

Patient Portal Preferences: Perspectives on Imaging Information

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Patient portals have the potential to provide content that is specifically tailored to a patient's information needs based on diagnoses and other factors. In this work, we conducted a survey of 41 lung cancer patients at an outpatient lung cancer clinic at the medical center of the University of California, Los Angeles, to gain insight into these perceived information needs and opinions on the design of a portal to fulfill them. We found that patients requested access to information related to diagnosis and imaging, with more than half of the patients reporting that they did not anticipate an increase in anxiety due to access to medical record information via a portal. We also found that patient educational background did not lead to a significant difference in desires for explanations of reports and definitions of terms.

Introduction

Patient portals give patients the opportunity to view their medical records online. Although portals are not yet ubiquitous, many institutions are preparing the necessary infrastructure, both as in-house-developed applications for specific healthcare facilities, such as the patient portal used by veterans at the Veteran's Administration, and as off-the-shelf software developed by third parties, such as Epic's MyChart. The content and functionality of these portals vary considerably. Portal features can include e-mailing practitioners, reviewing medication lists, and checking lab results. Many portals, such as the one offered by Kaiser Permanente, attempt to cover the breadth of health information encapsulated in a patient record (i.e., "general health" portals). Other portals have been designed to be diagnosis-specific (Arnold et al., 2013; Hess et al., 2006; Wagner et al., 2012). In contrast to general health portals, these diagnosis-specific portals tend to present a narrower, more detailed view of a particular diagnosis and comorbidities.

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Portals have the potential to be dynamic and tailored to patient information preferences. Tailored content also has the benefit of improving rates of health behavior changes (Noar, Benac, & Harris, 2007). User studies are commonly employed in application and software development, and the development of consumer portals can utilize this design approach. Types of information preferred can vary by diagnosis to reflect the desire of patients to see the information that is most relevant to their own disease. The study of information science states that “the purpose of information to the individual in their environment and information seeking, alongside how information is used, . . . generate a deeper understanding of the characteristics that influence and or activate information needs.” (Ormandy, 2010, p. 93). For example, while a diabetes patient may want to see his glucose levels plotted over time, others with different chronic conditions may find this information irrelevant. Here, we use the information-need definition of “the recognition that their [the patient’s] knowledge is inadequate to satisfy a goal, within the context or situation that they find themselves in a specific point in time” (Case, 2002, p. 5; Ormandy, 2010). Hence, information needs are subjective, influenced by the patient’s “goal/purpose, context, situation, [and] time” (Ormandy, 2010, p. 99). How a patient prioritizes an information need is dependent on the context and situation within which the patient exists as well as their coping approach. Patients may not look for information if they feel that have little ability to influence a health outcome.

Existing literature has indicated that cancer patients have specific information preferences. They tend to rate the importance of having electronic access to their medical records higher than do patients without cancer (Beckjord, Rechis, Nutt, Shulman, & Hesse, 2011). This suggests that cancer patients would be more likely to use a patient portal. In addition, cancer patients tend to access information online before first meeting with an oncologist (Castleton et al., 2011) and also commonly report wanting to access their medical information on diagnosis, prognosis, treatment, symptoms, survival information, and side effects (Davidson, Brundage, & Feldman-Stewart, 1999; Gore, Brophy, & Greenstone, 2000; Jenkins, Fallowfield, & Saul, 2001; Leydon, Boulton, Moynihan, Jones, & Mossman, 2000).

Similar to Ormandy (2010), other studies looking specifically at cancer patients have found that information needs also can vary based over time, such as with the stage of disease or treatment (McKemmish, Manaszewicz, Burstein, & Fisher, 2009). While information preferences are stable in the short-term, cancer patients whose condition has worsened tend to want less information (Butow, Maclean, Dunn, Tattersall, & Boyer, 1997). Specifically, 6 months after an initial consultation, it was found that cancer patients reported wanting less detailed information, although they still desired to hear good news. In contrast, other findings have demonstrated that Stage IIIB lung cancer patients, who did not have portal access, seek information to have an

“active/collaborative role in real treatment decisions” (Davidson et al., 1999, p. 512).

Information needs and preferences also have been shown to vary by demographics. Women have been shown to access more information than have men, younger patients tend to seek more information than do the elderly, and African Americans tend to search for health information less than do other races (Maibach, Weber, Massett, Hancock, & Price, 2006; Warner & Procaccino, 2004). These findings have suggested that information visualizations could be tailored not only by the diagnosis content within the record but also by the demographic information within.

We aim to develop a tool that automatically links supporting consumer health content to patient records. This linkage is intended to provide information to patients who want to know more about their condition. Patients directed to MedlinePlus information reported that they found the information easy to understand and of quality (Smalligan, Campbell, & Ismail, 2008). This suggests that MedlinePlus content could be a useful source for supplementing patient records. Before development of such a tool begins, it is necessary to poll the intended user population to ensure that there is an accurate user profile being considered and reflected in the design. While no application is likely to be endorsed by 100% of a user population without revision, realistic user profiles are essential to constructing a design that is relevant to the intended user (Rosenbaum, 1989; Thompson, Rozanski, & Haake, 2004). Therefore, it is necessary to survey the intended user population before design work begins. In this project, our focus is the design of an imaging-focused patient portal for individuals undergoing treatment for nonsmall cell lung cancer (NSCLC). For this purpose, we have designed an information schema based on a literature review of patient information needs and preferences, existing guidelines for practitioners and patients, and practitioner input (Table 1). The schema is used to determine the classes and concepts that will be made available via the portal. Those concepts found within it will be taken from a patient’s record and used to populate the portal visualization and linked to supporting content. Before using this information organizational structure to implement the portal, we sought additional information via a survey that was administered to patients seen at an outpatient lung cancer oncology clinic at our institution. Although the concepts are representative of patient preferences as indicated in the literature, we wanted to assess whether a sample of our local population has similar preferences and information needs. The survey results are to be used as a source to revise and update the schema. The results and analysis of the survey are the focus of this article. The revised schema will be used to create a database of concepts derived from an individual patient’s medical records. These concepts will be mined and matched via their Unified Medical Language System’s (UMLS’s) Concept Unique Identifier (CUI) to consumer health content.

