



**Response to CMS–0042–NC
Request for Information:
Establishment of a CMS Health Technology Access Initiative**

Submitted by:

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Introduction

Meeting Caregivers Where the System Doesn't

At Twilight Technologies, we've spent the last several years building tools that serve a long-overlooked but critical stakeholder in the Medicare ecosystem: the family caregiver. Every day, caregivers are managing medication lists, interpreting hospital discharge summaries, coordinating appointments, and navigating claims all without institutional support, training, or clear access to their loved one's health data. The existing system too often reduces them to "authorized representatives," when in truth they are the de facto care managers for millions of Medicare beneficiaries.

Our platform, the Illuminator, was created to help family caregivers navigate their loved ones' healthcare with ease. By ingesting and interpreting Medicare claims data through Blue Button 2.0 and layering in smart recommendations and care summaries, we make it possible for caregivers to finally see the whole picture. And with Twila, our new AI-powered concierge, we've gone a step further enabling families to ask natural-language questions, get personalized answers, and offload repetitive care tasks in a secure, responsive, and humane way.

I'm building this company because I've lived this challenge personally. When I first began my journey as a family caregiver to my Mother, I struggled to advocate for her when she could no longer advocate for herself. Most of the families we've worked with, and many others often feel that they're on their own as they begin to navigate Medicare, coordinate and assemble fragmented care, and struggle to understand what's covered or what's changing. Twilight was born from the frustration and realization that families do not have the tools needed to support them. Our work is rooted in making the invisible caregiver visible and powerful.

We are submitting this response because we believe this RFI comes at a pivotal moment. CMS and ONC have rightly recognized that future health technologies must center the patient experience and for many Medicare beneficiaries, that experience is carried by their caregiver. From our work, we've seen firsthand how even the most sophisticated users struggle with fractured portals, unclear billing, missing data, and the burden of simply trying to piece together what's going on. Without intervention, the digital divide in healthcare will widen, and tools will remain inaccessible to the people who need them most.

Our response draws from the lived experience of hundreds of families we've spoken to and supported, as well as the friction we've encountered integrating CMS data into caregiver-facing tools. It also reflects a forward-looking belief: that the caregiver deserves not only access, but advocacy and that CMS can lead the way in enabling a new generation of caregiving-ready technology.



Scope of Response:

This response focuses on two core sections of the RFI:

**“Patients & Caregivers” (PC-1 through PC-14) and
“Technology Vendors, Data Providers & Networks” (TD-1 through TD-19).**

We’ve selectively responded to the questions most aligned with our experience as a developer of caregiver-facing health technology built around CMS claims data, Medicare navigation workflows, and real-world usability. These responses draw from direct product development, implementation feedback, and the lived experiences of Medicare families using our platform, and our founder’s ongoing experience as an active caregiver, and builder in this space.

Twilight Technologies offers this response as a constructive contribution to the broader conversation about how we improve digital access, equity, and usability across the Medicare landscape. We recognize and appreciate the important work already being done by many organizations, alliances, and leaders across the ecosystem to advance interoperability, data transparency, and patient-directed access.

Our aim is not to critique any single effort or stakeholder, but to contribute real-world insights from the perspective of a company building tools specifically for family caregivers individuals who often operate outside formal care systems, yet play a pivotal role in care coordination and decision-making.

We hope that the ideas and experiences shared here help complement and enhance the collective progress being made across the health data community. Twilight is committed to working collaboratively to ensure that caregivers are not only acknowledged in policy but supported meaningfully in practice.



Patients & Caregivers:

PC-1. What health-management or care-navigation apps would help you (or loved ones) understand needs and next steps?

- **(a) Top things you'd like digital tools to do.**
- **(b) If a “personal assistant” existed, what tasks would you assign it?**

Today's family caregivers are being asked to perform the role of care coordinator, benefits navigator, medical historian, and advocate often with little more than a spreadsheet and a stack of Explanation of Benefits letters. At Twilight, we've been building the very tools we wished existed when our own families were navigating Medicare: tools that clarify what's happening, what's covered, and what to do next.

(a) Top things digital tools should do:

A modern health-navigation platform for Medicare families must do more than display data it must interpret, simplify, and guide. Based on feedback from our users and personal experience, the most valuable capabilities include:

- **Transforming Medicare claims and EOBs** into human-readable, plain-language summaries.
- **Displaying a timeline of care events**, prescriptions, diagnoses, and procedures giving caregivers a visual sense of what's happened and what's upcoming.
- **Notifying families of gaps or changes** in coverage, medications, or follow-up needs.
- **Centralizing documents, doctor contacts, and health history** in one secure, easy-to-access place.
- **Guiding next steps** such as “Your loved one had a recent hospitalization. Here's what to expect next and how to follow up.”

These are not just features, they are lifelines to overwhelmed families.

(b) If a “personal assistant” existed, what tasks would you assign it?

If caregivers had access to a trusted digital concierge, we would want it to:

- Summarize Medicare benefits and explain recent claims in plain English.



- Schedule and confirm appointments based on known providers or network directories.
- Track medications and prompt refills, reconcile prescription lists, or detect potential duplications.
- Prepare “portable health summaries” for ER visits, new specialists, or second opinions.
- Proactively surface recommendations, such as eligibility for home health services or reminders to follow up on labs or imaging.
- Offer emotional and logistical support especially during care transitions like rehab or hospital discharge.

PC-2. Do you have all your own / loved ones’ information in one place?

- **(a) If yes, what benefits?**
- **(b) If no, in which workflows would a single portal matter most?**
- **(c) Which data types were missing and why?**

Most caregivers do not have access to all of their loved one’s information in one place. In fact, the very idea of a “single source of truth” is a luxury few families enjoy. Health data today is fragmented, claims live in one system, clinical notes in another, and critical personal context (like living situation or family history) often lives offline, in someone’s head.

At Twilight, we built the *Illuminator* to act as a centralized, caregiver-friendly view that integrates Medicare claims, identifies key providers, flags active medications, and constructs a timeline of care. This has shown us what’s possible and how far the current system still is from serving caregivers effectively.

(a) If yes, what benefits?

Through the *Illuminator* and *Twila*, we’ve begun to create that “single pane of glass.” The benefits are immediate and meaningful:

- **Faster decision-making:** Families know who to call, when, and why without digging through paperwork.
- **Better coordination:** Caregivers can speak confidently with doctors and care managers because they’re no longer operating blind.



- **Less emotional overwhelm:** When people can see the full picture of care, it reduces anxiety, confusion, and second-guessing.
- **Improved transitions:** Whether it's a hospital discharge or rehab admission, caregivers have what they need to inform new providers.

(b) If no, in which workflows would a single portal matter most?

For families without centralized access (which is most), the greatest pain points show up in:

- **Care transitions** – when no one has a full summary of medications, diagnoses, or specialists involved.
- **Appointment preparation** – when caregivers must explain a loved one's history to a new doctor but don't have records.
- **Billing disputes** – when EOBs conflict with clinical events, and caregivers are left chasing paper trails.
- **Emergency care** – when seconds matter and a digital "go bag" could save hours of chaos (think Blue Button API data unlock / transform in acute / emergency situations).

(c) Which data types were missing and why?

The most common missing data includes:

- Clinical notes and discharge instructions, which often don't flow to caregivers even with consent.
- Medication histories, particularly after facility-based transitions (e.g., hospital to SNF to home).
- Durable medical equipment and service authorizations, which are buried in claims but not visible to families.
- Functional status, living situation, or social needs vital for care decisions, but almost never documented in systems caregivers can access.

These gaps exist not because the data doesn't exist, but because systems are not designed with caregivers in mind. They're designed for billing, compliance, or intra-clinical handoffs leaving the person doing the actual day-to-day coordination in the dark.

