Standard Terminology on Demand: Facilitating Distributed and Real-time Use of SNOMED CT During the Clinical Research Process
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Abstract:
The NIH roadmap endorses the use of data standards in clinical research that are compatible with health care data standards. To facilitate standards use, members of the Rare Disease Clinical Research Network have developed tools to support study investigators and research staff to code clinical research data using SNOMED CT at the point of research. This tool is customized to help the user will find desired and appropriate SNOMED CT concepts quickly.

Poster Proposal:
One goal of the Rare Disease Clinical Research Network (RDCRN) is to encourage data sharing and use of standardized data. To this end, the network (via a Data and Technology Coordinating Center, DTCC) is committed to the use of data standards, including SNOMED CT, the Consolidated Health Informatics (CHI) initiative’s recommended standard for diagnoses, problem lists, procedures, and anatomy. The DTCC has designed tools that support the collection of high quality data and encourage adherence to data standards. This poster will give an overview of the process and automated tools for accessing, searching, and navigating SNOMED CT real-time, at distributed and remote clinical study locations. As study data is entered into a secure web-based data collection system via on-line Case Report Forms, researchers have real-time access to a remote (commercial) terminology host that maintains SNOMED CT updates. The custom interface allows them to search for specific terms or browse the terminology’s native structure. Additionally, to simplify the coding task, only context-relevant subsets of SNOMED CT are presented. In theory, the coding should be more accurate if it is generated by the individual identifying the concepts or making the observations. These browsers make the conceptualization of the SNOMED CT structure and term navigation intuitive for the user. Additionally, these browsers can be designed to subset only “reasonable” concepts from the terminology and are built for usability. The usability and intuitive design of this tool eliminates the need for researchers to study the SNOMED CT terminology structure, and could increase compliance and quality of coding. These tools should reduce the time and complexities of the coding tasks, thereby reducing the burden of standards use on the research team. Close to 100 investigators and research staff representing over 15 studies in the Rare Disease Network have been trained on this tool. After RDCRN studies begin collecting data in March 2006, we can report feedback and preliminary evaluation data on this tool.

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