



Roundtable
Suzi Birz-supporting materials



THE UNIVERSITY OF
CHICAGO



DATA FOR THE
COMMON GOOD



Paris Conference for an International Childhood Cancer Data Partnership
Newcap Event Center (Paris, France), November 7-8, 2023



Data for the Common Good

Connect. Share. Discover.

Roundtable - Suzi Birz supporting materials



DATA FOR THE
COMMON GOOD



Paris Conference for an International Childhood Cancer Data Partnership
Newcap Event Center (Paris, France), November 7-8, 2023



commons.uchicago.edu

“The PCDC” - data, tools, and people

PEDIATRIC CANCER DATA COMMONS

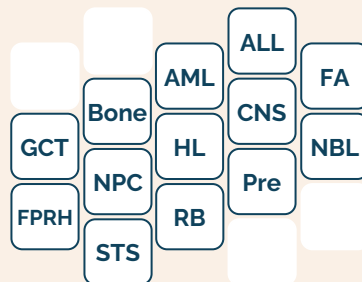
Advisory Groups



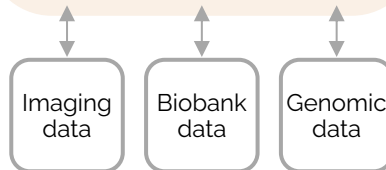
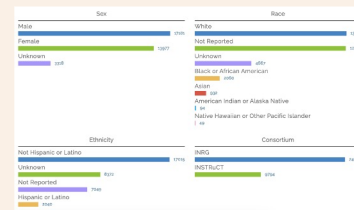
D4CG Team



Consortia



PCDC Data Portal



Data Dictionary Meetings

D4CG produces an initial draft dictionary. A data dictionary working group is formed and meets to discuss all aspects of the data dictionary

We align with existing D4CG conventions and data elements, augmenting these where required for new diseases, new domains, etc

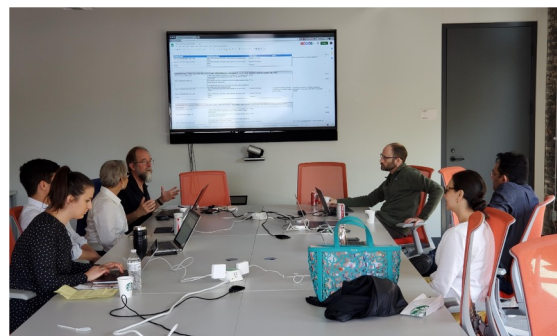
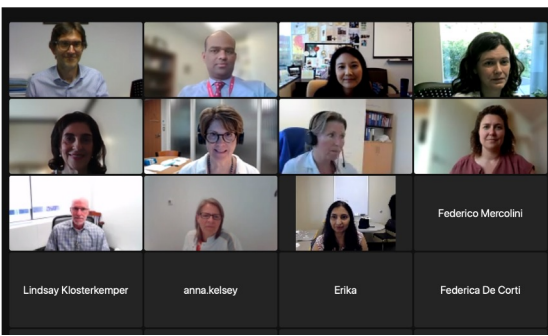
NBL (INRG) ☆ 📄 ☁

