

# Pediatric Cancer Data Commons

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University of Chicago  
7-November-2023



# A perfect storm

Rare diseases, siloed data,  
manual processes, lack of standards,  
difficult research questions





# DATA FOR THE COMMON GOOD

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



THE UNIVERSITY OF  
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DATA FOR THE  
COMMON GOOD

Paris Conference for an International Childhood Cancer Data Partnership  
Newcap Event Center (Paris, France), November 7-8, 2023  
<http://sam.am/Paris2023>



NATIONAL  
CANCER  
INSTITUTE

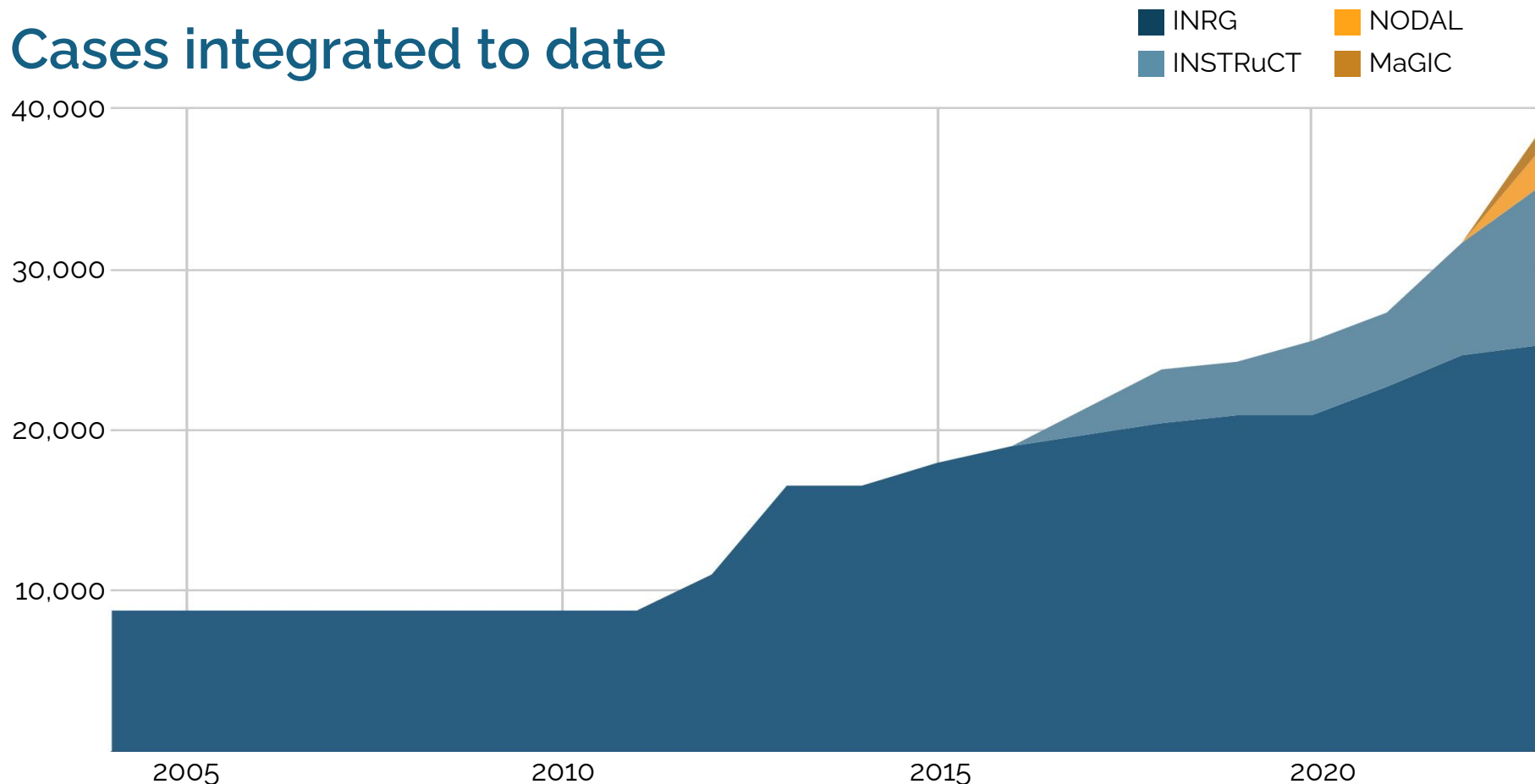


# Pediatric Cancer Data Commons (PCDC)

1. Provides a hub for researchers across **most pediatric cancers**
2. Facilitates **cross-disease research**
3. Develops **common core data dictionaries**
4. Creates **common governance structures**
5. Builds on an **active international network** of researchers
6. **Educates, trains, and increases data literacy** of the community
7. Sources data from **clinical trials, registries**, and (soon) **EHRs**



