

## **Gordon and Betty Moore Foundation Patient Care Program** *Mid-Course Review of the High-Need Patients Investigation*

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### **Overview**

The Moore Foundation's Patient Care Program has invested \$58.4 million<sup>2</sup> to date to improve care in the community for patients 65 years and older who have serious illness (such as cancer, lung disease, heart failure or a multiple of illnesses) and limited ability to perform everyday tasks (such as bathing, dressing and eating).

Grantmaking began in 2016 after an extensive strategic planning period by the program staff, in consultation with national experts, to determine priority investment areas. Initially, five areas were identified:

1. **Accountability and payment:** Develop ways to measure and report the quality of care provided to people with serious illness in community programs, and to incentivize the development of such programs with changes in reimbursement.
2. **Workforce:** Enhance the skills of the current and future workforce to meet the needs of high-need patients in the community, including family caregivers who provide the bulk of frontline services.
3. **Model programs:** Encourage the development of new community care models that provide safe, affordable, effective care, and support the spread and adoption of models that already have a track record.
4. **Public education:** Promote awareness and understanding of late-life and end-of-life issues, especially the need for advance care planning in the context of serious illness.
5. **Surveillance system:** Develop ways to monitor access to community care across the country and assess public knowledge and attitudes about issues related to serious illness and the public's readiness to manage individual and family concerns.

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<sup>1</sup> The foundation contracted with [Kate O'Malley, RN, MS](#), to conduct the interviews that were part of the mid-course review. Kate retired two years ago from the California Health Care Foundation, where as a senior program officer she led efforts to improve and spread palliative care throughout California. Kate has worked with many of the people interviewed but currently has no formal relationship with them.

<sup>2</sup> The \$58.4 million includes: 1) Grants totaling \$21.9 million that were made prior to the November 2016 board meeting when the trustees approved \$40 million for a three-year High-Need Patients Investigation; and 2) Grants totaling \$36.5 million that were made from 2017-2019 as part of the High-Need Patients Investigation.

Of the five areas identified, the foundation determined that the highest leverage opportunities were: 1) **accountability and payment** (accounting for 35 percent of grant dollars) and 2) **workforce** (35 percent). This emphasis was based on the number of evidence-based, smaller-scale efforts underway, the existing knowledge and relationships of foundation staff in these areas, and the number of potential grantee organizations that were well established and recognized as leaders and experts in the field.

The purpose of this review is to examine what has been accomplished to date by drawing upon the reflections of those in the field. Recognizing that most grants are not yet complete (30 are completed, with 38 still underway), this review serves as an update of progress and results to date, rather than a comprehensive review. It also presents future opportunities for the field and highlights certain areas in which progress toward sustainability may be achieved.

This mid-course review addresses the following four questions:

1. **Accomplishments:** What did the grants accomplish (outputs and outcomes) in the two priority areas?
2. **Impact:** How does the field assess the impact of the foundation's grantmaking and related activities?
3. **Durability:** How durable are the results?
4. **Lessons learned and opportunities:** What are the lessons learned and opportunities identified to help the field going forward?

Information was gathered primarily through 24 telephone interviews over a seven-week period between January 2 and February 26, 2019. Patient Care Program team members selected the informants to be interviewed. A dozen grantees were selected based on the size of relevant grants, grant maturity, the likelihood of the grants to impact patient experience and change the field, and the knowledge and involvement of grantees in the foundation's overall work. In addition, interviews were conducted with staff and leadership from six foundations with interest and funding expertise in this area, as well as six national experts in the field.

Information about the breadth and depth of grant outputs and outcomes is included in Appendix A. Selected grants are highlighted in Appendix B. A full grant list can be found in Appendix C.

## **Accountability and Payment**

Forty-five million Americans are living with one or more chronic conditions that are likely to worsen, rather than get better, and are experiencing functional limitations, such as limited mobility. As demographics continue to shift toward a higher number of elders, this growth is fueling demand for care where people want it most – in their

home and in their community (e.g., local doctor's office). Benefits of community-based care include a one-stop shop for health care, which has been shown to decrease the burden of coordination of care commonly done by sick patients themselves or by their families. Decreasing duplication of services and basing care on the goals of the individual can increase quality of life for the patient and produce cost savings for payers. Increasing demand for this type of care is creating new programs launched by health systems, hospices, medical groups and home health agencies.

**The need for comprehensive measures that define quality.**

In the context of serious illness, most available measures for quality of care focus on hospital-based palliative care programs or care provided by a hospice organization. These quality measures lack indicators that focus on the alignment between a patient's individual goals and preferences and the care provided and care outcomes. For example, new indicators could include whether a person's social and spiritual needs are met; the patient's engagement level with other community services such as transportation and meals; and the quality of conversations about serious illness care.

*"Measurement work is an excellent focus for foundation resources. The biggest challenge is to stick with it. I applaud the Moore Foundation."*

- Funder

In addition to measurement problems, the field struggles with a consistent payment model that would support the full range of services needed for people with serious illness to stay in their home safely.

The goals of the accountability and payment work are to:

- Establish a common measurement infrastructure at the national level that ultimately develops into an accountability program sponsored by a national accrediting body.
- Support development and testing of alternative payment models for people with serious illness, which would incentivize the development and availability of high-quality person- and family-centered care in community settings.

