BRICS | Biomedical Research Informatics Computing System

2023 BRICS WG SEMINAR

Biomedical Research Informatics Computing System (BRICS)

November 8th, 2023

CiSTAR

cdRNS
Common Data Repository for Nursing Science

National Ophthalmic Disease Genotyping Network
eyeGENE®

MTBI²
Uniformed Services University

PDBP
Parkinson's Disease Biomarkers Program

National Institute of Neurological Disorders and Stroke

FITBIR
Federal Interagency Traumatic Brain Injury Research
INFORMATICS SYSTEM

Logistics

Audio/Video	Please keep your microphone muted
Recording	• Today's seminar will be recorded • Will be posted on the BRICS website: https://brics.cit.nih.gov/
Break	• There is one (15) minute break midway through today's seminar • Scheduled for 10:20-10:35 am
Questions & Comments	• We encourage your participation today • Please use the chat for questions & comments. The chat will be monitored throughout today's seminar. • There will also be time after each speaker and at the end of the seminar to ask live questions.

Agenda

Time	Topic	Speaker(s)
9:00-9:10	Logistics Introduction	Alison Garcia Dr. Matthew McAuliffe
9:10-9:40	Innovative approach to clinical trials research: The NIH BRICS Unified platform	Dr. Dominic Nathan
9:40-10:00	BRICS: Data Science Platform for Accelerating Discovery	Dr. Matthew McAuliffe
10:00-10:20	BRICS: Advancing FAIR Data Principles and NIH's 2023 Data Sharing Plan	Dr. Olga Vovk Dr. Henry Ogoe
10:20-10:35	BREAK	
10:35-11:00	NIA Use Case API Query Tool- Using Python/R	Fatima Irfan Dan Gillis
11:00-11:20	FITBIR Use Case	Dr. Nsini Umoh
11:20-11:40	PDBP Use Case PDBP Google Cloud Migration	Andrea Lutz Kristine Treece
11:40-12:00	Questions & Closing Remarks	Alison Garcia Dr. Matthew McAuliffe

Chief, Scientific Application Services (SAS)

Dr. McAuliffe has been at NIH since 1998 and is currently the Chief of the Scientific Application Services (SAS) section in the Office of Scientific Computing Services (OSCS). He provides computational and engineering expertise to a variety of clinical and biomedical informatics activities at NIH and is committed to supporting data sharing and making data **FAIR** (Findable, Accessible, Interoperable, and Reusable). He leads the development of the Biomedical Research Informatics Computing System (BRICS) **(http://brics.cit.nih.gov/)** which is a comprehensive data informatics system designed to efficiently collect, validate, harmonize, and analyze research datasets.

In addition, Dr. McAuliffe strives to advance and empower scientific imaging research in the NIH intramural program, to this end, SAS has created and continues the development of the successful Medical Image Processing Analysis and Visualization application (MIPAV: **http://mipav.cit.nih.gov**).

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BRICS - Brief Introduction

Matthew J. McAuliffe, PhD (Biomedical Engineering)
Chief, Scientific Applications Services (SAS), CIT

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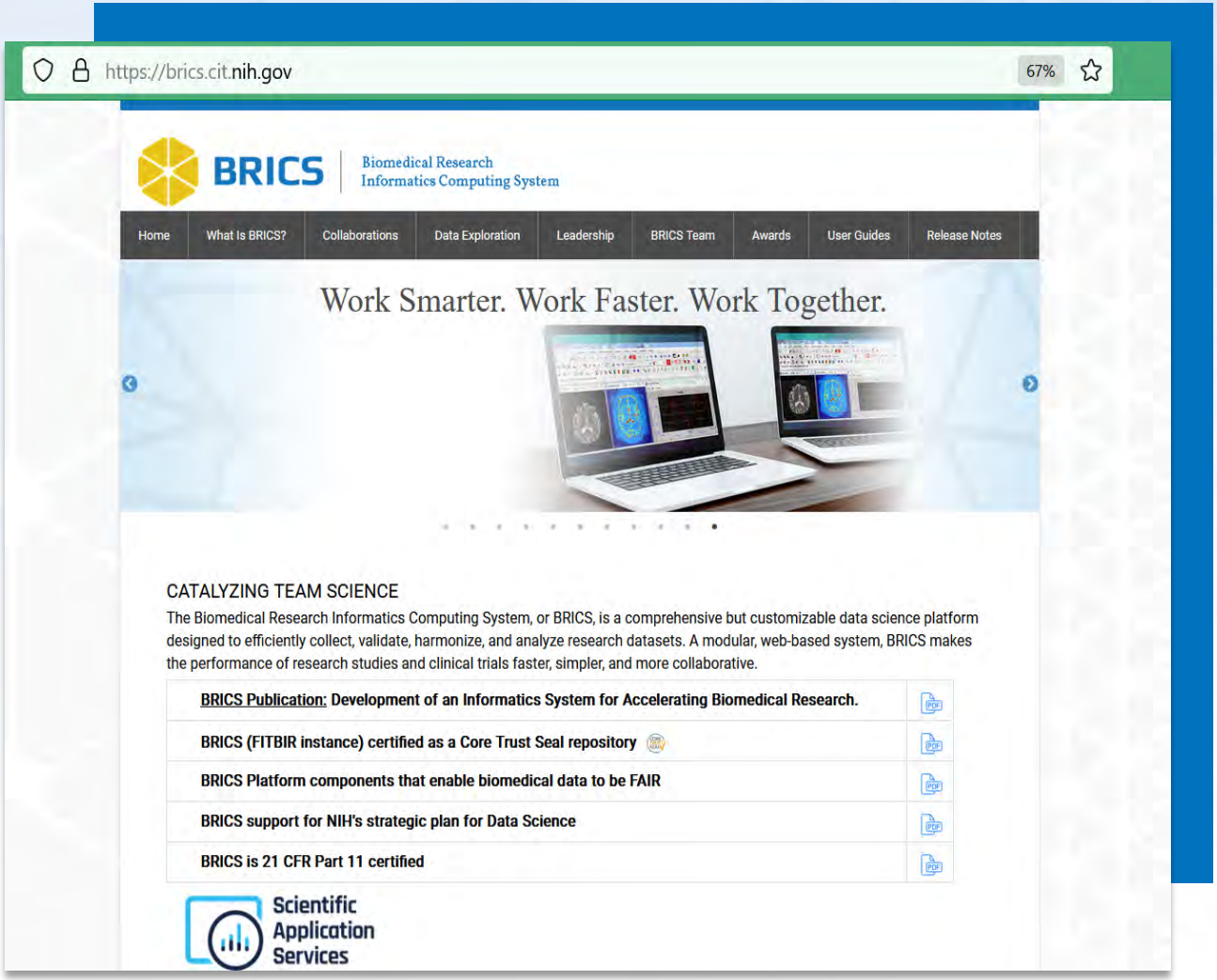
BRICS Website : https://brics.cit.nih.gov/



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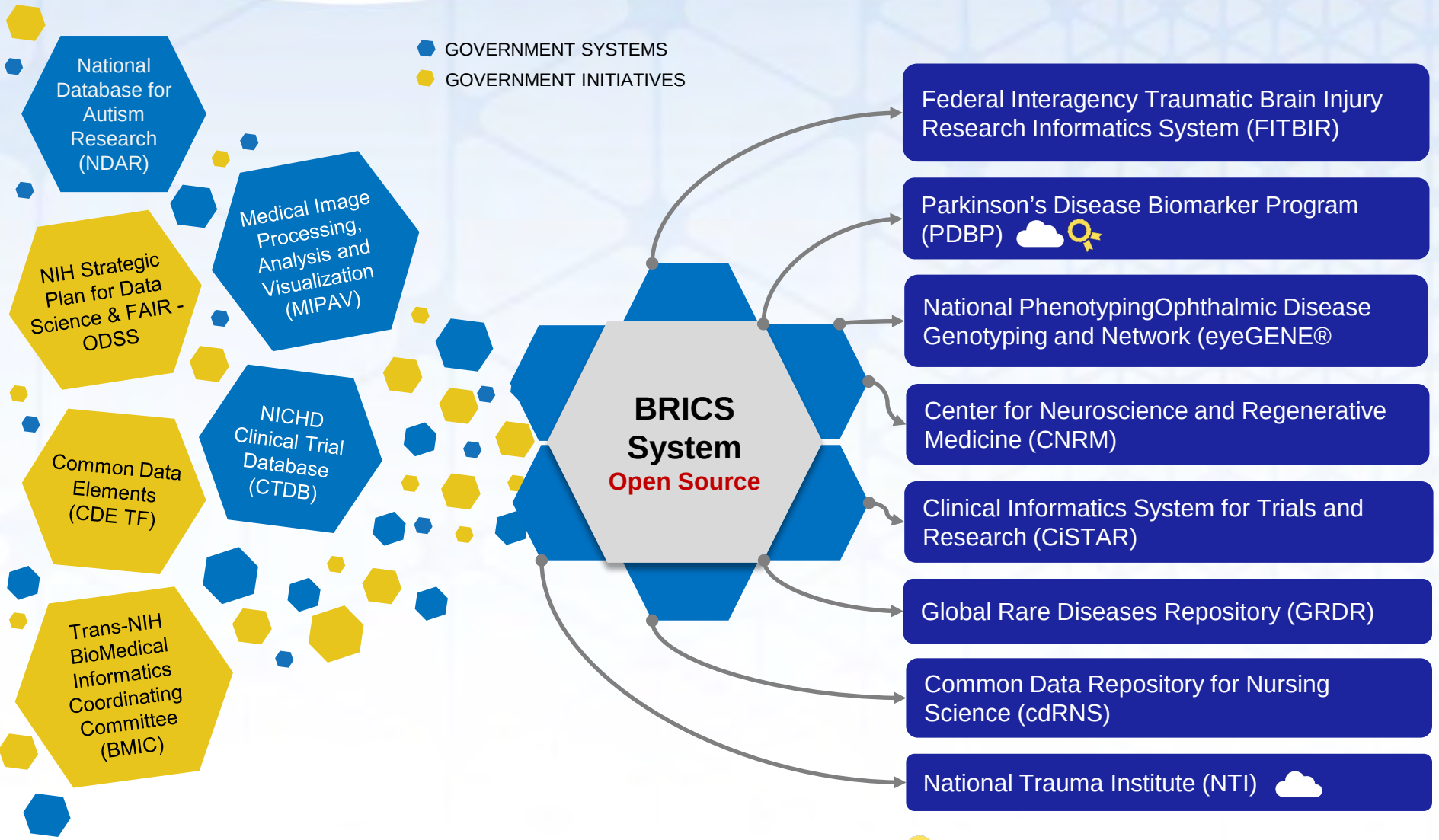
Building from existing projects



14th Annual Excellence.gov Awards Overall winner

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BRICS Statistics Across Instances

cdRNS Common Data Repository for Nursing Science

PDBP Parkinson's Disease Biomarkers Program

National Institute of Neurological Disorders and Stroke

MTBI² Uniformed Services University

~150

VIRTUAL SERVERS

300+

RESEARCH STUDIES

Close to 300K

RESEARCH PARTICIPANTS

7M+

RESEARCH RECORDS

National Ophthalmic Disease Genotyping Network eyeGENE®

CiSTAR Clinical Informatics System for Trials and Research

FITBIR Federal Interagency Traumatic Brain Injury Research INFORMATICS SYSTEM

Fabrics, Meshes, and Data lakes

Data fabric (Single BRICS instance): a data fabric is a single environment consisting of a unified architecture, and services or technologies running on that architecture, that helps organizations manage their data. The ultimate goal of data fabric is to maximize the value of your data and accelerate digital transformation

Data mesh – Ecosystem (multiple BRICS instances, Other Repos): Data mesh emphasizes data decentralization, autonomy, and productization. It's ideal for complex, large-scale data ecosystems where multiple domain teams must work independently and share data products. (RAS, FHIR, CDE, GA4GH –DRS)

Data lake (Meta Study) a centralized repository that allows you to store all your structured and unstructured data at any scale. You can store your data as-is, without having to first structure the data, and run different types of analytics—from dashboards and visualizations to big data processing, real-time analytics, and machine learning to guide better decisions.

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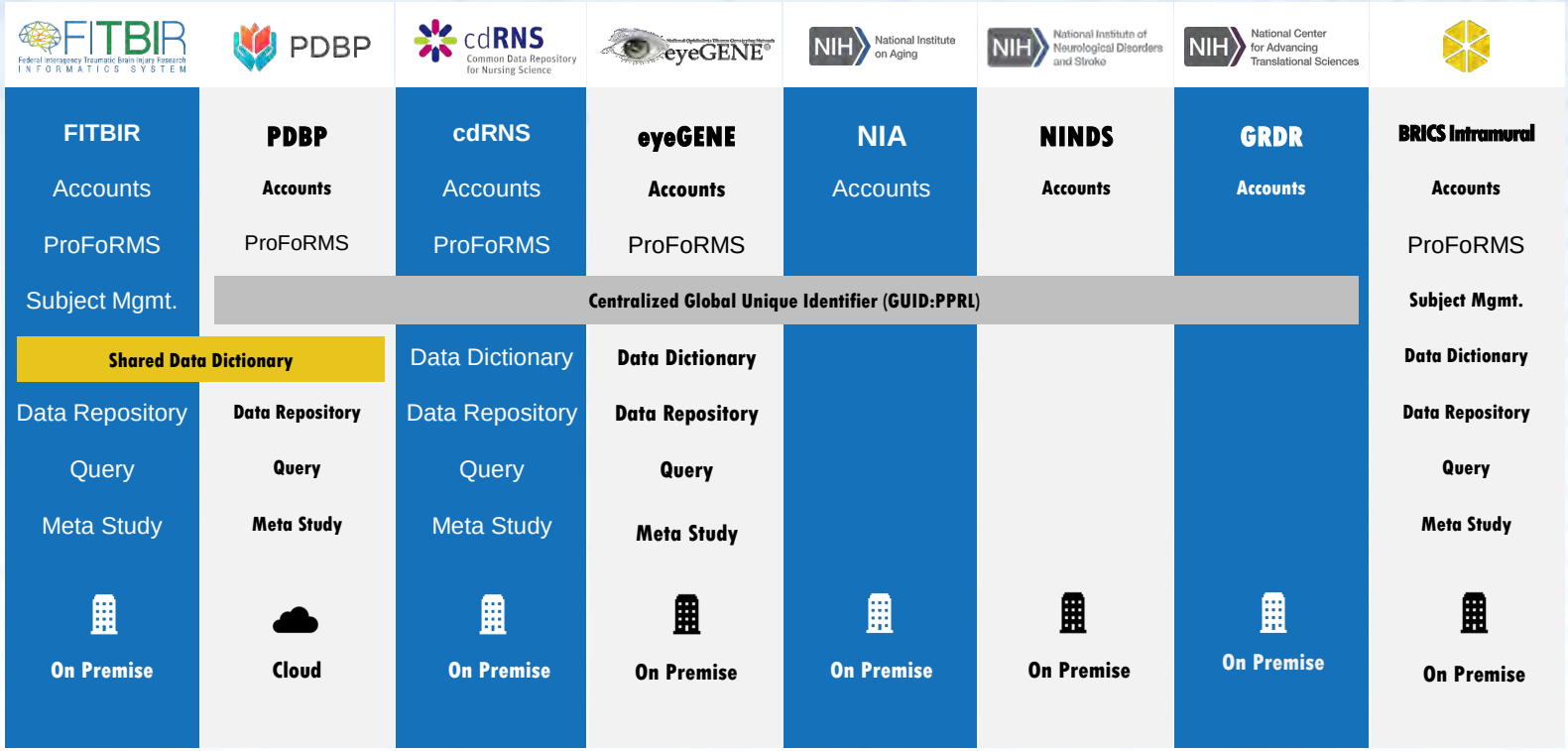
BRICS
Mesh And Fabric



Datatypes: Phenotypic, Imaging, and Omics

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Data Discovery

Interactive exploration of BRICS Studies, CDEs and Forms across all BRICS instances

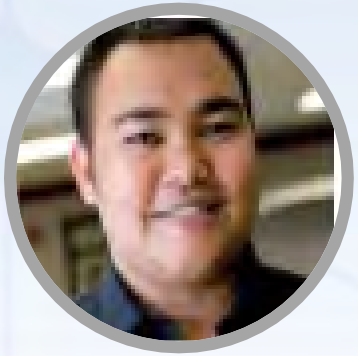
- CDRNS, FITBIR, NEI, PDBP, etc.

Find common FORMS / CDEs and explore how they're used across instances

- Which studies use common forms/CDEs
- See study participant demographic information by form/CDEs

Match CDEs through UMLS codes across instances

- Find CDEs with matching UMLS codes and see commonality / subject demographic information across instances



Dominic E. Nathan, PhD
Informatics Core Director
Military Traumatic Brain Injury Initiative

Dr. Dominic Nathan currently serves as the Bioinformatics Director for the Military Traumatic Brain Injury Initiative (MTBI2), [as a contractor]. Dr. Nathan manages inter-agency collaborative research information systems and resources to support MTBI2 and NIH research, clinical trials, and various repositories; where he has developed informatics infrastructure and tools and in an accelerated timeline to meet critical needs. Dr. Nathan completed post-doctoral training at Walter Reed National Military Medical Center, the Uniformed Services University of the Health Sciences and the NIH. Dr. Nathan is an adjunct professor at the USUHS and a research collaborator at the NIH. His past non-academic experience includes developing and managing an enterprise IT program for a fortune 500 company, and managing a stroke research lab at the VA. Dr. Nathan serves on several national and international biomedical engineering advisory committees, and he is a reserve officer in the US Public Health Service Commissioned Corps. Dr. Nathan's research interests are in advancing translational clinical research and applications.

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Innovative approach to clinical trials research: The NIH BRICS Unified Platform

Dominic E. Nathan, PhD
Bioinformatics Director,
Military Traumatic Brain Injury Initiative
Uniformed Services University of the Health Sciences
(Contractor)

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Disclaimer

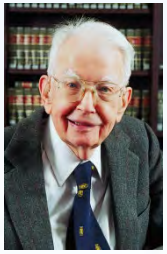
"The presenter has no conflicts of interest to disclose. The views, information or content, and conclusions presented do not necessarily represent the official position or policy of, nor should any official endorsement be inferred on the part of, the Uniformed Services University, the Department of Defense, the U.S. Government, Department of Health and Human Services, National Institutes of Health, or the Henry M. Jackson Foundation for the Advancement of Military Medicine, Inc."

Current clinical trials landscape within the NIH

- Emphasis on practical applications for direct care/treatment
- Very diverse and rich areas of clinical trials
  - Growing number of disparate data sources
  - Large amounts of data
  - Increasing burden (admin, support, regulatory resource, financial cost)
- Increasing use of AI and multi-modal analytics
- Systems:
  - Multiple siloed, localized systems (institutes, centers and labs)
  - Disparate and unequal resources
  - A uniform solution across the NIH is absent
- Data collection practices are highly variable, and curation is not emphasized
- Limited ROI for research investments

An unspoken research problem?

- >70% of researchers have tried and failed to reproduce another scientist's experiments [++]
- >50% have failed to reproduce their own experiments [++]
- Best-known reproducibility analyses, from psychology and cancer biology, found rates of around 40% and 10%, respectively [++]



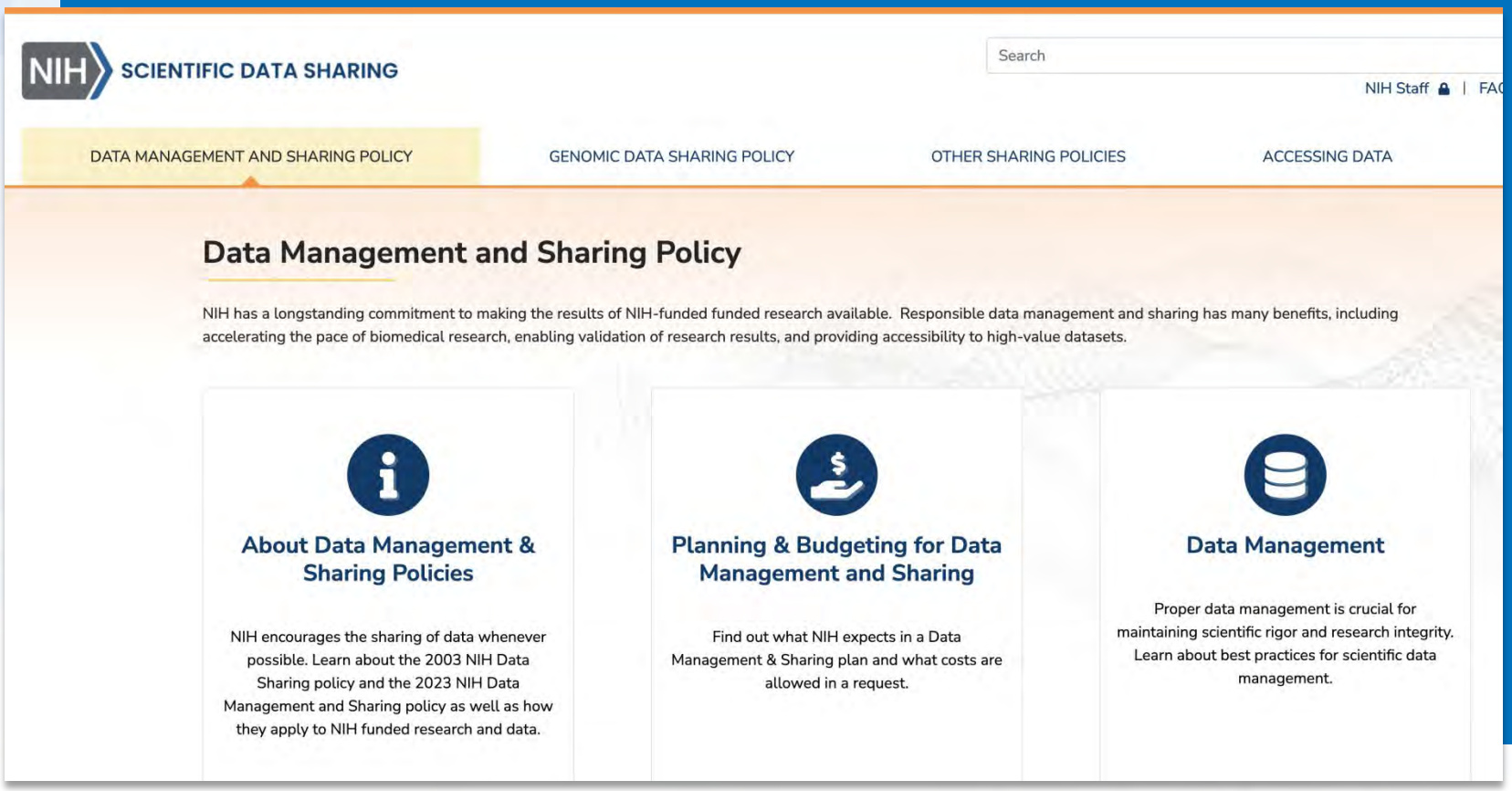
If you torture the data long enough, it will confess to anything
~ Ronald Coase

It is irresponsible to support research but not data stewardship, says Barend Mons.

Barend Mons

[++]Baker, M. 1,500 scientists lift the lid on reproducibility. *Nature* **533**, 452–454 (2016). https://doi.org/10.1038/533452a

The NIH is leading the way



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Current Protocol Design

Study 1

PLANNING

- HYPOTHESIS/GOALS
- DATA TO BE COLLECTED
- DATA ACCESS
- COLLECTION INSTRUMENTS

EXECUTION

- DATA COLLECTION
- ANALYSIS
- QA/QC
- PUBLICATION

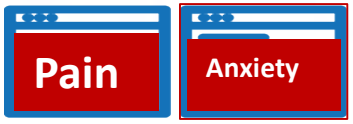
CLOSE OUT

- STORAGE

Study 2

PLANNING

- HYPOTHESIS/GOALS
- DATA TO BE COLLECTED
- DATA ACCESS
- COLLECTION INSTRUMENTS



EXECUTION

- DATA COLLECTION
- ANALYSIS
- QA/QC
- PUBLICATION

CLOSE OUT

- STORAGE

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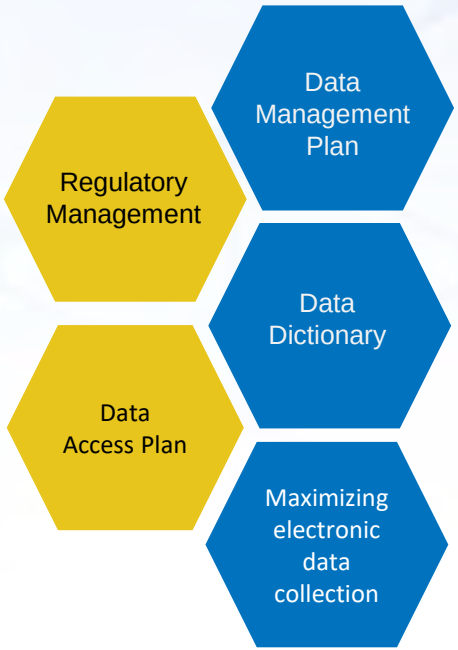
Rethinking Protocol Design: Emphasis on Curation

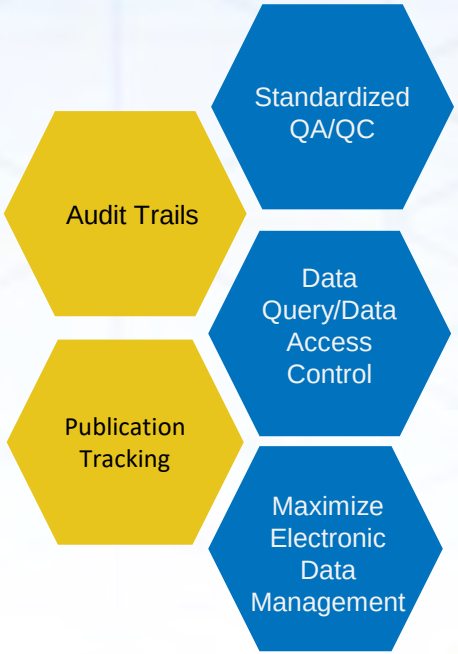
PLANNING

- HYPOTHESIS/GOALS
- DATA TO BE COLLECTED
- DATA ACCESS
- COLLECTION INSTRUMENTS



EXECUTION

- DATA COLLECTION
- ANALYSIS
- QA/QC
- PUBLICATION



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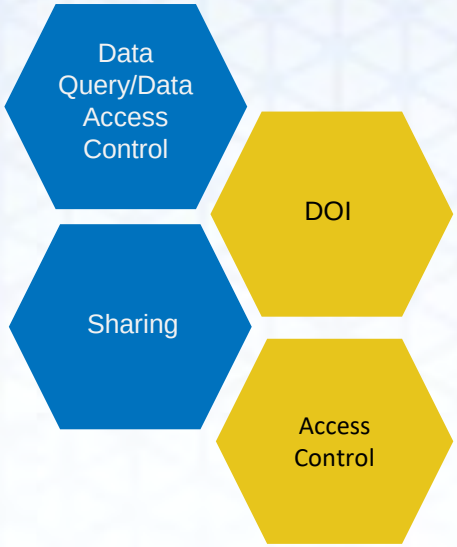
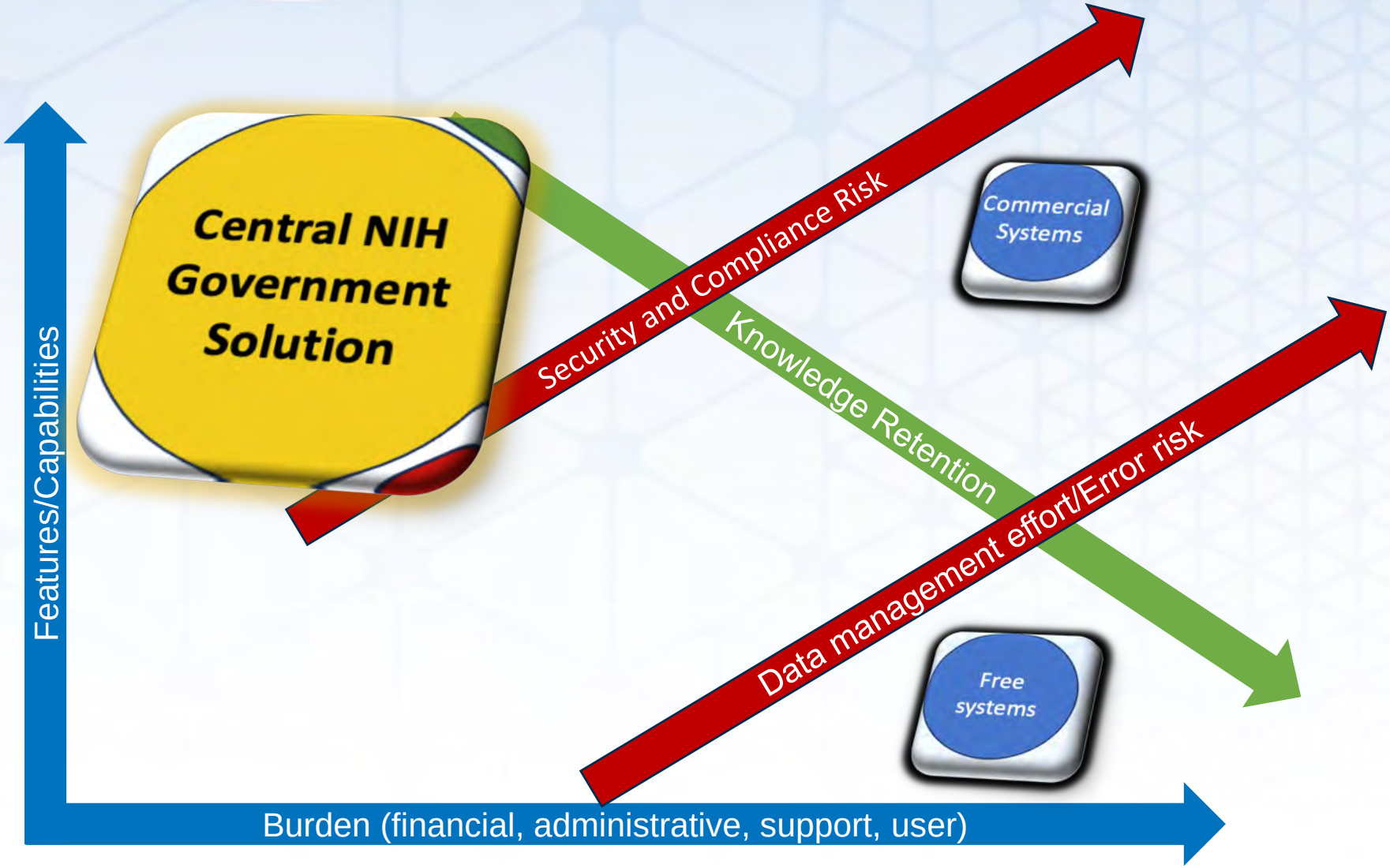
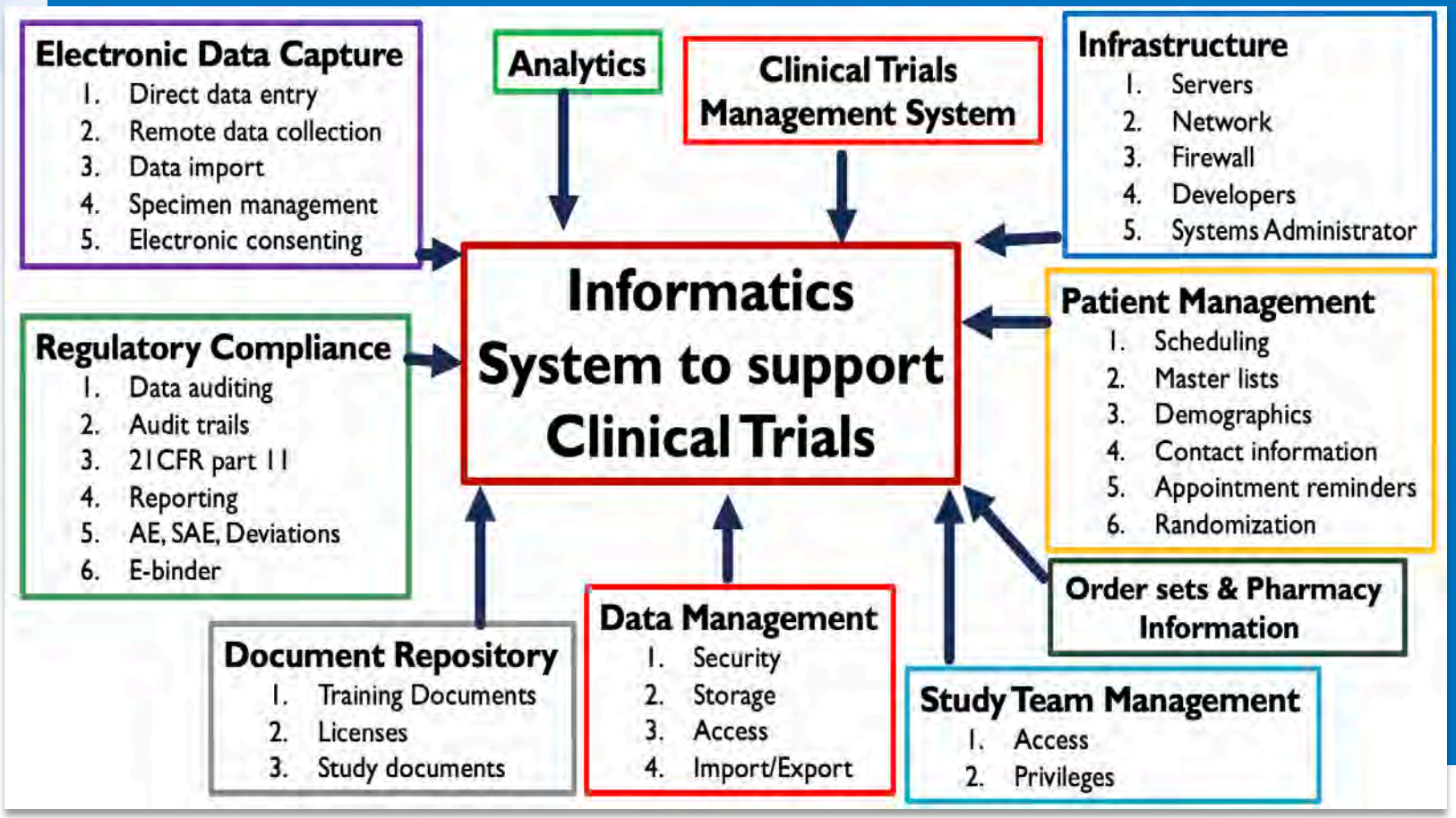


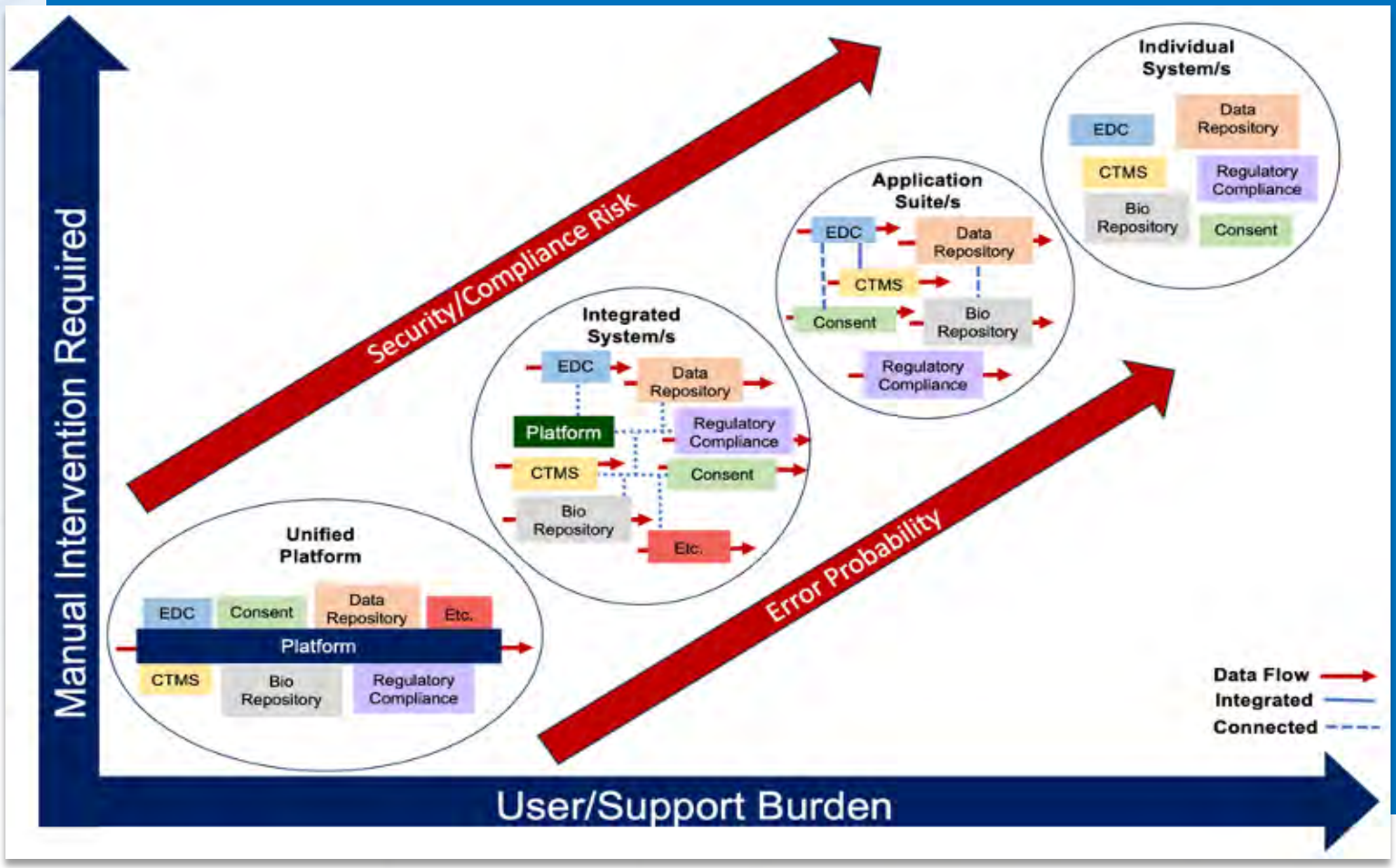
Platform options



Informatics considerations for clinical trials



Why a Unified PLATFORM?



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NIH Biomedical Informatics Computing System (BRICS)

- Collaborative NIH CIT, NIH NINDS, DoD platform
- Secure comprehensive web-based electronic data capture, storage, analytics and sharing platform
- Defined and documented data structures, conforms to NIH CDE guidelines for data collection and harmonization
- Fast Healthcare Interoperability Recourses (FHIR)
- Available API for more dynamic data analysis including AI and ML applications.
- Role based permissions and access
- Fulfills regulatory compliance needs
- Inbuilt subject management capabilities
- Ability to import and host any data
- BRICS is un-branded and un-associated with a particular disease or organization, it is highly customizable
- 21 CRF Part 11 compliant, and meets other federal regulatory requirements for clinical trials research
- Ability to pull data from CRIS via BTRIS

Plug & Play Components for the Full Research Lifecycle

BRICS offers researchers a secure platform and a suite of web-based and downloadable tools that can be shared across disease categories or deployed and branded independently, depending on the needs of your program.

Data Mapping & Transformation

Tool that translates data into CDEs used by BRICS to prepare for validation

Data Dictionary

Intelligent clinical research data dictionary that supports cross-system exchange

Data Repository

Functionality to define and manage studies and contribute or store data

ProFoRMS

Module for electronic data capture, subject management, and scheduling

Meta Study

Workspace that aggregates data and metadata across studies for reference

Global Unique Identifier

Cross-study Privacy Preserving Record Linkage System (PPRLS)

Continues…

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BRICS Tools

Query

Tool enabling filtering of submitted data using data elements and form structures

Clinical Trials Management System (CTMS)

Management of Clinical Trials by enabling insight into trial performance.

BRICS Imaging Tools

Enables quantitative analysis and viewing of medical images, such as PET, MRI, CT, or microscopy.

Forum

Discussion board for account users for posting messages, interacting with each other, and discussing various topics

Account Management

Create, approve, and manage user accounts.

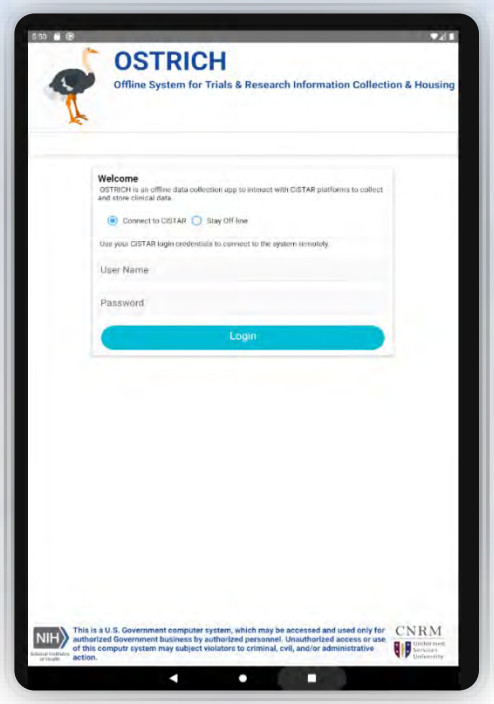
InET

Application for assigning new training, tracking current training, licenses and compliance.

Specimen Tracking and Management System (STAMS)

STAMS provides the path to container storage locations (e.g. freezer) that guides the user to the specific container and sample.

