REDCap: Finding and Reusing CDEs for Making Data Interoperable

Paul Harris, PhD
Vice President, Research Informatics
Professor, Biomedical Informatics
Vanderbilt University Medical Center

Agenda

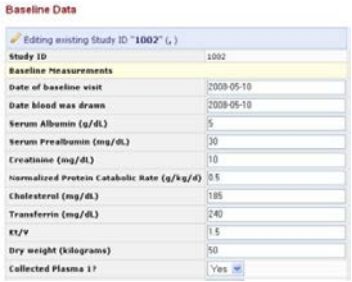
REDCap

REDCap Consortium

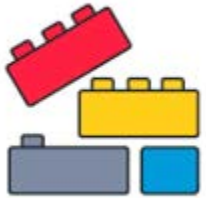
REDCap Platform

REDCap
Research Electronic Data Capture

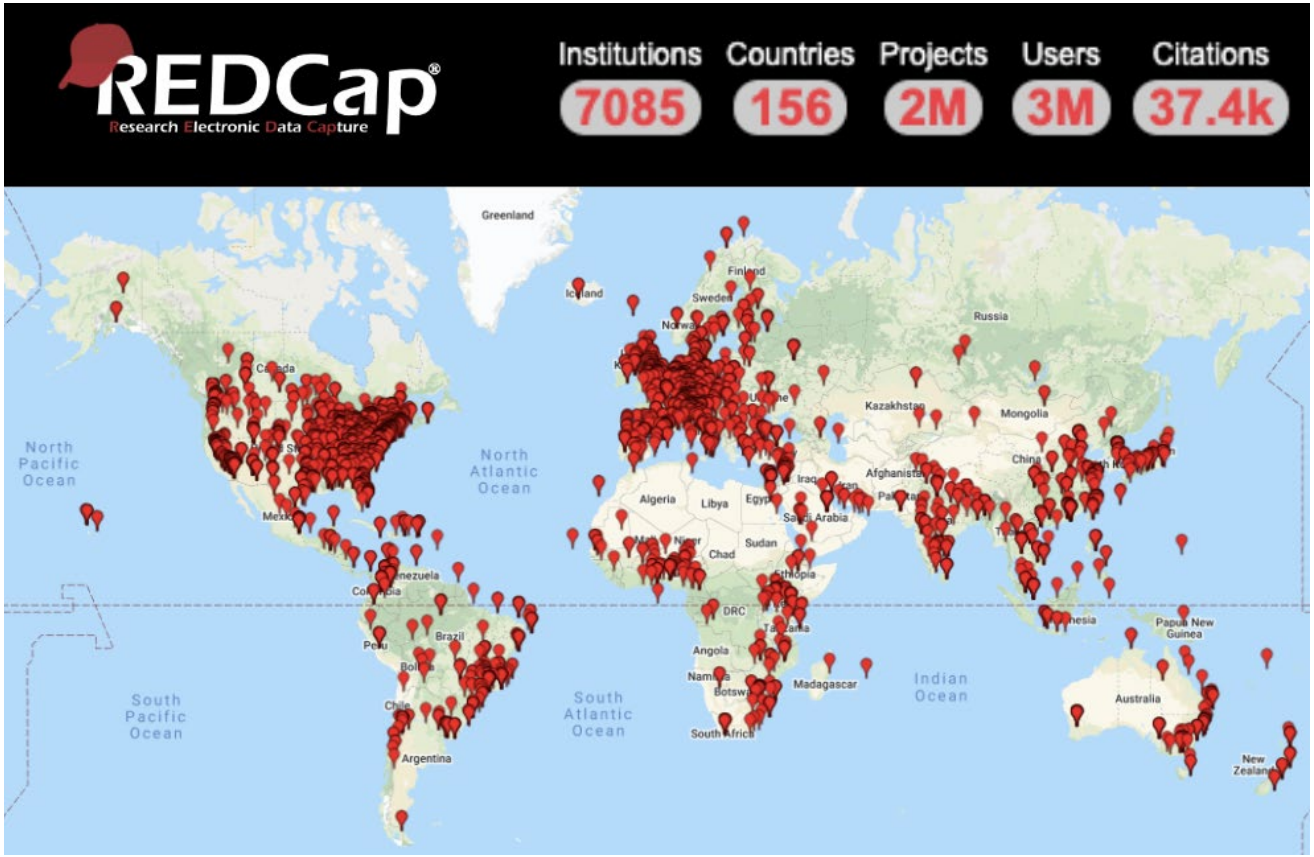
- A secure software platform designed to equip and empower clinical and translational researchers during the data collection planning, development, and deployment for clinical and translational research studies and trials.



- Is highly generalized and can be configured to support very diverse research use cases.

