When Bad News Comes Through the Portal: Strengthening Trust and Guiding Patients When They Receive Bad Results Before Their Clinicians

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DOI https://doi.org/10.1200/EDBK_433944

OVERVIEW

Communication in oncology was challenging long before the emergence of the US 21st Century Cures Act. Before 2021, a growing body of evidence had demonstrated the benefits of patients' access to and review of the clinical notes in their charts (open notes); however, studies examining the benefits of immediate access to test results were scarce until the implementation of the Cures Act's Information Blocking Rule. Individuals grappling with cancer today now possess immediate access to their laboratory results, imaging scans, diagnostic tests, and progress notes as mandated by law. To many clinicians, the implementation of the Cures Act felt sudden and presented new challenges and concerns for oncologists surrounding patients' potential emotional reactions to medical notes or lack of control over the careful delivery of potentially life-changing information. Despite data that show most patients want immediate access to information in their records before it is communicated directly by a health care professional, surveys of oncologists showed trepidation. In this chapter, perspectives from a patient with cancer, an oncologist, and a cancer psychiatrist (in that order) are shared to illuminate the adjustments made in clinician-patient communication amid the era of nearly instantaneous results within the electronic health record.

Accepted May 15, 2024
Published June 7, 2024

Am Soc Clin Oncol Educ Book 44:e433944
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OVERVIEW

In 2016, the Obama Administration enacted the 21st Century Cures Act (Cures Act), aimed at advancing therapies for cancer and other complex diseases.[1] A key provision of this legislation was introduced to streamline the research process by facilitating the sharing and exchange of patients' medical records among different health systems via digital formats.[2,3] This concept, known as *interoperability*, was designed to empower patients to access care more easily.[4]

While US patients already possessed the legal right to request and receive copies of their medical records under the Health Insurance Portability and Accountability Act of 1996,[5] the 21st Century Cures Act included an Information Blocking Rule—which went into effect nationwide in April 2021—that mandated immediate availability of patient records in digital formats (eg, data exchanged through electronic health records [EHRs]) without delay on patient request.[6] This aspect of the Rule aimed to alleviate the cumbersome process patients historically faced when requesting medical records (which often involved significant time, effort, and expense).[7] By removing these barriers, the flow of information between patients and referring clinicians was enhanced, thereby improving patient care.

Before the enactment of the Cures Act, a growing body of evidence demonstrated the benefits of transparent communication between patients and clinicians through patients' access to and review of the clinical notes in a patients' medical record[8–17] (commonly referred to as open notes). By the time the Cures Rule was enforced in 2021, more than 100 publications in academic literature had documented these effects.[18] However, studies examining the benefits of immediate access to test results were scarce until the implementation of the Information Blocking Rule. Earlier research had indicated that patients generally did not experience heightened anxiety when accessing test results before consulting with their clinicians, particularly when they received adequate information about the purpose of the tests beforehand.[19,20]

After the Information Blocking Rule went into effect, a 2023 study revealed that an overwhelming majority of patients (96%) expressed a desire to view their test results even before their ordering clinicians had the opportunity to review them—even if the results were considered not normal.[21] Although studies focused on clinician perspectives on patient access to cancer-related tests have been published, studies on patient views are scarce.[22–24]

Despite varying perspectives among patients and clinicians, the Information Blocking Rule remains in force. In 2024, the

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PRACTICAL APPLICATIONS

- Oncologists should consider their involvement and personal approach to using the patient portal as an extension of patient care. Clinicians should be proactive in conceiving its design and implementation.
- When establishing care with a new patient, elicit their understanding, experience, and comfortability in using digital technology; provide a tutorial of the expected use of the patient portal (eg, how quickly to expect a response, distinguishing which questions are appropriate for the patient portal); and work to enhance digital health literacy.
- Remember that the patient portal may inadvertently expedite serious conversations when the oncologist has not had time to prepare for those conversations. Oncologists need to exercise self-awareness and consider their readiness and preparation for serious illness conversations generated from the portal.
- Oncology clinicians should be aware of **truth dumping**, which is the careless exchange of clinical information without considering what the patient is understanding and experiencing from the conversation.
- Periodically revisit the patient experience in using the patient portal while eliciting feedback.

