



Happy 2024 from [Data for the Common Good](#) (D4CG)! 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](#).

## Upcoming Conferences

We're looking forward to these meetings in the next few 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](#).

- **COG Spring Meeting**, March 12-15 in Chicago, IL
- **SIOP Europe**, May 13-17 in Milan, Italy
- **ASCO Annual Meeting**, May 31-June 4 in Chicago, IL

## D4CG Annual Report



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

## D4CG Announcements

### New partnerships for Fanconi anemia and liver tumors

A new partnership with the [Fanconi Anemia Research Fund \(FARF\)](#) will make it possible to include data for Fanconi anemia (FA), a rare cancer predisposition syndrome, in the PCDC. FARF meetings have allowed us to connect with and learn more about the FA community as we prepare to work together to establish a consortium, develop a data dictionary, and harmonize data from registries in North America, Europe, and other parts of the world to enable new FA research.

We are also making exciting progress with the [Children's Hepatic Tumors International Collaboration \(CHIC\)](#) to make it possible for data for liver tumors to enter the PCDC. We met with CHIC in October to discuss strategic planning and data dictionary work, and in December, we began the line-by-line review of the liver tumors data dictionary.

### PCDC Data Portal continues to grow

We continue to work with PCDC consortia to bring more harmonized data into the [PCDC Data Portal](#). In November, a data update including additional germ cell tumor data from [MaGIC](#) and Hodgkin lymphoma data from [NODAL](#) brought the total number of participants in the portal to 39,527, spanning five cancer types.

We are also excited to announce that a sixth cancer type is coming to the portal soon! We look forward to welcoming our first data for acute myeloid leukemia (AML) to the portal at the end of January. This update will include data for 3,413 participants, collected and harmonized by [INTERACT](#) with support from the Leukemia & Lymphoma Society.

All are welcome to [create an account](#) and explore the data available for research in the portal.

### New PCDC advisory group will focus on AYA science

We formally launched our third PCDC advisory group in November with the inaugural meeting of the AYA Research Council (ARC), which will advise us on topics specific to adolescent and young adult (AYA) oncology. At their first meeting, the ARC adopted a charter, identified potential areas of focus for the council, and named four co-chairs: Jennifer McNeer (United States), Mike Roth (United States), Dan Stark (United Kingdom), and Gabriela Villanueva (Argentina). [Learn more and see all current council members on our website](#).

### New publication introduces the Sociome Data Commons

D4CG is part of a multidisciplinary consortium working to build the Sociome Data Commons, a research platform for large-scale data analysis including publicly-available geocoded datasets about non-clinical aspects of life affecting health, such as social, environmental, behavioral, psychological, and economic factors. A recent publication in the *Journal of Clinical and Translational Science* introduces the Sociome Data Commons, discusses insights gained in the development of the Commons, and presents a pilot project that leveraged the Commons to develop a preliminary machine learning model for predicting asthma exacerbations from pediatric asthma visits on the South Side of Chicago. Read the paper: [Sociome Data Commons: A scalable and sustainable platform for investigating the full social context and determinants of health](#).

