Journal of Biomedical Informatics
doi:10.1006/jbin.2002.1035

Representing Patient Preference-Related Concepts for Inclusion in Electronic Health Records

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Received January 16, 2002

In recent years shared decision making between patients and their health care providers and the inclusion of patient preferences in patient care have been, in theory, embraced as models for good clinical practice. Patients' experiences, values, and preferences are increasingly acknowledged as important pieces of evidence for appropriate health care decision making. To effectively use information about patient preferences in patient care, this information, which is gathered through a process of preference elicitation, needs to be integrated with other types of information, e.g., diagnoses, treatments, and patient status indicators within the context of a longitudinal electronic health record. This integration requires that patient preference-related concepts be represented nonambiguously and in a manner that renders them suitable for computer rather than human processing. In this article, the authors describe important patient preference-related concepts and illustrate the use of the LOINC semantic structure as a terminology model to create fully specified names for a sample of 15 preference elicitations from 8 published research articles.

Key Words: patient preferences; terminology models; concept representation; LOINC.

INTRODUCTION

In recent years shared decision making between patients and their health care providers and the inclusion of patient preferences in patient care have been, in theory, embraced as models for good clinical practice. Patients' experiences, values, and preferences are increasingly acknowledged as important pieces of evidence for appropriate health care decision making. To effectively use information about patient preferences in patient care, this information, which is gathered through a process of preference assessment, needs to be shared and integrated with other types of information, e.g., diagnoses, treatments, and patient status indicators within the context of a longitudinal electronic health record (EHR). This integration requires that patient preference-related concepts be represented non-ambiguously and in a manner that renders them suitable for computer rather than human processing. Commonly known as concept-oriented or reference terminologies (e.g., SNOMED reference terminology, and logical observation identifiers, names, and codes [LOINC]), such representations are built upon an explicit semantic structure (i.e., terminology model) that facilitates nonambiguous definition of terms, i.e., creation of fully specified names, and semantic interoperability among heterogeneous computer-based systems. A number of authors have reported the development and testing of terminology models for representation of diseases, surgical procedures, nursing diagnoses, nursing interventions, laboratory measurements, and standardized measures [1–7].

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1532-0464/01 $35.00

In this article, the authors describe important patient preference-related concepts and illustrate the use of the LOINC semantic structure as a terminology model to create fully specified names for a sample of 15 preference elicitations from 8 published research articles.

BACKGROUND

Patient Preference Concepts

The clinical, health services, and methodological literature has reported a rapid development of models, methods, and tools designed to help patients make health care decisions consistent with their preferences. The primary purpose of these decision aids (DAs) is to help patients consider relevant clinical information and clarify their personal values and preferences when facing difficult treatment or screening choices, particularly those that require trade-offs between risks and benefits of alternative options with uncertain outcomes. The feasibility of DAs in computer-based, multimedia [8, 9], or other formats, such as booklets [10, 11], audiotapes [10, 12–14], and videotapes [15] has been demonstrated. Evidence supports their usefulness in improving patients' ability to make informed decisions consistent with their preferences and patient outcomes. Evaluations of DAs have reported higher scores on cognitive functioning and social support [16], more active and satisfying participation in decision making [17], better scores on general health perceptions and physical functioning [18], improved knowledge [19], greater preference achievement [20, 21] and reduced decisional conflict [22].

Despite evidence of their usefulness, DAs have so far been "stand-alone" systems that are occasionally offered to patients, but are rarely used by clinicians as part of their practice [23]. Eliciting patient preferences is not only important to patients; this information could also assist clinicians in clinical decision making as a means to improve patient care and outcomes from the perspective of patients. Recently, newer types of decision support systems have been developed that are designed to assist clinicians in eliciting and including patient preferences in patient care as part of clinical practice [20, 21]. Integrating patient preferences in the longitudinal EHR provides important information not only for clinical decision making but for other purposes as well. For example, it could allow researchers to explore the variations in values patients place on clinical outcomes and aspects of their health as well as factors that influence patient preferences, such as demographic characteristics or health conditions. Access to patient preference information could also facilitate evaluations of patient outcomes from the perspective of patients or the degree to which care processes are consistent with patient preferences. Further, aggregated preference data obtained from patient subgroups has the potential to inform politicians and health policy makers about the preferences of different patient populations. While a number of factors (e.g., messaging standards, appropriate user interfaces) are necessary to combine patient preferences data with other clinical information in the EHR on a consistent basis and reuse these data for multiple purposes, efforts in this direction have also been hampered by the lack of a standardized representation of preference-related concepts and terminology models to represent those concepts in the EHR.

