

IARC and St. Jude Children's Research Hospital partner to expand global childhood cancer registration

Lyon, France, 15 February 2021 – A bilateral agreement is now in place between the International Agency for Research on Cancer (IARC) and St. Jude Children's Research Hospital (in Memphis, Tennessee, USA) to ensure a greater focus on childhood cancer registration systems. The agreement is called Targeting Childhood Cancer through the Global Initiative for Cancer Registry Development (ChildGICR). Together, the two partners have agreed to combine their respective technical strengths and global collaborative networks in order to enlarge the coverage of and improve the quality of population-based cancer registration of childhood cancer in low- and middle-income countries.

The World Health Organization (WHO) Global Initiative for Childhood Cancer was announced in September 2018. With this new global focus on childhood cancer, there is an urgent need for data to monitor progress in the fight against cancer in childhood. The WHO initiative is a collaborative effort between WHO, St. Jude, IARC, and other global health partners to increase survival rates of children with cancer globally to at least 60% by 2030, a goal that will result in an additional 1 million lives saved. However, only about 13% of the world's population of children is covered by cancer registries, which provide the data required to monitor and track progress in the fight against cancer.

"There is a lack of reliable data on childhood cancer, particularly in low- and middle-income countries. These data are critical to better understand childhood cancer and put in place efficient public health policies to tackle this disease," says IARC Director Dr Elisabete Weiderpass. "This new bilateral agreement will play a key role in implementing high-quality childhood cancer registration programmes and providing training in all aspects of childhood cancer registration in all participating countries."

The ChildGICR agreement will address three major focus areas: (i) implementing a global childhood cancer registration programme across the six WHO regions; (ii) creating a unique and innovative education programme on childhood cancer registration; and (iii) developing research areas to support implementation and education. Work is already under way. Implementation has started in Mexico, and countries in other WHO regions are joining in. An education programme will help to build capacity in the acquisition of globally comparable statistics. The research priorities include analysing barriers to and catalysts of data sharing, developing specific international data standards, and characterizing the financial hardships associated with childhood cancer.

"Cancer registries provide essential information to guide the prioritization of efforts focused on advancing cures for childhood cancer," says James R. Downing, M.D., president and CEO of St. Jude. "Without relevant, high-quality, and country-level data, we cannot accurately measure the impact of our work. Through this collaboration, we will build an international network of paediatric cancer registries. These

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registries will serve as a powerful tool for the global medical community in the fight against paediatric cancer.”

IARC and St. Jude signed the bilateral agreement in May 2020. It is independent of, and complementary to, the WHO Global Initiative for Childhood Cancer. The results of the ChildGICR effort will support all global stakeholders who are working to achieve the goals set by WHO, by increasing access to sustainable data systems, strengthening the registry workforce, and ensuring that comparable information is generated to inform good policy decisions.

“Effective information systems are needed to successfully reach the WHO Global Initiative for Childhood Cancer target of at least 60% survival for children with cancer,” says Dr Bente Mikkelsen, Director of the Department of Noncommunicable Diseases at WHO. “Investments in cancer registries and implementing supporting policies can increase access to cancer care for children. We must have accurate data to strengthen childhood cancer programmes and to monitor progress within countries and around the world. This is a necessary political choice.”

IARC launched the Global Initiative for Cancer Registry Development (GICR) in 2011 to address inequities in underserved populations through a network of six regional hubs that work in coordination to strengthen the quality of cancer data and their use in cancer control. Given the small proportion of children among cancer patients, the registries previously focused on the most common cancer types, which occur mostly in adults. The ChildGICR agreement will close the gap in registration of paediatric cancers. This is an important need, because cancers that occur in children are unique and different from cancers in adults. ChildGICR will help practitioners to understand how many children are diagnosed with cancer, visit clinics for treatment, and survive.

Regular updates on progress and activities will be available on the [ChildGICR website](#) as the project develops.

For more information about this agreement, read this special Q&A:

https://www.iarc.who.int/faq/iccd2021_childgicr/

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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, 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 emailing list, please write to com@iarc.fr.