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# Data Model for Personalized Patient Health Guidelines: An Exploratory Study

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## Abstract

*Practitioner guidelines simultaneously provide broad overviews and in-depth details of disease. Written for experts, they are difficult for patients to understand, yet patients often use these guidelines as a source of information to help them to learn about their health. Using practitioner guidelines along with patient information needs and preferences, we created a method to design an information model for providing patients access to their personal health information, linked to individualized, relevant supporting information from guidelines within a patient portal. This model consists of twelve classes of concepts. We manually reviewed and annotated medical records to demonstrate the validity of our model. Each class of the model was found within at least one patient's record, and seven classes of concepts appeared in over half of the patients' records annotated. These annotations show that the model produced by the method can be used to determine what guideline information is relevant to an individual patient, based on concepts in their health information.*

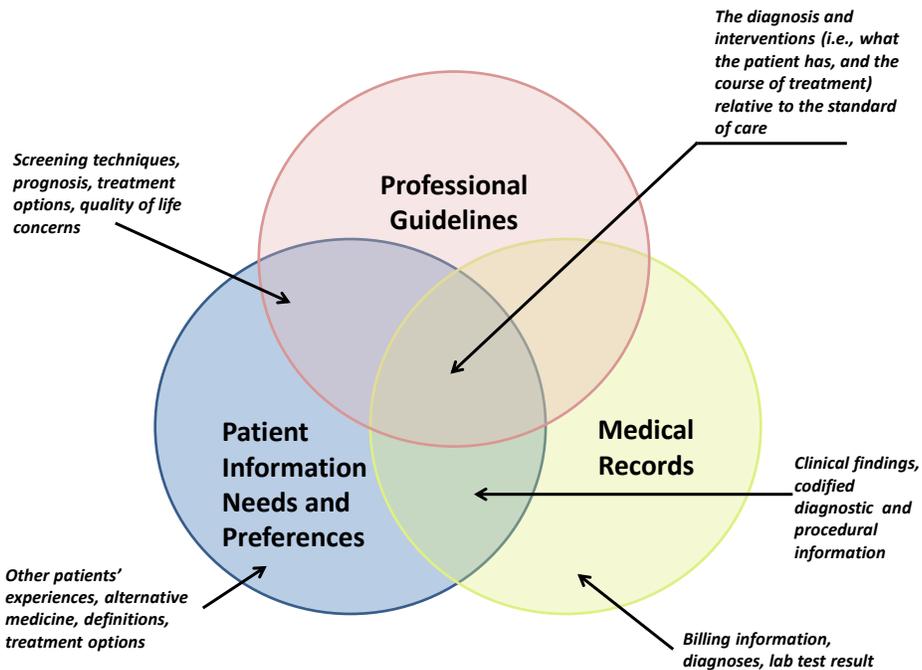
## Introduction

Patient portals are web-based applications designed to allow patients direct access to content from their medical record. Portals can also provide patients with general content relevant to their health, similar to what they would find at MedlinePlus<sup>1</sup>, the Mayo Clinic website<sup>2</sup>, or other consumer health websites. While not yet commonplace, large healthcare institutions are beginning to design and implement patient portals. Compelling reasons to do so include: the potential for an informed patient population, government endorsements via policy and funding, and ubiquitous digital infrastructure that allows patients easy access to information. Portals have the potential to empower patients; accessing personal health information encourages patient involvement, enabling them to make decisions based on the information they have received<sup>3</sup>. Applications that promote patient empowerment have also been shown to improve clinical outcomes and health statuses<sup>4</sup>.

Searching for health information is now the third most popular task completed online<sup>5</sup>. However, the content available to consumers spans a wide array of quality in their accuracy and completeness of information<sup>6</sup>. In addition, not all accurate sources regarding health and disease will be relevant to an individual. Here, we define “relevance” as how well the information meets the information needs of the user, based on the idea that information that satisfies the information need will fill the knowledge gap of the user<sup>7</sup>. Searching for health information, patients are left to mull content, attempting to determine what is applicable to their personal health and often having difficulty doing so<sup>1,8</sup>. Medical content intended for patient consumption lacks personal context; while letting individuals view information on subjects that concern them, such content does not provide a contextual overview or specific details regarding their diagnosis and the process of their care. Professional medical guidelines also lack a tailored view of the healthcare process relative to a given patient, often enumerating a spectrum of medical concepts (symptoms, test, diagnoses, etc.) that requires an expert to make logical inferences. As such, a lay patient looking at a guideline may be overwhelmed with information, and may not properly comprehend or appreciate the nuances within the guideline.

