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Patient-Centered Visualization for Personal Health Records

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Patient-Centered Visualization for

Personal Health Records

A dissertation submitted in partial satisfaction of the requirements

for the degree Doctor of Philosophy in Biomedical Engineering

by

Mary Catherine Zide

2016

ABSTRACT OF THE DISSERTATION

Patient-Centered Visualization for

Personal Health Records

by

Mary Catherine Zide

Doctor of Philosophy in Biomedical Engineering

University of California, Los Angeles, 2016

Professor Alex Anh-Tuan Bui, Co-Chair

Professor Corey Wells Arnold, Co-Chair

Shifts in the consumer health landscape including the active participation of consumers within
their care, the myriad of health information sources available to them, and the emphasis on
preventive care, require patients to have improved information access and health literacy skills.
Designers of eHealth tools must consider how best to meet the information needs of patients
given that prior research has indicated that needs vary, making it unlikely that there is a
homogeneous approach that will meet all needs. In spite of this, iterative design and inclusion of

consumer feedback in the design process remain underutilized. This dissertation addressed this gap by creating a protocol for the design of a patient-centered information visualization for a specific population of interest, implemented here with lung cancer screening patients. Building upon past efforts in eHealth design and usability testing, the design centered on a method to produce a conceptual information model, which consisted of a five-step process that documented patient information needs and identified content and methods to address those needs. The model integrated information from various health education sources and provided dynamic personalized displays of the educational information alongside an individual's radiology report. For this work, this model was displayed via a patient portal visualization, and evaluated by patients to determine whether patients reported the visualization as usable and whether using the visualization improved health literacy. These results were compared to a survey of general health consumers' information preferences and health literacy. Initial results confirm that health literacy and information preferences varied by demographics (including education and the number of times prior an individual had used a patient portal) and suggest that patients find the integration of educational information alongside their reports, in contrast to the reports alone, as easier to use. The results of this study can be used as guidelines to further additional design of eHealth tools.

This dissertation of Mary Catherine Zide is approved.

Ricky Kiyotaka Taira

Gregory H. Leazer

Denise R. Aberle

Corey Wells Arnold, Committee Co-Chair

Alex Anh-Tuan Bui, Committee Co-Chair

University of California, Los Angeles

2016

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Choose joy. Every single day.

VITA

2006	Bachelor of Arts in German University of California, Berkeley
2010	Master of Library and Information Science University of California, Los Angeles
2009-2014	National Library of Medicine Predoctoral Fellow Biomedical Engineering IDP Medical Imaging Informatics Group University of California, Los Angeles
2014-2016	Graduate Student Researcher Biomedical Engineering IDP Medical Imaging Informatics Group University of California, Los Angeles

Publications and Presentations

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CHAPTER 1 Introduction

1. Overview

Patient portals, which can be broadly defined as applications that provide patients with access to propriety content of their medical records from a specific institution or collaborating network of institutions, are increasing in use. Patient portals are similar but historically considered different from personal health records (PHRs). While the original definition of a PHR was of records maintained by an individual that could come from various sources, and the definition of portals containing solely records maintained by an institution [1], this distinction is becoming less pronounced, with portals often considered a type of tethered PHR [2-4]. For this work, the term portal was considered synonymous with the phrase patient portal. Use of portals is increasing, with rates differing across demographics. The provision of the content within patient portals seeks to inform patients, in order for them to make better healthcare decisions. The ability of a portal to inform is reflective of its functions and its content, as the two characteristics are influential on the perceived usability of the portal by the user. Usability, the subjective assessment of how useful a tool is to complete an objective, has been shown to affect use, with higher usability resulting in higher use.

The health status and medical diagnoses of a portal user have demonstrated to be in part related to patients' use objectives and information needs [5, 6]. Given this, it is critical for portal design to consider the user's diagnoses in determining what modules and content will be helpful in assisting the user to reach their use objectives. However, portal feature selection based on diagnoses is underutilized, with many portals designs implementing uniformity of modules and content across patient types. This study documented the differences in a specific patient

population's information needs and use objectives, and then employed these criteria to create a conceptual information model that served as the basis for a patient portal tailored toward the population of interest. This method of having an interface driven by the diagnosis and the protocol used for that diagnosis was assessed by the patient population and compared to a more traditional format of their record, to determine which format was deemed easier to use. This patient population's assessment was also compared to a more general population's usability assessment of portals.

1.1. Background and Motivations

There are numerous versions of patient portals now available, with both out-of-the-box and institutional-specific options common. In 2010, [7] found over 90 types of commercially available portals. However, only 7% of Americans were found to use portals. Despite low rates of use, federal policies such as Health Information Technology for Economic and Clinical Health Act (HITECH) and the Health Insurance Portability and Accountability Act (HIPAA) promote their development and implementation. As such, rates of use are expected to increase.

Patient portals functions vary and can include features such as problem lists, medications, and lab results. However, there is little consensus on what a portal should contain, with more explicit work on what a PHR should contain [2, 8-11] [12]. Although historically different in their propriety nature, much of their content is similar, and that which is considered essential for a PHR should also be considered when designing a portal.

Current implementations of portals tend to be general health, and include the same modules and content regardless of patient diagnoses or preferences [13-28]. Additionally, newer implementations are equipped with educational material and the incorporation of problem lists that function as summaries of the record. These enhancements assist in making the medical

records within portals more comprehensible. They do not account for personalized manifestations of disease and treatment or the health literacy level of individual patients. This is in spite of user information needs varying by demographics [29, 30] and changing with diagnoses [31, 32]. Coupled with a lack of provision for individual differences and differences within a diagnosis, designers of portals often do not engage in any formal methodology to ensure that the designed portal meets users' information needs or preferences.

1.2 Aims of the Dissertation

This work investigated whether patients demonstrated a usability preference for a portal with tailored educational content based on a conceptual information model that was patient-centered; whether that portal improved their knowledge of lung cancer screening; and whether their information needs and preferences varied by demographics. It also researched whether information needs, preferences, and lung cancer knowledge varied between patients who were undergoing lung cancer screening at UCLA and online health consumers who had a variety of diagnoses. Here, patient-centered was defined as concerned with patient information needs and preferences. The primary deliverables of this dissertation are: a conceptual informational model based on the information needs and preferences of lung cancer screening patients; a patient portal that utilizes the model as the basis for a visualization that is dynamically tailored to an individual patient; an eXtensible Markup Language (XML) schema that can be used to annotate patient records inter-institutionally, a survey designed to measure the patient information needs, preferences, and lung cancer screening health literacy of a lung cancer screening population; a survey designed to measure the information needs, preferences, and lung cancer screening health literacy of general health information consumers online; a usability study of a cohort of lung cancer screening patients at UCLA that utilized the survey designed for the lung cancer

screening population, and an online study that used the survey designed for general health consumers.

1.3 Summary of Contributions

- Conceptual information model design method. The conceptual information model design method used in this research identified the information in the patient record concerning the lung cancer screening process that was of interest to the patient, and thus preferred, as well as relevant to the lung cancer screening process. This method consisted of a multiple step process: a literature review of patient information needs and preferences, a review of practitioner guidelines for lung cancer screening, annotations of lung cancer reports, input from two physicians involved in lung cancer screening, and input from two informaticians working within the domain of health literacy.

- An XML (eXtensible Markup Language) annotation schema, that can be used for annotating patient records for concepts found within the conceptual information model for pairing concepts with educational content.

- A patient portal utilizing the conceptual information model listed above as the basis for visualizations of individual patients' lung cancer screening radiology reports. The conceptual information model was used as an annotation schema that was applied to each individual report, to link report contents with educational content. The portal also features additional educational content in the form of introductory content on the process of lung cancer screening, an introductory overview of lung anatomy, and a risk assessment calculator.

- A survey study of online health information consumers online. This study utilized the web service Mechanical Turk (MTurk) provided by Amazon to access a group of health

information consumers who ranged in demographics and diagnoses. This group was surveyed using a modified version of the survey distributed to UCLA patients.

- A usability study of a cohort of lung cancer screening patients at UCLA. This study demonstrated how the portal based on the conceptual information model was assessed on a scale of usability. It also investigated whether using the portal improved patients' knowledge of lung cancer.

- A comparison of the results from the survey of health consumers via MTurk and from the survey of patients at UCLA. This comparison demonstrated what differences in information needs, preferences, and lung cancer screening health literacy existed between lung cancer screening patients and a general population.

1.4 Organization of the Dissertation

The remainder of the dissertation is organized as follows. Chapter 2 provides background on the need for patient portals, current trends in portal design, and gaps between patient information needs and preferences and current portal iterations. Chapter 3 documents the methodologies used to design: the conceptual information, the XML schema, and the patient portal. It also documents the final product of the portal design illustrated with a typical patient's data. Chapter 4 discusses the usability experiment and survey design for the UCLA in-clinic usability study. Chapter 5 demonstrates the survey experiment design and survey creation for the MTurk online survey of health information consumers. Chapter 6 contains the results from both the in-clinic usability study and the online survey and compares these two sets of results. Chapter 7 provides a discussion of these results in comparison to each other and other similar work in the area. Chapter 8 provides a final summary of the results, and future work.

CHAPTER 2 Background and Motivation

My work in patient-centered conceptual information models furthers research completed in knowledge representation, health literacy and consumer informatics. The first section (2.1) demonstrates the need for patient portals within the current socio-technical environment by documenting patient information needs and preferences; it defines what a patient portal is and identifies different factors impacting portal design and use including use objectives, health literacy and clinicians' opinions. The second section (2.2) examines current trends within portal design including general health portals and diagnosis specific portals, defines usability and documents what current trends in usability testing have been observed in portal development. The third section (2.3) presents common web standards used in portal visualization and discusses some of the open challenges this research will address including: disease-oriented visualization, perceived usefulness, and patient-centered design.

2.1 The Need for Patient Portals

The need for patient portals is made evident in the evolving trends of health information searching. In 2000, it was noted that 46% of Americans had Internet access and 24% searched for health information online. By 2013, 72% of Americans with Internet access searched for health information online [33]. When compared to physical educational sources, online sources are: time independent, place independent, and consist of a web of ideas, or multiple forms of information that are integrated [34].

The rise of the Internet as a source for health information is driven by several factors, such as the general increase of Internet use, the growth of digital health resources, and the rising costs of healthcare (which often prompt patients to research health concerns on their own at no cost before seeking professional opinions). In addition, federal endorsements to digitize medical

records and promote patient access to records and other health information have increased access to patient records. In spite of consumers accessing information, that which they access does not always satisfy their information needs. Nearly half (44.9%) of Americans surveyed by [35] reported searching for cancer information; of those 41.3% were frustrated by the search and more than half (57.7%) were concerned about the information quality. These challenges notwithstanding, cancer patients were shown to utilize medical information online. [36] surveyed a group of patients' self-reported Internet use before and after the diagnosis of cancer, finding that use of the Internet either directly (i.e., patient themselves doing the research) or indirectly (i.e., someone else searching for the patient) increased. A statistically significant percentage (18.7%) claimed increased Internet use for seeking health information after diagnosis. No subjects reported a lower level of Internet use after diagnosis.

In addition to accessing general medical information, the Internet has also ushered in digital access to personal health information. The Health Insurance Portability and Accountability Act (HIPAA) and other legislation mandate that patients be able to access their records. Larger institutions (such as Kaiser Permanente) have already taken the initiative to provide access to patients via patient portals. Broadly, a patient portal is a secure website that provides individuals with access to their personal medical information [1, 37]. While availability of portals continues to grow [38-40], in 2011 it was found that only 10% of Americans used a portal [41]. Use by institution, however, can far surpass this. An excellent example in contrast is the patient portal provided by Kaiser, which has 4 million users out of 9 million patients total [42].

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 [43]. Applications that promote patient empowerment have also been shown to improve

clinical outcomes and health statuses [44]. Portals vary in content (e.g., clinical notes, lab results, procedure lists, etc.) and capabilities (e.g., ability to email a physician, renew a prescription, and correct content errors). Many portals, such as the one offered by Kaiser Permanente, provide information on the general health of the patient. As such, these portals cover the breadth of health information encapsulated in a patient record. However, general health portals tend to be used by patients for specific activities, including: emailing clinicians, reviewing medication lists, and checking lab results. The most-used features of the Kaiser Permanente portal include: scheduling appointments, accessing a staff directory, renewing prescriptions, and using their health encyclopedia [13].

Another use for portals is the management of chronic diseases [45]. In contrast to portals containing all health information, others have been designed to be disease-specific [45-48]. [49] found that patients with chronic conditions were more likely than those without to sign up for and use a patient portal, suggesting that portals focused on specific conditions could be more relevant to user needs. These disease-specific portals tend to present a more narrowly detailed view of a particular diagnosis and co-morbidities. Oriented around a disease, these portals posit that patients want a more focused information view because patient information needs will vary by disease/diagnosis.

2.1.1 Patient Information Needs and Preferences

Patient impressions of eHealth tend to be positive. [50] found that most patients believed that electronic health records (EHRs) and electronic health information exchanges (HIEs) would improve healthcare. Notably, this belief was higher in those patients whose doctors already used an EHR and/or were involved in an HIE. Support for HIE was also associated with consumers' comfort with sending personal health information (PHI) via the Internet and perceived HIE

benefits [51]. In [52], estimated amount of use was associated with perceived value of health management features, perceived potential to empower, and provider satisfaction. Relatedly, patients with access to relevant disease-specific information were also shown to better cope with anxiety associated with diagnosis and treatment [53].

Opinions of eHealth have shown to be higher in those diagnosed with cancer. [54] surveyed cancer survivors, cancer patients, and patients with no history of cancer. Survivors and cancer patients tended to have a more positive view of EHRs and the potential for access to its contents. However simply providing information does not necessarily address information needs. [35] found that 51.3% of participants agreed that cancer is caused by everything, while 75.2% stated that cancer prevention recommendations are too numerous to know which of them to follow. More needs to be done to satisfy specific information needs, as facilitation of patient information seeking is facilitation of their care participation [35].

Some information needs are documented throughout the patient population. Across various diseases, patients have shown interest in information on their diagnosis [6, 36, 55-59], treatment [24, 36, 55-61], common side effects of treatment [55, 58, 60, 61], symptoms [58, 60, 62, 63], and diagnostic tests [24, 56, 64]. In spite of these trends, information needs can vary by subgroup. [65] found that information preferences varied across demographics: those who wanted information and were likely to independently seek it out (i.e., without the help of a healthcare practitioner) tended to be young, educated, and female, while young men tended not to seek out health information. Older patients would access health information presented to them by their doctor, but were less likely to search for health information on their own.

Unsurprisingly, online health information preferences in particular have also been observed to vary by demographic parameters [66]. Women were more likely to search for health information

online, with 57% of American adult men accessing health information online in comparison to 64% of women. In terms of race and ethnicity, 65% of whites accessed digital health information, compared to 51% of African Americans, and 44% of Hispanics. Young adults composed the largest group of individuals using online health resources (72%). The percentage decreased in older age groups, with 71% of adults ages 30-49, 59% of adults ages 50-64, and 27% of adults age 65 or older accessing online medical information.

Focusing on patient portal use, [67] found that patient portal enrollment varied by race and ethnicity, with whites and Asians more likely to enroll than other races. Likewise, [28, 68] found that users of a patient portal were more likely to be white, younger and more affluent. [64] found that portal use was linked to health literacy level, and those of a lower literacy level had less use.

Patients have shown to want information specifically on illnesses and treatments, indicating needs can also vary by diagnosis. [55] noted that 87% of cancer patients wanted as much information as possible, regardless of whether it was positive or negative, and only 7% preferred to leave the decision of what information they should receive up to the doctor. Ninety-five percent wanted to know their chances of a cure. However, within the cancer population needs also varied by demographics. Age and gender were significantly associated with the amount of information desired [55], with trends mirroring those seen in other studies where older patients preferred to have less information and young women tended to want information on all possible treatments.

2.1.2 Practitioner Perspective

Practitioner preferences regarding patient access to information has varied. [69] found that physicians were less likely than patients to anticipate that portals would empower patients. A survey of clinicians [70] found that 82% wanted patients to actively participate in updating their

health records. However, only 31% believed patients should have full access to their record, and 65% stated patients should have limited access. Clinicians also demonstrated concern for the opportunity for patients to add content to personal health records (PHRs) and limit permissions to view that content [14]. While not the primary focus of portal development, considering practitioner concerns is crucial to facilitating patient use, as professionals are unlikely to advocate for systems that, in their opinion, prove too risky to a patient's psychological well-being. In [71], lack of endorsement by clinicians of particular portal features was associated with underutilization of those features, highlighting the need for practitioner investment in portals in order for interventions to succeed.

2.1.3 Content of a Portal

Medical records are rife with professional jargon unfamiliar to patients. Health literacy, the ability to understand health-related vocabulary and content, varies among patients. Thus, designers of portals must seek to create content that is comprehensible to a wide audience of users. In general, access is a major factor to be considered in portal design. Simply taking content from EHRs and directly transferring it to a site available to patients does not render the information useful or understandable. Current EHRs have been designed with professional users in mind. An outside assessment of existing portals [2] found that the resulting portals were often physician-oriented. Hierarchies, terminology, and task orientation are examples of design choices of EHRs geared toward assisting a medical practitioner. While patients may want to see some of the same information their doctors do, they will not necessarily want it presented in the same way, nor will they necessarily want to accomplish the same tasks. However, portals often do not differ in visualization from the EHRs they are associated with. Examples of portals that

present patients with the same record view as clinicians include PatCIS [15], Google Health, Microsoft HealthVault [19], and IDEATel [16].

As mentioned above, there is specific content from the medical record that patients have demonstrated interest in, but patients have also requested access to all information on the full trajectory of a disease (i.e., symptoms, diagnosis, prognosis, treatment, and survival) [6, 24, 36, 55-60, 62, 64, 72-74]. To make this content useful to patients, designers of portals must consider both the appropriate information visualization architecture and the language used to convey health information content.

2.1.4 Health Literacy

The design of portals is not the only obstacle to patient use of information from their medical records. Low levels of health literacy are seen as a considerable hurdle to accessing health information [75]. The U.S. Department of Health and Human Services (HHS) defines health literacy as patients' ability to acquire, read, and understand health information in order to make health decisions appropriate to their situation [76]. The National Center for Education Statistics (NCES) maintains that health literacy is crucial for all adults to understand and improve their health, as they encounter health information in a variety of digital and hardcopy formats (e.g., websites, blogs, federated search engines, magazine articles, pamphlets, prescription directions) [77]. [78] clearly demonstrated that health literacy had a statistically significant influence on patients' ability to recognize health terms. Many American adults also manage their elders' and children's healthcare information, making decisions surrounding these dependents' care. In 2009, 52% of online health-related searches were done on behalf of someone else, further affirming the need for a competent level of health literacy [77].

To be health literate, patients must be able to make sense of the information they receive, and increasingly, be able to search for medical information on their own. Patient health information is often written with these objectives in mind. However, many of these resources, including patient portals, contain medical jargon carried over from materials intended for physicians. These professional terms are difficult for patients to understand [14, 78-82]. Furthermore, while patients often indicate a desire to hear a diagnosis in professional terms, they also report higher levels of satisfaction when healthcare professionals use language that correlates with their own [83].

Although the percentage of educated users is anticipated to increase, more people overall are estimated to begin to access health information online as wireless connectivity grows [66]. Thus, an increase in nontraditional users of digital health information is also likely [79]. In fact, those groups with the lowest rates of eHealth use in 2002 had the highest relative increases in 2010 including: those who had less than a high school education (4% to 9%), individuals with functional impairment (10% to 23%), people age 75 years or older (12% to 27%), unmarried individuals (12% to 29%), those with poor self-rated health (11% to 25%), and nonwhites (7% to 21%) [84].

Additionally, private and government initiatives attempt to narrow the "digital divide" by providing online access to health information geared toward minorities and patients of lower socioeconomic status to help reduce healthcare costs and increase healthy living. This means that a growing number of patients accessing digital health resources will have less education, have less financial security, and will be more culturally diverse and older. With the increasing variety of patients using digital health resources, the vocabulary gap between healthcare professionals and patients becomes more significant [85]. Considering this discrepancy, the use of professional

terms and physician-oriented design in patient resources may effectively omit lay understanding. Indeed, [86] illustrated "mismatches" between patient and practitioner definitions for health concepts. Language used by professionals is reflective of their advanced education and expertise in the field of medicine. In contrast, patients' language is a product of their social and cultural experiences [87]. [88] found that patients' recall of information was enhanced using illustrations depicting medical and health concepts relevant to the individual's care.

Although health literacy has a significant impact on the usability of health information, there are additional concerns impacting portal design. Ease of access and quality affect use rates of healthcare technology [13, 89]. It is therefore necessary to design tools that not only contain quality information, but are easy to use to ensure broad adoption.

2.2 A Review of Current Portals

This section provides: a review of health portals, a comparison between the features offered in general and disease-specific portals, a review of favorable outcomes associated with portal use, a review of how portals containing diagnosis-specific content present that content to the patient, and a review of when and how usability studies of portals have been conducted.

Patient portals tend to provide either a general health overview, or a management view for a specific disease. Examples of general health overviews include Kaiser's myHealth [13], Patient-centered Access to Secure Systems Project (PCASSO) [15], and Akteonline [20]. Online portals for patients dealing with specific diagnoses have targeted: diabetes [45, 59, 90], hypertension [47], congestive heart failure [91], and glioblastoma multiforme (GBM) [46].

 [15] looked at different patient portals documented in literature including: the Patient Clinical Information System (PatCIS); the Informatics for Diabetes Education and Telemedicine

(IDEATel); PCASSO; and the System to Provide Patient Access to Records Online (SPPARO).

This review indicated that while physician-centeredness was a driving force to portal organizational architecture, organizations also touted patient-centeredness as a crucial aspect of healthcare [15]. Physician-centeredness is the impact the physicians have on both system design and patient's use of the system. EHRs are designed with the physician as the primary user, based on clinical workflow. Although patient-centered design (i.e., concerned with patient information needs and preferences) is a primary objective of portal design, it is challenging to stray from the current clinical narrative. The majority of the documents utilized by portals (lab results, clinical notes, etc.) are created by physicians for other physicians to use. Finding ways to display the same information in patient-centric formats proves difficult but is important to improve the patient experience. Another challenge is the multi-voiced representation within EHR documents. Patients may find it difficult to interpret these distributed clinician findings compared to a more unified structure [15]. As an example, consider the process of a tumor biopsy. Multiple clinical documents are produced for radiology, surgery, pathology, and oncology. The patient, however, often views the biopsy as a singular event. They may not be aware of the way their imaging was used to prepare for the procedure, or specific tests being performed on the tissue after a sample was taken. As part of the background review for this research, I conducted a review of existing portals, which is summarized in Tables 1-2. In this review, a distinction is made between general health and disease-specific portals. To conduct this review, the search engines Google Scholar and PubMed were used. The terms: "patient portal", "personal health record", "personal electronic health record", "PHR", "health portal", "patient health portal", "patient electronic health record", "personal health portal" were used to retrieve articles from the two search engines. Approximately 1-5 million articles were retrieved per phrase, and the first 100 of these

ranked by relevance were manually reviewed. In total, 27 distinct scholarly (peer-reviewed) journal articles on the topic of patient portals were identified and reviewed.

2.2.1 General Health Portals

General health portals amass information from the entirety of the patient record and tend not to orient information in a problem-centric manner. For example, they may show all radiology reports listed together as a single data source, rather than grouping them by a disease target or event. Consequently, general health portals present a large expanse of documents and provide patients with considerable access to personal health content. Fourteen of the twenty portals reviewed in this work are general health portals. Some are very basic, providing limited services. An example of this is MedAxess, a web portal used in Norway for patients to email their primary care physicians. Unlike the other portals reviewed here, it does not provide access to a patient's records or additional health information [92]. However, the majority of other general health portals do provide access to some record content. Common medical record content included in general health portals varies and can include: clinical notes [13-28], lab results [13-15, 17-24, 93], and allergies [14, 18, 19]. Common additional features included in general portals are: the ability to email the practitioner [13, 18, 20-28, 93], schedule appointments [13, 18, 20-24, 27, 28, 93], and renew prescriptions [13, 18, 27, 28].

2.2.2 Disease-Specific Portals

Disease-specific portals focus on one particular diagnosis, although they may contain information on other diagnoses that are comorbidities or relate significantly to the primary diagnosis. Content (physician documents, labs, etc.) is only included if it is relevant to the health concern of focus. Similar to general health portals, the content of these disease specific portals

can vary; however, they generally contain common features such as clinical notes [16, 48, 91, 94] and test results [91, 94].

2.2.3 Favorable Outcomes

Portal use has been associated with positive health outcomes including chronic illness management [95] and adherence to preventive care [96]. Portal use has also been associated with patient reported self-care management efficiency, office visit quality, care satisfaction, and patient trust in physicians [97, 98]. In [95], diabetic patients who used a patient portal had significantly improved LDL cholesterol, medication management, and an understanding of diabetes. In [96], patients who used a portal had higher rates of preventative service completion.

Similarly, individuals who had access to their medical records demonstrated an increased understanding of their record, reviewed findings, and communicated more with their practitioner [69, 91, 99]. Portals can also help with preventive care. Patients who used a portal that reminded them when preventive screening was due had twice the rate of adherence to screening protocol than those who did not use the portal [100].

2.2.4 Provision of Additional Supporting Content

Alongside providing access to medical record content and features that allow patients to make requests of a healthcare institution, portals can also provide patients with additional supporting information content. Directing patients towards this content can assist in informing patients regarding their health. This directing is accomplished either via links that lead to content outside the portal, or by housing the content within the portal itself. This section notes those portals reviewed for this dissertation that provide supporting content, and whether that content is provided by linking out or storing the content onsite.

Portal Name	Portal Features					General or Disease-Specific	Usability Study		
	Medical Records	Messaging	Diagnosis-Specific Information	General Education Information	Schedule Appointments		Survey	Activity Tracking	Focus Group/ Interview
PatCIS [15]	x					General	x	x	
IDEATel [16]	x		x			Diabetes	x		
PCASSO [15, 17]	x					General			x
SPPARO [91]	x	x	x			Congestive heart failure	x		
MedAxess [92]		x				General			x
MyHealth @Vanderbilt (MHAV) [93, 101, 102]		x		x	x	General			
Akteonline [20, 103]	x	x			x	General			
MyChart [18]	x	x			x	General	x		x
Practice-based Web Portal [99]	x			x	x	Unknown			x
MyCare Connection [94]	x	x	x			Arthritis, Diabetes Cystic fibrosis	x	x	
Care Online: Novel Networks to Enhance Communication and Treatment (CONNECT) [104]	x	x				Unknown			

Table 1. Portals reviewed.

Portal Name	Portal Features					General or Disease-Specific	Usability Study		
	Medical Records	Messaging	Diagnosis-Specific Information	General Education Information	Schedule Appointments		Survey	Activity Tracking	Focus Group/ Interview
myHealth [13]	x	x		x	x	General	x	x	
Microsoft HealthVault [14, 19]	x					General			
Google Health [5, 14, 19]	x					General			
Palo Alto Medical Foundation (PAMF) Portal [21]	x	x			x	General			x
Patient Gateway [22-24, 106]	x	x			x	General and diabetes-specific	x		
Diabetes STAR [48, 107]	x					Diabetes	x		
MyChildren's [25]	x	x			x	General	x		x
PatientSite [27, 28]	x	x				General		x	
IPHR [101]	x					Diabetes and breast cancer	x		

Table 2. Portals reviewed continued.

MyHeath@Vanderbilt (MHAV) is an example of a general health portal that contains additional health information in the form of general health literature [93]. MyHealth also gives patients access to additional general health literature [13]. In contrast, the Practice-based Web Portal directs patients to supplementary content in the form of links to quality, outside patient health

content [99]. Microsoft HealthVault does not provide directed additional content, but does facilitate searching with a specialized search engine focused on health information [19].

Portals can also enable users to contribute content. Akteonline allows patients to upload additional content such as photos as well as write in a medical journal [103]. Additionally, the portal does not provide access to additional educational content created by an authority source, but does have a forum for users to submit questions that can be answered by other users and healthcare providers [103].

While a few of the general health portals reviewed supply additional content, three of the four disease-specific portals include extra content. IDEATel gives patients access to additional educational materials alongside their records [16]. However, the relationship between the educational materials and their record is not demonstrated, nor are diagnoses (juvenile idiopathic arthritis, diabetes, and cystic fibrosis). In other words, patients can access additional health information, but the portal does not indicate how this information relates to the user. Through SPPARO, patients have tailored educational information based on the content of their diagnosis, but not specific to their record, again not illustrating how the additional content relates to their record. MyCare Connection, developed at Cincinnati Children's Hospital Medical Center (CCHMC), not only provides general educational content but also three different interfaces designed (one for each diagnosis) for access to an online version of a patient information packet [91]. The information packet provides patients with supplemental information; however, patients with the same diagnosis all receive the same information. The portal does not help to direct patients to information that is personally relevant to them (based on the content of their record) and thus does not limit cognitive overload or filter out irrelevant information beyond providing diagnosis-specific content.

2.2.5 User Studies

User studies determine the usability of a tool. Usability refers to how easy to use and learnable a tool is to a user. It therefore evaluates the effectiveness of the tool to help the user reach their objective [107]. Usability studies take many forms. In some cases, user preferences and responses are directly surveyed. In other cases, users are monitored while completing tasks, monitored over the number of steps taken to complete a task, and asked to think-aloud during completion of tasks. Another additional method for capturing usability is to engage users in focus groups or interviews. Broadly, the types of usability testing employed during development of a tool depend on the researchers' resources and their end goals. However, designs should be evaluated based on user goals prior to implementation, as it is difficult to correctly anticipate user needs without incorporating user feedback early in the design process [108, 109]. This perspective is also a strong tenet of software engineering, wherein users are engaged prior to the development of a program or application to ascertain typical use cases, potential prototype designs, and end expectations. Performing a set of preference surveys prior to design helps eliminate incorrect assumptions.

In spite of the demonstrated value of usability studies, the majority of the articles reviewing patient portal systems did not indicate that user studies (surveys, interface testing) were conducted before portals were made publically available. Those that did conduct user studies tended to do so after the portal had been released [13, 15-18, 21, 24, 25, 92, 99]. Arguably, surveying the user population only after development is an attempt to be patient-centered, but involves assumptions regarding patient beliefs, needs, and preferences in creating the initial design. The types of usability testing varied among portals and included: recording use of website features [13, 15, 91, 94], surveys [13, 15, 16, 18, 23, 25, 94, 102], focus groups [18, 21,

25, 102], and qualitative interviews [15, 17, 18, 92, 99]. Although the majority of researchers who did usability testing conducted surveys, some did not. While [99] did not complete a formal survey of patients, they did collect anecdotal interviews suggesting that patients felt they benefited from having access to the portal. However, as with [99], it is difficult to collect enough of these anecdotes to be of significance. Thus, while this assessment attempts to glean feedback from patients, it does not evaluate how well the design anticipated user needs.

While some studies conducted usability testing, their results were not well documented. CONNECT researchers [104] cited the need for usability studies and stated that CONNECT is user-centered, as patients were involved in every step of the design process. However, the article does not document how patients were involved. Without knowing users' involvement in the design process, the true patient-centeredness of the design is difficult to assess. With Kaiser's MyHealth, data for the survey was not published; although, it was noted that perceived usefulness and quality were predictors of use [13]. Likewise, the statistics from the PCASSO user study on satisfaction were not reported, making it difficult to know the extent that the portal met user expectations [17].

