

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



PCDC team members and collaborators at a summer event

Keep in touch with us!



You're Invited

Please join us **Thursday, July 21** at 11am CT for [The Common Good](#), a quarterly series of thought leadership talks hosted by the PCDC.



Addressing Global Disparities in Childhood Cancer: Now Is the Time

Join **Carlos Rodriguez-Galindo, MD**, director of St. Jude Global and chair of the Department of Global Pediatric Medicine. Dr. Rodriguez-Galindo will review the current estimates of the global burden of childhood cancer and disparities in access to quality care, and will discuss current initiatives to address them.

[Register](#)

Announcements

Pilot launch of survival analysis tools in PCDC data portal

In June, we added to the functionality of the [PCDC Data Portal](#) by introducing self-service survival analysis tools. The pilot launch of these tools represents the culmination of more than a year of discussions with PCDC collaborators and advisors, to whom we send our thanks. This pilot phase will be used to gather information on the usability and risks of the new tools.

All PCDC users are invited to participate in the pilot by using the new tools and providing feedback. You can create an account and explore the portal at [portal.pedscommons.org](#). Further information and documentation, including tutorial videos, are available [on our website](#).

Launch of GEARBOX clinical trials matching tool

As part of [The Leukemia & Lymphoma Society \(LLS\)](#) PedAL Master Clinical Trial, we are excited to have launched a clinical trials matching tool for clinicians to rapidly and accurately match children with relapsed acute myeloid leukemia to targeted treatments in North America. GEARBOX (Genomic Eligibility Algorithm at Relapse for Better Outcomes) is a web-based tool that uses a matching algorithm to identify potentially appropriate clinical trials based on COG eligibility criteria and the patient's clinical data, immunophenotype, and genomic profile. GEARBOX is accessible at [gearbox.pedscommons.org](#). Learn more about the LLS Dare to Dream Project, of which PedAL is a central part, [here](#).

The PCDC's partnership with LLS was recently highlighted in an interview with LLS Chief Medical Officer Dr. Gwen Nichols on Fox 32 Chicago. [You can watch the interview here](#).

PCDC public webinar video and materials

In May, we held our third annual PCDC public webinar, titled *Connect, Share, Discover: How Democratizing Data is Changing Research*. Featuring guest speakers, updates from the past year, and previews of new tools and projects, the video recording and slides from the webinar can be viewed [on our website](#).

Webinar on large-scale resources to accelerate pediatric cancer research

In April, our webinar series *The Common Good* featured Dr. Adam Resnick, Director of the Center for Data Driven Discovery in Biomedicine at Children's Hospital of Philadelphia and Principal Investigator of the Gabriella Miller Kids First Data Resource Center. If you missed Dr. Resnick's talk, [you can watch it here](#). All the talks in the *Common Good* series are collected [on our website](#).

PCDC team updates

This quarter we welcomed **Nicholas Ferraz** to the PCDC team as a Full Stack Developer. We are also excited to be working with a great group of student interns this summer: **Loreen Tume** is working with our data standards team; **Paul Murdoch**, **Will Andersen**, and **Mihir Putcha** with our technology team; and **Carlie Parpart** with our project management team.



Meeting highlights

In June we held PCDC Live!, an in-person event for our collaborators to meet in Chicago. Guest speakers included Dr. Richard Schilsky, Dr. Jamie Flerlage, Dr. Andy Kolb, and Dr. Julie Park.

PCDC Director Dr. Sam Volchenboum presented a talk about our work for the COG Annual Spring Meeting in April. [Watch the video here](#).

