

Submission to CMS RFI on the Health Technology Ecosystem (CMS-0042-NC)

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To the Administration and Team Reviewing this RFI:

Thank you for the opportunity to comment on CMS-0042-NC. I am Jean Ross, MHA, BSN, RN, co-founder and CEO of Primary Record, a nurse-led, family-centered Family Health Information Management System (FHIMS). Our founding team, an emergency-room physician, a special-needs caregiver, and a former critical-care nurse (me), has spent the past five years living the caregiver side of “interoperability” inside today’s health technology ecosystem.

The 21st Century Cures Act opened a historic door: patients are no longer spectators, but rightful stewards of their electronic health data. Yet the families and frontline clinicians we serve still juggle multiple logins and portals, chase faxed records, and rely on paper binders because the final mile, from legal access to usable record, remains unfinished. Primary Record exists to close that gap.

While our current paying customers today are families and independent care coordination businesses, we have spent the past 9 months learning directly from teams who orbit around the same high-need, complex patients: senior living staff, community paramedicine crews, transplant coordinators, government appointed guardians of older adult, and foster care case managers. These conversations have grounded our product development and informed every recommendation we submit here.

Although we intend to enroll as a TEFCA Individual Access Service, slow and often unenforced responses from some electronic health record (EHR) vendors to Patient-Access API requests led us to start elsewhere. Since 2022 we have integrated with 1upHealth’s FHIR Patient-Access APIs, allowing families to download their data into a shared workspace, add context, correct errors, and coordinate with their families and hired advocates and caregivers.

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That front-row seat has taught us that digital health succeeds or fails on three ground-level realities:

- Who pays?
- Which workflows actually change?
- Do the data pipes stay open?

While technical leaders such as the CARIN Alliance, CommonWell Health Alliance, 1upHealth, and the broader FHIR Builder community define the technical standards, our response to this RFI focuses on the realities family-centered care navigation and the real-world insights from Primary Record on adoption and scale.

We appreciate CMS's invitation to contribute these lessons and hope our experience helps pave a more connected, caregiver-friendly future for every American family no matter their zip code, education, or economic situation.

Lesson 1: “Who Pays?” comes before “Which API?”

Relevant RFI Questions: PC-1, PC-5, PR-1, PR-7, VB-3/VB-4

PC-5 asks how CMS can boost caregiver adoption; PR-1/PR-7 ask how to relieve provider burden; VB-3/VB-4 focus on transitions and value-based workflows.

Primary Record Insight:

Caregivers and families deeply value having a single, easy-to-use place to access, manage, and act on their family member's health information, especially during moments of care transition. But, real-world adoption stalls without financial infrastructure. Very few families are willing or able to take on the cost of a new subscription, and most provider and payer programs won't adopt digital caregiver tools unless they are reimbursable or align with existing billing models.

Caregiver voices (PC-1, PC-1a):

- “I have answers for any questions I get asked about medications, tests, or procedures at my fingertips.”
- “It's convenient when I am in the doctor's office with a family member or on the phone with an aging parent or grandparent, I can access health info / messages / test results to help them understand.”

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- “I find some of the health information in patient portals very confusing, when trying to access my mom's information...just seeing the words without explanation. I value being able to know even any part of what is going on with her”
- “It is helpful to have a record and know that I can access the information at any time.”
- “The ease of having all healthcare data, my personal story, in one easy to use location that travels with me allows me to better communicate information to my healthcare providers.”
- “It [Primary Record] is a great app that keeps all your health information in one place.”

These testimonials reflect the kind of real-world utility CMS is seeking: tools that simplify care navigation, improve communication between caregivers and clinicians, and reduce administrative burden.

Beyond convenience, Primary Record helps close digital equity gaps for families in rural communities, dual-eligible households, and caregivers with limited digital literacy. These groups often struggle with fragmented systems and are rarely equipped to navigate multiple patient portal logins or complex authentication flows. Proxy access is inconsistently implemented and difficult to manage, especially for families caring for aging parents, children with disabilities, or individuals across state lines. By letting the caregiver collaborate and contribute to the record directly, Primary Record simplifies access and ensures that essential care decisions aren't delayed by technical barriers. This caregiver-led model helps translate legal access into usable access, supporting CMS's equity goals in real-world settings.

Recommendation:

CMS should establish a reimbursable “Digital Care Coordination” code, or introduce an add-on to Chronic Care Management (CCM) or Transitional Care Management (TCM), that compensates nurses, advocates, and community-based care teams for coordinating care using a caregiver-accessible, patient-centered digital health record during high-risk transitions.

To ensure quality and standardization across this emerging category of tools, we recommend CMS develop a “Caregiver-Ready Seal” certification, modeled in part on the work initiated by the CARIN Alliance. This seal should identify tools that meet basic usability, access, security, and data-connection standards required for real-world

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caregiver engagement. It would give clinicians and caregivers confidence in selecting technologies and would support:

- Consistent, streamlined onboarding and training
- Predictable interoperability and patient data access
- Vendor accountability for usability and data quality

With this approach, digital caregiver tools move from “nice-to-have” apps to recognized infrastructure that supports CMS’s broader goals: reducing provider burden, improving outcomes during care transitions, and increasing equity in digital access for caregivers and families.

