

Connect.

Share.

Cure.

The Pediatric Cancer Data Commons  
at the University of Chicago

2019-2020

# 2019-2020

The past year has presented unforeseen challenges around the world. Yet despite significant interruptions to typical workflows and methods of collaborating, July 2019 through June 2020 has been a year of immense progress for the Pediatric Cancer Data Commons.

We've continued to integrate new pediatric cancer types into our work, which now includes seven kinds of cancer. We've streamlined our processes, preparing to add more in 2020. Together with our international collaborators, we've spent hundreds of hours establishing the consensus data dictionaries and governance processes and procedures that make it possible to collect, harmonize, and share data—critical to our central mission. We are now establishing the PCDC Consortium, which will bring all our different disease-specific groups together to enable cross-disease research and collaboration.

All this behind-the-scenes work has led to meaningful scientific progress. Our established data commons facilitated new publications with clinical impact, and we shared our vision with the world through presentations and papers about our methods and our first international public webinar. Support for a commons-based approach to cancer research is taking hold in the scientific community, and we are now leveraging our expertise in data standards and community-building for the National Cancer Institute's nationwide virtual cancer data infrastructure initiative.

None of the progress detailed here would be possible without you—our collaborators, funders, and supporters. Thank you for joining us as we break down barriers to progress and work together toward a new paradigm for pediatric cancer research.



Sam Volchenboum, MD, PhD

**PEDIATRIC CANCER**  
  
**DATA COMMONS**

# 2019-2020

## by the numbers

### Engagement

7 pediatric cancer disease groups



...with more in progress

1 cross-disease PCDC Consortium

11 disease group workshops

3 cross-disease meetings

### Consensus-building and governance

215 hours of work group discussion across 25 work groups

- 121 hours developing data dictionaries
- 50 hours of strategic planning
- 24 hours discussing governance
- 20 hours of pediatric sub-specialty discussion

### The data

4 disease-specific data dictionaries  
3 more in progress



1 draft cross-disease data dictionary

25,535 cases in the INSTRuCT and INRG data commons



2 data updates incorporated this year

### Research impact

199 active users of INRG and INSTRuCT cohort tools



7 datasets released to researchers

8 new publications



5 posters and presentations



### Support and sustainability

16 funding proposals submitted



7 awarded  
2 awaiting response



12 current sources of financial support

- 52.8% contracts
- 36.7% grants
- 10.5% gifts

# Connect.

Connecting data means **connecting people**. We harness the expertise and experience of a growing network of pediatric cancer researchers from all over the world.

# Share.

Driven by a spirit of **collaboration and consensus**, our work makes it possible to share previously siloed, now interoperable cancer data across research groups, institutions, and borders.

# Cure.

High-quality, accessible data drives discovery. Our ultimate goal is **changing the research paradigm** to better help scientists study, prevent, treat, and cure pediatric cancer.

## Our values

### Collaboration

Big data research in rare diseases is only possible when we work together. The PCDC is founded on productive, inclusive partnerships with researchers and organizations around the world.

### Consensus

We believe that transparent, consensus-based decision-making is the key to bringing international stakeholders together in an atmosphere of trust and collaboration to get things done.

### Diligence

From the technical detail of building strong infrastructure and flexible data dictionaries to the fine print of international legal agreements, we approach our work as stewards of data with dedication and integrity.

### Adaptability

The pediatric cancer research landscape is ever-evolving. We're committed to evolving along with it, responding to new opportunities and challenges nimbly and creatively.

### Empowerment

Our work drives discovery by empowering scientists to think bigger as they conduct new research, using data that might otherwise have sat siloed and unused to instead transform the future.

# How do you build a data commons?

Launched in 2014, the INRG Data Commons laid the groundwork for building a disease-specific pediatric cancer data commons. Since the launch of the INSTRuCT Data Commons in 2018, we have streamlined and scaled our processes for creating new commons, leading to a major expansion of our efforts.



## Stakeholders Engaged

The PCDC partners with a pre-established pediatric cancer consortium or works with leaders to identify cooperative research groups and other stakeholders who will form a consortium to guide commons development.



