VIEWPOINT

Digital Health Equity as a Necessity in the 21st Century Cures Act Era

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The release of final rules from the Office of the National Coordinator for Health Information Technology's (ONC) Cures Act in March 2020 places a new focus on patients' access to their health data.[1] The ONC rules make "health data more computable and [give] patients more control of their medical record."[1] Hopefully, patients will be able to interact more easily with their data through patient portals and mobile health apps, and "shop for care by comparing costs, understanding possible treatments, and expected health outcomes."[1] The new rules intend to increase the pace of innovation and investment in patient-facing tools. Building on more than 300 000 health apps and $7.4 billion in digital health investments in 2019 alone, this policy environment may significantly transform the ways patients access care.[2]

In light of the current coronavirus disease 2019 (COVID-19) pandemic, and the success in Taiwan and Singapore in using health information to identify, trace, track, and quarantine individuals, a more user-friendly system has become even more important.[3,4] However, improvements in patient self-management, care coordination, quality, and cost-effectiveness may be stymied by persisting digital divides. Given the recognition of the higher morbidity and mortality for underserved patients with COVID-19, including African Americans, understanding and eliminating these digital divides are critical.[5] Thus, the benefits of these innovations will require active efforts to ensure the needs of diverse groups are included in design and implementation strategies.

Two patient-facing tools, patient portals and mobile health apps, represent patients' primary digital touch points with the health care system, and the importance of these tools is expanded with the new rules. These modalities also serve as means to access telehealth services, collect data, and address population health, patient-reported outcomes, and social determinants of health. Patient portals are one of the earliest investments in telehealth technology, yet uptake has lagged among underserved populations, including patients of racial/ethnic minority groups, limited English proficiency, low socioeconomic status, older age, and low literacy.[6] For example, Anthony et al[6] found that patients on Medicaid or with less than a high school diploma were about twice as likely to be nonportal users. This is not only relevant for clinical care, but also for research as portals become trial recruitment tools.

Similarly, mobile apps have not been designed for underserved populations.[7] The ONC rules should prompt renewed efforts aimed at digital health equity. This will require guiding the commercial and regulatory landscape that currently influences the design and implementation of these technologies. In this Viewpoint, we highlight inequities in these digital health tools and

opportunities to apply an equity framework in the era of expanded patient access to data.

Technology Access

Broadband and device access is fundamental for patients to benefit from increased data access. However, an estimated 21 million people in the US lack broadband access.[8] This number is likely an underestimate because data on broadband access are inaccurate. This digital divide has primarily affected underserved patients, including rural populations. Federal programs, such as Lifeline, have been unsuccessful in addressing these gaps. As the health care system and industry focus on digital expansion, broadband access could become a social determinant of health, which will dictate patient care experience.

Beyond broadband, device access, whether via computer, tablet, or smartphone, is critical for patient engagement in a system that relies on mobile apps. Even though 81% of the US population owns a smartphone, there are gaps across literacy and socioeconomic status.[8] Notably, mobile-first populations, those who rely solely on their device for internet access, are largely from racial/ethnic minorities, which presents opportunities for patients who also tend to have worse health outcomes.

Digital Health Literacy

Closing digital divides necessitates not only technology access, but also supporting patients' use of these digital tools. Digital health literacy refers to the degree a patient can obtain, process, and understand digital services and information.[9] The combination of low health and digital literacy may limit a patient's ability to benefit from this expanded access. In digital health, one area of concern is security and privacy literacy. The new rules make it easier for patients using third-party apps to connect directly to their data. There may be apps that have not been vetted by health care institutions, thus putting patients at risk for security and privacy breaches. All patients are at risk, but lacking literacy represents another barrier to understanding already complex security safeguards and privacy policies.

In addition to requiring industry-standard security and privacy protocols, the ONC rules note that health care institutions could include a warning identifying an app as untrusted and giving patients the option to reject data access. Although this approach promotes patient involvement in their health care, it requires adequate literacy and educational supports, which are not currently in place.

Inclusive Design

These rules do not address the design barriers, such as complex user interfaces and data entry burden, present

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Table. Suggestions for Bringing Health Equity to Patient-Facing Digital Health Tools

Stakeholders	Suggestions
Govern-mental agencies	• Require future regulations and implementations of federal programs, such as Promoting Interoperability, to include metrics that assess not only overall use, but use of digital tools by underserved populations • Expand federal mandates guiding culturally appropriate care, like the CLAS standards, to be inclusive of technology-powered care • Enact policies that update broadband access data (ie, FCC broadband map) and increase broadband access (ie, Lifeline program, municipal broadband programs)
Vendors	• Develop linguistically and culturally tailored digital health tools to engage diverse populations • Collaborate with academic institutions to evaluate digital tools among underserved patients
Institutions	• Invest and implement in patient portals and mobile health apps that address the needs of underserved populations • Track digital health access and usage across sociodemographics, including race/ethnicity and language, to prevent worsening of digital divides • Focus on patient training in the deployment of new technologies to account for varied digital literacy levels, specifically as it relates to security and privacy • Develop workflows that allow clinical teams to engage with diverse patients across digital health platforms, such as telehealth
Clinical teams	• Offer access to digital tools to all patients, rather than based on presumed use of the technology • Encourage patients to use digital health tools as part of standard care
Patients	• Advocate for equitable implementation of digital health tools in their health care system

Abbreviations: CLAS, Culturally and Linguistically Appropriate Services; FCC, Federal Communications Commission.

in the current generation of portals and mobile apps. Increased data access offers the opportunity to engage underserved patients in novel ways, yet this goal is often not achieved. User-centered design is driven by an understanding and evaluation of users, tasks, context, and environment; however, this approach has been lacking in patient-facing technology.[10] Inaccessible design features, including a lack of focus on culture, literacy, and numeracy, limit the benefits of increased data access and worsen inequities. For example, a previous assessment of mobile apps found that a diverse group of patients with low health literacy could only complete half of data entry and retrieval tasks required to effectively use existing apps.[7] Patients cited frustration with design and navigation as one of the primary barriers. With these rules in place, inclusive design practices could help drive equity forward in digital health.

Suggestions for Promoting Health Equity in Digital Health Tools

To achieve the patient-centered goals promoted by the new ONC rules, several opportunities may be helpful to address well-known disparities in digital health tools. Creating a more equitable technology landscape in health care requires a multifaceted approach to policy and design (Table). First, federal, state, and local programs aimed at measuring and increasing broadband access should be expanded. Health care institutions can be involved by asking patients about their technology access as part of standard care. Second, the implementation of new digital health initiatives should include sociodemographic and literacy metrics. Third, the design of mobile app and patient portal interfaces should directly involve diverse patient populations and be inclusive of cultural, literacy, and linguistic needs. Fourth, federal equity mandates, such as the Culturally and Linguistically Appropriate Services standards, should be revised to provide guidance on how equity applies to digital health.

The field is still early in the development of patient-facing digital health, but the new ONC rules, along with the shift to digital care prompted by the COVID-19 pandemic, marks a turning point that could bring about rapid change. This demands close attention and action to ensure underserved populations are not left behind. Through inclusive approaches, the promises of increasing patient access to data and enhancing health equity can be achieved.

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