



June 16, 2025

**To:** Centers for Medicare & Medicaid Services  
Department of Health and Human Services  
Attention: CMS-0042-NC  
P.O. Box 8013  
Baltimore, MD 21244-8013

**From:**

National Alliance for Caregiving  
1730 Rhode Island Avenue NW, Suite 812  
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Coalition to Transform Advanced Care (C-TAC)  
601 Massachusetts Ave., NW Suite 520  
Washington, DC 20001

**RE:** CMS-0042-NC: Request for Information on Digital Health Products for Medicare Beneficiaries

**Introduction**

On behalf of the National Alliance for Caregiving (NAC) and Coalition to Transform Advanced Care (C-TAC), we appreciate the opportunity to respond to the CMS Request for Information regarding digital health products for Medicare beneficiaries as well as data interoperability and health technology infrastructure.

NAC is a national system change organization focused on building health, wealth, and access for family caregivers through research, cross-sector partnerships, and advocacy. We envision a society that values, supports, and empowers our nation's 53 million family caregivers to thrive at home, work, and life. Family caregivers form the backbone of our healthcare system and economy yet often go unrecognized.

C-TAC is a national non-partisan, not-for-profit coalition dedicated to ensuring that all those living with serious illness receive comprehensive, high-quality, person- and family-centered care, consistent with their goals and values. C-TAC is made up of over 200 national and regional organizations who share a common vision of improving care for patients and caregivers impacted by serious illness in the U.S., from the point of diagnosis through to the end of life.

NAC and C-TAC believe that our recommendations can be incorporated into a range of current and future demonstrations, both those with broad population focus and those that may be tailored to patients and caregivers living with serious illness.

This response draws from NAC’s comprehensive research, including *Caregiving in the U.S. 2020*, which surveyed 1,392 family caregivers and provides the most current understanding of caregiver experiences, needs, and technology usage patterns. This data reveals critical insights about the digital health ecosystem from the perspective of family caregivers—a population that is integral to Medicare beneficiary care but often overlooked in digital health policy development.

We would welcome the opportunity to facilitate collaboration between CMMI and leading private sector organizations developing innovative digital health solutions for family caregivers. Through our extensive network of technology companies, healthcare innovators, and research institutions, NAC and C-TAC can help convene stakeholders to provide ongoing insights that inform CMMI's policy development and implementation strategies in this critical area.

## **Patients and Caregivers: Digital Health Needs and Opportunities**

### **PC-1. Essential Health Management and Care Navigation Applications**

Our 2020 research reveals that family caregivers need digital health products that address care coordination challenges, which have grown significantly worse in recent years. Thirty-one percent of caregivers now report difficulty coordinating care among healthcare providers, representing a substantial increase from twenty-three percent in 2015.<sup>1</sup> This growing complexity demands sophisticated digital platforms that can seamlessly integrate communication between providers, caregivers, and patients while reducing the administrative burden that currently fragments care delivery.

Technology is of particular importance to those living with serious illness and their family caregivers, who typically receive uncoordinated care across multiple providers and specialties. These families need comprehensive information systems to manage the complexity of serious illness and make appropriate medical decisions with their family's knowledge and participation as needed. The fragmented nature of care for serious illness makes digital coordination tools essential for ensuring continuity and preventing medical errors during critical care transitions.

The most transformative digital health applications would support the complex medical tasks that fifty-eight percent of caregivers now perform, including injections, tube feedings, and catheter care.<sup>2</sup> Despite providing these critical nursing-level services, fewer than three in ten caregivers have had meaningful conversations with healthcare professionals about their caregiving duties, and only seven percent report receiving any formal training.

Digital training modules incorporating virtual reality platforms, step-by-step video guidance, and real-time clinical support could dramatically improve both caregiver competence and patient safety outcomes.

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<sup>1</sup> National Alliance for Caregiving and AARP. (2020). *Caregiving in the U.S. 2020*. Washington, DC.

<sup>2</sup> *Ibid*

Financial management represents another critical digital health opportunity, as fifty-eight percent of caregivers help manage their recipient's finances, with thirty percent finding this task highly time-consuming. Secure digital tools that integrate bill management, insurance navigation, and expense tracking could significantly reduce caregiver burden while improving financial outcomes for Medicare beneficiaries.<sup>3</sup> These platforms should incorporate predictive analytics to anticipate coverage decisions and streamline prior authorization processes.

If caregivers had access to a comprehensive digital personal assistant, they would prioritize automated medication management with real-time adherence monitoring and drug interaction alerts, integrated appointment coordination across multiple providers with transportation arrangement, real-time insurance coverage verification, emergency response coordination with immediate care team access, and respite care scheduling services that thirty-eight percent of caregivers indicate would be helpful to their situations.