Examples of accomplishments:

- Movement toward the development of an accreditation program for serious illness care, including testing quality measures in a learning collaborative of four care providers currently working in the community. The completed components of an accreditation program, including validated standards and process and outcome measures, will be ready in September 2020.
- Commitment by a national accrediting body (the National Committee for Quality Assurance) to integrate new measures for serious illness care into the Healthcare

Effectiveness Data and Information Set (HEDIS) measurement set, which is one of the most widely used performance improvement tools, with 190 million Americans enrolled in health plans that report HEDIS results.

- Creation of the [Serious Illness Quality Alignment Hub](#) to coordinate activities leading to a national accountability system. The hub brings together palliative care experts and U.S. health care quality leaders to determine a minimal set of quality measures and standards and then works to expedite their adoption by the needed accountability systems (e.g., public and private payers).
- Combination of three separate patient care registries focused on serious illness into a [single unified registry](#), which will be launched in September 2021.
- Development and publication of Clinical Practice Guidelines for Quality Palliative Care, 4th edition, which was released in October 2018. The guidelines establish a comprehensive foundation for gold-standard palliative care for all people living with serious illness, regardless of their diagnosis, prognosis, age or setting. The guidelines are available [online](#).
- A raised profile of the need for quality measurement in the high-need patient population, along with increased understanding of the inadequacy of existing measures among many parties – clinicians, policymakers, payers and purchasers, and academic researchers. This issue was highlighted in a recent [Health Affairs article](#), which was part of a larger special issue, available below.
- Successful convenings of expert groups to develop recommendations, strategies and guidelines for improving serious illness care, its quality and financing, leading to publication of special issues of [Health Affairs](#) and the [Journal of Palliative Medicine](#) as well as the [proceedings](#) of the National Academies of Sciences, Engineering and Medicine's Roundtable on Quality Care for People with Serious Illness. Not only were these convenings well attended, but participants rated them as valuable in post-convening surveys (e.g., they said they formed new relationships that helped coordinate various efforts underway in the field).
- Development and dissemination of a [financial modeling toolkit](#) that helps serious illness programs manage financial risk, thus enabling them to be sustainable under alternative payment models like accountable care organizations.

*"I made important face-to-face connections at convenings – people I only knew by reputation are now familiar colleagues."*

- Grantee

## Impact

The foundation's Patient Care Program team identified and funded organizations that play influential leadership roles on the national stage in closing the gaps in quality measures and accountability. Each grantee approaches the quality of care and accountability from a distinct vantage point.

*"The highest impact of this portfolio is a real coming together of the field of the right people at the right time to develop a clear message and a way forward."*

- Expert

In reviewing the accountability and payment grants, many experts and funders commented on the breadth and depth of the investments, the suitability of the grantees chosen for the work, and the opportunity to create alignment around the challenge of ensuring quality of care and patient safety in the context of serious illness. Based on the accomplishments to date, and the fact that many grants are still underway, these investments have materially contributed to building the field of accountability in serious illness care.

*"The Moore Foundation is to serious illness care in 2018 what the Robert Wood Johnson Foundation was to end-of-life care in the 1990s."*

- Grantee

For example, the field now has consensus on the accountability measures needed to support high-quality care for high-need patients in community settings. Once completed, the new measures developed will be ready to incorporate into a more robust accountability system that includes future accreditation standards for community-based serious illness programs.

## **Workforce**

The growth of novel serious illness care models raises new expectations of the patient's health care team. Many new models require different types of clinical skills that include providing palliative care (managing pain and symptoms), ensuring goal-concordant care, having serious illness (including late-life and end-of-life) conversations, and delivering care from an interprofessional team perspective. In addition, as more people with serious illness age and prefer remaining at home as long as possible, family members become part of the care team as they frequently take on the responsibility of providing care.

**Filling the workforce gap.** Many physicians and nurses are oriented toward treatment and cure and do not have adequate skills nor a comfort level with initiating conversations regarding patient wishes for their care at the end of life. To prepare the workforce to meet this need, several training programs have been developed by the field and were ready to scale nationally in 2016.

*"Family caregivers are an important and often overlooked part of the serious illness care team."*

- Grantee

The other key player in the serious illness workforce is the family caregiver who would also benefit from training and support. There are 40 million unpaid family caregivers who play a significant role in caring for relatives with chronic conditions and functional limitations. Many family caregivers provide nursing tasks, such as medication administration and wound care, for which they are not trained. In 2016, there were few resources available to educate them on how to care for loved ones, and many continue to feel left alone to manage complex care tasks and provide hands-on care every day.

The goals of the workforce grants are to:

- Make the expert clinical training models widely available to enhance the communication skills of physicians, nurses and social workers working in community-based programs that serve people with serious illness.
- Improve communication skills of clinicians around late-life and end-of-life communication.
- Support the needs of family caregivers and determine the ideal configuration of interprofessional team models that would best support a patient's needs.

Examples of accomplishments:

Clinician training and support

- By combining the educational programs of three national leaders, a "one door" [online portal](#) was created for health systems and clinicians seeking online and in-person training to improve clinicians' communication skills pertaining to serious illness values, goals and care options.

