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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

What Are Ethical Merits and Drawbacks of a Patient's Open and Direct Access to Clinical Information in Their EHRs During a Hospital Stay?

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Abstract

Electronic health records (EHRs) now generally offer patients immediate access to a broad swath of health information and data they are often not fully prepared to interpret or review. This commentary on a case considers risks and benefits of open access to EHRs and strategies for mitigating patient anxiety caused by immediate access, including improving patient understanding of data, tools to promote health literacy, and customizable EHR information access options.

Case

Dr C has just read the chest X-ray report for TH, a cardiology inpatient admitted earlier today. TH has also seen the chest X-ray report in their electronic health record (EHR), which they accessed from their hospital bed. TH suggests to Dr C, "I think I need a CT scan. I'm reading online that I have a lung nodule." Dr C spends the next 15 minutes explaining to TH why a CT is not necessary. "Your lung nodule was seen on X-ray 5 years ago. It has not changed in size or appearance since then, so you don't need a CT scan." TH is not convinced, looks worried, and continues to ask Dr C about a CT scan. Dr C continues to try to explain why a CT scan is not indicated and will not be ordered. Dr C thinks to themself, "This conversation would be so much easier if this patient couldn't see everything that was in the chart." Dr C wonders how to respond.

Commentary

Electronic health records (EHRs) have revolutionized modern health care, offering a digital platform to store and share patient information while enhancing efficiency, accuracy, and accessibility.[1] For patients, EHRs provide unprecedented access to their medical information—data that were historically difficult to obtain—which can support more active participation in care decisions when accompanied by tools that aid interpretation and application. Patient access to and use of EHRs has grown steadily, with the telehealth boom during the COVID-19 pandemic between 2020 and 2022 accelerating the trend.[2] Concurrently, the final rule implementing the federal 21st Century Cures Act supported patients' cost-free, timely access to their EHRs by adopting interoperability standards and prohibiting information blocking.[3] EHRs are thus uniquely positioned at the intersection of technology, patient autonomy, and clinical decision-making. This commentary on a case discusses ethical tensions arising from patients'

immediate access to test results and notes and how clinicians and health systems can help mitigate patients' anxiety.

Ethical Tensions in EHR Access

Open access to EHRs offers significant benefits to patients. It has been shown to enhance patients' satisfaction and engagement, thereby improving their understanding of their health conditions, treatment plans, and the rationale for care, which in turn supports better self-management and adherence to medical advice.[4,5] Surveys have found that most patients prefer receiving test results through portals immediately,[6] even before clinician contact, and few feel more worried after viewing their test results before discussing them with a clinician.[6,7] This transparency bolsters autonomy, enabling patients to monitor health trends, share records with others, and participate actively in care decisions, thereby challenging physicians' historically paternalistic role.[8,9,10] Furthermore, patient access to EHRs can lead to identification of medication errors,[10] enhanced medication adherence,[11] and improved communication between patients and health care professionals, which increases patient preparedness for consultations.[12]

However, open access to EHRs also has drawbacks. Patients might turn to unreliable online sources, such as forums or artificial intelligence, to interpret new test results. Reports often include pending results or preliminary diagnoses that are difficult to contextualize. Physicians worry that patients might misinterpret their results[13] or that access might cause undue emotional distress, provoking fear or anxiety, especially for those with severe or chronic conditions or those seeking mental health care.[14] Many patients might simply feel overwhelmed or be unwilling to interpret their results independently.[15] Additionally, discrepancies between clinical documentation and a patient's lived experience can lead to misunderstandings, conflicts, or strained patient-clinician relationships.[16] Privacy concerns are also significant, especially for sensitive information (eg, mental health or genetic data). Many patients and clinicians worry about data breaches or unauthorized access by insurers or government.[10,17] For vulnerable groups, such as adolescents or elders, proxy access can further compromise personal privacy, as restricting information sharing is often not feasible in EHR systems.[16] Practical barriers, such as internet access or hardware limitations, are often assumed to be the main challenges that patients face in accessing EHRs. These kinds of drawbacks of open access to EHRs must be carefully considered and addressed to avoid harming patients.

