

Request for Information CMS-2025-0050-0031

Thank you for the opportunity to comment from the team at PFCCpartners. PFCCpartners is a patient powered organization that seeks to transform the US healthcare system by leveraging the critical insights and experiences of patients, family caregivers and communities in partnership with health systems, federal improvement programs, research teams and measure developers. The PFAnetwork is convened as a program of PFCCpartners. The PFAnetwork includes over 1100 patient family partners, or people with lived experience receiving healthcare who partner with healthcare stakeholders and policy makers to ensure the perspective of patients and family caregivers are represented as in the design, implementation and evaluation of effective healthcare technology products. The following are a compilation of comments and experiences of our PFAnetwork and the PFCCpartners team, who are also lifelong users of the health system.

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?

As an organization dedicated to amplifying the voices of patients and family caregivers across the country, PFCCpartners brings forward this comment informed by more than a decade of experience partnering with people who rely on the health care system—often in its most vulnerable moments. We appreciate the opportunity to ensure those perspectives are represented in this discussion about the future of health technology.

We are supportive of the CMS Innovation Center Strategic Pillar to drive choice and competition by expanding choice for people. Elevating consumer power is a missing link to creating real, person-driven change in our health care system. But today, we as patients are still being asked to act as informed consumers in an environment where pricing is unclear, choices are opaque, and information is often too complex to use or unavailable to patients and family caregivers.

Early efforts at price transparency have focused on negotiated rates between providers and health systems. This approach is flawed. The complexity of billing and coding—particularly for common procedures—dilutes the practical, usable information patients need to make decisions. For example, something as seemingly straightforward as a spinal fusion might be listed under separate codes like CPT 22612 (lumbar spine fusion, single level) and CPT 22853 (insertion of interbody biomechanical device), without any clear explanation of the full cost or scope of the procedure. This makes it nearly impossible for a patient to plan, compare, or make informed choices. True price transparency would provide if not definitive pricing, prices that are based on their insurance coverage uniquely. Technology platforms that calculated costs based on consumer's coverage would provide real time information without the billing surprises that often accompany post encounter Explanation of Benefits.

We've also noticed that traditional quality and safety indicators, like hospital-acquired infections (HAIs), are not necessarily the top priorities for patients. While important, most people first want to know if they can trust their provider, if the care setting is accessible, if they will be treated with dignity, and if the provider understands their needs and values. Considerations like transportation, language access, and cultural

representation often matter more than published metrics—and yet they remain largely invisible in the tools we’re asked to use.

So, the pivotal question is: What information is helpful and understandable for people to drive meaningful choice?

Our recommendation is that CMS redesign its Compare websites using a model more aligned with consumer-centered platforms like AllTrails. That tool helps users quickly understand how many people have “used” a trail, how it is rated, what to expect, and whether it matches their needs. It is both expert-informed and crowd-validated. In health care, the equivalent might be:

- The number of times a provider or hospital has performed a procedure or treated a given condition.
- An average patient-reported outcome rating (e.g., post-operative satisfaction or mobility)
- Brief patient reviews on communication, follow-up, or accessibility
- Clear filters for patients to sort providers by languages spoken, proximity, or disability accommodations.
- General cost ranges for common procedures, instead of CPT-code-based fee breakdowns

These kinds of tools would support actual consumer power, not just theoretical transparency. They would also advance CMS’s broader strategic goals by making it easier for patients and families to identify high-quality care that meets their personal needs. We don’t need more data—we need better, simpler, more usable information that reflects what matters to people.

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?

Health information about self, for use in obtaining consistent, coordinated care.

- Medication tracking/reminders
- Plain language, personalized health information (diagnosis, meds, physician notes, etc.)
- Communicate with providers.
- Timely communication with providers and the care team
- Coordinate or share information with other family members.
- Prior Authorization tracking/reminders (specialist, medication, etc)

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.