Department of Health and Human Services (HHS) is poised to impose significant financial penalties on individual clinicians who fail to comply with this mandate, with fines reaching $1 million per occurrence, as administered through the Centers for Medicare and Medicaid Services.[25] However, some states, such as California and Kentucky, have enacted legislation prohibiting the immediate release of cancer-related test results, citing potential harms.[26]

Regardless of state-specific regulations, individuals grappling with cancer now possess access to their laboratory results, imaging scans, diagnostic tests, and progress notes as mandated by the Cures Act. In this chapter, perspectives from an oncologist, a patient with cancer, and a cancer psychiatrist (in that order) are shared to illuminate the adjustments made in clinician–patient communication amid the era of nearly instantaneous results within the EHR.

VIEWING TEST RESULTS THROUGH ONLINE PORTALS IS NOT NEW FOR PATIENTS WITH CANCER: A PATIENT PERSPECTIVE (Liz Salmi, AS)

In 2005, at age 25 years, I became a patient within the Kaiser Permanente health system in Northern California. Just one year prior, Kaiser became Epic's largest customer. Unbeknownst to me, I was among the first generation of patients who regularly interacted with clinicians via online portals. Accustomed to the convenience of online scheduling and prescription refills, I embraced a technological shift without realizing its historical significance in healthcare.

Three years later, in 2008, I suffered a severe seizure leading to the discovery of a grade 2 astrocytoma. Subsequent treatments—including two surgeries followed by 24 months of chemotherapy—thrust me into a whirlwind of medical interventions. During this time, I increasingly relied on the online patient portal to monitor my health, review results from tests, and coordinate with my health care team.

One day, 23 months into treatment, I had not heard from my neuro-oncologist over whether I was authorized to start the next round of an oral chemotherapy agent. Unsure of whether to begin, I proactively messaged my doctor: "*I had Day 23 labs today. Please order cycle 23 of [temozolomide]… I will have Day 28 labs next Sunday and message you again before taking anything.*" My doctor wrote back: "*Your labs… look fine. I refilled cycle 23 [temozolomide]… call/email us for the results before starting…. Heck, I think you know how to do this better than me, by now!.*" (S.P., MD, patient portal communication, received by L.S. on February 23, 2011.)

Since my diagnosis in 2008, a decade's worth of research now highlights the importance of transparent medical records in fostering trust between patients and clinicians particularly, among historically marginalized groups.[16,27,28] However, before the Information Blocking Rule went into effect, discrepancies persisted between patient and clinician perspectives on the accessibility of medical notes in oncology settings. In a head-to-head comparison of patient versus oncology clinician views published in 2020, nearly all of the patients surveyed felt that open, transparent access to notes was a good idea (98%), whereas just 70% of clinicians agreed.[14] To me, this discrepancy between patient and clinician views emphasized a need for further investigation into oncology patient experiences in viewing their medical information.

After the Cures Rule went into effect, growing public opinion favored immediate access to test results. A fall 2022 article published in *the New York Times* asked, "Your Medical Test Results Are Available. But Do You Want to View Them?"[29] In that article, the president of the American Medical Association was quoted as saying that access to test results was leading to mental or emotional harm. However, more than 800 readers of the *Times* had something to say, and most of them looked favorably on access to results.

Still, some oncologists remain apprehensive about patient access to test results, citing potential harm, which continues to reflect a disconnect between provider and patient preferences. A 2023 study published in the *Journal of Clinical Oncology-Oncology Practice* surveyed 198 oncologists about

their opinions over immediate release of test results.[30] The survey—which yielded an 18% response rate—concluded that immediately released clinical information to patients with cancer was not favored by 75% of survey respondents. Of the respondents, just half said their hospitals had a plan in place to deal with the requirements of immediate release. Of note, the study did not survey patients—an unfortunate oversight given that the Information Blocking Rule was intended to serve patients, not clinicians.

To me, what is important is not whether oncologists find immediate access to clinical results for patients with cancer helpful. What matters is whether patients find it helpful. Surveys of oncologists have not asked or evaluated these questions.

As someone who is still navigating the complexities of cancer treatment, I emphasize the importance of prioritizing patient perspectives in discussions surrounding access to health information. When I started this story, I was age 29 years. It is nearly 17 years later. Today I receive specialty neuro-oncology care at an academic medical center. Over the past 2 years, I have faced two recurrences.[31] This time around, I was able to rely on my health information in a way I could never before: I read my progress notes after every visit, which reminded me of my care plan and things I forget when I am struggling to remember so much in emotionally charged visits. Crucially, I spotted an inaccuracy in my medical record—a surgical report stated I was a right-handed patient, when in fact, I am ambidextrous.

