CONNECTING THE DOTS

The power of community to drive discovery

Data for the Common Good
at the University of Chicago

July 2022–June 2023

D4CG

Working toward a world where access to high-quality data is never a barrier to improving human health.

2022–2023

With a new name and an expansive vision to go with it, 2022-23 was an exciting time of transition for Data for the Common Good.

Over the past several years, the successes of the Pediatric Cancer Data Commons (PCDC) have brought us opportunities to apply our approach to lowering barriers to research beyond pediatric cancer. In January 2023, we officially launched our new lab identity as Data for the Common Good (D4CG). This name reflects the broadened scope of our mission as we work to improve human health through access to high-quality data wherever we can. While many of these new projects are still in their early stages, the recent progress of the monogenic diabetes consortium PREDICT shows the promise of our approach to make a meaningful difference in the study of rare diseases.

Meanwhile, our commitment to pediatric cancer research has not wavered. The central focus of much of our team is the continued development and expansion of the Pediatric Cancer Data Commons. We continue to invest in and grow this project at all levels: engaging with new stakeholders to bring in additional cancer types, harmonizing and integrating more data into the PCDC Data Portal, and expanding our vision for the PCDC to create a resource that can support studying cancer through an individual's full lifetime and benefit patients of all ages.

One of the greatest strengths of the PCDC is the community that has grown around it. To get to where we are today has taken the effort of hundreds of collaborators, who have worked with us to develop data dictionaries, harmonize data, and advance science through publishing both data-driven research and consensus papers. This multidisciplinary, consensus-based, community-centered approach is the foundation of our work and the core of what we are now beginning to build for other areas of human health.

The progress outlined in this report is a testament to the D4CG community. To our collaborators, supporters, funders, and most of all the patients and families who make it all possible: thank you for working alongside us for the common good.

Sam Volchenboum, MD, PhD

Reintroducing ourselves

Welcome to our first annual report as **Data for the Common Good**! After several years of operating under the name Pediatric Cancer Data Commons (PCDC), in January 2023 we officially launched our new lab identity. Our name reflects the scope of our work today, as we apply our approach to data sharing to make an impact in more areas of human health while continuing to invest deeply in pediatric cancer research.

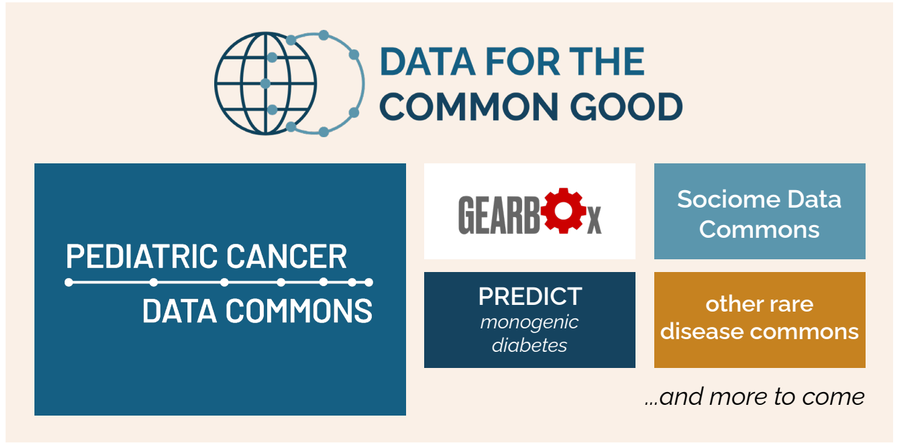
Who we are

Data for the Common Good includes our flagship project, the PCDC, as well as other projects that leverage our expertise in data sharing to study and improve human health—with more to come.

All our work is in service of our mission:

We build communities, platforms, and ecosystems that maximize the potential of data to drive discovery and improve human health.

D4CG structure



How we got here

To see where we are headed, it helps to look at where we came from. As D4CG evolves, our history shows how our work continues to build on itself, streamlining the process of creating new communities and tools so that we can both deepen and broaden our impact.

2004	INRG
2013	INRG data commons
2017	INSTRuCT
2019	PCDC-wide governance and data dictionary work
	Partnership with MaGIC
2020	INTERACT, HIBiSCus, NODAL
	Partnership with C3P
	INSTRuCT data commons
2021	INSPiRE, Global REACH
	PCDC Data Portal pilot
	GEARBOx pilot
	Sociome partnership
2022	NOBLE, Reproductive HOPE
	PCDC Data Portal launch
	PREDICT
	GEARBOx launch
2023	Fanconi anemia
	MaGIC and NODAL join PCDC Data Portal
	Launch of D4CG identity

For full names of consortia, please see Appendix 1.

PCDC beginnings

The seeds of the PCDC were planted in 2004 with the creation of INRG. In 2013, an INRG data commons became available. Following the path laid by INRG, INSTRuCT was formed in 2017.

By 2019, it was clear that our efforts could successfully be extended to more cancer types, and we received key funding that allowed us to begin developing the PCDC as one united entity.

The PCDC grows

Centralized work to build a shared technical infrastructure, a consistent data model, and repeatable governance structures and procedures allowed us to drastically streamline the process of onboarding new disease types. Throughout 2020 and 2021, the PCDC grew consistently.

