

# CANCER REGISTRIES

## The core of cancer control

Fundamentals of population-based cancer registries

### A global response to the cancer burden

Noncommunicable diseases (NCDs) were responsible for three quarters of the 20.5 million premature deaths at ages 30–69 years worldwide in 2016. Among NCDs, cancer ranks as the first or second cause of premature death in 138 countries worldwide, with the burden expected to double by 2040.

The United Nations Sustainable Development Goals include a health target of a one third reduction by 2030 in premature mortality from NCDs, including cancer. The 2017 World Health Assembly cancer resolution urges specific actions to tackle the increasing cancer burden by requesting WHO Member States to collect high-quality population-based incidence and mortality data on cancer as the means to inform cancer control planning and evaluation.

### The role of population-based cancer registries in cancer control

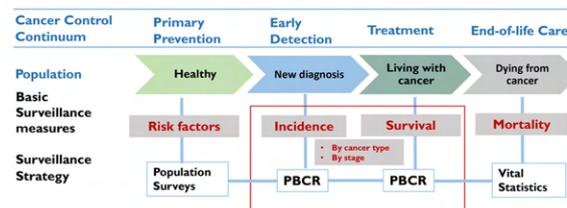
Population-based cancer registries (PBCRs) collect data on all reportable neoplasms in a geographically defined target population. They require well-developed diagnostic and treatment services for cancer that can be easily accessed by local residents.

PBCRs provide accurate and representative cancer statistics by compiling information on cancers among the residents of the population from multiple sources, including hospitals, diagnostic laboratories and vital statistics departments.

PBCRs have been in operation in many countries for decades, adhering to international standards set by their professional organization, the International Association of Cancer Registries (IACR), in collaboration with the specialized WHO cancer agency, the International Agency for Research on Cancer (IARC).

### Characteristics of population-based cancer registries

PBCRs collect, analyse and disseminate information on cancer incidence and survival in the community. Together with complementary data on risk factors from population surveys and mortality from vital statistics offices, incidence and survival are critical indicators to design and measure the impact of primary prevention, early detection, screening and cancer management (see figure below).



Source: Piñeros et al. A Global Cancer Surveillance Framework Within Noncommunicable Disease Surveillance: Making the Case for Population-Based Cancer Registries. *Epidemiol Rev.* 2017;39(1):161-169.

### Accelerating progress through cancer data: the Global Initiative for Cancer Registry Development (GICR)

The GICR, led by IARC, was established as a global partnership to help low- and middle-income countries to build cancer control programmes around accurate data. Six Regional Hubs have been established to contribute to the development of in-country capacity for cancer surveillance across defined regions.

Through collaboration with local institutions and regional experts, the Hubs provide the necessary technical training and support, advocate for the cause of cancer registries and contribute to the formation of regional networks to promote the use of comparable and high-quality data for the purposes of cancer planning.





## What type of cancer registry is needed to inform cancer control activities?

PBCRs are the only type of registry that can provide data for planning, monitoring and evaluation of cancer control activities in the community.

## Are the data from hospital-based cancer registries (HBCRs) a sufficient basis for cancer control?

No. Although HBCRs are of enormous value in assessing health-care services among the institution(s) they serve, the collected data are not an accurate reflection of cancer in the community. This is because HBCR data are based on patient attendance at one or more hospitals, and so the cancer profile is determined by referrals, which are partly based on the facilities and expertise within the institution(s).

## When a PBCR is established, does it need to be national?

No. In countries with larger populations and limited resources, it is feasible and appropriate to gradually scale up high-quality subnational PBCRs to provide an increasingly representative profile of the cancer burden nationally.

## What does a PBCR need to operate?

The basic components include:



**Staff:** A dedicated director and a sufficient number of registrars (based on case load) are essential. An IT expert is also desirable.



**Infrastructure:** The physical facilities required for operating a PBCR are office premises (furnishing, computer and filing), including the means to store information securely.



**Software:** This is required to enable data input, quality control, analysis and reporting. The **CanReg5** software developed by IARC is free and open source and available in seven languages.



**Expenses:** Running costs of a PBCR involve full- or part-time salaries, transportation costs for active data collection, office materials as well as IT maintenance and costs associated with reporting.

## How much does it cost to run a PBCR?

Although estimates vary among registries and countries, annual costs can be less than US\$ 0.1 per resident in the area covered by the registry.

## How long does it take a PBCR to provide results/information?

Most registries take about two years to report incidence data. They need to record all information from oncology services available for each cancer patient, distinguishing each new cancer diagnosis in the resident population from those already included in the database. The process can be time-consuming, requiring specialized coding and data consolidation skills.

## What training is required, and who can provide it?

PBCR staff require specialist skills that take time to develop. Different training and education modalities, including courses, continuous education, mentoring and tailored assistance, are critical to ensure the development of registry personnel. This has direct effects on the level of data quality. IARC and the GICR are contributing to build local capacity in cancer registration in low- and middle-income countries.

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