## **PC-2. Comprehensive Health Information Access**

Current access to unified health information remains fragmented and inadequate for caregivers managing complex care situations. While sixty percent of caregivers go online for caregiving-related tasks, they must navigate separate portals for each provider, creating significant administrative burden and increasing the likelihood of care coordination errors. Only fifty-three percent of caregivers use any technology or software to help with caregiving, suggesting that existing solutions fail to meet their practical needs or are too complex to implement effectively.

CMMI could play a crucial role in facilitating a comprehensive view into all health information, including integrated behavioral health and physical health data. Often behavioral health data is not viewable due to actual or perceived consenting and legal barriers. State models in Delaware and Maryland have demonstrated successful approaches to streamlining consent processes so that providers and caregivers can have a comprehensive view of a person's holistic health needs, breaking down silos between physical and mental health care.<sup>4</sup>

Additionally, comprehensive health information access should include the ability to access advance directives with interoperability between health systems and online repositories like [My Directives](#). This ensures that people's wishes are readily available, especially to family caregivers who serve as designated health care agents or surrogates during critical decision-making moments.

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<sup>3</sup> Ibid

<sup>4</sup> Dougherty, M., McGavin, R., Barnes, K., Lewis, R., Athimuthu, P., Adegun, A., & Mallonee, E. (2024). How health information exchanges support integration for behavioral health settings. Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services.

Unified health information access would provide the greatest value during care transitions when recipients move between home, hospital, and long-term care settings. Currently, sixty-five percent of caregivers communicate with healthcare professionals about their recipient's care, but this communication occurs across disconnected systems that don't share critical information.<sup>5</sup> During emergency situations, immediate access to complete medical history, medications, and care preferences could prevent medical errors and inappropriate treatments while reducing caregiver stress and improving outcomes.

The most significant barriers to comprehensive health information access include persistent interoperability gaps caused by lack of common standards, digital literacy challenges particularly among older caregivers and those with limited technology experience, and complex privacy and security concerns that require clear, ongoing consent processes especially for recipients with cognitive decline. Additionally, twelve percent of caregivers live in rural areas where limited broadband infrastructure creates fundamental access barriers that technology solutions alone cannot address.

### **PC-3. Current Technology Usage and Awareness Gaps**

Our research reveals substantial gaps between caregiver needs and current digital health product awareness. While thirty-five percent of caregivers use technology for tracking recipient finances and thirty percent manage health records digitally, only thirteen percent use apps, video, or wearable devices for recipient monitoring despite the clear potential benefits. Even fewer caregivers—just eleven percent—create electronic calendars for caregiving activities, suggesting that existing care coordination tools fail to meet their practical workflow needs.<sup>6</sup>

### **PC-4. Critical Missing Applications and Development Barriers**

One of the most significant gaps in current digital health offerings is the absence of culturally responsive training platforms that address the unique needs of diverse caregiver populations. Hispanic, African American, and Asian American caregivers provide more intensive care and face greater barriers to accessing support services, yet existing digital health products rarely incorporate cultural considerations or language preferences into their design. Integrated care navigation applications that seamlessly connect health management, social services, and financial assistance programs remain largely nonexistent despite clear caregiver need.

Caregiver-specific telehealth platforms designed for training and support rather than patient care represent another critical missing category. Current telehealth solutions focus primarily on provider-patient interactions and fail to address the educational and support needs of family caregivers who are performing increasingly complex medical tasks. Predictive analytics tools that anticipate care needs based on condition progression could dramatically improve care planning and reduce emergency situations, but these applications remain underdeveloped in the caregiver context.

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<sup>5</sup> Ibid

<sup>6</sup> National Alliance for Caregiving and AARP. (2020). Caregiving in the U.S. 2020. Washington, DC.

These applications don't exist primarily due to the lack of caregiver-centric design in health IT development, regulatory uncertainty around caregiver roles in digital health ecosystems, limited reimbursement mechanisms for caregiver-focused services, and insufficient research on caregiver technology adoption patterns and preferences.<sup>7</sup>

### **PC-5. CMS Role in Encouraging Adoption and Quality Assurance**

CMS should implement a comprehensive framework for reviewing and potentially endorsing digital health products that demonstrate effectiveness for caregivers and care recipients. This framework should consider not simply caregiver-oriented technology in isolation, but also technologies used by those receiving care and how these technologies interrelate to create a comprehensive care ecosystem. The existing [Personal Health Technology Institute \(PHTI\) framework](#) provides a valuable foundation that could be adopted or amended for this purpose, offering proven methodologies for assessing digital health technologies.

