

US DEPARTMENT OF DEFENSE BLAST INJURY RESEARCH PROGRAM COORDINATING OFFICE

Threat Analysis Establishing Large-Scale Data Repositories in a Military Healthcare Setting

The past decade of sustained combat operations has placed considerable stress on the MHS. As a result, researchers and medical providers have developed innovative healthcare strategies and techniques. Despite attempts to coordinate efforts, much innovation in military medicine occurs in a "stovepipe" fashion where similar efforts are replicated in parallel. Furthermore, much outcome data are either anecdotal or unpublished. The inability to share and monitor health outcomes can be costly to the Service Member and the MHS. Lastly, the MHS is facing patients with increasingly complex symptom presentations related to the homogeneous nature of combat injuries and related emotional injuries.

Efforts were made to design MHS electronic medical records, also known as the Armed Forces Health Longitudinal Technology Application (AHLTA), to allow for data extraction and analysis. However, much of these data are unusable, secondary to concerns regarding data accuracy and integrity. These concerns are often related to individual differences across medical providers in coding and notating patient history, treatment procedures, and diagnosis. These differences occur even between specialists in the same discipline and clinic. Despite these challenges, many clinics maintain databases for process improvement. While these efforts are noble, they are often hampered by poor information technology knowledge, ethical concerns (process improvement versus research and patient protection), and sustainability (time, resources, and frequent staff turnover).

To better understand the pathophysiology, disease progression, optimal diagnostic and evaluation, and associated outcome metrics in Service Members with TBIs and psychological health conditions, the Intrepid Spirit Concussion Recovery Center at the Naval Hospital Camp Lejeune initiated activities in FY15 to establish a clinical data registry. Data registries are organized systems (approved by an Institutional Review Board) that collect data for scientific, clinical, and/or policy purposes to elucidate the history of disease, determine effectiveness of healthcare services, measure or monitor safety, and/or measure quality. A registry allows sustainable and efficient exploration and publication of research findings and trends in clinical care. However, while a strong majority of clinicians value large scale data access and storage systems, a knowledge gap exists regarding how to leverage information technology and Institutional Review Board requirements for research purposes.