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HealthTree Foundation Response to CMS-0042-NC: Request for Information on the Health  
Technology Ecosystem  
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## Executive Summary

HealthTree Foundation is pleased to submit this response to CMS Request for Information CMS-0042-NC. HealthTree Foundation is a 501(c)(3) non-profit organization founded in 2012, dedicated to empowering patients with complex diseases by helping them own their health data, contribute to research, and participate meaningfully in their care.

Despite decades of regulatory progress—including the 2009 HITECH Act, the 2016 21st Century Cures Act, and the 2020 ONC Cures Act Final Rule—patient health data remains locked in fragmented silos across disparate systems and care settings. A maze of regulations (including HIPAA), misaligned incentives, limited data access, and the lack of patient involvement continue to stall progress toward lower costs and improved outcomes. In many ways, the U.S. healthcare system still behaves as if the internet doesn't exist.

According to the AHRQ Medical Expenditure Panel Survey and analysis by the Kaiser Family Foundation, the sickest 5% of U.S. patients account for over 50% of total healthcare expenditures. Yet we still lack a complete picture of these patients' health. Less than 30% of any individual's health data resides within a single EHR system. More than 50% of relevant data—including patient-reported outcomes, side effects, genomics, wearables, mental health, dental, physical therapy, and social determinants of health—is either scattered or uncaptured altogether.

This fragmentation stifles care coordination, hinders innovation, and inflates costs. EHR systems, designed primarily for billing—not healing—were never intended to serve as comprehensive health platforms. Without integrating patient-contributed data and inviting patients to be active participants in their care, we cannot close the loop on outcomes, nor hold patients accountable for managing aspects of their own health.

**The elephant in the room is that we've spent decades designing systems *around* the patient instead of *with* the patient. Patient data and patient involvement are the missing pieces of the healthcare puzzle, opening our eyes to new possibilities.**

This is not a theoretical assertion. As a nonprofit organization, HealthTree Foundation has spent the past decade directly engaging Medicare and Medicaid cancer patients—enabling them to own their health data, including EHR records, genomics, patient-reported outcomes, and real-world side effect information. Through this model, HealthTree empowers patients and fosters meaningful accountability in their care.

We don't propose that HealthTree is the solution, but rather HealthTree Foundation offers a validated, scalable model for patient-centered healthcare innovation model that directly addresses the data fragmentation, lack of accountability, and rising costs that hinder meaningful reform. This feat has been completed in partnership with thousands of cancer patients. Patients use the HealthTree platform to find their "cancer twins," explore optimal treatments, find clinical trials through AI matching and participate in research—demonstrating that when patients are engaged and their data is integrated, outcomes improve, costs decline, and innovation accelerates. A HealthTree-like model, combined with compassionate human support, ensures accessibility even for underserved or technologically inexperienced communities.

In this RFI response, we propose creating a solution that fills critical data gaps—including patient-reported outcomes and real-world side effects—while establishing a trusted framework for patient engagement, accountability, and longitudinal data sharing across the care continuum.

We propose that CMS leverages HealthTree's learning to launch a model that supports public-private partnerships to scale a national learning health system—one that bridges data and engagement gaps, supports closed-loop AI models, and fosters accountability across the care continuum. This type of approach will naturally resolve the issues facing today's value-based care approaches. Patients are not just partners in this model; they are the key to transforming the system from the inside out.

**Sources:**

<sup>1</sup> Office of the National Coordinator for Health IT (ONC), "Individuals' Access and Use of Patient Portals and Smartphone Health Apps, 2022"

<sup>2</sup> NEHI (Network for Excellence in Health Innovation), "Bend the Curve: A Health Care Leader's Guide to High Value Health Care," 2021

<https://www.kff.org/health-policy/101-health-care-costs-and-affordability/?entry=table-of-contents-how-has-u-s-health-care-spending-changed-over-time>

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## HealthTree Foundation Capabilities – A Patient-Centered Data Ecosystem for the Future of Healthcare

HealthTree Foundation's platform is a patient-led data infrastructure designed to overcome the entrenched fragmentation, inaccessibility, and underutilization of health data—particularly for complex diseases like cancer. Founded by cancer patient Jenny Ahlstrom and her husband, HealthTree reimagines the role of the patient from passive recipient to **data steward, research contributor, and care navigator**, unlocking the power of real-world data at scale.