# Cases integrated to date



2005

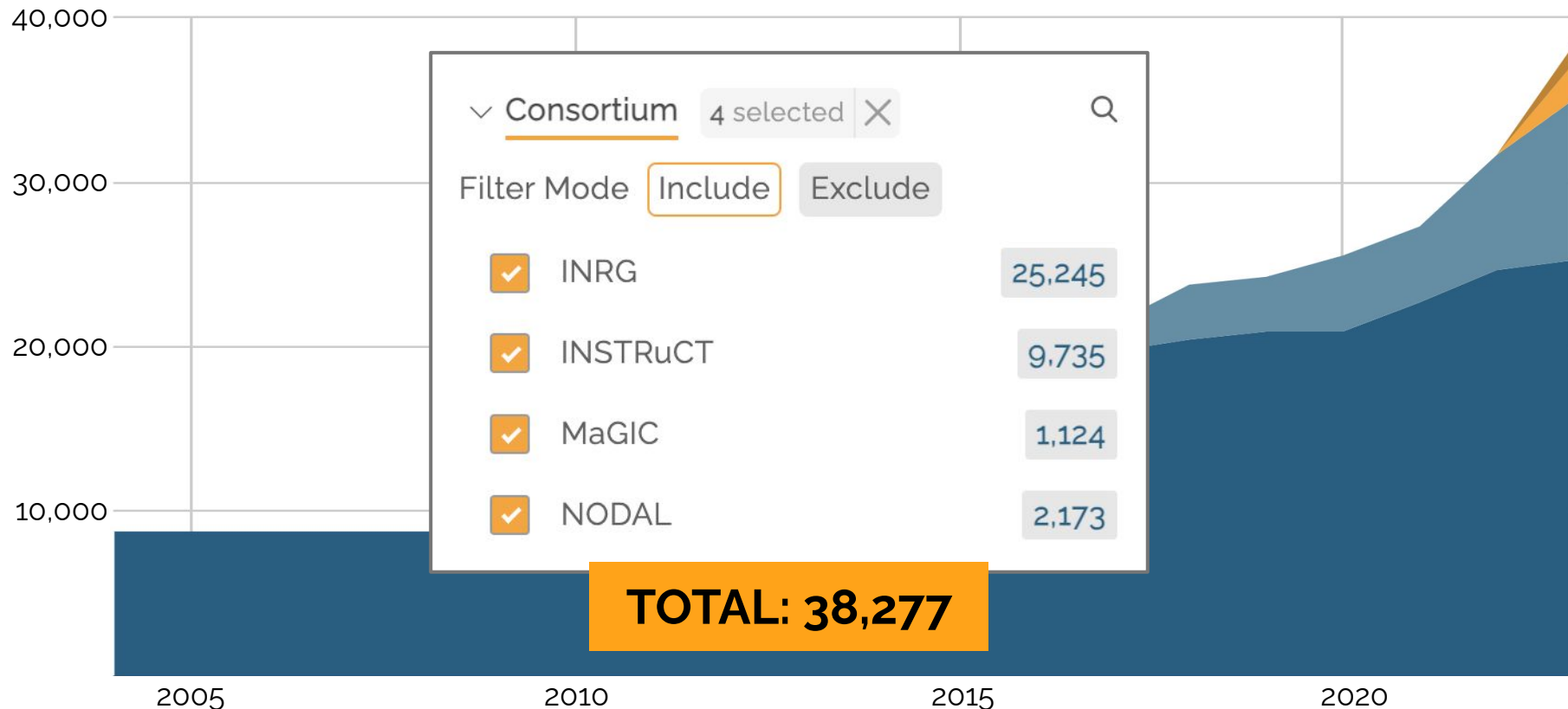
2010

2015

2020

# Cases integrated to date

INRG NODAL  
INSTRuCT MaGIC

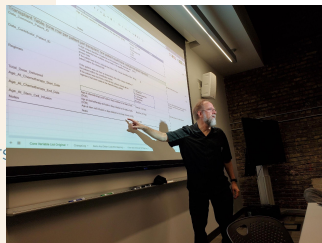


# Building a data commons—the D4CG way

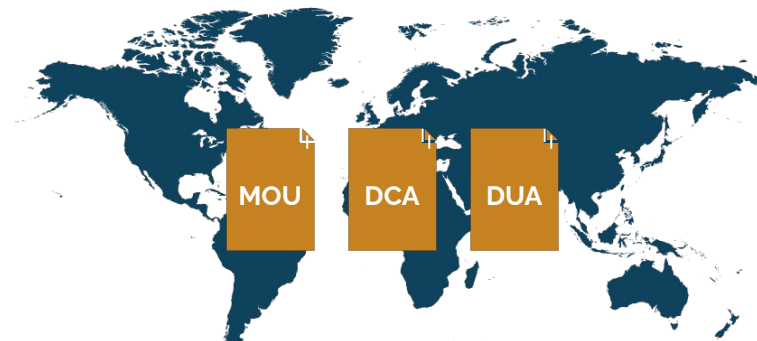
## Step 1: Establish a consortium



- PCDC Master Data Dictionary
- Acute Lymphoblastic Leukemia (ALL)
- Acute Myeloid Leukemia (AML)
- Central Nervous System Tumors (CNS)
- Ewing Sarcoma (EWS)
- Germ Cell Tumors (GCT)
- Hodgkin Lymphoma (HL)
- Neuroblastoma (NBL)
- Non-Rhabdomyosarcoma Soft Tissue Sarcoma (NRSTS)
- Osteosarcoma (OS)
- Predisposition
- Retinoblastoma (RB)
- Rhabdomyosarcoma (RMS)



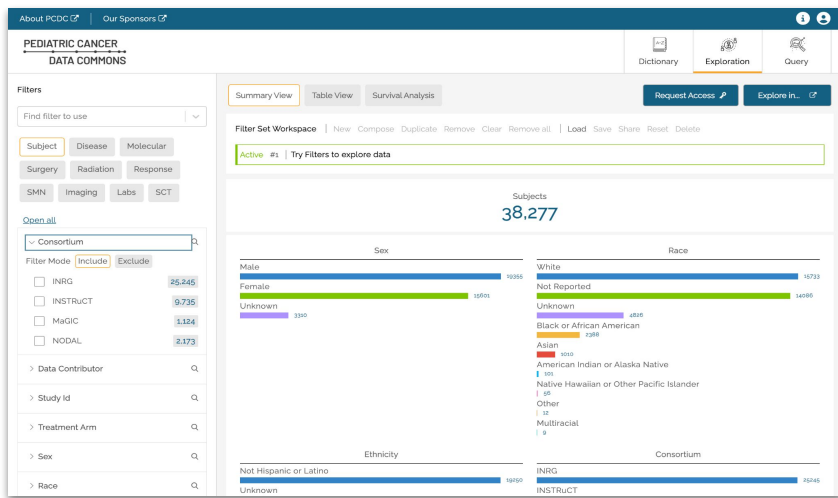
## Step 2: Develop and deploy data operations



## Step 3: Establish and implement governance



# Building a data commons—the D4CG way



**Step 4:** Develop and deploy the **technical infrastructure**

## PCDC Documentation

- PCDC Data Portal Acceptable Use Policy
- PCDC Data Portal Statistical Manual
- PCDC Data Portal User Guide
- PCDC Data Access and Governance
- PCDC Project Request Forms
- Privacy Notice
- PCDC Terms and Conditions
- GEARBOX Terms and Conditions
- Working with PFB Files



## Pediatric Cancer Data Commons Project Request Forms

Before submitting a project request form, please review the PCDC Data Access and Governance document to learn more about the data request process.



**International Soft Tissue Sarcoma Consortium (INSTRuCT)**, please complete and e-mail the form as indicated.

**International Neuroblastoma Risk Group (INRG)**, please click [here](#) to complete and e-mail the form as indicated.

**Step 5:** **Socialize and sustain** the commons

# Engage stakeholders

We employ a “big tent” philosophy.



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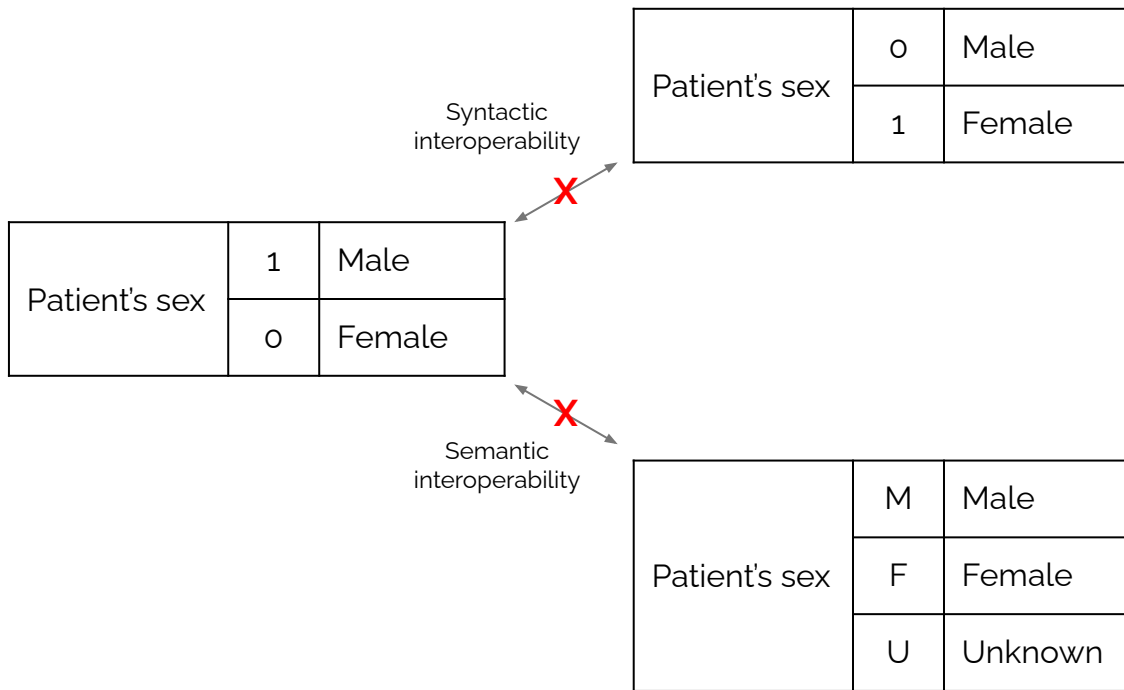
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NATIONAL  
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INSTITUTE

