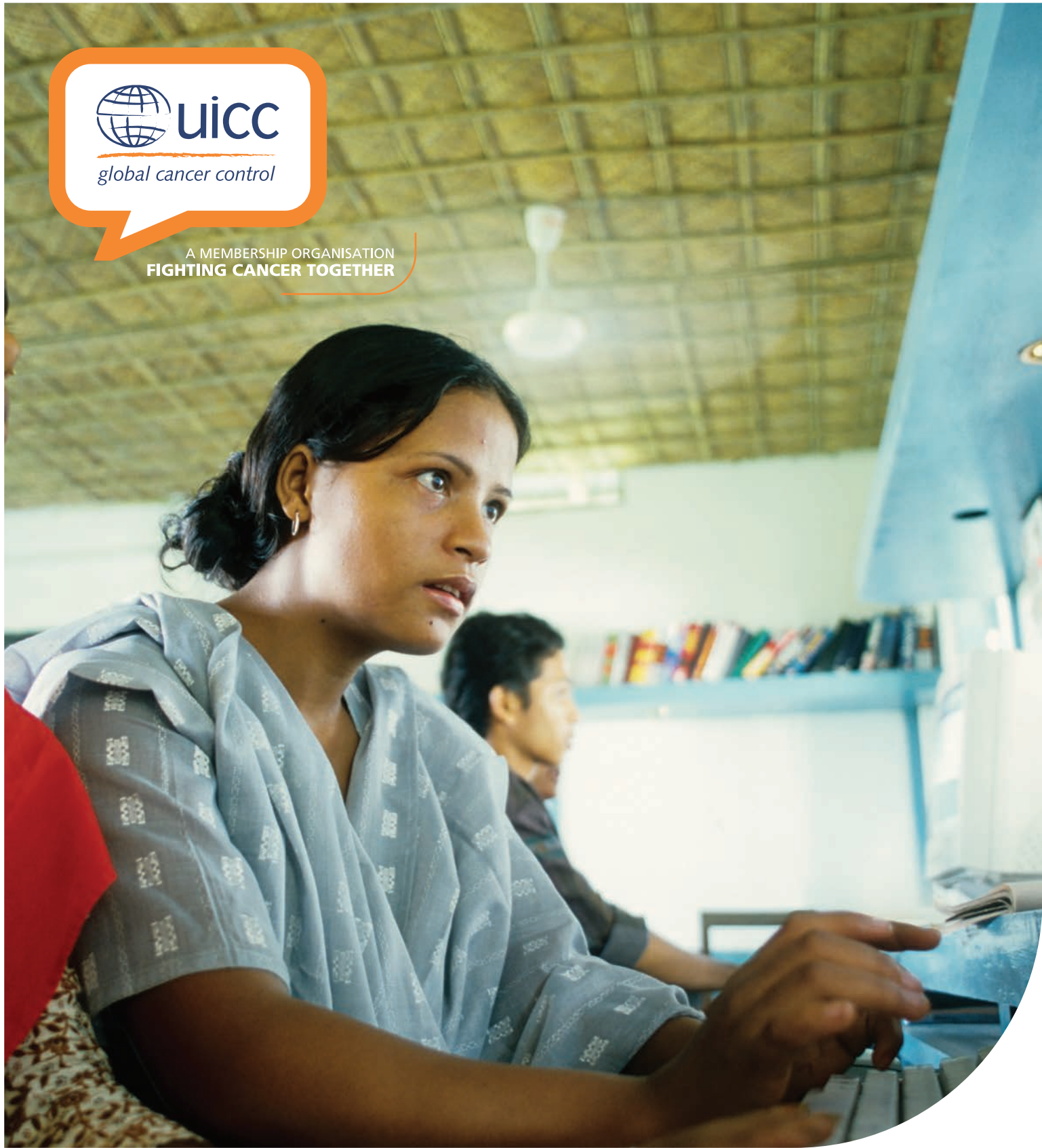




A MEMBERSHIP ORGANISATION  
FIGHTING CANCER TOGETHER



# CANCER REGISTRIES

Why, what  
and how?

International Agency for Research on Cancer



# WHY? IT'S TIME TO ACT NOW



All World Health Organization (WHO) member states have approved the Global Monitoring Framework on Non-communicable Diseases (NCDs). The framework includes a commitment to report on cancer incidence and type as an indicator for the 2025 mortality target. The WHO has developed a Global Action Plan for the Prevention and Control of Non-communicable Diseases 2013 to 2020. A key component is the monitoring of NCDs and their determinants and evaluation of progress over time at national, regional and global levels.

