGURES
A FUTURE**

Facts and Figures for a better

³FUTURE



3 Facts

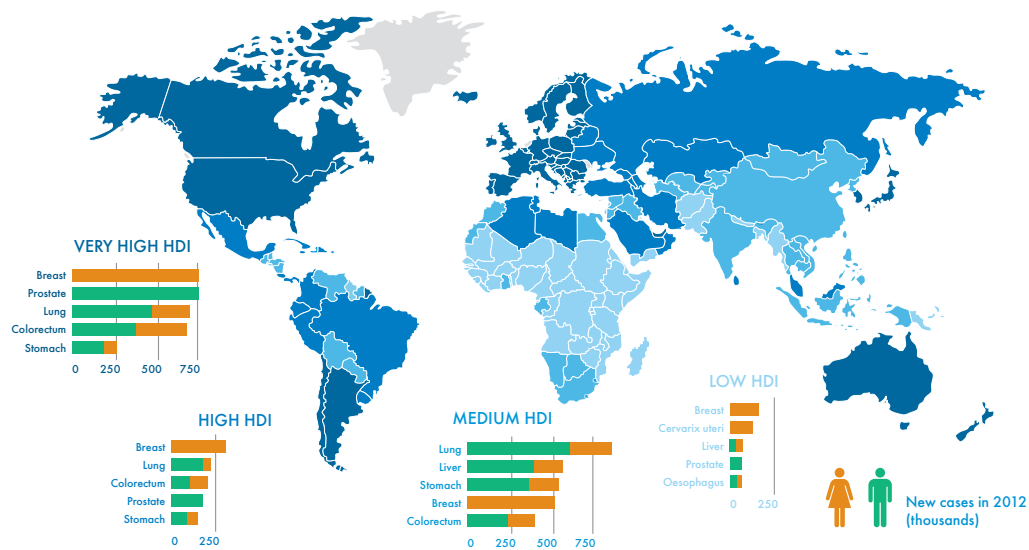
The threat to human and economic development posed by the growing burden of cancer in developing regions is widely recognized. Cancer is now one of the leading causes of morbidity and mortality worldwide, with an estimated 14.1 million new cases and 8.2 million cancer-related deaths in 2012. With 8 million of these new cancer

cases and over 5 million of the deaths, less developed countries bear more than half of this burden, but are the least equipped to cope with this situation. Also, in such 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 and ageing of the global population. It is predicted that by 2030 the number of new cancer cases will increase to 21.7 million, and the cancer-related deaths to 13 million globally. 13 million of the new cancer cases and 9 million of the deaths will occur in less developed regions.

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

The *Human Development Index (HDI)* published by the United Nations Development Programme combines indicators of life expectancy, educational attainment and income, reflecting both social and economic development. Many of the most frequent cancers in medium or low HDI countries - lung, stomach, liver, breast, colorectal, cervical cancer and Kaposi sarcoma - are amenable to primary prevention and early detection strategies as well as the implementation of and access to adequate treatment (see map below).

Most commonly diagnosed cancers by Human Development Index



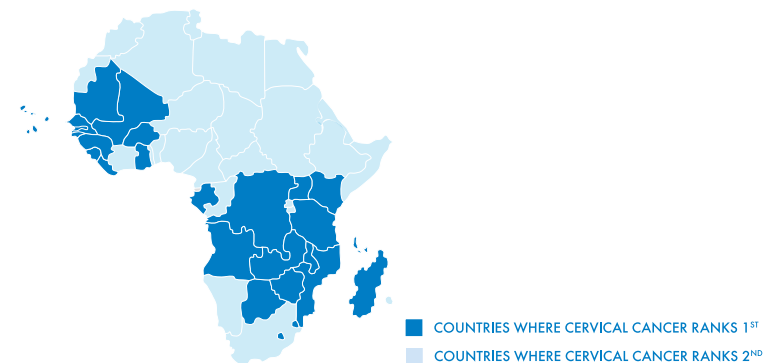
Source: GLOBOCAN, 2012

3 Figures

The work of population-based cancer registries (PBCR) is extremely important in the establishment of a baseline on which to plan interventions, as well as in their monitoring and evaluation. For instance, international comparisons of data show cervical cancer as an example of the burden disproportionately borne by countries

with a low HDI, a clear indication for action. National authorities can use information on the occurrence and outcome of this disease to formulate cervical cancer control plans and activities.

Cervical cancer among women in Africa



Source: GLOBOCAN, 2012

PBCR are therefore a cornerstone of evidence-based interventions. Yet, today there are great disparities in the worldwide coverage of the population by high-quality registries. There is a pressing need to expand this coverage in order to obtain more complete and reliable data to guide cancer control interventions. This does not necessarily mean that a national cancer registry need be established. Most of the requirements for planning and monitoring can be achieved through registration of a well-described subset (sample) from the national population, such as a specific region; the sample can then be extrapolated to the national level.