## Data Dictionary Established

The PCDC data standards team leads an international group of clinicians, researchers, and statisticians to develop and ballot the consensus data dictionary by which all data in the commons will be standardized.



## Data Contributors Committed

Data in the commons are contributed by participating cooperative groups that have collected clinical trials data according to standardized protocols. Each group signs a Data Contributor Agreement.



## Consortium MOU Signed

A Memorandum of Understanding is signed by all parties to form the consortium and create an executive committee responsible for strategic planning and approvals. Operating procedures and work groups are established.



## Cases in Commons

Participating cooperative groups contribute mapped and harmonized data from their closed clinical trials. After quality checks, the data are ingested into the commons, where users can explore available data with a cohort discovery tool.



## Analyses in Progress

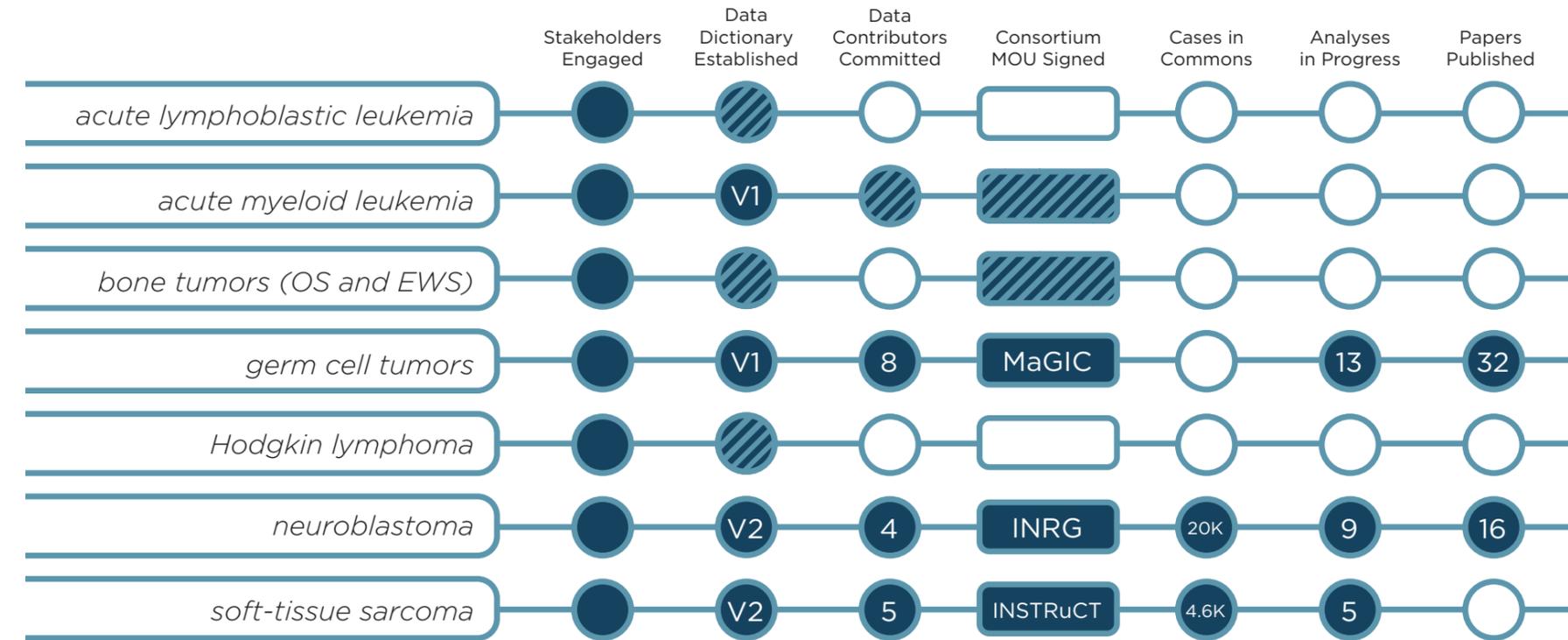
Researchers request data by submitting a project proposal. After approval by the consortium executive committee and execution of a Data Use Agreement, the relevant dataset is securely provided to the researcher.



