

CMS RFI Public Comment Submission

Interoperability Is Not a Privilege: A Patient's Fight to Rebuild Healthcare

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Table of Contents

Abstract:3

Executive Summary4

Section A: Definitions5

Section B: Patients and Caregivers 6

Section C: Providers8

Section D: Payers10

Section E: Technology Developers 12

Section F: Value-Based Care Organizations14

Section G: Public Health, Equity, and Infrastructure..... .16

Final Word: The Closing Argument18

References19

Abstract: This submission responds to CMS' Health Technology Ecosystem RFI by asserting that digital health equity cannot be achieved without interoperability, patient-led data control, pharmacy integration, and systemic reform. Written from the perspective of a patient, strategist, and published policy advocate, it challenges CMS to act on what we already know — and use existing standards to drive true coordination.

Interoperability Is Not a Privilege: A Patient's Fight to Rebuild Healthcare

Executive Summary: Let's Stop Pretending This Is Working

We have been "building digital health infrastructure" for years now. And yet, as a patient, every time I try to interact with the system—whether it's scheduling care, transferring records, or getting a straight answer on a prescription—I'm reminded of just how broken it is. We say "interoperability," but what we've built is a patchwork of proprietary silos, each demanding its own password and each leaving the patient behind.

This response is not about drafting more rules or layering on new platforms. It's about calling out the structural failures of implementation—and issuing a challenge: let's test what we already built, but for real, across stakeholders, and with patients at the center.

The CMS RFI is an opportunity to turn decades of policy and pilot programs into one national, actionable system. We propose the development of a CMS-backed testbed inspired by our Collabor8 model—an event-based approach that includes pharmacists, providers, patients, caregivers, payers, and tech vendors testing real workflows that occur during a care episode. Not a PowerPoint. A practice. Not in silos. In sync.

Section A: Definitions – Let's Talk Like Humans

“Digital tools.” “Digital health products.” “Patient portals.” What do these words actually mean to the people they claim to serve? If you can’t explain it without jargon, it’s probably not helping a patient. If I need 3 logins to see my meds, it’s not a tool—it’s a burden. So, here’s how we define things:

- Digital tools must work without a tutorial and should serve the user, not extract from them.
- Digital health products must inform or improve care, not just sit pretty on a phone screen.
- Health management applications should work when health happens—not only in clinics.
- Care navigation applications should guide—not gatekeep—our access to services.
- Personal health record apps should give full control to the patient: to share, to revoke, to delete.

We don’t need prettier portals. We need a shared understanding, built around the real-world use cases of the people who rely on these systems to survive.

Now that we’re speaking the same language, let’s talk about the people who matter most — and are too often left last: patients and caregivers.

Section B: Patients and Caregivers (PC-1 to PC-14)

Story First: We Are All Patients

Let’s start with this truth: every person reading this has been or will be a patient or caregiver. So why do we keep designing technology as if the humans who use it are someone else? Do we ever ask ourselves, “Would I want my mother navigating this?” If the answer is no, we’ve already failed.

The current digital health experience is fragmented and cruel. Patients must chase data across portals, explain their story ten times, and fight for access to their own records.

The very system built to "empower" us is actively exhausting us. Even though regulations technically allow me to access my data, in practice I am blocked by outdated tech, buried UIs, and companies who profit off making it hard.

There are no truly helpful apps because they are siloed. I need an app that connects my pharmacy to my provider to my wearable to my caregiver—and I need to control it. That means CMS should lead the way in creating a Universal Patient Identifier (UPI) and a Patient-Centered Data Exchange model, where I—not the vendor—manage who gets my information, for how long, and for what purpose.

Precision medicine cannot be achieved without patient-controlled data sharing. And privacy shouldn't mean obscurity. I should be able to see, revoke, and authorize access dynamically. Why do we keep asking patients to behave like developers or engineers? It's time to shift power, not just build portals.

In pharmacy, we are watching deserts grow. Access is shrinking. Pharmacists are cut out of the care team—even though they are the most frequently accessed health professionals. This makes no sense. Our testbed model includes pharmacists because you cannot achieve digital equity without pharmacy interoperability (Petzelt, 2023a).

CMS must acknowledge that care navigation doesn't start in a hospital—it starts in moments: at the counter, after hours, during a diagnosis. The patient should not be forced to work harder to stay alive.