While most health IT efforts begin with the provider or payer, **HealthTree begins with the patient**—the only entity with the legal and logistical ability to assemble a complete longitudinal health record. HealthTree empowers individuals to securely gather, understand, and share their health data across systems, enabling better care for themselves and others.

HealthTree Core Capabilities include:

- **Comprehensive Patient-Controlled Data Aggregation:** Automated EHR connections to over 1,000 US hospital systems (4,600+ hospitals) including structured and unstructured data, creating a complete, longitudinal, patient-owned medical record. Includes patient ability to add journaling and side effects/quality of life data.
- **AI and ML application:** Use of AI and ML to clean and validate the data, turning unstructured data into structured data. Use of AI to provide patient services including personalized treatment options, eligible clinical trials and connections to de-identified patient “twins.”
- **Integrated Real-World Evidence Research Platform:** Seamless interface for patients to opt-in to research questionnaires or biomarker collection with vetted researcher access to de-identified, permissioned datasets.
- **Interoperability and Open Standards Alignment:** Healthtree is a FHIR-native, API-first platform that integrates with TEFCA-participating systems and supports the USCDI standard. Allows third-party researchers and developers to build on top of the HealthTree dataset (with appropriate patient consent). Supplements CMS Blue Button 2.0 claims data with enriched, patient-verified medical histories.
- **Community, Coaching and Digital Literacy Support:** HealthTree is a community platform that enables patient connections in moderated forums, offers personalized coaching to facilitate understanding of medical records or prepare for visits and digital tool support. HealthTree is designed for older populations with human-assisted onboarding and provides a unique paper-record ingestion pipeline where patients authorize release of records via a simple paper consent form. With older adults in mind, HealthTree provides phone-based coaching to assist in onboarding as well as multi-media videos and language support for Spanish. This multi-pathway model removes the binary choice between “tech-savvy” and “left out.”

- **A Trusted Resource:** Patients join HealthTree because they understand that their data is protected and specifically used to 1) optimize their own care and 2) identify cures for themselves and others.

HealthTree is glad to engage in a public/private partnership and contribute the knowledge gained by its HealthTree solution to become to support a scalable **national digital health ecosystem**, supporting CMS's vision of seamless, secure, patient-directed data exchange.

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## HealthTree's Key Areas of Contribution to CMS Objectives

Based on the RFI issued by CMS and ASTP/ONC, the **HealthTree Foundation and its HealthTree platform** are uniquely positioned to respond to many key questions across the **Patients and Caregivers, Providers, Technology Vendors**, and **Value-Based Care** sections.

Below is a categorized list of the **most relevant questions** HealthTree can directly and meaningfully address:

### Patients and Caregivers (PC)

These questions relate to how patients access and use digital health tools—HealthTree's core competency.

#### PC-1.

What health management or care navigation apps would help you understand and manage your health needs?

- Imagine a health dashboard built on a patient-centered platform, one that helps individuals understand and manage their health through comprehensive data tracking and personalized care planning. Just as we can push a button in our cars to receive a real-time diagnostic report, patients should have access to that same level of insight for their own health.

For example, a cancer patient dashboard could allow users to explore personalized treatment options, discover relevant clinical trials, and use a "cancer twin" matching tool to connect with others who share similar diagnoses and treatment histories. This level of visibility and support empowers patients to make informed decisions, stay actively engaged in their care, and more confidently navigate complex conditions.