## Papers Published

Investigators publish and present their discoveries, leveraging data that might otherwise have sat siloed and unused to instead enable better understanding of childhood malignancies and improved outcomes for children with cancer.

## Our progress so far



# Connecting researchers

A primary goal of the PCDC is to serve as a hub for researchers across pediatric cancer specialties, connecting young investigators with seasoned researchers, clinicians with data scientists, and trainees with mentors. Ultimately, we aim to create opportunities for investigators to work together across geographic and disease specialty boundaries—enabling cross-disease research, minimizing duplicated efforts, and building an active network of pediatric cancer scientists all over the world.

## Thoughts from a Young Investigator

Reineke Schoot, MD, PhD, is a fellow and postdoctoral researcher at the Princess Máxima Center for Pediatric Oncology in Utrecht, Netherlands. She is the Chair of Young SIOPE, a group within the European Society for Pediatric Oncology (SIOPE), and member of the SIOPE board. Young SIOPE was founded in 2019 to foster a community among young investigators (YIs) in European pediatric oncology and to facilitate involvement of SIOPE YIs in research, development, and education.

As a YI, Dr. Schoot has taken on a coordinating role within the PCDC in the INSTRuCT imaging working group, which overlaps with her interest in sarcoma imaging. Dr. Schoot has initiated the first commons research project, investigating the use of radiological response as a primary outcome in clinical studies with rhabdomyosarcoma patients.



“INSTRuCT and the other PCDC projects reinforce collaboration between European and North American research groups.

In addition, both INRG and INSTRuCT are very motivated to involve junior colleagues, providing unique opportunities for YIs to extend their network, to learn from the experts in the field, and to participate in promising research projects.”

## INRG Strategy Development Committee

The INRG Strategy Development Committee, launched in 2019, creates opportunities for researchers to connect. To make it easier to plan projects, they have established a cohesive overview of the information currently available in the INRG commons as well as a list of all current and ongoing analyses. To encourage the involvement of researchers new to the INRG, they developed a list of planned projects for new investigators to co-lead or join. Finally, they have established a liaison and mentorship program through which members of the committee are available to help YIs get involved in research.

## Joining forces with the next generation

The PCDC stays connected with the next generation of physicians and researchers by working with students and trainees. Pritzker School of Medicine students can work with us as Clinical Data Standards Analysts while simultaneously earning their Masters in Biomedical Informatics. These students contribute meaningfully to our data commons while deepening their own data science skills and applying them in a real-world setting. When they return to medical school and residency, they bring with them knowledge and ideas they have developed with the PCDC.

Alex Plana, MD, MScBMI  
2018-2019, spring 2020

*Where is he now?*  
PGY-1 in Internal Medicine  
at the University of Chicago



“My time with the Pediatric Cancer Data Commons taught me the inner workings of health information database construction and management. As data collection processes become more and more crucial to research success, my experiences helped me gain insight into how such systems will impact my future as a clinician-researcher.”

“Working at the PCDC taught me so much about data standards, data management, and how to structure databases. This experience will be invaluable for me as I pursue my medical training, because the appropriate use of high-quality data has the potential to dramatically improve patients’ lives.”