Our vision is to flip that script and give caregivers the visibility and tools they need to act confidently on behalf of the people they love.



PC-4. What features are missing from today's apps?

• (a) Which apps should exist but don't, and why?

• (b) What workflows could CMS uniquely enable?

Most health apps today are either built for the provider workflow or narrowly focused on one task like appointment scheduling or document storage. The family caregiver, meanwhile, is often forced to juggle multiple incomplete tools that don't "speak the same language," don't integrate Medicare data, and don't offer human context.

Twilight Technologies exists to fill that gap. We're building the connective tissue between complex systems and real-world caregiving. And we believe CMS has a unique opportunity to enable an entirely new class of tools that prioritize usability, data interpretation, and support for non-clinical actors like family caregivers.

(a) Which apps should exist but don't, and why?

Here are some critical missing tools we believe should exist and that we're building toward:

- A real-time, caregiver-facing Medicare radar: something that not only shows what services have been used, but flags what's upcoming or overdue, explains why, and suggests action.
- A digital benefits translator: something that takes a claims feed or an EOB and returns a simple explanation like: "Your mom had a CT scan approved, and no action is needed unless she doesn't attend the follow-up."
- A care-plan synthesizer: one that pulls together doctor orders, SNF discharge instructions, and pharmacy updates into a single, caregiver-readable plan of care.
- A secure messaging bridge that allows caregivers to send structured updates or questions to providers especially in fragmented or post-acute environments where portals fall short.

These tools don't exist because the underlying data is hard to access, and current infrastructure doesn't view caregivers as primary users. But they should and could with modest policy support and technical alignment.



(b) What workflows could CMS uniquely enable?

CMS is in a powerful position to open up access, simplify complexity, and create incentives for innovation. A few examples:

- Standardized event notifications to third-party apps when a new claim, hospitalization, or high-risk event occurs. Right now, caregivers must constantly “pull” information; CMS could help shift toward real-time “push.”
- Expanded Blue Button access to include richer detail (e.g., care setting, ordering provider, care plan type) and better metadata to support AI summarization and UX personalization.
- Certification or endorsement of caregiver-focused apps, with emphasis on explainability, accessibility, and emotional load reduction not just data compliance.
- A CMS API bundle for caregiver tooling, combining claims, provider directories, plan benefits, and quality ratings into one simplified developer-friendly stack.

These changes don’t require reinventing the system. They require prioritizing the caregiver as a core user.

PC-5. How can CMS and partners spark patient & caregiver interest?

- **(a) Should CMS review or “badge” apps for efficacy/quality? What criteria?**
- **(b) What changes would enable timely, high-quality CMS and provider data?**

Caregivers don’t just need tools, they need trust. Right now, there is no clear signal from CMS that family caregivers are part of the intended audience for digital health products, much less a trusted guide to help them choose one. If CMS wants to drive meaningful engagement among caregivers and patients, it must meet them at the intersection of clarity, credibility, and control.

(a) Should CMS review or “badge” apps for efficacy/quality?

Yes, but it should do so carefully and thoughtfully, with caregiver-specific criteria. A CMS-endorsed “badge” could carry enormous weight if it means the app:

- Successfully connects to and interprets Medicare data using standard APIs.
- Demonstrates explainability: it can translate complex claims or benefit language into understandable summaries.
- Supports non-clinical users (caregivers, adult children, aides) through voice, UI, and emotional load design.



- Proves usability across tech literacy levels especially among Gen Xers and seniors.
- Maintains clear privacy and consent controls, including proxy or delegated access features.

We strongly encourage CMS to consider creating a certification path or innovation challenge focused on *caregiver-facing products* similar to the app galleries or nutrition labeling used in other sectors.

Ideas beyond badging data access, reimbursement, communications

- Expand Blue Button access to include richer metadata, provider attributes, and service categories, so tools can better personalize content.
- Explore reimbursement for digital navigators or family-engagement tools via Medicare Advantage supplemental benefits.
- Fund public awareness campaigns that show caregivers where to turn just as CMS has done for flu shots and telehealth.
- Introduce caregiver onboarding moments during events like hospital discharge, SNF transfer, or benefit renewal where CMS can point families to trusted digital tools.

(b) What changes would enable timely, high-quality CMS and provider data?

- Push-based claims event feeds (e.g. webhook-style updates) so that caregivers aren't stuck polling APIs weekly to detect new services.
- Metadata standards for claims, especially provider NPI-to-specialty mapping, encounter type, and care setting critical for interpretation.
- Unified API bundles that combine claims, provider directories, plan benefits, and cost data in one stack.
- Stronger participation incentives for providers to keep directory data accurate and EHI exports timely.

Above all, CMS must center the end-to-end user journey of a caregiver, not just the back-end compliance framework. If the agency does that, interest won't need to be sparked, it'll be met with gratitude.



PC-6. Which features make digital products truly accessible especially for tech-limited seniors & caregivers?

Accessibility is not just about screen readers and font sizes, it's about emotional clarity, cognitive load, and meeting people where they are. Many caregivers supporting Medicare beneficiaries are juggling full-time jobs, raising families, and helping parents who may be aging in place, in rehab, or managing multiple chronic conditions. For accessibility to be real, digital tools must offer relief not more work.

At Twilight, we've focused on designing *Twila* and the *Illuminator* to be immediately useful even for those who don't consider themselves tech-savvy. Here's what that looks like in practice:

Key Features that Enable Accessibility:

- Plain-language summaries: Claims, medications, and diagnoses are explained in simple basic terminology.
- One-click timeline view: Users can see a chronological map of care events without opening multiple tabs, remembering dates, or decoding codes.
- Voice-enabled support: Twila speaks aloud and listens using built-in browser tools, offering a conversation-style interface that feels more natural for many seniors or time-strapped caregivers.
- Minimal login friction: Tech-limited users get overwhelmed by identity verification loops. We support low-barrier onboarding, including proxy access and caregiver-as-primary-user modes.
- Mobile-first and print-friendly: Care plans, med summaries, and doctor visit histories are viewable on a phone or printable for use in a folder, ER, or doctor visit.

What CMS Could Do to Advance This:

- Encourage developers to test with real caregivers and seniors, not just clinical proxies or power users.
- Create evaluation rubrics or persona testing frameworks specifically for "Gen X caregivers" and "older adult beneficiaries with mild cognitive challenges" audiences currently underserved by health tech.



PC-8. Which health data are easy to get and which are valuable but hard to reach?

- (a) Hard-to-access examples (claims, clinical notes, prices, etc.)
- (b) Non-claims sources of highest value
- (c) Opportunities & challenges in stitching multi-source clinical data for research

For family caregivers, access to health data is rarely the issue its interpretation and integration. Twilight Technologies works directly with Medicare claims data through Blue Button 2.0, which provides a powerful starting point but only a partial picture.

We've learned that building clarity for caregivers often means navigating a fragmented, delay-prone, and overly technical data landscape. We've also seen how caregivers are forced into detective work, stitching together records from multiple providers, systems, and plan documents just to understand one person's health story.

(a) Hard-to-access examples:

- Clinical notes and discharge summaries: Critical for context but rarely shared or accessible, even with patient consent.
- Prior authorizations or denied services: Buried in plan documentation, not visible through standard CMS data.
- Provider quality data at the point of care decision-making especially for SNFs or home health agencies.
- DME and service utilization: Often delayed or bundled into claims in ways that obscure actual delivery.
- Mental health and behavioral data, which are frequently siloed or require separate access pathways.

Even with the Blue Button API, lag times of 3–4 weeks make real-time care coordination difficult, especially during transitions (e.g., hospital > SNF > home).

