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Designing for Techquity: Ensuring Open Notes Serve All Patients

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> The movement toward transparency is like a new medicine: It's designed to help the vast majority of people. (Tom Delbanco, MD, co-founder, OpenNotes, Beth Israel Deaconess Medical Center[1])

When Tom Delbanco and Jan Walker launched the first multisite OpenNotes trial in 2010, they anticipated the profound benefits that would come from patients reading their own clinical notes. For a decade prior, patients at Beth Israel Deaconess Medical Center had been able to view portions of their medical record and add comments through a homegrown electronic health record, PatientSite.[2,3] The results of that study, published in *Annals of Internal Medicine*, confirmed that patients valued this access, reported improved trust and engagement, and that clinicians saw little negative impact on workflow.[4] In the years since, more than 200 peer-reviewed publications have documented the benefits of note sharing across care settings and patients groups and have shown that it benefits all patients, not just the digitally savvy or worried-well. Patients who were older, or from traditionally underserved populations, or with cancer or chronic illness consistently report that reading their clinicians' notes helps them remember care plans, understand treatment rationales, and feel more in control of their health.[5-10]

The Twenty-First Century Cures Act, implemented in 2021, extended these benefits to all US patients by mandating that clinical notes be made immediately and electronically available on request.[11] For oncology patients, who face life-altering diagnoses, complex treatment regimens, and the need for coordinated care, open notes have particular potential to strengthen trust, support decision making, and improve outcomes. But as with any new medicine, transparency carries the risk of uneven distribution. Without careful attention, digital health innovations can deepen existing inequities in care rather than diminish them.

In the article that accompanies this editorial, Chimonas and colleagues examine disparities in open note access among nearly 125,000 patients at a high-volume cancer center.[12] Of the more than 800,000 notes made available over the course of a year, just under half were opened by patients or their proxies, with modest differences in access emerging by age, sex, and marital status. But striking disparities were observed by race, ethnicity, and language. Compared with White patients, Black patients were 37% less likely and Hispanic patients 15% less likely to open a single note. Patients who preferred a language other than English were 22% less likely to read any notes, and when they did, they opened significantly fewer than their English-preferring counterparts. These findings align with a long line of studies demonstrating that the digital divide persists across various platforms, populations, and diseases.

Patient portals now underpin key aspects of care, making the disparities identified by Chimonas et al a matter of deep concern for oncology. Portals deliver test results, support communication between patients and clinicians, and are increasingly integrated into clinical workflows. A recent review of more than 80 studies conducted between 2018 and 2024 found that the use of portals among patients with cancer grew substantially, likely accelerated by the COVID-19 pandemic and the Information Blocking Rule.[13] Similar to the study by Chimonas et al, the review highlighted persistent inequities in portal use. Across all cancer types, patients identifying as non-White or with limited English proficiency were significantly less likely to use portals. These gaps are not artifacts of technology adoption curves, rather they are indicators of structural inequities.

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Although gaps in portal use continue, previous work has shown that patients from underrepresented populations often report some of the strongest benefits from open notes.[14,15] Patients with lower health literacy, those with limited English proficiency, and those who are less well educated frequently describe notes as important tools for understanding their care and preparing questions for clinicians. That paradox of greater benefit but lower access underscores the urgency of addressing the disparities highlighted in this study.

Why do these inequities persist? Several mechanisms likely contribute. Language barriers are clear: Most portals in the United States are in English, with limited translation functionality. Health literacy barriers can play a role, and access to technology and portal usability remain uneven. Clinician behavior is also critical. Evidence suggests that when clinicians offer access to patient portals and actively encourage their use, adoption improves. If encouragement is not offered equitably across patient populations, disparities can widen.[16-18]

Achieving techquity requires intentionally designed solutions; it will not naturally emerge. Several strategies show promise. Autoenrollment into portals, rather than opt-in systems, has increased activation rates across diverse populations, including Latino, Black, Asian, and non–English-speaking patients.[19] Translation services, embedded into portal platforms or offered in other ways, can reduce language barriers.[20-22] An inclusive portal design optimized for mobile devices benefits patients with limited access to desktop computers or broadband internet. Shared access for care partners can support patients who rely on the help of friends or family members when navigating complex care, yet it is underused and poorly understood.[23-25]

Clinicians also play a central role. Training and scripts that normalize patient engagement with notes can help providers introduce portals as a standard part of care. When patients sense that clinicians support their use of notes, they are more likely to engage.[26]

Emerging artificial intelligence (AI) tools, such as large language models, may offer new ways for patients to engage with their clinical notes. Although most early evidence on the use of AI in health care has focused on clinicians,[27-29] nascent patient-focused work suggests that AI can help translate clinical notes into plain language explanations tailored to a patient's reading level or preferred language.[29] Although concerns about bias and accuracy must be addressed, these tools could expand the utility of notes for populations who stand to benefit most. Much like how the Dr. Google era empowered patients to seek information beyond the clinic, the era of AI may provide patients with new ways to understand and act on the information contained in their own medical records.

For oncology, the implications are profound. Cancer care often spans years, involves multidisciplinary teams, and requires patients to absorb and act on complex information under conditions of high stress. Equitable access to clinical notes can help ensure that all patients, not just the digitally privileged, can follow their care plans, engage in shared decision making, and build trust with their care teams. Without it, disparities in portal use risk exacerbating disparities in care outcomes.

The work by Chimonas et al offers both a warning and a call to action. Transparency is now the law. But transparency without equity is incomplete. Oncology leaders must commit to embedding equity into every stage of the digital transformation process. That means tracking portal and note use across demographic groups, identifying gaps, and investing in interventions that close them. It means advocating for vendors to build inclusive features and holding health systems accountable for implementation strategies that reach all patients. And it means recognizing that information is more than just a clinical resource, and it can be a determinant of health.

Delbanco's observation that transparency is like a new medicine remains true. But like any medicine, its benefits will depend on how it is prescribed, distributed, and supported. If we fail to address inequities in access, open notes may deepen inequities in oncology care. If we act intentionally, transparency can be a powerful force for techquity: ensuring that every patient has the opportunity to engage fully in their care.

The question before us is not whether transparency helps patients—it does. The question is whether we will ensure that it helps *all* patients.

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