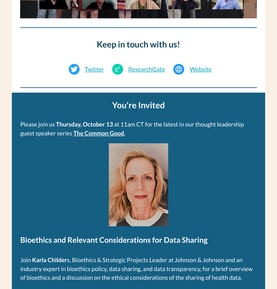
# PEDIATRIC CANCER DATA COMMONS

Welcome to the Pediatric Cancer Data Commons quarterly newsletter! Read on for announcements from PCDC headquarters, updates from our international collaborators, and invitations to upcoming events. Past newsletters are archived on our website. Please don't hesitate to reach out with suggestions and requests!

— The PCDC team



## Keep in touch with us!

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## You're Invited

Please join us **Thursday, October 13** at 11am CT for the latest in our thought leadership guest speaker series **The Common Good**.

### Bioethics and Relevant Considerations for Data Sharing

Join **Karla Childers**, Bioethics & Strategic Projects Leader at Johnson & Johnson and an industry expert in bioethics policy, data sharing, and data transparency, for a brief overview of bioethics and a discussion on the ethical considerations of the sharing of health data.

**Register**

## Announcements

### Neuroblastoma data join the PCDC Data Portal

This September, neuroblastoma data from INRG were integrated into the PCDC Data Portal, joining INSTRuCT rhabdomyosarcoma data. This milestone brings the total number of cases in the portal to 31,651, and marks the first time researchers have been able to use the Commons to perform cohort searches and analyses across multiple cancer types. In addition, INRG joined the ongoing PCDC analytics tool pilot, enabling users to pilot test a Kaplan-Meier survival analysis tool to explore the data.

Anyone may create an account to explore the PCDC Data Portal. Documentation and further details are available on our website.

### New publication on data commons development

The latest PCDC publication is an overview of the genesis, evolution, and progress of INSTRuCT, which aims to foster international research and collaboration focused on pediatric soft tissue sarcoma. Read the paper in *Pediatric Blood & Cancer* here: Creating a data commons: The INternational Soft Tissue Sarcoma ConsorTium (INSTRuCT)

### Building a data commons for monogenic diabetes

The PCDC is applying our approach to data commons development to a new area. Monogenic diabetes is an atypical form of the disease caused by changes to a single gene, representing 1-4% of cases of diabetes in the US. Data-generating research initiatives already exist, but are not coordinated, making this rare disease a strong fit for the PCDC approach to data commons development.

Working closely with the UChicago Kovler Diabetes Center, PREDICT (PREcision Diabetes ConsorTium) will lead the effort to build a commons that will include clinical data, patient-reported outcomes, and data from wearable devices such as continuous glucose monitors. The consortium is currently applying PCDC methods to building data dictionaries and developing governance structures. Any questions may be directed to Michael McCullough.

### PCDC in the media

PCDC Director Sam Volchenboum appeared on WTTW News to discuss the importance of data sharing to President Biden's Cancer Moonshot. Watch here (Sam's interview is about 4 minutes into the video).

Sam was a guest on the Solving Kids' Cancer podcast This Week in Pediatric Oncology, where he discussed progress and challenges around the PCDC and GEARBOx. Listen to the episode here.

In September, Sam joined WGN News along with St. Baldrick's Foundation volunteer event organizer Mary O'Brien to talk about Childhood Cancer Awareness Month and the advances made possible by fundraising efforts like Mary's. Watch the interview here.

Sam also joined the St. Baldrick's Foundation Impact Series to discuss the past, present, and future of the PCDC with St. Baldrick's CEO Kathleen Ruddy. Watch the conversation: How Big Data Fuels Research and Hope for Kids with Cancer.

The PCDC and our work with The Leukemia & Lymphoma Society were featured in an article about University of Chicago Medicine's efforts in fighting pediatric cancer: Comer Children's leads the way for advances in pediatric cancer research.

### Webinar on addressing global disparities in childhood cancer

In July, our webinar series The Common Good featured Carlos Rodriguez-Galindo, Director of St. Jude Global. If you missed Dr. Rodriguez-Galindo's talk, you can watch it here. All the talks in the Common Good series are collected on our website.

### PCDC team updates

The PCDC welcomed two new team members this quarter: **Seong Choi**, a Senior Software Analyst and Data Integration Engineer, and **Sandra Tilmes**, a Health Care Data Scientist who will focus on our work using data commons to study the sociome.

We are currently looking to add a **Senior Front End Developer** to our team! We invite you to share the job posting with your network.

### Meeting highlights

The PCDC was represented at SIOP 2022 in Barcelona, Spain last week. Thanks to all who met with us, checked out our poster, and stopped by our exhibition booth!

