FINAL REPORT

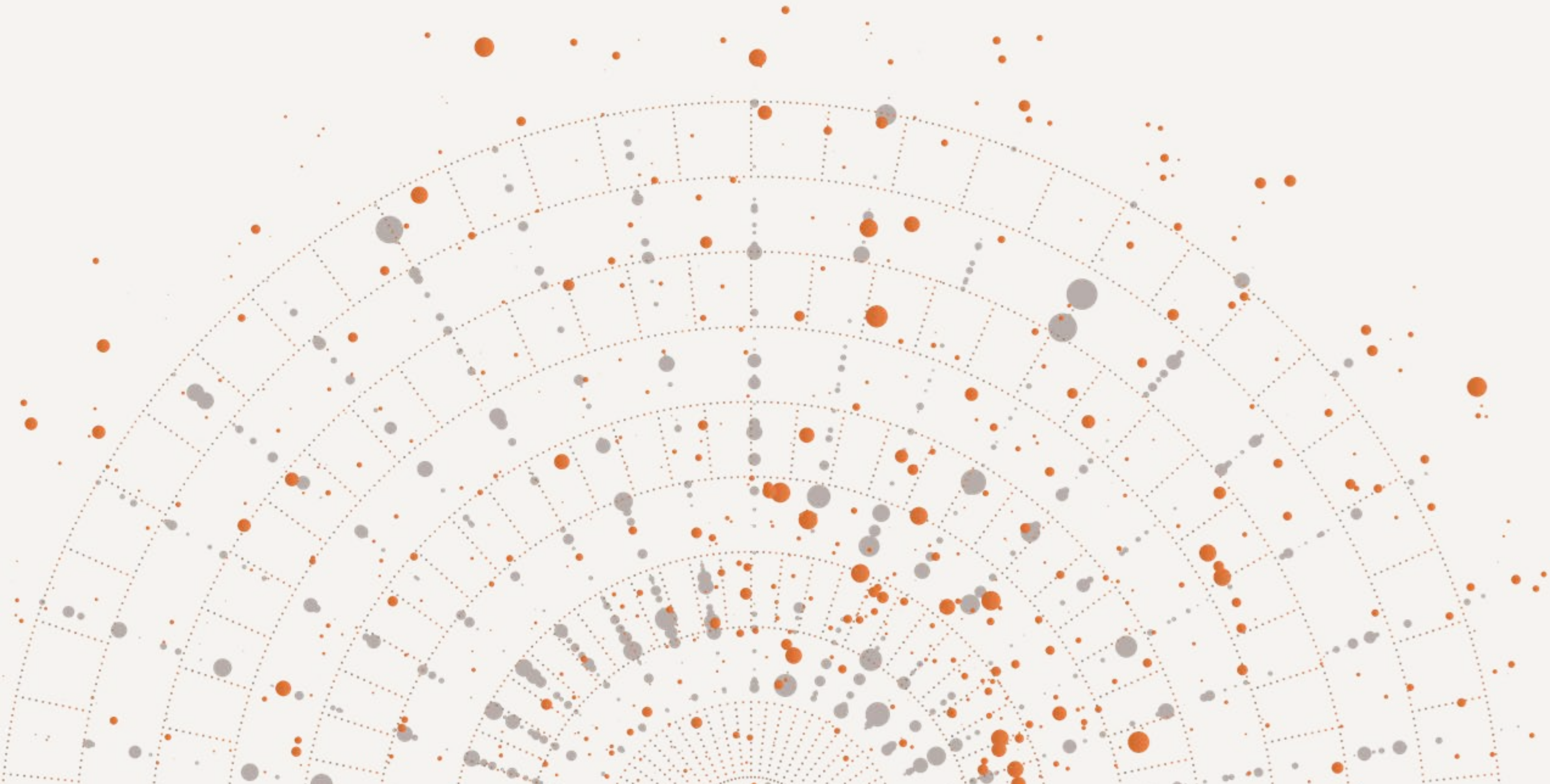
January 2025

# Advancing Compassionate and Equitable Care:

## Assessing a Decade of Investments in Serious Illness and End of Life

**Presented by:**
NORC at the University of Chicago

**Presented to:**
The John A. Hartford Foundation



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# 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. This work continues to grow in importance as we experience large shifts in demographics across the United States. Based on population projections, the number of older adults (65+) is expected to increase nearly 70 percent from 2020 to 2060, from 56 million to almost 95 million.[i] These demographic shifts have, and will continue to have, an impact on the health care system because 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 and funds additional initiatives in line with their overarching mission. The serious illness and end-of-life priority area is the focus of this 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.

