

Secretary Robert F. Kennedy  
Department of Health and Human Services  
200 Independence Avenue, S.W.  
Washington, D.C. 2020

June 16, 2025

Dear Secretary Kennedy,

Thank you for the opportunity to provide input into reshaping the health technology ecosystem from a patient perspective. By way of background, I have more than 30 years of experience in healthcare information technology having led a national consulting practice advising provider and payor organizations in the adoption of technology to improve care and reduce costs; lead and advised startups and large corporations in digital health and technology services to support enhanced access to information and changing market/regulatory needs; and, since 2012, have been on Medicare due to disability from a Traumatic Brain Injury (TBI) trying to navigate my own recovery. A second TBI in 2018 caused me to find a new care team which resulted in significantly improved outcomes and a return to work. Brain injury was designated a chronic condition in 2024.

While there have been advances in technology, interoperability, and transparency to support health and care management, there are significant barriers that make it unbelievably challenging for people to manage their own care. Patients have little/no control over data quality and usage. There are many sources of information to understand and manage conditions, but little integration of this with the care process and not all information is valid. It is difficult to determine what interventions may result in health improvements and despite “no surprises” there are still frequent out of pocket unexpected expenses. The lack of timely access to providers and especially specialists means that patients often accept whatever support they can find regardless of qualifications. Digital health is extremely convenient and has significant potential to reduce patient time and effort in pursuing care but needs oversight. Patient feedback is rarely solicited in a meaningful way and when it is, it is not clear how that information will be used or whether it will affect change. On top of that, our most private information is regularly monetized for purposes that we are not aware of with little direct benefit to us.

CMS has potential to streamline and provide clarity to this situation.

Sincerely,

Name Withheld for Privacy

## 1. Patient Needs

### 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?

Imagine if you were trying to book a flight somewhere. You pay monthly for a service that allows you to book flights but still can't get a flight for six months. Nobody can tell you whether the airline is safe or not, on-time, or has qualified pilots. They don't guarantee that you'll get to your destination, what it might cost, how many stops you might make, or when you might arrive. That is what navigating the US healthcare system is like today.

#### 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?

We need trusted apps to address these issues:

- Medicare may provide a list of providers, but not outcomes by diagnosis or chief complaint. It isn't sufficient to know who the closest Neurologist is on my health plan that speaks my language and accepts new patients if they focus on adult autism, not TBI. There needs to be better data available to patients and caregivers to find the right provider or evaluate a digital health service based on specific conditions. For TBI, patients may see a variety of specialists and therapists for many related conditions (neuro ophthalmologist, speech therapist, physical therapist). Providers' abilities and competency related to TBI need to be understood otherwise encounters can be a significant waste of time for patients and payments for CMS.
- Finding a qualified provider is challenging and there are long wait times for initial appointments. Patients therefore have little/no say in who they see and need to simply accept that the provider assigned to them will be able to manage their condition. Virtual-first consults should be supported to assist patients in assessing and connecting with qualified providers, and digital health services should be supported in areas where there are shortages of qualified providers.
- Patients see providers in different medical groups or aligned with different health systems, but their information is siloed in systems specific to each provider organization, payor, and intermediary and not presented to them in a unified, meaningful way. While there are improvements in data exchange, this should be patient-directed with clear permissions, audit trails, and understanding of how/when data is being de-identified and marketed or sold for other purposes. Patients should control how/when data is being exchanged and used, and when a patient removes consent, the information should be deleted.
- When shopping for a health plan, the information provided about potential costs prior to signing up for the plan and actual costs experienced can be significantly different. There should be a system/product to monitor, and hold plans accountable that is easy for patients to navigate and get resolution. If there is a third party (e.g. mail order pharmacy) that can be leveraged, that information should be provided in advance and sign-up expedited so there are no gaps in accessing medications. For example, this data could be run on the prior years' claims to provide a projection of future costs. I experienced exorbitant unexpected initial pharmacy charges at the beginning of the year; this should not happen.
- It is very challenging to apply for SSDI. I was shocked to find that I couldn't just export my medical information and upload it. Given that I could only concentrate for 45 minutes, reviewing my personal health record (e.g. MyChart), writing down info, and then typing it into the form took all my cognitive capacity. It should be much easier for patients to analyze and export their own health information, especially to support access to necessary social services.