TABLE 1. Patient portal schema with the classes bolded at the top of the columns and their corresponding concepts below.

Symptoms	Tumor	Mass	Smoking status	Diagnostic test	Diagnostic test continued
Weight loss	Tx	Mass present (Yes/No)	Smoker (Yes/No)	Thoracentesis	Thoracotomy
Fatigue	T0	Mass location	Pack year	Bronchoscopy	Fine needle aspiration
Chest pain	Tis	Mass size		LDH	Mediastinoscopy
Lung infection	T1			Sputum test	Blood test
Breathing trouble	T2			PET scan	Bone scan
Coughing blood	T3			Albumin	Pulmonary function test
Hoarse voice	T4			Chest X-ray	MRI
				Computed Tomography	
				Video-assisted Thoracoscopy	

Materials and Methods

We constructed a survey consisting of 14 multiple-choice questions, consisting of nine Likert scale items ranging from *strongly agree to strongly disagree*, one single-answer question on level of education, and four multiple-choice questions with multiple answers possible (i.e., “check all answers that apply”); and one short answer (see the Appendix). The questions asked in this survey were meant to establish basic patient preferences and perceptions about patient portals. The questions were applicable to portal design regardless of patient diagnosis; however, we intentionally surveyed this specific population of patients at a lung cancer screening clinic to glean their perspective as a user group. The content of the questions was based on a literature review of 25 peer-reviewed articles and one Pew Institute report on the topics of patient information needs, patients’ perceptions of portals, and observed outcomes of patients using portals (Ancker, Silver, Miller, & Kaushal, 2013; Bass et al., 2006; Beckjord et al., 2011; Butow et al., 1997; Castleton et al., 2011; Clauser, Wagner, Aiello Bowles, Tuzzio, & Greene, 2011; Davidson et al., 1999; Fisher, Bhavnani, & Winfield, 2009; Fox & Jones, 2009; Gore et al., 2000; Gravis et al., 2011; Hess et al., 2006; Jenkins et al., 2001; Keselman et al., 2007; Koch-Weser, Bradshaw, Gualtieri, & Gallagher, 2010; Leydon et al., 2000; Metz et al., 2003; Murray et al., 2002; Pyper, Amery, Watson, & Crook, 2004; Ross & Lin, 2003a, 2003b; Sarkar et al., 2010; Schwartz et al., 2006; Slaughter, Ruland, & Rotegard, 2005; Zeng-Treitler, Goryachev, Kim, Keselman, & Rosendale, 2007).

We then used themes found in these articles as a basis for questions. A theme was included if it appeared in the literature review (topics: patient information needs, patients’ perceptions on portals, and observed outcomes of patients using portals) twice or more, and was relevant to the domain of lung cancer treatment. Themes included:

- Types of information accessed by patients
- Types of content desired by patients
- Anxiety caused by information access
- Increases in questions posed to and conversations with practitioners driven by information access
- Concerns regarding portals
- Increases in patient adherence to practitioner directions

TABLE 2. List of literature and the topics each citation contains. Themes include: A: sources of information (doctor, website, etc.), B: types of information desired from medical record, C: preferred format(s) to view record, D: anxiety caused by information access or concerns of security, E: increased number of questions posed to doctor due to information access, F: increased communication with doctor due to information access, G: increased adherence to practitioner directions due to information access, and H: improved outcomes due to information access.

Citation	A	B	C	D	E	F	G	H
Castleton et al., 2011	x							
Metz et al., 2003	x							
Bass et al., 2006	x	x					x	
Schwartz et al., 2006	x	x			x			
Pew Survey	x	x	x					
Jenkins et al., 2001		x			x			
Davidson et al., 1999		x						
Gore et al., 2000		x						
Butow et al., 1997		x						
Clauser et al., 2011		x						
Grant et al., 2006		x						
Hess et al., 2006		x						
Beckjord et al., 2011			x	x				
Ross & Lin, 2003a, 2003b				x		x	x	x
Keselman et al., 2007								x
Johnson et al., 2012								
Pyper et al., 2004								
Gravis et al., 2011				x				
Fisher et al., 2009						x		
Ross & Lin, 2003a, 2003b								x
Ancker et al., 2013				x				

- Improved outcomes due to information access
- Locations of health information commonly accessed by consumers
- Record formats preferred by patients

The citations and corresponding themes from the literature review are presented in Table 2. Three additional questions were included to measure correlations between these themes and other patient characteristics: Question 1 was written to collect demographic information, and Questions 9 and 10 were included to assess patients’ self-reported computer skills and their ability to learn new computer skills. The questions were written by two graduate students with input from a faculty member and a thoracic oncologist. We filtered out questions that were redundant (i.e., those asking

TABLE 3. Education level ($N = 41$).

