In September 2011, for only the second time in its history, the UN General Assembly met on a health issue – the growing burden of noncommunicable diseases (NCD)\(^1\). Low- and middle-income countries are experiencing a faster growth of the burden than high-income countries, especially of cardiovascular disease and cancer. The incidence of cancer is set to rise rapidly in the next 10–20 years, primarily due to ageing of the population, resulting from control of mortality from infectious diseases and malnutrition, resulting in increased life expectancy. At the same time, extensive urbanization is accompanied by changing lifestyles, including widespread uptake of smoking, alcohol consumption, changes in diet, decreased physical activity and rising levels of obesity. These are the factors responsible for most of the cancer risk worldwide\(^2\).

The World Health Organization has long stressed the importance of comprehensive national cancer control programmes (NCCPs) as the most effective response to the growing burden of cancer, especially when resources are limited, and need to be deployed in the most efficient way possible\(^3\). Cancer control aims to reduce the incidence, morbidity, and mortality of cancer and to improve the quality of life of cancer patients through the systematic implementation of evidence-based interventions in prevention, early diagnosis, treatment, and palliative care. A cancer surveillance programme is an essential part of any NCCP, for evaluation of the current situation, setting objectives for cancer control, and defining priorities, and later in monitoring the progress of the implementation of the many individual cancer control activities.

While national mortality data are very useful in this context, vital statistics on deaths by cause are unavailable in most low-income countries, or cover very restricted populations, are incomplete, or are inaccurate (especially if cause of death is certified by nonmedical personnel). Some information on the cancer profile can be deduced from statistics derived from other data sources, such as hospital discharge statistics, or pathology department records. However, the picture that emerges is often quite a biased one, and much care is needed in the interpretation of the data. For this reason, all countries introducing a NCCP should attempt to include a population-based cancer registry (PBCR) as one of its components. The PBCR will provide statistical data on incidence, mortality, stage distribution, treatment patterns, and survival, and provides a basis for studies into the important causes of cancer in the local situation, and for providing information about the prevalence of exposure to these factors in the population\(^4\).

For planning purposes, a PBCR does not need to cover the entire national population (although for many epidemiological studies, this is highly desirable). Coverage of a sample of the population is adequate for many purposes, and it is perfectly possible to prepare national estimates from registry populations that are non-random\(^5\).
In most countries where medical facilities are limited, the registry generally covers one or more major cities, where treatment and diagnostic resources are concentrated, admitting that it is from these that the best quality information can be obtained. Although this permits the collection of quite accurate information on incidence, stage, survival, and deaths, this has the disadvantage that the data are for predominantly urban populations, and thought must be given to this in the planning and evaluation of cancer control programmes. On the other hand, the resources required for a PBCR of this size are quite modest, comprising, as well as a medical director (part-time with their usual duties), one or two trained data clerks, a personal computer, expenses for office supplies, and transport.

Cancer registration in LMIC

As in almost all health-related resources, PBCRs are relatively few in low and low-middle income countries; the percentage of population covered by cancer registries in the reference publication Cancer Incidence in Five Continents, vol IX, is 83% in North America and 32% in Europe, but only 6% in Central and South America, 4% in Asia and 1% in Africa. Those that do exist are generally of poorer quality than in high-income settings – in 2006, for example, about 11% of the population of Africa was covered by some 47 PBCRs that were members of the International Association of Cancer Registries while data from only five (covering 1% of the population) were judged to be of sufficient quality to appear in volume IX of CI5.

The reasons are not difficult to understand, and have changed little for decades; they relate to the lack of the infrastructure on which cancer registries in developed countries can build. Technical difficulties include inefficient health care infrastructure, poorly developed communications, unreliable population data, and cultural or religious constraints. Apart from the technical difficulties, cancer registries face other problems such as insufficient financial and material resources, few knowledgeable and trained personnel, little support and understanding from governments, policy-makers, and sometimes even from health professionals.

Despite these multiple problems, cancer registries have been established in many developing countries – even those in the World Bank’s categories on low- and low-middle-income, and over the years have provided invaluable data on the nature and evolution of the cancer patterns in their
communities, as well as providing a focus for valuable epidemiological studies. The key factors contributing to success include support from (local) Agencies (academic or governmental), enough resources for 4–5 years of running costs, a good theoretical background, trouble-free collaboration with key data providers, reliable hardware and software equipment, appropriate premises, trained personnel, and cooperation with other national and international registries.