This single payment pathway answers the question every enterprise technology buyer asks: “Who pays?” and transforms caregiver-first solutions from fragmented extras into aligned, billable care delivery tools.

Lesson 2: The Biggest Efficiency Gains Sit Inside Care Transition and Coordination Workflows

Relevant RFI Questions: PC-2b, PC-12, VB-3, VB-4

(PC-2b asks where single-source access matters most; PC-12, VB-3, and VB-4 focus on reducing duplication and improving care coordination in value-based settings.)

Primary Record Insights:

Across nearly every care setting we’ve interviewed, licensed professionals, especially nurses and social workers, are routinely pulled away from clinical work to chase records, reconcile conflicting information, and coordinate fragmented care. These tasks are invisible in most performance metrics, yet consume time and directly affect patient safety, continuity of care, and staff well-being.

At transplant centers, nurse coordinators shared that they can spend 2–3 hours per urgent inpatient workup gathering medical records, handling up to 5–6 such cases each week. That equates to nearly 18 hours per week of high-skill clinical time lost to administrative tasks. In programs managing 400+ post-transplant patients per coordinator with 24/7 call coverage, burnout is rampant. The average coordinator exits the role within three years.

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In pediatric cancer survivorship programs, even large institutions with full enterprise EHR access have reverted to managing care coordination via shared email inboxes. At one major children's hospital, over 40 full-time care managers used email and spreadsheets for transitions and family communication, despite being embedded in the nation's most widely adopted EHR. This reveals a core insight:

EHR access does not guarantee seamless coordination.

Without a digital tool that connects caregivers, external providers, and families, even resource-rich programs fall back on manual, siloed workflows.

In senior living communities, care teams often work completely outside of major data-sharing networks. As one executive director shared:

“It's not unusual for nurses to spend hours tracking down labs or discharge summaries just to give families a complete update. None of that time is captured, but it delays care and adds frustration for everyone.”

Another echoed:

“Every resident has their own team, hospital, primary care, family, specialists, and Medicare plan, and none of them are on the same system.”

In state guardianship and foster care programs, caregivers, often court-appointed volunteers or caseworkers, frequently lack access to patient portals or usable data. Despite holding legal decision-making authority, they're locked out of digital coordination tools and must rely on faxed forms or time-consuming phone calls to piece together a care plan.

Primary Record addresses these challenges by enabling real-time coordination during care transitions through a combination of patient access APIs, caregiver-entered notes from encounters and observations, and Optical Character Recognition (OCR) of uploaded documents. The medical profile owner can invite collaborators into a shared workspace where documentation is centralized, and AI tools are used to search, summarize, and surface key information that supports navigation and communication. However, the platform's full potential remains limited without a consistent, standardized framework for health data delivery.

Recommendation

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Require that the Summary of Care, already generated at key care-transition points, be delivered via a standards-based API to the caregiver-designated health management application at the same time it is sent to another provider.

This does not require a new document or workflow, it simply extends an existing delivery path to include the caregiver.

CMS can embed this standard in current electronic Clinical Quality Measures (eCQMs) (e.g., discharge planning or transition-of-care metrics) by tracking: “API-delivered transition bundle within 24 hours.”

This policy would:

- Enable real-time, seamless information flow to caregivers without new training or tech overhead.
- Support licensed care coordinators (nurses, social workers, advocates) who already do this work but currently rely on faxes and HIPAA request forms.
- Reduce provider burden by eliminating duplicate record requests and redundant documentation loops.
- Improve family engagement and care continuity during high-risk moments like discharge, hand-off, or home-based transition.

If CMS opens this delivery route, tools like Primary Record are ready to carry the data, connecting the people who already do the work to the information they need, when they need it.

Lesson 3: Fragile Patient-Access APIs Turn Caregivers into Human Middleware

Relevant RFI Questions: PC-2c, PC-8, PC-13, PR-4, PR-6, PR-7

(PC-2c and PC-8 ask what data are missing or hard to get; PC-13 covers information-blocking complaints; PR-4, PR-6, and PR-7 focus on standards, TEFCAs options, and provider burden.)

Primary Record Insights

1. Fragile API Infrastructure

Earlier this year, a configuration change by a major EHR vendor caused all medication and lab data to suddenly stop flowing into Primary Record across multiple patient

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accounts. There was no notification until our customer notified our team. The issue took 47 emails across three companies, the EHR vendor, the API intermediary, and our platform, to diagnose and resolve.