This review indicates that although researchers across the field note the importance of having tools that are user-centered, little work has been done to establish user needs before the development of a portal. Further, some of the work shows an EHR system, designed for clinicians, serving as the basis for patient portals [15, 16, 19]. For example, the PatCIS' interface is an altered version of the physician interface for the system [15]. PatCIS conducted usability studies; however, the interface design, and thus the paradigm, were created for physicians and then were used to assess how well this interface met patients' needs. Google Health and Microsoft HealthVault also provided patients and clinicians with the same view [19]. Similarly,

the PCASSO interface divided the content by the medical department in which the information was collected [15], a layout that remains suggestive of a physician's paradigm. Using an interface designed for physicians means that the designers of these portals likely took a limited consideration of the values, needs, and preferences of patients during interface design. This is in spite of an overwhelming consensus, that patients and clinicians use and understand very different language when discussing medical phenomena. Less well-documented – although alluded to – is that these differences in language reflect a difference in the way patients think about their health.

Some works did not appear to conduct any usability studying, even after deployment. As mentioned above, there does not appear to be documentation of user assessment for MHAV [93, 101, 102]. Akteonline also does not appear to have been assessed for user feedback either before or after initial deployment [20, 103]. Akteonline design did not evaluate the user paradigm with user studies; however it does have a method for users to alter the content on a personal basis, allowing patients to add content.

No user studies prior to the development of Google Health or Microsoft HealthVault are noted; although [14] looked at a group of military service members trying Google Health in comparison to others trying Microsoft HealthVault. This study found that the majority of participants, 169 (67.6%), preferred HealthVault. Google Health required schema enhancement to add access to clinical notes and radiology reports, which were not part of their initial application. Neither application makes use of metadata provided by the Department of Defense (DoD), and both have interfaces that required users to scroll through long lists of documents.

In contrast to the numerous applications reviewed here that either did usability testing only after deployment or conducted no usability testing, MyCare Connection is a prime example of

usability testing. Usability testing, when done correctly, is an iterative process that should occur throughout development and deployment. Prior to the development of MyCare Connection, surveys were distributed to the user population (in this case the parents of patients at CCHMC) to determine what tasks and features they thought were most important for a portal to have [94]. Once the portal was constructed, CCHM went through three rounds of usability testing, with alterations to the system based on user feedback. Usability testing consisted of individuals using the system to complete goal-oriented tasks while being timed and asked to think-aloud. There was no significant difference in rates of satisfaction with the system between rounds, yet the percentage of patients able to complete specific tasks, such as checking lab results, increased with each redesign. In each round the interface was also changed to include a page that focused on data content that was of specific interest for the user population (e.g., pulmonary function test results for cystic fibrosis). In spite of this attempt to alter the visualization based on the patient populations' area(s) of concern, patients from all three disease populations rarely consulted diagnosis-specific content first [94]. When users were surveyed after using the portal, the system scored high for interface appeal (a score of 5.9 out of 7); however, few were satisfied with the error messaging capabilities (a score of 2.3 out of 7), and less than 60% were satisfied with the system overall.

Patients using SPPARO were surveyed both prior to, and after using SPPARO regarding their impression of accessing their medical records online. These surveys did not prove to be as thorough as the usability testing done in MyCareConnection. Surveys did not ask specifics regarding the types of content or interface components patients would prefer to access. Instead, they queried about patients' associations with online access to their records in general [91]. The

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usability research done in this study was not actually reflected in the design, but could be put to use in redesigning a future update of the portal.

To be patient-centered, portal design must acknowledge that users will have varying preferences for the depth of information, as well as different levels of education and familiarity with health topics. To allow for these differences, supplemental educational material should be integrated into the patient view. This educational material should be tailored to the content of the patient's record, to limit information overload and to direct patients toward what is relevant. However, it should remain supplementary, available if the user opts to view it, but not required. Nonetheless, patient portal design must attempt to utilize documents created via a physician narrative to create a patient-centered visualization.

Patient portals primarily consist of textual content, but can also use graphs and images to help convey information. Images can assist in the abstraction and simplification of certain information. Consider the difference in data values as a list of numbers with dates, versus those same data points plotted on a timeline. The timeline can allow for overall patterns in the data to be more quickly identified. However, health information visualization needs to be both appropriate and easy to understand [110]. For instance, while plotting glucose levels over time may be appropriate to a patient who has diabetes, it may be irrelevant for a patient diagnosed with lung cancer. With the diabetic patient, plotting three readings a day may prove overwhelming when looking at a month's worth of data. Visualizations should be simple and uncluttered [110]. For the glucose example, this might mean having multiple views of granularity, such as a monthly view where the daily average glucose is plotted, and a day view where all three data points are plotted.

[110] also suggests making components as modules (demographics, procedures, clinical notes) so that components relevant to a particular patient can be easily selected. Similarly, [24] organized a portal into modules to allow for customization, such as importing medication lists based on diagnosis.

2.3 Technical Considerations and Implementations

2.3.1 Information Standards

[111] cited a standard framework for using clinical information in information technology (IT) and suggested it can be applied to patient IT as well. The proposed framework is comprised of five facets: vocabulary, clinical standards, messages, workflow, and technical standards. The vocabulary facet can utilize concept unique identifiers (CUIs) from the Unified Medical Language System (UMLS) to ensure that the same concept can be referenced across different reports, where it might be expressed with different terms. Messages for clinical information use the Health Level 7 (HL7) (version 3) message model, which can accommodate patients as creators of health information [112].

The majority of patient portals reviewed here use a remote server, allowing patients to either access their record via a browser or a proprietary server with dedicated software to provide access. Remote server architecture is seen as having the benefits of standardized data exchange and representation [113]. However, it requires strict adherence to security and carries the cost of development, maintenance and upgrading. Once logged on to a portal, patients can retrieve their actual documents via requests to the server as seen in [110]. These requests return documents formatted in XML.

2.3.2 Open Challenges

In this prospectus, I define a conceptual information model as a representation of entities and their relationships with one another. Here the conceptual information model contains medical entities relevant to the patient's healthcare experience, such as "diagnosis", "treatment", and "imaging." As patients' information preferences and needs have shown to vary by diagnosis, a portal must utilize an information model based specifically on the anticipated user population. For example, [60] found that cancer patients want to be more involved in decision making process than they were prior. To be involved, patients need more information relevant to their diagnosis and treatment options.

For a portal to be disease-specific, the information model should provide a disease-oriented view. A disease-oriented view offers a context for patients to understand the information within their record beyond the date that information was collected. Examples of the data collected will vary by disease, such as imaging for a patient undergoing screening for cancer. The model also assists in linking relevant supporting content, which is domain specific. Simply linking all possible definitions to a term is inappropriate, as it still requires the user to determine what is relevant to their health. Similarly, compiling all patient health information for a patient to browse does not limit cognitive overload or assist patients in determining what is relevant to them. Instead of merely amassing all content, a portal should filter out irrelevant content based on a patient's diagnosis and the content of their medical record. For example, while a patient with non-small cell lung cancer (NSCLC) can experience a variety of symptoms and undergo numerous diagnostic tests, they should not be directed towards all information on all possible symptoms and procedures. Rather, while they should have access to all information, they should be steered towards that which is reflective of their presentation and experience. This personal

presentation will vary from other NSCLC patients. For instance, a patient who is noted as a smoker in their record should receive information on smoking cessation. This same information to a non-smoker would be irrelevant.

Having content that is relevant to a patient's diagnosis is not enough to ensure that a portal will be used. To be successful, an application interface must be attractive and easy to use [110]. Perceived usefulness and quality are factors affecting use rates of healthcare technological tools [13]. It is, therefore, necessary to design tools that not only contain quality information, but are apparent in their usefulness and quality. Usability is in part a subjective assessment, but it can be defined as the user's assessment of how well the product performs based on their experience using it [107]. Usability assessments rely on the feedback from a group of intended users via usability testing.

While no patient tool will make all information clear, there is a need for tools that mediate between professional and patient health paradigms. To be beneficial to the patient, the paradigm must be patient-centered, in that it is focused on patient values, needs and preferences; and uses these foci as a guide for all design decisions [114]. This is not to oversimplify and state that all patients have the same paradigm. This work poses that the information relevant to a patient may depend on his or her diagnoses. For example, lung cancer patients rate access to information on: treatment, survival statistics, symptoms, and side effects of treatment as essential [60]. While these topics could be applicable to an array of diagnoses, the content of each is specific to the diagnosis, i.e., the treatment for diabetes is not the same as the treatment for lung cancer. It is likely that other patients dealing with cancer may want to see similar content, but patients not dealing with cancer may not be as interested in concepts like survival statistics.

To utilize a patient paradigm, informatics tools will utilize lay concepts, definitions, images and models to make relevant health content understandable to a wider audience of patients. Current implementations of some of these design features include: the HL7 information button [115] and MedlinePlus Connect [116]. Both of these features provide patients with access to additional information based on the content of their health records. These resources are no doubt of some assistance to a patient. This work investigated whether supporting information that was tailored to the patient, and made available within the portal, proved appealing.

This research theorizes that the medical document architecture needs to be improved upon if the content is intended to be patient-centered because medical document architecture does not focus on patient information needs as the primary objective. This dissertation tested whether patients preferred disease-oriented information architecture with integrated supporting information, and whether their portals should be constructed around the narrative of their diagnosis.

For this work, the information collected within the health practitioner paradigm (and reflective of the health record) was transformed, using a conceptual information model with the capacity to construct the information in a way that is reflective of the patient paradigm (reflecting patient information preferences). The conceptual model design method focused on capturing the patient experience in lung cancer screening. This model linked educational patient health information to record content, and was used as the basis for an interface to display that integration. Patients were surveyed to determine whether they preferred this disease-oriented, health information-integrated view, or a more traditional format.

CHAPTER 3 Conceptual Information Model

The primary foundation for this work is the method to design the conceptual informational model for lung cancer screening. This chapter defines what the conceptual information model is, how it was designed, and how it is used to create dynamic personal visualizations of patients' radiology reports that link those reports to additional educational content. The first section (3.1) defines what the conceptual information model is, what classes are contained within the model, what concepts are contained within those classes, the relations and supporting educational content for each concept, how supporting content was assessed in terms of literacy level, from what sources the supporting content was created, and how the model was used to annotate patient reports to link those reports with educational content. 3.2 describes the XML schema file for the model that can be used to instantiate a markup file for a web page utilizing the model. 3.3 illustrates the ontology used with this model. 3.4 documents the method that was used to create and revise the model. 3.5 demonstrates how the model was used to create a patient portal interface.

3.1 Information Model for Lung Cancer Screening Overview

The conceptual information model is used to design dynamic pairings of patient record content and supporting educational information for patients undergoing the lung cancer screening process. The conceptual information model contains concepts identified to be relevant to a patient in order to understand the lung cancer screening process and their test results. The method through which information was deemed relevant is outlined in 3.4. The goal of this research was to link concepts occurring within a patient's medical record with supporting educational health content to create integrated, personalized versions of educational content in an effort to improve the usability of the reports. The criteria for inclusion in the conceptual information model were that concepts: pertain to the screening process (identified by lung cancer

screening guidelines), were of patient interest (documented by a literature review of patient information needs and a survey of patient information needs), and were contained within a patient's medical record (made evident by the manual annotation of patient records). The information model consists of nine classes: *Symptom*, *Finding*, *Comorbidity*, *Smoking Status*, *Sputum Test*, *Pulmonary Function Test*, *Biopsy*, *Excision*, and *Imaging Test*.

Each class within the model contains concepts specifically related to that class. For example, within the class *Symptom* are the concepts: *chest pain*, *coughing blood*, *fatigue*, *hoarse voice*, *respiratory symptom*, and *weight loss*. Concepts for each class are located in Appendix A. The methodology through which concepts were included began with a review of the most common types of procedures, pathology, symptoms, and comorbidities from lung cancer screening and lung cancer guidelines from National Comprehensive Cancer Network (NCCN), the Merck Manual, and UpToDate [117-121]. The lists of the most common types of procedures, pathology, symptoms, and comorbidities taken from these sources were reviewed and revised by participating physicians.

The goal of this work was to improve patient record infomraiton usability. Usability is a subjective assessment, and difficult to caput, but understandability can be measured. Thus this model and the visualization produced by it are entitled Retrieving Understandable Medical Information (RUMI).
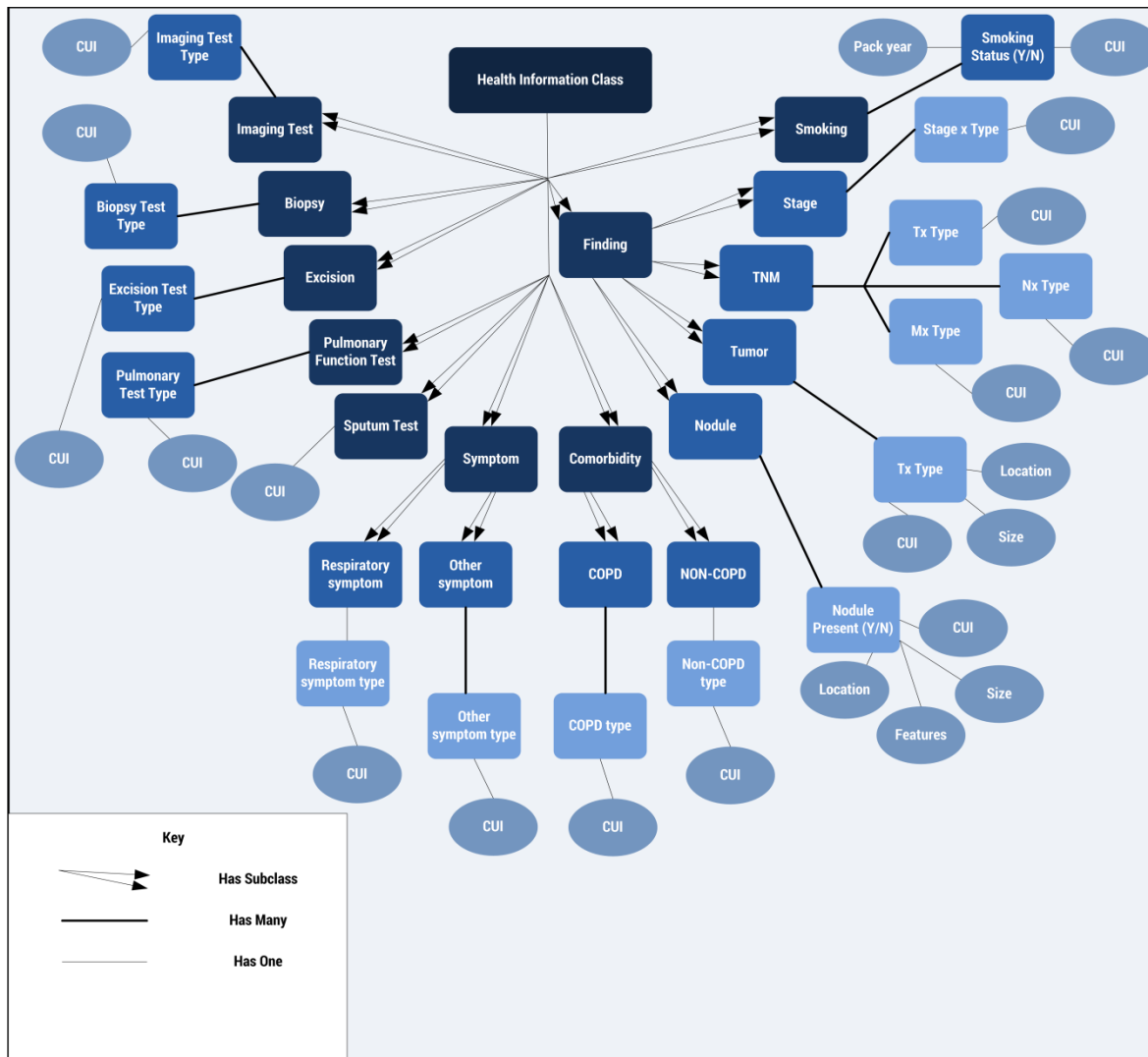
Figure 1. RUMI conceptual information model.

3.1.1. Classes, Concepts, and Relations within the Conceptual Information Model

The RUMI conceptual information model is seen in Figure 1. The concepts in the information model span a variety of relations. There are classes that have relations (e.g., parent-child) that are found in a typical hierarchical ontology, such as *Imaging Test*, *Comorbidities* and *Symptom*. However, the variable found within the class of *Smoking Status* demonstrates the chronology of tobacco use, and the classes of *Nodule* and *Tumor*, which are subclasses of the class *Finding*, have concepts' attributes that are physical qualities (*size*, *location*, *features*). A subclass of an

entity is indicated by double arrows connecting the two. The color of an entity is reflective of its hierarchical rank, with darker shades corresponding to higher levels.

3.1.2 Supporting Educational Content

Each concept in the model has supporting educational content, which is included to educate the user about the meaning of that concept and how it relates to the lung cancer screening process. The supporting information consists of two types of sources: information from professional guidelines and information from consumer health sources. Content sourced from professional guidelines was taken from the National Comprehensive Cancer Network (NCCN), the Merck Manual, and UpToDate [117, 121, 122]. Supporting consumer health information was taken from patient sources including: MedlinePlus, the National Cancer Institute (NCI), the Consumer Health Vocabulary (CHV) via the Unified Medical Language System (UMLS) Metathesaurus, NCCN for patients, Cancer.gov, and UpToDate for patients. [122-127] When suitable supporting content could not be harvested from these sources, supplemental content was written by a collaborating UCLA physician. Supporting content taken from the aforementioned sources was also reviewed by this physician and revised when deemed too confusing or simply unhelpful.

Patient-oriented sources, such as MedlinePlus, tend to provide introductory information and definitions of medical terms. The content of these consumer sources was written specifically with a lay audience in mind. This easy to understand terminology and foundational content provides a good basis for patients who are first encountering a concept, or who want less granularity of information.

Professional guideline content, in contrast, provides a rich amount of detail, coupled often by varying levels of certainty. Professional guidelines also provide likely treatments and other courses of action, given a particular symptom, finding, or diagnosis. This content is not well

suited to introduce patients to concepts. However, content written at this level can provide a much finer granularity of information, and provides further understanding in patients that are already familiar with basic knowledge on a topic. While the varying levels of certainty may not provide guarantees in terms of outcomes, they can help to communicate what factors are impacting outcomes.

Content from patient-oriented and professional sources were combined together to create one piece of educational content per concept. Although differences in focus and level of detail are seen between the original two types of supporting content, users had consistent information content provided via the conceptual information model. To do this, the topics from each type were combined. To address literacy level and desired description complexity, a participating physician assisted in revising the language of the supporting content of each type. This revision resulted in both the patient-oriented and the professional support content containing the same information themes, but the professional content utilized more scholarly language and occasionally more details. This distinction was quantified using the Simple Measure of Gobbledygook (SMOG) [128], which is explained in the next section.

3.1.3 Simple Measure of Gobbledygook (SMOG)

To ensure that the revised patient-oriented supporting content requires a lower literacy level than the professional content, each piece of supporting content was assessed with the Simple Measure of Gobbledygook (SMOG) [128]. The equation for determining written content's SMOG score is seen in Equation 1. SMOG has been used by researchers in the consumer health field to determine how difficult content is for the average consumer to read [128-130]. SMOG has been shown to be more conservative in its estimates of literacy level when compared to other literacy level assessment tools [129, 131]. All SMOG scores for the support content are in Appendix A.

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$$Grade\ Level = 1.0403 \times \sqrt{number\ of\ polysyllables \times \frac{30}{sentences}}$$

Equation 1. SMOG equation.

The majority of concepts have patient-oriented content that scored lower than the professional content. However, there are nine concepts that have higher SMOG scores for the patient-oriented content than the professional. Of these, four have patient-oriented and professional scores that are less than a one point (grade level) difference. The remaining five have more than one point but less than two. These concepts' educational content was left in this format as it was reviewed and approved by a physician as appropriate. While the majority of concepts have both a patient-oriented and professional definition, some classes and concepts only have a patient-oriented definition, as the participating physician did not find that any additional complexity in language or detail was necessary to further explain the concept.

3.1.4 Images with Definitions

Illustrative images accompanying definitions were taken from a variety of sources, with the majority taken from Medline Plus and Cancer.gov [123, 125]. These sources were identified through the process of consulting the sources listed above for consumer-sourced content. All images used were by expressed permission within the context of this study. To do this, all image sources were individually contacted via email to ask permission to use the specific sources for this dissertation. In the event the source did not own the content, as was the case with many of the Medline Plus images, the owner information was obtained, and the owner of the replication rights was contacted to ask for permission. While the images used were done so with explicit permission for the purpose of this research, additional uses of the portal, such as on a wider

scale, would require that new permissions be obtained. In the event no appropriate image was found from a consumer source or permission to reuse the image could not be obtained, then no image was provided for the definition. Professional sources of definition content were not used as potential sources for image content, to avoid the risk that displayed images would go beyond what an average person could understand and potentially cause additional confusion or stress.

3.1.5 Data Collection

Data necessary to populate the information model for each patient was based on report annotations, which were collected by two undergraduate students (trained by me) and myself. Enrolled patients' low dose CT (LDCT) radiology reports were obtained via CareConnect. These reports were saved as text files and stripped of all PHI except for the data on which the scan was conducted. The date was retained to provide users with a sense of accuracy by displaying the date on which they had the scan to confirm that they were viewing their own personal record. The need to support a sense of accuracy was necessary due to the lack of a log-on process, which is a more traditional way to not only keep information secure, but affirm its provenance and accuracy to a user.

3.1.5.1 Report Annotations

Report annotations were manually created from enrolled patients' LDCT radiology reports. Annotations were completed using BRAT [132]. The annotation protocol was based on a physician's consensus with example annotations completed by me. An annotation document outlining synonyms and examples was written based on this consensus and given to each annotator. The annotators used these materials to guide them during the annotation process to ensure consistent annotations. This list of synonyms can be found in Appendix B.

Annotations for each patient are stored in an ANN file. These annotations were used to retrieve model concepts' definitions that were contained in a MySQL table. All the content for a patient (report, annotations, and definitions) was retrieved and combined, with the annotated concepts from the report used to pull the concept definitions, creating a personalized set of supporting educational information for the patient.

Before the annotators began annotations of enrolled patients, a gold standard of internal consistency was reached by consensus during a training exercise. The training set consisted of 30 LDCT radiology reports that were formatted with the LungRads format but did not belong to a RUMI enrolled patient. Each annotator annotated all training set reports. Inter-agreement was assessed comparing annotation text spans' (i.e., each time a concept is annotated in a document) harmonic mean, or F-measure, as seen in [133]. The F-measure was used as there is no negative case count. The average F-measure for the training documents across all documents across all annotators was 0.992, demonstrating a high rate of precision and recall. Any conflict in annotations was resolved by consensus (2/3), and when consensus could not be reached, by a participating physician.

3.2 XML Schema of Conceptual Information Model

The model can also be instantiated via a developed XML annotation schema. The XML schema documents the model's classes and concepts as elements, with each class element containing concept elements and attributes for each concept element (i.e., CUI, definition). Both the class and concept elements are of a complex type, as class elements contain concepts and concepts contain attributes. The XML schema can be used to create an XML document for each patient report, annotating elements corresponding to model concept. The XML schema allows for this

model to be consistently instantiated in other settings. The XML schema file is located in Appendix A.

3.3 Annotation Ontology

As noted in UMLS documentation, multiple terms can have the same meaning, and thus be considered semantically the same concept. The annotation linking method of concepts to information utilized all English synonyms seen in Appendix B. This list primarily consisted of synonyms listed in the UMLS Metathesaurus for each concept, but was also augmented by synonyms found within UCLA patient reports that were compiled by me and reviewed by a physician. For the annotations, if the concept's unique identifier (CUI) preferred term or any of its synonyms occurred within a report, that term was annotated and linked to the CUI's associated supporting educational information. Examples of concepts that have had their synonym list expanded based on the content of radiology reports included: *stage I*, *stage II*, *stage III*, *stage IV*, *nodule*, *CT biopsy*, *CT* and *X-ray*. The concepts *stage I*, *stage II*, *stage III*, *stage IV* (respective CUIs "C0278504", "C0278505", "C0278506", "C0278987") were chosen as they specifically indicate staging for lung cancer. However, doctors writing reports will often not specifically use the words "lung cancer" before or after listing the stage, as this phrase is implicit to the context (the report's metadata, and other report content). Therefore, the *Stage* class concepts had their synonym lists expanded to include just the individual phrases "stage I", "stage II", "stage III", "stage IV", even when the phrase "lung cancer" did not follow or precede an individual phrase, as all reports annotated here were found within the domain of lung cancer. Similarly, the concepts *CT biopsy*, *CT*, and *X-ray* (respective CUIs "C3655554", "C0202823", "C0039985") were chosen as they are specific to the lung; given the context, the practitioner documenting these procedures did not always include the word "lung" before these concepts.

Thus, their synonym lists were also expanded to include these phrase not preceded by the word "lung."

Some concepts also had their synonym list expanded to include near relations within the UMLS Metathesaurus hierarchy. One example of this occurred with the concept *nodule*. Through the prior annotation of reports, it was found that clinicians also used the terms "lesion" and "opacity" in radiology reports as a synonym for *nodule* (CUI "C0034079"). However, in UMLS, *radiologic opacity* (CUI "C1265598") is a child of *finding of lesion* (CUI "C0577301"), while *lung lesion* is a child of *lung finding* (CUI "C0577914"). The UMLS lists *lung nodule* (CUI "C0034079") as another child of *lung finding*. As these concepts were seen during prior annotations and used synonymously by clinicians, the *nodule* synonym list included "opacity" and "lesion." Similar to the expanded synonym lists, these terms were annotated even if "lung" did not precede them, if the context implied they were pertaining to the lung.

All the manual expansions to the synonym list were reviewed by the collaborating physician, who approved of all additional synonyms. However, she also requested that the synonym "CXR" was added to *X-ray*; and "CT lung biopsy", "image guided biopsy", and "percutaneous lung biopsy" were added to *CT biopsy*.

3.4 Conceptual Model Design Method

The method to design this model consisted of several steps. First a standard literature review of portals and a review of professional guidelines were completed. Next patient surveys, annotations of patient reports, and feedback from two physicians and two informaticians were obtained. The model was reviewed and refined after each step reflecting the changes necessary that had been made evident after each source was consulted. The following section discusses each step in detail.

3.4.1 Literature Review

Thirteen journal articles on the subject of patient information needs and preferences were used to determine the types of informational content patients are interested in, as seen in Table 3 [134]. Articles that studied the information needs of cancer patients, and the information needs of other types of patients, were used. Selection criteria included: 1) articles written in the last 20 years, 2) articles published in a peer review journal, and 3) articles that documented information needs of patients. Themes occurring three or more times across the literature were noted. Prominent themes included the desire for information on: diagnosis, diagnostic tests, treatment options, symptoms, and common side effects of treatment.

A candidate list of clinical concepts with associated contextual explanations was then generated, based on a review of the NSCLC diagnosis guidelines from the National Collaborating Center for Cancer and UpToDate [119, 135]. These guidelines were visualized as a flowchart, composed of connected nodes. Each node was then considered a candidate concept for the model (Figure 2). Each theme from the literature was considered a class. With this candidate list, the data model was organized, with the constraint that concepts included in the model were indicative of classes seen in the literature review on patient information needs. Table 4 shows the initial model structure of patient information need classes and corresponding concepts taken from guidelines. Following this initial linking of candidate concepts to classes, pathology, laboratory, oncology, and radiology reports from sixty patients were manually annotated to determine the presence of these candidate concepts in clinical reports. These types of reports were included because it was anticipated that the model could potentially be applied to patients who are beyond the screening process as well. However, patients who have transitioned from screening to treatment are beyond the scope of this dissertation.

Citation	A	B	C	D	E
Bass et al. 2006 [36]	X	X			
Butow et al. 1997 [58]	X	X			
Clauser et al. 2011 [59]	X	X	X	X	
Davidson et al. 1999 [62]		X	X	X	
Grant et al. 2006 [24]	X	X			X
Gore et al. 2000 [56]	X	X			X
Hess et al. 2006 [61]	X	X			
Jenkins et al. 2001 [55]	X	X	X		
Koch-Weser et al. 2010 [74]				X	
Leydon et al. 2000 [57]	X	X	X		
Murray et al. 2002 [138]	X				
Sarkar et al. 2010 [65]					X
Slaughter et al. 2005 [139]				X	

Table 3. List of literature and the topics each citation contains. Themes include: A: Diagnosis, B: Treatment, C: Common side effects of treatment, D: Symptoms, E: Diagnostic tests.

The working list of concepts was revised further 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, concepts indicative of indeterminate nodules were found. These nodules had not been previously included in the model. This finding required enumeration of several new concepts concerning an indeterminate nodule. Additionally, a patient's smoking history was frequently mentioned in reports. As smoking history information and the presence of indeterminate nodules are relevant to understanding the application of a diagnostic guideline for NSCLC, these concepts were incorporated into the model. To determine what class to put the newly identified concepts in, the data model was examined from the bottom level up the schema. Since it was found that these concepts were not well represented by any of the existing classes, the list of classes was revised to add the classes

of *Nodule* and *Smoking Status*. All concepts and classes were then manually matched to their UMLS CUIs.
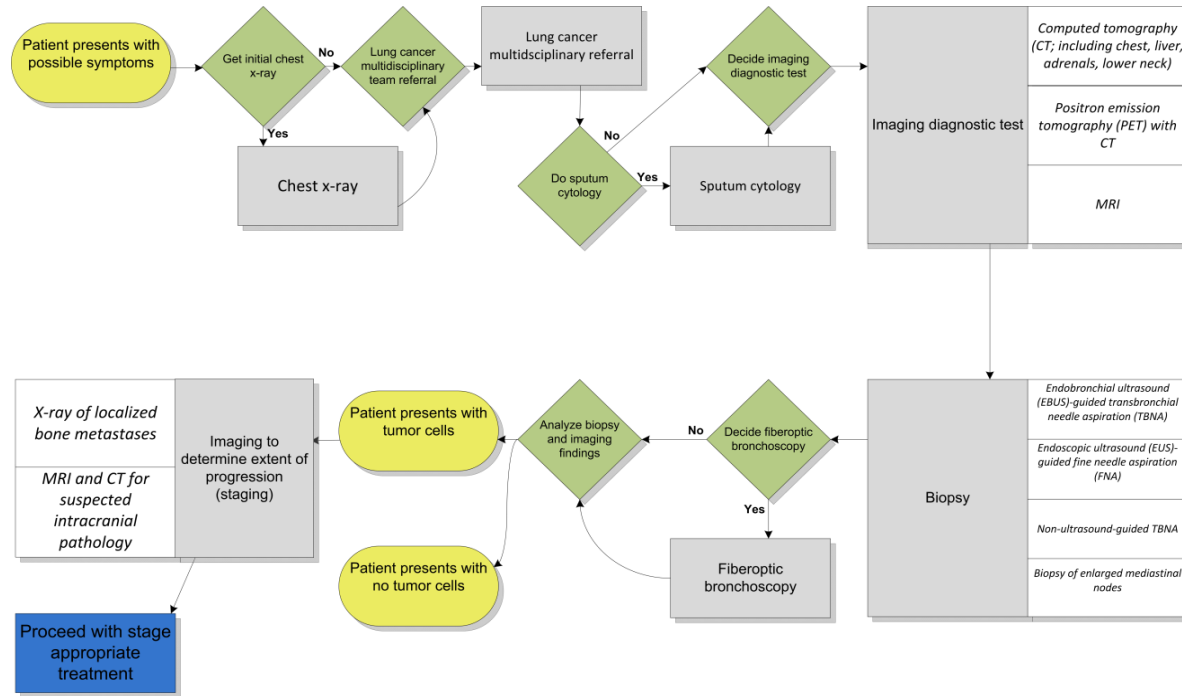
Figure 2. Flowchart depicting lung cancer diagnostic process clinical guidelines.

