AMA Journal of Ethics®

STATE OF THE ART AND SCIENCE

Lessons about So-Called "Difficult" Patients from the UK Controversy over Patient Access to Electronic Health Records

Federica Lucivero, PhD

Abstract

Increasing numbers of patients have direct access to their electronic health records (EHRs). Proponents of direct access argue that it empowers patients by making them more informed and offering them more control over their health and care. According to some proponents of patients' access to EHRs, clinicians' concerns about potential negative implications are grounded in a form of paternalism that protects clinicians' authority. This paper draws upon narratives from patients in the United Kingdom (UK) who have access to their EHRs and suggests strategies for moving beyond these controversies between proponents and critics of the system. It additionally shows that the very organizational, procedural, and technological infrastructure that promises patients' increased access to records can also exacerbate some patients' "difficult" behaviors.

Introduction

Fueled by the promise of increasing efficiency and reducing costs, digital health is high on the agenda of policymakers and health care organizations alike. Many governments—including the United States and the United Kingdom (UK)—have developed electronic health roadmaps that incentivize the introduction of wearable sensors monitoring patients' health parameters; interoperable software programs for data sharing, storage, and management; and platforms for remote communication [1-5].

Electronic health records (EHRs), which store patients' medical history and administrative information in electronic form, play a crucial role in this process of digitization and integration of health care [1-2, 6]. They are also increasingly becoming directly available to patients for care management purposes [7]. In 2015, for example, the National Health Service (NHS) England mandated that by 2016 primary care providers give patients direct access to their records through dedicated online platforms [8, 9], which enable patients to retrieve first-hand information about their health and care. Such access is expected to allow patients to be more in control of and proactively improve conditions for their well-being, ultimately fostering safer and easier care,

boosting biomedical research, empowering patients, and promoting a "partnership" between citizens and health care professionals [10-12].

The idea that patients can access their EHR online without physicians' mediation is, however, controversial. Firstly, general practitioners (GPs) and other clinicians are concerned that the very fact of having access to records may have negative consequences for patients' welfare. For example, it could make patients anxious about their health conditions. Or it could expose some patients to coercive demands of third parties (e.g., abusive partners or employers) to access their records, thus jeopardizing patients' trust that their medical history will remain [confidential](#) [13-16]. Also, health care professionals are worried that patient access to records could increase risks of litigation, require them to change the way they write on the records, and invite patients to ask questions on specific phrasing, thus increasing GPs' workload [14, 17]. In this sense, patients who access their records might be more "difficult" for physicians to manage.

Eric Topol maintains that health care professionals resist the revolutionary changes that digital technologies are generating in the field of health care and medicine. In his latest book, *The Patient Will See You Now: The Future of Medicine is in Your Hands*, he argues that such resistance derives from the widespread and persistent paternalism of the medical profession [18]. According to this interpretation, by accessing health-related information via EHRs, patients would enter unmonitored into a space that was traditionally reserved for clinical experts, thus subverting the traditional power relationship in the clinic and endangering what some might regard as clinicians' undisputed authority.

It would be misleading, however, to interpret the controversy over patient access to EHRs as an irreducible tension between those who are keen to empower patients and those who are fearful that such empowered patients would be more "difficult" to manage because they could challenge clinicians' authority. Drawing on narratives of two patients in Northern England who have been accessing their EHRs for several years, I will argue that this tension inheres not in diverging ideologies but in the very practice of giving patients access to EHRs. I will also suggest that the very organizational, procedural, and technological structures that afford patient access to EHRs can contribute to patients being "difficult."

Stories of EHR Access and Patient-Physician Partnership
NHS England maintains that access to detailed medical information allows patients to make decisions about their care and lifestyle and, ultimately, control their health conditions [1, 9-12]. The underlying assumption is that information produces action, which results in control, which leads to (em)power(ment) that implies responsibility for healthy behaviors. In this liberal concept of "empowerment" [19], patients are not merely expected to act responsibly and promote their own health when duly informed of

their conditions. Empowered patients are also supposed to work in partnership with physicians for the promotion or restoration of their health. But what are the terms of such partnership in the practical context of EHR access?

Patients become more "useful." Indeed, having access to records may encourage patients to engage more in their care. This benefit clearly emerges in the story of a young lady (fictitiously called Eva) who, at the time I interviewed her in 2015 as part of a qualitative study of EHR use, had been accessing her full records for eight years. She could view her GPs' free text notes and hospital referrals, as well as her test results. As Eva explains, she usually checks her record before she sees a clinician "so I can have a good knowledge myself of what is going on before going to see the GP." She added that on several occasions, a reading of her records has allowed her to play a more active part in the diagnosis of her condition as she could help her GP make connections.

> So rather than just sitting there and listening to a GP I can say "Well I have got these symptoms and if you look over the past six months I have had this several times and things like that." You sort of become more involved in that process of figuring out what is going on.