The ongoing debate surrounding the timing of information release is a distraction from the crucial task at hand: enhancing digital health literacy among patients. Patients across all phases of cancer treatment—from diagnosis to post-treatment surveillance, through the end of life—will likely experience the stress of waiting for the results from a new diagnosis, active treatment laboratory, recurrence, or to see if a treatment is working. This may result in confusion from reading abnormal results out of context. Such patients may be particularly vulnerable to incorrect or even intentionally misleading information. Oncology clinicians and patient advocates can work together to prioritize empowering individuals to more effectively use their online portals and emerging digital tools to access and interpret their health information.[32,33]

My own cancer journey underscores the significance of the Cures Act in enhancing patient engagement and ensuring accuracy in medical records. So, what do I suggest? As an experienced user of online patient portals, I am comfortable reviewing results online while awaiting further discussion with my oncologist. However, my advocacy work has highlighted the diverse preferences within patient communities regarding the pace at which patients wish to receive medical information. Recognizing this variability, it is imperative we equip patients with the knowledge and tools to customize their portal settings according to their individual needs and preferences.

Before ordering any new test, clinicians should offer anticipatory guidance about what a patient can expect when results are released to their portal. A conversation as simple as the following could be deployed at the time the test is ordered: "*I'm ordering a test. You might see the result before me. You have a choice: look immediately or wait to hear from us. What questions do you have?*"

COMMUNICATING WITH PATIENTS THROUGH THE PORTAL: A BUSY ONCOLOGIST'S PERSPECTIVE (Joleen Hubbard, MD)

For many clinicians, the 21st Century Cures Act heralding patient access to the EHR came suddenly, without warning or guidelines to help adapt this change to clinical practice. The first step of the rollout process was enacted by April 5, 2021, although many EHR systems had already released this functionality earlier. Clinicians had concerns about the appearance of their notes, patients' emotional response to medical note content, and the potential for adding more confusion for the patient.[14,34] Some oncologists adapted their notes to be easier for patients to read while others lengthened their notes for their patients' benefit or to protect themselves medico-legally.[35]

As an oncologist caring for many patients, the immediate release of testing results to my patients, however, felt like an abrupt and substantial change for which I was not prepared. This EHR functionality was rolled out without guidance on communication for clinicians or patients. There was little to no discussion on how to adapt to this revolutionary change in clinician-patient communication, other than a notice that the Department of HHS would be tracking the immediate release of information. That is, practices were notified that delaying the release of information to patients without an adequate justification could result in large fines. Personally, I felt trepidations about my patients receiving their results without my guidance on how to interpret them. The impact of the change was evident right away. Instead of walking into an appointment with patients asking, "What did my scans show?," I started walking into examination rooms with patients and family members in tears, already knowing the results. The change in the emotional dynamics of my practice left me wondering whether the ability of patients to see these results was more harmful than helpful.

After several years of navigating this change in how information is delivered to patients, emerging data suggest that unrestricted patient access to the EHR has been a positive change for patients overall. This technology has led to increased engagement from the patient, strengthening the patient-clinician relationship by a feeling of greater partnership in the management of their health. Understanding the benefits for patients of EHR access and addressing the

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unique challenges it presents is crucial for developing clinician communication strategies to prepare the patient for impact of EHR access. Ultimately this has great potential to translate into better outcomes for our patients.

Here, we present the advantages and challenges in this new era of transparency (Table 1).

Advantages of Immediate Access to Results for Patients

Improved Patient Knowledge and Engagement

In survey of patients from a variety of settings revealed largely positive experiences with access to the EHR.[27] Patients felt empowered with more knowledge about their clinical condition(s) and better recollect the management plan, which allowed them feel more in control of their health care and better prepared for their health care visits.[27] Only a small percentage of patients felt very confused (3.3%) or more worried (4.8%) after viewing their clinical notes. Interestingly, patients who were older, less educated, non-White, Hispanic, and non-English speaking patients were more likely to report major benefits from reading their notes.

