

PEDIATRIC CANCER DATA COMMONS

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

As the COVID-19 global pandemic has changed life as we know it, we've been adapting our work in pediatric oncology research to continue as smoothly as possible through all the challenges that face us. Many of our collaborators are currently hard at work in hospitals contributing their skills to respond to the crisis, and plans for the rest of the year continue to shift as the situation evolves. This past quarter, the PCDC Consortium made the most of online and phone alternatives to planned face-to-face meetings. We are grateful for the flexibility and engagement of all our collaborators as we continue to make progress together.

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. This is our second newsletter; if you missed the first one, [we're archiving them on our website here](#).

Your work makes the PCDC possible! Please don't hesitate to [reach out with your suggestions and requests](#).



(Our team photo looks a little different this quarter as we work remotely!)

In this email....

- **Announcements:** news from PCDC HQ
- **Let's Meet Up (Virtually):** ways to get involved
- **Disease Group Milestones:** what researchers around the world have been up to
- **CCDH Update:** our progress on a national cancer research effort

Keep in touch with us!



Announcements

New data commons publication in *Seminars in Oncology*

In a new publication in *Seminars in Oncology*, PCDC Director Sam Volchenbom and coauthors Ajay Major, MD, MBA, and Suzanne Cox, PhD, MPH, discuss the uses of big data in pediatric cancer, existing pediatric cancer registry initiatives and research, the challenges in harmonizing data to improve accessibility for study, and the future opportunities for innovation in this area. Read the paper: [Using big data in pediatric oncology: Current applications and future directions](#)

INSTRuCT cohort discovery tool now available

INSTRuCT have launched their cohort discovery tool, enabling researchers to query and explore the clinical data for rhabdomyosarcoma data in the INSTRuCT Data Commons.

[Register an account and sign in to use the tool here.](#)

We're hiring!

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

- [Full Stack Developer](#) (two positions)
- [Technical Project Manager](#)

Meeting Highlight: PCDC Consortium Leadership Meeting, March 17

[PCDC Consortium](#) leadership adapted to the cancellation of the in-person Children's Oncology Group Spring Meeting by coming together virtually to discuss progress to date and the 2020-2021 work plan to continue bringing together seven pediatric cancer data commons. The two-hour online workshop was attended by 27 individuals including disease group leadership, work group members, and the UChicago PCDC team.

Meeting Highlight: PCDC/DIPG Workshop, March 2

Maryam Fouladi and her [International Diffuse Intrinsic Pontine Glioma \(DIPG\)/Diffuse Midline Glioma \(DMG\) Registry and Repository](#) team hosted members of the PCDC team for a day-long workshop in Cincinnati. The PCDC and DIPG teams shared lessons learned and progress in international data collection and collaboration, and discussed avenues for future interoperability of data systems.



Let's Meet Up (Virtually)

With spring conferences being moved online and/or postponed, we're currently in the process of scheduling our data commons-related meetings to occur virtually when possible. Please stay tuned for updated meeting information. We look forward to connecting with you!

Other ways to get involved with the PCDC online:

- [Register an account on the INRG Data Commons](#)
- [Register an account on the INSTRuCT Data Commons](#)
- [Read about the latest research using INRG data](#)
- [Follow us on ResearchGate](#)

Disease Group Milestones

The PCDC Consortium is currently composed of seven 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!

ALL

- Data dictionary work has begun, with collaborators meeting twice a month to determine consensus data elements.

AML

- COG and BFM statisticians are reviewing the data dictionary to compile questions for PCDC team.
- Plans are underway to begin data harmonization efforts this spring.

Bone Tumors

- The Ewing sarcoma data dictionary is in the final review phase for the US portion.

Germ Cell Tumors (MaGIC)

- An updated Memorandum of Understanding and data contributor agreements are in circulation with the leaders of MaGIC's cooperative groups.

Lymphoma

- Work continues on the first version of the HL data dictionary based on North American studies.

Neuroblastoma (INRG)

- Cooperative groups will be sending updates and new data in the coming weeks.

Soft Tissue Sarcoma (INSTRuCT)

- The Imaging Work Group had its first conference call.
- The RMS v2.0 data dictionary and the NRSTS data dictionary are in final review by the INSTRuCT Executive Committee.

Other Groups

- PCDC team and CNS stakeholders from multiple institutions met to determine priorities and create a work plan to include CNS cancers in the PCDC.

CCDH Update

The PCDC team co-leads two [Center for Cancer Data Harmonization \(CCDH\)](#) workstreams.

Community Development Workstream: The PCDC team is working with CCDH leadership and project managers on the content and design for the CCDH website, which will provide information, resources, and support for cancer data nodes and researchers.

Data Model Harmonization Workstream: The team has documented and aligned data dictionaries for the Genomic Data Commons, Proteomic Data Commons, and Integrated Canine Data Commons and created an Aggregated Data Model (ADM). Work is currently being done to map the ADM to BRIDG.

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