Titel:

Pragmatic MDR: A Metadata Repository with Bottom-Up Standardization of Medical Metadata through Reuse

Abstract:

Background
The variety of medical documentation often leads to incompatible data elements that impede data integration between different institutions. A common approach to standardize and distribute metadata definitions are ISO/IEC 11179 norm compliant metadata repositories with top-down standardization. To the best of our knowledge, however, it is not yet common practice to reuse the content of publicly accessible metadata repositories for creation of case report forms or routine documentation. We suggest an alternative concept called pragmatic metadata repository, which enables a community-driven bottom-up approach for agreeing on metadata standards. A pragmatic metadata repository collects real-world documentation and considers frequent metadata definitions as high quality with potential for reuse.

Methods
We implement a pragmatic metadata repository proof of concept application and fill it with medical forms from the Portal of Medical Data Models. We apply this prototype in two use cases to demonstrate its capabilities for reusing metadata: integration into a study editor for suggestion of data elements and bulk metadata synchronization between two institutions. Moreover, we evaluate bottom-up standardization in a pragmatic metadata repository and two medical data managers that asses the quality of bottom-up standards for 24 important medical concepts.

Results
The resulting pragmatic prototype contains 466,569 unique metadata definitions. Integration into the study editor ODMEdit led to a reuse of 1,836 items and item groups. During the metadata synchronization, semantic coding of 4,608 data elements could be reused. Our evaluation revealed that for less complex medical concepts weak bottom-up standards might be established. However, more complex concepts show no convergence of data elements due to an enormous heterogeneity of metadata. Rating by two medical data managers with a self-designed questionnaire showed fair agreement for good item quality for the evaluated data elements (Kalpha = 0.50, 95% CI 0.43-0.56).

Conclusion
We demonstrated the feasibility of the pragmatic metadata repository concept for medical documentation. Applications of the prototype in two use cases suggests that it facilitates the reuse of data elements during the creation of case report forms and routine documentation. Our evaluation shows that bottom-up standardization based on a large collection of real-world metadata can yield useful results.