In 2015, the Institute of Medicine published a report titled Dying in America,[ii] which elevated issues and challenges related to the care delivered to individuals living with serious illness. This report highlighted the limited understanding and awareness of advance care planning, the inadequate clinician training and knowledge of the field, a lack of policies and payment models, and structural barriers for marginalized communities, among others. In November 2015, the Centers for Medicare & Medicaid Services (CMS) approved the first reimbursement codes to pay for advance care planning discussions between clinicians, patients, and families. Given the vast challenges summarized in the Dying in America report and an opportunity for change with CMS approval of the reimbursement codes, JAHF began strategically investing in this priority area, with its first grant awarded in 2016. Since then, JAHF has invested more than $19 million through 21 grants to 9 distinct organizations, plus numerous subcontract organizations to advance the field of serious illness and end-of-life care.

**As JAHF nears one decade of investing in serious illness and end-of-life care, the Foundation commissioned NORC at the University of Chicago to complete an overview and assessment of this priority area. The research, presented in this report, serves as a synopsis of the diverse but targeted and connected set of grants JAHF has awarded, and provides an aggregate summary of how these grants have impacted the field.** Through this assessment, five high-level outcomes were identified in support of the overarching goals: 1) increasing access to services through sharing best practices; 2) preparing the health care workforce through training; 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, three key themes emerged that cut across the outcomes, which are listed below and discussed in detail in the *Impact* section:

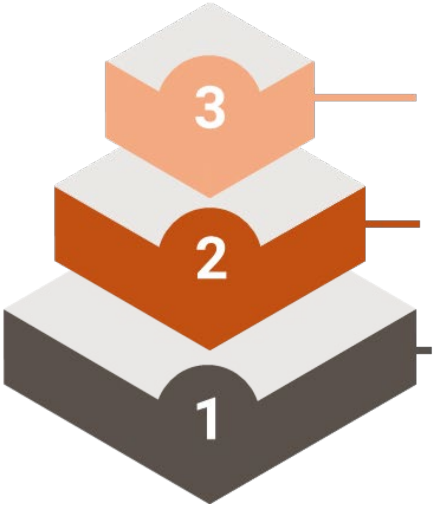
- JAHF's leadership and role as collaborator and convener
- Patients, families, and caregivers as central focal point
- A focus on promoting equitable care access

As with all their grantmaking, JAHF has funded an array of programs and initiatives through this portfolio, tackling a complex, timely, and important issue and addressing challenges including limited specialized training, public and practitioner misperception, a disconnected field, and a lack of supportive state and federal policies and payment models. Many of the grants in this portfolio are multiyear investments, signaling JAHF's commitment to the mission and recognition of the long time horizon needed to achieve systems-level change. Over nearly a decade, JAHF has shaped the agenda and priorities in the field of serious illness and end-of-life care and has built a robust network of organizations, clinicians, practitioners, and leaders poised to continue advancing the field.

## Assessment Approach and Methods

NORC conducted this review and assessment between August 2024 and early January 2025, using a three-phase, mixed-methods approach, as summarized in Figure 1. This included gathering quantitative data from existing program documentation to inform an impact framework and collecting qualitative data through surveys and interviews to provide context, details, and partner insights. Each phase is detailed below.

**Figure 1. Summary of mixed-method assessment approach.**



**Partner Engagement**
Survey and in-depth interviews to gather qualitative insights and diverse perspectives.

**Impact Framework**
Identified shared metrics and outcomes, summarizing grant impact and systemic change strategies.

**Discovery**
Reviewed program documentation to understand grant scope, objectives, and outcomes, informing impact framework and partner engagement.

1. **Discovery.** In the initial phase (August–September 2024), NORC conducted a thorough review of program documentation, including grant proposals, progress reports, staff member evaluations, and consultant assessments provided by JAHF. This review covered all 21 grants within this priority area, summarized in Table 1 in the following section. It offered valuable 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.** Building on the discovery phase, NORC developed an impact framework (September–October 2024) by identifying shared outcomes and key program metrics from existing grant reports. The framework served two purposes:

   - To generate summary statistics demonstrating the collective reach and impact of the grants

- To highlight the strategies grantees used to drive systemic change in serious illness and end-of-life care

The framework identified five high-level shared outcomes across the grants:

- Increasing access to services through sharing best practices
- Preparing the health care workforce through training
- Influencing public discourse through community engagement and messaging
- Informing public policy through research, recommendations, and technical assistance
- Increasing collaboration and partnerships through network building

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. Limitations 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.

3. **Partner Engagement.** NORC supplemented the quantitative analysis with a targeted partner engagement process through surveys and interviews (October–November 2024). 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. Examples of impact and quotes from these engagements are incorporated throughout the report.