Similar results are seen in an oncology-specific patient population.[14] In one study, 56% of patients felt reading their notes was important for preparing for their clinical visits, and only 4% of patients were confused by the information in their notes. A qualitative study of oncology patients who accessed their EHR also reported that patients felt more knowledgeable about their cancer and reading notes between visits helped patients recall the information discussed with their provider.[36] Greater understanding of their disease may have profound implications for oncology patients, as previous research has shown that improved knowledge and confidence in their health care management results management plans that are more reflective of their values and a greater ability to cope with side effects of treatment.[37]

Often the shock of receiving bad news is overwhelming for patients, making the discussion of next steps in management difficult to focus on. One of the benefits of immediate access to results in the patient portal is that patients can begin to process the emotions caused by the bad result before the appointment. Dealing with the feeling of bad news beforehand may allow for patients and families to be more engaged in the subsequent management discussion during appointments with their clinicians.

Improved Transparency and Trust

Another major benefit of the Cures Rule is that the immediate release of information directly to patients has increased trust in patient-clinician relationships. While clinicians initially feared patients may be offended or find fault in their visit notes, being able to view notes can lead to patients feeling better about their physician.[9] Among a general patient population, being able to ensure medical information is

TABLE 1. Four Situations Oncology Patients May Experience When Reviewing Results Through an Online Portal Before Talking With Their Clinical Team

	Scenario	Case Description
1	Relieved	A 54-year-old patient underwent a CT scan of the chest, abdomen, and pelvis following the completion of adjuvant therapy for stage III colon cancer. The results appeared on the patient portal a week before her appointment with her medical oncologist. She reviewed the results before coming to the appointment and was relieved to understand that there was no sign of cancer. She did not understand the entirety of the detailed report, but she was comfortable with the radiologist's impression, which said "no evidence of disease." She prepared a list of questions for her medical oncologist
2	Concerned and frightened	A 72-year-old female patient with a history of gastric cancer was undergoing surveillance with routine imaging. She reviewed the radiology report and became immediately anxious about the fact the report was much longer than previous reports. She was primarily concerned that her cancer would spread to her kidney and bones after reading about a renal cyst and degenerative changes in her spine. She considered avoiding her upcoming follow-up appointment with her medical oncologist because she did not want to hear that she has recurrent cancer
3	Prepared for the worst	A 37-year-old patient presented for a preoperative appointment after completing neoadjuvant chemotherapy and chemoradiation therapy for locally advanced rectal cancer. His CT scan of the chest, abdomen, and pelvis revealed multiple, new liver metastases. He received these results during dinner when a patient portal notification indicated that his results were ready to be viewed. When he arrived for his follow-up appointment, he was visibly upset and ready to argue with his physician as soon as he walked into the examination room. After a contentious discussion while reviewing results with the physician, the patient explained that he researched his disease on the Internet and demanded to be treated with a technology that is not available for metastatic colorectal cancer. After his medical oncologist explained that his cancer could not be treated with the same technology, he left the room abruptly, stating that he would seek another opinion from someone who knows what they are doing

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TABLE 1. Four Situations Oncology Patients May Experience When Reviewing Results Through an Online Portal Before Talking With Their Clinical Team (continued)

	Scenario	Case Description
4	Ready for next steps	A 47-year-old male patient underwent a biopsy of his liver that confirmed metastatic esophageal cancer. He had an esophagectomy only five months ago. His immediate follow-up imaging revealed the possibility of metastatic disease. Although he was quite devastated by the news, he was appreciative that his medical oncologist had prepared him and his wife for potentially bad news prior to receiving the biopsy report on the patient portal. He was appreciative that he was able to find out the biopsy results before his follow-up appointment because it allowed him and his wife time to think about their concerns and prepare many questions. During the appointment he stated, "I'm now ready to talk about next steps"

Abbreviation: CT, computed tomography.

reported accurately instills more confidence in their provider and their clinical care.[38] Similarly, oncology patients have reported that the ability to view what the clinician has written in the history of present illness promotes patients feeling heard and confident they are receiving good care.[36]

Improved Patient Outcomes

Since patients have had the ability to view their EHR, multiple studies have confirmed improved patient engagement leading to an increased likelihood of following clinician recommendations and improved health outcomes. Patients feel better prepared for their visits and bring questions to better enhance their understanding of their disease. They refer to the notes for better recollection of their health care plan, which is critical for patients with cancer who are often overwhelmed with information when starting a cancer treatment plan. Studies have shown how medication adherence improves when patients review clinicians' notes and understand the indications of their medications.[12,39,40] In oncology settings, this may have potential to improve survival, especially when patients are taking oral cancer treatments. In addition, electronic sources to review supportive care measures for adverse effects can improve cancer treatment tolerance.[41]