Patient preference concepts and the interpretation of preference data are closely linked to the methods used for preference elicitation and the underlying decision problem. A variety of methods exist. Examples of common techniques are the Standard Gamble (SG) [24], the Time Trade-Off, (TTO) [25], the Probability Trade-Off Technique (TTO) [26], and ranking methods or rating scales such as Visual Analogue Scales (VAS) [27]. Different methods produce differences in preference evaluations and are not interchangeable. For example, the SG and TTO are based on utility theory and result in utility functions that also capture patients' risk attitudes, whereas rating scales use a psychometric approach and elicit value functions. Both utility- and non-utility-based methods can produce seemingly similar numerical values (e.g., on a 0–1 scale) to express a patient's strength of preference for a particular decision, yet similar numbers may represent conceptually very different aspects. To illustrate this point, Table 1 shows examples of studies that applied various preference elicitation techniques. Most of these studies used scenarios to describe the health states or treatment or screening options for which patient preferences were elicited. As illustrated in the column to the far right, procedures used in these elicitations were very different, dependent on the underlying method, and the obtained values expressing the strength of preference are not comparable. For example, a utility value of 0.5 resulting from a TTO may express the proportion (in this case up to half) of the remaining life living with the described disease or health state a person is willing to give up for perfect health. A utility value of 0.5 in a SG may represent the maximum probability of death a person is willing to accept in a gamble to obtain perfect health rather than living with the described health state (where the scenario in the gamble is often composed of aspects of the person's own health). A value of 0.5 on a VAS may represent the value a person places on his current

TABLE 1
Examples of Differences in Preference Elicitations

Decision	Elicitation method	Preference Values	Scenario	Elicitation procedure
Preferences for treatment: Pregnancy termination [33]	Willingness to pay (WTP)	>0	Two treatment choices for pregnancy termination:	Subjects are asked to imagine that all pregnancy terminations are currently carried out by the tablet method, and then to name the maximum amount of money they are willing to pay to receive the operation method rather than the tablet method.
			1. Tablet method 2. Operation method	Obtained values represent the amount of money subjects are willing to pay for the operation method.
Preferences for health states: Laryngeal cancer [34]	Time trade-off (TTO)	0–1	3 symptom states for laryngeal cancer with 3 levels of severity	Subjects are asked to make a choice between living for 20 years in perfect health followed by death, or living 20 years with the low, moderate or high symptom severity scenario. The time period in perfect health is incrementally reduced until subject is unable to choose.
			• Low • Moderate • High	The obtained utility value represents the proportion of the remaining life living with the described health state a person is be willing to give up for perfect health.
Preferences for health states: Laryngeal cancer [34]	Ranking	1–5	As above	Subjects are asked to rank the 3 scenarios in descending order of preference. Obtained values represent the ordinal order of preference for the described health states in relation to each other.
Preferences for health states. Laryngeal cancer [34]	Visual analogue scale (VAS)	0–100	As above	Subjects are asked to indicate the desirability of each scenario by marking a point on the VAS in relation to "perfect health" (100) and "death" (0) as low and high anchors. Obtained values represent the value the subject places on health state scenarios in relation to scale anchors.
Preferences for adjuvant chemotherapy. Breast cancer [35]	Likert scale	0–6	Two treatment options, described with benefits and risks of each:	Subject are asked to rate the strength of preference for each of the two options on a Likert-type scale.
			• adjuvant chemotherapy • no adjuvant chemotherapy	Obtained values express an ordinal—level strength of preference for each option in relation to each other.
Preferences for screening method. Colon cancer [36]	Analytic hierarchy process (AHP)	1–5	5 screening options with descriptions of benefits and risks, and five decision criteria	Subjects are asked to make pairwise comparisons between 5 screening options relative to a set of decision criteria. Obtained values represent the ordinal rank order of preference for each option in relation to each other based on these criteria.
Preferences for treatment. Benign prostatic hyperplasia (BPH) [37]	Standard gamble (SG)	0–1	Scenario composed of subject's current BPH state on six BPH symptoms	Subjects are asked to make a choice between continuing living in current BPH state and a gamble with 2 possible outcomes: perfect health or death. The likelihood of perfect health and death are incrementally altered until subject is unable to choose between BPH state and the gamble. The obtained utility value represents the maximum probability of death a person is willing to accept in a gamble to obtain perfect health rather than living with the described health state.
Preferences for choice of surgical treatment. Breast cancer [13]	Balance scale	−7 to +7	Presentation of 2 treatment choices with associated benefits and risks: • Mastectomy • Lumpectomy	Subject are asked indicate the personal importance of each of the benefits and risks associated with the two treatment options in an values clarification exercise; then to indicate on a scale that has the two options as opposite anchors how strongly they lean towards the preferred option.
Preferences for illness management. Functional performance [21]	Likert scale	0–4	14 dimensions of functional performance	Subjects are asked to rate the importance of each functional performance dimension. Obtained values represent the patient's priority for treatment and care of each dimension.