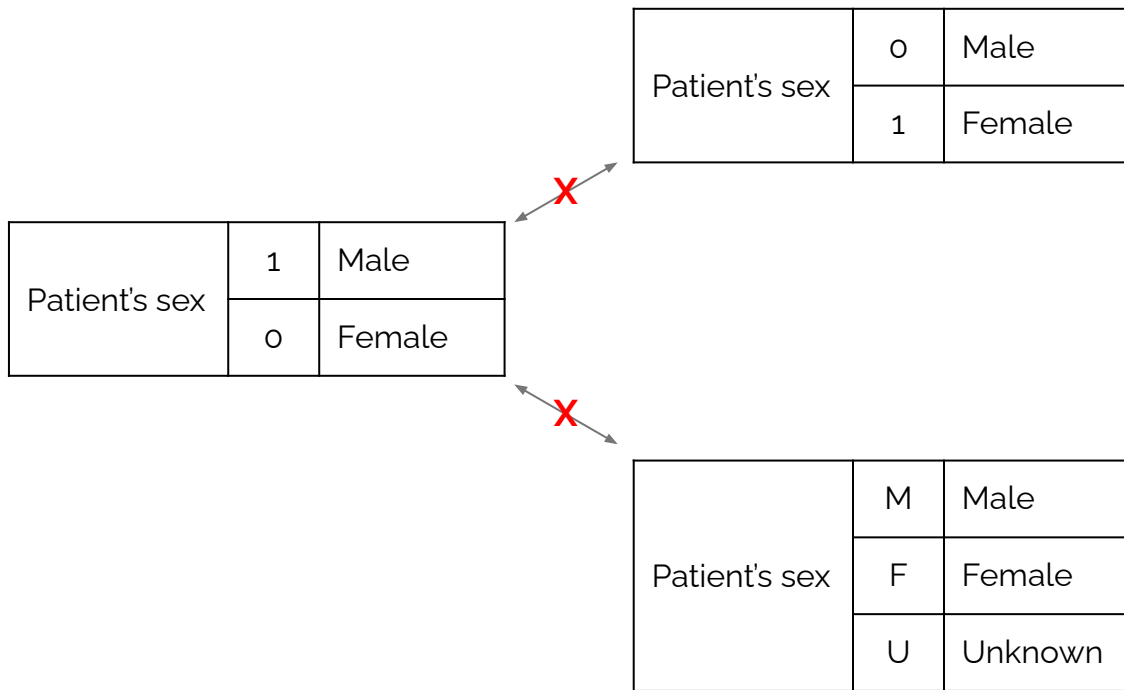


# The importance of data standards





# The importance of data standards



Sex	
Description	NCIt Code
Male	<a href="#">C20197</a>
Female	<a href="#">C16576</a>
Unknown	<a href="#">C17998</a>

# The importance of data standards

NIH NATIONAL CANCER INSTITUTE www.cancer.gov  
 NCI Term Browser EVS Enterprise Vocabulary Services  
 Terminologies Value Sets Mappings  
 Search: male  
 Contains Exact Match Begins With  
 Name Code Property Relationship  
 Back to search results Advanced Search  
 Hierarchy Value Sets Maps Help  
 Quick Links  
 View in Hierarchy View History View Graph Add to Cart Suggest Changes  
 Male (Code C20197)  
 Terms & Properties Synonym Details Relationships Mappings View All  
 Terms & Properties  
 Preferred Name: Male  
 Definition: A person who belongs to the sex that normally produces sperm. The term is used to indicate biological sex distinctions, cultural gender role distinctions, or both.  
 CDISC Definition: A person who belongs to the sex that normally produces sperm. The term is used to indicate biological sex distinctions, cultural gender role distinctions, or both. (NCI)  
 Label: Male  
 NCI Thesaurus Code: C20197 (Search for linked c4DSR metadata) (search value sets)  
 NCI Metathesaurus Link: C0086582 (see NCI Metathesaurus info)  
 Synonyms & Abbreviations: (see Synonym Details)  
 Human, Male  
 M  
 Male  
 MALE  
 male  
 External Source Codes:  
 UMLS CUI C0086582  
 Other Properties:

Patient's sex	1	Male
	0	Female

Patient's sex	F	Female
	U	Unknown

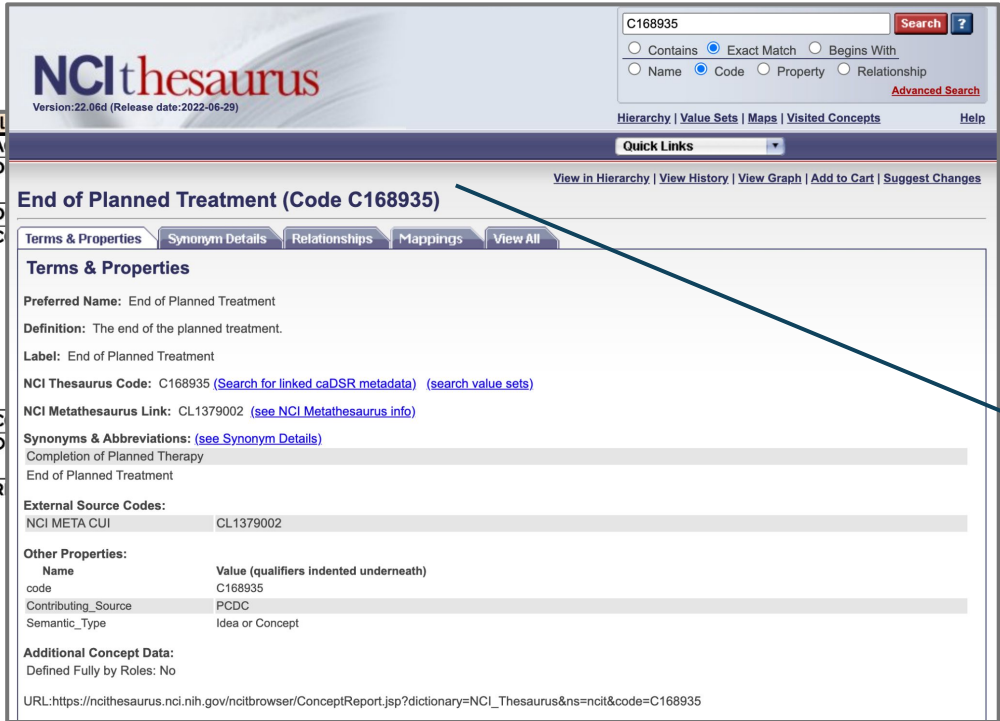
Sex	
Description	NCIt Code
Male	<a href="#">C20197</a>
Female	<a href="#">C16576</a>
Unknown	<a href="#">C17998</a>