If patients are the heart of this system, then providers are the arteries. But the current system clogs their workflows with forms, friction, and failure points. It's time to stop blaming them—and start supporting them with the tools and data they actually need.

So here are my responses to CMS' questions, not as hypotheticals, but from the trenches.

PC-1 to PC-4: What tools and features do patients and caregivers need?

We need a system where our data lives in one place, not twelve. A tool that lets me:

- Connect with my pharmacy, doctor, and insurer in real time.
- Share my genetic test, benefit coverage, and prior auth status.
- Authorize access once—and revoke it anytime.

The features missing today are simple: consent control, clarity, and continuity. CMS must fund and mandate the development of modular, patient-centered applications that follow us across care settings and devices.

PC-5 to PC-7: How can CMS support tool adoption and accessibility?

Adoption doesn't start with app stores—it starts with trust. CMS should launch a federated identity framework, where patients use a single credential (Login.gov, ID.me) across systems, with full transparency. You can't fix tool adoption if people don't feel safe or respected in the process.

Older adults and underserved patients need less complexity, not more features. Accessibility should be measured by burden reduction: fewer calls, fewer forms, faster answers. That's what progress feels like.

PC-8 to PC-10: What data is still hard to access?

Most of it. Pharmacy data. Genomic test results. Prior authorization status. Out-of-network visits. Lab results. Most patients still don't see the full picture, and even when they do, it's delayed or incomplete. CMS should require:

- Real-time data feeds to patients.
- Access to TEFCA-based exchange.
- A CMS version of Blue Button 2.0+ that includes payer and pharmacy feeds, not just claims.

PC-11 to PC-12: What use cases should we prioritize?

Prior auth transparency. Pharmacogenomics at point of care. Real-time benefits. Digital consent across systems. And pharmacy integration into care teams.

You can't achieve equity while pharmacies are digitally orphaned. Patients need a pharmacist who sees the same data their doctor does—and a payer who doesn't block them.

PC-13 to PC-14: How can we report information blocking and fix digital identity?

Reporting mechanisms must be safe, public, and fast—not hidden in back pages or legalese. Make it as easy as rating an app: "Were you blocked from accessing your records today? Tell us here."

And digital identity must be treated like a clinical safety issue. No more multiple logins. No more uncertainty. One ID. One trust layer. One standard.

Section C: Providers (PR-1 to PR-14)

Story First: The Hidden Privilege of Providers

Let's say the quiet part loud: providers are privileged within the healthcare data ecosystem. They have access. They have portals. They have decision support. But pharmacists don't. Patients don't. Caregivers don't. And that disparity shows up in every broken workflow we've documented.

Every lawmaker, every technologist, every payer—you're a patient, too. So why do we build things we wouldn't want our own kids or parents to use? Why do we call disconnected apps "empowering" when they make sick people chase their care across portals, passwords, and PDFs?

Today's system still doesn't work. And it's not for lack of money or standards or innovation—it's because we never center the people using it.

Digital health tools? I don't need another tracker. I need one place—one place—that sees me, holds all my data, and lets me say: "You can have this, and you cannot." I should control it—not beg for it. We need a universal patient identifier and a real-time revocation model. If my identity is digital, it should be sovereign.

And let's talk about health apps. Most aren't helpful because they're built in silos. I don't need 12 portals. I need a digital ecosystem that listens when I say I've already been tested. That knows I started a therapy. That reminds me when I need support—not when it's already too late.

The real question isn't "how can we give providers more tools?" It's: "how do we rebalance the power in healthcare toward actual coordination?"

Providers are overloaded with administrative tasks, yes. But those burdens are often self-reinforcing—because data isn't shared intelligently across systems. We see clinical decision support tools that are limited by incomplete patient data. We see EHRs that lock information away. We see providers who have responsibility but not visibility—and who get buried in clicks trying to do the right thing.

You can't walk into a hospital today and find a clinician who isn't burned out. Most aren't fighting technology—they're drowning in it. But the truth is, providers still get the benefit of the doubt, while pharmacists are excluded, patients are sidelined, and innovation waits on someone's comfort level.