## Motivation

A model for personalized patient guidelines can provide consumers with supporting information regarding their health, presented in a fashion that provides context and chronology, and allowing them to see how individual concepts and processes relate together and to their health. The design of this information model should tailor the content of guidelines to the content of individual medical records in order to support the understanding of relevant information and to lessen cognitive overload. In this work, we address the issue of developing a methodology to model relevant supporting information to medical record content. The construction of the model was defined by the overlap between patient information needs and preferences, relevant professional clinical guidelines, and medical record content. More specifically, content from each of these three domains was examined to determine shared concepts to be included in the model. Examples of each information source area may be seen in Figure 1. Using this model creation method, we were able produce a model that matches relevant supporting content from guidelines to those concepts patients are interested in within their medical records.



**Figure 1.** Venn diagram illustrating cross section of information areas of interest, which falls in the overlap of the three domains.

Patients undergoing diagnostic tests have numerous sources of traditional supporting information including pamphlets, informational clinics, and support groups. The provision of electronic health information is also widely available, as noted above, in the form of consumer health information sources<sup>1,2,9-11</sup>, and personal health records (PHRs). Even before a diagnosis is made, data is collected on symptoms, procedures and test results. The testing process is often a stressful time for patients, with new information being introduced, both via the healthcare setting and what patients find themselves online. Yet, there is a lack of a consistent, reliable linkage between personal health information, information found within a portal, and other online supporting content. Patients now have ensured access to their medical record via the Health Insurance Portability and Accountability Act, (HIPAA). If such content is to be ultimately comprehensible to patients (e.g., to make informed decisions about their own care), online methods such as patient portals should not simply display medical record content verbatim, but instead make the content understandable to consumers with changes in visual presentation, abstraction level, and vocabulary as necessary to accommodate the lay person.

Professional clinical guidelines provide views of multiple granularities on disease-specific information. However, like individual health records, the content of these guidelines contain medical jargon and typically require the lens of clinical experience and/or knowledge to properly understand the information. By way of illustration, a lung cancer

screening patient with a history of smoking and additional symptoms (e.g., cough, unexplained weight loss) may consult an online professional guideline (e.g., National Collaborating Center for Cancer<sup>12</sup>, Figure 2) to learn more about his risk factors and the diagnostic procedures. Yet, as such guidelines outline all possibilities, not just the relevant pathway to the individual's circumstances, the lay reader may become more confused (if not anxious) about his condition. Indeed, professional guidelines take multiple potential symptoms and findings into consideration, and do not represent a patient-specific series of events. For example, while some patients being assessed for non-small cell lung cancer (NSCLC) have an x-ray, others do not. Professional guidelines, although appropriate for practitioners, present information that is sometimes irrelevant, redundant or too complex for the information needs of an individual patient. Given this consideration, patient records cannot simply be linked to professional guidelines as a whole. Depending on the patient, only parts of the practitioner guidelines are applicable. Therefore, guidelines presented to a patient need to be tailored to the individual based on concepts present in their medical record.

<p><b>Diagnosis and Staging Imaging Techniques (National Collaborating Center for Cancer)</b>  Urgent chest x-ray for patients presenting with hemoptysis or other key symptoms/signs  Urgent referral to lung cancer MDT  Sputum cytology (not routinely recommended)  Contrast-enhanced computed tomography (CT) (including chest, liver, adrenals, lower neck)  Positron-emission tomography-computed tomography (PET-CT) scanning  Magnetic resonance imaging (MRI)  Endobronchial ultrasound (EBUS)-guided transbronchial needle aspiration (TBNA)  Endoscopic ultrasound (EUS)-guided fine-needle aspiration (FNA)  Non-ultrasound-guided TBNA  Biopsy of enlarged mediastinal nodes  Fibreoptic bronchoscopy  MRI and CT of head for suspected intracranial pathology  X-ray of localized bone metastases</p>
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**Figure 2.** List of imaging techniques from National Collaborating Center for Cancer page on lung cancer screening.