health state in relation to the low and high anchors on the scale. A patient's strength of preference expressed with these numerical values can, therefore, only be properly understood in the context of the decision problem and the elicitation method that give meaning to these values. The LOINC semantic structure offers an approach for non-ambiguously representing such preference elicitation concepts through the creation of fully-specified names.

LOINC

The initial observation names in the LOINC database were those for laboratory measurements and were designed to function in name–value pairs for Health Level Seven (HL7) messages related to laboratory results reporting [5, 6]. Observation names are based upon a formal semantic structure composed of six elements for composing fully specified names that distinguish measurements that are clinically different: (1) analyte/component; (2) kind of property measured or observed; (3) time aspect of the measurement or observation; (4) system/sample type; (5) type of scale of the measurement or observation; and (6) type of method used to obtain measurement. The content of the LOINC database continues to expand to other types of clinical observation names (e.g., vital signs, imaging studies) without change to the elements of the semantic structure; only definitions of the elements of the semantic structure have undergone minor extensions [6, 28]. Our decision to use the LOINC semantic structure rather than to derive a terminology model from patient preference concepts was based upon the semantic similarities between patient preference measurements and standardized assessments such as functional status measures, psychiatric diagnostic tools, and nursing-sensitive outcome assessments. Recent studies had demonstrated the utility of the LOINC semantic structure for representing the latter [2, 29], thus LOINC was judged to be a reasonable starting point for our analysis.

Representing Patient Preference-Related Concepts in LOINC

To illustrate representation of patient preference concepts using the LOINC semantic structure for the creation of fully specified names, a number of articles that described commonly used preference elicitation methods and decision problems were reviewed. Articles were selected from our bibliographic database of literature on shared decision making and decision aids that is regularly updated. We selected articles that (1) represented a variety of commonly described methods to elicit patient preferences such as the SG, TTO, or Willingness to Pay (WTP), or various types of ranking and or scales; (2) reported a research study with a main purpose of eliciting patient preferences for clinically important decisions such as treatment, screening, or illness management decisions, or for health states; (3) included a clear description of the elicitation procedures and the decision problem; and (4) contained the instruments that were used for the preference elicitations. We selected 8 articles with 15 preference elicitations.. While these articles do not represent all existing preference elicitation techniques and decision problems that exist, they are representative of the major techniques and sufficient to illustrate how important preference concepts can be adequately represented in LOINC. Additional decision problems and elicitation methods could be classified in a similar way as described for the selected studies.

Three distinct concept types are unique and essential for accurate representation of patient preferences: (1) the decision for which preferences are elicited, (2) the elicitation method used, and (3) the values expressing strength of preference. Also important is the description of the decision problem that provides the context for the decision. Consistent with other types of observations in the LOINC database, the first two concepts are suitable for formal definition using the LOINC semantic structure as is the scale by which the value is expressed, whereas the potential values and the scenarios for eliciting the preferences are appropriate for descriptive fields in the database.