Education level	Some high school	High-school graduate	Some college	Associate's degree	Bachelor's degree	Master's degree	PhD or other degree
	1 (2%)	5 (12%)	10 (24%)	2 (5%)	12 (30%)	6 (15%)	5 (12%)

TABLE 4. Multiple answers possible regarding types of information sources ($N = 41$).

Information Sources	Doctor	Family	Consumer health source	Search engines	Professional online sources	Other sources	Does not search for health information
	41 (100%)	14 (34%)	24 (59%)	24 (59%)	6 (15%)	1 (2%)	1 (2%)

TABLE 5. Multiple answers possible regarding types of health record information patients would like to see ($N = 41$).

Preferred formats	Paper	Internet	CD	USB key
	24 (59%)	29 (71%)	12 (29%)	5 (12%)

for the same information). We also eliminated questions that were relevant to patient information needs, but beyond the scope of the design of our portal (e.g., questions regarding preferences for medication lists, which have been indicated in prior literature, are not a feature included in our current design).

Data Collection and Analysis

In accordance with an approved institutional review board protocol, we distributed our survey to patients in an outpatient lung cancer oncology clinic at the University of California, Los Angeles (UCLA). Approximately 300 unique patients were scheduled during this period in the clinic, although some may have canceled their appointments. The survey was made available at visit check-in and was optional. Patients who chose to participate were given a paper copy of the survey to fill out and return to a sealed box that was located in the waiting area. All surveys were submitted anonymously. Forty-one patients participated in the survey, and SPSS Version 20 software was used to analyze the results. All results were rounded to the nearest full percent.

Results

The results are presented in Tables 3 to 8. The maximal education received of those surveyed was as follows: Twelve percent had a high-school diploma, 24% had attended some college, 5% had an associate's degree, 30% had a bachelor's degree, 27% had a master's degree or higher, and only 2% ($n = 1$) had not graduated high school. Fifty-nine percent of respondents reported getting medical information from online consumer health sources such as MedlinePlus. Similarly, 59% indicated that they used search engines (Google,

Yahoo!, etc.) to access health information. One hundred percent reported getting medical information from their doctor. These findings show that while all participants utilize their practitioner as a source of health information, over half also are using common online sources.

Patients demonstrated a strong preference for accessing their health information even though only half of them had used online consumer health resources. Only 2% ($n = 1$) did not want to see his personal medical information. Ninety percent ($n = 37$) wanted to see information about their health problems, 90% ($n = 37$) wanted information about their radiology test results, and 81% ($n = 33$) responded that they would like to see information about their doctor's notes. Patients surveyed also demonstrated a preference for digitally formatted records, as 71% ($n = 29$) wanted to see their records via the Internet while 59% ($n = 24$) wanted to see their records via paper copy.

Those surveyed indicated a desire to see information pertaining to their radiology test results, with 47% ($n = 19$) strongly agreeing and 24% ($n = 10$) agreeing that they would like to view their radiology images; 20% ($n = 8$) were neutral. Seven percent ($n = 3$) strongly disagreed when asked if they would like to see their radiology images. The majority of patients showed an interest in seeing relevant image findings; 93% ($n = 38$) wanted to know the important findings that the doctor observed in their images, and 78% ($n = 32$) wanted to read explanations of their radiology reports. No difference in preferences for explanations of radiologic information between education levels was observed; 78% ($n = 18$) of those with a bachelor's degree or higher wanted to see explanations of radiology reports while 78% ($n = 14$) of those with less than a bachelor's degree wanted to see explanations of radiology reports. Similarly, education did not make a significant difference in term-definition preferences. Of those surveyed who had less than a bachelor's degree, 66% ($n = 12$) desired to see radiology term definitions when compared to 52% ($n = 12$) of those who had a bachelor's degree or higher, $\chi^2 = 1.411$, $p = .49$. These results suggest a need to revise the schema to better include actual images and the terms used to describe findings within images.

TABLE 6. Multiple answers possible regarding health record formats patients would like to see ($N = 41$).

Preferred formats	Paper	Internet	CD	USB key
	24 (59%)	29 (71%)	12 people (29%)	5 people (12%)

TABLE 7. Multiple answers possible regarding health record information content patients would like to see ($N = 41$).

Information desired from radiology images	Important things the doctor saw	How radiology images were created	Images that show health problems	Explanations of radiology reports	Definitions for confusing terms	Do not want to see radiology images/reports
	38 (93%)	10 (24%)	27 (66%)	32 (78%)	25 (61%)	1 (2%)

TABLE 8. Number of respondents by level of agreement with indicated statement ($N = 41$).

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%)

This desire for radiologic information may be linked to patients expect that images will help them manage their health and that the images provide a record documenting how they respond to treatment; 47% ($n = 19$) of respondents strongly agreed and 34% ($n = 14$) agreed that understanding their medical images would help them to manage their health problems. Furthermore, of those who wanted to “know important things the doctor saw” in their images, 85% ($n = 28$) agreed or strongly agreed that understanding their medical images would help them manage their health problems.

