



## 3<sup>rd</sup> Stakeholders Meeting July 19, 2021

All times are Eastern Time Zone (ET)

9:00 – 9:20 AM

### Welcome and Opening Remarks

**Walter Koroshetz, MD** | Director, NINDS

**Commander Travis M. Polk, MD, FACS** | Director, Combat Casualty Care Research Program, U.S. Army Medical Research and Development Command (USAMRDC)

9:20 – 9:50 AM

### NIH ODSS Perspective on FAIR data principles

**Susan Gregurick, PhD** | Associate Director for Data Science, NIH

9:50 – 10:45 AM

### Patient Perspective

The session focuses on the experiences of those with a history of TBI and their caregivers. It will also provide the patient and caregiver perspective on participating in research studies, data sharing, and the prioritization of unanswered research questions.

*Moderator:* **Radha Holavanahalli, PhD** | Rehabilitation Program Specialist, National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR)

*Panelists:* **Richard Anderson** | Brain Injury Alliance of New Jersey, TBI Survivor  
**Rose Anderson**, Caregiver  
**Captain Johnny Cebak, DO, PhD** | Mayo Clinic, TBI Survivor  
**Julie Self**, Caregiver  
**Allan L. Service, PhD** | TBI Model Systems National Data and Statistical Center, TBI Survivor

10:45 – 11:00 AM

**BREAK**

### Session I: Current State of FITBIR

*Moderator:* **Rebecca Berman, PhD** | Health Program Specialist, NINDS

11:00 – 11:15 AM

### Overview of FITBIR Policies & Holdings

Data submission, access policies, and FITBIR holdings  
**Nsini Umoh, PhD** | Program Director, TBI, NINDS

11:15 – 11:45 AM

### FITBIR Processes & Operations

Initiation of a study, Common Data Elements/Form usage, support during submissions, data quality control, and the closeout process.

**Alison Garcia, BSE** | Project Manager, Center for Information Technology (CIT), NIH



**11:45 AM – 12:15 PM**

**FITBIR Technological Capabilities & Development**

IT security and PII protections, interoperability (APIs, BioSend), development of neuropathology library, and future developments  
**Matt McAuliffe**, PhD | Co-Director FITBIR, CIT, NIH

**12:15 – 12:30 PM**

**Session 1 Panel Discussion and Q & A**

**12:30 – 1:00 PM**

**BREAK**

**Session II: Stakeholders Session**

*Moderator:* **Dwayne Taliaferro**, PhD | Health Science Program Manager, Congressionally Directed Medical Research Programs (CDMRP)

**1:00 – 1:45 PM**

**Data Submission Experiences**

The session will highlight three large-scale studies submitted to FITBIR, including a summary of available data and meta-data for each study.

**ADAPT: Laurie Silfies** | Systems/Programmer, University of Pittsburgh

**CARE: Melissa Baker** | Patient Coordinator, Datalys Center

**CENC: Sreekanth Kamineni** | Database Analyst, University of Utah

**1:45 – 2:30 PM**

**Data Access Experiences**

This session will discuss novel findings and publications based on the re-use of FITBIR data and will inform attendees about the process of data selection and access.

**Tayo Obafemi-Ajayi**, PhD | Associate Professor, Computational Learning Systems Lab, Missouri State University

**David Okonkwo**, MD, PhD | Director of the Neurotrauma Clinical Trials Center, University of Pittsburgh

**Nicola de Souza**, MSc | PhD Candidate, School of Graduate Studies, Rutgers Biomedical and Health Sciences

**2:30 – 2:45 PM**

**BREAK**

**2:45 – 3:45 PM**

**Session III: Moderated Panel Discussions**

**FITBIR Experience - Usability**

This session will be a moderated discussion of the processes of submitting and accessing FITBIR data, including challenges, methods development, and pipelines to improve efficiencies.

*Moderator:* **Matt McAuliffe**, PhD | Co-Director FITBIR, CIT, NIH

*Panelists:* **Kristen Dams-O'Connor**, PhD | Professor of Rehabilitation Medicine and Neurology, Icahn School of Medicine at Mount Sinai

**Amy Jak**, PhD | Professor of Psychiatry, University of California, San Diego



**Christine MacDonald**, PhD | Professor of Neurological Surgery, University of Washington

**Dave Mellick**, PhD | Director of Research Operations, Craig Hospital

**3:45 – 4:45 PM**

### **Best Data Management Practices**

The goal of this session is to discuss best practices in data management within laboratories and institutions for alignment with FITBIR policies and structures, such as data curation and quality control, cross-mapping, and the use of common data elements.

*Moderator:* **Christie Vu**, PhD | Health Science Program Manager, Congressionally Directed Medical Research Programs (CDMRP)

*Panelists:* **Vibeke Brinck**, MS | Director of System Engineering, QuesGen Systems, Inc.  
**Adam Ferguson**, PhD | Director of Data Science, Brain and Spinal Injury Center (BASIC) and Professor, Department of Neurological Surgeries, University of California, San Francisco  
**Michelle Harris** | FITBIR Operations  
**Dominic Nathan**, PhD | CNRM Informatics Director, Center for Neuroscience and Regenerative Medicine  
**Elizabeth Wilde**, PhD | Associate Professor, University of Utah

**4:45 – 5:45 PM**

### **FITBIR Policy, Holdings, and Health Disparities**

This session will provide background information about known TBI-related health disparities and will address whether FITBIR policies and holdings can enable better understanding and approaches to reduce these disparities.

*Moderator:* **Richard Benson**, MD, PhD | Director of the Office of Global Health and Health Disparities, NINDS

*Panelists:* **Patrick Bellgowan**, PhD | Deputy Associate Director, NINDS  
**Matthew Breiding**, PhD | Team Lead, Division of Injury Prevention, CDC  
**Stacey Chambers**, MS | Scientific Project Manager, NINDS  
**Nathalia Jimenez**, MD, MPH | Pediatric Anesthesiologist, Seattle Children's Hospital  
**Erica Littlejohn**, PhD | Science & Technology Policy Fellow, Office of Global Health and Health Disparities, NINDS  
**Xinzhi Zhang**, MD, PhD | Chief, Health Inequities and Global Health Branch Center for Translation Research & Implementation Science National Heart, Lung, and Blood



Institute | National Institutes of Health

**5:45 – 6:00 PM**

**Closing Remarks**

**Patrick Bellgowan, PhD** | Deputy Associate Director, NINDS