*"By combining forces, we were able to create powerful educational programs that were tailored to individual needs while greatly increasing our reach."*

- Grantee

- High-need patients will benefit from the development and dissemination of training materials for patients and clinicians to work together and create care plans that are aligned with patient goals. This work by Yale University is connected to the educational programs developed by VitalTalk and the "one door" portal for synergy. In addition, nurses in intensive

care units have access to video skills training so they can learn to lead conversations about end-of-life decisions and goals of care. This work is coordinated with VitalTalk to broaden their focus beyond physicians.

- Patients with dementia and their family caregivers will benefit from the development, evaluation and dissemination of a video-based toolkit that prepares primary care providers for dementia-specific communication skills and how to address advance care planning with this patient population. The toolkit will be publicly released in early 2020.
- Research is underway on how to best organize interprofessional teams to care for older adults, including the quality and cost implications of various team models. Four manuscripts have been submitted as a result of this work and seven more are in the planning stages.
- Field leaders came together to develop and disseminate recommendations to strengthen the workforce that provides care in the community for high-need patients. The program team convened 40 influencers and their recommendations were highlighted in a November 2018 Health Affairs blog, [Strengthening the Workforce for People with Serious Illness: Top Priorities from a National Summit](#). This work will be highlighted in special editions of the Journal of the American Geriatrics Society and Health Affairs in 2019.
- Health Affairs plans to publish a thematic issue on strengthening the workforce for community-based serious illness care in June 2019.

#### Family caregiver training and support

- Through the creation of the [Family Caregiving Institute](#) at the Betty Irene Moore School of Nursing at the University of California, Davis, research priorities to better understand and meet the complex needs of 40 million family caregivers are being identified, examined and addressed. A [national symposium](#) in March 2018 focused on the heterogeneous challenges faced by family caregivers (e.g., the unique care needs of a particular illness, rural vs. urban settings or inclusion of under-represented populations in caregiving research) as well as the use of technology to optimize care. The strategies were socialized among professionals in the field during the November 2018 meeting of the Gerontological Society of America and will be published in the society's journal in 2019.
- The Family Caregiving Institute partnered with AARP's Home Alone Alliance to create resources and tools for family caregivers, including [educational videos](#) on common nursing tasks. Three have been produced to date focused on wound care, mobility and managing medication.

## Impact

Funding in this area is improving skills and performance of the high-need patient care workforce, specifically by improving the communication skills of clinicians around late-life and end-of-life choices, examining the issues faced by family caregivers and direct care workers in the home, convening experts and influencers to make recommendations for the field, and exploring new caregiving roles in a changing health system. A productive partnership among VitalTalk, Ariadne Labs and the Center to Advance Palliative Care to improve the communication skills of clinicians would not have been considered or undertaken without Moore Foundation impetus. The grantees report that these education programs can now scale from reaching 20,000 to 200,000 clinicians per year.

The Family Caregiving Institute at the Betty Irene Moore School of Nursing gives voice to unpaid family caregivers, who provide more than 80 percent of long-term care to older adults but remain largely invisible in the health care system. The institute's focus is to lessen the burden on the mental, physical and financial health of family caregivers and ensure that their quality of life does not suffer. Already, the school has initiated a research agenda to improve the health and well-being of caregivers. Based on input from national leaders in November 2018, the top three areas being explored are evaluating technologies that can empower family caregivers to play active roles in health care decision-making, determining where technology best fits into the trajectory of caregiving, and understanding the diversity of family caregiving approaches and the complex structures of families. Progress in these areas will add important knowledge to the field and help shape policies and programs supporting family caregivers.

Another focus of the workforce grants is the dissemination of research findings in peer-reviewed journals, which serve to bring new ideas, approaches and data to the evolving field and influence policy. For example, the upcoming Health Affairs issue on serious illness will provide information for the five- to ten-year workforce projections of the Health Resources and Services Administration.

In reviewing the workforce grants, several funders and experts stressed the importance of developing a workforce with skills that meet the needs of people with serious illness so new programs can hire the right staff and existing programs can expand. By scaling evidence-based educational models on communication with the incumbent workforce, these investments point the way to potential solutions.



## Durability

Given that most grants still have from months to years before they are completed, it is too early to determine the durability of the investments overall. Still, it is possible to speculate based on the progress to date and the quality of the grantee pool. The grantees who are working on accountability and payment issues are established organizations, who are acknowledged national leaders in the field who will champion these issues over the long haul. Funding from the Moore Foundation enabled them to take up topics (e.g., establishing quality measures for people with serious illness and increasing the skill level of clinicians to support end-of-life decision-making) that were already of keen interest but lacking time and resources. With the resources provided by the foundation, grantees have successfully used the power of national convenings, work groups, conferences, roundtables and publications to attract and engage many more influencers in the success of the work and its longevity.

*"Five years ago, only hospice cared about serious illness; now everyone does."*

- Grantee

Some grantees had ideas for continuation of their work after the foundation's funding is completed, including creating new organizations to focus specifically on the new work. An example of that is the unified registry work with the American Academy of Hospice and Palliative Medicine and the workforce-focused grants with the Center to Advance Palliative Care, Ariadne Labs and VitalTalk (as described in Appendix B).