#### PC-2.

*Do you have easy access to your health information in one location?*

- *On behalf of cancer patients*, HealthTree integrates with over 1,000 medical systems (4,600+ hospitals), simplifying the data aggregation process. This unified view empowers individuals to better understand their condition, share accurate information with care teams, and actively participate in treatment decisions—eliminating the fragmentation that often hinders coordinated care.

**PC-3.**

*Are you aware of apps useful to Medicare beneficiaries and their caregivers?*

- Yes, HealthTree is a proven digital health platform already used by thousands of older adults with cancer, including Medicare and Medicaid beneficiaries. It helps patients and caregivers manage complex care by providing access to aggregated health records, personalized treatment options, clinical trial matching, and tools for tracking symptoms, side effects, and treatment progress. Its user-friendly design and support services make it particularly valuable for older adults and their caregivers navigating serious illnesses.

**PC-4.**

*What features are missing in apps today?*

- Many health apps today fail to manage complex conditions effectively because they lack access to complete, longitudinal patient data. Despite billions invested by tech giants like Microsoft and IBM, their health platforms struggled—not due to lack of capital or technology, but because they failed to earn patient trust and could not consistently access or integrate patient-level data. The core challenge isn't technical—it's a trust problem.

Without meaningful patient involvement and access to comprehensive health information, most apps are limited in functionality. They often lack structured treatment histories, insight into lines of therapy, integration of genomic and patient-reported outcomes, and tools for real-time decision support. The HealthTree pilot addresses these gaps by providing cleaned and structured whole-patient records, personalized treatment planning, clinical trial discovery, and community-based learning through “cancer twin” connections. These features have been helpful for empowering patients and caregivers navigating serious or chronic illnesses—yet remain absent from most digital health apps today.

**PC-5.**

*What can CMS do to encourage digital health product adoption?*

- CMS can encourage digital health adoption by supporting models that build patient trust, data transparency, and meaningful value exchange. HealthTree's patient-led approach shows that when individuals control their data, understand how it will be used, and see personal benefits from their participation, adoption increases significantly. Patients must trust that their data will not be misused or used to deny care, and they must retain ownership over how it is accessed and shared. CMS can further drive adoption by

promoting privacy-preserving, patient-centered platforms; incentivizing providers who integrate certified digital tools; and ensuring that these technologies deliver both clinical and personal value to patients and caregivers.

**PC-6.**

What features make apps accessible to Medicare beneficiaries?

- Apps that are accessible to Medicare beneficiaries must prioritize **simplicity, human support, and personalization**. HealthTree achieves this through a human-centered approach that includes guided onboarding, live coaching, and a simplified user interface specifically designed for older adults and individuals with limited technological experience. By combining intuitive design with personalized assistance, HealthTree helps Medicare beneficiaries navigate complex health information, engage with their care, and use digital tools with confidence—ensuring that no one is left behind in the transition to digital health.

**PC-7.**

*How should CMS collect real-world data on digital health product impact?*

- CMS should support the collection of real-world evidence (RWE) by partnering with platforms that enable **longitudinal tracking of patient outcomes, treatment effectiveness, and user engagement**. The HealthTree pilot collects this type of data by integrating EHRs, genomics, and patient-reported outcomes with real-world usage patterns—capturing insights on how digital tools impact care decisions, symptom management, and overall health outcomes over time. CMS can build on this model by promoting standardized RWE reporting frameworks, incentivizing platforms that support continuous outcome measurement, and ensuring patient-contributed data is included as a valid source of clinical and quality evidence.

