

## SPECIAL ARTICLE OPEN ACCESS

# Improving Care for Those Living With Serious Illnesses and Individuals Approaching End of Life: A Decade of Investments

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## ABSTRACT

**Background:** The mission of The John A. Hartford Foundation (JAHF) is to improve the care of older adults. Since 1982, JAHF has invested more than \$724 million to advance the aging and health fields. The focus of this article is JAHF's serious illness and end-of-life priority area. This article seeks to understand the impact of JAHF's investment in this priority area and how JAHF's grantmaking strategy contributed to this impact.

**Methods:** NORC at the University of Chicago (NORC) conducted this assessment from August 2024–January 2025. It was conducted using a three-phase, mixed-methods approach. The assessment included a thorough document review of all grant documentation, the development of an impact framework to summarize outcomes and key program metrics, and surveys and interviews with partners.

**Results:** This assessment identified five outcomes, each supported by key program metrics; outcomes include 1) increasing access to services through sharing best practices; 2) providing professional training to the health care workforce; 3) influencing public discourse through community engagement and messaging; 4) informing public policy through research, recommendations, and technical assistance; and 5) increasing collaboration and partnerships through network building.

**Conclusions:** This assessment highlights JAHF's role of catalyst, collaborator, and convener. JAHF's approach to grantmaking—including mission alignment, commitment, flexibility, active engagement, and focus on collaboration—contributed to the impact achieved by grantees.

## 1 | Introduction

The mission of The John A. Hartford Foundation (JAHF) is to improve the care of older adults. Since 1982, JAHF has invested more than \$724 million to advance the aging and health fields. Based on population projections, the number of older adults (65+) is expected to increase nearly 70% from 2020 to 2060, from 56 million to almost 95 million [1]. These demographic shifts have, and will continue to have, an impact on the health care system as care needs typically increase with age. As the

U.S. population ages with more chronic conditions and medical and functional complexity, there is increased urgency to expand access to high-quality, person-centered care that supports older adults' health and well-being.

JAHF currently has three priority areas: creating Age-Friendly Health Systems, supporting family caregivers, and improving serious illness and end-of-life care. It also funds additional initiatives in line with its overarching mission. The serious illness and end-of-life priority area is the focus of this

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## Summary

- Key points
  - Beginning in 2016, The John A. Hartford Foundation dispersed over \$19 million to improve the care for those living with serious illnesses and individuals approaching end of life.
  - The grants in this priority area led to five primary outcomes: (1) increasing access to services through sharing best practices; (2) providing professional training to the health care workforce; (3) influencing public discourse through community engagement and messaging; (4) informing public policy through research, recommendations, and technical assistance; and (5) increasing collaboration and partnerships through network building.
- Why does this paper matter?
  - This article seeks to understand the impact of The John A. Hartford Foundation's investment in the field of serious illness and end-of-life care and how the foundation's grantmaking strategy enabled this impact.

summary report and assessment. JAHF's grantmaking in this priority area seeks to increase access to high-quality palliative care and other evidence-based models and practices, to educate and prepare the health care workforce, to foster collaboration and community-based solutions, and to inform public policy solutions that are supportive of the needs of patients, families, and caregivers. JAHF began strategically investing in this field following a 2015 Institute of Medicine report titled *Dying in America* [ii], which identified issues and challenges related to the care delivered to individuals living with serious illnesses. JAHF formalized this priority area in 2016 and has since invested more than \$19 million through 21 grants to nine distinct organizations, plus numerous subcontract organizations.

This article seeks to understand the impact of JAHF's investment in improving care for those living with serious illnesses and individuals approaching end of life, and how JAHF's grantmaking strategy contributed to this impact. NORC at the University of Chicago (NORC), an objective research organization with subject matter expertise in aging and health and methodological expertise in policy and program evaluation, conducted a thorough assessment of grantees and their work between August 2024 and January 2025. Through information collection and synthesis, NORC identified five high-level outcomes that support overarching goals: 1) increasing access to services through sharing best practices; 2) providing professional training to the health care workforce; 3) influencing public discourse through community engagement and messaging; 4) informing public policy through research, recommendations, and technical assistance; and 5) increasing collaboration and partnerships through network building. In addition to the five outcomes, this report highlights how JAHF's grantmaking strategy and approach helped maximize the impact of grantees' work. JAHF funded an array of programs and initiatives tackling a complex issue from different perspectives while maintaining focus on the core mission. In addition, JAHF awarded multiyear investments with flexible

funding, supporting grantees in their systems change work. Over nearly a decade, JAHF has played an active role as convener and leader in the field, shaping and developing a robust network of organizations, clinicians, practitioners, and leaders.