# Summary of Grants

JAHF formalized its serious illness and end-of-life priority area in 2016 and has since directly invested $19.56 million through 21 grants to 9 distinct organizations, plus numerous subcontract organizations in partnership. These grants have been awarded to a range of organizations focused on different aspects of the ecosystem, including workforce preparation, policy, communication and messaging, and informing patients and families of their choices. While this report focuses only on grants awarded under the formal serious illness and end-of-life portfolio beginning in 2016, JAHF's prior investments in this area underscore its early leadership and commitment to this field. In addition to the grants summarized in Table 1, JAHF has invested in other organizations and initiatives with closely related work, such as Grantmakers in Aging and the Health and Aging Policy Fellows Program, among others.

### Table 1. Grant Summaries

| Details | Summary of Grants |
|---|---|
| **National Academies of Sciences, Engineering, and Medicine** | The goal of these grants was to empower individuals nearing the end of life. In Phase 1, the Roundtable on |

| Details | Summary of Grants |
|---|---|
| **Total Funding:** $511,415<br>**Funding Period:** 2016-2024<br>**Grants:**<br>1) *Roundtable on Quality of Care for People with Serious Illness, Phase I*<br>2) *Roundtable on Quality of Care for People with Serious Illness, Phase II*<br>3) *Roundtable on Quality of Care for People with Serious Illness Support* | Quality Care for People with Serious Illness fostered dialogue via meetings, public workshops, and background papers to advance policy and research efforts in serious illness care. Phase 2 built on this work by addressing barriers to policy and practice, supporting the uptake of recommendations from the 2015 *Dying in America* report, and serving as a platform for leaders in government, health care, and communities to generate and implement innovative solutions for improving care at the end of life. JAHF continued to participate in and support the Roundtable in future years. |
| **University of Washington**<br>**Total Funding:** $9,847,029<br>**Funding Period:** 2016-2025<br>**Grants:**<br>1) *Building a Collective Strategy to Accelerate Progress in End-of-Life Care*<br>2) *Building Public Engagement and Access to Palliative and End-of-Life Care for Persons Living with Serious Illness*<br>3) *Disseminating Evidence-Based Messaging about Palliative and End-of-Life Care for Persons Living with Serious Illness* | These grants supported a coordinated national effort, backed by multiple funders, to scale innovative approaches that improve serious illness and end-of-life care. In its first phase, six innovators were supported to develop and deploy new interventions targeting patients, clinicians, and policymakers. The continuation grant expanded the initiative, supporting seven innovators to scale their efforts while developing a unified public message to increase awareness of and engagement with palliative care, advance care planning, and end-of-life care. The final phase, still underway, focuses on increasing access to these services for older adults by driving public demand, reshaping public messaging, and partnering with the Age-Friendly Health Systems movement to advance a broader cultural shift in care. This work supports Message Lab, a collaborative effort aimed at improving communication and disseminating messaging principles. Subgrantee and collaborative organizations within this grant include:<br>• American Academy of Hospice and Palliative Medicine<br>• Ariadne Labs: Serious Illness Care Program<br>• The Coalition to Transform Advanced Care (C-TAC)<br>• The Conversation Project / Institute for Healthcare Improvement<br>• The National Coalition for Hospice and Palliative Care<br>• The National Hospice and Palliative Care Organization<br>• National Physician Orders for Life-Sustaining Treatment (POLST)<br>• Respecting Choices<br>• The Society for Post-Acute and Long-Term Care Medicine/AMDA<br>• VitalTalk |

