NCCR and STAR Overview:

CDC and NCI Collaborate on Unique Initiatives for Pediatric Cancer Research

The Centers for Disease Control and Prevention (CDC) and the National Cancer Institute (NCI) have complementary initiatives to improve surveillance activities that inform our scientific understanding of pediatric cancer. CDC and NCI central cancer registries hold structured data on every cancer case within their respective catchment areas.

Childhood cancer patients experience many adverse long-term outcomes such as side effects of treatment, recurrence of cancer, and subsequent primary cancers. It is critically important to establish a coordinated national approach to long-term follow-up with these patients, as they may move to other states later in life or be treated in multiple facilities in different states.

NCI's National Childhood Cancer Registry (NCCR)

The Childhood Cancer Data Initiative symposium[1] hosted by NCI in 2019 identified a "critical need to collect, analyze, and share data to address the burden of cancer in children, adolescents and young adults." A subsequent 2020 report[2] from the NCI Board of Scientific Advisors highlighted the value of using data from existing registries. The NCCR brings together data from a variety of sources into a coordinated infrastructure that will support research on pediatric and adolescent cancers and survivorship issues.

The NCCR has five main goals:

1. Build a core database for the NCCR using abstracts from central cancer registries and supplemented with other data sources, including:
   - Residential history, social determinants of health, and measures of financial toxicity.
   - Comprehensive treatment and outcomes information derived from cancer abstracts, linkages with national pharmacy and claims data, and real-world clinical information systems.
   - Radiation treatment from the Proton Therapy Registry and other radiation facilities.
   - Multi-state matches through the Virtual Pooled Registry.
   - Death and cause of death from the National Death Index and state vital records.
2. Monitor and assess data quality.
3. Report on progress of monitoring childhood cancer in the U.S.
4. Develop processes for controlled data access for secondary research for a broad set of investigators.
5. Develop an administrative and governance plan for continued NCCR efforts.

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[1] https://www.cancer.gov/news-events/cancer-currents-blog/2019/lowy-ccdi-symposium-childhood-cancer
[2] https://deainfo.nci.nih.gov/advisory/bsa/sub-cmte/CCDI/CCDI%20BSA%20WG%20Report_Final%2006061620.pdf

CDC's Childhood Cancer STAR Project

In 2018, Congress signed into law the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act to help address the burden of childhood cancer. The law requires CDC to expand capacity within the National Program of Cancer Registries (NPCR) to help central cancer registries collect and make the data on pediatric cancer cases available within weeks of diagnosis.

The Childhood Cancer STAR Project has four main goals:

1. Develop a cloud-based informatics system to improve case finding, reportability, and timeliness of pediatric, adolescent, and young adult cancer cases. This informatics system builds on registries' existing infrastructure for electronic pathology reporting.
2. Report cancers diagnosed in children and young adults to central cancer registries in near real-time.
3. Publish 12-month data for public use within 6 months of submission to CDC.
4. Improve public health professionals' access to recent pediatric and young adult cancer information to improve enrollment in clinical trials and plan programs that help cancer patients get the care they need.

NCCR and STAR Initiatives to Improve Public Health Surveillance and Secondary Research on Pediatric Cancer

NCI NCCR Initiatives	CDC STAR Initiatives	Joint Efforts
• Use data from SEER registries and selected NPCR registries. • Link to LexisNexis for residential history information. • Link to the Virtual Pooled Registry to capture subsequent primary cancers. • Link to external sources such as pharmacy, radiology, pathology, and genomics to enhance data. • Collaborate with the Childhood Cancer Research Network and the Pediatric Proton Consortium Registry. • Work with NCI Cancer Centers to receive additional data. • Leverage and evaluate advanced program interfaces (APIs) to extract information from pathology reports automatically. • Collaborate with clinicians, pediatric cancer specialists, epidemiologists, and others.	• Build an enhanced informatics system upon existing cancer registry infrastructure. • Improve understanding of existing registry processes and best practices. • Pilot and scale a cloud-based informatics system to multiple NPCR central cancer registries. • Explore implementation of a cloud-based informatics system in NPCR central cancer registries. • Maintain partnerships with registries, reporting facilities, organizations, and advocacy groups. • Improve access to recent pediatric, adolescent, and young adult cancer data for researchers and other public health professionals. • Scale best practices to other NPCR central cancer registries.	• Improve electronic pathology reportability and data transmission between hospitals and central cancer registries. • Use automated methods to screen pathology reports to reduce the manual burden of reporting cancer cases to registries. • Capture information on initial and subsequent primary cancers diagnosed in children in real time. • Identify and collect additional data necessary to support research on childhood cancer.

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