*"Funding of this magnitude can really produce system-level changes."*

- Grantee

The following are examples of future opportunities or events that could occur to promote durability:

- The Center for Medicare & Medicaid Innovation could complete a successful pilot of its recently announced new payment model for patients with serious illness. (The new payment model, which is scheduled to launch in January 2020 as part of a larger [Primary Cares Initiative](#), is [based on proposed models developed](#) by two of the foundation's grantees, the Coalition to Transform Advanced Care and the American Academy of Hospice and Palliative Medicine.) A successful demonstration could lead to a permanent change in reimbursement for high-need Medicare beneficiaries, similar to the hospice regulations in the mid-1980s. Accountability strategies and workforce models that the foundation has funded could become integrated into this revised Medicare payment structure.
- The National Committee for Quality Assurance could market its completed accreditation standards for community-based serious illness care programs (it has indicated a willingness to do so), and payers could require accreditation as a condition of reimbursement or to be included in a health plan's provider network.

- The Family Caregiving Institute could develop robust training approaches to support family caregivers and promote national implementation and access.

## Lessons Learned and Opportunities

Interview informants were asked to reflect on the grant portfolio. While grantees mainly shared lessons on implementation and planning, experts and funders shared their perspectives on the field as a whole. This section presents these insights as potential opportunities and lessons for future grantmaking in the field. Note that while valuable lessons could be drawn from the experience of foundation staff, they were not interviewed as part of this review.

- **Share funding strategy with other funders.** Of the 24 individuals interviewed, many knew of the Moore Foundation’s general grantmaking focus but only a handful had any detailed awareness of the scope of investments in high-need patients. While some of the grants have been the result of co-funding partnerships, some funders have indicated that it would have been useful to have a clear sense of the Moore Foundation’s funding strategy in this space to coordinate funding and possibly avoid duplications. The sharing of information about funding of this magnitude would be useful for other funders in this space.

*“It was hard to get a clear sense of the focus of the portfolio. There were lots of shots at lots of targets.”*  
- Funder

- **Incentivize partnerships among grantees.** Several grants promoted new business partnerships between smaller-scale programs to have wider impact. When grantees were able to develop a shared vision for the work, they were able to transcend their allegiance to their own individual products and create something new with a better chance of sustainability. When grantees came together at different stages of development, the trust that developed over time allowed more mature programs to help the less developed one. Partnerships are possible and improve efficiency.

*“[All this funding] – is it letting 1,000 flowers bloom or creating a shark tank?”*  
- Grantee

- **Align and coordinate outputs.** Several grantees commented on the value of closer mandatory coordination among grantees working on related topics. This was especially true among the grantees working on accountability and payment, who sometimes learned informally about Moore Foundation-funded efforts similar to their own funded project. One grantee suggested routine briefings among related grantees to avoid duplication of tools like payment calculators and sharing progress on developing quality measures.

- **Seek alternate ways to share lessons.** There is a long time between completing a manuscript and having the information available for use by the field. This has been frustrating as the field has evolved so rapidly. Building some type of social media into research and dissemination projects could ensure faster uptake of new lessons, as well as self-publishing as white papers or issue briefs.

*"This portfolio provides a great framework for the field in terms of models, accountability and payment. What's missing overall is operational readiness, [the penetration of serious illness care practices uniformly at the provider level]."*

- Expert

- **Share outcomes with the field.** Consider publishing the outcomes from this work or have a convening (either in person or through webinar) to present and discuss findings. Funders are especially interested, but the audience could be broader. The dissemination of outcomes at the conclusion of the grants would be useful for the field.
- **Confusion about terminology persists.** The field lacks a unifying definition of who is being served, using a variety of terms including: complex, chronic illness; advanced illness; serious illness; palliative care; high-need patients; and frail elders. This remains an important issue and may be at least partly resolved by the new serious illness payment model that was recently announced by the Center for Medicare & Medicaid Innovation. The payment model, which will start being pilot-tested in January 2020, will define the characteristics of the patients who should receive specialized care to address their serious illnesses. This could have a major impact on the field by either narrowing or increasing the number of patients and providers eligible to participate in the new payment model. A potential future opportunity is to support efforts in the field to clarify and reach consensus on these topics.
- **Understanding of the field of serious illness.** Given the challenge in defining terms, several responders spoke of the lack of clarity that remains in health care about serious illness, different approaches and the basic differences between palliative care and hospice. Despite rapid spread of this kind of care, one should not assume the health care system overall understands the complexity of care for people with serious illness.
- **Focus on workforce.** Several responders noted that workforce is the dominant issue in caring for high-need patients, especially in the community. Nonprofessional caregivers are an important part of the care team. As a potential future opportunity, many grantees could provide advice, recommendations and guidance about approaches to strengthen the workforce at a regional level.

## **Conclusion**

By investing in a variety of approaches and organizations related to accountability and payment, the foundation catalyzed the development of new quality measures for care of people with serious illness, raising awareness and building support by bringing influential stakeholders to the table, with tangible results. In the area of workforce, the foundation's interest and investments have helped overcome the lack of resources for family caregivers and helped provide the communication skills that doctors and nurses need to assist people with serious illness consider their options for care and make hard decisions. Because most high-need patients grants are still underway, the full impact of these grants cannot be determined at this time. However, grantees, other funders and experts in the field hold very positive views about strategic importance and impact of the work funded by the Moore Foundation and completed thus far by its grantees and are strong advocates for sharing any lessons learned.

