

CANCER REGISTRATION IN EMERGING HEALTH SYSTEMS: THE INCTR CANCER REGISTRY PROGRAMME



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Cancer registries are an essential component of cancer control programmes aiming for the most efficient use of limited resources to combat the rising impact of cancer in low- and middle-income countries. A registry covering a limited sample of the national population costs little, but in low-income countries there are multiple technical and structural barriers to overcome. In Africa, in particular, there are few high quality cancer registries. INCTR's cancer registry programme is coordinating an African Cancer Registry Network which, working with other partners, aims to improve the functioning of existing registries, and to assist in the establishment of new ones.

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 worldwide².

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 possible³. 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 population⁴.

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-random⁵.

Figure 2: Participants and Faculty of the AFCRN Advanced Registration Methods course, Blantyre, Malawi, 9-13 July 2012



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 registries⁹.

Cancer registration in Africa

The history and current status of cancer registration in Africa was documented in the 2003 IARC publication “Cancer in Africa”¹⁰. 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).
 - Development of a model “Annual Report” for use in African registries.
 - 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. AFCRN members forward any requests they receive, and the website serves to channel requests in future. ●

Dr Donald Maxwell (Max) Parkin graduated in Medicine at Edinburgh in 1968, and received a doctorate in Epidemiology from the same university in 1985. After working in UK, mainly in health service information and planning, he moved in 1981 to the International Agency for Research on Cancer (IARC/WHO) in Lyon, France, as Head of the Descriptive Epidemiology Unit. Since 2004, he has been part time visiting senior research fellow at the University of Oxford's Clinical Trials Service Unit (CTSU), and also holds part time appointments at Wolfson Institute of Preventive Medicine (Queen Mary University, London), and at IARC Lyon.

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.

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