

# PEDIATRIC CANCER DATA COMMONS

Happy 2023 and welcome to the [Pediatric Cancer Data Commons](#) quarterly newsletter! Read on for announcements from PCDC headquarters and updates from our international collaborators. Past newsletters are [archived on our website](#). Please don't hesitate to [reach out with suggestions and requests!](#)

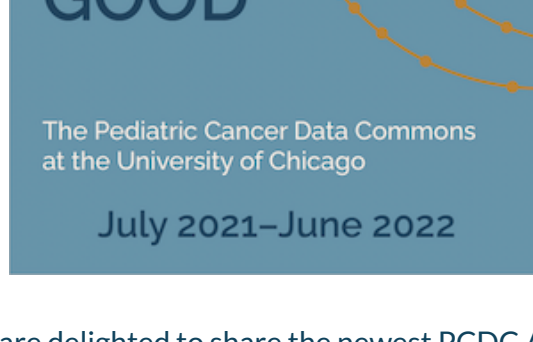
— The PCDC team



## Keep in touch with us!



## 2021-22 Annual Report



In case you missed it, we are delighted to share the newest PCDC Annual Report, which illustrates our progress over the period of July 2021–June 2022.

[Browse the report online or download a PDF copy here.](#)

## Announcements

### PCDC to integrate nasopharyngeal carcinoma

The PCDC continues to expand with the recent addition of a group focused on nasopharyngeal carcinoma (NPC). This group will bring together data for the Commons from a diverse and potentially growing list of countries, including Austria, Australia, Canada, France, Germany, India, Israel, Italy, Switzerland, Turkey, and the United States.

The PCDC NPC group gathered interested stakeholders at their hybrid kickoff meeting during the SIOPE conference in September. The new group has already made significant progress thanks to their dedicated members: a first version of an NPC data dictionary is in draft, and governance discussions are underway.

### New publication highlights MaGIC-PCDC partnership

A new publication from the Malignant Germ Cell International Consortium (MaGIC) in the British Journal of Cancer discusses ways to advance research in germ cell tumors. Among other recommendations, the paper highlights MaGIC's successful partnership with the PCDC and the importance of the standardized data model we have developed together. Read the paper here: [Advancing clinical and translational research in germ cell tumours \(GCT\): recommendations from the Malignant Germ Cell International Consortium](#)

### PCDC launches External Advisory Board

This November marked the inaugural meeting of the PCDC External Advisory Board (EAB). This group of clinical, data science, and digital health experts has been convened to share their unique experience and offer high-level strategic advice on our initiatives. At their first meeting, the EAB self-selected co-chairs Parker Moss (United Kingdom) and Sam Blackman (United States). Sam Volchenbom gave a brief overview of the PCDC's current portfolio and the group discussed future areas of opportunity. [Meet all the members of the EAB here.](#)

### New funding to expand GEARBOX

The PCDC has received a U01 grant from the National Institutes of Health to expand [GEARBOX](#), the decision support tool we developed with The Leukemia & Lymphoma Society (LLS) to help match patients with relapsed and refractory AML to clinical trials. This new funding, along with a grant from the Fund for Innovation in Cancer Informatics and our initial support from LLS, will enable us to extend this matching tool to be used for additional types of cancer. Our efforts are beginning with extending GEARBOX to ALL, with future plans to include neuroblastoma, rhabdomyosarcoma, Ewing sarcoma, and osteosarcoma.

### Interview with Sam Volchenbom on OsteoBites podcast

In October, Sam was a guest on the MIB Agents podcast OsteoBites to discuss the process of building a data commons and lessons learned along the way. [Listen to the episode here.](#)

### PCDC team updates

This quarter, the PCDC team welcomed our new Senior Front End Developer, **Tianyun Zhang**.

We are currently looking to add a **Healthcare Data Standards Analyst** to our team! We invite you to share [the job posting](#) with your network.

### Meeting highlight: ASH

PCDC team members traveled to New Orleans in December to participate in meetings during the American Society of Hematology conference. Sam Volchenbom presented on our progress developing [GEARBOX](#) with The Leukemia & Lymphoma Society. We also had the opportunity to discuss potential collaborations with groups focused on ALL, AML, and other blood cancers.



Pictured with Sam are our PCDC Scientific Advisory Committee co-chairs, Jamie Flerlage and Daisuke Tomizawa.