Many countries have developed and implemented the strategy of National Cancer Control Plans (NCCPs) in order to most effectively utilise resources for prevention, treatment, rehabilitation and palliative care, and to set a research agenda.

NCCPs require vigilant surveillance and monitoring:

- What is the cancer burden in the country and how is it likely to evolve?
- How successful are the implemented cancer control policies?

Two cancer surveillance mechanisms are available and complementary:

- For mortality: vital statistics on deaths (by cause)
- For morbidity: disease (cancer) registers

They are complimentary, and having both available is ideal, but for many low- and middle-income countries (LMICs), national vital statistics (mortality statistics, by cause) are unavailable, partial, or inaccurate due to inadequate health system infrastructure and/or resources.

It is necessary to acknowledge that cancer registration is always feasible. Unlike other diseases, cancer is relatively easy to monitor. Cancer at an advanced stage is recognisable and can almost always be identified (even if it kills an untreated patient).

# WHAT? THE POPULATION- BASED CANCER REGISTRY



Population-based cancer registration is a well-established concept. The first cancer registries were established over 70 years ago and today there are more than 700 cancer registries worldwide. In developing countries, their progress is notably slower as they face the very same obstacles as other health services – that is a lack of financial resources and expertise.

In order to plan and evaluate health services, we need to know what is happening at a population level – a population of a whole country or province or even a substantial sector. This requires a population-based cancer registry (PBCR) (see Table).

Clinical registries and pathology-based registries serve another purpose, that is, to guide clinical management in the institution where they are located. Clinical registries collect individual cancer patient reports by physicians in a given hospital. Pathology-based registries record cancer cases diagnosed in pathology laboratories.

A National Cancer Registry is often thought as an ideal tool but may not always be feasible due to the scale or cost of implementation. 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 subset sample can then be extrapolated to the national level.

The PBCR aims to record relevant information on all cases of cancer diagnosed within the target population.

**Diagnosed:** Cancer cannot be recorded if it never comes to medical attention. This may occur in rural populations far from medical facilities and therefore it is advised to start with a target population which has access to diagnostic and treatment services.

**Recorded:** All cases are recorded even if diagnosis is based on clinical examination alone without confirmatory tests or only on a death certificate. The basis of the diagnosis is recorded so the likely accuracy can be judged.

**Relevant information:** There are about 10 essential items recorded that relate to the patient and their diagnosis. This list can be expanded according to needs and/or resources.

**Target population:** It is critical to have reliable census-based estimates by age-group on the target population that is being registered. Without this information, it is impossible to accurately calculate and compare rates of cancer with other populations.

## Population-Based Cancer Registries: some myths and misconceptions

- ⊘ **Myth** - A population-based cancer registry must have national coverage to be effective
- ⊘ **Myth** - A population-based registry requires door-to-door surveys to identify which members of the community have cancer
- ⊘ **Myth** - A pathology or hospital-based registry can be used for cancer surveillance purposes

# TYPES OF REGISTRY: CHARACTERISTICS, PURPOSE AND UTILITY IN CANCER CONTROL

REGISTRY TYPE	CHARACTERISTICS	PURPOSE	CAN A REGISTRY BE USED IN FORMULATING CANCER PLANS?
Hospital-based Cancer Registry	Collects information on all cases of cancer treated in one or more hospitals.	Useful for administrative purposes and for reviewing clinical performance.	<b>NO.</b> Incomplete and inaccurate sample. Dataset is based on patient attendance at given hospital(s). Cancer profile will be biased, determined by facilities and expertise available within key institutions.
Pathology-based Cancer Registry	Collects information from one or more laboratories on histologically diagnosed cancers.	Supports need for laboratory-based services and serves as quick 'snapshot' of cancer profile.	<b>NO.</b> Incomplete and inaccurate sample. Dataset is based only on laboratory-based surveillance. Cancer profile will be biased, determined by cancers for which tumour tissue investigations were undertaken.
Population-Based Cancer Registry	Systematically collects information on all reportable neoplasms occurring in a geographically-defined population from multiple sources.	Compares and interprets population-based cancer incidence data. Supports population-based actions aimed at reducing the cancer burden in the community.	<b>YES.</b> The systematic ascertainment of cancer incidence from multiple sources can provide an unbiased profile of the cancer burden and how it changes over time; PBCR can play a unique role in planning and evaluating cancer control programmes.



