

As an individual, board-certified patient advocate, the primary carepartner to two disabled adults, and a patient myself, I appreciate the opportunity to provide comments on the CMS RFI on Health Technology Ecosystems.

As a patient advocate for over 25 years, each day I work with patients and their families as they navigate life-altering, life-limiting diagnoses, such as cancer, while navigating our complex healthcare system. Each day, I connect patients and their loved ones to the information, tools, and technology they need to make informed decisions about their care.

Most of my work is concentrated in helping patients gain access to and understand the power of their health information and how to utilize that power to navigate barriers, inequities in access to care, and fragmentation in coordination of care.

Over the years, I've had the privilege to serve as a member of the HITAC United States Core Data for Interoperability (USCDI) Task Force, the Interoperability Standards Workgroup, as an invited subject matter expert to the HTI-1 HITAC Proposed Rule Task Force, and a contributor to various ONC efforts. I've had the opportunity to amplify the patient and carepartner perspective in collaborations with like of the American Medical Association (AMA), the American Information Management Association (AHIMA), SHIFT, HIMSS Public Policy Committee, the Sequoia Project Consumer Voices Project, HLTH Foundation Techquity Coalition, HL7 Patient Empowerment Workgroup, the Society for Participatory Medicine, Digital Medicine Society (DiMe), and served as a CancerX Fellow. I'm grateful for the opportunity to provide comments from the intersection of these experiences and my daily patient advocacy work.

As we dream big about finishing interoperability and building a healthcare ecosystem of the future, may we ground ourselves in the quote from Hubert H. Humphrey that greets all who enter the halls of the Health and Human Services building *"The moral test of a government is how that government treats those who are in the dawn of life- the children; the twilight of life- the elderly; and the shadows of life- the sick, the needy, and the handicapped."*

PC-1. What health management or care navigation apps would help you understand and manage your (or your loved ones) health needs, as well as the actions you should take?

a. What are the top things you would like to be able to do for you or your loved ones' health that can be enabled by digital health products?

Relieving extreme patient administrative burden, minimizing cognitive burden and decision paralysis, and reducing human suffering are top priorities that digital health products can directly address. There is extensive research demonstrating significant rates of physician burnout. Patients, their carepartners, caregivers, and families also suffer from extreme burnout. Patient administrative burden is a silent public health crisis that significantly impacts those living with a life-altering, life-limiting diagnosis or multiple comorbidities as well as those living with social drivers of health.