- Tracking pre-authorizations and filing appeals

- Get my records from one provider and send them to the next one.
- Make me an appointment.
- Something to help with managing information between providers/specialists' insurance and pharmacy.
- Transparency to where things are in process (referrals, pre-authorizations, DME, etc.) - i.e. direct line to insurance provider to coordinate expense.
- Billing questions and disputes
- Coordinate communication and coverage between private insurance (primary) and Medicare/Medicaid and the VA Health System
- Manage all my portals.
- Support with connecting to the various departments (for example, communicating with billing to clarify charges)
- Manage all my case managers.

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)?

- In general, there is inequitable access to technology and understanding its uses amongst patients and family caregivers.

I do not have easy access to my own health information in a single location. In fact, I have never had access to a complete record of my own health, despite living with chronic mitochondrial disease for more than 33 years. The nature of this condition has required specialized, ongoing, and coordinated care across multiple health systems, but no single provider, no portal, and no platform has ever been able to consolidate that care into a full, coherent picture of my health. I've spent decades navigating this fragmented system—filling gaps myself, making repeated requests, logging into countless portals, chasing faxes, paying fees, and trying to piece together a puzzle with missing and outdated pieces.

This challenge isn't abstract for me—it's deeply personal. My two brothers and I were all diagnosed with mitochondrial disease after a seven-year diagnostic journey that involved 16 different health systems. Between us, we had 36 surgeries as children. At one point, we were being followed by eight different specialists at once. Some of our early paper records were even lost in a fire when I was in elementary school. The idea that I—or any patient with a complex medical history like mine—could access a full, consolidated health record is not just unrealistic. It's impossible in the system as it exists today.

Electronic health record systems were not designed to solve this problem. They were created as billing and documentation tools for institutions—not as relationship tools for people. As patients and caregivers, we are presented with portals that do not talk to each other, filled with documents that are

hard to read and harder to organize. Even the concept of “access” is misleading: being allowed to view fragmented PDFs does not equate to understanding or owning one’s health information.

We urge CMS to draw a distinction between data access and true health information empowerment. Health records should not just log what happened—they should help people know what it means and what to do next. Today’s EHR systems fall short of that standard because they were never intended to support person-centered coordination, let alone continuous, informed care management.

We recommend that CMS promote the evolution of EHR systems into tools that function more like customer relationship management (CRM) platforms—supporting providers in maintaining continuous, proactive, and coordinated relationships with the people they serve. These systems should help both patients and care teams see the full picture: what care has been provided, by whom, with what results, and what comes next.

Until we build a system that consolidates and clarifies health information around the person—not the institution—people will remain disconnected from their own care. We need more than data. We need information we can trust, understand, and use.

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

In May 2025, I needed follow-up care after receiving dental implants. My original provider quoted the next phase of the procedure at \$9,000—well out of reach for me financially. I decided to explore more affordable options, but to do so safely, I needed my dental records, including the type of implants used.

It took over five phone calls, a \$30 fee, and more than three weeks just to receive my records. When I followed up to ask what kind of implant components were in my mouth, I was met with resistance and even judgment. The dental office told me, “That’s why we don’t encourage our patients to go elsewhere for follow-up care.” Almost like they wanted to punish me or make things more difficult because I wanted to seek care elsewhere.

Still, I persisted. I was able to use the records I obtained to move forward with another qualified provider who charged just \$2,000 for the same procedure—a \$7,000 savings. That is a meaningful financial difference for me and for many others. But it came with anxiety: Would the parts fit? Had I received all the right information? Would something be missing because I hadn’t been given a full picture?

The benefit of accessing my records was clear: I made a better financial decision, stayed within my means, and continued necessary care. But the emotional and administrative burden I carried to achieve that outcome should not be overlooked. Patients shouldn’t have to fight this hard or feel this uncertainty just to act in their own best interest.

This experience shows that access to health information—when it’s accurate, timely, and complete—can lead to better value in care and greater independence for patients. But it also reveals the significant work still needed to ensure that such access is consistent, respectful, and patient-centered.

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?

