Thank you for the opportunity to provide comments on the Interoperability Roadmap. In theory, I applaud this interoperability roadmap. But sadly, I do not think this roadmap is feasible for the following reasons:

1) There is little to no incentive for the multitude of EMR/EHR vendors to have their systems “talk to each other.” Frankly, I don’t see Cerner or Epic (or take your pick since there are tons out there!) wanting to have their systems be compatible. For example, at the Mayo Clinic they are replacing their existing EMR system at some of their locations to match the systems at other locations so all locations can work together. This means re-training for employees and learning a new system for patients when the existing one is replaced. What a waste of time and money! But definitely a financial gain for the vendors. And as I write this, I would consider the HIE vendors as part of this too. New York used to have 12 HIEs but last I knew they were down to six in a consolidation effort (which makes sense!).

2) There is such an emphasis on lowering healthcare costs and again in theory yes let’s do it! Pharmaceutical prices, brand names and generics, are going up and they vary in cost widely from state to state and within state and across companies. Walgreen’s was going to charge me over $600 for a 30-day generic, whereas Costco charged $199 for the exact same 30-day generic supply. What a huge difference. Furthermore, since that drug was not FDA approved for my specific illness, my insurance company would not cover the cost. This is yet another issue of the lack of transparency and the reality that lowering costs is not about the patient.

3) Besides the vendors and pharmacies raking in the dollars, there is the health insurance companies. Premiums are more costly, which is ironic since the deductibles are higher. I keep paying more for no change in service. So I am confused as to what cost of lowering healthcare is – I get that proactive screening and other wellness programs are out there as a mechanism for increasing awareness and lowering ER visits. But that to me is not the only driver for lowering the cost of care and not the reality of the average patient. And there appear to be a lot more levels of approval for certain services and drugs now – again adding to time, paper, and expense of resources (in direct opposition to lowering costs).

4) In clear absentia from the stakeholder list in my opinion is the aspect of disability (other than SSA in the use cases). There is so much to say on this I don’t know where to start. For those who are sick and unlucky enough to go through the private and/or public disability process this too should be a consideration in data elements and stakeholders. While admittedly I have little respect for the federal ERISA law given my experience and that in itself needs an overhaul, I nonetheless think while governance is being discussed, why not have this stakeholder at the table.

5) Time of doctors and their staff. They are being inundated and I just don’t see this as realistic unless there are incentives! I am already displeased with doctors who limit their appointment time now to 15 minutes. And those doctors who now focus on a computer screen instead of me the patient. This is concerning since we are striving to improve the quality of care.

6) Data sets. I haven’t spent much time thinking through the reality of this but years ago I went through JIEM training – perhaps the success in the justice system of setting up common nomenclature can be leveraged as y’all go work this process.

7) Use cases. It is a thorough list and I don’t think limiting it to three would helpful. I think this proves just how challenging this roadmap is and just how many different bodies and systems exist. The best I can offer is to suggest categorizing at a high level and then if time permits test more detailed scenarios.

8) Engaging patients. In theory again, great but in reality even for those patients who want to be engaged it is a challenge. I have a chronic illness and have spent way too much time the past year in various doctors’ offices. At one provider I didn’t have access to my portal for over six months (and the vendor wasn’t penalized for this and about 30-40% of the practice’s patients could not access like me). I have different logins for all the portals – which is confusing to me, especially when I am having a bad health day when my chronic conditions flare, and I am relatively young. Undoubtedly this must be confusing for caretakers too! Some portals are robust and others are not. None of these portals are in an HIE so I don’t have access to my pharmacy records. It is so disparate and frustrating. Health education shouldn’t start at employment, it should start in school and become part of the curriculum if we truly want to be a patient centered system. Another idea would to be fund foundations to also support engaging patients (and/or their caregivers) and helping them navigate as needed.

I love the concept of interoperability but just don’t see this roadmap being able to overcome the education, training, and incentivizing working together to achieve the three goals set forth by ONC.

Sincerely,

A concerned patient (& former healthcare consultant)

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