Sam Volchenboum spoke at the MIB Agents FACTOR Osteosarcoma Conference as part of the "Big Data and Biobanks" panel. Watch the video here.

The next conference we plan to attend is the ASH Annual Meeting in New Orleans this December. Please reach out if you would like to meet with us there!

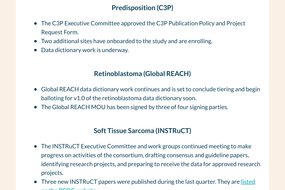
## Scientific Advisory Committee Update

The Scientific Advisory Committee convened in September for a discussion around several current PCDC efforts. Planning for the inaugural meeting of the PCDC External Advisory Board is underway, and SAC members offered insight on top priorities and discussion topics to bring to this new group. We also reviewed the current geographical reach of the PCDC and the array of groups contributing data, with an eye toward opportunities for continued growth. The next SAC meeting is scheduled for December, and we look forward to continuing to keep you informed about our progress.

— SAC co-chairs Jamie Fierlage and Daisuke Tomizawa

## Disease Group Milestones

The PCDC Consortium is currently composed of ten individual disease groups, each in its own stage of development. Stay informed about the accomplishments of each disease group and see what your colleagues across the globe are working on!




*Data commons progress as of October 2022. Learn more about these milestones here.*

### ALL

- Dana-Farber Cancer Institute has signed an agreement with the PCDC to include pediatric ALL clinical trial data.
- We continue to build on international relationships and are beginning to plan a committee with engaged stakeholders.

### AML (INTERACT)

- EuPAL and JCCG have shared clinical trial data, including demographic and disease characteristics, which are currently undergoing quality control. Data harmonization for treatment and molecular data is underway.
- Data harmonization continues with COG and St. Jude.
- We are in the process of expanding to include other data contributors.

### Bone Tumors (HIBiSCus)

- Data harmonization has begun for osteosarcoma data.
- The EWS data dictionary work group has been meeting biweekly and making progress on an international consensus data dictionary for Ewing sarcoma.

### CNS Tumors (INSPIRE)

- INSPIRE is in the process of balloting v1.0 of the INSPIRE data dictionary.
- Talks to execute data contributor agreements are underway.

### Germ Cell Tumors (MaGIC)

- MaGIC has announced a new leadership model which will now include a consortium Chair and three consortium Vice-chairs, representative of the three main areas of expertise within MaGIC. The Vice-chairs have been named as James Nicholson (pediatric oncology), Michelle Lockley (gynecologic oncology), and Aditya Bagrodia (genitourinary oncology).

### Hodgkin Lymphoma (NODAL)

- NODAL held an in-person meeting during the COG Fall meeting in New Orleans. Updates were provided on the HL data dictionary and data contributor data harmonization progress. The group identified potential projects to be pursued when the data are available.

### Neuroblastoma (INRG)

- The INRG Task Force held a virtual meeting to share many exciting recent developments, including updates on data quality, plans to add genomics data, plans to add relapse patient data, activities of the Strategy Development Committee, plans for INRG Risk Classification 2.0, and the new features of the PCDC Data Portal. The meeting was attended by 68 participants from 18 countries.
- There is a new INRG publication: Pattern and predictors of sites of relapse in neuroblastoma: A report from the International Neuroblastoma Risk Group (INRG) project.

### Predisposition (C3P)

- The C3P Executive Committee approved the C3P Publication Policy and Project Request Form.
- Two additional sites have onboarded to the study and are enrolling.
- Data dictionary work is underway.

### Retinoblastoma (Global REACH)

- Global REACH data dictionary work continues and is set to conclude tiering and begin balloting for v1.0 of the retinoblastoma data dictionary soon.
- The Global REACH MOU has been signed by three of four signing parties.

### Soft Tissue Sarcoma (INSTRuCT)

- The INSTRuCT Executive Committee and work groups continued meeting to make progress on activities of the consortium, drafting consensus and guideline papers, identifying research projects, and preparing to receive the data for approved research projects.
- Three new INSTRuCT papers were published during the last quarter. They are listed on the PCDC website.

### Other Groups

- The nasopharyngeal carcinoma (NPC) group reached their first milestone with a hybrid kick-off meeting at SIOP Barcelona on September 30, where they officially began governance and data dictionary discussions.

## Thanks for reading!

We'll be back with another newsletter next quarter. In the meantime, let us know your questions and feedback. We look forward to working together to transform pediatric cancer research!

—The UChicago PCDC Team

We are grateful to our sponsors and donors for making our work possible.