

# Representation by Standard Terminologies of Health Status Concepts Contained in Two Health Status Assessment Instruments Used in Rheumatic Disease Management

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## ABSTRACT

*Health and functional status data have been shown to have clinical utility in predicting outcome. Various metadata registries in the form of patient self-administered health assessment questionnaires have been incorporated into routine clinical care and clinical research of patients with rheumatic disease. Examples of such health assessment instruments are the Clinical Health Assessment Questionnaire (CLINHAQ) and the Modified Health Assessment Questionnaire (MHAQ). These instruments contain concepts that are an integral part of the health and functional status domain. Using an automated indexing tool we examined the clinical content coverage by SNOMED RT and the Unified Medical Language System (UMLS) Metathesaurus for health and functional status concepts identified in the MHAQ and CLINHAQ. Significant differences existed between the overall representational ability of SNOMED and UMLS for concepts identified in the MHAQ (49%, vs. 77% respectively,  $p < .005$ ) and for concepts identified in the CLINHAQ (30% vs. 64% respectively  $p < .005$ ). Representational capability by SNOMED-RT and UMLS for concepts in a given health assessment instrument was carried across four semantic classes of "attitudes", "symptoms", "activities", and "social attributes". The conceptual content coverage of health status assessment concepts contained in the MHAQ and CLINHAQ by SNOMED-RT and UMLS was incomplete but better for UMLS with its panoply of vocabulary sources. This observed overall improved representation by UMLS appeared to be due to better representation of concepts in "activities" and "social attributes" semantic classes. Representation of health or functional status concepts in a computerized medical record should be founded on a universally agreed concept model of that domain. Established functional and health status metadata registries can serve as important sources for concepts and candidate classes within that domain.*

## INTRODUCTION

A fundamental requirement for the universal application of computerized clinical information systems is the ability to represent patient data in a form that is both computationally tractable and uniformly standardized across clinical domains. The importance of this requirement is embodied in the extensive collective and collaborative efforts of groups working toward development of controlled clinical vocabularies and terminologies. Formidable in itself, the challenge of developing a comprehensive controlled clinical vocabulary is augmented further when features of extensibility to accommodate evolving clinical care concept models, not previously incorporated in the initial iterations of standard terminology structures, are included as goals. These challenges can be met through adoption of a universally conforming and comprehensive approach to the representation of medical information and knowledge that will permit precise expression and exchange of medical observations vital to clinical decision, quality measurement and outcome assessments.

The individual and societal impact of chronic rheumatic diseases such as rheumatoid arthritis is expressed through the development of functional disability, pain, and/or ensuing constitutional or psychological stress on the patient. The incorporation of metadata registries in the form of standardized health assessment questionnaires into the routine monitoring of patients with rheumatoid arthritis (RA) has been promulgated as an important component in the tracking of patient outcomes and therapy effectiveness.<sup>1</sup> The American College of Rheumatology recommends the inclusion of corroborative data supplied from an established health assessment instrument in its criteria for assertion of clinical improvement in patients with rheumatoid arthritis<sup>2</sup>. Examples of such instruments

include the Stanford Health Assessment Questionnaire (HAQ)<sup>3</sup> and its two derivatives, the Modified Health Assessment Questionnaire (MHAQ)<sup>4</sup>, and the Clinical Health Assessment Questionnaire (CLINHAQ)<sup>5</sup>. The rationale and enthusiasm for the routine use of these instruments centers on evidence that they can predict adverse outcomes in ways that surpass traditional physiological measures<sup>6</sup>. If these instruments have an important role in the health care process then it would be incumbent on a universally accepted standard nomenclature to adequately represent the findings and concepts they contain. Specific knowledge of the representational capability of emerging controlled clinical vocabularies for the concepts embodied in patient self-report health status instruments is lacking. Comprehensiveness, robust expressiveness, and flexibility that is extensible across medical domains, are desired features that should form the guiding developmental principles of any universally adopted representation of medical information.<sup>7,8</sup> An important component of the development process of a representation scheme involves iterative information and concept representation challenges within multiple medical domains and contexts of medical care. Gaps or deficiencies as a result of such efforts can indicate areas requiring vocabulary expansion or new concept model proposals. Evidence pointing to the clinical utility and value of patient self-report health assessment questionnaires begs the question of their conceptual content coverage by emerging controlled clinical vocabularies. Despite the proliferation of numerous metadata registries functioning as health assessment instruments, there have been no attempts to our knowledge, to formally define an information model for the domain of functional health status or functional health status assessment.

SNOMED-RT is a widely recognized controlled clinical vocabulary<sup>9</sup>. In its current form it contains over 180,000 clinical concepts, which through post-coordination abstraction can robustly represent in an extensible manner a large number of clinical expressions. SNOMED will converge with the most recent National Health Service of the United Kingdom's CT version 3 terminology (previously known as the Read Clinical Codes). As a result of this convergence SNOMED-RT is anticipated to rapidly emerge as a front-running standard clinical terminology for future electronic medical records. An articulated principle of SNOMED-RT is that it be concept based, complete and comprehensive in its clinical domain coverage, and that it be responsive to the needs that emerge in the clinical arena.