## Childhood Cancers – a special case?

“Childhood cancers are ascertained by population-based cancer registries generally, although there are a number of population-based cancer registries dedicated to collecting data on paediatric cases exclusively. Both approaches are relevant to childhood cancer surveillance. The general cancer registries should ensure that these rare cancers are given due attention, while the paediatric registries should strive for as accurate and complete data as possible.”

*Dr Eva Steliarova-Foucher, International Agency for Research on Cancer*



## Can policy increase the effectiveness of a cancer registry? A call to making cancer a reportable disease

“Establishing cancer as a reportable disease is a desirable step. When cancer registries receive notifications of cancer cases from diagnostic and treatment facilities, such reporting will be improved, but it is certainly NOT a guarantee this will be complete. More important is the reassurance that a legal basis for cancer registration provides to the owners of the data (in hospitals in both public and private sectors) that allowing access of the cancer registry to personal data on cancer patients does not constitute a breach of confidentiality.”

*Dr Maxwell Parkin, Principal Investigator of the African Cancer Registry Network*

# HOW? STEPS TO GETTING STARTED



## THE BASICS

### 1. How to choose your registry target

- Unless the country is small or wealthy, choose one or more subsets of the national population as the registry target – it is possible to make national estimates from the results of the sample(s).
- Choose a defined geographic area with diagnostic services for cancer, so that almost all residents will be diagnosed and treated there. It's easy to exclude non-residents but hard to find members of the target population if they go elsewhere for cancer services.
- In settings where resources are limited, the registry will almost always be involved in active search for cases. Expecting medical staff to notify cancer cases to a registry never works (as for most infectious diseases).

### 2. How to record and collect the information

The sources of information are the records in:

- Diagnostic laboratories (especially pathology)
- Hospitals that treat cancer patients (and within them, those services specialising in oncology)
- Hospices that care for the dying (most offer care and support to the cancer patient)
- Vital statistics departments (that register deaths by cause, and not just occurrence of death)

The method of collecting information from these sources varies depending on:

- Local circumstances, in particular whether there are pre-existing patient registries (manual or computerised) with the relevant information on the cancer patient and their diagnosis; and
- Individual institution's readiness to share the data.

Policies, mandating the communication of cancer cases to the cancer registry, create an enabling environment in which the registry operates.

### 3. What the registry needs

- Physical facilities: an office with the usual furnishings, and computers;
- Some running expenses, for office consumables, and transport for visits to information sources in the registry area;
- Staff. Cancer registration demands patience and skill: dedicated staff are essential. How many depends on the registry size and the complexity of data collection (how many hospitals, pre-existing registers, etc). A small registry, covering a population of less than half a million may manage with a single member of staff, larger ones will require more and some specialisation in roles (supervisor, data collectors, secretary). A registry manager may have a higher educational qualification; junior staff can usually be recruited from those with (senior) school leaver certificates.

#### The Kampala registry in Uganda

*3 staff: 1 Director and 2 full time staff – registry manager and data clerk*

Manage a population-based cancer registry for a catchment area with a population of 2 million (about 1,000 new registrations per year)

#### The Harare registry in Zimbabwe

*5 staff: 1 Registry manager, 1 executive assistant and 3 health information assistants*

Manage a population-based cancer registry for a catchment area with a population of ca. 1.5 million (population of Harare city) and passive coverage of the whole country (approximately 5,000 new cases a year).

## KEY REQUIREMENTS

- A motivated and respected Director is essential and the surest guarantee of success;
- Sustainable structural resources. Local funds for staff salaries and running expenses are essential. No registry can survive long term as a research project or relying on outside donors;
- Commitment. The registry's success will depend on the support of the concerned Ministry or Programme Owner and the essential cooperation of the medical profession to the cause of cancer registration. An Advisory Group comprising of stakeholders (Representatives of funder(s), sources and users of data) should meet regularly to plan operations.