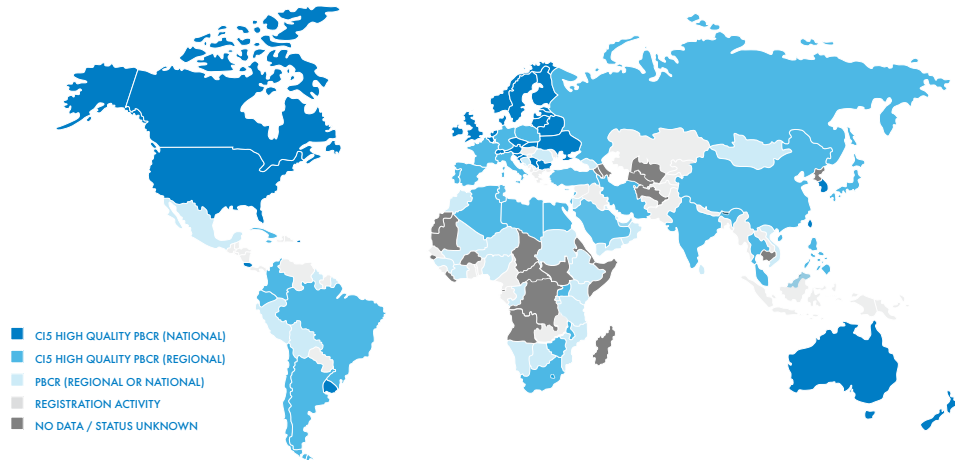
The problems with which cancer registries in developing countries are confronted are complex and often interdependent, such as staff availability and qualifications; inadequate information technology support; difficulties in transportation to reach hospitals to retrieve data; lack of diagnostic facilities; lack of pathologists and consequent long reporting delays, compounded by poor verification of data; no formal death certification; and – paramount – a lack of sustained 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.

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 be considered not as a luxury for a population but as a cost-effective investment that will make it possible to determine where the real needs are, to spend the money where it matters most and to measure the impact of effective interventions.

The United Nations, its specialized health agencies, and major non-governmental organizations emphasize the critical importance of improved monitoring of cancer incidence, mortality and survival at national and regional levels, because this will generate evidence to guide the development of effective cancer prevention and control

strategies. The adoption in 2013 by the World Health Assembly of a global monitoring framework for the prevention and control of noncommunicable diseases (NCDs) turns this priority into a formal commitment. On a global level, however, there are large inequities in the existence, coverage and quality of cancer registration, as shown in the map below. The percentage of the population covered by cancer registries that meet the necessary quality standards for inclusion in Volume X of the reference publication *Cancer Incidence in Five Continents (CI5)* varies considerably between Europe and North America vs Asia, Central and South America, and Africa.

Status of cancer registration worldwide (2013)

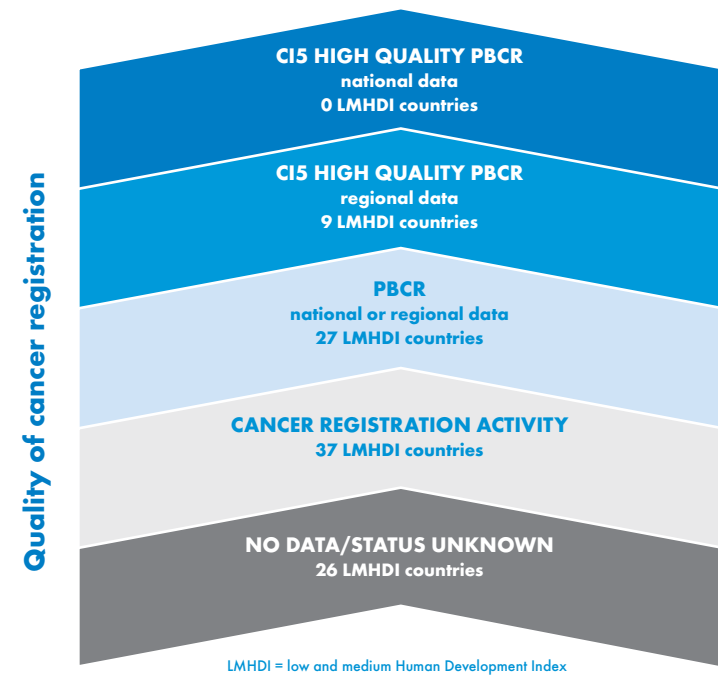


Convened by the International Agency for Research on Cancer (IARC) in 2011 and backed by several international, regional, and major national organizations, the **Global Initiative for Cancer Registry Development (GICR)** aims to place cancer and its surveillance firmly on the emerging global NCD agenda, developing the capacity to produce reliable, high-quality information on the burden of cancer so that effective policies for cancer control can be developed, implemented and evaluated. This means saving lives and improving the situations of cancer patients and their families.

GICR is implemented through Regional Hubs – IARC regional resource centres capable of supporting the establishment and functioning of population-based 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.