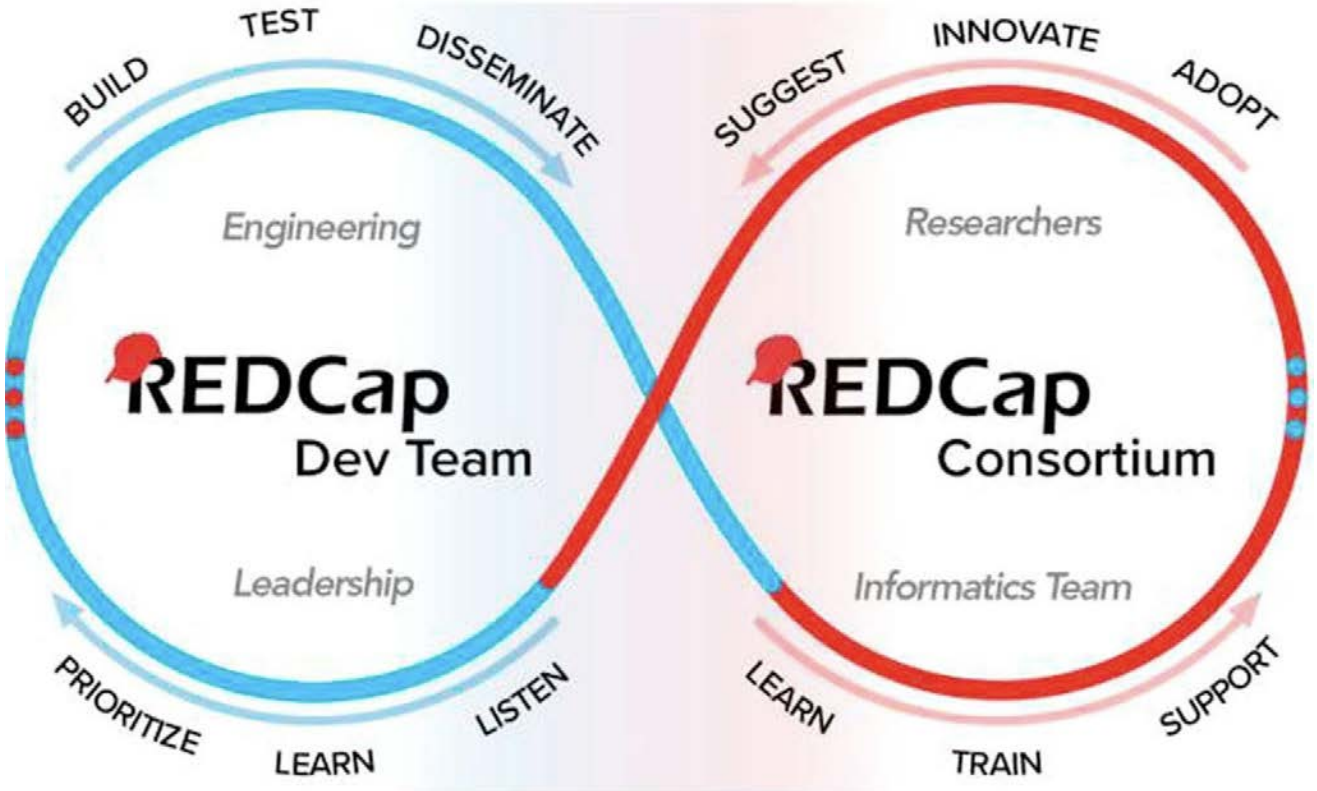


REDCap Consortium



REDCap software is available at no cost to academic, non-profit, and government organizations

REDCap Consortium - Empowerment → Innovation



REDCap Consortium - Empowerment → Innovation

~ 20 Years

~ 1 Functional Release Per Month

REDCap Consortium - Scientific Impact

NIH National Institutes of Health Office of Portfolio Analysis iCite

New Analysis | Global RCR Stats | How to cite | Help

Results

Citing Papers | Referenced Papers

Influence | Translation | Citations

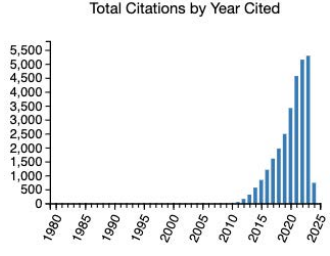
Roll over table headers for definitions; visit the Global RCR Stats page for percentile tables

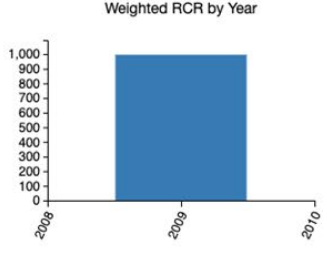
~ 1000 x average publication citation rate

Total Pubs	Pubs Per Year	Cites Per Year				Relative Citation Ratio (RCR)				Weighted RCR
		MAX	MEAN	SEM	MED	MAX	MEAN	SEM	MED	
1	1.00	1887.60	1887.60	0.00	1887.60	995.65	995.65	0.00	995.65	995.65

Total Citations

28314





Customization

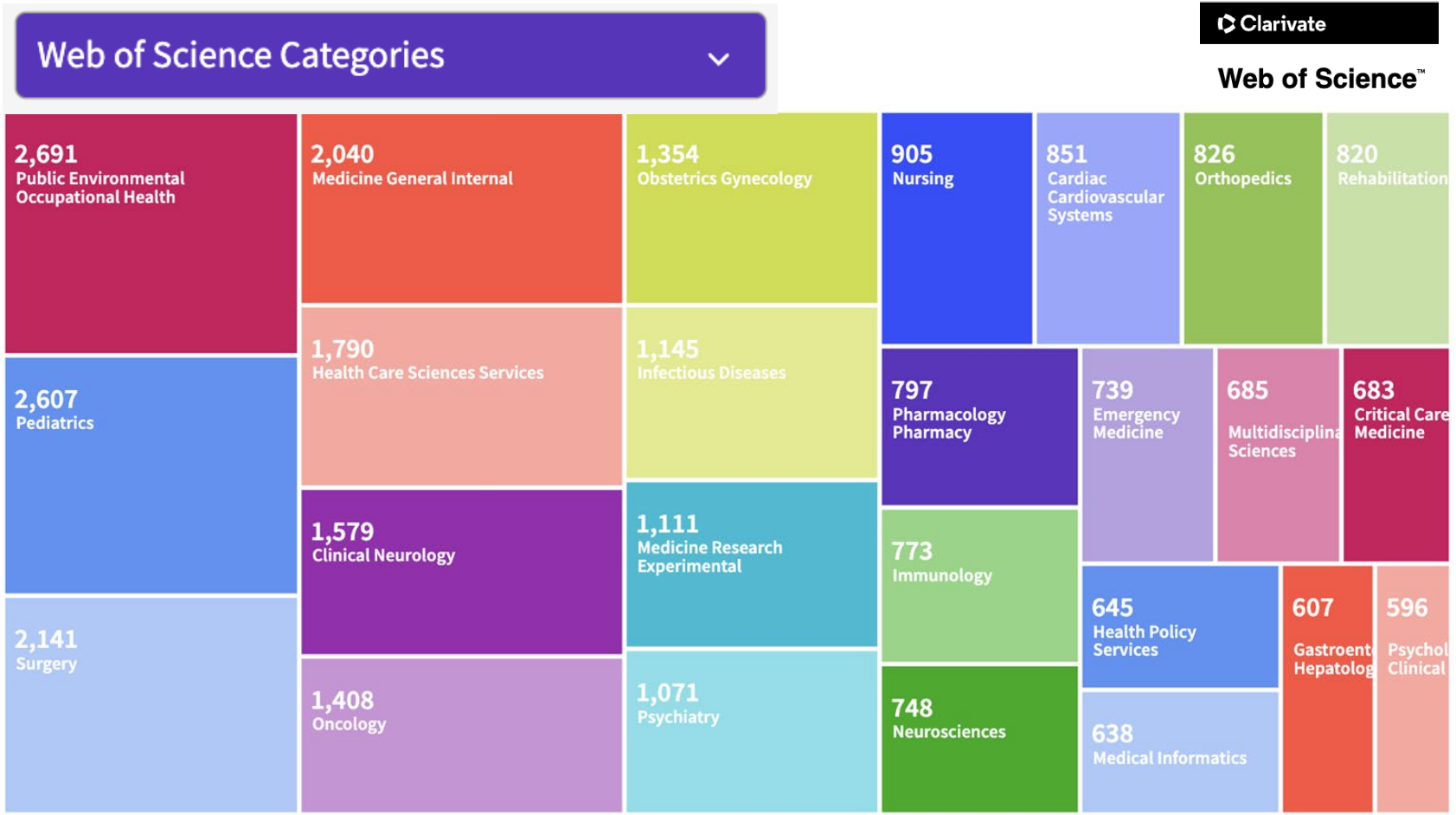
As you make changes below, the summary information and charts above are updated.