Table 2 shows the semantic structure elements as defined for standardized assessments, while Table 3 displays the fully specified names of the 15 preference elicitations using the LOINC. Component includes the focus of the preference elicitation along several dimensions, e.g., screening vs treatment, disease or health condition of interest, and whether the preference relates to a current or future situation. The particular method of elicitation is defined in the Method element, e.g., WTP, SG, TTO, ranking, along with the fact that it is a patient-reported value rather than a clinician-observed value. For the formal definition of preference elicitation measurements, the other required elements of the LOINC semantic structure are straightforward, consistent with LOINC element definitions for other clinical observation names, and require no extensions. Values are listed in Table 3 for illustrative purposes only. Potential values associated with observation names are not part of the LOINC semantic structure, but are included in descriptive fields in the database as is the decision scenario that provides the context for the decision. Figure 1 shows a decision scenario

TABLE 2
Definitions for Elements of Clinical LOINC Semantic Structure for Standardized Assessment Measurements

1. Component—Attribute of a patient or an organ system within a patient; name of the scale item
2. Property—kind of quantity related to a substance
   2.1. Finding—atomic clinical observation, not a summary statement as an impression; can be professional or nonprofessional; can be of any scale type
   2.2. Impression—a diagnostic statement, always an interpretation or abstraction of some other observations and almost always generated by a professional
3. Timing—interval of time to which the measurement applies
   3.1. Point—single point in time
   3.2. Interval—more than a single point; specified in minutes, hours, days, weeks, months, etc.
4. System (sample)—individual or group who is the object of the measurement
   4.1. Patient/client
   4.2. Family
   4.3. Caregiver
   4.4. Child
   4.5. Community
   4.6. Parent–child dyad
   4.7. Patient–caregiver dyad
5. Scale—type of scaling used in the measurement of the item
   5.1. Quantitative—numeric value that relates to a continuous numeric scale (e.g., visual analog scale)
   5.2. Ordinal—reported either an integer, ratio, a real number of range; ordered categorical responses (e.g., semantic differentials, Likert-type scales; yes/no; positive/negative)
   5.3. Nominal—nominal or categorical responses that do not have a natural ordering; typically have a coded value (e.g., diagnosis)
   5.4. Narrative—free text narrative
6. Method—method of completing the measurement
   6.1. Observed (professional's rating)
   6.2. Reported (patient/client self-report)

along with related preference elicitation measurement and LOINC semantic structure for the measurements.

DISCUSSION

The LOINC semantic structure appears appropriate as a terminology model for the formal definition of preference-related concepts for clinically relevant decisions such as treatment, screening, illness management, and health states as represented by the 15 preference elicitations in the analysis. The primary limitation of the analysis was the types of preference-related concepts in the sample, which may not be representative of the full scope of preference elicitations of interest. Preferences are often elicited for a range of purposes other than clinical, e.g., cost-effectiveness analysis, consumer surveys.

Several issues associated with formal definition of preference elicitation concepts require clarification and development of a consistent approach for representation in EHRs. For example, although not described in the selected articles, in some cases patients' caregivers may provide clinicians with preferences on behalf of the patient, e.g., in situations where the patient is unconscious or incapacitated in other ways, but where the caregiver knows the patient's preferences well. In this instance, the Sample for the measurement remains the patient, but there is a need to disambiguate between a measurement elicited from the patient and a measurement elicited from someone else on behalf of the patient. A possible approach to represent this type of elicitation from a proxy is to extend the definition of the Method element to include reports by someone other than the patient, e.g., Reported by proxy, in addition to Reported and Observed.

Preferences may change over time, and there is evidence that changes in patient preferences are associated with changes in patients' health states [30, 31]. While all articles included in this analysis described patient preferences at a single point in time, changes in patient preferences and the manner in which they are associated with different phases in a patients' illness trajectory may be important information. If the timing of the measurement is explicitly identified in the preference elicitation, e.g., prechemotherapy and post-chemotherapy, such temporal notions may be appropriate for incorporation in the Timing element. In most instances, however, these measurements are more appropriately linked through the information model supporting the EHR.

A number of preference elicitation measurements may relate to a single decision scenario (see Fig. 1). The grouping of these measurements is useful for clinical decision making as well as research purposes. The creation of a LOINC battery such as that used for an Electrolyte panel is a possible solution to this need [5]. Alternatively, this need could be satisfied through a hierarchical relationship (e.g., PART-OF or IS-A) within a concept-oriented terminology or as a kind of template within a document architecture [6].