3.4.2 Survey

A survey of 41 lung cancer patients at UCLA was conducted [136]. This survey provided data on this specific group of patients' perceptions of patient portals and what types of information they deemed to be useful to include in portals. Survey results can be found in Appendix C. This population was surveyed, in contrast to lung cancer screening patients, as the screening clinic was still in a planning stage and did not provide direct access to lung cancer screening patients.

Findings from the survey were supportive of patient portals and the provision of access to radiological content. In regards to a patient portal visualization, only 1 person (2.4%) did not want to see their personal medical information. 90.2% wanted to see information about their health problems, 90.2% wanted information about their radiology test results, and 80.5% wanted

to see information about their doctor's notes. Patients surveyed also demonstrated a preference

for digitally formatted records, as 70.7% wanted to see their records via the Internet.

Class	Number of Citations	Concepts Mapped to Class
Diagnosis	7	Tx, T0, Tis, T1, T2, T3, T4
Diagnostic Tests	3	bronchoscopy, thoracentesis, LDH, PET scan, albumin, chest X-ray, computed tomography, pulmonary function test, MRI, thoracotomy, fine needle aspiration, mediastinoscopy, blood test, bone scan, sputum test, video assisted thoracoscopy
Symptoms	4	weight loss, fatigue, chest pain, lung infection, breathing trouble, cough, hoarse voice

Table 4. Model based solely on literature review and guidelines.

Regarding viewing radiological images, 46.3% strongly agreed that they would like to view their

radiology images. 24.4% agreed, while 19.5% were neutral about whether they would like to see

their images and 7.3% strongly disagreed that they would like to see them. 92.6% wanted to

know the important findings the doctor observed in their images, and 78% wanted to read

explanations of their radiology reports. 46.3% strongly agreed and 34.1% agreed that

understanding their medical images would help them manage their health problems.

Anticipating how viewing their information would affect them, 29.3% strongly disagreed that

accessing their information via a patient portal would increase their anxiety, 22% disagreed, and

22% were neutral about whether accessing their information via portal would increase their

anxiety. 19.5% agreed that it would increase their anxiety and 7.3% strongly agreed. 29%

strongly agreed that patient portal access would cause them to ask their doctor more questions,

45.2% agreed, 19.4% were neutral. 3.2% disagreed that portal access would cause them to ask

more questions, and 3.2% strongly disagreed. 45.2% strongly agreed that a patient portal would

help them to follow their doctor's instructions, 45.2% agreed, and 3.2% were neutral. 3.2%

disagreed that a portal would help them to follow their doctor's instructions. Based on this

survey, patients have demonstrated a preference for diagnosis-specific information and radiological content.

3.4.3 Further Revisions

After speaking with two physicians, it was decided to present a finer detail of the diagnostic test class, refining it into five subclasses of diagnostic type (*Imaging Test*, *Biopsy*, *Excision*, *Sputum*, and *Pulmonary Function Test*). More detail regarding the *Nodule* class was also included, with the addition of the attributes of *solid nodule, ground glass,* and *multiple ground glass*. The distinctions between the types of nodule observed direct the rest of the screening process, and thus, required the addition of these concepts. The *Comorbidities* class was also added, as comorbidities are often noted in screening reports.

Additionally, as mentioned prior, one participating physician reviewed the consumer definitions for each concept. Definitions deemed too complicated for a patient looking at content for the first time were rewritten by that physician. During this process, new initial consumer definitions were written for concepts in the classes *Stage*, *Tumor*, *Biopsy*, *Excision*, and *Imaging Test*.

Additionally, another physician and two health informaticians reviewed the model instantiated as the patient portal visualization and made additional suggestions regarding introductory content for the portal visualization which is discussed in the next section. This introductory content, although not formally included in the model, supports the information found in the model by providing context to new screening patients.
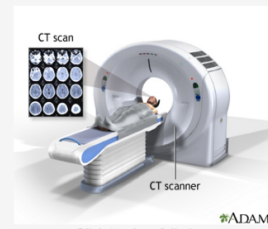
Figure 3. RUMI homepage module 1 overview of lung cancer screening.

3.5 Portal Application

The portal application utilizes the conceptual information model to populate itself. The following sections will outline the portal application pages in details, discussing the content of each and the relation of that content to the information model.

3.5.1 Homepage

The portal application homepage is seen in Figures 3-5. The homepage consists of three primary modules or sections. These modules contain content that is not necessarily found within the patient LDCT report, but was deemed helpful to understanding the screening process by participating experts, including two informaticians working at the UCLA Louise Darling Biomedical Library and the two afore mentioned physicians.
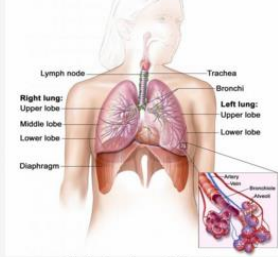
The first module provides an introduction to lung cancer screening. The reasoning for this was that patients undergoing cancer screening for the first time are likely to have questions regarding the science behind screening protocol, some of the common reasons one is selected for screening, and of what the first step of screening usually consists. The information used to create

this introduction to the screening protocol for lung cancer is taken primarily from [118] with revisions based on input from the participating physician.

Figure 4. RUMI homepage module 2 overview of lung anatomy.

The second module is an overview of lung anatomy. These concepts within the lung anatomy were chosen based on the NCI lung anatomy overview [123]. Each anatomical concept can be clicked on, resulting in a pop-up window that contains a definition of it.

The third module on the homepage is a risk calculator based on the Tammemägi risk assessment [137]. Users can input their specific information using the various drop-down menus and then enter these criteria to receive a risk score. The code used to implement the calculator on the RUMI homepage was originally written by Dr. Frank Meng, a faculty member with UCLA's Department of Radiology, and was validated by comparing input values and output risk scores between Dr. Meng's calculator and a calculator made available by Dr. Tammemägi [138]. However, the risk scores produced by the model range from 0 (low risk) to 0.03 (high risk). In

order to convey the level of risk, without distracting the patient with a score that may be unintuitive, only the risk level and not the actual score is displayed to the patient.

Learn about your risk

Your risk is calculated using a risk model based on your criteria of:

Age	65 ▾
Race	White ▾
Education	Postgraduate or professional degree ▾
Height (ft. in.)	5' 6" ▾
Weight (lbs)	148 ▾
Chronic obstructive pulmonary disease (COPD)	No ▾
Personal history of cancer	No ▾
Immediate family history of cancer (mother, father, sister, brother)	Yes ▾
Smoker	Former ▾
Average number of cigarettes I smoke or did smoke per day	30 ▾
Number of years I have smoked	34 ▾
Number of years since I quit smoking	0 ▾
Submit	Clear
6-year probability of lung cancer:	High Risk

Figure 5. RUMI homepage module risk calculator.

Also available via the homepage is a link on the left side of the page, the text of which is the date on which the patient underwent a LDCT scan. The user can click on this link and be redirected to the Report Viewer page, which is seen in Figure 6.

Figure 6. RUMI report viewer.

3.5.2 Report Viewer

Upon arriving at the Report Viewer page, the user can see their full report within the central frame. In the left sidebar are the set of concepts that are found within that report, meaning that the concept list is dynamic, based on the annotations for the patient's report within the database. A user can click on any of these concepts to see them highlighted within the report text, in order to view the concepts within context. Within the report, a user can click on an annotated concept and a pop-up window containing its definition will display with both a consumer and a professional definition, and when available, an image. An example of this is seen in Figure 7. While the consumer definition will display by default, the user can easily click on the "Professional" tab within the window to display the professional definition. Setting the consumer-sourced content as the default option for the definition view was done as participating physicians felt that it would be better to err having patients view information they are already

familiar with, than to have them view new information that is potentially overwhelming or too complex when they desire more introductory content.
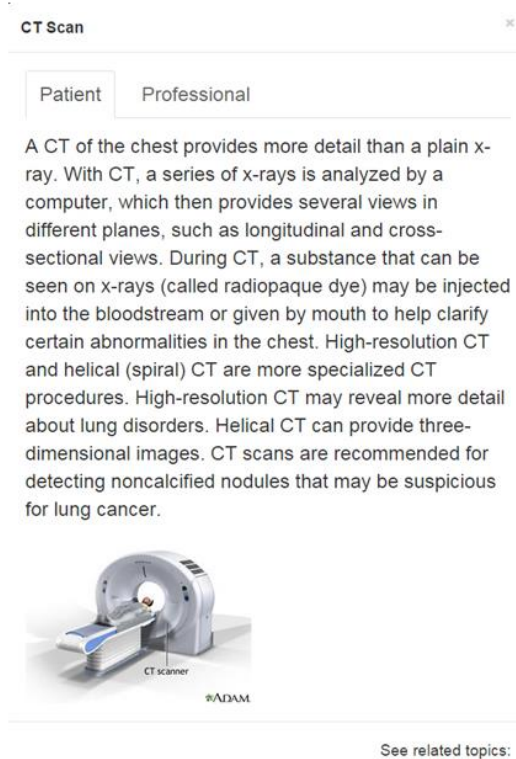
Figure 7. View of pop-up window for a concept definition.

3.5.3 Linkage of Educational Information with the Portal

The conceptual information model is used as a basis for a visualization within a patient portal interface. Specifically, the portal displays the linkage of a patient's LDCT report with the educational information available for each concept in the model. This link is created via two methods. The first is the annotation method, which utilizes the annotation task mentioned above, to provide direct automatic links between individual words (instantiations of concepts) in the patient report and concept definitions. The second linkage method is the provision of the entire model's concepts and educational content without annotations. This second linkage method

provides patients the ability to browse additional information that they would not have access to if only the annotation method was used.

Figure 8. Library main page of the RUMI portal.

3.5.4 Library

To browse all definitions contained within the conceptual information model, the user would need to click on the "Library" link seen within the banner on each page within the portal. The main Library page, seen in Figure 8, initially displays all of the classes of concepts from the conceptual information model, each as its own accordion menu containing the concepts within that class. The user must click on a class, e.g., *Imaging Procedure*, to see the concepts within it, e.g., *CT scan*. The user can then click on any concept and the right side of the page will populate with the same definition content available via the Report View pop-up definition windows.

CHAPTER 4. Usability Study

This chapter documents the usability study of the patient portal. As the portal was based on the conceptual information model, this usability study acted not only as an assessment of the portal but of the model as well. The first section (4.1) discusses the different components of the survey. The second section (4.2) documents IRB approval for the survey as an assessment tool, and for the usability survey itself. 4.3 outlines the organization of the usability study and 4.4 contains the methods for recruiting patients to the study. 4.5 and 4.6 examine the organization of each step in the study in more detail.

4.1 Survey Composition

The survey used in the usability study was comprised of three different types of questions: patient information preference questions, lung cancer and lung cancer screening knowledge questions, and demographic questions. Each one of these three types of questions had different sources. All three types were reviewed by a supervising physician, and revised by her to better serve the population of interest. All survey questions for Step I are in Tables 5, 6, and 7. The language for the survey in each step varied slightly, the variations in the survey for Step II are located in Appendix D.

4.1.1 Patient Portal Preference Questions

The patient portal preference questions were taken from the Personal Health Information Technology Survey (PHITS), which was created and validated by [139]. The PHITS survey was first used in a study of patients using a portal to review their health information. Originally, it contained eleven sections, with 32 total questions. For this work, only the questions that pertained to the domains of perceived usefulness, perceived ease of use, personalization, patient-

clinician communication, and health information understandability were used. The questions from these sections of [139] are seen in Table 5. All question responses for this section conformed to a seven point Likert scale ranging from 1 to 7 (1 completely disagree, 7 completely agree). However, the exact wording of the survey questions depended on where in the usability test process the participant was (mock-up, portal, or paper). The differences in question wording are provided in Appendix D. These differences in language reflected the different tasks the participant was completing during their current step in the usability test.

Patient Information Preference	
Variable Name	Question
becomeSkill	It should be easy to become skillful at using a portal.
commun	Using a portal can assist my face-to-face communication with my healthcare providers.
easyLearn	Portals like RUMI are easy to learn how to use.
easyOperate	Portals like RUMI are easy to operate.
educKnow	Using a portal like RUMI can provide me with healthcare knowledge and education.
effectiveness	Using a portal like RUMI can enhance my effectiveness in personal health management.
efficient	A personalized portal like RUMI can make me efficient in managing my personal health information.
managePHI	A portal can be useful to manage my personal health information.
notDiff	Portals are not difficult to use.
portAccomTask	Using a portal can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information.
productivity	Using a portal like RUMI can increase my productivity in managing my personal health information.
reduceTime	A personalized portal like RUMI can reduce my time spent on managing my personal health information.
suitNeeds	A personalized portal can suit my needs of managing my personal health information.
termVocab	Using a portal like RUMI can improve my understanding of medical terminology and vocabulary.

Table 5. Survey questions Step I.

4.1.2 Lung Cancer Knowledge and Lung Cancer Screening Knowledge Questions

Lung Cancer Screening Knowledge	
Variable Name	**Question**
blood	Coughing up blood is a frequent sign of lung cancer.
chance	In the past, before the CT scan was introduced, the chance of dying due to lung cancer after diagnosis was: (Answer options: high, somewhat high, somewhat low, low)
common	Lung cancer is one of the most common cancers.
complaint	A person can have lung cancer without any signs.
cough	A change of cough pattern is a frequent sign of lung cancer.
hereditary	Lung cancer may be hereditary.
contagious	Lung cancer is contagious.
madeX	CT images are made with X-rays.
normalCT	What is the meaning of a "normal" CT scan?
risk	Someone who has quit smoking has a higher risk of developing lung cancer than someone who has never smoked.
screenToday	What disorders are you being screened for today? (**Note: Step I only.**)
LDCT	Low radiation dose chest CT (LDCT) is a good screening test for lung cancer.
negLDCT	A negative LDCT means I do not have lung cancer.
additionalTests	If I have a negative LDCT scan, I don't need to undergo additional screening tests for lung cancer.
positiveLDCT	A positive LDCT scan means that I probably have lung cancer.
quitSmoke	A negative LDCT scan means I don't need to quit smoking.

Table 6. Survey questions Step I (continued).

Eight of the questions within this section were taken from the validated survey in [140]. When deemed unclear by a participating physician, these questions were rewritten. The additional questions focused primarily on the screening procedure at UCLA and were written by the same participating physician and added to this section. All lung cancer and lung cancer screening knowledge questions consisted of statements that could be answered with "yes", "no", or "I don't know" unless otherwise noted. These questions are located in Table 6.

4.1.3. Demographic Questions

Demographics	
Variable Name	**Question**
Age	What is your age group?
Education	What is your highest level of education?
Income	What is your approximate annual income?
Internet	In one week, how many hours do you spend on the Internet?
Race	What race(s) best represent you?
Sex	What is your sex?
Used	How many times have you used a patient health portal?
Ethnicity	Are you Hispanic?

Table 7. Survey questions Step I (continued).

The third type of questions included in the survey was demographic questions, the majority of which were taken from the U.S. Census [141]. In addition to these questions, I added questions to document the amount of time a participant spent online, the number of times prior to the usability study a participant had used a patient portal, and the geospatial information of each participant's ZIP code.

4.2 IRB Approval

To conduct usability testing at UCLA, permission to use human subjects had to be obtained via an Internal Review Board (IRB) at the UCLA Office of the Human Research Protection Program. Instead of submitting a new application, this work was approved as an amendment to the IRB application for the RUMI grant [142]. In contrast to the original grant, the population of interest for this usability study was not lung cancer patients but lung cancer screening patients. The experiment also slightly varied in the number of steps and arms in comparison to the experiment outlined in the original grant, as did the survey questions. For these reasons, the amendment was submitted to the IRB and was approved in July 2015.

4.3 Organization of Experiment

The experiment consisted of a two part cross-over study. The goal of this experiment was to determine: 1) did patients prefer the dynamic view of information provided by the portal over the paper version of their record, 2) did patients report the portal as easy to use, and 3) what was the lung cancer and lung cancer screening knowledge of a screening patient? An overview of the study visualized as a flowchart is seen in Figure 8. Each step within the study is discussed in more detail below. Usability testing was conducted from July 2015 to February 2016.
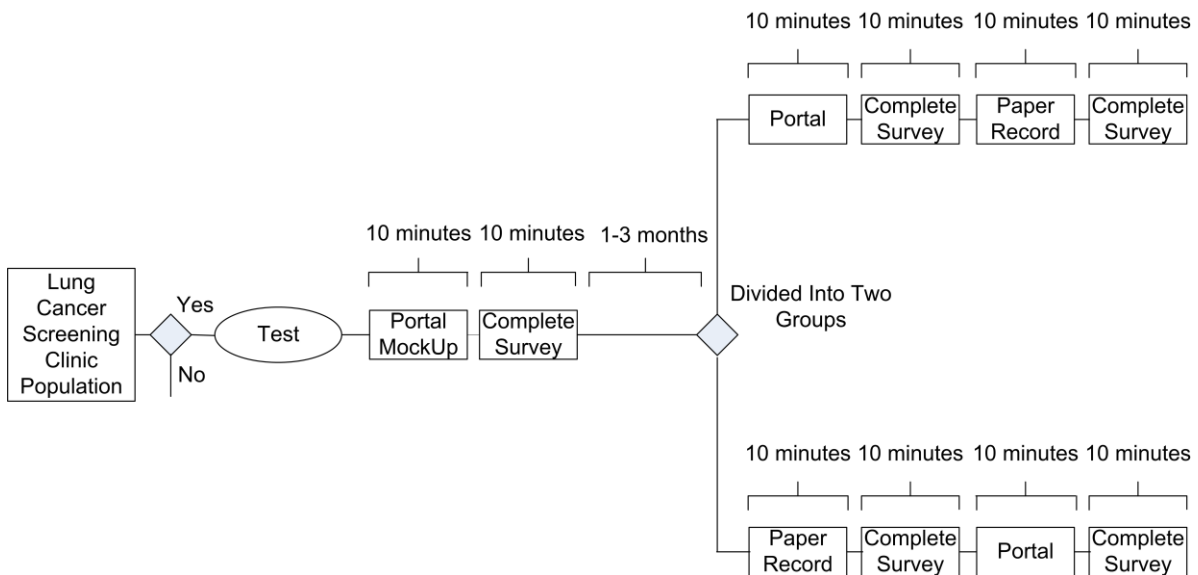
Figure 9. Flowchart of Usability Testing.

4.4 Recruitment

This study targeted to enroll 100 participants into Step I to facilitate the full participation of at least 49 subjects in both steps, in anticipation of patient drop out. Based on power analysis conducted by a supervising statistician, 49 patients provided a large enough sample size to achieve 80% statistical power. As of June 2015, on average, 30 patients a month were seen at the lung cancer screening clinic. Recruitment for the usability study was conducted from July 2015 – February 2016. Recruitment occurred via the phone. All patients who were scheduled for a

LDCT scan during the recruitment period at either UCLA Medical Plaza or UCLA Outpatient Radiology Santa Monica were contacted. This patient population was identified using UCLA's EHR CareConnect, in accordance with the IRB protocol.

When the patient was successfully reached, they were read the screening script resulting in one of three outcomes: 1) they did not qualify for the study, 2) they qualified for the study but did not want to enroll, 3) they qualified for the study and agreed to enroll. When the patient was not reached but an answering service or voicemail was available, a message introducing myself and an overview of the research was left for the patient. If a voicemail was left, the patient was then called a second time no less than 48 hours later. If during the second call the patient was reached, they were read the screening script resulting in one of the three outcomes outlined above. If the patient was not reached, no message was left during the second call. No more than two screening calls were made per patient unless the patient explicitly requested that they be contacted more than two times.

4.5 Step I

Each patient who enrolled in the study was met 30 minutes before their scheduled LDCT scan appointment to complete Step I in the usability study. This time window was chosen to give patients enough time to complete both the lung cancer screening clinic's intake forms and the RUMI usability test. After the patient completed the intake forms, they participated in the Step I usability test. On occasion, the usability test could not be completed before they were called in for their appointment. In the event the patient did not finish the usability test before they were called by the radiology technician to complete their scan, they completed the usability study Step I after they were finished with their scan. Before the actual usability test Step I was conducted,

participants signed the authorization form that outlined both steps of the usability study, potential risks and benefits of the study, and their rights.

4.5.1 Typical Patient Profiles

During the Step I usability test, patients were provided with access to the portal showing one of two typical patients' reports, since their own reports had yet to be generated. These reports were taken from UCLA radiology and were reviewed by the participating physician. The reports were similar to those of actual enrolled patients in that they used the Lung-RADS structured report template. This type of report contained minimal PHI but was manually scrubbed to remove the small amount present, with scrubbed values replaced with random values. Once scrubbed of all PHI, the reports were used as the basis for two mock-up use cases within the RUMI patient portal.

4.5.2 Coding of Step I Results

After patients completed the test, their Step I survey results were marked with a unique identifier (ID) that was assigned to them as part of the study and is in no way related to their medical record number (MRN) or any PHI information. Once survey results were marked with a unique ID, the answers were manually coded by myself or one of two research assistants. The coded data was randomly audited to ensure data quality.

4.6 Step II

To complete Step II of the study, as outlined in Figure 8, enrolled patients were contacted approximately four weeks after they completed Step I. During Step II, patients viewed their LDCT report both within the portal (referred to as Step II portal) and in hardcopy format (referred to as Step II paper). The four week follow up period was observed to provide

physicians with the time necessary to have reviewed the LDCT scan results, and to have discussed them with the enrolled patient, in an effort to reduce any additional stress that was caused by the LDCT scan results. A letter notifying physicians of their patient's enrollment in the study and the four week window between Step I and Step II was sent out within 14 days of the enrolled patient completing Step I. This letter was drafted by myself in conjunction with the supervising physician, signed by the physician, and is in Appendix E.

To complete the Step II usability test, patients were contacted via phone. If patients were reached via phone, they were reminded of their prior participation and asked to reaffirm their willingness to participate in Step II. If patients were not reached during the first attempt at contact, a message was left reminding them of their past participation, suggesting that they could return the call and indicating that I would call back within 72 hours. In an effort to ensure a high rate of study completion, enrolled patients who had completed Step I were called up to three times in an attempt to schedule them for participation in Step II.

Enrolled patients who reaffirmed their commitment to participate in Step II were met at their next upcoming UCLA medical appointment. Patients were met 45 minutes prior to their appointment, in order to give them enough time to complete the two steps within the usability study and the intake paperwork for their appointment. Patients were assigned to one of two groups to complete Step II, with the order alternating based on their chronological rank in Step II completion. The first and all subsequent odd patients to complete Step II were assigned to Group One, in which they viewed their record via the portal first and then on paper. The second and all subsequent even patients to complete Step II were assigned to Group Two, in which they viewed their record on paper first and then via the portal.

4.7 Analysis Methods for Survey Results

All data analysis utilized SPSS version 20 statistical analysis software. Univariate associations between demographics and patient information preference questions used ANOVAs unless the demographic had only two categories, in which case a *t*-test was used. Univariate associations between demographics and lung cancer knowledge questions used Chi-square tests.

All univariate analyses with significant results were used to create stepwise logistic regression models. Logistic regression was used to make the data as parsimonious as possible, as the number of cases per group was limited. Alongside *p*-values, log-odds and prediction probabilities, Nagelkerke R^2 values were also reported. The Nagelkerke R^2 statistic was used to demonstrate how useful the independent variables were in predicting the dependent variable [143].

Paired observations analysis used the Wilcoxon signed-rank test to detect differences in patient information preferences in Step I in comparison to Step II portal, and Step II portal to Step II paper. McNemar tests were performed to identify any significant differences in lung cancer screening knowledge answers between Step I and Step II portal, and Step II portal to Step II paper. As the number of cases varied considerably between the in-clinic study and the MTurk study (N=15 versus N=473), proportions were used to compare answers between the two sets of data with the chi square homogeneity of variance method, as advised by a statistician.

CHAPTER 5 Auxiliary Web Survey Design

This chapter discusses an additional version of the survey used within the usability study, which was conducted to approximate the information needs and preferences, as well as lung cancer and lung cancer screening knowledge, of the average health consumer who is not undergoing lung cancer screening. The results from this survey were compared with the results from the lung cancer screening patients at UCLA, and elucidated the differences in information needs and knowledge between the two populations. This version of the survey is referred to as the MTurk survey in this text. 5.1 documents the differences in this survey in comparison to the in-clinic survey. 5.2 illustrates the methods through which the survey was conducted, and 5.3 discusses the methods used for analysis.

5.1 Difference in MTurk Survey to In-Clinic Survey

The majority of the questions for this survey were the same as those included in the in-clinic survey, save for a difference in referencing a generic portal versus the RUMI portal. However, the in-clinic survey was longer, with seven additional patient information preference questions, eight additional lung cancer screening knowledge questions, and one additional demographic question. The patient information preference questions that were cut were done so as they discussed the same areas (e.g., perceived usefulness) as other included questions, in an attempt to have made the survey briefer in order to facilitate completion. The lung cancer screening questions that were not included were those added in a later revision of the survey. The demographic not collected by the MTurk survey was ethnicity (i.e., Hispanic or Non-Hispanic).

5.2 Methods

A version of the survey was distributed online to obtain a baseline of consumers' health information needs and preferences, as well as their lung cancer screening knowledge. This version of the survey was rewritten to reference the general idea of a patient portal, providing examples of a portal within the introduction, instead of explicitly referencing the RUMI portal. Recruitment criteria included that participants were age 18 or older and American citizens. The recruited participants were not exclusively lung cancer screening patients. Instead, this survey was a proxy study, where individuals were asked to put themselves within the role of the population of interest, as seen in [144, 145]. To put participants in the role of a typical lung cancer screening patient, background information about the population of interest, e.g., demographics, history, and medical protocol for lung cancer screening, was provided to participants within the introduction. The survey in its entirety is in Appendix F.

The survey was distributed via the website MTurk, a site devoted to human intelligence tasks [146]. The survey was available via the MTurk website for three weeks in the month of May 2015. Two hundred fifty participants age 41 and older, and 250 participants age 40 and younger were actively recruited. Participants were compensated with $1 per completed survey; each participant completed one survey. Only surveys with no missing data were used. Participants who returned surveys with missing data were contacted via email and invited to supply the missing data points. There was no consistent pattern to the types of data elements not completed.

5.3 Analysis Methods for Survey Results

A power analysis demonstrated that for 0.95 power with an α=0.025, 324 participants were required. Survey results were analyzed using SPSS version 20 software. A comparison of means using *t*-tests and one-way ANOVAs were used for univariate analysis of the patient information

needs and preference questions. Univariate analysis of lung cancer screening knowledge questions utilized Chi-square analysis. Logistic regression for demographic effects on response variables was done for all demographics that had significant *t*-test, ANOVA or Chi-square results.

CHAPTER 6 Results

This chapter documents the results from both the in-clinic usability study of lung cancer screening patients at UCLA and the survey results of the online health consumers via MTurk. Section 6.1 focuses on the results for the in-clinic usability study, including: demographic frequencies, univariate results, logistic regression, and paired observations. Section 6.2 concentrates on the results for the online survey, including: demographic frequencies, univariate results, and logistic regression. Section 6.3 compares the in-clinic Step I results to the MTurk survey results. All results for the analysis performed in Chapter 6 (*t*-scores, *F*-ratios, *p*-values, etc.) are found in Appendices G and H.

6.1 Usability Study In-Clinic Results

Fifteen participants were recruited and participated in Step I of the RUMI usability test, which consisted of viewing a patient portal with an average person's lung cancer screening LDCT report. Of those, seven completed Step II, which consisted of the two tasks of viewing their LDCT report via the portal and viewing a paper copy of their report. The remainder of this section discusses the various results for Steps I and II of the study.

6.1.1 Demographic Frequency Results

All demographic frequencies are seen in Tables 8 and 9. The number of cases varied per demographic group. Different age groups were represented, with participants from age 40 to beyond 70. However, the majority of participants were ages 61-70. The majority of participants had some college experience, and two-thirds (66.7%) had a Bachelor's degree or more education. All participants were either non-Hispanic or declined to state their ethnicity. More than half of participants (60%) made $51,000 or more annually. Just over half (53.4%) spent ten hours a

week or less online, but 53.3% had used a patient portal 11 times or more prior to this study. The
majority of participants were white (80%), and men slightly outnumbered women (53.3% versus
46.7%).

Demographic Group		Frequency	Percentage
Age	40-50	2	13.3%
	51-60	2	13.3%
	61-70	7	46.7%
	70 and beyond	4	26.7%
Education	High school	1	6.7%
	Some college, no degree	3	20.0%
	Associate's degree	1	6.7%
	Bachelor's degree	6	40.0%
	Graduate degree	4	26.7%
Ethnicity	Hispanic or Latino	0	0%
	Not Hispanic or Latino	12	80.0%
	Preferred not to answer	3	20%
Income	$0-$35,000	3	20.0%
	$36,000-$50,000	1	6.7%
	$51,000-$75,000	3	20.0%
	$75,000 or greater	6	40.0%
	Preferred not to answer	2	13.4%
Average weekly time spent on Internet	0 hours	1	6.7%
	1-5 hours	3	20.0%
	6-10 hours	4	26.7%
	11 hours or more	5	33.3%
	Preferred not to answer	2	13.4%

Table 8. Demographic frequencies for in-clinic usability study, N=15.

Demographic Group		Frequency	Percentage
Race	White	12	80.0%
	Mixed and other races	3	20%
Sex	Male	8	53.3%
	Female	7	46.7%
Approximate number of times having used a portal	Never	3	20.0%
	1-10 times	3	20.0%
	11-50 times	6	40.0%
	51 or more times	2	13.3%
	Prefer not to answer	1	6.7%

Table 9. Demographic frequencies for in-clinic usability study, N=15 (continued).

6.1.2 Univariate Results

Independent *t*-tests and one-way analysis of variances (ANOVAs) were used in univariate analyses of patient portal information preference questions to identify significant differences in information needs and preferences grouped by demographic variables. Chi-square tests were used in univariate analyses of lung cancer screening knowledge question answers to identify significant differences in lung cancer screening knowledge between demographic groups. All variables grouped by type are located in Chapter 4 section 4.1.

These categories of variables were the same for the Step II analyses seen in 6.1.3 (univariate analysis for Step II portal task and univariate analysis for Step II paper record task) and a subset was used for the in-clinic to MTurk comparison seen in 6.3.

6.1.2.1 Univariate Results Patient Information Preferences Step I

There were no significant results for the univariate analyses for information needs and preferences in Step I. The lack of significant results may have been due, in part, to the number of cases (N=15). All results are located in Tables 74 and 75 in Appendix G.

