

## Federal Interagency Traumatic Brain Injury Research (FITBIR) Informatics System Overview

### What is FITBIR?

- ✓ Central repository for phenotypic, genomic, and imaging data from traumatic brain injury (TBI) studies
- ✓ Free web-based application with a user-friendly interface to contribute and access data (<http://fitbir.nih.gov>)

### Data Repository

- ✓ Define and manage study information
- ✓ Contribute, upload and store research data that is associated to each study

### Globally Unique Identifier (GUID)

- ✓ Enables data to be associated with a subject without exposing/transferring Personally Identifying Information (PII)
- ✓ Made up of random alpha numeric characters, not generated from PII
- ✓ Subject's GUID is independent but can be associated with one or more studies

### Query (FITBIR v2.0)

- ✓ Provide functionality for querying, reporting, and exporting data in FITBIR

### Development Timeline



The basis of the FITBIR Informatics System is Biomedical Research Informatics Computing System (BRICS), which is organized by modules.

### Data Dictionary

- ✓ Provides common definitions so data is consistently captured and recorded across TBI studies
- ✓ Incorporates and extends the Common Data Element (CDE) definitions developed by the National Institute of Neurological Disorders and Stroke (NINDS)
- ✓ Contains NINDS Data Elements (CDE), unique DE, and Form Structures (FS) which are placeholders for CDE and DE

### ProFoRMS ( Protocol & Form Research Management System ) (FITBIR v1.6)

- ✓ Overview from dashboard
- ✓ Manage research studies
- ✓ Set up roles and privileges to access research data
- ✓ Create forms, questions and build up user's own Question List
- ✓ Manage subject information and schedule visits
- ✓ Collect data and submit to FITBIR