



CASE STUDY

HEALTH INFORMATICS



RESEARCH ACCELERATES AT NIH WITH ONE-STOP-SHOPPING FOR DATA

Client: National Institutes of Health, Clinical Center

Advances in information system technologies are dramatically increasing the usability and usefulness of large stores of data. In medical research, these advances have spawned a long-term vision of greatly accelerating the journey from bench research findings to patient treatments. Though the timeline for realizing this vision is not clear, CSC has been helping the Clinical Center at the National Institutes of Health (NIH) in Bethesda, Md., take some important early steps with a new data repository called BTRIS – the Biomedical Translational Research Information System.

Two major benefits of BTRIS are winning praise from NIH researchers and motivating the agency to invest in the larger vision:

- BTRIS tools and universal data coding streamline researchers' retrieval of relevant data for study and analysis
- BTRIS automates many routine administrative reporting activities, so that researchers have more time for research.

HOW BTRIS ACCELERATES RESEARCH

Available to all NIH Institutes and Centers, BTRIS is a single repository that makes clinical research data from various sources available to the entire intramural community (subject to well-established policies for data access and use). NIH Principal Investigators and members of their protocol teams can access identifiable data for patients on their own active protocols, and any NIH researcher can access de-identified data for all protocols, active or terminated.

BTRIS contains clinical research data from two Institutes in addition to the Clinical Center, and this is where the system's power becomes evident. Data formats or terminologies often vary from one data source to another. Without some kind of standardization, researchers must query each data source separately and manually make the data consistent before working with it. BTRIS standardizes data by translating each item into a code specified in the Research Entities Dictionary (RED), which captures underlying meanings or concepts. With the RED codes, researchers can extract a comprehensive set of like data from disparate sources, and BTRIS tools support construction of comprehensive queries based on user-defined search criteria. It is now a simple task to assemble and download the exact data set needed for a particular purpose.

MANY ENTHUSIASTIC USERS

Launched in summer 2009, BTRIS gathered fans quickly. With its intuitive interface, new users with only a short orientation could navigate data and create reports that none of NIH's legacy information systems could produce. In addition, BTRIS automates routine activities that used to require significant researcher time. For example, an IRB Inclusion Enrollment Report, which presents demographic information on certain subjects in human protocols, involved hours of manual data collection and manipulation. Now it's created automatically in seconds.

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BTRIS also has increased the sheer amount of electronic data available to researchers. Though all data now in BTRIS were stored in some electronic form before being loaded, some of the old storage media were not accessible in any practical way. To get at that information, researchers had to go back to original paper or microfiche records. Once the information was in BTRIS, one research team found it could quickly organize lab and medication data going back to 1976 and publish longitudinal studies it had wanted to do for years.

BTRIS not only saves researchers' time, but it also gives them confidence that data is accurate. Manual processes, which are unavoidable in combining data from multiple sources, tend to introduce errors during transcription or data manipulation. Data from a BTRIS query is exported directly to a single Excel file, and BTRIS's tools support complicated searches and analyses that were difficult even to imagine in the past.

OUR HISTORY WITH BTRIS

CSC began working on BTRIS near the end of 2007, collaborating with NIH on a demonstration system, which was received enthusiastically. We spent the next year on the initial release of BTRIS, developing the requirements, use case models, solution architecture, ETL data load programs, and Web-based access to the system. In addition, we were responsible for testing BTRIS, which went live as scheduled on July 30, 2009. Since launch, we have managed operations and helped with system deployment and user training.

Our project team of twenty brings skills in project management, architecture, healthcare data warehousing, Web services development, medical terminology, data analysis, testing, database administration, systems administration, change control and other key areas.

LOOKING TO THE FUTURE

As of mid-2010, the time of this writing, CSC is in the midst of a development phase that involves loading clinical data from a third institute, adding access to radiographic images, improving usability, and expanding functionality to address new requirements. Integration of data from all remaining Institutes and Centers is expected to be completed by 2013, after which another expansion is anticipated, enabling BTRIS to collect information from NIH research partners such as academic medical centers collaborating on protocol studies.

This incremental implementation allows major design issues to be identified early, when it's easier and less costly to resolve them. The approach also gives NIH a return on its investment long before all BTRIS data and functionality are available. The solution architecture is flexible enough to accommodate all source data types that may be required, even those that don't yet exist, and it is designed to be easily adapted for interoperability with other biomedical data repositories.

All these factors mean that BTRIS is well-positioned to become a core NIH research system over the next several years. That would give it an intramural user population of about 5,000 researchers, who potentially could use data from thousands of protocols. Of course, the ultimate beneficiaries will be the people who use the new medications and treatment protocols developed through the research that BTRIS supports.

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