(b) Non-claims sources of highest value:

- Post-acute care status updates (ADLs, progress toward discharge goals)
- Medication reconciliation records, especially during care transitions



- Patient-generated inputs like symptom tracking, social supports, or caregiver observations
- Provider directories and open appointment slots, ideally surfaced through FHIR
- Social Determinants of Health (SDOH) markers housing, food security, transportation that are vital for planning care at home

These sources would supercharge caregiver tools like Twila by turning static data into real-time context and smarter next-step guidance.

(c) Opportunities & challenges in stitching multi-source clinical data for research:

There's enormous promise in building multi-source views of care but the challenge is consistency and consent.

- **FHIR APIs are a game-changer** when implemented well, but mapping inconsistencies and authentication complexity remain real barriers for consumer apps.
- **Caregiver consent protocols** are not standardized, making it harder to access a complete record set.
- **Data gaps between payer and provider** (e.g., SNF documentation, community supports, palliative care) can mislead tools that rely solely on claims.
- **Normalizing event types across EHR vendors** is still a heavy lift even when data is accessible.

Twilight has begun to explore lightweight integrations to supplement CMS claims with SDOH intake, facility-level updates, and patient-reported info offering a clearer picture to both families and researchers alike.



PC-9. Blue Button 2.0 adds only basics; what additional CMS data would be most useful?

- (a) Current access difficulties
- (b) Suggestions to improve the API
- (c) Any non-CMS data that should flow through the same pipe

Twilight Technologies is built on top of the Blue Button 2.0 API, and we want to affirm: it's one of the most powerful and promising innovations CMS has introduced in the digital health space.

The ability to pull structured, longitudinal Medicare claims data with user consent has enabled us to deliver timelines, medication lists, provider maps, and condition histories that help caregivers understand and navigate the health journey of their loved ones. The Blue Button API gave us the infrastructure to build *The Illuminator* a tool that turns raw CMS data into something actionable and meaningful.

That said, there are clear opportunities to expand its impact.

(a) Current access difficulties:

- Time lags: Claims data can be delayed by several weeks, which limits its utility for real-time care decisions, especially during discharge or acute transitions.
- Provider metadata gaps: NPIs are included, but specialties, affiliations, and care settings are often missing making it harder to identify the role or context of a provider in the care journey.
- Service-level clarity: Claims include service codes, but without clear descriptions, making it difficult for caregivers to interpret what happened.
- Lack of linkages to plan documents: Understanding *what was done* is less helpful without knowing *whether it was covered* and *what to expect next*.

(b) Suggestions to improve the API:

- Add real-time or near-real-time event triggers (e.g., webhook-style updates) when new claims are posted or major events occur.
- Expand provider metadata to include name, specialty, care setting (e.g., inpatient, SNF, outpatient), and contact info where possible.



- Surface service summaries in plain language or allow apps to associate descriptions using a CMS-sanctioned translation table.
- Incorporate DME, home health services, and authorization data more transparently.
- Allow caregivers with consent to opt-in to additional context, such as SDOH flags or assessments captured during care episodes.
- Create a BB+ sandbox or innovation environment where developers like us can test new layers, formats, or linked resources.

(c) Any non-CMS data that should flow through the same pipe:

To maximize utility, we'd strongly advocate for a "multi-source pipeline" model where caregivers can authorize access to:

- Prescription fill data from PBMs and retail pharmacies (e.g., NCPDP feed)
- Facility-level care updates from SNFs, rehab centers, or home health agencies
- Lab and imaging results, where available through partnerships or standard exchange
- Patient-generated updates (e.g., symptoms, goals, care preferences)
- Plan benefit details and cost-estimator logic for out-of-network care or specialty services

We already have accomplished incredible things with Blue Button 2.0. But with just a few well-placed expansions, CMS can unlock a new generation of tools that understand what's happening, not just record it.



PC-12. What operational data use-cases would best ease navigation or competition?

Example CMS lists: binding cost estimates, schedule viewing, third-party appointment management, public quality metrics, provider-match tools.

- **(b) What's possible today?**
- **(c) Near-future possibilities**
- **(d) Very valuable but hard goals**

Families navigating Medicare today are expected to perform at the level of care coordinators, benefits managers, and scheduling assistants without access to any of the infrastructure that professionals use. This is where CMS can have an outsized impact: by enabling consumer-friendly, third-party tools to act as real-time navigators across the fragmented health system.

At Twilight, we've begun prototyping workflows where our assistant, *Twila*, could coordinate key operational tasks on behalf of caregivers. But to scale these ideas, we need CMS's help both in unlocking data and validating these use cases as legitimate extensions of Medicare navigation.

(b) What's possible today?

- Using Blue Button claims data, we can build a timeline of past appointments, diagnoses, and providers, which helps caregivers piece together what happened.
- With a linked NPI directory and ZIP code, we can surface lists of nearby specialists a loved one has seen or may need to see again.
- Some commercial APIs (e.g., for scheduling or maps) let us preload calls to providers to check availability or plan transportation.
- Within our UI, caregivers can print summaries to bring to appointments, reducing redundant data collection or missed information.

(c) Near-future possibilities

With additional CMS support or clearer APIs, tools like Twila could:

- Initiate appointment requests directly through open scheduling APIs (FHIR Scheduling or third-party integrations).



- Pull real-time provider availability, filtered by specialty, location, and network participation.
- Auto-fill benefit verification tools using plan and procedure codes already linked to Medicare data.
- Track cost estimations, coverage limits, or prior auth needs before a service is scheduled.
- Proactively warn caregivers when a doctor has dropped out of a plan network or a facility's quality rating has declined.

This would shift family caregivers from reactive responders to proactive navigators.

(d) Very valuable but hard goals

- Binding cost estimates for specific procedures, visible before scheduling.
- Automated rescheduling flows in the event of hospitalization, rehab admission, or missed appointments.
- Smart benefit matching that scans a person's current needs (e.g., needing home care after surgery) and identifies unused supplemental benefits.
- Cross-provider care summaries built by AI, with approval from caregivers, and shared ahead of appointments.

PC-14. Digital-identity credentials (CLEAR, Login.gov, ID.me, etc.)

- **(a) Current sign-up challenges**
- **(b) Potential benefits**
- **(c) Downsides**
- **(d) How wider CSP use improves access**
- **(e) Roles for CMS/payers, providers, developers**
- **(f) How CMS can nudge patients to obtain credentials**



Digital identity is one of the most underappreciated but absolutely critical barriers to engagement for family caregivers. At Twilight, we see it constantly: caregivers eager to do the right thing, only to be stopped by a login wall they can't get through not because they're unwilling, but because the system isn't built for proxy access, flexible consent, or real-life context.

(a) Current sign-up challenges

- **Verification loops fail** when the person trying to access the account isn't the beneficiary, but a spouse, adult child, or health advocate.
- **Tech-challenged users** abandon signup due to unclear steps, broken flows, or lack of support.
- **ID proofing services** can reject seniors due to limited credit histories or outdated photo ID formats.
- **Caregivers lack "clean" credentials** of their own; they operate on behalf of others, often informally.

(b) Potential benefits

- Standardized, reusable credentials could allow caregivers to access multiple services on behalf of loved ones without friction.
- Could streamline login across Medicare, health plan portals, and third-party caregiver tools like Twila.
- When paired with proper consent structures, it opens the door for trusted, multi-user collaboration on care.

(c) Downsides

- Without thoughtful consent and role configuration, identity frameworks can exclude caregivers or introduce risk (e.g., locked accounts).
- A one-size-fits-all credential system could further alienate those with low digital literacy or privacy anxiety.