2021-22 saw the major milestone of introducing the PCDC Data Portal. Our work began to branch out with the release of GEARBOx.

Becoming D4CG

In 2022-23, we've continued to think big with the PCDC, adding still more cancer types and building out our advisory structure. We're working to make the PCDC a resource that will support studying cancer through the entire life cycle, including pre-cancer syndromes and post-treatment effects.

Meanwhile, our efforts to extend the D4CG model beyond pediatric cancer are beginning to bear fruit with the formation of PREDICT, the Sociome Data Commons, and more projects in the works.

A year of the PCDC Data Portal

A growing resource

The PCDC Data Portal, the public platform for exploring and requesting data from the Pediatric Cancer Data Commons, was piloted in 2021 and released with INRG and INSTRuCT data in 2022. In its first full year of use with multiple cancer types, the portal has allowed researchers around the world to perform cohort discovery and start projects with PCDC data. Meanwhile, we've continued to improve and refine the interface and tools as well as integrate more harmonized data—with five cancer types now in the portal and more to come.

BY THE NUMBERS

585

registered data portal users

261 active in the last six months of FY23

90

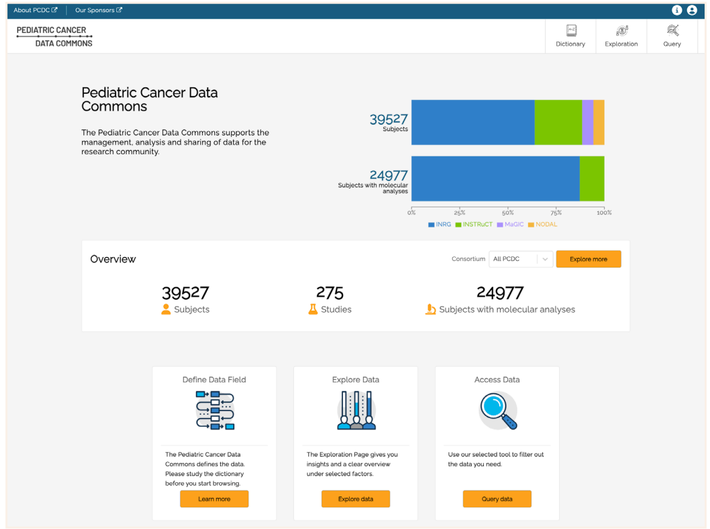
survival curves generated

Portal users logged in from

35

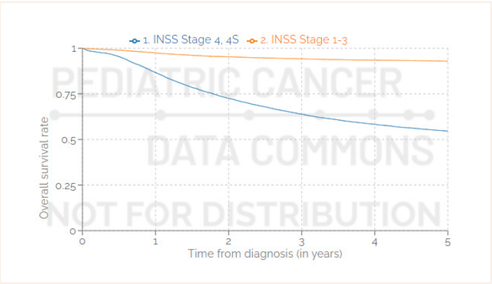
countries

72% USA
28% other countries



Explore the PCDC Data Portal:
portal.pedscommons.org

User guide, tutorial videos, and more:
docs.pedscommons.org



Survival curve generator

The PCDC data portal now includes a tool for generating Kaplan-Meier survival curves, a useful data visualization for comparing outcomes for different groups of patients. We launched this tool after completing an extensive pilot phase during which we tested and evaluated numerous safeguards to protect data from statistical misuse.