| Details | Summary of Grants |
|---|---|
| **American Bar Association Fund for Justice and Education**<br>**Total Funding:** $151,997<br>**Funding Period:** 2017-2018<br>**Grants:**<br>1) *Advancing Legal and Medical Collaboration in Advance Care Planning* | The goal of this grant was to improve advance care planning by aligning efforts between lawyers and clinicians to ensure patients' care goals and wishes are understood, documented, and honored. The project developed best practice guidelines to address gaps in training, coordination, and communication between the two fields. |
| **Fordham University and Twin Cities Public Television**<br>**Total Funding:** $1,131,000<br>**Funding Period:** 2017-2021<br>**Grants:**<br>1) *Documentary Planning*<br>2) *Fast Forward*<br>3) *Fast Forward Outreach and Impact* | This three-part initiative supported the creation, production, and distribution of a groundbreaking PBS documentary on the importance of advance care planning for the last phase of life. The first phase developed the documentary's outline, key segments, budget, and distribution plan. The second phase focused on producing the film, which used real-life stories to explore finances, caregiving, and living arrangements. The final phase focused on optimizing the documentary's impact through press outreach, public screenings, and social media engagement. These efforts aimed to reshape the national conversation on aging and inspire viewers to prepare for this life stage. |
| **Center for Health Policy Development / National Academy for State Health Policy (NASHP)**<br>**Total Funding:** $1,911,753<br>**Funding Period:** 2018-2025<br>**Grants:**<br>1) *Supporting the Continuum of Palliative Care: A Resource Hub for State Policymakers*<br>2) *Expanding and Sustaining the Continuum of Care: A Resource Hub for State Policymakers*<br>3) *Building State Policies to Improve Care for People with Serious Illness* | The goal of these grants is to expand access to palliative care for older adults with serious illness through state policies. The first phase focused on engaging state leaders, developing resources, and enhancing the quality of palliative care services. The second phase targeted key policy opportunities and assisted states in advancing access to care. In the final phase, which is still underway, NASHP launched a Serious Illness Policy Academy, provided technical assistance, and developed actuarial models to help states design Medicaid palliative care benefits. |
| **Grantmakers in Health (GIH)**<br>**Total Funding:** $30,000<br>**Funding Period:** 2018; 2021-2022<br>**Grants:**<br>1) *Network Building and Support Phase 1*<br>2) *Network Building and Support Phase 2* | Over two years, these grants elevated awareness of serious illness and end-of-life care through conferences, webinars, articles, and innovative formats like virtual coffee hours, focusing on topics such as COVID-19's impact and health equity. This work built on prior momentum and included conference sessions, webinars, podcasts, and publications, addressing disparities in palliative care access and exploring opportunities for policy advocacy. |
| **The Center to Advance Palliative Care (CAPC)**<br>**Total Funding:** $3,910,742 | Building on prior JAHF funding to CAPC, these grants supported four key objectives: expanding palliative care |

| Details | Summary of Grants |
|---|---|
| **Funding Period:** 2019-2025<br>**Grants:**<br>1) *Improving Access to Quality Palliative Care*<br>2) *Achieving Sustainable Change in the Care of Older Adults with Serious Illness*<br>3) *7 Funders Group; Equitable Access to Quality Palliative Care for Black Americans: A Scan of Challenges and Opportunities* | access in community settings, increasing clinician training, fostering investment through partnerships with the American Hospital Association, and securing adequate financing through Medicare Advantage and Accountable Care Organization learning communities. The follow-up grant, still underway, continues this mission by integrating palliative care into home-based care, advancing health equity with new resources, and identifying scalable practices for age-friendly care. This funding also supported the development of a sustainable business model, ensuring CAPC's long-term viability. |
| **FAIR Health**<br>**Total Funding:** $2,065,064<br>**Funding Period:** 2021-2026<br>**Grants:**<br>1) *A National Initiative to Advance Cost Information in Shared Decision-Making for Serious Health Conditions*<br>2) *A National Initiative to Advance Cost Information in Shared Decision-Making for Older Adults with Serious Health Conditions: Phase II Implementation Project* | The goal of these grants was to expand shared decision-making and health care engagement among older adults by developing tools that provide both clinical and cost information to improve financial health literacy. Building on a prior planning grant, this active initiative includes a needs assessment, tool development, evaluation, and dissemination to empower older patients, caregivers, and clinicians in making informed care decisions. The decision-making tools aim to enhance patient engagement, increase awareness, and address challenges in older adult care. |

# Impact

The Foundation's investment in this priority area has helped build and shape the field of serious illness and end-of-life care. The Foundation has brought together diverse partners—including health care systems; clinicians and practitioners; organizations with expertise in communications, policy, and training; and other funders focused on older adults, aging, and health care—to develop a robust network of individuals and organizations working to enhance care for those living with serious illnesses and individuals approaching end of life. The Foundation has fostered system-wide collaboration, taking a leadership role in coordinating a traditionally disconnected field, with partners engaging in research, policy, and operations from different perspectives without leveraging learnings from across the field. Through the work of the Foundation and the grant-funded initiatives, networks and partnerships exist today with shared goals and a unified direction. Per one grantee, the Foundation has acted as the "North Star" for this field.

> **"[The Foundation] encourages our grantees to build strong partnerships and leverage their networks to maximize their impact. Collaboration is essential for driving systemic change."**
>
> **- Amy Berman, Senior Program Officer**
> **The John A. Hartford Foundation**

This assessment identifies five shared outcomes across this portfolio of grants: 1) increasing access to services through sharing best practices; 2) preparing the health care workforce through training; 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. 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, the Foundation has supported and encouraged programs and policies that benefit underserved groups and promoted equitable access to care. Overall, these comprehensive efforts have contributed to a more inclusive and effective approach to serious illness and end-of-life care, resulting in improvements that benefit patients, families, and communities.