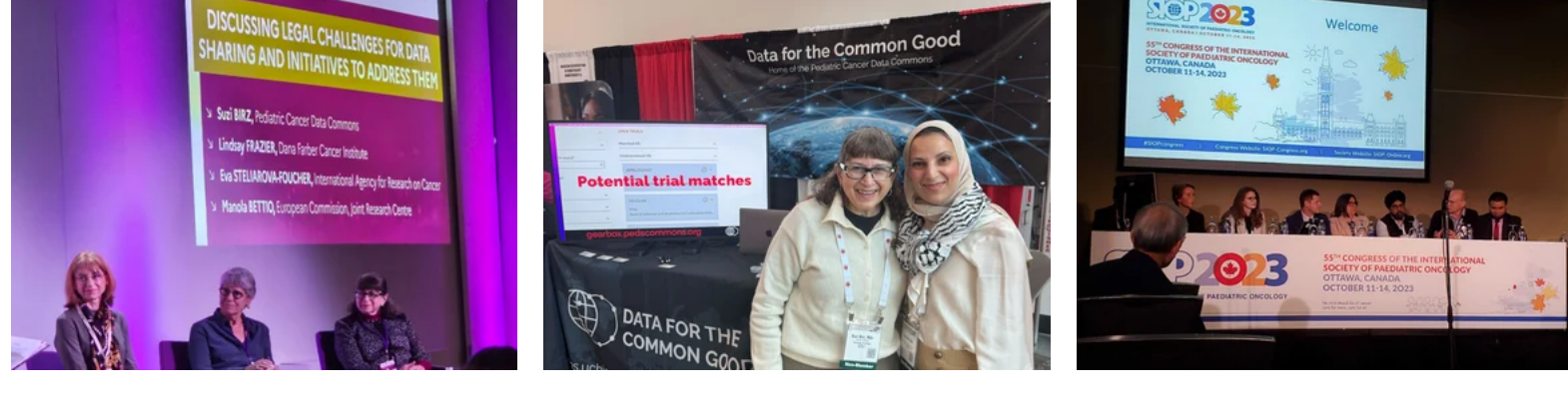
### PCDC public webinar video and materials

In October, we held our fourth annual D4CG public webinar, featuring updates from our team and talks from guest speakers Jaime Guidry Auvil, PhD, Director of the National Cancer Institute's Office of Data Sharing; Louis Philipson, MD, PhD, a renowned endocrinologist and a world authority on diabetes; and Mike Roth, MD, an expert in adolescent and young adult (AYA) oncology. If you missed it, the video recording and slides from the webinar [can be viewed on our website](#).

### Recent meeting highlights

Conferences have kept us busy—and energized—this autumn and winter!

- Conferences afforded opportunities for many PCDC consortia, including HIBISCus, NODAL, NOBLE, INSTRuCT, INTERACT, and Reproductive HOPE, to hold in-person or hybrid meetings to advance their work.
- We demonstrated PCDC tools at our exhibition booths at ASH, ISCAVAHL, and SIOP.
- At SIOP, Kirk Wyatt presented a poster about how we implemented and tested safeguards during our pilot release of portal analytics tools.
- Bradley Carlson presented "Using A Standardized Nomenclature to Semantically Map Oncology-Related Concepts from Common Data Models to a Pediatric Cancer Data Model" at the AMIA Annual Symposium.
- Sam Volchenbom and Suzi Birz participated in workshops and panels and Sam gave a keynote at the Paris Conference for an International Childhood Cancer Data Partnership. Several members of PCDC consortium executive committees were also speakers at this meeting.



## ★ Science Spotlight ★

Welcome to the Science Spotlight, where we highlight the scientific advancements made possible by our consortia and data commons. In each feature we'll hear from a consortium about some recent or ongoing research, how it was done, and what makes it exciting and meaningful.

This quarter, [INSTRuCT](#) profiles several recent consensus papers in which they offer guidelines for imaging and molecular testing that could be used to inform future clinical trial protocols for soft-tissue sarcoma.