(d) How wider CSP use improves access

- If CMS allows pre-vetted credentials from widely-used CSPs (e.g., Login.gov, MyChart, banking apps), it reduces the barrier to entry.
- Makes integration easier for third-party apps like ours, especially when coupled with OAuth and delegated access standards.

(e) Roles for CMS/payers, providers, developers

- **CMS** can define “care proxy roles” in FHIR access protocols and encourage credential portability across services.
- **Payers** should adopt consistent identity flows and support multi-user authorization.
- **Developers** (like us) can design inclusive workflows where identity + consent are layered and human, not just clinical.

(f) How CMS can nudge patients to obtain credentials

- Include credential sign-up steps **during care moments**: hospital discharges, welcome packets, or EOB explanations.
- Offer a “**Care Team Setup**” moment in Medicare onboarding: “Who else helps manage your care?”
- Provide **low-friction educational moments** via MyMedicare.gov and the Medicare & You handbook.

Twilight’s long-term vision is to help family caregivers log in once, act with permission, and never have to “reprove” their legitimacy at every digital doorstep. CMS can make that possible not by solving everything at once, but by embracing flexibility, context, and empathy in how identity is managed.



Technology Vendors, Data Providers & Networks:

TD-1. What CMS actions (next 2 years vs. long-term) would excite developers to build Medicare-facing products?

Twilight Technologies exists because CMS created one of the most visionary access tools in federal healthcare: **the Blue Button 2.0 API**. But despite its power, there are still significant barriers to building products that truly serve Medicare beneficiaries, especially tools for caregivers who live outside traditional patient-provider structures.

To energize developers in the next two years, CMS could:

- **Expand event-driven access:** Shift from batch-based claims updates to real-time (or near real-time) notifications that allow systems to respond dynamically when something changes in a patient's journey.
- **Open access to richer provider metadata:** Developer adoption slows when we can't tell if a provider is a cardiologist or a podiatrist, or where they practice. Standardized specialty and setting tags would unlock smarter routing and UI decisions.
- **Develop a "CMS DevKit":** A bundled developer experience that includes claims access (Blue Button), provider directories, benefits info, and quality scores in a single, well-documented API hub.
- **Support for delegated access / caregiver proxy identity patterns** out of the box so that developers don't need to invent brittle workarounds just to serve the person who's actually managing care.
- **Provide structured test data and sandboxes** that reflect real-world conditions, especially for transitional care episodes and chronic management scenarios.

Longer-term, CMS could:

- **Champion caregiver-focused use cases** in ONC certification programs or demonstration models.
- **Offer infrastructure grants or accelerators** for non-clinical care platforms, the way ONC has supported EHR usability in the past.



- **Create or endorse trust frameworks** (identity, consent, data provenance) that make it easier to onboard new users with less friction and legal ambiguity.
- **Support “nudgeable” APIs** where developers can both read and push structured information (e.g., caregiver updates, goals, or symptom trackers) with patient consent.

TD-2. Extra CMS data to spur innovation

- **(a) Which additional CMS data via APIs?**
- **(b) Which external sources add most value next to Blue Button?**
- **(c) Obstacles today**
- **(d) Other APIs CMS/ONC should consider**

The Blue Button 2.0 API gave innovators like us the foundation to create products that help families see and understand their Medicare care journey. But if CMS wants to create a thriving ecosystem of personalized, user-centric tools, it must treat claims data as a starting point, not an endpoint.

(a) Which additional CMS data via APIs?

- **Real-time claims status updates:** Current claims take weeks to surface, which undermines any proactive caregiving workflow. We need webhook or push-based models.
- **Prior authorization and service denial records:** These are some of the most confusing and stressful parts of the Medicare experience and they're invisible to families.
- **Provider metadata:** NPIs alone are not useful. Developers need access to specialties, affiliations, care settings, and quality data at the NPI level.
- **Care setting indicators:** Whether a service was delivered inpatient, in a SNF, in home health, or outpatient dramatically changes how it should be interpreted.
- **Coverage details and benefit limits:** Knowing what was done is far less useful than understanding what was *covered*, what was *denied*, and what's *left available*.



(b) Which external sources add most value next to Blue Button?

- **Retail pharmacy fill data:** Claims show what was prescribed but not what was picked up.
- **Hospital discharge summaries or CCDs:** Critical for transitions of care, especially when caregivers are the handoff point.
- **SNF/home health status updates:** Families are often left in the dark during the most fragile parts of the care journey.
- **Patient-generated data:** Daily observations, goals, preferences, and symptoms give needed context for AI-driven care summaries.

(c) Obstacles today

- **Latency:** Even the best CMS data is too delayed for time-sensitive decision-making.
- **Fragmentation:** Claims, clinical, plan, and quality data are all in separate silos with different formats, standards, and APIs.
- **Identity model mismatch:** CMS systems still largely assume the “user” is the patient, not the caregiver. This blocks legitimate access.
- **Limited test environments:** Developers can’t prototype workflows with multiple data sources because test data lacks realism.

(d) Other APIs CMS/ONC should consider

- A **Care Navigation API**, combining claims, coverage, provider metadata, and discharge predictions.
- A **Caregiver Consent & Proxy API**, standardizing how authorized non-beneficiaries access and interact with CMS data.
- A **Service Insights API**, surfacing utilization patterns, service limits, and upcoming eligibility thresholds (e.g., “home health available again after X days”).
- A **Provider Directory 2.0 API**, aligned with FHIR, that includes real-world availability, affiliations, and quality metrics.



TD-3. Digital identity implementation

- **(a) Challenges & benefits**
- **(b) Security & exchange impact of mandatory IAL2/AAL2 credentials**
- **(c) Effect of requiring OpenID Connect**

For caregiving-facing products like Twila and the Illuminator, digital identity is both a gateway and a guardrail. We've found that even the most motivated users, often adult children caring for aging parents, hit roadblocks when trying to connect their loved one's Medicare data due to unclear or overly rigid identity verification requirements.

A more modern, flexible identity layer would reduce onboarding friction, enhance trust, and enable better delegation and consent management across caregiver relationships.

(a) Challenges & benefits

Challenges:

- Strict ID proofing protocols (e.g., ID.me) often fail for older adults without recent credit activity or modern ID formats.
- Caregivers struggle to onboard because most systems assume the end user is the beneficiary.
- Lack of delegation support makes it nearly impossible to design inclusive flows for non-primary users.

Benefits:

- A unified identity framework could enable cross-platform access (CMS, provider portals, 3rd-party tools).
- When paired with consent and role granularity, it could unlock multi-user collaboration in real-world caregiving teams.
- Trust frameworks can enable interoperability without repeated logins, while also supporting security.

(b) Security & exchange impact of mandatory IAL2/AAL2 credentials

While IAL2/AAL2 credentials increase assurance, requiring them universally can backfire especially for underserved populations and older adults. If CMS or ONC mandates these levels without exceptions:



- Caregiver access may be unintentionally blocked, especially in underserved or cross-cultural caregiving contexts.
- Abandonment risk increases, as users fail to complete verification or lack access to needed documents.
- It may drive developers to work around CMS data entirely, reducing the safety and quality of information used in tools.

A tiered or adaptive model where IAL2 is encouraged but IAL1 is permitted for non-clinical access or caregiver modes would better reflect the diversity of use cases while still supporting security best practices.

(c) Effect of requiring OpenID Connect

Requiring OpenID Connect (OIDC) is a strong move and would significantly improve interoperability and developer experience. We support this shift.

- OIDC enables clean, secure, standards-based authentication flows that work across platforms.
- It would make it easier for developers to offer single sign-on or delegated login experiences, streamlining the onboarding of caregivers.
- It aligns with existing identity practices in other industries and would reduce reliance on brittle or custom integrations.

