

Poster 041

Insuring the Integrity of Clinical Registries: An Example of Cleaning a Large Multicenter Neurologically Ill Patient Database

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Introduction

With the push toward using large data sets in critically ill patients, the use and management of registries is becoming more relevant. Clinical registries provide insight about associations and patterns in diagnosis, disease, and treatment. The integrity of the data is of utmost importance. This poster describes the quality control and data management methods for maintaining the integrity of a multicenter trial Registry.

Methods

We employed modifications to Van Den Broeck's method of data organization to clean and manage the END-PANIC registry. The data management consisted of five phases: 1) Screening phase, 2) Data Organization, 3) Diagnostic phase, 4) Treatment phase, and 5) Missing data phase. The screening phase consisted of distinguishing missing and extraneous data elements, outliers, inconsistent patterns/distributions and unexpected analysis results. The data organization phase consisted of treating blank cells and highlighting errors with data input. The diagnostic phase was used to clarify the true nature of the data points, and make sure the data presented was biologically possible. The treatment phase consisted of correcting variables. The missing data phase consisted of determining whether the missing data was informative or noninformative.

Results

Currently the multi-center registry houses ~3.5 million discrete data points from 3,272 patients. There was a high correlation between the Texas, Ohio and California locations, and NPi, DVL, CVL, MCVL, and Pupil Size. There was a low correlation between the Texas, Ohio and California locations, and Pupil Latency and presence/absence of cataracts. Missing data was informative for age, race and ethnicity, and distribution of missing data caused an inquiry into methods for collecting data and implementation plans for change.

Conclusions

This interdisciplinary method for cleaning and managing the END PANIC registry was able to identify and rectify errors. We would recommend others to use the methods to build, clean and manage clinical registries.