Nicole Dussault, MScBMI  
2019-2020

*Where is she now?*  
Finishing her fourth year  
of medical school

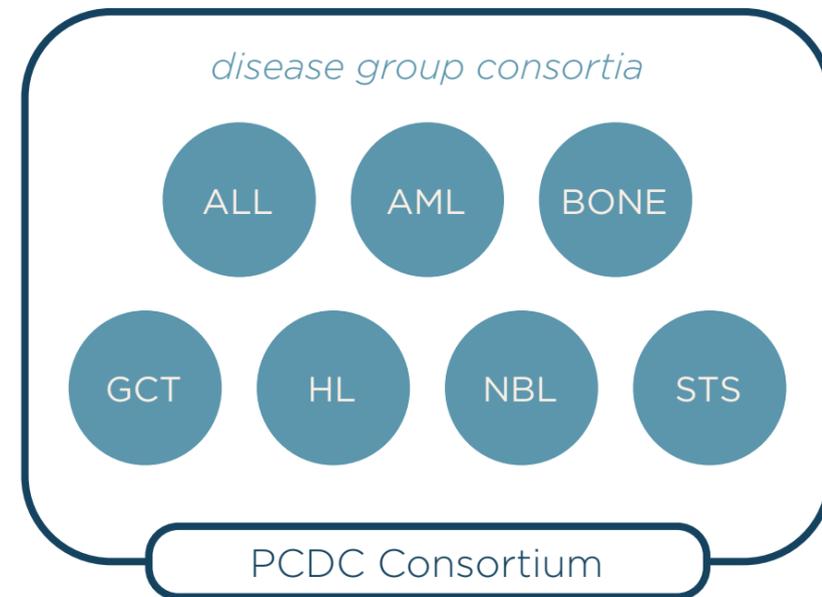
# A shared foundation

## The PCDC Consortium

The PCDC Consortium was created in 2019 to expand and streamline PCDC efforts across more types of childhood cancer. Building on our initial successes in neuroblastoma and soft-tissue sarcoma, the Consortium scales our work to include acute myeloid leukemia, acute lymphoblastic leukemia, germ cell tumors, Ewing sarcoma, osteosarcoma, and Hodgkin lymphoma.

With each new data commons, we are able to better streamline the development process by leveraging similar technological underpinnings and established consensus-based governance processes. The PCDC Consortium creates a formal structure to integrate this work, further facilitating the development of the commons and allowing us to work in alignment with the National Cancer Institute's plan for the Cancer Research Data Commons framework.

The development of a common core data dictionary and common governance structure is now in progress. Over the next two years, we will harmonize data from each disease group to the consensus data model, build cohort discovery and data visualization tools, and extend our work to the larger research community through outreach and education. This project will enable innovative cross-disease research and set a standard for future cancer data commons endeavors.



## Building consensus

The PCDC's success and growth is driven by discussion with and consensus from our collaborators, as we develop and implement best practices across all aspects of data commons development. With so many stakeholders all over the world, robust governance practices are key to making sure everyone's voice is heard and progress is made in a reliable and repeatable way.

A governance work group composed of experts from all of our established and in-process disease consortia has been convened to develop guidance on the overall governance processes for the PCDC Consortium. In the past year, this group has outlined policies and recommendations for:

- Ratifying data dictionary changes
- Accepting contributions of new data
- Reviewing and approving requests for the release of data for research
- Authorship, manuscript review, and publication (in progress)

## What's next?

A massive technical upgrade will soon be implemented across the PCDC. By moving away from the model where each commons is hosted on its own separate infrastructure, the PCDC can truly be a data commons for all pediatric cancer. In the coming months we will transition to a new infrastructure using Gen3, the open-source platform that powers the NCI's Genomic Data Commons. Moving to this infrastructure will foster interoperability between the PCDC and other commons, ultimately making it easier to combine clinical data from the PCDC with data types (such as genomic, imaging, immunologic, or proteomic) from other sources.

