

NCI CHILDHOOD CANCER DATA INITIATIVE

In March 2019, the NCI announced the Childhood Cancer Data Initiative (CCDI), which focuses on the development of a framework to “collect, analyze, and share data to address the burden of cancer in children, adolescents, and young adults.” Data-sharing is especially critical for tackling pediatric cancers because they are rare, affecting a total of 16,000 patients a year in the United States.

The database would integrate multiple types of data, including genomics, proteomics, imaging, pathology, and clinical data including side effects and patient and caregiver reported outcomes.



Privacy and ethical issues regarding data-sharing will also need to be addressed as governance frameworks are developed.

