My Public Comment on ONC Health IT Strategic Plan:

As an individual who sought health care as a cognitive communicative impaired patient and suffered harm from the negligence of her health system as a result, I have grave concerns for this movement towards integrating IT and removing opportunities for patients to communicate with our care professionals. Knowing how our capitalist health system is run as a business that stresses efficiency and cost cutting, one can easily see the motivation for health administrators to cut down on the time our most costly professionals (our doctors' and specialists') spend on care delivery and to streamline the efficiency of their interactions with us, their patients- to the detriment of patient safety. This is a predictable pathway leading towards decreasing the quality of care delivered to patients, especially those who most urgently and frequently need communication with our care professionals: patients with complex and chronic health conditions and patients with diverse communication abilities.

It is well known that the health system currently fails the patient populations who have difficulty understanding and using spoken and written English language, who suffer cognitive communication impairments due to their medical and mental condition, whose cognitive condition can be described on the neurodivergent spectrum, and patients with non-mainstream, "other" communication and learning abilities. If we examine evidence of how these patients populations fared during the COVID pandemic, we see these system-wide deficiencies were made even more apparent than they were before. It is therefore, even more disturbing, in the light of these failures, that our health administrators now want to limit/ impinge upon/ remove what little opportunities patients currently have to interact with their care professionals and replace these people-to-people interactions with automation/ IT.

We all know how difficult it is to communicate with companies online and over the phone when we are greeted by a bot replying to our inquiries when asking for help to resolve a specific issue. Our first instinct is to ask to speak with a real person. This is what will happen when you introduce more IT into our health care experience and ignore this human need; our administrators of the system will undoubtably fail to prepare for this trend by not hiring enough IT support staff and medical/ mental health staff to address and meet these needs. Patients who are struggling with their health condition and are generally overwhelmed with life stresses will resent, ignore and delete nagging reminders of appointments, shut off their notifications and resume to focus instead on our lives managing our health day-to-day. This is what we are doing already with the pesky "pings" from overly numerous confirmation notifications for dental and optometry appointments.

From the ever-increasing commercialization of our basic health needs, we see how our health system views the future through a business model lens: corporations are flooding us with unwanted health messages, institution newsletters and commercial advertisements.   We can see development of a cleared path towards third parties obtaining our private medical and mental health information to target us with ads from malpractice lawyers (this happened to me after repeat surgery involving a titanium mesh plate implant, was told they gained access to me through its product number). This is a violation of our patient rights to privacy and not to be financially exploited.

It would be more meaningful to patients like myself who have difficulty with IT interactions, if our health system were to actually address and meet our specific patient needs. Again, our system currently fails to provide us care that satisfies the checklists of A Roadmap for Hospitals: Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care. (1) The failure of this fundamental step in the care delivery process means that the above-mentioned patient populations in the system are receiving less than quality patient care: care that is not adequate, timely, effective,

coordinated, individualized, comprehensive and meets their whole person needs. Because we lack or have difficulty with accessing information to participate in our own health care which is essential for obtaining quality patient care. This system-wide failure stems not only from a shortage of our care professionals, such as social workers, case managers, nurses and translators, from a drive to shorten face-to-face time spent with our care professionals, but is functionally amplified by a structural-cultural attitude that patients with communication needs are not worth the dollars spent on staffing to ensure our needs are met. We know this is not true: that each and every patient deserves the right to be empowered and informed and to participate in their care to the greatest extent.

By further taking the human interaction out of patient care, and replacing those opportunities to exchange communication, with IT/ bot-mediated interactions, the following patient safety issues are created:

- Confusion and frustration of the IT user
- Mis-direction of the IT user to unwanted information, waste of time (especially in cases where urgency is imperative) and phone battery
- Crashing of computer or phone, software update requirements when our (older) technology becomes obsolete
- Learning to navigate new programs proves difficult for some patients, some patients do not even use the phone or computer -are not IT-savvy, require additional education just to "make it work"
- Patients with visual impairments are often excluded or experience difficulties with communicating through devices
- Patients who do not use English language are often excluded and experience difficulties
- Patients who require communication assistance are often excluded and experience difficulties
- Patients who do not have access to technology or limited internet coverage due to rural location, economic situation, etc. are often excluded and experience difficulties
- Use of IT as a replacement of our interactions with care professionals- limits opportunities which are essential for communicating patient needs to obtain quality patient care.
- IT can be detrimentally used to filter out patient inquiries which may be urgent or critical (as we are currently hearing complaints from our care professionals about having to answer them)
- IT will not be able to handle the diverse nature of our patient communications with our care professionals and thus create a barrier to addressing and meeting our needs.

Sadly, as we see with the trends of our capitalist health administrators who do not realize the capacity of our federal purse and that our federal government can fund any program it chooses to (2), I foresee this program will be implemented as an underfunded service that creates an additional barrier to patients seeking care who require additional IT-access and usage support. I foresee it will increase the disparity of health equity where the majority of privileged, IT-learned patients will use without a hitch while a minority of us patients struggle with navigation and use of this IT and consequently struggle to use our health system.

References:
1) A Roadmap for Hospitals: Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care. (2010) The Joint Commission.

2) Alan Greenspan: "There is nothing to prevent the federal government from creating as much money as it wants..." https://www.youtube.com/watch?v=DNCZHAQnfGU