**PC-8.**

*What data is valuable but hard to access?*

- Some of the most valuable data in healthcare—such as patient-reported outcomes (PROs), real-world outcomes, genomic data, and lines of therapy—is also the hardest to access. Much of this information resides in the patient’s memory, is scattered across multiple systems, or buried in unstructured clinical notes. Traditional EHRs rarely capture this data in a usable format, and inconsistent data standards further contribute to fragmentation, inaccuracy, and underutilization. The HealthTree pilot has addressed these challenges by inviting patients to contribute critical data not found in standard EHRs and by using a panel of doctors plus AI-assisted tools to clean, structure, and validate information from diverse sources—including imaging, clinical notes, and cross-provider EHRs. Bridging these data gaps, creates a more complete and actionable patient record that supports better care decisions and outcomes.

**PC-9.**

*What additional CMS data sources would be useful via API?*

- Patients, doctors and researchers would benefit from Part C claims, social determinants of health data, better FHIR data standards adherence across hospitals and imaging via Blue Button 2.0 expansion.

**PC-10 & PC-11.**

*What is the role of TEFCA and HIEs in access?*

- Health Information Exchanges (HIEs) play a valuable role in facilitating provider-to-provider data sharing at the regional level. However, they are built on a provider-centric model, remain fragmented, and lack seamless national-scale interoperability. While TEFCA aims to address these limitations by creating a standardized framework for data exchange, both systems still miss a significant portion of the patient story—particularly the 50% of health data that lives outside traditional EHRs, such as patient-reported outcomes, genomics, and real-world side effect data.

HealthTree's approach complements both TEFCA and HIEs by serving as a patient-mediated data hub. It aggregates records directly from multiple EHR systems, enriches them with patient-contributed data, and enables longitudinal, federated research across institutions. This model ensures more complete data access and puts patients at the center of data sharing, engagement, and accountability.

**PC-12.**

*What are valuable operational use cases?*

- HealthTree enables several high-value operational use cases that directly align with CMS priorities. By aggregating clinical, genomic, and patient-contributed data into a longitudinal record, HealthTree supports closed-loop care coordination across fragmented systems, enhances AI-driven clinical decision support, and powers real-world evidence generation through federated research models. The platform fills critical gaps in TEFCA and HIE coverage by capturing the 50% of patient data typically missing from EHRs—such as patient-reported outcomes, side effects, and wearable data. It also fosters patient engagement and accountability, especially among Medicare and Medicaid populations, while providing tools for identifying care inefficiencies, improving resource allocation, and supporting value-based payment innovation. Having sufficient, accurate data allows optimal treatment paths to be identified at an individual level, reframing the idea from value based care to optimized care for each patient.

## Providers (PR)

These questions address how providers use or contribute to digital health tools. HealthTree facilitates provider access to comprehensive records.

**PR-1.**

*How can CMS encourage providers to use approved digital health products?*

- To encourage provider adoption of approved digital health products, CMS should align incentives with tools that enhance clinical decision-making and support better patient outcomes. A patient-centered data approach—integrating EHRs, genomics, and patient-reported outcomes—can enable a continuous learning feedback loop that increases provider trust and usage. CMS can accelerate adoption by funding demonstration projects that highlight real-world impact and clinical value. The most effective tools will offer actionable insights through closed-loop feedback, support clinical workflows, improve outcomes, and reduce costs—all while empowering both patients and providers in a value-based care environment.

**PR-4.**

*What standards or policies could improve admin workflows like intake or appointment setting?*

- CMS can improve administrative workflows by supporting a standardized, digital intake form that is automatically prefilled using a patient's longitudinal health history—including EHRs, and patient-reported outcomes, dramatically increasing accuracy while reducing redundant questions and provider review time. (Let's face it, this is something that every single patient wants)

In second opinion or high-complexity cases, this approach can save hours of prep and enable faster, life-saving decisions. CMS can encourage adoption by promoting enhanced FHIR-based intake standards, incentivizing providers who use pre-visit digital data collection, and certifying tools that integrate seamlessly with EHR systems and patient-facing platforms.