## 2 | Methods

NORC conducted the assessment employing a three-phase, mixed-methods approach:

1. **Discovery:** NORC conducted a thorough review of all grant proposals, progress reports, staff member evaluations, and consultant assessments. This review of all 21 grants provided insights into each grant's scope, objectives, and outcomes, which informed the development of the impact framework and surveys and interviews with partners.
2. **Impact Framework:** NORC developed a framework by identifying shared outcomes and key program metrics from existing grant reports. The impact framework generated summary statistics to demonstrate the collective reach and impact of the grants and highlights strategies used by grantees to drive systemic change. The impact framework is summarized in Figure 1 with five outcomes and program metrics to support each outcome. While not an exhaustive record of every grant output, the framework captures key data points that provide a comprehensive overview of achievements within the priority area.
3. **Partner Engagement:** NORC supplemented the quantitative analysis with a targeted partner engagement process. This qualitative approach captured nuanced perspectives and individual experiences that quantitative data alone could not convey. All grantees and partners were invited to participate, with 11 organizations completing the survey and nine individuals participating in six interviews, including grantees, subgrantees, co-funders, and JAHF staff. Overall, 15 grantees and partner organizations contributed insights through either surveys or interviews.

## 3 | Results

This assessment identified five shared outcomes across this portfolio of grants, as summarized in Figure 1 and discussed in detail in the following sections. Table 1 summarizes the achievements of grantees across the five outcomes and associated metrics. Universally, the programs and activities funded were person-centered—incorporating input from patients, families, and caregivers—ensuring that care aligns with individual needs and empowering individuals with the education and tools necessary for informed decision-making. Furthermore, by employing tailored community engagement strategies, JAHF has supported and encouraged programs and policies that benefit underserved groups and promote equitable access to care.

### 3.1 | Increasing Access to Services

Grantees in this priority area enhanced access to care by developing and sharing best practices, providing technical assistance,

## The John A. Hartford Foundation's serious illness and end of life priority area led to five outcomes that shaped the field



**FIGURE 1** | Grants made through The John A. Hartford Foundation's serious illness and end of life priority area support the overarching goal of improving care for those living with serious illnesses and approaching end of life. This assessment identified five outcomes, each with program metrics that demonstrate the collective reach and impact of the grants in this priority area.

creating educational resources, and promoting innovative care models to a range of audiences including clinicians, health systems, community-based organizations, policymakers, payers, and patients. The Center to Advance Palliative Care (CAPC), a grantee, reported that 83% of hospitals with 50+ beds had palliative care programs in 2020, up from 69.6% in 2012 [iii]. While this assessment did not collect direct patient impact data, grantees reported that sharing best practices, tools, and knowledge has contributed to palliative care services growth, summarized in Table 1.

Over 2000 practitioners received direct technical assistance on serious illness and end-of-life care during the grant period. Support included expert-led virtual office hours, best practices for telehealth in palliative care, and step-by-step guidance for launching palliative care programs in home, clinic, and long-term care settings.

From 2016 to 2024, grantees developed 150+ resources—toolkits, messaging guidelines, best practices, resource hubs, websites, checklists, educational modules, and decision-making tools—tailored for health systems, clinicians, families, caregivers, and policymakers. These resources were viewed or downloaded over 346,000 times. Incorporating patient and caregiver

input ensured alignment with care needs and empowered informed decision-making about end-of-life treatment options.

Through the JAHF Tipping Point Challenge with CAPC and the University of Washington's work with a collaborative of innovative organizations, more than 220 replicable and effective care models were gathered and disseminated to clinicians, health system leaders, and other practitioners during the grant periods. These initiatives shared best-in-class approaches to providing end-of-life services, spurred ongoing innovation in the field, and encouraged others to adopt scalable models.