## **Appendix A: Impact – Key Outputs and Outcomes for High-Need Patients Grants**

<b>Impact</b>	
<b>Grantee</b>	<b>Evidence of impact.</b> <i>Includes: number of people trained; number of downloads/web views; additional funds raised; and other signs of uptake (i.e., regulation/legislation)</i>
Coalition to Transform Advanced Care	The Center for Medicare & Medicaid Innovation recently announced a new alternative payment model to support patients with serious illness. The new payment model, which is scheduled to launch in January 2020 as part of a larger <a href="#">Primary Cares Initiative</a> , is <a href="#">based on proposed payment models</a> developed by two of the foundation's grantees, the Coalition to Transform Advanced Care and the American Academy of Hospice and Palliative Medicine (see below for details about the latter).
University of Washington	Publication of March 2018 special issue of the Journal of Palliative Medicine, featuring 11 papers developed for a May 2017 quality measurement convening.
Health Affairs	Publication of July 2017 Health Affairs special issue about serious illness and end-of-life themes; coming soon is a June 2019 Health Affairs special issue on strengthening the workforce for serious illness care.
Hospice and Palliative Nurses Foundation	The fourth edition of the <a href="#">Clinical Practice Guidelines for Quality Palliative Care</a> , released in October 2018, has been downloaded 17,000 times and featured in more than 26 national publications. Also, the grantee was able to raise an additional \$150,000 from three other foundations that we recommended (Stupski Foundation, Gary and Mary West Foundation and The John A. Hartford), which allowed for a literature review of the evidence to be included in the updated guidelines.
American Academy of Hospice and Palliative Medicine	Received a three-year \$5.5 million grant from the Centers for Medicare & Medicaid Services to develop quality measures for serious illness care; also, raised another \$282,500 from Cambia Health Foundation to support the registry unification project.
Center to Advance Palliative Care	200 serious illness programs trained on how to thrive under value-based payments; 98 percent of programs participating in the payment accelerator said it was helpful and 88 percent secured at least one new partner relationship.
National Academies of Sciences,	Successfully raised funds to cover the whole cost of running the Roundtable on Quality Care for People with Serious Illness (we contributed \$250,000 of the total \$2 million budget); the proceedings

Engineering and Medicine	from the last workshop was the most read publication in October 2018 (more than 1,200 downloads).
Ariadne Labs, Center to Advance Palliative Care and VitalTalk	850 clinicians trained in communications skills specific to serious illness, with an anticipated 1,000 more by the end of the project; 83 national communication faculty (trainers trained), with an additional 179 to be trained by end of the grant.
Ariadne Labs	Seven health systems engaged in implementing system-wide serious illness communications projects; doubling of second cohort to an additional 14-20 systems engaged in implementation work.
University of Louisville Research Foundation	206 social workers registered to take inaugural social worker certification exam for palliative care (and 188 actually took the test). A second exam cohort of an additional 200+ social workers in fall/summer of 2019.
University of California, San Francisco	May 2018 Workforce Summit recommendations and commissioned papers to be published in special edition of the Journal of the American Geriatrics Society (April/May 2019).

<b>Output</b>	
<b>Type of grant output</b>	<b>Number produced (completed to date and additional outputs expected to be produced as projects finish up)</b>
Blogs	Completed to date: 8 Expected when projects finish: 1
White papers and summary publications	Completed to date: 18 Expected when projects finish: 27
Peer-reviewed articles	Completed to date: 34 Expected when projects finish: 22
Special issues of publications	Completed to date: 2 Expected when projects finish: 3
New products (including tools/toolkits, videos/documentaries and website enhancements)	Completed to date: 46 Expected when projects finish: 12
Accreditation/certification programs	Completed to date: 1 Expected when projects finish: 1
New quality measures	Expected when projects finish: 4
Alternative payment models	Completed to date: 1
Additional funds raised (including through co-funding with other foundations and getting approved for government grants)	Completed to date: 12 out of 68 total grants

## **Appendix B: Highlights from the Moore Foundation’s High-Need Patients Grant Portfolio**

### **Grants reviewed in the portfolio**

	<b># of grants in portfolio</b>	<b># of grants included in interview process</b>	<b>% of portfolio (\$) represented in interview process</b>
<b>Accountability and payment</b>	32	12	60%
<b>Workforce</b>	16	9	83%
<b>Model programs</b>	11	1	5%
<b>Public education</b>	7	0	0%
<b>Surveillance system</b>	1	1	100%
<b>Other**</b>	1	0	0%
<b>Total:</b>	<b>68</b>	<b>23</b>	<b>53%</b>

\*\*Other: One grant invests in both accountability and payment and workforce

### **Key grant details**

#### **1. Grantee organization: National Committee for Quality Assurance (NCQA):**

NCQA’s quality measures rate how well health plans and clinicians do at getting the right care to the right person at the right time, with measure sets tailored to the kinds of patients in Medicare, Medicaid and other health delivery systems. The Moore Foundation awarded NCQA two grants (which totaled \$2,436,534) to develop an accreditation/accountability program for community-based serious illness care.