This paper presents the results of an attempt to examine the representational capability of SNOMED-RT in representing the clinical concepts of health or functional status assessment embodied in the MHAQ (Modified Health Assessment Questionnaire) and the CLINHAQ, (Clinical Health Assessment Questionnaire). These two health status assessment data structures were designed to provide comprehensive coverage in areas specific to the care of arthritis patients. The MHAQ, and CLINHAQ were selected because of their increasing use in the care of patients with arthritis. Health assessment instruments appear to be an integral part of the scientific research and routine clinical aspects of care of patients with chronic rheumatic disease. An assessment of the representational capacity of SNOMED RT and UMLS for concepts and terms contained in widely used health assessment instruments is logically of interest. Such assessments can potentially stimulate the iterative development of conceptual data models for the health status information domain thus forming a basis for computerized capture of its information content.

## METHODS

Entire texts of the MHAQ and CLINHAQ were obtained from versions published in the literature. Each item within each health assessment instrument was parsed into kernel concept terms by a board certified rheumatologist and internist with 12 years of clinical experience. The individual terms representing kernel concepts were assigned a semantic class from among the following types:

- Attitudes –Patient attitudes and self processed opinions about overall status or state of health.
- Symptoms –Symptoms, both somatic and psychiatric.
- Activities –Specific activities intended to reflect particular daily living functions and devices depended on for such.
- Personal, social and demographic attributes - Work, disability status, living environment, and educational level.

Each term was entered into the Mayo Vocabulary Processor (MVP), an automated JAVA based indexing tool, to determine if a corresponding matching term existed in the February 1999 Beta SNOMED RT and UMLS using Metaphrase™. The version of SNOMED RT used in this analysis, the

most recent available version at the time of this writing, was released for evaluation of revisions to the Diagnosis axes only but retained all historical content pertaining to other axes. When original parsed terms from the health assessment instrument under consideration yielded no match from the MVP a synonym or synonymous expression was chosen that was equivalent. The matching corresponding SNOMED RT term and code for each health status instrument assessment kernel concept term was noted and recorded in a spreadsheet. The reviewer then determined if the SNOMED RT term provided complete conceptual content capture for each corresponding health assessment instrument kernel concept recorded. Any match that in the judgment of the reviewer failed to provide a complete capture of the conceptual content of the health assessment instrument kernel concept term was designated a failure. Each failing match was subjected to a failure analysis. Failures were classified as failure either due to complete semantic mismatch, failure due to mismatching qualifier, or failure due to mismatching modifier. Summary statistics were compiled. The total number of unique kernel concepts was determined for each semantic class. The total number of complete matches and the percent completely matched terms were calculated. For failed matches the percents of failures representing complete semantic failure, modifier failures, and qualifier failures, were determined. Match percentages were also determined for common semantic classes contained in each health status assessment instrument.

### Results

Table 1 shows the overall match percents for kernel concepts contained in the MHAQ and CLINHAQ by terms provided by SNOMED RT and UMLS Metathesaurus. As reflected by term concept match percents, both SNOMED-RT and the UMLS Metathesaurus provided incomplete coverage of the health status concepts recognized by the expert to be contained in the MHAQ and CLINHAQ. Representation of these concepts appeared to suffer more under SNOMED RT. SNOMED RT in this tested version was able to match only 49% of health status concepts in MHAQ and only 30% of health status concepts in the CLINHAQ. UMLS was able to provide concept term matching that was better than SNOMED RT with matching terms provided in 77% of MHAQ concepts and 64% of CLINHAQ.

		SNOMED - RT	UMLS
	Total Concepts N (%)	Total Matches N(%)	Total Matches N(%)
MHAQ	88 (100)	43 (49)	68 (77)
CLINHAQ	132 (100)	40 (30)	85 (64)

The results of the failure analysis performed on the concept term match failures are shown in Tables 2a and 2b. Match failures occurred due to complete semantic failure for 40% and 55% of the match failures in the MHAQ under SNOMED and UMLS respectively, and for 67% and 62 % of the match failures in CLINHAQ under SNOMED and UMLS respectively. Mismatching qualifier failures represented the second most common cause for concept match failure in both the MHAQ and CLINHAQ by SNOMED and UMLS.

UMLS				
Concept Source	Total Failed Matches N (%)	Complete Semantic Failure N (%)	Mismatch Qualifier Failure N (%)	Mismatch Modifier Failure N (%)
MHAQ	19 (100)	11(55)	5 (25)	4 (20)
CLNHQ	47 (100)	29 (62)	10 (21)	8 (17)

SNOMED-RT				
Concept Source	Total Failed Matches N (%)	Complete Semantic Failure N (%)	Mismatch Qualifier Failure N (%)	Mismatch Modifier Failure N (%)
MHAQ	45 (100)	18 (40)	14 (31)	13 (29)
CLNHQ	92 (100)	62 (67)	27 (29)	3 (4)

Matching statistics for the four semantic classes of health assessment concepts identified by the expert's analysis of the concept domain of the MHAQ and CLINHAQ are reported in Tables 3a, 3b. Differences between percent matching across the health status concept semantic classes under each terminology source were not statistically significant by pairwise t

test comparison. Within a given health assessment instrument there were no statistically appreciable differences in representational capacity by SNOMED or UMLS across the four semantic classes of health status concepts.