A key grant-supported effort, the Roundtable on Quality Care for People with Serious Illness, facilitated by the National Academies of Sciences, Engineering, and Medicine, convened 40+ organizations—providers, policymakers, payers, and advocates—to develop best practices and policy recommendations. The roundtable hosted 20+ public workshops and webinars, producing findings that were downloaded over 24,000 times. Its work influenced national and state palliative care policies and fostered cross-sector collaboration.

FAIR Health, another grantee, developed tools using health care claims data to provide personalized cost-of-care

**TABLE 1** | Summary of Impacts: Outcomes, Metrics, and Achievements.

Outcome	Metric	Achievement
Access	Practitioners receiving technical assistance	2013
Access	Best practice resources developed	156
Access	Views or downloads of best practice resources	346,614
Access	Replicable, effective care models gathered and disseminated	222
Workforce	Clinicians engaged in training opportunities	88,122
Workforce	Courses completed	726,356
Workforce	Workshops provided	97
Workforce	Practitioners that attended workshops	11,742
Public Discourse	Individuals engaged through outreach activities	370,059
Public Discourse	Educational resources created	1955
Public Discourse	Webinars delivered	103
Public Discourse	Webinar attendance	10,620
Public Discourse	Presentations at conferences, summits, and meetings	200
Public Discourse	Radio and podcast interviews	920
Public Discourse	Blog posts published	88
Public Discourse	Contributions to articles	154
Public Discourse	News mentions	407
Public Discourse	Published articles in academic and professional journals	33
Public Discourse	Videos produced	49
Public Discourse	Feature-length documentary produced	1
Public Discourse	Audience of feature-length documentary	1,350,000
Policy	Policy-related documents	49

(Continues)

**TABLE 1** | (Continued)

Outcome	Metric	Achievement
Policy	Instances of policy-related technical assistance	28
Policy	Policy workshops	4
Policy	State policy team attendance at workshops	24
Policy	States with policy advancements	14
Collaboration	Organizations engaged in partnerships	215
Collaboration	Unique organizations engaged in grant-funded work	193
Collaboration	Network building activities	63

Source: NORC assessment of JAHF program documentation including grant reports, staff evaluations, and consultant assessments during active grant periods from 2016–2024.

information. By increasing pricing transparency, these tools support informed decision-making and equitable care access. FAIR Health is piloting the tools with four health systems in the Age-Friendly Health Systems (AFHS) initiative. AFHS is an initiative of JAHF and the Institute for Healthcare Improvement, in partnership with the American Hospital Association and the Catholic Health Association of the United States, that aims to improve health care for older adults by following evidence-based care practices that focus on what matters to patients [iv]. This connection between serious illness and end-of-life care and AFHS is an example of how JAHF funds initiatives that span multiple priority areas, strengthening collaboration and furthering the overarching mission of improving care for older adults.

### 3.2 | Providing Professional Training

Work in this priority area has enhanced health care professionals' ability to provide comprehensive care for patients with serious illnesses. Multiple grantees trained clinicians and practitioners, equipping them with tools and resources to provide person-centered care, summarized in Table 1.

CAPC trained approximately 80,000 clinicians during the grant period, with nearly 725,000 courses completed. Course topics included pain and symptom management, communication skills, and caregiver support. CAPC also introduced an Age-Friendly Healthcare Learning Pathway, covering patient goals, medication management, cognitive issues, and mobility optimization within the AFHS framework and aligning with other JAHF initiatives. CAPC also connected health care professionals and



community-based organizations to enhance workforce capabilities and provide compassionate, patient-centered care.

Beyond CAPC, grantees trained over 88,000 clinicians in risk reduction, home-based palliative care, age-friendly health care, and patient communication. These courses incorporated input from patients, families, and caregivers to ensure relevance and empower clinicians to support well-informed end-of-life treatment decisions.

JAHF grants also supported nearly 100 workshops, training more than 11,000 practitioners, including clinicians, medical and nursing professionals, and policymakers. Workshops addressed value-based payment opportunities, advance care planning, primary care delivery, family caregiving, and managing end-of-life care during COVID-19. Many focused on underserved populations, promoting equitable care access and culturally sensitive communication.

Ariadne Labs, a subgrantee of the University of Washington, contributed to training efforts through its Serious Illness Care Program. Ariadne Labs directly trained over 500 clinicians across 20+ health systems in the Serious Illness Conversation Guide and indirectly trained more than 13,800 clinicians by disseminating training materials used in train-the-trainer methods. These efforts equipped clinicians with effective communication tools to engage patients in meaningful discussions about their goals, values, and care preferences.