Right now, most health information systems are optimized for billing—not for people. Records are fragmented because the infrastructure was built to support transactions between entities, not to support continuity for patients. PFAnetwork members overwhelmingly stated their frustration with multiple patient portals and the limitation of information available to them. Additionally, many PFAnetwork members have experienced errors in their patient portals, which they have no ability to fix.

It would be transformative if health systems were incentivized and equipped to optimize infrastructure for the collection, verification, exchange, and usability of individual health information—not as a means to an end for getting paid, but as an integral part of the *business of health care*.

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)?

Patient portals rely on the health system to upload information into the system for the patients to access. That filter creates portals with limited usefulness and limited information. In the case of some diagnostics and other critical information sharing, delays in the process can have large impacts on health outcomes.

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?

- MyChart
- Apple Health Products

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

- Billing and coverage for anticipated treatments
- Apps/EHR systems don't talk to each other
- More personalized interpretation of health information through AI / intelligence
- Not all providers are on the health system apps
- Patients included in communication between pharmacy and provider

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

There should be an app that allows patients to take control of their health information at the point of care—seamlessly, and without administrative burden. I dream of walking into a provider's office, scanning a QR code (or selecting the provider's name), and by the time you walk out, the app has compiled and updated your personal health record using the information generated from that visit. It would supplement your existing data, verify your identity and consent, and consolidate records across systems into one secure, person-owned digital record.

From there, I could selectively share my relevant health history with other providers—whether for second opinions, follow-up care, specialist referrals, or even emergencies. Clinicians would receive timely, accurate, and verified health information without needing to chase paperwork or rely on outdated summaries. Patients would finally have autonomy over their health information. And we could eliminate—or at least dramatically reduce—the strain on medical records departments, which today serve as a bottleneck for access and care continuity.

I believe this kind of app does not yet exist for two reasons:

1. **The system is still oriented around institutional ownership of data, not person-centered portability.** Most health information systems were not designed to be interoperable across organizations, and even fewer were built with the patient as the primary holder of the record. This has created structural and cultural resistance to tools that shift control into patients' hands.
2. **Incentives are not aligned to prioritize health information flow.** Health systems are not reimbursed for sharing information efficiently, nor are they penalized for the friction patients experience when trying to access it. As a result, innovation in this space has focused on compliance and billing integration rather than user-centered design or seamless data portability.

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

- Care coordination between service lines and providers
- Patient and family engagement efforts to better support the needs of patients through engagement of people with lived experience navigating chronic disease in the healthcare system as co designers of the technology solutions.
- Implement infrastructure requirements that hold health systems responsible for Community Benefit obligations by building better connections to community organizations to support social needs.
- CMS is uniquely positioned to demonstrate and operationalize the pivotal role that health plans could play in coordinating health information on behalf of patients. Outside of the patient themselves, health plans often have the most complete view of a person's care history—across systems, services, and time. They hold a vast repository of claims data, pharmacy records, specialist referrals, and care utilization patterns. Rather than letting this information remain locked in administrative systems, CMS should set the expectation that health plans proactively support patients in accessing and owning their health information.

Patients should not have to request their records from a dozen different provider offices, wait weeks, or be denied access to data that health plans already use to manage reimbursement. CMS can lead by creating standardized, automated workflows that health plans must implement to gather, secure, and release relevant health information directly to patients—giving people access to a consolidated view of their care journey.

Leaving interoperability and access solely up to providers and patients has not—and will not—deliver the transformation needed to improve our health system. Health plans are an essential, underused resource in this equation. CMS has both the authority and influence to define how plans can and should serve as trusted stewards of patient-accessible information.

- CMS is also uniquely positioned to reimagine prior authorization—not just as an administrative hurdle, but as a structured opportunity for patient-centered value-based care planning.

Right now, prior authorization is one of the most influential workflows in clinical decision-making, yet it is inaccessible and often invisible to the very people it affects. It dictates which treatments, medications, or procedures are approved or delayed, but patients rarely have a voice in the process. Worse, health plans themselves are often unreachable, nontransparent, and wrapped in intentionally complex procedures that create barriers for even the most persistent patients.

