



Welcome to the [Data for the Common Good](#) (D4CG) quarterly newsletter! Read on for announcements from D4CG headquarters, Pediatric Cancer Data Commons updates, highlights from recent meetings, and more. Past newsletters are [archived on our website](#). Please don't hesitate to [reach out with suggestions and requests](#).



Hello from our most recent hybrid team meeting!



Call for Nominations: AYA Research Council

We are launching an AYA Research Council (ARC) to provide expertise and guidance on specific issues faced by adolescent and young adult (AYA) cancer researchers. We are seeking nominations for **members at large** to serve on this council.

Membership is not limited to scientists; we aim to include those active in AYA research and advocacy, AYA topic experts, and people with lived experience of AYA cancer. Serving on the ARC will be a commitment of two one-hour meetings per year, with the option to participate in additional meetings and workshops. Self-nominations are welcome. Please [email nominations to Suzi Birz](#).

[Send us a nomination](#)

Upcoming Conferences

We're looking forward to these meetings in the next few months. If you're attending, we hope to see you there! If you'd like to schedule a meeting with D4CG at any of these conferences, please reach out to [Suzi Birz](#).

- **Children's Oncology Group Fall Meeting**, September 5-8 in Atlanta, GA
- D4CG is excited to host the **NCI Informatics Technology for Cancer Research Annual Meeting**, September 11-14 here at the University of Chicago
- **Fanconi Anemia Research Fund Scientific Symposium**, September 28-October 1 in Vancouver, Canada
- **MaGIC Annual Meeting**, October 1-4 in Edinburgh, Scotland
- **SIOP Congress 2023**, October 11-14 in Ottawa, Canada

D4CG Announcements

Developing an automated clinical trials matching tool

A D4CG-led team has published a new paper describing our development of an automated patient-centric clinical trials matching tool. This required using natural language processing to extract inclusion and exclusion criteria from free text in clinical trial protocols, then comparing the criteria with patient clinical and demographic information to generate a ranked list of relevant clinical trials. The tool was validated against manual versions of the same process, and shows the potential to save time and money when matching patients to trials by reducing the cumbersome process of manual data extraction.

We look forward to continuing to refine this work with the ultimate goal of lowering barriers to access for clinical trials enrollment. Read the paper in *JCO Clinical Cancer Informatics*: [Automated Matching of Patients to Clinical Trials: A Patient-Centric Natural Language Processing Approach for Pediatric Leukemia](#).

New funding for osteosarcoma from MIB Agents

We are honored to be among the [2023 MIB Agents OutSmarting Osteosarcoma](#) grant recipients. This funding, announced at the FACTOR conference in June, will support our work to bring [harmonized osteosarcoma data](#) into the Pediatric Cancer Data Commons. We are grateful to receive this support [Because of Annaleigh](#).

Sue Cohn receives ANRA Lifetime Achievement Award

Sue Cohn, whose work as co-founder and Executive Committee co-chair of [INRG](#) helped lay the initial foundation for the PCDC, was [recognized for her contributions](#) to neuroblastoma research at Advances in Neuroblastoma Research conference for her Lifetime Achievement Award. Dr. Cohn was also profiled by the SIOP Women Leaders Network in the [2023 Almanac of Women Leaders in Paediatric Oncology](#).

PCDC milestones

The [Pediatric Cancer Data Commons](#) continues to grow! A few highlights this quarter from our consortia:

- A new group has been formed to collect and harmonize oncofertility data for the PCDC. Reproductive HOPE (Reproductive Health Outcomes and Preservation Evaluation Collaborative) is currently drafting a Memorandum of Understanding.
- Information about past and ongoing research projects can now be found online for both [INRG](#) and [INSTRuCT](#).
- INSPiRE has completed v1.0 of the [data dictionary for embryonal CNS tumors](#).

D4CG team updates

Data for the Common Good welcomes our newest team members: **Spencer Claxton**, Front End Developer, and **Kaitlyn Ott**, Healthcare Data Standards Analyst.

Meeting Highlights: April-June 2023



D4CG had a full spring season of conferences and events! We were grateful to connect with our colleagues, contribute to the discussion of important research, and meet new collaborators and friends.