6.1.2.2 Univariate Results Lung Cancer Screening Literacy Step I

All significant results for the lung cancer screening literacy question responses for Step I are located in Table 10. The predictor with the greatest frequency for lung cancer screening knowledge questions, race, had six significant results. For all of these questions, rates of correct answers were higher for those who were white than for other races. When asked, "Coughing up blood is a frequent sign of lung cancer", and "A person can have lung cancer without any signs", 91.7% of white participants answered the question correctly, while only 33.3% of nonwhites or multi-racial participants answered the question correctly. When asked, "Lung cancer is contagious", 100% of white participants answered the question correctly, in comparison to 66.7% of others. Similarly, when asked, "A low radiation dose chest CT (LDCT) is a good screening test for lung cancer", 100% of whites answered correctly, and 100% of others did not. For the question, "A change of cough pattern is a frequent sign of lung cancer", 53% of whites answered correctly and none of participants from other racial groups answered correctly. When asked, "CT images are made with X-rays", whites had a lower rate of correct answers than seen in other significant results (40%) but had a higher rate than other groups for this question (0%).

Hours online was the second most frequently associated predictor. However, there was no discernable trend across results. When asked, "A low radiation dose chest CT (LDCT) is a good screening test for lung cancer", those who indicated the amount of time they spent online weekly had higher rates of correct answers (100%) than those who declined to state the amount of time they spent online (0%). When asked, "What disorders are you being screened for today", those who spent less time (10 hours or less a week) had higher rates of correct answers (100%) than those who spent 11 hours or more (60%). This trend was reversed for the responses to "Coughing up blood is a frequent sign of lung cancer." For this question, those that spent six

hours or more a week online had higher rates of correct answers (100%) than those who spent five hours a week or less time (50%).

Group	Question	x^2	p-Value
Hours online	Coughing up blood is a frequent sign of lung cancer.	10.040	0.040
	Low radiation dose chest CT (LDCT) is a good screening test for lung cancer.	10.000	0.019
	A positive LDCT means I probably have lung cancer.	10.486	0.019
	What disorders are you being screened for today.	10.000	0.019
Race	CT images are made with X-rays.	7.500	0.024
	Coughing up blood is a frequent sign of lung cancer.	5.104	0.024
	Lung cancer is contagious.	4.286	0.038
	A person can have lung cancer without any signs.	4.286	0.038
	Low radiation dose chest CT (LDCT) is a good screening test for lung cancer.	10.000	0.002
	A change of cough pattern is a frequent sign of lung cancer.	4.286	0.038
Education	Lung cancer is contagious.	15.000	0.005
	A person can have lung cancer without any signs.	10.833	0.029
Sex	If I have a negative LDCT scan, I don't need to undergo additional screening tests for lung cancer.	6.875	0.032
Age	Someone who has quit smoking has a higher risk of developing lung cancer than someone who has never smoked.	9.643	0.022

Table 10. Significant univariate results for lung cancer screening knowledge questions Step I.

The education demographic had two significant sets of answers. When asked, "Lung cancer is contagious", all those with some college or more education had correct answers while all those with high school diploma had incorrect. However, increases in degree obtained did not correlate consistently with correct answers. When asked, "A person can have lung cancer without any signs", those with a Bachelor's degree or higher had 100% correct answers. Those with an Associate's degree or a high school diploma had 0% correct answers, while those with some college (no degree awarded) had a higher rate of correct answers than those with an Associate's degree (66%).

The demographic groups of sex and age each had one significant set of results. When asked, "If I have a negative LDCT scan, I don't need to undergo additional screening tests for lung cancer", 25% of male participants answered correctly and 50% of women answered correctly. For the demographic age, answers varied significantly for the question, "Someone who has quit smoking has a higher risk of developing lung cancer than someone who has never smoked", yet lacked a discernible trend. Both participants in groups ages 51-60 and over 71 had 100% correct answers, while those ages 61-70 had slightly lower rates of correct answers (86%) and those ages 40-50 exhibited the lowest rates (0%).

Although not significant, when asked, "A negative LDCT scan means I don't need to quit smoking", 100% of participants answered correctly ("No"), indicating that all participants were aware that smoking cessation is key to adherence.

6.1.3 Univariate Analysis for Step II

Of those who completed Step I (N=15), slightly less than half completed Step II (N=7). The following subsections summarize the univariate analyses for the two tasks in Step II (viewing their record via the portal, i.e., Step II portal, and on paper, i.e., Step II paper).

6.1.3.1 Univariate Results Patient Information Preferences Step II Portal

There were no significant results for the univariate analyses for information needs and preferences when answers were compared among different demographic groups. Again, the lack of detected significant results may have been due, in part, to the low number of cases (N=7). A larger number of cases may illuminate differences that were unapparent within this limited case set.

6.1.3.2 Univariate Results Lung Cancer Screening Literacy Step II Portal

Two lung cancer knowledge questions had significant results sets, as seen in Table 11. When asked, "Lung cancer is one of the most common cancers", answers differed significantly by education level, but increases in education did not linearly correlate with increases in rates of correct answers. All of those who had less than a Bachelor's degree answered the question correctly, as well as 100% of those who had more than a Bachelor's degree. However, 100% of those with a Bachelor's degree answered this question incorrectly.

Group	Question	x^2	p-Value
Education	Lung cancer is one of the most common cancers.	7.000	0.030
Number of times using a portal	CT images are made with X-rays.	9.800	0.044

Table 11. Significant univariate Step II portal results for lung cancer screening knowledge questions.

When asked, "CT images are made with X-rays", answers differed significantly by the number of times a participant had used a patient portal. However, those who had used one less than 11 times and those had used one more than 50 times had 100% incorrect answers. In contrast, 80% of those who had used a portal 11-50 times prior to this usability study answered correctly.

6.1.3.3 Univariate Results Patient Information Preferences Step II Paper Reports

There were five patient information questions with significant answers when grouped by education level in response to patients viewing paper copies of their CT reports as seen in Table 12. For this summary discussion, Likert scale responses were condensed to "agree" (consisting of the survey answers "agree", "somewhat agree", and "completely agree") and "disagree" (consisting of the answers "disagree", "somewhat disagree", and "completely disagree"). Across questions, those with a Bachelor's degree tended to have lower levels of agreement. When asked the questions: "It should be easy to become skillful at using this copy of my record", "This copy

of my record can assist my communication with my healthcare providers", "This copy of my record is easy to learn how to use", "This copy of my record is easy to operate", and "Using this copy of my record can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information", none of those who had a Bachelor's degree agreed. This consistency in responses was seen for all five questions with other education levels as well. For all five questions, 100% of those who had some college agreed, and 50% of those who went to graduate school agreed.

Group	Question	F	p-Value
Education	It should be easy to become skillful at using this copy of my record.	24.286	0.006
	This copy of my record can assist my communication with my healthcare providers.	33.657	0.003
	This copy of my record is easy to learn how to use.	11.558	0.022
	This copy of my record is easy to operate.	11.978	0.020
	Using this copy of my record can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information.	11.173	0.023

Table 12. Significant univariate Step II paper results for patient information preferences.

6.1.3.4 Univariate Results Lung Cancer Screening Literacy Step II Paper Reports

Significant results for the univariate analysis of lung cancer screening questions for Step II paper reports are seen in Table 13. When grouped by the number of times participants had used a portal, rates of answers to the question, "CT images are made with X-rays", significantly differed. Those who had used a portal 11-50 times had the highest rate of correct answers (80%), while none of those who has used a portal ten times or less, or more than 50 times, had correct answers.

Answers to the questions: "A person can have lung cancer without any signs", "A positive LDCT scan means that I probably have lung cancer", and "A negative LDCT scan means I don't need to

quit smoking", also varied significantly, with all of those who had used a portal 11 times or more, and none of those who had used a portal ten times or less, answering correctly.

Group	Question	x^2	p-Value
Portal use	CT images are made with X-rays.	9.800	0.044
	A person can have lung cancer without any signs.	7.000	0.030
	A positive LDCT scan means that I probably have lung cancer.	7.000	0.030
	A negative LDCT scan means I don't need to quit smoking.	7.000	0.030
Race	A person can have lung cancer without any signs.	7.000	0.008
	A positive LDCT scan means that I probably have lung cancer.	7.000	0.008
	A negative LDCT scan means I don't need to quit smoking.	7.000	0.008

Table 13. Significant univariate Step II paper results for lung cancer screening knowledge questions.

Answers to three of these questions, "A person can have lung cancer without any signs", "A positive LDCT scan means that I probably have lung cancer", and "A negative LDCT scan means I don't need to quit smoking", also varied significantly grouped by race. For each of these questions, all of those who identified as white answered correctly while those of another race answered incorrectly.

6.1.4 Logistic Regression Analysis for Significant Univariate Results

Independent Variable	Survey Question	Log-odds	p-Value	Nagelkerke R^2	Prediction Correct
Education by Race	A person can have lung cancer without any signs.	0.693	0.001	0.668	80%

Table 14. Significant regression result for Step I.

Logistic regression was performed for all variables that had significant results for univariate analysis in Step I as seen in Table 10. Regression was not done for Step II portal or paper record results, as the total number of cases for these Step II tasks (N=7) is below the recommended 15. Independent variables that had significant results for the same dependent variable were combined into the same regression model. To conduct logistic regression, all dependent variables (lung

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cancer knowledge answers) were converted to binary variables. Binary variables consisted of "correct answer" and "incorrect answer." There was one significant result for this analysis, as seen in Table 14.

6.1.5 Wilcoxon Signed-Rank Test Paired Observations for Step I and Step II Portal

It was originally anticipated that this study would conduct paired *t*-tests to compare Steps I and II portal patient information preference questions, as this is the common method used to detect differences between two interval dependent variables for a matched pair. However, the dependent variable data in this results set violated the assumptions of significant outliers and normally distributed data required to perform this analysis. Given these violations, the statistician advising this analysis suggested that the Wilcoxon signed-rank test be performed.

There were no significant changes in patient answers to the patient information preference questions when compared between Step I and Step II portal. All *z*-scores and *p*-values are located in Table 86 in Appendix G. There was also no obvious trend of improvement across question answers for Step II in comparison to Step I, although three questions had higher median ratings in Step II portal. The median rank of each statement during each step is found in Table 15, as well as the number of cases where the score was higher for the Step II assessment, the number of cases where the score remained the same across the two step assessments, and the sum total of cases where the score either improved in Step II or remained the same.

Question	Median Rank Step I	Median Rank Step II	Step II > Step I	No Change Between Steps	Total No Change or Improvement
It should be easy to become skillful at using this portal.	6	7	4	2	6
This portal can assist my communication with my healthcare providers.	6	6	1	5	6
This portal is easy to learn how to use.	5	5	1	3	4
This portal is easy to operate.	5	5	3	3	6
This portal can provide me with healthcare knowledge and education.	6	6	1	4	5
This portal can enhance my effectiveness in personal health management.	6	5	1	3	4
This portal can make me efficient in managing my personal health information.	6	6	3	2	5
This portal can be useful to manage my personal health information.	6	6	2	3	5
This portal is not difficult to use.	6	5	2	3	5
This portal can increase my productivity in managing my personal health information.	6	7	2	3	5
This portal can reduce my time spent on managing my personal health information.	6	6	3	1	4
This portal suits my needs of managing my personal health information.	5	6	3	3	6
Using a portal like RUMI can improve my understanding of medical terminology and vocabulary.	6	7	2	3	5
Using this portal can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information.	6	5	2	3	5

Table 15. Median rank results for comparison of patient information preferences Step I and Step II, N=7.

6.1.6 McNemar Paired Observations for Step I and Step II Portal

A McNemar test was performed to identify any significant differences in lung cancer screening knowledge question responses between Step I and Step II portal; there were no significant results for this analysis. Only those eight questions that were asked to all seven participants across both steps were compared. The additional lung cancer screening questions were added during a later revision and thus were not answered by all seven participants during Step I. All McNemar p-values are located in Table 88 in Appendix G. While there were no significant differences in the answers to the lung cancer screening questions during Step I and Step II, some answer rates did change over time. The rate of correct answers to questions decreased for three of the eight questions compared, as seen in Table 16. Only one question had an improved rate of correct answers in Step II.

Question	Correct Answer Step I	Correct Answer Step II
Coughing up blood is a frequent sign of lung cancer.	86%	42%
In the past, before the CT scan was introduced, the chance of dying due to lung cancer after diagnosis was:	29%	42%
Lung cancer is one of the most common cancers.	71%	71%
A person can have lung cancer without complaint.	86%	86%
A change of cough pattern is a frequent sign of lung cancer.	57%	42%
Lung cancer maybe hereditary.	29%	29%
CT images are made with X-rays.	57%	57%
Someone who has quit smoking has a higher risk of developing lung cancer than someone who has never smoked.	71%	42%

Table 16. Lung cancer screening question rate of correct answers in Step I and Step II portal.

6.1.7 Wilcoxon Signed-Rank Test Paired Observations for Step II Portal and Step II Paper

Question	Median Rank Step II Portal	Median Rank Step II Paper	Step II Portal > Step II Paper	z-score	p-Value
It should be easy to become skillful at using this portal/copy of my record.	7	5	6	2.232	0.026

Table 17. Significant results for comparison of patient information preferences Step II portal and Step II paper, N=7.

A Wilcoxon signed-rank test was also performed to compare the patient information preference answers between Step II portal and Step II paper. There was one significant difference in rating of this question between the two tasks (Table 17). The median rating for each statement for each task (portal and paper) is located in Table 18. Slightly more than half of statements (eight of 14) had a higher median rate of agreement for the portal in comparison to the paper task. Another four had the same median rate of agreement across tasks.

Question	Median Rank Step II Portal	Median Rank Step II Paper	Step II Portal> Step II Paper	No Change Between Tasks	Total No Change or Improvement
It should be easy to become skillful at using this portal/copy of my record.	7	5	6	1	7
This portal/copy of my record can assist my communication with my healthcare providers.	6	5	4	3	7
This portal/copy of my record is easy to learn how to use.	5	5	1	5	6
This portal/copy of my record is easy to operate.	5	5	2	3	5
This portal/copy of my record can provide me with healthcare knowledge and education.	6	6	2	3	5
This portal/copy of my record can enhance my effectiveness in personal health management.	5	5	2	4	6
This portal/copy of my record can make me efficient in managing my personal health information.	6	5	2	4	6
This portal/copy of my record can be useful to manage my personal health information.	6	6	3	3	6
This portal/copy of my record is not difficult to use.	5	4	4	1	5
This portal/copy of my record can increase my productivity in managing my personal health information.	7	5	5	1	6
This portal/copy of my record can reduce my time spent on managing my personal health information.	6	5	4	2	6
This portal/copy of my record suits my needs of managing my personal health information.	6	5	2	3	5
Using this portal/copy of my record can improve my understanding of medical terminology and vocabulary.	7	5	3	4	7
Using this portal/copy of my record can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information.	5	6	3	1	4

Table 18. Median rank results patient information preferences comparison Step II portal and Step II paper, N=7.

6.1.8 McNemar Paired Observations for Step II Portal and Step II Paper

A McNemar test was performed to identify any significant differences in lung cancer screening knowledge question answers between Step II paper and Step II portal; there were no significant results for this analysis. All McNemar *p*-values are located in Table 89 in Appendix G. For all ten questions, the rate of correct answers was either the same between the two tasks or higher during the paper task (Table 19).

Question	Correct Answer Step II Portal	Correct Answer Step II Paper
Coughing up blood is a frequent sign of lung cancer.	42.8%	57.1%
In the past, before the CT scan was introduced, the chance of dying due to lung cancer after diagnosis was:	42.8%	42.8%
Lung cancer is one of the most common cancers.	57.1%	57.1%
A person can have lung cancer without any signs.	85.7%	85.7%
A change of cough pattern is a frequent sign of lung cancer.	42.8%	42.8%
Lung cancer may be hereditary.	57.1%	57.1%
CT images are made with X-rays.	42.8%	42.8%
Someone who has quit smoking has a higher risk of developing lung cancer than someone who has never smoked.	42.8%	57.1%

Table 19. Rates of correct answers to lung cancer screening literacy questions Step II portal and Step II paper.

6.1.9 Free Text Analysis

All free text responses to the questions, "Please list in a few words what concerns you might have about using a patient portal", and "Please list in a few words what effect, if any, using a portal would have on you", for both Step I and Step II portal were coded inductively for themes. The most common themes occurring across both questions in both steps were: security, health literacy, information access, and positive (but non-specific) associations. Table 20 contains the frequency of occurrence across steps and in total for the four most common themes. All themes are contained in Table 92 in Appendix G. Here, security was defined as the outcome of having

one's medical record or personal information accessed by an unauthorized person. Health literacy was defined as the ability to read, understand, and apply health information to one's own health situation. Information access was defined as the ability to locate the specific information desired or the inability to do so. Positive association in this context was defined as any positive comment that is unspecific, such as "good effect" or "using it would be positive."

Health literacy was the most common topic mentioned, and of the eight times mentioned, seven occurred when patients were asked about the anticipated effect of a portal. Information access was the second most common, occurring six times, across both Step I and Step II, but only in response to the "concerns" question in Step II, and in response to the "effect" question across steps. Security occurred as a topic only during Step I in response to the "concerns" question. Despite being favorable comments, positive associations only occurred in response to the "concerns" question across steps.

Free Text Topics	Concerns Step I	Concerns Step II	Effect Step I	Effect Step II	Total Concerns	Total Effect	Total
Security	3	0	0	0	3	0	3
Health literacy	1	0	5	2	1	7	8
Information access	0	2	2	2	2	4	6
Positive association	2	1	0	0	3	0	3

Table 20. Most common themes in answers to free text questions.

6.1.10 Expansion of Ontology

Those participants who completed Step II were asked to highlight words or phrases within the paper copy of their record not currently included in the conceptual information model that they would like to see defined. Of the 39 additional terms highlighted, seven were requested by two or more patients (Table 21). All requested terms are contained in Tables 93 and 94 in Appendix G.

Terms	Number of Patients Requesting
Coronal MIPS	2
dFOV	3
Helical mode	2
MIPS	3
Prospective reconstructions	2
Sagittal MIPS	2
USPSTF	2

Table 21. Most commonly requested additions to the conceptual information model.

6.2 Online Survey Results

The following section documents the results from the online survey via MTurk of 473 participants. It contains the demographic frequencies, univariate, and regression analyses results.

6.2.1 Demographics

The majority of participants were white (N=389), and Asians were the second largest group although far smaller in size than whites (N=26). Participants were almost evenly divided by sex. The majority of participants had some college education, only 27 participants had high school as their highest level of educational attainment. Income was skewed toward lower levels, with the majority indicating they made $35k or less annually. Participants tended to spend more than 11 hours a week online, and most had used a patient portal ten times or less. The majority of participants were not chronically ill, nor did they smoke.

Demographics			
Race	White	389	82.2%
	Asian	26	5.4%
	American Indian	2	0.4%
	Pacific Islander	2	0.4%
	Black	25	5.2%
	Another race	7	1.4%
	Unknown or preferred not to answer	3	0.6%
	Two or more races	18	3.8%
Average weekly time spent on Internet	1-5 hours	35	7.3%
	6-10 hours	87	18.3%
	11 hours or more	349	73.7%
	Preferred not to answer	2	0.4%
Sex	Male	244	51.5%
	Female	228	48.2%
	Other	1	0.2%
Income	$0-35,000	237	50.1%
	$36,000-50,000	95	20%
	$51,000-75,000	80	16.9%
	$76,000 or more	55	11.6%
	Preferred not to answer	6	1.2%
Number of times using a portal	Never	174	36.7%
	1-10 times	216	45.6%
	11-50 times	71	15%
	51 times or more	9	1.9%
	Preferred not to answer	3	0.6%
Education	High school	27	5.7%
	Some college	164	34.6%
	Associate's degree	63	13.3%
	Bachelor's degree	176	37.2%
	Graduate degree	43	9%

Table 22. Demographic results for the MTurk survey.

6.2.2 Univariate Analysis Patient Portal Questions

Independent Variable	Survey Question	F-Ratio/ t-Score	p-Value
Sex*	Portals are not difficult to use.	0.339	0.009
	Using a portal can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information.	1.718	0.044
Chronic illness	A portal can be useful to manage my personal health information.	6.026	0.003
	Using a portal can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information.	7.053	0.001
	A personalized portal can suit my needs of managing my personal health information.	3.413	0.034
	It should be easy to become skillful at using a portal.	6.622	0.001
Portal use	A personalized portal can suit my needs of managing my personal health information.	4.317	0.002
	Using a portal can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information.	4.252	0.002
	A portal can be useful to manage my personal health information.	2.803	0.025
	Using a portal with a health encyclopedia can provide me with healthcare knowledge and education.	2.803	0.025
	It should be easy to become skillful at using a portal.	3.600	0.007

Table 23. Statistically significant results for patient portal preferences MTurk Survey. *Analysis performed using an independent *t*-test.

Males tended to have a less positive rating of portals than females. For all significant results, males rated portals statements lower. For example, the average answer to the question, "Portals are not difficult to use" (p=0.009) was 4.97 for males and 5.32 for females.

Those with a chronic illness tended to have more positive view of portals, with higher average ratings of statements than those without a chronic illness. For all four questions with significant results, the average answer was higher for chronically ill participants. For the question, "A portal can be useful to manage…" the average rating was 6.24 for chronically ill participants, while the average answer for those not reporting a chronic illness was 6.14 (p=0.003). This trend was also

seen across the insignificant patient portal preferences results, with chronically ill participants having more positive ratings of the statements. Those with a chronic illness tended to have more positive view of portals, with higher average ratings of statements than those without a chronic illness. For all four of these questions, the average answer was higher for chronically ill participants. For the question, "A portal can be useful to manage…" the average rating was 6.24 for chronically ill, while the average answer for those not reporting a chronic illness was 6.14 (p=0.003).

Differences in answers significantly varied for the number of times participants had used a patient portal for five questions. However, there was no consistent trend seen across answers, with some higher ratings associated with more portal use, while other higher ratings were associated with less.

6.2.3 Univariate Analysis Lung Cancer Screening Knowledge Questions

The predictor chronic illness was most frequently associated with correct responses for the lung cancer screening knowledge questions. The significant results for all lung cancer screening questions are contained in Table 24. Those with a chronic illness had a higher rate of correct answers for three of the four significant results.

The predictor with the second greatest frequency of correct responses for the lung cancer screening knowledge questions was hours spent online, with three answers. However, there was no consistent linear pattern observed within the rates of answers, those who spent more time occasionally had a higher rate of correct answers, and for other questions a lower rate.

Independent Variable	Survey Question	x^2	p-Value
Education	In the past, before the CT scan was introduced, the chance of dying due to lung cancer after diagnosis was:	34.58	0.005
Income	A change of cough pattern is a frequent sign of lung cancer.	16.63	0.034
	Coughing up blood is a frequent sign of lung cancer.	17.00	0.030
Smoking habit	Lung cancer is one of the most common cancers.	10.30	0.036
Hours spent online	CT images are made with X-rays.	15.68	0.016
	To complete a CT scan, subjects must undress their upper body.	18.01	0.006
	Lung cancer is contagious.	13.93	0.030
Sex	Coughing up blood is a frequent sign of lung cancer.	23.43	0.000
Chronic illness	CT images are made with X-rays.	12.82	0.012
	To complete a CT scan, subjects must undress their upper body.	12.05	0.017
	A change of cough pattern is a frequent sign of lung cancer.	12.42	0.014
	Lung cancer is contagious.	56.55	0.000
Portal use	Lung cancer is contagious.	34.80	0.000

Table 24. Significant univariate analysis for lung cancer knowledge questions.

6.2.4 Logistic Regression Analysis for Significant Univariate Results

Independent Variable	Survey Question	Log-odds	p-Value	Nagelkerke R^2	Prediction Correct
Portal use	It should be easy to become skillful at using a portal.	0.996	0.016	0.024	32.6%
Chronic illness	A change of cough pattern is a frequent sign of lung cancer.	0.611	0.008	0.020	52.4%

Table 25. Significant logistic regression analysis results for MTurk data.

Logistic regression was done for all variables that had significant results for univariate analysis as seen in Tables 23 and 24. Independent variables that had significant results for the same dependent variable were also combined into additional regression models. To conduct logistic regression, all dependent variables (patient portal preference and lung cancer knowledge answers) were converted to binary variables. For the patient portal preferences, binary variables consisted of "agree" and "disagree." For lung cancer knowledge, binary variables consisted of

"correct answer" and "incorrect answer." Significant logistic regression results are seen in Table 25.

6.3 Comparison of In-Clinic and MTurk Results

This section discusses the results of comparing the data gathered in the usability study at UCLA (in-clinic) with that gathered via the survey distributed online via MTurk. As the number of cases varied considerably (N=15 versus N=473), proportions were compared using the chi-square homogeneity of variance method. To maximize the number of cases for the in-clinic group, the data from Step I of the usability test was compared to that from the MTurk survey. All results are contained in Tables 90 and 91 in Appendix G. Statistically significant results are found in Table 26. Results were significantly different for three patient information preference questions.

	Survey Question	*p*-Value
Survey group	Using a portal like RUMI can assist my communication with my healthcare providers.	0.031
	Using a portal can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information.	0.028
	A personalized portal like RUMI can suit my needs of managing my personal health information.	0.000

Table 26. Significant differences in proportions between in-clinic and MTurk data.

When asked, "Using a portal like RUMI can assist my communication with my healthcare providers", 13.3% of MTurk participants were neutral, while 9.5 disagreed, and 77.2 agreed. In comparison, in-clinic participants agreed 93.4% of the time, were neutral in 0% of cases, and disagreed in 6.6% of cases.

When asked to rate the statement, "Using a portal can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information", more in-clinic participants disagreed with the statement, and more MTurk participants were neutral. Of MTurk participants, 2.9% disagreed, while 6.7% of those in-clinic disagreed. 7.2% of MTurk

participants felt neutral about the statement, in comparison to 0% of in-clinic participants. 89.9% of MTurk participants agreed with the statement, and 93.3% of in-clinic participants agreed.

When asked to rate the statement, "A personalized portal like RUMI can suit my needs of managing my personal health information", a higher rate of those in-clinic disagreed with the statement (6.7%) than those from MTurk (4.4%). However, a larger percent of those from MTurk felt neutral about the statement than those in-clinic (4.4% versus 0%). In-clinic participants had a lower rate of agreement, with 86.7%, in comparison to the 91.2% of MTurk participants who agreed.

CHAPTER 7 Discussion

This chapter summarizes the results of this study, compares the study results to other work in the field, identifies how main themes from the results can be applied to future portal development, reflects on these main themes within the greater context of consumer informatics, and identifies limitations with this study.

7.1 Demographics within In-Clinic Cohort

For the in-clinic study, those that participated tended to be white, have a college degree (Bachelor's degree or higher), and made $51,000 or more per year. While all of the in-clinic participants were current or former smokers, these demographic statistics are in contrast to the national statistics on smokers, in which smokers are more likely to live below the poverty level, and tend to have less than an undergraduate degree [1]. These differences in income and education of the in-clinic participants in comparison to national trends suggest that the applicability of these results to a different population of smokers may be limited.

7.2 Demographics within MTurk Cohort

For the MTurk survey, the majority of participants were also white. The majority of participants had some college education; however, a lower percentage (48.2%) had achieved a Bachelor's degree or higher education level in comparison to the in-clinic group (66.7%). Income levels were lower than in the in-clinic cohort, roughly half of respondents reported an annual income of $35,000 or less. Participants also spent more time online than those in the in-clinic study. Most MTurk participants (73.7%) spent more than 11 hours a week online and only 33.3% of in-clinic participants spent this much time. This amount of time spent online was expected for participants on MTurk, as they were working online. They had also used a portal less frequently than the in-

clinic cohort, 45.6% had used a portal ten times or less or had never used a patient portal in comparison to 40% of in-clinic participants. This rate of portal use for MTurk participants suggests that responses to the survey were both a measure of needs for those who had experience using a portal, and expectations for those who had not used a portal before.

7.3 Trends in Information Preference Results In-Clinic Cohort

In Step I and Step II portal, in-clinic patient information preferences did not significantly vary by demographic groups. This lack of significance detected may have been due to the lower number of cases (N=15, N=7 respectively). While all 15 who completed Step I were recruited to complete Step II, three declined and five were unreachable by phone, despite several attempts. The three who declined to participate in Step II cited that the experiment was too time consuming. More cases would determine absolutely if there were any significant differences in information preferences for portals in this cohort. Significant differences for information preferences between demographic groups have been found in [1-4].

For Step II paper, those with a Bachelor's degree had lower levels of agreement with patient information preference statements than other groups. For this task in Step II, participants were rating the usability of the paper copy of their report, meaning that those with a Bachelor's degree found a paper copy of their record less useful than those who had more or less education. A similar trend in other work has not been documented, and it was unclear why those with a Bachelor's degree found paper records less useful than other groups. Another cofounding factor not apparent here may have influenced these results.

7.4 Trends in Information Preference Results MTurk Cohort

MTurk participant information preferences varied by three predictors: use of a portal, diagnosis of a chronic illness, and sex. However, while use of a portal was a significant predictor for patient information preferences in the MTurk survey, it lacked a consistent trend, meaning that increased use of a portal did not linearly correlate with ratings of usability. Although sustained use of technology has been linked with perceived usability in [147], in this study usability ratings occasionally decreased with increased use. In contrast, chronically ill MTurk participants tended to have more positive opinions of patient portals. A similar trend was seen in [95], where chronically ill patients had a more positive opinion of Health Information Technology (HIT). Information preferences also varied by sex, as women had more positive opinions of portals. While use does not equal preference, positive ratings may have been influenced by the higher use of portals observed in women (19.7% had used a portal more than ten times, compared to 14.3% of men), which is consistent with higher eHealth resource use observed in women in [66, 148, 149].

7.5 Trends in Lung Cancer Screening Literacy Results In-Clinic Cohort

In Step I, lung cancer screening knowledge differed by race for six questions, with those who were white having higher rates of correct answers than those who were not. This trend was also observed in Step II paper, with whites having higher rates of correct answers to three questions. Other work suggested that minorities may have lower level of health literacy due to cofounding factors such a lower levels of education [150]. Similar to other work, in this study 66.6% of non-white participants had some college (no degree awarded) or less education in comparison to 25% of whites, suggesting a likely contributing factor.

In Step I, lung cancer screening health literacy also varied by the amount of time spent online; however, there was no obvious trend that correlated linearly with use in either direction. This is in contrast to the findings in [151, 152], where increased time online was associated with increased health literacy. Education was a significant predictor for lung cancer screening health literacy in Step I and Step II portal. However, there was not a clear linear correlation between increased literacy and increased education level. In contrast, other research associated lower levels of education with lower health literacy [153, 154].

Use of a portal was significantly associated with lung cancer screening health literacy in Step II portal, but also lacked any linear relationship. Additionally, use of a portal was significantly associated with lung cancer screening health literacy in Step II paper. While the results in Step II paper also lacked a linear relationship, there was a trend for those who had used a portal 11 times or more to have higher rates of correct answers for three of the four significant associations. However, for one question, "CT images are made with X-rays", a higher percentage of correct answers was seen in those who had used a portal 11-50 times, but not for those who had used one more than 50 times, in comparison to those who had used one ten times or less. Use of a patient portal was associated with higher health literacy in [155] and use of the Internet for health information activities was associated with higher health literacy in [156]. In contrast, results of this study did not demonstrate a similar pattern.