## Background

Linking medical record content to supporting information has become commonplace for clinicians, with numerous electronic health record (EHR) systems providing decision support. It has been proposed that patients may be provided with additional information via their PHR in a similar manner<sup>13</sup>. However, the linkage of supporting information for patients via hyperlinks and embedding content is relatively new. MedlinePlus Connect is a web service that accepts ICD-9 codes and returns links to health information<sup>14</sup>. To use this service, institutions must opt in and provide concept unique identifiers (CUIs) from reports. This process also requires the patient to leave the content of their health portal and visit pages from the MedlinePlus website. Numerous healthcare organizations are now using this web service, including Columbia University Medical Center, Sutter Health System and the University of Utah. This system is dependent on correct CUIs in order to retrieve relevant information. However, this pairing of supplemental information can be hindered by incorrect or inexact matches, exclusion of appropriate child matches (e.g., choosing "cough" instead of "chronic cough"), and context dependent definitions<sup>15</sup>.

Kaiser Permanente has designed an in-house encyclopedia for patients using their portal<sup>16</sup>. Patients can access the encyclopedia pages while onsite. Each page contains specific information on a medical concept. Yet, the content accessible is not specific to the patient. While patients should not be prevented from viewing additional content that is not necessarily related to the patient, neither MedlinePlus Connect nor the Kaiser Permanente encyclopedia directs patients towards information that focuses on the concepts that have a positive occurrence in their record. In other words, patients can be directed toward information on a biopsy, even if it was decided not to do a biopsy but the word "biopsy" is mentioned in a report. Moreover, while online resources like MedlinePlus Connect can direct patients to relevant supporting information, they do not fully demonstrate how concepts may relate within the framework of a patient's encounter and the narrative of the PHR.

Although there are numerous information models for health information (Heath Level 7's [HL7] Clinical Document Architecture [CDA], Digital Imaging Communications in Medicine [DICOM], etc.), the majority are standards created to support interoperability among healthcare institutions, with practitioners as the end users<sup>17</sup>. To the best of our knowledge, none focus solely on the patients' information needs and how to link patient record content with supporting content. Often, patient information models are the product of using an information model designed for clinicians and then implementing it for a patient view of the information<sup>18-20</sup>. Little study has been done on how patient information needs and preferences should inform information models for patients.

In prior work, we conducted a survey of 41 patients who were undergoing screening or treatment for lung cancer at a clinic in UCLA, regarding their information needs and preferences<sup>21</sup>. Question topics were the result of a literature review of patient information needs and preferences. Results demonstrated that patients were particularly interested in concepts that were important to their diagnosis (90%) and imaging (90%). This earlier work and insight helps guide the development of the proposed information model.

## Material and Methods

### Class Definition: Literature Review

To test the process of designing the model, the domain of lung cancer screening was chosen. To create an explanatory information model that links guideline information with clinical data for the patient, we first defined a set of classes through a literature review of patient information needs. This literature review is the same utilized to design the survey in McNamara et al. 2014<sup>21</sup> and was performed in March 2013. To conduct this literature review, we used Google Scholar and PubMed search engines to find articles on patient information needs, using the terms "patient information needs", "patient portal" and "patient information preferences". Approximately 5 million articles were returned; however after manually reviewing several pages of ranked results, we observed that the relevance of articles to our study diminished. For example, large numbers of articles focused on other groups' information needs or medical procedures involving the portal vein, both subjects are outside the scope of this study. We reviewed the first 100 articles returned by PubMed and the first 50 returned by Google Scholar ranked by relevance. To be included, an article had to discuss patient information needs and preferences, and be published in the last twenty years. Articles were deemed to discuss patient information needs and preferences based on the content of their title and abstract. In total, 26 pertinent articles were identified. We choose to specify our class set from this literature review, as defining a model relevant to patient information needs is our overarching goal, rather than deriving classes from clinical guidelines, which may be irrelevant to patients. We then analyzed the subset of documents that met our criteria of content and publication years and noted themes that occurred throughout. If a theme was noted in at least three separate articles, the articles in which it was included were added to our focused annotated bibliography. This process resulted in thirteen articles within the focused annotated bibliography<sup>22-34</sup>. Each theme from the bibliography was included as a candidate class. This literature review resulted in the five candidate classes of: Diagnosis<sup>23, 24, 28, 29, 31, 33, 35, 36</sup>, Treatment<sup>22-24, 28-31, 33, 35</sup>, Common Side Effects of Treatment<sup>22, 23, 29, 35</sup>, Symptoms<sup>22, 29, 37, 38</sup>, and Diagnostic Test<sup>24, 30, 34</sup>. As made evident by the literature review, these classes of concepts appear to be popular across patient populations, as such information helps patients to understand their diagnosis and cope with prognosis and treatment. These initial candidate classes could thus serve as the basis for class creation across domains of cancer screening.

