Clinical Research Repositories Increase Investment Value

Like data registries and other medical databases, a clinical research repository employs common data elements and a data dictionary to aggregate and standarize research study data so it can be shared for broader use.

A research repository is more robust and useful, however, including in-depth and detailed clinical information. Ideally, a repository provides additional informational services; uses a consistent identifier system to make its provided data persistent, unique and citable; and engages experts to review the data and ensure its quality.

A research repository will also include data-sharing protocols: rules for when data will be released and what to include, submission of data, and how data will be shared.

REPOSITORY EXAMPLES

FEDERAL INTERAGENCY TRAUMATIC BRAIN INJURY RESEARCH INFORMATICS SYSTEM (FITBIR)—FITBIR shares research data across the entire TBI research field and facilitates collaboration among laboratories and interconnectivity with other informatics platforms. FITBIR accelerates research progress by allowing re-analysis of data and re-aggregation, integration and rigorous comparison with other data, tools and methods.

ALZHEIMER'S DISEASE NEUROIMAGING INITIATIVE (ADNI)—Researchers are mandated to contribute standardized data to ADNI in a timely manner; and the database is quality controlled and monitored to ensure standards are met. More than 4,000 researchers have accessed ADNI data, resulting in more than 400 publications.

NATIONAL DATABASE FOR AUTISM RESEARCH (NDAR)—Begun in 2007 with support from five institutes at the NIH, NDAR promotes scientific collaboration and datasharing among autism spectrum disorder investigators. Its goal is to explore ways to aggregate and curate existing autism data in order to speed research on the causes and treatment of ASD.

NATIONAL HEART, LUNG AND BLOOD INSTITUTE (NHLBI)—NHLBI developed a data-sharing protocol focused on balancing the interests of study participants, investigators and the research community. It now includes data on more than 560,000 participants from 100 Institute-supported clinical trials and observational studies.

CLINICAL RESEARCH REPOSITORY BENEFITS

- Promote the publication of new research with effective use of existing data
- Enable replication of findings through re-analysis of pooled data files
- Enable meta-analysis using individual patient data
- Reinforce the principle of open scientific inquiry
- Encourage the development of different theoretical perspectives, especially in an interdisciplinary setting
- Provide additional value at little cost, optimizing the use of financial and human resources
- Minimize the need to recruit individuals for research studies, as fewer studies can potentially answer more questions
- Reduce the possibility that a granting organization double-funds the same project

The **NATIONAL TRAUMA INSTITUTE** leads a coalition of national trauma surgery organizations that advocates in Congress for sustained, annual funding for a Trauma Research Repository. Once established, the National Trauma Research Repository will provide the means for storage, compilation and analysis of trauma data, providing a great deal more data than investigators are able to collect on their own and a much faster route to the large datasets required to draw conclusions to improve trauma care.

The analyses and recommendations resulting from the shared information in this repository are expected to lead to significant changes in practice to save lives and improve patient outcomes after injury in both military and civilian populations. Visit NationalTraumaInstitute.org for more information.

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