7.6 Trends in Lung Cancer Screening Literacy Results MTurk Cohort

Similarly as seen with the in-clinic population, for the online survey via MTurk, time spent online was a significant predictor lacking a consistent pattern, meaning that increases in time spent online did not have a linear relationship with literacy rates. In contrast, chronic illness demonstrated a consistent pattern as it was positively associated with increased lung cancer

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screening health literacy in the MTurk survey. Interestingly, some studies have found that chronically ill patients may have lower health literacy [151, 157], while others found that those with a chronic illness reported higher rates of literacy regarding test results [158]. In the MTurk survey, it may be that the higher performance observed was related to higher levels of educational attainment, as those respondents reporting chronic illness in the MTurk survey more frequently had Associate, Bachelor's, and Master's degrees than those reporting no chronic illness (14.6% versus 12.9%, 39.8% versus 36.8%, and 9.7% versus 8.8% respectively). This is in contrast to studies that have suggested that chronically ill patients may have lower health literacy, suggesting they would perform less well on a survey of health knowledge questions [151, 157].

7.7 Significant Regression Analyses

Regression analysis was significant for the in-clinic usability study only for the predictors education level and race and the question, "A person can have lung cancer without any signs." The p-value (0.001), Nagelkerke R^2 (0.668), and positive prediction value (0.8) all indicate that this model performed moderately well. For the MTurk survey, portal use and chronic illness were found to have significant regression models (p-values 0.016 and 0.008) associated with the questions, "It should be easy to become skillful at using a portal", and "A change in cough pattern is a frequent sign of lung cancer". However, as indicated by the low Nagelkerke R^2 values (0.024 and 0.020) and positive prediction values (32.6% and 52.4%), these models did not perform well.

7.8 Paired Observations In-Clinic Step I and Step II Portal

The paired analyses for the in-clinic usability study Step I and Step II portal patient information preferences yielded no significant results. As mentioned above, sustained use of technology has

been linked with increased perceived usability [147], however here no significant increase in usability ratings of the RUMI portal was seen after participants used the portal a second time. Although not significant, the majority of answers (more than 50%) to each patient portal preference question stayed the same or improved in rating (on a seven point Likert scale) for most questions. For four of the 14 questions, improvement or remaining the same was true for six of seven cases. These results suggested that seeing the portal display their own CT report, in contrast to an average patient's report, did not decrease a patient's rating of its usability. However, for ten of the 14 questions, the number of ratings that remained the same was larger than the number of ratings that had improved, indicating that patients' usability rating of the portal did not improve once it contained their report. It is possible that viewing their own report, which is personally relevant and thus more impactful, may have affected the usability ratings in Step II portal.

For the lung cancer screening health literacy questions, there was a higher rate of correct answers in Step I for three of the eight questions in comparison to correct answers in Step II portal. In contrast, one of the questions had a higher rate of correct answers in Step II portal. The remaining questions' correct answer rates remained constant from Step I to Step II portal. It was not clear why after being screened, rates of correct answers to certain lung cancer screening questions decreased. It was also not apparent whether this change reflected a change in information retention (e.g., the factual information remembered by the patient) or whether this reflected a change in opinion (e.g., how the patient felt about the question). However, as participation in Step II occurred on average five weeks after patients were scanned, it was possible that participants were able to recall less information about lung cancer screening than when they were first scanned. Although the portal homepage contained some of the answers to

these questions, it was likely that participants did not look at it as closely the second time, as the educational information was not novel.

7.9 Paired Observations In-Clinic Step II Portal and Paper

The paired observation analysis for the different tasks within Step II (portal and paper) had one significant result for responses to the statement, "It should be easy to become skillful at using this portal/copy of my record", (p=0.026). For this question, six of seven participants rated the portal as more useful than the paper copy of their report. Although not significant, six of the other 13 patient information preference questions had a higher median Likert rating for the portal in comparison to the paper record, and an additional five had the same median rating. These results suggested that participants found the portal to be moderately more easy to use than the paper copy of their record.

The paired observation analysis for lung cancer screening literacy showed no significant difference in rates of correct answers between the paper and portal tasks, indicating that use of the portal did not improve literacy. For two of the lung cancer screening questions, the rate of correct answers during the paper task was higher than during the portal task, meaning that a higher percentage of users answered correctly when using the paper copy of their record than when using the portal. However, when comparing rates of correct answers for this question by the order in which users completed the tasks (portal first or paper first), those who used the portal first had higher rates of correct answers. In other words, those who had used the portal before completing the paper task had higher rates of correct answers than those who had not used the portal before the paper task. This suggested that the higher rates of correct answers observed during the paper task may have been influenced, in part, by the information within the portal that patients had seen minutes prior.

7.10 Paired Observations Step I In-Clinic Cohort and MTurk Cohort

For the analysis that compared answers from the in-clinic usability study Step I (N=15) to the MTurk survey (N=473), three patient information preference questions had significant differences in answers, but the only observable pattern was that MTurk participants had a higher rate of "neutral" answers for all three questions. It was possible that the in-clinic participants, who were observed, felt pressured to answer "agree" or "disagree", in contrast to the MTurk participants, who were not observed at the time they took the survey. While there was no consistent pattern observed with rates of agreement or disagreement across all questions, those in-clinic agreed at a higher rate for two of three questions. This higher agreement by the in-clinic group (the group undergoing lung cancer screening) was similar to the higher rate at which chronically ill patients positively viewed HIT in [95].

7.11 Free Text Analyses In-Clinic Cohort

In-clinic participants' free text responses to the questions, "Please list in a few words what concerns you might have about using a patient portal", and "Please list in a few words what effect, if any, using a portal would have on you", had four reoccurring themes: security, health literacy, information access, and general positive association (e.g., "Using a portal could be good"). The topic security occurred only during Step I when asked the "concerns" question. The lack of reoccurrence in response to the "concerns" question in Step II portal, suggested that patients may have felt less concerned about security as they became familiar with using the portal. This trend was also noted in the MTurk survey, with a slight decrease in the rate of concern for security as portal use increased. While 130 or 33% of those in the MTurk study who had used a portal 10 times or less (N=390) were concerned about security, 26 or 32% of those who had used a portal 11 times or more (N=80) were concerned. Similar to this trend, in other

work security was a concern of two-thirds of health information consumers, however users of PHRs had less observed concern [2]. Other studies on patient portals found that concerns regarding security were the most common negative association regarding patient portals both with patients and clinicians [159].

The topic health literacy occurred throughout Step I and Step II in response to the "effect" question in both steps and to the "concerns" question in Step I. Although participants listed this topic in response to the "concerns" question, this did not appear to be an actual concern, meaning something they anticipated as negative or difficult. Rather it was mentioned positively every time it was used, and it was not clear why it was entered as a response to the "concerns" question, unless it was because this question occurs first before the "effect" question and participants may have thought the "concerns" question would be their only chance to mention both positive and negative effects.

The topic information access was mentioned across Step I and II in response to both the "effect" question and in Step II in response to the "concerns" question. Unlike health literacy, this topic was mentioned positively and negatively. An example of a negative mention was: "Incomplete access to data." The combination of some people having indicated that the portal provided access to the information they wanted while others stated it lacked access to the information they wanted suggested that the current iteration of the portal satisfied some but not all information needs.

The topic positive association was provided in response to both the "concerns" question in Step I and Step II but not in response to the "effect" question. While it was not known why participants would only mention this theme in response to the "concerns" question when these statements were by default positive or beneficial in sentiment, it was possible that, like responses regarding

health literacy to the "concerns" question, respondents thought the "concerns" question would be their only chance to mention both positive and negative effects.

7.12 Additional Terms for the Ontology In-Clinic Cohort

Six of the seven additional terms that two or more patients requested be added to the conceptual information model ontology (Chapter 6 Table 21) pertain to the process of imaging. Although some of the terms contained the same words (e.g., "coronal MIPS" and "sagittal MIPS"), terms were considered to be different if they referred to one or more unique concepts in the UMLS Metathesaurus. For this reason, three different unique phrases that contained the abbreviation "MIPS" were included. Requests for so many terms that fit within the subject of the imaging process suggested a need to expand the imaging class of the conceptual information model to include concepts that focused on the detailed process of taking and reading the image.

7.13 Synthesis of Findings

This dissertation made a foundational contribution to consumer informatics by identifying themes that can be used as the basis for guidelines for patient portal development. A summarization of these themes and their impact on the field of consumer informatics are as follows:

- The identification of different user groups' information preferences. Similar to other works [1-4], this study found variations in information preferences across different patient groups including: race, education, sex, and diagnosis of a chronic illness. While many of these findings tended to mirror trends seen in other work (e.g., females found patient portals more useful than males), this study found that older participants (within the in-clinic cohort) had higher rates of portal use than the younger participants (in the

MTurk cohort). The higher use of patient portals in an older population was in contrast to other studies that have suggested the portals remain underutilized by older populations. The fact that participants were from a screening population may have been a cofounding factor that encouraged use, similar to other studies that have shown an increase in Internet use after the diagnosis of cancer. Information preferences also varied between the in-clinic cohort and the MTurk cohort. In comparing the MTurk to the in-clinic cohort, MTurk participants had higher rates of neutrality (neither agreeing nor agreeing with a statement). However, results also suggested that portal users were interested in some information that spanned across cohorts.

- The demonstration that some information needs were not solely tied to a specific diagnosis but also concerned the care processes involved. The conceptual information model growth task demonstrated that those undergoing lung cancer screening were interested in terms that were not specific to lung cancer screening, but to the domain of imaging in general. As these were radiology reports, this finding was not unexpected.

- A validation of both diagnosis-specific and general information provision. As noted in Chapter 2, the majority of portals developed have been general health portals. Others have been designed as diagnosis-specific to better address the variations in information needs seen among different diagnosis groups in other studies. The diagnosis-specific method used here was validated by the visualization being rated as easy to use by in-clinic participants. However, the study findings that only some information preference questions had significant differences when comparing the in-clinic cohort to others who had not undergone lung screening, and that patients were interested in terms that were not diagnosis-specific, demonstrated that diagnosis-specific information was helpful in

addition to more general content. Applying this finding to portal visualization design suggests that the dichotomy between general and disease-specific design oversimplifies user needs. Instead, a visualization that provides different diagnosis-specific modules in combination with other types of information including more general information may prove most useful.

- The effect lack of knowledge had on articulated information needs. It is possible that patients requested all terms they did not know, regardless of context. Inherent to this possibility was the influence of their naivety in the choice, as they requested what they thought they wanted to know as opposed to what they wanted to know. If patients were provided with educational content for all unknown terms, they may not have been as satisfied as they anticipated. However, while there is no guarantee that provision will satisfy, this method of asking participants what they want to see is an inverse process of inferring it from information based on other studies, and is complementary to it.

- The effect of literacy level on information needs. The usability of educational information within a portal is influenced by a participant's ability to understand it, or their literacy on a given topic. Assessment of an individual's level of literacy can inform the provision of the information content that would be most helpful to them. In other words, those who have a low level of literacy likely require more introductory content on a topic than those who have a higher level. However, when assessment cannot be conducted before content is provided, having multiple levels of content in terms of complexity and thoroughness may prove beneficial. This was the method used by this intervention. In this work, literacy rates were observed to vary by a variety of demographics, including race and education. Variations in health literacy by race have

been observed to be in part due to the cofounding factor of education [150], which was supported by the results from this study.

- The need for further development of educational tools. Although the results did not directly support the finding that additional educational information provided alongside a patient's medical record improved health literacy, these results should not be viewed as invalidating the need for educational information to contextualize patient records. Rather, there were other possible influences, including: that despite best efforts the information provided in the portal did not well address the information needs of users, or that the limited number of in-clinic study cases caused for differences to go undetected, or that being observed in the in-clinic study impacted responses. These possibilities support the need for iterative usability studies to improve patient portal design. Further study is required to determine what additional educational information would improve patients' lung cancer screening health literacy.

- The observation of information avoidance behavior. Other studies have suggested that patients want to see their medical information. Results from this study both confirmed and conflicted with this assertion. While all in-clinic participants opted to see their information, a desire not to see information was a common reason cited when individuals declined to participate. This finding may also have been, in part, spurred by the potential diagnosis in focus, as being diagnosed with lung cancer would have negative consequences for most participants. Another implementation of the method used here instantiated in a domain of medical pathology with a more positive association, such a pregnancy, or that which is associated with better outcomes, such as breast cancer screening, may have lower rates of information avoidance.

- The influence of the domain's information representation in the application of this method. How well a diagnosis is understood and if its care is standardized are also influential on the outcome of the application of this method. For example, little about the causes and trajectory of migraines is applicable to the migraine population as a whole. Rather, catalysts, symptoms, and treatment vary highly interpersonally and on occasion even within an individual over time. The method designed in this work would be difficult to apply to a domain of care such as this, where protocol varies highly and underlying causes are not well documented.

7.14 Limitations

Given the small sample size for the in-clinic study, significant findings may not be representative of other populations. Additionally, a larger number of cases would allow for detection of other significant differences. The limited sample size for the in-clinic study is the product of a lengthy IRB process coupled with patients' freewill to not enroll in the study, or enroll and subsequently dropout. As both IRB protocol and patients' choice are necessary to ensure ethical care, acquiring a larger number of cases would require an additional time investment, which was beyond the current scope of this dissertation.

Even with a larger number of cases, the results would likely vary in characteristics from the average smoker. Although the exact demographic statistics for all patients within the lung cancer screening clinic at UCLA are unknown, 305 UCLA lung cancer screening patients filled out a brief survey during enrollment to the clinic, and survey results indicate that slightly over half have a Bachelor's degree or higher educational attainment and 73.4% are white. Similarly, people living within the medical service study area (MSSA) for the UCLA hospital tend to be white and with incomes in excess of $46,000/annually [160]. In contrast, nationally, Native

Americans and mixed-race individuals have the highest prevalence of smoking, as do those who live below the poverty line [161].

For the MTurk survey, several limitations may have influenced the results. Most importantly, a convenience sample of the first 500 respondents to a survey posted on MTurk was used. As such, the results derive from Internet users; those with less Internet experience may well have different views regarding patient portals and lung cancer screening health literacy than those documented here. Respondents also had higher levels of education than that seen in the U.S. population [162], which may have influenced health literacy. Moreover, although respondents were specifically asked not to look up answers to lung cancer questions, there is no guarantee that responses were not informed by additional online queries. In addition, a digital survey format may have introduced potential bias. Others have found that patients who have used eHealth technology had more positive opinions of it than those who do not [50], suggesting that experience with technology can cause one to regard it more favorably. Here, completing a digital survey on eHealth may have biased respondents to rate statements about patient portals more highly.

CHAPTER 8 Conclusions and Future Work

This chapter summarizes the contributions and findings made as a result of this dissertation. Potential areas of future work building off this research are also presented.

8.1 Summary and Results

This dissertation responded to the demand to provide patients with eHealth tools that address their information needs. The approach created a method to produce a conceptual information model that linked concepts from lung cancer screening reports reflective of patient information needs to educational content, in an effort to make the reports more useable to patients and improve health literacy within the domain of lung cancer screening. This method required the identification of the concepts that were reflective of patient information needs and preferences that were relevant to the domain of lung cancer screening, and the educational sources that contained information on these concepts. Once the model was created via the method, it was implemented as a patient portal visualization. This visualization was used by patients to determine whether patients found it usable and to see whether it improved their health literacy on the topic of lung cancer screening. Additionally, a survey of general health consumers was conducted online to determine whether they found portals in general to be usable and to document their lung cancer screening health literacy. The specific contributions of this dissertation are summarized as follows:

- The design of a method to produce a conceptual information model for lung cancer screening patients reflective of their information needs and preferences. This method consisted of five steps: an annotated bibliography on the subject of patient information needs and preferences, a diagram of professional lung cancer screening guidelines, a

survey of lung cancer patients, concept annotations of lung cancer reports, consultations with two physicians, and two healthcare informaticians.

- An XML annotation schema for the conceptual information model that can be used to implement the annotation of patient records. The schema is a direct instantiation of the model that allows patient LDCT reports from any location to be annotated, in order to implement the conceptual informational model across institutions.

- The design of a patient portal that used the conceptual information model as the basis for a dynamic tailored view of patients' LDCT reports. The portal instantiated the model using JavaScript and HTML, and provided users with a digital version of their record annotated by the model, linking their record to educational information for concepts within the model.

- A survey that documented a lung cancer screening population's information needs, preferences, and their health literacy on the topic of lung cancer screening.

- An abridged version of the survey that documented a general population's information needs, preferences, and their health literacy on the topic of lung cancer screening.

- A usability study of the produced portal by a subgroup of the UCLA lung cancer screening population (i.e., in-clinic cohort) using the survey mentioned above.

- An online study of the general population via MTurk utilizing the abridged version of the survey.

- A comparison of the results of the in-clinic usability study and the online study. This comparison investigated the differences in information needs, preferences, and the lung cancer screening health literacy of both groups.

The conceptual information model was the product of an iterative process, and was revised after each step. The usability of the model and its impact on lung cancer screening health literacy was demonstrated via the usability study. The results of the in-clinic study showed that patients rated the portal as easier to use than a paper copy of their record, but that prolonged use did not improve health literacy within the topic of lung cancer screening. The comparison between the in-clinic cases and those from the online survey showed that there was not a significant difference in lung cancer screening health literacy for the two groups, but there was a slight difference in portal usability assessment, with online participants more likely to be neutral about some usability questions.

The experience of conducting this study also provided insight into both best practices regarding health informatics usability study design, and anecdotal evidence about what patients want from a patient portal. In regard to how to access the population of interest, lung cancer screening patients, one must consider that it is often difficult to recruit patients to participate in studies. This difficulty is increased when the population of interest is dealing with the possibility of a chronic or terminal diagnosis. Lung cancer screening patients are going through a stressful time when they participate in screening, and are vulnerable to emotions the screening process may evoke. They should be treated with the same respect and courtesy as any patient, but additionally with extra consideration to the impact the screening process may have on them. Although omitting the term "cancer" from the screening script only slightly increased the average number of patients enrolled in a month period (2 vs. 2.3 patients), revising the script appeared to increase the number of participants who were willing to listen to the screening script in its full form. It also appeared to have made patients less agitated when speaking with them during the screening process. While information should never be obscured from the patient, it is important to

anticipate the perspective of the patient, and to design resources, including the vocabulary used while interacting with the patient, that take into account this perspective.

Related to intervention design, the IRB process was extensive and required considerable time. This stringent process is necessary to protect patients. It also requires researchers interested in accessing a patient population to have the foresight not only to plan ahead, but also to attempt to design protocol that anticipates what is achievable. However, it is impossible to anticipate everything, and issues will likely arise that require a revision of the intervention and, thus, a revision of the IRB materials. Researchers within the area of consumer informatics must allot additional time to account for this process.

Working individually with a patient during the in-clinic portion of the usability study provided the opportunity to speak directly with patients, and collect anecdotal evidence alongside the quantitative data collected via the survey. Several themes emerged from these conversations including: the desire to have easy-to-use eHealth tools available at home, the desire to see radiology images, participation fatigue, and the importance of participant appropriate hardware. While those who participated appeared happy to do so, many expressed disappointment that the tool would not be made available to them online for them to access at home. In future studies, if a researcher cannot provide home access to the specific tool they are testing in a usability study, they may want to consider directing patients to additional publically available sources to help address patients' information needs in the moment.

Many participants also expressed disappointment that the access to their LDCT report did not include access to their actual LDCT scan. Other studies have also shown that patients were interested in their radiology images. Images were excluded here due to concern about

introducing confusion or stress caused by viewing the scans. However, based on this response, it would be worth reconsidering their addition to a future version of the portal.

Researchers should also consider the physical infrastructure used in their usability testing, and make it appropriate for the population of interest. In retrospect, I would not have used a laptop with a trackpad mouse, nor asked users to hold the laptop on their laps, to administer a usability test to participants who were on average age 61-70. Several users expressed difficulty being able to use the trackpad mouse, as well as the discomfort of having the laptop on their lap.

Finally, when designing a survey tool, researchers need to strike a balance between completeness and brevity. Ideally, a survey will gather all the data that is desired; however, too lengthy a survey can induce participation fatigue and even dropout. For future use, I would take the current version of the survey and attempt to pare it down further, to encourage more participants to carry on through Step II of the study.

8.2 Future Work

While this research has undertaken considerable effort to identify the information needs and preferences of the lung cancer screening community, identified how these needs differ from other groups, and determined whether a portal visualization based on a conceptual information model addressing these needs affected patients' usability assessment and health literacy for lung cancer screening through a usability study, additional work is required to eliminate the possibility that there are currently undetected trends. A power test demonstrated that 49 participants would achieve an 80% statistical power. Due to the possibility of fall-out, as observed here with eight of the 15 participants not returning for Step II, enrollment of 100 patients would ensure the completion of both steps of the study by 49 patients.

Given the results of the usability study, the model should be revised to include new concepts requested by participants and to better address lung cancer screening health literacy. New concepts would include additional contributions to the image test class. Currently, the class contains only concepts for types of imaging (CT, MRI, etc.). However, ontology expansion results in Chapter 6 indicated that patients were interested in knowing concepts about the orientation of the view, the features, and standardization of an image (e.g., coronal MIPS, atherosclerotic calcification, helical mode). As CT images are now the guideline for lung cancer screening and patients have demonstrated interest in the imaging process, it may prove beneficial to revise the image class to eliminate the other imaging type concepts (e.g., X-ray, MRI) that are less common in lung cancer screening, and focus in more detail on concepts regarding the process of the CT scan (e.g., radiation dose, image area, image features). This would result in an image class that is narrower in scope and more detailed.

To improve lung cancer screening health literacy, other approaches could be implemented to supplement the educational content. An increase in the number of illustrations, or the addition of animations used to accompany the educational content, could improve information retention, as it was shown to do in other studies. Additionally, adding a gamification element was shown to improve other consumer informatics outcomes, including in interventions with users ages 50 years and older, and could also be utilized here. Further, as lung cancer screening protocol has changed in the last decade, the information within the portal should be seen as only one measure working in tandem with other public health education outlets in a multimedia approach to improve the public's awareness regarding lung cancer screening.

The model was in part the result of feedback from two physicians, both radiologists, who provided their insights into what was helpful educational content for patients to better understand

the process of lung cancer screening. While these two physicians used their professional opinions to weigh in on the design, this assessment is likely to vary physician to physician. It would be useful to include feedback from additional physicians, particularly general clinicians and thoracic oncologists, as these two specialist groups work closely with patients who undergo lung cancer screening.

Additionally, all annotations done for patient reports for this study were conducted manually by myself or one of two trained assistants. While this method ensured high accuracy of annotations, it is not a feasible approach for a larger scale study. To implement a larger study using this portal visualization, an automated means of performing annotations, such as natural language processing (NLP), would be necessary.

8.3 Concluding Remarks

The requirement to address patient information needs and improve health literacy levels within specific domains, including lung cancer screening, continues to grow in importance brought on by several factors. One factor is the shift in the healthcare paradigm emphasizing the patient as a member of the healthcare team; another is the emphasis on preventive care. A third is the ubiquitous access consumers have to health information in various forms (personal, educational, social). This evolving consumer health landscape suggests that patients will require information that satisfies their information needs and improves health literacy rates in order to actively participate in their care and make choices that are representative of their personal priorities.

This study demonstrated that health literacy varied by demographics within the in-clinic cohort, and health literacy and information preferences varied by demographics within the online (MTurk) cohort. Between the two groups, there were some significant differences in information preferences. Additionally, patients' prognoses and emotional experiences due to health

conditions vary. These variations suggest that health information visualizations should be representative of the unique characteristics, diagnoses, and experiences of the patient in question. This study has made a significant contribution to eHealth design for lung cancer screening, the results of which can be used as the foundation for additional work in this area.

APPENDIX A RUMI Conceptual Information Model

RUMI model all classes, concepts, CUIS, and definitions

Class	Concept	CUI
Biopsy		
	Biopsy	**C0189485**
Consumer Definition	After anesthetizing the skin, a doctor directs a biopsy needle into a tumor and obtains cells or a small piece of tissue to be sent to the laboratory for analysis. A biopsy can be used to diagnose lung cancer.	
Professional Definition	NSCLC cannot be diagnosed or accurately staged via noninvasive methods alone. Histopathologic data obtained by tissue sampling is required. It should be emphasized that sampling the primary tumor is diagnostic only. In contrast, sampling abnormalities that may be related to metastatic sites (e.g., enlarged lymph nodes, pleural effusion) can be diagnostic and provide additional staging information. In general, the sampling target should be the lesion that will establish the highest disease stage. Sampling both the primary tumor and the potentially metastatic lesion is occasionally required.	
	Biopsy CT	**C2315679**
Consumer Definition	During a biopsy CT, a chest CT scan is used to find the exact spot for the biopsy. You sit with your arms resting forward on a table. You should try to keep still and not cough during the biopsy. The doctor will ask you to hold your breath. The skin is scrubbed and a local pain-killing medicine (anesthetic) is injected. The physician will make a small (about 1/8-inch) cut in the skin, and will insert the biopsy needle into the abnormal tissue, tumor, or lung tissue. A small piece of tissue is removed with the needle and sent to a laboratory for examination. When the biopsy is done, pressure is placed over the site. Once bleeding has stopped, a bandage is applied. A chest X-ray is taken immediately after the biopsy. The procedure usually takes 30 - 60 minutes. Laboratory analysis usually takes a few days.	
Professional Definition	CT shows many characteristic anatomic patterns and appearances that may strongly suggest the diagnosis. CT also can guide core needle biopsy of accessible lesions and is useful for staging. The area is scrubbed and a local anesthetic is injected. The physician will make a small incision in the skin, and will insert the biopsy needle into the abnormal tissue, tumor, or lung tissue. The sample is then sent to the lab for analysis.	

Table 27. RUMI concepts.

Class	Concept	CUI
Biopsy		
	Bronchoscopy	**C0006290**
Consumer Definition	Bronchoscopy is a direct visual examination of the airways through a flexible viewing tube (a bronchoscope). A bronchoscope has a camera at the end that allows a doctor to look down through the larger airways (bronchi) into the lungs. If a doctor suspects lung cancer, the airways can be examined and specimens can be taken from any areas that look cancerous. For at least 6 hours before bronchoscopy, the person should not eat or drink. A sedative is often given to ease anxiety, and atropine may be given to reduce the risks of spasm of the voice box and slowing of the heart rate, which sometimes occur during the procedure. Sometimes the person is given general anesthesia before bronchoscopy. The throat and nasal passage are sprayed with an anesthetic, and the bronchoscope is passed through a nostril or mouth and into the airways of the lungs.	
Professional Definition	Bronchoscopy is introduction of an endoscope into the airways. Flexible fiber optic bronchoscopy has replaced rigid bronchoscopy for virtually all diagnostic, and most therapeutic, indications. Bronchoscopy should be done only by a pulmonologist or trained surgeon in a monitored setting, typically a bronchoscopy suite, operating room, or ICU (for ventilated patients). Patients should receive nothing by mouth for at least 6 hours before bronchoscopy and have IV access, intermittent BP monitoring, continuous pulse oximetry, and cardiac monitoring. Supplemental O2 should be used. Premedication with atropine 0.01 mg/kg IM or IV to decrease secretions and vagal tone is common, although this practice has been called into question by recent studies. Patients usually receive conscious sedation with short-acting benzodiazepines, opioids, or both before the procedure to decrease anxiety, discomfort, and cough. In some centers, general anesthesia (e.g., deep sedation with propofol and airway control via endotracheal intubation or use of a laryngeal mask airway) is commonly used before bronchoscopy. The pharynx and vocal cords are anesthetized with nebulized or aerosolized lidocaine (1 or 2%, to a maximum of 250 to 300 mg for a 70-kg patient). The bronchoscope is lubricated and passed through the nostril, the mouth with use of an oral airway or bite block, or an artificial airway such as an endotracheal tube. After inspecting the nasopharynx and larynx, the clinician passes the bronchoscope through the vocal cords during inspiration, into the trachea and then further distally into the bronchi.	
	Fine needle aspiration	**C1510483**
Consumer Definition	A fine needle aspiration is the removal of tissue or fluid from the lung using a thin needle. A CT scan, ultrasound, or other imaging procedure is used to locate the abnormal tissue or fluid in the lung. A small incision may be made in the skin where the biopsy needle is inserted into the abnormal tissue or fluid. A sample is removed with the needle and sent to the laboratory. A pathologist then views the sample under a microscope to look for cancer cells.	
Professional Definition	Needle aspiration, the removal of tissue or fluid from the lung using a thin needle, is best for peripheral lesions and is particularly useful if infectious etiologies are strongly considered because using the transthoracic approach, as opposed to bronchoscopy, avoids the possibility of contamination of the specimen with upper airway organisms.	

Table 28. RUMI concepts (continued).

Class	Concept	CUI
Biopsy		
	Thoracentesis	**C0189477**
Consumer Definition	Thoracentesis is the removal of fluid from the pleural cavity through a needle inserted between the ribs. The cells from the fluid are then looked at with a microscope to see if there are cancer cells. Thoracentesis is best done with the patient sitting upright and leaning slightly forward with arms supported.	
Professional Definition	Thoracentesis is a puncture through the chest wall for the purpose of aspirating pleural fluid. It is used to determine the etiology of a pleural effusion (diagnostic thoracentesis), to relieve dyspnea caused by pleural fluid (therapeutic thoracentesis), and, occasionally, to carry out pleurodesis. Thoracentesis can be safely done at the patient's bedside or in an outpatient setting. Presence and location of pleural fluid are verified by physical examination (chest percussion) and usually by imaging techniques. Ultrasonography, CT, or both may be useful if chest X-rays are equivocal, if prior thoracentesis attempts were unsuccessful, or if the fluid is loculated. The clinician doing the procedure usually uses bedside ultrasonography to localize the effusion and confirm that it is free flowing. Use of ultrasonography increases success rates and decreases complications. Thoracentesis is best done with the patient sitting upright and leaning slightly forward with arms supported.	
Comorbidity		
	Comorbidity	**C0009488**
Consumer Definition	The condition of having two or more diseases at the same time.	
Professional Definition	None	
	Chronic obstructive asthma	**C0375333**
Consumer Definition	Asthma is a chronic inflammatory disorder of the airways. The chronic inflammation leads to recurrent episodes of wheezing, breathlessness, chest tightness, and coughing, particularly at night or in the early morning. It requires spirometry to diagnose. Treatment is usually successful in reversing inflammation and airway narrowing. In a minority of people with asthma, the chronic inflammation permanently restricts airflow. When this airway narrowing cannot be completely reversed with treatment, the person is said to have COPD.	
Professional Definition	Chronic obstructive asthma requires spirometry, with pre- and post-albuterol values, in order to be diagnosed accurately. It is a chronic lung condition that demonstrates both reversibility and obstruction. The stepwise approach to pharmacotherapy is based on increasing medications until asthma is controlled, and decreasing medications when possible to minimize side effects. The patient's management should be adjusted, if needed, at every visit.	

Table 29. RUMI concepts (continued).

