Querying four decades of clinical research data at the National Institutes of Health

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The National Institutes of Health's Biomedical Translational Research Information System (BTRIS) is a repository of intramural clinical research data collected from 1976 to present, in two NIH electronic health records and a variety of clinical trials data management systems. The BTRIS repository is a Microsoft SQL-server database that partitions data into “events” and “observations” and then further partitions data into “measureable” (laboratory and vital signs-related), “substance” (medication-related) and “general (other, including text reports). Each data domain (demographics, laboratory, medications, problem lists, etc.) are assigned to one particular set of event and observation tables. All data are in identified form, but most fields within an observation or event are free of personally identifiable information. The user interface was modeled on the i2b2 Workbench design using NET, HTML5, JavaScript/jQuery, XML and JSON. From March 1, 2013 to present, the system has been used 1400 times to produce summary results, with downloading of detailed 97 data sets ranging in size from a few hundred rows of data to over one million rows. The presentation will provide a demonstration of system features, summarize the kinds of queries that users have been posing over the first eighteen months of usage, describe efforts to remove identifiers from clinical text, and describe the method by which non-NIH researchers can get access to BTRIS data for research purposes.

Biography

James Cimino is a board certified internist who completed a National Library of Medicine informatics fellowship at the Massachusetts General Hospital and Harvard University and then went on to an academic position at Columbia University College of Physicians and Surgeons and the Presbyterian Hospital in New York. He spent 20 years at Columbia, carrying out clinical informatics research, building clinical information systems, teaching medical informatics and medicine, and caring for patients, rising to the rank of full professor in both Biomedical Informatics and Medicine. His principle research areas includes desiderata for controlled terminologies, mobile and Web-based clinical information systems for clinicians and patients, and a context-aware form of clinical decision support called “infobuttons”. In 2008, he moved to the National Institutes of Health, where he is the Chief of the Laboratory for Informatics Development and a Tenured Investigator at the NIH Clinical Center and the National Library of Medicine. His principle project involves the development of the Biomedical Translational Research Information System (BTRIS), an NIH-wide clinical research data resource. In addition, he conducts clinical research informatics research, directs the NLM's postdoctoral training program in clinical informatics, participates in the Clinical Center's Internal Medicine Consult Service, and teaches at Columbia University as an Adjunct Professor of Biomedical Informatics.

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