## Increasing Access to Services

Grantees in this priority area enhanced access to care for patients and families by developing and sharing best practices with practitioners across the sector, including clinicians, health systems, community-based organizations, policymakers, payers, and patients. Strategies include providing targeted technical assistance, developing and disseminating educational resources, and sharing innovative care models that practitioners can leverage in their own work and within their local communities. According to the Center to Advance Palliative Care (CAPC), one of the grantees in this portfolio, 83 percent of hospitals with 50 or more beds had a palliative care program in 2020, compared to 75.5 percent in 2016 and 69.6 percent in 2012.[iii] While this assessment was not able to gather data on the number of patients receiving care as a direct result of grant-funded work, grantees reported that activities like sharing best practices, tools, and knowledge have contributed to the growth of palliative care services.

During the grant period, over **2,000 practitioners**—including palliative care leaders and staff members from community-based organizations, hospitals, and health systems—received direct technical assistance on serious illness and end-of-life care. Examples of this support include small group virtual office hours with experts, best practices in utilizing telehealth to provide palliative care services, and step-by-step program guidance for palliative care program startup in home, clinic, and long-term care settings.

From 2016 to 2024, grant funding supported the development of over **150 resources,** such as toolkits, messaging guidelines, best practices, resource hubs, websites, checklists, educational modules, and decision-making tools. The resources cater to a wide range of audiences, such as health systems, clinicians, families and caregivers, and policymakers, and were **viewed or downloaded more than 346,000 times** during the grant reporting periods. By incorporating input from patients, families, and caregivers, these resources align care with their needs and empower them with evidence-based educational materials for informed decision-making about end-of-life treatment options.

### Impact by the Numbers

**2,000+ practitioners** received direct technical assistance

**150+ resources** developed to improve access to care

**346,000+ views or downloads** of resources during grant reporting periods

**220+ replicable and effective care models** gathered and disseminated

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 adoption of scalable models by others.

A notable example of grant-supported efforts that has expanded access to care is the **Roundtable on Quality Care for People with Serious Illness**, facilitated by the **National Academies of Sciences, Engineering, and Medicine**. This initiative brought together more than **40 organizations**—including health care providers, policymakers, payers, and patient advocates—to develop and disseminate best practices and policy recommendations. The roundtable held over **20 public workshops and webinars**, producing findings that have been downloaded more than **24,000 times**, reaching clinicians, medical and nursing students, educators, and state and federal policymakers. The roundtable's efforts have influenced national and state-level policies on palliative care, enhanced collaboration across sectors, and promoted the adoption of innovative care models.

Another example is **FAIR Health**, which utilized grant support to develop innovative tools that provide patients with personalized cost-of-care information from health care claims data. By empowering patients and their families with transparent pricing information and educational resources, FAIR Health's initiatives have enabled more informed decision-making, aligning care with patient needs and promoting equitable access to services. FAIR Health is partnering with **four health systems across the country** to pilot these tools, each of which is participating 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, which aims to improve health care for older adults by following evidence-based care practices that focus on what matters to patients. This connection between serious illness and end-of-life care and AFHS is an example of how JAHF intentionally funds initiatives that span multiple priority areas, strengthening collaboration and furthering the overarching mission of improving care for older adults.

Through these comprehensive efforts, grantees are working to increase access to services by sharing knowledge and best practices with health care professionals, community-based organizations, and patients.

## Preparing the Health Care Workforce

Work in this priority area has also enhanced the capacity of health care professionals to provide comprehensive care to patients living with serious illnesses. Multiple grantees provide direct training for clinicians and practitioners, equipping them with tools and resources to provide person-centered care.

### Impact by the Numbers

**88,000+ clinicians** engaged in training opportunities

**725,000 courses** completed during the grant period

**Nearly 100 workshops** provided training to over **11,000 practitioners**

**CAPC** has contributed to clinician education by training approximately **80,000 clinicians** through its courses during the grant period, with nearly **725,000 courses** completed. These courses covered essential aspects of palliative care, such as pain management, communication skills, symptom management, and caregiver support. CAPC also introduced an **Age-Friendly Health Care Learning Pathway**, which educates participants on delivering high-quality, evidence-based care using the AFHS framework—another area of intentional overlap across JAHF priority areas. Course topics include clarifying patient goals, managing medications, addressing cognitive issues, and optimizing mobility. CAPC's work also brings together health care professionals and community-based organizations, leveraging networks to enhance workforce capabilities and provide compassionate, patient-centered care.