Concept Source	SNOMED-RT			
	Differences not significant ( $p > .10$ ) by pairwise t test comparisons among semantic classes			
	Attitudes	Symptoms	Activities	Social
MHAQ	63 (5/8)	58 (7/12)	44(27/61)	57(4/7)
CLINHAQ	40 (4/10)	38(12/32)	27(21/77)	23 (3/13)

Concept Source	UMLS			
	Differences not significant ( $p > .10$ ) by pairwise t test comparisons among semantic classes			
	Attitudes	Symptoms	Activities	Social
MHAQ	63 (5/8)	75 (9/12)	80(49/61)	86(6/7)
CLINHAQ	70 (7/10)	65 (21/32)	57(44/77)	85(11/13)

Concept Source	p value			
	Attitudes	Symptoms	Activities	Social
	MHAQ	p=1.00	p= .25	p<.001
CLINHAQ	P = .17	P = .07	p<.005	p<.05

Table 4a shows differences between the representational capacities of SNOMED RT™ and UMLS for each health status semantic class in the CLINHAQ and MHAQ. For the MHAQ, increased apparent representational capacity of its concepts by UMLS vs. SNOMED RT™ was seen most significantly “Activities” concepts. For the CLINHAQ improved representation by UMLS seemed to be most significant for concepts in “Social” and “Activities” classes.

### Discussion

We attempted to evaluate the representational capability of the (2/99) Beta release of SNOMED-RT and the UMLS for concepts contained in health assessment metadata registries currently in widespread use for assessment and monitoring of

patients with rheumatic diseases, particularly rheumatoid arthritis. The Beta release of SNOMED used was the most recent available version at the time of this writing.

The concepts identified within these metadata registries were divided into semantic classes that we feel should be included as class types for a conceptual data model of the health status assessment domain. Our approach intends to be in the spirit of the “model centric” approach to standards development promulgated by HL7’s Message Development Framework that outlines the steps in the analysis of requirements for standards.<sup>10</sup> This first pass analysis of the conceptual content coverage of health status assessment events by SNOMED-RT highlights conceptual domains that can potentially be better served with representation standards. Conceptual content coverage by SNOMED-RT and UMLS was below their conceptual content coverage seen for concepts contained in raw clinical texts sampled from random medical records<sup>11</sup>. No particular semantic health status concept class within a given health status assessment instrument accounted for a disproportionate share of the coverage inadequacy of SNOMED RT™ or UMLS. Improvement in representation of a health status assessment instrument’s concepts seemed to be most significantly propagated by representation of “Activities” class concepts in the MHAQ, and “Activities” and “Social Attributes” concepts for the CLINHAQ.

The Beta version of SNOMED-RT studied in this analysis represented enhancements to the Diagnostic axis terms. This evaluation version was presumed to carry its cumulative historical content in other axes. All matching terms for abstracted health status concepts came from the “F” and “S” axes.

Currently popular metadata registries for health or functional status assessment, while providing proven utility in the world of the paper medical record, contain limitations that render them potentially vestigial in the approaching world of automated medical records. Fixed data registries represent fixed instantiations of a yet to be formally expressed metadata concept model, and thus lack the flexibility and robustness to capture data that are important but which happen to not conform to its data definition. Encounters with these limitations have been experienced by designers and authors of these instruments and have prompted instrument registry revision efforts that still do not escape the

vulnerabilities resulting from the panoply of data rich expressions that can exist in the medical record<sup>12</sup>.

We believe a more enduring and rewarding approach to the domain of health status assessment is a model-centric approach. We propose the development of a conceptual data model as a starting point for the iterative development of a common universally acknowledged health status assessment information model that can be responsive to conforming efforts directed towards health status data acquisition across multiple clinical domains and chronic disease conditions. Health status assessment instruments or other such data gathering methods that conform to a uniform information concept model would enjoy the benefits of the ability to abstract appropriately tagged or so defined patient data elements in an automated record founded on a shared information model. Instruments, data sets, and registries conforming to a uniform conceptual model could be constructed on the fly and allow side-by-side comparison of patient health status data on the same patient at the same point in time.

Health and functional status concepts should be included in any representation effort directed at the general health care domain. These concepts are integral components of efforts to reach conclusions on patient outcomes, disease impact, and effectiveness of therapeutic resource allocation. Representational deficits by current medical terminologies for the health status domain should prompt a model centric approach to representing the information needs of that domain that will help to surpass constraints of any single metadata registry. Such an approach will ensure that health and functional status assessment efforts realize the benefits of an automated electronic medical record

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