

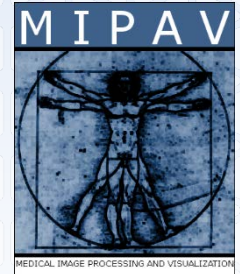
# Biomedical Research Informatics Computing System (BRICS)



**NDAR** National Database  
for Autism Research



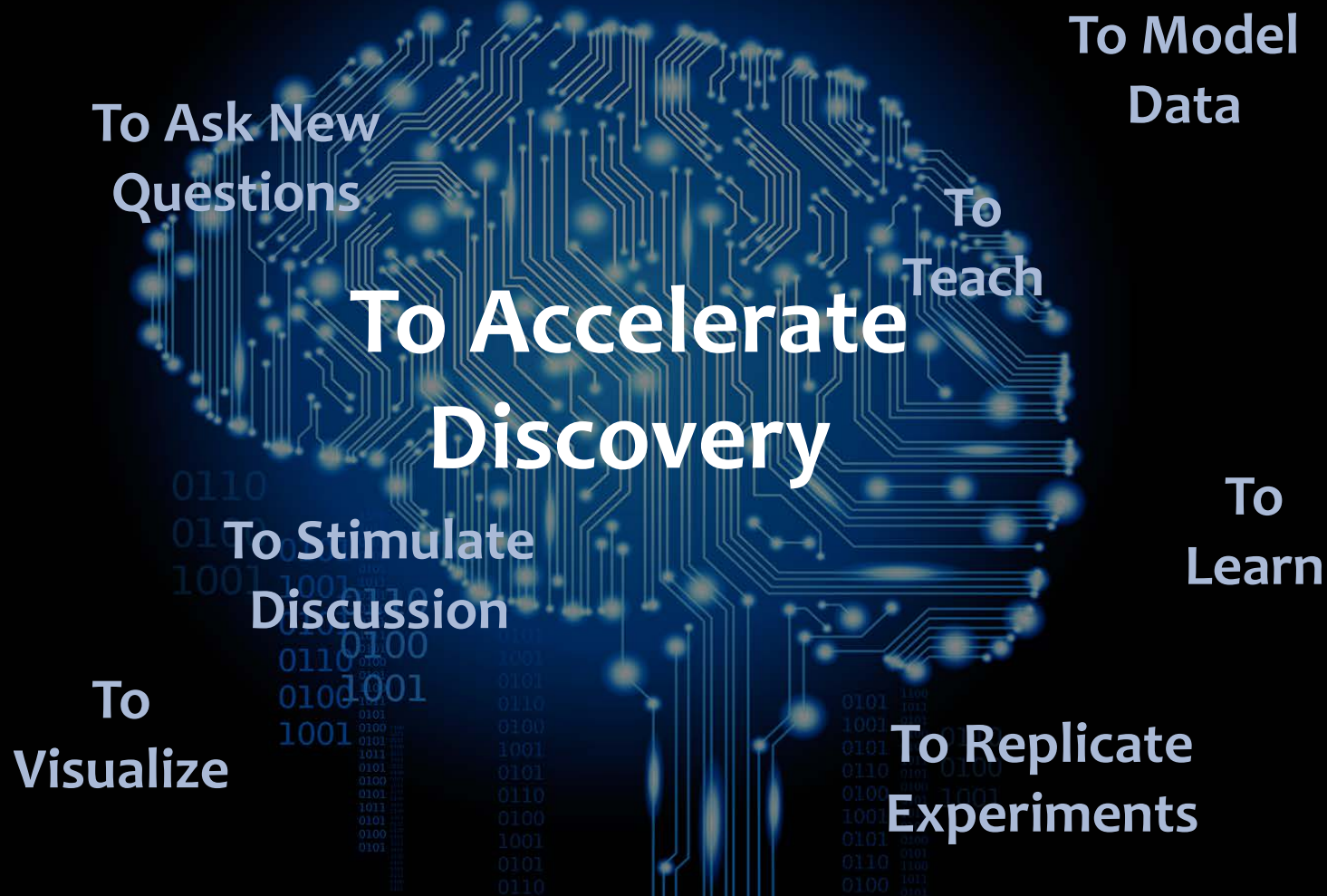
**Parkinson Disease BioMarker  
Data Management Resource**