However, success depends on:

- **Broad availability of credential providers** (Login.gov, MyMedicare.gov, ID.me, etc.).
- **Clear patient-delegation frameworks**, so that caregivers can sign in without fraud risk or functional dead ends.

Twilight supports a future where caregivers can use familiar identity credentials paired with appropriate consent to access and manage their loved one's Medicare journey. We encourage CMS and ONC to move decisively in that direction, while maintaining flexibility for real-world contexts.



TD-4. How can CMS push open, standards-based public APIs over proprietary endpoints?

The key to unlocking a vibrant ecosystem of Medicare-facing tools is standardized, open, and predictable access. Proprietary endpoints slow innovation, increase integration cost, and leave caregivers and patients dependent on one-size-fits-some solutions.

At Twilight, we've made it our mission to build FHIR-first, Blue Button-integrated tooling that works with open standards. But it's clear that the private market still defaults to walled gardens especially in provider and MA plan systems unless CMS sets the tone.

CMS can push open APIs by:

1. Leading by example:

- Continue improving and expanding the **Blue Button 2.0 API** as a reference implementation of consumer-friendly FHIR usage.
- Publish an evolving **CMS FHIR Roadmap**, with public milestones for claims, benefits, provider directories, coverage, and more.
- Offer public **sandbox environments** with realistic Medicare test data and full developer documentation.

2. Supporting public utility APIs:

- Back the creation and ongoing maintenance of a federally hosted or trusted FHIR endpoint directory, with real-time availability and standard metadata.
- Subsidize open-source developer tools, SDKs, and compliance libraries to lower the cost of entry for small teams and startups.

3. Enforcing transparency:

- Mandate that any certified system (EHR, HIE, MA plan portal, provider API) publicly disclose endpoint access rules, uptime metrics, and any fees.
- Prohibit "pseudo-open" APIs that require private credentials, expensive licensing, or non-standard formats.



Why it matters:

If CMS doesn't push hard for open standards, the ecosystem will fracture. Major incumbents will build their own "interpretation layers," and consumers including caregivers will end up with tools that are siloed, brittle, and incompatible with one another.

TD-5. Would a nationwide directory of FHIR endpoints help and who should run it? Should it be free?

Yes, a nationwide FHIR endpoint directory would be a game-changer, and yes, it should be free and open to developers.

As a startup building caregiving tools that rely on Medicare claims and clinical context, we regularly encounter fragmentation and discovery issues. There is no reliable, centralized way to query which providers, payers, or systems expose which APIs, where those endpoints live, or how to request access. That lack of transparency slows innovation and creates barriers for new entrants.

Why a national FHIR directory would help:

- **Improves interoperability at the developer layer:** Especially for third-party tools like ours that aren't tied to a specific EHR or payer system.
- **Supports automated care navigation:** We could dynamically surface verified endpoints for data exchange, referrals, scheduling, and patient context handoff.
- **Reduces developer waste:** Right now, countless hours are spent crawling outdated documentation or relying on trial-and-error requests.
- **Lowers onboarding time** for small vendors and public-benefit tech teams.
- **Enables verification and trust:** Knowing an endpoint is authenticated, CMS-approved, and standards-compliant builds trust on both ends.

Who should run it?

Ideally, this directory should be:

- **Publicly governed (CMS or ONC-hosted), or**
- **Run by a federally funded utility** that is neutral, open, and transparent.



Participation should be required for any FHIR-capable organization receiving federal funding (e.g., MA plans, ACOs, certified EHRs), and contributions to the directory should be automated via FHIR CapabilityStatements or similar self-updating metadata.

Should it be free?

Yes absolutely. Access to the directory must be free for developers, patients, and public-interest researchers. Charging for discovery infrastructure creates artificial bottlenecks that disproportionately impact startups, safety-net providers, and patient-facing innovators.

If CMS is serious about building a “Medicare app ecosystem,” then a free, maintained, trusted FHIR directory is basic plumbing to unlock rapid innovation.

TD-7. Has USCDI improved exchange?

- **(a) Still missing data elements?**
- **(b) Gaps due to format vs. usage?**
- **(c) Would adding more elements help or bloat?**
- **(d) Would a less-structured, non-proprietary format be better with modern AI?**

USCDI has improved baseline data alignment, but we’re still a long way from “plug-and-play” usability especially when designing for caregivers instead of clinicians. While we appreciate the intent behind USCDI, its real-world impact on app builders has been inconsistent, largely due to gaps in both format and adoption.

From the perspective of building caregiving-facing products, USCDI sets the floor but not the ceiling for what we need to build understandable, supportive, and timely care tools.

(a) Still missing data elements?

Yes particularly data types that reflect the lived caregiving experience, such as:

- Discharge instructions and care transition notes
- Social context and functional status (e.g., ADLs, IADLs)
- Home health and DME service authorizations
- Patient and caregiver-reported outcomes
- Plan benefit utilization and limits



- Longitudinal medication reconciliation across settings

These elements are essential for continuity of care and for surfacing personalized, AI-driven insights. Yet they're often absent, inconsistent, or locked in PDFs.

(b) Gaps due to format vs. usage?

The bigger issue isn't just what's included in USCDI it's how inconsistently the data is recorded, structured, and made accessible.

- **EHRs record data differently**, even when elements are nominally "USCDI-aligned."
- **APIs return data in deeply nested structures**, which are hard to parse without extensive mapping logic.
- **Lack of labeling or metadata** (e.g., who ordered a medication, care setting context) limits interpretability.
- **FHIR implementation guides vary**, resulting in inconsistent field mapping across endpoints.

(c) Would adding more elements help or bloat?

Both. More elements are needed, but only if:

- They're clearly defined, widely adopted, and enforced consistently.
- Accompanied by example payloads and UX-contextual guidance.
- Mapped to patient/caregiver-centric use cases, not just clinical workflows.

Otherwise, adding fields risks increasing complexity without improving usability. What matters most is semantic consistency and interpretability, not just surface coverage.

(d) Would a less-structured, non-proprietary format be better with modern AI?

In many cases yes. At Twilight, we're actively using LLMs to transform fragmented, semi-structured medical data into clean, digestible summaries for caregivers. This is only possible because:

- We have narrative context in addition to structured fields.
- We train on caregiver-use patterns.



A dual model structured field *plus* access to loosely formatted narrative (with provenance) would accelerate AI adoption and make products like Twila smarter, faster.

TD-8. Which ONC certification criteria & standards work best today?

From the perspective of a startup building consumer- and caregiver-facing tools, the most effective ONC standards are the ones that are both enforceable and interoperable in the wild. We want to build once and trust that what we build will work across systems. Right now, that's only partially true.

Certification criteria and standards that are working well today:

- **FHIR R4:** While not perfect, it has become a shared foundation across EHR vendors, APIs, and innovation programs. When endpoints conform to R4 with consistent profiles, development accelerates dramatically.
- **SMART on FHIR / OAuth 2.0:** This combo offers a predictable, secure login and consent workflow for consumer apps. It enables developers to avoid reinventing the wheel for authentication and aligns with privacy requirements.
- **US Core Profiles** (to the extent they're enforced): They offer a practical floor for expected data types and help reduce mapping variability though enforcement and example coverage still need work.
- **Blue Button 2.0** (claims-centric but ONC aligned): While not a formal ONC certification stream, it reflects ONC's push toward open standards and has been instrumental in enabling innovation like ours.
- **Patient-facing API access:** Requiring this in EHR certification criteria has opened new doors though uptake and consistency still vary.

Where standards succeed:

- They reduce "guesswork" about field names, data types, and authorization methods.
- They let small teams like ours move fast without spending 80% of our time untangling edge cases or reverse-engineering payloads.
- They give caregiver- and patient-focused tools a shot at clean integration and scalable impact.