A semantic structure that supports nonambiguous definition through the creation of fully specified names and computer processing of preference-related concepts is a requirement for integration of such concepts into EHRs. Use of a standard semantic structure facilitates the incorporation of concepts into concept-oriented terminologies built upon the semantic structure [32]. This paper illustrates the adequacy

TABLE 3
Formal Definition of Preference-Related Concepts According to LOINC Semantic Structure

Component	Property	Timing	Sample	Scale	Method	Values
Preferences for treatment. Pregnancy termination. Current [33]	Finding	Point	Patient	ORD	Reported. WTP	Yes/No
Preferences for treatment. Pregnancy termination. Current [33]	Finding	Point	Patient	QN	Reported. WTPV	>0
Preferences for treatment. Pregnancy termination. Future [33]	Finding	Point	Patient		Reported. WTP	Yes/No
Preferences for treatment. Pregnancy termination. Future [33]	Finding	Point	Patient	QN	Reported. WTPV	>0
Preferences for health states. Laryngeal cancer [34]	Finding	Point	Patient	QN	Reported. TTO	0–1
Preferences for health states. Laryngeal cancer [34]	Finding	Point	Patient	ORD	Reported Ranking	1–5
Preferences for health states. Laryngeal cancer [34]	Finding	Point	Patient	QN	Reported. VAS	0–100
Preferences for treatment. Benign prostatic hyperplasia (BPH) [37]	Finding	Point	Patient	QN	Reported. SG	0–1
Preferences for treatment. Benign prostatic hyperplasia (BPH) [37]	Finding	Point	Patient	QN	Reported. PTO	1–3
Preferences for health states. Functional status [38]	Finding	Point	Patient	QN	Reported. SG	0–1
Preferences for adjuvant therapy. Breast cancer [35]	Finding	Point	Patient	ORD	Reported. Decision board	Yes/No
Preferences for adjuvant therapy. Breast cancer [35]	Finding	Point	Patient	QN	Reported. Likert scale	0–6
Preferences for screening method. Colon cancer [36]	Finding	Point	Patient	QN	Reported. AHP	1–5
Preferences for choice of surgical treatment. Breast cancer [13]	Finding	Point	Patient	QN	Reported Balance scale	−6 to +6
Preferences for illness management. Functional performance [21]	Finding	Point	Patient	QN	Reported. Likert scale	0–4

Note. ORD, ordinal; QN, quantitative. WTP, Willingness to Pay; WTPV, Willingness to Pay Value; TTO, Time Trade-Off Technique; VAS, visual analogue scale; SG, standard gamble; AHP, analytical hierachy process; PTO, probability trade-off technique.

Decision: Preferences for treatment: Pregnancy termination
Elicitation Method: Willingness to pay (WTP)

Question to elicit WTP and WTP value (Elicitation procedure)[a]
Imagine that all terminations are currently carried out by the tablet method.

(1) Would you be willing to pay anything in order to receive the operation method rather than the tablet method?
(2) What is the maximum amount you would be willing to pay to receive the operation method rather than the tablet method? Please use this card to think about the maximum you would be willing to pay.

$0	$60	$140	$300	$800
$5	$70	$160	$350	$900
$10	$80	$180	$400	$1000

and so on . . .

Fully specified LOINC Name

Component	Property	Timing	Samples	Scale	Method	Value[b]
Preferences for treatment. Pregnancy termination. Current [33]	Finding	Point	Patient	Ordinal	Reported. WTP	Yes/No
Preferences for treatment. Pregnancy termination. Current [33]	Finding	Point	Patient	Ordinal	Reported. WTP	$350 Operation method

FIG. 1. Example of preference elicitation and its representation using the LOINC semantic structure. [a]This example is taken from Ref. [33]. [b]Appropriate for representation in descriptive fields in the LOINC database rather than as part of the fully specified name.

of LOINC as a terminology model to represent patient-preference assessment-related concepts. As health care moves toward greater patient participation in clinical decision making, and patient preferences are more and more acknowledged as important pieces of information for appropriate clinical decision making, the ability to accurately represent patient preference-related concepts in LOINC and integrating them with other clinical information in the longitudinal EHR is, therefore, an important step in this direction.

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