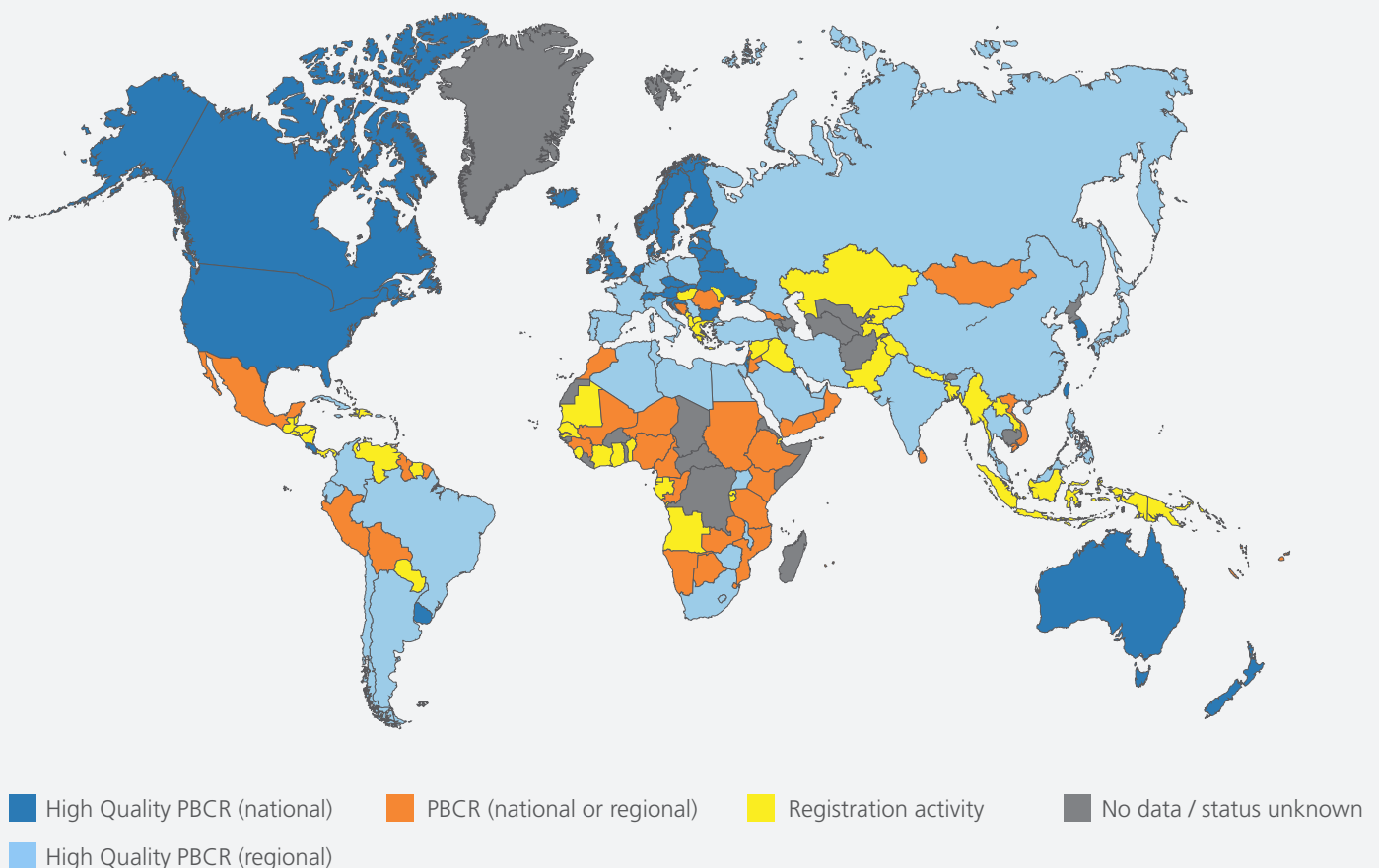
## THE KEY FACTS

- Disease surveillance is essential in programmes to control NCDs and especially for cancer incidence and type
- Population-based cancer registries are needed for surveillance and monitoring of a National Cancer Control Plan
- Cancer registration is always possible, even in low resource settings
- A national cancer registry is not essential – coverage of a regional population will almost always be more cost effective.

“When benefits are considered, the investment in financial terms is often less than anticipated and is cost-effective.”

Check the status of cancer registration in your country on the GICR map [www.gicr.iarc.fr](http://www.gicr.iarc.fr) (status: October 2013).

## GLOBAL STATUS OF CANCER REGISTRATION



## TECHNICAL ASSISTANCE

The IARC-led multi-agency Global Initiative for Cancer Registry Development (GICR) was launched in 2011 to establish effective mechanisms to expand the coverage and quality of data from PBCR in less developed countries and to attain a global fund for such activities. Now in its operational phase, a series of IARC Regional Hubs for Cancer Registration are being rolled out in Africa, Asia and Latin America, with plans for the Caribbean and Pacific Islands.