- EHR data is often incorrect, and there is no easy way for patients to correct this information. This is especially concerning when data are then de-identified and used for insights (garbage in/garbage out).
- Systems should provide a transcript of a provider encounter that a patient can refer to (preferably with active reminders) or forward to a caregiver. Many people must attend encounters with their loved ones just to hear what is being said so they can help provide support between visits. CMS should support Medicare patients and families using these types of services in settings with their providers, even if the provider has not vetted the system itself.
- Having a symptom tracker can be very helpful for a patient. Often, we show up for a visit and want to be helpful but cannot remember objectively what has been going on.
- As a TBI survivor, I recorded voice notes and short clip videos and created daily reminders for medications and therapeutic exercises. Even with all of this, I was not 100% compliant and sometimes forgot how I was supposed to do something. During Covid, a provider called me on the phone to check in and see how I was doing since visits were cancelled. This was a HUGE help as she was able to guide me quickly and provide some tips. There are lots of companies creating great apps for support between visits which should be encouraged. These, in combination with quick virtual visits (video and/or audio) are key to supporting recovery.
- Treatments are often offered in an encounter, but patients may not be given clear information on outcomes or cost.
  - Outcomes and cost data should be readily available to patients.
  - Patients have a wealth of information on what works and doesn't work, but the system does not support patient data input.
- There are medications that I have taken for years which are critical to my cognitive function, yet insurance may decide to require a prior authorization, there is no/little advance notification, and this results in either a huge out of pocket expense or several week gap while my provider completes forms and my pharmacist follows-up as well. This whole process should be streamlined so that prior authorization is not needed when there is medical benefit.
- When renewing or refilling prescriptions (especially example above), patients should be able to see where the medication is in the process (e.g. request received, provider contacted, payor denied/authorized, estimated cost, fill date). Often someone is waiting for information from another party and the patient needs to get involved to provide reminders.
- When travelling, refilling medications can be difficult/impossible due to variability in state law. Consistent prescription refill laws and processes across states are needed so that prescriptions can be obtained regardless of location.
- It is nearly impossible to talk to an actual person at a health system. While AI agents can be helpful, sometimes you need an individual. Technology should assist individuals in doing their jobs by automating routine tasks, prioritizing efforts, and offering insights, but should not replace human intervention and judgement

**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.**

- Provide positive feedback about my amazing care team so they get the credit they deserve.
- Schedule annual visits and health maintenance based on recommendations specific to my conditions and family history.
- Track symptoms and prepare for visits (questions to ask).

- Record and summarize visits so I can remind myself of what was said and share them with caregivers when needed.
- Ensure that follow-up visits are scheduled and calculate potential payments.
- Provide clear reminders for any pre-appointment instructions including ordering medication, equipment, etc.
- Advocate for virtual visits whenever possible so that I do not have to waste time traveling.
- Provide clear reminders for post-procedure follow-up (including ordering materials).
- Provide automated check-ins to help me assess whether I am getting better, having an adverse reaction, or can do something to improve my outcomes.
- Refill prescriptions, identify the cheapest/fastest way of obtaining medications, and project future costs.
- Anticipate and address any needs for prior authorization.
- Reminders for physical/speech/occupational therapy or other daily activities with videos and feedback.
- Evaluate whether my insurance plan is paying claims correctly on my behalf.
- Alert me when my data is being accessed or shared (by whom, when, for what purpose, what data fields).
- Alert me if I should be on a different health plan so that I am prepared for open enrollment.

**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)?**

No, unfortunately, although I am aware of and have been involved in large-scale employer efforts to develop this since the early 2000s. I have access to much of my info across multiple MyChart accounts, but other information is on different systems or completely inaccessible (e.g. images, vision prescriptions).