Total Pubs: 1

From 2009 To 2009 | Only research articles | Only papers cited by clinical articles | Only clinical articles | Clear Filters | Export

PMID	Year	Title	Authors	Journal	NIH Percentile	RCR
18929686	2009	Research electronic data capture (REDCap)--a metadata-driven methodology and workflow proce	Paul A Harris, Robert Taylor, Robert Th	J Biomed Inform	100.0	995.65

REDCap Consortium - Scientific Impact



REDCap Consortium - Empowering Large Research Programs

RARE DISEASES
CLINICAL RESEARCH NETWORK

All of Us
RESEARCH PROGRAM
The Future of Health Begins With You

THE NIA ALZHEIMER'S DISEASE RESEARCH CENTERS PROGRAM
National Alzheimer's Coordinating Center

RECOVER
Researching COVID to Enhance Recovery

An Initiative Funded by the National Institutes of Health

TRIAL INNOVATION NETWORK

ECHO
Environmental influences on Child Health Outcomes
A program supported by the NIH

DS-I Africa
Data Science for Health Discovery and Innovation in Africa

H3Africa
Human Heredity & Health in Africa

Agenda

REDCap CDE Workflow (Current State)

REDCap NIH/NLM CDE Repository Project

2021 - Central Question

Standardization of data elements is a necessary component of advancing interoperable datasets for research. Unfortunately, the problem with common data models is that there are so many and they are hard to find and implement. Can we build NLM CDE search features into REDCap to prompt or guide researchers to adopt common data element (CDE) standards during case report form creation?

Project Description

We built a CDE library function within the REDCap project creation workflow that allows researchers to utilize NLM CDEs while building research case report forms and surveys.

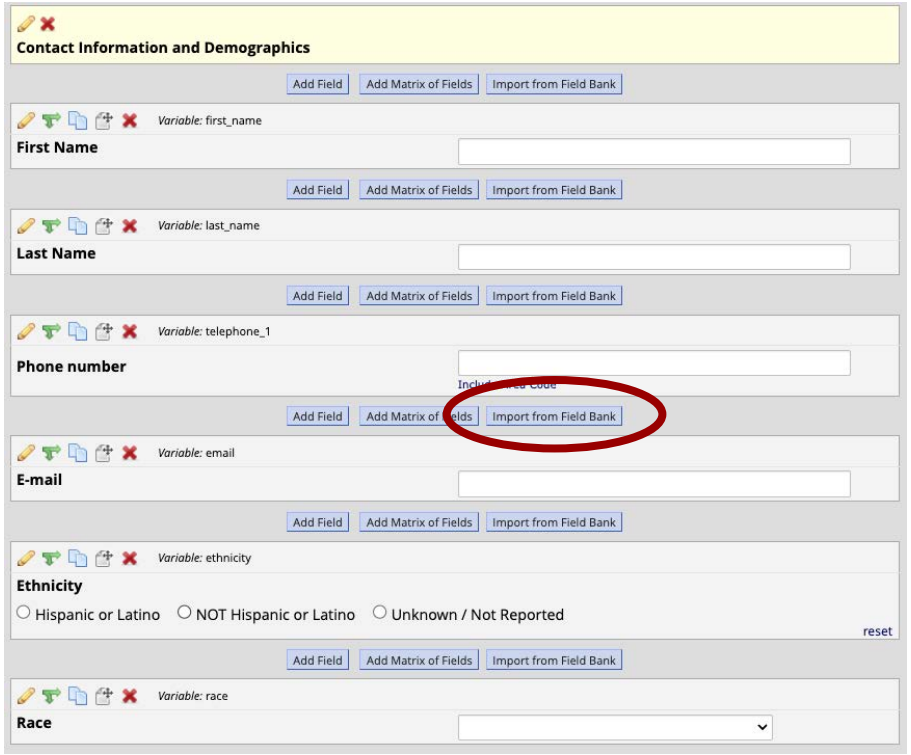
Approach

The CDE library within REDCap leverages the public application programming interface available from the NIH CDE Repository to search and retrieve metadata associated with NLM-curated CDEs.