Thirty-two percent ($n = 13$) agreed that it was currently difficult for them to find information about their health problems, and 37% ($n = 15$) were neutral. When those who were neutral are eliminated and when the remaining answers are dichotomized into those who did and did not graduate from college, 50% ($n = 7$) of those with less than a bachelor’s degree agreed it was difficult to find information while 46% ($n = 6$) of those with a bachelor’s degree or higher agreed that it was difficult. Again, these differences were not statistically significant, $\chi^2 = 4.043$, $p = .132$.

Patients tended to rate themselves as technologically savvy, as 64% ($n = 26$) strongly agreed and 24% ($n = 10$) agreed that they already had the computer skills necessary to use a patient portal. Five percent ($n = 2$) were neutral about whether they had the computer skills necessary to use a patient portal while 2% ($n = 1$) disagreed that they had the

skills, and 5% ($n = 2$) strongly disagreed. Forty-seven percent ($n = 19$) strongly agreed that they could learn the computer skills necessary to operate a patient portal; 32% ($n = 13$) agreed, 7% ($n = 3$) were neutral, 2% ($n = 1$) disagreed, and 2% ($n = 1$) strongly disagreed. Of the five respondents who disagreed, strongly disagreed, or were neutral about whether they currently had the skills to use a patient portal, three people agreed or strongly agreed that they could learn the skills. Of the 12 people who did not want to see their record online, 9 reported having the computer skills necessary to use a patient portal. Of the 29 people who did want to see their record online, 27 reported having the computer skills to use a patient portal. However, when dichotomized into groups of those who reported currently having computer skills and those who did not, these differences were not significant, $\chi^2 = 2.598$, $p = .107$.

Slightly over half of the patients surveyed did not anticipate that accessing their medical health information would increase their anxiety; 29% ($n = 12$) strongly disagreed and 22% ($n = 9$) disagreed that accessing their information via a patient portal would increase their anxiety; 22% ($n = 9$) were neutral about whether accessing their information via portal would increase their anxiety; 20% ($n = 8$) agreed that it would increase their anxiety, and 7% ($n = 3$) strongly agreed; 71% ($n = 29$) thought the access would cause them to ask more questions; 32% ($n = 13$) strongly agreed that patient portal access would cause them to ask their doctor

more questions; 39% ($n = 16$) agreed, and 25% were neutral ($n = 10$). Two percent ($n = 1$) disagreed that portal access would cause them to ask more questions, and 2% ($n = 1$) strongly disagreed.

When dichotomized into those who currently reported having the computer skills to use a patient portal and those who do not, and with those who were neutral on whether portal access would increase their anxiety eliminated, only one person reported that they did not currently have the computer skills. They also strongly disagreed that portal access to their record would cause them more anxiety. Of the 31 respondents in this subgroup who reported currently having the computer skills to use a portal, 11 strongly disagreed that portal access to their record would increase their anxiety, 9 disagreed that access would increase their anxiety whereas 8 agreed and 3 strongly agreed that portal access to their record would increase their anxiety. However, these differences were not statistically significant, $\chi^2 = 1.720$, $p = .632$.

More than 90% of patients surveyed thought that information access via a portal would help them follow their doctor's instructions; 49% ($n = 20$) strongly agreed that a patient portal would help them to follow their doctor's instructions whereas 42% ($n = 17$) agreed and 5% ($n = 2$) were neutral that a patient portal would help them to follow their doctor's instructions. Two percent ($n = 1$) disagreed that a portal would help them to follow their doctor's instructions; 93% of those surveyed agreed or strongly agreed that using a portal would help them talk to their doctor. Of those, 95% agreed or strongly agreed that a portal would help them follow their doctor's instructions.

The last question on the survey asked patients to list any other additional concerns that they had about viewing their personal information. Of the 41 people surveyed, 7 wrote in an answer. One patient wrote about the need to make the information accessible to family members. Another patient wrote about the need to break down medical terminology and make it comprehensible to patients. Six wrote about concerns regarding the security of the contents within a patient portal.

Discussion

We distributed a survey to 41 patients at a lung cancer clinic at UCLA to determine their preferences regarding patient portals. Participants indicated that they would like to view information on their diagnoses (90%) and radiology results (90%). The majority (88%) of patients agreed or strongly agreed that they already possessed the skills necessary to use a patient portal. These findings suggest that patients want access to diagnosis-specific content via a portal. This desire for access mimics observed patient information-seeking behavior trends, which have shown that patients are increasingly searching online for disease-related content (Fox & Jones, 2009). These increases in the rates of consumers searching for health information have likely increased patient confidence in the ability to use a patient portal.

Regarding those patients surveyed who searched online, slightly over half (59%) of them utilized a search engine or consumer health website for health information, yet the majority (71%) indicated that they would like to access their health information online via a portal. In combination, these results suggest that consumer health sites need to strive to be more accessible, as patients do want online resources. One possible way to make consumers' health content more accessible is to automatically link it to a patient's record, a goal of our ongoing research. Survey results emphasizing the desire to view medical images will help revise the schema to better accommodate images and descriptions of image findings, with concepts for image findings and anatomy seen in images. The revised schema will be used to create a database of concepts, consisting of what schema concepts are present in an individual patient's record. Concepts will be mined from patient records using the natural language processing program of MetaMap and automatically linked to via their UMLS's CUI to the schema. Concepts will then be linked via the schema to a database of their definitions and other consumer health content such as patient information pages taken from MedlinePlus and the National Comprehensive Cancer Network. These concepts and their related report content as well as consumer health content will be the basis of a portal visualization, tailored to the patient.