**a. If so, what are some examples of benefits it has provided?**

**b. If not, in what contexts or for what workflows would it be most valuable to use one portal or system to access all such health information?**

- Search: Find qualified providers on your health plan and a potential pre-diagnosis based on symptoms.
- Schedule: Find the first available appointment for a qualified provider (either virtual or face-to-face depending on patient preference), who has good outcomes, speaks the same language, and is within a reasonable distance.
- Calendar: Add the appointment to my calendar and calendar of caregiver (including directions and parking info) with notifications for any pre-work (papers to be completed, pre-authorizations, co-pays/co-insurance, tests, etc.). This is helpful in supporting elderly parents.
- Symptom Tracker and Visit Prep: Help organize thoughts and discussion points before the visit.
- Visit Documentation: Provide relevant information to the provider and staff and keep the remainder confidential.
- Summary: Provide a *clear summary* of what was discussed (patient and provider) and any follow-up recommendations and referrals.
- Be Healthy: Provide helpful and customized reminders and alerts (video, audio) to obtain/take medications, do interventions/therapies, daily activities, referral coordination.
- Control Cost: Anticipate/estimate costs and find/manage cheaper alternatives (e.g. medication refills, DME).
- Track: Monitor progress, outcomes and trends. Provide support or notify if attention is needed.
- Evidence and Learning: Provide new medical evidence and guidance that you might want to discuss with your provider.

- Pay: Ensure that bills are processed correctly. Provide on-line bill pay or payment plan if needed.
- Alert: Identify trends for individuals or across the family that might require intervention or escalation (e.g. genetic counseling or other support).
- Ask: Ask questions to provider or care team (or AI proxy) across health systems.
- Correct: Resolve data errors or provide updates.

Some other examples:

- Proactively analyzing potential expenditures prior to open enrollment to choose an appropriate plan for next year.
- Allowing providers from multiple organizations to collaborate on a unified single care plan.
- Providing a clear care plan for the patient and caregivers.
- Trending and reviewing cause/effect (e.g. medication > blood pressure).
- Providing feedback (e.g. interactions, efficacy, patient-reported outcomes).
- Clarifying life threatening allergies or providing critical information in case of emergency or incapacitation.
- Evaluating prior interventions and determining efficacy.

Information needs to be downloadable by patients for their own purposes (e.g. manipulation in Excel).

**c. Were there particular data types, such as x-rays or specific test results, that were unavailable? What are the obstacles to accessing your own or your loved ones' complete health information electronically and using it for managing health conditions or finding the best care (for example, limitations in functionality, user friendliness, or access to basic technology infrastructure)?**

- Most obstacles are because EHRs have been implemented by organizations to support their providers' specific workflows and organizational missions, and data exchange between systems does not produce a complete longitudinal medical history. For example, it may be possible to generate a referral online to a specialist affiliated with your primary care physician's network, but not to generate a referral to the best, most qualified, first available specialist within 10 miles of your home that is part of your health plan. EHRs were designed to be "sticky" or align a patient with a certain health system, not to allow them to pursue independent care.
- While portals focus on health system administrative tasks (copay collection, insurance collection, bill pay online) they do not simplify patient processes (still manual forms to complete).
- There can be a lack of understanding that patient time and knowledge are valuable. Patients have no control over information on their portal. For example, I receive different health maintenance reminder frequencies for mammograms from two different health systems (one annually, the other bi-annually).
- Radiology images are an obstacle because they are maintained in systems (PACS and VNAs) controlled largely by Radiology groups and not integrated with EHRs, except for reports. I always get electronic copies of all imaging due to some significant interpretation issues between the Neuroradiologist and my Neurologist. Diagnostic-quality images need to be easily accessible and reviewable between systems (not just radiology reports) and available for patients. Bottom line: everyone on the team (including the patient) needs access to the complete chart. Please encourage patient-viewable images with AI guidance for review and understanding by patients.
- It is frustrating but common to complete paper forms with requested background information such as relevant prior exams (from portal data) even though these exams were mostly performed at the same site and could have been pre-printed for patient verification.