This framework should include basic safety and privacy review ensuring HIPAA compliance and robust security standards, caregiver-specific efficacy evaluation measuring impact on caregiver stress and burden alongside care recipient outcomes, and assessment evaluating accessibility for individuals dually eligible for Medicare and Medicaid who often face the most complex care coordination challenges.

Quality criteria should emphasize demonstrated reduction in caregiver burden or stress, improved care recipient health outcomes, enhanced care coordination efficiency, and proven accessibility across diverse populations with varying levels of technology experience. Additional criteria should assess the interoperability of caregiver tools with existing patient technologies and electronic health records to prevent the creation of isolated digital silos. This review process should be transparent and provide clear pathways for developers to understand requirements and receive feedback on their products.

To enable timely access to high-quality data, CMS should expand Patient Access API requirements to include caregiver-designated access with appropriate consent mechanisms, develop standardized caregiver data elements and FHIR profiles for caregiver information and care plans, and streamline prior authorization processes for caregiver-administered medical equipment and supplies. These policy changes would create the data infrastructure necessary for effective caregiver-focused digital health solutions while ensuring integration with broader health IT ecosystems.

### **PC-6. Accessibility and Usability Requirements**

Digital health products serving Medicare beneficiaries and their caregivers must incorporate universal design principles including large fonts, high contrast displays, and voice navigation options to accommodate varying levels of visual and motor ability.

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<sup>7</sup> Lindeman, D.A., Kim, K.K., Gladstone, C., & Apesoa-Varano, E.C. (2020). Technology and Caregiving: Emerging Interventions and Directions for Research. *The Gerontologist*, 60(S1), S41-S49.

Authentication processes should balance security requirements with usability concerns, reducing complex password requirements while maintaining appropriate protection of sensitive health information.

Offline functionality represents a critical requirement for rural caregivers with limited connectivity, ensuring that essential features remain available during network outages or in areas with poor internet service. Twenty-four-hour technical support with human assistance for technology troubleshooting acknowledges that many caregivers lack the technical expertise to resolve complex digital issues independently, particularly during high-stress caregiving situations.

### **PC-7. Real-World Data Collection and Evaluation**

CMS should establish comprehensive real-world data collection methods that integrate digital health tool usage data with existing Medicare claims information to identify correlations between technology adoption and healthcare utilization patterns. This approach would provide objective evidence of clinical and economic impact while protecting beneficiary privacy and supporting continuous improvement in digital health offerings.

Standardized caregiver-reported outcome measures should be developed and implemented to track changes in caregiver burden, stress levels, and quality of life associated with digital health tool usage. These instruments should be validated across diverse caregiver populations and incorporate both quantitative metrics and qualitative assessment of user experience and satisfaction.

Provider-reported implementation metrics should track adoption rates, usage patterns, and clinical integration challenges to identify barriers to successful deployment and inform technical assistance efforts. This data should be supplemented with mixed-methods evaluation combining quantitative usage analytics with qualitative interviews and focus groups to understand the full impact of digital health interventions on caregiver and care recipient experiences.

### **Conclusion**

The intersection of family caregiving and digital health represents a critical opportunity to improve care quality, reduce costs, and enhance the sustainability of our healthcare system. With fifty-three million family caregivers providing an estimated six hundred billion dollars worth of unpaid care annually, investments in caregiver-focused digital health infrastructure will yield significant returns for Medicare beneficiaries, their families, and the healthcare system overall.

CMS has the opportunity to lead by example in recognizing and supporting the digital health needs of family caregivers. By implementing comprehensive policies that address technology access barriers, promote interoperability and standards development, and incentivize provider adoption of caregiver-inclusive solutions, CMS can create a more effective and equitable digital health ecosystem that truly serves the needs of Medicare beneficiaries and their essential care partners.

The growing complexity of caregiving situations, evidenced by increasing care coordination difficulties and the high prevalence of medical task performance among family caregivers, demands immediate attention to digital health solutions that can support both caregivers and care recipients. Without proactive policy intervention to address access concerns and implementation barriers, digital health advances risk exacerbating existing disparities rather than improving outcomes for all Medicare beneficiaries.

We appreciate CMS's leadership in advancing digital health innovation and look forward to continuing collaboration to ensure family caregivers are valued and supported in their vital role. If you have any questions about this submission, please contact Elaine Dalpiaz, Vice President for Government Affairs and Policy, National Alliance for Caregiving.

**Sincerely,**

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National Alliance for Caregiving

Jon Broyles  
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Coalition to Transform Advanced Care (C-TAC)