Finally, with immediate access, patients now have the ability to review their charts for accuracy.[42,43] Correcting details in the EHR—such as prior treatment, symptoms, or medical history—may hold implications for patient safety and the consideration of potential treatment options. Accurate information in the record becomes even more crucial in an era where artificial intelligence tools are being used to screen patients for clinical trials.[32]

Challenges of Patient Access to the EHR

Addressing Anxiety

While viewing notes from a clinic visit can provide patients with improved knowledge about their cancer (open notes)—which helps provide a better sense of control and alleviate anxiety about their condition—for patients with metastatic and incurable disease, this may lead to increased anxiety.[36] Receiving bad news through the EHR *before* a discussion with a provider differs greatly from being able to review information that was discussed *after* the appointment. In a pre-Cures Rule era study of 95 patients exploring the impact of obtaining test results online, those patients whose test result was abnormal were more likely to have negative emotions (56% *v* 21%; $P = .003$) and to contact their physician more (44% *v* 15%; $P = .002$), compared with patients whose results were normal.[44]

Many oncologists carry a great sense of responsibility to deliver difficult news to patients with great care. Communication courses are provided during fellowship training and beyond to enhance cancer care delivery in a way that is most meaningful to patients. Understandably, the thought of patients receiving bad news via a portal, often before the oncology team has reviewed results, raises questions about the impact on patients' emotional well-being and the state of oncology practice.

Although most research on this topic has not been cancer-specific, the data show that the majority of patients would prefer to receive news immediately, regardless of whether the information is good or bad.[21] Understandably, those who received abnormal results had increased worry compared with those who received normal results (16.5% *v* 5%); however, 95.3% of patients would like to continue to have immediate access to their results through their patient portal despite worrisome results. A study of Swedish cancer patients revealed that immediate access to results reduced the patients' level of scanxiety.[45] Even patients with normal results can have anxiety trying to understand the medical terminology of benign findings on imaging studies and biopsies.

The current challenge is to determine *how, when, and with whom* patients would like to receive information, in the manner most comfortable for them. Some patients prefer to be at home and process their reactions in a private place, surrounded by people who are supporting them. Other patients may opt to wait to receive results directly from their provider who can help interpret the findings and explain what this means for them right after receiving the news. In this situation, patients would have decided to forego looking in the EHR ahead of their appointment.

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Addressing Misinformation

In a survey of patients who had immediate access to results, approximately 40% of patients sought additional information after reviewing them.[21] Their most common sources of information were the Internet (39.9%), another health care provider (14.1%), and a family member or relative (9%). For many patients, an Internet search full of a broad range of best case and worst case scenarios and varying degrees of information quality can be quite daunting. Not uncommonly, patients may receive recommendations for unproven or alternative treatments by well-meaning friends and family members. The task of trying to determine what information is valid and reliable can be overwhelming.

With the ability to view clinical notes, data show that approximately 23% of patients with cancer contacted their provider as a result of information they read in their notes, although the majority of the providers (89%) surveyed felt that it happened infrequently.[14] This is higher than reported in the general population (7%),[9] but there has not been a direct comparison. It is unclear if, and to what degree, the immediate release of cancer-related test results has contributed to increased communication via the online portal. A substantial increase could overwhelm an already burdened medical system, although studies about immediate access to test results during the peak of the COVID-19 pandemic have shown how access to sensitive results can help patients and their extended networks (family, friends, colleagues) plan for the future.[20] Arranging an appointment, either in-person or virtual/telemedicine, lets patients know an exact time results will be discussed so that patients are not left in limbo wondering when they will be contacted. Providing sources of reputable and accurate information on prognosis and/or management to prepare patients for the discussion may be beneficial.

BUILDING TRUST WHEN WORRISOME NEWS COMES ELECTRONICALLY: A PSYCHIATRIST'S PERSPECTIVE (Daniel C. McFarland, DO, MS)

Managing communication through the patient portal may help facilitate the clinician-patient relationship if/when communication is handled appropriately. It may not be possible to prevent bad news from reaching patients before a clinical interpretation can be rendered. The Cures Act, along with the use of patient portals, reinforces the need for communication that is tailored specifically for individual patients and their circumstances. Navigating the patient portal should be addressed when establishing oncologic care. Inevitably, communication patterns in oncology and the use of the patient portal will evolve over time, but for the moment, best communication practices should be driven by patient preference. This is an area that warrants research and quality improvement initiatives.

