REGISTRAR PIP

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National Cancer Institute's (NCI)
Childhood Cancer Data Initiative (CCDI)

Background

Childhood cancers represents approximately 1% of all cancers diagnosed annually in this country but it is one of the leading causes of death in children over the age of one. While there have been advances in childhood cancer research over the last 50 years, there's still a need for quicker progress to improve outcomes for children with cancer because far too many of the growing number of survivors continue to face significant long-term physical, emotional, and cognitive effects due to their cancer and treatment. NCI is committed to doing more to better understand the full impact of pediatric cancer in our children.

Historically, information related to these cancers has been primarily stored only at the facility where a child was treated, making it difficult to answer scientific questions about these rarer cancers. In 2019, there was a lack of efficient ways to collect, share, and integrate data from individual centers that care for children and young adults with cancer. This limited the potential for researchers to collaborate and produce complex analyses, hindering our understanding of how pediatric cancer originates and evolves and the ability to develop more effective and safer treatments.

Project

Enter CCDI, the NCI initiative focused on enhancing the sharing of clinical care and research data of our youngest cancer patients in order to improve our understanding of cancer biology more quickly and ultimately be able to improve:

- Preventive measures
- Treatment
- Quality of life
- Survival

NCI recognized data sharing is the driver essential to progress. This is the third year of funding for a total proposed investment of $500 million over 10 years. The intention of the CCDI is to develop a merged infrastructure to help manage and share data, including a searchable catalog of pediatric data, tools, and resources.

In simplistic terms, the CCDI is the "data hog wannabe" initiative for all childhood cancers in the United States. In providing funding for this project, the goal is to make it easier for researchers and oncology clinicians to learn from the experience of every young person with cancer and make better-informed decisions for these patients.

Progress to Date

Since CCDI began in 2019, work has focused on five recommendations from the NCI Board of Scientific Advisors (BSA) working group that identified predominant data sharing opportunities in childhood cancer:

- Enhance and reduce barriers to data sharing
- Establish a merged infrastructure
- Create a resource catalog of data, biospecimens, and tools
- Aggregate preclinical testing and cancer model data to aid in rapidly applying the knowledge in the clinical setting
- Develop a national strategy for testing and collecting data from every child

Here are just a couple of improvements to data sharing, aggregation, and analysis since the implementation of the CCDI began that might be interesting to us as registrars:

NCCR*Explorer is an interactive web application that provides incidence and survival statistics for cancers in children, adolescents and young adults ages 0-39, using data from the National Childhood Cancer Registry (NCCR). It provides detailed statistics for a cancer site by sex, race/ethnicity, and age, and allows for comparison across cancer sites and subsites. Here is the link to the application:

https://nccrexplorer.ccdi.cancer.gov/application.html

The NCCR*Explorer provides comprehensive and frequently requested incidence and survival statistics based on the International Classification of Childhood Cancer. It includes:

- Trends Over Time
- Recent Rates
- Rates by Age at Diagnosis
- 5-year Relative Survival

With the NCCR*Explorer one can:

- Create custom graphs and tables
- Download data and images
- Share links to results

Extract Data from Electronic Health Records (EHCs) in Real Time

EHRs offer a lot of data that document the patient's full medical journey as well as long-term outcomes. **Fast Healthcare Interoperability Resources (FHIR)** is emerging as the standard to support this task. The HL7® FHIR® standard defines how healthcare information can be exchanged between different computer systems regardless of how it is stored in those systems. It is based on internet standards widely used by industries outside of healthcare.

Some of the tools for real time data flow using the FHIR standard include **Research Electronic Data Capture (REDCap)**, which offers a way of taking some clinical data directly from the EHR, and ExtractEHR, which mines information from EHRs. REDCap is a secure, reliable, and feature-rich web application used to build and manage HIPAA- and IRB-compliant online surveys and databases. Researchers can create and design surveys in a web browser and engage potential respondents using a variety of notification methods.

There is potential for greater collaboration by our standard-setters (e.g., CoC, NCI, NPCR), our cancer registry software venders, our EHR vendors, and the CTR community to use these tools and other emerging tools to enhance the data collection process. These efforts would ultimately allow us to capture and code even more data items, thus making the registry even more valuable to researchers, clinicians, and administrators. This is certainly not beyond the realm of possibilities. Talk about strengthening registrar job security and ultimately providing even more value to our patients!

Process Improvement Pointers • Feedback/Questions to Registrar-PIP@FredHutch.org
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Conclusion
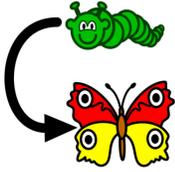
The current goal of the CCDI is to continue to accelerate progress against pediatric cancer. Maximizing the use of available data will have a significant impact on the ability to hasten this progress by providing important insights into prevention and opening up new opportunities for earlier diagnosis and safer, more effective treatments.

CCDI has made significant progress over the past 2 years in developing a broad stakeholder community, all of whom are working toward a shared vision. The CCDI community has the potential to transform childhood cancer treatments and outcomes, and if it is used as a model for data collection, sharing and research in adult cancers, our jobs will likely continue to evolve. This is simply another reminder that for registrars, change is our only constant.