GICR is committed to helping registries currently not attaining the necessary quality criteria to achieve publication in CI5, and to helping those registries which were included in CI5, to maintain this level of quality – remembering that, ultimately, the function of high-quality data is to help guide national cancer control interventions. The general principle is that of a stepwise development of registries, in order to raise each country to the next level of quality and availability of cancer registration within an allocated time span.

GICR stepwise implementation to strengthen and transform cancer registration



Although the development of cancer registries can be addressed through a multi-partner approach, such as the one advocated by GICR, the 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 is not only a life-saving but also a cost-effective approach.

GICR was launched at the World Cancer Leaders' Summit in November 2011 and in its first two years has made considerable progress, with work towards the establishment of Regional Hubs for Cancer Registration covering Asia, Africa and Latin America; many site visits to enable situation analyses; as well as local and

regional training courses in cancer registration methods and use of data. New functionalities for the CanReg software were developed; research collaborations were established and advocacy activities in support of cancer registration were carried out. A selection of Regional Hub activities is shown below:



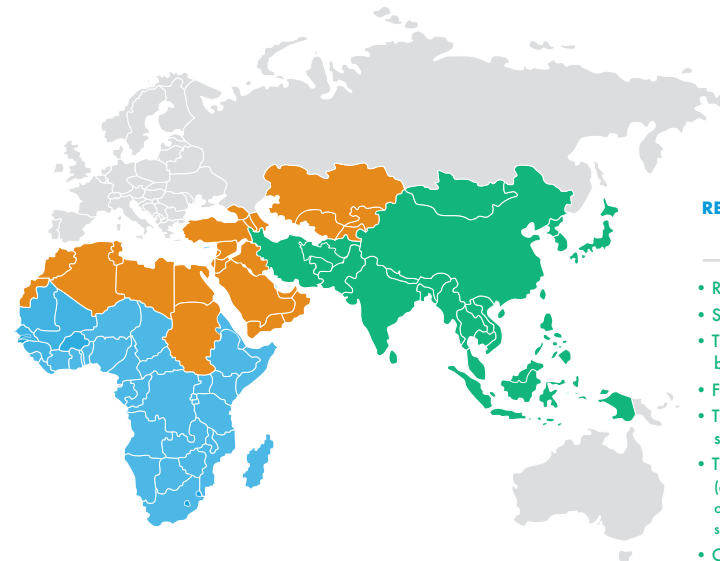
REGIONAL NETWORK HUB FOR LATIN AMERICA
coordinated by the National Cancer Institute (Argentina)

- Regional Network Hub established in January 2014
- Hub model includes a Coordinating Centre and several Contributing Centres
- One advanced regional training course in Spanish
- Advocacy and networking activities in collaboration with major regional stakeholders



REGIONAL HUB FOR NORTH AFRICA, CENTRAL AND WEST ASIA
based at the Izmir Cancer Registry (Turkey)

- Regional Hub established in September 2013
- Site visits to two countries
- One regional training course



REGIONAL HUB FOR SOUTH AND EAST ASIA
based at Tata Memorial Centre, Mumbai (India)

- Regional Hub established in November 2012
- Site visits to seven countries
- Three Collaborative Research Agreement between registries and IARC
- Four regional training courses
- Three CanReg5 trainers trained; software installation in several registries
- Three research projects (data quality; cancer registry costing exercise in two countries; population-based survival for selected cancer sites in Mumbai)
- Communication channels and online support mechanism set up



REGIONAL NETWORK HUB FOR SUB-SAHARAN AFRICA
in collaboration with the African Cancer Registry Network (AFCRN)

- Regional Network Hub established in September 2012
- Site visits to twelve countries
- One advanced and one practical training course in English; one intermediate course in French
- Collaboration agreements with thirteen AFCRN member registries
- Six collaborative research projects (breast cancer size and staging; cancer registry costing exercise; survival from four cancers; survival in childhood cancer; oesophageal cancer in East Africa; expression of hormone receptors in West, East and Southern Africa)
- Advocacy and networking activities

Discussions are in progress for future Regional Hub development in the Caribbean and Pacific Islands.

Your support to GICR is important!

GICR estimates that a minimum investment of 15 million US dollars over 5 years is required to make a difference in the 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 fundraising efforts are continuing to enable 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.

- 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 full 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



LEARN MORE at <http://gicr.iarc.fr>

CONTACT US at gicr@iarc.fr

The Global Initiative for Cancer Registry Development is supported by international, national and regional organizations including:

International Agency for Research on Cancer



International Association of Cancer Registries



A steadily increasing number of institutions and individuals 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.



**GLOBAL INITIATIVE
FOR CANCER REGISTRY
DEVELOPMENT**

**INITIATIVE MONDIALE
POUR LE DEVELOPPEMENT
DES REGISTRES DU CANCER**

**INICIATIVA MUNDIAL
PARA EL DESARROLLO
DE REGISTROS DE CÁNCER**