



Welcome to the [Data for the Common Good](#) (D4CG) quarterly newsletter! Read on for announcements from D4CG headquarters, Pediatric Cancer Data Commons updates, highlights from recent meetings, and more. Past quarterly newsletters are [archived on our website](#). Please don't hesitate to [reach out with suggestions and requests](#).

D4CG Annual Report



In case you missed it: we are happy to share our latest D4CG Annual Report! [Browse the report online or download a PDF copy here.](#)

Upcoming Conferences

We're looking forward to these meetings in the next several months. If you're attending, we hope to see you there! If you'd like to schedule a meeting with D4CG at any of these conferences, please reach out to [Kat Bouzein](#).

- ◆ [FDA-NIH Rare Disease Day](#), February 27-28 in Bethesda, MD
- ◆ [HIMSS25](#), March 3-6 in Las Vegas, NV
- ◆ [SIOPEL Spring Conference](#), March 13-15 in Cardiff, UK
- ◆ [LRF AYA Lymphomas Scientific Workshop and Consortium Meeting](#), March 20-21 in Jersey City, NJ
- ◆ [SIOP Europe](#), May 12-16 in Budapest, Hungary

D4CG Announcements

DaSH workshop brings D4CG team to India

This month, six members of the D4CG team had the opportunity to travel to India to build and strengthen our collaborations and learn from our colleagues there. Support from a University of Chicago [Provost's Global Faculty Award](#) allowed us to make this trip, which included visiting Bai Jerbai Wadia Hospital for Children and Tata Memorial Hospital in Mumbai and Rajiv Gandhi Cancer Institute & Research Centre in Delhi as well as conducting our first [Data Sharing and Harmonization \(DaSH\) workshop](#). The two-day DaSH workshop brought together clinicians and researchers from throughout India at the [University of Chicago Center in Delhi](#) to share experiences and ideas for building local capacity for data sharing and increasing Indian representation in Pediatric Cancer Data Commons consortia as researchers, data contributors, and advisory group members.

We had a wonderful time meeting and learning from our colleagues and look forward to deepening our collaborations. We are grateful to the dedicated doctors and researchers who took the time to meet with us, and especially thank our coordinators in Mumbai and Delhi, Girish Chinnaswamy and Ramandeep Arora, as well as the UChicago Center in Delhi team.



DaSH workshop participants at the UChicago Center in Delhi.

[See more photos from our trip here!](#)

New D4CG project to focus on the ethics of multimodal AI

We are thrilled to share that new support from the [Chan Zuckerberg Initiative](#) has made it possible for us to begin a project focused on multimodal artificial intelligence (MAI). By incorporating community engagement and ethics throughout the entire development lifecycle, AI can be more equitably implemented, more trusted by the community, and more responsive to community's needs. To this end, we will be developing a pediatric-specific framework for implementing MAI for the study of rare diseases.

Our work will include:

- Co-creating and publishing an ethical framework for responsible and equitable pediatric rare disease MAI development and deployment. We will work closely with communities, stakeholders, and researchers, as well as ethicists at the University of Rochester and Loyola University, to develop this framework.
- Within this framework and with community involvement, testing and refining an MAI algorithm applied to monogenic epilepsies.
- Delivering an MAI model for monogenic epilepsies that predicts cognitive function based on a combination of raw EEG data, clinical data, and genetic data.

We look forward to sharing more about this project as it progresses.

Watch our webinar on data collaboration in rare epilepsies

In November, D4CG hosted a webinar bringing together key voices in epilepsy patient advocacy, data science, and medical research to explore novel ways we can simplify research data management and improve outcomes for patients. If you missed it, you can watch the recording here: [Advancing Data Collaboration in Rare Disease and Epilepsy Research](#)

Introducing the PCDC Lived Experience Advisory Panel

In November, the PCDC Lived Experience Advisory Panel (LEAP) held its inaugural meeting. This group is composed of pediatric cancer patient advocates who have a personal experience with pediatric cancer, either as a patient or family member of a patient, who are passionate about the study of pediatric cancer. LEAP will provide strategic and operational guidance for the Pediatric Cancer Data Commons. At their first meeting, LEAP members got to know each other, reviewed and offered feedback on the charter for the group, and discussed the key topics they would like this panel to address.

First publication from diabetes consortium PREDICT

In their first publication, the Precision Diabetes Consortium (PREDICT) discusses how following the Data for the Common Good model has enabled them to successfully establish a multicenter data commons for monogenic diabetes, as well as a consensus data dictionary that will be utilized to address critical gaps in understanding of these rare types of diabetes. View the abstract or read the paper here: [Advancing Monogenic Diabetes Research and Clinical Care by Creating a Data Commons: The Precision Diabetes Consortium \(PREDICT\)](#)

Fall/winter meeting highlights

D4CG had a busy fall season of conferences and meetings! We are always so grateful for these opportunities to connect and share ideas with our colleagues. A few highlights from this quarter:

- We hosted D4CG booths and presented posters at the [SIOP Annual Congress](#) and [AMIA Annual Symposium](#).
- [INSTRuCT](#) presented research powered by the PCDC at the [CTOS Annual Meeting](#).
- [NODAL](#) presented a poster at the [International Symposium on Hodgkin Lymphoma \(ISHL13\)](#).



D4CG is hiring!

We are currently looking to fill the following roles. We hope you'll share with any members of your network who might be interested!