Minimizing Patient Anxiety

Given these potential concerns, the question arises of how to mitigate patient anxiety caused by immediate access to EHRs. One solution lies in clinicians and systems proactively framing the presentation of medical data. While most EHRs include reference ranges for common tests, which inform patients whether their results are "normal," they often lack the contextual or explanatory tools necessary for patients to fully understand their significance. Enhanced educational resources, such as simplified trend analyses, clinician-provided summaries, and links to accessible, verified medical explanations, can bridge this gap. Incorporating visual aids and graphics can further clarify results, particularly in complex cases or for patients with reduced health literacy.[18] Whenever possible, test result interfaces should be designed to provide clear takeaway results for each result in text form or in carefully designed graphics. In complex cases that require synthesis of multiple laboratory values or tests (for example, for patients wondering about their current liver function in the setting of a drug-induced liver injury), determining a takeaway message may require expert interpretation or

complex algorithms.[19] While this commentary focuses particularly on test results that have potential for misinterpretation, principles of data framing can and should be extended to other areas of the EHR, such as clinical notes or imaging reports, which similarly can arouse patient distress or confusion. Using plain language summaries or inviting patients to respond or annotate their records might help reduce patient-clinician information asymmetry.

Customizable access features can offer another solution, allowing patients to choose when and how they view their data. Sensitive results, such as imaging or genetic findings, could be delayed until a clinician has provided interpretation. For example, patients could choose to delay receiving results about distressing items during working hours or until they have social support with them. These patient-centered strategies not only reduce distress but also respect varying levels of health literacy and personal preferences. Additionally, institutions could benefit from establishing formal processes that allow patients to flag entries in their EHR for clarification or to request a follow-up discussion with a clinician in order to reduce confusion and ensure that patient concerns are addressed promptly. Implementing these measures would enable health care systems to better balance transparency and support by informing patients and giving them opportunities to cultivate self-knowledge from EHR information without overwhelming them.

Balancing Benefits and Risks

As mentioned, the Cures Act final rule mandates that patients be given timely access to most health information in their EHRs, including clinical notes and test results.[3] For clinicians, this provision means, in practice, that results are often released before they have had a chance to interpret them—raising the risk of patient confusion or distress and prompting questions about when release of information could be delayed or restricted. Under the Cures Act final rule, 8 information blocking exceptions are outlined, including a "Preventing Harm Exception" that permits information blocking in cases in which it is "reasonable and necessary to prevent harm to a patient or another person."[3] Now, it is even more important that any restriction on patient access to EHR information be done thoughtfully and only when necessary, with the goal of not simply limiting patient distress but truly preventing harm understood as physical, psychological, or social consequences resulting from premature release of medical information.

Physical harm can occur if immediate access to results causes delay in appropriate clinical intervention or care; psychological harm can involve emotional distress, fear, or anxiety; and social harm can arise in the case of sensitive information, such as mental health or genetic data, leading to stigma or discrimination. While both patients and clinicians have been shown to value information transparency, the immediate release of test results remains controversial among clinicians,[20] although most patients prefer to receive test results immediately[6]; this mismatch highlights the importance of setting expectations regarding communication of results before tests are underway. Indeed, a large survey has highlighted the need to improve result interpretation by patients, given that patients who received abnormal tests results were more likely to report being worried than those with normal results.[6]

Any restriction of patient access should be initiated by physicians when there is legitimate possibility of harm (eg, when the results are complex, potentially alarming, or could be misinterpreted) or by patients. Physicians should assess potential for different types of harm in individual cases, carefully weighing factors such as a patient's

emotional state, complexity of results and ensuing intervention plans, and risks of care delays. Allowing patients to choose how much information they wish to view immediately, instead of waiting until a clinician offers interpretative help, could be another effective approach. Developing tools that allow patients to flag results and request clinician clarification could help prevent unnecessary worry and promote better communication. Overall, it's more important than ever to engage patients in conversations about their EHR access preferences and expectations.

Recommendations

Although patient TH's ability to immediately access their record may prove to be challenging and a source of current stress for Dr C, it highlights the importance of clinicians providing more educational resources to patients and ensuring they have realistic expectations regarding future test results. Additional knowledge about incidental pulmonary findings and clinical decision-making tools, such as the Mayo Clinic Solitary Pulmonary Nodule malignancy risk score,[21] could contextualize patient TH's findings, thereby alleviating their fear. While perhaps initially challenging for clinicians like Dr C, these efforts would foster greater patient agency. Over time, this approach could help strengthen patient-clinician relationships and help promote trust.

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Editor's Note

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The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

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