That said, ONC-certified standards work best when:

- Paired with strong enforcement and test coverage
- Supported with real-world examples
- Aligned with CMS incentives and developer feedback

If ONC wants to encourage scalable innovation, it should keep investing in interoperable, patient-permissioned, and caregiver-aware standards and retire anything that adds administrative burden without enabling real-world usability.

TD-9. Should certification pivot to API-first?

- **(a) Benefits**
- **(b) Drawbacks**
- **(c) How to require APIs for all chart data**
- **(d) Policy moves so providers respond with high-quality data**
- **(e) Could bulk-data EHRs reduce provider quality-reporting burden and how?**

Yes ONC certification should decisively shift toward an API-first model. APIs are the foundation of every consumer-grade experience in banking, travel, logistics, and now healthcare. But the current certification structure still treats APIs as “add-ons” to legacy systems rather than as the primary infrastructure through which data is shared, managed, and acted upon.

For developers like us building tools like Twila and the Illuminator an API-first world means fewer workarounds, more consistency, faster deployment, and a better experience for Medicare families.

(a) Benefits of API-first certification

- **Real-world interoperability:** APIs enable live connections between EHRs, payers, CMS systems, and consumer tools far beyond document exchange.
- **Better user experiences:** Structured APIs support apps that are interactive, real-time, and responsive not just data viewers.
- **Lower integration costs:** API-first standards reduce the time and technical debt needed to build for multiple systems.



- **Improved transparency and auditability:** With standard endpoints and payloads, it's easier to measure completeness, latency, and compliance.
- **Faster innovation cycles:** Teams can prototype, test, and deploy features without waiting for custom integrations or point-to-point agreements.

(b) Drawbacks (and how to mitigate them)

- Small providers may struggle to adopt or maintain APIs especially if not using cloud-native EHRs.
- Security and identity concerns may increase.
- Legacy systems may claim hardship but many already expose data via APIs; the issue is enforcement, not feasibility.

(c) How to require APIs for all chart data

- Expand certification criteria to mandate FHIR endpoints for all USCDI and EHI-export elements, not just a subset.
- Require support for both patient-facing and third-party app connections via OAuth and open registration.
- Mandate structured metadata on FHIR endpoints (e.g., CapabilityStatement requirements) to ensure discoverability.

(e) Could bulk-data EHRs reduce provider quality-reporting burden and how?

Yes if properly supported, Bulk FHIR APIs could transform quality measurement by:

- Auto-generating numerator/denominator cohorts without manual abstraction.
- Enabling batch-level care summaries for payers, registries, or research.
- Allowing third parties to analyze care patterns across populations with minimal provider IT effort.



TD-10. Further steps ONC should take to enforce the Cures Act “API condition of certification.”

Twilight’s development of caregiver-facing tools has revealed a troubling pattern: while many systems claim API conformance under ONC certification, real-world accessibility is inconsistent, brittle, or intentionally restricted. The Cures Act “API condition of certification” was a crucial step forward but its enforcement has yet to match its promise.

If ONC wants this condition to deliver on its potential, it must move from checklist-based certification to real-world performance validation.

We recommend the following steps:

1. Public API availability verification

- Require certified HIT developers to publish and maintain a public, discoverable list of API endpoints, including:
 - Authentication method (e.g., SMART on FHIR)
 - Base URL and FHIR version
 - Supported resources (e.g., Encounter, Medication, Observation)
 - Patient access and third-party app registration process
- Establish a federally maintained endpoint registry, similar to a DNS for certified FHIR APIs.

2. Transparent app registration standards

- Prohibit “arbitrary or unreasonable delays” in app review, registration, or connection for certified systems.
- Define a standard app onboarding SLA (e.g., 5 business days) with required reasons for denial.
- Require support for dynamic registration and open client apps unless a compelling security reason exists.



3. Live ecosystem testing

- Add a certification requirement for demonstrated, live third-party data exchange not just sandbox mockups.
- Allow CMS or ONC to crowdsource test results or monitor real-world API behavior using tools like Inferno, Touchstone, or public API test suites.

4. Escalation pathways for developers

- Establish a clear, well-publicized enforcement pathway for developers who encounter information blocking or API noncompliance.
- Allow devs to submit structured complaints, with supporting logs or screenshots, and receive timely responses.

Right now, too many APIs exist only in theory. They check the box but not the need. Stronger enforcement would protect caregivers, patients, and the developers trying to build for them.

TD-11. EHI-Export has been live a year

- **(a) Should it morph into a standardized API spec?**
- **(b) Workflow improvements?**
- **(c) Should CMS support its use through policy?**

The current EHI Export requirement is an important step toward patient and caregiver access but in practice, it often results in large, unusable dumps of raw data in proprietary formats, PDFs, or XML bundles that require technical expertise to decipher.

From our perspective, EHI Export is conceptually powerful but functionally inadequate for caregivers or consumer-facing apps. If CMS and ONC want to unlock the true potential of EHI, it must evolve from “document drop” to “data stream.”



(a) Should it morph into a standardized API spec?

Absolutely. We recommend that EHI Export evolve into a FHIR-based, bulk-access API that includes:

- All structured data elements defined under USCDI and USCDI+
- Narrative data (e.g., discharge summaries, visit notes) where permissible under HIPAA
- Standardized formats and resource bundles that developers can parse reliably
- OAuth-based delegated access for caregiver and proxy scenarios

This API should allow for both full historical pulls and incremental updates, supporting both research and care coordination use cases.

(b) Workflow improvements?

Yes. The current EHI Export process is often opaque, delayed, or disconnected from actual care workflows. Improvements should include:

- A self-service portal for patients/caregivers to request and download/export data in structured form
- Event-driven exports (e.g., after hospital discharge, new diagnosis) instead of only on-demand pulls
- A notifications API or webhook trigger for developers to know when new EHI is available
- Consent scaffolding to allow patients to delegate access to third-party apps like Twila

(c) Should CMS support its use through policy?

Yes, and urgently. CMS can:

- Require key stakeholders to offer API-based EHI Export as a condition of participation
- Tie EHI Export usability and timeliness to Promoting Interoperability or digital quality incentives
- Include consumer-facing testing in certification (e.g., "Can a caregiver access and understand this export?")



TD-12. Should CMS endorse non-CMS data networks, and under what criteria/metrics?

Yes, CMS should endorse non-CMS data networks, but only under clear, accountable conditions that protect data quality, access rights, and developer usability. For innovators like us building for Medicare beneficiaries and caregivers, the ecosystem is fragmented, inconsistent, and often opaque by design.

If CMS endorses third-party networks without clear criteria, we risk reinforcing closed ecosystems that limit real innovation and reduce trust. But with the right guardrails, CMS endorsements could steer the market toward trusted, usable, and FHIR-aligned infrastructure.

Criteria CMS should require before endorsing a non-CMS network:

1. FHIR-first architecture

- The network must expose structured data using current FHIR standards (e.g., R4) and support patient/caregiver-facing APIs.

2. Transparent onboarding and documentation

- Public developer docs, open API access policies, and minimal friction to registration for patient-permissioned apps.

3. Patient and caregiver access

- Explicit support for third-party apps acting on behalf of patients or authorized caregivers, with clear consent flows.

4. Data completeness and fidelity

- Proven ability to return core clinical data sets (USCDI and beyond) with low error rates and acceptable latency.

5. Equitable pricing and access

- No predatory pricing for API access; must be accessible to startups, safety-net providers, and non-commercial actors.



6. **Quality and uptime metrics**

- Required reporting on endpoint availability, response times, and success rates for data queries.

7. **Governance accountability**

- Public-facing governance structure that includes consumer voices, not just payers and vendors.