A conceptual, albeit somewhat distanced, approach to this new communication landscape is perhaps the best way to understand it. In other words, addressing communication challenges arising from the patient portal comes down to understanding its meaning and the specific nature of trust in the oncology setting.

To begin with, a historical perspective should be enlightening. Communication in oncology has always been challenging and susceptible to common culturally bound notions of the place and the time. Communication around emotionally laden topics like cancer is often dealt with in diametrically opposing ways.[46] In a previous era, information was routinely withheld. However, once societal norms allowed for discussion with patients and families about cancer, there has always been a risk of going from truth telling to truth dumping.[47] Withholding information and truth dumping are both deleterious to patient wellbeing and significantly erode trust and the clinician-patient relationship.[48] Both approaches are doctor-centric, not patient-centric. They rid the clinician of needing to handle the information with care. Withholding information impinges on the transfer of information while truth dumping transfers the information carelessly.

At its worst, information dispensing through the medical portal is an electronic form of truth dumping, but at its best, it functions as an enhanced version of shared decision making (SDM).[49] The portal allows patients to gather information, resources, and become increasingly informed regarding their care. The patient portal facilitates an informed perspective that allows patients the opportunity to make decisions according to their values and wishes. Of course, raw information can never replace the oncologist's perspective and interpretation which is ultimately what the patient with cancer seeks.

Oncologists attempt to balance several key communication goals. The EHR can assist but may also detract from these goals if not handled proficiently and proactively. Oncologists ensure that information is transferred while balancing how patients and families understand the information. SDM represents the ideal mode of communication in the context of serious medical illness because it allows for respect for patient autonomy while balancing the ethical demands of beneficence, nonmaleficence, and justice.[50] SDM rests comfortably between the overarching paternalistic approach to patient care and the passively involved physician as supplier of information without needed interpretation or deliberation.[51] However, SDM requires societal convergence on the appropriateness of topics to be discussed. In addition, it requires physicians to be competent communicators who can acquire an accurate understanding of what the patient is thinking and feeling.[52] Gaining this insight requires more than active listening and cognitive insight of the patient's experience, it requires self-awareness to delineate where one's emotions are activated and how the patient's emotions are distinct from one's own.[53,54] The patient portal and the potential for distress from real-time information may convene a heavy affective load on oncologists and their

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teams who are expected to respond in a timely manner to urgent patient requests. Consequently, it may become more difficult for oncology teams to plan for tough conversations.

Historically, the doctor-patient power differential was mirrored in the disparity of medical information. Clinicians have it and patients need it—or at the very least, its interpretation. Of course, medical information through the patient portal turns the lopsided information distribution on its head. The passage of objective information freely from EHR and the clinician exposes or demystifies this power differential, medical or clinical judgment and ultimately the management of disease. At its best, the equalization of power differential allows for easily communicated and understood SDM where clinician and patient enter a partnership. As mentioned before, SDM allows for the greatest amount of information transfer and fidelity to patient values while fully considering options. However, it is not a universally accepted or comfortable mode of communication for all patients or clinicians. Patients may have conflicting ideas about how they would like to enter the medical relationship while clinicians who are not entirely comfortable with the power dynamic between clinician and patient may (unconsciously) seek its annihilation or hide behind its presence to avoid the relational aspect of clinician-patient communication.

The patient portal can allow for these manifestations of the clinician's tendencies to become magnified. The portal not only challenges communication in medicine in real-time and to a substantial extent but also offers growth in the development of clinician-patient communication. The quick exchange of information risks a situation of truth dumping or information dispensing without engaging with the patient's situation and deliberation of their choices and options.

In other words, presenting a set of treatment choices to a patient may be straightforward, but communication is much more challenging when tailoring the deliberation to the patient's needs and aligning with their perspective. Patient-centered communication helps the patient arrive at a choice that is their own consistent with their values. The patient portal may improve the basis for patient communication and information transfer while also complicating the handling of emotion around that communication.

