

## For Researchers

TED IP Documents and included study data inventories.

TED Research Collaboration Policy <sup>[1]</sup>

TED Metadataset\_DUA\_OUT <sup>[2]</sup>

TED Data Contribution and Use Agreement <sup>[3]</sup>

TED Metadataset Collaboration Request Form <sup>[4]</sup>

TED Metadataset TOC\_Final\_1-29-2016.xlsx <sup>[5]</sup>

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**\*\*Please note that collaboration requests for TRACK-TBI data are only being fielded for the TRACK-TBI Pilot Study, clinical trial ID NCT01565551.\*\***

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### **FITBIR: Federal Interagency Traumatic Brain Injury**

The Federal Interagency Traumatic Brain Injury Research (FITBIR) informatics system was developed to share data across the entire TBI research field and to facilitate collaboration between laboratories, as well as interconnectivity with other informatics platforms. Sharing data, methodologies, and associated tools, rather than summaries or interpretations of this information, can accelerate research progress by allowing re-analysis of data, as well as re-aggregation, integration, and rigorous comparison with other data, tools, and methods. This community-wide sharing requires common data definitions and standards, as well as comprehensive and coherent informatics approaches. Click here <sup>[6]</sup> to learn more about FITBIR.

### **National Research Action Plan**

On August 31, 2012, President Obama issued an Executive Order directing the Departments of Defense, Veterans Affairs, Health and Human Services, and Education, to develop a National Research Action Plan on post traumatic stress disorder, other mental health conditions, and Traumatic Brain Injury to improve the coordination of agency research into these conditions and reduce the number of affected men and women through better

prevention, diagnosis, and treatment.? Click here <sup>[7]</sup> to read the full action plan.

## **NINDS Common Data Elements**

Streamline Your Neuroscience Clinical Research using content standards that enable clinical investigators to systematically collect, analyze, and share data across the research community. The NINDS strongly encourages researchers who receive funding from the Institute to ensure their data collection is compatible with these common data elements (CDEs). Learn more about the CDE Project <sup>[8]</sup>.

## **InTBIR**

The International Initiative for Traumatic Brain Injury Research (InTBIR) is a cooperative effort of the European Commission (EC), the Canadian Institutes of Health Research (CIHR) and the National Institutes of Health (NIH) to coordinate and leverage clinical research activities on traumatic brain injury (TBI) research. InTBIR's goal is to improve health care and lessen the global burden of TBI by 2020 through the discovery of causal relationships between treatments and clinically meaningful outcomes. InTBIR seeks to encourage well-designed, hypothesis-driven studies that include the collection of high quality data followed by rigorous statistical analysis. Learn more about InTBIR <sup>[9]</sup>

## **Precision Medicine Initiative**

Launched with a \$215 million investment in the President's 2016 Budget, the Precision Medicine Initiative will pioneer a new model of patient-powered research that promises to accelerate biomedical discoveries and provide clinicians with new tools, knowledge, and therapies to select which treatments will work best for which patients. More information on this initiative from Office of the President, can be found here <sup>[10]</sup>. The NIH also has more information on this initiative here <sup>[11]</sup>.

## **CENTER-TBI**

CENTER-TBI is a large European project that aims to improve the care for patients with Traumatic Brain Injury (TBI). It forms part of the larger global initiative InTBIR: International Initiative for Traumatic Brain Injury Research with projects currently ongoing in Europe, the US and Canada. The Center-TBI website can be found here <sup>[12]</sup>.

## **BEST (Biomarkers, EndpointS, and other Tools) Resource**

Effective, unambiguous communication is essential for efficient translation of promising scientific discoveries into approved medical products. Unclear definitions and inconsistent use of key terms can hinder the evaluation and interpretation of scientific evidence and may pose significant obstacles to medical product development programs. In the spring of 2015 the FDA-NIH Joint Leadership Council identified the harmonization of terms used in translational science and medical product development as a priority need, with a focus on terms related to study endpoints and biomarkers. Working together with the goals of improving communication, aligning expectations, and improving scientific understanding, the two agencies developed the BEST (Biomarkers, EndpointS, and other Tools) Resource. The BEST glossary aims to capture distinctions between biomarkers and clinical assessments and

to describe their distinct roles in biomedical research, clinical practice, and medical product development. To access the glossary, click here <sup>[13]</sup>.

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**Source URL:** <https://tbiendpoints.ucsf.edu/researchers>

#### Links

[1]

[https://tbiendpoints.ucsf.edu/sites/tbiendpoints.ucsf.edu/files/TED%20Research%20Collaboration%20Policy\\_03-23-2018.pdf](https://tbiendpoints.ucsf.edu/sites/tbiendpoints.ucsf.edu/files/TED%20Research%20Collaboration%20Policy_03-23-2018.pdf)

[2] [https://tbiendpoints.ucsf.edu/sites/tbiendpoints.ucsf.edu/files/TED%20Metadataset\\_DUA\\_OUT\\_03-26-2018.pdf](https://tbiendpoints.ucsf.edu/sites/tbiendpoints.ucsf.edu/files/TED%20Metadataset_DUA_OUT_03-26-2018.pdf)

[3]

<https://tbiendpoints.ucsf.edu/sites/tbiendpoints.ucsf.edu/files/TED%20Data%20Contribution%20and%20Use%20Agr>

[4]

<https://tbiendpoints.ucsf.edu/sites/tbiendpoints.ucsf.edu/files/TED%20Metadataset%20Collaboration%20Request%2>

[5] [https://tbiendpoints.ucsf.edu/sites/tbiendpoints.ucsf.edu/files/TED%20Metadataset%20TOC\\_Final\\_1-29-2016.xlsx](https://tbiendpoints.ucsf.edu/sites/tbiendpoints.ucsf.edu/files/TED%20Metadataset%20TOC_Final_1-29-2016.xlsx)

[6] <https://fitbir.nih.gov/>

[7]

[https://www.whitehouse.gov/sites/default/files/uploads/nrap\\_for\\_eo\\_on\\_mental\\_health\\_august\\_2013.pdf](https://www.whitehouse.gov/sites/default/files/uploads/nrap_for_eo_on_mental_health_august_2013.pdf)

[8] <http://www.commondataelements.ninds.nih.gov/ProjReview.aspx>

[9] <http://intbir.nih.gov/>

[10] <https://www.whitehouse.gov/the-press-office/2015/01/30/fact-sheet-president-obama-s-precision-medicine-initiative>

[11] <http://www.nih.gov/precisionmedicine/>

[12] <https://www.center-tbi.eu/>

[13] <http://www.ncbi.nlm.nih.gov/books/NBK338448/>