# 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<sup>1</sup> 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<sup>2</sup> 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:
  - o 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.

<sup>&</sup>lt;sup>1</sup> <u>https://www.cancer.gov/news-events/cancer-currents-blog/2019/lowy-ccdi-symposium-childhood-cancer</u>

<sup>&</sup>lt;sup>2</sup> <u>https://deainfo.nci.nih.gov/advisory/bsa/sub-cmte/CCDI/CCDI%20BSA%20WG%20Report</u> Final%20061620.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 realtime.
- 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	•	Build an enhanced	•	Improve electronic
	registries and selected NPCR		informatics system upon		pathology reportability and
	registries.		existing cancer registry		data transmission between
•	Link to LexisNexis for		infrastructure.		hospitals and central cancer
	residential history	•	Improve understanding of		registries.
	information.		existing registry processes	•	Use automated methods to
•	Link to the Virtual Pooled		and best practices.		screen pathology reports to
	Registry to capture	•	Pilot and scale a cloud-		reduce the manual burden
	subsequent primary		based informatics system to		of reporting cancer cases to
	cancers.		multiple NPCR central		registries.
•	Link to external sources		cancer registries.	•	Capture information on
	such as pharmacy,	•	Explore implementation of a		initial and subsequent
	radiology, pathology, and		cloud-based informatics		primary cancers diagnosed
	genomics to enhance data.		system in NPCR central		in children in real time.
•	Collaborate with the		cancer registries.	•	Identify and collect
	Childhood Cancer Research	•	Maintain partnerships with		additional data necessary to
	Network and the Pediatric		registries, reporting		support research on
	Proton Consortium Registry.		facilities, organizations, and		childhood cancer.
•	Work with NCI Cancer		advocacy groups.		
	Centers to receive	•	Improve access to recent		
	additional data.		pediatric, adolescent, and		
•	Leverage and evaluate		young adult cancer data for		
	advanced program		researchers and other public		
	interfaces (APIs) to extract		health professionals.		
	information from pathology	•	Scale best practices to other		
	reports automatically.		NPCR central cancer		
•	Collaborate with clinicians,		registries.		
	pediatric cancer specialists,				
	epidemiologists, and others.				

Contact information:

NCCR Project – <u>ncichildhoodcancerdatainitiative@mail.nih.gov</u>

STAR Project – <u>cancerinformatics@cdc.gov</u>