Patient Trust

The underlying issue for patients around engaging with patient portal communication is trust. Trust in medicine or oncology, as a concept, has meaning beyond several colloquial uses of the term. Trust in common parlance can mean confidence in, to rely upon, to hope for, or even to have a belief in (eg, I trust the train will arrive on time, I trust the weather report, I trust science). However, the trust that patients feel in allowing clinicians to inform them and carry out medical decisions is much more than these connotations of trust, which are all innately passive or in nature and without self-imposed agency. Trust in medicine is active. It is relational and not passive or transactional. It cannot be replaced or commodified. It expresses agency and a deliberate decision to enter a relational interaction with another person or institution independent of actual or perceived outcomes. Its essence is fiduciary.

Trust Is Built on (Demonstrated) Interest

Uncompromised interest in patients and their well-being (their interest) is what constitutes trust as a relational rather transactional endeavor. Interest and attitudes that dictate sets of behaviors cannot be commodified and transferred. Lack of transparency, but more importantly, competing interests (ie, financial, personal, commercial, or even academic) can erode patient trust once the demonstration of commitment is compromised. Surprisingly, this happens frequently and without much consideration in modern day clinical care. From the health care perspective of patients as consumers of health care, little attention seems to be given to the trust eroding effects of direct-to-consumer advertising or the incorporation of an increasing number of specialists who never obtain a full picture of the patient. However, these common structural entities signal divided health care system interests that are not necessarily or directly attuned to patient interest (ie, the system values cost savings, technology, or even physician well-being over patient interest) and undermine patient trust. At the same time, patients are adaptable and for many who have become accustomed to ever-changing clinicians or the shortening amount of time in consultation, trust is transferred from the individual clinician to the system—but it is still experienced by the patient as a relationship. The famous Frances Peabody[55] quote, "One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient" is a reminder of this North Star that medicine can only be oriented directly toward patients and their well-being and that trust is requisite to medical care; it is not often mentioned, but without it, the current notions of medical practice are lost.

Hillen et al[56] found that trusting oncologists was correlated with perceived honesty, patient-centered communication, clinical organization (ie, knowing the patient's case), in addition to technical competence. Similarly, trust in oncology nursing was associated with trust facilitating behaviors, nurse attributes (virtues), and influencing patient's health and psychosocial well-being.[57] Unsurprisingly, both findings suggest that patients trust the demonstration of sustained, committed interest to their medical needs. The relational aspect of clinical care requires attention and commitment. However, just like any other relationship, it can become strained with too many outside interests competing for the clinician's attention.

Some patients may test the clinician's interest in them through the patient portal, which is why addressing patient

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portal communication proactively by setting limits and boundaries is crucial to modern oncology practice.

Components of Trust in Medicine: How Does Trust Fit Into the EHR?

The EHR challenges trust and the clinician-patient relationship in numerous ways. Interest and commitment to patient care are on full display and may even be tested by patients at times as the interface between patient care and documentation closes in. Wolfensberger and Wrigley advocate for a pattern-based definition of trust in medicine that may be helpful in considering patient trust in establishing, cultivating, or re-establishing trust in oncology practice. The pattern is defined as: (1) an *expectation of action and behavior*—trust is not wholesale but contingent on an expected attitude toward the trusted relationship; (2) the *presence of uncertainty* and risk for the trustee—there is a moral hazard associated with trusting (ie, there is always a risk in trusting-trust becomes redundant when risk is eliminated); (3) a *free choice to trust*—trust must be intentional, it cannot be accidental, and given freely from an autonomous agent who has decided to trust; (4) the feeling of *betrayal, not simply disappointment* when trust is breached indicating its moral component; (5) a *relationship between to moral agents*—the trustor and trustee must be autonomous to demonstrate free choice and the commitment required for trust; and (6) the presence of *trust justification* which can vary from evidence of trustworthiness to a testimonial basis for the legitimacy for trust. This latter aspect forms the basis for merit, status, or professionalism-based trust, which may be important for many but not all patients. Often, disagreements about who or what to trust are met with an argument appealing to justification, but clearly there are many more components to trusting. Patients who trust our care are experiencing uncertainty (ie, cancer), are free to choose and actively decide (who to trust), have an expectation of clinician behavior and attitude, feel that their care is predicated on the relationship, and would feel betrayed in being let down from the relationship or its expected behaviors.

Medical education imparts moral aspects of clinical care but tends to assume the presence of trust. This is surprising since trust in professions like medicine started declining in the 1960s and has never rebounded despite terrific advances in medical care.[58] Patient portals seem to signal transparency but may not actually enhance trust just as increased safety in medical care has also not improved trust. However, communication through the patient portal should raise awareness and concern around patient trust.