File Edit View Insert Format Data Tools Extensions Help

50% \$ % .0 .00 123 Raleway

A1 🔍 RowType

1	A	B	C	D	E	F	G	H
RowType	VariableName	DataType	Tier	VariableSource	VariableDescription	VariableCode	PermissibleValue	
2	TD	Subject Identifier						
3	TG	<i>Will be included in every table</i>						
4	VD	PCDC_SUBJECT_ID	String		ALLIAMJGCTH A unique subject id assigne nct:C175600	.._undefined_		
5								
6								
7	DD	Protocol						
8	TD	Subject Characteristics						
9	TG	<i>One row per subject per study</i>						
10	VD	HONEST_BROKER_SUBJECT_ID	String	1	ALLIAMJCSJC The identifier assigned to t nct:C168949	.._undefined_		
11	VD	CONSORTIUM	Code	1	ALLIAMJCSJC The consortium under whic	.._undefined_		INRG
12	PD							
13	VD	DATA_CONTRIBUTOR_ID	Code	1	ALLIAMJCSJC An identifier assigned to a c nct:C168950	.._undefined_		COG
14	PD							GPOH
15	PD							JCCG
16	PD							JINCS
17	PD							JNBSG
18	PD							SIOPEN
19	PD							
20	VD	STUDY_ID	Code	1	ALLIAMJCSJC A sequence of characters u nct:C83082	.._undefined_		
21	PD							ANBL0531
22	PD							ANBL0032
23	PD							ANBL1232
24	PD							ANBL1221
25	VD	AGE_AT_ENROLLMENT	Integer	3	ALLIAMJCPIEW The age (in days) when the nct:C168843	.._undefined_		
26	VD	YEAR_AT_ENROLLMENT	Integer	3	GCTINBL The year at which a subject nct:C177353	.._undefined_		
27	VD	TREATMENT_ARM	Code	2	ALLIAMJCSJSE A specific treatment plan w nct:C15538	.._undefined_		"Need treatment arms"
28	PD							Unknown
29	PD							Not Reported
30	PD							.._undefined_
31	VD	EFS_CENSOR_STATUS	Code	2	NBLINRSTSRM The length of time after prii	.._undefined_		Censored
32	PD							Not Censored
33	PD							Unknown
34	PD							Not Reported
35	PD							.._undefined_
36	VD	AGE_AT_CENSOR_STATUS	Integer	2	NBL Age (in days) of the subject	.._undefined_		
37								
38								
39	DD	Protocol						
40	TD	Time Period						
41	TG	<i>One row per subject per time perio</i>						
42	VD	SUBMITTER_ID	String	2	ALLIAMJCSJC An ID provided by the data	.._undefined_		
43	VD	PARENT_SUBMITTER_ID	String	2	ALLIAMJCSJC The SUBMITTER_ID of the l	.._undefined_		
44	VD	TIME_PERIOD_TYPE	Code	2	ALLIAMJCSJC The type of time period bei	.._undefined_		
45	PD							Disease Phase
46	PD							Course
47	VD	DISEASE_PHASE	Code	2	ALLIAMJCSJC The phase of the cancer trc nct:C168878	.._undefined_		



Regulatory Framework - MOU, DCA, DUA

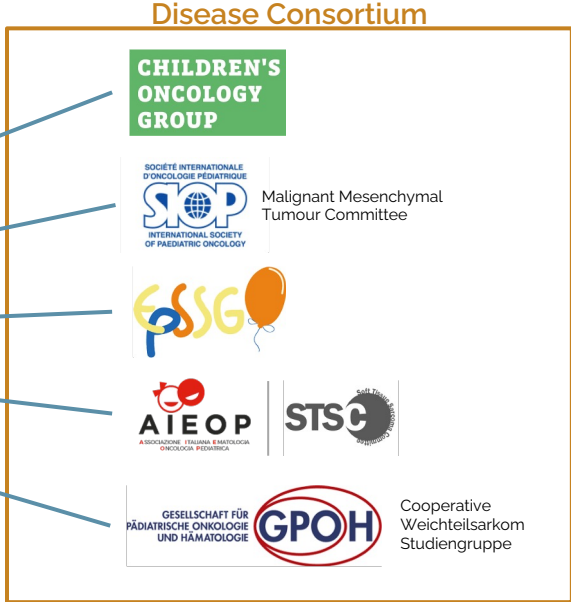


Data Use Agreement (DUA)

Data Contributor Agreement (DCA)