**Grant highlights:** At the end of the grant in September 2020, all the needed parts of an accreditation program focused on high-need patients in community settings will be developed and will have been tested by four programs that care for seriously ill patients.

**Grant details:** The NCQA grants support the development of an accreditation program for serious illness care, including testing quality measures in a learning collaborative of four care providers currently working in the community. This grant raised the profile of the need for measurement in the high-need patient group and greatly increased the

understanding of the inadequacy of existing measures among many parties – clinicians, policymakers, and payers and purchasers. Developing and testing new ways to measure quality of care is time consuming and expensive; the Moore Foundation support was a key motivator to propel this work forward. Because the grant is still in process, it cannot be known yet if a stand-alone accreditation program for community services for high-need patients will find a market and be sustainable. However, NCOA has made the internal commitment to integrate new measures into existing programs, like its health plan accreditation process, which will ensure sustainability for this investment.

**2. Grantee organization: American Academy of Hospice and Palliative Medicine (AAHPM):** Started in 1988, this national body is the professional organization for physicians specializing in hospice and palliative medicine, nurses and other health care providers. AAHPM dedicates itself to advancing hospice and palliative medicine and improving the care of patients with serious illness. The Moore Foundation awarded AAHPM two grants (which totaled \$2,879,004) to create a single unified national palliative care registry to advance quality improvement and accountability for serious illness care.

**Grant highlights:** Three separate patient care registries developed by members of AAHPM and focused on serious illness care will be combined into a single unified registry, which will be launched in September 2021.

**Grant details:** The AAHPM grants aim to integrate three separate clinical registries focused on serious illness into a single unified registry, which will streamline data collection efforts, get more robust data for analysis, bolster sustainability and efficiency of the registry, and reduce confusion in the field over which registry to support. The unified registry will be a significant advance for the field in terms of standardization of care and a core set of quality outcomes. It will allow providers to compare their performance on issues like pain control and symptom management with other clinical groups. For patients and families, the registry will provide needed reassurance that the issues important to them (i.e., engaging in advance care planning conversations) are occurring systematically. AAHPM leaders said the skills they developed as a Moore Foundation grantee helped the organization mature in a powerful way and develop skills and confidence to expand its influence and try new things. One example is the work with the Centers for Medicare & Medicaid Services (CMS) currently underway to develop patient-reported outcome measures, in the areas of pain and symptom management and communication, for patients with serious illness. AAHPM applied for and won a three-year, \$5.5 million grant from CMS to complete this measure development work. Although the registry unification project is not completed, the three collaborating organizations have resolved many technical and operational issues through a constructive process, and they plan to form a separate nonprofit organization to manage the registry.

**Other foundation support:** Cambia Health Foundation



**3. Grantee organization: Center to Advance Palliative Care (CAPC):** With its beginnings from a grant from the Robert Wood Johnson Foundation, and now celebrating its 20<sup>th</sup> year, CAPC is a national organization dedicated to increasing the availability of quality palliative care services for people facing serious illness. The Moore Foundation awarded five grants to CAPC, totaling \$7,387,665. Four of the grants were in the accountability and payment space. Two grants focused on helping serious illness programs thrive under value-based payment arrangements; one grant supported the build-out of a registry of community-based serious illness programs; and one grant was to establish a coordination hub to achieve accountability for community-based serious illness care. The fifth and final grant was in the workforce area, to train clinicians to have end-of-life conversations (see #5 below for the discussion about the “trio grant”).

**Grant highlights:** The Moore Foundation’s grants supported CAPC’s work to develop payment models for serious illness care, create a registry of community providers serving high-need patients, and establish a hub to coordinate activities leading to an accountability system for serious illness care. The work of the hub (its official name is “The Serious Illness Quality Alignment Hub”) is scheduled to wrap up in September 2020.

**Grant details:** As a key player on the national stage, CAPC is a logical and credible partner to influence care delivery for high-need patients. The Moore Foundation has awarded five grants to CAPC since 2016, with the accountability coordination hub as the key grant. The hub brings together palliative care experts and U.S. health care quality leaders, such as the National Quality Forum, to first determine a minimal set of quality measures and standards and then expedite their adoption by the accountability systems like CMS, private health plans, purchasers and state health officials. Outputs include: identifying 10 accountability leverage points (i.e., CMS oversight of private Medicare Advantage plans); evaluating over 60 opportunities to impact those leverage points; securing a broad range of insights on the feasibility of each opportunity; and then selecting the ones with the most likelihood to improve access and quality of care for people with serious illness.

**4. Grantee organization: Hospice and Palliative Nurses Foundation:** The Hospice and Palliative Nurses Foundation is part of the Hospice and Palliative Nurses Association, and it served as administrative home for this grant. The work was completed by the National Consensus Project for Quality Palliative Care, comprised of 16 national organizations with extensive expertise with palliative care and hospice. The Moore Foundation awarded an \$828,000 grant to support the development, stakeholder endorsement, dissemination and implementation of Community-Based Practice Guidelines for Quality Palliative Care.