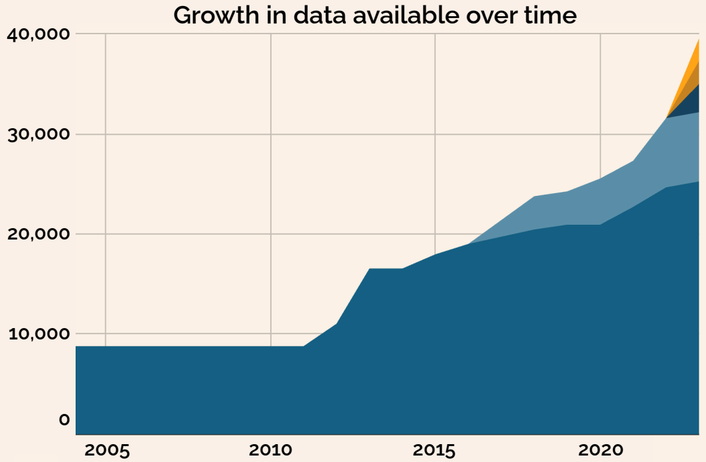
BY THE NUMBERS

39,527
total participants in the portal

3,507 added in FY23
4,269 added in late 2023

25% increase since FY22

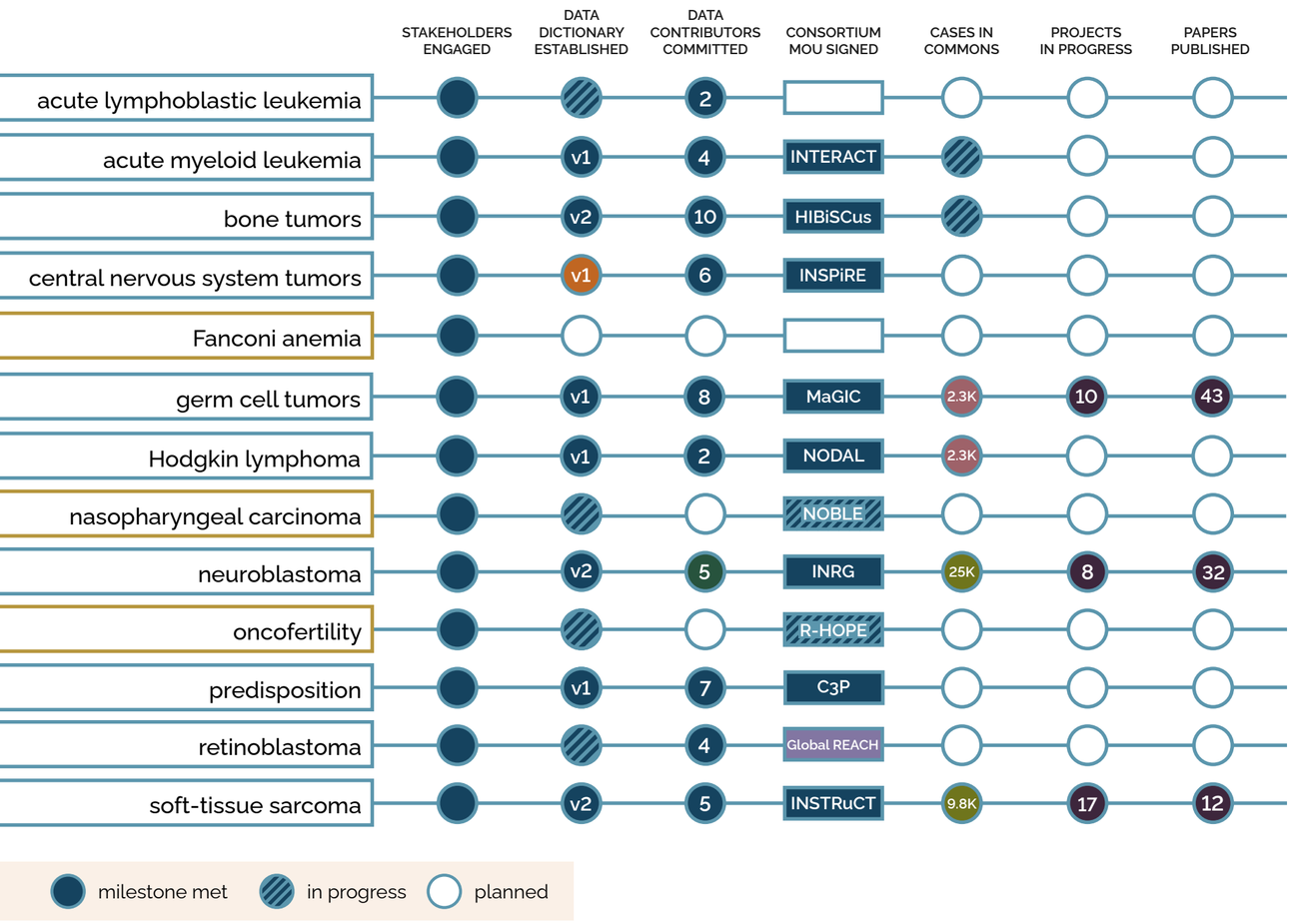
Data for
5
cancer types



- Neuroblastoma (INRG)
- Rhabdomyosarcoma (INSTRuCT)
- Non-rhabdomyo-sarcoma soft-tissue sarcoma (INSTRuCT)
- Germ cell tumors (MaGIC)
- Hodgkin lymphoma (NODAL)

PCDC behind the scenes

Underlying what you see in the PCDC Data Portal is the hard work of many dedicated individuals. Our collaborators work in disease-specific consortia to develop data dictionaries, share and harmonize data across institutions and borders, implement governance, and drive the science of the PCDC.



BY THE NUMBERS

13
disease groups

9 with signed Memoranda of Understanding

46
countries

sharing data with PCDC's committed data contributors

11
complete data dictionaries

3 more in progress

2022-23 PCDC milestones

To learn more about what each of these steps entails, visit **sam.am/milestones**.

- **New groups** were formed to focus on nasopharyngeal carcinoma and oncofertility. A **new partnership** was established to include Fanconi anemia, a disease associated with increased cancer risk, in the PCDC.
- The first version of the **data dictionary** for central nervous system tumors was completed.
- INRG welcomed a new **data contributor**, St. Jude Children's Research Hospital.
- Global REACH signed their **Memorandum of Understanding**, officially establishing their consortium.
- Data from MaGIC and NODAL joined the **PCDC Data Portal** for the first time.
- **New participants** were added to the PCDC Data Portal for INRG and INSTRuCT, including the first non-rhabdomyosarcoma soft-tissue sarcoma data for INSTRuCT.
- **New projects** are in progress and **new papers** were published by INRG, INSTRuCT, and MaGIC.

For full names of consortia, please see Appendix 1.

The power of community

Creating opportunities for discovery isn't just about connecting data—it's about connecting people. One of the greatest benefits of building the Pediatric Cancer Data Commons has been the ability to bring together some of the world's foremost experts in their subjects into multidisciplinary groups devoted to working together to advance science.

Guidance for thoughtful growth

The PCDC has now convened three advisory groups composed of a diverse and accomplished array of experts who share their insights and help guide our work.

