Patient-centered Radiology Reporting for Lung Cancer Screening

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Abstract: Medicine is slowly transitioning toward a more patient-centered approach, with patients taking a more central role in their own care. A key part of this movement has involved giving patients increased access to their medical record and imaging results via electronic health portals. However, most patients lack the knowledge to fully understand medical documents, which are generally written above their comprehension level. Radiology reports, in particular, utilize complex terminology due to radiologists' historic function as consultants to other physicians, with little direct communication to patients. As a result, typical radiology reports lack standardized formatting, and they are often inscrutable to patients. Numerous studies examining patient preference also point to a trend for more accessible radiology reports geared toward patients. Reports designed with an infographic format, combining simple pictures and standardized text, may be an ideal format that radiologists can pursue to provide patient-centered care. Our team, through feedback from patient advisory groups, developed a patient-friendly low-dose computed tomography lung cancer screening report with an infographic format that is both visually attractive and comprehensible to the average patient. The report is designed with sections including a description of low-dose computed tomography, a section on individualized patient results, the meaning of the results, and a list of the next steps in their care. We believe that this form of the report has the potential to serve as a bridge between radiologists and patients, allowing for a better patient understanding of their health and empowering patients to participate in their health and health care.

Key Words: radiology reporting, lung cancer screening, patient-centered medicine

(*J Thorac Imaging* 2020;00:000–000)

PURPOSE AND BACKGROUND

Introduction

Patient portals, facilitated by electronic health records (EHRs), are providing patients with increased access to their medical records, as medicine transitions toward a more patient-centered approach. Despite this movement, efforts to present medical information in an accessible and attractive format are generally lacking. The possible benefits of patients having access to their medical record, including radiology reports, are numerous.[1] Most importantly, if patients, through access to their medical records, improve their understanding of their medical condition and options available to them, they can participate in shared decision-making and become more engaged in their care, leading to improved outcomes. In addition, informed and engaged patients can participate in ensuring follow-up for imaging test results that may be lost in the transmittal of the results between the radiologist and the referring provider.[2] More specifically, patient portals can improve communication between health care providers and patients, which can potentially minimize patients lost to follow-up, a known problem in patients with incidental imaging findings.[3] Conversely, when suboptimally implemented, patient portals can exacerbate misunderstanding by presenting arcane jargon, for example, contained in typical radiology reports, which could lead to increased confusion and anxiety. Furthermore, a majority of patients lack the literacy level of physicians, as demonstrated by The 2003 National Assessment of Adult Literacy, which found that 43% (93 million) of adult Americans read at either a Basic or Below Basic level, defined as being capable of "no more than the most simple and concrete literacy skills" and "simple and everyday literacy activities," respectively.[4] To better serve patients, through patient portals, it is imperative that all physicians create resources and present medical information in formats that are easy for a majority of patients to understand and act on. For radiologists, that charge is to create a version of their reports in a patient-friendly format.

Current State of Radiology

Historically, radiologists have operated as doctor-to-doctor consultants, rarely interacting with patients.[5] Patients, in turn, have traditionally been reliant on referring physicians to communicate the results of their imaging. This lack of patient-provider contact has shaped and influenced the modern radiology report's context and structure. Radiology reports are typically not written with the patient as the intended recipient; instead, utilizing both formatting and medical terminology, they are catered toward fellow medical professionals. Furthermore, numerous institutions are utilizing speech-recognition software to dictate reports, which has resulted in reports that are often freeform, riddled with technical jargon, and are subject to occasional basic language errors that may undermine patient confidence in both the report and the radiologists themselves.[6] Because of the widespread adoption of EHRs, catalyzed by federal incentives included in the "meaningful use" program, and the subsequent proliferation of electronic patient portals, patient access to radiology reports has grown considerably and, with that, the role of radiologists as more patient-facing

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DOI: 10.1097/RTI.0000000000000469

physicians.[5,7] Reports containing difficult to decipher medical language and reports filled with errors are now readily visible to patients. This increase in direct patient access to radiologist reports is transforming the role of radiologists to one that is now more patient-facing.