**Grant highlights:** The Clinical Practice Guidelines for Quality Palliative Care, 4th edition, was released in October 2018. The guidelines establish a comprehensive

foundation for gold-standard palliative care for all people living with serious illness, regardless of their diagnosis, prognosis, age or setting. The guidelines are available [online](#).

**Grant details:** The new edition of the guidelines was endorsed by more than 80 national organizations. The guidelines implicitly acknowledge that there is an insufficient supply of palliative care specialists to meet the need of those with serious illness. Therefore, the guidelines urge health care professionals and institutions to integrate palliative care into the services they provide to people living with serious illness, including cancer, heart failure, lung disease and other conditions. The additional value of this edition is the focus on community-based care – the guidelines cover all health care locations where people living with serious illness receive their care: outpatient clinics and office practices, cancer centers and long-term care facilities, as well as homeless shelters, dialysis units and especially at home. During the grantee interview process, we learned that an accreditation program for community-based palliative care has been developed by Community Health Accreditation Partner (not a Moore Foundation grantee) and will be offered in 2020; this work was based on the National Consensus Project’s guidelines.

**Other foundation support:** Additional support for the systematic review of the research evidence was provided by Gary and Mary West Foundation, The John A. Hartford Foundation and Stupski Foundation.

**5. Grantee organizations: VitalTalk, Ariadne Labs and CAPC:** Through research funded by the National Institutes of Health, VitalTalk has proven that communication skills about serious illness and goals of care are learnable and that clinicians are eager to learn when using the right method. Its innovative, interactive clinician and faculty development courses improve communication skills on an individual and institutional level. The Serious Illness Project at Ariadne Labs demonstrated significant improvements in the frequency, timing and quality of conversations; quality of life; and high acceptability among patients and clinicians in a large randomized controlled trial in cancer patients. CAPC’s 12 geographically diverse centers of excellence – a highly successful and well-established network called Palliative Care Leadership Centers (PCLCs) – trained over 1,200 hospital teams between 2005 and the present, and more than 80 percent then successfully established sustainable palliative care teams via in-person training, technical assistance, long-term mentoring and infrastructure. The Moore Foundation awarded the three organizations grants totaling \$6,657,673 to create and unify an approach to enhancing clinician communication skills to improve the care of seriously ill patients and their families nationally.

**Grant highlights:** These three grants aimed to create a “one door” portal for health systems and clinicians seeking online and in-person training to improve clinicians’ communication skills pertaining to end-of-life values, goals and care options.

**Grant details:** The three grants support a coordinated effort between three organizations, VitalTalk, Ariadne Labs and CAPC. (Patient Care Program staffers internally refer to the effort as the “trio grant.”) The goal is creating a “one door” portal for health systems and clinicians seeking online and in-person training to improve clinicians’ communication skills pertaining to serious illness and end-of-life goals and care options. The aim is to create efficiency in training efforts and reduce fragmentation and confusion – for example, the online portal helps to identify which educational program best meets the needs of the health system or individual clinician. The in-person training approach has grown from 250 to over 500 active clinical faculty; demand for this work continues to grow and is a key part of changing health care culture and reorienting care around the solicited and expressed wishes of the individual and family. Although it was challenging to work together because each organization was at a different stage of development and had a vested interest in its unique approach, the organizations are now much further along in terms of business modeling and getting to scale with their educational efforts. The grants improved their ability to deliver skill-building training to large systems by a factor of 10. It created synergy between leaders in the field as well as a mutual appreciation of strengths. Finally, this work aligned well with that of another Moore Foundation grant to Ariadne Labs (that project was aimed at building capacity for health systems to broadly implement serious illness conversations).

**6. Grantee organization: The Family Caregiving Institute at the Betty Irene Moore School of Nursing at UC Davis:** The Moore Foundation awarded a three-year, \$5,000,000 grant to UC Davis to establish a Family Caregiving Institute at the Betty Irene Moore School of Nursing.

**Grant highlights:** This grant funded the launch of the Family Caregiving Institute to support the health and well-being of persons with chronic and serious illness, and their family caregivers.

**Grant details:** Through this grant, the Family Caregiving Institute is working to establish caregiver competencies, advance support and resources for caregivers, and develop a professional workforce to train and support caregivers. Over the past two years, the Family Caregiving Institute has successfully recruited national leaders as faculty members and has established a leadership role in family caregiving as a key policy issue. Through its Research Priorities in Caregiving Summit in 2018, the Family Caregiving Institute further strengthened its reputation, serving as a magnet for smart and well-connected individuals and organizations to focus on this topic and develop strategies and tools to improve support for family caregivers.

**7. Grantee organization: University of California, San Francisco (UCSF):** The HealthForce Center (formerly Center for the Health Professions) was founded in 1992. For over two decades, the center’s research and publications have helped health care leaders and policymakers better understand the health workforce and develop

successful strategies and policies. The Moore Foundation awarded a \$600,000 grant to UCSF to organize an expert convening and produce a series of papers and recommendations that strengthen the health workforce that provides care for people with serious illness.

**Grant highlights:** This grant supports the development and dissemination of recommendations to strengthen the workforce that provides care in the community for high-need patients.

