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# **HEALTH LAW: PEER-REVIEWED ARTICLE**

How Could Legal Standards Promote Equitable Access to EHRs? Jessica L. Roberts, JD

### Abstract

Electronic health records (EHRs) enable patients to access their health records anytime, from anywhere with internet connectivity. Yet not all Americans benefit from these innovations. EHRs can be hard to access for people with a range of disabilities. This lack of access perpetuates inequity and, thus, demands ethical and legal attention. Some federal laws and regulations require accessible EHRs, but even these protections can fall short. This article argues that more clearly defined obligations for EHR developers and clinicians are necessary.

## **Accessing Health Information**

Electronic health records (EHRs) have made obtaining health data easier than ever before. EHRs are effectively "digitized medical chart[s]" that allow clinicians to readily access and manage patients' information. Integrating EHRs into clinical practice can increase efficiency and improve quality of care. 1,2 Specifically, EHRs allow clinicians to coordinate treatment plans with other clinicians and to detect and mitigate errors. Patients, too, can review parts of their health records 24 hours a day, 365 days a year, from anywhere with an internet connection. Patients' reading and understanding of key information in their EHRs can motivate communication and adherence. However, not all patients can reap these benefits.

Americans with disabilities experience significant health inequity, and inaccessible EHRs could exacerbate that inequity. Moreover, issues that impede access for patients with disabilities could also affect other populations, such as elderly patients and patients with limited education.<sup>2</sup> Inaccessible EHRs are at odds with clinicians' legal<sup>3</sup> and ethical duties<sup>4,5,6,7</sup> to practice inclusively. Thankfully, current federal regulations require covered providers to ensure that information technology is accessible to those with disabilities.<sup>8</sup> Although federal disability rights laws do not apply to technology developers<sup>3,9</sup> and can go underenforced,<sup>10</sup> ethical duties of both clinicians and EHR developers provide a foundation on which to ground health systems' parallel duties to ensure that patients with disabilities can meaningfully access and use their health data.

## Inaccessibility of EHRs

Many websites and apps are inaccessible to people with disabilities. They might use small font, include content written at a high literacy level, rely on complex and hard-to-navigate user interfaces, lack the capacity to customize, or be incompatible with

assistive technology, such as screen-reading or voice-control software. As a result, many health technologies, including EHRs, might be inaccessible to people with disabilities.<sup>3</sup>

Research on EHR adoption has identified a variety of disabilities—including physical, cognitive, and visual—as barriers to successfully using EHRs.² For example, a 2024 study that evaluated the compatibility of 3 popular, open-source EHR systems with 3 common screen readers—software tools that people with visual disabilities use to access digital content—found that, although the "EHR systems evaluated offer a respectable level of accessibility for visually impaired users," developers could build more inclusive EHR systems.¹¹ The study emphasized that "users and organizations should prioritize accessibility when selecting and implementing EHR systems to ensure all users can access and benefit from the system's content."¹¹ Similarly, researchers in Australia identified barriers to EHR access for patients with intellectual disabilities and suggested ways to improve their experiences.¹² Among the suggestions were ensuring that information in EHRs is "informative, concise, and easy-to-understand" and that support is available to help people with intellectual disabilities benefit from their possible value.¹²

Inaccessible EHRs do more than just deny patients with disabilities the opportunity to benefit from new health technologies. They can also compound existing inequalities. Over 70 million adults in the United States reported having a disability in 2022.<sup>13</sup> As a group, people with disabilities tend to have worse health outcomes and lower patient satisfaction than people without disabilities.<sup>3,14</sup> They are also at higher risk for several chronic conditions and tend to consume more health care.<sup>3</sup> Their heightened health risks and frequent health care consumption mean that patients with disabilities have more health data to manage across clinicians and organizations. Thus, patients with disabilities might seem particularly well-positioned to reap the benefits of EHRs. But if patients with disabilities cannot access their EHRs, that inaccessibility could perpetuate or exacerbate existing inequities. Consequently, both law and ethics require ensuring that patients with disabilities can use these important technologies.

### Legal Obligations to Ensure EHR Accessibility

The inaccessibility of many EHRs is surprising, given that health care providers have legal obligations to offer care equitably and inclusively. In particular, several federal disability rights laws apply to health care.<sup>3</sup> These provisions state that covered providers cannot discriminate based on disability when practicing medicine.<sup>3</sup> While some of these laws have been in effect for decades, the statutes themselves do not directly address virtual health care. To fill this gap, 2 federal agencies—the Department of Health and Human Services (HHS) and the Department of Justice (DOJ)—adopted digital accessibility standards in 2024.<sup>3,9,15,16</sup> These HHS and DOJ regulations, which apply to certain federally funded health care providers and state and local entities, respectively, stipulate:

A recipient [of federal financial assistance] shall ensure that the following are readily accessible to and usable by individuals with disabilities: (1) Web content that a recipient provides or makes available, directly or through contractual, licensing, or other arrangements; and (2) Mobile apps that a recipient provides or makes available, directly or through contractual, licensing, or other arrangements.<sup>15</sup>

A public entity shall ensure that the following are readily accessible to and usable by individuals with disabilities: (1) Web content that a public entity provides or makes available, directly or through contractual, licensing, or other arrangements; and (2) Mobile apps that a public entity provides or makes available, directly or through contractual, licensing, or other arrangements.<sup>16</sup>

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Because patients access EHRs through either websites or apps, the new rules require these technologies to be "readily accessible to and usable by" <sup>15</sup> individuals with disabilities. The regulations also offer much needed clarity regarding what constitutes digital accessibility. They require covered entities to comply with level AA of version 2.1 of the Web Content Accessibility Guidelines, <sup>9,15,16</sup> which are international standards for digital accessibility. By specifying the version of the guidelines and level of compliance required by federal law, HHS and DOJ clarified the scope of these obligations. <sup>9</sup>