Matthew J. McAuliffe, Ph.D., NIH/CIT



# Why share data? Big Data



# BRICS Modules



## DATA DICTIONARY

### Defines and Validates Data

- Creates, manages, and searches data elements and form structures
- Validates research data against the defined validation rules



## DATA REPOSITORY

### Study Management and Data Submission

- Defines and manages study information and access
- Contributes, uploads, and stores the research data
- Defines federated data stores



## GUID

### Global Unique Identifier System

- Allows researchers to share data specific to study participants
- Correlates participants across studies without exposing personally identifiable information (PII)



## PROFORMS

### Clinical Trial / Research

- Defines electronic case report forms
- Schedules and collects clinical data
- Exports, analyzes and reports on collected data



## QUERY

### Query, Report and Export Data

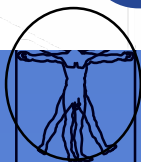
- Includes locally collected research data
- Includes research data from defined, federated sites



## MIPAV IMAGE PROCESSING

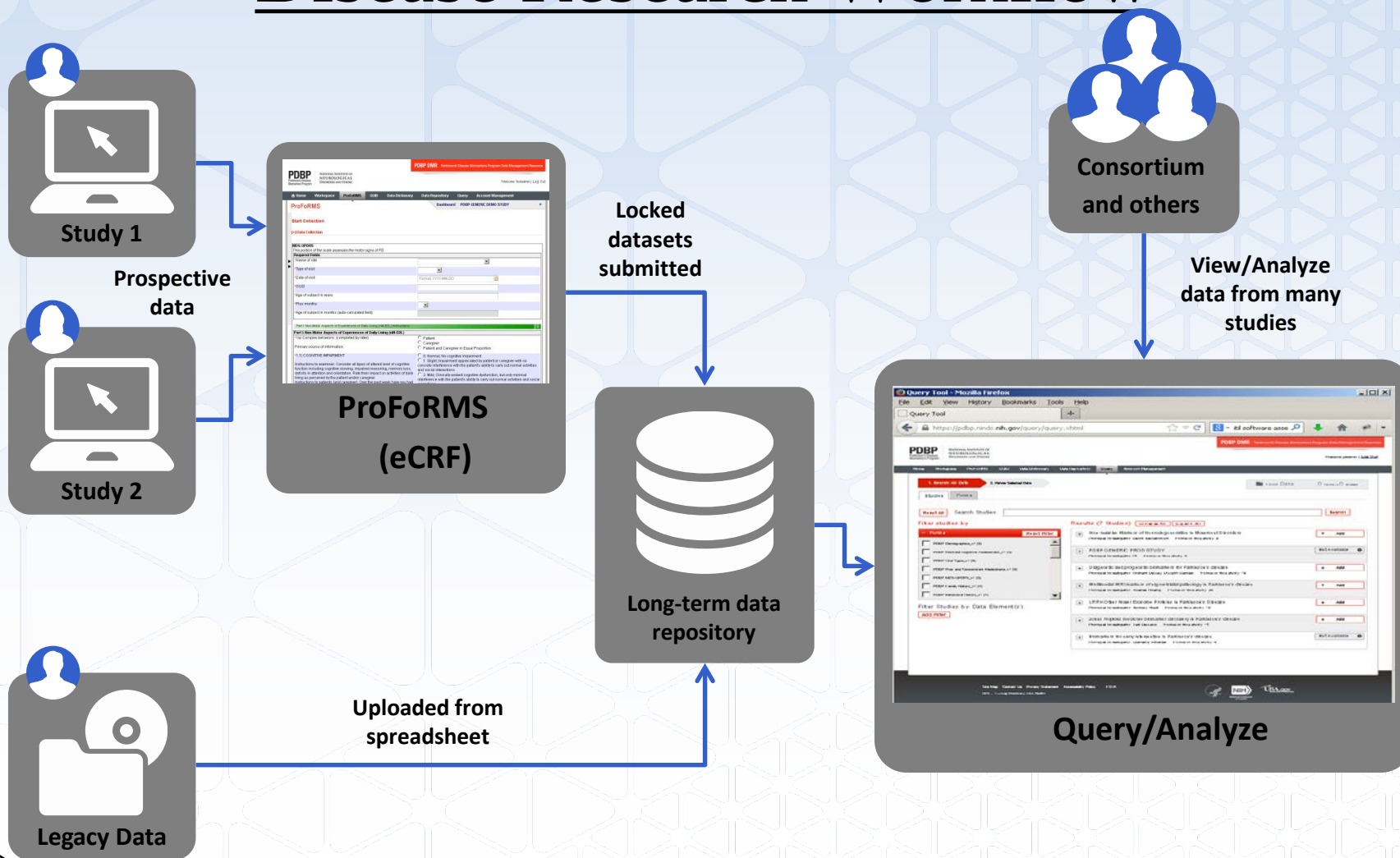
### MIPAV Imaging Data Submission

- Image submission tool
- Image analysis tool
- 3D Image visualization



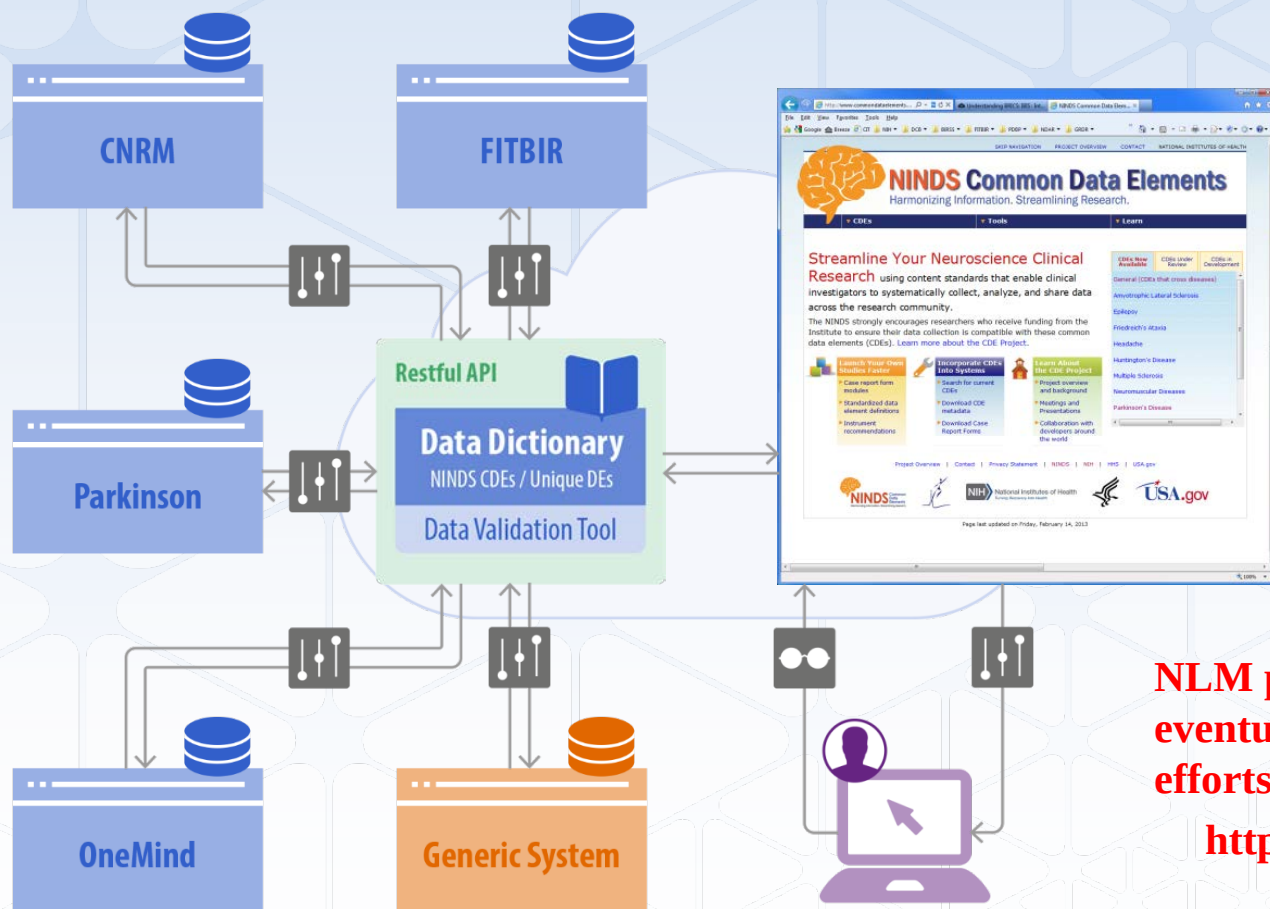
# PDBP/FITBIR

## Disease Research Workflow



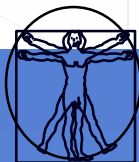


# Standardization, Standardization, Standardization Data Dictionary, CDEs, UDEs



**NLM project to expose and  
eventually harmonize NIH CDE  
efforts**

**<http://www.nlm.nih.gov/cde>**





Center for Information  
Technology  
Division of Computational  
Bioscience

https://dictionary.fitbir.nih.gov/portal/dictionary/se Search Data Elements : FITB... x

File Edit View Favorites Tools Help

Google CIT NIH DCB BIRSS FITBIR PDBP NDAR GRDR MIPAV NCS CDEs CDISC

# FITBIR

Federal Interagency Traumatic Brain Injury Research  
INFORMATICS SYSTEM

Welcome Matthew | [Log Out](#)

Home Workspace ProFoRMS GUID Data Dictionary Data Repository Query Account Management

