International Agency for Research on Cancer

World Health Organization

IARC/WHO and IACR launch new guidelines for planning and developing cancer registries in low- and middle-income settings

Lyon, France, 26 May 2014 - The International Agency for Research on Cancer (IARC), the World Health Organization (WHO), and the International Association of Cancer Registries (IACR) today launch new guidelines for establishing cancer registries. The publication, titled "Planning and developing population-based cancer registration in low- and middle-income settings", provides essential guidance on the key steps in planning a registry, including accessing sources of information, monitoring the quality of the data, and reporting results. The guidelines serve as a vital tool to help low- and middle-income countries attain the highest possible standard of cancer registration, and address the limitations and challenges these registries may face. Cancer registries are critical for evaluating the impact of national control programmes, including vaccination, screening, and treatment efforts. They also serve to catalyse research into causes of the disease.

"Supporting countries in improving the quality of their cancer registry data has always been a high priority for IARC," explains Dr Freddie Bray, Deputy Head of the IARC Section of Cancer Information, who coordinated the publication. "These guidelines show that cancer registration is always possible, even in low-resource settings. With a concerted team effort as well as political commitment, it is possible to successfully develop a population-based cancer registry capable of delivering high-quality data for cancer surveillance and monitoring, and thus support the planning and evaluation of cancer services."

Population-based cancer registries aim to record relevant information about all cases of cancer diagnosed within a target population. These new guidelines are funded by the GAVI Alliance, and are part of the ongoing effort of IARC's Global Initiative for Cancer Registry Development (GICR, http://gicr.iarc.fr) to support population-based cancer registration in low- and middle-income countries. The strategy is founded on the development of IARC Regional Hubs to provide localized and tailored training, technical assistance, and advocacy to countries in various regions around the world.

Population-based cancer registries have become a definitive resource for measuring cancer burden, and for understanding the causes of cancer and the prospects for cancer control. Whereas in high-income countries the expansion of registry data has catalysed changes in national cancer control planning and has played a significant role in determining the cancer burden and its geographical variation, much remains to be done in low- and middle-income countries to ensure a similar development.

"Registry coverage with high-quality data remains well below 10% in Africa, Asia, and Latin America, and there is an urgent need to support the initiation, expansion, and development of registries in many low- and middle-income countries," stresses Dr Roberto Zanetti, President of IACR, an organization with member registries across all continents, and a close partner of IARC. "This new publication will provide invaluable guidance to all those who are seeking to establish or are in the early stages of developing a registry."

Cancer is a leading cause of death worldwide, but low- and middle-income countries bear the brunt of the disease, with approximately 70% of cancer deaths. High-quality data on cancer incidence and survival are valuable indicators of progress in the fight against cancer. Cancer incidence is part of the set of indicators measured by the WHO noncommunicable diseases (NCDs) global monitoring framework to report on progress in implementing the WHO global NCD action plan developed following the United Nations General Assembly high-level meeting on NCDs in 2011.

"Such information is critical to develop effective national policies for cancer prevention and control," says IARC Director Dr Christopher P. Wild. "High-quality data can allow governments to make informed decisions and direct funds where they are most needed. With WHO Member States agreeing to record 'cancer incidence, by type of cancer, per 100 000 population', countries have a responsibility to establish

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population-based cancer registries and to report on progress. IARC is committed to working with WHO and its Member States to achieve this goal."

The publication is now available online in pdf format without charge. Print and e-pub editions will soon be released, and will be distributed widely to partner registries around the world, also free of charge. French and Spanish versions are also in preparation.

Citation

Freddie Bray, Ariana Znaor, Patricia Cueva, Anne Korir, Rajaraman Swaminathan, Andreas Ullrich, Susan A. Wang, and Donald Maxwell Parkin (2014). *Planning and developing population-based cancer registration in low- and middle-income settings.* Lyon, France: International Agency for Research on Cancer (IARC Technical Publication No. 43).

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The International Agency for Research on Cancer (IARC) is part of the World Health Organization. Its mission is to coordinate and conduct research on the causes of human cancer and the mechanisms of carcinogenesis, and to develop scientific strategies for cancer control. The Agency is involved in both epidemiological and laboratory research, and disseminates scientific information through publications, meetings, courses, and fellowships. If you wish your name to be removed from our press release e-mailing list, please write to com@iarc.fr.