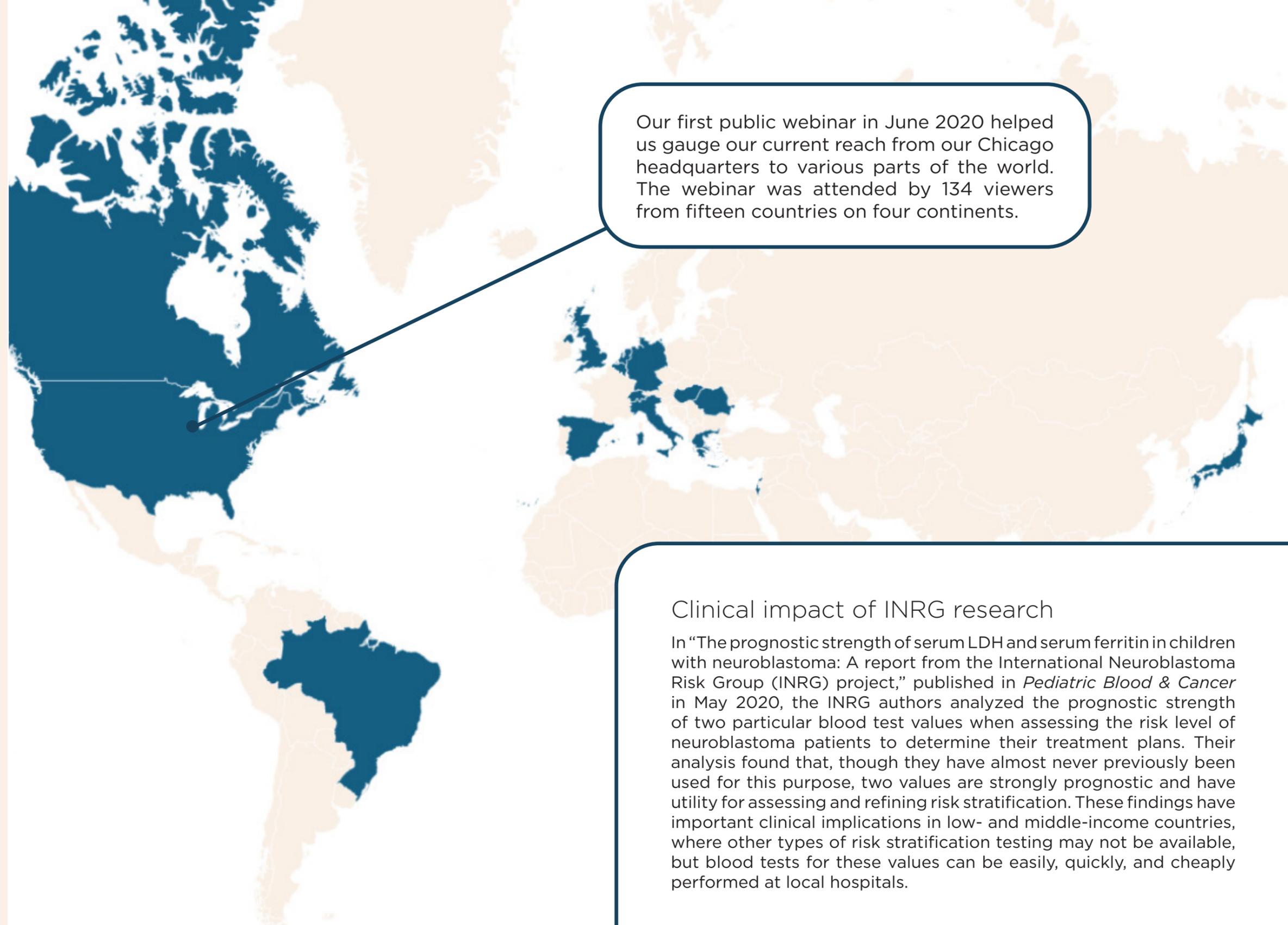
# Local data, global benefits

A global approach to pediatric cancer research could be instrumental in closing the enormous gap in survival between high- and low-income countries. Diseases that are commonly cured in high-income countries, such as acute lymphoblastic leukemia, have a 20 percent long-term survival rate in some parts of the world.\* The vast majority of pediatric cancer research to date has occurred in countries with majority populations of European descent, which is particularly concerning given that genetic factors can both drive cancer risk and help determine the best course of treatment. The more diverse the data in the PCDC is, the more value it has for future patients everywhere.

For this reason, one of our key goals is to expand the reach of our partnerships into as many parts of the world as possible. Our existing consortia have laid a strong foundation for this, developing productive approaches for all the logistical, legal, and regulatory work that international collaboration requires. As a result, we are currently engaged with cooperative groups across the US, Canada, many European countries, Japan, and Latin America.

All of these groups have contributed to our work developing consensus data standards. As we move forward, we intend both to harmonize data from more regions and countries and to share these data standards as widely as possible.