Class	Concept	CUI
Comorbidity		
	COPD	**C0024117**
Consumer Definition	Chronic Obstructive Pulmonary Disease (COPD) is a lung disease that makes it hard for you to breathe. Coughing up mucus is often the first sign of COPD. Chronic bronchitis and emphysema are common COPDs. Having COPD is linked with lung cancer risk.	
Professional Definition	Chronic Obstructive Pulmonary Disease (COPD) makes breathing difficult. Coughing up mucus is a common symptom of COPD. A history of COPD is associated with lung cancer risk and this association may be largely caused by smoking.	
	Emphysema	**C0034067**
Consumer Definition	Emphysema is a type of chronic obstructive pulmonary disease (COPD) involving damage to the air sacs (alveoli) in the lungs. As a result, your body does not get the oxygen it needs. Emphysema makes it hard to catch your breath. You may also have a chronic cough and have trouble breathing during exercise.	
Professional Definition	Emphysema is the enlargement of air spaces distal to the terminal bronchioles where gas-exchange normally takes place. This is usually due to destruction of the alveolar wall. Pulmonary emphysema can be classified by the location and distribution of the lesions.	
	Pulmonary fibrosis	**C0034069**
Consumer Definition	Pulmonary fibrosis harms the tissues deep in your lungs. The air sacs in your lungs and their supporting structures become scarred and make your lungs thick and stiff. That makes it hard for you to catch your breath, and your blood may not get enough oxygen. Patients with diffuse pulmonary fibrosis seem to be at a higher risk for lung cancer	
Professional Definition	In pulmonary fibrosis, the lungs develop progressive scarring for unknown reasons. It is thought that aging causes the lungs' response to normal stresses to become abnormal and harmful, causing scarring. Patients with diffuse pulmonary fibrosis seem to be at a higher risk for lung cancer even after age, gender, and a history of smoking are taken into consideration.	
Excision		
	Excision	**C0396565**
Consumer Definition	Removal of tissue from the lung by surgery.	
Professional Definition	None	

Table 30. RUMI concepts (continued).

Class	Concept	CUI
Excision		
	Thoracotomy	**C0039991**
Consumer Definition	Thoracotomy is an operation in which the chest wall is opened to view the internal chest organs, to obtain samples of tissue for laboratory examination, and to treat disorders of the lungs and heart. Thoracotomy is a major operation and therefore is used less often than other diagnostic techniques. Thoracotomy is used when other procedures fail to provide adequate information. The lung problem is identified in more than 90% of people who undergo this operation because the sample site can be seen and selected and because large tissue samples can be taken. Thoracotomy is also often used when cancerous tissue is to be removed from the lung. Thoracotomy allows a surgeon to see and remove all involved tissue. Thoracotomy requires general anesthesia in an operating room. An incision is made in the chest wall, and tissue samples of the lung are removed for microscopic examination.	
Professional Definition	Thoracotomy is an operation in which the chest wall is opened to view the internal chest organs, to obtain samples of tissue for laboratory examination, and to treat disorders of the lungs and heart. Thoracotomy is a major operation and therefore is used less often than other diagnostic techniques. It is done to evaluate and treat pulmonary problems when noninvasive procedures are nondiagnostic or unlikely to be definitive. The lung problem is identified in more than 90% of people who undergo this operation because the sample site can be seen and selected and because large tissue samples can be taken. Thoracotomy is also often used when cancerous tissue is to be removed from the lung. Thoracotomy allows a surgeon to see and remove all involved tissue. Thoracotomy requires general anesthesia in an operating room. An incision is made in the chest wall, and tissue samples of the lung are removed for microscopic examination.	
	VATS	**C0752151**
Consumer Definition	Video-assisted thoracic surgery (VATS) is a recently developed type of surgery that enables doctors to view the inside of the chest cavity after making only very small incisions. It allows surgeons to remove masses close to the outside edges of the lung and to test them for cancer using a much smaller surgery than doctors needed to use in the past. It is also useful for diagnosing certain pneumonia infections, diagnosing infections or tumors of the chest wall, and treating repeatedly collapsing lungs. Doctors are continuing to develop other uses for VATS.	

Table 31. RUMI concepts (continued).

Class	Concept	CUI
	VATS (continued)	**C0752151**
Professional Definition	VATS is a minimally invasive surgical treatment that is currently being investigated in all aspects of lung cancer. It can be considered for patients with no anatomic or surgical contraindications, as long as there is no compromise of standard oncologic dissection principles of thoracic surgery. Indications for VATS include correction of spontaneous primary pneumothorax, bullectomy and lung volume reduction surgery in emphysema, wedge resection, and, in some medical centers, lobectomy and even pneumonectomy. Less common indications are excision of benign mediastinal masses; biopsy and staging of esophageal cancer; sympathectomy for severe hyperhidrosis or causalgia; and repair of traumatic injuries to the lung, pleura, and diaphragm. Although some pulmonologists do pleuroscopy, VATS is done by thoracic surgeons. Both procedures are similar to chest tube insertion; a trocar is inserted into an intercostal space through a skin incision, through which a thoracoscope is inserted. Additional incisions permit the use of video cameras and accessory instruments. Patient positioning on the operating table is typically the lateral decubitus position with the operative side up.	
Finding		
	Finding	**C0243095**
Consumer Definition	A finding is an observation of a phenomenon. A phenomenon can be a variety of things, including: an infection, a cyst, or a tumor. Procedures or tests are used to determine what exactly the finding is and what treatments, if any, should be undertaken.	
Professional Definition	None	
	Lymph node N1	**C0441962**
Consumer Definition	The degree of regional lymph node involvement (based on the number and location of lymph nodes).	
Professional Definition	None	
	Lymph node N2	**C0441960**
Consumer Definition	The degree of regional lymph node involvement (based on the number and location of lymph nodes).	
Professional Definition	None	
	Lymph node N3	**C0441961**
Consumer Definition	The degree of regional lymph node involvement (based on the number and location of lymph nodes).	
Professional Definition	None	

Table 32. RUMI concepts (continued).

Class	Concept	CUI
Finding		
	Lymph node Nx	**C0445085**
Consumer Definition	Regional lymph node involvement cannot be evaluated.	
Professional Definition	None	
	Metastasis M0	**C0445034**
Consumer Definition	There is no distant metastasis.	
Professional Definition	None	
	Metastasis M1	**C0441971**
Consumer Definition	There is a distant metastasis.	
Professional Definition	None	
	Metastasis Mx	**C0445039**
Consumer Definition	A distant metastasis cannot be evaluated.	
Professional Definition	None	
	Nodule	**C0028259**
Consumer Definition	A nodule is a small round piece of tissue. Many people have nodules. A nodule can be caused by cancer, infections, scar tissue, or other conditions. Most nodules are benign--not cancer.	
Professional Definition	A solitary pulmonary nodule is defined as a discrete lesion < 3 cm in diameter that is completely surrounded by lung parenchyma. Solitary pulmonary nodules are most often detected incidentally when a chest X-ray is taken for other reasons. Nonpulmonary soft-tissue densities caused by nipple shadows, warts, cutaneous nodules, and bone abnormalities are often confused for a nodule on chest X-ray. The goal of initial testing is to estimate the malignant potential of the solitary pulmonary nodule. The first step is a review of plain X-rays and then usually CT.	
	Nodule ground glass	**C3544345**
Consumer Definition	Ground glass nodules look like hazy clouds in a CT scan. Ground glass nodules have a malignancy rate of 59%.	
Professional Definition	Ground glass nodules have a low density and look like hazy clouds in a CT scan. Ground glass nodules have a malignancy prevalence of 59%.	
	Nodule location	**C0450429**
Consumer Definition	The location of a nodule within your body at the time the report was written.	
Professional Definition	None	

Table 33. RUMI concepts (continued).

Class	Concept	CUI
Finding		
	Nodule multiple ground glass	**C0860516**
Consumer Definition	Ground glass nodules look like hazy clouds in a CT scan. Ground glass nodules have a malignancy rate of 59%.	
Professional Definition	Ground glass nodules have a low density and look like hazy clouds in a CT scan. Ground glass nodules have a malignancy prevalence of 59%. When there are multiple ground glass nodules, careful assessment is needed to determine whether patients have 1) a malignant nodule and benign nodules, 2) several synchronous lung cancers, or 3) a dominant malignant nodule with metastases.	
	Nodule size	**C0449457**
Consumer Definition	The observed size of a nodule at the time the report was written.	
Professional Definition	None	
	Nodule solid	**C0205208**
Consumer Definition	Solid nodules look white on a CT scan. Solid nodules have a malignancy rate of 11%. Solid nodules are more likely to be faster-growing.	
Professional Definition	Solid nodules are high density and look white on a CT scan. Solid nodules have a malignancy prevalence of 11%. Solid nodules are more likely to be invasive and faster-growing.	
	TNM	**C1515169**
Consumer Definition	The TNM staging system is based on the size and/or extent (reach) of the primary tumor (T), whether cancer cells have spread to nearby (regional) lymph nodes (N), and whether metastasis (M), or the spread of the cancer to other parts of the body, has occurred.	
Professional Definition	Classification of neoplasm according to the characteristics of the tumor (T), such as size; the degree of involvement of the lymph nodes (N); and the amount of detectable metastasis (M).	
	Tumor	**C0024121**
Consumer Definition	Tumors can be benign or malignant. Benign tumors aren't cancer while malignant ones are. Cells from malignant tumors can invade nearby tissues. They can also break away and spread to other parts of the body.	
Professional Definition	None	
	Tumor location	**C2063960**
Consumer Definition	The location of a tumor within your body at the time the report was written.	
Professional Definition	None	

Table 34. RUMI concepts (continued).

Class	Concept	CUI
Finding		
	Tumor size	**C1300453**
Consumer Definition	The observed size of a tumor at the time the report was written.	
Professional Definition	None	
	Tumor stage	**C1300072**
Consumer Definition	The extent of a cancer in the body. Staging is usually based on the size of the tumor, whether lymph nodes contain cancer, and whether the cancer has spread from the original site to other parts of the body.	
Professional Definition	None	
	Tumor stage I	**C0278504**
Consumer Definition	In Stage I, the tumor is present only in the lung only and is 3 centimeters or smaller. For Stage I and II disease, the standard treatment approach is surgical resection.	
Professional Definition	In Stage I, cancer has formed. Stage I is divided into stages IA and IB. Stage IA: The tumor is in the lung only and is 3 centimeters or smaller. Stage IB: Cancer has not spread to the lymph nodes and one or more of the following is true: the tumor is larger than 3 centimeters but not larger than 5 centimeters, cancer has spread to the main bronchus and is at least 2 centimeters below where the trachea joins the bronchus, cancer has spread to the innermost layer of the membrane that covers the lung, part of the lung has collapsed or developed pneumonitis (inflammation of the lung) in the area where the trachea joins the bronchus. For stage I and II disease, the standard approach is surgical resection with either lobectomy or pneumonectomy combined with mediastinal lymph node sampling or complete lymph node dissection. Lesser resections, including segmentectomy and wedge resection, are considered for patients with poor pulmonary reserve.	

Table 35. RUMI concepts (continued).

Class	Concept	CUI
Finding		
	Tumor stage II	**C0278505**
Consumer Definition	In Stage II, the tumor is growing in size, and may have lymph node involvement. For Stage I and II disease, the standard approach is surgical resection.	
Professional Definition	Stage II is divided into stages IIA and IIB. Stage IIA non-small cell lung cancer can indicate that cancer has spread to certain lymph nodes on the same side of the chest as the primary tumor; the cancer is (a) 5 cm or smaller, (b) has spread to the main bronchus, and/or (c) has spread to the innermost layer of the lung lining. Or stage IIA non-small cell lung cancer can indicate that cancer has not spread to lymph nodes; the cancer is (d) larger than 5 cm but not larger than 7 cm, (e) has spread to the main bronchus, and/or (f) has spread to the innermost layer of the lung lining. Stage IIB non-small cell lung cancer can indicate that cancer has spread to certain lymph nodes on the same side of the chest as the primary tumor; the cancer is (a) larger than 5 cm but not larger than 7 cm, (b) has spread to the main bronchus, and/or (c) has spread to the innermost layer of the lung lining. Part of the lung may have collapsed or become inflamed (not shown). Or stage IIB non-small cell lung cancer can indicate that (d) the cancer is larger than 7 cm; (e) has spread to the main bronchus, (f) the diaphragm, (g) the chest wall or the lining of the chest wall; and/or (h) has spread to the membrane around the heart. There may be one or more separate tumors in the same lobe of the lung; cancer may have spread to the nerve that controls the diaphragm. For stage I and II disease, the standard approach is surgical resection with either lobectomy or pneumonectomy combined with mediastinal lymph node sampling or complete lymph node dissection. Lesser resections, including segmentectomy and wedge resection, are considered for patients with poor pulmonary reserve.	
	Tumor stage III	**C0278506**
Consumer Definition	In Stage III, the cancer has spread locally in the chest. Stage III disease is treated with chemotherapy, radiation therapy, surgery, or a combination of therapies.	
Professional Definition	Stage III is divided in Stage IIIA and IIIB. Stage IIIA is divided into three presentations depending on the size of the tumor, where the tumor is found, and which lymph nodes have cancer (if any). Stage IIIA non-small cell lung cancer presentation 1: cancer has spread to certain lymph nodes on the same side of the chest as the primary tumor. The cancer may have spread to (a) the main bronchus; (b) lung lining, chest wall lining, or chest wall; (c) diaphragm; and/or (d) membrane around the heart; and/or (e) there may be one or more separate tumors in the same lobe of the lung. Cancer may have spread to the nerve that controls the diaphragm, and part or all of the lung may have collapsed or become inflamed. Stage III disease is treated with chemotherapy, radiation therapy, surgery, or a combination of therapies.	
	Tumor stage IV	**C0278987**
Consumer Definition	In Stage IV, the cancer has spread beyond the primary site in the chest where it started. Chemotherapy, targeted drugs, radiation therapy, and surgical procedures may be used to reduce tumor burden, relieve symptoms, and improve quality of life.	

Table 36. RUMI concepts (continued).

Class	Concept	CUI
Finding		
	Tumor stage IV (continued)	**C0278987**
Professional Definition	In stage IV, the tumor may be any size and cancer may have spread to lymph nodes. One or more of the following is true: (1) there are one or more tumors in both lungs; (2) cancer is found in fluid around the lungs or the heart; and/or (3) cancer has spread to other parts of the body, such as the brain, liver, adrenal glands, kidneys, or bone. Chemotherapy, targeted drugs, radiation therapy, and surgical procedures may be used to reduce tumor burden, relieve symptoms, and improve quality of life.	
	Tumor T0	**C0475371**
Consumer Definition	With stage T0, there is no evidence of primary tumor.	
Professional Definition	None	
	Tumor T1	**C0475373**
Consumer Definition	Stage T1 is a clinical and/or pathologic primary tumor where the cancer is limited.	
Professional Definition	A T1 tumor is a tumor less than 3 cm in size without invasion more proximal than the lobar bronchus.	
	Tumor T2	**C0475372**
Consumer Definition	Stage T2 refers to a finding of primary tumor growth beyond the level of precancerous cells.	
Professional Definition	A T2 tumor is a tumor that is less 3 cm but greater than 7 cm, or with any of the following characteristics: involves the main bronchus less than or equal to 2 cm distal to carina, invades the visceral pleura, associated with atelectasis or obstructive pneumonia that extends to the hilar region but does not involve the whole lung.	
	Tumor T3	**C0475373**
Consumer Definition	Stage T3 is a primary tumor finding usually indicating that the cancer is invading local tissue.	
Professional Definition	A T3 tumor is a tumor that is greater than 7 cm in size or with any of the following: invades the chest wall, diaphragm, phrenic nerve, mediastinal pleura, parietal pericardium, or main bronchus greater than 2 cm distal to carina but not the carina, atelectasis or obstructive pneumonitis of the entire lung, separate tumor nodules in the same lobe.	
	Tumor T4	**C0475751**
Consumer Definition	Stage T4 is a primary tumor finding indicating that the cancer has invaded neighboring structures.	
Professional Definition	A T4 tumor is a tumor that has invaded the mediastinum, heart, great vessels, trachea, recurrent laryngeal nerve, esophagus, vertebral body, or carina.	
	Tumor Tis	**C0475413**
Consumer Definition	With stage Tis, abnormal cells are present but have not spread to neighboring tissue; although not cancer, the abnormal cells may become cancer and is sometimes called preinvasive cancer	
Professional Definition	Tis is carcinoma in situ, abnormal cells are present but have not spread to neighboring tissue.	

Table 37. RUMI concepts (continued).

Class	Concept	CUI
Finding		
	Tumor Tx	**C0332377**
Consumer Definition	Primary tumor cannot be evaluated.	
Professional Definition	None	
Imaging Test		
	Imaging test	**C2711710**
Consumer Definition	Imaging tests provide a picture of the body's interior—of the whole body or part of it. Most imaging tests are painless, relatively safe, and noninvasive (that is, they do not require an incision in the skin or the insertion of an instrument into the body). Imaging tests may use the following: radiation, as in X-rays, computed tomography (CT), and radionuclide scanning; sound waves, as in ultrasonography; magnetic fields, as in magnetic resonance imaging (MRI); substances that are swallowed, injected, or inserted to highlight or outline the tissue or organ to be examined.	
Professional Definition	All patients with suspected NSCLC should undergo contrast-enhanced computed tomography (CT) that extends through the lungs, liver, and adrenal glands. CT is ideal for tumor node metastasis (TNM) staging as it can: characterize the primary tumor and define its relationship to the chest wall and mediastinal structures, identify mediastinal lymph nodes that are enlarged and suspicious for malignant involvement, detect contralateral lung, chest wall, or upper abdominal lesions that are suspicious for metastasis. Most patients require additional imaging. This may include whole body positron emission tomography (PET), integrated PET/CT imaging, CT of the brain, and magnetic resonance imaging (MRI). Each of these modalities and a recommended approach to imaging patients with suspected NSCLC are reviewed separately.	
Imaging Test		
	CT scan	**C0202823**
Consumer Definition	A CT of the chest provides more detail than a plain X-ray. With CT, a series of X-rays is analyzed by a computer, which then provides several views in different planes, such as longitudinal and cross-sectional views. During CT, a substance that can be seen on X-rays (called radiopaque dye) may be injected into the bloodstream or given by mouth to help clarify certain abnormalities in the chest. High-resolution CT and helical (spiral) CT are more specialized CT procedures. High-resolution CT may reveal more detail about lung disorders. Helical CT can provide three-dimensional images. CT scans are recommended for detecting noncalcified nodules that may be suspicious for lung cancer.	

Table 38. RUMI concepts (continued).

Class	Concept	CUI
Imaging Test		
	CT scan (continued)	**C0202823**
Professional Definition	New multidetector CT scanners generate high-resolution imaging with radiation exposure significantly less than for diagnostic chest CT scanning. Low-dose CT (LDCT) refers to a noncontrast study obtained with a multidetector CT scanner during a single maximal inspiratory breath-hold with a scanning time under 25 seconds. High-resolution (1.0 to 2.5 mm interval) images are reconstructed using a soft tissue or thin-section algorithm. The overall average effective dose of low-dose CT used in the National Lung Screening Trial was 2 mSv, compared with 7 mSv for a standard-dose diagnostic chest CT examination. CT scans are recommended for detecting noncalcified nodules that may be suspicious for lung cancer depending on their type (e.g., solid, ground glass) and size.	
	MRI	**C0024485**
Consumer Definition	MRI is a procedure in which radio waves and a powerful magnet linked to a computer are used to create detailed pictures of areas inside the body, and can be used to stage tumors close to the diaphragm. However, MRI takes longer to do and is more expensive than CT. Also, the resolution of MRI is lower than CT for diagnosing abnormalities in the lungs, and therefore MRI is not frequently used for chest imaging. Unlike CT, MRI does not use radiation.	
Professional Definition	MRI of the chest is slightly more accurate than high-chest high resolution CT for staging apical tumors and cancers close to the diaphragm and provides an evaluation of the vasculature surrounding the tumors.	
	PET scan	**C0032743**
Consumer Definition	PET is an imaging technique that has been useful in study of soft tissues such as cancer, the cardiovascular system and the brain. Glucose molecules are combined with a compound that is visible using PET. These molecules are injected intravenously, where they accumulate in rapidly metabolizing tissue (such as in cancerous lymph nodes), making these tissues visible on PET scans. PET scans are often combined with CT scans to provide two different methods to visualize lung tumors.	
Professional Definition	PET uses radioactively labeled glucose (fluorodeoxyglucose) to measure metabolic activity in tissues. It is used in pulmonary disorders to determine whether lung nodules or mediastinal lymph nodes harbor tumor (metabolic staging) and whether cancer is recurrent in previously irradiated, scarred areas of the lung. PET is superior to CT for mediastinal staging because PET can identify tumor in normal-sized lymph nodes and at extrathoracic sites, thereby decreasing the need for invasive procedures such as mediastinoscopy and needle biopsy. Current spatial resolution of PET is 7 to 8 mm; thus, the test is not useful for lesions < 1 cm. PET reveals metastatic disease in up to 14% of patients in whom it would not otherwise be suspected. The sensitivity of PET (80 to 95%) is comparable to that of histologic tissue examination. False-positive results can occur with inflammatory lesions, such as granulomas; slowly growing tumors (e.g., bronchoalveolar carcinoma, carcinoid tumor, some metastatic cancers) may cause false-negative results. Newer combined CT-PET scanners may become the most cost-effective technology for lung cancer diagnosis and staging	

Table 39. RUMI concepts (continued).

Class	Concept	CUI
Pulmonary Function Test		
	Diffusing capacity	**C0978275**
Consumer Definition	Lung diffusion testing measures how well the lungs exchange gases. This is an important part of lung testing, because the major function of the lungs is to allow oxygen to "diffuse" or pass into the blood from the lungs, and to allow carbon dioxide to "diffuse" from the blood into the lungs.	
Professional Definition	None	
	Pulmonary function test	**C0024119**
Consumer Definition	Pulmonary function tests measure the lungs' capacity to hold air, to move air in and out, and to exchange oxygen and carbon dioxide. These tests are better at detecting the general type and severity of lung disorder than at defining the specific cause of problems; however, these tests can be used to diagnose some specific disorders, such as asthma and emphysema.	
Professional Definition	None	
	Spirometry	**C0037981**
Consumer Definition	Spirometry is the measurement of volume of air inhaled or exhaled by the lung, including measurement of forced expiratory volume in one second (FEV1) and forced vital capacity (FVC), is the most readily available and most useful pulmonary function test. In a spirometry test, while you are sitting, you breathe into a mouthpiece that is connected to an instrument called a spirometer. The test takes 10 to 15 minutes, and carries no risk.	
Professional Definition	Quantitative measures of inspiratory and expiratory flow are obtained by forced spirometry. In assessments of expiratory flow, patients inhale as deeply as possible, seal their lips around a mouthpiece, and exhale as forcefully and completely as possible into an apparatus that records the exhaled volume (forced vital capacity [FVC]) and the volume exhaled in the first second (the forced expiratory volume in 1 sec [FEV1]). Most currently used devices measure only airflow and integrate time to estimate the expired volume. In assessments of inspiratory flow and volume, patients exhale as completely as possible, then forcibly inhale. These maneuvers provide several measures. The FVC is the maximal amount of air that the patient can forcibly exhale after taking a maximal inhalation. The FEV1is the most reproducible flow parameter and is especially useful in diagnosing and monitoring patients with obstructive pulmonary disorders (e.g., asthma, COPD). FEV1 and FVC help differentiate obstructive and restrictive lung disorders. A normal FEV1 makes irreversible obstructive lung disease unlikely whereas a normal FVC makes restrictive disease unlikely.	

Table 40. RUMI concepts (continued).

Class	Concept	CUI
Smoking status		
	Smoking status	**C1519386**
Consumer Definition	Smoking is bad for your health. Smoking harms nearly every organ of the body. Cigarette smoking causes 87 percent of lung cancer deaths. It is also responsible for many other cancers and health problems. These include lung disease, heart and blood vessel disease, stroke and cataracts. Most smokers who quit do so for health or economic reasons. People who want to quit smoking can get help from health care practitioners, who can provide support and recommend ways to change behavior. Other sources for help include telephone help (quit) lines, the Internet, and package inserts in nicotine replacement products.	
Professional Definition	Most smokers who quit do so for health or economic reasons. About 70% of U.S. smokers say they want to quit and have already tried to quit at least once. Withdrawal symptoms are a major barrier to quitting (smoking cessation). About 20 million smokers in the United States (almost half of all smokers) try to quit each year. Most do not use any supportive counseling or other proven aids to quitting. Only about 5% of such people are successful long term. Most quitters resume smoking within days, weeks, or months. Many people quit and resume smoking repeatedly. In contrast, the 1-year success rate for people using proven methods to achieve long-term success in quitting is 20 to 30%. People who want to quit smoking can get help from health care practitioners, who can provide support and recommend ways to change behavior. Other sources for help include telephone help (quit) lines, the Internet, and package inserts in nicotine replacement products.	
	Smoker	**C0337664**
Consumer Definition	Smoking status is an indication of a person's current tobacco and nicotine consumption as well as some indication of smoking history. About one half of current smokers will die prematurely of a disorder caused by smoking. The leading smoking-related health problems are the following: coronary artery disease (mainly heart attacks and angina), lung cancer, chronic obstructive pulmonary disease (COPD).	
Professional Definition	A dose-response relationship exists between smoking tobacco and the risk of developing lung cancer: however, there is no risk-free level of tobacco exposure. The relative risk for lung cancer is approximately 20-fold higher for smokers than for nonsmokers. Cessation of tobacco smoking decreases the risk for lung cancer.	

Table 41. RUMI concepts (continued).

Class	Concept	CUI
Sputum test		
	Sputum test	**C1262031**
Consumer Definition	A sputum sample is obtained by coughing up the material that comes from the lungs into a specimen container. The sample is transferred to a slide and examined under a microscope. Although sputum tests can be diagnostic of NSCLC, not every patient produces sputum. Additionally, only 20 to 25 percent of patients with proven lung cancer will have positive sputum. Thus, a negative test does not exclude the diagnosis of NSCLC and a second test will often be necessary for this purpose.	
Professional Definition	A sputum sample is obtained by coughing deeply and expelling the material that comes from the lungs into a specimen container. The sample is transferred to a slide and examined under a microscope. Although cytologic specimens can be diagnostic of NSCLC, not every patient produces sputum. Additionally, they are positive in only 20 to 25 percent of patients with proven lung cancer . Thus, a negative test does not exclude the diagnosis of NSCLC and a second procedure will often be necessary for this purpose. Similarly, when sputum cytology is positive, additional testing will often be necessary for staging, especially when mediastinal or distant metastases are suspected.	
Symptom		
	Symptom	**C1457887**
Consumer Definition	A symptom is a physical or mental feature that a patient experiences and may indicate she/he has a condition or disease. Some examples of symptoms are headache, fever, fatigue, nausea, vomiting, and pain. About 25% of lung cancer cases are without symptoms, and are found during chest imaging.	
Professional Definition	A symptom is a physical or mental feature that a patient experiences and may indicate she/he has a condition or disease. Some examples of symptoms are headache, fever, fatigue, nausea, vomiting, and pain. About 25% of lung cancers are asymptomatic and are detected incidentally with chest imaging. Symptoms and signs can result from local tumor progression, regional spread, or distant metastases. Paraneoplastic syndromes and constitutional symptoms may occur at any stage of the disease. Although symptoms are not specific to the classification or histology of the cancer, certain complications may be more likely with different types.	

Table 42. RUMI concepts (continued).

Class	Concept	CUI
Symptom		
	Chest pain	**C0008031**
Consumer Definition	Chest pain is the sensation of unpleasant feeling indicating potential or actual damage to some body structure felt in the chest. Chest pain is a very common complaint. Pain may be sharp or dull, although some people with a chest disorder describe their sensation as discomfort, tightness, pressure, gas, indigestion, burning, or aching. Sometimes, people also have pain in the back, neck, jaw, upper part of the abdomen, or arm. Other symptoms, such as nausea, cough, or difficulty breathing, may be present depending on the cause of the chest pain. However described, chest pain should never be dismissed without an explanation of its cause.	
Professional Definition	Chest pain is the sensation of unpleasant feeling indicating potential or actual damage to some body structure felt in the chest. Chest pain is a very common complaint. Pain may be sharp or dull, although some people with a chest disorder describe their sensation as discomfort, tightness, pressure, gas, indigestion, burning, or aching. Sometimes, people also have pain in the back, neck, jaw, upper part of the abdomen, or arm. Other symptoms, such as nausea, cough, or difficulty breathing, may be present depending on the cause of the chest pain. However described, chest pain should never be dismissed without an explanation of its cause. Many patients are well aware that chest pain is a warning of potential life-threatening disorders and seek evaluation for minimal symptoms. Other patients, including many with serious disease, minimize or ignore its warnings. Pain perception (both character and severity) varies greatly between individuals as well as between men and women.	
	Coughing blood	**C0019079**
Consumer Definition	Coughing up blood from the respiratory tract is called hemoptysis. The amount of blood produced can vary from a few streaks of blood mixed with normal sputum to large amounts of pure blood. Other symptoms, such as fever and difficulty breathing, may be present depending on the cause of hemoptysis. Although hemoptysis can be frightening, most causes turn out not to be serious. Blood-streaked sputum is common in many minor respiratory illnesses, such as upper respiratory infections and viral bronchitis. Sometimes the cause is blood from the nose that has traveled down the throat and then is coughed up. Such blood is not considered hemoptysis.	
Professional Definition	The term hemoptysis typically refers to expectoration of blood originating from the lower respiratory tract. The amount of blood produced can vary from a few streaks of blood mixed with normal sputum to large amounts of pure blood. The blood can blood originating from any part of the respiratory tract, usually from hemorrhage in the lung parenchyma (pulmonary alveoli) and the bronchial arteries. Other symptoms, such as fever and difficulty breathing, may be present depending on the cause of hemoptysis. Bronchitis, bronchogenic carcinoma, and bronchiectasis are the most common causes of hemoptysis in developed countries. Blood from the upper respiratory tract and the upper gastrointestinal tract can also be expectorated and, thus, mimic blood coming from the lower respiratory tract, a situation called pseudohemoptysis.	

Table 43. RUMI concepts (continued).

Class	Concept	CUI
Symptom		
	Fatigue	**C0849970**
Consumer Definition	Fatigue is having little energy. It usually follows mental or physical activity.	
Professional Definition	Fatigue is state of weariness following a period of exertion, mental or physical, characterized by a decreased capacity for work and reduced efficiency to respond to stimuli.	
	Hoarse voice	**C0019825**
Consumer Definition	A hoarse voice is an unnaturally deep or rough quality of voice. A hoarse voice can be due to infection, voice overuse, irritants, or other causes.	
Professional Definition	A hoarse voice is an unnaturally deep or rough quality of voice. A harsh or raspy voice can be secondary to laryngeal infection, voice overuse, irritants inhalation, vocal cord paralysis, vocal cord polyps, and malignant neoplasms arising from or spreading to the larynx.	
	Respiratory symptom	**C0037090**
Consumer Definition	Respiratory system manifestations of diseases of the respiratory tract or of other organs.	
Professional Definition	None	
	Weight loss	**C0237352**
Consumer Definition	Involuntary weight loss refers to weight loss that occurs when a person is not dieting or otherwise trying to lose weight. Because everyone's weight goes up and down slightly over time (such as during an illness), doctors typically become concerned only when people lose more than about 10 pounds (4 to 5 kilograms) or, in smaller people, 5% of their body weight.	
Professional Definition	When involuntary weight loss exceeds 10 percent of usual weight (in nonobese persons), the etiology and potential cause of weight loss must be investigated. Involuntary weight loss exceeding 20 percent of usual weight is often associated with severe protein-energy malnutrition, nutritional deficiencies, and multi-organ dysfunction.	

Table 44. RUMI concepts (continued).