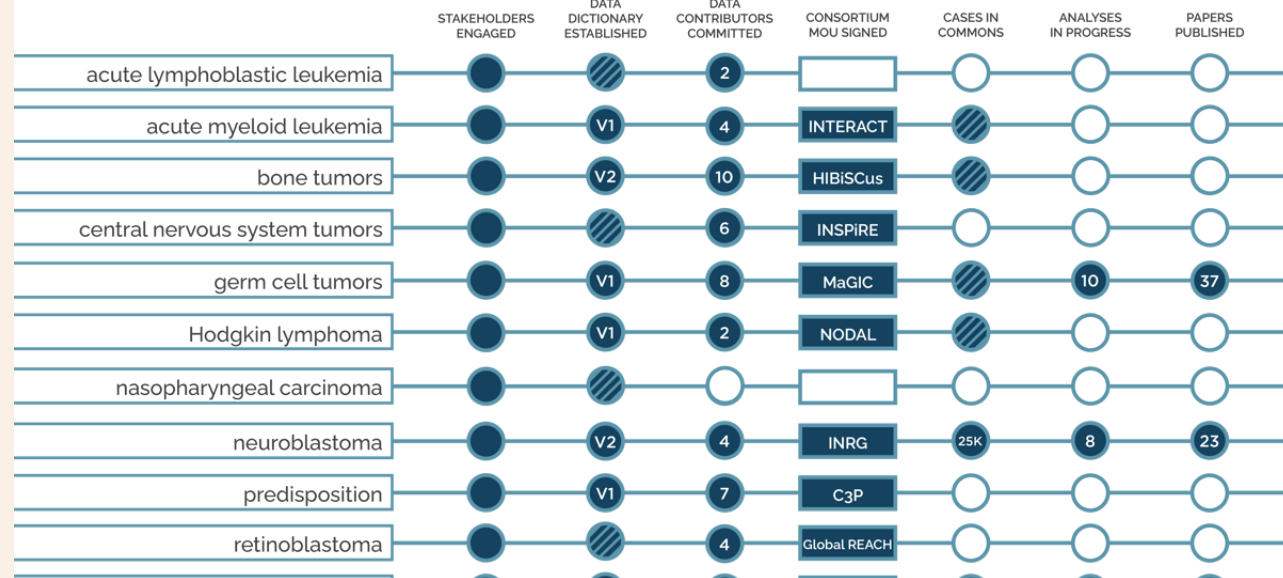
## Scientific Advisory Committee Update

With our meeting in December, the [Scientific Advisory Committee](#) began its second year of advising on PCDC initiatives. We heard about recent PCDC activities, including the launch of the External Advisory Board and usage of the PCDC Data Portal. SAC members provided their insight on several important discussion topics, including metrics to evaluate the PCDC's success and impact over time, opportunities for expansion into more parts of the world, and ways to increase the involvement of parent, family, and patient advocates in the PCDC's work. We look forward to meeting again in March and keeping you updated on our progress.

— SAC co-chairs Jamie Flerlage and Daisuke Tomizawa

## Disease Group Milestones

The PCDC Consortium is currently composed of eleven 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 January 2023. Learn more about these milestones [here](#).

### ALL

- The ALL group has formed a planning committee including international experts to address rare subtypes for ALL.

### AML (INTERACT)

- Data have been received from EuPAL and JCCG, and will be received from COG in January.
- The INTERACT is excited to add AYA data and has begun the governance process for including AYA groups.

### Bone Tumors (HIBISCUS)

- EWS data dictionary progress continues.
- The HIBISCUS Executive Committee is working to set annual goals for 2023.

### CNS Tumors (INSPIRE)

- Balloting of v1.0 of the CNS tumors data dictionary continues.
- Data contributor agreements are in progress.

### Germ Cell Tumors (MaGIC)

- MaGIC has launched a newsletter and released their first issue.

### Hodgkin Lymphoma (NODAL)

- NODAL held an in-person meeting during ASH in New Orleans.
- Work continues to harmonize data from COG and St. Jude.

### Nasopharyngeal Carcinoma

- The NPC group's governance discussions are underway; drafting of an Executive Committee structure is in progress.
- Data dictionary work is in progress.

### Neuroblastoma (INRG)

- An in-person meeting of the INRG Task Force is being planned for May 14, preceding the ANR meeting in Amsterdam.
- Work continues to expand the neuroblastoma data dictionary to include more genomic, relapse, and response data.

### Predisposition (C3P)

- The [C3P homepage](#) is now live on the PCDC website.
- Data dictionary work is ongoing.
- The C3P agreement is executed to allow data into the Commons.

### Retinoblastoma (Global REACH)

- The Global REACH Memorandum of Understanding has been signed and executed by all four signing parties: COG, EURbG, GALOP, and IRbC.
- The group is in the process of selecting co-chairs.
- Data dictionary work continues, nearing finalization of v1.0 of the RB data dictionary.

### Soft Tissue Sarcoma (INSTRuCT)

- INSTRuCT held a hybrid meeting with participants in Rome and via Zoom. The meeting was attended by 90 researchers from 11 countries, including 49 who attended in person.
- Work continues to quality assurance review the NRSTS data, and it will soon be added to the PCDC Data Portal.

### Other Groups

- Discussions to initiate bringing oncofertility data to the PCDC are now in progress.

## 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