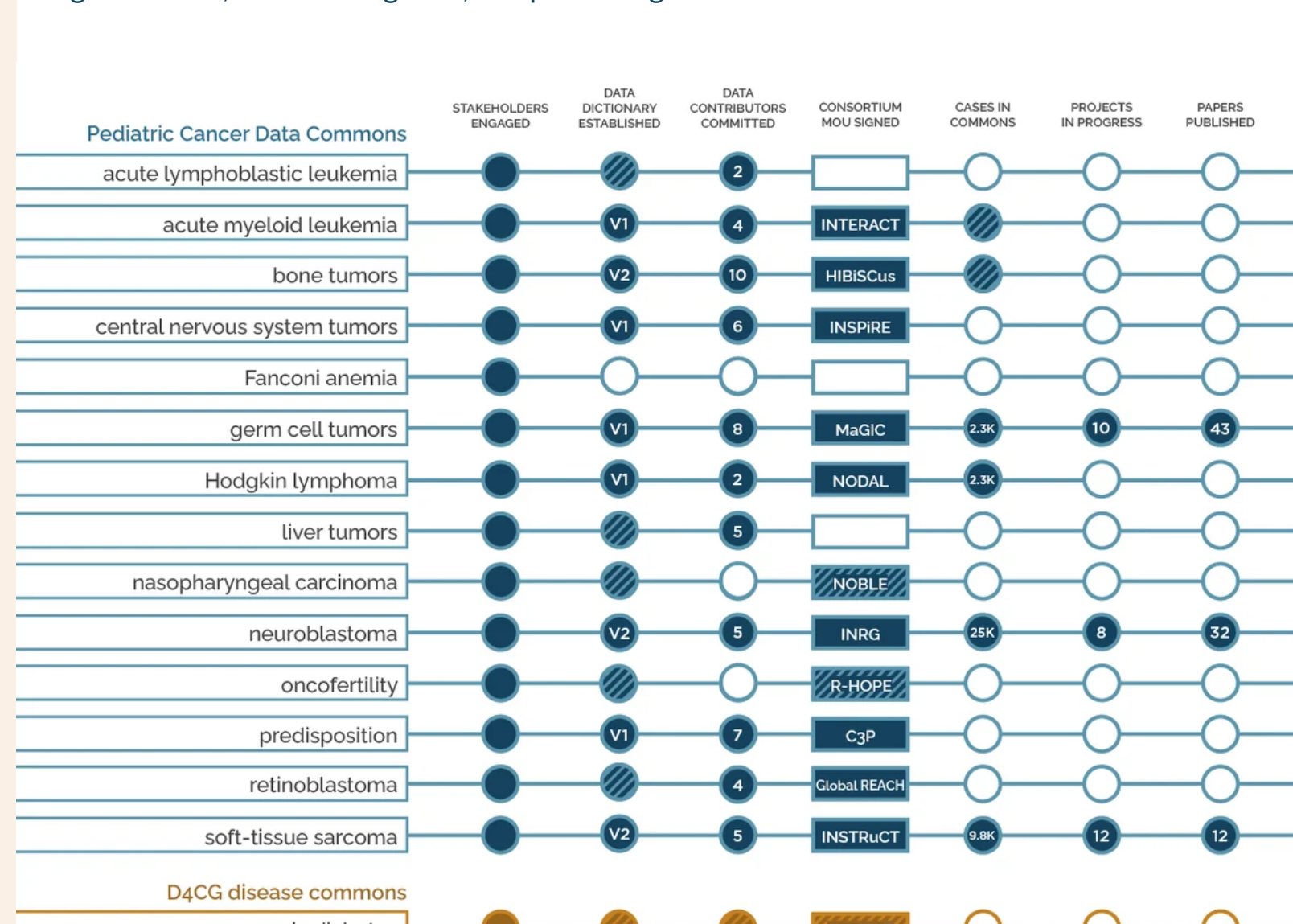
[Read the Science Spotlight!](#)

## Recent Publications

- **Data in pediatric oncology: Something old, something new**, authored by D4CG Senior Clinical Advisor Kirk Wyatt, was published in [Pediatric Blood & Cancer](#).
- **Sociome Data Commons: A scalable and sustainable platform for investigating the full social context and determinants of health** was published in the [Journal of Clinical and Translational Science](#).

## 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 January 2024. Learn more about these milestones [here](#).

## PCDC Data Portal Update

- **New data**
  - SJCRH/HOD05 data were added for NODAL, bringing the total for this consortium to 2,254.
  - DFCI Registry data were added for MaGIC, bringing the total for this consortium to 2,293.
- Running lists of all [data release updates](#) and [software updates](#) for the portal are now available on our documentation website.

## PCDC Advisory Group Update

- As detailed above, our new **AYA Research Council (ARC)** held its inaugural meeting in November, adopted a charter, and identified co-chairs.
- The **External Advisory Board (EAB)** held its annual meeting in November. Discussion centered around strategies for growth and opportunities for leveraging artificial intelligence (AI).
- The **Scientific Advisory Committee (SAC)** met in December, marking two years of quarterly meetings since this committee was launched. The SAC also discussed potential uses for AI in our work.
- We are now planning a combined workshop with interested members from both the EAB and the SAC to delve deeper into the topic of AI.