Data Collection



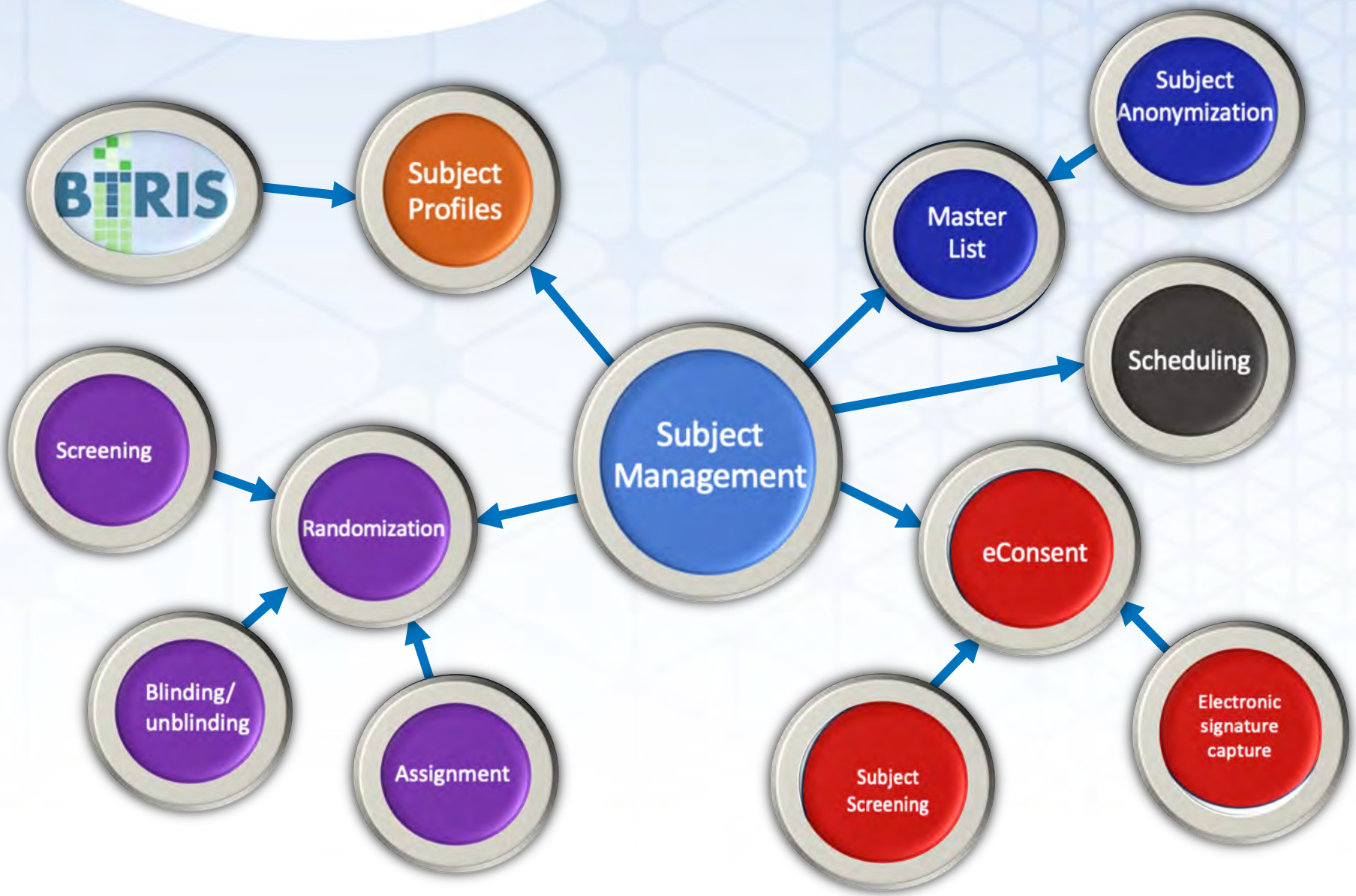
1. Collection occurs via electronic case report forms (eCRFs/eforms)
2. E-forms:
   - Standard forms
   - Non-standard/unique forms
3. Includes PROMIS library and measures (CAT assessments)
4. In built workflow for QA/QC – individual form locking
5. Full audit trail for data collection
6. Output data in PDF or CSV format
7. Clinical data (Direct pull from BTRIS)
   - Consent information
   - Subject demographics
   - Clinical data – assessments, labs, etc.
8. Offline data collection capabilities

Data Dictionary
Form Structure Example

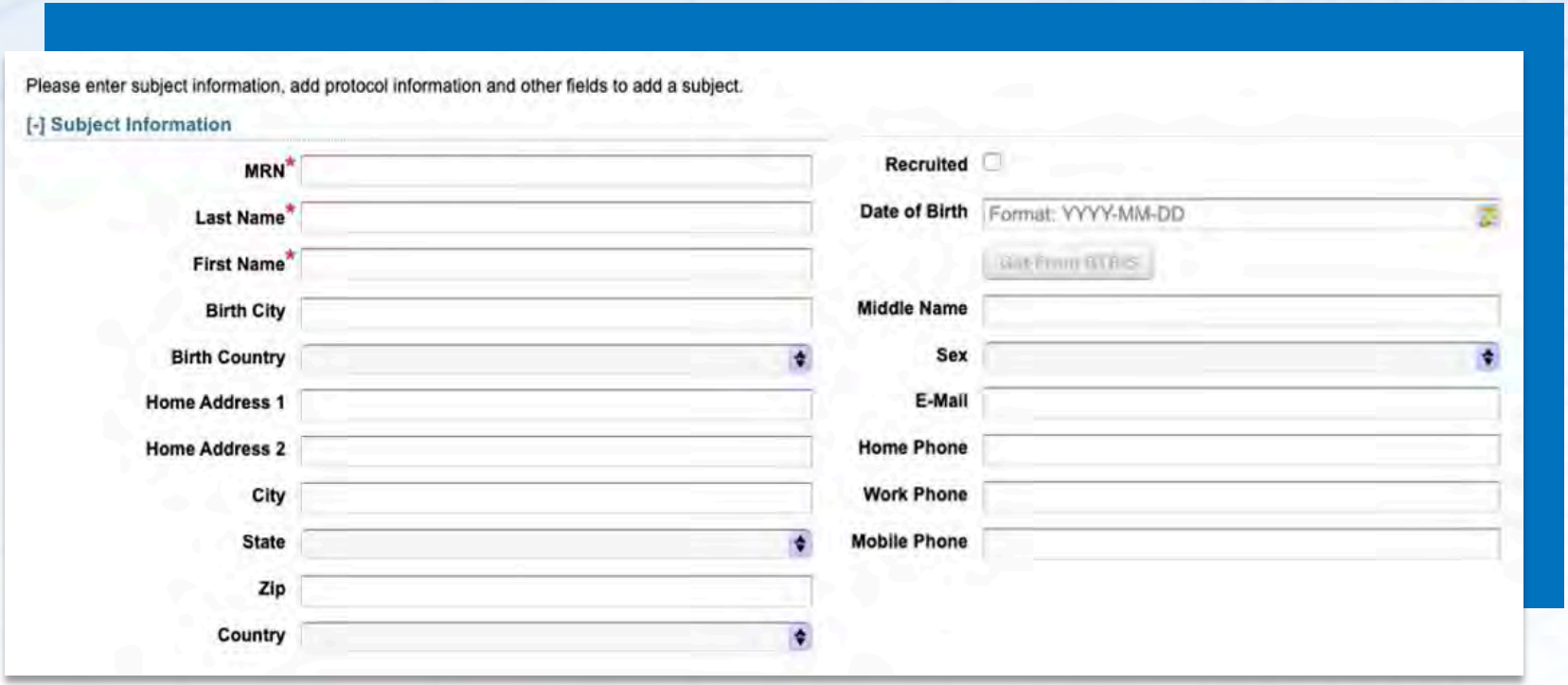
▼ PCL-5 (Appears Up To 1 Time)

#	TITLE	SHORT DESCRIPTION	VARIABLE NAME	REQUIRED?	TYPE
1	PTSD Checklist for DSM-5 (PCL-5) - Memories of stressful experiences scale	Severity scale of repeated, disturbing and unwanted memories of stressful experiences, as part of PTSD checklist for DSM-5 (PCL-5)	PCL5MemoStrsExpScl	Recommended	CDE
2	PTSD Checklist for DSM-5 (PCL-5) - Dreams of stressful experiences scale	Severity scale of repeated, disturbing and unwanted memories of stressful experiences, as part of PTSD checklist for DSM-5 (PCL-5)	PCL5DreamsStrsExpScl	Recommended	CDE
3	PTSD Checklist for DSM-5 (PCL-5) - Upset when being reminded of stressful experiences scale	Severity scale of suddenly feeling or acting as if stressful experiences happen again, as part of PTSD checklist for DSM-5 (PCL-5)	PCL5UpsetRemindStrsExpScl	Recommended	CDE
4	PTSD Checklist for DSM-5 (PCL-5) - Strong physical reaction scale	Severity scale of upset feeling when people remind the subject of stressful experiences , as part of PTSD checklist for DSM-5 (PCL-5)	PCL5StrgPhysicalReactnScl	Recommended	CDE
5	PTSD Checklist for DSM-5 (PCL-5) - Stressful experiences happen again scale	Severity scale of strong physical reactions when people remind the subject of stressful experiences , as part of PTSD checklist for DSM-5 (PCL-5)	PCL5StressfulExpHappenAgnScl	Recommended	CDE
6	PTSD Checklist for DSM-5 (PCL-5) - Avoid memories, thoughts feelings scale	Severity scale of avoiding memories, thoughts and feeling related to stressful experiences , as part of PTSD checklist for DSM-5 (PCL-5)	PCL5AvdMemoThtsFeelngReltdScl	Recommended	CDE
7	PTSD Checklist for DSM-5 (PCL-5) - Avoid external reminders scale	Severity scale of avoiding external reminders of stressful experiences, as part of PTSD checklist for DSM-5 (PCL-5)	PCL5AvdExtalRemindersScl	Recommended	CDE

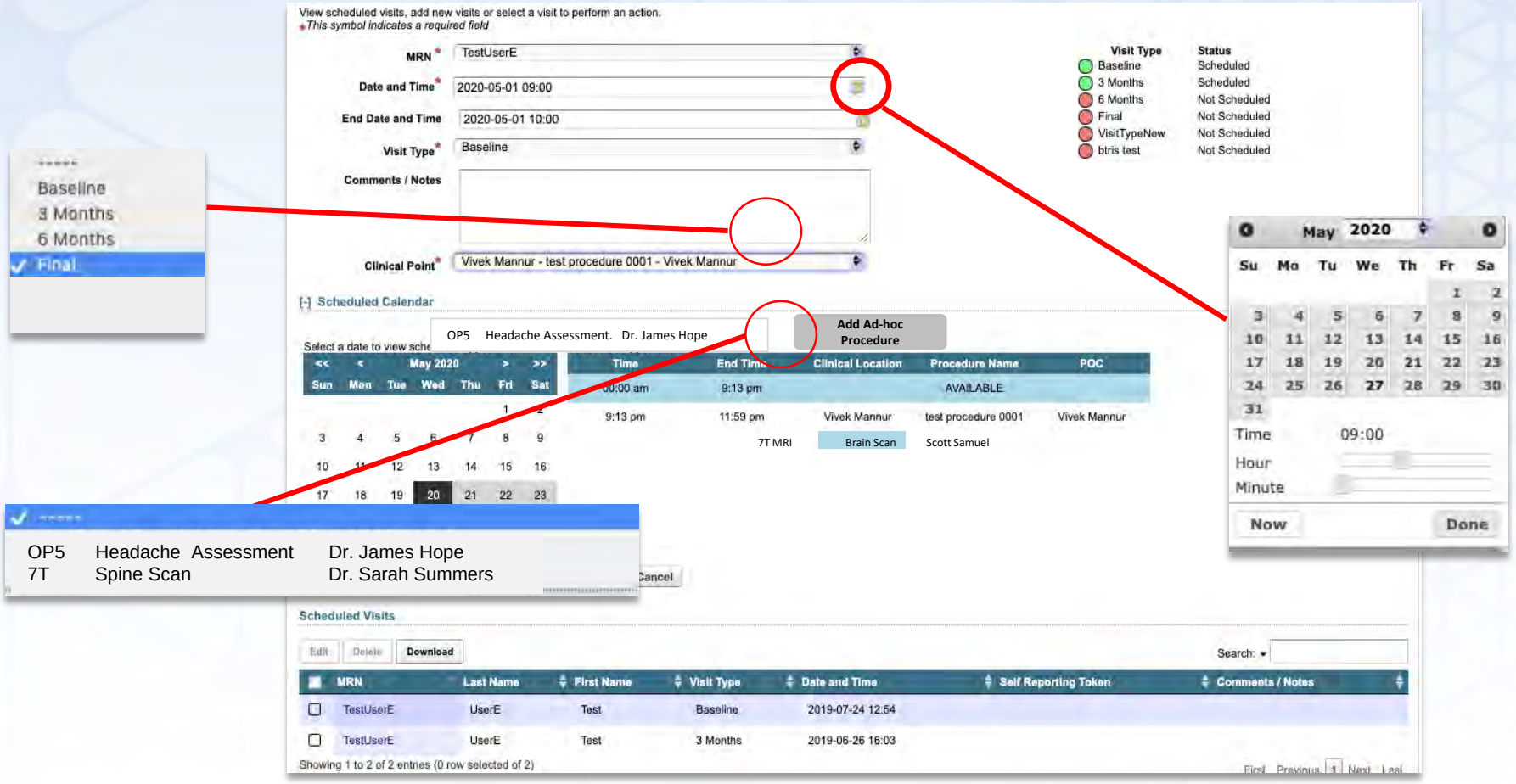
Subject Management



Subject Management



Scheduler


View scheduled visits, add new visits or select a visit to perform an action.
*This symbol indicates a required field
MRN* TestUserE
Date and Time* 2020-05-01 09:00
End Date and Time 2020-05-01 10:00
Visit Type* Baseline
Comments / Notes
Clinical Point* Vivek Mannur - test procedure 0001 - Vivek Mannur
Visit Type
Baseline
3 Months
6 Months
Final
VisitTypeNew
btris test
Status
Scheduled
Scheduled
Not Scheduled
Not Scheduled
Not Scheduled
Not Scheduled
Baseline
3 Months
6 Months
Final
[-] Scheduled Calendar
OP5 Headache Assessment. Dr. James Hope
Add Ad-hoc Procedure
May 2020
Time
End Time
Clinical Location
Procedure Name
POC
00:00 am
9:13 pm
AVAILABLE
9:13 pm
11:59 pm
Vivek Mannur
test procedure 0001
Vivek Mannur
7T MRI
Brain Scan
Scott Samuel
May 2020
Su Mo Tu We Th Fr Sa
Time 09:00
Hour
Minute
Now
Done
OP5 Headache Assessment Dr. James Hope
7T Spine Scan Dr. Sarah Summers
Cancel
Scheduled Visits
Edit
Delete
Download
Search:
MRN
Last Name
First Name
Visit Type
Date and Time
Self Reporting Token
Comments / Notes
TestUserE UserE Test Baseline 2019-07-24 12:54
TestUserE UserE Test 3 Months 2019-06-26 16:03
Showing 1 to 2 of 2 entries (0 row selected of 2)
First Previous 1 Next Last

Look Up and Print Schedules

Generate Schedule

Duration: Start Date 2020-05-14 End Date 2020-05-21

Schedule Filters:

Protocol: Select or Search a Protocol...

Clinical Location: Select or Search a Clinical Location...

Subject: Select or Search a Patient's Name...

Generate Report

Protocol Number	Patient ID (MRN / GUID / SubjectId)	Patient Name	Visit Type	Visit Date / Time	Procedure	Clinical Location	Point Of Contact	Comments / Notes
VIVEK_002	Patient_1 / CISTARUA812CL8 / Patient_1	1, Patient	Baseline	2019-05-29 00:00:00	test procedure 0001	OP5	Vivek Mannur	
VIVEK_002	Patient_1 / CISTARUA812CL8 / Patient_1	1, Patient	3 Months	2020-01-31 11:11:00	60cc	CC1	Vivek Mannur	
VIVEK_002	Patient_1 / CISTARUA812CL8 / Patient_1	1, Patient	Final	2019-07-26 13:21:00	60cc	OP5	Vivek Mannur	
VIVEK_002	Patient_1 / CISTARUA812CL8 / Patient_1	1, Patient	6 Months	2019-06-24 12:46:00	HAM Brain	CC1	Vivek Mannur	
VIVEK_002	Patient_1 / CISTARUA812CL8 / Patient_1	1, Patient	3 Months	2019-05-29 00:00:00	60cc	OP5	Vivek Mannur	
VIVEK_002	Patient_2 / CISTARUH677BCX / Patient_2	2, Patient	btris test	2020-05-20 21:13:00	test procedure 0001	CC1	Vivek Mannur	

Electronic Consent form

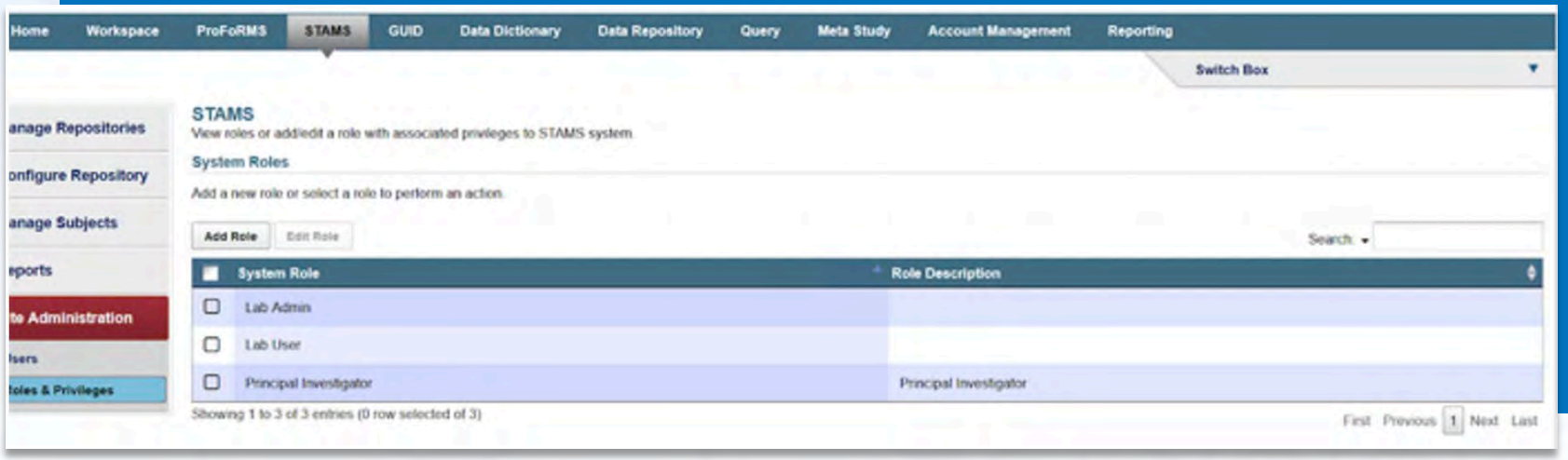
SIGNATURE OF PARTICIPANT

BY SIGNING THIS CONSENT FORM, YOU FREELY AGREE TO TAKE PART IN THE RESEARCH IT DESCRIBES	x I agree to take part in the research described in this consent form.
Printed Name of Participant	Sarah Summers
Participant's Signature e	
Date and Time	2020-06-24. 01:25 PM

SIGNATURE OF INDIVIDUAL ADMINISTERING CONSENT

Printed Name of Administering Individual	Janice Joplin
Signature of Administering Individual	
Date and time	2020-06-24. 01:25 PM

Samples Management and tracking



Option to link samples and clinical data.

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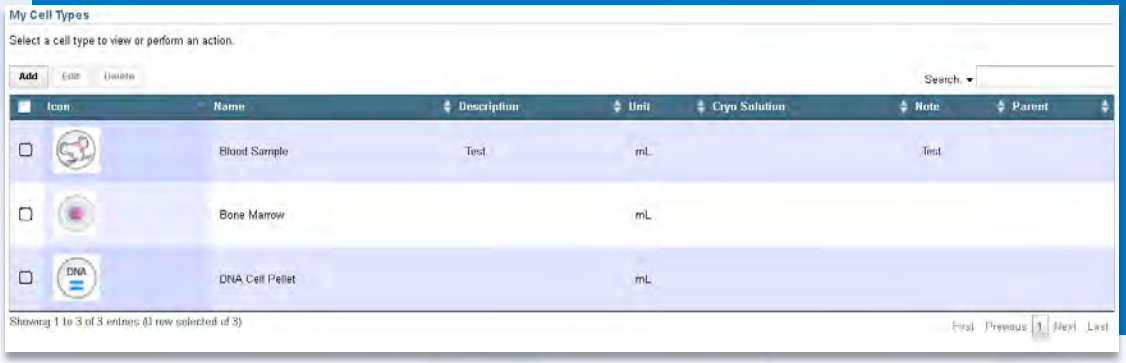
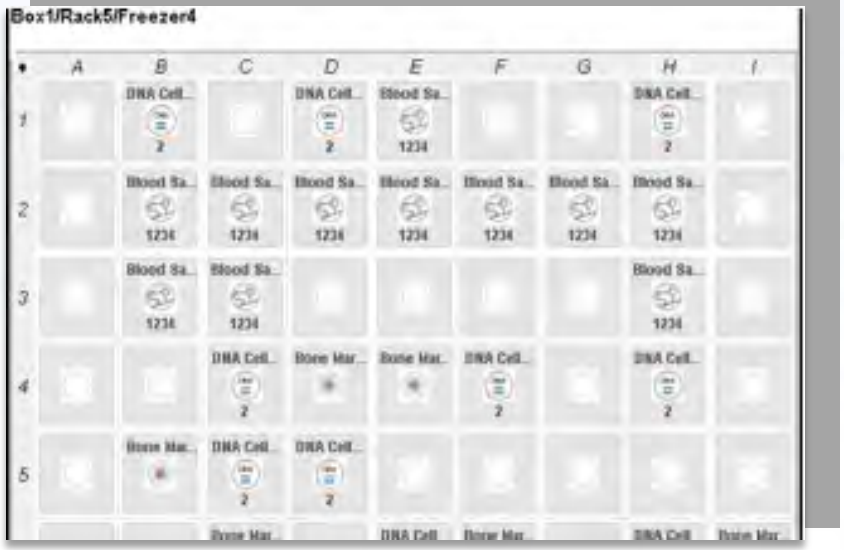
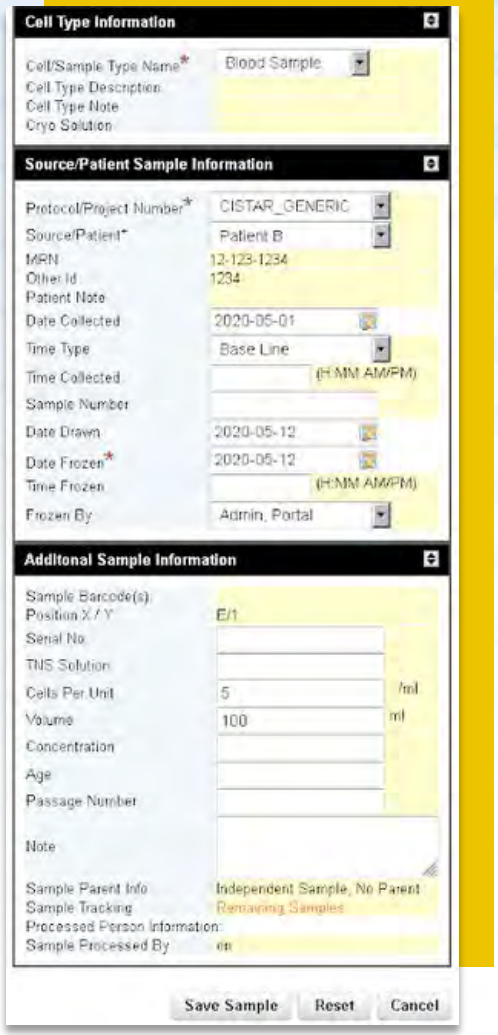
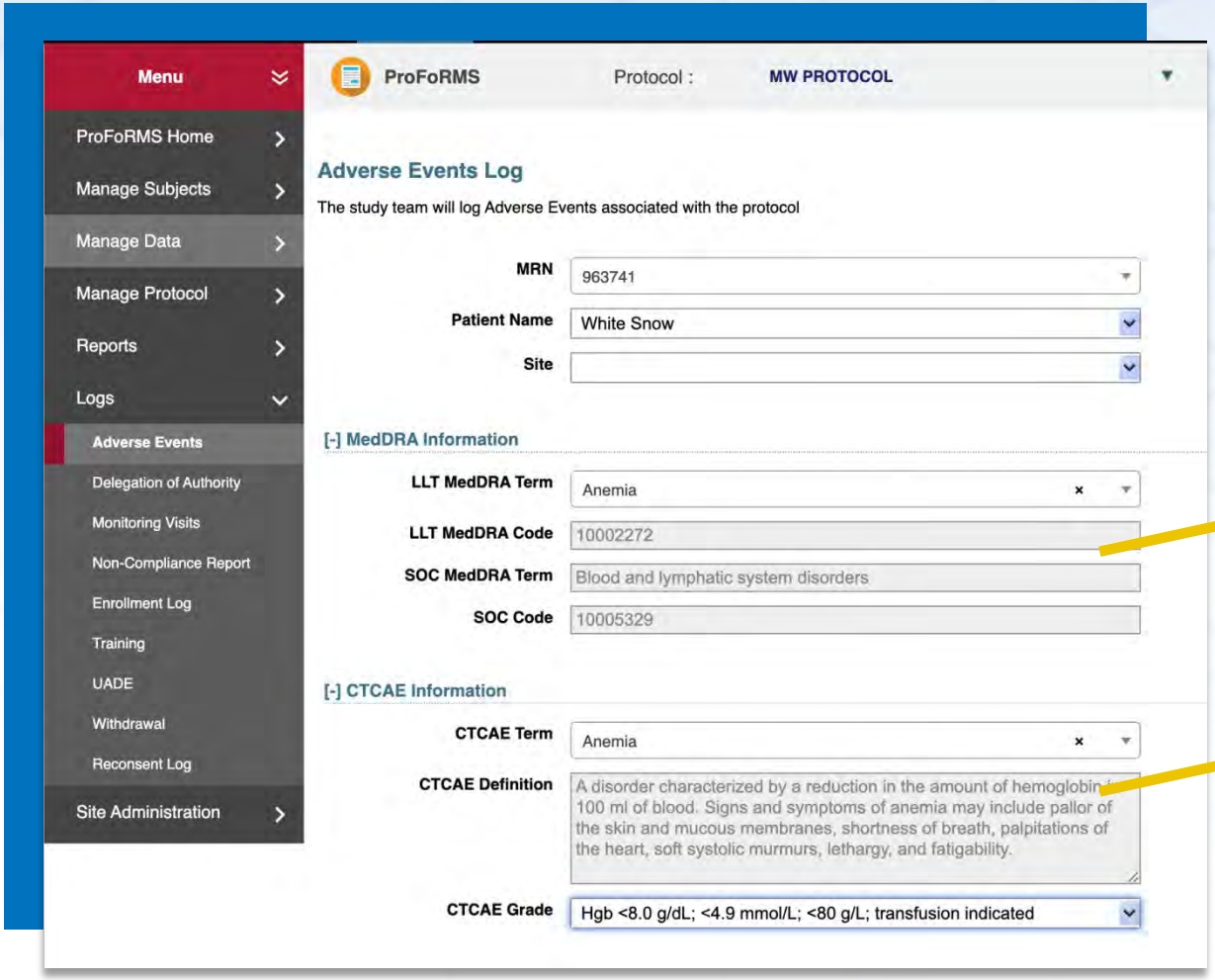
Samples Management and Tracking







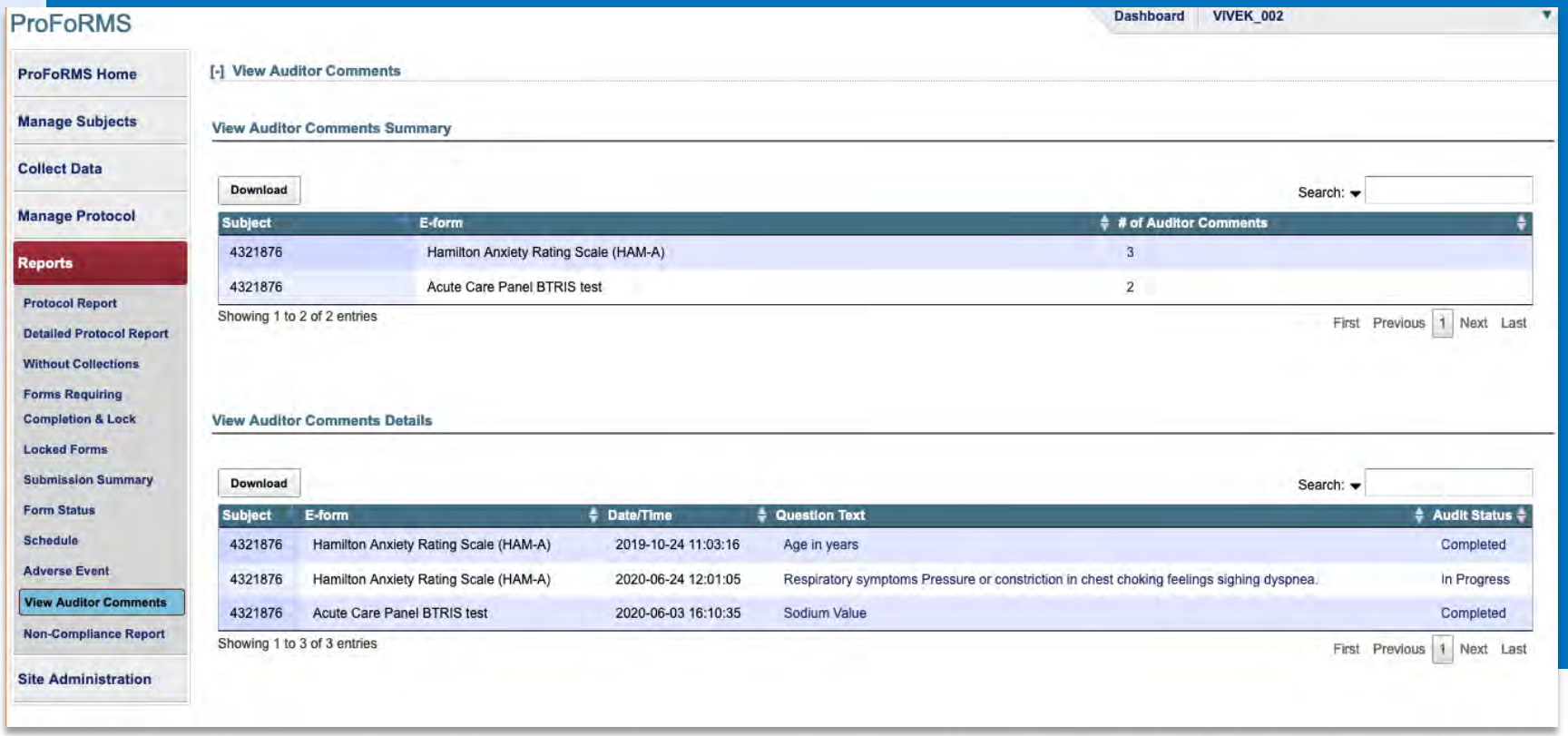
Adverse event reporting



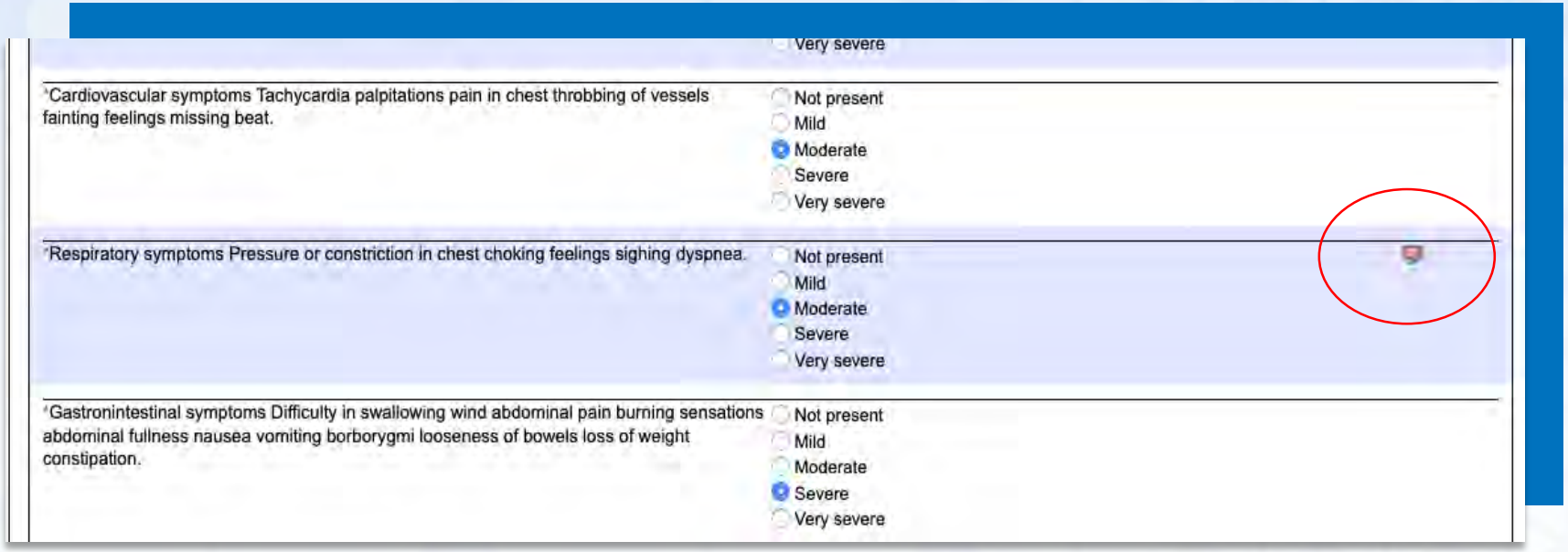
MedDRA Integration

CTCAE Integration

Study Monitoring

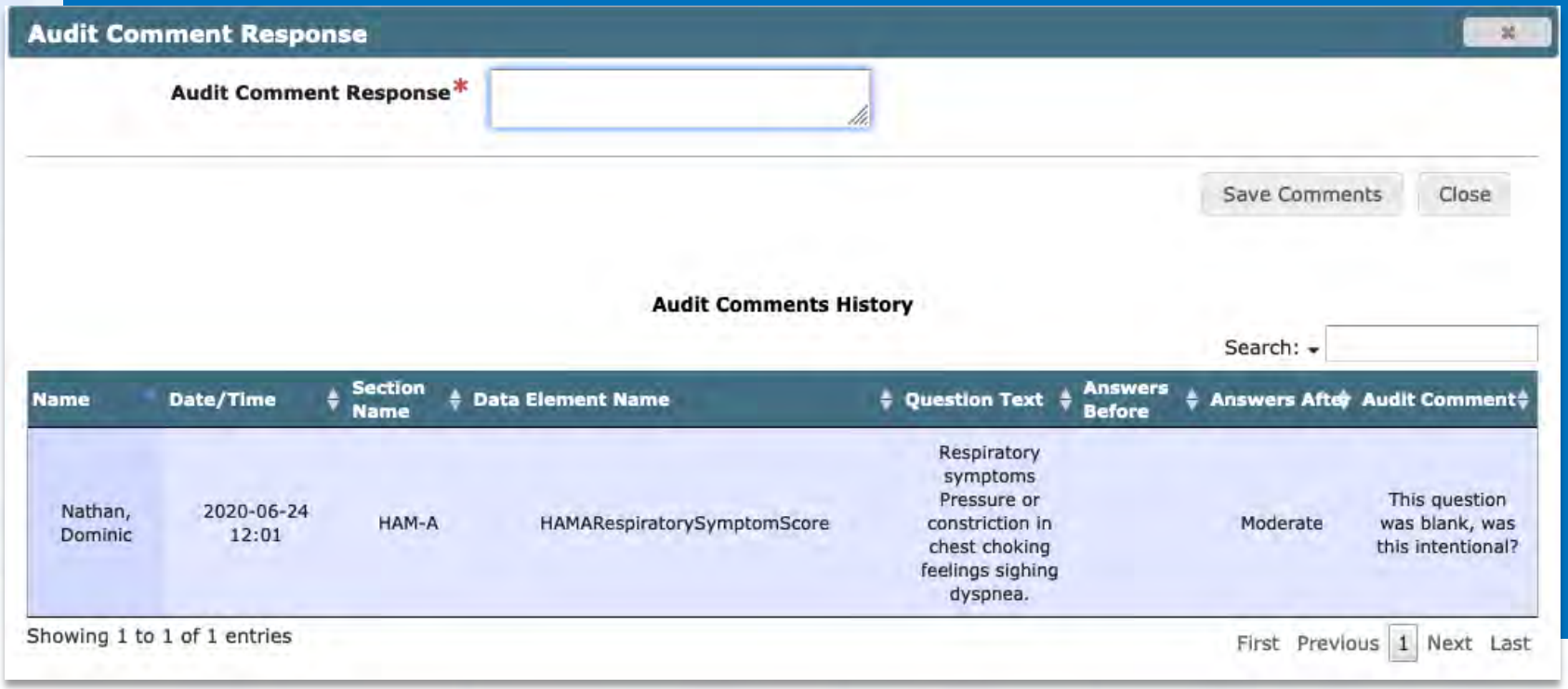


Study monitoring – data audit



	Very severe
[3]Cardiovascular symptoms Tachycardia palpitations pain in chest throbbing of vessels fainting feelings missing beat.	Not present Mild (•) Moderate Severe Very severe
[4]Respiratory symptoms Pressure or constriction in chest choking feelings sighing dyspnea.	Not present Mild (•) Moderate Severe Very severe
[5]Gastronintestinal symptoms Difficulty in swallowing wind abdominal pain burning sensations abdominal fullness nausea vomiting borborygmi looseness of bowels loss of weight constipation.	Not present Mild Moderate (•) Severe Very severe

Study monitoring – data audit



Data Audit Trail

Data Collection Audit Log

eForm Name: Headache Diary - CGRP
Protocol Name: Test-102
Subject ID: TBI_INVVA809RTY
Collection Visit Date: 2022-01-19 16:01
Scheduled Visit Date: 2022-01-19 16:01
Visit Type: diary test

Form Summary Status

Download

Search:

NAME	DATE/TIME	ACTION	# OF QUESTIONS ANSWERED	E-SIGNATURE
Subject	2022-01-19 16:02	Started		
Subject	2022-01-19 16:02	Completed		Signed