Scientific Advisory Committee (SAC)

Membership
Consortium representatives and domain experts with knowledge of the PCDC, who provide strategic and operational guidance on PCDC efforts

Progress
The SAC, in its second year of quarterly meetings, advised us on topics including ethical considerations for linking data between platforms and strategies for increasing patient and family involvement in the PCDC.

External Advisory Board (EAB)

Membership
Clinical, data science, and digital health experts not affiliated with the PCDC, who share their experience and offer high-level strategic advice

Progress
The EAB had its inaugural meeting in November 2022 and has brought a big-picture perspective to advising us on topics like thoughtful strategies for expansion and possibilities for leveraging artificial intelligence.

AYA Research Council (ARC)

Membership
Consortium representatives and domain experts with knowledge of AYA research who provide strategic and operational guidance on cross-disease AYA science

Progress
Launched in November 2023, the ARC will amplify the perspective of the adolescent and young adult (AYA) cancer population in order to drive cross-disease research and address the unique needs of this community.

For a list of all advisory group members, please see Appendix 3.

BY THE NUMBERS

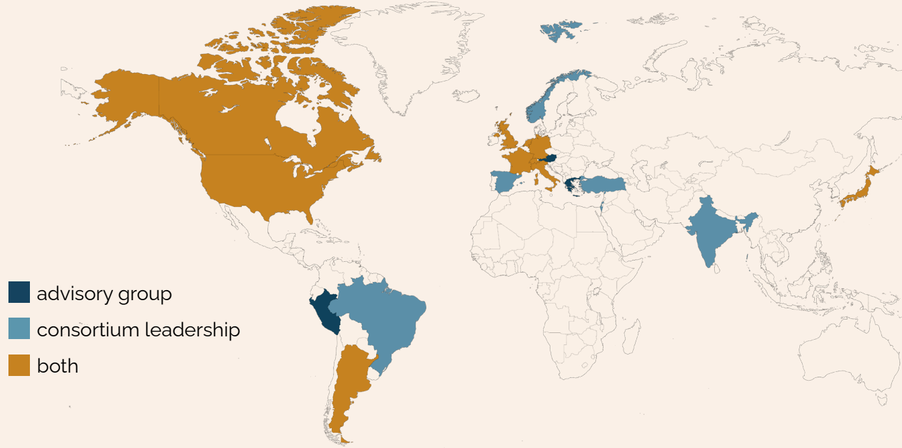
80
members of
3 PCDC advisory groups

121
members of
10 consortium leadership committees

19
countries represented

An international PCDC community

As we seek to include data from as many parts of the world as possible in the PCDC, our consortium leadership and advisory groups also include an international perspective. We are grateful that more than 150 individuals contribute their time and expertise to the PCDC in this official capacity, along with the many collaborators who are involved in consortia and data-contributing groups in other ways.



Publication highlight: expert consensus

The significance of margins in pediatric non-rhabdomyosarcoma soft tissue sarcomas: Consensus on surgical margin definition harmonization from the INternational Soft Tissue SaRcoma ConsorTium (INSTRuCT)

The structure of a consortium lends itself to fruitful collaboration. In addition to conducting projects with PCDC data, these multidisciplinary groups of experts work together to synthesize existing research and produce consensus statements that can guide improvements in both research and clinical practice. INSTRuCT working groups published three such consensus papers this year. For example, in this paper they offer international harmonized recommendations for surgical margin assessment and definitions in children and adolescents with soft tissue tumors so that future research can be conducted with common guidelines.

Making a difference

As the PCDC grows, it is powering new research with the potential to change clinical practice and improve patient outcomes, as well as advancing the field of data sharing. We're committed to continuing to increase its impact by expanding our vision, working inclusively, and creating a comprehensive resource for studying cancer through an individual's entire lifetime.

Our new online dashboard shows publications and projects in progress by consortium. Visit **sam.am/pcdcresearch** to see the latest.

Publication highlight: impacting care

Clinical and biological features prognostic of survival after relapse or progression of INRGSS stage MS pattern neuroblastoma: A report from the International Neuroblastoma Risk Group (INRG) project

Only with access to aggregated, harmonized data can researchers study very rare subsets of already rare diseases. An example of the type of work made possible by the PCDC is this paper, which addresses a knowledge gap by studying outcomes after relapse from stage MS neuroblastoma. Thanks to INRG data, said co-author Steven DuBois, "These findings will enable clinicians to better counsel and treat these rare patients with relapsed stage MS disease."

Publication highlights: sharing our methods

Creating a data commons: The INternational Soft Tissue SaRcoma ConsorTium (INSTRuCT)

Advancing clinical and translational research in germ cell tumours (GCT): recommendations from the Malignant Germ Cell International Consortium

Publishing about the behind-the-scenes work of data sharing is an important part of driving progress in our field. In papers like ours on INSTRuCT, we hope that sharing details such as our governance methods and how we overcame early challenges can help others working toward similar goals. In their paper, among other recommendations, MaGIC authors highlighted their successful partnership with the PCDC and the importance of the standardized data model we have developed together.

For more publication information, please see Appendix 2.

BY THE NUMBERS

10 new publications in FY2023

35 projects now approved or in progress

Thinking bigger

To make the PCDC the most impactful resource it can be, we are thinking beyond strict definitions of pediatric cancer.