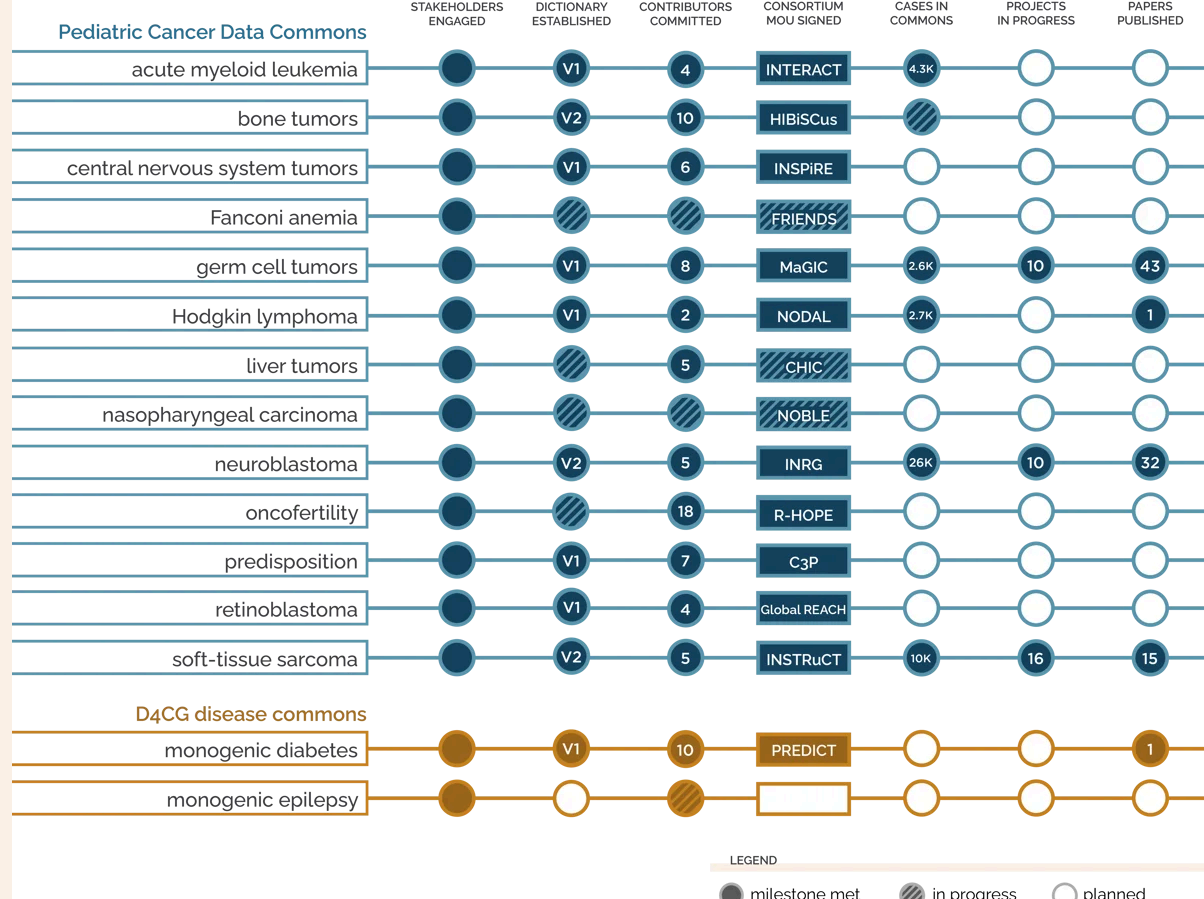
- [Program Director, Direct-from-Patient Contributed Health Data](#)
- [Senior DevOps Engineer](#)

Recent Publications

- [Rethinking Human Abstraction as the Gold Standard](#) was published in [JCO Clinical Cancer Informatics](#).
- [Advancing Monogenic Diabetes Research and Clinical Care by Creating a Data Commons: The Precision Diabetes Consortium \(PREDICT\)](#) was published in the [Journal of Diabetes Science and Technology](#).
- [Lymph Node Staging and Treatment in Pediatric Patients With Soft Tissue Sarcomas: A Consensus Opinion from the Children's Oncology Group, European paediatric soft tissue sarcoma Study Group, and the Cooperative Weichteilsarkom Studiengruppe](#) was published in [Pediatric Blood & Cancer](#).

Data Commons Progress

Bringing data together for the Pediatric Cancer Data Commons and our other D4CG data commons is the work of many dedicated groups of researchers, clinicians, statisticians, and other experts. This tracker shows each group's progress on the journey of establishing governance, harmonizing data, and publishing research.



Data commons progress as of February 2025. Learn more about these milestones [here](#).

PCDC Data Portal Update

- A data update on January 14 added a total of 448 new participants to the portal for INTERACT, INTERACT, and NODAL, as well as updates to existing data. The portal now includes a total of 45,565 participants.
- Software updates included improvements to administrative functionality as well as a new Biospecimen filter. This Biospecimen filter, currently available for INRG data, allows users to filter for participants with a COG specimen at the [Biopathology Center at Nationwide Children's Hospital](#) when building cohorts. Users who identify patients with biospecimens as part of their cohort for a research project proposal may then use the standard [COG process for obtaining COG biospecimens](#).
- The details of all [data release updates](#) and [software updates](#) for the portal are available on our documentation website.

PCDC Advisory Group Update

- The [External Advisory Board](#) met in November. The meeting included discussions of the potential for collaboration with industry partners and the benefits and challenges of engaging directly with patients regarding data sharing.
- The [Scientific Advisory Committee](#) met in December. The meeting included a presentation from INRG and discussion of new diagnosis-specific PCDC groups in progress.
- As discussed above, the [Lived Experience Advisory Panel](#) held their first meeting in November.

We are grateful to our [sponsors and donors](#) for making our work possible.