Legally binding

How data must be stored and protected
How data can be used for research

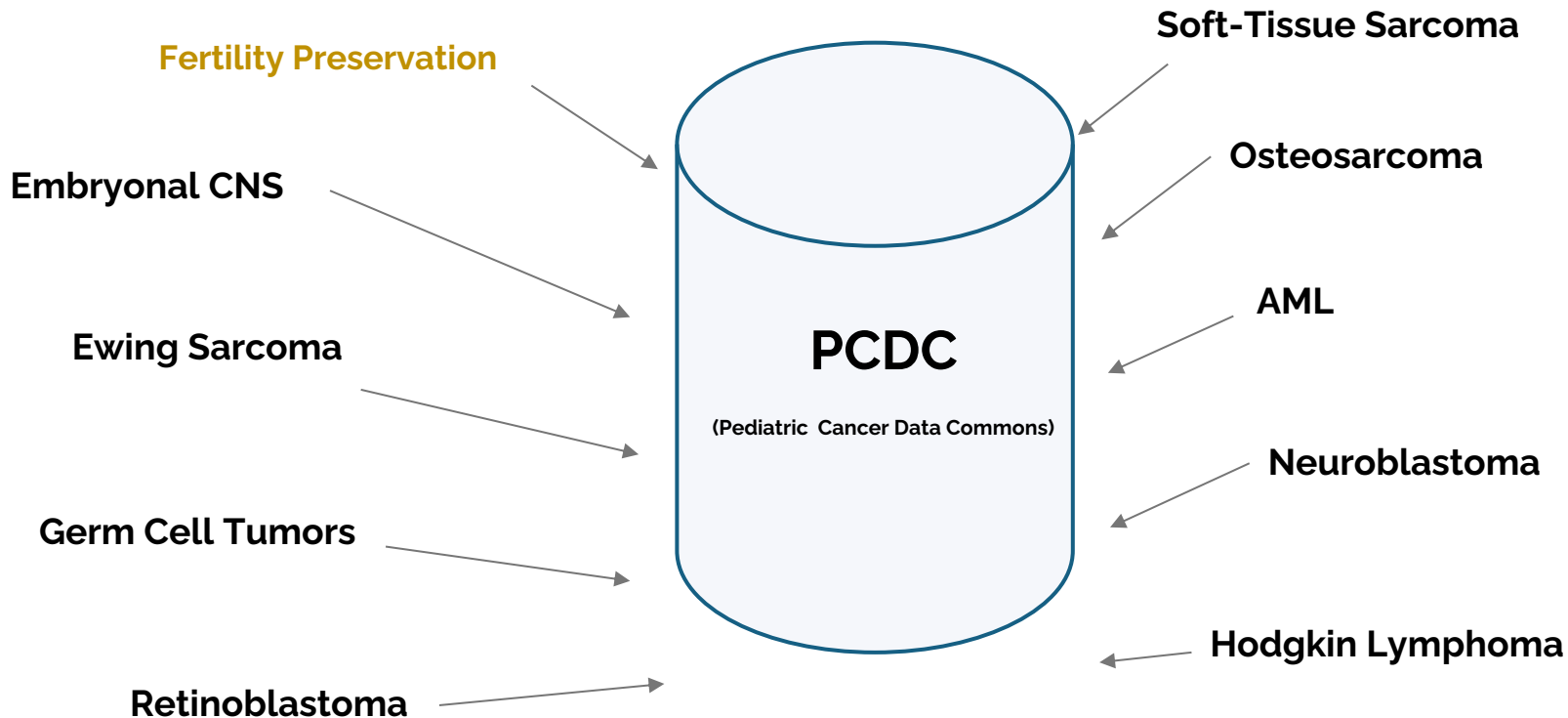


Memorandum of Understanding (MOU)

Not legally binding

Executive Committee membership
Publication policy

“Commons” at two levels



Model v. Dictionary

The D4CG data standards team maintains a single data model.

Individual disease's data dictionaries are limited views of this overarching PCDC model.

Variables and values (collectively concepts) are grounded in controlled terminologies like the NCI which provides the semantic backbone for interoperability

Goal: minimal conceptual overlap (i.e., to use the same variables to capture the same *type* of data)

Domains	Tables	AML	neuroblastoma	Hodgkin's lymphoma
Protocol	Subject Characteristics	✓	✓	✓
Protocol	Time Period	✓	✓	✓
Protocol	Off Protocol Therapy Or Study	✓	☐	✓
Demographics	Demographics	✓	✓	✓
Demographics	Medical History	✓	☐	✓
Demographics	Survival Characteristics	✓	✓	✓
Demographics	Family Medical History	☐	☐	✓
Testing	Vitals And Anthropometrics	✓	☐	✓
Testing	Laboratory Test	✓	✓	✓
Testing	Genetic Analysis	✓	✓	☐
Testing	Function Test	✓	☐	✓
Testing	Immunohistochemistry	☐	☐	✓
Testing	Imaging	☐	☐	✓
Disease Attributes	Histology	✓	✓	✓
Disease Attributes	Disease Characteristics	✓	✓	✓
Disease Attributes	Tumor Assessment	☐	✓	✓
Disease Attributes	Staging	☐	✓	✓
Treatment	Radiation Therapy	✓	☐	✓
Treatment	Stem Cell Transplant	✓	☐	✓
Treatment	Medication	✓	☐	✓
Treatment	Transfusion Medicine Procedure	✓	☐	✓
Treatment	Cellular Immunotherapy	✓	☐	☐
Treatment	Biopsy And Surgical Procedures	☐	☐	✓
Treatment	Protocol Treatment Modifications	☐	☐	✓
Response	Minimal Residual Disease	✓	☐	☐
Response	Subject Response	✓	✓	✓
Events	Adverse Events	✓	☐	✓
Events	Subsequent Malignant Neoplasm	✓	✓	✓
Events	Patient Reported Outcomes Metadata	☐	☐	✓
Events	Late Effects	☐	☐	✓