## Search Data Elements

Search Locations

Narrow your search

Show  entries

**Ownership**

☒ All

☐ Mine

**Status**

☐ Draft

☐ Awaiting Publication

☐ Published

**Modified Date**

**Element Type**

☐ Common Data Element

☐ Unique Data Element

**Disease** 

☐ Amyotrophic Lateral Sclerosis

☐ Congenital Muscular Dystrophy

☐ Duchenne Muscular Dystrophy/Becker Muscular Dystrophy

☐ Epilepsy

☐ Friedrich's Ataxia

**Population**

☐ Adult

☐ Pediatric

☐ Adult and Pediatric

☐ Preclinical

| Title                                                                                                               | Variable Name                 | Element Type | Creation Date | Modified Date | Status               |
|---------------------------------------------------------------------------------------------------------------------|-------------------------------|--------------|---------------|---------------|----------------------|
| <a href="#">0-Back Reaction Time Correct Answers</a>                                                                | zeroback_RTC                  | UDE          | 2014-04-16    | 2014-04-16    | Draft                |
| <a href="#">0-Back accuracy</a>                                                                                     | zeroback_ACC                  | UDE          | 2014-04-22    | 2014-04-22    | Draft                |
| <a href="#">1-Back accuracy</a>                                                                                     | oneback_ACC                   | UDE          | 2014-04-22    | 2014-04-22    | Draft                |
| <a href="#">1-Back Reaction Time Correct Answers</a>                                                                | oneback_RTC                   | UDE          | 2014-04-22    | 2014-04-22    | Draft                |
| <a href="#">2-Back Accuracy</a>                                                                                     | twoback_ACC                   | UDE          | 2014-04-22    | 2014-04-22    | Draft                |
| <a href="#">2-Back Reaction Time Correct Answers</a>                                                                | twoback_RTC                   | UDE          | 2014-04-22    | 2014-04-22    | Draft                |
| <a href="#">260/230 ratio of biosample purity</a>                                                                   | Sample260_230Ratio            | UDE          | 2014-04-01    | 2014-04-01    | Published            |
| <a href="#">260/280 ratio of biosample purity</a>                                                                   | Sample260_280Ratio            | UDE          | 2014-04-01    | 2014-04-01    | Published            |
| <a href="#">36-item Short Form Health Survey (SF-36) - bodily pain score</a>                                        | SF36BodyPainScore             | CDE          | 2014-04-01    | 2014-04-01    | Awaiting Publication |
| <a href="#">36-item Short Form Health Survey (SF-36) - cut time on work activities emotional problems indicator</a> | SF36CutTimeWrkActEmotProblInd | CDE          | 2014-04-01    | 2014-04-01    | Awaiting Publication |
| <a href="#">36-item Short Form Health Survey (SF-36) - cut time on work activities physical health indicator</a>    | SF36CutTimeWrkActPhyHlthInd   | CDE          | 2014-04-01    | 2014-04-01    | Awaiting Publication |
| <a href="#">36-item Short Form Health Survey (SF-36) - difficulty work activities physical health indicator</a>     | SF36DiffWtWrkActPhyHlthInd    | CDE          | 2014-04-01    | 2014-04-01    | Awaiting Publication |
| <a href="#">36-item Short Form Health Survey (SF-36) - difficulty work activities physical health indicator</a>     | SF36DiffWtWrkActPhyHlthInd    | CDE          | 2014-04-01    | 2014-04-01    | Awaiting Publication |

Showing 1 to 25 of 10931 entries

First Previous 1 2 3 4 5 Next Last



# Query across studies supported by the use of CDEs

DEMO

  
Federal Interagency Traumatic Brain Injury Research  
INFORMATICS SYSTEM

Welcome poolegarcia | [Log Out](#)

[Home](#) [Workspace](#) [ProFoRMS](#) [GUID](#) [Data Dictionary](#) [Data Repository](#) **Query** [Account Management](#)

1. Search All Data

2. Refine Selected Data

YOUR Data

13 forms in 1 study

Studies

Forms

CURRENTLY FILTERING STUDIES BY Text: "manley" ✕

Reset All

Search Studies

Search

Filter studies by

Forms

Reset Filter

☐ TRACK-TBI Surgery\_v2 (1)  
☐ TRACK-TBI Abbreviated Injury Scale\_v1 (1)  
☐ Track TBI Subject\_v3 (1)  
☐ TRACK-TBI Intensive Care Unit\_v1 (1)  
☐ TRACK-TBI CT\_v1 (1)  
☐ TRACK-TBI Assessment Baseline\_v1 (1)  
☐ Track-TBI Intracranial Pressure\_v1 (1)  
☐ TRACK-TBI Hospital\_v1 (1)

Results (2 Studies)

Collapse All

Expand All

☐ Transforming Research and Clinical Knowledge in Traumatic Brain Injury (TRACK-TBI)  
Principal Investigator: Geoff Manley Forms in this study: 13

Forms

TrackTBI\_Surgery

✓ Added

TrackTBI\_Subject

✓ Added

TrackTBI\_CT

✓ Added

TrackTBI\_ICP

✓ Added

TrackTBI\_AIS

✓ Added

TrackTBI\_ICU

✓ Added

TrackTBI\_AssmBaseline

✓ Added

TrackTBI\_Hospital

✓ Added