### 3.3 | Shaping Public Discourse

JAHF grants raised awareness of serious illness and end-of-life services by engaging the public and sharing resources like articles, white papers, blogs, and videos. The magnitude of impact achieved in shaping public discourse is summarized in Table 1.

These initiatives reached at least 370,000 people, including clinicians, health system leaders, patients, and families. Outreach activities included focus groups, interviews, and community events that provided vital information and resources on end-of-life care. JAHF grants also supported the creation of over 1900 resources and disseminated information through webinars, conferences, blogs, interviews, articles, and videos.

These grants have helped shape public discourse around serious illness and end-of-life care through initiatives like the University of Washington's Message Lab and The Conversation Project. Message Lab has been instrumental in uniting health care professionals, organizations, and funders to foster collaboration in addressing system-wide communication challenges. This initiative developed the Serious Illness Messaging Toolkit, which aims to improve communication and make information more understandable and accessible to the public. The collaborative group conducted over 50 webinars and delivered more than 110 presentations, widely sharing the messaging principles. With 13 published articles and a social media campaign that achieved more than 2 million impressions, Message Lab

disseminated evidence-based communication strategies to a broad audience. In addition, Message Lab provided language guidance to media outlets like *The New York Times*, influencing how serious illness and end-of-life care are discussed in mainstream media. By shaping the narratives presented to the public, they have helped to normalize conversations about serious illness, reduce stigma, and promote a more informed and compassionate public dialogue. Similarly, The Conversation Project has raised public awareness by creating conversation guides on how to discuss end-of-life care wishes, incorporating input from patients, families, and caregivers. By aligning care with their needs and empowering them with education for informed decisions, The Conversation Project has worked to improve public perception and encourage more people to engage in meaningful conversations about their care preferences.

### 3.4 | Informing Public Policy

Grants have informed policy through the development of written resources, technical assistance, policy workshops, and advocacy, as summarized in Table 1. Grantees have been instrumental in influencing policy at both the state and federal levels, ensuring serious illness and end-of-life care receive needed attention and support for systemic improvement.

Grantees developed nearly 50 policy-related documents, including briefs, scans, recommendations, and comment letters. Grantees provided 28 instances of technical assistance to state policy teams and offered four policy workshops engaging 24 state teams. These efforts equipped policymakers with critical information and guidance to enact meaningful changes in health care policy.

To directly influence policy, grantees completed additional activities:

- Held meetings to share data and research with policymakers at the Centers for Medicare and Medicaid Services, the National Institutes of Health, the Veterans Health Administration, and the Federal Office of Rural Health Policy.
- Supported efforts to advance the Palliative Care and Hospice Education and Training Act (PCHETA), a bill advocating for improved education and resources in palliative and hospice care. The most recent version of the bill was introduced in the Senate on July 11, 2023 [v].
- Provided policy recommendations directly to the Biden-Harris administration, influencing national health care priorities and strategies.
- Advanced state policy in at least 14 states, leading to significant improvements in access to and quality of serious illness care.

According to the National Academy for State Health Policy (NASHP), as of August 2024, 28 states have public education and information programs on palliative care, up from 13 states in 2020. By September 2024, 23 states had active palliative care advisory councils. Between 2022 and 2024, 21 states enacted legislation or allocated funds to expand palliative care initiatives [vi].

Organizations like NASHP and the Coalition to Transform Advanced Care (C-TAC) have been pivotal in these policy advancements. NASHP utilized grant funding to convene state policymakers and develop state Medicaid community palliative care benefits leading to significant policy changes, like Hawaii's Medicaid state plan amendment approval and Ohio's inclusion of palliative care as a required service. NASHP's work has influenced both state and federal policies, effectively shaping the broader policy landscape for serious illness care.

Similarly, C-TAC contributed by developing advanced illness principles and influencing legislation on advance care planning. Through the Leadership Council of Aging Organizations, C-TAC fostered collaboration among health care professionals, organizations, and funders to address serious illness and end-of-life care system-wide. Consistent with other grant-funded initiatives, NASHP and C-TAC incorporated patient, family, and caregiver perspectives into their policy initiatives to ensure that policies align with care needs. In addition, NASHP and C-TAC engaged with communities to advocate for policies that benefit underserved groups, promoting equitable access to care.