# Building a consensus data dictionary

Off Protocol Therapy/Study: one row per subject per off protocol therapy/study per reason off						
<b>AGE_OFF</b>	Number	Age in Days When Off Protocol Therapy or Study	<a href="#">C172678</a>	Age of subject (in days) when		
<b>DISEASE_PHASE</b>	Code	Disease Phase	<a href="#">C168878</a>	The stage or period of an in	Initial Diagnosis	<a href="#">C156813</a>
					Relapse	<a href="#">C38155</a>
<b>DISEASE_PHASE_NUMBER</b>	Number	Disease Phase Number	<a href="#">C173258</a>	The number of the disease		
<b>COURSE</b>	Code	Protocol Treatment Course	<a href="#">C168807</a>	The type of protocol treatm	Prephase	<a href="#">C168826</a>
					Induction	<a href="#">C158876</a>
					Intensification	<a href="#">C173105</a>
					Consolidation	<a href="#">C15679</a>
					Stem Cell Transplant Conditioning	<a href="#">C168794</a>
					Maintenance	<a href="#">C15688</a>
					Palliative Treatment	<a href="#">C15292</a>
					Other	<a href="#">C17649</a>
<b>COURSE_NUMBER</b>	Number	Course Number	<a href="#">C166235</a>	The number assigned to a c		
<b>OFF_TYPE</b>	Code	Off Protocol Therapy or Study	<a href="#">C173256</a>	The code used to designate	Protocol Therapy	<a href="#">C173257</a>
					Study	<a href="#">C29851</a>
<b>REASON_OFF</b>	Code	Off Protocol Therapy or Study Reason	<a href="#">C173519</a>	The reason a subject went	Death	<a href="#">C93546</a>
					Lost to Follow-Up	<a href="#">C70740</a>
					Completion of Planned Therapy	<a href="#">C168935</a>
					Physician Decision	<a href="#">C48250</a>
					Withdrawal of Consent	<a href="#">C48271</a>
					Subject/Guardian Refused Further Treatment	<a href="#">C168934</a>
					Disease Progression	<a href="#">C35571</a>
					Relapse	<a href="#">C38155</a>
					Adverse Event	<a href="#">C41331</a>
					Secondary Malignancy	<a href="#">C4968</a>
					Other	<a href="#">C17649</a>
					Unknown	<a href="#">C17998</a>
					Not Reported	<a href="#">C43234</a>

<http://sam.am/datadictionaries>

# Building a consensus data dictionary



**NCI Thesaurus**  
Version: 22.06d (Release date: 2022-06-29)

Search: C168935  
 Contains  Exact Match  Begins With  
 Name  Code  Property  Relationship

Quick Links: [View in Hierarchy](#) | [View History](#) | [View Graph](#) | [Add to Cart](#) | [Suggest Changes](#)

**End of Planned Treatment (Code C168935)**

**Terms & Properties**  
 Preferred Name: End of Planned Treatment  
 Definition: The end of the planned treatment.  
 Label: End of Planned Treatment  
 NCI Thesaurus Code: C168935  
 NCI Metathesaurus Link: CL1379002

**Other Properties:**

Name	Value (qualifiers indented underneath)
code	C168935
Contributing_Source	PCDC
Semantic_Type	Idea or Concept

Age of subject (in days) when		
The stage or period of an in	Initial Diagnosis	C156813
	Relapse	C38155
The number of the disease		
The type of protocol treatm	Prephase	C168826
	Induction	C158876
	Intensification	C173105
	Consolidation	C15679
	Stem Cell Transplant Conditioning	C168794
	Maintenance	C156888
	Palliative Treatment	C15292
	Other	C17649
The number assigned to a c		
The code used to designate	Protocol Therapy	C173257
	Study	C29851
The reason a subject went	Death	C93546
	Lost to Follow-Up	C70740
	Completion of Planned Therapy	C168935
	Physician Decision	C48250
	Withdrawal of Consent	C48271
	Subject/Guardian Refused Further Treatment	C168934
	Disease Progression	C35571
	Relapse	C38155
	Adverse Event	C41331
	Secondary Malignancy	C4968
	Other	C17649
	Unknown	C17998
	Not Reported	C43234

<http://sam.am/datadictionaries>

# Data collection is highly localized

<input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Unknown <i>English</i>	<input type="checkbox"/> 男 <input type="checkbox"/> 女性 <input type="checkbox"/> わからない <i>Japanese</i>
<input type="checkbox"/> ذكر <input type="checkbox"/> أنثى <input type="checkbox"/> مجهول <i>Arabic</i>	<input type="checkbox"/> Homme <input type="checkbox"/> Femelle <input type="checkbox"/> Inconnue <i>French</i>
<input type="checkbox"/> Männlich <input type="checkbox"/> Weiblich <input type="checkbox"/> Unbekannt <i>German</i>	<input type="checkbox"/> 男性 <input type="checkbox"/> 女性 <input type="checkbox"/> 未知 <i>Chinese</i>

# CDE mapping solves the localization problem

Male  
 Female  
 Unknown  
*English*

男  
 女性  
 わからない  
*Japanese*

ذكر  
 أنثى  
 مجهول  
*Arabic*

Homme  
 Femme  
 Inconnue  
*French*

Männlich  
 Weiblich  
 Unbekannt  
*German*

男性  
 女性  
 未知

C20197  
C16576  
C17998

The screenshot shows the NCI Thesaurus web interface. At the top, it says 'NIH NATIONAL CANCER INSTITUTE' and 'www.cancer.gov'. Below that, it says 'NCI Term Browser' and 'EVS Enterprise Vocabulary Services'. There are tabs for 'Terminologies', 'Value Sets', and 'Mappings'. A search bar is visible with a search button. Below the search bar, there are radio buttons for 'Contains', 'Exact Match', and 'Begins With', and checkboxes for 'Name', 'Code', 'Property', and 'Relationship'. There are also links for 'Back to search results' and 'Advanced Search'. Below the search bar, there are links for 'Hierarchy', 'Value Sets', and 'Maps'. The main content area shows the entry for 'Male (Code C20197)'. It has tabs for 'Terms & Properties', 'Synonym Details', 'Relationships', 'Mappings', and 'View All'. The 'Terms & Properties' tab is selected. The entry shows the preferred name 'Male', a definition, a CDISC definition, a label, and various codes and links.