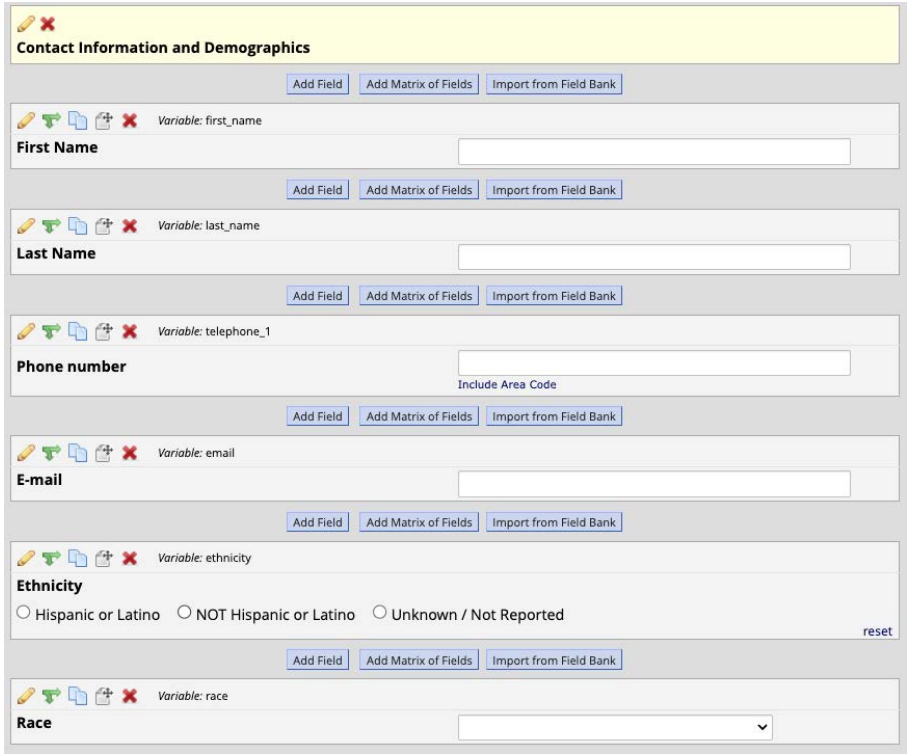
Progress / Results

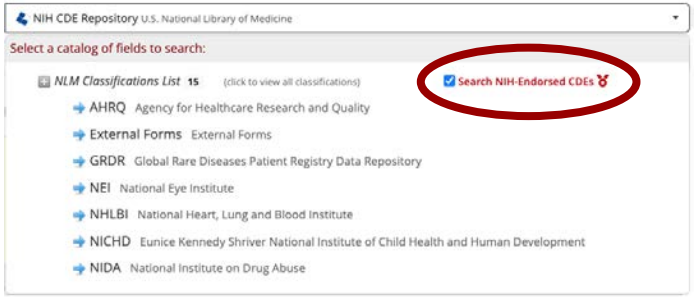
We released the new “Field Bank” feature in REDCap in January, 2021. We cannot see context in REDCap installations, but have recorded 12,338 CDEs imported into projects at ~ 250 institutions.