\*Source: World Health Organization



Our first public webinar in June 2020 helped us gauge our current reach from our Chicago headquarters to various parts of the world. The webinar was attended by 134 viewers from fifteen countries on four continents.

## Clinical impact of INRG research

In “The prognostic strength of serum LDH and serum ferritin in children with neuroblastoma: A report from the International Neuroblastoma Risk Group (INRG) project,” published in *Pediatric Blood & Cancer* in May 2020, the INRG authors analyzed the prognostic strength of two particular blood test values when assessing the risk level of neuroblastoma patients to determine their treatment plans. Their analysis found that, though they have almost never previously been used for this purpose, two values are strongly prognostic and have utility for assessing and refining risk stratification. These findings have important clinical implications in low- and middle-income countries, where other types of risk stratification testing may not be available, but blood tests for these values can be easily, quickly, and cheaply performed at local hospitals.

# Expanding our network

As a result of our core work of building and growing the PCDC, our team's expertise has been tapped by national efforts to make cancer data more accessible, interoperable, and impactful.

## Clinical trials matching with GEARBOX

As part of The Leukemia & Lymphoma Society PedAL Initiative, the PCDC team is currently building a tool to rapidly and accurately match children with acute myeloid leukemia (AML) to clinical trials. GEARBOX (Genomic Eligibility Algorithm at Relapse for Better Outcomes) is a web-based tool to match children with relapsed AML to a targeted treatment based on clinical factors and the specific abnormalities driving their cancer. Clinical researchers will use the tool to search based on their patient's clinical data, immunophenotype, and genomic profile. GEARBOX will use a matching algorithm to build a list of appropriate trials based on its database of COG eligibility criteria, helping doctors quickly connect patients to lifesaving treatments.

## NCI data thesaurus

For data standards to truly change the research paradigm, they must be consistently used across as many organizations as possible. To support this on a national level, the PCDC team collaborates with the National Cancer Institute to ensure the consistent application of terms and codes represented in their data thesaurus, known as NCIt. We benefit from the use of NCIt terms in our PCDC data dictionaries, while also using our team's expertise to improve NCIt by acting as a standards authority and contributing any missing terms related to pediatric cancer.

## Center for Cancer Data Harmonization

In 2019, with funding from the National Cancer Institute (NCI), we began leading the development of the Center for Cancer Data Harmonization (CCDH) alongside four other institutions. The CCDH is a key component of the NCI's Cancer Research Data Commons (CRDC) initiative, a vision for a nationwide virtual infrastructure that will provide researchers access to cancer data across many different data types and scientific domains. The work of the CCDH team will drive the interoperability and accessibility of the data within the CRDC.

Our expertise in data standards and harmonization and our experience bringing disparate data together for the PCDC mean that our team can contribute to the CCDH in multiple ways. We co-lead two of the project's five workstreams: Data Model Harmonization and Community Development.

## CCDH Data Model Harmonization

This workstream, co-led by Brian Furner, will make it possible for the CCDH to bring disparate data across various data commons together under a standardized, interoperable data model. This team works closely with the CCDH Tools and Data Quality Workstream to plan, develop, and implement tools to align the data models of the various commons. This work is critical to create a global data ecosystem that aligns the diverse perspectives of project stakeholders.

## CCDH Community Development

To develop a deeper understanding of the existing cancer data landscape, the needs of researchers, and opportunities for improvement, this team is conducting focus group interviews with representatives from core US cancer data repositories and commons. The specifications and requirements they gather will inform the development of the Center's resources. This group will also liaise between the CCDH team and project stakeholders once the Center has launched.

# Turning data into discovery

While many of the disease groups within the PCDC are still in the stages of establishing and populating data commons, data from the INRG, INSTRuCT, and MaGIC commons are already leading to new discoveries.

## In press: INSTRuCT consensus papers

In addition to sharing data, collaboratively producing manuscripts is a way for consortia to build community and contribute to science. In the past year the members of INSTRuCT have written several expert consensus papers based on previously published findings, three of which have now been accepted for publication in *Pediatric Blood & Cancer*. While much of the work enabled by the PCDC is based on the larger datasets made available by a commons-based approach, these papers illustrate how scientific progress can come not just from combining data, but also from connecting researchers around the world.