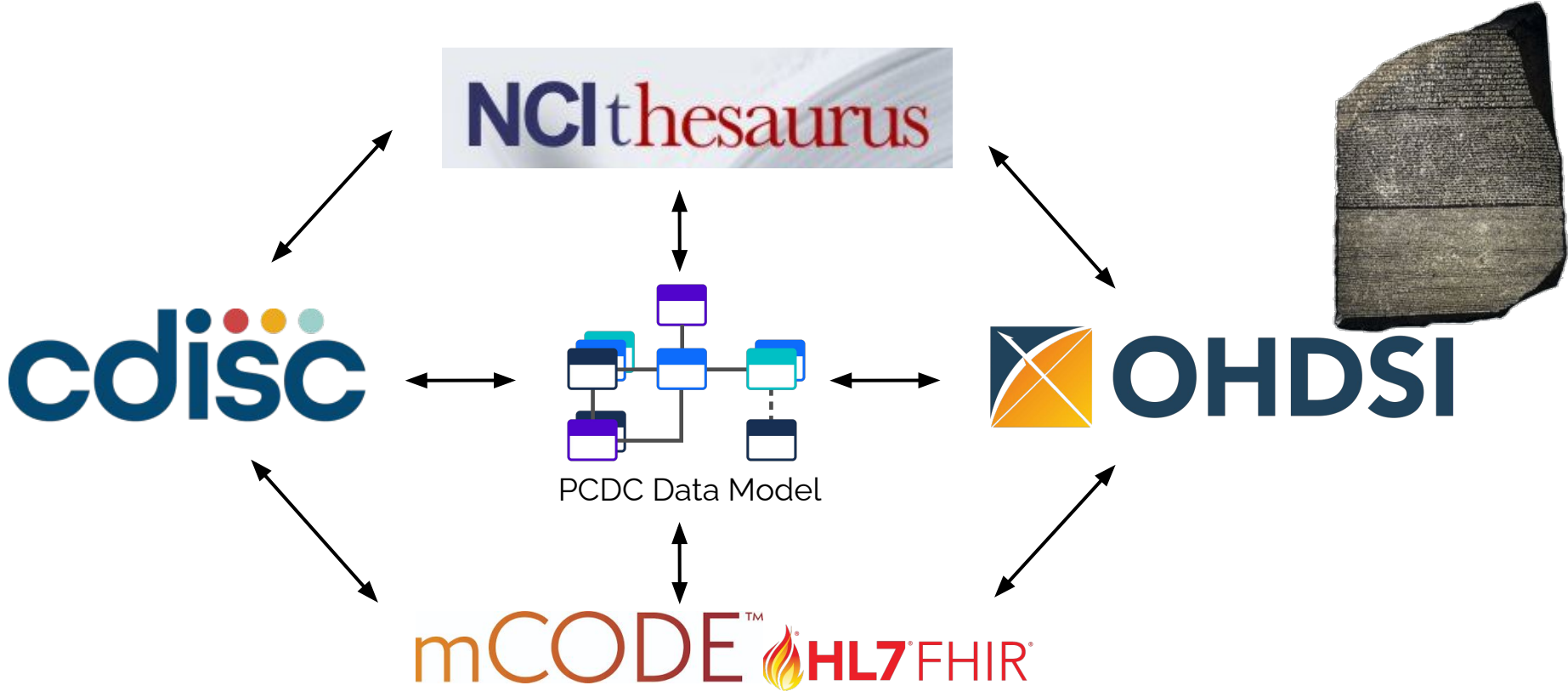


# PCDC data dictionaries

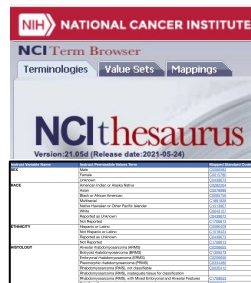
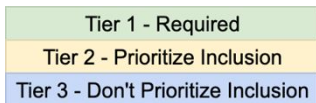
- PCDC Master Data Dictionary
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- Retinoblastoma (RB)
- Rhabdomyosarcoma (RMS)

<http://sam.am/datadictionaries>

# Data dictionary interoperability



# Getting data into the PCDC





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<http://sam.am/Paris2023>



# PCDC worldwide participation

## Worldwide Data Use Agreements

US - 8 master agreements  
(+21 addenda/projects)

Non-US - 6 master agreements  
(+5 addenda/projects)

## Worldwide Data Contributor Agreements

US - 7 master agreements  
(+18 addenda)

Non-US - 13 master agreements  
(+12 addenda)

### N. America

CBTN  
COG  
DFCI  
IDIPGR  
NRG  
PNOC  
RBTC  
St. Jude



### Europe

AIEOP  
CCLG  
COSS  
CRCTU  
EEC  
EpSSG  
EuPAL  
GPOH  
GEIS  
GSF-GETO  
ISG  
MRC  
NCRI  
SIOPE  
SIOPEN  
SSG  
SFCE  
UNICANCER



### Asia

JCCG  
SIOPEN  
EpSSG  
COG

### S. America

SOBOPE  
EpSSG  
GALOP  
GLATO

### Oceania

COG  
EpSSG

# New cancer-related consortia

post transplant  
lymphoproliferative  
disease

acute  
lymphocytic  
leukemia

acute myeloid  
leukemia

**INTERACT**

bone tumors  
(OS and EWS)