In addition to CAPC, other grantees provided training for clinicians and practitioners, resulting in training more than **88,000 clinicians** through the grant periods. Course topics included critical areas such as reducing risk, home-based palliative care, age-friendly health care, and patient communication. By incorporating input from patients, families, and caregivers, these courses aligned care with their needs and empowered clinicians with the education necessary to support patients and their families to make well-informed decisions about their end-of-life treatment decisions. This focus on **patient, family, and caregiver perspectives** ensured that the training was relevant and impactful.

JAHF grants also supported nearly **100 workshops**, providing training to more than **11,000 practitioners**. Primarily attended by clinicians, medical and nursing professionals, and state and federal policymakers, these workshops covered topics such as understanding and pursuing value-based payment opportunities, advance care planning, primary care delivery, family caregiving, and managing end-of-life care during COVID-19. These workshops focused on **practices benefiting underserved groups**, **promoting equitable care access**, and **culturally sensitive communication**.

**Ariadne Labs**, a subgrantee of the University of Washington, has made contributions through its **Serious Illness Care Program**. This system-level care delivery model, developed by palliative care experts at Ariadne Labs, provided direct training of the **Serious Illness Conversation Guide** to over **500 clinicians** across more than **20 health systems** during the grant period. Additionally, Ariadne Labs has indirectly trained more than **13,800 clinicians** through the dissemination of training materials that were used in train-the-trainer methods. Equipping clinicians with effective communication tools and strategies enhances clinicians' ability to engage in meaningful conversations with patients about their goals, values, and preferences.

Through these efforts, JAHF grants have prepared the health care workforce by providing **direct training to professionals and organizations**, incorporating **patient and caregiver perspectives**, and engaging communities to promote equitable care. Grantees reported that this work has supported improvement in the quality of serious illness and end-of-life care provided by health care professionals across various settings.

## Shaping Public Discourse

JAHF grants have raised awareness of serious illness and end-of-life services by actively engaging with the public and disseminating a wide range of resources, including articles, white papers, blogs, and videos. During the grant period, these initiatives supported engagement with at least **370,000 individuals**. This outreach encompassed interactions with clinicians and health system leaders, as well as focus groups and interviews with patients and families. Community events were organized to provide information and resources on end-of-life care, ensuring that vital knowledge reached those who needed it most. To help educate and inform the public, practitioners, and policymakers, JAHF grants supported the creation of over **1,900 resources** and disseminated a vast amount of information through **webinars, conferences, blogs, interviews, published 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**, Message Lab disseminated evidence-based communication strategies to a broad audience. Their social media campaign achieved more than **2 million impressions**, amplifying the reach of their guidance on effective language use. Moreover, Message Lab provided language guidance to prominent 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 encouraged more people to engage in meaningful conversations about their care preferences.

### Impact by the Numbers

**370,000+ individuals** engaged through outreach efforts

**1,900+ resources** created to educate the public, practitioners, and policymakers

**100+ webinars**, reaching more than **10,000 attendees**

**200+ presentations** at conferences, summits, and meetings

Inclusion in over **900 radio interviews** and **9 podcasts**

**88 blogs** published and contributions to over **150 articles**, generating **400+ news mentions**

**30+ articles** published in academic and professional journals

**50 videos** produced, including a feature-length documentary viewed by over **1.35 million individuals**

Both example initiatives have tailored their strategies to engage communities effectively, advocating for practices that benefit underserved groups and promoting equitable access to information. They have ensured that diverse populations are included in the conversation and that their specific needs are addressed. Through these efforts, the grants have not only raised awareness but also fostered a more inclusive and collaborative public discourse on serious illness and end-of-life care.

## Informing Public Policy

Grants have informed the policy landscape through the development of written resources, provision of technical assistance, organization of policy-specific workshops, and direct advocacy activities. Grantees have been instrumental in influencing policy at both state and federal levels, ensuring that serious illness and end-of-life care receive the attention and support needed for systemic improvement.

Grantees developed nearly **50 policy-related documents**, including policy briefs, scans, recommendations, and coordinated comment letters. They provided **28 instances of policy-related**

**technical assistance** to state policy teams and offered **four policy workshops**, engaging **24 state policy teams**. These efforts equipped policymakers with the necessary information and guidance to enact meaningful changes in health care policy.