How CMS can enforce this:

- Publish a CMS-Endorsed Network Registry, updated quarterly and open to public review.
- Tie endorsement to participation in value-based care programs, MA Star Ratings, or public health partnerships.
- Require regular recertification and developer satisfaction surveys for continued endorsement.

Why this matters:

Without CMS intervention, third-party data networks will drift toward vendor lock-in, inconsistent practices, and anti-competitive behaviors. But with transparent endorsement, CMS can guide the ecosystem toward trust, usability, and equitable access especially for caregiver-focused applications like ours.

TD-13. What new opportunities (and obstacles) emerge from APIs exposing full EHI?

• (a) Primary obstacles

• (b) Trade-offs between USCDI scope and full EHI

The opportunity to access full EHI via APIs is transformational but only if the data can be trusted, interpreted, and acted upon.

As developers building tools for family caregivers, we're excited about full EHI access because it moves us beyond summary snapshots and into the context-rich detail that real care coordination requires. But we also see that volume without structure can be paralyzing especially for non-clinical users.



(a) Primary obstacles

1. Format chaos

- Full EHI exports often include documents in dozens of formats PDFs, scanned notes, HL7 v2, CDA bundles, and semi-structured text.
- Without standardization or consistent FHIR translation, this overwhelms both developers and end-users.

2. Noise vs. signal

- Caregivers don't want everything they want the right things: medication changes, diagnoses, next steps, post-discharge instructions. Exposing full EHI without filtering mechanisms creates cognitive overload.

3. Latency and access fragmentation

- Full EHI often arrives via export requests or delayed batch jobs, making real-time workflows infeasible.
- Some EHRs still have siloed sensitive records (e.g., mental health, substance use) even when technically "included."

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4. Consent and privacy ambiguity

- Patients and caregivers often don't know what they're authorizing when they opt in to "full EHI."
- Without granular scopes or explanation layers, trust can erode especially in vulnerable communities.

(b) Trade-offs between USCDI scope and full EHI

- USCDI = cleaner, safer, but limited. It's easier to parse and structure, but often lacks the nuance needed for care transitions or risk assessment.
- Full EHI = richer, but chaotic. It may include critical insights (e.g., prior surgery notes, discharge summaries, functional assessments) but the signal is buried in unstructured formats.



Twilight's approach is to blend both:

- We use structured USCDI+ data as the base for care timelines, condition tracking, and medication lists.
- We layer in AI summarization to extract meaning from full claim and EHI narratives without showing the user every raw record.
- We prioritize readability, emotional clarity, and actionability over completeness.

To unlock full EHI without drowning the user:

- CMS should require FHIR-native exports wherever possible.
- Developers should have access to resource metadata (e.g., timestamps, author, care setting) for filtering.
- ONC should promote narrative-to-summary transformation tools, possibly open source or certified, to aid patient-facing design.

TD-14. Networks & FHIR APIs

- **(a) How many endpoints does your network hit, and how are they identified?**
- **(b) Connection methods (g(10) endpoints, TEFCA XCA, proprietary)**
- **(c) Do you interconnect with other networks and under what framework?**

As a developer of consumer-facing tools especially for family caregivers our architecture doesn't look like a typical HIE or payer platform. Instead, we connect to dozens of data endpoints dynamically based on patient context, CMS authorization, and care patterns.

The challenge is not the volume of endpoints it's finding, connecting to, and trusting them.

(a) How many endpoints does your network hit, and how are they identified?

- Our primary interactions are with CMS (Blue Button 2.0) and FHIR-based provider/payer APIs exposed by EHRs or MA plans.
- We plan to activate 10–30 endpoints per active user over the life of their engagement, depending on user requirements, available endpoints, and opportunities to enhance the user experience.



If CMS offered a reliable, queryable endpoint registry, our integration costs would drop dramatically.

(b) Connection methods

- We primarily use OAuth2 + SMART on FHIR, where supported.
- Blue Button 2.0 remains the most developer-friendly model with clear docs, predictable flows, and real FHIR support.

The result is a fragmented experience for caregivers trying to connect the dots.

(c) Do you interconnect with other networks and under what framework?

At this stage, our integrations are direct-to-source.

We're eager to participate in a future where caregiver-focused apps can plug in to a trusted data backbone but only if:

- Standards are aligned (FHIR R4+)
- Identity and delegation are supported
- Connection is as easy as OAuth, not a six-month legal process



TD-15. Bulk-FHIR APIs benefits and disadvantages.

Bulk FHIR APIs offer significant promise particularly for tools like Twila and the Illuminator that aim to build longitudinal, whole-person timelines from fragmented claims and clinical records. But like many powerful features, they come with infrastructure, usability, and standards trade-offs that CMS should help resolve.

Benefits:

1. Full health record views

- Bulk FHIR enables rapid export of all known health data for a Medicare beneficiary or group, which is essential for:
 - Onboarding a new user with a full care timeline
 - Supporting longitudinal condition management (e.g., diabetes, dementia)
 - Building retrospective analysis to inform proactive care suggestions

2. Research and policy modeling

- Enables structured cohort analysis without requiring manual abstraction or expensive, high-touch integrations.

3. Reduces load from repeated API calls

- Bulk access dramatically lowers the number of requests needed when compared to querying each resource individually this is vital for caregiver tools where response time and completeness both matter.

4. Supports pre-processing and AI enrichment

- We can preprocess full datasets and build caregiver-facing summaries or alerts using LLMs, which is much harder with piecemeal data.

Disadvantages and trade-offs:

1. Latency and batching complexity

- Many Bulk FHIR endpoints return asynchronous job queues, requiring polling and complex job management logic unfriendly for smaller dev teams or real-time



tools.

2. File formats and post-processing burden

- Output is often raw NDJSON files that require extra tooling to parse, store, and manage. Many teams aren't equipped for this.

3. No partial delivery support

- If the request fails or times out mid-export, you often have to restart from scratch.

4. Access control and authorization are still vague

- There's little clarity on how proxy users (like caregivers) can initiate a bulk export legally and securely.

Recommendation:

CMS and ONC should:

- Develop Bulk FHIR developer toolkits, including sample scripts, validation suites, and UI patterns.
- Encourage support for batching by context (e.g., "all records for a care transition" vs. full historical download).
- Clarify proxy access and caregiver consent workflows for apps that serve non-clinician users.
- Align Bulk FHIR specs with EHI Export evolution to avoid dual-maintenance burdens.



TD-16. Trade-offs between point-to-point vs. shared-network models

- **(a) Do current rules encourage scale?**
- **(b) What changes would improve alignment?**

As a developer of family caregiver tools, we've learned that point-to-point models limit our ability to scale efficiently but shared-network models are often not accessible to us at all. The result is a fragmented ecosystem where innovation requires both deep integration overhead and policy workarounds just to get basic data flowing.

We believe CMS and ONC should encourage shared-network participation, but only if those networks are:

- Standards-aligned (FHIR-native)
- Patient/caregiver-inclusive
- Transparent and developer-friendly

(a) Do current rules encourage scale?

Not effectively. Today's rules allow for interoperability, but don't reward it or enforce equal access across network types.

- Point-to-point models (e.g., OAuth with individual EHRs) are technically possible, but require:
 - Repeated credentialing
 - Varying endpoint quality
 - Custom integration logic per partner
- Shared networks are structurally scalable but they're still inaccessible to most third-party or consumer-facing apps due to:
 - Opaque legal processes
 - Lack of caregiver support
 - No developer onboarding model



So we're stuck in a gray zone where nothing scales easily neither connection volume nor user access.

(b) What changes would improve alignment?

To move the ecosystem forward, CMS and ONC should:

1. Treat data networks like infrastructure

- Require federally endorsed networks to support consumer apps, not just provider nodes.