I don't say this to attack providers—I say this as someone who's had to explain a diagnosis five different times to five different doctors in the same health system. The

system was too fragmented, and my records were never complete. I had a PGx test in my hands that no one looked at. I brought it to my pharmacist, who knew what to do with it. My doctor? Didn't even ask.

We cannot achieve precision medicine if pharmacists are excluded from the workflow. And we cannot expect providers to succeed if they're locked into EHRs that refuse to open up.

Systems like Epic still avoid mandates others must follow. Smaller providers can't afford the innovation lift. Rural clinics are locked out of new standards due to cost and complexity. We need a CMS-led testbed to level the playing field: prove what works, and fund the rest so everyone can adopt—not just the academic medical centers.

We also need to stop asking providers to be administrators. AI should handle prior auth preprocessing, data reconciliation, and documentation hygiene. Let people do the human work. This is not about more dashboards—it's about workflows that feel like common sense.

PR-1 to PR-4: What do providers need to integrate digital health tools?

Providers need trust, time, and tools that don't increase clicks. Tools must embed in the workflow, not sit on the side. They need:

- Interoperable EHR plug-ins (FHIR-first).
- Clinical decision support fed by PGx, SDOH, REMS, and payer data.
- Real-time collaboration with pharmacists, not just referrals.

PR-5 to PR-6: How should CMS support implementation?

CMS should tie implementation funds to real-world demonstration of reduction in administrative burden, not tool deployment. Give providers shared savings for using precision tools (PGx, digital therapeutics) in place of excessive trial-and-error prescribing. And give pharmacists provider status.

PR-7 to PR-9: What's blocking provider engagement?

Fear, fatigue, and poor incentives. Many feel burned by previous waves of tech adoption. CMS must:

- Simplify documentation via automated capture.
- Require vendor accountability on usability.

- Demand EHR interoperability as a condition of Medicare participation.
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PR-10 to PR-14: What training and support is needed?

Training should not be a class. It should be baked into the tool. Think: just-in-time guidance, embedded UX cues, and AI that summarizes patient history. We need grants for interdisciplinary training hubs—doctors, pharmacists, care coordinators learning together, not in silos.

Section D: Payers (PY-1 to PY-14)

Story First: The Data They Hold Could Save Lives — But It's Still Locked Away

The data they hold could save lives. But it's still locked up, delayed, and denied—because payers are allowed to slow-walk reform.

Let's be clear: the Change Healthcare breach didn't just expose data—it exposed the fragility of the entire infrastructure. One payer-driven system cracked, and pharmacies, patients, and providers were paralyzed. It's not just a cybersecurity issue—it's a power imbalance.

Payers hold the richest datasets in the ecosystem: claims, eligibility, prior auth, benefits, coverage. But most of this still doesn't show up at the point of care—because they're not required to move at the speed of the patient. They don't live with the consequences of delay. We do.

I once paid \$25 per prior auth. Just to submit. No guarantee of approval. That's not coverage—it's cruelty. And it happens every day to people without my knowledge, voice, or privilege.

If CMS does not act now to mandate real-time payer data exchange, we are wasting decades of interoperability standards.

PY-1 to PY-5: What payer innovations support interoperability?

When forced, payers can deliver. Blue Button 2.0 showed it. But they won't do it voluntarily.

The most promising innovations use:

- FHIR APIs for coverage transparency

- OIDC and federated ID frameworks for identity and consent
 - Collaborative regional testbeds to align payer–provider–pharmacy data sharing
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PY-6 to PY-8: What’s missing from payer engagement?

Accountability. Payers are still not held to the same standards as providers and vendors.

CMS should enforce:

- Bi-directional FHIR support
 - Public interoperability scorecards
 - Penalty structures for noncompliance, using Star Ratings, audit leverage, and plan approval
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PY-9 to PY-11: How can CMS support payer alignment?

Use the same model as TECCA. If you participate in Medicare Advantage, you must:

- Share data across certified APIs
 - Participate in shared testbeds
 - Allow pharmacists and patients access to prior auth and benefit details before treatment starts
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PY-12 to PY-14: What data should payers share, and how?

All of it that affects care: formulary, benefits, auth status, coverage gaps, out-of-pocket forecasts.

Not as PDFs. As structured, actionable data embedded in patient-facing tools and provider workflows.

