
Introduction

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Biographical notes: Timothy B. Patrick is Associate Professor and Director of the Health Care Informatics and Health Care Administration programs at the University of Wisconsin-Milwaukee, College of Health Sciences. His research focuses on metadata schema for representing questions and answers, measurements of the quality of translation of evidence into practice, readability of healthcare information for laypersons, and ontology mapping.

James E. Andrews is an Associate Professor and Director at the University of South Florida, School of Information. His research focus is within the interdisciplinary field of biomedical informatics, with interests in clinical research informatics, controlled terminologies and other standards, and information seeking behaviours in various health contexts. He works collaboratively with researchers from USF Health, within SLIS, and elsewhere.

Rachel L. Richesson is an Associate Professor and Informaticist at the University of South Florida College of Medicine. She directs strategy for the identification and implementation of data standards for a variety of multi-national multi-site observational and intervention research studies and clinical research networks.

Healthcare research and practice are driven by data collection based on asking and answering questions. Data collection for clinical studies is directed by research protocols informed by evidence, and patient assessments are a critical component of clinical care standards and practice guidelines. Whether intended to support clinical research or patient care, the data collection efforts manifest in the development of and the answering of relevant questions, and the assignment of permissible values to data elements. Given their critical role in healthcare research and practice, the curation of question and answer set repositories and Information Retrieval issues related to those repositories are fundamental aspects of biomedical and healthcare informatics. This special issue includes five papers that address state-of-the-art solutions and novel attempts to define the informatics aspects of meta-data, questions, and value sets.

These papers emerge from a variety of practice settings and knowledge domains, and take very different approaches to the representation and utilisation of data elements and structured assessment items and instruments. In all cases, the approaches are designed to represent a standard approach to the problem, and, if these ideas gain traction and are well-accepted, can be considered standards. New areas heretofore not standardised include public health and patient registries. Other papers represent more mature standards such as LOINC, but describe their application to new areas that indeed have competing standards. The papers in this collection include:

Questions on Public Health Forms: The Metadata Required to Describe Standard Data Elements Deployed in Dynamic Contexts by Kristi Eckerson and Tim Morris describes the metadata required to describe reusable questions that can be used to define data collection instruments for the domain of Public Health and Emergency Preparedness and Response.

LOINC®: A Universal Catalogue of Individual Clinical Observations and Uniform Representation of Enumerated Collections by Daniel J. Vreeman et al. reports on the model contained in LOINC for representing variables, answer lists, and the collections that contain them. The use of this LOINC model is intended to facilitate sharing of clinical observations among clinical care and research systems.

United States Health Information Knowledgebase (USHIK) by Chuck Penozza et al. describes the United States Health Information Knowledgebase (USHIK). USHIK is an ISO 11179-based publicly-accessible registry and repository of healthcare metadata maintained by the Agency for Healthcare Research and Quality (AHRQ).

Standardising Clinical Data Elements by Meredith Nahm et al. reports on the development and implementation of methodology for standardising clinical data elements. The method is demonstrated in the two domains of Tuberculosis (TB) and Acute Coronary Syndromes (ACS). The methodology utilises the ISO 11179 standard, Unified Modeling Language (UML) class and activity diagrams.

The Use of SNOMED CT to Support Retrieval and Re-use of Question and Answer Sets for Patient Registries by Rachel Richesson et al. describes the metadata and standards adopted by the PRISM (Patient Registry Item Specifications and Metadata for Rare Diseases) project. PRISM is a library of registry questions representing a variety of rare diseases.

The call for papers for this special interest journal was well received. The papers in this collection were selected by the editors for their significance and innovation. All of the papers here clearly define the domain and representation issues. All of the papers describe real standardisation problems in real settings, but all have a slightly different notion of data elements and the metadata required for their use. The current

papers are US-based and describe US systems, programs, and standards. This was not by design but by circumstance. We do hope that all readers find these topics of interest, and will consider implications for their work. The selection of papers here address questions and answers that are relevant to clinical care as well as research and public health and decision support. We encourage readers to find commonalities in data representation and metadata across approaches and hope that this collection will stimulate informaticians, policy makers, and system architects to define and adopt common or harmonious approaches to data representation for various purposes. We would like to thank all the authors for their timely contributions and joint efforts in enhancing the papers to accommodate reviewer and editors comments. We wish to express our sincere gratitude to the anonymous reviewers from multiple countries whose efforts had a positive impact on the quality of papers presented here. We also thank Liz Harris of the IJFPM for guidance and help.