

## Chapter 16

# Characterizing Data Discovery and End–User Computing Needs in Clinical Translational Science

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### ABSTRACT

*In this paper, the authors present the results of a qualitative case-study seeking to characterize data discovery needs and barriers of principal investigators and research support staff in clinical translational science. Several implications for designing and implementing translational research systems have emerged through the authors' analysis. The results also illustrate the benefits of forming early partnerships with scientists to better understand their workflow processes and end-user computing practices in accessing data for research. The authors use this user-centered, iterative development approach to guide the implementation and extension of i2b2, a system they have adapted to support cross-institutional aggregate anonymized clinical data querying. With ongoing evaluation, the goal is to maximize the utility and extension of this system and develop an interface that appropriately fits the swiftly evolving needs of clinical translational scientists.*

### INTRODUCTION

Rapid advances in information technology are opening up new avenues for conducting research in biomedicine. The application of new technologies has enabled greater ability to generate, capture and analyze biological data for basic research, but

there remain significant challenges in integrating and translating these data with clinical data into forms that can be used to improve clinical outcomes. Clinical translational science is an emerging interdisciplinary field that seeks to facilitate the translation of biomedical research advances from the laboratory to improve clinical and public health outcomes and vice-versa (Zerhouni, 2007).

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Institutions that are part of the 46 member Clinical Translational Science Award (CTSA) consortium, sponsored by the National Institutes of Health (NIH) are beginning to develop, implement and support research on improving human health, both in local environments as well as collaboratively across sites. Individual CTSA sites are composed of researchers with expertise across the clinical research workflow, including biostatistics, informatics, bioethics, as well as community outreach and clinical translational research scientists. Within this novel consortia, there are challenges to consider in developing and incorporating information tools and methods that can catalyze and advance research both into as well as across the rapidly evolving and increasingly heterogeneous clinical research environments.

To better characterize the data discovery needs and end-user computing practices of clinical translational scientists and to steer the development of a novel cross-institutional clinical data discovery project, we conducted a pilot study involving semi-structured interviews with twelve principal investigators and research support staff working on a range of clinical research projects within the University of Washington's Medical Center, and affiliated with the UW CTSA site, the Institute of Translational Health Sciences (ITHS). We adopted the widely-used techniques of user and task analysis (Hackos & Redish, 1999) and focused on understanding workflows in translational research, data gathering methods, and previous experience in developing or customizing data discovery tools.

Our findings shed light on the diversity of user needs and expertise within clinical translational science and the potential barriers scientists face in accessing clinical data and using existing querying systems. The diversity exists not only in terms of the technical prowess of the scientists, but also in the range of their research questions, which still typically rely on and require customized data discovery and analysis features for domain specific work. The implications of these results are

useful for supporting and enhancing our on-going project implementation as well as to other clinical data-discovery systems that seek to integrate and catalyze collaboration across complex and heterogeneous data domains.

At a higher level, we have found it critical to understand the context of use and the querying practices of clinical translational scientists early in the development process of our system, as the resulting computational tools become necessarily integrated components of the research enterprise, though in novel ways that test existing expectations of the end-user researchers. Developing query access to clinical data systems for research is particularly unique and challenging, as in addition to managing patient data privacy and data security, establishing methods to extract, analyze and compare highly heterogeneous clinical data challenges normative assumptions of how researchers understand and interact with operational clinical health environments. This challenge is enhanced when multiple institutions seek to build collaborative services of this form, and is demanding new roles and expertise to support characterization, deployment and support of these new systems. We plan to continue our partnership with end-user translational scientists by employing an iterative development process to refine use-cases and to better understand user perceptions, end-user computing needs and usability issues to maximize the overall utility of clinical research systems.

## **BACKGROUND AND MOTIVATION**

We have implemented and are extending Informatics for Integrating Biology and the Bedside (*i2b2*), an interoperable open source software architecture that for our project facilitates the discovery of anonymized aggregate clinical data of patients who may meet eligibility criteria for clinical trial recruitment (e.g., counts). This Cross-Institutional Clinical Research Project (CICTR) effort is a generalization of the Harvard implementation

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