We often blame the payer for broken access, but the developer built the digital walls we now can’t scale. Payers approve care — developers determine how it’s delivered. If the platforms fail, so does everything else.

Section E: Technology Developers (TD-1 to TD-12)

Story First: You Cannot Code for Care If You've Never Felt the Cost of Failure

You cannot code for care if you've never felt what it's like to beg for it.

Too many developers are building healthcare tech without understanding healthcare suffering. This isn't ridesharing. It's not a finance app. If your design fails, someone might not get a medication in time. Someone might die waiting for a prior auth. Someone might go bankrupt from navigating a maze of "solutions" that solve nothing.

The worst part? We already have most of the tools we need: APIs, data standards, secure ID platforms. What we lack is activation—and empathy. Tech in healthcare is often built in conference rooms far from the bedside, the pharmacy counter, or the discharge moment.

I've seen this firsthand—watching my pharmacist try to help me with a critical treatment, only to be blocked from seeing the clinical note, the PA form, the REMS guidance, or the PGx results. A developer coded that wall. Not because they were cruel, but because they weren't connected to the experience. They weren't asked to care like a patient. Or a caregiver. Or a pharmacist whose hands are tied.

Developers in healthcare must start with the same hat we all wear—the patient hat.

And CMS must demand this from vendors: not just compliance with specs, but evidence of usability, accessibility, and outcomes.

TD-1 to TD-3: What makes health tech usable and effective?

Usability isn't clicks—it's clarity. Effectiveness is not feature count—it's workflow fit.

- Build like you're sitting with the patient.
- Design for the time of crisis, not just ideal use cases.
- Embed precision tools (PGx, SDOH, DTx) where they naturally belong: within the care moment, not as external steps.

TD-4 to TD-6: How should CMS guide future tech development?

CMS should create a public, rotating patient–developer–policy advisory panel, reviewing products before they hit implementation. Also:

- Mandate interoperability testing in real clinical scenarios
- Fund tech adaptation, not just innovation
- Reward vendors that serve community health settings, not just hospitals

TD-7 to TD-9: How can developers understand real-world needs?

Require them to shadow pharmacists, patients, and caregivers for a full day of lived care. No demos. No PowerPoints. Just witness the failures. Then let them code.

CMS should also create a shared testbed registry—where all tools can be tested against real workflows quarterly, not annually.

TD-10 to TD-12: How do we support alignment and sustainability?

By getting out of the silo mindset. Use lessons from banking, aviation, even logistics—industries that figured out shared credentialing, real-time data, and modular design.

We're not inventing a new wheel. We're refusing to use the one that works.

Section F: Value-Based Care Organizations (VB-1 to VB-12)

Story First: If Value Isn't Centered on the Patient, It's Just Another Billing Code

Value-based care is not a billing model. It's a moral compass. If the compass points to revenue instead of outcomes, we've lost the map.

We've been told value-based care will fix everything. But that promise was always made from the top down—designed around cost savings, not people. If this were really about value, we would start where the most trust lives: the pharmacist's counter. We would build workflows that put patients before margins, and we would stop letting PBMs and payers operate with fewer clinical responsibilities than the people handing out life-saving medications.

Let's be real: the current system lets payers deny care faster than pharmacists can approve it. It lets manufacturers game the rebate system while patients go broke. It lets PBMs siphon money from the supply chain and then blame others when pharmacies shut down.

And who gets squeezed? Patients. Pharmacists. Independent providers.

We must rebuild value-based care around the people who actually deliver care—not the ones who abstract it into spreadsheets.

CMS has the authority to lead this reset. And it must. Because no amount of risk-sharing contracts will fix what happens when no one's accountable for the lived experience of the patient.

VB-1 to VB-4: What must change to make value-based care real?

We must:

- Reclassify pharmacists as clinical providers, not vendors
- Hold PBMs to strict transparency, ethical contracting, and real impact reporting
- Shift payer metrics from “cost avoidance” to measurable health improvement
- Fund SDOH interventions through pharmacy and community providers, not middlemen

VB-5 to VB-7: What tools support better outcomes in value-based models?

The precision toolbox again:

- PGx at the point of prescribing
- DTx for behavior change and symptom support
- AI to guide care decisions, not replace them
- Real-time benefit and coverage tools across providers, payers, and pharmacies

And most of all: shared platforms that let patients, pharmacists, and providers work from the same playbook—not walled gardens.