While this paradigm shift from a behind-the-scenes player to a more central role has occurred, the structure, format, and presentation of the radiology report have remained mostly stagnant. This is particularly troublesome considering most radiology reports are not written at a grade level most patients can understand and that patient and health literacy is one of the greatest barriers to the access and use of online health information.[8] A typical US adult reads at an eighth-grade level or below.[9] An average Medicare beneficiary reads at a fifth-grade level.[10] However, regardless of low target population literacy is, many medical documents, including patient education materials, are written at a higher reading level.[11] This is despite the Joint Commission and American Medical Association recommending that patient education materials be written at a fifth grade or below level and sixth grade or below level, respectively.[12,13] Radiology reports, in particular, grade out at an elevated literacy level.[14,15] Martin-Carreras et al's[14] 2019 study found that only 4% (4094) of 97,052 consecutive radiology reports collected across a 5-week period from the Penn Medicine health system was at a reading level of eighth-grade or lower, while the mean reading level was 13th grade. Even nonradiologist clinicians can find reports difficult to understand or needlessly elaborate, with Bosmans et al[16] finding that 49.9% (354/710) referring providers surveyed noting the language and style of radiology reports were unclear, while 17% believed that reports were unnecessarily complicated.

Beyond the elevated reading level, many institutions have an embargo policy on radiology reports, delaying the release of reports for several days up to a few weeks after a radiologist issues the report. This policy allows referring physicians time to view patient results, formulate a plan, and prepare to deliver news to the patient via a phone call or in person. While embargoes give physicians time to prepare, they also have drawbacks. Care may be delayed, and patients may grow anxious and feel shut out from their own care.[17] As embargoes shorten due to patient demand for more timely access to their imaging report findings, the likelihood that a patient views a radiology report before discussing it with their referring provider grows and, with it, the opportunity for frustration and confusion in radiology report formats not geared toward patients.

What Patients and Physicians Prefer

The transition toward a shared decision-making approach to health management and disease treatment has prompted radiologist and nonradiologist physicians to alter the current methods of radiology reporting, including standardizing language and structure and simplifying the language in reports.[18] Furthermore, surveys of both radiologists and other referring providers provide evidence that a structured, itemized report with headings is preferable to one written in prose, especially when the examination is complex.[16]

Numerous studies support the idea that patients prefer easy-to-understand reports in addition to rapid access through electronic portals.[19–22] For example, Basu et al[19] investigated patient-preference about the speed of access, finding that a large proportion of patients wish for the quickest possible access to imaging reports regardless of the result. Studies into preferences beyond the speed of access, such as Henshaw and colleagues' study, investigate how patients and physicians prefer reports to be distributed. Henshaw and colleagues distributed an online survey to 2450 patients seeking to assess the accessibility and importance of portal-released radiology reports. In addition, the authors surveyed 48 referring physicians and interviewed a group of physicians to evaluate physician opinions. A total of 508 patients responded, with 74% of responders finding reports easy to access and 88% of patients believing that the ability to access the reports through an online system was important. Referring doctors' sentiments mirrored those of patients', with 88% of physicians finding reports released to patients via an electronic portal helpful.[20] Similarly, Johnson and colleagues conducted 2 separate studies aimed at investigating how patients preferred to receive their reports. The first study involved 2 focus groups with patients who recently underwent magnetic resonance imaging, the majority of whom preferred to receive immediate access to results via an online system.[21] The second study was an onsite survey. While the sample size was small (n = 53), the majority of patients preferred immediate or 3-day delayed access to radiology results. More importantly, most patients (79.2%) preferred to receive notification of results through an online portal, as compared with the historic communication of results (ie, over the telephone or via mail), with 81.1% of patients reporting that they would likely use an online portal system. Of note, Johnson and colleagues also investigated whether patients would seek further resources to better understand the reports, and found that patients would seek more information through resources such as the Internet, a medical dictionary, or knowledgeable friends. They thus postulated that many patients would likely be unable to fully understand a standard radiology report.[22] Taken together, these studies indicate that there is a clear patient preference for receiving rapid access to results through an online portal system in a format that is easily comprehended. However, due to the current format of reports, patients and physicians alike worry that patients will fail to fully understand their results.[20,23] In particular, physicians worry about reports with clinically significant and worrisome findings, which are often lengthier and more complex. When reports are poorly organized and difficult to understand, not only do patients' confidence in their health care team and organization erode but also patients may not understand their medical situation and treatment options, leading to confusion and poor follow-up. To adapt to, and aid in, the creation of a more patient-centered approach, radiology reports must evolve to a format that patients are able to understand.

