June 10, 2024

“Advancing Health Equity by Design (HEBD) and Health Information Technology: Proposed Approach, Invitation for Public Input, and Call to Action” is a proposal by the Office of the National Coordinator for Health Information Technology (ONC) to address health disparities. The goal is to ensure that technology is designed and implemented in a way that anticipates, avoids, and reduces health disparities, rather than exacerbating them. This includes designing for the diversity of uses and users and promoting health equity through the lifecycle of technologies.

American Psychiatric Association (APA) provided the below responses to ONC’s request for feedback:

1. Do you think this draft identifies the core issues and heads in the right direction? Are there changes you recommend based upon your own experiences with health inequities and health equity by design?

The human element in any system is going to be challenging. In public health, there is a concept of intentionally designing systems so that the best/healthiest option is also the easiest option. This minimizes the friction of adoption and makes the best choice “mindless.” In this case, if HEBD produces systems or workflows that are more onerous than existing ones, it will result in delaying or resistance to adopting these principles.

2. What ways do you design and integrate health equity in health information technology, exchange, and use, across your work in health care and delivery? What are the exemplars and lessons you would share with ONC in your comments?

Gather SDOH data from patients and incorporate that into clinical decision-making. However, medical workflows are already onerous for psychiatrists. Would this be adding on even greater work requirements?

3. What are your immediate priorities for health equity by design, and your long-term priorities?

- Rural communities and providers who lack resources.
- Unequal access to broadband and affordable connectivity
- Patient education and know-how on using health technology, wearables, etc.
- Inclusion of patients with Serious Mental Illness (SMIs)
Immediate priorities for HEBD should not be clinician-focused, but rather, patient-focused. How can HEBD be used to empower my patients to improve their lives? They often don't want to see the big picture - they want to focus on their immediate needs and priorities. Can we design systems that allow them to leverage data to meet their goals? For example, could HEBD, through AI, help my patients write compelling letters to social services that advocate effectively for housing accommodations based on their unique SDOH and health needs?

4. What are the leading barriers to health equity and health equity by design that you experience in your efforts? How do you think ONC can help?

Lack of data
Not enough data based on occasional pilot programs or innovative ideas (without implementation testing), and they are doing so before the basic foundations are in place. Easily accessible and actionable data that fits seamlessly into workflow is a major barrier. Another barrier is that our EMR systems are used by clinicians from multiple different specialties. Can an effective HEBD solution for psychiatry be equally useful for pulmonology?

Digital divide
There are sizeable gaps in certified health IT access among psychiatrists and even larger gaps among other mental health professionals. The ability to exchange information, even with outpatient services designed to support individuals with mental illness (e.g., community-based housing for the mentally ill, partial hospital programs, case management programs), continues to rely primarily on printing needed information and sending it by fax. In terms of mobile phones, 15% do not have access, others may have shared access (complicating privacy concerns), and of those with access, they may have flip phones, limited cell coverage areas, limited access to ancillary WiFi, and limited data plans. All these factors would lead to substantial decrements in the number of individuals with their own access to the kind of features that are envisioned (e.g., real time language support).

- Americans aged 65 and older (18 percent of the population) are most likely to have a chronic disease, but almost half (40 to 45 percent) do not own a smartphone or have broadband Internet access.
- People experiencing poverty report lower rates of smartphone ownership (71 percent), broadband Internet access (59 percent), and digital literacy (53 percent) compared to the general population.
- People who are Black or Hispanic report having lower computer ownership (Black: 58 percent; Hispanic: 57 percent) or home broadband Internet access (Black: 66 percent; Hispanic: 61 percent) than White respondents (82 and 79 percent, respectively), although smartphone access is nearly equal (Black: 80 percent; Hispanic: 79 percent; White: 82 percent).
**Lack of interoperability**
The exchange and attainment of health information external to one’s own health system is still lacking. Some reasons are because of information blocking, but also due to interoperability being cumbersome, costly to health systems, and adds burden to clinicians that is greater than the added value to clinicians/patients in most circumstances. Things like ability to close the referral loop, communicating with all other members of the health care delivery system, prior authorizations are still a challenge much less considering social service and community-based organizations, etc.

The report discusses "providers", and note "(clinical, behavioral, etc.)", however, the fact that "behavioral" is being split off from "clinical" in this policy document is, at its face, problematic and perpetuates the non-equitable "carve-out" system that we know has undermined parity for decades.

**Administrative burden and lack of resources**
As with treatment related referrals, a large part of the problems that are encountered are:
1. lack of service availability (either in general, at reasonable cost, and/or in geographic proximity to the individual) and
2. restrictive and onerous intake criteria

Having an electronic connection from a hospital EHR to the local shelter system is not going to matter if the individual is rejected if they arrive after a certain cutoff time. Similarly, an electronic connection won't matter if social security disability requires multiple layers of onerous paperwork and review, which are challenging for disabled individuals to complete. The same is true for the vast majority of services that we refer to. The reason that elaborate systems of case management and intensive case management are needed (as well as high ratios of hospital social workers/nursing care managers to beds) are related to the challenges of navigating the available resources, NOT the lack of electronic connectivity or EHR exchange.

**Privacy concerns**
There has been debate about informational privacy in terms of health information exchange. The opportunities for patient control of their information in a granular way are long since passed. The inclusion of a much broader range of organizations including government run programs (depending on state law) and faith-based organizations (depending on the faith related health/social beliefs) leads to even more privacy challenges, especially for reproductive health, Sexual Orientation and Gender Identity, and genomic data. We have now, unfortunately, seen that health-related information can quickly be leveraged against individuals through judicial decisions, legislative changes, etc. Protections that we wouldn't have thought necessary a decade ago no longer exist. If we can't count on information being protected within health care, how do we think it can be protected in social and community services now, in a year, or 10 years?

API/app "innovation", as we've seen, is often aimed at data mining, and selling and the innovative benefits for patients have been, in general, less prominent than for start-ups and investors, while leading to significant questions about algorithmic bias, insertion of other biases, and privacy leaks. The increasing number of debilitating cyberattacks on the health system will only be facilitated if larger numbers of APIs,
apps, and interfaces (e.g., to multiple agencies with variable cybersecurity practices) are deployed. The HTI-1 algorithmic transparency rule is positive but does not address the totality of possible pitfalls and most users are not sophisticated enough to interpret the information about the algorithm and bias.

5. What additional activities, if any, do you think ONC should undertake to implement Health Equity by Design fully and effectively?

Consider how HEBD training will be provided for clinicians and patients. Training people to use the system being designed should be part of the design of the system.

6. Are there any activities described above that you think are having unintended, adverse effects on health equity by design?

Can smaller practitioners bear the cost of HEBD? Can larger organizations be agile enough for it? Will the burden of implementing HEBD principles be on the organization or the EMR companies such as EPIC?

References