

PEDIATRIC CANCER DATA COMMONS

Welcome to the quarterly newsletter for collaborators, colleagues, and supporters of the [Pediatric Cancer Data Commons \(PCDC\)](#).

If you're new to the PCDC, welcome! This newsletter's purpose is to highlight opportunities to get more involved, make it easier to learn from each other as we work toward common goals, and facilitate cross-disease research collaborations. Past newsletters are [archived on our website](#). Please don't hesitate to [reach out with your suggestions and requests](#).



The UChicago PCDC team and our vision: Connect. Share. Cure.

In this email....

- **Second Annual PCDC Public Webinar:** join us on May 26
- **PCDC Consortium Y3 Work Groups:** contribute your expertise
- **Announcements:** news from PCDC HQ
- **Disease Group Milestones:** updates from researchers around the world

Keep in touch with us!



We hope you'll join us May 26 for our **second annual PCDC Public Webinar: Growing a Data Sharing Community**. We'll share some highlights from the past year and talk about the future growth for which we are planting the seeds today. This webinar is open to all; please feel free to share with anyone you think may be interested! [Register here](#).

Join a PCDC Consortium Work Group

PCDC collaborators, our work groups are seeking your expertise and opinions. All four groups below are open to new membership this year. We're especially looking for representation from **statisticians** and from **researchers outside the United States**. If you are interested in joining a work group or have any questions, please contact [Kat Blumhardt](#).

- **Data Dictionary:** Build and maintain the data dictionary for common core elements for pediatric oncology clinical trials.
- **Governance:** Develop, document, and execute consensus on governance structure, policies, and procedures.
- **Data Analytics:** Develop an integrated platform for cross-disease cohort discovery and analytics.
- **Engagement:** Advise on outreach and engagement strategies and activities.

Announcements

PCDC continues to grow

The PCDC's scope has now expanded to ten disease groups with the inclusion of retinoblastoma, supported by a gift from the [Children's Cancer Research Fund](#). Two other disease groups officially launched their consortia this quarter, with the signing of Memoranda of Understanding to create NODAL (Hodgkin lymphoma) on February 24 and INTERACT (AML) on March 1.

Sam Volchenbom to co-chair new CCDI Coordination Center

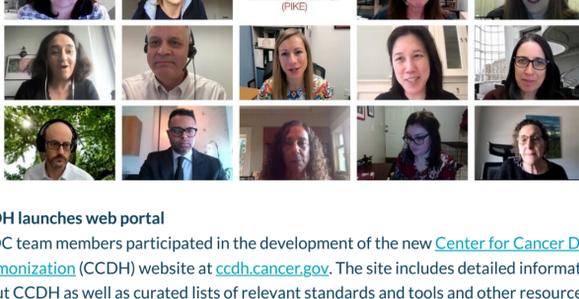
Leveraging his expertise in data sharing from leading the PCDC, our director [Sam Volchenbom](#) will co-chair a new NCI [Childhood Cancer Data Initiative](#) (CCDI) committee tasked with developing guidelines and approaches to address cross-cutting needs and align priorities across CCDI working groups.

New interview in CRAACO newsletter

The most recent issue of the Clinical Research as a Care Option (CRAACO) newsletter includes an interview with Sam Volchenbom about our approach to data standards and our plans for the future. Find "[How a Pediatric Oncologist is Tackling Data Standardization as a Grassroots Phenomenon](#)" on page 16.

PCDC groups meet to share their insights

The first PCDC Progress, Insights, and Knowledge Exchange (PIKE) was held in February to allow representatives across all PCDC disease groups to meet and learn from one another. Each group presented a report on their progress thus far and a discussion was held to begin the process of standing up a Scientific Advisory Committee.



CCDH launches web portal

PCDC team members participated in the development of the new [Center for Cancer Data Harmonization](#) (CCDH) website at [ccd.h.cancer.gov](#). The site includes detailed information about CCDH as well as curated lists of relevant standards and tools and other resources to support data harmonization, aggregation, and modeling.