REDCap NIH/NLM CDE Repository Project

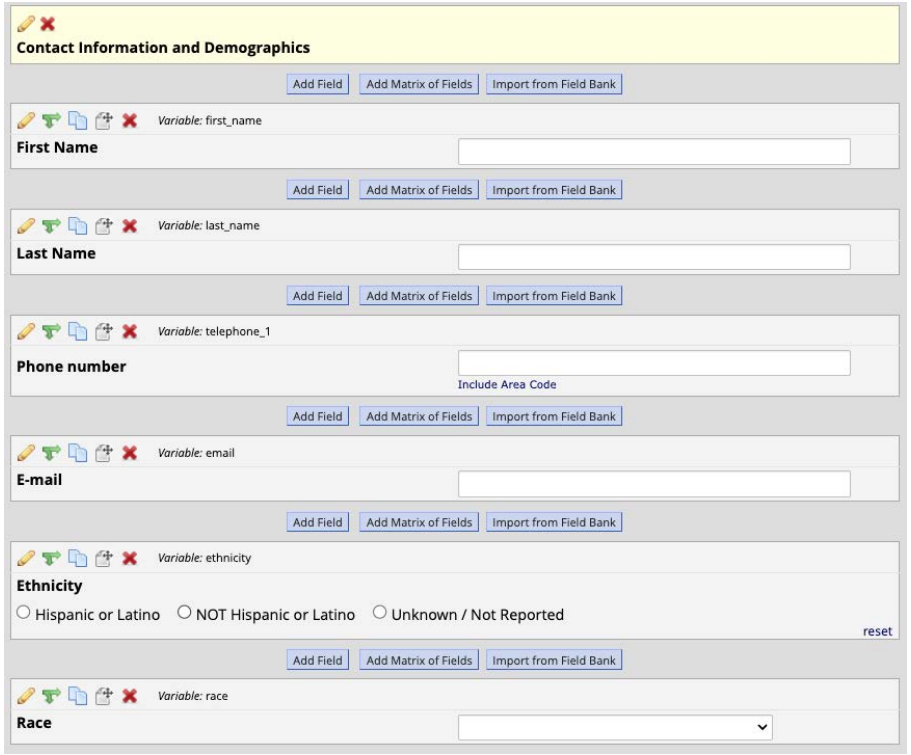


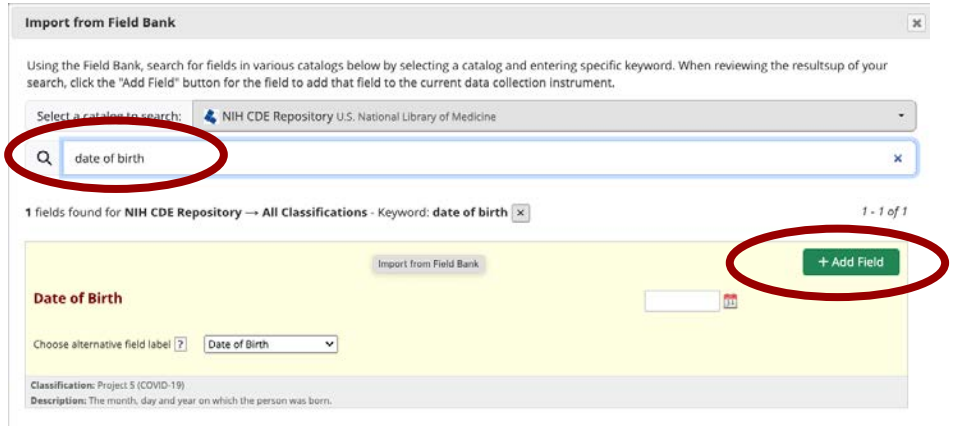
REDCap NIH/NLM CDE Repository Project



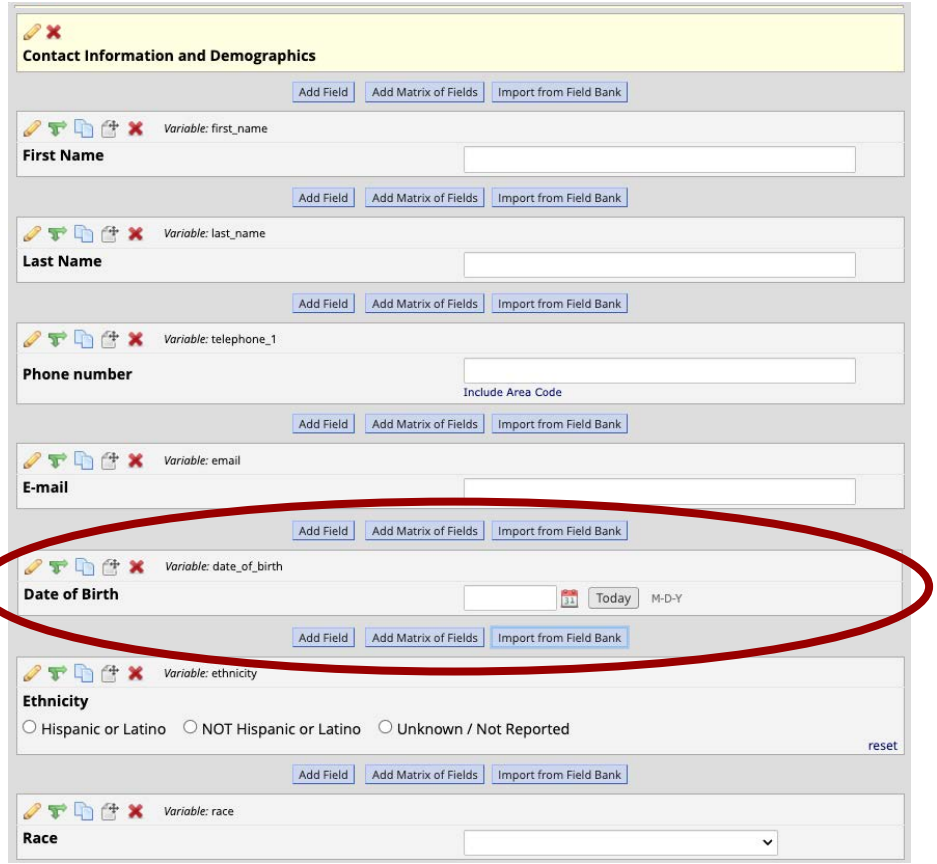


REDCap NIH/NLM CDE Repository Project

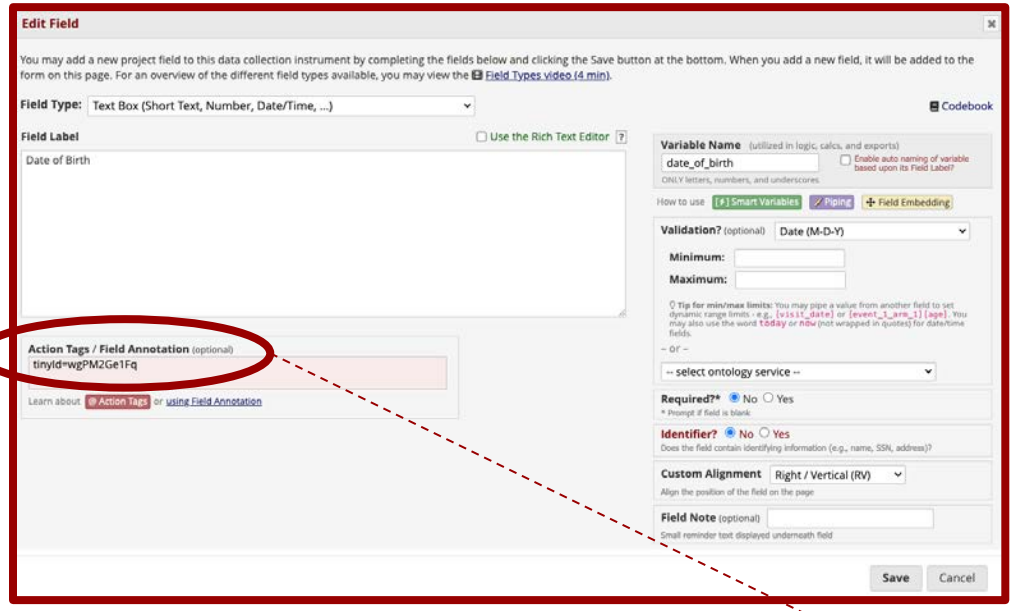


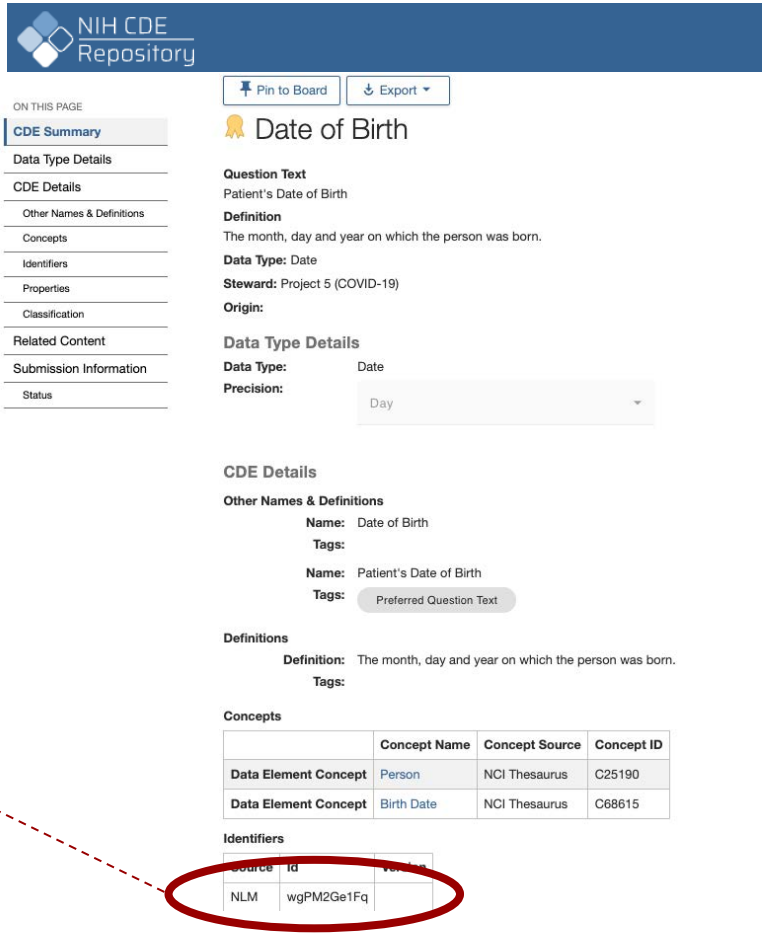


REDCap NIH/NLM CDE Repository Project



REDCap NIH/NLM CDE Repository Project

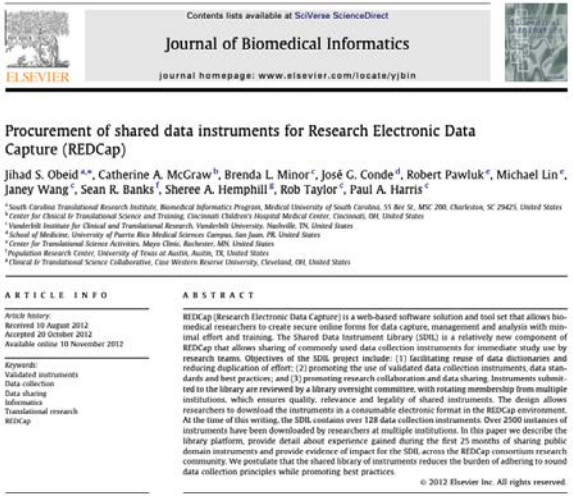




Agenda

REDCap CDE 2.0 Brainstorming

REDCap Shared Library



Contents lists available at SciVerse ScienceDirect

Journal of Biomedical Informatics

journal homepage: www.elsevier.com/locate/yjbin

Procurement of shared data instruments for Research Electronic Data Capture (REDCap)

Jihad S. Obeid [a,*], Catherine A. McGraw [b], Brenda L. Minor [c], José G. Conde [d], Robert Pawluk [e], Michael Lin [e], Janey Wang [c], Sean R. Banks [f], Sheree A. Hemphill [g], Rob Taylor [c], Paul A. Harris [c]

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REDCap

ABSTRACT

REDCap (Research Electronic Data Capture) is a web-based software solution and tool set that allows biomedical researchers to create secure online forms for data capture, management and analysis with minimal effort and training. The Shared Data Instrument Library (SDIL) is a relatively new component of REDCap that allows sharing of commonly used data collection instruments for immediate study use by research teams. Objectives of the SDIL project include: (1) facilitating reuse of data dictionaries and reducing duplication of effort; (2) promoting the use of validated data collection instruments, data standards and best practices; and (3) promoting research collaboration and data sharing. Instruments submitted to the library are reviewed by a library oversight committee, with rotating membership from multiple institutions, which ensures quality, relevance and legality of shared instruments. The design allows researchers to download the instruments in a consumable electronic format in the REDCap environment. At the time of this writing, the SDIL contains over 128 data collection instruments. Over 2500 instances of instruments have been downloaded by researchers at multiple institutions. In this paper we describe the library platform, provide detail about experience gained during the first 25 months of sharing public domain instruments and provide evidence of impact for the SDIL across the REDCap consortium research community. We postulate that the shared library of instruments reduces the burden of adhering to sound data collection principles while promoting best practices.