Showing 1 to 2 of 2 entries

First Previous 1 Next Last

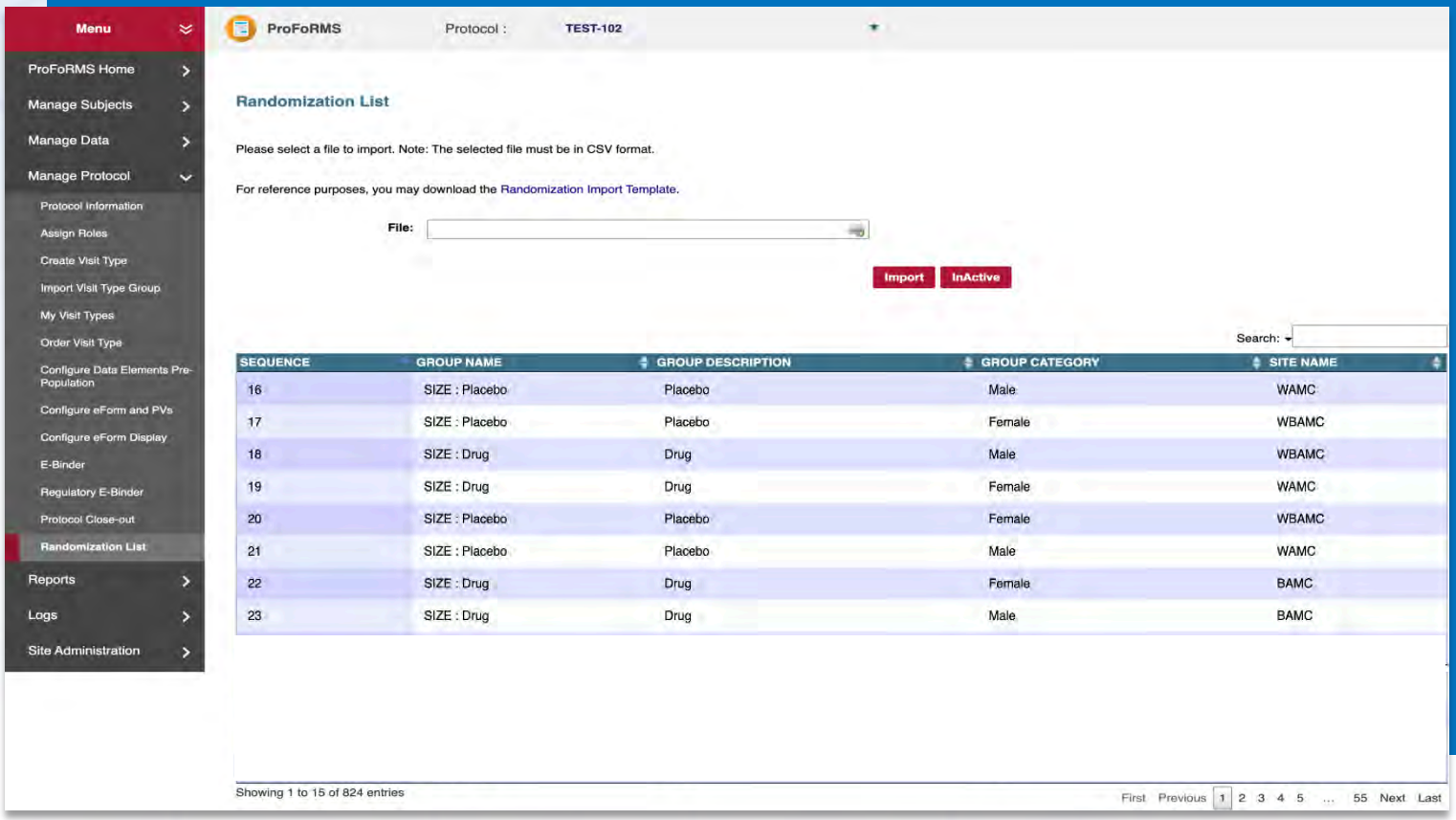
In Progress Entries

Download

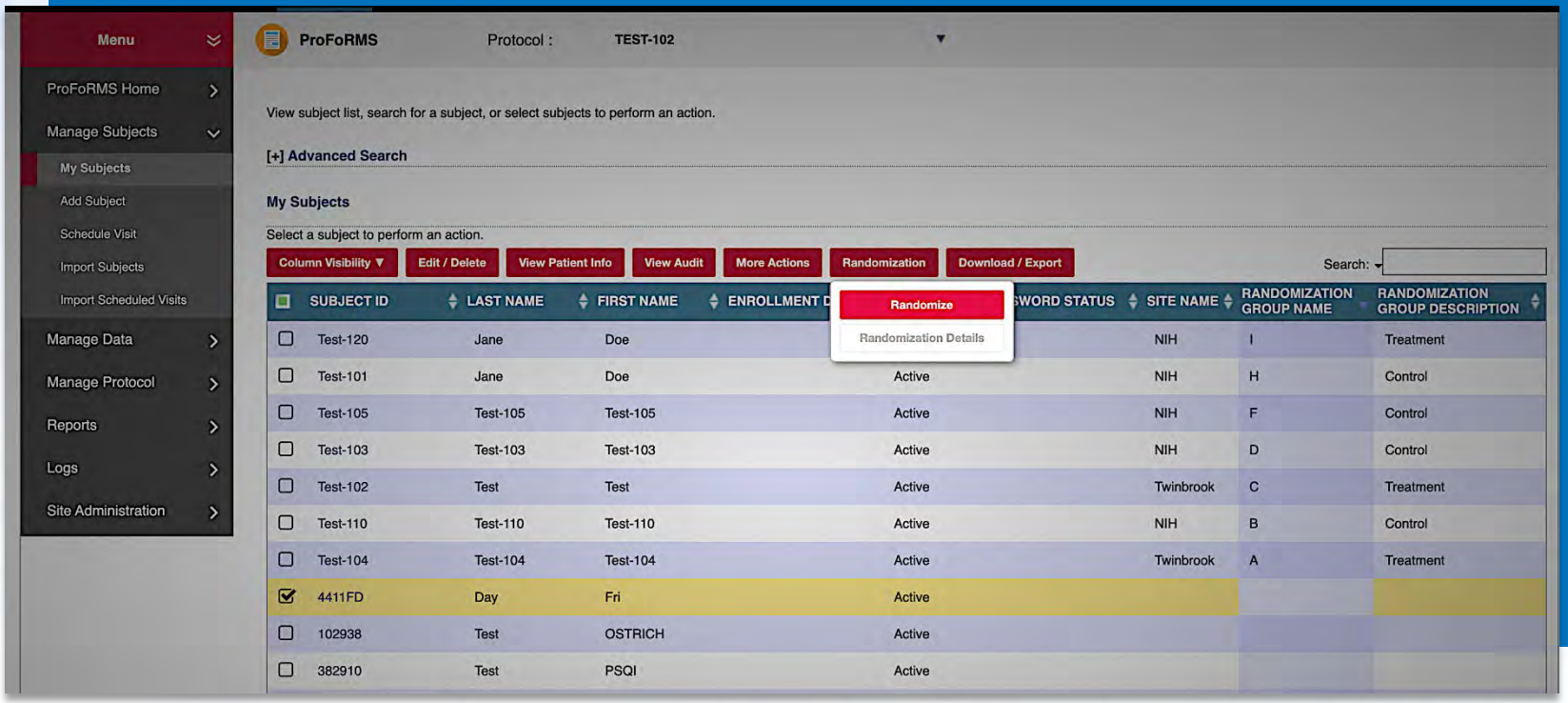
Search:

NAME	DATE/TIME	SECTION NAME	DATA ELEMENT NAME	QUESTION TEXT	ANSWERS BEFORE	ANSWERS AFTER
Subject	2022-01-19 16:02	Main	GUID	Global Unique ID (GUID) which uniquely identifies the subject:		TBI_INVVA809RTY
Subject	2022-01-19 16:02	Main	VisitDate	Visit date:		2022-01-19 16:01
Subject	2022-01-19 16:02	Main	SiteName	Name of the site:		Twinbrook
Subject	2022-01-19 16:02	Headache Diary	HPFIDDayRecordInfoDate	For what day are you recording information?		2022-01-04
Subject	2022-01-19 16:02	Headache Diary	HPFIDTimeRIghtNowTxt	What time is it right now:		3
Subject	2022-01-19 16:02	Headache Diary	HPFIDAM_PMTyp	AM or PM		AM
Subject	2022-01-19 16:02	Headache Diary	HATodayInd	Did you have a headache today (select one)?		Yes

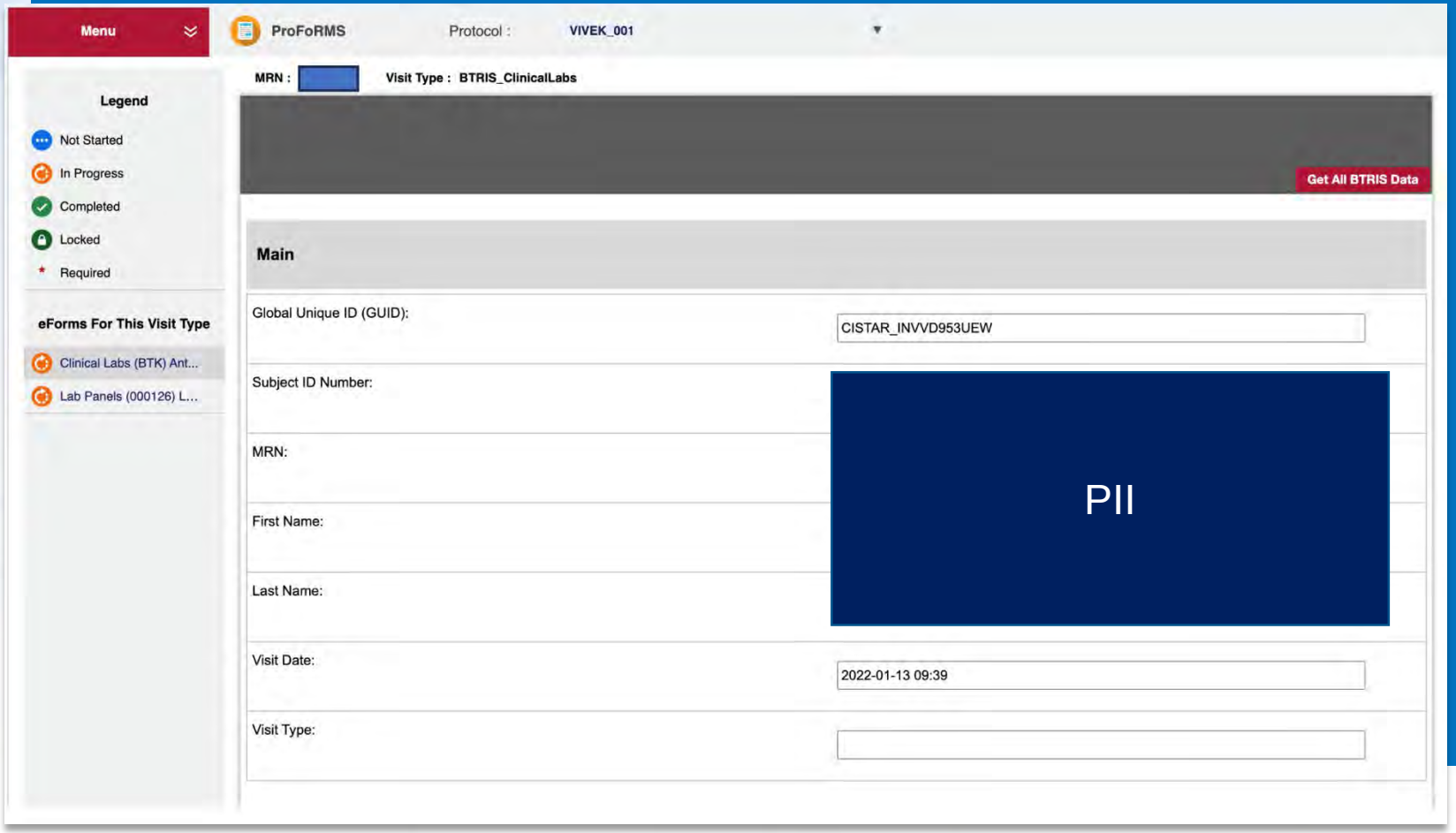
Randomization Control



Randomization process



Pull in CRIS data via BTRIS

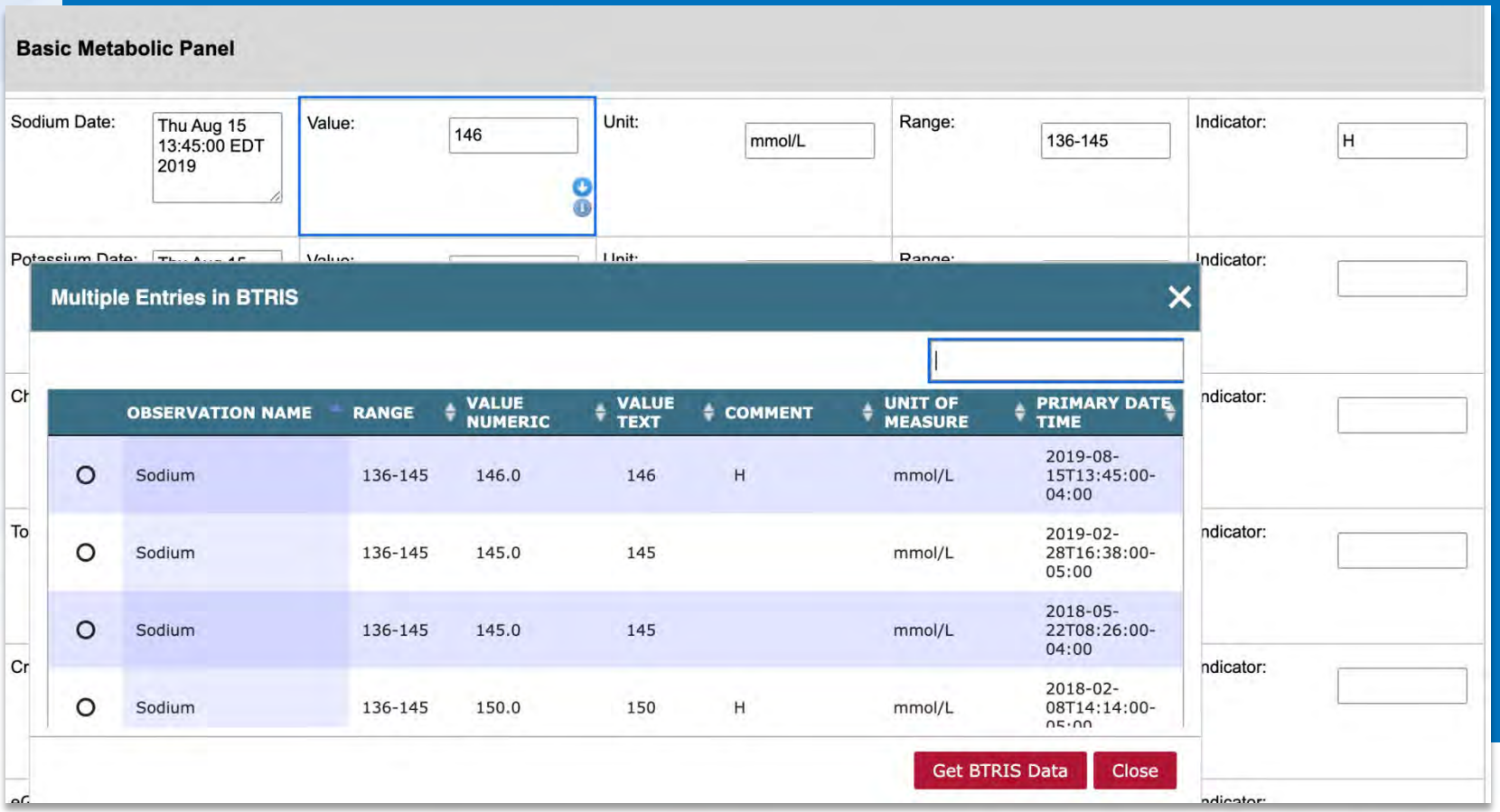


Pull in CRIS data via BTRIS

CBC with Diff

WBC Date:	Wed Mar 28 21:16:00 EDT 2018	Value:	5.00	Unit:	K/uL	Range:	4.23-9.07	Indicator:	
RBC Date:	Wed Mar 28 21:16:00 EDT 2018	Value:	5.00	Unit:	M/uL	Range:	4.63-6.08	Indicator:	
HGB Date:	Wed Mar 28 21:16:00 EDT 2018	Value:	12.0	Unit:	g/dL	Range:	13.7-17.5	Indicator:	L
HCT Date:	Wed Mar 28 21:16:00 EDT 2018	Value:	67.0	Unit:	%	Range:	40.1-51.0	Indicator:	H
MCV Date:	Wed Mar 28 21:16:00 EDT 2018	Value:	100.0	Unit:	fL	Range:	79.0-92.2	Indicator:	H
MCH Date:	Wed Mar 28 21:16:00 EDT 2018	Value:	29.0	Unit:	pg	Range:	25.7-32.2	Indicator:	
MCHC Date:	Wed Mar 28 21:16:00 EDT 2018	Value:	32.0	Unit:	g/dL	Range:	32.3-36.5	Indicator:	L
RDW Date:	Wed Mar 28 21:16:00 EDT 2018	Value:	12.0	Unit:	%	Range:	11.6-14.4	Indicator:	

Pull in CRIS data via BTRIS



Summary

- Change in perspective - protocol development – emphasis on data curation
- Optimal solution maximizing ROI – NIH government solution
- BRICS demonstrates practical applications of research best practices
- Many mature tools (data dictionary, access control, in built QA/QC, etc.)
- Ability to share data with industry harmonization practices
- Robust data management capabilities and access control
- Intuitive features and user interface
- FHIR, API – AI/ML support
- Truly unified platform

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Acknowledgements


Dominic Nathan, PHD Lead


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Lily Fan


Lloyd Dalias


Mahlet Wondemagegn


Rohith Vallabhaneni


Sindhu Prasannakumar


Sireesha Kolla


Sridevi Sharvirala


Vivek Mannur


Alaa Haddad


Alex Trudov


Alexander Burnett


Alexandra Bokinsky


Alison Garcia


Andrea Lutz


Andy Van Avery


Basir Kader


Benjamin Richmond


Brandi Williams


Christina Nguyen


Colton Farlow


Dagm Sirak


Dan Gillis


Derrick Fox


Erkan Ince


Erik Meyer


Fatima Irfan


Francis Chen


George Popkhadze


Henry Ogoe


Josh Eng


Joshua Park


Kevin Armengol


Krissy Treece


Lakshmi Katuri


Mallisa Johnson


Michelle Harris


Michael Strump


Mihir Bhave


Nalaka Premathilaka


Nikhil Chamarthi


Nishith Pandya


Olga Vovk


Priya Raju


Preeti Roy


Rajeev Nedumpally


Regina Ball


Ronnie Tan


Ryan Stewart-Frederick


Sanghursh Jain


Scott Mitchell


Sid Ambarkar


Taylor Truong


Tuhin Zaman


Warren Overholt

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We thank all our users, and contributors to the various working groups

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Questions?

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CiSTAR

cdRNS Common Data Repository for Nursing Science

National Ophthalmic Disease Genotyping Network eyeGENE®

MTBI² Uniformed Services University

PDBP Parkinson's Disease Biomarkers Program

National Institute of Neurological Disorders and Stroke

FITBIR Federal Interagency Traumatic Brain Injury Research Informatics System

An NIH Data Science Platform for Accelerating Discovery

Matthew J. McAuliffe, PhD (Biomedical Engineering)

Chief, Scientific Applications Services (SAS), CIT

BRICS | Biomedical Research Informatics Computing System

Our Team

SAS Team | **Clinical Trials Research Team** | **Sapient**

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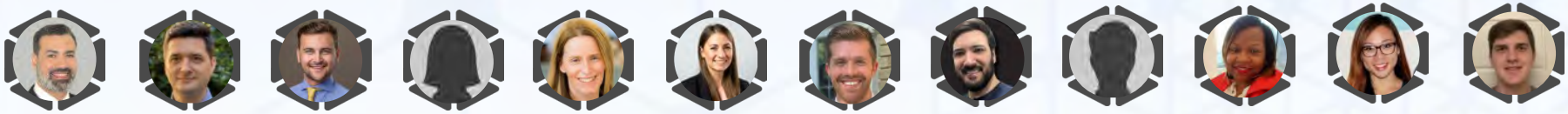

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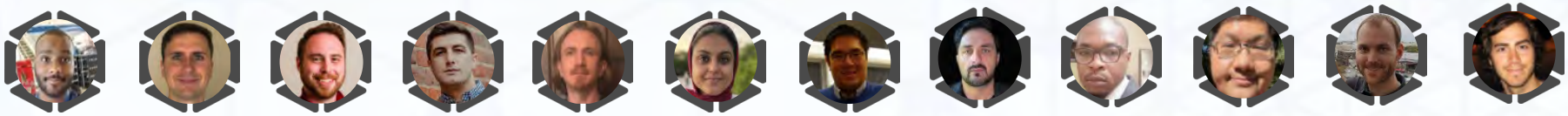

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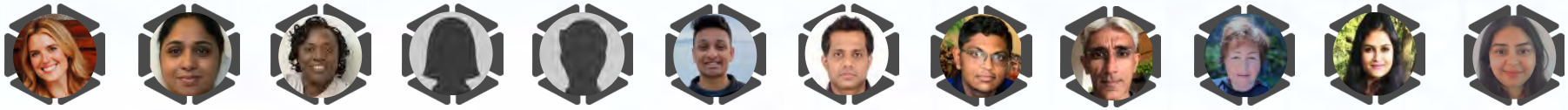

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Sanghursh Jain
Scott Mitchell
Sid Ambarkar
Taylor Truong
Tuhin Zaman
Warren Overholt

Desired Characteristics For Repositories NOT-OD-21-016

This supplemental information is intended to help researchers choose data repositories suitable for the preservation and sharing of data (i.e., scientific data and metadata) resulting from National Institutes of Health (NIH)-funded and conducted research. NIH promotes the use of established data repositories because deposit in a quality data repository generally **improves the FAIRness (Findable, Accessible, Interoperable, and Re-usable) of the data.**

Desirable Characteristics for All Data Repositories.
The characteristics in this section are relevant to all repositories that manage and share data resulting from Federally funded research:

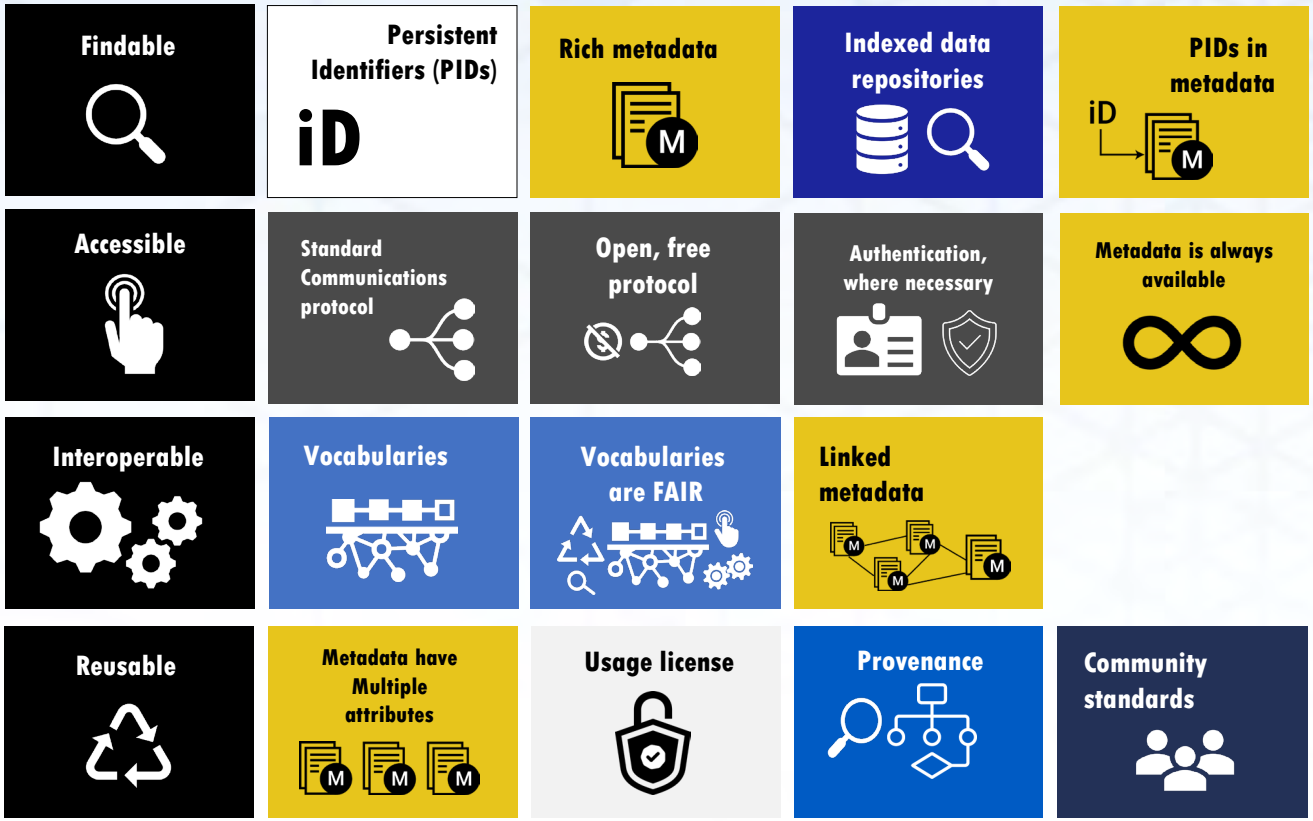
A. Unique Persistent Identifiers
B. Long-Term Sustainability
C. Metadata
D. Curation and Quality Assurance
E. Free and Easy Access
F. Broad and Measured Reuse
G. Clear Use Guidance
H. Security and Integrity
I. Confidentiality
J. Common Format
K. Provenance

II. Additional Considerations for Repositories Storing Human Data (even if de-identified)

A. Fidelity to Consent
B. Restricted Use Compliant
C. Privacy
D. Plan for Breach
E. Download Control
F. Violations
G. Request Review

Making Data Fair

Committed to compliance with Findability, Accessibility, Interoperability, and Reusable (FAIR) principles for scientific data.



The TRUST Principles

T	**Transparency**	***Public evidence of the repository services offered.***
R	**Responsibility**	***Commitment to provide high quality services.***
U	**User community**	***Focus on the uses of the data and services offered.***
S	**Sustainability**	***Capability to support long-term data preservation & use.***
T	**Technology**	***Commitment to infrastructure to support operations.***

The FITBIR System

R16. The technical infrastructure of the repository provides for protection of the facility and its data, products, services, and users.

Compliance Level:

4 – The guideline has been fully implemented in the repository

Reviewer Entry

Reviewer 1

Comments:
4 – The guideline has been fully implemented in the repository
Accept with changes.

Reviewer 2

Comments:
Acceptable at Compliance Level 4 after some clarifications. See comments below.

Response:

The FITBIR system resides in a badged, monitored, and audited secure data center within CIT on the restricted NIH Campus. The backup infrastructure is supported by an alternate secured backup site in Sterling, Virginia. The hardware, software, networking and applications are all maintained by the FITBIR system administration team, in accordance with NIH policies and procedures. The FITBIR admin team maintains all servers and storage according to strict and well-defined laws and regulations (e.g. FISMA moderate; https://www.nist.gov/programs-projects/federal-information-security-management-act-fisma-implementation-project). In accordance to FISMA Moderate systems, the FITBIR systems adhere to the NIST 800-53 (https://nvlpubs.nist.gov/nistpubs/SpecialPublications/NIST.SP.800-53r4.pdf) security standards and guidelines. All documentation is held in either NSAT system at NIH or Confluence, the content management system. Both NSAT and Confluence are internal only.

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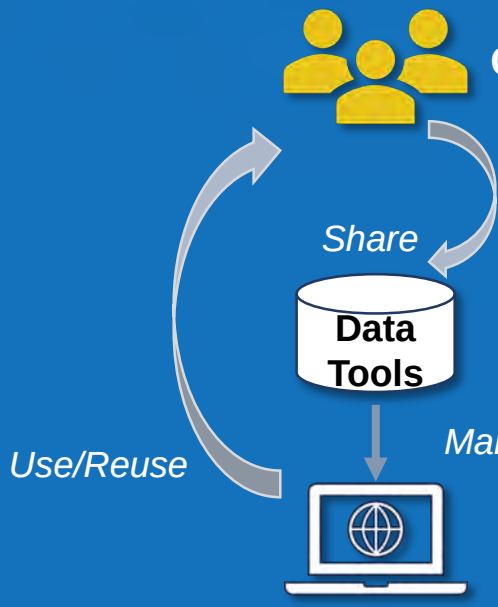
Data Sharing Ecosystem



Community ⟷ **NIH**

Data Management & Sharing Policy
Desirable Characteristics of Repositories

FAIR Principles
Software FAIR principles

Data Resource ⟷ TRUST Principles

Lifecycle management

METRICS

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BRICS Major Capabilities

1. Provides a fully functional Data Dictionary that supports Common Data Elements (CDEs) and automated curation using the CDEs as well as Unique DEs.
   a. OMOP 6.0 version
   b. BTRIS support
   c. FHIR resources/profiles
2. Supports **FHIR** connectivity/data – Prototype using HAPI server.
3. **Core Trust Seal** certified – (FITBIR, working on NEI commons)
4. Uses a hashcode ID system (PPRL), called the GUID, to support de-identified data collection across data types and studies
5. Automated DAC and Biospecimen Review Access Committee (BRAC) support
6. Deployable on prem servers as well as the **Cloud**.
7. Electronic data collection (eCRF – ProFoRMS) that is 21CFR part 11 compliant. Provides access to PROMIS tools, PSR, offline collection …
8. Translation/mapping tool source data to BRICS instance data consistent with CDEs
9. Data types supported: phenotypic, imaging, omics

BRICS systems supported:
https://brics.cit.nih.gov/partners

BRICS Tools | Plug & Play Components for the Full Research Lifecycle

BRICS offers researchers a secure **comprehensive** platform and a suite of web-based and downloadable tools that can be shared across disease categories or deployed and branded independently, depending on the needs of your program.

Data Mapping & Transformation

Tool that translates data into CDEs used by BRICS to prepare for validation

Data Dictionary

Intelligent clinical research data dictionary that supports cross-system exchange, CDEs

Data Repository

Functionality to define and manage studies and contribute or store data

ProFoRMS

Module for electronic data capture (EDC), subject management and scheduling, etc, (21 CFR part 11 compliant)

Meta Study

Workspace that aggregates data and metadata across studies for reference

Global Unique Identifier

Cross-study Privacy Preserving Record Linkage System (PPRLS)

[Introducing BRICS | BRICS (nih.gov)]

Continues…

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Query

Tool enabling filtering of submitted data using data elements and form structures

Clinical Trials Management System (CTMS)

Management of Clinical Trials by enabling insight into trial performance.

BRICS Imaging Tools

Enables quantitative analysis and viewing of medical images, such as PET, MRI, CT, or microscopy.

Forum

Discussion board for account users for posting messages, interacting with each other, and discussing various topics

Account Management

Create, approve, and manage user accounts.

InET

Application for assigning new training, tracking current training, licenses and compliance.

STAMS: Specimen Tracking And Management System

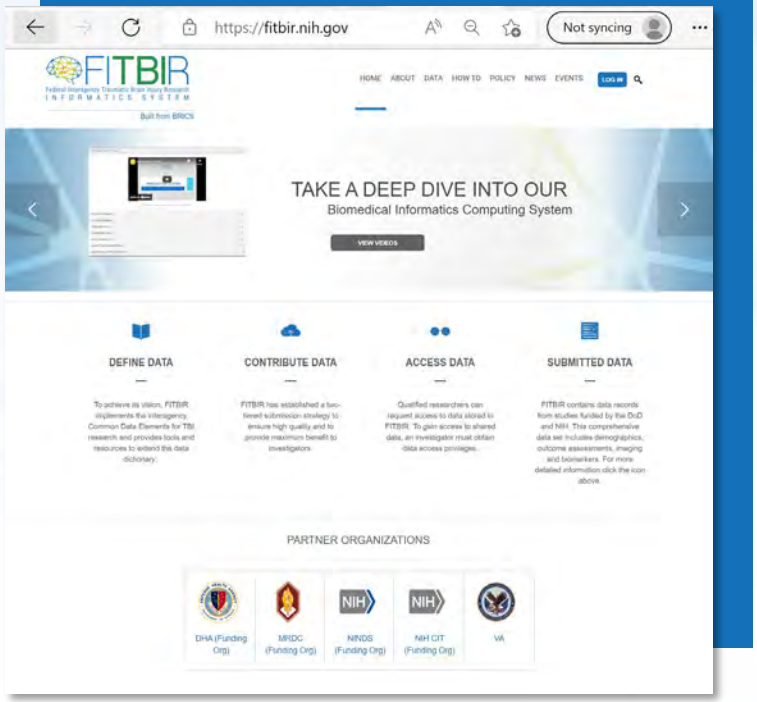
Provides the path to container storage locations (e.g. freezer) that guides the user to the specific container and sample.

Introducing BRICS | BRICS (nih.gov)

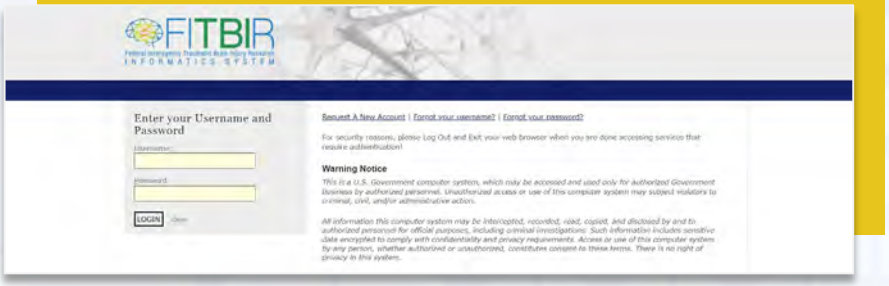
Public and Portal Access

BRICS programs can create a public-facing landing page that provides access to a login portal for authorized customers.

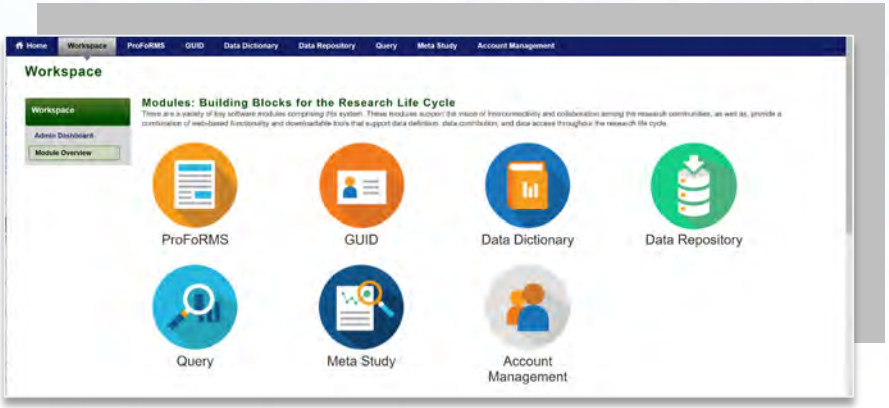
Public Landing Page



Portal Login Page



Controlled Access Portal



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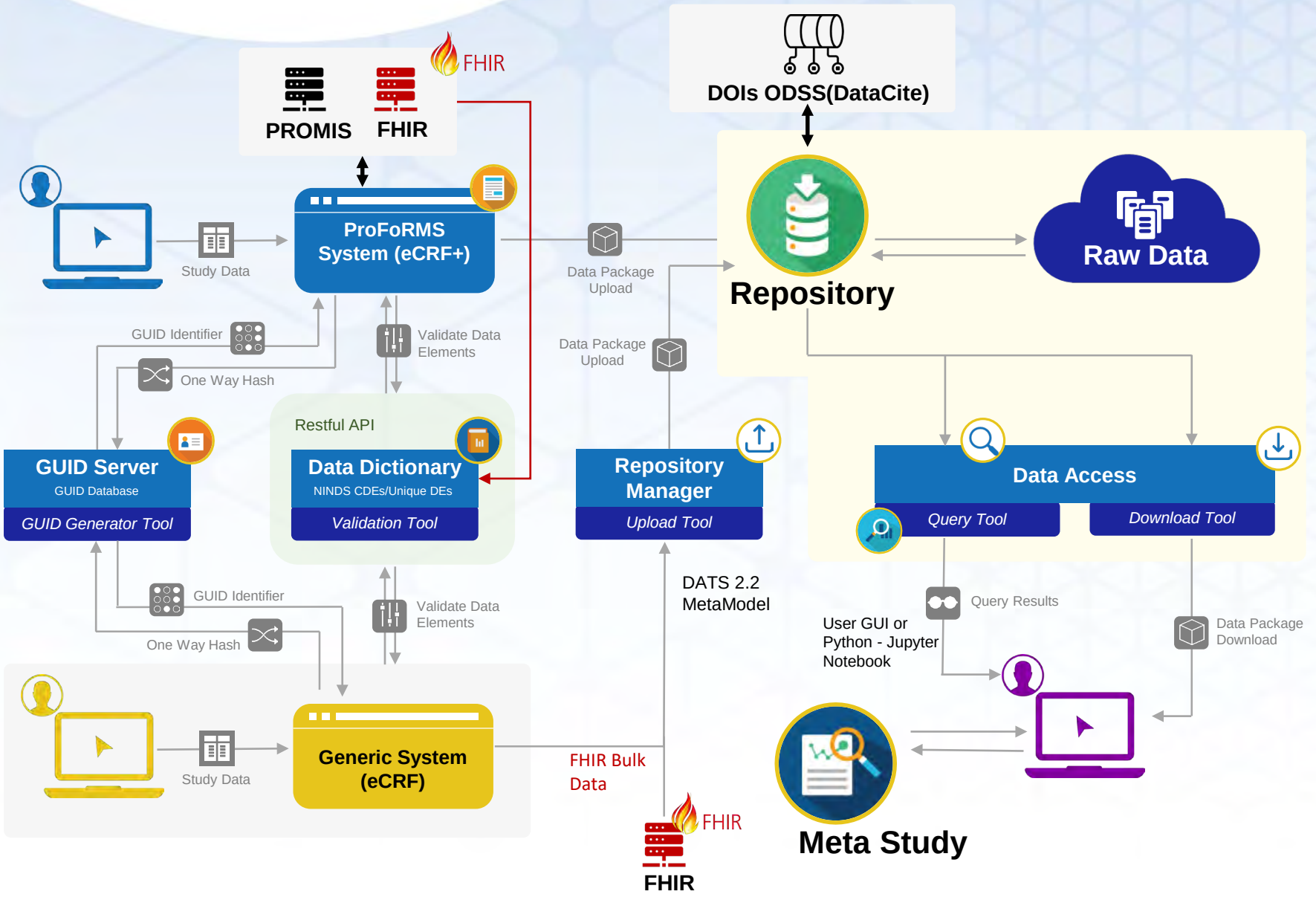
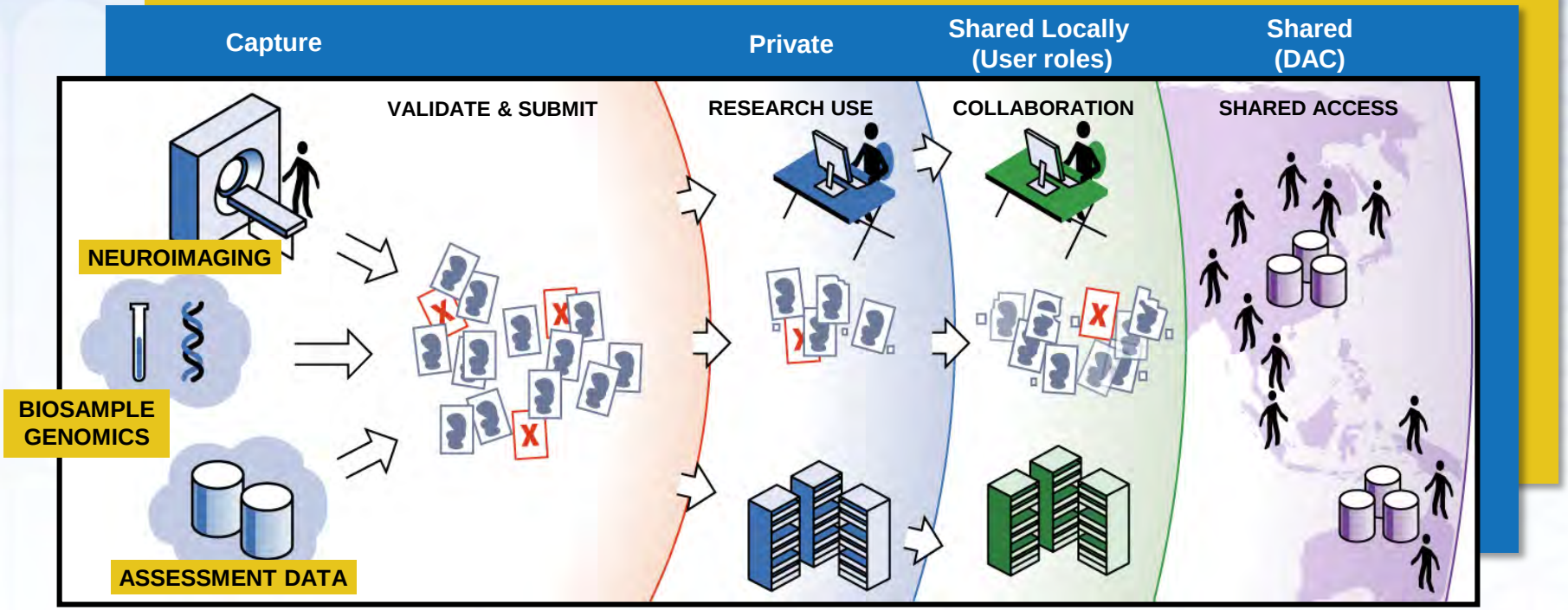
System Overview



Submission/Data Sharing Dataflow



New functionality Cloud (STRIDES)

- Parkinson's Disease Biomarker Program (PDBP)

AMP PD Google

- All BRICS instances – backup

Privacy Preserving Record Linkage (PPRL) Global Unique Identifier System (GUID)

[1] Johnson SB, Whitney G, McAuliffe M, Wang H, McCreedy E, Leon Rozenblit L, Evans CC. Using Global Unique Identifiers to Link Autism Collections. J. Am. Med. Inform. Assoc., Vol. 17, No. 6, 689-695, 2010. PMCID: PMC3000750.

Global Unique Identifier System

- Creates unique random subject identifiers without exposing personally identifiable information (PII)
- Protects privacy of each research participant
- Associates participants across data types and studies

Helps researchers

- Aggregate data for specific study participants over time and space

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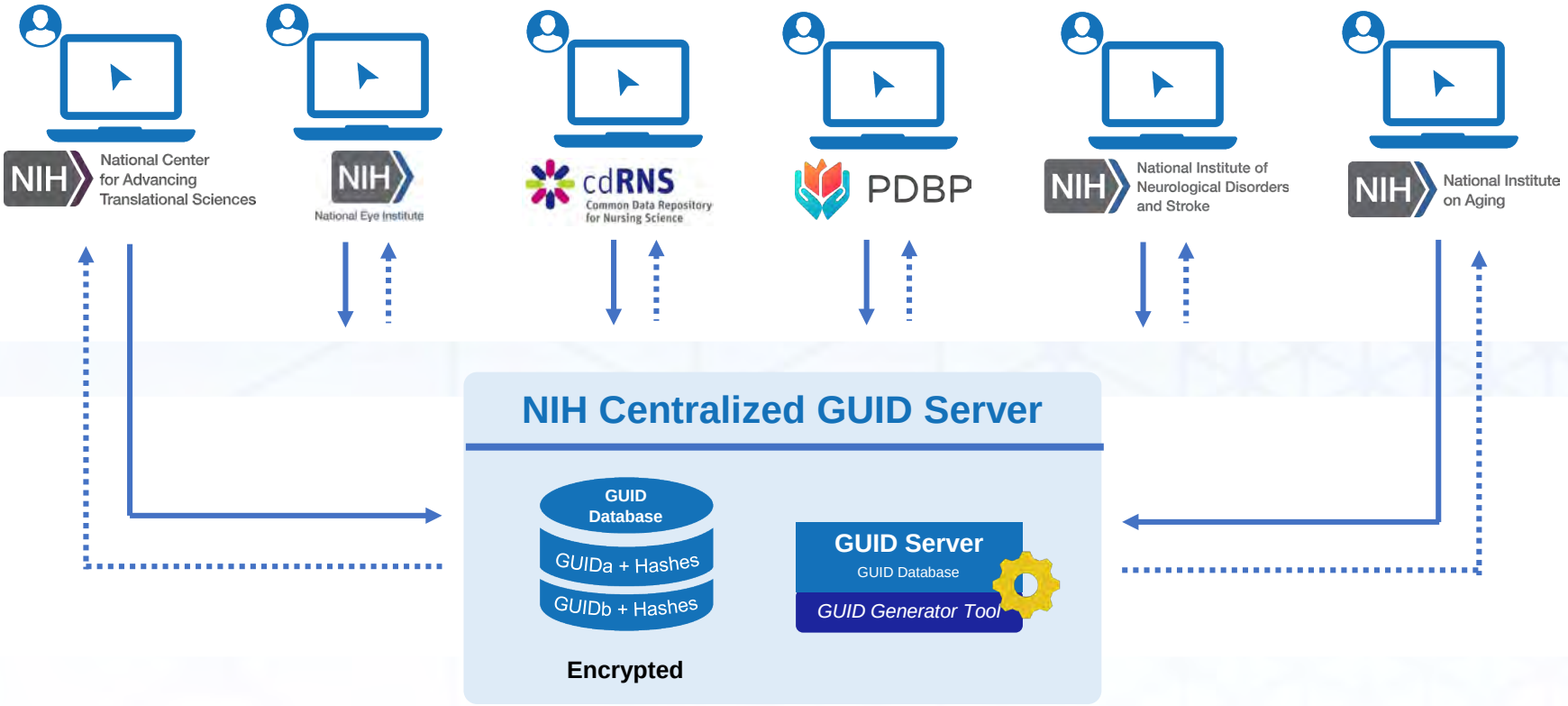
New Functionality
Intramural Centralized PPRL



Meta-Study

Data store for primary and secondary research data

The **Meta Study** module's main use cases are:

1. **Meta Analyses:**
   - Facilitates aggregation of data from different studies within the BRICS Repository module for meta-analyses
   - Accommodates upload(s) of data **external** to BRICS to be included in meta-analyses.