**PR-7 & PR-8.**

*How can CMS reduce provider burden for interoperability and quality measurement?*

- The provider-centered interoperability model isn't working. The providers have no incentives and many disincentives to share data. In many cases, providers have financial or competitive disincentives to share patient data. Interoperability efforts lack teeth without meaningful enforcement or accountability mechanisms. Fragmented EHR systems include only a fraction of a patient's complete health data.

A better solution would be to put the power in the hands of the patients who are motivated to connect and share their data. A patient-centered model addresses key gaps by aggregating data across systems, aligning and empowering patients to contribute and share so they can receive benefits from their data. Additional policy levers such as promoting an improved FHIR-based standards, incentivizing the use of certified patient-facing tools, and allowing shared accountability models where patients actively contribute to quality data capture could change the game.



More detailed patient-reported outcomes will assist in providing detailed quality feedback to key stakeholders.

#### Technology Vendors and Data Providers (TD)

These questions examine APIs, standards, and data integration. HealthTree is built around open APIs, FHIR standards, and patient-permissioned data flow.

##### **TD-1.**

*How can CMS stimulate developer interest in digital health products?*

- CMS should support pilot programs and reimbursement pathways for products that demonstrate value in patient engagement, outcomes improvement, and care coordination. CMS could also stimulate developer interest by creating a clearer path to real-world adoption, reimbursement, and data integration for digital health products. Today, many developers face uncertainty around regulatory alignment, lack of access to standardized patient data, and unclear incentives for providers to adopt their tools. Perhaps by endorsing and certifying open APIs (similar to open banking), improved FHIR-based standards, and patient-mediated data exchange models, CMS can lower technical barriers and unlock innovation.

##### **TD-2.**

*What data is most valuable via CMS APIs?*

- Some of this information is available with the EHR data. Having said that, valuable data available through CMS APIs includes claims and encounter data, which offer a comprehensive view of services, costs, and care patterns; Part D prescription history for medication reconciliation and decision support; provider attribution data for care coordination; social determinants of health (SDOH) indicators for equity and risk analysis; and enrollment and eligibility information to assess coverage and costs. To maximize impact, this data should be timely, FHIR-standardized, and accessible through patient-mediated platforms. HealthTree builds on this foundation by integrating CMS data with patient-reported outcomes and genomics to deliver more complete, actionable insights for personalized care and quality improvement.

##### **TD-4.**

*How can CMS promote open APIs over proprietary ones?*

- One way CMS can accelerate the adoption of open APIs is by reducing the regulatory fear and legal uncertainty that often discourage providers and developers from engaging with interoperable, patient-facing tools. While HIPAA protections remain critical, the threat of steep fines for unintentional violations—particularly in patient-directed data sharing—has a chilling effect on innovation. CMS and OCR could issue safe harbor provisions or clarifying guidance that protect providers and developers when using certified open APIs that empower patients to access and share their health data.

- While FHIR APIs are currently versioned, it isn't uniformly applied by vendors. CMS could require semantic versioning of all certified FHIR APIs and promote conformance testing and certification tied to specific FHIR versions and create centralized version documentation requirements for certified API vendors.

#### **TD-7 & TD-10.**

*How could USCDI be improved? How should API certification evolve?*

- The current U.S. Core Data for Interoperability (USCDI) is a foundational step toward standardizing health data exchange, but to fully support patient-centered innovation and value-based care, it must evolve to include richer, real-world, and patient-generated data. This should encompass patient-reported outcomes (PROs), side effect tracking, genomic and molecular test results, lines of therapy and treatment response, social determinants of health (SDOH), wearable and device data, and mental and behavioral health indicators. These data elements are essential for enabling closed-loop care, personalized medicine, and the development of research-driven learning health systems.
- API certification should evolve to ensure not only conformance to technical standards but also usability, version control, and patient access functionality for example, CMS could tie certification to real-world use metrics, such as successful patient data sharing or improved quality measurement.