**HIBiSCus**

Fanconi  
anemia

central nervous  
system tumors

**INSPIRE**

germ cell  
tumors

**MaGIC**

Hodgkin  
lymphoma

**NODAL**

neuroblastoma

**INRG**

nasopharyngeal  
carcinoma

**NOBLE**

oncofertility

**Reproductive  
HOPE**

Langerhans cell  
histiocytosis

cancer  
predisposition

**C3P**

retinoblastoma

**Global REACH**

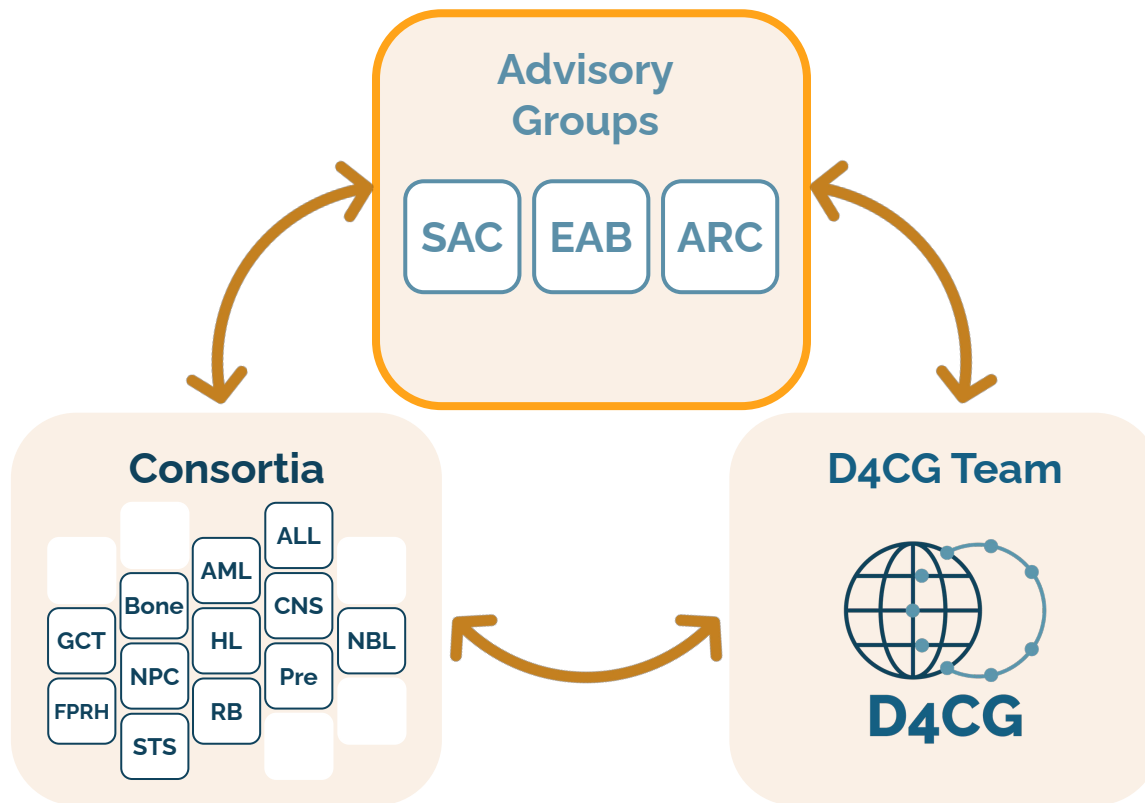
soft-tissue  
sarcoma

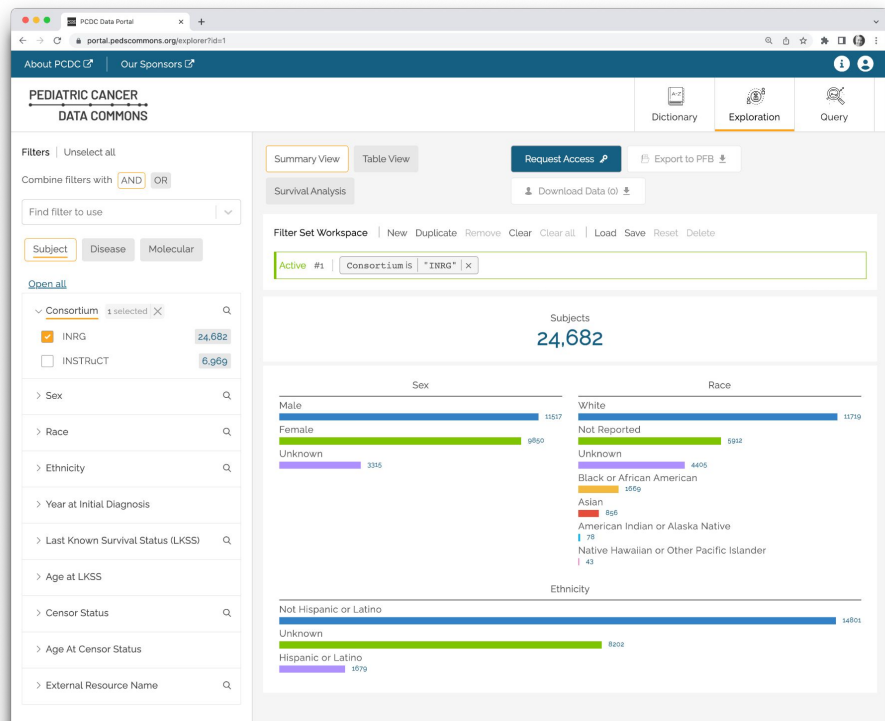
**INSTRuCT**

myelodysplastic  
syndrome



# PCDC advisory groups structure





<http://portal.pedscommons.org>

The screenshot displays the PCDC Data Commons interface. On the left, a filter sidebar shows 'Subject' filters: Consortium (1 selected), INRG (24,682), and INSTRuCT (6,969). The main workspace shows a filter set for 'Stage' with 4 selected options: Stage 1 (4,122), Stage 2a (1,279), Stage 2b (1,777), and Stage 3 (3,700). Stage 4 is unselected (11,413). The main view displays 24,682 subjects with horizontal bar charts for Sex, Race, and Ethnicity.

Stage	Count
Stage 1	4,122
Stage 2a	1,279
Stage 2b	1,777
Stage 3	3,700
Stage 4	11,413

<http://portal.pedscommons.org>

PCDC Data Commons Portal

PEDIATRIC CANCER DATA COMMONS

Summary View | Table View | Request Access | Export to PFB | Download Data

Filter Set Workspace

Active #1 | Consortium is "INRG" | X

Subjects: 24,682

Sex: Male (11917), Female (9850), Unknown (3315)

Race: White (9741), Not Reported (3088), Unknown (3310), Black or African American (2852), Asian (764), Hispanic or Latino (1018)

Ethnicity: Not Hispanic or Latino (11917), Unknown (3315), Hispanic or Latino (1018)

Stage 4 selected

- Stage 1: 4,122
- Stage 2a: 1,279
- Stage 2b: 1,777
- Stage 3: 3,700
- Stage 4: 11,413

Save changes to the current Filter Set

Name: INSS Stage 1, 2a, 2b, 3

Description: Describe the Filter Set (optional)

Filters

Consortium is "INRG" AND Stage System is "INSS" AND Stage is any of "Stage 3", ...

Back to page | Save changes

<http://portal.pedscommons.org>

Survival type: Overall Survival

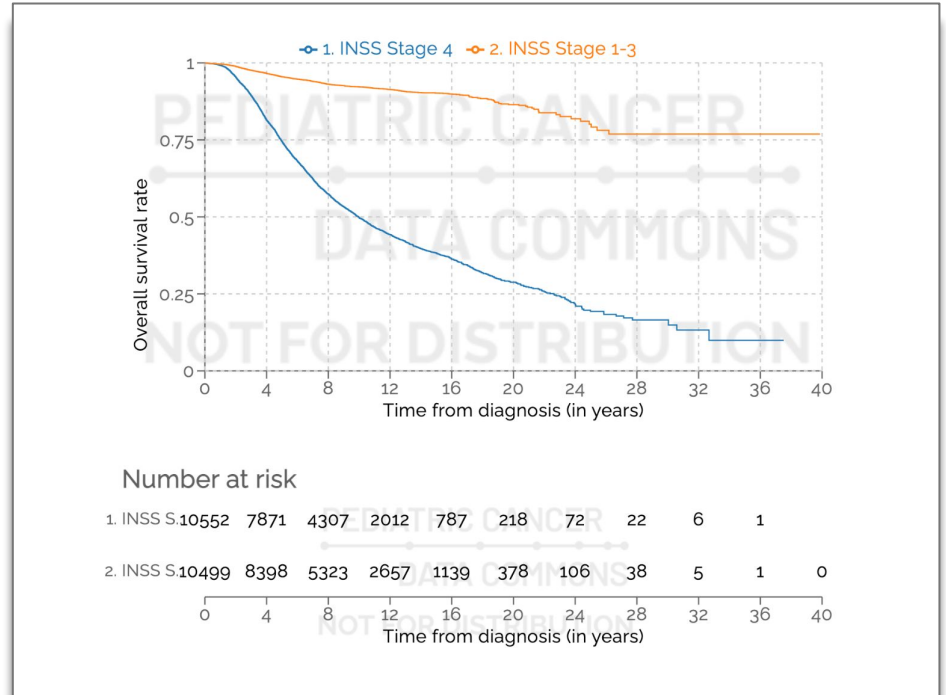
Start time (year): 0

End time (year): Optional; max value if left blank

Time interval (year): 4

Select Filter Set to analyze: Add

- > 1. INSS Stage 4 10552/11413 X
- > 2. INSS Stage 1-3 10499/10878 X



<http://portal.pedscommons.org>

# Cohort discovery - linking to Genomic Data Commons

The screenshot shows the Pediatric Cancer Data Commons interface. A modal window titled "Find Cohort in An External Data Commons" is open, allowing users to search for cohorts in external data commons. The modal includes a dropdown for "Data Commons" (currently set to "Select data commons"), a "Filters" section with "Select data commons" and "Genomic Data Commons" options, and buttons for "Back to page" and "Open in new tab". The background interface shows a "Filter Set Workspace" with 38,277 subjects and various filters for Subject, Disease, Molecular, Surgery, Radiation, Response, SMN, Imaging, Labs, and SCT.