- It is more frustrating to have radiology reports then indicate “no relevant priors” after going through the trouble of gathering info and providing it.
- Therapy notes (e.g. speech and physical) are largely unavailable online. This is challenging because they can be complex, exhausting visits with instructions that are difficult for patients and caregivers to remember. Having instructions online with video would be helpful.
- Other paper forms, such as self-assessments, are typically not found online so it is difficult for patients to track progress.
- While portals may have a section for a Care Plan, I have not found any information in this section. It would be helpful if patients had a clear understanding of their care plan they could share with family members.
- Sometimes there is too much information, but it isn’t meaningful. For example, in managing the care of my family there are lots of results to review but when the data doesn’t seem to be trending in the right direction, there is no advice about what to do, and getting someone to answer questions is challenging (may require multiple messages to different providers).
- Other times, overly restrictive access policies on information for minors inhibit parents from understanding and supporting their children’s care. For example, some portals do not allow results to be displayed at all for kids.
- Pharmacy data is a particular struggle. Often patients have complicated medication lists that are not well-reconciled between health systems, are redundant, and it’s difficult to find the right prescription to refill online because payors have different requirements. When there is a medical emergency or a new emerging or critical condition, it’s confusing to understand whether all medications should be continued, which medications are the priority, any timing considerations, and potential interactions to be aware of. Patients need some guidance on what to take, when, and can play a role in cleaning up the medication list so that it is effective.
- Dental information and coverage for dental and/or oral surgery under Medicare can be very confusing. This should be better integrated.
- Often there are forms that need to be submitted by patients for reimbursement (e.g. contact lenses). Automating these processes would be helpful.

Bottom line: it’s difficult to know if you are getting the maximum benefit from your plan because data are fragmented.

**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?**

I am aware of many that are under development. Too numerous to list. However, there are no comprehensive applications to support TBI recovery. There are applications or digital health services for headache/migraine, neuroplasticity, diagnosing cognitive decline, depression/anxiety, physical therapy, supplemental insurance that provides access to select TBI-specialists, and other point solutions. There is nothing coordinated and comprehensive.

**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?

CMS has a unique opportunity to encourage innovation while simplifying payment processes, enforcing consistent quality metrics, leveraging feedback from patients and making sure they have unfettered access and

control over their own information, and providing safeguards to protect people from the risks of emerging technologies.

Many startups are focusing on large cost containment/outcome opportunities (e.g. cancer, heart disease, blood pressure, diabetes). Health system innovation groups are developing health system-specific applications (e.g. digital front doors) but not truly from the patient's perspective. Larger EHR vendors are likely to develop their own solutions rather than integrating with emerging products. Meanwhile, tons of organizations are developing great products to address a myriad of problems. There will be lots of consolidation.

From the patient's perspective, being diagnosed with a new or chronic condition is overwhelming. People need to understand what the condition is, what it means, what the risks are, who is qualified to treat them, what interventions may be used, and what they can do between visits/encounters to improve their outcomes or monitor progress, and what it might cost. Despite the prevalence of EHRs and a variety of apps, very little of this information is available to patients. There are lots of emerging solutions which are typically specific to a single condition (or the same conditions such as diabetes and heart disease), may include virtual visits, and have varying levels of data security and transparency. There are a few entities that can provide outcomes data across health systems, but for the most part people are limited to the processes driven by their primary healthcare provider's health system and their insurance company, with very little choice or self-determination.

It is very challenging to find accurate, unbiased information to help navigate what the condition means, who is qualified to treat the condition and has good outcomes, what the options are, what treatment might cost, and what can be done between encounters/visits to optimize health. Currently, most of the health information is held in EHRs owned by health systems provided by a single vendor, and while there are standards for data exchange, very little information is available to patients, families, and caregivers. Medical innovation happens every day and it is very difficult to stay on top of all the opportunities and determine what might be relevant. As previously stated, information in the EHR may not be accurate and there is little opportunity for patient/caregivers to correct or provide feedback (and this imperfect information is then being used for AI-driven insights). Some health systems have turned to charging individuals for messaging which creates a barrier to a healthy exchange of information where patients might tell providers what is and isn't working. With increasing use of AI or chatbots it is nearly impossible to speak to an individual and have an issue resolved. Some of the need for AI is purely because health systems have become so large they do not understand their own processes and people and must navigate a myriad of payor conditions to be paid for services.

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

Ideally, people would have their own medical information at their disposal, be able to control with whom it is shared (and for what purpose) and have a potential roadmap of care and services with cost that is independent of specific health systems so they can make decisions on the best payor/plan, providers, and interventions to maintain or improve their health.

CMS can also offer more tailored resources based on patients' conditions. As a younger person with a qualifying condition, answering basic questionnaires is not a good use of my time.