The desire to see medical terms defined did not differ significantly between those who had a bachelor's degree or higher (52%) and those who had less than a bachelor's degree (66%), $\chi^2 = 1.411$, $p = .49$. Similarly, the preference to see explanations of radiology reports was not statistically different for those who had graduated college (78%) and those who had not (78%). In addition, the rate of difficulty in finding health information did not differ statistically, $\chi^2 = 4.043$, $p = .132$, between college graduates (46%) and those without a college diploma (50%). These results suggest that within our population, there was no difference in the percentage of people, regardless of their education, who want this information. Further, it attests to the gap between lay and professional medical knowledge, that even those with higher levels of education require extra information to make sense of their health records.

Although the majority of patients (71%) agreed or strongly agreed that using a patient portal would cause them to ask more questions, 51% disagreed or strongly disagreed that access would increase their anxiety whereas 22% were neutral. This suggests that patients are aware that access to more information may lead to more questions, but that slightly over half do not fear the content within their medical records. While half of the patients did not indicate that portal access would increase anxiety, six of the seven who wrote in the short-answer question stated their concerns regarding security. These findings mirror those of other reports on patients' concerns regarding patient portals. Although physicians cited in other studies feared that access to actual record content will cause patients anxiety, patients have tended to not report increases in anxiety due to access (Wald

et al., 2007; Wiljer et al., 2010), but instead have tended to report concerns relating to the security of the portal (Beckjord et al., 2011; Grant et al., 2006). Our results agree that patients are concerned not necessarily with their own access to their records but with unauthorized others accessing their records. While there are policies in effect to protect patient records from unauthorized access, such as those mandated by the Health Insurance Portability and Accountability Act, more needs to be done to make these efforts apparent to the public and to prevent the breaches that likely contribute to patient concerns.

Interestingly, when dichotomized by those who reported having the computer skills to use a patient portal and those who did not, only those within the group who reported having the skills also acknowledged that the portal may cause anxiety. None of those without the computer skills acknowledged that the portal may cause anxiety. Of the 31 patients who currently reported having the computer skills to use the portal, 11 (35%) agreed or strongly agreed that portal access would increase their anxiety. While these difference were not statistically significant, $\chi^2 = 1.720$, $p = .632$, they suggest that patients with more technological skills may be more aware of the potential for information to cause additional stress, perhaps due to their past experiences.

Despite the lack of radiologic content in most available portals, patients indicated a preference for radiology results; 81% agreed or strongly agreed that their medical images would help them to understand their medical information. However, this rating may be in part due to the fact that the patients surveyed were already being treated for lung cancer. As information needs are influenced by context (Ormandy, 2010), further study is needed to see if patients without a prior history of lung cancer (i.e., lung cancer screening patients) would want to see their radiology information. Given that patients in this survey responded favorably to the idea of access to radiology information and images, and that radiologic content plays a significant role in the diagnosis and treatment of lung cancer, it is important to study how best to revise the schema to better incorporate imaging data into a patient portal. As with other medical record content (e.g., clinical notes, laboratory results), the radiology information that is provided to physicians cannot simply be transferred to a patient portal. Patients will understand and utilize the information differently than will practitioners, requiring radiologic content to be displayed in a view that is relevant to their information needs. One possibility is to provide patients with images that indicate the region of interest to direct their focus to the areas relevant to their diagnosis. However, patients also should have the option to access finer levels of detailed information, such as a complete image series, if they so desire. At the same time, to mitigate the possibility of information overload, patients should be guided via an information narrative. The schema being developed is a narrative for information that is problem-oriented, to integrate information into the context of the diagnosis.

Two thirds of the participants either agreed that finding health information was difficult or were neutral on the issue, despite the education level of the study population, with 98% having graduated high school and 57% having a bachelor's degree or higher. The majority (88%) of patients also reported already having the computer skills necessary to use a portal. When dichotomized into those who have less than a bachelor's degree and those who have a bachelor's degree or higher, little difference was seen in the rates of patients rating information as hard to find (less than a bachelor's degree: 50%, bachelor's degree or higher: 46%, $\chi^2 = 4.043$, $p = .132$), wanting radiology terminology defined (less than a bachelor's degree: 66%, bachelor's degree or higher: 52%, $\chi^2 = 1.411$, $p = .49$), or wanting radiology reports explained (less than a bachelor's degree: 78%, bachelor's degree or higher: 78%, $\chi^2 = 0.001$, $p = .97$). These results suggest a patient population with adequate levels of technological skill and education, yet one that has difficulty finding and understanding health information. This demonstrates the need to develop tools that provide patients with health information that is easy to access and that is recognizably of quality. Despite the increases in patients accessing health information online, little research has been done to demonstrate why consumers trust specific digital sources (Kantor, Bullinger, & Gal, 2012), and patients still cite the need to determine the quality of a source (McKemmish et al., 2009). Perceived ease of access and quality are factors affecting use rates of healthcare technological tools (Rogers, 1995; Silvestre, Sue, & Allen, 2009). To ensure use, it is therefore necessary to design tools that not only contain quality information but also are easy to use and of evident quality. By ensuring use, these tools can teach patients disease-specific skills, such as how a cancer patient can look for clinical trials, that will allow them to make informed decisions concerning their health, which promotes patients as partners within the healthcare arena (Smith, Saunders, Stuckhardt, & McGinnis, 2012).