Also in 2024, HHS promulgated regulations<sup>8</sup> interpreting the Affordable Care Act's antidiscrimination provision. <sup>17</sup> Pursuant to the agency regulations, "a covered entity [eg, a provider] must ensure that its health programs and activities provided through information and communication technology are accessible to individuals with disabilities." The rule also requires "health programs and activities provided through websites and mobile applications" to comply with the standards for federally funded entities and state and local governments. In other words, covered entities must conform to the standards outlined above. However, covered entities do not have to make their information and communication technology accessible if doing so would impose an undue financial or administrative burden or fundamentally alter the nature of their programs or activities.<sup>8</sup>

While these recent rules offer clarity, their potential impact is unclear. The statutes that the regulations implement vastly predate the recent rules by the span of decades. Despite these laws, people with disabilities experience exclusion and discrimination, including in health care. The persistence of this inequality—even with broad federal legislation—could be in part due to underenforcement. Consider the fact that the Americans with Disabilities Act's *physical* accessibility rules have been in effect for decades, yet many covered entities remain inaccessible. These statutes rely predominantly on private litigants to enforce them through lawsuits. Lawsuits are time-consuming and expensive, and federal disabilities rights laws offer very limited remedies. As a result, potential plaintiffs and their lawyers might not deem it worth the effort to file a claim. Many legal violations might, therefore, go unchallenged.

Additionally, the new regulations do not apply to developers.<sup>3,9</sup> They target the individuals and entities that interact with patients—in other words, clinicians and their institutions—not the entities that design and sell the technology. As a result, the developers of EHRs do not have legal obligations regarding accessibility. Perhaps, then, it is unsurprising that the creators of EHRs have not prioritized accessibility. Hopefully, the new rules will generate a demand for more accessible EHRs.<sup>3,9</sup> Even with clear federal guidance regarding accessibility, noncompliance is still possible. The HHS and DOJ provisions might be underenforced. However, the following section argues that designers and clinicians have ethical obligations to create and adopt more accessible EHRs.

## Ethical Obligations to Ensure EHR Accessibility

Beyond law, ethical principles articulated by medical associations demand that EHRs be accessible. Principle 2 of the World Medical Association Code of Medical Ethics states: "The physician must practise medicine fairly and justly and provide care based on the patient's health needs without bias or engaging in discriminatory conduct on the basis of age, disease or disability, creed, ethnic origin, gender, nationality, political affiliation, race, culture, sexual orientation, social standing, or any other factor." Thus, clinicians have ethical obligations not to discriminate based on disability when providing care.

Likewise, the American Medical Association (AMA) *Code of Medical Ethics* upholds nondiscrimination as an important value. Principle I stipulates that "[a] physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights," and Principle IX requires doctors to "support access to medical care for all people." AMA *Code* Opinion 11.2.7, "Responsibilities to Promote Equitable Care," includes an obligation to "identify institutional policies and practices that perpetuate or create barriers to equitable care." And AMA *Code* Opinion 8.5, "Disparities in Health Care," explains that physicians "ethically are called on to provide the same quality of care to all patients without regard to medically irrelevant personal characteristics" and that, as part of that duty, physicians should "[p]rovide care that meets patient needs and respects patient preferences." Ethics thus requires that clinicians provide care equitably and inclusively.

The AMA has also issued opinions dealing with the use of technology in medicine. While most focus solely on patient privacy and data security, Opinion 1.2.12, "Ethical Practice in Telemedicine," states that "physicians should ... [a]dvocate for policies and initiatives to promote access to telehealth/telemedicine services for all patients who could benefit from receiving care electronically." 18

While the above opinions support more accessible EHRs in the abstract, they might be insufficient. The AMA should consider adopting an opinion on inclusive technology that could explain that obligations to provide equitable health care extend to information and care online.

Additionally, developers have ethical obligations of their own. The Association for Computing Machinery (ACM) has its own code of ethics that includes a reporting process and states that computing professionals should "be fair and take action not to discriminate," including against users with disabilities.<sup>19</sup> It stipulates:

The use of information and technology may cause new, or enhance existing, inequities. Technologies and practices should be as inclusive and accessible as possible and computing professionals should take action to avoid creating systems or technologies that disenfranchise or oppress people. Failure to design for inclusiveness and accessibility may constitute unfair discrimination.<sup>19</sup>

EHRs inaccessible to people with disabilities violate the principle of nondiscrimination. Thus, while developers do not have the same legal obligations as clinicians and their institutions, they do have an ethical responsibility to design inclusive technology. The ACM strongly advocates for accessible technology, including by encouraging developers to help establish digital accessibility rules like the ones described earlier. However, the prevalence of technology inaccessible to people with disabilities suggests that the organization could do more to promote its core values. The AMC thus might consider investing more in educating developers about accessible digital design and in identifying potential violators.

## Conclusion

EHRs are an important innovation not only for clinicians and providers but for patients. Direct access to records, when utilized, could make patients more informed and engaged, leading to better outcomes and improved quality of care. However, access barriers can deny people with certain disabilities the opportunity to benefit. Despite long-standing federal disability rights laws, people with disabilities experience inequity both on- and offline. And websites and apps inaccessible to this group are a ubiquitous problem that extends to health care. New regulations could help address this issue by

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articulating specific digital accessibility standards for developers. Yet even if they fall short, clinicians and developers have ethical obligations to facilitate access and inclusion. These responsibilities support ensuring accessible EHRs. However, professional organizations for both clinicians and developers should consider further action to enable people with disabilities to more equitably reap the benefits of health technology innovations.

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