

# The role and status of population-based cancer registration

Population-based cancer registration represents the gold standard for the provision of information on cancer incidence in a defined population; PBCRs can serve to identify possible causes of cancer in the community and to assess the impact of cancer control activities. A functioning health care system is, however, of critical importance to achieve full case ascertainment and an unbiased picture of the true cancer burden.

Fig. 2.1 compares present levels of the national Human Development Index (HDI) (Fig. 2.1A) versus available sources of cancer incidence (Fig. 2.1B) and mortality (Fig. 2.1C) data. Cancer incidence and mortality data are more commonly available in countries that have attained high or very high levels of HDI; such countries have a longer history of reasonably complete national mortality statistics, and many have developed

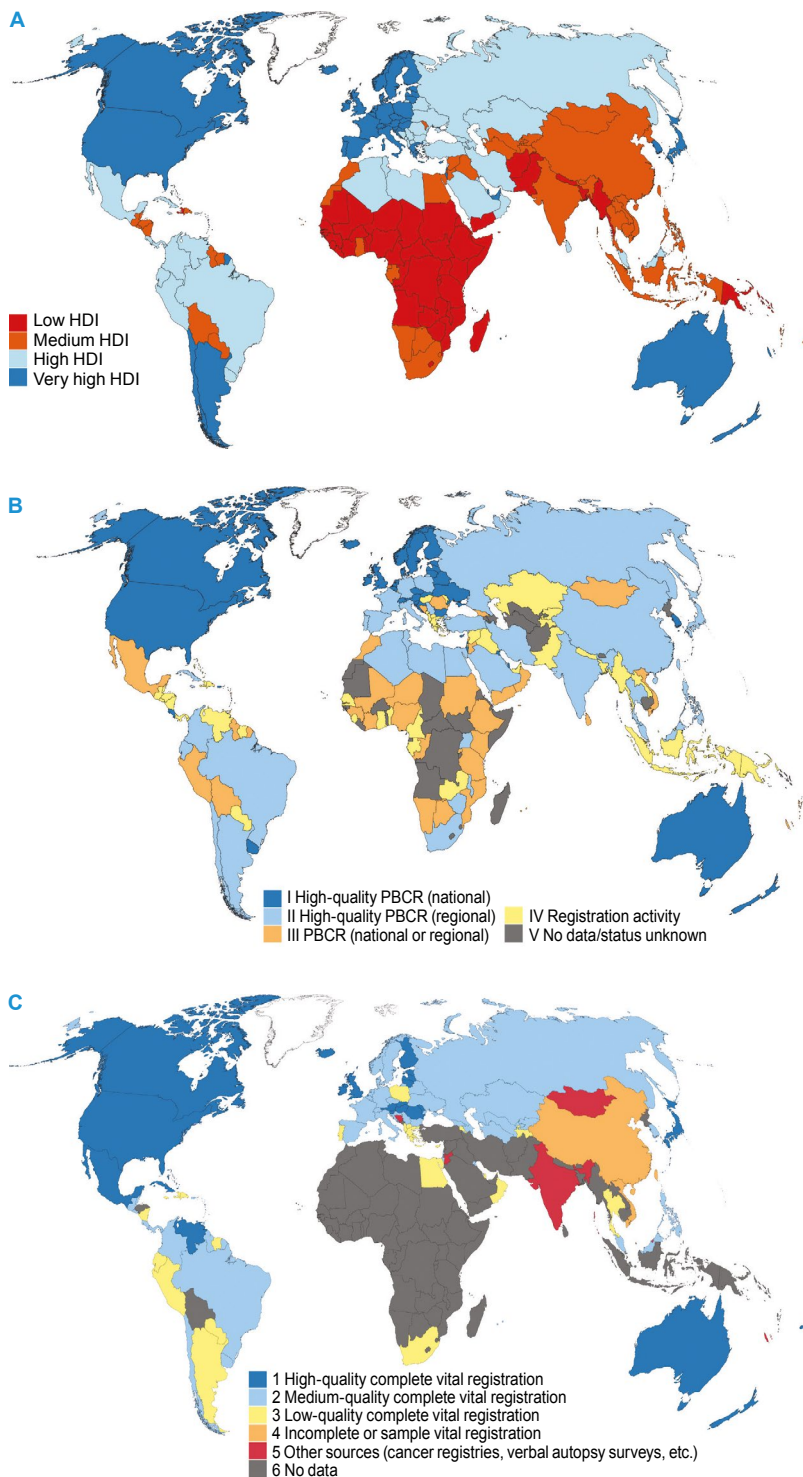
either a national PBCR or one or more regional PBCRs over the past decades, notably during the 1970s and 1980s. In such settings, the activities of PBCRs have developed far beyond the basic role of estimating rates and comparing cancer profiles in different populations (Parkin, 2006). Registries expand their range of activities as they develop, undertaking studies of cancer causes and prevention, and providing the information required in planning and evaluating cancer control programmes (see Box 2.1).

The situation is different for countries presently categorized as having low or medium HDI. In many of these areas of the world, most notably in sub-Saharan Africa and South Asia, both vital registration and PBCR systems of reasonable quality have been slower to emerge.

