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PRESS RELEASE

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The French National Cancer Institute and the U.S. National Cancer Institute Announce Efforts to Build an International Childhood Cancer Data Partnership

Pediatric cancers are a complex and diverse group of diseases. Research into these cancers is further complicated by the fact that there often may be only a few cases a year of different pediatric cancers diagnosed in any one country. The generally limited national data sets available on pediatric cancers impedes global advancements in foundational research related to these cancers. This limitation also hinders progress in developing effective treatments for pediatric cancers.

Recently, France's National Cancer Institute (INCa) and the United States' National Cancer Institute (NCI) collaborated to organize the Paris Conference for an International Childhood Cancer Data Partnership. This initiative marks crucial initial steps toward advancing collaborative efforts in this field. Implementing, improving, and accelerating pediatric cancer data-sharing efforts have the potential to drive significant progress in pediatric cancer research. However, there is a need to ensure data security, standardize information, and ensure compliance with national standards across collaborating countries involved in sharing childhood cancer data.

The conference, held on November 7 and 8, 2023, included more than 150 key stakeholders with expertise in pediatric oncology, statistics, academia, medicine, and pharmacology. In addition to government experts from INCa and NCI, experts from many other countries and cancer institutions helped to facilitate robust discussions on the challenges and opportunities of establishing an international data-sharing initiative. The diversity of stakeholders reflected the broad support and commitment to efforts that can help provide catalysts for research breakthroughs and foster the development of new treatments.

In this spirit of international collaboration, the conference took place in the framework of the G7 Cancer initiative. Launched on May 9, 2023, the G7 Cancer initiative aims to strengthen cooperation between organizations to accelerate the fight against the disease and to meet the most complex challenges¹.

The conference provided a platform for these international experts to explore four initial areas of focus:

- Harmonization of Clinical and Biological Data
- Interoperability
- Data Governance and Data Exchange
- Innovative Models and Data Management

That work is continuing, and experts worked on a conference report published today – on **International Childhood Cancer Day**. Subsequently, the group of experts will identify critical research questions whose complexity would benefit from the international sharing of childhood cancer data. Additionally, they will aim to map available resources and address legal obstacles, foster trust, and amplify collaborative initiatives.

[Download the report here.](#)

The conference program and presentation slides showcased during the event are available on the conference's official website for reference.



“We know that pediatric cancers represent a formidable challenge due to their heterogeneity and the limited number of cases diagnosed in each country annually. It is no secret that this scarcity of data restricts our ability to understand these cancers and develop new treatments. No single country possesses sufficient data to conduct the breakthrough research needed on these tumors.”

In response to this reality, the International Childhood Cancer Data Partnership aims to bring together countries with high-quality data and a willingness to explore solutions to share these data. This is how we will manage to dismantle barriers and accelerate progress for children with cancer.”

Director General of the French National Cancer Institute Thierry Breton (left) and President and Professor Norbert Ifrah (right).

¹ The G7 Cancer member organizations are: the French National Cancer Institute (INCa), Cancer Australia, the Canadian Institute of Health Research (CIHR), Cancer Research UK (CRUK), the German Cancer Research Center (DKFZ), the Japan National Cancer Center (NCC), the United States National Cancer Institute (NCI) and the International Agency for Research on Cancer (IARC).



“At NCI, we are deeply committed to powering the research that will change the outlook for pediatric cancers. International collaboration can help to close the gaps in our data and scientific understanding that slow our progress toward more effective approaches against these cancers that leave so many children, young people, families, and loved ones around the world with too few options and too little hope.”

Partnering with INCa to help spearhead this initiative is an exciting step that will open the door to important life-saving discoveries.”

Dr. W. Kimryn Rathmell, Director, U.S. National Cancer Institute



“The Biden-Harris Administration, through the President’s Cancer Moonshot, has put this nation on a path to reduce the cancer death rate by at least 50 percent over the next 25 years. It is especially important we do everything we can to help young people who are engaged in a battle against cancer. With the continued emergence of breakthrough treatments and innovative technologies, the goal to end cancer as we know it is more than achievable.”

Research is fundamental to the fight against cancer, and we are committed to funding research and engaging in partnerships with our counterparts around the world. I am confident this partnership with the French will yield important information that will further accelerate all these efforts.”

Secretary Xavier Becerra, U.S. Department of Health and Human Services

About the French National Cancer Institute

The French National Cancer Institute (INCa) was established under the French Public Health Act of August 9, 2004, as the State health and science agency specialised in cancer control. It includes State representatives, charities, health insurance funds, hospital federations and research organizations and operates under the dual auspices of the French Ministry of Health and Solidarities and the French Ministry of Higher Education, Research and Innovation. It provides an integrated approach encompassing all cancer-control aspects (health, scientific, social and economic) and intervention areas (prevention, screening, care, research) to benefit patients and their relatives. To catalyse progress, the INCa acts as an interface with patients, their friends and families, the healthcare system users, the general public, healthcare professionals, researchers, experts and decision-makers. The Institute ensures the implementation of the ten-year cancer control strategy 2021-2030 <http://www.e-cancer.fr/> [twitter](https://twitter.com/inca)

PRESS CONTACT

French National Cancer Institute

For media enquiries please contact the PR Manager on 00(33) 1 44 10 14 44/00 (33) 6 20 72 11 25 or presseinca@institutcancer.fr