Cancer Registries

The Facts
Population-based registries collect information on the occurrence and outcome of cancer in defined population groups (usually the inhabitants of a city, region, or country). For each new cancer case, registries record details of the individual affected, the nature of the cancer, information on treatment, and on follow-up, especially with respect to survival from the disease.

A Global Solution
Regardless of a country’s resource setting, cancer registries play an important role in research into the cause of cancer, by providing data on patterns and trends. They are also crucial for the development and monitoring of successful National Cancer Control Plans, and for identifying priorities in public health. Registries must identify reliable resources of data, establish data validation procedures, and quality control measures. To ensure that cancer cases are properly recorded, and that the statistical data gathered can be used to make valid comparisons, cancer registries should also conform to accepted working practices and standards. The International Agency for Research on Cancer (IARC) only uses regional and national data that are considered to meet high standards of completeness and validity to publish the Cancer Incidence in Five Continents (CI5) series. In the latest volume IX of CI5, only 8% of the world population is represented, predominantly from high and middle income regions. Working to improve not only the quantity but quality of population-based registries, particularly in low- and middle-income countries (LMICs) is therefore critical.

As of 2006, almost 80% of the world population was not covered by population-based cancer registries, most living in low- and middle-income countries.

Supporting Evidence
As the only available source of reliable, population-based information on cancer incidence, prevalence and survival rates, cancer registries have an essential role in the implementation and monitoring of initiatives which aim to improve the quality of care and survival prospects for cancer patients. Cancer registries also undertake a range of public health surveillance and health protection functions, with cancer registration information being specifically used to:

- monitor trends in cancer incidence, prevalence and survival across time, and among different areas and social groups.
- evaluate the effectiveness of cancer prevention and screening programmes.
- evaluate the quality and outcomes of cancer care, through the provision of comparative data about treatment patterns and outcomes.
- evaluate the effect of environmental and social factors on cancer risk and support other investigations into the causes of cancer. In the UK for example, cancer registration information has been used to investigate cancer risks in relation to power lines, landfill sites and mobile phones.
- investigate differences in cancer incidence, survival and access to treatment among social groups and thus contribute to programmes aimed at reducing inequalities in health outcomes.
- support the work of cancer genetic counselling services for individuals and families who have a higher risk of developing cancer.
- support recalls of specific groups of cancer patients, for example women who were treated for Hodgkin’s disease with radiotherapy and may have an increased risk of developing breast cancer. 

Figure 1: countries with a national (dark green), or at least one regional (light green), population-based cancer registry with data of sufficient quality for inclusion in Cancer Incidence in Five Continents, volume IX.
Meeting the Challenge

One of the greatest challenges associated with collecting and analysing cancer registry data in many low- and middle-income countries is the lack of basic health services, particularly in rural areas, which results in many cancer cases going un-diagnosed, un-treated, and therefore un-recorded. Even in areas serviced by hospitals and clinics, patients with advanced tumours, or those for whom treatment is not available may not be admitted to hospital at all. Other challenges include: lack of stability of the population which can complicate the definition of residents for population-based registries, lack of trained personnel and follow-up, and lack of data-processing facilities.

Establishing and strengthening cancer registries requires not only financial resources but also recognition of the importance of these data, ongoing commitment to data collection, and trained personnel. Capacity building opportunities for health practitioners (including in the areas of data management, privacy issues, analytic capability and metrics), as well as provision of the necessary hardware to support data collection and processing are therefore crucial to support the establishment of effective population-based registries in low- and middle-income countries.

Leveraging collaborations to establish cancer registries in LMICs: The Cancer Registry in Cali, Colombia

Some countries have successfully established cancer registries by collaborating directly with academic institutions. One such registry is the Cancer Registry in Cali, Colombia, the first and longest-running population-based cancer registry in Latin America, which covers a population of 1.8 million people. Dr. P. Correa started the registry in 1962, in the Department of Pathology of Del Valle University, and it has continued uninterrupted operations ever since. The National Cancer Institute in the U.S. provided training and guidance, and assisted with securing the initial funding for the registry. Since its inception, the registry has been financed and maintained primarily by an academic institution, the Del Valle University, with a small budgetary allocation.

Data from the Cali Cancer Registry have been published in seven volumes of CIR, a tribute to the data’s quality and completeness. Data from the Cali Cancer Registry have guided targeted interventions that have led to improved outcomes. For example, high incidence rates of cervical cancer prompted national screening programmes. Screening successfully resulted in a shift in stage at diagnosis, with lower rates of invasive cervical cancers and more identification of in situ cancers. In 1998, the Cali Cancer Registry participated in the creation of a new population-based cancer registry in the southern city of Pasto. The Pasto Cancer Registry covers a population of 350,000 and is the second population-based registry in Colombia.

The Gambia National Cancer Registry (GNCR)

The Gambia National Cancer Registry (GNCR) is one of the very few national, population-based cancer registries in the whole of Africa. It was established in 1986 to record data on the pattern of cancer occurrence in The Gambia, and in particular to support the long-term follow-up of the Gambia Hepatitis Intervention Study (GHIS), coordinated by the International Agency for Research on Cancer (IARC) to evaluate the efficacy of the hepatitis B vaccination in childhood for the prevention of chronic liver disease and hepatocellular carcinoma.

The GNCR is remarkable amongst cancer registries in Africa in achieving a broad coverage, including a substantial proportion of the rural population. It provides an unbiased description of the cancer profile in the population and an unparalleled opportunity to study cancer occurrence and outcome in a low-income country in sub-Saharan-Africa. The data generated by the GNCR demonstrated just how prevalent liver cancer is in this region and stimulated a substantial number of additional research collaborations on liver and other cancers of importance in the population. These included extensive investigations of the role of aflatoxin and its interaction with HBV infection in the etiology of liver cancer and, more recently, studies on breast cancer. The high coverage and quality of the data from the GNCR also permitted one of the rare studies of cancer survival in an African population, showing just how poor the outcomes were compared to high-resource countries.

The GNCR is a model of how investment in the cancer registry infrastructure, aimed at collecting quality data on cancer in low- and middle-income countries, provides not only vital information on the cancer burden but also stimulates fresh ideas to investigate the causes and prevention of the common cancers in a region.

References

1. United Kingdom Association of Cancer Registries: http://www.ukacr.org/content/what-cancer-registration