SMOG scores for all RUMI concept

Class	Concept	SMOG Score Consumer	SMOG Score Professional
Biopsy			
	Biopsy	16.2	17.2
	Biopsy CT	15.3	17.3
	Bronchoscopy	18.3	19.9
	Fine needle aspiration	17.3	28.7
	Thoracentesis	16.9	20.2
Comorbidity			
	Comorbidity	13.8	No professional
	Chronic obstructive asthma	18.3	20.6
	COPD	13.1	16.2
	Emphysema	16.7	20
	Pulmonary fibrosis	15.1	18.6
Excision			
	Excision	16.2	No professional
	Thoracotomy	19	19.6
	VATS	20.6	24
Finding			
	Finding	18.6	No professional
	Lymph node N1	18	24.3
	Lymph node N2	18	19.6
	Lymph node N3	18	23.2
	Lymph node Nx	18	No professional
	Metastasis M0	13.8	No professional
	Metastasis M1	13.8	No professional
	Metastasis Mx	16.2	No professional
	Nodule	12.2	19.6
	Nodule ground glass	12.2	15.1
	Nodule location	13.8	No professional
	Nodule multiple ground glass	12.2	19.6
	Nodule size	8.1	No professional
	Nodule solid	11.4	14.7
	TNM	18	22.1
	Tumor size	8.1	No professional
	Tumor	13.8	No professional
	Tumor location	13.8	No professional

Table 45. SMOG literacy scores for RUMI concepts.

Class	Concept	SMOG Score Consumer	SMOG Score Professional
Finding			
	Tumor stage	13.8	No professional
	Tumor stage I	15.1	19.3
	Tumor stage II	15.1	18.2
	Tumor stage III	20.2	18.8
	Tumor stage IV	19.6	18
	Tumor T0	16.2	No professional
	Tumor T1	18.6	16.2
	Tumor T2	16.2	26.2
	Tumor T3	19.6	27.1
	Tumor T4	19.6	23.2
	Tumor Tis	20.9	18
	Tumor Tx	16.2	No professional
Imaging test			
	Imaging test	23.6	23
	CT scan	18.3	17.8
	MRI	18.8	23.2
	PET scan	19.2	19.7
Pulmonary function test			
	Pulmonary function test	11.4	17.6
	Diffusing capacity	16.2	22.5
	Pulmonary function test	23.8	No professional
	Spirometry	20	19.6
Smoking status			
	Smoking status	15.1	14.7
	Smoker	20.9	19.6
Sputum test			
	Sputum test	16.6	19.6
Symptom			
	Symptom	17.5	19.8
	Chest pain	17.2	18
	Coughing blood	16.8	20.5
	Fatigue	17.2	26.2
	Hoarse voice	17.2	21.5
	Respiratory symptom	18	No professional
	Weight loss	17.2	23.8

Table 46. SMOG literacy scores for RUMI concepts.

XML Schema

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APPENDIX B Synonyms List for all RUMI Concepts

Name	CUI	
X-ray	C0039985	
		Chest Xray
		Chest X ray
		Chest X-ray
		Chest Xrays
		Chest X rays
		Chest X-rays
		Chest radiography
		CXR
		Thoracic X rays
		Thoracic X ray
		Thoracic X-ray
		Thoracic Xray
		Radiologic examination
		X-ray of the chest
		X ray of the chest
		Xray of the chest
		Thoracic radiography
		X ray chest
		X-ray chest
		Xray chest
		CXR
		X-ray NOS chest
		Xray NOS chest
		X ray NOS chest
		Two view chest
		Two view chest
CT scan	C0202823	
		Chest CT scan
		CT scan chest

Table 47. RUMI ontology synonym list.

Name	CUI	
CT scan (continued)	C0202823	
		Chest CT scan
		CT scan chest
		Chest CT scan
		Chest CT
		Chest CT scans
		CT chest
		CT thorax
		CAT scan of thorax
		Thorax CT
		Computerized axial tomography of thorax
		CT scan of the chest
		Computerized tomogram thorax
		LDCT
		Lung low dose CT
		CT lung low dose
		CT
		Lung CT
		CT Lung
MRI	C0024485	
		Magnetic resonance imaging
		Magnetic resonance
		MR
		MRI
		MRI scan
		Magnetic resonance study
		Magnetic resonance technique
		NMR
		Nuclear magnetic resonance
		CT scan chest

Table 48. RUMI ontology synonym list (continued).

Name	CUI	
MRI (continued)	C0024485	
		NMR imaging
		NMR scan
		NRM tomography
		Nuclear magnetic resonance NOS
		Nuclear magnetic resonance imaging
PET scan	C0032743	
		PET
		Positron emission tomography
		Imaging PET
		PET imaging
		PET scan
		Positron emission tomogram
		PET Scans
		Scan PET
		Tomography, Positron Emission
		Positron emission tomography scan
		Positron emission tomographic imaging
		PET/CT
Biopsy CT	C2315679	
		CT guided lung biopsy
		Image guided lung biopsy
		Percutaneous lung biopsy
Bronchoscopy	C0006290	
		Bronchial endoscopy
		Bronchoscopies
		Tracheobronchial endoscopy
		NMR
Thoracentesis	C0189477	
		Pleural tap

Table 49. RUMI ontology synonym list (continued).

Name	CUI	
Thoracentesis (continued)	C0189477	
		Pleurocentesis
		Chest aspiration
		Pleural aspiration
		Procedure thoracentesis
		Aspiration pleural cavity
		Pleuracentesis
		Pleural cavity aspiration
		Pleural cavity tap
		Puncture of pleural cavity for aspiration
		Thoracic paracentesis
Fine needle aspiration	C1510483	
		Aspiration biopsy
		Aspiration fine needle biopsy
		Aspirations fine needle biopsy
		Biopsy aspiration
		Biopsy fine needle
		Fine needle aspiration biopsy
		Aspiration biopsies fine needle
		Aspiration biopsy fine needle
		Aspiration fine needle
		Biopsies fine needle
		Biopsies fine needle aspiration
		FNA biopsy
Other biopsy	C0189485	
		Biopsy
		Lung biopsy
		Biopsy lung
		Biopsies
		Pleural tap

Table 50. RUMI ontology synonym list (continued).

143

Name	CUI	
Other biopsy (continued)	C0189485	
		Lung biopsies
		Biopsies lung
		Biopsy of the lung
		Tissue sampling percutaneously
VATS	C0752151	
		Video assisted thoracic surgery
		Video assisted thoracic surgeries
		Surgery video assisted thoracic
		Surgery video assisted thoracoscopic
		Thoracic surgeries video assisted
		Thoracic surgery video assisted
		Thoracoscopic surgery video assisted
		Thoracoscopic surgeries video assisted
		Video assisted thoracoscopic surgery
Mediastinoscopy	C0025065	
		Endoscopy procedures on the mediastinum
		Examination of chest cavity below breast bone using an endoscope
		Endoscopic exploration of mediastinum
		Mediastinal endoscopy
Thoracotomy	C0039991	
		Thoracotomies
		Incision of the chest wall
		Incisions of chest wall
		Incision of thorax
		Opening of chest
		Thoracic incision
		Chest wall incision
		Biopsies
		Pleural tap

Table 51. RUMI ontology synonym list (continued).

Name	CUI	
Spirometry	C0037981	
		Spirometry test
		Spirometry testing
		Spirometry tests
Body plethysmography	C0182320	
		Body plethysmographs
		Body plethysmograph
		Plethysmograph body
		Plethysmographs body
Diffusing capacity	C0978275	
		Lung diffusion gas
		Lung diffusion test
		Thoracoscopic surgery video assisted
		Thoracoscopic surgeries video assisted
		Video assisted thoracoscopic surgery
Mediastinoscopy	C0025065	
		Endoscopy procedures on the mediastinum
		Examination of chest cavity below breast bone using an endoscope
		Endoscopic exploration of mediastinum
		Mediastinal endoscopy
Thoracotomy	C0039991	
		Thoracotomies
		Incision of the chest wall
		Incisions of chest wall
		Incision of thorax
		Opening of chest
		Thoracic incision
		Chest wall incision
Pulmonary function test	C0024119	
		Lung function test
		Pulmonary function test
		Respiratory function test
Sputum test	C1262031	
		Sputum testing
		Sputum tests

Table 52. RUMI ontology synonym list (continued).

Name	CUI	
Smoker	C0337664	
		Smoking history
		History of smoking
		Smokes
		XX year smoking history
		cigarette use
		XX pack year cigarette use
		XX pack year active cigarette use
		former smoker
		XX PKYs
Pulmonary fibrosis	C0034069	
		Cirrhosis lung
		Fibrosis lung
		Fibrosis lungs
		Lung cirrhosis
		Lung fibrosis
		Fibrosis
		Fibrosis pulmonary
		Fibrosis: Absent
		Fibrosis: Present
COPD	C0024117	
		Chronic obstructive lung disease
		Chronic obstructive pulmonary disease
		Airway obstruction chronic
		Chronic airway obstruction
		Chronic obstructive airway disease
		Lung disease obstructive
		Lung obstruction disease chronic
		Obstruction airway chronic
		Obstruction lung disease chronic
		Respiratory tract disorder chronic obstructive
		Respiratory tract disorder obstructive chronic
		Chronic obstructive airways disease
		Chronic obstructive bronchopneumopathy
		Obstructive airways disease

Table 53. RUMI ontology synonym list (continued).

Name	CUI	
Emphysema	C0034067	
		Lung emphysema
		Pulmonary emphysema
		Emphysema pulmonary
		Emphysema: Absent
		Emphysema: Present
Chronic bronchitis	C0008677	
		Bronchitis chronic
Chronic obstructive asthma	C0375333	
		Asthma chronic obstructive
Nodule	C0028259	
		Nodules
		Micronodule
		Opacity
		Opacities
		Micronodules
		Nodules (Category X-X): None
		Nodules (Category X-X): Present
Ground glass	C3544345	
		Ground glass opacity
Multiple ground glass	C0860516	
		Ground glass opacities
Solid	C0205208	
		Solid opacities
Nodule location	C0450429	
		Right lower lobe
		RLL
		Right upper lobe
		RUL
		Lung function test
		Pulmonary function test
		Respiratory function test
		Chronic obstructive airways disease
		Chronic obstructive bronchopneumopathy
		Obstructive airways disease

Table 54. RUMI ontology synonym list (continued).

147

Name	CUI	
Nodule location (continued)	C0450429	
		Right middle lobe
		RML
		Left lower lobe
		LLL
		Left upper lobe
		LUL
Nodule size	C0449457	
		aa x bb
		mean x mm
		mm
Tumor	C0242379	
		Malignant neoplasm of the lung
		Lung cancer malignant
		Lung malignancy
		Cancer of the lung
		Cancer of lung
		Cancer pulmonary
		Cancers lung
		Lung cancer
		Lung cancer
		Lung malignancy
		Lung malignancies
		Lung tumor
		Lung tumors
		Lung malignant tumors
		Lung malignant tumor
		Malignant lung neoplasm
		Malignant neoplasm lung
		Lung function test
		Pulmonary function test
		Respiratory function test
		Chronic obstructive airways disease
		Chronic obstructive bronchopneumopathy
		Obstructive airways disease

Table 55. RUMI ontology synonym list (continued).

148

Name	CUI	
Tumor (continued)	C0242379	
		Pulmonary cancer
		Lung neoplasm malignant
		Malignant tumor of lung
		Malignant tumor of the lung
		Cancer lung
		Cancer pulmonary
		Cancers lung
		Cancers pulmonary
		Pulmonary cancers
		Carcinomatosis
TNM	C1515169	
		Staging TNM
		TNM staging system
		TNM staging
Tx	C0332377	
		Malignant neoplasm TNM staging primary tumor Tx
		Tumor stage Tx
		Tx cancer stage finding
		Tx primary tumor finding
		Tx primary tumor stage finding
		Tx stage finding
		Tx tumor stage
		Tx stage
		Tx category
Tis	C0475413	
		Malignant neoplasm TNM staging primary tumor Tis
		Tumor stage Tis
		Tis cancer stage finding
		Tis primary tumor finding
		Pulmonary function test
		Respiratory function test
		Chronic obstructive airways disease
		Chronic obstructive bronchopneumopathy
		Obstructive airways disease

Table 56. RUMI ontology synonym list (continued).

149

Name	CUI	
Tis (continued)	C0475413	
		Tis primary tumor stage finding
		Tis stage
		Tis stage finding
		Tis TNM finding
		Tis tumor finding
		Tis tumor stage
		Tumor stage Tis
		Tis category
		Tis carcinoma in situ
T0	C0475371	
		Malignant neoplasm TNM staging primary tumor T0
		T0 stage
		T0 cancer stage finding
		T0 primary tumor finding
		T0 primary tumor stage finding
		T0 stage
		T0 stage finding
		T0 TNM finding
		T0 tumor finding
		T0 tumor stage
		Tumor stage T0
		T0 category
		Tumor stage T0
T1	C0475372	
		Malignant neoplasm TNM staging primary tumor T1
		Tumor stage T1
		T1 cancer stage finding
		T1 primary tumor finding
		Tis primary tumor finding
		Pulmonary function test
		Respiratory function test
		Chronic obstructive airways disease
		Chronic obstructive bronchopneumopathy
		Obstructive airways disease

Table 57. RUMI ontology synonym list (continued).

Name	CUI	
T1 (continued)	C0475372	
		T1 primary tumor stage finding
		T1 stage
		T1 stage finding
		T1 TNM finding
		T1 tumor finding
		T1 tumor stage
		Tumor stage T1
		T1 category
T2	C0475373	
		Malignant neoplasm TNM stage primary tumor T2
		Tumor stage T2
		T2 cancer stage finding
		T2 primary tumor finding
		T2 primary tumor stage finding
		T2 stage
		T2 stage finding
		T2 TNM finding
		T2 tumor finding
		T2 tumor stage
		Tumor stage T2
		T2 category
T3	C0475374	
		Malignant neoplasm TNM staging primary tumor T3
		Tumor stage T3
		T3 cancer stage finding
		T3 primary tumor finding
		T3 primary tumor stage finding
		T3 stage finding
		Tis primary tumor finding
		Pulmonary function test
		Respiratory function test
		Chronic obstructive airways disease
		Chronic obstructive bronchopneumopathy
		Obstructive airways disease

Table 58. RUMI ontology synonym list (continued).

Name	CUI	
T3 (continued)	C0475374	
		T3 TNM finding
		T3 tumor finding
		T3 Tumor stage
		Tumor stage T3
		T3 stage
		T3 category
T4	C0475751	
		Malignant neoplasm TNM stage primary tumor T4
		Tumor stage T4
		T4 cancer stage finding
		T4 primary tumor finding
		T4 primary tumor stage finding
		T4 stage
		T4 stage finding
		T4 TNM finding
		T4 tumor finding
		T4 tumor stage
		Tumor stage T4
		T4 category
Nx	C0445085	
		Malignant neoplasm TNM stage regional lymph node Nx
		Lymph node stage Nx
		Node stage Nx
		Nx cancer stage finding
		Nx lymph node finding
		Nx lymph node stage
		Nx node stage
		Nx regional lymph node stage finding
		Nx regional lymph node finding
		Pulmonary function test
		Respiratory function test
		Chronic obstructive airways disease
		Chronic obstructive bronchopneumopathy
		Obstructive airways disease

Table 59. RUMI ontology synonym list (continued).

Name	CUI	
Nx (continued)	C0445085	
		Nx stage
		Nx stage finding
		Nx TNM finding
		Nx stage
		Nx category
N0	C0441959	
		Malignant neoplasm TNM stage regional lymph node N0
		Node stage N0
		Lymph node stage N0
		N0 cancer stage finding
		N0 lymph node finding
		N0 lymph node stage
		N0 node finding
		N0 node stage
		N0 stage
		N0 stage finding
		N0 TNM finding
		N0 category
		Node stage N0
N1	C0441962	
		Malignant neoplasm TNM stage regional lymph node N1
		Lymph node stage N1
		N1 cancer stage finding
		N1 lymph node finding
		N1 lymph node stage
		N1 node finding
		N1 node stage
		N1 regional lymph node stage finding
		Nx regional lymph node finding
		Pulmonary function test
		Respiratory function test
		Chronic obstructive airways disease
		Chronic obstructive bronchopneumopathy
		Obstructive airways disease

Table 60. RUMI ontology synonym list (continued).

153

Name	CUI	
N1 (continued)	C0441962	
		N1 regional lymph nodes finding
		N1 stage
		N1 stage finding
		N1 TNM finding
		Node stage N1
		N1 category
		Node stage N1
N2	C0441960	
		Malignant neoplasm TNM stage regional lymph node
		Lymph node stage N2
		N2 cancer stage finding
		N2 lymph node stage
		N2 node finding
		N2 node stage
		N2 regional lymph node stage finding
		N2 regional lymph nodes finding
		N2 stage
		N2 stage finding
		N2 TNM finding
		Node stage N2
		N2 category
		Node stage N2
N3	C0441961	
		Malignant neoplasm TNM stage regional lymph node N3
		Lymph node stage N3
		N3 cancer stage finding
		N3 lymph node finding
		N3 lymph node stage
		N3 node finding
		N3 node stage
		Respiratory function test
		Chronic obstructive airways disease
		Chronic obstructive bronchopneumopathy
		Obstructive airways disease

Table 61. RUMI ontology synonym list (continued).

Name	CUI	
N3 (continued)	C0441961	
		N3 regional lymph node stage finding
		N3 regional lymph nodes finding
		N3 stage
		N3 stage finding
		N3 TNM finding
		Node stage N3
		N3 category
Mx	C0445039	
		Malignant neoplasm TNM staging distant metastasis Mx
		Metastasis stage Mx
		Mx cancer stage finding
		Mx distant metastasis finding
		Mx distant metastasis stage finding
		Mx stage
		Mx metastasis stage
		Mx metastasis finding
		Mx stage finding
		Mx TNM finding
		Metastasis stage Mx
		Mx category
M0	C0445034	
		Malignant neoplasm TNM staging distant metastasis M0
		M0 cancer stage finding
		M0 distant metastasis finding
		M0 distant metastasis stage finding
		M0 metastasis finding
		M0 metastasis stage
		M0 stage
		N3 node finding
		N3 node stage
		Respiratory function test
		Chronic obstructive airways disease
		Chronic obstructive bronchopneumopathy
		Obstructive airways disease

Table 62. RUMI ontology synonym list (continued).

Name	CUI	
M0 (continued)	C0445034	
		M0 stage finding
		M0 TNM finding
		Metastasis stage M0
		M0 category
		Metastasis stage M0
M1	C0441971	
		Malignant neoplasm TNM staging distant metastasis M1
		Metastasis stage M1
		M1 cancer stage finding
		M1 distant metastasis finding
		M1 distant metastasis stage finding
		M1 Metastasis finding
		M1 metastasis stage
		M1 stage
		M1 stage finding
		M1 TNM finding
		Metastasis Stage M1
		M1 category
		Metastasis stage M1
Stage I	C0278504	
		Lung cancer non-small cell stage I
		Non-small cell lung cancer stage I
		Stage I non-small cell carcinoma of the lung
		Stage I non-small cell lung cancer
		Stage I non-small cell lung carcinoma
		Stage I NSCLC
		NSCLC stage I
Stage II	C0278505	
		Lung cancer non-small cell stage II
		N3 node stage
		Respiratory function test
		Chronic obstructive airways disease
		Chronic obstructive bronchopneumopathy
		Obstructive airways disease

Table 63. RUMI ontology synonym list (continued).

Name	CUI	
Stage II (continued)	C0278505	
		Non-small cell lung cancer stage II
		Stage II non-small cell carcinoma of the lung
		Stage II non-small cell lung cancer
		Stage II non-small cell lung carcinoma
		Stage II NSCLC
		NSCLC stage II
Stage III	C0278506	
		Lung cancer non-small cell stage III
		Non-small cell lung cancer stage III
		Stage III non-small cell carcinoma of the lung
		Stage III non-small cell lung cancer
		Stage III non-small cell lung carcinoma
		Stage III NSCLC
		NSCLC stage III
Stage IV	C0278987	
		Lung cancer non-small cell stage IV
		Non-small cell lung cancer stage IV
		Stage IV non-small cell carcinoma of the lung
		Stage IV non-small cell lung cancer
		Stage IV non-small cell lung carcinoma
		Stage IV NSCLC
		NSCLC stage IV
Tumor location	C2063960	
		Right lower lobe
		RLL
		Right upper lobe
		RUL
		Right middle lobe
		Lung cancer non-small cell stage II
		N3 node stage
		Respiratory function test
		Chronic obstructive airways disease
		Chronic obstructive bronchopneumopathy
		Obstructive airways disease

Table 64. RUMI ontology synonym list (continued).

Name	CUI	
Tumor location (continued)	C2063960	
		RML
		Left lower lobe
		LLL
		Left upper lobe
		LUL
Tumor size	C1300453	
		aa x bb
		mean x mm
		mm
Fatigue	C0849970	
		Feel tired
		Feel tire
		Tired feeling
		Feeling fatigued
		Feeling tired
Hoarse voice	C0019825	
		Hoarseness
		Hoarse
		Husky voice
		Hoarseness of voice
		Voice hoarseness
		Croaky voice
		Hoarseness - throat symptom
		Hoarse voice quality
Weight loss	C0237352	
		Unexplained weight loss
		Progressive weight loss
		Right middle lobe Lung cancer non-small cell stage II
		N3 node stage
		Respiratory function test
		Chronic obstructive airways disease
		Chronic obstructive bronchopneumopathy
		Obstructive airways disease

Table 65. RUMI ontology synonym list (continued).

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Name	CUI	
Breathing trouble	C2707921	
		Shortness of breath
		Trouble breathing
		Shortness of breath with exertion
		Trouble breathing with exertion
		Dyspnea
Coughing blood	C0019079	
		Hemoptysis
		Blood coughed
		Blood spit up
		Blood spitting up
		Blood streaked sputum
		Bloody sputum
		Cough up blood
		Coughing up blood
		Spit up blood
		Spitting up blood
		Sputum bloody
		Coughing up blood streaked sputum
		Expectoration of blood streaked sputum
		Expectoration of bloody sputum
		Expectoration of hemorrhagic sputum
		Blood in sputum
Chest pain	C0008031	
		Pain thoracic
		Thoracic pain
		Thorax pain
		Pain chest
		Pain in chest
		Pain thorax
		Thoracalgia
		Chest discomfort
		Chest pains
		Pains chest
		Thorax painful

Table 66. RUMI ontology synonym list (continued).

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Name	CUI	
Respiratory symptom	C0037090	
		Respiratory symptom
		Respiratory sign
		Respiratory compliant
		Complaint of the respiratory system
		Symptom of the respiratory system

Table 67. RUMI ontology synonym list (continued).

APPENDIX C Background Survey for Conceptual Information Model

Survey of 41 lung cancer patients, * indicates multiple answers per question possible			
Education			
	Some high school	1	2
	High school	5	12%
	Some College	10	24 %
	Associates Degree	2	5%
	Bachelor Degree	12	30%
	Graduate Degree	6	15%
	PhD	5	12%
Preferred formats for health information			
	Paper	24	59%
	Internet	29	71%
	CD	12	29%
	USB key	5	12%
Information desired from radiology images			
	Important things the doctor saw	38	93%
	How radiology images were created	10	24%
	Images that show health problems	27	66%
	Explanations of radiology reports	32	78%
	Definitions for confusing terms	25	61%
	Do not want to see radiology images/reports	1	2%

Table 68. Survey results of 41 lung cancer patients at UCLA conducted as basis for the RUMI conceptual information model.

Question	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Did not respond
Like to see radiology images	19 (47%)	10 (24%)	8 (20%)	0 (0%)	3 (7%)	1 (2%)
Understanding medical images will help patient manage their problems	19 (47%)	14 (34%)	5 (12%)	2 (5%)	1 (2%)	0 (0%)
Difficult to find health information	0 (0%)	13 (32%)	15 (37%)	9 (22%)	3 (7%)	1 (2%)
Patient has the computer skills to use portal	26 (64%)	10 (24%)	2 (5%)	1 (2%)	2 (5%)	0 (0%)
Patient could learn the computer skills to use portal	19 (47%)	13 (32%)	3 (7%)	1 (2%)	1 (2%)	4 (10%)
Seeing records via portal will increase anxiety	3 (7%)	8 (20%)	9 (22%)	9 (22%)	12 (29%)	0 (0%)
Portal will help patient talk with doctor	18 (44%)	20 (49%)	2 (5%)	0 (0%)	0 (0%)	1 (2%)
Portal will help patient follow instructions	20 (49%)	17 (42%)	2 (5%)	1 (2%)	0 (0%)	1 (2%)

Table 69. Survey results of 41 lung cancer patients at UCLA conducted as basis for the RUMI conceptual information model (continued).

APPENDIX D Surveys Used in Step II of the In Clinic Usability Study

Patient Information Preference	
Variable Name	**Question**
becomeSkill	It should be easy to become skillful at using this portal/ this copy of my record.
commun	Using this portal/ copy of my record can assist my face to face communication with my healthcare providers.
easyLearn	This portal/copy of my record is easy to learn how to use.
easyOperate	This portal/copy of my record is easy to operate.
educKnow	Using this portal/copy of my record can provide me with healthcare knowledge and education.
effectiveness	Using this portal/copy of my record can enhance my effectiveness in personal health management.
efficient	This portal/copy of my record can make me efficient in managing my personal health information.
managePHI	This portal/copy of my record can be useful to manage my personal health information.
notDiff	This portal/copy of my record is not difficult to use.
portAccomTask	Using this portal/copy of my record can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information.
productivity	Using this portal/copy of my record can increase my productivity in managing my personal health information.
reduceTime	This portal/copy of my record can reduce my time spent on managing my personal health information.
suitNeeds	This portal/copy of my record can suit my needs of managing my personal health information.
termVocab	Using this portal/copy of my record can improve my understanding of medical terminology and vocabulary.

Table 70. Survey questions for Step II.

Lung Cancer Screening Knowledge	
Variable Name	**Question**
blood	Coughing up blood is a frequent sign of lung cancer.
chance	In the past, before the CT scan was introduced, the chance of dying due to lung cancer after diagnosis was: (Answer options: high, somewhat high, somewhat low, low)
common	Lung cancer is one of the most common cancers.
complaint	A person can have lung cancer without any signs.
cough	A change of cough pattern is a frequent sign of lung cancer.
hereditary	Lung cancer may be hereditary.
contagious	Lung cancer is contagious.
madeX	CT images are made with X-rays.
normalCT	What is the meaning of a "normal" CT scan?
risk	Someone who has quit smoking has a higher risk of developing lung cancer than someone who has never smoked.
LDCT	Low radiation dose chest CT (LDCT) is a good screening test for lung cancer.
negLDCT	A negative LDCT means I do not have lung cancer.
additionalTests	If I have a negative LDCT scan, I don't need to undergo additional screening tests for lung cancer.
positiveLDCT	A positive LDCT scan means that I probably have lung cancer.
quitSmoke	A negative LDCT scan means I don't need to quit smoking.

Table 71. Survey questions for Step II (continued).

APPENDIX E Patient Enrollment Physician Notification Letter

Month Dayth Year

Dear Colleague,

This letter is to inform you that your patient, NAME, has been enrolled in a study that investigates how patients would like to view the information from their radiology reports. This study is supervised by Dr. Denise Aberle and Dr. Kathleen Ruchalski of the Dept. of Radiological Sciences at UCLA. Specifically, this study targets patients undergoing a thoracic low-dose CT scan for lung cancer screening, and provides them the opportunity to see the report generated from this imaging procedure alongside educational content via a patient portal, or computer application.

To eliminate the possibility of unexpected stress on the patient, we will wait to show the patient their record until after they have had the chance to discuss the results with you. To facilitate this, we will not invite the patient to view their record until four weeks after their imaging procedure.

If you have any concerns or questions, please feel free to contact, Dr. Denise Aberle, by sending an email to daberle@mednet.ucla.edu.

Sincerely yours,

Professor of Radiology and Bioengineering

Vice Chair, Research

Department of Radiological Sciences

David Geffen School of Medicine at UCLA

APPENDIX F Abbreviated Verison of Survey Used in MTurk Study

Demographics	
Variable Name	**Question**
Age	What is your age group?
Education	What is your highest level of education?
Income	What is your approximate annual income?
Internet	In one week, how many hours do you spend on the Internet?
Race	What race(s) best represent you?
Sex	What is your sex?
Used	How many times have you used a patient health portal?
Patient Information Preferences	
Variable Name	**Question**
becomeSkill	It should be easy to become skillful at using a portal.
commun	Using a portal can assist my face to face communication with my healthcare providers
encyc	Using a portal with a health encyclopedia can provide me with healthcare knowledge and education.
educKnow	Using a portal with a health encyclopedia can provide me with healthcare knowledge and education
managePHI	A portal can be useful to manage my personal health information.
notDiff	Portals are not difficult to use.
portAccomTask	Using a portal can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information.
suitNeeds	A personalized portal can suit my needs of managing my personal health information.

Table 72. Survey questions for MTurk survey.

Lung Cancer Screening Knowledge	
Variable Name	**Question**
blood	Coughing up blood is a frequent sign of lung cancer.
chance	In the past, before the CT scan was introduced, the chance of dying due to lung cancer after diagnosis was: (Answer options: high, somewhat high, somewhat low, low)
common	Lung cancer is one of the most common cancers.
complaint	A person can have lung cancer without any signs.
cough	A change of cough pattern is a frequent sign of lung cancer.
hereditary	Lung cancer may be hereditary.
contagious	Lung cancer is contagious.
madeX	CT images are made with X-rays.

Table 73. Survey questions for MTurk survey (continued).

APPENDIX G All Survey Results from In-Clinic Usability Study

		A	B	C	D	E	F	G
Age	*F*-ratio	.301	2.269	.807	.714	1.174	1.390	.564
	p-value	.824	.137	.516	.564	.364	.298	.650
Education	*F*-ratio	0.253	0.808	0.532	0.357	0.374	.429	0.715
	p-value	0.901	0.548	0.716	0.833	0.822	.785	0.601
Income	*F*-ratio	0.340	1.215	0.468	1.327	1.215	1.246	0.742
	p-value	0.845	0.369	0.758	0.332	0.369	0.359	0.587
Hours online	*F*-ratio	0.836	0.413	1.743	1.881	0.487	0.650	0.498
	p-value	0.504	0.748	0.221	0.197	0.699	0.601	0.692
Sex	*F*-ratio	1.072	0.850	0.565	-0.270	0.545	0.075	0.800
	p-value	0.313	0.411	0.582	0.791	0.595	0.941	0.438
Race	*F*-ratio	-0.579	0.239	-0.732	0.000	-0.406	-0.869	-0.620
	p-value	0.572	0.815	0.477	1.000	0.692	0.401	0.546
Portal use	*F*-ratio	0.836	0.413	1.743	1.881	0.487	0.650	0.498
	p-value	0.504	0.748	0.221	0.197	0.699	0.601	0.692

Table 74. Univariate Step I results for patient information preference questions. . A. It should be easy to become skillful at using a portal. B. Using a portal like RUMI can assist my communication with my healthcare providers. C. Portals like RUMI are easy to learn how to use. D. Portals like RUMI are easy to operate. E. Using a portal like RUMI can provide me with healthcare knowledge and education. F. Using a portal like RUMI can enhance my effectiveness in personal health management. G. A personalized portal like RUMI can make me efficient in managing my personal health information.

