

A rally for traumatic brain injury research

When members of the International Initiative for Traumatic Brain Injury Research (InTBIR) met in Vancouver (BC, Canada) on Oct 17–18, 2013, some notable stakeholders from the US National Institutes of Health (NIH) could not join them. The temporary shutdown of the US federal government had just been put to an end the night before. But the attendees' feeling of frustration about the absence of some collaborators did not cloud their enthusiasm, and the InTBIR network reaffirmed its pledge to improve patients' outcomes by 2020.

Traumatic brain injury (TBI) research has historically been neglected and underfunded. The major funding agencies behind InTBIR (The European Commission's Health Directorate, NIH, and the Canadian Institutes of Health Research, and their military partners) have now aligned their national programmes and dedicated more than US\$80 million to the initiative. Such an unprecedented coordinated strategy reflects the urgent need to tackle a global public-health crisis. In Europe alone, TBI causes an estimated 75 000 deaths per year and more than 1 million hospital admissions; but these estimates are thought to be even higher in other continents. Warfare, violence and terrorism, and road traffic accidents contribute to the huge global burden of TBI; long-term sequelae are both psychological and physical. Furthermore, recurring mild TBI can lead to chronic traumatic encephalopathy—evidence that is starting to affect policies of sports organisations.

As documented in a Personal View, adding to the complexity of a disease for which heterogeneity is an intrinsic feature, substantial differences in patient management exist even among specialist centres in the setting of clinical trials. Not surprisingly then, given the lack of guidelines based on high-quality evidence, inconsistencies in management of both paediatric and adult patients are pervasive. For instance, a recent study of paediatric TBI centres in France, Spain, the UK, and the USA found a great deal of variability in key therapy goals, such as those set up at individual centres on intracranial hypertension and metabolic therapies, or brain monitoring of partial pressure of oxygen.

In Vancouver, Graham Teasdale (University of Glasgow, UK) reminded attendees of the need to strike the right balance between aiming to improve standardised versus personalised clinical care. Without denying that challenge,

InTBIR members emphasised the opportunities to exploit heterogeneity in presentation, care, and outcomes, by means of rigorous observational studies and comparative effectiveness analyses to tackle both standardised and personalised care. Four major InTBIR studies in the civilian population have either started recruitment or will do so soon: the Approaches and Decisions for Acute Pediatric TBI (ADAPT) study, an observational comparative effectiveness study of 1000 children with severe TBI; the Collaborative European NeuroTrama Effectiveness Research in TBI (CENTER-TBI), a longitudinal study to characterise disease phenotypes and compare clinical care in more than 5000 patients, with a concurrent registry to collect data from up to 40 000 patients; the Collaborative Research on Acute Traumatic Brain Injury in Intensive Medicine in Europe (CREACTIVE) study, an epidemiological and comparative effectiveness study of patients with moderate-to-severe TBI in more than 100 intensive care units; and the Transforming Research and Clinical Knowledge in Traumatic Brain Injury (TRACK-TBI) study, which will enrol 3000 patients for further analyses of comparative effectiveness and diagnostic and prognostic markers. Although each of these studies (plus a plethora of smaller projects also part of InTBIR) should provide a wealth of data, unique potential lies in their synergies. The integrated analysis of findings will be feasible because data collection is standardised according to NIH common data elements (CDEs). And the newly implemented Federal Interagency TBI Research (FITBIR) Informatics System will equip the initiative with a data sharing platform. However, the difficulties of establishing a transnational, open-access research culture are not to be underestimated, and the most heated discussions in Vancouver covered the intricacies of the use of CDEs, legal and ethical barriers to data sharing, and the effects of data sharing in the current academic system of rewards.

The InTBIR community is nevertheless committed to address these obstacles over the next few months. In doing so, they will not only accelerate progress in TBI, but also facilitate the integration of InTBIR with other brain research networks for swift public health improvements. The next meeting of the consortium to review progress will take place in 2 years—hopefully political disruption in Washington, or elsewhere, won't hold any investigator back on that occasion. ■ *The Lancet Neurology*



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For more on InTBIR see [Editorial Lancet Neurol](#) 2012, **11**: 651

For more on long-term effects of mild TBI see [Neuron](#) 2012; **76**: 886–99

For the study in TBI paediatric centres see [Pediatr Crit Care Med](#) 2013; **14**: 811–18

For more on TBI common data elements see http://www.commondataelements.ninds.nih.gov/TBI.aspx#tab=Data_Standards

For more on FITBIR see <http://fitbir.nih.gov/>