Welcoming AYA data

Some cancer types in the PCDC, like germ cell tumors and Hodgkin lymphoma, frequently affect adolescent and young adult (AYA) patients. Rather than allowing these data to be siloed, intentionally including other age groups in the PCDC will make more research across populations possible. Our new AYA Research Council is advising us as we aim to serve the unique needs of this community and benefit patients of all ages.

Connecting the dots through a lifetime

We envision the PCDC as a resource for studying the full life cycle of cancer, including pre-cancer syndromes and post-treatment effects. This is why the PCDC includes groups like C3P (childhood cancer predisposition), Fanconi anemia (a condition that increases the risk of developing cancer), and Reproductive HOPE (fertility preservation and reproductive outcomes after cancer treatment). In addition, we are now working on developing a platform for tracking long-term follow-up data.

A network for change

D4CG is proud to be part of a much larger ecosystem of organizations and individuals committed to improving human health. Whether we are meeting new potential parters and collaborators, sharing our work and learning from others at conferences, or contributing to multi-institutional national initiatives, we know that we can do more when we work together.

The NCI Childhood Cancer Data Initiative

D4CG and the PCDC are an important part of a national data sharing ecosystem through the National Cancer Institute's Childhood Cancer Data Initiative (CCDI). We are contributing our expertise in data harmonization to two projects that support the CCDI's efforts to improve cancer prevention, treatment, quality of life, and survivorship and to ensure that researchers learn from every child with cancer.

CCDI Data Federation

With a collaborative group of institutions, we are working to make the multiple data commons involved in the CCDI able to interoperate by developing and implementing a common harmonized data model and API for queries across the PCDC, St. Jude, Seven Bridges, and the Gabriella Miller Kids First Data Resource Center.[1]

C3DC

We continue to participate in developing the Childhood Clinical Data Commons (C3DC), a data node of the CCDI that will act as the primary source of individual-level data describing participants' demographic and clinical characteristics. C3DC will interoperate with other CCDI data type-specific nodes such as genomics, imaging, and proteomics.[2]

1. We have received $722,292 in funding for this project, 100% of which is financed with federal money.

2. We have received $1,039,349 in funding for this project with an Option Period to extend for additional funding in an amount of $823,921. The total anticipated budget for this project is $1,863,270, 100% of which is financed with federal money.

In-person connections

We have been delighted over the past year to return to connecting with our colleagues in person at conferences and meetings around the world. We are grateful for these opportunities to present our research and methods, participate in panel discussions, catch up with collaborators, and meet many new friends. We hope to see even more of you in the coming year!

A few highlights of many included:

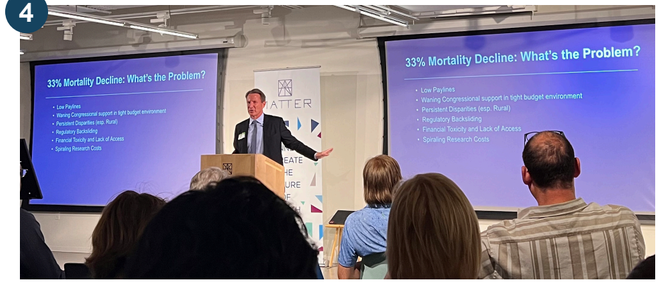
- Presenting on our progress developing GEARBOx at ASH 2022
- Attending a roundtable hosted by Teen Cancer America to discuss challenges faced by adolescent and young adult patients *(photo 1)*
- Being presented with an OutSmarting Osteosarcoma grant at the FACTOR Osteosarcoma Conference *(photo 2)*
- Moderating a panel and working group for hundreds of participants at the Childhood Cancer Data Initiative Annual Symposium
- Sharing PCDC Data Portal demos at our exhibition booths at SIOP 2022 and SIOP Europe 2023 *(photo 3)*
- Hearing talks from INRG researchers and presenting a poster at Advances in Neuroblastoma Research 2023
- Hosting a live D4CG event here in Chicago, featuring a keynote from former NCI Director Ned Sharpless *(photo 4)*

1

2

3

4



The D4CG approach

Our method of building a data commons, developed through years of work with the PCDC, is inclusive, consensus-based, and strongly focused on data quality and usability. When we became Data for the Common Good, we committed ourselves to bringing this expertise to wherever we could have the greatest impact. The past year of progress demonstrates the promise of the D4CG approach to empower research across many different areas of health care.

Establish a consortium.

We employ a "big tent" philosophy, drawing from far and wide to bring together as many collaborators as we can.

Develop and deploy data operations.

Consistent data standards and harmonized data are the key to creating a commons that is truly useful and impactful.

Establish and implement governance.

Agreements allow data to be shared while protecting patient privacy and complying with international regulations.

Develop and deploy the technical infrastructure.

A platform that makes it easy to perform cohort discovery and request standardized data creates opportunities for discovery.

Socialize and sustain the commons.

We build communities, not just tools. This work becomes sustainable when it is supported by a robust, committed group of collaborators.