## 1. What is the status of population-based cancer registration worldwide?

The concept of population-based cancer registration has been in existence for well over half a century, with the first PBCR founded in the 1930s. Currently, there are more than 700 PBCRs worldwide, although their pace of development has been much slower in LMICs than in high-income countries. This reflects a shortage of human and financial resources in LMICs, rather than a lack of awareness of need. The *Cancer Incidence in Five Continents* (CI5) series (<http://ci5.iarc.fr>) published by IARC and the International Association of Cancer Registries (IACR) is regarded as the definitive source of high-quality cancer incidence data, and in Volume X published incidence data for the period circa 2003–2007.

**Fig. 2.1.** Global maps depicting (A) the development level of individual countries, according to the four-level Human Development Index (HDI), based on quartiles, for 2012; (B) status of population-based cancer registries (PBCRs), as of mid-2013; (C) status of vital registration systems, as of mid-2013. Source for A, B: Data compiled from the United Nations Development Programme.



Although there is a substantial disparity between high-HDI countries and low- or middle-HDI countries in coverage in CI5 (e.g. almost complete coverage in North America compared with < 10% in South America, Asia, and Africa), the circumstances are less bleak when it is considered whether cancer information is available and can be built upon in a given country in these regions.

A series of IARC Regional Hubs for Cancer Registration in Africa, Asia, and Latin America have been established and will be the first point of call for countries within the respective regions. The Hubs in liaison with IARC develop specific tools in support of registries to:

- assess cancer registry quality, publication, and presentation of data
- assess capacity for registry development and evaluate the quality of existing registries
- monitor overall progress in expanding coverage of cancer registration
- coordinate the development, follow-up, and evaluation of formal agreements between individual cancer registries and IARC, covering specific activities consistent with the needs and recommendations and a time-limited plan
- coordinate research projects, including the development of monographs in collaboration with IARC, including continental reports based on all available registry data in the Hub region.

Currently, the registration status of the 138 countries within the six Hubs can be placed into one of five categories, as indicated in Fig. 2.1B:

Grade I. High-quality PBCRs (included in CI5 Volume X) and nationally representative (registries with coverage of  $\geq 50\%$  of the country's population)

Grade II. High-quality PBCRs (included in CI5 Volume X) and regionally representative (< 50% coverage)

Grade III. National or regional registries that are, or are close to becoming, population-based (rates can be calculated)

Grade IV. Registration activity: hospital- and/or pathology-based systems (rates cannot be calculated), or documented evidence of efforts to establish a PBCR

Grade V. No data available, or status of registration unknown.

### 1.1 Countries graded as I or II

Countries with high-quality PBCRs (graded as I or II) may appear to need less support from IARC and the Hubs, yet empirically, several flagship registries in LMICs deemed of high quality (e.g. included in a CI5 volume) have subsequently languished, and sustainability of high-quality data from well-functioning registries is an obvious concern. There is a need to develop within-country and regional networks

in support of the development of standards of quality and comparability, and to foster collaborations between registries. Staff from PBCRs graded as I or II in LMICs have unique experience and expertise to offer in support of the Hub activities, having successfully developed PBCRs under similarly challenging circumstances. Such experts are crucial in developing a roster of regional experts who collaborate with IARC and the Hubs as mentors and trainers, taking part in site visits to registries in targeted countries, and joining the teaching faculty of regional courses.

### 1.2 Countries graded as III or IV

A particular aim of the Hubs is to raise registration quality standards in those countries where registration systems

are in place, or where there are local actions under way to develop these. The target for direct support is then those countries graded as III (national or regional PBCRs, including those close to becoming population-based) or IV (countries where hospital- and/or pathology-based systems are in place, or local efforts are under way to establish a PBCR). The focus is on building upon, enhancing, and extending existing registry activities and resources to invoke a significant change in the status of such cancer registries towards high-quality registration. Actions include:

- developing clearly defined operational procedures for registration
- ensuring that a suitably trained and appropriately skilled workforce is in place

**Box 2.1.** Examples of the use of population-based cancer registries in cancer control. Source: Adapted from Parkin (2006), by permission from MacMillan Publishers Ltd, copyright 2006.

The World Health Organization (WHO) notes that population-based cancer registries (PBCRs) are a core component of cancer control strategy (WHO, 2011). There are important roles for PBCRs in estimating the current cancer burden, examining recent trends, and predicting their probable future evolution. The scale and profile of cancer can be evaluated in terms of incidence and mortality, but other dimensions are often considered, including prevalence, person-years of life lost, and quality- or disability-adjusted life years. An appraisal of the current situation provides a framework for action, and cancer control planning should include the setting of explicit targets, which permits the success (or otherwise) of interventions to be monitored.

#### Primary prevention

The effectiveness of preventive interventions against cancer has rarely been evaluated by randomized controlled trials; more usually,

success has to be inferred from observations after the introduction of programmes. This can involve comparing observed versus expected incidence rates (allowing for a time lag for the effects to emerge), with the expected rates based on a prediction model of some kind. This approach can be used, for example, to evaluate the success of interventions against tobacco smoking, and to assess the observed and expected impact of national implementation of the hepatitis B and human papillomavirus (HPV) vaccines.