Trust and the Patient Portal

The patient portal extends the clinic outside of its four walls into the real-time characteristics of the modern digital age. This is daunting for clinicians, especially with those who may find boundaries challenging to manage. However, the basic components of appropriateness and commitment to the patients are fundamentally similar. The electronic basis of communication needs to be dealt with up-front and proactively especially given the urgency inherent in most oncology care. As a communication extender, there are distinct advantages for the enterprise of clinical care, but there are also many pitfalls where communication can be misaligned and lead to dissatisfaction. For the most part, clinician communication is now on full display and uncovered. Of enormous importance is that helping patients mitigate the uncertainty of the patient portal, along with the uncertainty of their clinical care, builds trust. The communication exercise of dealing with the patient portal upfront and proactively should be considered to solidify the trust component of the relationship.[59]

Setting the Stage: Introducing the Patient Portal

The patient portal must be introduced, explained, and tailored to the patient to implement its communication advantages. Patients must know that the portal exists, what it does for them, and how to use it. This education should be applied based on an assessment of health literacy and tailored to the patient's understanding and desire use of the portal. Patients may find the portal helpful, terrifying, or somewhere in between. For this reason, open communication, which is allowed to evolve, is essential. In other words, this assessment is fluid and should be expected to change with time and with patients' needs and situations. Many patients who initially find the portal strange or daunting may come to appreciate it, whereas others who are initially excited about it may end up preferring to have face-to-face or clinician-directed communication.

Clinicians should invite patients to discuss the portal to ascertain their understanding and appreciate how they might want to use it. At the same time, the clinician may want to describe their practice patterns and what they have found works in their respective practices. This allows clinicians to set up expectations and boundaries. It should be an open-ended discussion with an intended outcome of mutual agreement on how to use the portal. Suggested topics might include turn-around time or the types of issues that may be discussed via the portal versus in-person. Patients may want to know if they should send follow-up messages, eg, for the most part, portal usage will be demonstrated by using it, but patients will appreciate the effort to set up guidelines for its usage.

Operationalizing the Portal

Clinicians, staff, and patients may have varying opinions regarding how effectively the portal is operationalized. Clinicians should make periodic assessments of the portal and what their patients prefer in terms of communication and whether their preferences have changed. Demonstrating this interest and commitment to communication will solidify trust. In addition, Kissane et al, highlight several actions that

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also help build trust in medicine: (1) handling of complicated information and complex clinical situations (eg, discussing death and dying); (2) building health literacy (eg, training patient to use the EHR or internet, countering misinformation, providing guidance on ethical actions and morally based commitment to patients); (3) considering explanatory models of illness and culture (eg, align illness understanding between clinician and patient); and (4) addressing health disparities.[60] The patient portal builds on these categories and allows clinicians to operationalize these principles. Ongoing communication with time to reflect allows for patients to integrate and understand what they are experiencing. At its best, the patient portal allows for better alignment of health care understanding and goals.

FUTURE DIRECTIONS

Communication in oncology was challenging long before the emergence of the Cures Act in the United States. The patient portal represents a new model of immediate information transfer in health care heralding patient engagement and cooperation and presents myriad individually based communication challenges that must be met with a collaborative attitude and style to avoid frustration and encourage the building of trust. Underlying the ethical importance from which this legislation emerged, trust has emerged as an ever-present aspect of communication in oncology that can only be ignored at the clinician's peril considering the rapid transfer of information in current oncology practice.

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST AND DATA AVAILABILITY STATEMENT

The following represents disclosure information provided by authors of this manuscript. All relationships are considered compensated. Relationships are self-held unless noted. I = Immediate Family Member, Inst = My Institution. Relationships may not relate to the subject matter of this manuscript. For more information about ASCO's conflict of interest policy, please refer to www.asco.org/rwc.

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Research Funding: Senhwa Biosciences (Inst), Bayer (Inst), Merck (Inst), Taiho Pharmaceutical (Inst), Treos Bio (Inst), Seagen (Inst), Trovagene (Inst), Translational Research in Oncology (Inst), Incyte (Inst), Pionyr (Inst), G1 Therapeutics (Inst), Pfizer (Inst)

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No other potential conflicts of interest were reported.

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