## Sharing our methods

A collaborative data-sharing approach has the potential to change the entire landscape of cancer research. As we build the PCDC, our mission includes sharing our methods and lessons learned with the scientific community and assessing further opportunities to advance the state of the art in this field. In the paper “Using big data in pediatric oncology: Current applications and future directions,” published in February 2020 in *Seminars in Oncology*, PCDC Director Sam Volchenbom, MD, PhD, 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.

## Publications

Moroz V, Machin D, Hero B, Ladenstein R, Berthold F, Kao P, Obeng Y, Pearson ADJ, Cohn SL, London WB. The prognostic strength of serum LDH and serum ferritin in children with neuroblastoma: A report from the International Neuroblastoma Risk Group (INRG) project. *Pediatr Blood Cancer*. 2020 Aug;67(8):e28359. doi: 10.1002/pbc.28359. Epub 2020 May 30.

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Campbell K, Shyr D, Bagatell R, Fischer M, Nakagawara A, Nieto AC, Brodeur GM, Matthay KK, London WB, DuBois SG. Comprehensive evaluation of context dependence of the prognostic impact of MYCN amplification in neuroblastoma: A report from the International Neuroblastoma Risk Group (INRG) project. *Pediatr Blood Cancer*. 2019 Aug;66(8):e27819. doi:10.1002/pbc.27819

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## Presentations

Plana A, Furner B, Palese M, Kolb EA, Nichols G, Volchenbom S. Building International Pediatric Cancer Data Commons: The Pediatric Acute Leukemia (PedAL) Initiative. Poster presented at: 51st Congress of the International Society of Pediatric Oncology; October 23-26, 2019; Lyon, France.

Furner B, Oliwa T, Graglia L, Kisler B, Laurie F, Evans J, Tian J, Johnson J, Veetekat R, Hanusik R, Dearry A, Cohn S, Volchenbom S. Linking clinical trials data with images via the Pediatric Cancer Data Commons and the National Biomedical Imaging Archive (NBIA). Poster presented at: Childhood Cancer Data Initiative Symposium; July 29-31, 2019; Washington, DC.

Furner B, Plana A, Palese M, Nichols G, Kolb EA, Volchenbom S. The Pediatric Acute Leukemia (PedAL) Initiative - an innovative platform for real-time matching of children with relapsed AML to early-phase clinical trials. Poster presented at: Childhood Cancer Data Initiative Symposium; July 29-31, 2019; Washington, DC.

Plana A, Furner B, Birz S, Palese M, Volchenbom S. A Synthesized Common Data Model and Data Standards for the University of Chicago's Pediatric Cancer Data Commons. Poster presented at: Childhood Cancer Data Initiative Symposium; July 29-31, 2019; Washington, DC.

Plana A, Furner B, Palese M, Birz S, Hawkins DS, Volchenbom S. Rapid consensus building and development of the International Soft Tissue Sarcoma Consortium (INSTRuCT) data commons. Poster presented at: Childhood Cancer Data Initiative Symposium; July 29-31, 2019; Washington, DC.

# It takes a village

A paradigm-shifting effort like the PCDC is impossible to approach alone. Our work is founded on collaboration and connection, and our progress thus far is the combined result of contributions from individuals, cooperative groups, and institutions all over the world.

Just as integral to our success is the support we receive from those who believe in our work. The generosity of our funders—foundations, government organizations, and families committed to fighting childhood cancer—inspires us to dream big and drives our progress toward a better future for pediatric cancer research. Thank you for being a part of the PCDC.

**The Andrew McDonough B+ Foundation** helped us expand our capacity to rapidly develop and maintain consensus data dictionaries for each of our disease groups and to align our data dictionary process with NCIt in order to better share our data standards with other researchers.

**Cancer Research Foundation** supported our data harmonization efforts as we worked with collaborators to transform existing data into the format needed for data ingestion in our new Gen3 platform.

**Children's Research Foundation** provided support for building the PCDC as well as funding for individual PCDC-affiliated research projects.