The screenshot shows the National Cancer Institute GDC Data Portal. A table of cohorts is displayed with columns for Case ID, Project, Primary Site, Gender, Files, and Available Files per Data Category. A search bar and "Upload Case Set" button are visible. The table lists various cohorts with their respective details.

Direct connection to other data commons  
(Genomic Data Commons, Gabriella Miller Kids First)

<http://portal.pedscommons.org>



# Engagement / Education

## Education

- Promoting data literacy through training
- Young / early stage investigator seminars

## Engage the community

- Webinars
- Thought leadership
- Live events
- Patient and family involvement
- International advisory board



YouTube channel page for Pediatric Cancer Data Commons (PCDC). The page displays the channel name, 15 subscribers, and a 'SUBSCRIBE' button. Below the channel header, there are several video uploads with thumbnails and titles. The thumbnails feature the PCDC logo and various scientific graphics. The video titles include 'The Common Good: Carlos Rodriguez-Galindo', 'PCDC Public Webinar: Connect, Share, Discover', 'The Common Good - Adam Resnick', 'Transforming the Way Researchers Share Data', and 'The Common Good - Sam Blackman'.

Goals

Data Operations

Governance

Platform

Engagement

Sustainability

sam.am/pcdcresearch

	A	B	C	D			
1	<b>INRG Research</b>						
	<i>Click on a description to view the original project proposal.</i>						
2	INRG #	Principal Investigator	Description	Project Type	Status	Publication	Presentation
3	2022-04	Mallory Taylor Thomas Cash Wendy London Julie Park Meredith Irwin	<a href="#">Outcomes for patients aged 12-18 months with Stage M MYCN non-amplified neuroblastoma and unfavorable biologic features (Mixed Phenotype Toddlers)</a>	Investigator	In Progress		Presented at ANR 2022
4	2022-03	Hanxiao Yu Xingda Zhan Mark Appelbaum Gudrun Schleiermacher statistician to be named	<a href="#">Prognostic impact of segmental chromosome alterations in high-risk neuroblastoma patients on immunotherapy: A report from the International Neuroblastoma Risk Group (INRG) project</a>	Investigator	In Progress		
5	2022-02	Boris Decarolis Wendy London Susan Cohn Andrew Pearson	<a href="#">Survival of patients with low-, intermediate-, or high-risk neuroblastoma over a 35 year period</a>	Investigator	In Progress		
6	2022-01	Wendy London Ramya Ramanujachar Kavitha Srivatsa Paola Angelini	<a href="#">Neuroblastoma in adolescents and adults- a study of clinical and biological features and outcomes</a>	Investigator	In Progress		
7	2021-01	Kevin Campbell Pei-Chi Kao Arlene Naranjo Takehiko Kamijo Ramya Ramanujachar Wendy London Steven DuBois	<a href="#">Clinical and Biological Features Predictive of Survival After Relapse of Stage MS Neuroblastoma: A Report From the International Neuroblastoma Risk Group Project</a>	Investigator	Published	<a href="#">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.</a> <i>Pediatr Blood Cancer.</i> 2023 Feb;70(2):e30054. Epub 2022 Oct 31. doi: 10.1002/pbc.30054.	
8	2020-03	Riyue Bao Stefani Spranger Kyle Hernandez Yuanyuan Zha Peter Pytel Jason Luke Thomas Gajewski Samuel Volchenbom Susan Cohn	<a href="#">Validation of a T-cell inflammatory signature and outcomes in patients with neuroblastoma</a>	Investigator	Published	<a href="#">Immunogenomic determinants of tumor microenvironment correlate with superior survival in high-risk neuroblastoma.</a> <i>J Immunother Cancer.</i> 2021 Jul;9(7):e002417. doi: 10.1136/jitc-2021-002417. PMID: 34272305; PMCID: PMC8287618.	



## PATIENT INFORMATION

...

## Demographics

^

What is the patient's current age (in years)?

13

What is the patient's biological sex?

 Male Female

## Disease

^

What is the patient's current diagnosis?

Embryonal Carcinoma

Does the patient currently have, or have they in the past had, refractory disease?

 Yes No Not sure

Is the patient's disease currently refractory?

 Yes No Not sure

Does the patient currently have, or have they in the past had, confirmed or suspected relapse disease?

 Yes No Not sure

What is the patient's ECOG score?

ECOG 1 (Lansky/Karnofsky 70-80)

## OPEN TRIALS

## Matched (1)

^

20-489

*i* v

Title

A Study of Codrituzumab in Children and Young Adul...

## Undetermined (1)

^

H-47757 AGAR

*i* v

Title

Interleukin-15 Armored Glypican 3-specific Chimeric...

## Unmatched (5)

^

RHM CHI0811

*i* v

Title

Phase I Study of 131-I mIBG Followed by Nivolumab ...

NCI-2021-00913

*i* v

Title

Testing the Combination of Two Immunotherapy Dru...

## PATIENT INFORMATION

...

## Demographics

^

What is the patient's current age (in years)?

What is the patient's biological sex?

 Male Female

## Disease

^

What is the patient's current diagnosis?

Does the patient currently have, or have they in the past had, refractory disease?

 Yes No Not sure

Is the patient's disease currently refractory?

 Yes No Not sure

## OPEN TRIALS

## Matched (1)

^

20-489

i

^

## Title

A Study of Codrituzumab in Children and Young Adults With Solid Tumors and Have Not Responded to Treatment or Have Come Back After Treatment

## Description

The purpose of this study to find out whether codrituzumab is a safe treatment that causes few or mild side effects in children and young adults who have solid tumors that express the protein GPC3. The researchers also want to study the way codrituzumab is absorbed, distributed, and cleared from the body.

## Locations

- Cincinnati Children's Hospital Medical Center
- Memorial Sloan Kettering Cancer Center

## Link

- [ClinicalTrials.gov](https://clinicaltrials.gov)

# Connecting the dots



pediatric, AYA, or  
adult cancer



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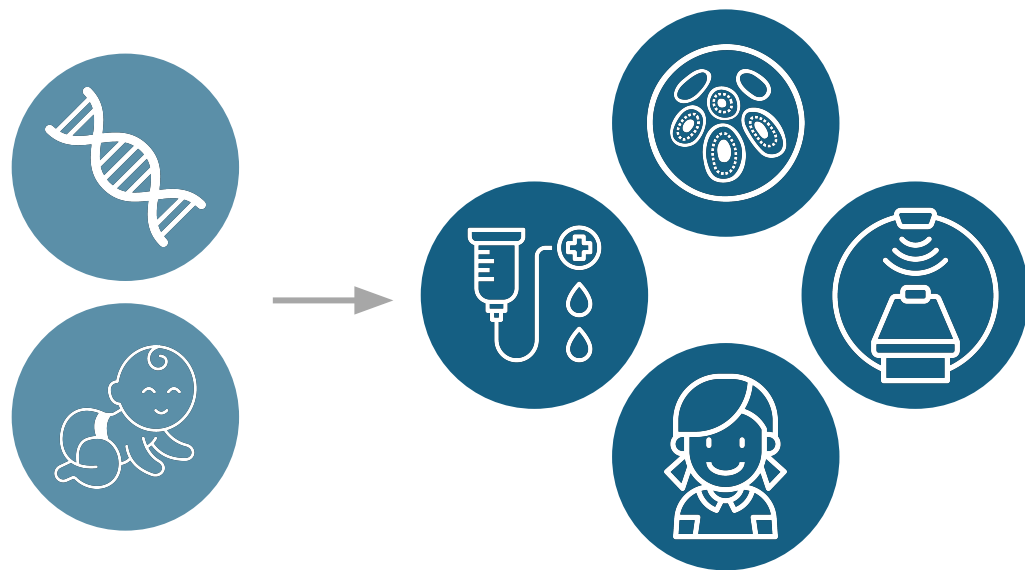
<http://sam.am/Paris2023>