#### **TD-13.**

*What could be achieved with full access to EHI?*

- With increased provider and patient participation, full access to Electronic Health Information (EHI) would enable an integrated, longitudinal view of patient health that could transform modern medicine. Platforms like HealthTree have already piloted this model, demonstrating how comprehensive access to data empowers providers to deliver fully informed second opinions, offer precision treatment recommendations, and match patients to clinical trials in real time.

Patients would be able to manage their care across providers, contribute valuable data to research, and receive tailored insights to guide their treatment decisions and daily behavior. With this rich, multi-dimensional dataset, AI systems could evolve from today's open-loop predictions to closed-loop learning models, significantly improving clinical accuracy, safety, and personalization. Quality measurement would become real-time and automatic, while accountability tools could be integrated into patient-facing systems to support engagement and better health outcomes.

Ultimately, full access to EHI would shift the healthcare system from reactive and fragmented to proactive, integrated, and accountable—laying the foundation for a true learning health system that delivers better outcomes for all stakeholders at a lower cost.

## Value-Based Care Organizations (VB)

These questions focus on how digital tools can support APMs and population health. HealthTree's work in real-world evidence and outcome tracking directly apply to this section.

### **VB-1.**

*What incentives would help ACOs use digital tools more effectively?*

- To help ACOs use digital tools more effectively, CMS should align incentives around data completeness, patient engagement, and real-time quality improvement. Key strategies include offering shared savings bonuses tied to patient-generated data (e.g., PROs, side effects, SDOH), reimbursing for digital care coordination activities, and rewarding ACOs that use tools to capture quality metrics beyond claims data. CMS can also support adoption through integration subsidies and clear regulatory guidance. Platforms like HealthTree show that when patients contribute structured data, providers can deliver more personalized, proactive care—reducing costs and improving outcomes.

### **VB-2 & VB-3.**

*How can AI, care coordination, and quality metrics be better integrated?*

- *Sorry to be a broken record here, but this is important.* AI, care coordination, and quality metrics can be more effectively integrated through patient-centered platforms that unify data, support real-time insights, and streamline clinical workflows. In fact, without patient involvement results and outcomes are very difficult to measure. HealthTree Foundation has demonstrated this model by combining AI-powered dashboards, risk stratification tools, and shared decision-making interfaces using data from EHRs, genomics, and patient-reported outcomes. This approach enables care teams to deliver proactive, personalized care while automatically capturing quality metrics based on actual outcomes. CMS can support this integration by incentivizing the use of tools that connect AI insights with care coordination and real-time quality tracking—advancing value-based care and reducing provider burden.

### **VB-4.**

*What data types are essential for success in VBC?*

- *This is one area where patient involvement and feedback can really move the bar.* HealthTree delivers structured data from EHRs, genomics, and PROs—exactly what VBC programs need to drive personalized interventions. Success in value-based care (VBC) depends on access to complete, longitudinal, and patient-centered data. Without sufficient data, VBC risks delaying or denying appropriate care. With it, providers can identify the best treatment for each individual patient, improve outcomes, and reduce unnecessary costs—advancing the core goals of value-based care.

## Summary

HealthTree Foundation respectfully submits this overview to demonstrate how a patient-led approach can address critical systemic barriers in alignment with CMS's priorities for interoperability, patient empowerment, equity, and value-based care. By enabling individuals to aggregate and control their complete longitudinal health data, HealthTree offers a practical, scalable pilot model that can be implemented with minimal regulatory change.

Over the past 13 years, HealthTree has worked directly with thousands of cancer patients and partnered with over 200 leading U.S. research hospitals to enable seamless data exchange, real-world evidence generation, and personalized treatment planning. Our platform reduces provider burden, accelerates clinical trial access, promotes health equity among Medicare beneficiaries, and fosters trust through transparent, consent-based data sharing. As a nonprofit founded by patients, for patients, HealthTree stands ready to serve as a national model for a patient-centered, interoperable, and outcomes-driven digital health ecosystem in collaboration with CMS and ONC.