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## Importance of economic evaluation of cancer registration in the resource limited setting: Laying the groundwork for surveillance systems<sup>★</sup>

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All governments have approved the Global Monitoring Framework on Non-communicable Diseases (NCDs), which includes a commitment to reduce premature NCD (including cancer-related) deaths by 25% by 2025. The global monitoring framework requires WHO member states to collect *cancer incidence, by type of cancer per 100,000 population* – one of 25 indicators to monitor progress toward the 25 by 25 targets [1]. Population-based cancer registries are units that collect and report high quality data on cancer incidence. The data generated by population-based cancer registries are essential for informing health programs, policies and strategies regarding cancer screening and treatment, and for evaluating the impact of national programs for cancer prevention, screening, and treatment [2,3]. However, there are large differences in the existence, coverage and quality of cancer registration across

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<sup>★</sup>The findings and conclusion of this presentation do not necessarily represent the official position of the U.S. Centers for Disease Control and Prevention.

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### Author contributions

Mona Saraiya: Lead author; editorial conception and design, editorial draft, revised editorial for intellectual and scientific content; reviewed and approved final version to be published.

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### Conflicts of interest

None.

the world. The percentage of the population covered by cancer registries that meet the quality standards for inclusion in global statistics (*Cancer Incidence in Five Continents – CI5*) ranges from near-complete coverage in North America to less than 10% coverage in Asia, Central and South America, and Africa [4] (See Fig. 1).

Given these stark statistics, there is an urgent need to initiate sustainable cancer registration models in many countries and to improve existing registration infrastructure to ensure that high quality population-based cancer incidence data are available. The global community requires information on the resources required to initiate, improve and expand cancer registration in order to fund registries adequately. In this monograph, cost and resource data are presented from cancer registries in five countries: India, Kenya, Uganda, Barbados and Colombia. A standardised activity-based cost approach [5–7], validated in the United States setting, was pilot-tested and adopted for use internationally. The results from 11 registries included in this monograph show wide variation, with the cost of registration for a single cancer case varying from about \$4 to \$113 for registries in low and middle income countries. The global team of collaborators identified several factors that might explain the differences in cost including size of area served, quality of the data available at provider sites, number of reporting facilities and cost of living variation. A key finding is that in all settings the cost of cancer registration at the population level in the coverage area is extremely small, a few cents per individual served across the population.

Cancer registration requires adequate resources to generate high-quality statistics but the benefit gained through data-driven policies can be substantial; prevention, early detection of cancers and appropriate treatment can significantly reduce the burden from cancer. In the United States, it cost on average \$65 to register a cancer case [8] and approximately \$75 million is spent on cancer registration activities annually. In contrast, over \$157 billion was spent on cancer treatment in 2010 [9] and the cost of lost productivity due to premature cancer mortality was approximately \$130 billion [10]. Furthermore, global and national statistics often do not capture the substantial financial burden experienced by many cancer patients and their families, particularly in low and middle income countries. In India, for example, cancer patients often pay large out-of-pocket expenses for treatment, which can severely impact, or even exhaust, household savings [11,12].

The series of manuscripts published in this monograph offer several lessons for planning and supporting cancer registration. First, the lack of continuous sustained support for registry infrastructure can lead to disruptions in data collection and potential inefficient use of resources. The contribution of a host institution (be it an academic entity or hospitals or other type) improves sustainability but support from the national government or other entities may be key for most cancer registration to produce high-quality data. Second, although registries incur substantial fixed cost, higher volume registries will have lower cost per case, generating large economies of scale. Innovative models and approaches to share resources can result in lower registration costs. These could include the development of integrated NCD registries, especially for island nations with small populations in the Caribbean and Pacific, including the US Virgin Islands and the US-affiliated Pacific Islands. Third, the data presented in this monograph can serve as baseline information to identify efficiencies in data collection methods, which is consistently reported as a high cost activity