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

a. **What role, if any, should CMS have in reviewing or approving digital health products on the basis of their efficacy, quality or impact or both on health outcomes (not approving in the sense of a coverage determination)? What criteria should be used if there is a review process? What technology solutions, policy changes, or program design changes can increase patient and caregiver adoption of digital health products (for example, enhancements to data access, reimbursement adjustments, or new beneficiary communications)?**

- Patients and caregivers are interested in digital health products. They look up information online because it is not being provided to them from a trusted partner or they cannot get access to providers in a timely fashion.
- As a patient, I am very reluctant to use a digital health product provided by my payor because my perception is that it is designed to reduce payor cost, not necessarily to improve my overall health, and because I do not trust or have transparency into how these applications are being monetized.
- A CMS “Consumer Reports” for digital health products from the patient perspective could be very beneficial. This might involve evaluating and comparing products based on:
  - Privacy/security
  - Clinical judgement
  - Proven vs. experimental
  - Applicable use cases
  - Cost
  - Transparency on other uses of information (e.g. remarketing of de-identified data)
  - Outcomes
  - Patient feedback
- There could be cases where using a digital health tool, in conjunction with provider guidance, might support lower premiums or higher reimbursement. For example, using a vetted remote patient monitoring (RPM) product to understand a newly diagnosed condition and maintain recommended interventions on schedule could result in reduced costs for the patient.
- The products need to be broader than the typical diabetes, heart disease, etc. and encompass a wider variety of conditions (e.g. patient-specific). Patients often have more than one chronic condition.

b. **What changes would enable timely access to high quality CMS and provider generated data on patients?**

- Providers are overburdened by managing the varying requirements of payors and plans to the point where it is inhibiting people from wanting to be physicians. CMS needs to play a role in simplifying requirements so that providers can focus on practicing medicine.
- CMS can encourage payor/provider/digital tool data exchange where payors and digital tools provide providers with integrated information they have on patients (enrollment, outcomes) to support effective patient care, not make determinations.
- CMS can encourage payors to listen to providers in care decisions.
- CMS can also reimburse digital health interventions by qualified providers (video or audio) at the same rate as face-to-face encounters. In my own experience, having only 45 minutes of focus time twice a day and having over 100 encounters in my first year after my 2<sup>nd</sup> TBI, more than 75% of my “cognitively available time” was spent pursuing my healthcare recovery. This included traveling to/from visits, having visits, taking medications, following therapy plans, renewing prescriptions, and following up on incorrectly processed payments. Much of this work was unnecessary, and many of these encounters could have been just as effective online. Reducing the burden on patients reduces cost and improves outcomes.



- CMS can provide information to patients on provider outcomes and plan costs.
- CMS can continue to rate plans based on outcomes, but it would also be helpful to encourage plans with broader provider networks. My payor decision was driven this year by the fact that my Neurologist is only covered by one plan (the one that owns his medical group). This consolidation is driving a lack of choice.

**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?**

- A core limiting factor in rural areas is broadband access, which implies that there is an ongoing need for audio-only visits.
- Products need to be easy to use with multi-factor identification.
- Several entities are creating guidelines around the use of AI. Similarly, CMS should employ aspects of these guidelines or create an aligned framework to provide transparency around:
  - Data security – how information is captured and used, and for what purpose. Ideally, patients should have a complete audit trail of where and how their data (identified and de-identified) has been used and the ability to withdraw their information from use.
  - Data quality – how information can be corrected.
  - Data validity – protocols behind decision-making.
  - Data interoperability, controlled and directed by patients.
  - Transparency – any financial relationships the company has and how those are managed. A vetting system so there can be trust that information is not being re-marketed or used for other purposes.
  - Provider qualifications – decisions being made by an individual board certified in a relevant specialty.
  - AI use transparency – there are several groups working on this, and while it has potential (and brings many concerns) there needs to be substantial transparency regarding any AI-derived components.
  - Ability to over-ride and speak with an actual person.
  - Ability to report (and receive reports on) adverse events.
  - Ability to provide patient or caregiver feedback in a *meaningful* way.

**PC-7. If CMS were to collect real-world data on digital health products' impact on health outcomes and related costs once they are released into the market, what would be the best means of doing so?**

This information could be part of the CMS web site and announced through media channels, professional associations, academies, standards bodies, and patient advocacy groups.