



**Global Initiative for Cancer Registry Development in Low- and Middle-Income Countries:
quality information to support effective cancer control**

A number of international organisations actively involved in the worldwide promotion of cancer prevention, control and research and with specific concerns regarding cancer in Low- and Middle-Income Countries (LMIC), were represented at a meeting held by the International Agency for Research on Cancer (IARC), Lyon, France on 6-7 July 2011. The meeting led to a joint affirmation by the partners of the critical importance of building local capacity in cancer registration as a fundamental component of a national cancer control plan and more widely, as a model for the development of a coordinated approach to surveillance for non-communicable diseases.

High-quality population-based cancer registries (PBCR) collect and classify information on all new cases of cancer in a defined population, providing accurate data on incidence and survival. In lower-resource settings, hospital-based registries can be an important step towards the establishment of PBCR, but only the latter provide an unbiased description of the cancer patterns and trends in the catchment populations. This information is vital for national governments for the purposes of assessing the burden of cancer in the community, for planning health services and as a foundation for evaluating the impact of cancer control strategies.

There remains a notable lack of high-quality PBCR in Africa, Asia and Central and South America. Despite the overwhelming need, only small proportions of the populations in these continents are adequately monitored by effective PBCR. Only about a third of the countries in the three continents have some form of PBCR meeting standards suitable for planning purposes. Overall it is estimated that approximately 1, 4 and 6% respectively of the populations in these three continents are resident within areas covered by PBCR included in the most recent volume of Cancer Incidence in Five Continents, the IARC reference publication on the burden of cancer worldwide.

While fully recognising the many difficulties involved in carrying out reliable disease surveillance in these regions, the partners agreed that it is essential to radically change this situation. Appropriate phased interventions over the next 5-10 years are required to bring about substantive increases in the number, quality and population coverage of PBCR in lower resource settings.

To bring about this level of change, the following actions have been proposed:

1. The establishment of six IARC regional registration resource centres (hubs), over the next five years, to provide training, support, infrastructure and advocacy to local networks of cancer registries. Each hub is to be staffed by trained trainers, epidemiologists and registry IT system support workers;
2. The development of regional networks of cancer registries to facilitate collaborative initiatives, data sharing and joint analyses;
3. Advocacy to Ministries of Health to demonstrate the value of sustained support to registration as a cost-effective step in developing and monitoring the progress of cancer control programs;

4. The production of a full suite of relevant multilingual, distance-training material for cancer registries, available electronically and on a web-based platform;
5. Continued development of the population-based registration software CanReg to provide a non-commercial, user-friendly platform for maintaining registry databases and providing primary data analysis tools capable of exploiting current telecoms and IT provision;
6. Rapid local, regional and global analysis, publication and dissemination of registry data to ensure timely and full utilisation by national and international stakeholders;
7. International monitoring of progress in expanding coverage of the population of LMIC by cancer registration.

In order to achieve these ambitious goals, it is estimated that a minimum of 5 million USD will be required to support this global initiative for cancer registration over the next 5 years.

The organisations present at the meeting agreed to co-ordinate their efforts by supporting and actively participating in the implementation of the Global Initiative for Cancer Registry Development in Low- and Middle-Income Countries.