Interview with Sam Volchenbom on pediatric cancer podcast

Sam was interviewed alongside Ruby Kaufman and her family, whose work with the Rally Foundation for Childhood Cancer Research raised the initial seed funding for INSTRuCT after Ruby was diagnosed with rhabdomyosarcoma in 2015, on the "Help and Hope Happen Here" podcast. [Listen to the interview here](#).

PCDC team updates

This quarter we welcomed two new members to our UChicago team. **Kelvin Zuccaro** started in January as Consortia Coordinator, focusing on our work to integrate retinoblastoma and CNS tumors into the PCDC. **Debra Venckus** joined us in March as a Full Stack Developer focusing on the CCDH project. We're also happy to share that PCDC gap year alum **Nicole Dussault** will begin her residency in internal medicine at Duke University this fall.

We're hiring!

We're currently looking to fill the following roles at the PCDC. Please share these job postings with your network!

- [Senior Clinical Data Standards Analyst](#)
- [Semantic Engineer](#)

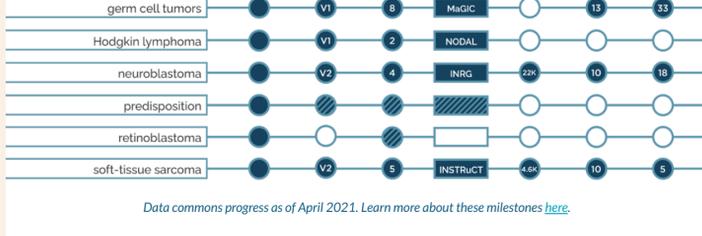
Meeting highlights

The PCDC highlighted in several online conferences this quarter. Highlights included:

- Our team presented an [initial demo of our new Gen3 portal](#), a work in progress, at AMIA in March. A full launch is planned for later this year.
- Our abstract titled "The INRG visualization and analytics platform" was included in the ANR virtual meeting in January ([page 630 of this PDF](#)).

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 April 2021. Learn more about these milestones [here](#).

ALL

- Work is underway to prioritize data to ingest once the COG DCA is signed.
- Meetings are ongoing with other US-based groups to gauge interest and inform about our work.

AML (INTERACT)

- The INTERACT MOU was signed by representatives from JCCG, COG, St. Jude, and EuPAL on March 1.
- All cooperative groups are actively working on data contributor agreements.
- A demo of the GEARBOX matching tool was presented at COG.

Bone Tumors (HIBISCus)

- The Executive Committee is adding additional representatives and working to refine the MOU with a goal to sign in April.

CNS Tumors

- The group has established consensus to proceed with one unified consortium for CNS tumors.
- An MOU and consortium naming are in progress.

Germ Cell Tumors (MaGIC)

- Consortium vice-chair James Nicholson will deliver one of the keynote lectures at [SIOP 2021](#): "Germ Cell Tumours: What we have learned from MaGIC and how this model of collaboration can apply to other cancers"

Hodgkin Lymphoma (NODAL)

- The NODAL MOU was signed by representatives from COG and St. Jude on February 24.
- Planning meetings are underway to address data preparation and establish work groups to identify and address clinical questions.

Neuroblastoma (INRG)

- The INRG Task Force convened to share recent developments.
- The Strategy Development Committee and Genomics Committee met to advance their respective missions.

Retinoblastoma

- Initial planning meetings have convened stakeholders from North America, South America, Central America, and Europe to identify collaborators and data contributors.
- Data dictionary work is anticipated to begin in April.

Predisposition

- The PCDC has established a partnership with C3P to work together on data harmonization, governance, and infrastructure for predisposition data.

Soft Tissue Sarcoma (INSTRuCT)

- The Executive Committee and clinical discipline work groups continue to meet and advance INSTRuCT initiatives.
- Planning is underway for the INSTRuCT Spring Meeting.

In the interest of keeping this newsletter succinct, we will no longer be including updates on our Center for Cancer Data Harmonization (CCDH) work here. If you'd like to follow along with our progress, we invite you to visit the new Portfolio section of the [PCDC website](#), as well as the newly-launched [CCDH website](#).

—The UChicago PCDC Team