The Role of Infographics in Communicating Information

Pictures linked to a text have the potential of increasing both attention and recall of information in health care, especially for patients with lower literacy skills. Radiologists, in their aim to communicate clearly, use medical terminology due to its precision and familiarity. However, even patients with extensive education can find medical terminology puzzling, and merely writing reports at a sixth-grade reading level may be insufficient to convey information to those at the lowest reading levels.[24] Davis et al[24] reported that simplified polio information pamphlets improved comprehension in higher-level readers, but failed to do so for those who were

poor readers. These results indicate that simplified text, while useful, is only a partial solution to addressing the needs of lower literacy patients.

Infographics are a potential solution to help communicate complex information in an accessible, comprehensible manner that is more understandable and more engaging to readers. The presence of illustrative information allows readers to envision relations in textual information, permitting the construction of a mental model that can augment understanding.[25,26] For example, Kool and colleagues' 2 randomized control studies with participants from the general public compared the effectiveness of a text versus infographic/illustrated brochure in the usage of an inhaler chamber. They found that the addition of an illustrated guide resulted in improved performance when compared with text-only instructions.[27] Other studies provide further support that images help improve patient understanding. Two separate studies evaluated the effect of providing picture and text instructions versus text-only instructions to patients presenting to the emergency department with lacerations.[28,29] The prospective randomized control study by Delp and Jones[28] involved 234 patients and revealed that patients receiving illustrations were far more likely to answer wound care instructions correctly (46% vs. 6%, respectively), especially when analyzing those with less than a high school education in the treatment groups. The other study evaluated 101 patients and found results consistent with Delp and Jones' study.[29] The results of these studies and others support the idea of utilizing pictures in conjunction with simplified text to convey health information in a more comprehensible manner to patients.

Implementation of a Patient-centered Report in Practice

To address the trend in health care toward a more patient-centered approach and the challenges of conveying complex information to patients with varying literacy levels, our team at the University of Virginia embarked on a mission to create a patient-friendly radiology report that would be easy to understand, attractive in format, and provide actionable next steps. We selected low-dose lung cancer screening (LCS) reports as our initial use case for the following reasons: (1) established structured reporting system (Lung-Rads), (2) only a few possible categories of results, and (3) timeframe for delivery of results. The first draft of our report was co-designed by our study team and marketing team. The final language and format used in our patient-friendly LCS report were approved by our patient, family, and community advisory forum who, through an iterative process, provided feedback leading to the design presented in this manuscript. Our advisory forum, composed of 10 patients and caregivers, meets monthly and provides feedback on a variety of issues affecting patients and their families at our institution. This group kindly agreed to allow us to present our concept and give us feedback over the course of ~6 months. We also enlisted a prominent lung cancer advocate and member of the American College of Radiology Patient and Family Centered Commission (PFCC), Andrea Borondy Kitts, to provide feedback on the language and accessibility of the report. Common feedback included simplifying language, creating more relevant analogies, and reducing the overall amount of text. The report design described below was the output of our iterative efforts.

The patient-friendly LCS report was designed primarily in Adobe Illustrator and Adobe InDesign, with support in visuals with content adapted from Adobe Stock. All of these products are accessible, fairly inexpensive, and offer an array of tools to make marketing content more engaging for patients. The Adobe platforms also offer an extensive support system of videos, guides, and templates that allow even beginners the ability to create a polished design.