### Concept Definition: Guideline review

To generate a candidate list of clinical concepts (e.g., normalized instances of nouns found within the diagnosis guidelines) with associated contextual explanations, we reviewed the lung cancer diagnosis guidelines from the National Collaborating Center for Cancer and UpToDate<sup>12, 39</sup>. As seen in Figure 3, these guidelines were visualized as a flowchart, composed of connected nodes.

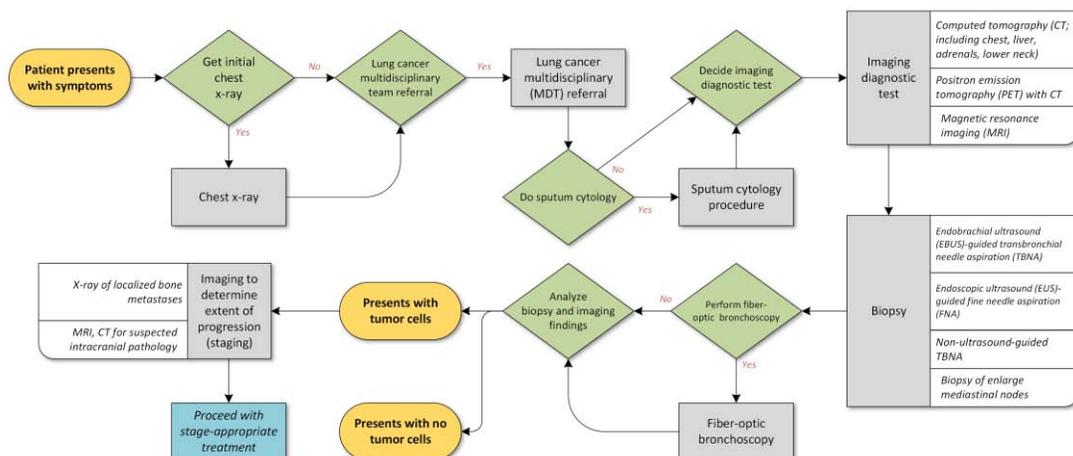


Figure 3. Simplified version of practitioner guidelines for lung cancer diagnosis.

Each node was then considered a candidate concept for the model. With this candidate list, we began to organize the data model, with the constraint that concepts included in the model were representative of classes seen in our literature review on patient information needs, and that the classes included were indicative of the screening process as made evident in our review of the professional guidelines. Table 1 shows our initial model structure of patient information need classes and corresponding concepts.

**Table 1.** Initial model of concepts and classes.

Class	Tumor	Symptoms	Diagnostic Test
<b>Number of Sources Citing Information Need</b>	8 <sup>23,24,28-30,33,35,40</sup>	4 <sup>22,27,29</sup>	3 <sup>24,30,34</sup>
<b>Guideline Concepts mapped to Class</b>	Tx, T0, Tis, T1, T2, T3, T4	Weight Loss, Fatigue, Chest Pain, Lung Infection, Breathing Trouble, Cough, Hoarse Voice	Sputum Test, Bronchoscopy, Thoracentesis, LDH, PET Scan, Albumin, Chest X-ray, Computed Tomography, Video Assisted Thoracoscopy, Pulmonary Function Test, MRI, Thoracotomy, Fine Needle Aspiration, Mediastinoscopy, Blood Test, Bone Scan

### *Manual Annotation of Medical Reports*

After this initial linking of candidate concepts to classes, we manually annotated pathology, laboratory, oncology, and radiology reports from ten patients to determine the presence of these candidate concepts in reports. We then revised the working list of concepts based on the actual content of reports. This process helped to ensure that the smallest units of information within the model – the concepts – were indeed reflective of the content of reports. During this process, we found that there were concepts indicative of indeterminate nodules, which had not been previously included in the model. This finding required enumeration of several new concepts concerning an indeterminate nodule. We also found that sometimes instead of reporting a TNM stage, a Roman numeral stage was instead reported. Additionally, we found that a patient’s smoking history is frequently mentioned in their reports. As smoking history information is relevant to understanding the application of a lung cancer guideline, we decided that these concepts should be incorporated into the model. However, it was found that these concepts were not well-represented by any of the existing classes. Thus, we revised the list of classes to add the classes of Nodule, Stage and Smoking Status. All concepts and classes were then manually matched to their Unified Medical Language System (UMLS) concept unique identifiers (CUIs).