PREDICT: a monogenic diabetes data commons

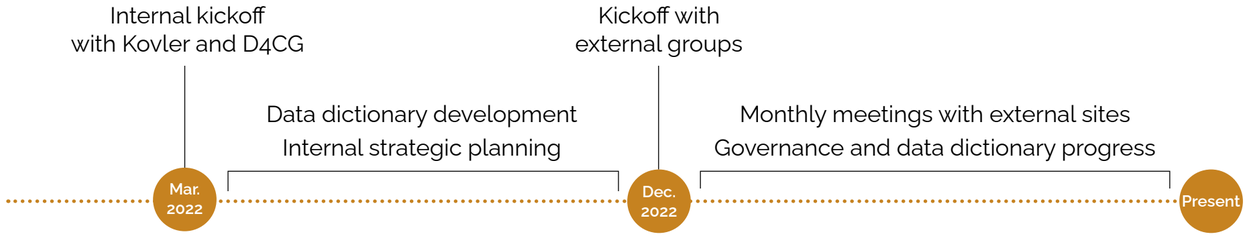
Monogenic diabetes, a subtype of diabetes caused by changes to a single gene, represents less than 5 percent of cases of diabetes in the US. This rarity makes research more difficult and means that a single source for aggregated patient data will be a critical resource for researchers to advance science and clinical practice. In partnership with the Kovler Diabetes Center, part of the University of Chicago Biological Sciences Division, PREDICT (PREcision DIabetes ConsorTium) has engaged stakeholders from more than a dozen institutions to build a commons that will bring together previously siloed data for this disease.

PREDICT spent this year applying D4CG methods to developing a data dictionary and implementing governance structures. The consortium Memorandum of Understanding as well as Data Contributor Agreements with contributing sites are in progress. By harmonizing existing clinical research data and standardizing data collection, PREDICT will help to identify patients with possible monogenic diabetes and better understand treatment response according to genotype and long-term outcomes.

PREDICT partners

Baylor University
Boston Children's Hospital
University of Chicago
Children's Hospital of Philadelphia
University of Colorado/
Barbara Davis Center for Diabetes
Indiana University
Massachusetts General Hospital
University of Maryland
University of Michigan
University of Nebraska
NorthShore University Health System
Stanford University

PREDICT timeline



Powering innovation

The success of the D4CG approach allows us to work at the forefront of a variety of efforts to improve the status quo of research and clinical care. Based on our work in rare disease data commons, we are contributing to a resource for including non-clinical Sociome data in medical research for a fuller picture of health. We also remain committed to applying our expertise to improving clinical trials enrollment to make a difference in the lives of patients today.

A data commons for the Sociome

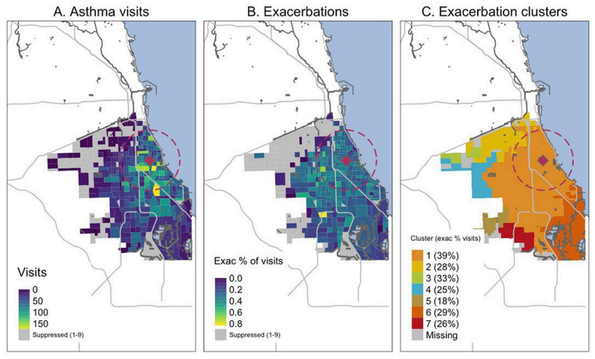
The Sociome refers to the non-clinical aspects of life affecting health: social, environmental, behavioral, psychological, and economic factors. D4CG is part of a multidisciplinary consortium headquartered at the Chicago Institute for Translational Medicine (ITM) working to build the Sociome Data Commons, a research platform for large-scale data analysis including publicly-available geocoded datasets about Sociome factors. This resource will allow researchers to integrate the social context of disease with clinical and genomic data to better understand, predict, and treat numerous conditions and improve human health.

A pilot project conducted this year leveraged the Sociome Data Commons as a use case, developing a preliminary machine learning model for predicting asthma exacerbations from pediatric asthma visits on the South Side of Chicago. Important variables in the predictive model included age of housing units, neighborhood poverty, violent crime, urban flooding, and proximity to pollution.

BY THE NUMBERS

22 datasets were used in the Sociome asthma pilot study

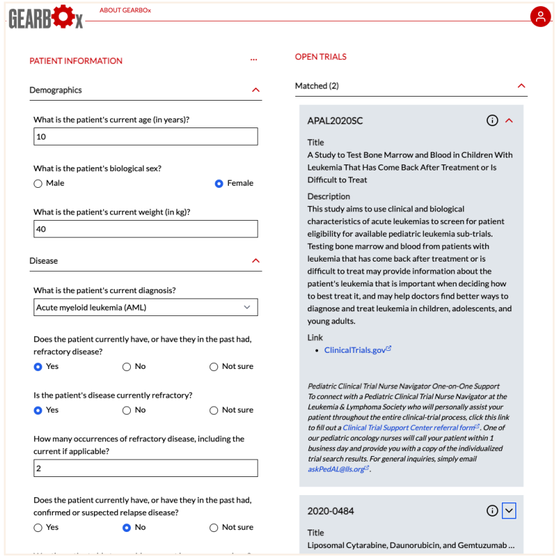
- Economic activity
- Environmental exposures
- Public safety
- Demographics
- Access and mobility
- Property



Asthma visits 2017-2019 by census tract. A. Asthma visit counts (continuous); B. Exacerbations as a proportion of all asthma visits; and C. Spatial clustering for exacerbations. The University of Chicago hospital is in red and its 5 mile perimeter is represented with a dashed red line.