The new patient-centered report, depicted in Figure 1, is divided into 3 distinct sections, with patient-identifying information listed across the top banner (Fig. 1). The sections are clearly delineated to provide visual cues to patients to help them locate key information with regard to their health. Our patient-friendly LCS report comes in 3 varieties: low risk, indeterminate risk, and high risk. While the basic layout and visual content remain the same, the results and follow-up directions differ on the basis of imaging findings.

The first section is titled "About the Low-Dose CT Scan." This section is intended to mimic the "technique" section of a typical radiology report, but, instead of including scan parameters, contrast administration, and other scan techniques, the focus is on accessible language containing analogies to topics most individuals are more familiar with, such as radiation exposure from a plane flight, and it stresses that the scan is painless, to reduce any anxiety the patient may have about undergoing the examination. In addition, the effectiveness of the examination and why it is preferable to other options is also reinforced. Bullet points help to condense information from a paragraph format and are more visually appealing and take less time and effort to review. Paired with the written content of the first section are 2 important visuals. The first is a simple computed tomography (CT) scanner icon adapted from medical themed icons that are available on a variety of stock websites. Our preference is Adobe Stock based on the current frequency of use. The icons are simple line drawings but obvious in intent. The icon, paired with the content from the text and title, helps patients better understand the type of examination they had performed. To the right of the CT scanner icon is a visual representation of the smaller amount of radiation the patient receives during this test compared with a typical CT scan. By visually representing the radiation in a mostly empty space (reminiscent of a low temperature in a thermometer), patients are reminded that the radiation amount is negligible and not harmful.

The second section is titled "My Results." Whereas the first section remains the same across all 3 versions of the patient-friendly report, the second section is catered to each patient's individual results. In this section, the visuals take up more space. This change in layout is intentional—emphasizing risk on the basis of the finding of the examination is the most important piece of information that can be conveyed in the LCS report. The gradient bar visually conveys severity, ranging from white in the "Low Risk" section up to a brighter orange color for "High Risk." The second visual is a simple outline of a human torso and lungs. At the bottom corners of the torso, a directional "R" and "L" are included to cue the patient to how the image is oriented. Note in the "High-Risk Report" that the area of concern is a red circle, fading out to the edges. It is difficult to display the exact size and shape of a nodule on a small infographic; hence, the visual instead highlights the specific area of concern. The bullet points contained in this section provide greater detail about nodules identified during the scan. Using the "High-Risk Report" as an example, if a nodule is identified, the size and location are described in the text. There is also additional information about risk