### *Revision Based on Survey Results*

Based on survey results from McNamara et al. 2014<sup>21</sup>, we revised the model one more time to include concepts pertaining to the imaging process and concepts relevant to diagnosis. To provide for more detail regarding imaging, the Diagnostic Test class was broken into five classes (Imaging, Biopsy, Excision, Pulmonary Function, and Other Diagnostic Test). To focus on concepts relevant to diagnosis, the Comorbidity class was added. The Comorbidity class contains concepts that are lung disease comorbidities common in smokers.

### *Manual Annotation of Medical Records*

To determine the overlap between the model’s concepts and those within patient records, the first author manually annotated an additional unseen 60 patients’ oncology, pathology, radiology and laboratory documents. First, a combination of report types (e.g., imaging, pathology, radiology, oncology) and keywords (e.g., "tumor", "smoking", "diagnosis", etc.) were used to filter documents that contained a concept of interest. These reports were then manually reviewed to determine if the concept was present. If, after reviewing these documents there remained unobserved concepts, a patient's entire report set of documents was reviewed to ensure no concept present in a history was unaccounted for.

## **Results**

The finalized information model consists of twelve classes, as seen in Table 2. Nodule is the class that captures the presence of an indeterminate nodule, as well as its location and size. Tumor, while referencing the same nodule, is only utilized when there is confirmation of cancerous cells. Related to this, the class of TNM contains concepts of individual stages of tumor progression, as taken from the TNM staging system of lung cancer<sup>41</sup>. As made evident by

annotations, sometimes Stage I-IV is reported instead of TNM, so the Stage class contains concepts to account for this method of staging. The Smoking class contains a concept that confirms a smoking habit (yes/no), and once confirmed, quantifies it with the concept of pack year history. The Symptom class does not contain every symptom a patient with lung cancer might experience. Rather, it contains only those symptoms commonly experienced by patients as noted in Corliss et al.<sup>9</sup>

The first revision of the model produced a single Diagnostic Test class containing a wide range of diagnostic tests (pulmonary function, imaging, biopsy) that can be used in the diagnosis of lung cancer, as indicated by the National Comprehensive Cancer Network and UpToDate<sup>12, 39</sup>. However due to surveyed patients' interest in imaging, it was decided that the Diagnostic class should be divided into five new classes to allow for a finer granular representation of concepts pertaining to imaging. The five classes are: Biopsy, Imaging, Excision, Pulmonary Function, and Other Diagnostic Test. The Biopsy class is meant to cover all likely types of biopsies associated with the screening process, with the concept "Other Biopsy" to accommodate all other types of biopsy. Similarly, the Imaging, Excision, and Pulmonary Function classes contain concepts reflective of the most common types of concepts associated with them. The Other Diagnostic class contains those concepts that didn't fit into any of the other Diagnostic classes, but were found in the guidelines and reflective of patient information preferences. The Comorbidity class is concerned with smoking related comorbidities, as the majority of lung cancer patients either have smoked or were exposed to second hand smoke.

Out of the 60 patients records annotated for the concepts within these twelve classes, 33 contained the class TNM, 49 contained the class Tumor, and 21 had concepts from the class Stage. 57 patients had concepts from the class Nodule, 35 had concepts from the class Smoking, 56 had concepts from Biopsy class. The Comorbidity class was found in 24 patients' records, 5 patients had concepts from the class Excision. 58 patients had concepts from the class Imaging. Only one patient exhibited concepts from the Pulmonary Function class, one patient had concepts from the Excision class, and one patient had a concept from the Other Diagnostic class. 37 patients had concepts from the Symptoms class.

**Table 2.** Revised Model of Classes and Concepts.

Symptoms	TNM	Tumor	Stage	Nodule	Smoking Status	Comorbidity	Excision	Imaging	Biopsy	Pulmonary Function Test	Other Diagnostic Tests
Weight Loss	TxNxMx	Tumor Present (Y/N)	I	Nodule Present (Yes/No)	Smoker (Yes/No)	COPD	Video-Assisted Thoracic Surgery (VATS)	X-ray	CT-Guided Lung Biopsy	Spirometry	Sputum Test
Fatigue		Tx	II	Nodule Location	Pack Year	Pulmonary Fibrosis	Mediastinoscopy	Computed Tomography	Brochoscopy	Body Plethysmograph	Bone Scan
Chest Pain		T0	III	Nodule Size		Chronic Obstructive Asthma	Thoracotomy	PET Scan	Fine Needle Aspiration	Gas Diffusion	
Lung Infection		Tis	IV	Ground Glass		Chronic Bronchitis		MRI	Thoracentesis		
Breathing Trouble		T1		Multiple Ground Glass		Emphysema			Other Biopsy		
Coughing Blood		T2		Solid							
Hoarse Voice		T3									
		T4									
		Metastases									
		Tumor Location									
		Tumor Size									