2. **Data Store (Data lake):**
   - Facilitates storage of data from studies that do not have requirements to upload data to the BRICS Repository module.
   - Supports the **NIH Data Management and Sharing Policy**
   - NOTE: data stored inside of the Meta Study Data Store will not be validated or stored in the Data Repository module and it also will not be queryable.

Digital Object Identifiers (DOIs) (ODSS\DataCite)

Makes research more effective by connecting research outputs and resources–from data and preprints to images and samples

Connecting data and publications supports:

- Research validation
- Data Reuse
- Metrics

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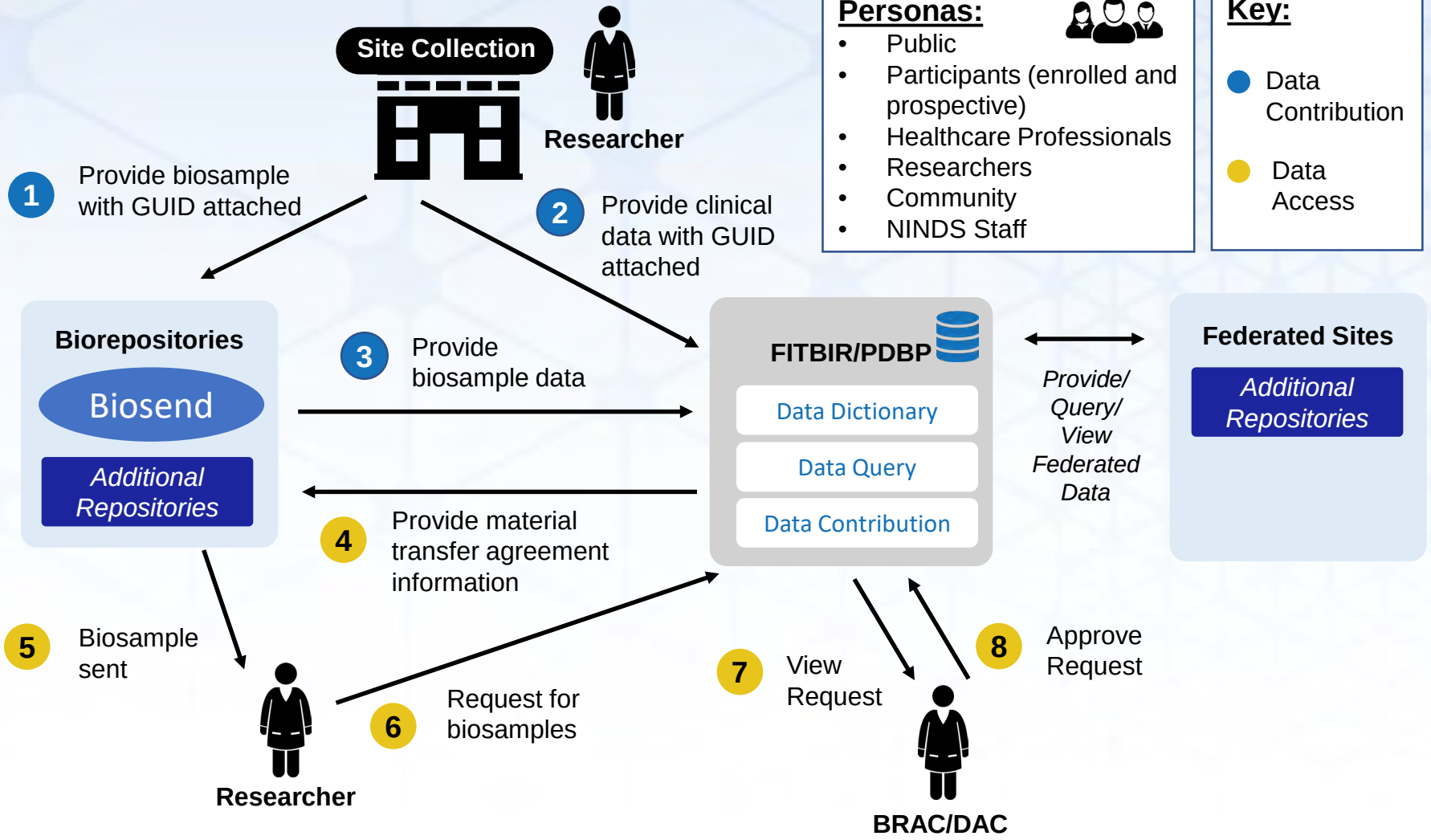
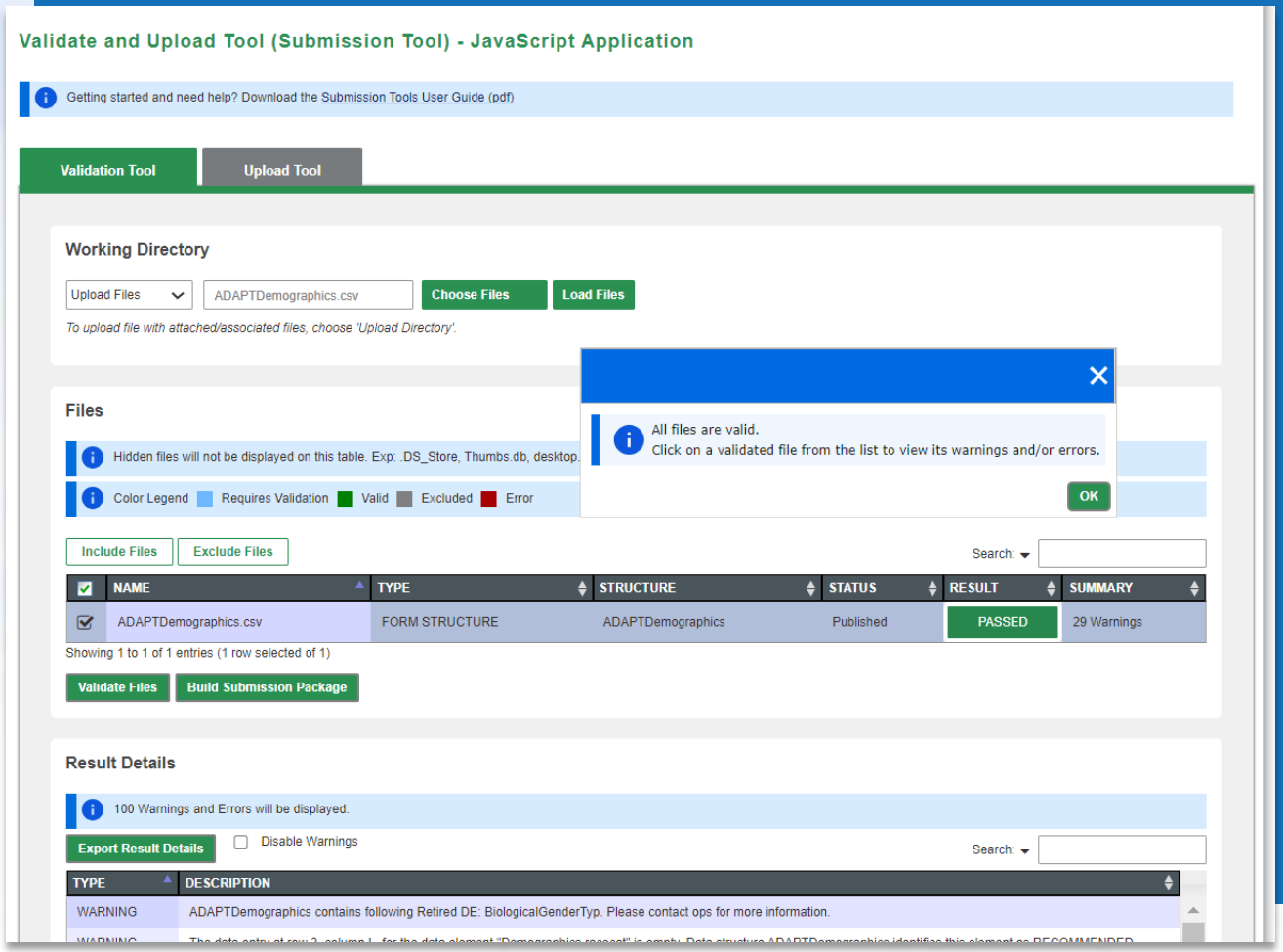
FITBIR/PDBP Biosample Workflow

Personas:
- Public
- Participants (enrolled and prospective)
- Healthcare Professionals
- Researchers
- Community
- NINDS Staff

Key:
- Data Contribution
- Data Access

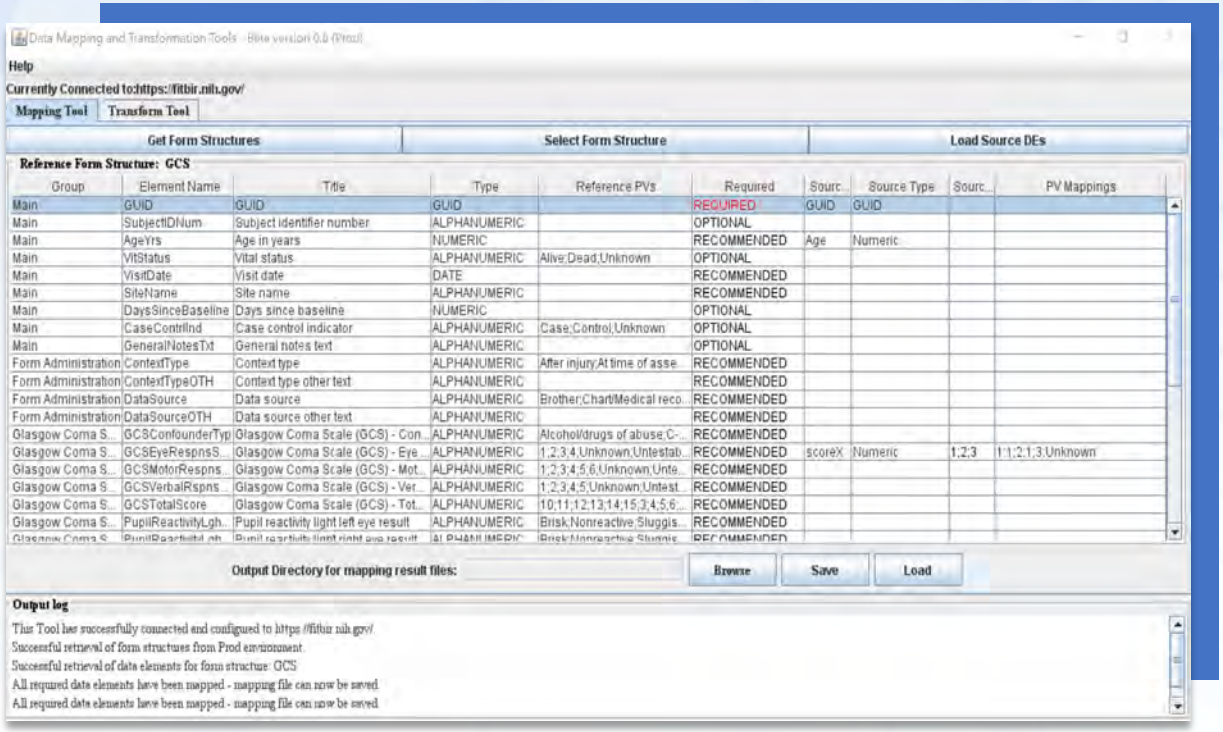


Validation/Submission Tool



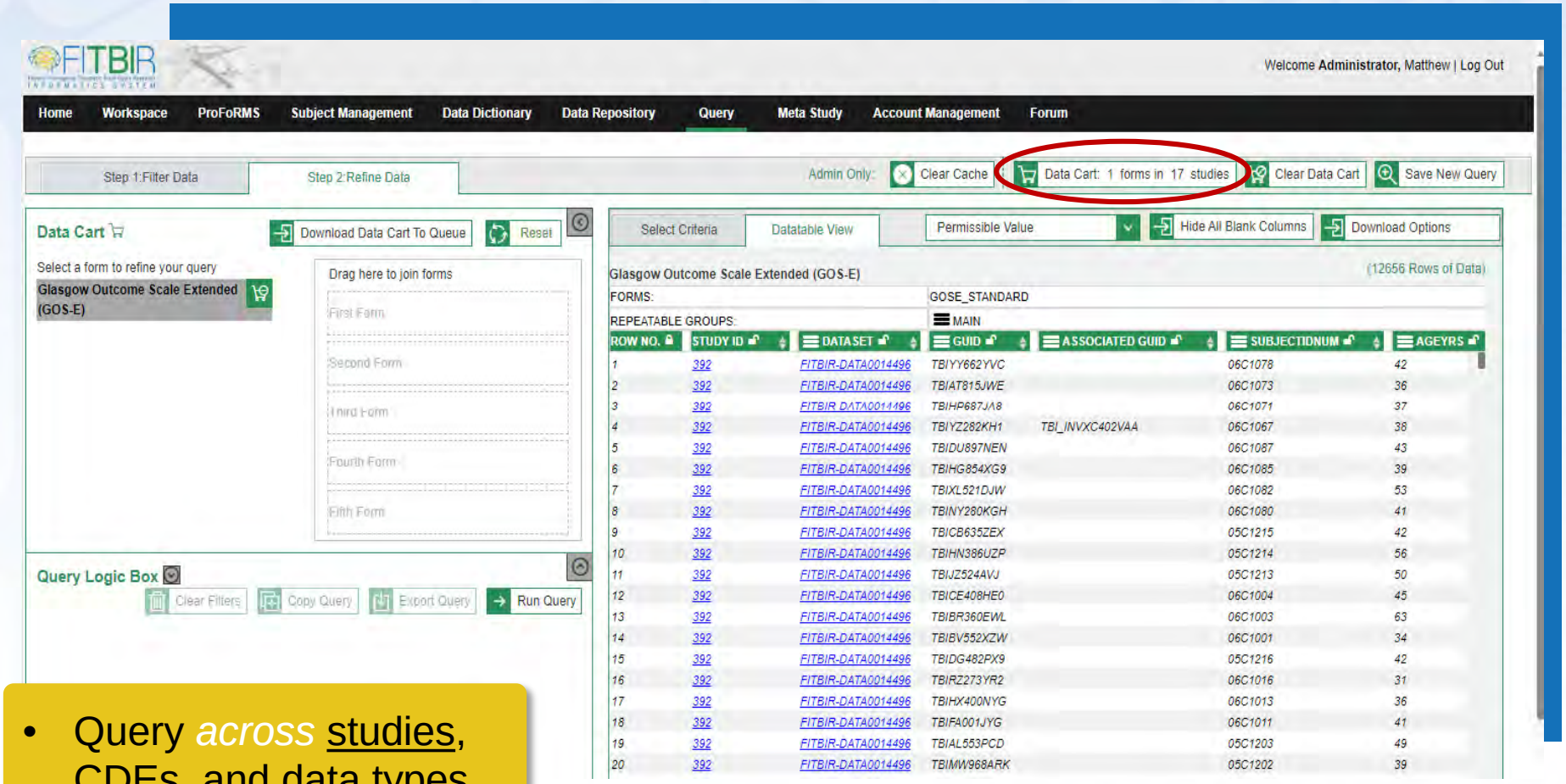
- More universal implementation – From Java Webstart to JavaScript
- Validation at CDE level and Form level

Translation Tool



- The tool supports data definition, data mapping, data transformation, and data access through the research cycle.
- Researchers can easily load their Data Elements (DEs) and Permissible Values (PVs) in the form of a data dictionary to be paired with (or mapped to) eligible BRICS elements and their values within the BRICS Data Dictionary.

Query Tool



- Query *across* studies, CDEs, and data types
- API

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API Query Tool
Programmatic access to the data

Authenticate RAS (11/2023)

- *Query*
- *Retrieve data*
- *Analysis*

Researcher
Data Scientist

Jupyter Notebooks
Python, R,
AI/ML libraries

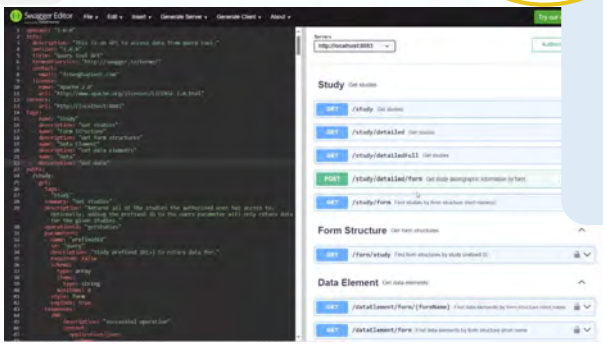
Rest API

Rest API

FITBIR Data

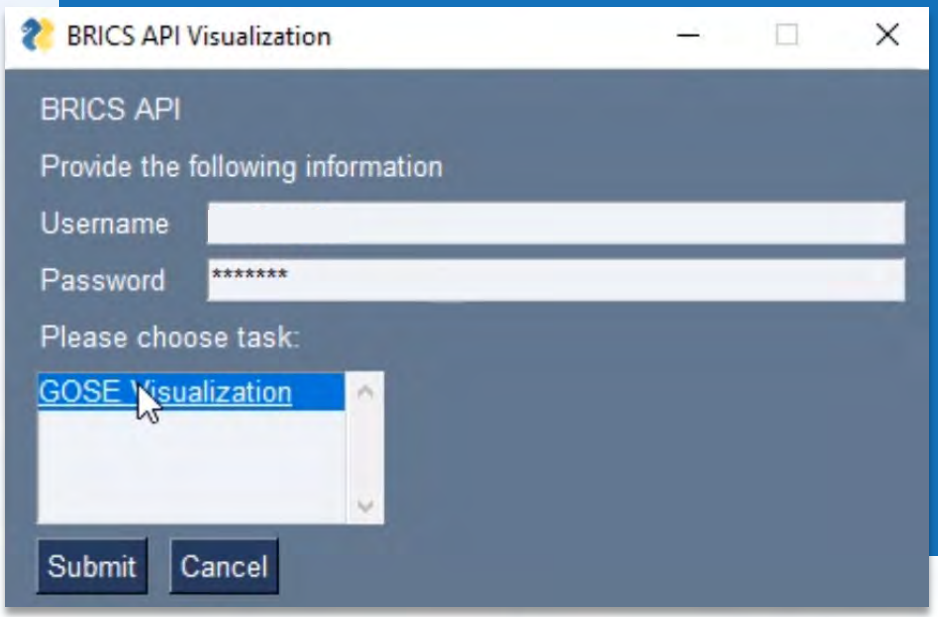
PDBP Data

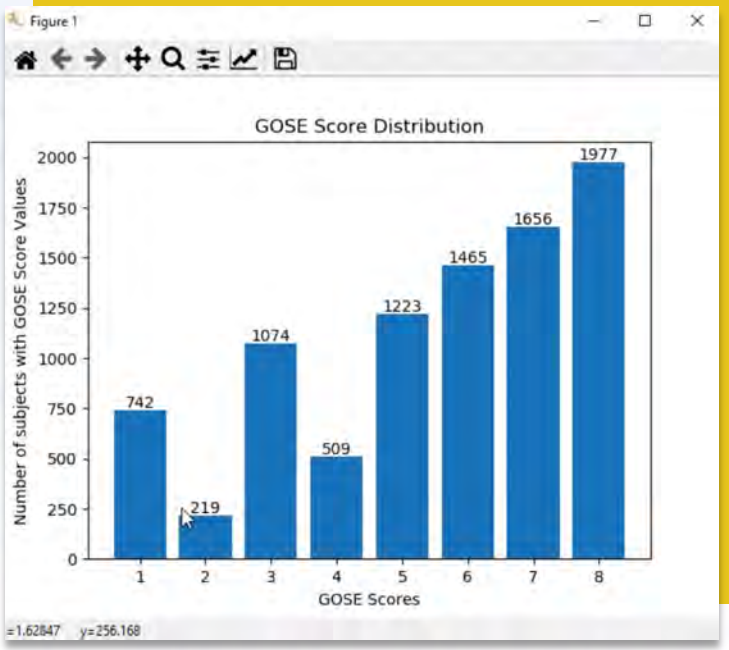
BRICS Informatics Systems



Application GUI – Query/Output

Python Code





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Why We Need Common Data Elements (CDEs)

Common data elements (CDEs) help researchers share and combine datasets, meet funding requirements, and save time.

Why We Need CDEs

1. **Interoperability:** CDEs facilitate data integration across studies.
2. **Data Quality:** They ensure accurate and consistent data collection.
3. **Time and Cost Savings:** CDEs expedite research project startup.
4. **Statistical Power:** Pooling data enhances statistical robustness.
5. **Comparative Analysis:** Researchers can compare data with existing datasets.
6. **Collaboration:** Common data language fosters interdisciplinary cooperation.
7. **Data Sharing:** CDEs promote reproducibility and data sharing.
8. **Regulatory Compliance:** They may be required by regulatory bodies and funders.
9. **Mapping Consistency:** Enables consistent mapping to UMLS concepts, making it easier to update mappings as UMLS evolves.

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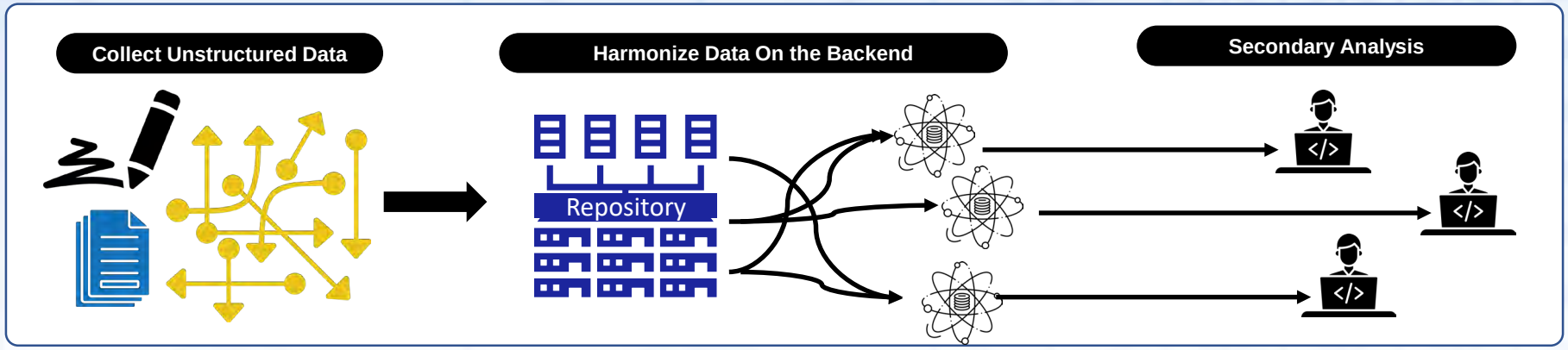
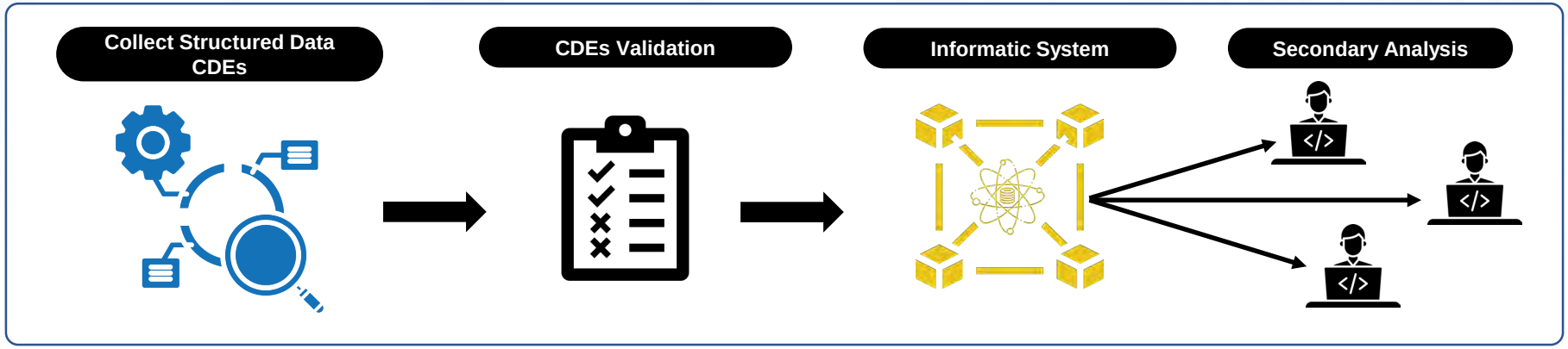
CDEs and Harmonization

Collection of unstructured data from each study independently and harmonize data on the backend – highly inefficient – e.g. 50-70% researchers/postdoc time is spent on data wrangling (QAQC, validation, harmonization). B. Mons DATA STEWARDSHIP FOR OPEN SCIENCE
Implementing FAIR Principles, CRC Press Taylor & Francis Group, 2018

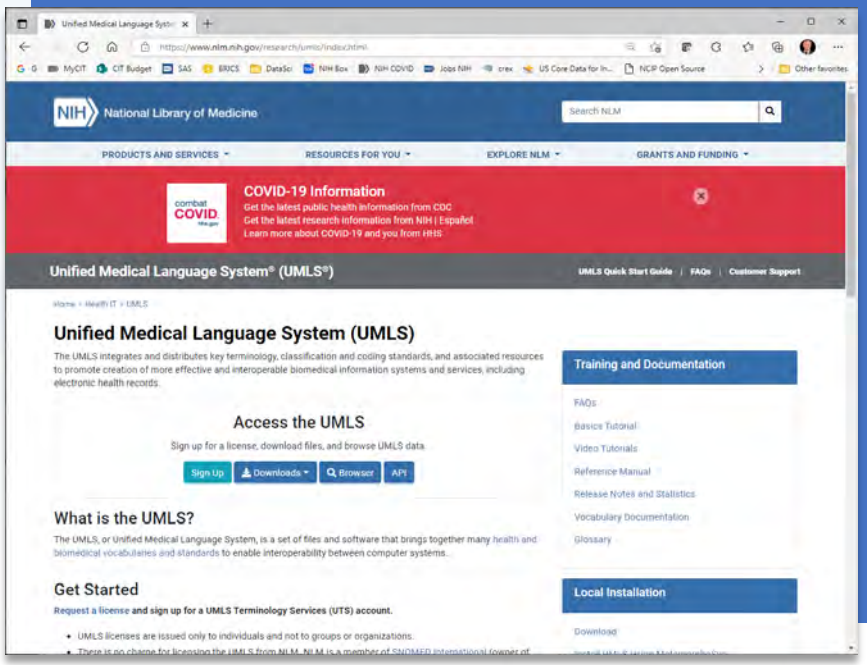


Structured data using CDEs and validating data on submission – supports FAIR



Unified Medical Language System (UMLS)

The UMLS integrates and distributes key terminology, classification and coding standards, and associated resources to promote creation of more effective and interoperable biomedical information systems and services, including electronic health records.



Adding UMLS coding per CDE, UDE and Permissible Values

- Supports programmatic analysis of the data making data stored in a BRICS repository more AI ready.

- Makes BRICS DEs more consistent with NLM's DE efforts supported by the CDE Governance group.

Common Data Elements - CDEs

Common Data Element: Gender Type

view more in the data dictionary

Status: Published

Variable Name: GenderTyp

Definition: Self-reported gender of the participant/subject. Gender is the socially constructed identity of sex. Gender is equated with phenotypic sex. Gender may differ from the sex of an individual determined genetically.

Guidelines & Instructions: Choose one. Response is obtained by report of the participant/subject or caretaker.

References: The NIH Guidelines on Inclusion of Women and Minorities as Subjects in Clinical Research: The Office of Management and Budget Directive No. 15 (http: //grants.nih.gov/grants/funding/women_min/guidelines_update.htm)

Preferred Question Text: What is the subject's gender?

Notes: The NIH Guidelines on Inclusion of Women and Minorities as Subjects in Clinical Research: The Office of Management and Budget Directive No. 15 (http://grants.nih.gov/grants/funding/women_min/guidelines_update.htm)

Population: Adult and Pediatric

Input Restrictions: Single Pre-Defined Value Selected

Data Type: Alphanumeric

Mapping to external dictionaries

Search:

ROW NO	PERMISSIBLE VALUE	DESCRIPTION	CODE	CONCEPT IDENTIFIER	CONCEPT NAME	TERMINOLOGY SOURCE
1	Female	Female	1	C0086287/C1705497	Females/Female, Self-Report	UMLS
2	Male	Male	2	C0086582/C1706180	Males/Male Gender, Self Report	UMLS
3	Not reported	Not Reported	222	C1706613	Not Stated	UMLS
4	Unknown	Unknown	999	C0439673	Unknown	UMLS
5	Unspecified	Undifferentiated/Indeterminant/Inte	555	C1704620	Intersex	UMLS

Showing 1 to 5 of 5 entries

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RAS
Research Authentication Service (includes MFA)

RAS PHASE 1: (End of October 2023)
The traditional username/password Log in flow for BRICS will soon be replaced by NIH's Researcher Auth Service (RAS). This change will require all users to follow a set of steps to Log in/sign up for RAS and link your BRICS account to your RAS account. RAS supports 2 identity providers, a NIH PIV/CAC card, or an account with Login.gov.

RAS PHASE 2: (Spring 2024)
Include additional Identity Providers as needed. Enhancement request that come from the users based upon the initial release

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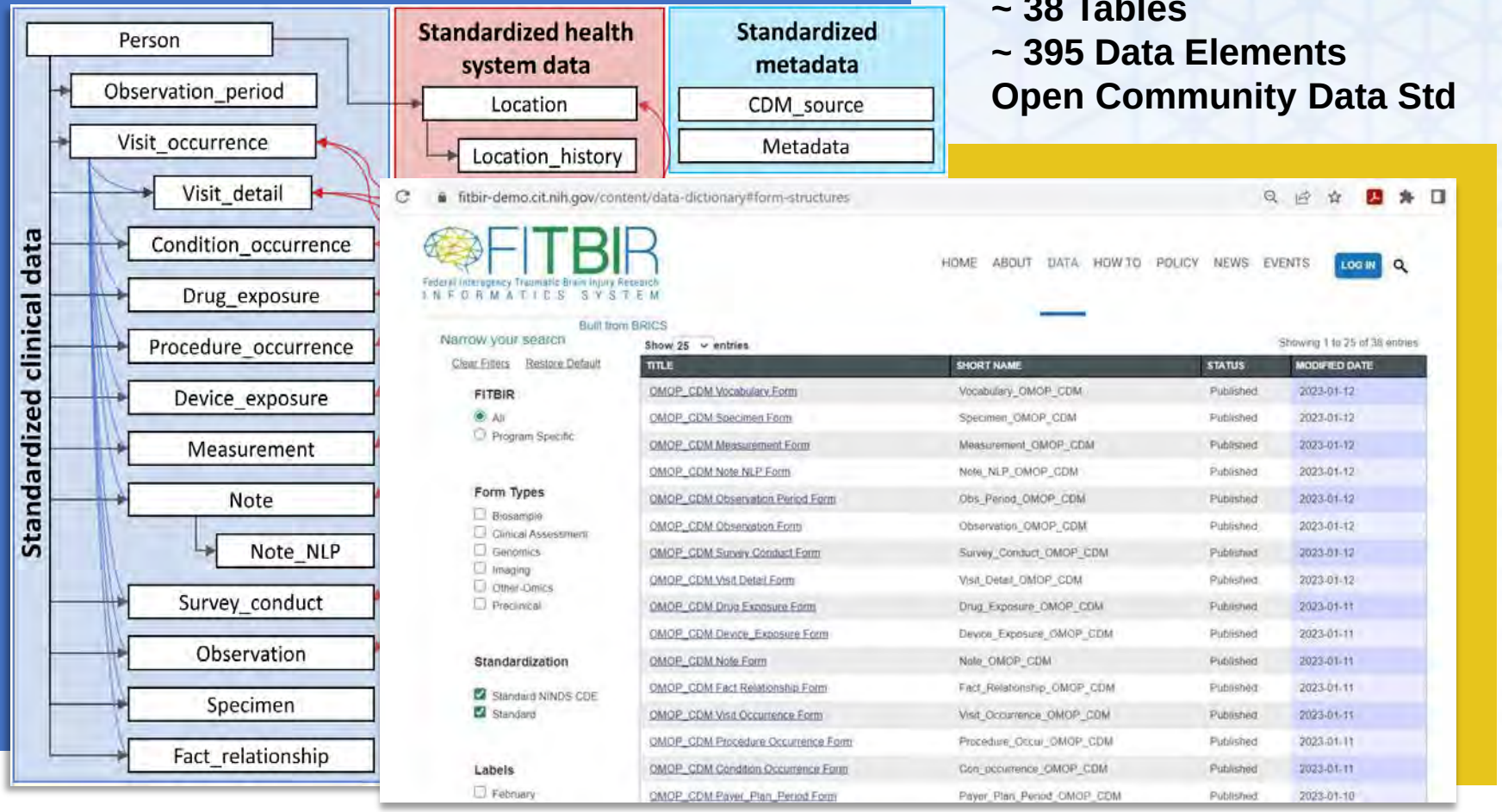
OMOP Observational Medical Outcomes Partnership Common Data Model (v6.0)



~ 38 Tables
~ 395 Data Elements
Open Community Data Std

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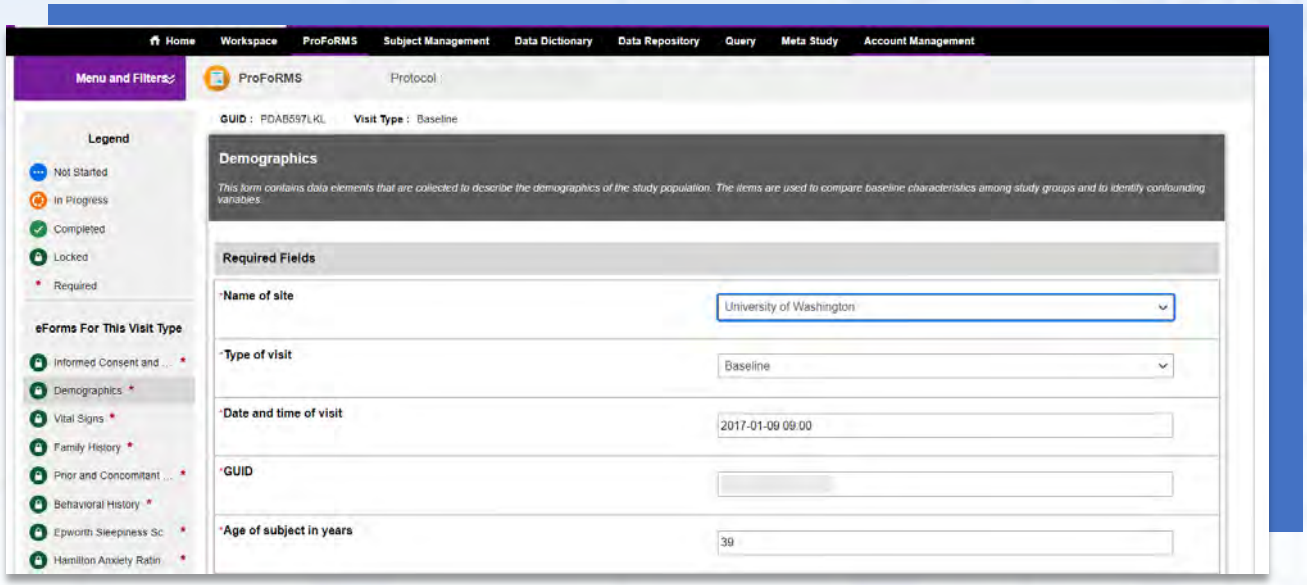
ProFoRMS – Renders Form Structures to Acquire Subject Data

ProFoRMS, BRICS' subject data entry tool, offers a secure, seamless, and functional customer experience.