Eva's account interestingly clarifies the way in which access to records fosters patients' agency: it allows them to take an auxiliary role in consultations. Rather than acting as autonomous decision makers in control of their health, patients are turned into disciplined assistants for clinicians.

Clinicians need to see the records. This collaborative relationship between patient and clinician maintains its traditional power asymmetry—an asymmetry that appears clearly in the story of Fiona (a pseudonym), an older patient with multiple morbidities whom I interviewed in 2015 as part of the same qualitative study of EHR use. On one occasion, her ophthalmologist would not schedule an eye surgery until she could be assured by the neurosurgeon that it would be compatible with Fiona's neck condition. Although the neurosurgeon wrote a letter giving the green light and the letter was stored in Fiona's GP records, the ophthalmologist could not access the letter from the hospital's informatics system. Fiona's assurance that the letter was in her records was not enough, as the ophthalmologist could not take the risk of scheduling a surgery when she had not seen the letter. Although Fiona was trustworthy enough to access her full EHRs and view information her own consultant could not retrieve, her word was not trusted, as the specialist needed to witness the presence of the letter in her records. In this asymmetry of decisional power and access to information, Fiona could still negotiate to use the ophthalmologist's computer to access her patient portal and show the neurosurgeon letter. As a disciplined assistant, Fiona inserted the digits to open her file and submit it to the expert eye of the physician who could then deliberate and schedule her surgery.

"*That's the way we do it.*" Such a supportive role is, however, informal and not always accepted. In some cases, patients' ability to access information is not acknowledged by health care professionals. As Fiona recalls, she had to take a penicillin allergy test, but the immunology department did not have access to her full medical records to check whether she had to suspend any medication before taking the test. Rather than trust Fiona or ask her to access her records on a department computer, the department waited to receive access to her full medical records through official channels. When the department finally got access to the relevant information and realized that indeed she had to suspend a drug she was taking, it was too late and Fiona's test was rescheduled six months later, delaying several other clinical treatments. A frustrated Fiona explains:

> The ridiculous part about it was [that] I was the person who gave that information about what medication I was on to the immunology consultant in the first place. So in other words they were chasing stuff around, information I had given them.... I said "Why didn't you ring me?" and they said "Because we needed to see it in the notes." And I said "Yes but I am the person who told you the information that went in the notes in the first place" [and they said] "That's the way we do it."

This time not only was Fiona not trusted about her account of what was in her records, she was also not allowed to assist the experts by granting them access. From Fiona's perspective, her consultants were being untrusting and dismissive of her access to correct information. From the point of view of the clinicians, Fiona could be perceived as "difficult" because she expected to be trusted on her word and did not seem to understand the safeguards in place to protect records' security. The impasse, however, is not due to a conflict between an empowered patient and a paternalistic clinician; instead, it is built into the organizational, procedural, and technological infrastructure that enables patient access to records.

Conclusion
Online, real-time access to records is expected to put patients in a position of power in the clinical relationship, as they have access to information that is traditionally reserved for clinical experts. In fact, digital access to health information in the UK might merely enable patients to take the role of assistants who engage in some form of useful labor that fills in the information gaps in current health care systems. Organizational and technological structures, however, may prevent even such a limited role, as clinical professionals are ultimately accountable for clinical decisions. This absence of patient power is exemplified in the last case discussed above in which Fiona had access to information her consultants could not directly access but could exercise no power or offer no assistance, as clinical responsibility finally rests with the health care professionals and puts them at the center of the flow of clinical information.

While policy roadmaps in the US, the UK, and other European countries incentivize digitally enabled "patient-centered" solutions that promise to give patients control and responsibility over their own health, existing health care infrastructures at the national level are not designed for patients to be in control and may even frustrate such attempts. This conflict between intention and its realization is not an ideological divergence between supporters of patient autonomy and empowerment and conservative paternalists protecting physicians' authority. In my interview with Fiona, it was apparent that consultants could not simply trust Fiona's words because they were operating in a system that normatively assigns to them the roles of protecting patient safety and information security as well as overseeing the fair distribution of health care resources. These normative roles are designed and implemented in an organizational, procedural, and technological infrastructure that requires them to "see with their own eyes" before making decisions. The same infrastructure also allows patients direct access to information that is not directly accessible to clinicians. The promise of patient self-management, control, and centrality in health care practices, therefore, is inherently at odds with the normative framework that guides the design of such practices.

It is crucial for policymakers to acknowledge these internal contradictions and to solve them by engaging in a dual task: redefining rights, duties, and responsibilities within our health care systems to include patients in more active roles while, at the same time, nuancing the rhetoric of empowerment via access to records to realistically express the role that patients can have in the context of their care.

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Federica Lucivero, PhD, is a Marie Curie Fellow in the Department of Global Health & Social Medicine at King's College London (KCL). She is also the KCL representative in the working group on mHealth guidelines at the European Commission. With expertise spanning different areas and disciplines—ethics and social studies of science and technology, governance of innovation, philosophy of science and technology—she conducts research on the ethical, social, and political aspects of mobile health solutions.

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