CMS can transform this dynamic by requiring health plans to use prior authorization as a channel for engaging patients directly—through shared decision-making, individualized needs assessments, and real-time care plan communication. If patients are expected to navigate a value-based system, they must be included in the conversations that determine what care is approved and when. Value in healthcare has been defined by patients and family caregivers as falling into three domains: Access, Affordability and Experience, which mirrors the Triple Aim.

Reimagining prior authorization this way would align the administrative processes that drive care with the values, preferences, and realities of the people receiving that care. CMS is in a unique position to lead this change—and doing so would meaningfully advance the goals of person-centered, value-based care.

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

- Engage patients and family caregivers in the development and design of the products
- Ensure organizations designing the products are trustworthy and knowledgeable of person-centered design practices
- Secure and protected products
- Establish structures to receive ongoing patient and family caregiver feedback on what they need and what would help their health journey
- Require peer to peer learning opportunities so that patients can learn how to use technology platforms from others using it for the same purpose.
- Require apps be available in multiple languages

- Learn from patients who have barriers to technology/internet access about their specific challenges and address them.
- Have mini community events inside of a CVS pharmacy like giving for free patients picking up their prescriptions.

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)?

Suggest CMS establish Shark Tanks that include representation from CMS, Beneficiaries, health plans, clinicians and healthcare executives to review new technology solutions with criteria based on person centeredness, transparency, added value, reduction of resources and human centered design (including patients and family caregivers). Technology developers would pitch their product, in plain language (because if people can't understand it, they aren't going to use it) to earn a CMS recommendation for use.

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

- Quicker CMS turnaround of data to its partners who review and analyze various data sets to provide the best quality improvement and patient and family engagement interventions.

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?

- Engage Medicare beneficiaries and family caregivers (with limited prior experience) in design to understand what would make them accessible and easy.
- Implement peer to peer learning opportunities for people with lived experience to support others with similar needs. For example, we have an 84-year-old patient family partner who lives in a retirement community who desires to help her community members learn about the value of accessing their patient portals and access them, but she does not have the curriculum to do so.

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?

- Surveys
- Listening sessions

- Build an evaluation feature into the product - make it easy for patients to provide their feedback in real time.
- If patients were involved upstream in the design of health technology products, the products are more likely to produce results patients find valuable.

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

In our experience and that of many of our PFAnetwork members, health data is often difficult to find in a timely manner that is useful for decision making. CMS Compare websites, while offering great insights, are difficult to find and navigate and were largely untapped by many of our members. Patients and family caregivers often look to LeapFrog for patient safety scores, which provide important information as well. During several focus groups with our members, we learned that patients want to understand the quality of services provided, beyond safety measures and beyond patient experience data. Patients want to know about how many times a surgeon has performed a procedure, what the expected recovery time will be and how well that clinician communicate with the patient and other healthcare professionals.

PC-10. How is the Trusted Exchange Framework and Common Agreement™

(TEFCATM) currently helping to advance patient access to health information in the real world?

To be transparent, I was not aware of TEFCATM and had to use ChatGPT to understand it. As a result, I have more questions than responses. I will note that of the 14 direct responses received from our PFAnetwork members in preparation of this RFI response, no one mentioned TEFCATM or Health Information Exchanges. This makes me wonder, do patients KNOW if their providers are participating in TEFCATM or Health Information Exchanges. For example, I just asked ChatGPT if my provider participated in TEFCATM or and HIE. To my surprise, my data is shared with other organizations with EPIC through the Care Everywhere platform. Which is even more surprising, when I realize that my Cancer Center is also an EPIC user, but these two systems rely on me to inform the other. I would say that this exercise demonstrates that are not made aware of where their data is and health systems are not using this platform effectively, at least not in my urban, university affiliated health system and National Cancer Institute facility.

We completely support the efforts at interoperability, but only if patients have ownership for what is in them. Imagine if I owned my own data and had the opportunity to participate in TEFCATM, I would control where my information went and would have real access. The need for data use complicated agreements would be minimized or eliminated because the data is mine to provide.