		H	I	J	K	L	M	N
Age	*F*-ratio	1.074	0.816	0.896	1.831	0.026	1.694	1.118
	p-value	.400	0.511	0.474	0 .200	0.994	0.226	0.384
Education	*F*-ratio	0.274	0.358	0.611	0.143	0.853	0.175	0.447
	p-value	0.888	0.833	0.664	0.962	0.524	0.946	0.772
Income	*F*-ratio	1.306	0.533	0.884	1.824	0.422	1.810	1.253
	p-value	0.338	0.715	0.511	0.208	0.789	0.211	0.356
Hours online	*F*-ratio	0.464	1.131	0.884	0.341	0.705	0.413	0.716
	p-value	0.761	0.401	0.511	0.844	0.608	0.796	0.602
Sex	*t*-score	0.514	0.462	0.475	0.020	1.731	0.156	0.722
	p-value	0.616	0.651	0.643	0.985	0.107	0.879	0.483
Race	*F*-ratio	-0.562	-0.534	-0.307	-0.599	-0.624	-0.292	-0.322
	p-value	0.584	0.602	0.763	0.560	0.544	0.775	0.752
Portal use	*F*-ratio	0.564	0.737	0.381	1.065	0.301	0.812	0.621
	p-value	0.651	0.554	0.769	0.407	0.824	0.516	0.617

Table 75. Univariate Step I results for patient information preference questions (continued). H. A portal can be useful to manage my personal health information. I. Portals like RUMI are not difficult to use. J. Using a portal can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information. K. Using a portal like RUMI can increase my productivity in managing my personal health information. L. A personalized portal like RUMI can reduce my time spent on managing my personal health information. M. A personalized portal like RUMI can suit my needs of managing my personal health information. N. Using a portal like RUMI can improve my understanding of medical terminology and vocabulary.

		A	B	C	D	E	F	G	H
Age	x^2	6.346	2.399	8.464	4.286	8.571	2.085	1.830	5.077
	p-value	0.096	0.494	0.206	0.638	0.199	0.555	0.608	0.534
Education	x^2	2.019	5.625	7.375	13.333	10.000	5.960	6.146	4.405
	p-value	0.732	0.229	0.497	0.101	0.265	0.202	0.189	0.819
Income	x^2	1.750	2.121	6.806	8.789	7.875	2.431	1.750	3.949
	p-value	0.782	0.713	0.558	0.360	0.446	0.657	0.782	0.413
Hours online	x^2	10.000	8.061	7.836	5.289	6.235	3.928	10.040	9.022
	p-value	**0.019**	0.089	0.450	0.726	0.621	0.416	**0.040**	0.340
Sex	x^2	2.637	1.029	0.134	0.938	0.714	0.077	0.268	0.746
	p-value	0.104	0.310	0.935	0.626	0.700	0.782	0.605	0.689
Race	x^2	0.577	3.068	7.500	0.417	1.111	4.286	5.104	2.946
	p-value	0.448	0.080	**0.024**	0.812	0.574	**0.038**	**0.024**	0.229
Portal use	x^2	3.111	6.081	8.750	9.333	5.185	3.111	6.081	4.667
	p-value	0.375	0.108	0.188	0.156	0.520	0.375	0.108	0.587

Table 76. Univariate Step I results for lung cancer screening knowledge questions. A. What disorders are you being screened for today. B. What is the meaning of a "normal" CT result. C. CT images are made with X-rays. D. In the past, before the CT scan was intro introduced, the chance of dying due to lung cancer after diagnosis was. E. Lung cancer is one of the most common cancers. F. A change of cough pattern is a frequent sign of lung cancer. G. Coughing up blood is a frequent sign of lung cancer. H. Lung cancer may be hereditary.

		I	J	K	L	M	N	O	P
Age	x^2	1.224	2.946	9.643	9.861	9.861	5.139	5.486	**
	p-value	0.747	0.400	**0.022**	0.362	0.362	0.526	0.483	**
Education	x^2	15.000	10.833	5.625	2.593	7.444	6.194	3.194	**
	p-value	**0.005**	**0.029**	0.229	0.274	0.282	0.185	0.526	**
Income	x^2	3.949	1.131	2.121	**	8.438	6.375	10.500	**
	p-value	0.413	0.889	0.713	**	0.491	0.383	0.105	**
Hours online	x^2	**	8.556	5.289	10.000	10.486	6.181	5.486	**
	p-value	**	0.073	0.259	**0.019**	**0.019**	0.403	0.483	**
Sex	x^2	1.224	0.603	0.603	0.741	5.833	6.875	1.319	**
	p-value	0.268	0.438	0.438	0.389	0.120	**0.032**	0.517	**
Race	x^2	4.286	4.286	0.417	10.000	2.593	2.593	1.667	**
	p-value	**0.038**	**0.038**	0.519	**0.002**	0.459	0.274	0.435	**
Portal use	x^2	**	3.111	3.111	4.444	6.667	6.042	5.000	**
	p-value	**	0.375	0.375	0.217	0.672	0.419	0.544	**

Table 77. Univariate Step I results for lung cancer screening knowledge questions (continued). I. Lung cancer is contagious. J. A person can have lung cancer without any signs. K. Someone who has quit smoking has a higher risk of developing lung cancer than someone who has never smoked. L. Low radiation dose chest CT (LDCT) is a good screening test for lung cancer. M. A negative LDCT means I do not have lung cancer. N. If I have a negative LDCT scan, I don't need to undergo additional screening tests for lung cancer. O. A positive LDCT scan means that I probably have lung cancer. P. A negative LDCT scan means I don't need to quit smoking. **No statistics are computed because the variable is a constant.

		A	B	C	D	E	F	G
Age	*F*-ratio	0.301	2.269	0.807	0.714	1.174	1.390	0.564
	p-value	0.824	0.137	0.516	0.564	0.364	0.298	0.650
Education	*F*-ratio	0.622	0.165	0.837	0.197	0.084	1.160	3.020
	p-value	0.582	0.853	0.497	0.829	0.921	0.401	0.159
Income	*F*-ratio	0.438	0.714	0.083	0.432	0.714	0.343	0.278
	p-value	0.742	0.606	0.965	0.746	0.606	0.799	0.840
Hours online	*F*-ratio	0.101	0.247	0.055	0.347	0.476	0.249	0.090
	p-value	0.954	0.860	0.980	0.796	0.721	0.858	0.961
Sex	*F*-ratio	-0.480	-0.845	-1.511	-1.056	-0.331	0.067	-0.361
	p-value	0.672	0.437	0.191	0.339	0.754	0.949	0.733
Race	*F*-ratio	0.255	0.378	0.378	0.663	0.732	0.189	-0.305
	p-value	0.809	0.721	0.721	0.537	0.497	0.858	0.772
Portal use	*F*-ratio	0.185	0.449	2.034	0.694	0.605	0.686	0.662
	p-value	0.838	0.667	0.246	0.551	0.589	0.555	0.564

Table 78. Univariate Step II results portal for patient information preference questions. A. It should be easy to become skillful at using a portal. B. Using a portal like RUMI can assist my communication with my healthcare providers. C. Portals like RUMI are easy to learn how to use. D. Portals like RUMI are easy to operate. E. Using a portal like RUMI can provide me with healthcare knowledge and education. F. Using a portal like RUMI can enhance my effectiveness in personal health management. G. A personalized portal like RUMI can make me efficient in managing my personal health information.

		H	I	J	K	L	M	N
Age	*F*-ratio	1.074	0.816	0.896	1.831	0.026	1.694	1.118
	p-value	0.400	0.511	0.474	0.200	0.994	0.226	0.384
Education	*F*-ratio	3.755	0.127	2.301	6.074	3.206	0.390	0.101
	p-value	0.121	0.884	0.216	0.061	0.148	0.700	0.906
Income	*F*-ratio	0.259	0.527	0.344	0.490	0.278	0.497	0.714
	p-value	0.852	0.694	0.798	0.714	0.840	0.710	0.606
Hours online	*F*-ratio	0.119	0.750	0.051	0.112	0.065	0.160	0.810
	p-value	0.943	0.591	0.982	0.947	0.975	0.917	0.567
Sex	*F*-ratio	-0.067	-1.067	-0.096	-0.529	-0.926	-0.690	0.105
	p-value	0.949	0.335	0.931	0.643	0.397	0.521	0.921
Race	*F*-ratio	-0.189	0.674	0.234	-0.076	-0.305	0.314	1.660
	p-value	0.858	0.530	0.824	0.943	0.772	0.766	0.158
Portal use	*F*-ratio	0.398	1.182	0.347	0.173	0.662	0.292	1.393
	p-value	0.696	0.395	0.726	0.847	0.564	0.761	0.347

Table 79. Univariate Step II portal results for patient information preference questions (continued). H. This portal can be useful to manage my personal health information. I. Portals like RUMI are not difficult to use. J. Using a portal can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information. K. Using a portal like RUMI can increase my productivity in managing my personal health information. L. A personalized portal like RUMI can reduce my time spent on managing my personal health information. M. A personalized portal like RUMI can suit my needs of managing my personal health information. N. Using a portal like RUMI can improve my understanding of medical terminology and vocabulary.

		A	B	C	D	E	F	G
Age	x^2	**	6.125	7.778	1.283	4.278	4.278	3.208
	p-value	**	0.409	0.255	0.733	0.233	0.233	0.782
Education	x^2	**	3.208	4.278	7.000	0.194	0.194	3.500
	p-value	**	0.524	0.370	**0.030**	0.907	0.907	0.478
Income	x^2	**	3.208	10.111	3.733	4.278	4.278	6.125
	p-value	**	0.782	0.120	0.292	0.233	0.233	0.409
Hours online	x^2	**	7.438	6.417	3.325	2.917	2.917	8.750
	p-value	**	0.282	0.378	0.344	0.405	0.405	0.188
Sex	x^2	**	3.938	0.194	0.058	0.194	0.194	0.875
	p-value	**	0.140	0.907	0.809	0.659	0.659	0.646
Race	x^2	**	2.917	2.917	0.467	0.875	0.875	0.875
	p-value	**	0.233	0.232	0.495	0.350	0.350	0.646
Portal use	x^2	**	9.800	4.200	1.120	2.100	2.100	3.500
	p-value	**	**0.044**	0.380	0.571	0.350	0.350	0.478

Table 80. Univariate Step II portal results for lung cancer screening knowledge questions. A. What is the meaning of a "normal" CT result. B. CT images are made with X-rays. C. In the past, before the CT scan was introduced, the chance of dying due to lung cancer after diagnosis was. D. Lung cancer is one of the most common cancers. E. A change of cough pattern is a frequent sign of lung cancer. F. Coughing up blood is a frequent sign of lung cancer. G. Lung cancer may be hereditary. **No statistics are computed because the variable is a constant.

		I	J	K	L	M	N	O	P
Age	x^2	**	1.556	7.000	**	1.283	2.236	**	**
	p-value	**	0.670	0.321	**	0.733	0.525	**	**
Education	x^2	**	2.917	2.167	**	2.100	4.958	**	**
	p-value	**	0.233	0.705	**	0.350	0.084	**	**
Income	x^2	**	2.916	6.000	**	4.550	4.958	**	**
	p-value	**	0.405	0.423	**	0.209	0.175	**	**
Hours online	x^2	**	7.000	7.000	**	7.000	3.938	**	**
	p-value	**	0.072	0.136	**	0.072	0.268	**	**
Sex	x^2	**	0.875	1.333	**	2.100	0.194	**	**
	p-value	**	0.350	0.513	**	0.147	0.659	**	**
Race	x^2	**	0.194	6.000	**	0.467	0.875	**	**
	p-value	**	0.659	0.050	**	0.495	0.350	**	**
Portal use	x^2	**	0.467	8.250	**	1.120	2.100	**	**
	p-value	**	0.792	0.083	**	0.571	0.350	**	**

Table 81. Univariate Step II portal results for lung cancer screening knowledge questions (continued). I. Lung cancer is contagious. J. A person can have lung cancer without any signs. K. Someone who has quit smoking has a higher risk of developing lung cancer than someone who has never smoked. L. Low radiation dose chest CT (LDCT) is a good screening test for lung cancer. M. A negative LDCT means I do not have lung cancer. N. If I have a negative LDCT scan, I don't need to undergo additional screening tests for lung cancer. O. A positive LDCT scan means that I probably have lung cancer. P. A negative LDCT scan means I don't need to quit smoking. **No statistics are computed because the variable is a constant.

		A	B	C	D	E	F	G
Age	F-ratio	0.232	0.311	0.097	0.065	0.210	0.134	0.224
	p-value	0.869	0.819	0.957	0.975	0.884	0.933	0.874
Education	F-ratio	24.286	33.657	11.558	11.978	3.675	6.571	2.987
	p-value	**0.006**	**0.003**	**0.022**	**0.020**	0.124	0.054	0.161
Income	F-ratio	0.714	1.049	0.962	1.370	4.878	2.214	8.143
	p-value	0.606	0.485	0.512	0.401	0.113	0.265	0.059
Hours online	F-ratio	0.565	1.015	0.912	0.567	1.743	1.571	3.571
	p-value	0.675	0.495	0.529	0.674	0.330	0.360	0.162
Sex	t-score	-0.434	-0.410	-1.025	0.218	-0.378	-0.242	0.153
	p-value	0.683	0.699	0.352	0.836	0.721	0.818	0.884
Race	t-score	-0.366	-0.733	-0.845	-0.102	-0.615	-0.205	-0.598
	p-value	0.729	0.497	0.437	0.922	0.565	0.846	0.576
Portal use	F-ratio	1.100	1.455	1.766	0.342	1.048	0.857	1.089
	p-value	0.416	0.335	0.282	0.729	0.431	0.490	0.419

Table 82. Univariate Step II paper record results for patient information preference questions. A. It should be easy to become skillful at using this copy of my record. . B. This record can assist my face-to-face communication with my healthcare providers C. This copy of my record is easy to learn how to use. D. This copy of my record is easy to operate. E. This copy of my record can provide me with healthcare knowledge and education. F. This copy of my record can enhance my effectiveness in personal health management. G. This copy of my record can make me efficient in managing my personal health information.

		H	I	J	K	L	M	N
Age	*F*-ratio	0.403	0.132	0.215	0.060	0.056	0.230	0.295
	p-value	0.763	0.935	0.881	0.977	0.980	0.870	0.829
Education	*F*-ratio	6.120	6.829	11.173	3.755	1.531	2.768	2.039
	p-value	0.061	0.051	**0.023**	0.121	0.321	0.176	0.245
Income	*F*-ratio	0.484	0.535	1.407	0.580	6.393	9.171	6.687
	p-value	0.717	0.690	0.393	0.667	0.081	0.051	0.076
Hours online	*F*-ratio	0.286	0.570	1.086	0.535	3.150	1.906	0.305
	p-value	0.835	0.672	0.474	0.690	0.186	0.605	0.655
Sex	*F*-ratio	-1.352	-1.103	-0.609	-1.116	0.110	-0.053	-0.353
	p-value	0.234	0.320	0.569	0.315	0.917	0.960	0.739
Race	*F*-ratio	-0.598	-0.592	-0.628	-0.189	-0.234	-0.641	-0.220
	p-value	0.576	0.580	0.558	0.858	0.824	0.550	0.835
Portal use	*F*-ratio	1.571	2.598	1.259	1.950	1.286	1.179	0.579
	p-value	0.314	0.189	0.377	0.256	0.371	0.396	0.601

Table 83. Univariate Step II paper record results for patient information preference questions (continued). H. This copy of my record can be useful to manage my personal health information. I. This copy of my record is not difficult to use. J. Using this copy of my record can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information. K. This copy of my record can increase my productivity in managing my personal health information. L. This copy of my record can reduce my time spent on managing my personal health information. M. This copy of my record suits my needs of managing my personal health information. N. Using a portal like RUMI can improve my understanding of medical terminology and vocabulary.

		A	B	C	D	E	F	G
Age	x^2	**	6.125	6.222	1.500	4.278	4.278	3.733
	p-value	**	0.409	0.399	0.682	0.233	0.233	0.713
Education	x^2	**	3.208	6.222	6.000	0.194	2.236	5.600
	p-value	**	0.524	0.183	0.051	0.907	0.327	0.231
Income	x^2	**	3.208	10.889	3.000	4.278	2.236	4.200
	p-value	**	0.782	0.092	0.392	0.233	0.525	0.650
Hours online	x^2	**	7.438	4.667	2.625	2.917	2.917	7.700
	p-value	**	0.282	0.587	0.269	0.405	0.405	0.261
Sex	x^2	**	3.938	1.556	0.000	0.194	1.215	2.100
	p-value	**	0.140	0.459	1.000	0.659	0.270	0.350
Race	x^2	**	2.917	1.556	0.600	0.875	1.556	0.467
	p-value	**	0.233	0.459	0.439	0.350	0.212	0.792
Portal use	x^2	**	9.800	2.800	1.500	2.100	2.100	1.120
	p-value	**	**0.044**	0.592	0.472	0.350	0.350	0.891

Table 84. Univariate Step II paper record results for lung cancer screening knowledge questions. A. What is the meaning of a "normal" CT result? B. CT images are made with X-rays. C. In the past, before the CT scan was introduced, the chance of dying due to lung cancer after diagnosis was. D. Lung cancer is one of the most common cancers. E. A change of cough pattern is a frequent sign of lung cancer. F. Coughing up blood is a frequent sign of lung cancer. G. Lung cancer may be hereditary. **No statistics are computed because the variable is a constant.

		H	I	J	K	L	M	N	O
Age	x^2	**	7.000	8.250	**	1.283	5.542	7.000	7.000
	p-value	**	0.072	0.220	**	0.733	0.476	0.072	0.072
Education	x^2	**	1.556	3.250	**	2.100	6.125	1.556	1.556
	p-value	**	0.459	0.517	**	0.350	0.190	0.459	0.459
Income	x^2	**	1.556	3.000	**	4.550	7.000	1.556	1.556
	p-value	**	0.670	0.809	**	0.208	0.321	0.670	0.670
Hours online	x^2	**	7.000	6.375	**	7.000	4.375	7.000	7.000
	p-value	**	0.072	0.173	**	0.072	0.626	0.072	0.072
Sex	x^2	**	0.875	2.000	**	2.100	2.917	0.875	0.875
	p-value	**	0.350	0.368	**	0.147	0.233	0.350	0.350
Race	x^2	**	7.000	6.000	**	0.467	2.917	7.000	7.000
	p-value	**	**0.008**	0.053	**	0.495	0.233	**0.008**	**0.008**
Portal use	x^2	**	7.000	6.375	**	1.120	7.000	7.000	7.000
	p-value	**	**0.030**	0.173	**	0.571	0.136	**0.030**	**0.030**

Table 85. Univariate Step II paper record results for lung cancer screening knowledge questions (continued). H. Lung cancer is contagious. I. A person can have lung cancer without any signs. J. Someone who has quit smoking has a higher risk of developing lung cancer than someone who has never smoked. K. Low radiation dose chest CT (LDCT) is a good screening test for lung cancer. L. A negative LDCT means I do not have lung cancer. M. If I have a negative LDCT scan, I don't need to undergo additional screening tests for lung cancer. N. A positive LDCT scan means that I probably have lung cancer. O. A negative LDCT scan means I don't need to quit smoking. **No statistics are computed because the variable is a constant.

Question	z	*p*-value
It should be easy to become skillful at using this portal.	-0.962	0.336
It should be easy to become skillful at using a portal.		
This portal can assist my communication with my healthcare providers.	-0.447	0.655
Using a portal like RUMI can assist my communication with my healthcare providers.		
This portal is easy to learn how to use.	-0.368	0.713
Portals like RUMI are easy to learn how to use.		
This portal is easy to operate.	-0.921	0.357
Portals like RUMI are easy to operate.		
This portal can provide me with healthcare knowledge and education.	0.000	1.000
Using a portal like RUMI can provide me with healthcare knowledge and education.		
This portal can enhance my effectiveness in personal health management.	-1.134	0.257
Using a portal like RUMI can enhance my effectiveness in personal health		
This portal can make me efficient in managing my personal health information.	-0.412	0.680
A personalized portal like RUMI can make me efficient in managing my personal health information.		
This portal can be useful to manage my personal health information.	-0.184	0.854
A portal can be useful to manage my personal health information.		
This portal is not difficult to use.	0.000	1.000
Portals like RUMI are not difficult to use.		
This portal can increase my productivity in managing my personal health information.	-0.365	0.715
Using a portal like RUMI can increase my productivity in managing my personal health information.		
This portal can reduce my time spent on managing my personal health information.	0.000	1.000
Using a portal like RUMI can reduce my time spent on managing my personal health information.		
This portal suits my needs of managing my personal health information.	-0.736	0.461
A personalized portal like RUMI can suit my needs of managing my personal health information.		
Using this portal can improve my understanding of medical terminology and vocabulary.	-0.378	0.705
Using a portal like RUMI can improve my understanding of medical terminology and vocabulary.		
Using this portal can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information.	-0.184	0.854
Using a portal can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information.		

Table 86. Wilcoxon signed-rank test paired observations results comparing Step I to Step II portal answers.

Question	z	p-value
It should be easy to become skillful at using this portal. It should be easy to become skillful at using this copy of my record.	-2.232	**0.026**
This portal can assist my communication with my healthcare providers. Using this copy of my record can assist my communication with my healthcare providers.	-1.841	0.066
This portal is easy to learn how to use. This copy of my record is easy to learn how to use.	-0.447	0.655
This portal is easy to operate. This copy of my record is easy to operate.	-0.184	0.854
This portal can provide me with healthcare knowledge and education. This copy of my record can provide me with healthcare knowledge and education.	-0.736	0.461
This portal can enhance my effectiveness in personal health management. This copy of my record can enhance my effectiveness in personal health management.	-1.069	0.285
This portal can make me efficient in managing my personal health information. This copy of my record can make me efficient in managing my personal health information.	-1.069	0.285
This portal can be useful to manage my personal health information. This copy of my record can be useful to manage my personal health information.	-1.134	0.257
This portal is not difficult to use. This copy of my record is not difficult to use.	-1.382	0.167
This portal can increase my productivity in managing my personal health information. This copy of my record can increase my productivity in managing my personal health information.	-1.807	0.071
This portal can reduce my time spent on managing my personal health information. This copy of my record can reduce my time spent on managing my personal health information.	-1.219	0.223
This portal suits my needs of managing my personal health information. This copy of my record can suit my needs of managing my personal health information.	-0.730	0.465
Using this portal can improve my understanding of medical terminology and vocabulary. This copy of my record can improve my understanding of medical terminology and vocabulary.	-1.633	0.102
Using this portal can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information. This copy of my record can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information.	-0.649	0.516

Table 87. Wilcoxon signed-rank test paired observations results comparing Step II portal and Step II paper answers.

Question	McNemar p-value
Coughing up blood is a frequent sign of lung cancer.	0.250
In the past, before the CT scan was introduced, the chance of dying due to lung cancer after diagnosis was:	1.000
Lung cancer is one of the most common cancers.	1.000
A person can have lung cancer without complaint.	1.000
A change of cough pattern is a frequent sign of lung cancer.	1.000
Lung cancer may be hereditary.	1.000
CT images are made with X-rays.	1.000
Someone who has quit smoking has a higher risk of developing lung cancer than someone who has never smoked.	0.500

Table 88. McNemar paired observations results comparing Step I to Step II portal answers.

Question	McNemar p-value
Coughing up blood is a frequent sign of lung cancer.	1.000
In the past, before the CT scan was introduced, the chance of dying due to lung cancer after diagnosis was:	1.000
Lung cancer is one of the most common cancers.	1.000
A person can have lung cancer without complaint.	1.000
A change of cough pattern is a frequent sign of lung cancer.	1.000
Lung cancer may be hereditary.	1.000
CT images are made with X-rays.	1.000
Someone who has quit smoking has a higher risk of developing lung cancer than someone who has never smoked.	1.000

Table 89. McNemar paired observations results comparing Step II portal and Step II paper answers.

Question	x^2	p-value
It should be easy to become skillful at using this portal. It should be easy to become skillful at using a portal.	7.896	0.246
This portal can assist my communication with my healthcare providers. Using a portal like RUMI can assist my communication with my healthcare providers.	13.880	**0.031**
This portal can provide me with healthcare knowledge and education. Using a portal like RUMI can provide me with healthcare knowledge and education.	12.327	0.055
This portal can be useful to manage my personal health information. A portal can be useful to manage my personal health information.	11.333	0.079
This portal is not difficult to use. Portals like RUMI are not difficult to use.	7.669	0.263
This portal suits my needs of managing my personal health information. A personalized portal like RUMI can suit my needs of managing my personal health information.	51.430	**0.000**
Using this portal can improve my understanding of medical terminology and vocabulary. Using a portal like RUMI can improve my understanding of medical terminology and vocabulary.	51.430	**0.000**
Using this portal can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information. Using a portal can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information.	14.125	**0.028**

Table 90. Chi-square homogeneity results comparing Step I to MTurk Survey answers for information preferences.

Question	x^2	p-value
In the past, before the CT scan was introduced, the chance of dying due to lung cancer after diagnosis was:	0.799	0.939
Lung cancer is one of the most common cancers.	3.657	0.161
A person can have lung cancer without any signs.	2.353	0.308
A change of cough pattern is a frequent sign of lung cancer.	2.208	0.332
Lung cancer is contagious.	0.538	0.764
CT images are made with X-rays.	2.713	0.258
Someone who has quit smoking has a higher risk of developing lung cancer than someone who has never smoked.	3.113	0.211

Table 91. Chi-square homogeneity results comparing Step I to MTurk Survey answers for lung cancer screening, questions are the same for both versions of the survey.

Free Text Topics	Concerns Step I	Concerns Step II	Effect Step I	Effect Step II	Total Concerns	Total Effect	Total
Security	3	0	0	0	3	0	**3**
Positive association	2	1	0	0	3	0	**3**
Health literacy	1	0	5	2	1	7	**8**
Information access	0	2	2	2	2	4	**6**
Suggestions	1	0	0	0	1	0	**1**
Communication	1	0	0	0	1	0	**1**
Data errors	1	0	0	0	1	0	**1**
Scheduling	0	0	1	0	0	1	**1**
Anxiety	0	0	1	0	0	1	**1**
Hardware failure	0	1	0	0	1	0	**1**
Useful	0	0	0	1	0	1	**1**
Extraneous effort	0	0	0	1	0	1	**1**

Table 92. All themes occurring in response to questions about concerns and effects of using a portal in the in-clinic usability test.

Terms	Number of Patients Requesting
Coronal MIPS	2
dFOV	3
Helical mode	2
MIPS	3
Prospective reconstructions	2
Sagittal MIPS	2
USPSTF	2
Atelectasis	1
Atheroslecrotic calcification	1
Axial	1
Axillary	1
Bronchiectasis	1
Bronchiolectasis	1
Calcifications	1
Category 1	1
Category 2	1
Category 3-4B	1
Consistent with cysts	1
Coronal reformation	1
Cylindrical brinchiectasis	1
Fibrosis	1
Helical	1
Hiatal hernia	1
Intrathoracic	1
Left circumflex coronary	1
Lingula	1
Low attenuation lucencies	1
Low radiation dose tachnique	1
Mild atherosclerotic	1
Mild diffuse peribronchial	1
Mildy patulous	1
Peribronchiolar thickening	1
Pericardial effusion	1

Table 93. All terms requested by Step II patients to be added to the conceptual information model.

Terms	Number of Patients Requesting
Pleura	1
Sagittal reformation	1
Supraclavicular	1

Table 94. All terms requested by Step II patients to be added to the conceptual information model (continued).

APPENDIX H All Survey Results from MTurk Usability Study

		A	B	C	D	E	F	G
Age	*F*-ratio	1.358	1.662	1.222	1.150	0.574	1.312	1.346
	p-value	0.221	0.116	0.289	0.330	0.777	0.243	0.227
Education	*F*-ratio	0.277	1.679	1.173	0.919	0.299	1.094	1.561
	p-value	0.893	0.154	0.322	0.453	0.878	0.359	0.327
Income	*F*-ratio	0.950	0.771	1.424	0.278	0.682	0.567	0.531
	p-value	0.440	0.544	0.225	0.892	0.604	0.687	0.713
Smoking habit	*F*-ratio	0.914	1.099	1.117	1.875	0.801	0.519	1.483
	p-value	0.402	0.334	0.328	0.155	0.450	0.596	0.228
Hours online	*F*-ratio	1.217	0.191	1.678	1.009	0.288	2.349	1.876
	p-value	0.303	0.903	0.171	0.388	0.834	0.072	0.133
Sex	*F*-ratio	2.277	3.089	0.442	0.293	0.339	1.718	0.001
	p-value	0.108	0.108	0.172	0.136	**0.009**	0.044	0.172
Chronic illness	*F*-ratio	6.622	0.133	0.701	6.026	0.523	7.053	3.413
	p-value	**0.001**	0.876	0.496	**0.003**	0.593	**0.001**	**0.034**
Portal use	*F*-ratio	3.600	0.852	2.803	2.803	2.203	4.252	4.317
	p-value	**0.007**	0.493	**0.025**	**0.025**	0.068	**0.002**	**0.002**

Table 95. All results for MTurk information preference questions. A. It should be easy to become skillful at using a portal. B. Using a portal can assist my face to face communication with my healthcare providers C. Using a portal with a health encyclopedia can provide me healthcare knowledge and education. D. A portal can be useful to manage my personal health information. E. Portals are not difficult to use. F. Using a portal can make me accomplish tasks (e.g., review my diagnoses and tests) quickly in managing my personal health information. G. A personalized portal can suit my needs of managing my personal health information.

		A	B	C	D	E	F	G	H	I
Age	x^2	16.57	40.25	5.71	11.21	10.92	23.20	9.71	15.74	9.93
	p-value	0.280	0.063	0.973	0.669	0.692	0.057	0.783	0.329	0.767
Education	x^2	6.15	34.58	12.26	8.73	2.61	10.32	7.25	13.50	12.50
	p-value	0.630	**0.005**	0.140	0.365	0.956	0.243	0.510	0.096	0.130
Income	x^2	6.39	16.22	9.90	16.63	17.00	8.09	11.00	11.10	11.01
	p-value	0.603	0.437	0.272	**0.034**	**0.030**	0.425	0.202	0.196	0.201
Smoking habit	x^2	0.91	13.97	10.30	3.00	3.94	1.84	3.33	4.16	3.49
	p-value	0.922	0.082	**0.036**	0.557	0.414	0.764	0.503	0.384	0.479
Hours online	x^2	15.68	11.70	0.97	7.45	3.99	10.35	13.93	6.45	4.32
	p-value	**0.016**	0.469	0.986	0.281	0.677	0.110	**0.030**	0.375	0.633
Sex	x^2	3.36	11.19	7.79	4.62	23.43	4.60	6.23	1.03	2.72
	p-value	0.499	0.191	0.099	0.328	**0.000**	0.331	0.182	0.904	0.605
Chronic illness	x^2	12.82	9.98	1.37	12.42	0.85	4.54	56.55	6.38	7.67
	p-value	**0.012**	0.266	0.849	**0.014**	0.930	0.338	**0.000**	0.172	0.104
Race	x^2	30.13	35.39	33.23	35.33	38.54	35.59	21.94	35.31	29.26
	p-value	0.657	1.000	0.505	0.405	0.272	0.393	0.945	0.406	0.699
Portal use	x^2	9.93	9.90	4.22	5.37	6.14	9.95	34.80	8.38	10.16
	p-value	0.269	0.871	0.837	0.717	0.631	0.268	**0.000**	0.396	0.254

Table 96. All results for MTurk lung cancer screening knowledge questions. A. CT images are made with X-rays. B. In the past, before the CT scan was introduced, the chance of dying due to lung cancer after diagnosis was: C. Lung cancer is one of the most common cancers. D. A change of cough pattern is a frequent sign of lung cancer. E. Coughing up blood is a frequent sign of lung cancer. F. Lung cancer may be hereditary. G. Lung cancer is contagious. H. A person can have lung cancer without any signs. I. Someone who has quit smoking has a higher risk of developing lung cancer than someone who has never smoked.

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