# The Childhood Cancer Data Initiative: Data Sharing Is Essential to Progress

The Childhood Cancer Data Initiative aims to change the course of how cancer in young people is prevented, diagnosed and treated.

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By Douglas Lowy, MD

NCI has been busy laying the groundwork for a plan to develop an innovative childhood cancer initiative with an aggressive focus on data sharing. The goal of the initiative is to speed progress for children and adolescents and young adults (AYAs) with cancer and their families. It would be initiated with a proposed increase to NCI's budget of $50 million beginning in fiscal year 2020 and continuing, as proposed by the White House, for a total of 10 years.

In recent years, we've seen great progress in treating children with cancer. In the 1970s, just over 50% of children diagnosed with cancer could expect to survive 5 years or longer. But advances in treatment have raised that figure to higher than 80% today.

However, the higher survival rates have not been seen across all pediatric cancers. Progress against some types has been limited. In addition, we still have very little insight as to why some children do very well on treatment and then later suffer a relapse.

For those children who do survive, the long-term and delayed effects from cancer and its treatment can severely diminish their quality of life. And, despite improvements in treatment, the specific causes of most pediatric cancers remain largely unknown.

Even one child dying from cancer is one child too many. Clearly, there is much more we must do to address the challenges that have hindered more rapid progress.

At NCI, we strongly believe that harnessing the power of data can be a driver of that progress, which is why the institute plans to use these proposed funds to create the Childhood Cancer Data Initiative (CCDI).

The aim of the CCDI is to establish more efficient ways to share and use childhood cancer data to help identify novel therapeutic targets and approaches, underpin new drug development, and enable new research pursuits to better understand the biology of childhood cancers.

Given that childhood and AYA cancers are relatively uncommon, accounting for approximately 1% of cancers diagnosed annually in the United States, we have a limited amount of clinical and genomic data available to study. Moreover, we currently lack efficient ways to collect, share, and integrate data from individual centers that care for children and AYAs with cancer. This greatly limits the potential for researchers to collaborate and produce complex analyses, hindering our understanding of the pathogenesis of pediatric cancer and the development of more effective and safer treatments.

## Learning From Every Young Person With Cancer

The CCDI will help to maximize the utility of data collected from as many childhood and AYA cancer patients as possible, from institutions around the country and around the world. Through improved data federation, the CCDI will connect these data with an infrastructure to facilitate sharing. In doing so, we can make it easier for researchers and oncology teams to learn from the experience of every young person with cancer and make better-informed decisions for their pediatric and AYA patients.

The CCDI will be the first of its kind in terms of the quality, size, and scope of data accessibility, making it an immensely valuable asset for young patients with cancer, their families, clinicians, and researchers. The initiative has the potential to chart a path that could change the course of how cancer in young people is prevented, diagnosed, and treated.

The goals of the initiative are also aligned with efforts underway at NCI to implement the research provisions of the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act of 2018. These provisions encourage NCI to continue to support and conduct childhood and AYA survivorship research, and to enhance collection of samples for childhood and AYA cancer research. NCI anticipates that the CCDI will complement this work: data from specimens collected through STAR Act efforts will contribute to the CCDI, and CCDI data resources will also enable future survivorship research.

## Shaping the Direction of the CCDI

Since the announcement of the proposed new funding for childhood cancer research in February, we have been working with Secretary of Health and Human Services Alex Azar and the White House to help inform the public about the new initiative.

To shape the scientific direction of the CCDI, NCI is hosting a planning symposium July 29–31 in Washington, DC. The symposium will gather leaders and stakeholders from academic, government, industry, and advocacy communities to discuss scientific and clinical research data needs, opportunities for developing a connected data infrastructure, ways to provide meaningful datasets for clinical care and associated research progress, and policies around collecting and sharing data. We encourage members of the public to watch the symposium by videocast.

A poster session at the symposium will provide presenters the opportunity to share their ideas for shaping the initiative. I invite you to submit an abstract by June 15. Consideration will be given for abstracts submitted up until June 30 if space is still available.

To encourage as many people as possible to engage in the initiative and share their thoughts, we will be launching an online public idea repository at the end of June. This is an opportunity for anyone who is interested—patients, parents, advocates, researchers, data scientists, engineers, businesses, philanthropists—to submit their ideas for how to accelerate progress against pediatric cancer. NCI will present a report on the public's submissions at the CCDI symposium so that they may be part of the scientific dialogue. Submissions received after mid-July will be considered at a later date.

An Opportunity and a Responsibility

The CCDI complements NCI's ongoing efforts to support a broad range of biomedical research that addresses childhood and AYA cancers, with the goal of adding to our long history of contributing to important advances, from the first uses of chemotherapy to cure children with acute lymphoblastic leukemia to the first immune-based therapies, such as dinutuximab (Unituxin) for neuroblastoma, for childhood cancers.

I am truly excited about this bold data initiative and am confident it will provide a blueprint for establishing similar data resources for adult cancers, as well as diseases beyond cancer. Importantly, maximizing the use of available data will have a profound impact on our ability to hasten progress against childhood and AYA cancers by providing important insights into prevention and opening up new opportunities for earlier diagnosis and safer, more effective treatments. We have an opportunity, and a responsibility, to use this moment to learn from every child with cancer.

I encourage you to sign up to receive email updates on the progress of CCDI.

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