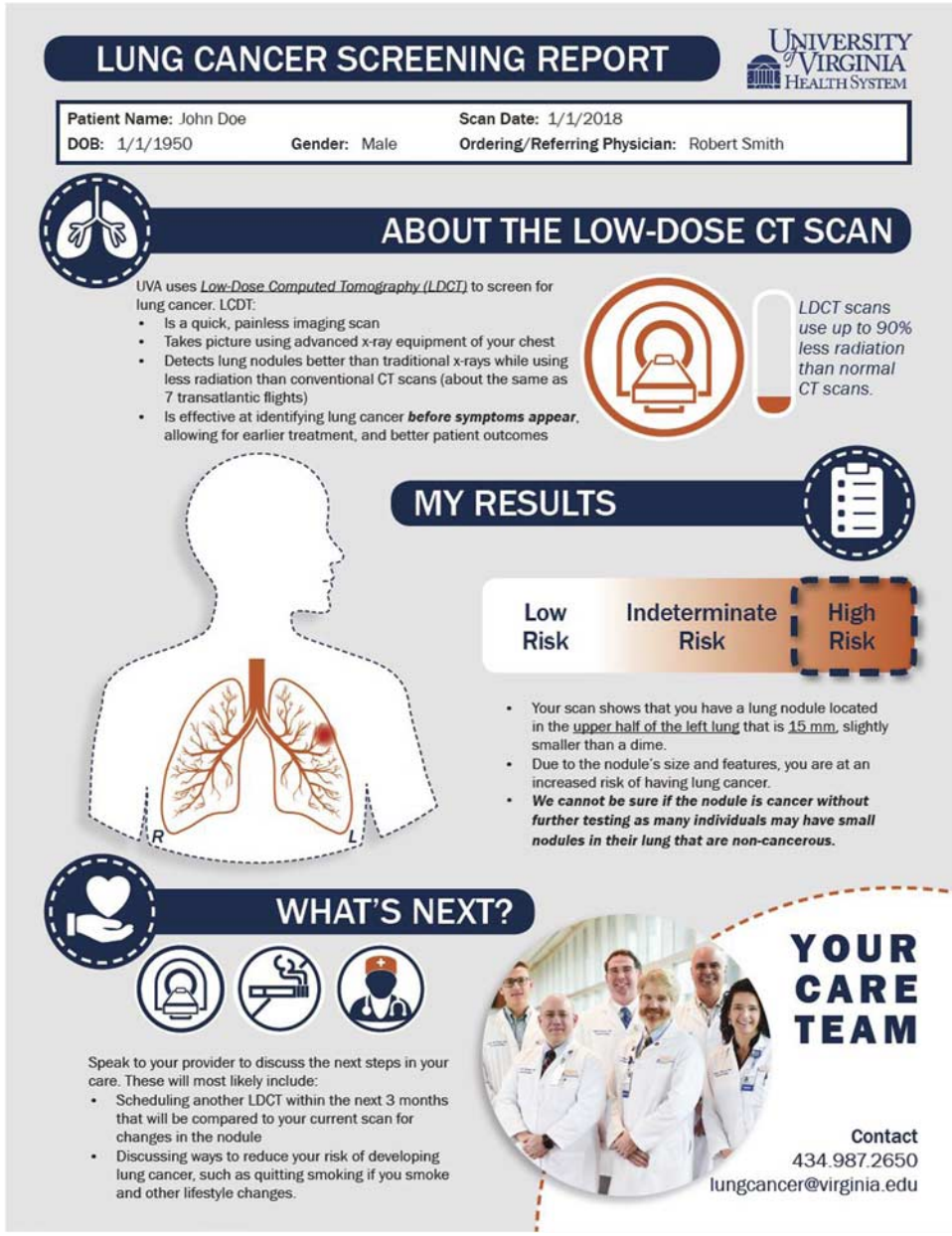

FIGURE 1. Sample report of an entire patient-friendly report for a "High Risk" screening scan shows the 3 portions of the report: "About the Low-Dose CT Scan" has information about the LDCT. "My Results" has details on the patient's scan. "What's Next" has information on the next steps the patient can take, while the lower right corner shows a picture of the care team with contact information. LDCT indicates low-dose computed tomography. full color online

assessment when a nodule is identified. The final bullet is in bold to call attention to the fact that LCS is not diagnosing cancer, but rather identifying whether a nodule is present or not. The intent of the patient-friendly LCS report is to improve patient engagement with their health and not to unnecessarily raise anxiety.

The final section is titled "What's Next" and is intended to provide actionable next steps for the patient after reviewing the findings noted on their scan. The section begins with 3 small icons, which refer to the steps included in all the reports: stop smoking, discuss with your provider, and schedule another screening within a certain amount of time. This section is paired with a subsection in the bottom right corner titled "Your Care Team," which provides pertinent contact information for our LCS team, including a phone number and email address that patients can easily access. There is also a picture of all of our current thoracic radiologists, taken on-site by a member of our marketing team to humanize the report.

We believe that our patient-friendly LCS report incorporates many key elements of good design; it is functional, esthetically pleasing, and hopefully intuitive from a patient standpoint. We believe that traditional radiology reports intended for referring providers rather than patients

tend to lack these qualities. The design for the new LCS report attempts to bridge the gap between form and function and attempts to facilitate better patient understanding of health in order to empower patients to share information about their health with other individuals who they are close to.