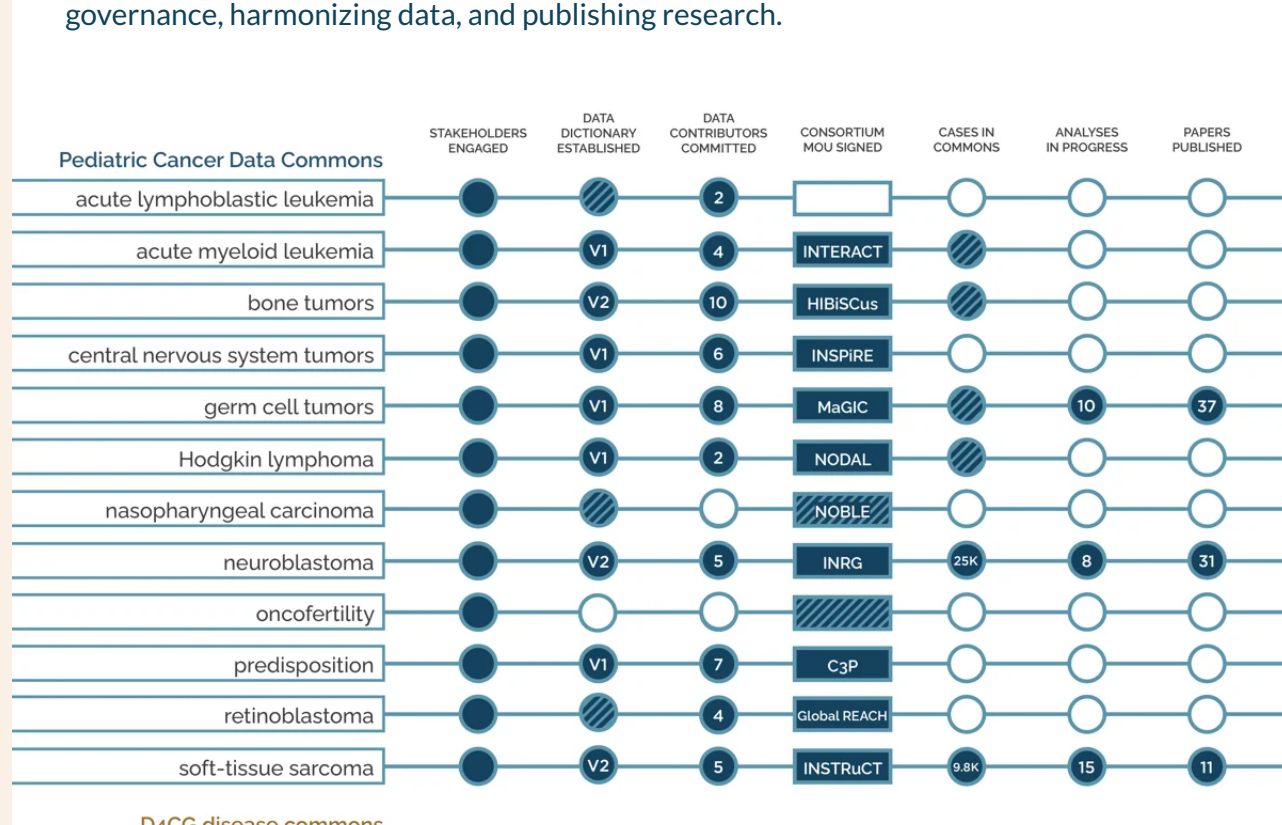
- Sam Volchenbom participated in a symposium on advancing pediatric drug development at the [AACR annual conference](#).
- D4CG representatives attended a roundtable hosted by [Teen Cancer America](#) to discuss challenges faced by AYA patients.
- We attended [SIOP Europe](#) and shared demos of the PCDC Data Portal at our exhibit booth. Sam was a panelist in the plenary session "Big Data and AI in childhood cancers: hype or hope?"
- We enjoyed talks from INRG researchers at the [Advances in Neuroblastoma Research](#) meeting, and Brian Furner presented "Building a REDCap on FHIR Tool to Abstract Neuroblastoma Data from Electronic Health Records (EHRs): A Proof-of-Concept Study."
- At the [ASCO Annual Meeting](#), we participated in the session "Putting It Together: Big Data in Pediatric Oncology," and Sam chaired a discussion on the importance of data harmonization in major pediatric oncology big data programs.
- We were happy to see friends new and old at our event [D4CG Live!](#), which featured a keynote from former NCI Director Ned Sharpless as well as presentations from patient advocate Sarah Bartosz and D4CG collaborators.
- At the [Global AYA Cancer Congress](#), Sam presented on global advances in AYA research.
- At the [FACTOR Osteosarcoma Conference](#), we were honored to receive an [OutSmarting Osteosarcoma grant](#), and Suzi Birz participated in the panel discussion "Leveraging Computational Biology to Accelerate Discovery."
- Both the [INRG](#) Task Force and [INSTRuCT](#) met this quarter to discuss research activities and other topics.

Recent Publications

- **Clinical and biological features prognostic of survival after relapse or progression of INRGSS stage MS prognostic of survival after relapse or progression of neuroblastoma: A report from the International Neuroblastoma Risk Group (INRG) project** was published in [Pediatric Blood & Cancer](#).
- **Automated Matching of Patients to Clinical Trials: A Patient-Centric Natural Language Processing Approach for Pediatric Leukemia** was published in [JCO Clinical Cancer Informatics](#).

Data Commons Progress

Bringing data together for the Pediatric Cancer Data Commons and our other D4CG data commons is the work of many dedicated groups of researchers, clinicians, statisticians, and other experts. This tracker shows each group's progress on the journey of establishing governance, harmonizing data, and publishing research.



Data commons progress as of July 2023. Learn more about these milestones [here](#).

PCDC Data Portal Update

- **New data**
 - St. Jude and COG added 682 neuroblastoma participants. There are now 25,364 INRG participants and 35,158 total participants in the portal.
- **New filters**
 - Additional filters have been added under the Subject category for Data Contributor, Treatment Arm, and Study ID.
 - Filter categories have been added for Surgery, Radiation, Response, and SMN (subsequent malignant neoplasm).

PCDC Advisory Group Update

- The **Scientific Advisory Committee** met in June and discussed strategies to invite more patient and family voices to the PCDC, including the development of a patient advocacy group to be part of our advisory structure.
- A planning workshop was held in June to further detail the charter for the **AYA Research Council (ARC)**.