

InTBIR "Deliverables" Survey Summary Dec. 12, 2016

Purpose: The last session of the October 2016 InTBIR Annual Meeting addressed the topic of deliverables for InTBIR, and the action items and workgroups needed to achieve them. Time constraints and a limited number of participants remaining at the meeting curtailed the discussion. Therefore, a survey was sent to all of the meeting participants to gather input on this important question.

Results: There were five responses to the survey.

- **Question 1: To lessen the burden of TBI and achieve InTBIR key objectives, please suggest 1 - 3 InTBIR deliverables.**
 - Validity and reliability of CDE outcome instruments: Comparative psychometrics of key outcomes in different contexts of use.
 - Identify similarities and differences in pediatric and adult TBI by comparing the 5P and ADAPT studies to relevant adult TBI cohorts.
 - Develop an clinically usable evidence-based classification of TBI severity, including milder types without imaging findings
 - Determine the predictors of outcomes following pediatric TBI
 - A reliable biomarker
 - External validation using other data cohorts and cost effectiveness study to augment the TRACK study that compared outcomes for ED discharge to ICU, hospital floor, or home.
 - Determine profiles of TBI outcomes based on early findings in children and adults
 - Generate hypotheses around promising therapies using comparative effectiveness design for TBI
 - Better outcome measures
 - Patho-anatomical or -physiological classification system for TBI clinical trial enrichment. Anticipated date of completion

- **Question 2: To achieve the scientific/clinical deliverables identified in #2, what are some action items for 2017?**
 - Identify priority sets of CDE outcomes
 - Identify health economists and other experts to collaborate with for the cost effectiveness components mentioned in deliverable #2.
 - Explore the data sets for practice variability for therapy as to use as basis for comparative effectiveness research
 - Everyone agree to full and open sharing of data
 - Establish consensus on key metrics supporting use in TBI
 - Literature review of classification systems for other disorders, especially CNS disorders like stroke and trauma to identify approaches, methods and tools.
 - Open analytics platform for collaboration

- **Question 3: To achieve the data sharing needed for international collaboration, what are some action items for 2017.**
 - Overview of databases and routes to integration
 - Upload InTBIR metadata into accessible databases (e.g. OBI BrainCode, Human Brain Project, FITBIR) and federate the databases to enable querying for the identification of relevant data sets for collaborative project
 - I would keep your example above!
 - Need a pathway/policy to permit upload of deidentified data that is acceptable to varying ethics committees
 - Provide a list a "qualified" repositories
 - Establish consensus on key metrics supporting use in TBI

- Literature review of classification systems for other disorders, especially CNS disorders like stroke and trauma to identify approaches, methods and tools
 - Open analytics platform for collaboration
 - Pilot studies with core sets of data
 - Identify state of the science analytical and visualization tools for classification and provide access to InTBIR investigators.
 - Have clear directions within each consortium with regards to preferred database system to be used
 - Need data management support for data upload (federation)
 - Enable inter-country exchange of data through a simple broker
 - Create a searchable database for biospecimens.
 - Require all studies to formally publish the data
- **Question 4: What InTBIR working groups are needed to achieve the InTBIR key objectives and deliverables identified in #2.**
 - All of the following workgroups proposed (Fluid biomarkers, Neuroimaging, Process and policies, Data management, Data curation and quality, Data analytics, Emerging technologies, Outcome assessments, and Steering Committee) were viewed as helpful toward achieving the InTBIR deliverables by 100% of the respondents.
- **Question 5: Please share any other suggestions that you have to promote the success of InTBIR.**
 - Going forward there are exciting opportunities for collaboration on a number of topics including: - Comparative effectiveness research - Studies of genetic associations - Prognosis research - Outcomes instrument development.
 - In addition to the 3 deliverables mentioned, many others are possible and this is not a prioritized list, but rather a range of relatively easy to very challenging ones.
 - Would like to explore ways to make InTBIR more relevant to low and middle-income countries.
 - Continue with meetings and working groups; put in place a steering committee for InTBIR to clarify directions for the whole group

Conclusions:

- The small response rate suggests that a steering committee is essential for inter-study engagement by the investigators and steps to create such a committee will be undertaken by the InTBIR Executive Committee.
- The investigators who responded to the survey will be contacted to see if some of their suggestions can be added to an “Idea Board” for InTBIR.
- The tasks and members of existing InTBIR Workgroups will be updated and posted on the InTBIR website. New groups may also be formed and/or subdivided in 2017.