To design applications that are accessible, consumer informatics should utilize user modeling, a subspecialty of human-computer interaction design. User modeling "infers unobservable information about a user from observable information" (Zuckerman & Albrecht, 2001, p. 5). This observable information (i.e., the user's actions), in combination with the context of the domain in which the observable information takes place, can be used to create a model of the user within the computational environment. The user model helps the system to "say the 'right' thing at the 'right' time" (Fischer, 2001, p. 70). In other words, an accurate user model helps the system to determine what the user's goals are and to meet those objectives. Identification of a patient's goals given a particular context are crucial to the identification of the user's information need (Ormandy, 2010), and thus the provision of user-centered design.

Limitations of this study include that the population sampled was small and from one institution, making the results not generalizable. To achieve a 95% confidence interval for the question of the preferred format in which patients want to view their record, with a sample proportion of 0.5, at

least 100 participants would be necessary. It is therefore not clear if these results would transfer to the general lung cancer patient population, requiring larger studies to be conducted. In addition, further study is warranted to determine the average technological ability and health information literacy level of lung cancer patients. It is possible that patients with higher levels of health literacy felt more comfortable filling out the survey and thus returned it at a higher rate.

Finally, as six of the seven participants who answered the short-answer question listed security as a concern, it would be useful to rewrite the survey to include a Likert-scale question on patients' impressions of portal security. Responses would help determine whether this concern for security is common. If found to be common, designers of portals could improve designs to make security measures already occurring more obvious to the end user.

Conclusion

Survey results collected in this study highlight the need for portals that provide patients with accessible quality content; allow patients to feel that access is secure; and incorporate a variety of data from medical records, including radiologic images. Further consideration is required to determine how best to utilize radiologic content in a patient portal, how to improve design to make portals more accessible, and how to increase the transparency of confidentiality policies in play. The results from this survey will be used in our ongoing work to design a patient portal for patients undergoing lung cancer treatment. The portal will utilize survey results as a source to consider how to link personal health information with supporting content, and to decide what features should be included. Examples of this will be the inclusion of radiology images, and a feature that indicates what part of an image is related to a patient's diagnosis and stage in the care process, due to patient preferences. New concepts will be added to the schema to facilitate access to radiological images and supporting content for each class of concepts.

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References

- Ancker, J.S., Silver, M., Miller, M.C., & Kaushal, R. (2013). Consumer experience with and attitudes toward health information technology: A nationwide survey. *Journal of the American Medical Informatics Association*, 20(1), 152–156.
- Arnold, C.W., McNamara, M., El-Saden, S., Chen, S., Taira, R.K., & Bui, A.A.T. (2013). Imaging informatics for consumer health: Towards a radiology patient portal. *Journal of the American Medical Informatics Association*, 20(6), 1028–1036.
- Bass, S., Ruzek, S., Gordon, T.F., Fleisher, L., McKeown, N., & Moore, D. (2006). The relationship of internet health information use with patient behavior and self efficacy: Experiences of newly diagnosed cancer patients who contact the National Cancer Institute's cancer information service. *Journal of Health Communications*, 11(2), 219–236.
- Beckjord, E.B., Rechis, R., Nutt, S., Shulman, L., & Hesse, B.W. (2011). What do people affected by cancer think about electronic health information exchange? Results from the 2010 LIVESTRONG Electronic Health Information Exchange Survey and the 2008 Health Information National Trends Survey. *Journal of Oncology Practice*, 7(4), 237–241.
- Butow, P.N., Maclean, M., Dunn, S.M., Tattersall, M.H.N., & Boyer, M.J. (1997). The dynamics of change: Cancer patients preferences for information, involvement, and support. *Annals of Oncology*, 8(9), 857–863.
- Case, D.O. (2002). *Looking for information: A survey of research on information seeking, needs and behavior*. San Diego, CA: Academic Press Elsevier Science.
- Castleton, K., Fong, T., Wang-Gillam, A., Waqar, M.A., Jeffe, D.B., Kehlenbrink, L., & Govidan, R. (2011). A survey of internet utilization among patients with cancer. *Supportive Care in Cancer*, 19(8), 1183–1190.
- Clauser, S.B., Wagner, E.H., Aiello Bowles, E.J., Tuzzio, L., & Greene, S.M. (2011). Improving modern cancer care through information technology. *American Journal of Preventive Medicine*, 40(5s2), s198–s207.
- Davidson, J.R., Brundage, M.D., & Feldman-Stewart, D. (1999). Lung cancer treatment decisions: Patients' desire for participation and information. *Psycho-Oncology*, 8(6), 511–520.
- Fischer, G. (2001). User modeling in human-computer interaction. *User Modeling and User-Adapted Interaction*, 11(1–2), 65–86.
- Fisher, B., Bhavnani, V., & Winfield, M. (2009). How patients use access to their full health records: A qualitative study of patients in general practice. *Journal of the Royal Society of Medicine*, 102(12), 538–544.
- Fox, S., & Jones, S. (2009). The social life of health information. In Pew Institute (Ed.), *Pew Internet and American Life Project* (p. 1). Washington DC: Pew Research Center.
- Gore, J.M., Brophy, C.J., & Greenstone, M.A. (2000). How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer. *Thorax*, 55(12), 1000–1006.
- Grant, R.W., Wald, J.S., Poon, E.G., Schnipper, J.L., Gandhi, T.K., Volk, L.A., & Middleton, B. (2006). Design and implementation of a web-based patient portal linked to an ambulatory care electronic health record: Patient gateway for diabetes collaborative care. *Diabetes Technology and Therapeutics*, 8(5), 576–586.
- Gravis, G., Protiere, C., Eisinger, F., Bohlen, J.M., Tarpin, C., Coso, D., & Viens, P. (2011). Full access to medical records does not modify anxiety in cancer patients: Results of a randomized study. *Cancer*, 117(20), 4796–4804.
- Hess, R., Bryce, C.L., McTigue, K., Fitzgerald, K., Zickmund, S., Olshansky, E., & Fischer, G. (2006). The diabetes patient portal: Patient perspectives on structure and delivery. *Diabetes Spectrum*, 19(2), 106–109.
- Jenkins, V., Fallowfield, L., & Saul, J. (2001). Information needs of patients with cancer: Results from a large study in UK cancer centers. *British Journal of Cancer*, 84(1), 48–51.
- Johnson, A.J., Easterling, D., Nelson, R., Chen, M.Y., & Frankel, R.M. (2012). Access to radiologic reports via a patient portal: clinical simulations to investigate patient preferences. *J. Am Coll Radiol*, 9(4), 256–263.
- Kantor, P.B., Bullinger, J.M., & Gal, C.S. (2012). Patient decision-making modes and causes: A preliminary investigation. *Journal of the American Society for Information Science and Technology*, 63(7), 1339–1349.
- Keselman, A., Slaughter, L., Smith, C.A., Kim, H., Divita, G., Browne, A., & Zeng-Triettler, Q. (2007). Towards consumer friendly PHRs: Patients' experience with reviewing their health records. Paper presented at the American Medical Informatics Association Symposium, November 2007.
- Koch-Weser, S., Bradshaw, Y.S., Gualtieri, L., & Gallagher, S.S. (2010). The internet as a health information source: Findings from the 2007 Health Information National Trends Survey and implications for