This was not an isolated event. API connections frequently break silently, without any alert or failover. When that happens, caregivers and care teams are left in the dark. Patients assume they're sharing up-to-date information with family or a professional care manager, but in reality, the data may be incomplete or outdated for days or weeks. Trust is lost, and most revert to printing documents, sharing patient portal logins, or disengaging from digital health apps.

2. Incomplete APIs

At a skilled nursing facility, we learned that nurses were required to call the designated point of contact anytime lab, imaging, or a medication order was submitted. These orders, represented in FHIR as ServiceRequest, are essential to know what was requested, not just what results came back.

But through the patient-facing APIs, these orders were unavailable resulting having to understand how to connect to the EHR's marketplace to access rather than leveraging the 21st Century Cures Act. Even though the APIs surfaced results, they offered no visibility into pending, canceled, or scheduled orders. As a workaround, each shift a nurse must set aside time to call the resident's point of contact.

This is another example where our skilled workforce is being used as human APIs to manually retrieve, translate, and relay clinical data that should be automated and accessible through certified patient access channels.

Recommendations

1. Treat Patient API Reliability as a Safety Issue

Just as duplicate scans or missed medication changes create risk, unreliable APIs jeopardize and erode trust of caregivers and care teams relying on patient access APIs.

- CMS should require public uptime dashboards and audit logs for patient-facing APIs. One tool we've found helpful is Lantern (lantern.healthit.gov), an open-source project from ONC and Mettle Solutions, LLC. Lantern monitors and provides information on the availability of FHIR API service base URLs (endpoints) across U.S. healthcare organizations. It also visualizes FHIR

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Capability Statements and patient data availability. We believe Lantern, or a similar public dashboard, should be better understood and integrated into CMS oversight efforts.

- Financial penalties should apply when data outages or missing USCDI elements persist, especially when unreported. → *Relevant to PR-7*

2. Expand the Required Data Payload for Patient Access APIs

Current APIs do not support full care coordination. CMS should require patient-facing APIs to include:

- *DiagnosticReport* (for results)
- *ImagingStudy* (for scan metadata)
- *DocumentReference* (for notes and referrals)
- *ServiceRequest* (for lab/imaging/consult orders)

These are already part of the US Core Implementation Guide and are essential for safe transitions and coordination between hospital, doctor offices, home, and senior living communities.

3. Enable One-Click Information Blocking Reporting

The ONC portal for submitting access complaints is too complex and unknown to most caregivers. We recommend allowing certified apps to embed a “Report Access Problem” button, which auto-fills:

- The failing endpoint
- The type of data missing
- The timeframe and patient consent status

This would help CMS and ONC identify systemic access failures and prioritize enforcement. → *Relevant to PC-13*

A Final Note on Enforcement & Privacy Concerns

None of this will matter unless CMS and ONC actively enforce the patient access rules already in place. We’ve seen too many examples of:

- APIs returning less data than the patient portal
- Endpoints silently failing, with no alerts to the patient or app

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- EHR vendors and data aggregators blaming each other, leaving the caregiver stuck in the middle

Without visible enforcement and real consequences, the cost and complexity of compliance continues to fall on families and the community-based professionals supporting them.

But enforcement alone isn't enough, we also need to address the growing mistrust families and care teams feel around digital health systems. Accessing deeply personal medical data on behalf of another individual is not something most people take lightly. In fact, gaining trust has been one of the hardest barriers for our team to overcome.

What helped us turn that corner was building visible, user-driven transparency into our platform:

- A Trust Center that documents in plain language
- An activity feed to audit every interaction, and always available, showing exactly who has accessed, edited, or shared inside a Primary Record
- A granular permission model so families know who can view or edit information and at what level

We understand and share, the public's concern about any system that centralizes control over health information. That's why we believe the future of patient access depends on partnerships that center trust, not just technology. Nurses, care coordinators, and advocates already have a large percent of the public's confidence. CMS should lean into these trusted networks, not work around it.

Digital trust doesn't scale on good intentions. It scales when:

- The data is there, every time, in full
- Access is clearly explained and visibly controlled
- The tools reflect the values of the people using them

We urge CMS to match its technical mandates with stronger enforcement, greater visibility, and support for public-private models that embed trust at every level. Primary Record was founded to solve a big problem: families and care teams are drowning in disconnected, incomplete, and inaccessible health information while trying to support the people they love.



Alignment with TEFCA Goals

Primary Record is designed with TEFCA's vision in mind. We are actively preparing to enroll as an Individual Access Service (IAS), and our platform already supports FHIR-based data completeness, longitudinal health record management, and consent-driven data sharing. Through real-world deployment, we've gathered insights into data delivery gaps, caregiver access barriers, and workflow integration challenges, lessons that could meaningfully inform future QHIN benchmarks, IAS certification criteria, and patient experience metrics.

By sharing these three lessons, we hope to contribute meaningfully to the roadmap CMS is building, one that supports the growing number of caregivers in this country. There are clear places to focus, clear wins to pursue, and a growing community ready to help. Our team looks forward to being part of that future.

Here to help,

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