### 3.5 | Increasing Collaboration and Partnerships

JAHF grants have cultivated and maintained partnerships that increase collaboration and knowledge sharing across diverse partners, summarized in Table 1. These grants supported partnerships among 215 organizations, including health systems, universities, funders, patient organizations, community-based organizations, disease associations, and policy groups. During the grant periods, 193 unique organizations were brought together through grant-funded work. Additionally, the grants supported more than 60 network-building activities, such as working groups, advisory committees, listening sessions, planning meetings, and summits, providing the time and space for diverse organizations to collaborate effectively.

A notable example of this collaborative effort is the University of Washington's Message Lab, which united 12 organizations to develop shared strategies for improving communication in serious illness and end-of-life care. Message Lab also integrated public messaging about serious illness with the AFHS initiative, thereby increasing awareness of AFHS among serious illness clinicians. By fostering such collaboration, Message Lab advanced a cohesive approach to communications around serious illness and end-of-life care, while also amplifying the reach and impact of the AFHS initiative. Similarly, Grantmakers In Health and Grantmakers In Aging played a pivotal role in bringing funders together. They facilitated a funders community that grew from 17 foundations to approximately 30 foundations participating regularly. This community provides a forum for partnership, co-funding of initiatives, and sustaining funding despite changing priorities among individual organizations. Their efforts exemplify how bringing together diverse funders enhances collaboration to address serious illness and end-of-life care on a broader scale.

## 4 | Discussion

This report summarizes the impact achieved by the diverse set of grants funded through this priority area, including grant achievements across five outcomes. Limitations to this assessment include variations in reporting across grants, availability of data, and the retrospective nature of the analysis, which only covers activities during the funding period. As a result, this report may underestimate the full scope of impact.

In addition to the impact created through the portfolio of grants, this assessment also highlights how JAHF's grantmaking strategy and approach contributes to the impact achieved in improving care for those living with serious illnesses and individuals approaching the end of life. Throughout NORC's research, grantees and partners emphasized the role of JAHF as a catalyst, collaborator, and convener.

### 4.1 | Mission Alignment, Patience, and Flexibility

JAHF's mission to improve older adult care is focused, enabling diverse yet strategic investments by knowledgeable staff. The grants awarded in this priority area address challenges from multiple angles, ranging from convening state leaders to supporting research, providing training and technical assistance, shaping public messaging, and advancing public policy, while still maintaining overarching mission alignment, which has helped to strengthen the field from different perspectives. Beyond the focused mission, JAHF grants are often multiyear investments, demonstrating the foundation's commitment and recognition that systems change work takes time. This patience allows for impact to mature over longer time horizons. Additionally, JAHF regularly provides flexible funding and collaborates closely with grantees, allowing resources to be directed toward emerging needs. JAHF has a track record of embracing innovative ideas despite potential barriers to success. This flexibility became particularly important during the COVID-19 pandemic, where challenges, needs, and resources shifted quickly.

### 4.2 | Active Engagement, Leadership, and Collaboration

From the beginning of their formal investment in serious illness and end of life, JAHF played an active role in coordinating a traditionally disconnected field. Through strategic leadership and regular engagement, JAHF has helped unite healthcare professionals, policymakers, and practitioners to set a cohesive agenda and mobilize collaborative efforts. Per one grantee, JAHF has acted as the "North Star" for the field. JAHF encourages grantees to build strong partnerships and leverage their networks, often providing funding for organizations to spend the time and resources to foster this collaboration. JAHF helped build and maintain relationships among organizations with little history of collaborating and working together, recognizing that collaboration is essential for driving systems change. JAHF's investments have not only advanced awareness and adoption of palliative care principles,

but also fostered networks that will sustain progress well into the future.

Taken together, JAHF's commitment, flexibility, mission alignment, leadership, and promotion of collaboration have allowed grantees to maximize the impact of their grant-funded work, strengthening the serious illness and end-of-life field.

### Author Contributions

NORC authors conducted analysis, accessed materials from foundation archives, developed summary tables, first draft and final revision of manuscript. Foundation staff involved in conception of report, delineation of reports and materials to NORC authors, review and edit of draft manuscript.

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### Conflicts of Interest

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