across the registries. Electronic data collection approaches could increase efficiency and reduce cost of cancer registration. Fourth, cancers such as nonmelanoma skin cancers, represent a significant proportion of cases and their monitoring may not be an efficient use of resources for cancer registries with limited funding. In the United States, a decision was made to exclude these cancers based on the number of cases that would need to be found and data collected. Lastly, monitoring and prioritizing cancers that have evidence-based interventions may be important for cancer registries. For example, many cancer registries in the Caribbean collect information on high grade pre-invasive cervical cancer (cervical intraepithelial neoplasia III or CIN III)—these may be important for monitoring impact of screening and vaccination. In the United States, select cancer registries have opted to begin looking at CINIII in cancer registries after several decades of not collecting these data [13].

CDC is partnering with a large number of countries, national and international partners, including the International Agency for Research on Cancer, to improve cancer registration and with the Bloomberg Data for Health Initiative to improve cause of death globally [14], both with a specific focus on low and middle income countries. The series of studies presented in this monograph is an important step forward in generating the required evidence-base and CDC remains committed to working with a broad coalition of stakeholders to further advance sustainable models for NCDs, in particularly cancer registration in the future.

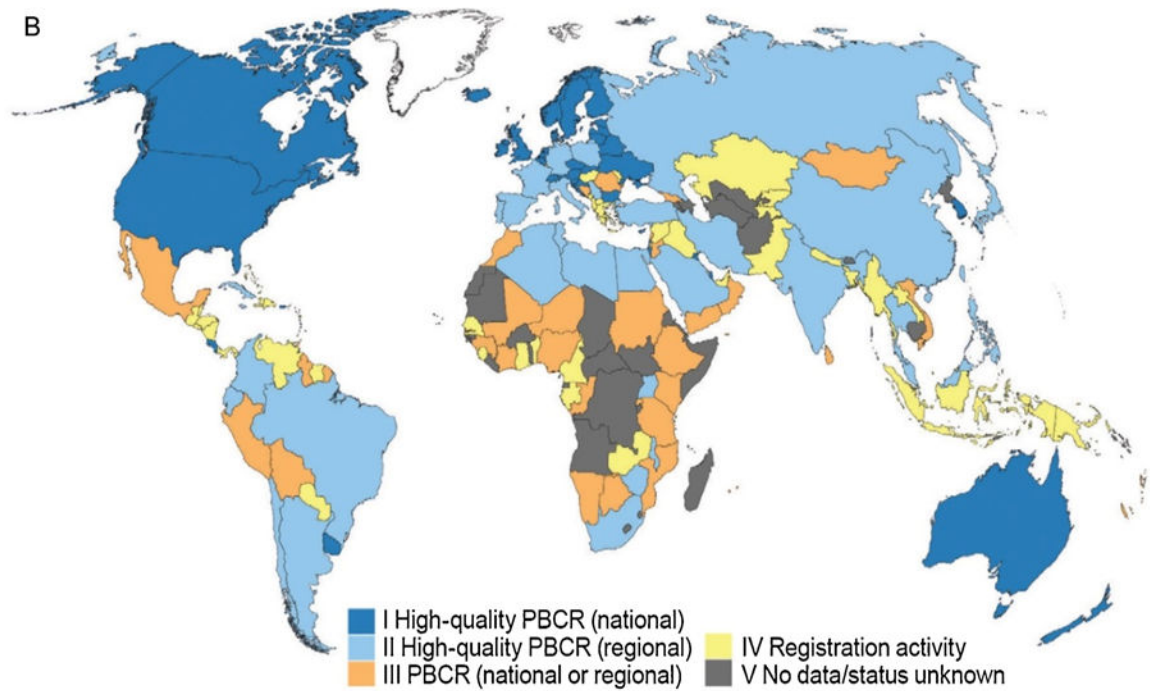
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**Fig. 1.**

Global status of Population-Based Cancer Registration as of mid-2013.

Notes: PBCR stands for Population-Based Cancer Registries. “High-quality PBCR” implies publication in *Cancer Incidence in Five Continents Volume X*. Source: Courtesy of Freddie Bray, IARC.