Cancer registration in Africa

The history and current status of cancer registration in Africa was documented in the 2003 IARC publication “Cancer in Africa”\(^9\). Although rather few registries from sub-Saharan Africa have been published in “Cancer Incidence in Five Continents” (Table 1), in the 2003 volume, incidence rates from some 23 registries were published in comparative tables, as well as data on the relative frequencies of cancer in many more.

It is doubtful that the situation with respect to overall number of registries, and the quality of their data, has much improved since that time. Although various agencies – notably the UICC and the US NCI had lent technical assistance over the years, much of the impetus to support nascent registries, and to provide the sort of technical and intellectual backup required to maintain the longer established ones had come from WHO and its technical Agency, IARC, and, backed by the latter, the IACR. Most of this was withdrawn during the period 2004–2009. Recently, however, IARC has launched a new “Global Initiative for Cancer Registry Development in Low- and Middle-Income Countries (GICR)”; in collaboration with several other partner organizations (see: http://gicr.iarc.fr/). This provides for a regional approach that aims to benefit cancer registries through:

- technical and scientific support tailored to the specific conditions in the region;
- increased access to training opportunities to address specific capacity-building needs;
- recognition of the value of cancer registration through regional advocacy work;
- a mentoring role, which will, in time, enable registries to make full use of the data they produce.

INCTR and cancer registration in Africa

Working groups and sessions on cancer registration have long figured in INCTR conferences, but a formal Cancer Registry Programme was established only in 2007. Initially, the focus was on support – technical and financial – to those registries in East Africa where other programmes of INCTR – on Burkitt lymphoma for instance – were operative.

The African Cancer Registry Network (AFCRN) was formally inaugurated on 1 March 2012. It is supported via the Cancer Registry Programme. AFCRN has succeeded and expanded the activities of the East African Cancer Registry Network (EARN), which was established in January 2011, thanks to the support of the Doris Duke Charitable Foundation (USA). The aim of the EARN project was to improve the effectiveness of cancer surveillance in five east African countries by providing expert evaluation of current problems and technical support to remedy identified barriers, with long-term goals of strengthening health systems and creating research platforms for the identification of problems, priorities, and targets for intervention. The success of the EARN project has attracted further support, including a grant from the pharmaceutical company GlaxoSmithKline (GSK) – Oncology division. This has permitted expansion of activities to the whole of sub-Saharan Africa. These financial contributions to the work of cancer registration in Africa are a recognition of the increasing burden of noncommunicable diseases, and especially cancer, in the continent, and the need for adequate surveillance as a fundamental part of any rational programme for cancer control.

Early in 2012, the members agreed that, as part of IARC’s Global Initiative for Cancer Registration, the Network would act as a consortium to provide a “Regional Hub” for the registries in the countries of sub-Saharan Africa. The role of the Regional Hub is to provide a centre of expertise to support cancer registration activities through provision of training and technical support, acting as a focus for collaborative research, and provision of opportunities for networking of members. Although no single centre in Africa has the capacity to deliver
the range of services and expertise required, the AFCRN members, acting as a consortium, have the relevant capacity to do so.

The AFCRN Hub will provide a permanent mechanism to provide local support to expand and enhance cancer surveillance for the whole of sub-Saharan Africa.

The programme of work for 2012–13 includes:
- Extension of the Network. As of December 2012, there were 21 members of AFCRN (Figure 1).
- Networking (annual review meeting, website).
- Provision of training – two advanced courses – in Malawi (Figure 2) and Nigeria, and two basic training courses (four weeks, in Uganda and Kenya) are planned.
- Support for registration:
  - User support for CANREG-5.
  - Technical support to registries for publication of their data.
- Collaborative Research, includes:
  - Presentation of time trends in incidence in Kampala (Uganda) and Harare (Zimbabwe).
  - Documenting stage at diagnosis of breast and cervix cancers (in collaboration with the American Cancer Society).
  - Calculation of 3 and 5 year relative survival of breast, cervix, oesophagus and prostate cancers in four East African registries.
  - Developing protocols for methods of estimating completeness of registration appropriate to cancer registries in Africa.
- Estimating the costs of cancer registration in at least three African registries, in terms of cost per case registered (in collaboration with the US Centers for Disease Control).

With respect to collaborative research projects involving external (to the Network) researchers, a research committee has been established. Requests for research collaborations involving more than one member are referred to the committee. AFRCN members forward any requests they receive, and the website serves to channel requests in future.

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Dr Parkin’s main research interests are in descriptive epidemiology (international cancer patterns and trends), with a major concern for cancer registration, and in cancer prevention and control. He has published more than 300 papers in the international literature.

References