- **21 CFR Part 11**
  Fully compliant with 21 CFR Part 11
- **Network Connectivity**
  Supports offline data collection
- **Scheduling**
  Built-in subject scheduler
- **PSRs**
  Supports patient self-report modules (PSRs), such as PROMIS
- **BTRIS**
  Enables access to BTRIS data
- **Reporting**
  Built-in reports generator
- Open source

MIPAV Image Submission Workflow

Imaging data submission

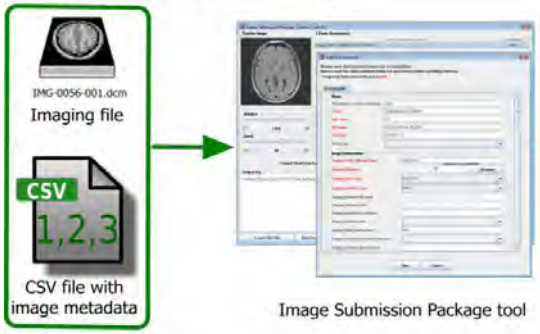
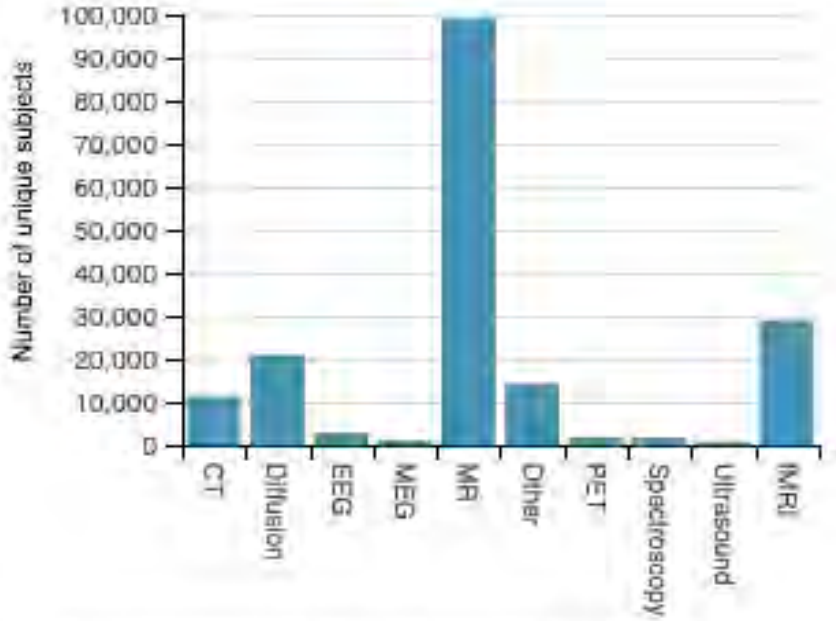


Image Submission Package tool

Clinical data submission

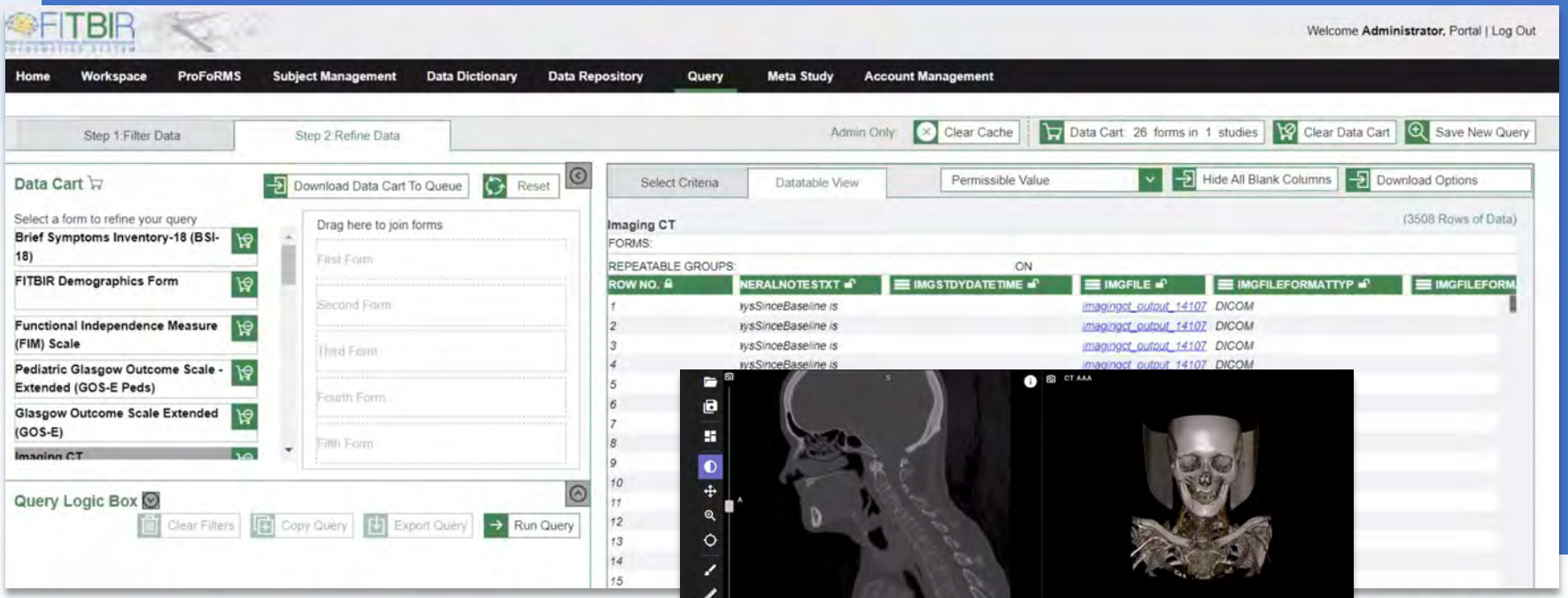
CSV file with clinical data

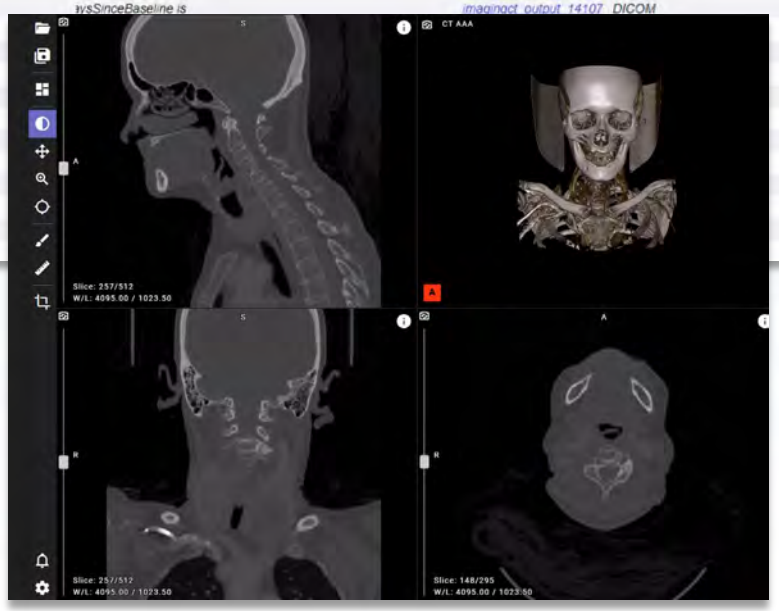
Image Volumes Per Modality



Total number of Image Volumes: 179729

Imaging





BRICS integrates VolView (https://volview.kitware.com/) into the Query Tool

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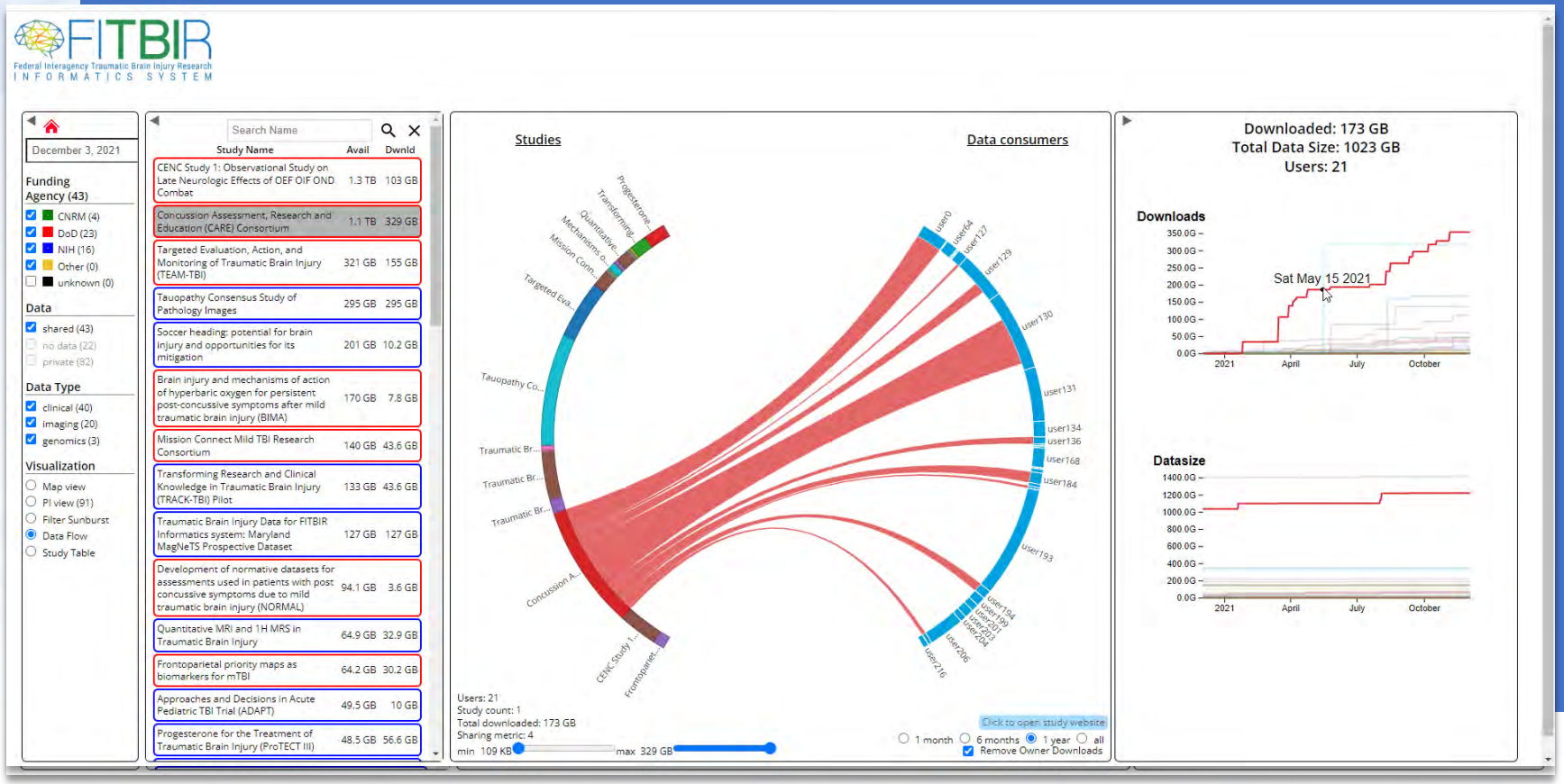
Data Use/Collaboration Visualization Metrics



Future Goals

- Data workbench - develop comprehensive data analysis tools
- Continue API development – validation and submission
- Continue UMLS mapping to CDEs
- Deploy to the Cloud for other BRICS instances
- Research Authentication Services (RAS) phase 2
- CommonAPI
- FISMA high

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BRICS: Advancing FAIR Data Principles and NIH's 2023 Data Sharing Plan

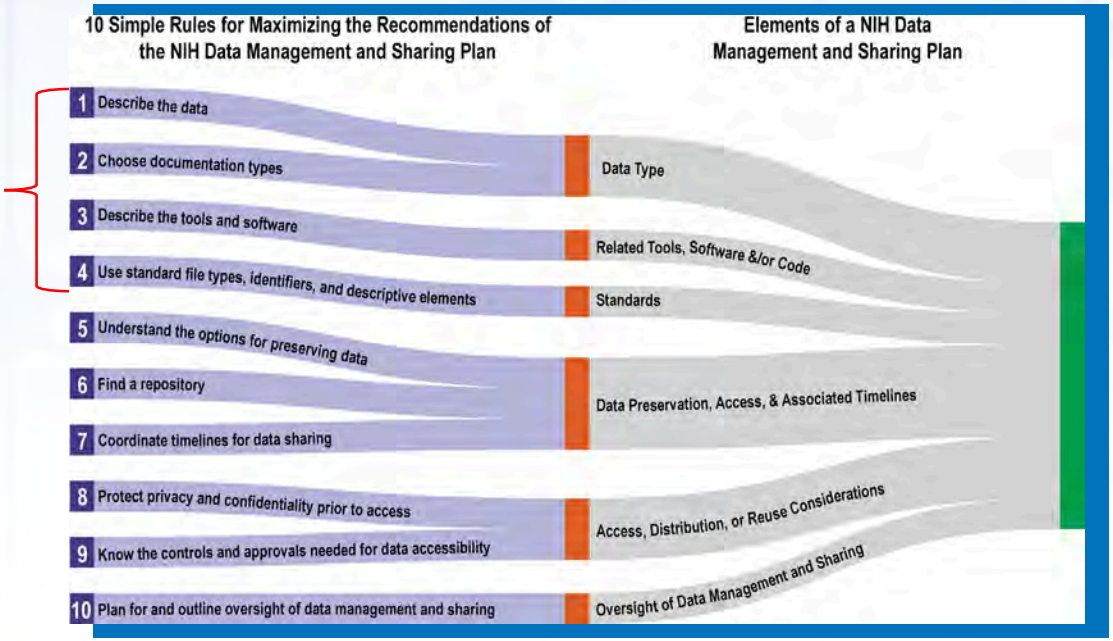
Unified Medical System (UMLS)

Olga Vovk

Advancing FAIR Data Principles and NIH's 2023 Data Sharing Plan

The National Institute of Health (NIH) has issued a new NIH Policy for Data Management and Sharing. The policy came into effect on January 25, 2023.

- It requires researchers, who submits an NIH research application, to submit a plan outlining how scientific data from their research will be **managed and shared**.



Source: Gonzales S, Carson MB, Holmes K. Ten simple rules for maximizing the recommendations of the NIH data management and sharing plan. PLoS Comput Biol. 2022 Aug 3;18(8):e1010397. doi: 10.1371/journal.pcbi.1010397. PMID: 35921268; PMCID: PMC9348704.

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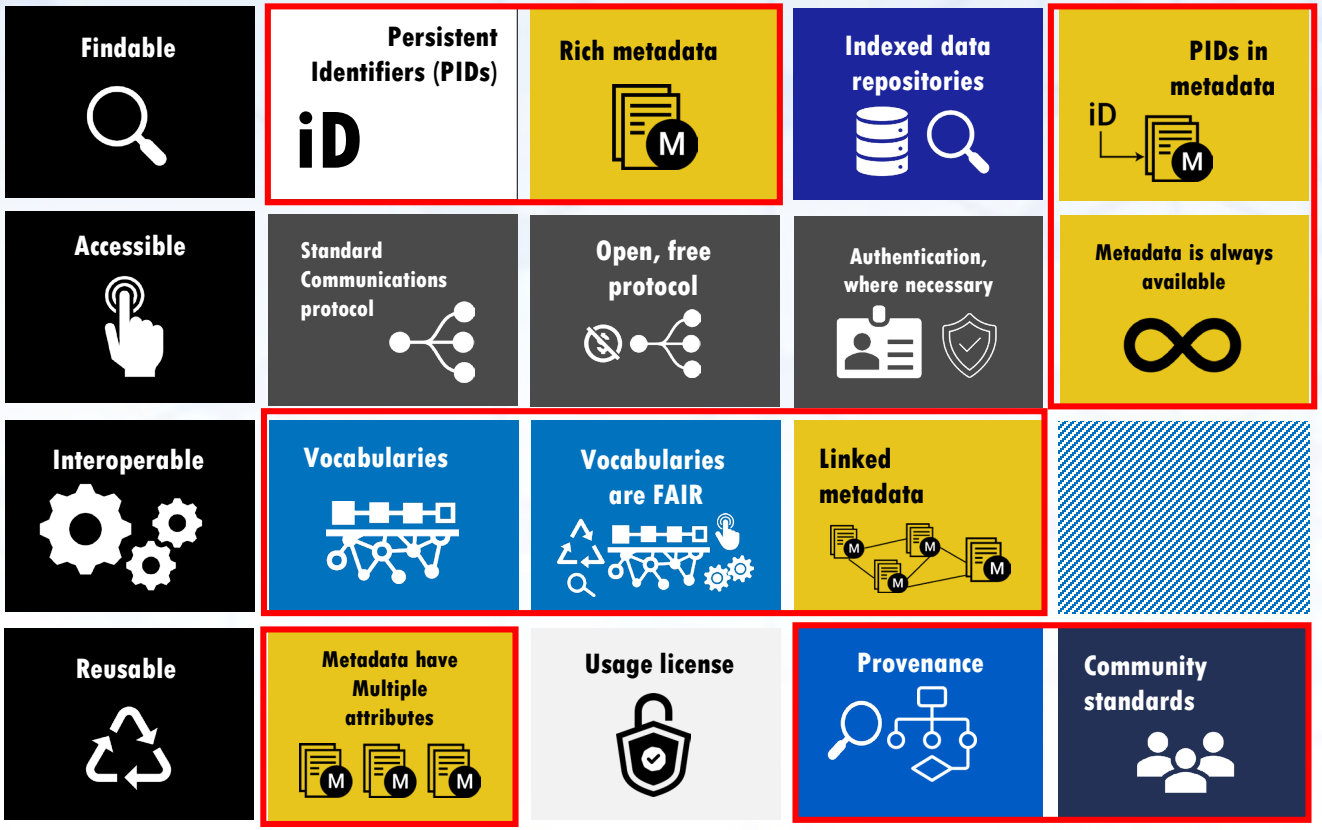
BRICS data dictionary is built on FAIR principles:

Findability, Accessibility, Interoperability, and Reusability (FAIR) principles

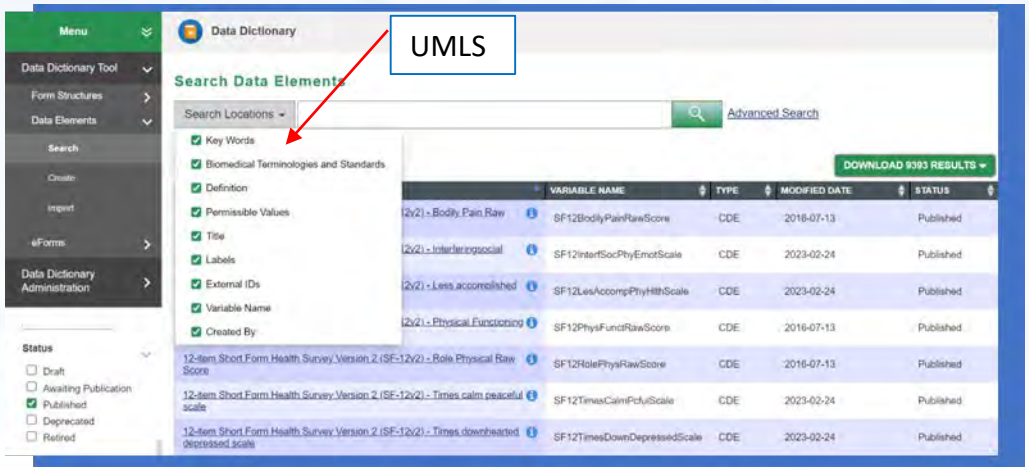


- Uses common data elements (CDEs) to collect data;
- Incorporates standard controlled vocabularies Effectively find, query, and report data;
- Supports data exchange between independent informatics systems.

Advancing FAIR Data Principles and NIH's 2023 Data Sharing Plan

- The count of CDEs in BRICS DDs is big (~9 K published CDEs in FITBIR only) and growing.
- That affects how we manage data dictionaries, including searching, curating, creating, and the most important - re-using of CDEs.
- That affects data analysis and data discovery.

Issues common for all large CDE repositories



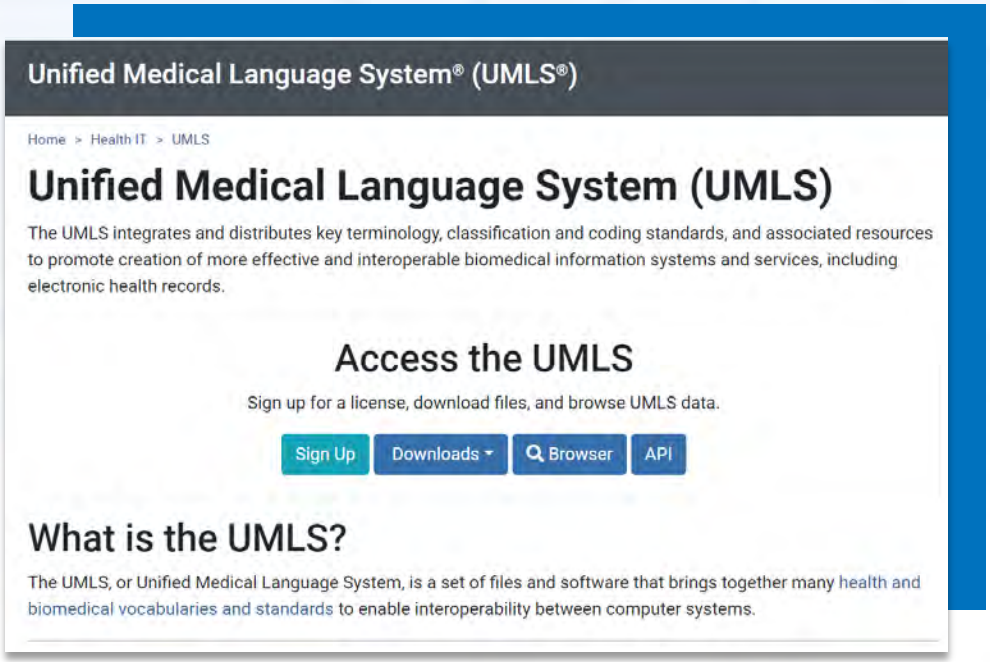
Over the years, we tried various ways to organize CDEs, such as:

- Keywords;
- CDE/UDE cross-mapping;
- Linking CDEs with close semantics
- Building the ETL tool(s).
- **The most recent initiative** we took to make BRICS to comply with the latest NIH Policy for Data Management and Sharing
  - is adding the option of organizing CDEs based on their semantics.

New Functionality:
mapping CDE semantics to UMLS concepts

UMLS as a terminology source

The Unified Medical Language System (UMLS) Metathesaurus, supported by NLM is a large biomedical thesaurus that is organized by concept, or meaning. It links synonymous names from over **200 different terminologies and vocabularies**.

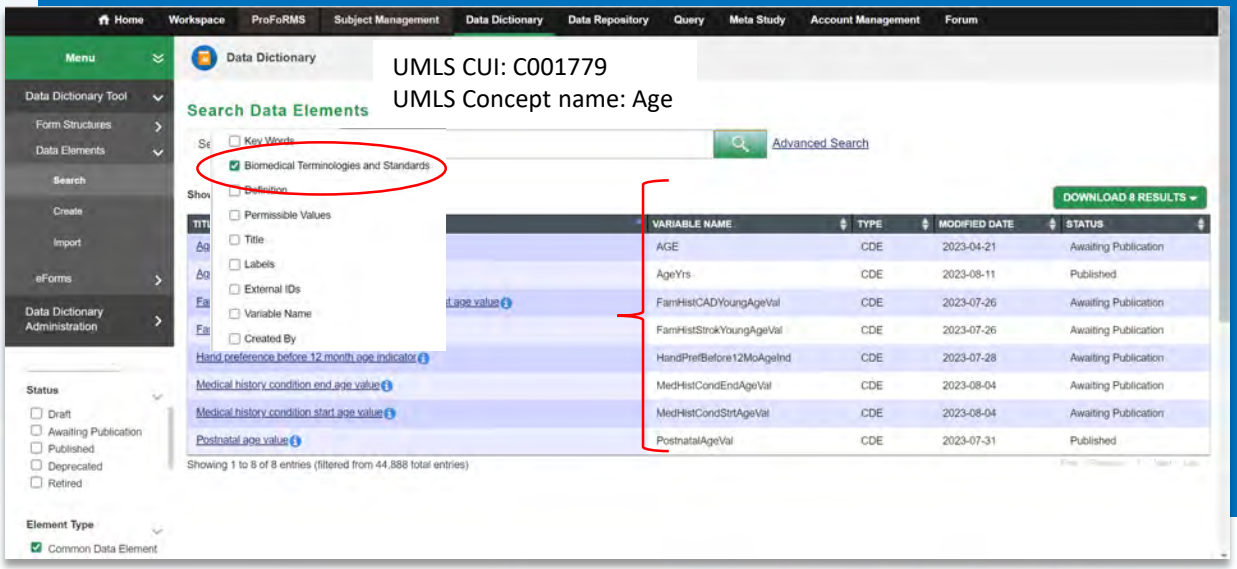


Why UMLS?

- The Unified Medical Language System (UMLS) has been a critical tool in biomedical and health informatics for more than 30 years.
- The UMLS brings together vocabularies and standards in the biomedical field **to facilitate interoperability among different computer systems, projects**, and **applications**.

New Functionality: mapping CDE semantics to UMLS concepts

- *Added UMLS coding per CDE, UDE and Permissible Values*
- *Added the ability to search for CDEs/UDEs by concept name and/or concept identifier*

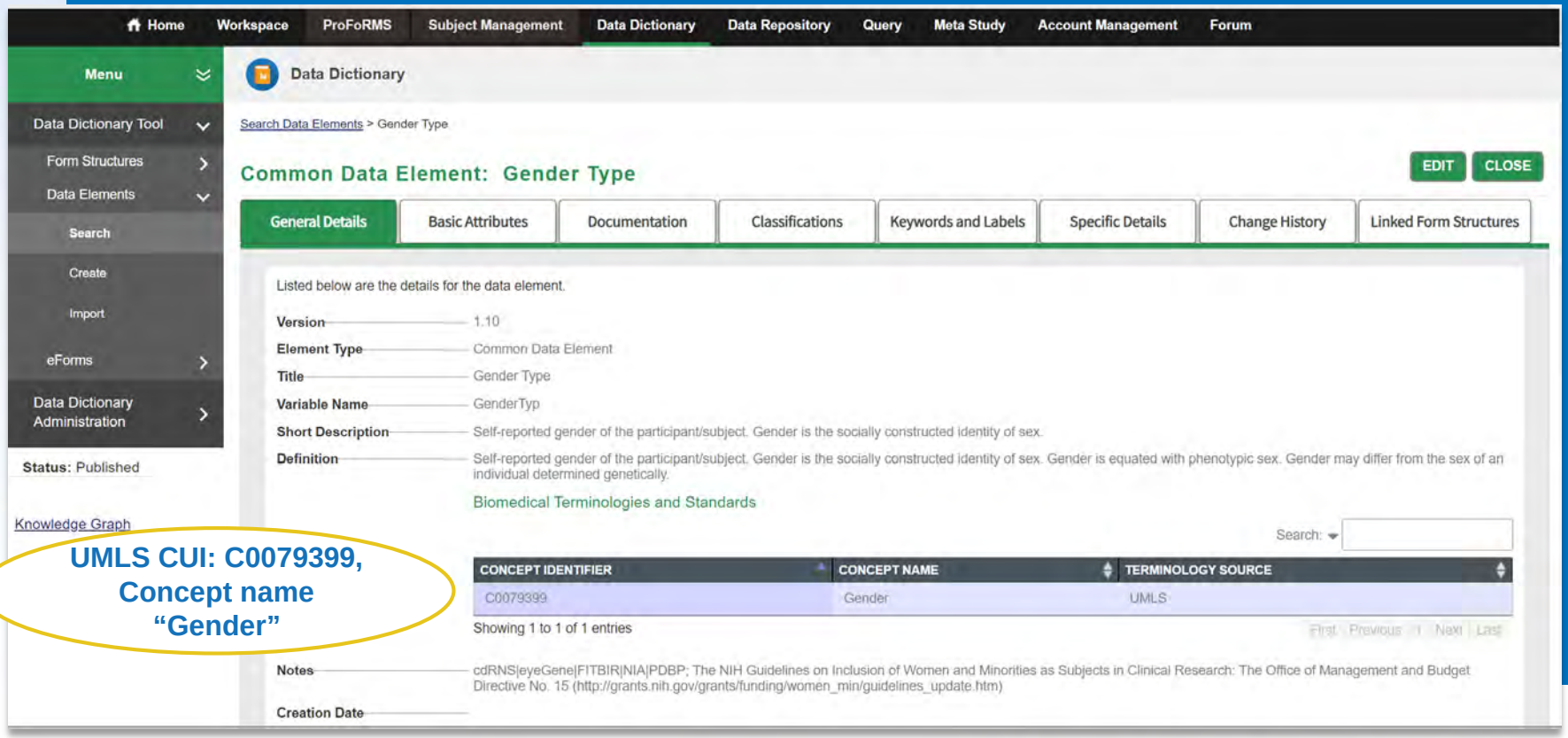


- Supports programmatic analysis of the data.
- Makes data stored in a BRICS repository more AI ready.
- Supports data discovery.

So far, we mapped ~2K CDEs to UMLS concepts

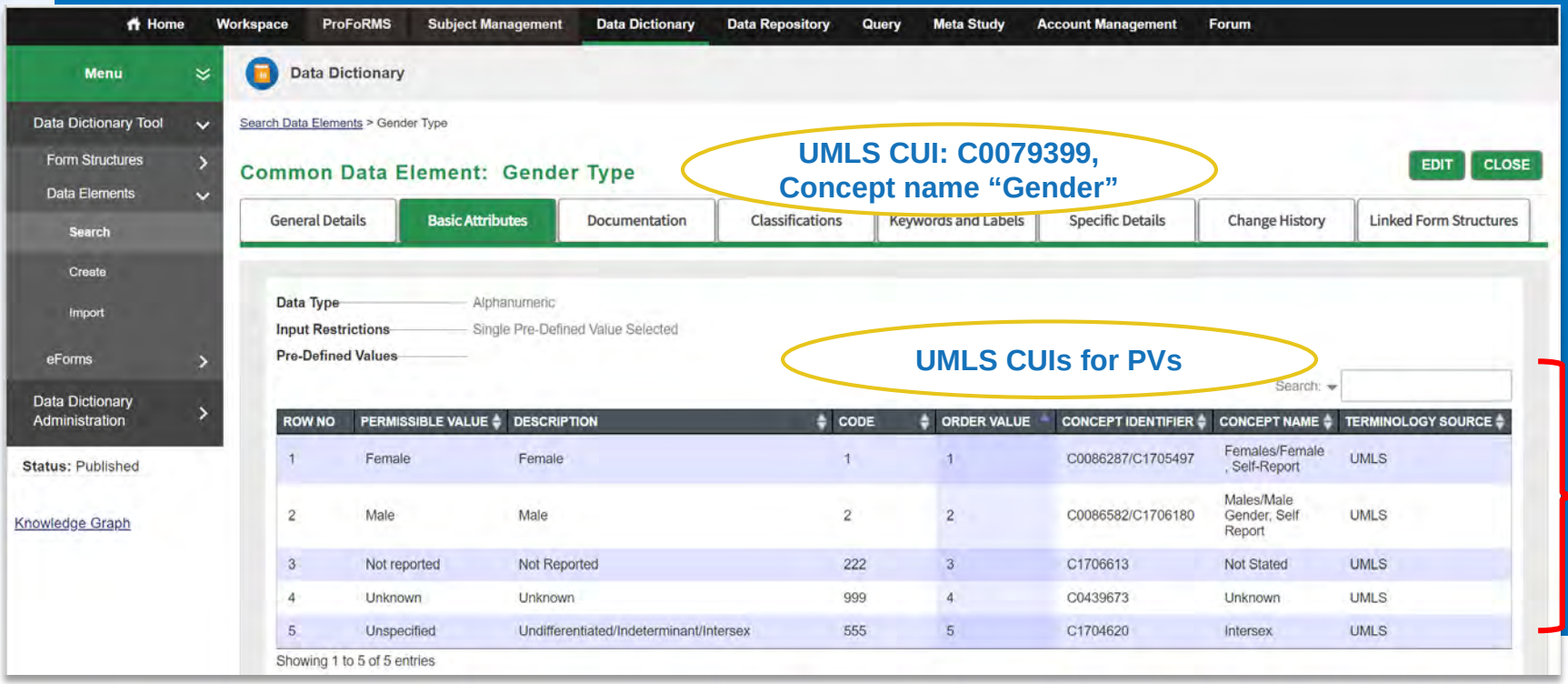
New Functionality: mapping CDE semantics to UMLS concepts

Adding UMLS CUIs to BRICS data element attributes' list



New Functionality: mapping CDE semantics to UMLS concepts

Adding UMLS CUIs to reflect semantics of permissible values



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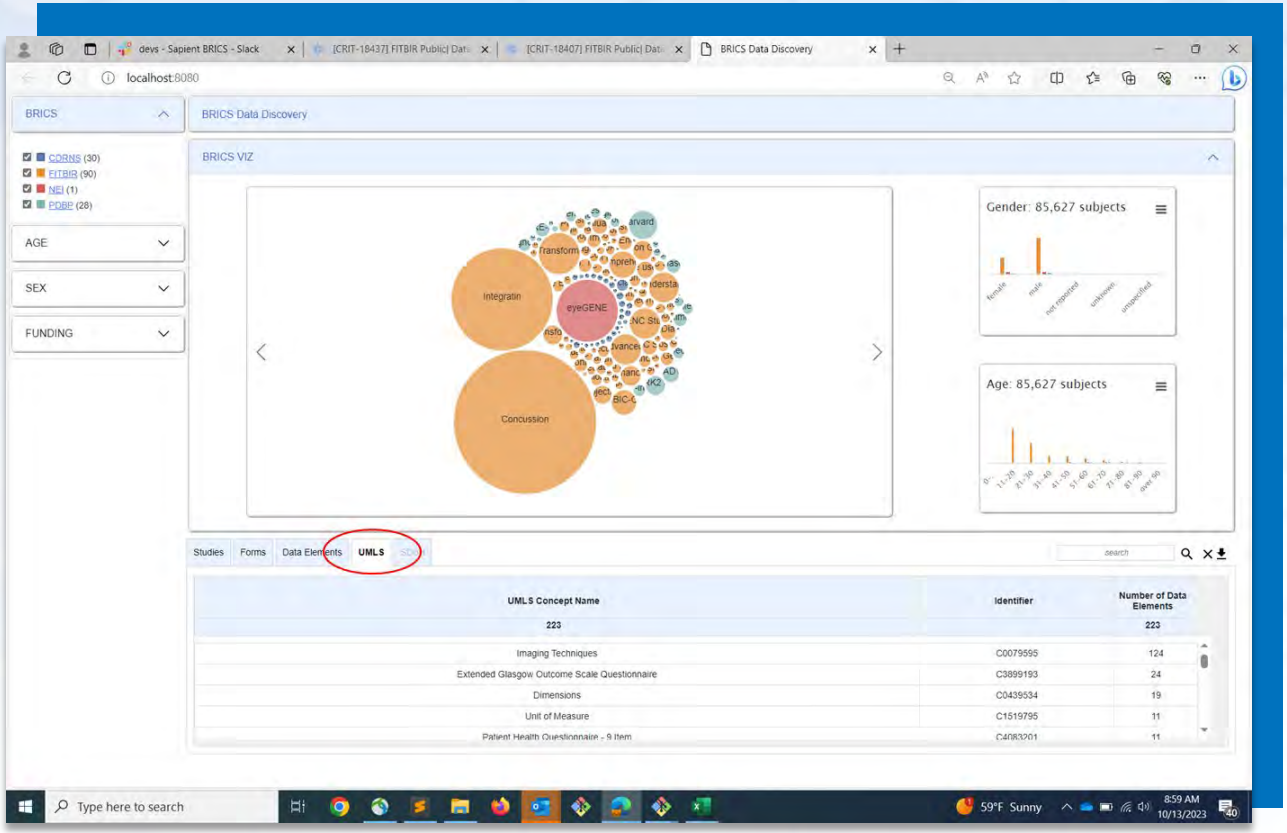
New Functionality: use of UMLS CUIs for data discovery



BRICS Data Discovery Tool searches for data across BRICS instances

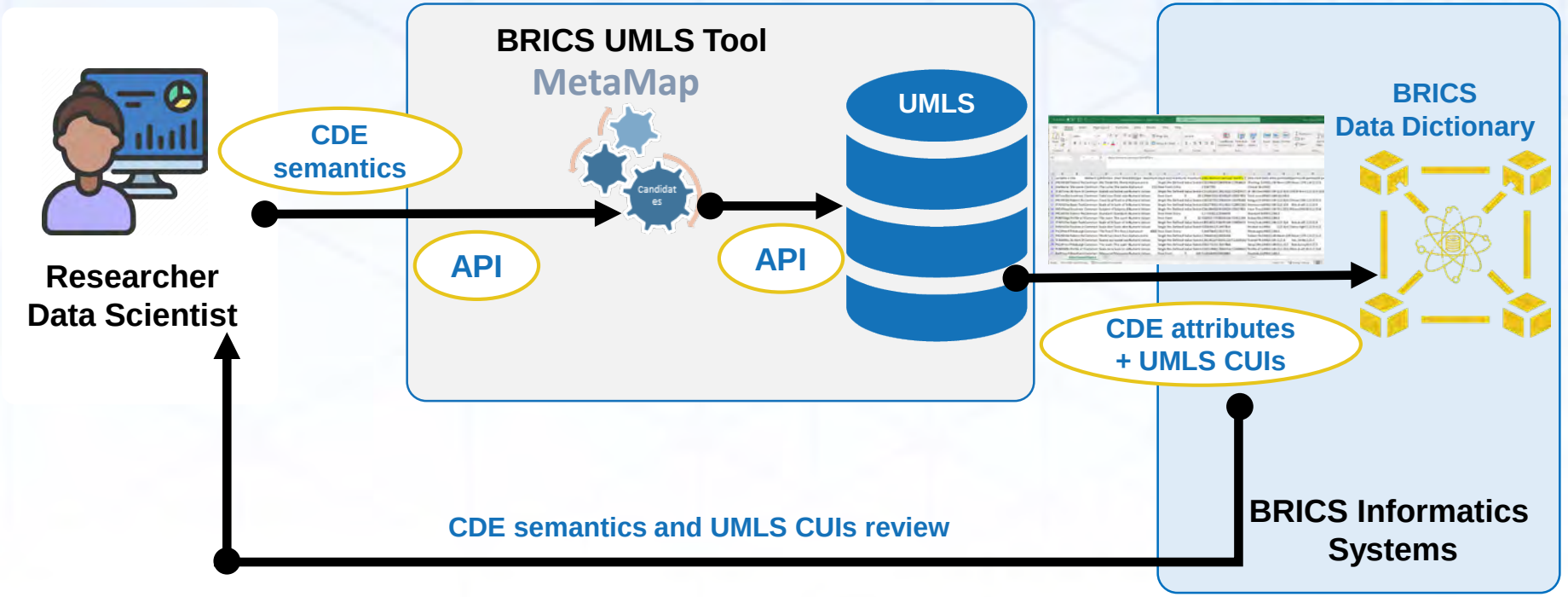
1. **based on CDE/UDE** or when there is no common elements across instances,
2. **based on DE UMLS concepts**.
   - If CDEs/UDEs have shared semantics/UMLS CUIs they will be found.

New Functionality: BRICS UMLS Tool

We did not want to have the mapping CDEs semantic to UMLS as a manual process.

We built BRICS UMLS Tool

- Highly configurable.
- Semi-automatic querying and assigning relevant UMLS CUIs to selected CDE attributes.



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Future Work

1. Expanding the use of UMLS CUIs for data discovery
2. Ability to query data for UMLS CUIs/concepts in the Query tool
3. Enhance the **BRICS UMLS tool** with ability to:
    - Search in data dictionary for CDEs/UDEs with similar semantics
    - Provide the user with a feedback regarding CDE semantics

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Enriching the FAIRness of BRICS using the OMOP CDM

Henry Ogoe, PhD (Biomedical Informatics)

Contractor, OSCS - CIT

CiSTAR

cdRNS Common Data Repository for Nursing Science

National Ophthalmic Disease Genotyping Network eyeGENE®

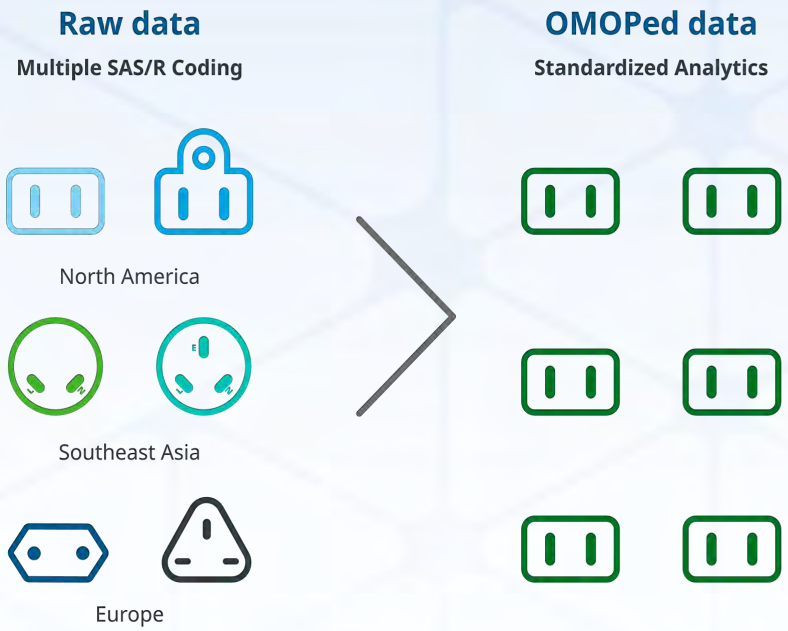
MTBI² Uniformed Services University

PDBP Parkinson's Disease Biomarkers Program

National Institute of Neurological Disorders and Stroke

FITBIR Federal Interagency Traumatic Brain Injury Research Informatics System

What is OMOP CDM?

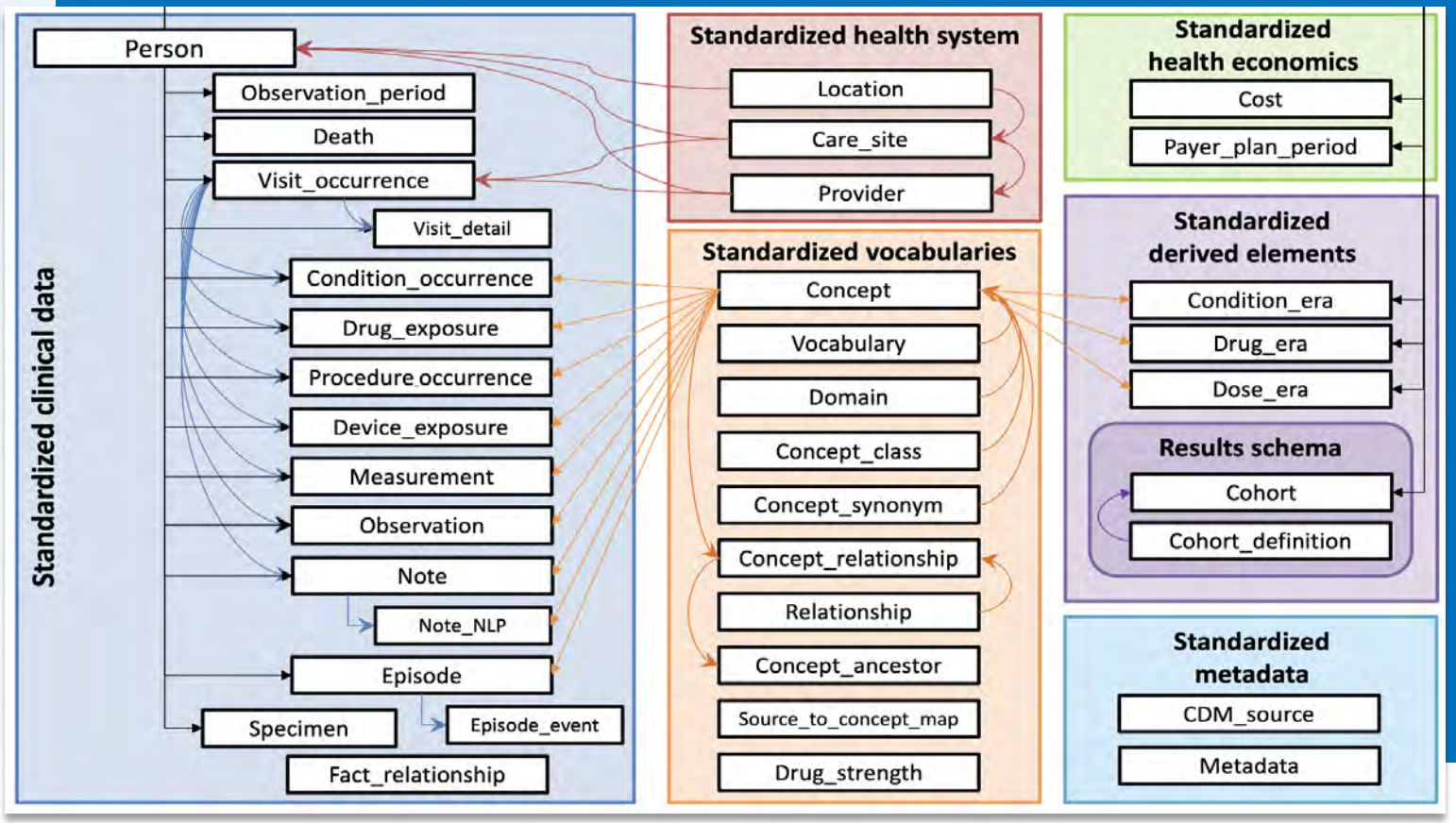


The Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM) is an open community data standard, designed to standardize the structure and content of observational data and to enable efficient analyses that can produce reliable evidence.

