Responses from Dave deBronkart, dave@epatientdave.com, Nashua NH, 603-459-5119

ENFORCE.

My overall message to HHS is that this entire exercise will be a waste of breath and energy unless you ENFORCE regulations. Hospitals have strong commercial incentives not to make it easy for patients to take their business elsewhere, so it's no surprise that hospitals do not commonly make it easy to download your case information and go elsewhere. (By far the greatest attention I've ever had on LinkedIn was when I did exactly that - downloaded my data and took my business elsewhere. https://www.linkedin.com/posts/epatientdave_patientautonomy-medicalrecords-patientcentric-activity-7026611151106908160-eaXr/)

Below are my comment on specific items in the RFI. As you'll see, I often find myself tightly aligned with the views of Josh Mandel MD, and I have in several places linked to his comments.

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?

BACKGROUND CONTEXT: We need unlimited and complete access to all our data, across ALL providers and devices. Without that, no apps can possibly produce their full potential value. Lack of all data will limit the business potential and consumer benefit of any innovator's product, and will especially hamper what any AI (generative or predictive) could contribute.

APPS / TOOLS: By far the most important thing we lack now is an integrated, all-provider picture of our STATUS, our DATA, and our PLANS. It means every single provider is limited to only a partial view of the info that might affect his/her clinical judgement. This lack also makes it extremely laborious for the family to stay on top of things.

If HHS wants to reduce our NEED for care, and reduce INEFFICIENCY caused by missing information, it will be widely beneficial to to mandate (and ENFORCE) that all of a patient's data must be truly available to anyone with a legitimate use for it - ESPECIALLY the family.

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

Constantly monitor status, when there's a problem underway, and be alerted when action is needed. That's a universal principle.

As an active user of generative AI myself, I VERY much want my LLM to have access to my comprehensive medical record when I authorize it.

b. If you had a personal assistant to support your health needs, what are the top things you would ask them to help with? In your response, please consider tasks that could be supported or facilitated by software solutions in the future.

Aside from answering any questions I had, I'd want it to handle conversing with LLMs at my providers and at CMS, coordinate care across providers, keep track of all appointments and

prescriptions across providers, etc. In short, take care of the administrative burden, so I can pay attention to my health.

PC-2. Do you have easy access to your own and all your loved ones' health information in one location (for example, in a single patient portal or another software system)?

The short answer is no, of course not. There's not a soul in America who does, as far as I know.

Beyond that, I refer you to the excellent response to PC-2 from Josh Mandel MD. https://joshuamandel.com/cms-rfi-collab/?singlePane=true#principle_patient_primacy

PC-3. Are you aware of health management, care navigation, or personal health record apps that would be useful to Medicare beneficiaries and their caregivers?

There are many, but only a small fraction of what will be possible when actual interoperability is realized and generative AI can do meaningful things with far more complete data.

PC-4. What features are missing from apps you use or that you are aware of today?

a. What apps should exist but do not yet? Why do you believe they do not exist yet?

As HHS CTO Todd Park said years ago, "To innovators, data is fuel!" Without fuel, the best rocket engine gets nowhere.

b. What set of workflows do you believe CMS is uniquely positioned to offer?

I don't see why CMS should provide any workflows. I certainly don't want the government to be a sole gateway for all our health data; I want it to enforce regulations on the behavior of providers who currently have no motivation to liberate our records. Hire cops - potentially former ICE agents - to go out and respond when patients report that they can't get their data.

PC-5. What can CMS and its partners do to encourage patient and caregiver interest in these digital health products?

I fully endorse the excellent submission on PC-5 by Josh Mandel MD. He is 100% aligned with my own thinking.
https://joshuamandel.com/cms-rfi-collab/?singlePane=true#pc-5

PC-6. What features are most important to make digital health products accessible and easy to use for Medicare beneficiaries and caregivers, particularly those with limited prior experience using digital tools and services?

It's useful to provide a "knob," so to speak (a setting), for detail vs simplicity. Happily, today that's enormously easier than before, because LLMs are designed to "explain it to me like I'm 8" or "give me more detail on that" or whatever we ask for.

I'll wager that a few years from now everyone will have gotten the hang of tell the computer (or app or website) "I don't understand what you said," both in the sense of "That was too complicated" and in the sense of "Hang on there - what makes you say that? More info please."

PC-8. In your experience, what health data is readily available and valuable to patients or their caregivers or both?

Again I support Josh Mandel's response.
https://joshuamandel.com/cms-rfi-collab/?singlePane=true#pc-8

PC-10. How is the Trusted Exchange Framework and Common Agreement™ (TEFCA™) currently helping to advance patient access to health information in the real world?

Again I support Josh Mandel's response.
https://joshuamandel.com/cms-rfi-collab/?singlePane=true#pc-10

PC-13. PC-13. How can CMS encourage patients and caregivers to submit information blocking complaints to ASTP/ONC's Information Blocking Portal? What would be the impact? Would increasing reporting of complaints advance or negatively impact data exchange?

DO SOMETHING when a complaint is submitted. HIRE ENOUGH COPS and RESPOND to every complaint as if you actually cared about it. No previous administration has done this, and as in every part of life (from overdue library books to highway behavior and credit card fraud), perpetrators NOTICE what gets enforced and what doesn't. I know countless people (including myself) who long ago stopped wasting their breath filing HIPAA complaints or data correction requests.

The US hospital industry has shown repeatedly that it changes behavior when something materially affects a provider's bottom line, either in incentives or penalties. We must align government action with government's agenda, ie with making interop real.