Challenges

Numerous challenges are involved in both creating and scaling an effort to create patient-friendly reports. We were fortunate to have an in-house design expert (C.S.) with the talent to create a visually attractive report. Access to such a resource may not exist at all institutions. While the structured reporting language and limited result categories of low-dose LCS provide an ideal use case to test such an endeavor, other instances (eg, emergency care) do not lend themselves as easily to the creation of patient-friendly reports, both because of the potential complexities of findings and the time available to issue the report. While the creation of patient-friendly reports is of potential benefit to patients, the additional time burden on the radiologists must be minimized to allow for adoption by radiologists. In order to routinely create and disseminate patient-friendly reports, an IT infrastructure must exist for seamless integration into a radiologist's workflow. We are in the process of creating this infrastructure at our institution. Our goal is to allow a radiologist to generate a standard report with keywords that will automatically trigger the generation of the patient-friendly correlate upon sign off. This patient-friendly report will then populate the patient portal.

Beyond the institutional and technical difficulties of creating a report and integrating it into hospital workflow, there are also challenges for patients. These issues include, but are not limited to, lack of access to/use of the Internet, lack of awareness/use of patient portals, and language barriers. Internet usage and access have increased over time, with 81% of the US population having access to the Internet as of 2016. This leaves nearly 20% of the population without access to potential online reports. Furthermore, there is a substantial gap between age groups, state, and demographics in terms of Internet access. In the population of householders over 65 years of age, for example, only 67.8% of individuals have an internet subscription, compared with 89.2% for those 35 to 44 years of age. Heterogeneity of access across the United States is also notable, wherein 80% of residents of Washington state have access to the Internet, and only 59% of residents of Mississippi regularly access the internet.[30] While 90% of health care organizations offer patient portal access, less than half of patients, especially older individuals, have actually integrated the tool into their daily lives for reasons ranging from ease of use to lack of knowledge about portals.[31] While English is the main language spoken, written, and read in the United States, the 2017 American Community Survey revealed that 21.6% of the US population spoke a language other than English at home, while 8.6% of the US population is considered limited in English-speaking proficiency.[32] Furthermore, the Migration Policy Institute's examination of the 2012 Program for International Assessment of Adult Competencies found that nearly 40% of immigrant adults lack basic English literacy skills.[33] Expanding the report to address all populations is imperative, but will be a substantial challenge going forward. Whether patients prefer our patient-friendly LCS reports to traditional radiology reports and whether the patient-friendly design improves understanding of imaging findings is currently being evaluated at our institution via a survey.

CONCLUSIONS/DISCUSSION

Medical paternalism is quickly fading in Western medicine due to greater access to publicly available patient information found on such resources as the World Wide Web and due to a greater desire of patients to participate in shared decision-making. The adoption of EHRs and the rise of patient portals allow patients near-instant access to their medical records including radiology reports. Radiologists have an opportunity to empower patients and participate in the patient-centered care movement by providing patients with a better understanding of their medical condition and the possible steps in care moving forward through improved patient-centered reporting.

Pictures, when coupled with simple text, are one potential way to communicate health information to patients.[24,27–29] Studies such as Delp and Jones provide evidence that patients provided with text and pictures have a superior understanding and recall health information better compared with patients who only receive text-based information. Thus, reports incorporating infographics such as our proposed patient-friendly LCS report may allow patients to better comprehend, and thus better participate, in their care.

A large portion of the population has access to vast amounts of information via smart mobile devices. The onus is on the medical community to provide tailored health care information to patients in a format they can both understand and which provides value to them. Imaging has become more critical to decision-making in health care, and patients will benefit from interventions to equip them with more knowledge about their imaging results. When a patient does not understand their imaging study results, they may fail to recognize the importance of follow-up recommendations, leading to lack of attendance at follow-up appointments, difficulties with adhering to treatment regimens, and with managing their own health. Improving patient understanding of their health can empower patients to better manage their health, resulting in improved health outcomes.[34] To continue to provide quality health care, radiology may benefit by adapting and exploring ways to develop a more patient-centered approach. Our patient-friendly radiology report for LCS is one such effort.

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