**Comer Development Board** supported PCDC project management, governance, and communications team members as we worked to expand outreach and communications across our growing list of stakeholders.

**The Leukemia & Lymphoma Society** accelerated our international AML data commons work, including data dictionary consensus, data harmonization, and governance, and enabled us to develop clinician support tools and data standards/infrastructure support for the LLS PedAL Initiative.

**The Matthew Bittker Foundation** enabled neuroblastoma-specific work including data harmonization and dataset updates, data quality assurance and control checks, INRG governance and management, and data commons maintenance.

A contract with the **National Cancer Institute** made it possible for us to pilot the inclusion of imaging data in the INRG Data Commons.

Another contract with the **National Cancer Institute** enabled our team to participate in leading the development of the Center for Cancer Data Harmonization.

**Neuroblastoma Children's Cancer Society** enabled neuroblastoma-specific work including enhancements to the INRG data dictionary and support of the INRG Task Force work groups.

**A gift made in memory of Payton O'Brien** provided seed funding for initial osteosarcoma data profiling and stakeholder engagement efforts as we work to establish an international osteosarcoma consortium.

**Rally Foundation for Childhood Cancer Research** supported our developers as they created and launched the initial INSTRuCT cohort discovery tool.

**St. Baldrick's Foundation** helped us unite researchers from seven pediatric cancer groups to lay the fundamental governance and data model groundwork for cross-disease cohort discovery and data exploration tools to be built on the Gen3 platform.

**An anonymous foundation** supported our development of consensus data dictionaries and the integration of our data standards with the NCIt.

# Our team

As a relatively new and rapidly growing group, building a strong PCDC team has been a significant priority for this past year.

Bringing together the group you see here is one of our favorite accomplishments of 2019-2020.



Suzi Birz, MScMI, FHIMSS  
*Regulatory and Data Governance Consultant*

Kathryn Blumhardt, MS  
*Project Manager*

Brian Furner, MS  
*Director of Applications Development*

Luca Graglia, MS  
*Lead Software Engineer*

Bobae Kang  
*Front End Developer*

Maura Kush  
*Lead Clinical Data Standards Analyst*

Tom O'Hara, PhD  
*Full Stack Developer*

Monica Palese, MPH  
*Director of Operations*

Sarah Paracha, MS  
*Clinical Data Standards Analyst*

Caitlin Pike  
*Communications Manager*

Shazia Sathar  
*Technical Project Manager*

Jian Tian  
*Senior Software Engineer*

Sam Volchenboum, MD, PhD  
*Principal Investigator and Pediatric Oncologist*

## The PCDC team by the numbers

13 people



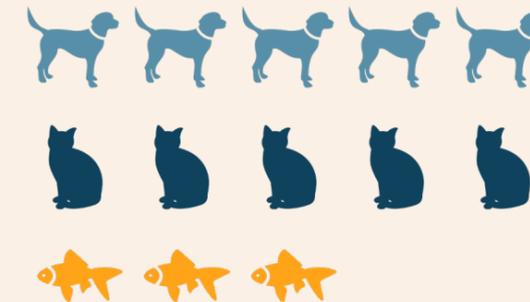
from 5 countries and 8 US states

31% prefer tea

69% prefer coffee



Between us, we have 13 pets,



speak 14 languages,

play 9 musical instruments,

and have run 73 half and full marathons.

## Stay connected!

[commons.cri.uchicago.edu](https://commons.cri.uchicago.edu)

Follow us on Twitter and ResearchGate:

[twitter.com/PedsDataCommons](https://twitter.com/PedsDataCommons)

[researchgate.net/lab/Pediatric-Cancer-Data-Commons-Samuel-Volchenboum](https://researchgate.net/lab/Pediatric-Cancer-Data-Commons-Samuel-Volchenboum)

Questions about getting involved or supporting the PCDC?

Email Monica Palese at [mpalese@bsd.uchicago.edu](mailto:mpalese@bsd.uchicago.edu)



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CHICAGO

PEDIATRIC CANCER  
DATA COMMONS