## Discussion

Based on a literature review of patients' information needs, we designed a method to create an information model for patients that links medical record concepts with guideline content. This method consisted of looking at patient information needs and preferences, and determining which of those also fell within the domains of practitioner guidelines and medical record content. The model is intended to aid in patients' information comprehension. Screening for any disease is complicated and detailed, and can be stressful for the patient, as they encounter and process new information. By providing classes of concepts relevant to the information needs of patients that can be linked to guideline content, the model promotes directing patients to contextualized information relevant to their health. We demonstrated the application of this model within the domain of lung cancer screening by manually annotating 60 lung cancer patient records. While no one class' concepts were present in every record, every class was represented in at least one patient's record. The model's concepts can therefore be used to annotate a patient's record and collect

a set of domain specific concepts. These concepts can then be used to determine what guideline content is relevant to a particular patient's record, based on the concepts within the record. For example, if the concept "CT Guided Lung Biopsy" is found within a patients' record, additional supporting information on the process of getting a CT lung biopsy can be provided to the patient within the same application (i.e. a portal), in which they are accessing their record.

In a prior study, we surveyed 41 patients at a lung cancer clinic at the University of California Los Angeles, to determine how accurately this information model reflected their perceived needs<sup>21</sup>. The survey results support the relevance of our model. 66% wanted information about their health problems, and 90% wanted to know about information on their diagnosis. While less than half (32%) agreed that it was difficult to find information, 61% would like to see terminology from their medical reports defined. This alludes to patients having information available to them, but not necessarily being able to understand it, reaffirming a need to make medical record content more accessible to patients.

Although the concepts of the model are specific to the domain of lung cancer, this method of reviewing patient information needs and preferences, guideline review, and medical record annotation can be used to create an information model for patients undergoing screening in another domain of cancer. In addition, the model produced by the method will likely be similar across cancer domains. Many of the classes produced by this information model method, with perhaps the exception of smoking, would likely be reproduced when the method was implemented in another domain, for instance that of breast cancer. The classes of Nodule, Tumor, and Stage are applicable within breast cancer, as unknown phenomena can be captured by the concept "nodule", and malignant findings are referred as a "tumor" and staged using the same hierarchy of staging. Likewise, while the type of imaging most common varies by type of cancer (mammogram for breast cancer), the Imaging class can easily be altered to focus on those methods most prominent with a particular diagnosis.

Implemented within a portal, this model may allow patients to more effectively learn about concepts within their medical record. While users can currently read their records and then search for information online on concepts found within the record, the proposed model facilitates the automatic linking of record content to educational content by filtering content for an individual patient based on disease presentation within their record. To realize this, natural language processing (NLP) tools may be trained to mine model concepts from patient records, and links from the records to the educational content can be provided via a patient portal. For example, if a patient were to see the concept "CT scan" within their record, they could be provided with links to the definition of a CT scan, images of a CT scanner, example CT scan results, and information on why a CT scan is used in lung cancer screening. This provision of educational content is similar to the personal health record level three as presented in Krist and Woolf 2011<sup>43</sup>.

Limitations of this work include: a limited sample size from one institution was used to learn concepts for the model, the assumption that patients' perceptions of what they want to see from their record aligns with their actual information needs, and that annotations in this work were created by one researcher. These limitations may have biased our results to make the model appear to fit better than it will with records from other institutions, or for other annotators.

Our future work includes using this model within a portal as the basis for an information visualization that links patient medical information to guideline content, thus creating personalized guidelines. User studies will be conducted to determine the extent to which the model is successful in helping patients to understand information regarding their lung cancer diagnostic process. We are currently in the process of designing a patient portal that utilizes this model. Once this program is finalized, we will recruit patients from a UCLA lung cancer screening clinic to use the portal and complete a survey based on their perceptions of how well the model meets their information needs. Additional future work may also include the automation of the annotation process using NLP.

## **Conclusion**

We designed and implemented a method to create an information model that links concepts from medical records to relevant information from practitioner guidelines indicative of patient information needs and preferences. Classes for the model were derived from a literature review on patient information needs and populated with concepts found in professional guidelines. Here the application focused on the domain of lung cancer, but is anticipated to be applicable across cancer domains. The revised model was used to annotate 60 patients' records, where it was found that each class was present in at least one patient's record, and that seven of the twelve classes were present in over 30 patients' records.

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