2. Create a “developer lane” for network participation

- Publish a standard onboarding workflow for FHIR-based tools to connect via network and stakeholder participants.

3. Incentivize scale via simplicity

- Offer bonus points in programs like MA Star Ratings or ACO REACH for participants that expose standardized FHIR APIs via a shared network or directory.

4. Add transparency mandates

- Require public disclosure of network participation, API availability, latency, and third-party access policies so developers can make informed decisions.

5. Fund public-good intermediaries

- Create or support shared data networks designed for patient and caregiver tools, not just institutional actors.

For small teams trying to help real people navigate Medicare, scale without access is meaningless. CMS has the chance to support both if it backs the right networks and ensures they remain open in spirit, not just on paper.



TD-17. Given operational costs, what role should CMS/ONC play in keeping data-sharing networks viable?

If CMS and ONC want a vibrant, equitable data-sharing ecosystem, they can't just mandate access; they must also invest in the infrastructure that supports it.

Right now, the cost burden of interoperability often falls on the shoulders of developers, caregivers, and small innovators who lack the resources to manage shifting standards, inconsistent access, and institutional gatekeeping.

Twilight Technologies would gladly connect to more networks, support more use cases, and empower more families if the cost of doing so didn't scale linearly with each new integration.

CMS and ONC should play the following roles:

1. Fund public-good infrastructure

- Support the ongoing development and maintenance of national FHIR endpoint directories, patient access APIs, and shared metadata registries.
- Back shared sandbox environments and open-source tools (e.g., validation libraries, test suites, reference implementations) that reduce overhead for startups and safety-net providers.

2. Incentivize real participation not just availability

- Offer grants, demo funding, or quality credit for networks and vendors that:
 - Support live connections with consumer/caregiver-facing apps
 - Provide transparent pricing (or zero-cost) access for public benefit tools
 - Meet usability and latency benchmarks for third-party API access

3. Stabilize the policy environment

- Ensure that once a network builds toward CMS-certified standards, those standards don't shift every 18 months.



- Maintain version support windows that let small teams plan updates without falling out of compliance overnight.

4. Publish a public “network health scorecard”

- Track and publish metrics like:
 - Time to onboard a third-party app
 - API uptime and error rates
 - Real-world caregiver/patient satisfaction
- Use this to reward networks that go beyond compliance and support real usability.

If data-sharing networks are public goods, they should be supported like public infrastructure. The future of care navigation depends on it especially for families trying to advocate inside a system that wasn’t designed for them.

TD-18. Information blocking

- **(a) Real examples vendors face (non-response, unusable responses)**
- **(b) Extra policies to discourage blocking**
- **(c) Actor categories lacking disincentives**

As a developer working to empower family caregivers, we regularly encounter information blocking behaviors often subtle, sometimes blatant, but always harmful to patient-centered innovation. These are not technical limitations.

(a) Real examples vendors face:

- **App registration “dead ends”**
Some EHR vendors require third-party apps to register via obscure portals with no published documentation, no contact information, and no SLA for review or approval.
- **Static or outdated endpoint metadata**
CapabilityStatements often list endpoints that are deprecated, unresponsive, or return incomplete FHIR resources even when they claim ONC certification.



- **“You’re not a provider” gatekeeping**
Several networks and platforms reject legitimate app requests simply because the app represents a patient or caregiver, not a licensed clinical entity.
- **Legal onboarding bottlenecks**
Some networks require non-negotiable BAA or developer agreements just to retrieve a patient’s own data delaying launches by weeks or months.

These practices undermine trust in the ecosystem and drive developers away from CMS-aligned data infrastructure.

(b) Extra policies to discourage blocking:

- **Require transparent, public app onboarding standards**
All certified APIs should offer developer registration within a reasonable SLA (e.g., 5 days).
- **Define and publish patient/caregiver inclusion requirements**
ONC should enforce that patient- and caregiver-facing tools are entitled to equal access under API certification conditions.
- **Introduce graduated penalties**
Start with public warnings, escalate to funding risk, and eventually decertify vendors that engage in systemic obstruction.

(c) Actor categories lacking disincentives:

- **Payers** (especially MA plans)
Many still maintain walled-garden portals or inconsistent “APIs” that fall far short of ONC standards.
- **Health information networks (HINs)**
Some charge excessive fees for access or require cumbersome onboarding processes that exclude small developers.
- **EHR vendors in post-acute and specialty settings**
These systems often fall through regulatory gaps despite playing a critical role in longitudinal care.



TD-19. Price-transparency implementation

- **(a) Current shortcomings in content, format, timeliness**
- **(b) Workflows that would benefit most**
- **(c) Most valuable improvements for patients, providers, payers**
- **(d) What would further motivate solution development?**

True price transparency is still largely theoretical for the families we serve. While CMS has mandated public machine-readable files and some shoppable service tools, the reality is that most caregivers have no clear idea what a given test, procedure, or rehab stay will cost until after the bill arrives.

For caregivers already juggling clinical, emotional, and logistical burdens, this lack of cost clarity adds avoidable financial stress and delays decision-making.

(a) Current shortcomings:

- Machine-readable files are inaccessible to humans or simple apps.
Most hospitals and MA plans publish chargemasters or negotiated rate tables in formats that require data science skills to interpret.
- Tools are not personalized.
The few tools that exist don't reflect a person's specific plan, deductible status, or service history.
- Timing mismatch.
By the time cost estimates are visible, the service has often already occurred (especially in emergencies or acute transitions).
- No real linkage to care navigation.
There's no integration between what something will cost and what CMS data shows has already occurred, is pending, or is recommended.

(b) Workflows that would benefit most:

- **Care transitions** (e.g., hospital > SNF, SNF > home care) where families must choose between options quickly and cost is a major factor.
- **Chronic condition management** (e.g., diabetes, COPD, dementia) where decisions around testing frequency, specialists, or therapies impact long-term affordability.



- **Rehab and DME planning**, where device costs and rental timelines are often opaque and not surfaced until billing.
- **Pre-surgical planning** and imaging referrals are frequent sources of surprise bills.

(c) Most valuable improvements:

- **Plan-specific estimators** embedded in apps like Twila, powered by CMS plan metadata and historical cost patterns.
- **Real-time estimate APIs** that allow apps to ping expected cost for a procedure, given plan + provider + care setting.
- **“Cost radar” integrations** that alert families when they’re approaching coverage limits or likely to incur non-covered charges.
- **Structured explanation of benefits APIs**, translating claims into understandable summaries with cost breakdowns and “what to expect next.”

(d) What would further motivate solution development:

- **Public test environments** with realistic pricing data formats.
- **CMS-backed pricing APIs**, with minimum support for common CPT/HCPCS services, plan codes, and geographic cost variation.
- **Certification or incentives** for tools that demonstrate cost literacy improvement and reduce downstream billing disputes.
- **Clarity on enforcement** of price transparency regulations so developers know where the gaps are and what’s safe to build against.



Illuminator Product Videos:

Below are representative links to our product, the Illuminator.

Illuminator Overview Video:

<https://www.loom.com/share/b01aecae44b84937b9e0d57caf0d9407>

Illuminator Recent Updates:

<https://www.loom.com/share/e6c69e1bd0e1461baff7ff552489692e>

CareGraph - A Visualized History of Healthcare Events:

<https://www.loom.com/share/14e55ce49b6041169a0272e94f22604e>

Accessing Providers, Specialists, Labs & Facilities:

<https://www.loom.com/share/fb43675e8f764c95a527b816eadfa93e>

Easy Access to Medications & Rx History:

<https://www.loom.com/share/5b91a76f4d134862a00b76e49c060cbb>