

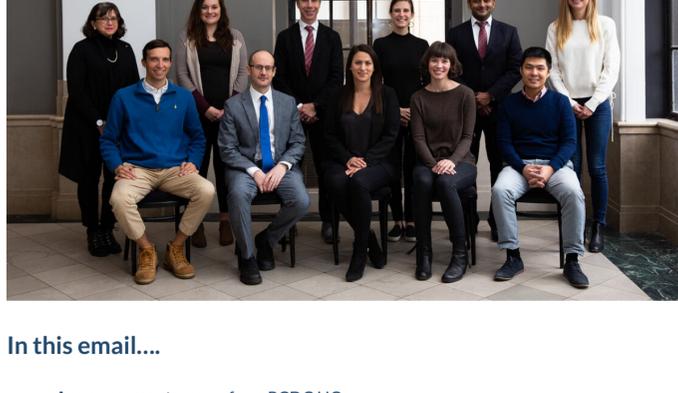
PEDIATRIC CANCER DATA COMMONS

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

In 2019, the PCDC grew from three separate disease-specific commons towards a united PCDC Consortium that now includes seven disease areas, with the potential for more to join. Our goal at PCDC headquarters is to **serve as a hub** connecting researchers across pediatric cancer specialties.

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.

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



In this email....

- **Announcements:** news from PCDC HQ
- **Let's Meet Up:** noteworthy upcoming meetings
- **Disease Group Milestones:** what researchers around the world have been up to
- **CCDH Update:** our progress on a new national cancer research effort

Keep in touch with us!



Announcements

PCDC leading national cancer data harmonization effort

[PCDC staff have begun work](#) on the National Cancer Institute-funded [Center for Cancer Data Harmonization \(CCDH\)](#) as part of a multi-disciplinary team of experts in cancer, data standards, and technology spanning five partner institutions. [Learn more about CCDH and our role here](#). This newsletter will include a brief quarterly progress update.

INSTRuCT highlighted at Rally Foundation Gala

[Rally Foundation for Childhood Cancer Research's](#) High Risk High Reward Grant provided the funding that enabled us to create INSTRuCT. Sam recently spoke about the impact of this work on rhabdomyosarcoma research at a Rally gala. [Watch the video on Rally's blog](#).

PCDC collaborates with NCI to improve data thesaurus

The PCDC's clinical data standards team is collaborating with the National Cancer Institute (NCI) to ensure the consistent application of terms and codes represented in their data thesaurus, known as NCIt. This partnership allows the PCDC to benefit from the use of NCIt terms in our data dictionaries while also improving NCIt by acting as a standards authority and contributing any missing terms related to pediatric cancer.

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!

- [Clinical Data Standards Analyst](#)
- [Front-End Web Developer](#)
- [Technical Project Manager](#)

CCDI working group taps PCDC expertise

The [Childhood Cancer Data Initiative \(CCDI\)](#) is a national effort to establish more efficient ways to share and use childhood cancer data for research and the development of new therapies. The NCI Board of Scientific Advisors Working Group of experts selected to advise on the development and implementation of the CCDI includes our director, Sam Volchenbom. His service on this group leverages our experience building the PCDC to help this NCI initiative succeed.

Meeting Highlight: International Society of Paediatric Oncology (SIOP) 51st Congress, Lyon, France - October 22-25, 2019

At this meeting, we held the inaugural PCDC All-Commons Workshop. Forty participants came together to discuss a potential vision for combining data into a multi-disease commons ([executive summary available here](#)). We also presented a [poster about PedAL](#) and participated in INSTRuCT workshops to agree on a non-rhabdomyosarcoma data dictionary and review recent work from breakout workgroups.



Let's Meet Up

Here's where our team will be in the next few months. Disease groups listed under each conference are tentatively planning meetings.

March 17-20

Children's Oncology Group (COG) Spring Meeting
Chicago, USA

PCDC Meeting: March 17, 2-5pm
Tentative group meetings: HL

May 2-9

International Society of Paediatric Oncology (SIOP/E)
Valencia, Spain

Tentative group meetings: AML, PCDC-Wide, Young Investigators

May 9-12

Advances in Neuroblastoma Research (ANR)
Amsterdam, The Netherlands

Tentative group meetings: INRG

May 12-14

4th International Symposium on Childhood, Adolescent and Young Adult Hodgkin Lymphoma (ISCAYAHL)

Berlin, Germany

Tentative group meetings: HL

May 29-June 2

American Society of Clinical Oncology (ASCO) Annual Meeting
Chicago, USA

Tentative group meetings: INSTRuCT, AML, SBF Consortium

Can't make it to a meeting? Get involved with the PCDC online:

- [Register an account on the INRG 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!

Neuroblastoma (INRG)

- HR prognostic biomarkers project meeting was held at SIOP19 in Lyon.
- The INRG Genomics Committee had its first meeting.

Lymphoma

- A data dictionary was started using CRFs from COG and St. Jude. Data elements were assigned to work groups by topic, which is a new approach for the PCDC.

Germ Cell Tumors (MaGIC)

- Data contributor agreements are in progress, with approval already received by the Brazilian research group.

ALL

- US disease group representatives were identified and convened via teleconference to discuss preliminary plans.

Other Groups

- Initial meetings have been held with retinoblastoma and brain tumors researchers to assess data availability, funding resources, and timelines.

Soft Tissue Sarcoma (INSTRuCT)

- The Executive Committee met in London on December 5, focused on governance.

Bone Tumors

- Ewing sarcoma data dictionary work continues with US physicians and will expand to include the international group this year.
- Review of the osteosarcoma data dictionary will begin soon.

AML

- A second AML data dictionary line-by-line review with a wider audience of US and EU collaborators took place in Orlando coinciding with the ASH conference. The AML data dictionary version 1 is now complete.
- PCDC is working with leaders at Hematologies to gather specifications and draft a data contributor agreement for flow cytometry data. Flow cytometry variables have been added to the AML data dictionary.

CCDH Update



The [Center for Cancer Data Harmonization \(CCDH\)](#) project launched in October 2019 and held its second in-person workshop December 12-13 in Corvallis, Oregon.

An initial six-month planning phase is ongoing through March 2020. For the workstreams co-led by our PCDC team, this time is an information-gathering period focused on understanding the current state of the cancer data ecosystem and identifying opportunities for improvement as the Center is created.

Community Development Workstream: A first round of interviews with CCDH nodes has been completed with Data Commons Framework (DCF), Human Tumor Atlas Network (HTAN), Integrated Canine Data Commons (ICDC), Imaging Data Commons (IDC), Genomic Data Commons (GDC), and Proteomics Data Commons (PDC).

Data Model Harmonization Workstream: Efforts have been focused on close review of the following Cancer Research Data Commons (CRDC) node data models: GDC, PDC, and ICDC. This work will result in consistently formatted data model artifacts for the CRDC nodes that will facilitate production of the harmonized CRDC-H model, a key deliverable for the first phase of the CCDH contract.

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.

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