OHDSI
OBSERVATIONAL HEALTH DATA SCIENCES AND INFORMATICS

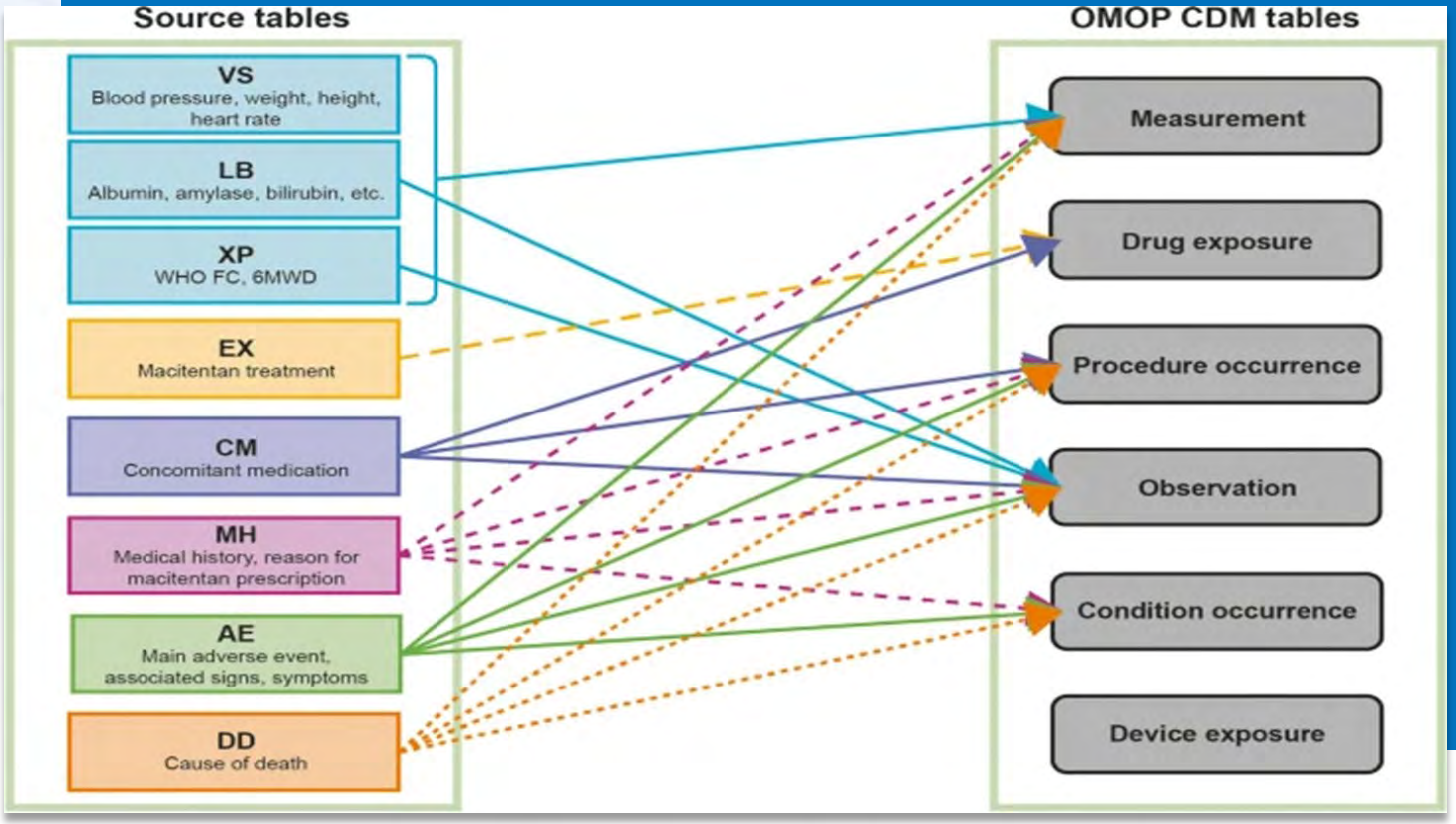
Technical Overview

Person–centric, relational database schema; ~38 Tables & ~ 400 DE



Why would I care about OMOP in BRICS?

Regardless of data source (registry, EHR, or Claims) all we need is 38 FS & ~ 400 DE



Bringing OMOP to BRICS

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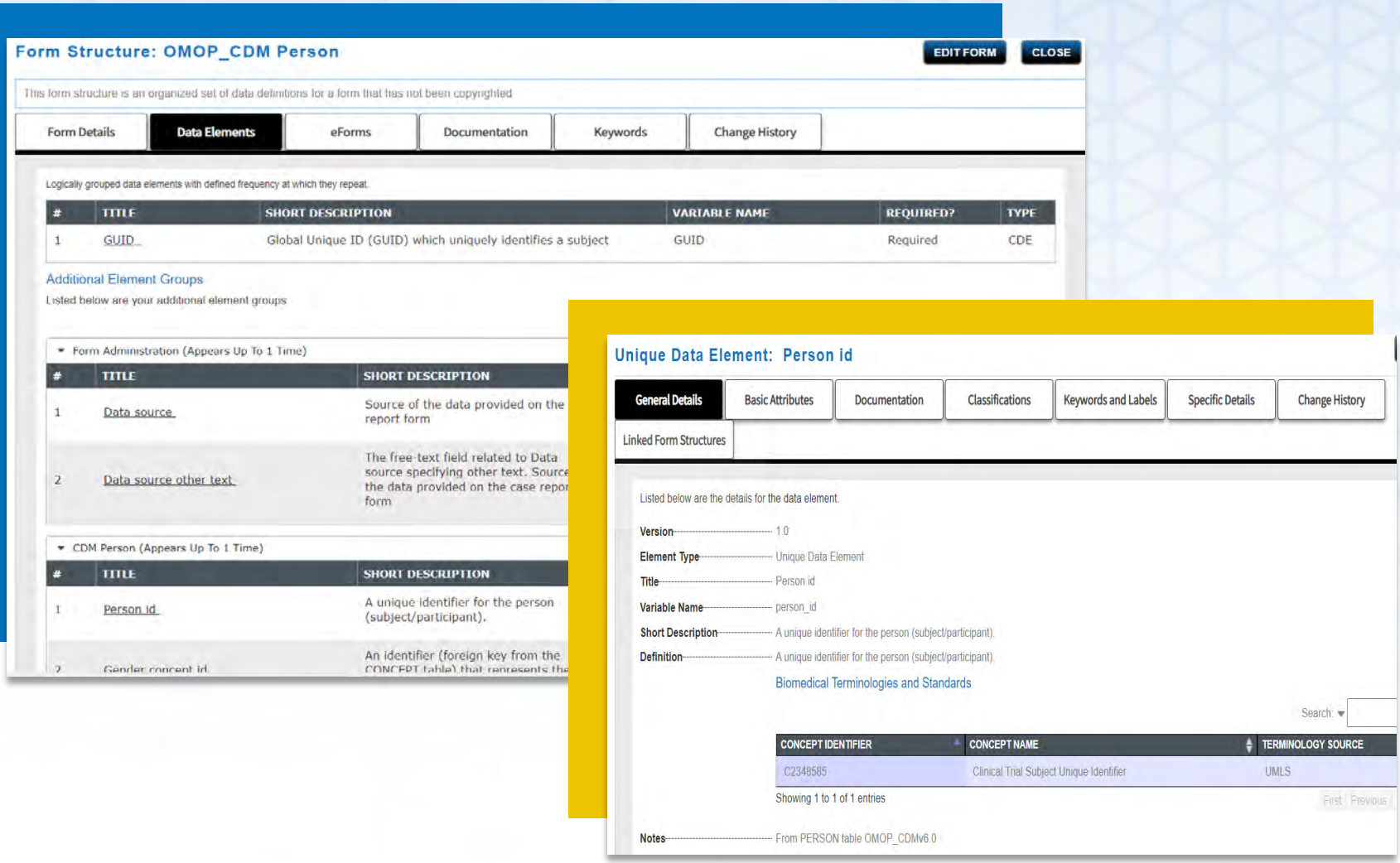
Bringing OMOP to BRICS



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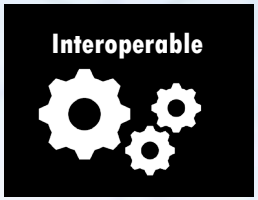
Why does it enrich BRICS' FAIRness?

- Persistent identifiers (person_id, event_id, concept_id) for metadata

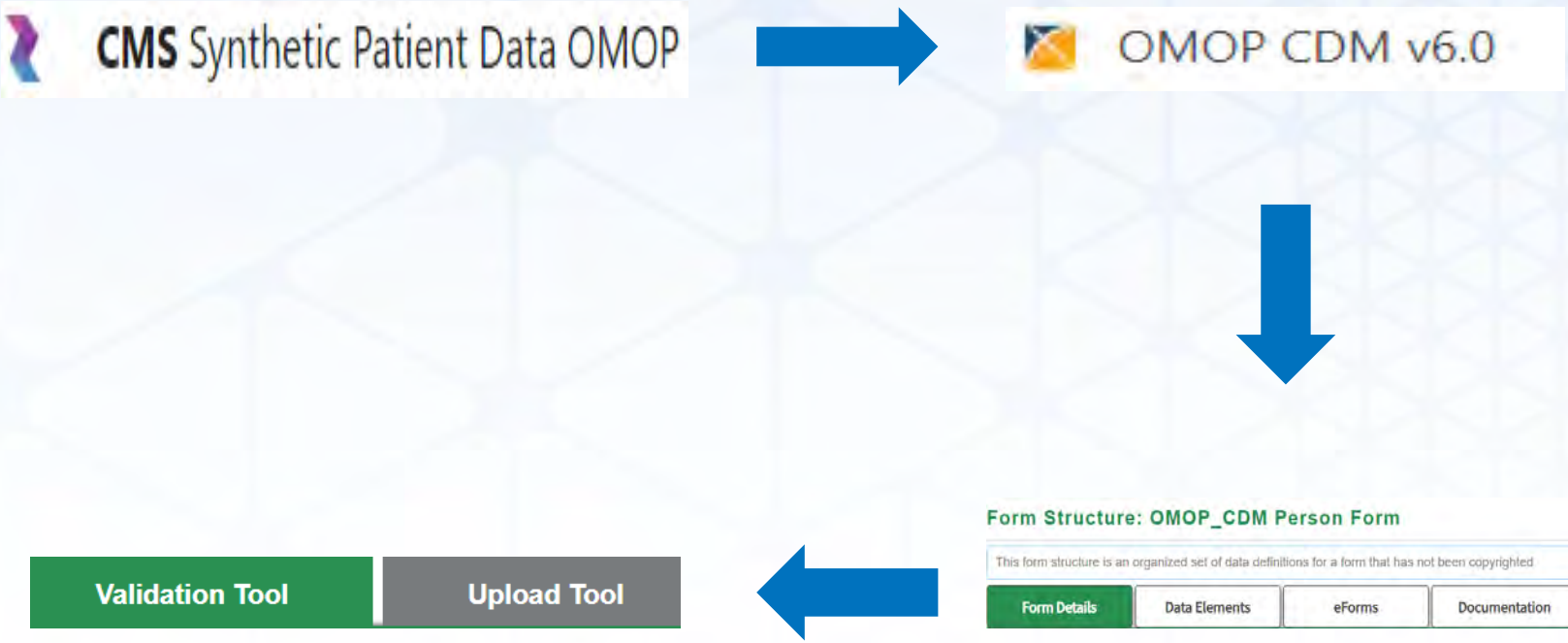


- OMOP CDM
- Standard Vocabularies
- Relationships between source and standard vocabularies

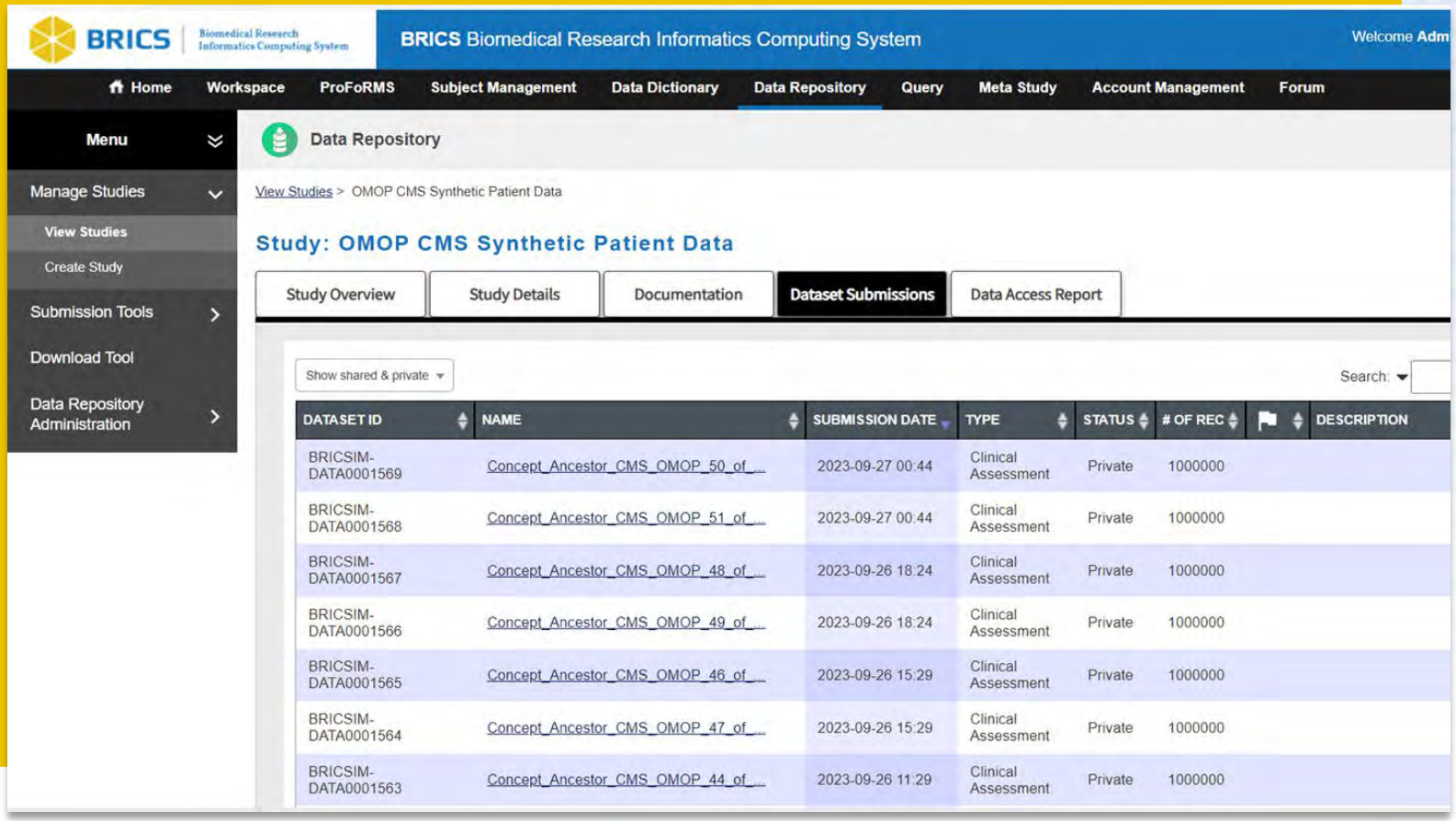
- Standardized data accessibility, and
- Communications via BRICS Query Tools

- OMOP CDM
- Standard Vocabulary
- Methods Library for best-practice observational research*

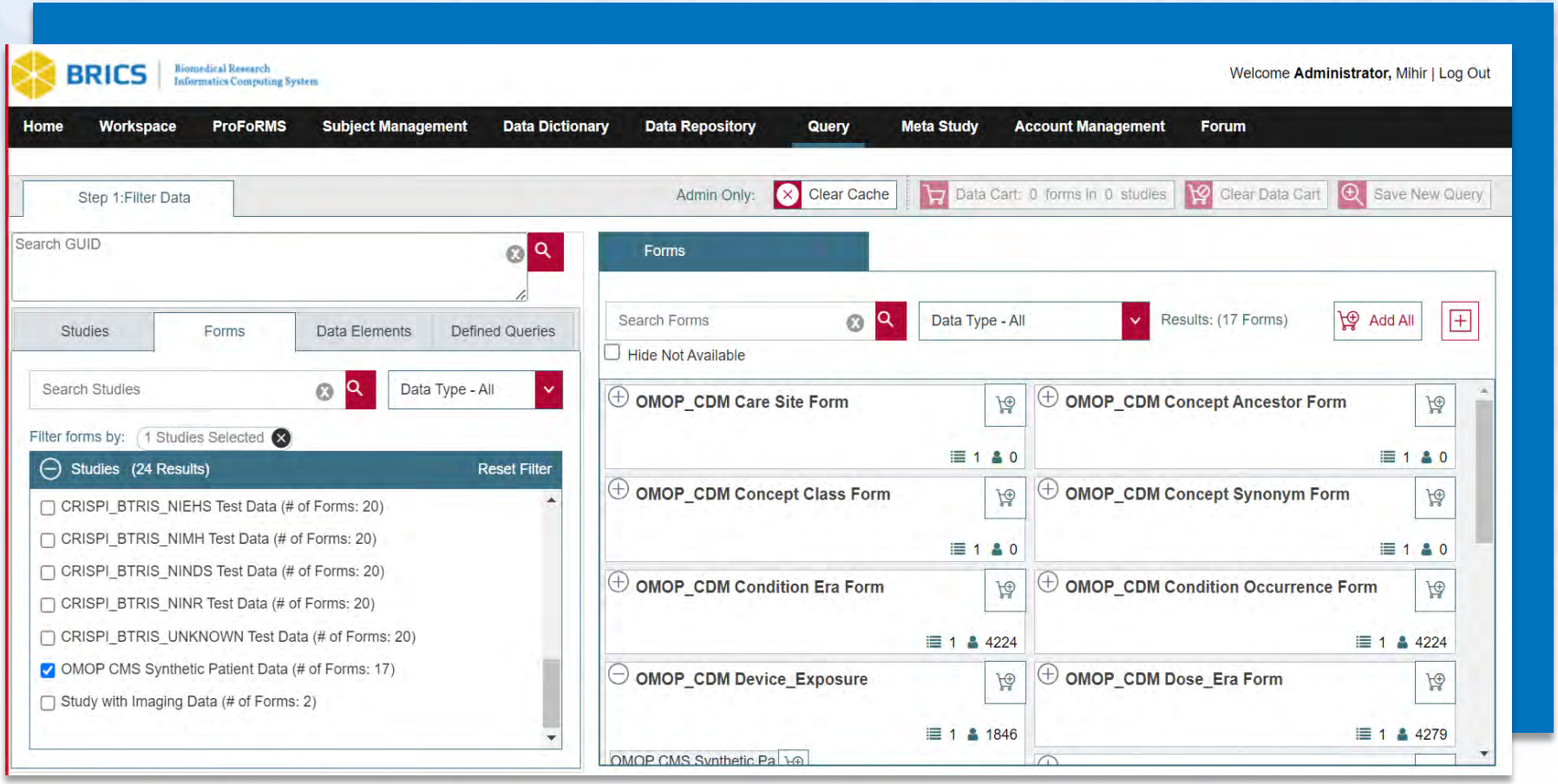
Proof-of-Concept: ETL CMS Synthetic Patient Data to BRICS Instance



ETL Results: BRICS study



ETL Results: Query Tool



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Future Goals

- Explore and leverage OHDSI Analytics libraries like ATLAS to support various data-analytics use cases in the BRICS **Query Tool** to enhance **Reusability**

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Take-home

It is now possible to stand up a **BRICS** instance that is **OMOP CDM** enabled

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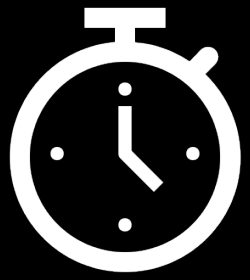
Thank you!

Q&A



BREAK: 10:20AM – 10:35AM

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cdRNS Common Data Repository for Nursing Science

National Ophthalmic Disease Genotyping Network eyeGENE®

MTBI² Uniformed Services University

PDBP Parkinson's Disease Biomarkers Program

National Institute of Neurological Disorders and Stroke

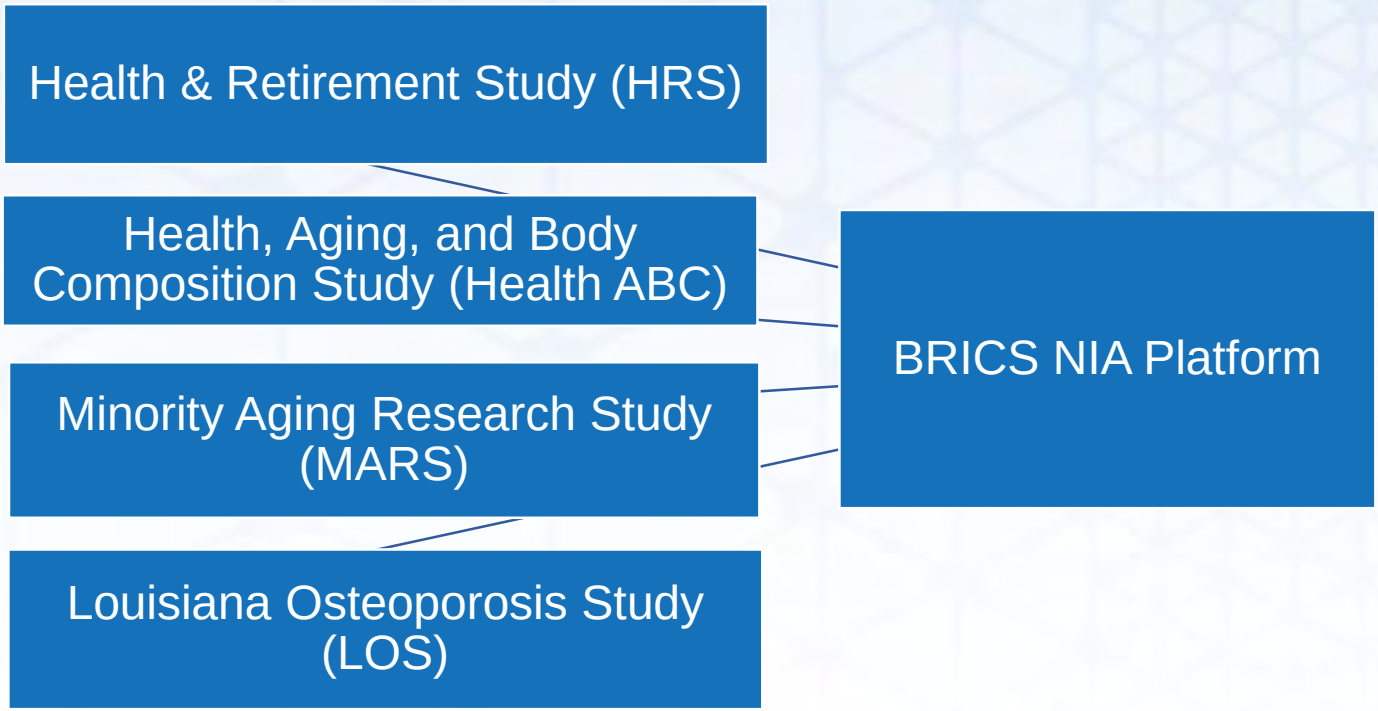
FITBIR Federal Interagency Traumatic Brain Injury Research Informatics System

Biomedical Research Informatics Computing System (BRICS)

NIA (National Institute on Aging) Pilot Project

Fatima Irfan

Process Overview: 4 Studies

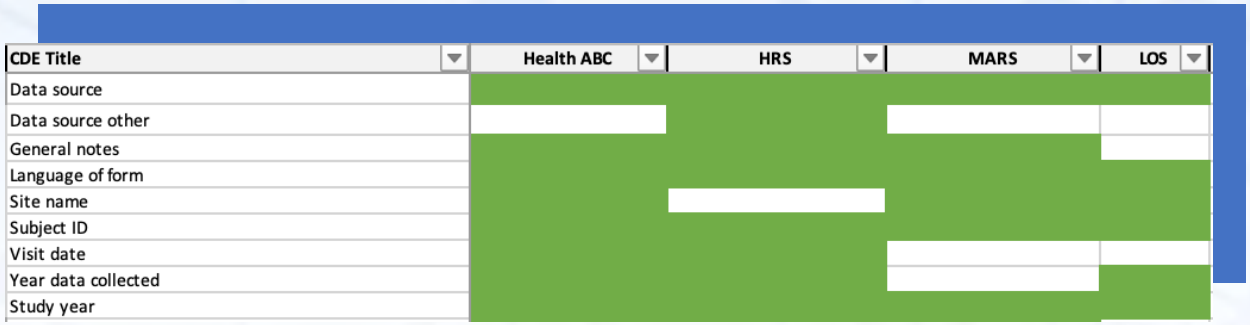


Cohort Discovery

- Collaborative approaches among cohorts could expedite epidemiological discovery by assembling multi-level data collected across the lifespan and providing a framework for multi-disciplinary work
- Foster communication among investigators leading cohort studies on aging research
- Promote collaborative research projects for topics not easily addressed by a single study

Process Overview: CDE Definition

- We looked across study data to identify ~120 Common Data Elements, defined as variables that are present in 2+ studies



CDE Title	Health ABC	HRS	MARS	LOS
Data source				
Data source other				
General notes				
Language of form				
Site name				
Subject ID				
Visit date				
Year data collected				
Study year				

Snapshot of Data Inclusion Factsheet

- This was an iterative process, as it required multiple phases of combing through data documentation and dictionaries

Process Overview: 4 Form Structures

- We grouped those 120 variables into 4 form structures

NIA Demographics Form

NIA Medical History Form

NIA Vital Signs Form

Daily Living and Physical Ability Form

Process Overview: Data Transformation

- We transformed the data to fit into our CDE definitions
- Data elements are sometimes collected differently across studies, so we sought to harmonize them

Variable	General Descriptio	Value labels
DIFFPP	Difficulty pushing/pulling	0=No 1=Yes

Health ABC

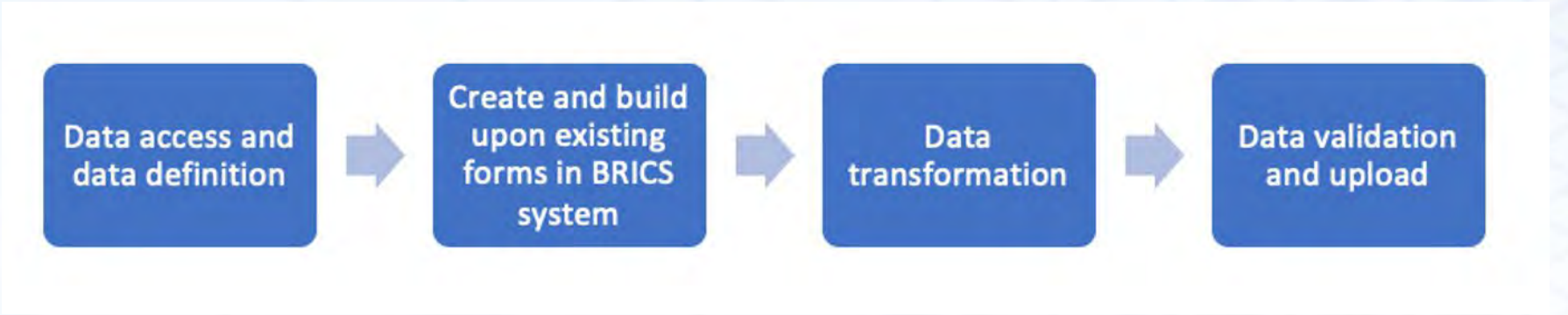
How difficult is it for you to...

B4r. ...pull or push large objects like a living room chair? [IMPUTED]

V318 Code	Frequency
1	9303
2	1577
3	766
4	843
6	163

HRS

General ETL Process



Current State

- Currently, we have data across 4 studies and 4 forms, reflecting 1 year of study data for 16,613 participants
- We can query data across studies, with lots of flexibility in filtering
- We can now download harmonized data from multiple studies with a complete data dictionary

Future Work

- Currently, we are working on uploading year 2 data across 4 studies
- We are also working on uploading all year 1 data for HRS
  - Still a pilot, with all data remaining private
  - Will be able to run analyses in system, with all the data and documentation in a clear, accessible, and easy to use format

Demo

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cdRNS Common Data Repository for Nursing Science

National Ophthalmic Disease Genotyping Network eyeGENE®

MTBI² Uniformed Services University

PDBP Parkinson's Disease Biomarkers Program

National Institute of Neurological Disorders and Stroke

FITBIR Federal Interagency Traumatic Brain Injury Research Informatics System

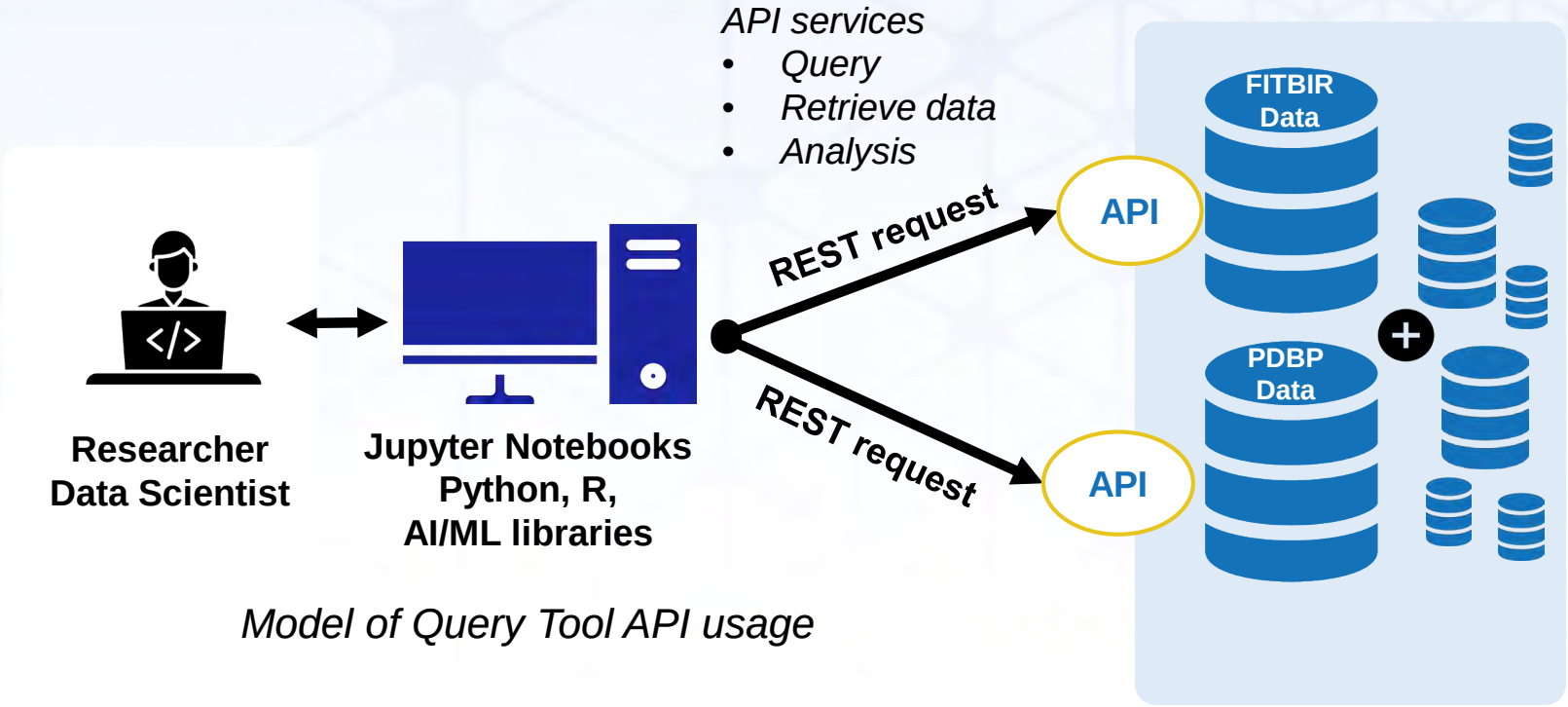
Biomedical Research Informatics Computing System (BRICS)

Query Tool API

Dan Gillis
FITBIR Imaging

Methods to Query Data

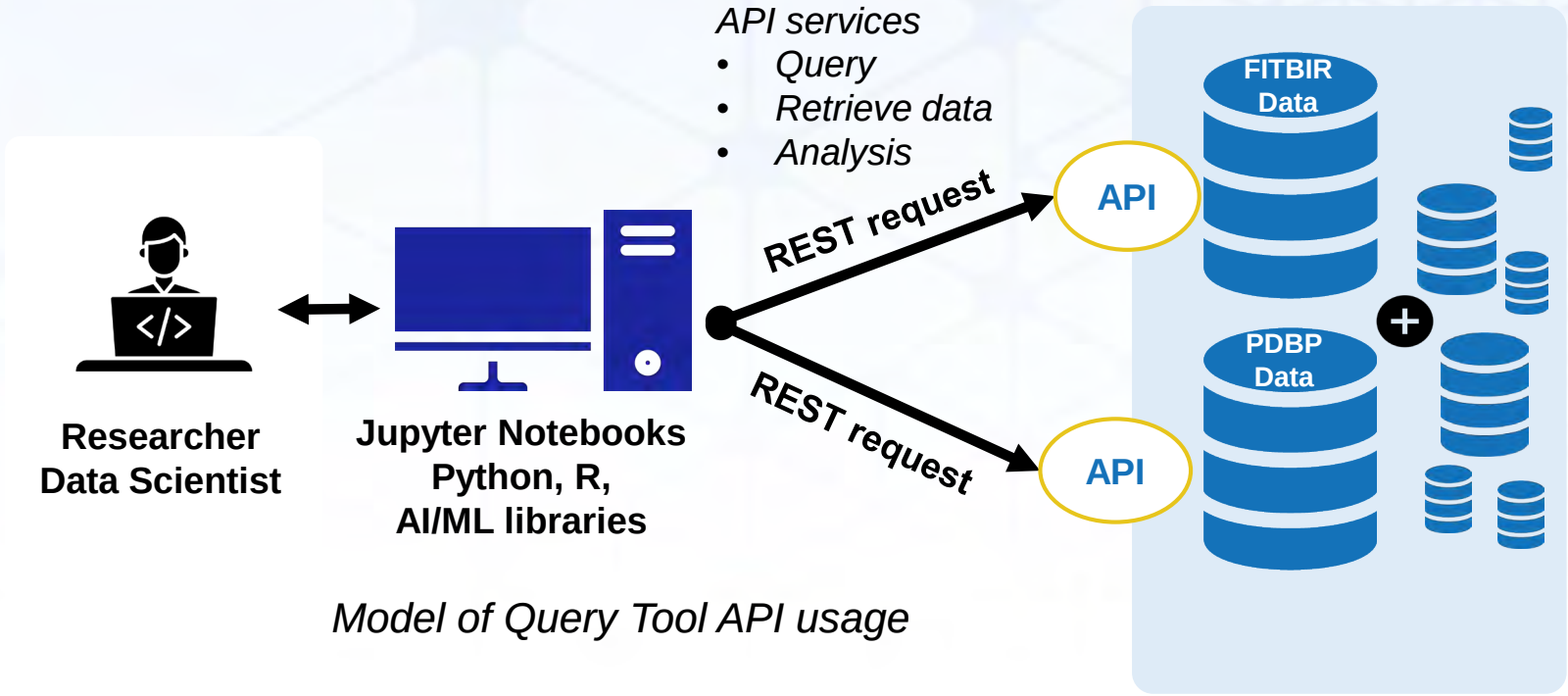
- Two methods to query data on a BRICS instance
  - Web Query Tool – GUI, access through browser
  - **Query Tool API – Programmatic access through REST services**
- This presentation gives an overview of this API



Model of Query Tool API usage

What is the Query Tool API?

- Application Program Interface for the Query Tool
- A way for computer programs to communicate with the Query Tool
- The API defines services that the Query Tool can perform for users
  - Each service is accessed through its own endpoint URL
- Access using authentication token



Model of Query Tool API usage

What can we do with the API?

- Find all studies using a specific form structure
- Find every form structures submitted for a study
- Query data across multiple studies and form structures
  - Filter results based on data element values
  - Perform joins across form structures
- Download files associated with query results
- **Everything we can do with the browser-based Query Tool**

Why would we want to use the API?

- **The API provides programmatic access to the Query Tool**
  - Data accessors can use the Query Tool services in their own programs & notebooks
- **Using the API extends the power of the Query Tool**
  - Instantly create plots of data returned
  - Directly download query results
  - Generate filters based on the results of previous queries
  - Build data transformation pipelines and easily apply them to multiple queries

API Examples
GOSE Scores

API - Scenario

- Example scenario for using the API
- Suppose we are interested in seeing how age affects outcomes from patients suffering from traumatic brain injuries
  - Target metric: GOSE (Glasgow Outcome Scale Extended) total score
- To start, we want to see the distribution of GOSE scores for:
  - All subjects with GOSE data on FITBIR
  - Subjects ages 20 to 30

API - Overview

- We want to do the following:
  - Find which studies have GOSE data submitted
  - Find all GOSE scores submitted to FITBIR
  - Find GOSE scores for our filtered age range
  - Create bar graphs to view the distribution of scores
- We can do all of this with the API
- For next slides, output of code outlined in red

API – Authentication

- Get authentication token
  - Obtained by logging in using RAS
- Generate header to be used in API requests

```
token = getpass.getpass("Enter your user token")
```

```
Enter your user token ........
```

```
def gen_base_headers(token):
    return {"Authorization": f"Bearer {token}"}

base_headers = gen_base_headers(token)
```

Add token to notebook to authenticate requests

API – Find Studies

- **Find all studies with GOSE data**
- Input: GOSE form structure name
- Output: data about studies with GOSE form structure

```
base_qt_url = "https://fitbir.nih.gov/gateway/query-api"
gose_form_name = "GOSE_Standard"

## 1. Find studies which have GOSE data

def find_studies_with_form(form_names, headers):

    studies_with_form_url = f"{base_qt_url}/study/form"
    form_params = {"formName": form_names}
    return requests.get(studies_with_form_url, params=form_params, headers=headers)

studies_with_gose_request = find_studies_with_form(gose_form_name, base_headers)
studies_with_gose_request.raise_for_status()
studies_with_gose_metadata = studies_with_gose_request.json()[0]
```

Query code

```
There are 17 studies with form: GOSE_Standard
```

	abstract	status	id	title
0	Traumatic brain injury (TBI) in older adults i...	Public	FITBIR-STUDY0000266	AIM: TBI Impact of Aging on the Immune Respons...
1	Traumatic brain injury (TBI) is a major cause...	Public	FITBIR-STUDY0000240	Adding Legacy Clinical Data to the Federal Int...
2	Background:\r\n\r\n- A person who has a trauma...	Public	FITBIR-STUDY0000272	Biomarkers-Driven Development of Experiemental...
3	This study's overall goal is to establish a la...	Public	FITBIR-STUDY0000263	CENC Study 1: Observational Study on Late Neur...

Query results

API – All GOSE Data

- **Retrieve all GOSE data on FITBIR**
- Input: GOSE form structure name
- Output: all GOSE data on FITBIR

```
def make_query(form_data, headers, filters=None):
    # form_data and filters should be lists
    query_url = "https://fitbir.nih.gov/gateway/query-api/data/csv"
    form_and_filter = {
        "formStudy": form_data,
    }
    if filters is not None:
        form_and_filter["filter"] = filters
    return requests.post(query_url, headers=headers, json=form_and_filter)

gose_form_data = [make_form_data(gose_form_name)]

overall_gose_request = make_query(gose_form_data, headers=base_headers)
```

Query code

Number of rows for GOSE_Standard is 12656.