To directly influence policy, grantees participated in several key activities:

- **Holding informative meetings** to share data and research, advancing dialogue and educating policymakers at organizations such as CMS, the National Institutes of Health, the Veterans Administration, and the Federal Office of Rural Health Policy.
- **Supporting 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.
- **Providing recommendations directly to the Biden-Harris administration**, influencing national health care priorities and strategies.
- **Advancing state policy in at least 14 states**, leading to significant improvements in access to and quality of serious illness care.

Based on the **National Academy for State Health Policy's (NASHP)** state policy tracking, as of August 2024, **28 states have education and information programs** for the public about palliative care, up from 13 states in 2020. As of September 2024, **23 states have active palliative care advisory councils**. Between 2022 and 2024, **21 states enacted legislation and/or allocated budgetary funds** that support and expand initiatives around palliative care.

## Impact by the Numbers

Nearly **50 policy-related documents** developed

**28 instances** of policy-related technical assistance provided to state policy teams

**4 policy workshops** offered, engaging **24 state policy teams**

**14+ states** saw advancements in policy due to grant activities

Organizations like **NASHP** and the **Coalition to Transform Advanced Care (C-TAC)** have been pivotal in these policy advancements. NASHP utilized grant funding to **engage and convene state policymakers**, uniting them to develop state Medicaid community palliative care benefits. This collaborative effort led to significant policy changes, such as **Hawaii receiving approval for a Medicaid state plan amendment** and **Ohio adding palliative care as a required service**. By empowering states like Hawaii and Ohio to receive CMS approval for incorporating palliative care into their Medicaid programs, NASHP's work has influenced both state and federal policies, effectively shaping the broader policy landscape for serious illness care.

Similarly, C-TAC engaged in **policy advocacy and development** by creating advanced illness principles and contributing to legislation addressing advance care planning issues. Through participation in organizations like the Leadership Council of Aging Organizations, C-TAC provided valuable policy insights and 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.

Through these efforts, the grants have facilitated meaningful policy solutions that enhance the accessibility of serious illness and end-of-life care. By influencing policy at multiple levels and ensuring that the voices of patients and families are central to these changes, the grants have contributed to a more compassionate and effective health care system for those facing serious illness and approaching end of life.

## Increasing Collaboration and Partnerships

JAHF grants have cultivated and maintained partnerships that increase collaboration and knowledge sharing across diverse partners. 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.

> **"The foundation's support for this community is key—it's the sweet spot for bringing funders together regularly to discuss strategies, pain points, opportunities, and challenges, all within a formal network."**
>
> **- Emily Hinsey, Chief Program Officer Grantmakers In Aging**

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.

### Impact by the Numbers

**215 organizations** engaged in partnerships

**193 unique organizations** brought together through grant-funded work

**60+ network-building activities** supported

Through these efforts, the grants have effectively increased cooperation among partners and funders. By uniting various entities and focusing on shared goals, they have fostered a more inclusive and effective approach to addressing the challenges within this field.

## Health and Aging Policy Fellows

JAHF also funds the Health and Aging Policy Fellows (HAPF) program, which aims to build leaders that can serve as change agents in health and aging policy, ultimately improving the health care of older adults. The fellowship provides training and enrichment and professional networking to prepare Fellows to affect policy. While not formally a part of the portfolio of grants under the serious illness and end-of-life priority area or part of this assessment, **20 of the nearly 180 HAPF focus on issues related to serious illness and end of life.** Each of these 20 individuals is recognized as a leader in the field, including one that received a MacArthur Foundation Fellowship, known as the Genius Award.

These 20 HAPFs come from a range of roles across the health care sector, including practicing geriatricians and palliative care physicians, professors, researchers, health system leaders, public health professionals, economists, social workers, and policymakers. The Fellows focus on many issues within serious illness and end of life, including health needs of rural individuals, veterans, and LGBTQ+ older adults; end-of-life decision making; ethical treatment of older adults; and building AFHS and palliative medicine in nursing homes, among others. Fellows' research and practice focuses on specific health needs, including kidney disease, dementia, cancer, lung cancer, COPD, fall prevention, and those with multiple chronic conditions. In addition, some HAPFs are focused on care delivery, including the provision of value-based care for seriously ill older adults, studying novel palliative care delivery models, and new methods for financing long-term care.

JAHF's investment in the HAPF program is another way the Foundation **continues to build and develop the field of serious illness and end-of-life care.** Fellows have published papers, blogs, articles, and books focused on advancing research and policy related to serious illness and end of life. HAPFs have helped author bills, participated in government committees, and contributed to the reauthorization of the Older Americans Act. The investment in these individual leaders helps to create long-lasting systems change through policies and practices at organizations, health systems, and various levels of government.