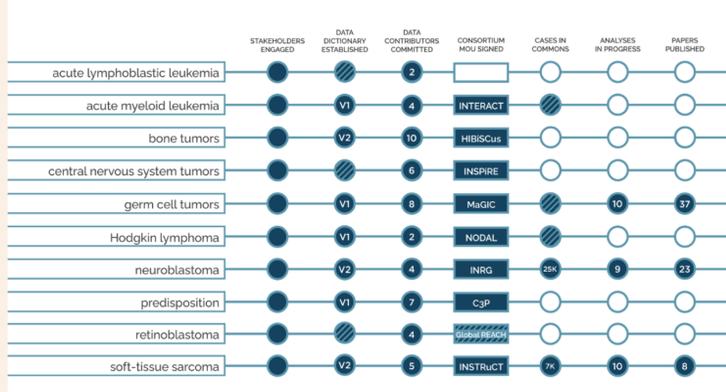
Scientific Advisory Committee Update

The Scientific Advisory Committee convened in June to discuss several topics important to the PCDC. We were pleased to welcome our first patient advocate to the SAC at this meeting. The committee discussed and shared feedback on the minimum sample size reporting threshold for the PCDC data portal, reviewed the planned membership for the External Advisory Board, and briefly discussed upcoming tools to be added to the PCDC data portal. The next SAC meeting is scheduled for September, and we look forward to continuing to keep you informed about our progress in future newsletters.

— SAC co-chairs: Jamie Flerlage 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 July 2022. [Learn more about these milestones here](#).

ALL

- The ALL data dictionary is in progress and harmonization has begun with current data contributors.
- Work to formalize an ALL consortium continues with other data contributors across the US and globally.

AML (INTERACT)

- Harmonized data sets from EuPAL are currently undergoing quality control by our data specialists.
- A DCA has been executed with St. Jude to contribute data to INTERACT.
- We continue to work with other data contributors to harmonize data sets.

Bone Tumors (HIBISCUS)

- Grupo Latinoamericano Oncología Pediátrica (GALOP) has joined HIBISCUS as a new data contributor and consortium member.
- The OS V2 data dictionary is complete and data harmonization will begin soon.
- The EWS international data dictionary group will begin meeting in July.

CNS Tumors (INSPIRE)

- A DCA with Pacific Pediatric Neuro-Oncology (PNOC) has been executed.
- Governance work continues with drafting of the publication policy and project request forms.
- Data dictionary work also continues with a balloting process expected to occur soon for the embryonal section of the CNS data dictionary.

Germ Cell Tumors (MaGIC)

- After three very long years, MaGIC recently held a successful in-person Annual Meeting hosted by Deb Billmire at Indiana University.

Hodgkin Lymphoma (NODAL)

- The NODAL Executive Committee approved the publication policy and project request form, which are [available on the PCDC website](#).
- A DCA has been executed with St. Jude to contribute data to NODAL.
- COG and St. Jude are harmonizing data to contribute to the PCDC.
- The NODAL Executive Committee continues to meet and plan the analyses and work to come.

Neuroblastoma (INRG)

- The INRG is working with the PCDC data standards team to expand the INRG data dictionary to include molecular, response, and relapse data.
- A DCA has been executed with St. Jude to contribute data to INRG.
- The INRG Strategy Development Committee continues to look for opportunities for early career investigators.
- The INRG Executive Committee is planning a virtual INRG Task Force meeting for September to review the advances in INRG over the past year.

Predisposition (C3P)

- This study protocol is currently active at five sites with two additional sites pending activation.
- The PCDC data standards team and C3P leadership met to discuss how to effectively integrate elements into the PCDC data model.

Retinoblastoma (Global REACH)

- Retinoblastoma data dictionary work continues.
- Governance and policy drafting work also continue as we anticipate a Global REACH MOU signing soon.
- As Global REACH work continues to gain traction, consortium members have shared information about Global REACH and the PCDC at retinoblastoma conferences.

Soft Tissue Sarcoma (INSTRuCT)

- Achieving a vision crafted in 2017, the INSTRuCT data set was updated to a total of 6,969 RMS participants from COG, CWS, EpSSG, and MMT.
- The INSTRuCT Executive Committee is happy to have the RMS data available for use with the new PCDC Data Portal survival analysis tools and to participate in the pilot.
- The INSTRuCT Executive Committee welcomed all INSTRuCT participants to the in-person and virtual meeting during which accomplishments and activities were reported and six approved projects were presented by their principal investigators.

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