Chapter 80
Patient-Centered Clinical Trials Decision Support Using Linked Open Data

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ABSTRACT

Patients often want to participate in relevant clinical trials for new or more effective alternative treatments. The clinical search system made available by the NIH is a step forward to support the patient's decision making, but, it is difficult to use and requires the patient to sift through lengthy text descriptions for relevant information. In addition, patients deciding whether to pursue a given trial often want more information, such as drug information. The authors' overall aim is to develop an intelligent patient-centered clinical trial decision support system. Their approach is to integrate Open Data sources related to clinical trials using the Semantic Web's Linked Data framework. The linked data representation, in terms of RDF triples, allows the development of a clinical trial knowledge base that includes entities from different open data sources and relationships among entities. The authors consider Open Data sources such as clinical trials provided by NIH as well as the drug side effects dataset SIDER. The authors use UMLS (Unified Medical Language System) to provide consistent semantics and ontological knowledge for clinical trial related entities and terms. The authors' semantic approach is a step toward a cognitive system that provides not only patient-centered integrated data search but also allows automated reasoning in search, analysis and decision making using the semantic relationships embedded in the Linked data. The authors present their integrated clinical trial knowledge base development and a prototype, patient-centered Clinical Trial Decision Support System that include capabilities of semantic search and query with reasoning ability, and semantic-link browsing where an exploration of one concept leads to other concepts easily via links which can provide visual search for the end users.

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1. INTRODUCTION

Clinical trials are important, not just to researchers testing new treatments, but also to patients with serious diseases. In today's world in which patients take greater charge of their own health, it is common for patients to search the Internet for relevant clinical trials. In fact, the NIH makes all of its trials available on ClinicalTrials.gov for exactly this purpose. However, the task of sifting through lots of clinical trial descriptions to find the most appropriate one can be onerous (Atkinson, Saperstein, Massett, Leonard, Grama, & Manrow, 2008). There is a great need for developing a health knowledge repository that links different data from different sources scattered on the Web, with semantic relationships between data (Chun & MacKellar, 2012). The semantic representation with explicit relationships can provide a system with intelligence, such as automated reasoning and search in supporting patient's decision on the clinical trials. The proposed system thus requires an interdisciplinary approach of Cognitive Informatics (Wang et al., 2010) that covers the areas of information modeling, of cognitive processes of human brain, and medical decision making.

Our overall aim is to build this kind of cognitive information processing system that allows patients to search open clinical trial information that returns only the trials that best fit a patient's characteristics and information needs. In this paper, we focus on developing the clinical trial knowledge repository, which uses a Linked Open Data model to pull together data, both from the clinical trials and from other related datasets; in particular, side effect information. In this paper, we will give an overview of the architecture of this system, and then show how the ontology-based knowledge representation allows patients to view side effect information for treatments mentioned in particular clinical trials.

Patients and their caregivers search for clinical trials differently than physicians do. Patients typically do not have their own electronic health record (EHR), but often have a good recollection of their past treatments. If they moved between institutions during treatment, their knowledge may even be better than that in any one institution's records. The typical questions that patients may ask regarding the clinical trials include:

1. What are the possible interventions that I might receive during the trial?
2. What are the possible or known risks or side effects of this trial?
3. Will the drugs I am taking have any negative interactions with one given in the trial?
4. What tests and procedures are involved?
5. Am I eligible to participate in this trial?

Patients' concern with side effects of treatments in a trial is shown in a very common query on patient-focused cancer discussion boards: "I am considering trial XYZ – can anyone let me know what the side effects are?" In order to answer some of these questions, the clinical trial data should be integrated with other data sources that represent drugs and their side effects or drug-drug interactions. Patients may also be intimidated by the need to read lengthy text-based descriptions of eligibility criteria and the need to type in search terms in text boxes (Atkinson, Saperstein, Massett, Leonard, Grama, & Manrow, 2008). Thus, a search tool aimed at patients should not only answer these patient-oriented questions, but rely on a more text-based interface without precise medical terms. By gaining insight into the cognitive process that a patient or caregiver goes through when searching for suitable clinical trials, we can better serve their needs. Rather than a patient having to repeat tedious steps on a variety of web resources, we can model this cognitive task in a comprehensive, connected, and guided system.