The future of clinical trials enrollment

GEARBOx, a decision support tool for clinicians to rapidly and accurately match children with relapsed acute myeloid leukemia to clinical trials in North America, was launched in 2022 as part of The Leukemia & Lymphoma Society Dare to Dream Project. This year, we worked to improve, expand, and further refine this important tool.



Our plans for GEARBOx

- Include additional trials
- Add new features, such as the automatic ingestion of clinical and genomic patient information
- Expand to additional tumor types, including ALL, neuroblastoma, rhabdomyosarcoma, Ewing sarcoma, and osteosarcoma
- Explore possibilities for more automated methods for abstraction of eligibility criteria

Explore GEARBOx:
gearbox.pedscommons.org

We're also exploring possibilities for leveraging artificial intelligence to support clinical trials matching. In our paper "**Automated Matching of Patients to Clinical Trials: A Patient-Centric Natural Language Processing Approach for Pediatric Leukemia**," we detailed our development of a tool for using natural language processing to extract inclusion and exclusion criteria from free text in clinical trial protocols and generate a ranked list of relevant trials.

Partnerships for progress

The accomplishments and plans in this report are only possible because of the generosity and commitment of our funders and partners. Here is some of what you enabled this year. Thank you for investing in our vision for a better future.

Cancer Research Foundation helped to further international outreach for the PCDC, including the integration of retinoblastoma data from Latin America.

Children's Cancer Research Fund continued to support our retinoblastoma consortium Global REACH as they implemented governance policies and developed their data dictionary.

Children's Research Foundation provided continued support for strengthening and expanding PCDC collaborations.

Comer Development Board helped to sustain the centralized project management, governance, and engagement operations of the Pediatric Cancer Data Commons.

The Fund for Innovation in Cancer Informatics supported the work of improving the GEARBOx clinical trials matching tool and making it possible to extend it to additional types of cancer.

Gray Foundation continued to enable the development of the PREDICT monogenic diabetes consortium and data commons.

Jeffrey Pride Foundation and ***Aileen S. Andrew Foundation*** supported the Pediatric Cancer Data Commons through Project Every Child.

The Leona M. and Harry B. Helmsley Charitable Trust provided essential initial funding for PREDICT.

The Leukemia & Lymphoma Society, as part of its Dare to Dream Project, continued to provide essential support for both our AML consortium INTERACT and the use and further development of GEARBOx.

A contract with the ***National Cancer Institute*** and ***Leidos*** enabled D4CG to participate in developing the Childhood Clinical Data Commons, a data node of the CCDI.

Another contract with the ***National Cancer Institute*** allowed us to work on developing and implementing a harmonized data model across multiple CCDI data commons.

The ***Neuroblastoma Children's Cancer Society*** provided funding for INRG, with a focus on efforts to better understand and treat secondary illness and side effects in neuroblastoma survivors.

St. Baldrick's Foundation supported the PCDC's central operations, including governance, project management, and engagement, as well as enabling our partnership with C3P.

Rally Foundation for Childhood Cancer Research supported our bone tumors consortium HIBiSCus as they harmonized data, as well as supporting project management for the PCDC as a whole.

The ***Sarah Jane Adicoff Endowment for Research in Rhabdomyosarcoma***, through ***Seattle Children's Foundation***, provided support for INSTRuCT.

Team Bright Side is enabling us to begin the pilot development of a long-term follow-up platform for survivors of childhood cancer, and also continued to support the development of an ALL consortium.

A contract with the ***US Department of the Interior*** enabled us to continue integrating PCDC data standards with the NCI Cancer Research Data Commons.

An anonymous foundation continued to support our development of consensus data dictionaries.

In addition to the funding highlighted here, which was received during the 2022-23 fiscal year, we are grateful and excited to welcome these organizations supporting us in 2023-24 and beyond. We look forward to reporting next year on the advances made possible by your support!

- **Children's Oncology Group Foundation**
- **Fanconi Anemia Research Fund**
- **Friends of T.J. Foundation**
- **Maddie's Promise**
- **MIB Agents**
- **SebastianStrong Foundation**
- **Summer's Way Foundation**

The D4CG team

The Data for the Common Good team continues to grow along with the scope of our work. Our team brings together a diversity of experience and education around a shared vision as we work together to maximize the power of data and improve lives.

Suzi Birz, MScMI, FHIMSS
Regulatory and Data Governance Consultant

Kat Bouzein, MS
Program Manager

Lauren Chan, PhD, RD
Postdoctoral Researcher

Seong Choi
Senior Software and Data Integration Engineer

Wanda Clark-Jenkins
Administrative Specialist

Spencer Claxton
Front End Developer

Ellen Cohen, MPP
Deputy Director

Nicholas Ferraz, MS
Full Stack Developer

Brian Furner, MS
Senior Director of Data and Technology

Luca Graglia, MS
Director of Software and Infrastructure Services

Enal Hindi, MS
Senior Project Manager

Steve Krasinsky
Full Stack Developer

Jooho Lee, PhD, MSLIS
Semantic Engineer

Mei Li, MS
Healthcare Data Standards Analyst

Maya Maric
Project Manager

Paul Murdoch
Junior Backend Developer

Kaitlyn Ott, MS
Healthcare Data Standards Analyst

Rolando Palacios, MS
Technical Project Manager

Caitlin Pike
Director of Communications

Jabari Taylor, MPH
Project Manager

Sandra Tilmon, MS, MPH
Healthcare Data Scientist

Sam Volchenboum, MD, PhD
Director and Pediatric Oncologist

Michael Watkins, PhD
Manager of Data Standards and Modeling

Kirk Wyatt, MD
Senior Clinical Advisor

Tianyun Zhang, MS
Senior Front End Developer

Connect with us

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Explore PCDC tools
pedscommons.org