# Discussion

This assessment highlights JAHF's leadership in the field of serious illness and end of life. Grantees stressed **the role of JAHF as catalyst, collaborator, and convener that has positively impacted and shaped the field**. JAHF's **dedication and long-term commitment** to funding research and collaborative partnerships has allowed impact to mature over longer time horizons. While a lot of progress has been achieved in this priority area, challenges persist. The networks and partnerships that JAHF has helped build and maintain will be important to overcoming challenges and continuing to make progress.

**Shaping the Field.** According to interviewees, JAHF has served as a critical catalyst and convener in shaping the serious illness and end-of-life field. Through strategic leadership, JAHF has acted as the "North Star" for the sector, uniting health care professionals, policymakers, and practitioners to set a cohesive agenda and mobilize collaborative efforts. JAHF successfully brought together organizations from different parts of the health care sector, as well as helped build and maintain relationships among organizations with little history of working and collaborating together. The Foundation'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.

**Approach to Grantmaking.** JAHF's commitment to long-term, systemic change is reflected in its focus on single issues, long-term commitment to fostering sustainable solutions, and willingness to embrace innovative ideas despite potential barriers to success. By addressing challenges from multiple angles—whether through convening state leaders, supporting research, providing training and technical assistance, shaping public messaging, or advancing public policy—the Foundation has effectively built a robust ecosystem of partners for serious illness and end-of-life care. The Foundation's hands-on grantmaking approach, marked by core support and flexibility, has empowered grantees to maximize their impact while remaining mission-aligned. This comprehensive strategy has laid the groundwork for the field's continued evolution and growth.

**Challenges.** Despite much progress, the field continues to face challenges. Sustainable state and federal funding is a pressing issue, as many initiatives largely depend on philanthropic support due to inconsistent state and national payment models. Measuring impact, particularly patient experience and satisfaction, remains difficult, complicating efforts to demonstrate the return on investment often needed to secure continued financial support. Despite great progress made through JAHF grants, public misconceptions about palliative care (often equating it with withholding necessary curative care) hinder broader acceptance. Disparities in access remain a challenge due to geographic and institutional differences and variations in organizational capacity, resources, leadership commitment, availability of trained specialists, and care models. Additionally, the lack of integration with related disciplines, such as disease-specific care and health equity, presents an opportunity to leverage broader expertise and resources in the future for a continuously evolving field.

**Sustaining Progress.** Grantees report that JAHF's ability to influence, lead, and foster collaboration is a direct result of its thoughtful approach to grantmaking. By emphasizing collaboration, knowledge sharing, and the convening of diverse partners, JAHF has helped advance the field and create lasting impact. Its strategic guidance and flexible support have enabled grantees to address challenges and innovate effectively. While JAHF supported the development of sustainable models for many of its grantees—including business models that prioritize diverse revenue streams and cost-effective strategies, as well as care models designed to deliver scalable, effective services—there remains a need to expand these efforts. Diversifying funding sources and aligning serious illness and end-of-life care with broader health system reforms will be essential for long-term success. Maintaining the collaborative spirit cultivated by JAHF will be critical to ensuring that progress in serious illness and end-of-life care continues to benefit patients and families moving forward.

# Conclusion

As JAHF nears one decade of investing in the serious illness and end-of-life priority area, this multi-method assessment synthesizes the achievements accomplished by the grants and assesses how this work has shaped the field. The grants in this priority area have worked to increase access to services by sharing knowledge and best practices. Grant-funded work has increased the capacity of clinicians to provide patient-centered palliative care through direct training efforts and educational workshops. Many initiatives focused on communication and messaging, shifting public perception, and raising awareness. Other initiatives focused on influencing, developing, and advocating for policy change at the state and federal levels. In addition to these activities, JAHF built, supported, and maintained partnerships and networks bringing together diverse organizations. It is likely that many of these organizations would not have collaborated with one another without the influence of JAHF. All of the funded programs and activities were person-centered, incorporating input from patients, families, and caregivers, to align care with individual needs, while also using tailored community engagement strategies to support underserved groups and promote equitable access to care.

Throughout this assessment, grantees highlighted JAHF's pivotal role in building the serious illness and end-of-life field. The Foundation has served as a catalyst and a leader, shaping the agenda through financial investment, active engagement, and hands-on involvement with grantees, other funders, and leaders. JAHF's strategic investments and collaborations have helped address challenges such as limited specialized training, public and practitioner misperception, and policy gaps in the sector. This investment and JAHF's commitment to long-term, flexible support have been fundamental in supporting individuals and organizations across the health care sector as they work to improve access and quality of serious illness and end-of-life care for patients, families, and caregivers across the United States. The support for building a strong and healthy network of organizations helps ensure that this work will continue in the future.

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