- health communication. *Journal of Health Communications*, 15(S3), 279–293.
- Leydon, G.M., Boulton, M., Moynihan, C., Jones, A., & Mossman, J. (2000). Cancer patients information needs and information seeking behavior: In-depth interview study. *British Medical Journal*, 320, 909–913.
- Maibach, E.W., Weber, D., Massett, H., Hancock, G.R., & Price, S. (2006). Understanding consumers' health information preferences development and validation of a brief screening instrument. *Journal of Health Communication: International Perspectives*, 11(8), 717–736.
- McKemmish, S., Manaszewicz, R., Burstein, F., & Fisher, J. (2009). Consumer empowerment through metadata-based information quality reporting: The breast cancer knowledge online portal. *Journal of the American Society for Information Science and Technology*, 60(9), 1792–1807.
- Metz, J.M., Devine, P., DeNittis, A., Jones, H., Hampshire, M., Goldwein, J., & Whittington, R. (2003). A multi-institutional study of internet utilization by radiation oncology patients. *International Journal Radiation Oncology, Biology, Physiology*, 56(4), 1201–1205.
- Murray, S.A., Boyd, K., Kendall, M., Worth, A., Benton, T.F., & Clausen, H. (2002). Dying of lung cancer or cardiac failure: Prospective qualitative interview study of patients and their carers in the community. *British Medical Journal*, 325(7370), 929–934.
- Noar, S.M., Benac, C.N., & Harris, M.S. (2007). Does tailoring matter? Metaanalytic review of tailored print health behavior change interventions. *Psychological Bulletin*, 133(4), 673–693.
- Ormandy, P. (2010). Defining information need in health—Assimilating complex theories derived from information science. *Health Expectations*, 14(1), 92–104.
- Pyper, C., Amery, J., Watson, M., & Crook, C. (2004). Patients experiences when accessing their online electronic patient records in primary care. *British Journal of General Practice*, 16(3), 154–164.
- Rogers, E.M. (1995). *Diffusion of innovations*. New York, NY: Free Press.
- Rosenbaum, S. (1989). Usability evaluations versus usability testing: When and why? *IEEE Transactions on Professional Communications*, 32(4), 210–215.
- Ross, S.E., & Lin, C.T. (2003a). The effects of promoting patient access to medical records: A review. *Journal of the American Medical Informatics Association*, 10(2), 129–138.
- Ross, S.E., & Lin, C.T. (2003b). A randomized controlled trial of a patient accessible medical record. *American Medical Informatics Association Symposium Proceedings*, 990(2003), 990.
- Sarkar, U., Karter, A.J., Liu, J.Y., Alder, N.E., Nguyen, R., Lopez, A., & Schillinger, D. (2010). The literacy divide: Health literacy and the use of an internet-based patient portal in an integrated health system—Results from the diabetes study of northern California (DISTANCE). *Journal of Health Communication*, 15(S2), 183–196.
- Schwartz, K.L., Roe, T., Northrup, J., Meza, J., Seifeldin, R., & Neale, A.V. (2006). Family medicine patients' use of the internet for health information: A MetroNet study. *Journal of the American Board of Family Medicine*, 19(1), 39–45.
- Silvestre, A.L., Sue, V.M., & Allen, J.Y. (2009). If you build it, will they come? The Kaiser Permanente model of online health care. *Health Affairs*, 28(2), 334–344.
- Slaughter, L., Ruland, C., & Rotegard, A.K. (2005). Mapping cancer patients' symptoms to UMLS concepts. Paper presented at the American Medical Informatics Association, November 2005.
- Smalligan, R.D., Campbell, E.O., & Ismail, H.M. (2008). Patient experiences with MedlinePlus.gov: A survey of internal medicine patients. *Journal of Investigative Medicine*, 56(8), 1019–1022.
- Smith, M., Saunders, R., Stuckhardt, L., & McGinnis, J.M. (2012). *National Academies Press (Ed.), Best care at lower cost: The path to continuously learning health care in America*. Washington, DC: Institute of Medicine.
- Thompson, K.E., Rozanski, E.P., & Haake, A.R. (2004). Here, there, anywhere: Remote usability testing that works. Paper presented at the Proceedings of the Fifth Conference on Information Technology Education, October 2004.
- Wagner, P.J., Dias, J., Howard, S., Kintziger, K.W., Hudson, M.F., Soel, Y.H., & Sodomka, P. (2012). Personalized health records and hypertension control: A randomized trial. *Journal of the American Medical Informatics Association*, 19(4), 626–634.
- Wald, J., Burk, K., Gardner, K., Feygin, R., Nelson, E., Poon, E. et al. (2007). Sharing electronic laboratory results in a patient portal—A feasibility pilot. In I. Press (Ed.), *Medinfo. MEDINFO*, pp. 18–22.
- Warner, D., & Procaccino, J.D. (2004). Toward wellness: Women seeking health information. *Journal of the American Society for Information Science and Technology*, 55(8), 709–730.
- Wiljer, D., Leonard, K.J., Urowitz, S., Apatu, E., Massey, C., Quartey, N., & Catton, P. (2010). The anxious wait: assessing the impact of patient accessible EHRs for breast cancer patients. *BMC Medical Informatics and Decision Making*, 10(1), 46–56.
- Zeng-Treitler, Q., Goryachev, S., Kim, H., Keselman, A., & Rosendale, D. (2007). Making texts in electronic health records comprehensible to consumers: a prototype translator. Paper presented at the American Medical Informatics Association Conference, November 2007.
- Zuckerman, I., & Albrecht, D.W. (2001). Predictive statistical models for user modeling. *User Modeling and User-Adapted Interaction*, 11(1–2), 5–18.