	Study ID	Dataset	GOSE_Standard.Main.GUID	GOSE_Standard.Main.ASSOCIATED GUID
0	392	FITBIR-DATA0014496	TBIYY662YVC	NaN
1	392	FITBIR-DATA0014496	TBIAT815JWE	NaN
2	392	FITBIR-DATA0014496	TBIHP687JA8	NaN

Query results

API – Filtered Age GOSE Data

- **Retrieve filtered age GOSE data**
  - Join with demographics form to filter by age
- Input:
  - GOSE and demographics form names
  - Ids of studies with GOSE data
  - Age filter
- Output: filtered age GOSE data

```
fitbir_demo_form_name = "DemogrFITBIR"

gose_form_data_20_30 = [
    make_form_data(gose_form_name),
    make_form_data(fitbir_demo_form_name, studies=study_ids_with_gose_data)
]
filters_20_30 = [
    make_filter(
        fitbir_demo_form_name,
        "Main Group",
        "AgeYrs",
        rangeStart="20",
        rangeEnd="30",
        mode="inclusive"
    )
]

gose_20_30_response = make_query(
    gose_form_data_20_30, filters=filters_20_30, headers=base_headers
)
```

Query code

```
Number of rows for GOSE_Standard is 2410.
```

	GUID	GOSE_Standard.Study ID	GOSE_Standard.Dataset	GOSE_Standard.Main.GUID
0	TBICX708BGN	NaN	NaN	NaN
1	TBICU683PDB	NaN	NaN	NaN
2	TBI_INVHZ302UH8	246.0	FITBIR-DATA0000712	TBI_INVHZ302UH8
3	TBI_INVHZ302UH8	246.0	FITBIR-DATA0000712	TBI_INVHZ302UH8

Query results

API – Distribution of Scores

- Generate bar graphs
  - Overall scores
  - Filtered age scores

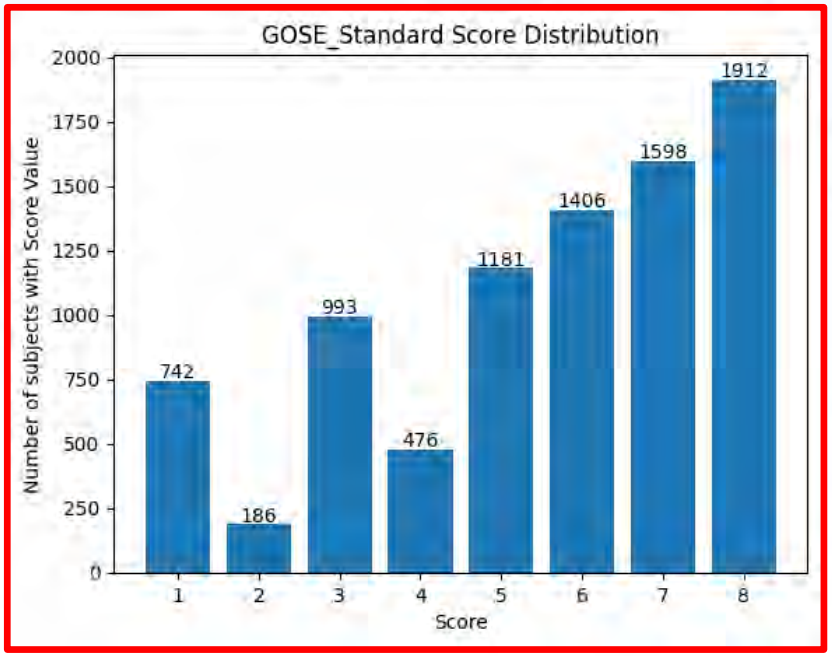
Bar graph code

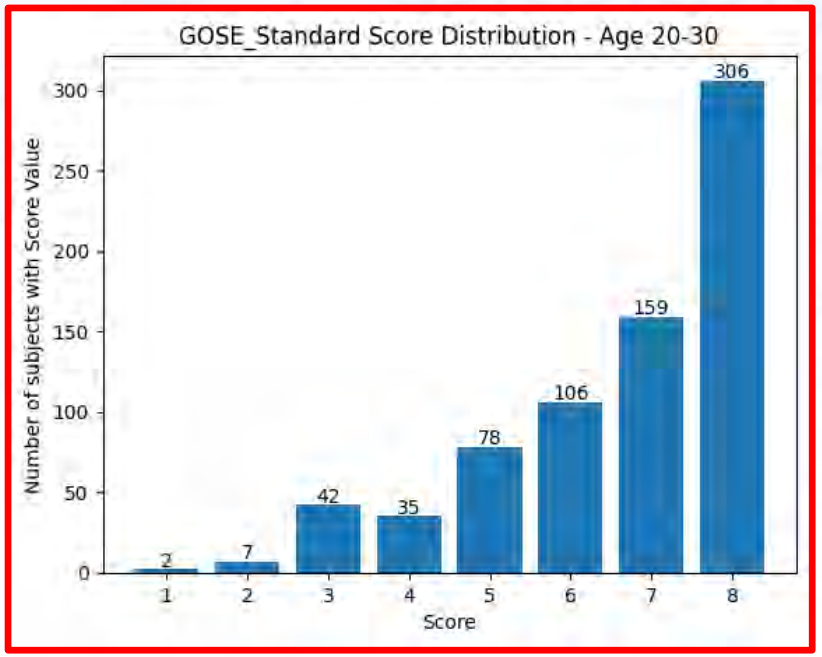
```
gose_outcome_score_de = "GOSE_Standard.Form Completion.GlasgowOutcomeScalExtScore"
overall_score_data = overall_gose_df[gose_outcome_score_de].value_counts()

make_graph_of_counts(overall_score_data)
```

```
score_20_30_data = gose_20_30_df[gose_outcome_score_de].value_counts()

make_graph_of_counts(score_20_30_data, title_addition=" - Age 20-30")
```





Bar Graphs Showing Distribution of Scores

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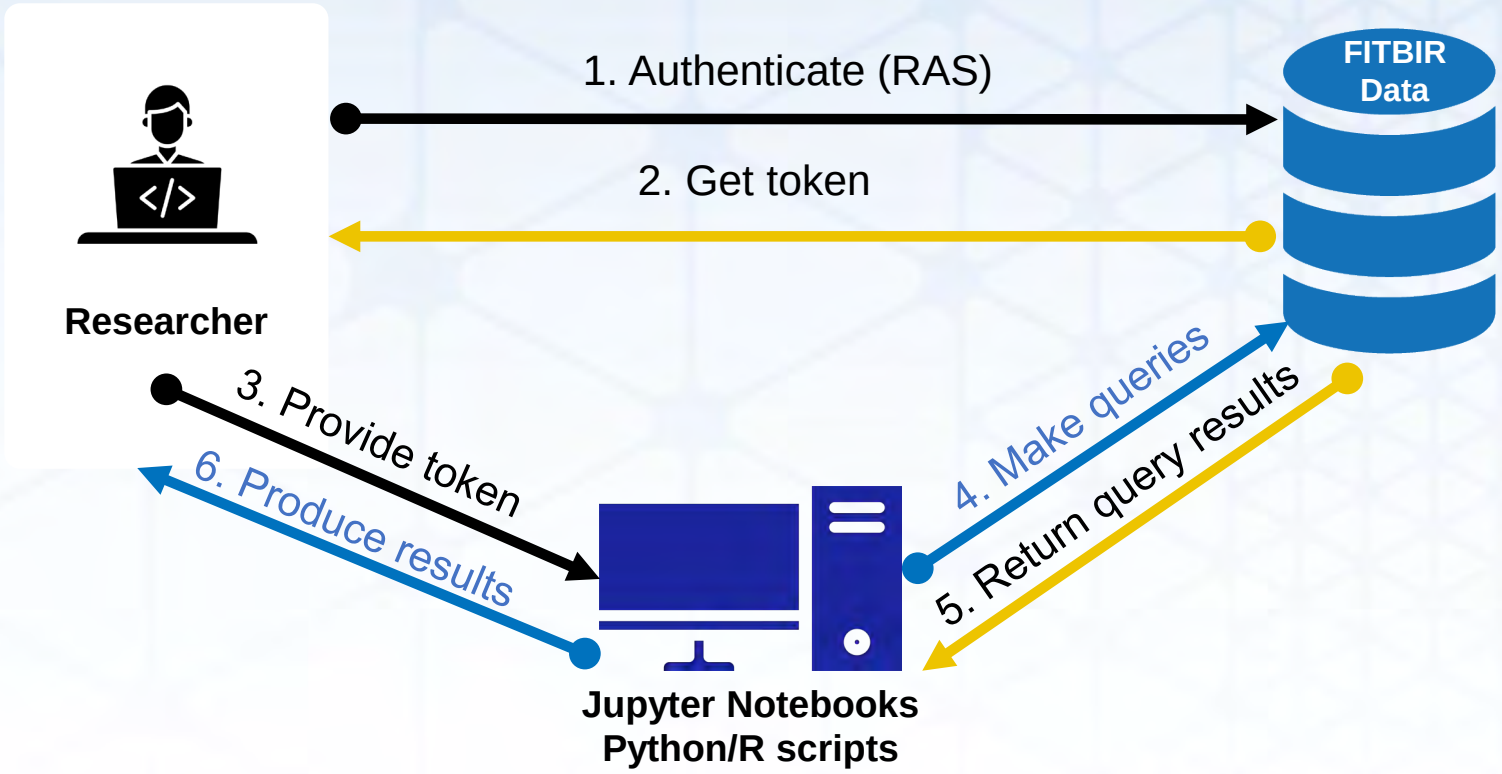
Additional Slides

Simple Model of API Usage



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FITBIR USE CASE

Nsini Umoh, PhD, Program Director, Repair and Plasticity NIH/NINDS

FITBIR
Federal Interagency Traumatic Brain Injury Research
INFORMATICS SYSTEM

CiSTAR

cdRNS
Common Data Repository for Nursing Science

National Ophthalmic Disease Genotyping Network
eyeGENE®

MTBI²
Uniformed Services University

PDBP
Parkinson's Disease Biomarkers Program

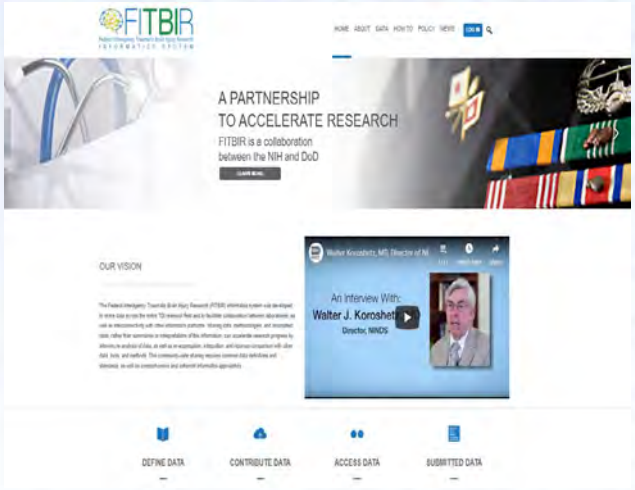
National Institute of Neurological Disorders and Stroke

FITBIR
Federal Interagency Traumatic Brain Injury Research
INFORMATICS SYSTEM

Background

The Federal Interagency Traumatic Brain Injury Research (FITBIR) Informatics System is a national registry for clinical TBI research data that integrates heterogeneous datasets allowing access to high quality, multi-study, metadata analyses

- Prospective clinical TBI studies
  - U.S Army Medical Research & Development Command (MRDC) and NIH Requirements to submit data to FITBIR
- Includes high-quality and reproducible data such as: Patient Characteristics and Demographics, Neuroimaging, Clinical Assessments, Behavioral History, Varied Data Types (text, numeric, image)
- Aggregates raw data from all investigators in a common format
  - Common Data Elements (CDEs) – information that describes a piece of data collected in a study
  - Global Unique Identifiers (GUIDs) – identifiers for study participants to facilitate deidentified data sharing and tracking across multiple studies



TBI Research Landscape

NINDS Common Data Elements
Harmonizing information. Streamlining research.

TRACK-TBI
Transforming Research and Clinical Knowledge in Traumatic Brain Injury
International Traumatic Brain Injury Research Initiative

NCAA-DOD Grand Alliance CARE Consortium

adapt
Approaches and Decisions in Acute Pediatric TBI Trial

TBI Endpoints Development
A collaborative for advancing diagnosis and treatment of TBI

FITBIR
Federal Interagency Traumatic Brain Injury Research INFORMATICS SYSTEM

LIMBIC CENC

NIH National Institute of Neurological Disorders and Stroke

DHA Defense Health Agency

VA U.S. Department of Veterans Affairs

Data Types in FITBIR

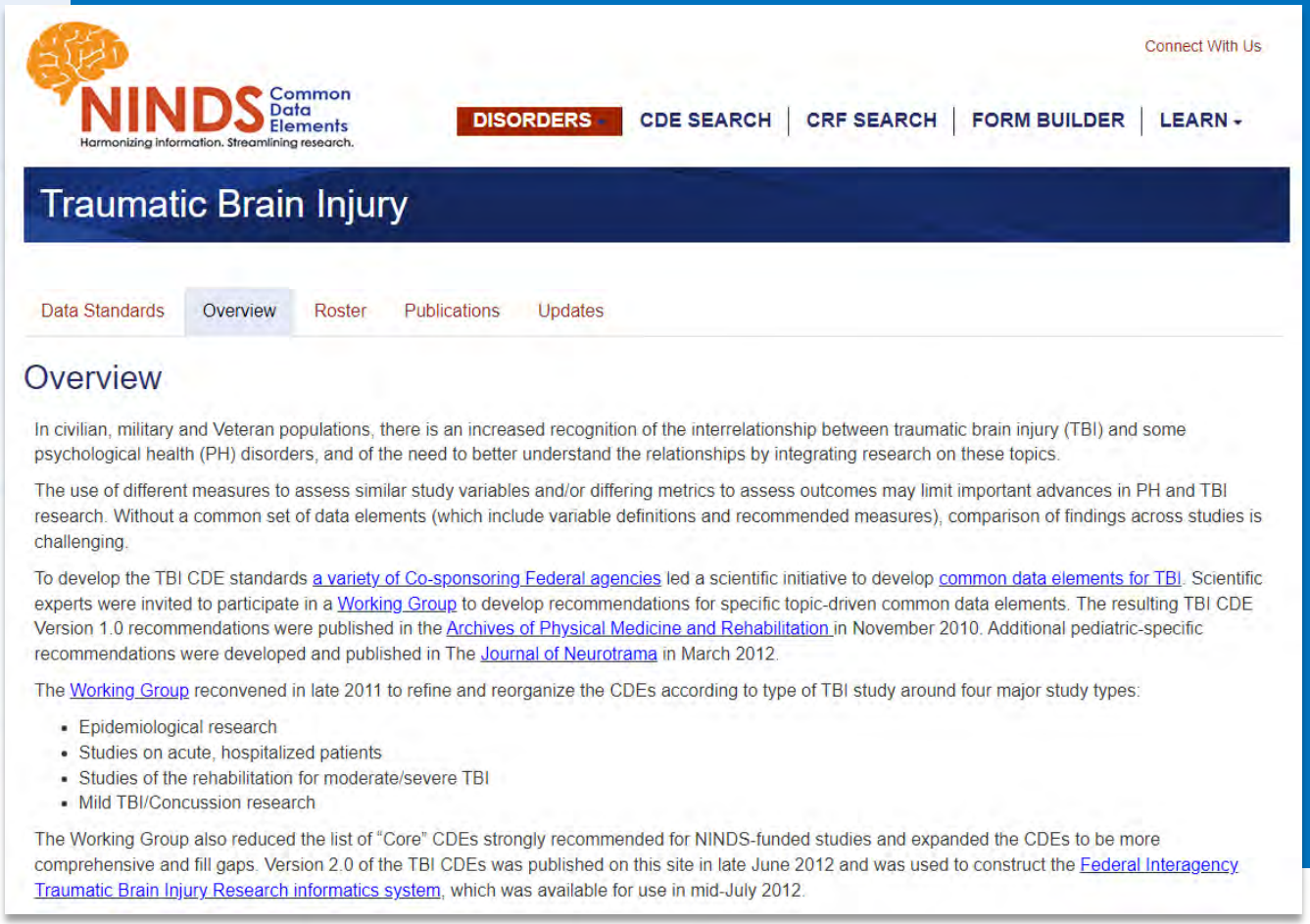
Today

- Human Subject Data
- Clinical
- Imaging
- Genomics
- `Neuropathology Data

Future

- Preclinical Data

Data Dictionary



NINDS Common Data Elements
Harmonizing information. Streamlining research.

Connect With Us

DISORDERS | CDE SEARCH | CRF SEARCH | FORM BUILDER | LEARN

Traumatic Brain Injury

Data Standards | Overview | Roster | Publications | Updates

Overview

In civilian, military and Veteran populations, there is an increased recognition of the interrelationship between traumatic brain injury (TBI) and some psychological health (PH) disorders, and of the need to better understand the relationships by integrating research on these topics.

The use of different measures to assess similar study variables and/or differing metrics to assess outcomes may limit important advances in PH and TBI research. Without a common set of data elements (which include variable definitions and recommended measures), comparison of findings across studies is challenging.

To develop the TBI CDE standards a variety of Co-sponsoring Federal agencies led a scientific initiative to develop common data elements for TBI. Scientific experts were invited to participate in a Working Group to develop recommendations for specific topic-driven common data elements. The resulting TBI CDE Version 1.0 recommendations were published in the Archives of Physical Medicine and Rehabilitation in November 2010. Additional pediatric-specific recommendations were developed and published in The Journal of Neurotrama in March 2012.

The Working Group reconvened in late 2011 to refine and reorganize the CDEs according to type of TBI study around four major study types:

- Epidemiological research
- Studies on acute, hospitalized patients
- Studies of the rehabilitation for moderate/severe TBI
- Mild TBI/Concussion research

The Working Group also reduced the list of "Core" CDEs strongly recommended for NINDS-funded studies and expanded the CDEs to be more comprehensive and fill gaps. Version 2.0 of the TBI CDEs was published on this site in late June 2012 and was used to construct the Federal Interagency Traumatic Brain Injury Research informatics system, which was available for use in mid-July 2012.

FITBIR Policy

- **Use of Common Data Elements**
  - Researchers conducting NIH- and DOD-supported TBI human-subjects research are required to use the TBI Common Data Elements (CDEs), in an effort to create standardized definitions and guidelines about the kinds of data that should be collected, and how to collect this data in clinical studies of TBI.
- **Data Sharing**
  - Investigators have 12 months from the end of the award period before data and supporting materials will be available to the general research community (via a controlled and tracked approval process, i.e., Data Access Committee Approval).
- **FITBIR Data Access**
  - Investigators and institutions seeking data from the FITBIR Informatics System will be expected to meet data security measures (such as physical security, information technology security, and user training) and will be asked to submit a Data Access Request that is signed by the investigator.

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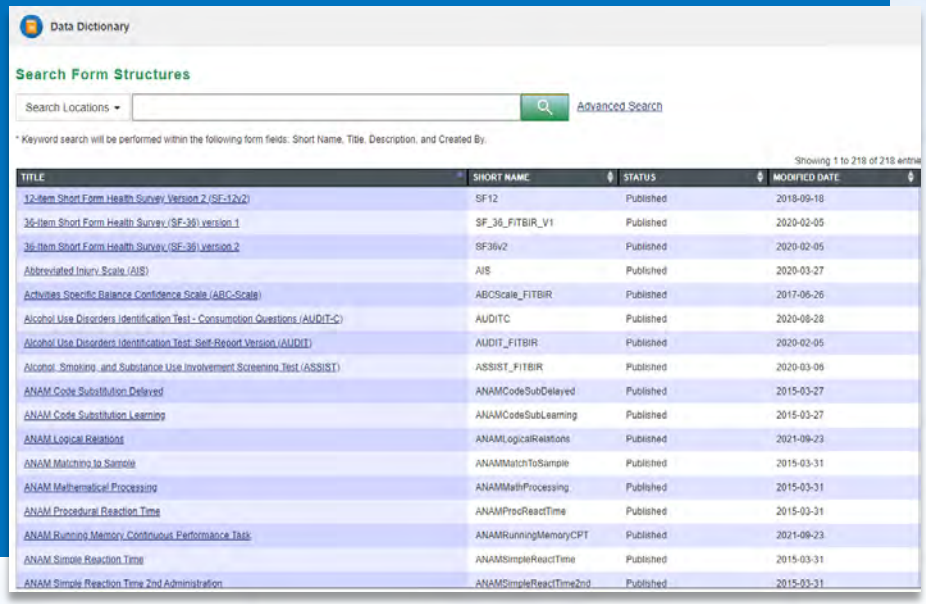
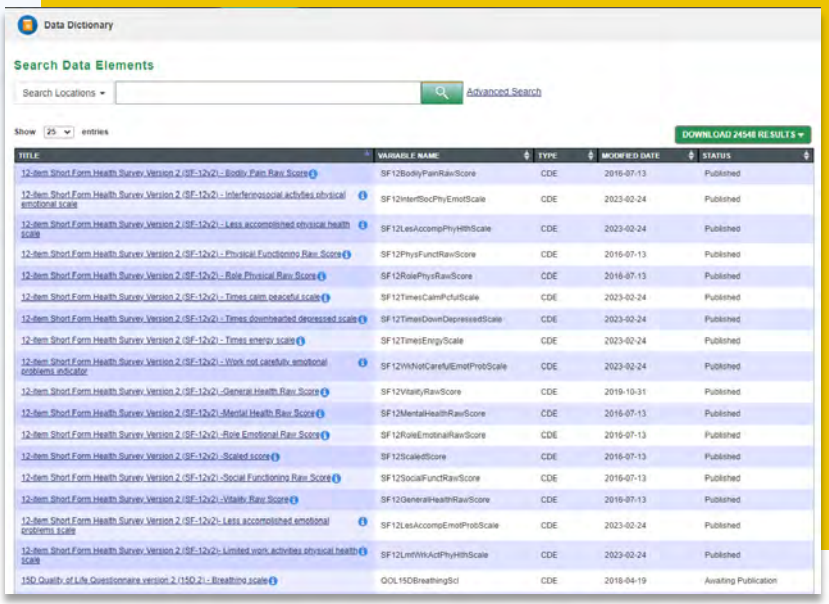
Data Dictionary
Form Structures & Data Elements

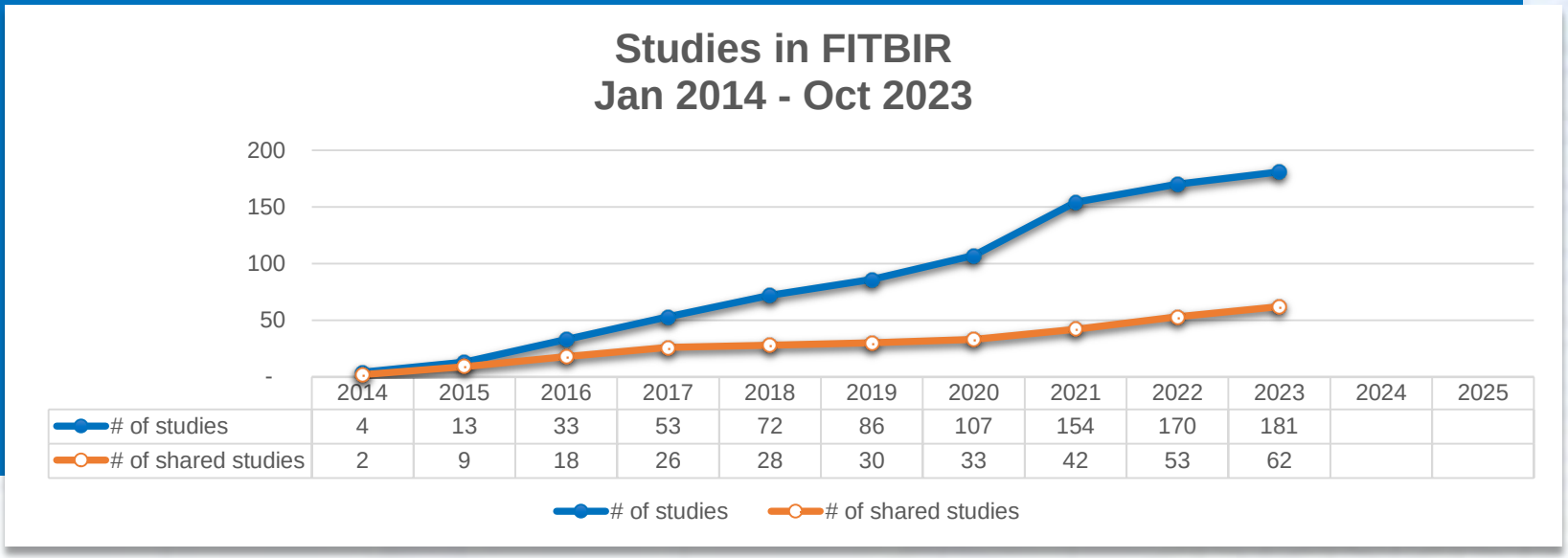


# of Standard NINDS TBI Form Structures in FITBIR: **179**

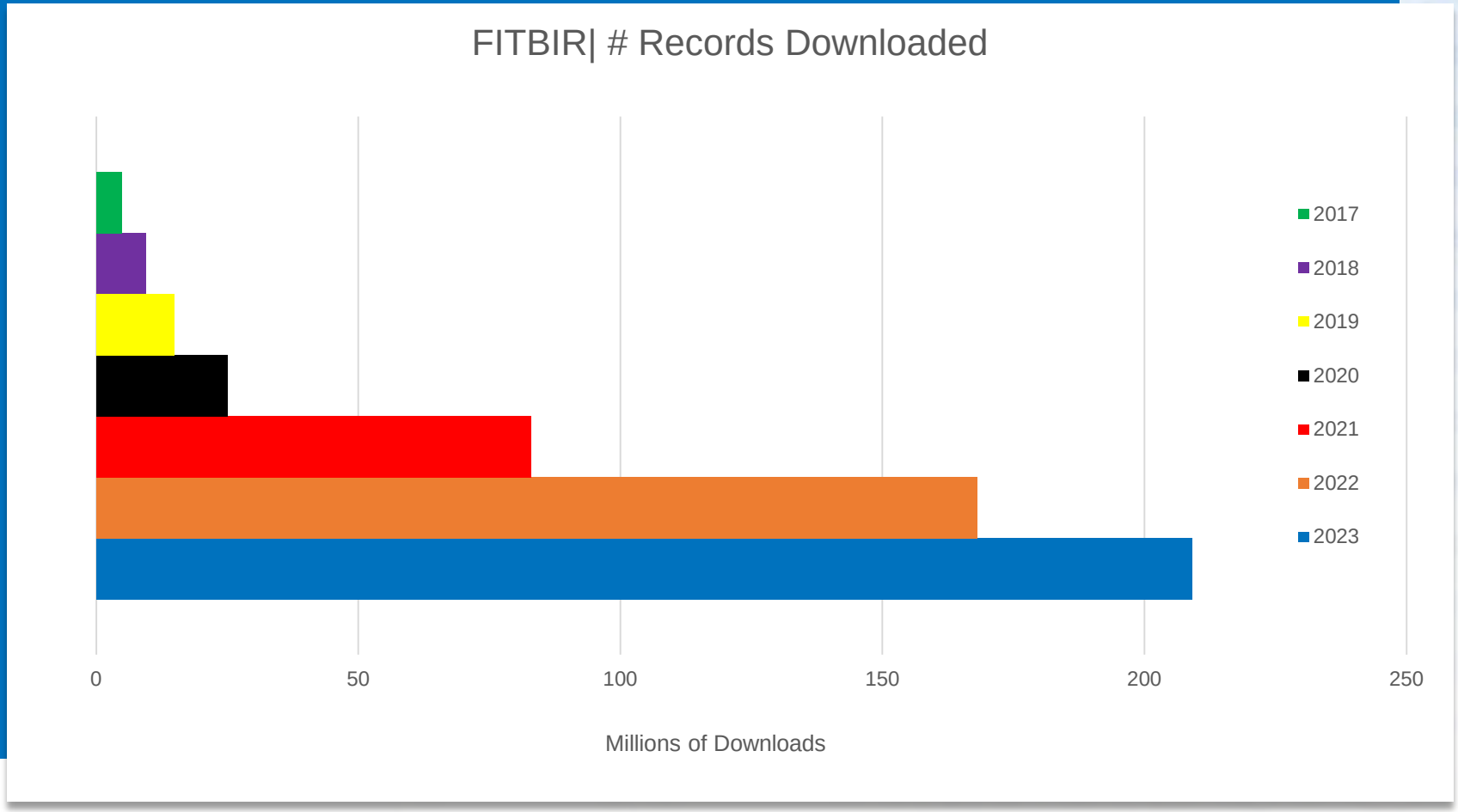
# of TBI CDEs in FITBIR: **8,099**



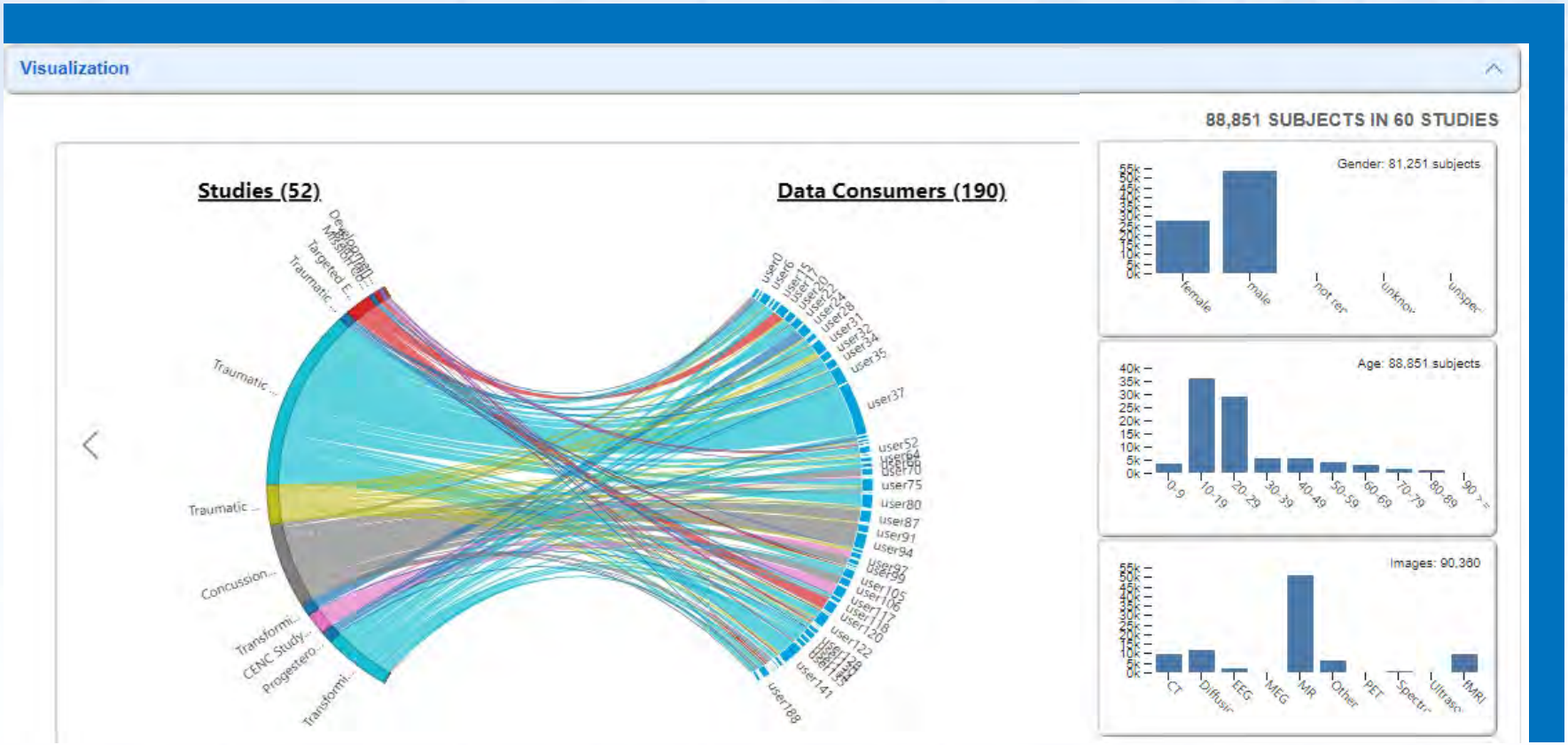
FITBIR Data Statistics



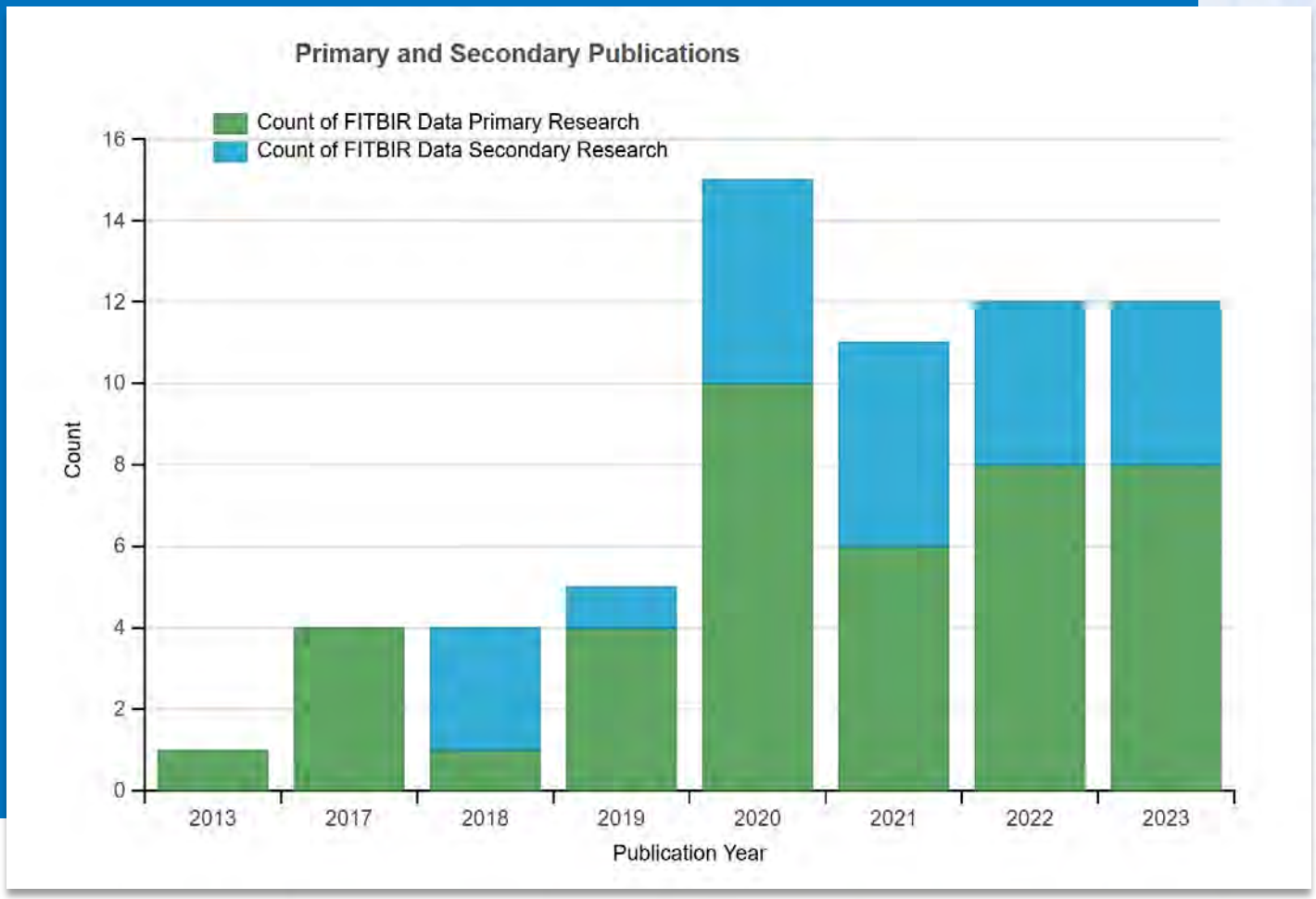
Data Access


FITBIR| # Records Downloaded
2017
2018
2019
2020
2021
2022
2023
0
50
100
150
200
250
Millions of Downloads

Data Visualization



FITBIR Summary Data



Data Management and Sharing Policy

Applications for Receipt Dates BEFORE Jan 25 2023

Applications for Receipt Dates ON/AFTER Jan 25 2023

NIH has issued the Data Management and Sharing (DMS) policy (effective January 25, 2023) to promote the sharing of scientific data. Sharing scientific data accelerates biomedical research discovery, in part, by enabling validation of research results, providing accessibility to high-value datasets, and promoting data reuse for future research studies.

Under the DMS policy, NIH expects that investigators and institutions:

- Plan and budget for the managing and sharing of data
- Submit a DMS plan for review when applying for funding
- Comply with the approved DMS plan

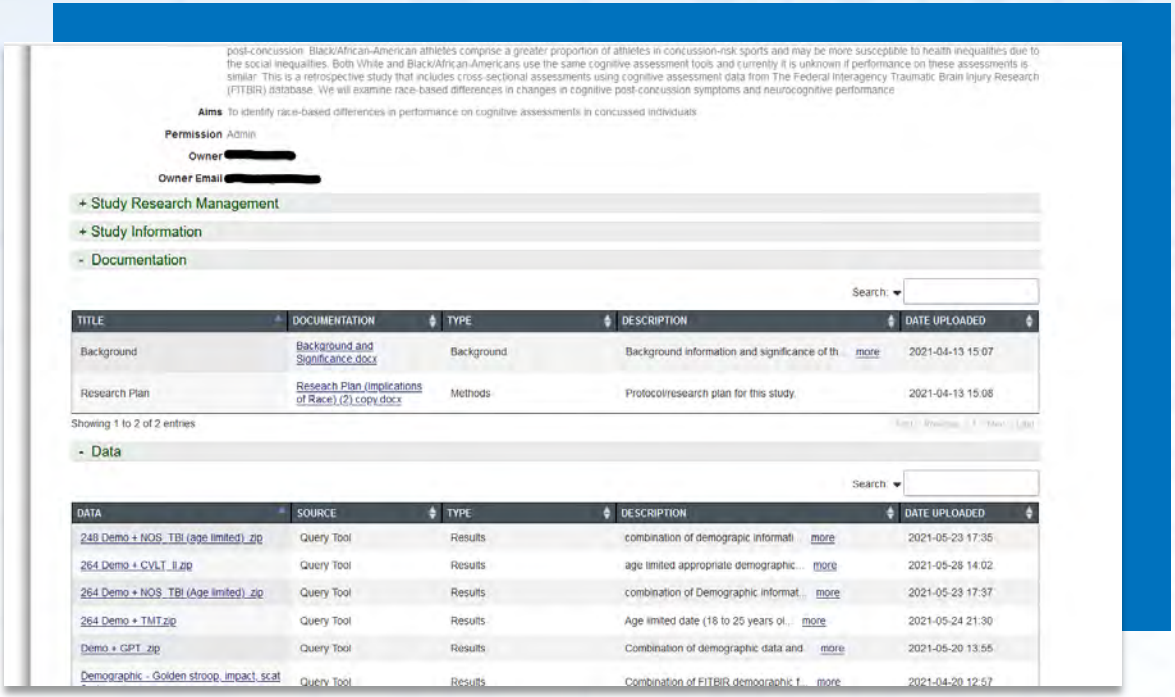
Each of the steps below will help you integrate data management and sharing into your funding application and research process. Select a step to learn more.

PLANNING & BUDGETING | SUBMISSION & REVIEW | IMPLEMENTING

FITBIR Meta Study

What is a Meta Study?

- A workspace where research data and metadata can be stored and referenced.
- A Meta Study can contain many different types of "data“
  - Tabular data
  - Software files
  - Scripts
  - Reference documents
  - FITBIR queries
- The Meta Study is assigned a DOI that can be cited for journal publications
- Notice to the community



Accomplishments & Next Steps

Preclinical CDEs developed to foster **reproducibility and transparency** among laboratories.


A call for transparent reporting to optimize the predictive value of preclinical research

Story C. Landis[1], Susan G. Amara[2], Khusru Asadullah[3], Chris P. Austin[4], Robi Blumenstein[5], Eileen W. Bradley[6], Ronald G. Crystal[7], Robert B. Darnell[8], Robert J. Ferrante[9], Howard Fillit[10], Robert Finkelstein[11], Marc Fisher[12], Howard E. Gendelman[13], Robert Golub[14], John L. Goudreau[15], Robert A. Gross[16], Amelie K. Gubitz[1], Sharon E. Hesterlee[16], David W. Howells[17], John Huguenard[18], Katrina Kelner[19], Walter Koroshetz[1], Dimitri Krainc[20], Stanley E. Lazic[21], Michael S. Levine[22], Malcolm Macleod[23], John M. McCall[24], Richard T. Moxley III[25], Kalyani Narasimhan[26], Linda J. Noble[27], Steve Perrin[28], John D. Porter[1], Oswald Steward[29], Ellis Unger[30], Ursula Utz[1] & Shai D. Silberberg[1]

NINDS BioSEND

NINDS funded biofluid repository is receiving samples from multiple NINDS TBI studies and is coordinating their catalog with FITBIR to allow for searching and ordering. https://biosend.org/

Incorporating additional trauma data into FITBIR

- Ongoing Discussion with JPC-6
  - Data Types
  - CDE development by SMEs specific to trauma
  - Criteria for accepting data
  - Metastudy module vs data repository

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Parkinson's Disease Biomarker Program

Andrea Lutz

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Overview

- Who's involved?
- PDBP DMR Stats
- Data Collection
- Biosample Request & Order Process

Who's involved?

- **PDBP Investigators**
  - Roger Albin, Roy Alcalay, Alberto Ascherio, Thomas Beach, Sarah Berman, Bradley Boeve, F. DuBois Bowman, Shu Chen, Alice Chen-Plotkin, William Dauer, Ted Dawson, Paula Desplats, Richard Dewey, Ray Dorsey, Jori Fleisher, Kirk Frey, Douglas Galasko, James Galvin, Dwight German, Lawrence Honig, Xuemei Huang, David Irwin, Kejal Kantarci, Anumantha Kanthasamy, Daniel Kaufer, Qingzhong Kong, James Leverenz, Allan Levey, Carol Lippa, Irene Litvan, Oscar Lopez, Jian Ma, Lara Mangravite, Karen Marder, Laurie Orzelius, Vladislav Petyuk, Judith Potashkin, Liana Rosenthal, Rachel Saunders-Pullman, Clemens Scherzer, Michael Schwarzschild, Nicholas Seyfried, Tanya Simuni, Andrew Singleton, David Standaert, Debby Tsuang, David Vaillancourt, David Walt, Andrew West, Cyrus Zabetian and Jing Zhang
- **PDBP Program and Review Staff**
  - Deb Babcock, Chris Swanson-Fischer, Sophie Cho, Christina Fang, and Rebecca Price
- **PDBP Data Management Resource (DMR) Operations Team**
  - Andrea Lutz, Ronnie Tan, Kristine Treece
- **Biorepositories**
  - BioSEND & NINDS Human Cell and Data Repository (NHCDR)

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PDBP DMR Stats

342 DMR USERS

26 Countries

>56,000 Submissions

>62M Downloads

Study Population

- Parkinson's Disease (2002)
- Dementia with Lewy Bodies (373)
- PSP (120)
- MSA (99)
- CBD (7)
- ET (30)
- Healthy Controls (792)

Assessments

- Neurobehavioral/Cognitive
- Autonomic/Olfaction/Sleep
- Motor function
- Imaging

Biospecimens Collected (Longitudinal)

- DNA
- RNA
- Plasma
- Serum
- Whole Blood
- CSF
- PBMCs
- Urine

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Assessments

- Neurobehavioral/Cognitive
- Autonomic/Olfaction/Sleep
- Motor function
- Imaging

Clinical Coordinator

Biospecimens Collected (Longitudinal)

- DNA
- RNA
- Plasma
- Serum
- Whole Blood
- CSF
- PBMCs
- Urine

ProFoRMS

Biospecimens

API

Data Repository

Query Tool

Biorepository
(BioSEND @ Indiana University)

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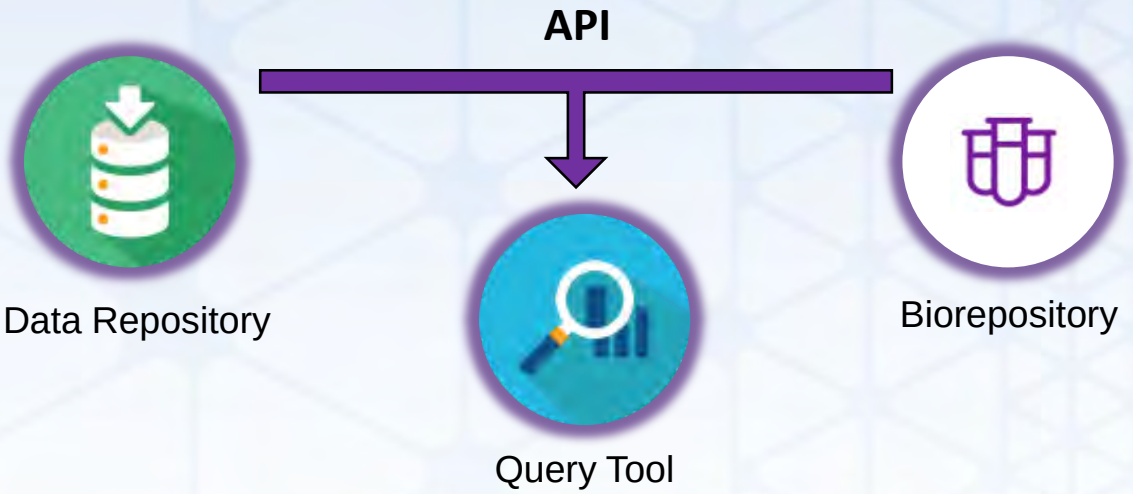
NINDS Biorepository PDBP Biosample Catalog



	SAMPLE INFORMATION		
NEURODIAGNOSIS	ORDERABLEBIOSAMPLEID SELECT ALL		SAMPCOLLTYP
Dementia with Lewy Bodies		*1732322*	*Serum*
Dementia with Lewy Bodies		*1732342*	*DNA*
Dementia with Lewy Bodies		*1732310*	*RNA*
Dementia with Lewy Bodies		*1732314*	*Plasma*
Dementia with Lewy Bodies		*1732330*	*CSF*
Parkinson's Disease		*2200324*	*DNA*
Parkinson's Disease		*2200327*	*Plasma*
Parkinson's Disease		*2200336*	*Blood*
Parkinson's Disease		*2200321*	*RNA*

Are you interested in acquiring these samples?