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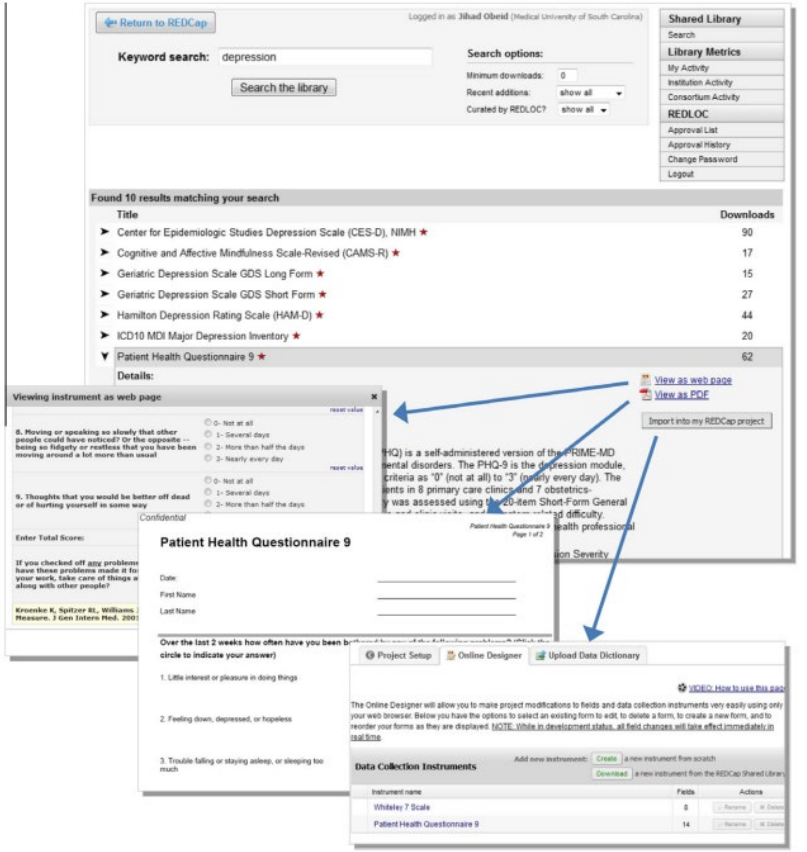


Metrics (Q3, 2023)

- Total Instruments: **3,738**
- Total Downloads: **201,504**

REDCap Shared Library - PROMIS$_{(API)}$ + PhenX External

Keyword search: promis

Search the library

Search options:

Language: - All -

Type: show all

Minimum downloads: 0

Recent additions: show all

Shared Library
Search
Library Metrics
Consortium Activity

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 >>

Found 1869 results matching your search Didn't find what you were looking for? Suggest a validated instrument for library inclusion

Title	Downloads
PROMIS-29+2 Profile/Battery v2.1 (PROPr) [Battery]	204
PROMIS - 29 Profile/Battery v2.0 [Battery]	499
PROMIS - 43 Profile v2.0 (Spanish)	15
PROMIS - 43 Profile/Battery v2.0 [Battery]	36
PROMIS - 57 Profile v2.0 (Spanish)	19
PROMIS - 57 Profile/Battery v2.0 [Battery]	62
PROMIS Item Bank v1.0 - Trastornos del Sueño - Cuestionario Abreviado 6a	6
PROMIS Item Bank v1.0 - Trastornos del Sueño - Cuestionario Abreviado 8a	4
PROMIS Item Bank v1.1 - Trastorno Emocional - Enojo	6
PROMIS Item Bank v1.1- Efectos del Dolor	16
PROMIS Item Bank v1.2 - Capacidad de Funcionamiento Físico	15
PROMIS - Ca Bank v1.0 - Anxiety [Adaptive instrument]	211
PROMIS - Ca Bank v1.0 - Depression [Adaptive instrument]	206
PROMIS - Ca Bank v1.0 - Fatigue [Adaptive instrument]	136
PROMIS - Ca Bank v1.1 - Pain Interference [Adaptive instrument]	200
PROMIS - Ca Bank v1.1 - Physical Function [Adaptive instrument]	183
PROMIS Banco - Versión Padres v1.0 - Actividad física [Adaptive instrument]	28
PROMIS Banco - Versión Padres v1.0 - Alteraciones relacionadas con el sueño [Adaptive instrument]	10

Keyword search: phenx

Search the library

Search options:

Language: - All -

Type: show all

Minimum downloads: 0

Recent additions: show all

Shared Library
Search
Library Metrics
Consortium Activity

Found 1 results matching your search Didn't find what you were looking for? Suggest a validated instrument for library inclusion

Title **Downloads**

PhenX Toolkit [External Instrument Library]

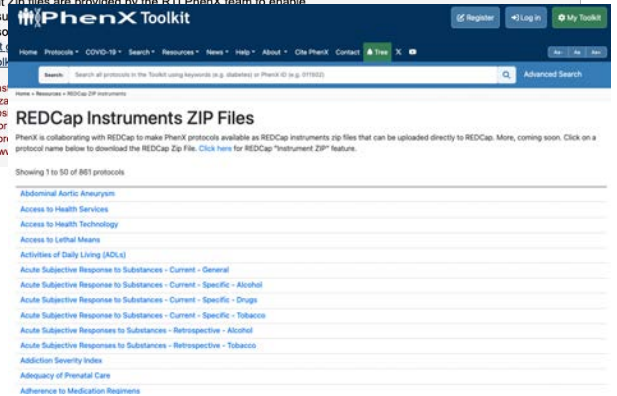
Details:

Institution: REDLOC

Description: The PhenX Toolkit provides standard measures related to complex diseases, phenotypic traits and environmental exposures. Use of PhenX measures facilitates combining data from a variety of studies, and makes it easy for investigators to expand a study design beyond the primary research focus. REDCap Instrument Zip files are provided by the RTI PhenX team to enable use of PhenX measu… other resources is so… review PhenX Toolkit … https://www.phenxtoolk…

NOTE: This is not an ins… in any way. The organiza… distributed on their webs… Vanderbilt University nor … for the veracity of the fo… their website (https://ww…

Go to this library



REDCap Shared Library - CDASH Instruments

Journal of the Society for Clinical Data Management

Cheng AC, et al. Creating and Disseminating CDASH Harmonization Electronic Case Report Forms on the REDCap Shared Data Instrument Library. *Journal of the Society for Clinical Data Management*. 2022; 2(1): 7, pp. 1–5. DOI: https://doi.org/10.47912/jscdm.172

ORIGINAL RESEARCH

Creating and Disseminating CDASH Harmonization Electronic Case Report Forms on the REDCap Shared Data Instrument Library