#### Early detection and screening

Cancer registry data have been used widely in the evaluation and monitoring of screening programmes. Where there is no information on the screening status of individuals, time trends can be examined, in terms of incidence, for cancers for which screening should prevent invasive disease (e.g. cervical cancer), or mortality, for programmes that

are designed to detect early invasive cancers (e.g. breast, colon, and prostate cancer). No reduction in incidence should occur in programmes detecting early invasive cancers; indeed, the introduction of screening should bring about a rise in incidence (as prevalent, asymptomatic cases are detected), followed by a fall, with cumulative incidence unchanged over what it would have been without screening.

#### Evaluating cancer care

Although essential as a measure of the success of cancer control activities in different populations, trends in mortality rates are not ideal, as they are influenced by both incidence and survival. The objective of measuring population-level survival is to give an indication of the possible role of the process of diagnosis and care, and not simply the effectiveness of a specific treatment, as a determinant of survival differences.

- establishing robust links with all the clinical services where cancer patients are diagnosed and treated
- ensuring that relevant ministries and other officials commit to a sustained support of registry activities and build population-based cancer registration into their cancer control strategies.

### 1.3 Countries graded as V

In large countries with ambitious plans but no cancer registration systems in place at present (graded as V), there may be opportunities for high-level negotiations to enable an international task force of surveillance experts to participate in a timetabled set of initial and follow-up visits, as a means of accelerating the development of a registry programme.

## 2. Essential differences between population-based cancer registries and other types of cancer registry

PBCRs systematically collect information on all reportable neoplasms occurring in a geographically defined population from multiple sources. There are two other important types of cancer registry with different functions than PBCRs: hospital-based cancer registries (HBCRs) compile data on cancer cases diagnosed and/or treated in a defined institution or institutions, and pathology-based cancer registries record cancer cases diagnosed in pathology laboratories, mostly based on histopathology or cytology reports. Depending on how the care system is organized, data on a more or less biased subgroup of cancer patients are thus collected.

HBCRs have been developed in many LMICs, particularly in Asia and Latin America, often at the initiative of dedicated clinicians. They serve a range of purposes, providing, for example, information about the diagnosis and treatment of patients in relation to specific tumour characteristics and their clinical outcome. The data from HBCRs and pathology-based systems are an integral part of hospital and laboratory management, respectively, by serving administrative purposes and aiding the review of performance.

The purposes of and fundamental differences between hospital-based, pathology-based, and population-based cancer registries are summarized in Table 2.1. Perhaps owing to their relative ease of establishment, a misconception has been perpetuated that HBCRs and pathology-based

**Table 2.1. Characteristics, purposes, and uses of different types of cancer registries**

Registry type	Characteristics	Purpose	Can this type of 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	NO. An incomplete and biased sample of the population. Data set is based on patient attendance at given hospital or hospitals. Cancer profile is determined by referrals, in part based on the facilities and expertise within key institutions.
Pathology-based cancer registry	Collects information from one or more laboratories on histologically diagnosed cancers	Supports the need for laboratory-based services and serves as a quick “snapshot” of the cancer profile	NO. An incomplete and biased sample of the population. Data set is constructed from laboratory-based surveillance only. Cancer profile 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	The comparison and interpretation of population-based cancer incidence data support 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 in the population and how it is changing over time. These registries have a unique role in planning and evaluating cancer control programmes.

registries can function beyond their clinical, managerial, and administrative roles. Both types of system are of great value in providing a quality assessment of the services rendered, but they can deliver no clear picture as to the underlying local, regional,

or national epidemiology of cancer. As the collected data derive from either patient attendance at a given hospital (HBCRs) or the number of cancers that have been biopsied (pathology-based systems), inclusion as a case is determined by the extent

of facilities and expertise available within the respective institutions. The aggregated cases recorded therefore comprise a subset of the total case load, and thus such systems have little utility in planning, monitoring, or evaluating cancer programmes.

## Key points

- The roles of hospital-based, pathology-based, and population-based cancer registries are different and complementary. The first two types of registry serve important administrative and clinical functions, but only PBCRs provide an unbiased profile of the present cancer burden and how it changes over time. PBCRs have a unique role in planning and evaluating population-based cancer control actions aimed at reducing the cancer burden in the community.
- Although there is a lack of high-quality data in LMICs, as witnessed by the present lack of coverage in *Cancer Incidence in Five Continents*, the circumstances are more positive when one considers the cancer information available in many LMICs. Many countries have national or regional registries that aim to become population-based, and serve as a starting point from which the registration systems can be further developed.
- To support the local planning and development of PBCRs in countries within defined regions, a series of IARC Regional Hubs for Cancer Registration in Africa, Asia, and Latin America have been established. A tailored set of local activities in a given country are provided to increase the data quality, coverage, and utility of PBCRs in serving cancer control purposes.