Sign up for our newsletter and conference previews
sam.am/D4CGnews

Connect with us on LinkedIn
linkedin.com/company/d4cg

Questions about getting involved or supporting D4CG?
Email Kat Bouzein at kblumhardt@uchicago.edu

Thank you!

The progress in this report is truly a team effort. We are grateful to our consortium members and data contributors, data portal users, advisory group members, funders and partners, University of Chicago and Biological Sciences Division colleagues, and all those working alongside us to fight pediatric cancer and improve human health. Most of all, we thank the patients and families without whom our work would not be possible.

Appendix 1: Consortium Names

C3P - Consortium for Childhood Cancer Predisposition
Global REACH - Global REtinoblastoma Alliance for CHildren
HIBiSCus - Harmonization International Bone Sarcoma Consortium
INRG - International Neuroblastoma Risk Group
INSPiRE - International central Nervous System Pediatric REsearch consortium
INSTRuCT - INternational Soft Tissue saRcoma ConsorTium
INTERACT - INTERnational pediatric Acute myeloid leukemia ConsorTium
MaGIC - Malignant Germ cell International Consortium
NOBLE - NasOpharyngeal carcinoma gloBaL partnErship
NODAL - hodgkiN lymphOma DatA coLlaboration
PREDICT - PREcision DIabetes ConsorTium
Reproductive HOPE - Reproductive Health Outcomes and Preservation Evaluation

Appendix 2: Publications, July 2022-June 2023

Hettmer S, Linardic CM, Kelsey A, et al. Molecular testing of rhabdomyosarcoma in clinical trials to improve risk stratification and outcome: A consensus view from European paediatric Soft tissue sarcoma Study Group, Children's Oncology Group and Cooperative Weichteilsarkom-Studiengruppe. *Eur J Cancer.* 2022 Sep:172:367-386. doi: 10.1016/j.ejca.2022.05.036

Pashankar F, Hanley K, Lockley M, et al. Addressing the diagnostic and therapeutic dilemmas of ovarian immature teratoma: Report from a clinicopathologic consensus conference. *Eur J Cancer.* 2022 Sep;173:59-70. doi: 10.1016/j.ejca.2022.06.006

Fonseca A, Lobo J, Hazard FK, et al. Advancing clinical and translational research in germ cell tumours (GCT): recommendations from the Malignant Germ Cell International Consortium. *Br J Cancer.* 2022 Oct;127:1577–1583. doi: 10.1038/s41416-022-02000-4

Wyatt KD, Birz S, Hawkins DS, et al. Creating a data commons: The INternational Soft Tissue SaRcoma ConsorTium (INSTRuCT). *Pediatr Blood Cancer.* 2022 Nov;69(11):e29924. doi: 10.1002/pbc.29924

Campbell K, Kao PC, Naranjo A, et al. Clinical and biological features prognostic of survival after relapse or progression of INRGSS stage MS pattern neuroblastoma: A report from the International Neuroblastoma Risk Group (INRG) project. *Pediatr Blood Cancer.* 2023 Feb;70(2):e30054. doi: 10.1002/pbc.30054

Schoot RA, Ferrari A, von Kalle T, et al. Imaging recommendations for the management of pediatric non-rhabdomyosarcoma soft tissue sarcoma (NRSTS): Consensus statement of the International Soft Tissue Sarcoma Consortium (INSTRuCT). *EJC Paediatr Oncol.* 2023 Mar;1:100008. doi: 10.1016/j.ejcped.2023.100008

Konneh B, Lafin JT, Howard J, et al. Evaluation of miR-371a-3p to predict viable germ cell tumor in patients with pure seminoma receiving retroperitoneal lymph node dissection. *Andrology.* 2023 May;11(4):634-640. doi: 10.1111/andr.13317

Sparber-Sauer M, Ferrari A, Spunt SL, et al. The significance of margins in pediatric non-rhabdomyosarcoma soft tissue sarcomas: Consensus on surgical margin definition harmonization from the INternational Soft Tissue SaRcoma ConsorTium (INSTRuCT). *Cancer Med.* 2023 May;12(10):11719-11730. doi: 10.1002/cam4.5671

Xu L, Pierce JL, Sanchez A, et al. Integrated genomic analysis reveals aberrations in WNT signaling in germ cell tumors of childhood and adolescence. *Nat Commun.* 2023 May 6;14(1):2636. doi: 10.1038/s41467-023-38378-9

Lafin JT, Scarpini CG, Amini A, et al. Refining the serum miR-371a-3p test for viable germ cell tumor detection. *Sci Rep.* 2023 Jun 29;13(1):10558. doi: 10.1038/s41598-023-37271-1

Appendix 3: Advisory Group Members

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