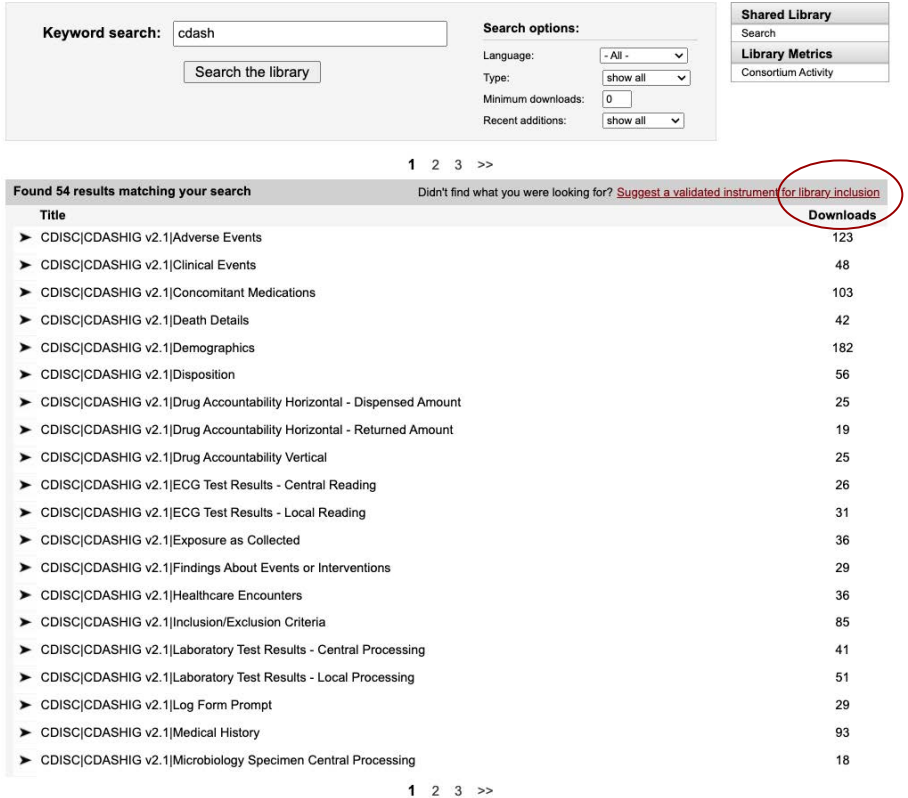
Alex C. Cheng*, Rhonda Facile†, John Owen†, Richard Marshall†, Kathleen Mellars†, Nan Kennedy*, Brenda L. Minor*, Kyle Mcguffin* and Paul Harris*

Introduction: A guiding principle behind the development and deployment of the REDCap data management platform has always included attention to workflow design that allows easy implementation of best practices for clinical and translational researchers. CDISC standards such as CDASH have helped the clinical research community improve the efficiency, actionability, and quality of their clinical trials data, but have had limited uptake among the academic institutions.

Objective: To create a scalable methodology to convert CDISC CDASH electronic case report forms (eCRFs) instrument metadata into REDCap data dictionaries for the purpose of simplifying adoption and use of CDASH instruments by research teams across the REDCap Consortium.

Implementation: We have used our replicable methods to translate metadata from 34 CDASH Foundational eCRFs and 20 CDASH Crohn's Disease eCRFs into REDCap eCRF metadata and have made these instruments available in the REDCap Shared Data Instrument Library for widespread sharing and uptake across the REDCap Consortium. Users can import the standardized eCRFs directly into their REDCap projects for immediate use in clinical trial data collection.

Conclusion: Disseminating CDISC standards through the REDCap community will increase the accessibility of these standards for academic medical centers. Having academic clinical researchers using CDISC standards may lead to more research datasets that interoperate with pharmaceutical sponsored trials, and more discoveries from secondary use of clinical research data.



REDCap CDE 2.0 Brainstorming

\+ CDE **Collections**

NATIONAL CANCER INSTITUTE
Center for Biomedical Informatics & Information Technology

Manage | View | Collaborate | Data Interchange | Personalize

>>Favorites>>NCI Standard CRFs

isplay Values | View | Delivery Options | Add to Guest User Cart

mplate Rows 1..130 of 130 1 Request

iew	1 Form Name	Public ID	Version	Owned By
	Adverse Event/Serious Adverse Event CTCAE v3 NCI Standard Template	2748814	3.00	NCI Standards
	Adverse Event/Serious Adverse Event CTCAE v4 NCI Standard Template	3265657	3.00	NCI Standards
	Adverse Event/Serious Adverse Event CTCAE v4.0 CDISC Aligned NCI Standard Template	6988567	1.00	NCI Standards
	Adverse Event/Serious Adverse Event CTCAE v5.0 CDISC Aligned NCI Standard Template	6984728	1.00	NCI Standards
	Adverse Event/Serious Adverse Event CTCAE v5.0 NCI Standard Template	6081561	1.00	NCI Standards
	Brief Pain Inventory-BPI CDISC Aligned NCI Standard Template	7093187	2.00	NCI Standards
	Concomitant Medication CDISC Aligned NCI Standard Template	6984232	1.00	NCI Standards
	Concomitant Medication NCI Standard Template	2867231	2.00	NCI Standards
	Consent CDISC Aligned NCI Standard Template	6936999	1.00	NCI Standards

Shared Library

REDCap CDE 2.0 Brainstorming

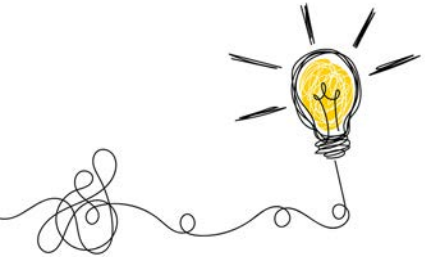
NIH CDE Repository

\+ Future CDE **Collections**

API

Shared Library

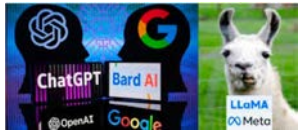
REDCap CDE 2.0 Brainstorming



NIH CDE Repository

\+ Future CDE **Collections**

API



Case Report Form
+ Survey Creation
Workflow Prompts

Thank You