Coordinated by IARC in collaboration with designated local Principal Investigators in each Hub, the objective of the Hub is to assist in a sustainable expansion of high-quality PBCR within defined Hub regions, by providing the necessary:

- Mentorship and support
- Targeted training
- Guided research capacity; and
- Advocacy tools

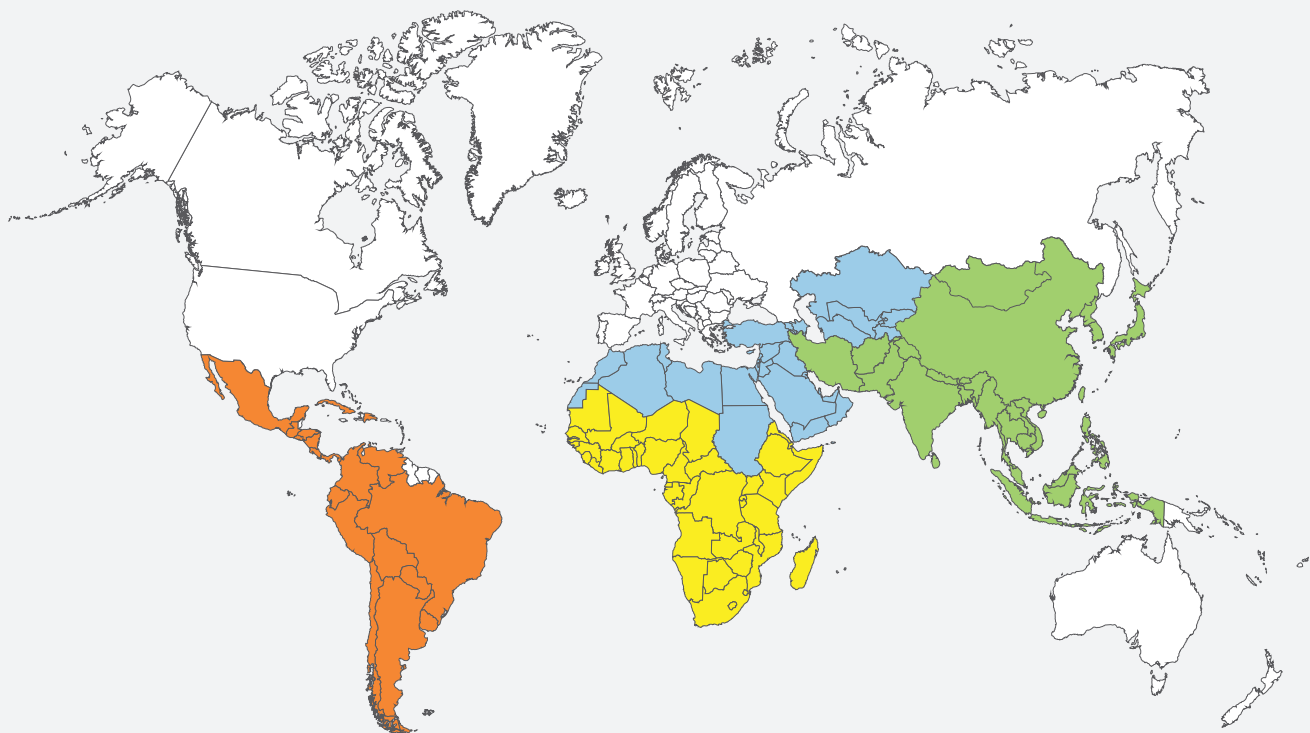
Technical support is available at the local level via IARC-coordinated Regional Hubs and through the GICR (see below).

## STATUS UPDATE

- In October 2012 an IARC Regional Hub for Cancer Registration became operational in Mumbai (India), covering South and East Asia;
- The African Cancer Registry Network (AFCRN) is functioning as a Regional Network Hub covering sub-Saharan Africa since September 2012;
- In September 2013, a Regional Hub to cover West and Central Asia, and North Africa has become operational at the Izmir Cancer Registry (Turkey);
- A Regional Network Hub for Latin America will become operational in early 2014;
- Discussions are on-going to establish Regional Hubs in the Caribbean and Pacific Islands in 2015.

For more information about the Global Initiative for Cancer Registry Development and for details on how to become involved, please contact [gicr@iarc.fr](mailto:gicr@iarc.fr) or visit [www.gicr.iarc.fr](http://www.gicr.iarc.fr).

## IARC REGIONAL HUBS FOR CANCER REGISTRATION



Latin America

South and East Africa

Sub-Saharan Africa

West, Central Asia and North Africa



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UNION FOR INTERNATIONAL CANCER CONTROL  
UNION INTERNATIONALE CONTRE LE CANCER  
62 route de Frontenex, 1207 Geneva, Switzerland  
Tel +41 (0)22 809 1811 Fax +41 (0)22 809 1810  
Email [info@uicc.org](mailto:info@uicc.org) Website [www.uicc.org](http://www.uicc.org)

**International Agency for Research on Cancer**



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