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How to Apply for PDBP Biosamples

Step 1: Determine Sample Availability

Investigators are encouraged to learn about samples held in the various repositories before applying.

Make sure you have an account in the PDBP DMR

Search for sample availability in the Query Tool

Step 2: Submit Online Application

All investigators interested in obtaining biosamples must submit an online application for approval.

Applications are submitted through an online webform

- Biosketch
- Research Strategy
- Table Summary of Samples of Interest

Step 3: PD BRAC Reviews Application

All applications are submitted to the PD BRAC for review. Upon approval, an investigator is able to obtain biosamples.

Investigators notified of the outcome by email

- Approve
- Approve upon revisions
- Deny

You're approved!

NIH National Institute of Neurological Disorders and Stroke

6001 Executive Blvd.
NSC Bethesda, MD. 20892-9535
Phone: 301-496-5745
Fax: 301-402-1501
Email: karen.david@nih.gov

14 November 2019

Jane Doe, PhD
University of PDBP
jdoe@PDBP.edu

RE: Parkinson's Disease Biospecimen Resource Access Committee Approval

Dear Dr. Doe,

You have been approved access to the samples summarized in the table below, for your project "TBD". Samples to be released are subject to availability.

Name of Cohort Sample and Data Set	Number of Samples	Biosample Type	Volume or concentration	Any other criteria to be considered	# Longitudinal subjects, visit types and number of samples per visit
PDBP – PD Cases	30	CSF	1 x 200 uL	Hemoglobin <0.2	Baseline visit
PDBP – Controls	30	CSF	1 x 200 uL	Hemoglobin <0.2	Baseline visit

Sincerely,

Margaret Sutherland, PhD
Program Director, Parkinson's Disease Biomarkers Program

Karen David, PhD
Parkinson's Disease Biomarkers Program Biospecimen Resource Access Committee Coordinator

Onboarding/Sample Distribution meeting

PDBP Biosample Order Demo

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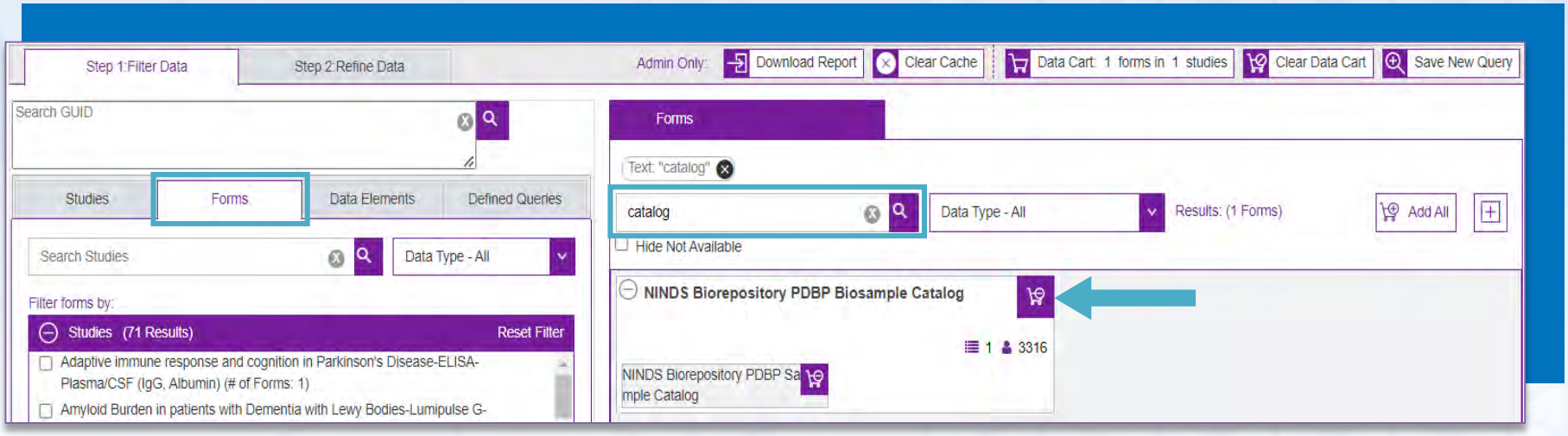
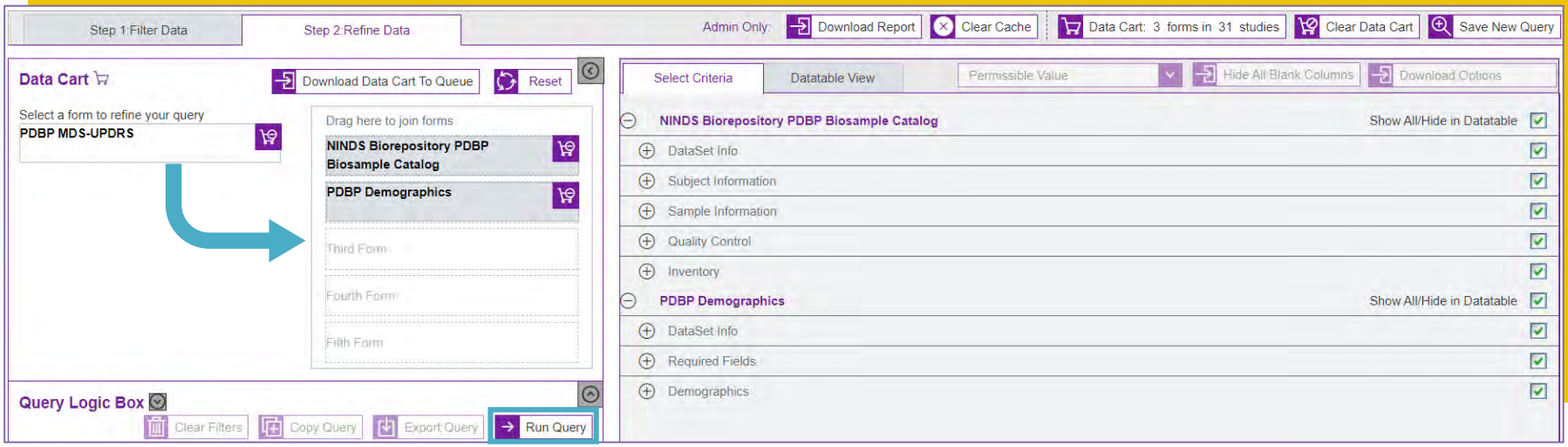
Selecting & Ordering Samples





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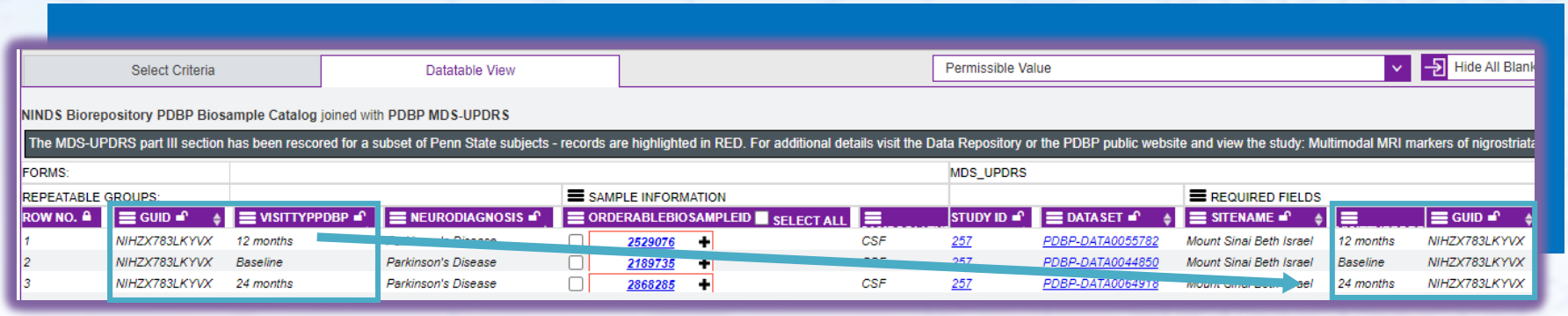
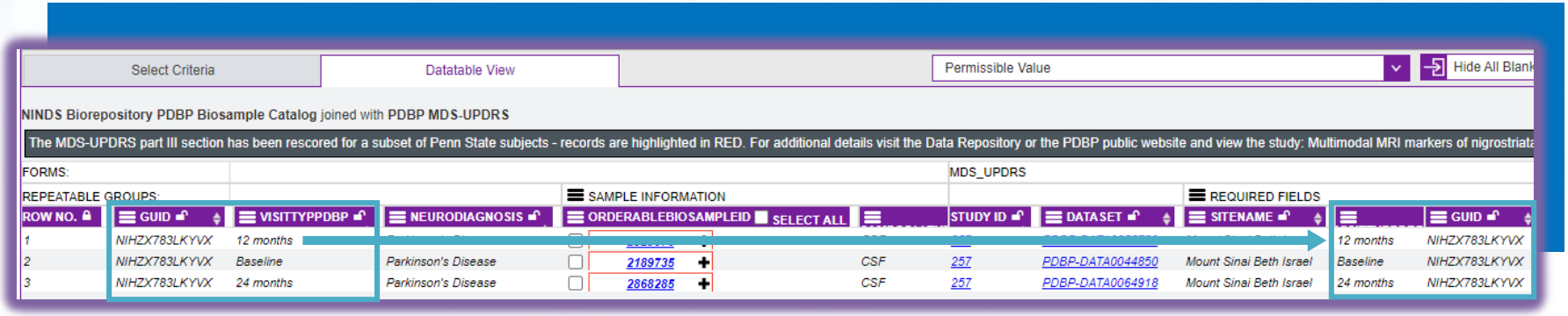
Joining on GUID & Visit Type

Old way



New way



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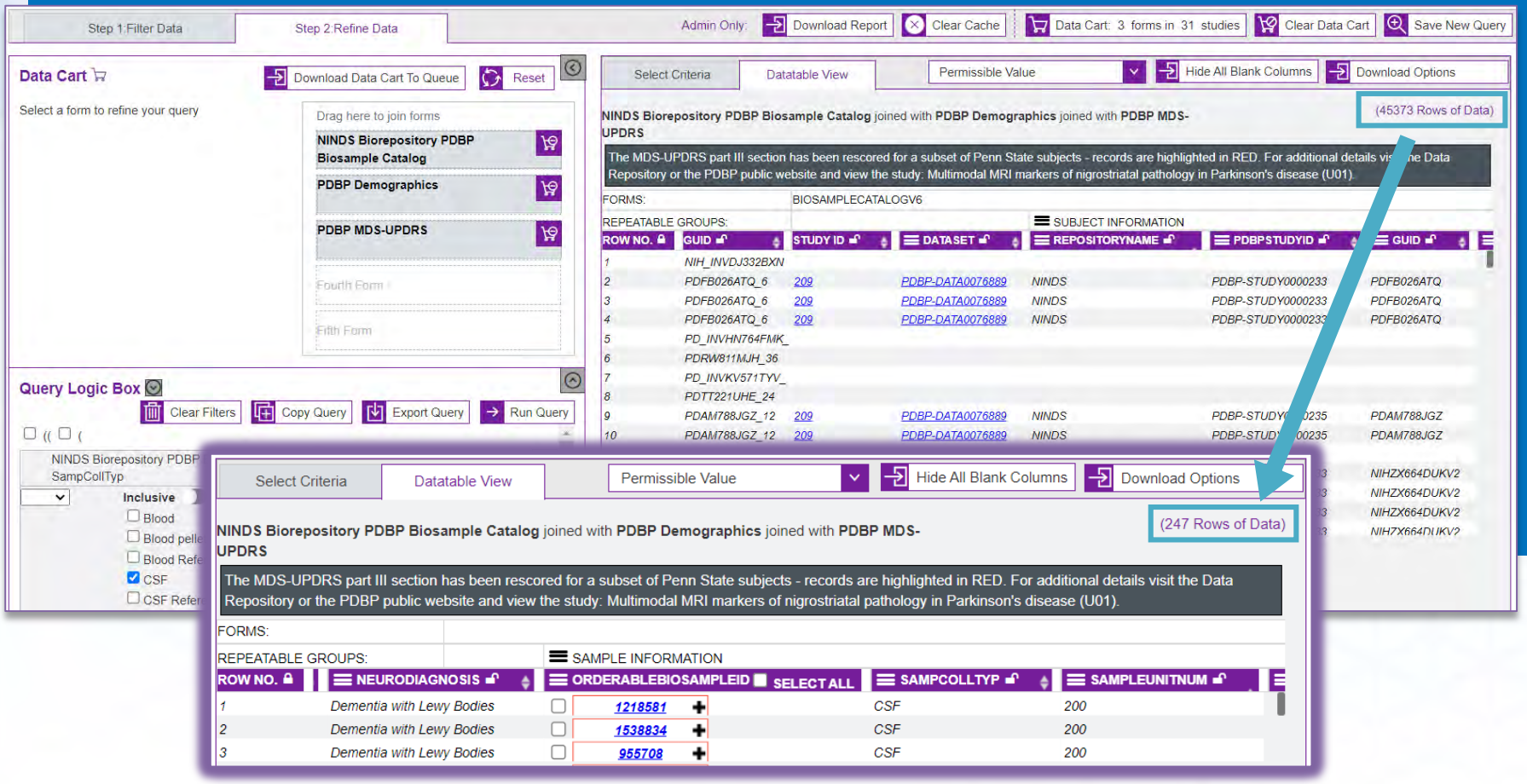
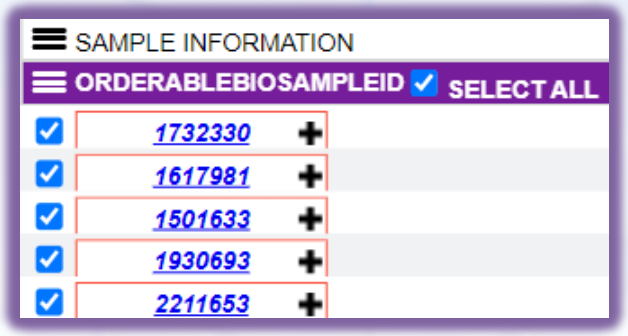
Apply filters



Select these samples to order



Download to CSV & continue additional analysis & filtering

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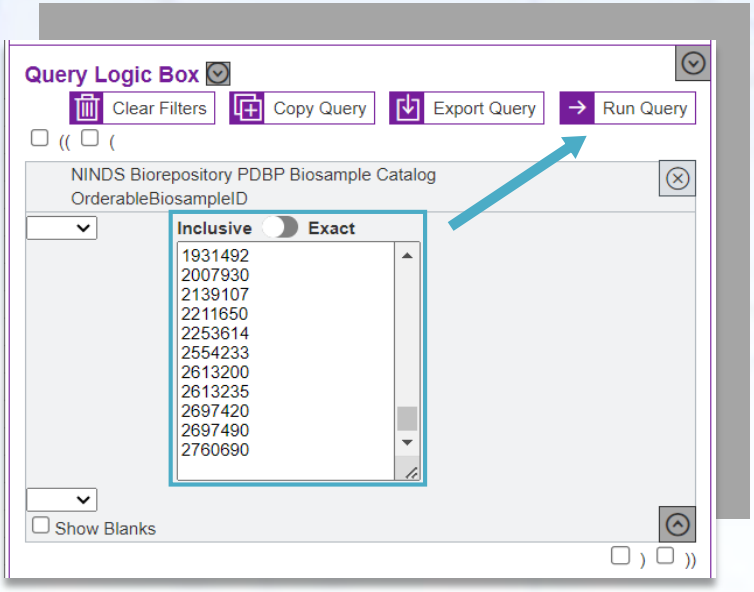

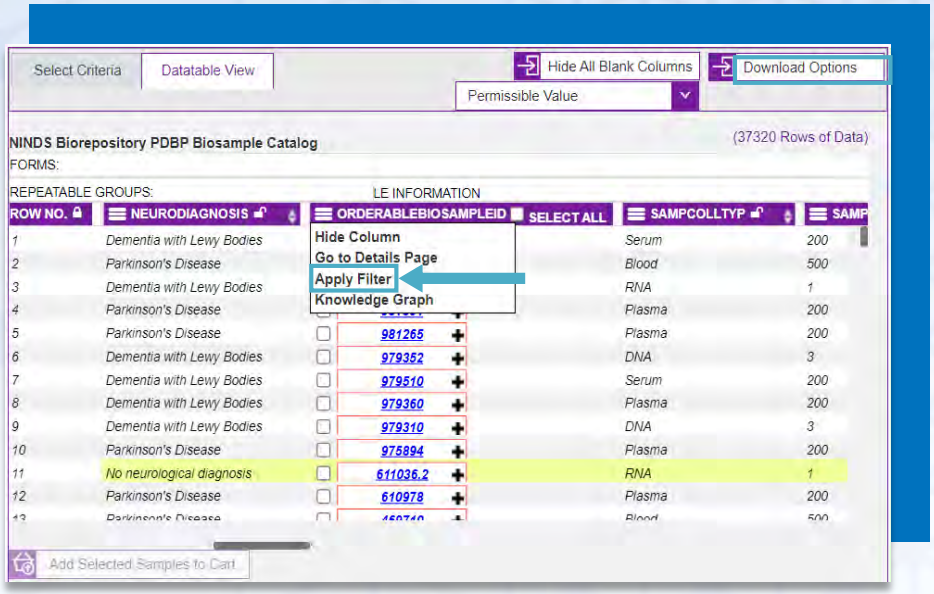

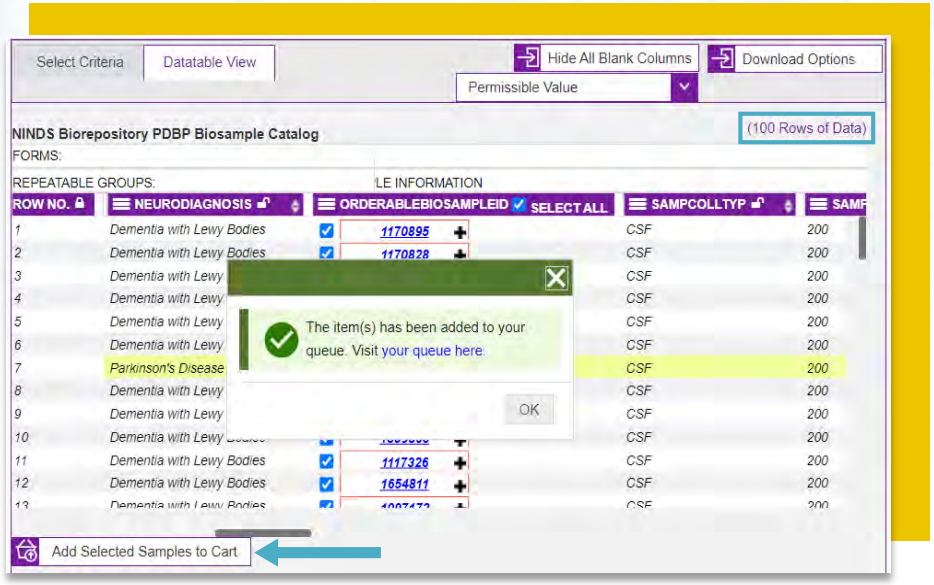

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Update aliquot # here

View Your Bio Materials Queue

Remove From Queue

Mass Quantity: Update Search:

	SAMPLE ID	REPOSITORY	SAMPLE TYPE	GUID	VISIT TYPE	INV	INV DATE	QTY	UNIT #	UOM
☐	816295	NINDS	CSF	PDDJ916LE2	Baseline	31	2023-02-22 19:00:00.0	1	200	ul
☐	816330	NINDS	CSF	PDDD367DR5	Baseline	37	2023-02-22 19:00:00.0	1	200	ul
☐	839609	NINDS	CSF	PDXJ187HKB	Baseline	36	2023-02-22 19:00:00.0	1	200	ul
☐	839679	NINDS	CSF	PDVA055XLM	Baseline	40	2023-02-22 19:00:00.0	1	200	ul
☐	862076	NINDS	CSF	PDNL259EGP	Baseline	22	2023-02-22 19:00:00.0	1	200	ul
☐	862109	NINDS	CSF	PDFW922MC1	Baseline	37	2023-02-22 19:00:00.0	1	200	ul
☐	885081	NINDS	CSF	PDWF428BU7	Baseline	38	2023-02-22 19:00:00.0	1	200	ul
☐	885118	NINDS	CSF	PDHW849XZE	Baseline	38	2023-02-22 19:00:00.0	1	200	ul
☐	885152	NINDS	CSF	PDJT283PFW	Baseline	29	2023-02-22 19:00:00.0	1	200	ul
☐	885221	NINDS	CSF	PDHE978YX5	Baseline	34	2023-02-22 19:00:00.0	1	200	ul
☐	890190	NINDS	CSF	PDZE783AFK	Baseline	37	2023-02-22 19:00:00.0	1	200	ul
☐	890228	NINDS	CSF	PDMP821KF0	Baseline	31	2023-02-22 19:00:00.0	1	200	ul
☐	890263	NINDS	CSF	PDUZ232NGV	Baseline	36	2023-02-22 19:00:00.0	1	200	ul
☐	927789	NINDS	CSF	PDEH060EUK	Baseline	37	2023-02-22 19:00:00.0	1	200	ul
☐	941541	NINDS	CSF	PDUL086YY3	Baseline	30	2023-02-22 19:00:00.0	1	200	ul

Showing 1 to 15 of 100 entries (0 row selected of 100)

First Previous 1 2 3 4 5 6 7 Next Last

Select samples then add to order

ADD TO ORDER

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Order Form

Biosample Orders

Owner: Lutz, Andrea
Owner Organization: PDBP

Order #:

Fields marked with a * are required.

Order Title: *

Add Supporting Documentation *

A signed copy of your Parkinson's Disease Biospecimen Resource Access Committee (BRAC) approval letter should be uploaded with your order.

UPLOAD SUPPORTING DOCUMENTATION

Attached Files:

FILENAME

Add Comment

(limit 4000 char)

Shipping Address

Ship To Name: *
Ship To Institution: *
Ship To Phone: *
Affiliation: *
Affiliation Phone: *
Affiliation Email: *
Affiliation Special Instructions: *
Address 1: *
Address 2:
City: *
State: *
Zip: *

CANCEL | SAVE AND EXIT | SAVE AND SUBMIT

DMR Admin

Reviews, approves & submits order in PDBP DMR

BioSEND

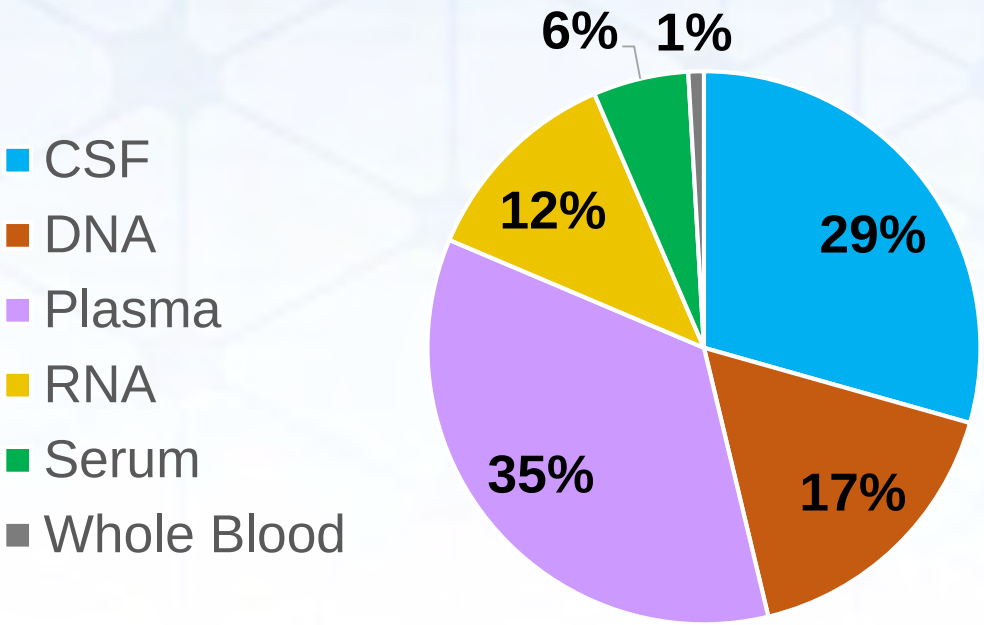
Receives & prepares order, ships blinded samples to researcher

Researcher

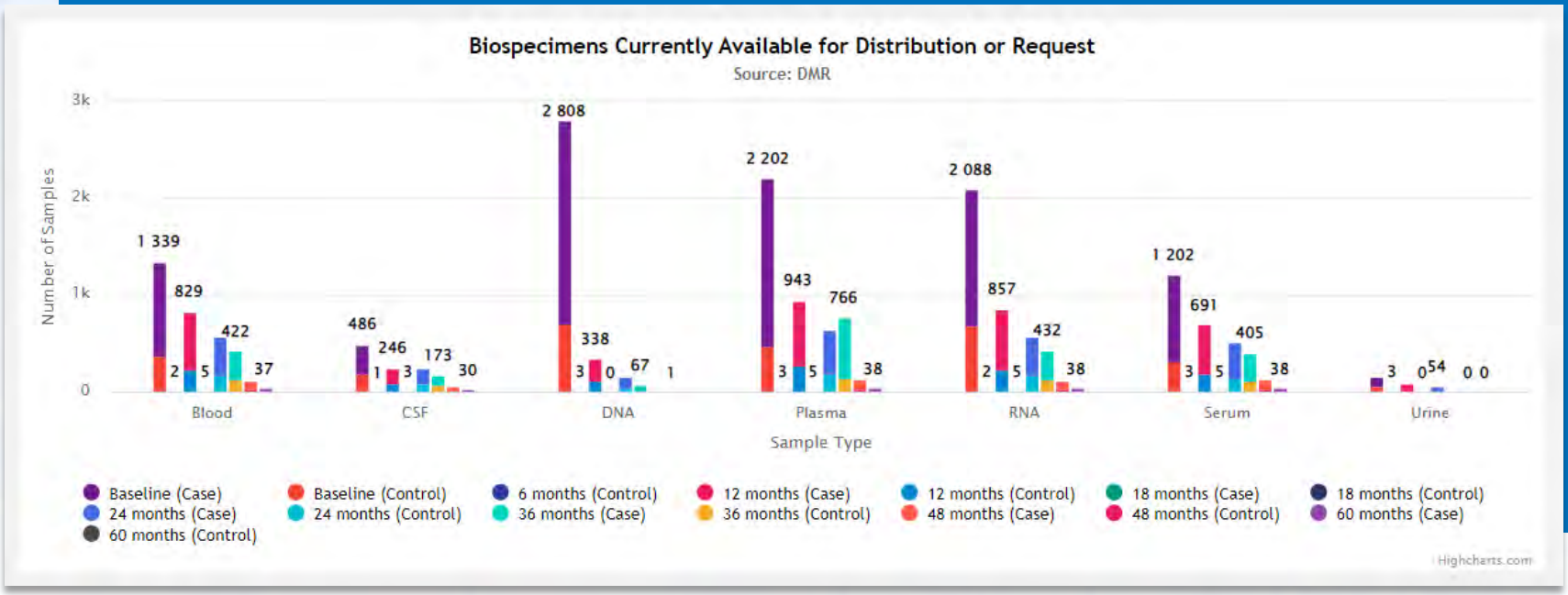
Receives samples, performs analysis, submits results back to PDBP DMR

BioSEND Distribution Summary

108 distributions to
52 separate investigators totaling **34,403 sample aliquots**.



PDBP Public Website




RESEARCH ARTICLE
Cross-sectional Associations of β-Amyloid, Tau, and Cerebrovascular Biomarkers With Neurodegeneration in Probable Dementia With Lewy Bodies
Daniel Ferreira, PhD, Scott A. Przybelski, BS, Timothy G. Lesnick, MS, Christopher G. Schwarz, PhD, Patricia Diaz-Galvan, PhD, Jonathan Graff-Radford, MD, Matthew L. Senjem, MS, Julie A. Fields, PhD, David S. Knopman, MD, David T. Jones, MD, Rodolfo Savica, MD, PhD, Tanis J. Ferman, PhD, Neill Graff-Radford, MBBCh, Val J. Lowe, MD, Clifford R. Jack, MD, Ronald C. Petersen, MD, PhD, Eric Westman, PhD, Brad F. Boeve, MD, and Kejal Kantarci, MD
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RESEARCH ARTICLE
β-Amyloid Load on PET Along the Continuum of Dementia With Lewy Bodies
Correspondence
Dr. Kantarci
kantarci.kejal@mayo.edu
npj | parkinson's disease
www.nature.com/npjparkd
ARTICLE OPEN
MRI data-driven clustering reveals different subtypes of Dementia with Lewy bodies
Anna Inguanzo, Konstantinos Poulakis, Rosaleena Mohanty, Christopher G. Schwarz, Scott A. Przybelski,
Patricia Diaz-Galvan
Frederik Barkhof
Zuzana Nedelska
Eric Westman
Article | Open Access | Published: 16 December 2022
Identification and prediction of Parkinson's disease subtypes and progression using machine learning in two cohorts
Anant Dadu, Vipul Satone, Rachneet Kaur, Sayed Hadi Hashemi, Hampton Leonard, Hirotaka Iwaki, Mary B. Makarious, Kimberley J. Billingsley, Sara Bandres-Ciga, Lana J. Sargent, Alastair J. Noyce, Ali Daneshmand, Cornelis Blauwendraat, Ken Marek, Sonja W. Scholz, Andrew B. Singleton, Mike A. Nalls, Roy H. Campbell & Faraz Faghri
npj Parkinson's Disease 8, Article number: 172 (2022) | Cite this article
Front Neurosci. 2023; 17: 1145923.
Published online 2023 Jul 6. doi: 10.3389/fnins.2023.1145923
PMCID: PMC10357515
PMID: 37483339
Neuronally enriched microvesicle RNAs are differentially expressed in the serums of Parkinson's patients
Morris A. Aguilar, Shauna Ebanks, Havell Markus, Mechelle M. Lewis, Vishal Midya, Kent Vrana, Xuemei Huang, Molly A. Hall and Yuka Imamura Kawasawa
A Preliminary Comparison of the Methylome and Transcriptome from the Prefrontal Cortex Across Alzheimer's Disease and Lewy Body Dementia
Daniel W. Fisher, Jessica Tulloch, Chang-En Yu and Debby Tsuang
Front. Neurol., 09 November 2022
Sec. Movement Disorders
APDM gait and balance measures fail to predict symptom progression rate in Parkinson's disease
D. Campbell Dewey, Shilpa Chitnis, Morgan C. McCreary, Alexander Pantelyat, Richard B. Dewey Jr.
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Genetically-informed prediction of short-term Parkinson's disease progression
Hossein J. Sadaei, Aldo Cordova-Palomera, Jonghun Lee, Jaya Padmanabhan, Shang-Fu Chen, Nathan E. Wineinger, Raquel Dias, Daria Prilutsky, Sandor Szalma & Ali Torkamani
npj Parkinson's Disease 8, Article number: 143 (
ORIGINAL ARTICLES
Research Priorities of Individuals and Caregivers With Lewy Dementia
A Web-based Survey
Holden, Samantha K. MD, MS; Bedenfield, Noheli MHA; Taylor, Angela S.; Bayram, Ece MD, PhD; Schwilk, Chris PhD; MSCE; Duda, John MD; Shill, Holly MD; Paulson, Henry L. MD; Stacy, Kelly PhD, MHA, RN; Wood, Julia MOT, OTR/L; LPC; Sha, Sharon J. MD, MS; Litvan, Irene MD; Irwin, David J. MD; Quinn, Joseph F. MD; Goldman, Jennifer G. MD, MS; MD; Taylor, John-Paul PhD; Boeve, Bradley F. MD; Armstrong, Melissa J. MD, MSc
Author Information
Alzheimer Disease & Associated Disorders 37(1):p 50-58, January-March 2023. | DOI: 10.1097/WAD.0000000
Joint Modeling Study Identifies Blood-Based Transcripts Link to Cognitive Decline in Parkinson's Disease
D. Weimin Li MS, Joseph J. Locascio PhD,
.1002/mds.29213
he authors declare there is no commercial or t related to this study.
zhen Fundamental Research Program
nds for the Central Universities, Sun Yat-sen on of China (31900475), Guangdong Basic and and Young Talent Recruitment Project of
Review article
Sex differences in dementia with Lewy bodies: Focused review of available evidence and future directions
Shannon Y. Chiu, Kathryn A. Wyman-Chick, Tanis J. Ferman, Ece Bayram, Samantha K. Holden, Parichita Choudhury, Melissa J. Armstrong
Journal of Neurology
https://doi.org/10.1007/s00415-023-11810-2
ORIGINAL COMMUNICATION
Check for updates
Seed amplification assay results illustrate discrepancy in Parkinson's disease clinical diagnostic accuracy and error rates
John Stephen Middleton · Hanna Lynn Hovren · Nelson Kha · Manuel Joseph Medina · Karen Ruth MacLeod · Luis Concha-Marambio · Kendal Jay Jensen

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Questions?

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PDBP Cloud Initiative

Krissy Treece, Project Manager PDBP

- In early 2022, the BRICS team started investigating a potential move to the Cloud for PDBP

- December 16, 2022, the BRICS team successfully deployed PDBP to the Cloud

PDBP Cloud Initiative

Motives

- NIH encouragement to move projects to the cloud
- Allow for future enhancements to PDBP's scalability and performance
- Prepare for large AMP PD data merge

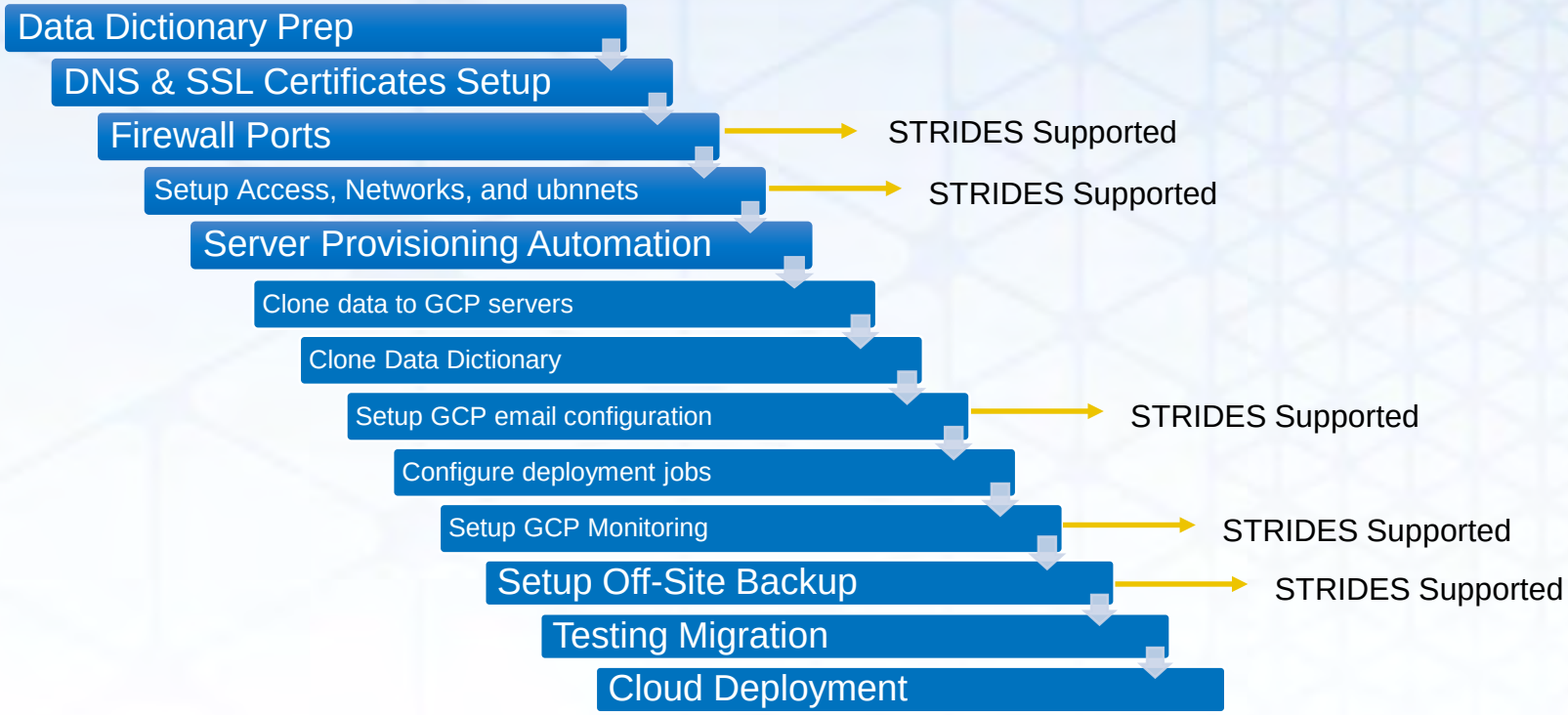
Accelerating Medicines Partnership Parkinson's Disease (AMP PD)

- The Accelerating Medicines Partnership Parkinson's Disease (AMP PD) program is a public-private partnership between the National Institutes of Health (NIH), multiple biopharmaceutical and life sciences companies, and non-profit organizations.
- It is managed through the Foundation for the NIH (FNIH)
- It contains over 2TB of data and is currently housed in the Google Cloud
- **Future plans are to merge all of the AMP PD data into PDBP**

Cloud Services Analysis

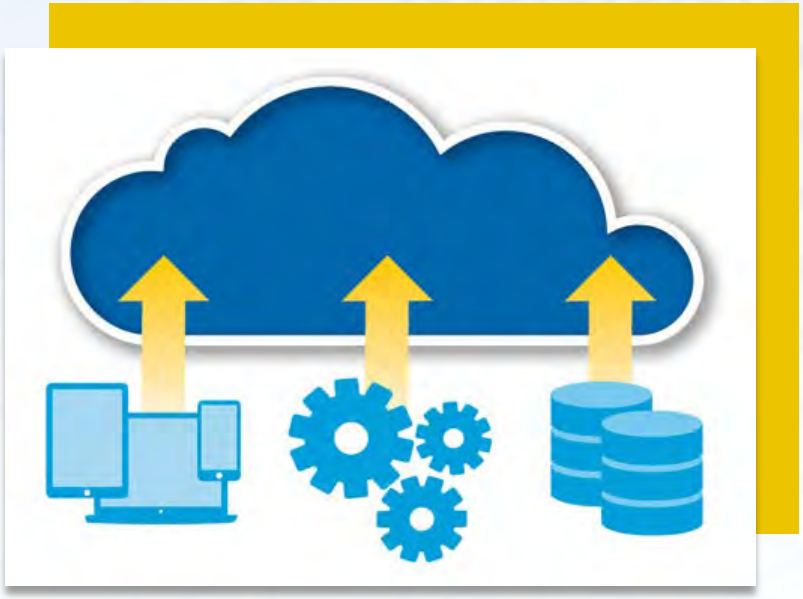
- BRICS team interviewed Google Cloud and Amazon Cloud support teams
- We prepared a full comparison of the two platforms based on our needs
- After completing our analysis, the NIH PDBP team was able to select **Google Cloud** as the best option
  - Cost, support, enhancement capabilities, ease of data transfers
- Deployed under the STRIDES model

PDBP Cloud Development



PDBP Cloud Deployment

- On December 2022, the BRICS team deployed the PDBP instance to the Google Cloud.
  - This was a lift and shift operation
- 3 different environments (Stage, UAT, and Production)
- Roughly 6-7 TB of data
- Transition went smoothly with strong support from the STRIDES team



Assessment and Authorization (A&A)

NIST COMPUTER SECURITY RESOURCE CENTER CSRC

- The A&A process is a comprehensive assessment and/or evaluation of an information system policies, technical / non-technical security components, documentation, supplemental safeguards, policies, and vulnerabilities.
- Based on the NIST 800-53 Rev 5 Framework - (Rev 5 Control Families)
- Required to receive and maintain the Authority To Operate (ATO)
- Full review is required before being put into production, and every 5 years thereafter
- **BRICS is in the process of a full review**
- A&A stages:
  - Assessment Stage - The assessment is a comprehensive analysis of the management, operational, and technical security controls in an information system, made in support of A&A.
  - Authorization Stage - The final authorization decision, final ATO received

Laying the Groundwork

The PDBP Cloud initiative has laid the groundwork for the accelerated deployment of future instances to the cloud.

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Questions?

Take the Poll

Access Code:

99 93 48 99

https://www.menti.com/bltm2op5jcnk

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Closing Remarks