

Re: Public Comment on Draft Federal Health IT Strategic Plan

Dear Dr. Tripathi,

I applaud the ONC for the attention prominently paid in the draft Strategic Plan to the issues that matter most to patients: 1) Reducing preventable harm in healthcare, 2) Identifying and mitigating bias that can lead to unfair discrimination and disparity in treatment outcomes, 3) Safeguarding patient privacy and the right of patients to know and consent to how our personal health information will be used, and 4) Improving the accuracy, timeliness and effective communication of diagnoses.

While I appreciate the opportunity to provide Public Comment on the draft Strategic Plan, I urge the ONC to do more, strategically, to engage patients and families with lived experience as users of healthcare and, increasingly, users of health IT in the further development and implementation of Strategic Plan.

It is critical that the Federal Health IT Strategic Plan ensure that health IT is deployed in a manner that treats individuals as information subjects, not information objects. The most effective and authentic way to accomplish this mission is to robustly engage patients and families in the implementation of the Strategic Plan and its oversight, in addition to its development.

Despite important progress such as the 21st Century Cures Act and its attendant medical record access and information blocking rules, health IT today is too often a one-way conduit where providers give information and instructions to patients, but only accept back information that they want to receive. Patients are eager to report errors in our health records as well as experiences and outcomes that can contribute to improved care. Patient-reported experience and outcomes measures need to become routinely incorporated into clinical care. More broadly, I urge ONC to recognize in its Strategic Plan that patients are now proactively able to access reliable, personalized medical information outside the information constraints that the current generation of clinicians takes for granted, and learn from our experiences.

Goal 1 (Promote Health and Wellness): I support all of the objectives under Goal 1.

I'm also supportive of increasing the privacy and security of EHI, especially around consumer health applications. Consumers/patients need to be provided with accurate and fully transparent information about how their information will be used, and if their data will be sold. Patients have the right to know how their health data, even if de-identified, will be used, especially if it is monetized. We encourage further work in this area, policies and procedures for obtaining informed consent to EHI use lags, and patients currently have no remedies under HIPPA to object to the sharing or sale of their health data.

Under Objective B, I support the plan to build on the collection of evidence needed to improve the use of EHI and promote equitable access to health IT literacy resources.

Goal 2 (Enhance the Delivery and Experience of Care): I support all of the objectives under Goal 2 of the Strategic Plan. I suggest noting under Objective A that increasing transparency and understanding of health data that goes into algorithm-based decision support tools is very important to ensuring the confidence of patients, the general public, and health policymakers, not just providers.

Goal 3 (Accelerate Research and Innovation): I support all objectives under Goal 3, with the essential caveat that diverse patients, family members, and patient advocates are included as key stakeholders in all discussions regarding the use of healthcare data to accelerate research and innovation. Understanding what matters to patients is particularly important when setting research priorities given the inevitable finite budgets that will be allocated to research and innovation in the health IT space. Similarly, it is important that patients are not limited in accessing their own data that is being used for research and innovation. If their data is available to researchers and other health IT users, it should also be available to patients to support their own healthcare decision-making.

There is a concern that patient data will be used to drive improvements in healthcare economic efficiency, with little benefit to the patients themselves. For example, the cost of care for patients should decrease if patient data is used to train an AI tool that replaces the need for a certain role that is important to patients in their care journey. Again, ensuring patients and family members are involved as key stakeholders in decision-making about research priorities and how healthcare data will be used is essential to mitigate these concerns.

Goal 4 (Connect the Health System with Health Data: I support all objectives under Goal 4. Regarding Object A, which addresses the continued advancement of health IT capabilities, I urge ONC to recognize the value of patient-reported experiences and outcomes to actually improving the safety and quality of healthcare as well as identifying bias. I strongly support the strategies outlined in Objective C to improve access to health IT by underserved communities and populations.

Today, there are systems that allow physicians to query real-world evidence databases with an individual patient's clinical information and be advised about the probable best course of treatment. Those databases are developed and maintained by for-profit entities, providers, and provider organizations using them have a financial interest in patients relying on their providers for treatment, and patients are regularly having their information sold to third parties without their knowledge or consent. Only the power of the federal government will ensure that patient rights are protected as this field continues to rapidly grow. The ONC Strategic Plan has the potential power to shape the field, by optimizing opportunities for advancing IT use while establishing parameters that prevent misuse.

Thank you for the opportunity to share my views.

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