Appendix

- 1) What is your highest level of education?
 - Some high school
 - High school graduate
 - Some college
 - Associate's degree
 - Bachelor's Degree
 - Master's degree
 - Professional degree
 - Other
- 2) Where do you get your health information? Check all that apply.
 - From my doctor
 - From family/friends
 - From online consumer health sources, those written for a consumer audience (e.g., MedlinePlus, Mayo Clinic, chat forums)
 - Online professional sources, those written for a professional medical audience (e.g., PubMed, UpToDate)
 - Google/Yahoo!/Bing (search engines)
 - Other
 - I do not search for health information
- 3) What information would you like to see from your personal medical record? Check all that apply.
 - My health problems
 - My medications
 - My lab results
 - My radiology results (e.g., information about your medical images)
 - My doctor's notes (e.g., what the doctor writes during a visit with you)
 - I don't want to see my personal medical information
 - Other
- 4) How would you like to see your personal medical record? Select all that apply.
 - Paper copy
 - On the internet
 - On a CD
 - On a USB stick
 - Other
 - I don't want to see my personal medical information

- 5) I would like to view my radiology images (e.g., X-ray, MRI, CT).
- Strongly agree
 - Agree
 - Neutral
 - Disagree
 - Strongly disagree
- 6) What information would you like to get about your radiology images? Select all that apply.
- I would like to know important things the doctor saw in my images
 - I would like to know how my radiology images were created
 - I would like to see images that show my health problems
 - I would like to read explanations of my radiology reports
 - I would like to see definitions for confusing medical terms used in my radiology report
 - I don't want to see my radiology reports and images
- 7) Understanding my medical images will help me to manage my health problems.
- Strongly agree
 - Agree
 - Neutral
 - Disagree
 - Strongly disagree
- 8) It is difficult for me to find information about my health questions.
- Strongly agree
 - Agree
 - Neutral
 - Disagree
 - Strongly disagree
- 9) I have the computer skills necessary to use a secure website like a patient portal.
- Strongly agree
 - Agree
 - Neutral
 - Disagree
 - Strongly disagree
- 10) I could learn the computer skills necessary to use a secure website like a patient portal with the assistance of a nurse or medical assistant.
- Strongly agree
 - Agree
 - Neutral
 - Disagree
 - Strongly disagree
- 11) Accessing my medical record with a patient portal will increase my anxiety.
- Strongly agree
 - Agree
 - Neutral
 - Disagree
 - Strongly disagree
- 12) A patient portal will help me talk to my doctor about my health problems.
- Strongly agree
 - Agree
 - Neutral
 - Disagree
 - Strongly disagree
- 13) A patient portal will help me to follow my doctor's instructions.
- Strongly agree
 - Agree
 - Neutral
 - Disagree
 - Strongly disagree
- 14) A patient portal will cause me to ask my doctor/nurses more questions.
- Strongly agree
 - Agree
 - Neutral
 - Disagree
 - Strongly disagree
- 15) Please list any other concerns you may have about viewing your personal health information.