VB-8 to VB-10: How can CMS incentivize progress?

- Reward the use of open APIs and certified standards
 - Penalize use of proprietary lock-ins and black-box analytics
 - Offer grants for regional collaboratives that include pharmacists and patients as co-designers, not observers
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VB-11 to VB-12: What's the biggest risk in current value-based strategies?

The risk is this: we're building the future with the same hands that broke the past.

And unless we listen—deeply—to those who've lived the consequences, we'll fail again.

Section G: Public Health, Equity, and Infrastructure (PH-1 to PH-10)

Story First: A System Is Only as Strong as the People It Leaves Behind

Public health isn't a safety net. It's the foundation. And when that foundation cracks, we don't fall through it—we fall on it.

We saw this during COVID. We see it every day in rural health deserts. In pharmacies closing. In moms skipping meds to afford their child's care. In Black and Indigenous communities who've been over-surveilled, under-served, and digitally excluded.

Equity isn't a buzzword. It's a design requirement. If a digital tool doesn't work for everyone, it's not innovation—it's discrimination at scale. And infrastructure that excludes is infrastructure that fails.

We don't need another pilot. We need permanent plumbing. We need broadband in every home, a device in every hand, and digital health that doesn't punish you for being poor, sick, or rural.

If CMS is serious about interoperability, it must treat it like public health infrastructure: non-negotiable, nationally funded, and accountable to those it serves.

PH-1 to PH-3: How can CMS make interoperability a tool for equity?

- Require vendors to submit equity impact reports with all CMS-certified solutions.
- Invest in digital access grants for rural, tribal, and historically marginalized communities.
- Mandate inclusive UI/UX standards so accessibility isn't an afterthought.

PH-4 to PH-6: What infrastructure gaps must be addressed?

- Expand broadband through health equity zones, not just ZIP codes.
- Provide low-cost, interoperable devices via Medicaid and Medicare Advantage supplemental benefits.
- Fund technical assistance hubs to help safety net clinics implement interoperable tools.

PH-7 to PH-8: How can public health systems integrate with clinical and pharmacy data?

- Establish unified, bi-directional pipelines between public health agencies and EHR/pharmacy systems.
- Incentivize community pharmacies and FQHCs to share de-identified data for real-time surveillance and response.

PH-9 to PH-10: What are the long-term infrastructure needs CMS must prioritize?

- Treat data liquidity as essential infrastructure—like water or electricity.
- Fund and enforce national standards for consent, identity, and exchange. Not just rules—but rails.

We cannot achieve public health if we continue to build private wealth on public failure. If CMS leads with equity, the system will follow.

Final Word: The Closing Argument

This isn't a white paper. It's a warning. And a call.

We've built empires of health data. We've launched frameworks and funded pilot after pilot. But patients are still waiting for records. Pharmacists are still shut out. And the third leading cause of death in this country? Medical error. It just moved up—from fourth to third. That's not just a statistic. That's a failure to learn. A failure to listen. A sign that all the programs we keep funding and designing aren't solving what actually matters (SafeRX Pharmaceuticals, 2024).

That didn't happen by accident. It happened because we overcomplicated the obvious and ignored the voices in the room who already knew how to fix it.

This paper isn't about theory. It's about survival. It's about the daughter who had to become a data advocate to stay alive. It's about the pharmacist who had to work around

the system just to get someone a life-saving medication. It's about the mother, the father, the child, the caregiver—who deserved better.

If you want real answers, stop asking only the so-called experts. Ask the daughter who buried her 48-year-old father a week before her wedding—because insurance delayed a PGx test that could've flagged a chemo interaction and bought him time. Ask someone like me, given two years to live, who didn't survive because of a prestigious institution, but because of relentless grit, late nights, and a family that refused to stop fighting.

This wasn't won in a boardroom. It was won in heartbreak, tenacity, and the refusal to accept a system that treats lives like line items.

If we want something different, we must build with people who have everything to lose and nothing to prove—not those motivated by ego, money, or legacy.

Let's try something real. Something new.

CMS: You have the power to stop the next death-by-fragmentation.

You have the tools. The standards. The people.

Now you have the truth. From someone who lived it.

My hope is that you'll use it.

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