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INSTITUTE



# Connecting the dots



cancer  
predisposition  
syndrome

pediatric, AYA, or  
adult cancer



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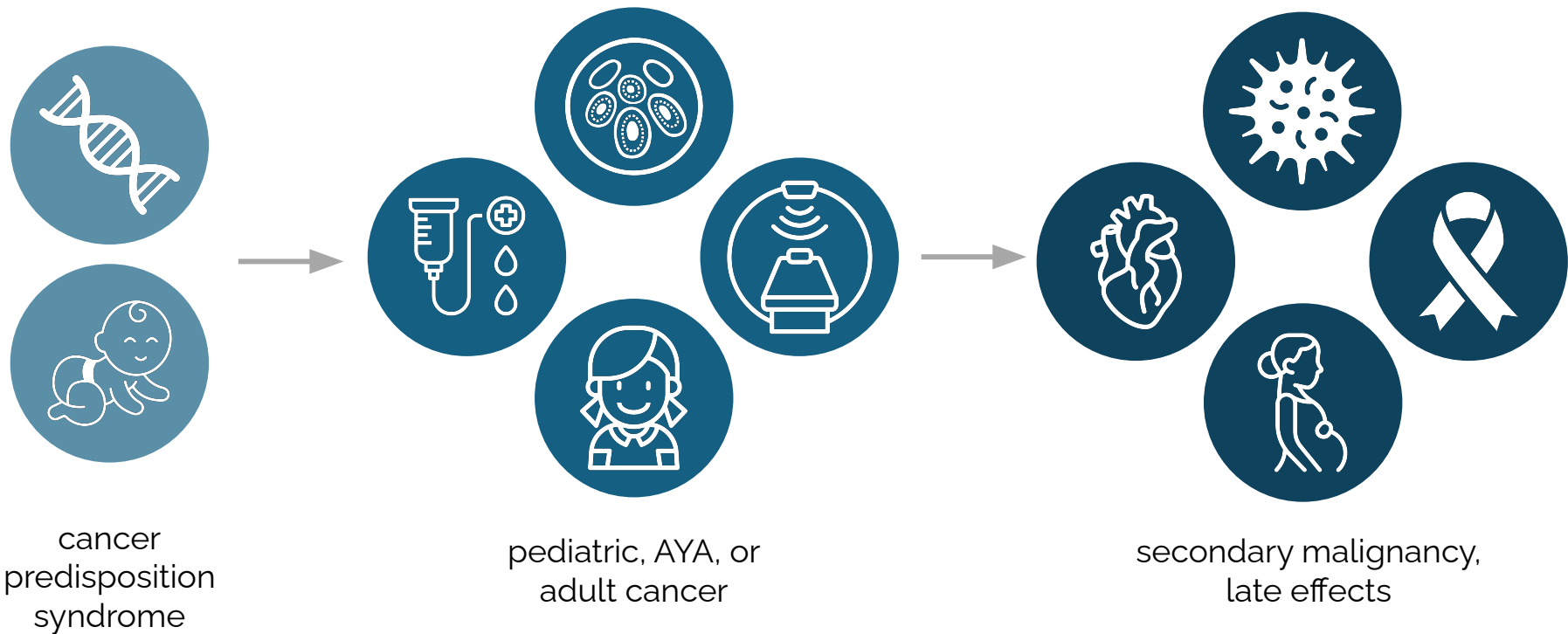
<http://sam.am/Paris2023>



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CANCER  
INSTITUTE



# Connecting the dots



# Why use the D4CG model for other rare diseases?



**Lack of data** hinders research for rare diseases.



Lack of community consensus and **deficient data standards** make data aggregation difficult or impossible.



Researchers cannot **make progress and improve patient outcomes** without high-quality data.



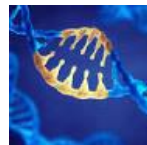
We envision a world where **access to high-quality data** is never a barrier to **improving human health**.



food allergies

PEDIATRIC CANCER  
DATA COMMONS

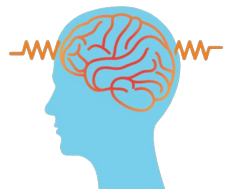
pediatric cancer



monogenic  
diabetes



Crohn's disease



epilepsy



Sociome



other rare diseases



...and more

# A model for transforming human health



- Studying rare diseases requires **collaboration and sharing**
- Data sharing must be built on a foundation of **trust and consensus**
- **Connecting disparate data types** and sources enriches research
- **Consensus data standards** are critical for the success of national and international data ecosystems – allowing aggregation across trials and diseases
- **Early adoption of data standards** and consideration for the **lifecycle of the data** are critical to accelerating progress and discovery

# Do research with the PCDC and stay connected

[portal.pedscommons.org](https://portal.pedscommons.org)

Explore the PCDC Data Portal

[sam.am/datadictionaries](https://sam.am/datadictionaries)

Access data dictionaries

[slv@uchicago.edu](mailto:slv@uchicago.edu)

[suzi@uchicago.edu](mailto:suzi@uchicago.edu)

Sign up for our email list!

[sam.am/D4CGnews](https://sam.am/D4CGnews)

# Sustainability is key

Thank you to these funders for supporting our work in FY23 and/or FY24.



United States  
Department of the Interior



Aileen S. Andrew  
Foundation



Sarah Jane Adicoff Endowment for  
Research in Rhabdomyosarcoma



DATA FOR THE  
COMMON GOOD

Paris Conference for an International Childhood Cancer Data Partnership  
Newcap Event Center (Paris, France), November 7-8, 2023  
<http://sam.am/Paris2023>



# Thank you!

consortium members

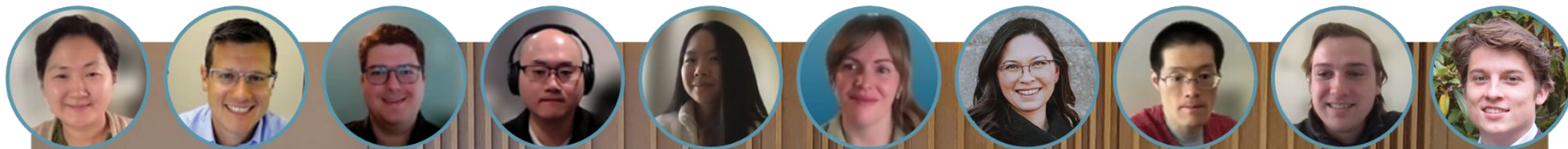
collaborators

data portal users

advisory group members

funders

patients and families



None of this would be possible without YOU.



THE UNIVERSITY OF  
CHICAGO



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