**Grant details:** The May 2018 Workforce Summit was a unique gathering of 40 key influencers from many sectors, and new relationships formed and common interests identified across sectors. Summit participants made 16 recommendations in seven broad areas, and dissemination of these recommendation is underway, including in a November 2018 Health Affairs blog, [Strengthening the Workforce for People with Serious Illness: Top Priorities from a National Summit](#). This work also was highlighted in special editions of the Journal of the American Geriatrics Society and Health Affairs (to be published in May 2019).

## **Appendix C: High-Need Patients Investigation Grant List**

### **Accountability and Payment**

#### **(#5393.01) American Academy of Hospice and Palliative Medicine: Creation of a Unified Registry for High-Need Patients**

**September 2018 – September 2021/\$2,407,813**

This grant supports the development and launch of a single unified national palliative care registry to advance quality improvement and accountability for serious illness care. The registry aims to have at least 180 programs using the new unified registry, which enables the field to advance quality improvement and accountability for the care of patients with serious illness.

#### **(#5399.01) National Committee for Quality Assurance: Advancing Accountability through Accreditation for Community-Based Serious Illness Care**

**September 2018 – September 2020/\$2,417,777**

This grant supports the development of an accountability/accreditation program for serious illness care, including testing quality measures in a learning collaborative comprised of four programs that care for seriously ill patients in the community. This project will result in the completed components of an accountability/accreditation program, including validated standards and process and outcome measures. It also will produce two white papers, which will detail the project's results.

#### **(#7485) Dartmouth College, The Dartmouth Institute for Health Policy & Clinical Practice at Geisel School of Medicine: Creation of a Palliative Care Learning Health System Incubator**

**June 2018 – June 2021/\$2,151,375**

This grant supports the development of a person-centered, registry-based health care delivery process – and a related information technology platform – that will systematically gather longitudinal data on health status and prescribed treatments and apply evidence in real-time to improve outcomes and care experiences for people with serious illness. Outputs of this grant will include a formative evaluation assessing pilot results of the registry-based learning health system, including experiences of patients, families and clinicians and feasibility, utility and uptake of the model, and a how-to guide to help serious illness programs that are interested in implementing the registry-based learning health system.

**(#6902) RAND Corporation: Developing Measures of the Care Experienced by High-Need Patients**

**November 2017 – November 2020/\$2,221,658**

This grant supports the development, testing and approval of new survey tools and the development of quality measures to assess how high-need patients and their family caregivers experience care received in community-based serious illness programs. The new survey tools and the quality measures should be completed by late 2020, and an article describing them will be submitted to a peer-reviewed journal.

**(#6851) Bipartisan Policy Center: Policy Recommendations for Improving Community-Based Serious Illness Care**

**October 2017 – January 2019/\$687,502**

This grant supports the development and release of a report outlining the challenges associated with providing appropriate care in the community to patients with serious illness, including specific policy recommendations to address the issues of payment, telehealth, workforce and family caregivers. The first part of the report is available [HERE](#) and the second part of the report is available [HERE](#).

**(#6889) National Quality Forum: Advancing Quality Measures for Community-Based Serious Illness Care**

**September 2017 – November 2020/\$1,080,000**

This grant supports the development of a workgroup, a series of annual convenings, and implementation tools all related to advancing quality measures for community-based serious illness care. The workgroup, three annual stakeholder convenings, and implementation tools should be completed by late 2020.

**(#6878) Center to Advance Palliative Care: A Coordination Hub to Achieve Accountability for Community-Based Serious Illness Care**

**September 2017 – September 2020/\$2,445,000**

This grant supports a national effort to prioritize, coordinate and monitor opportunities and activities that lead to a robust accountability system for community-based serious illness care. The expected outcome is increased adherence to community-based serious illness care guidelines, standards and/or quality measures.

**(#6363) LeadingAge: Options for Financing a Senior Housing-Based Coordinated Care Model**

**May 2017 – May 2019/\$116,000**

This project will convene experts and develop a white paper about options for financing a senior housing-based coordinated care model. The expert convening will be held in early 2018, and the white paper should be available in early 2019.

**(#6471) Coalition to Transform Advanced Care: Planning for a Serious Illness Care Payment Model Simulator**

**May 2017 – October 2017/\$179,908**

This grant supports planning activities for the development of a payment model simulator for serious illness care, including a paper-based prototype of the simulator and a timeline, budget and business plan to develop the full simulator.

**(#6212) Vanderbilt University Medical Center: Hospice Oversight and the Role of Regulatory Data in the Hospice Quality Reporting Program**

**March 2017 – December 2017/\$52,096**

This grant was made to support the research and the development of two papers about the current hospice oversight process, including an exploration of whether and how information from hospice quality assurance efforts could fit into future public reporting. The first paper can be found [HERE](#). The second paper can be found [HERE](#).

**(#5399) National Committee for Quality Assurance: Serious Illness Standards and Process Measures for Accountability**

**February 2017 – August 2018/\$2,229,100**

This grant was made to support the development of serious illness care standards and process measures suitable for inclusion in accountability and accreditation programs, including testing in a learning collaborative comprised of 11 community-based programs. The white paper is available [HERE](#).

**(#5977) Hospice and Palliative Nurses Foundation: Community-Based Practice Guidelines for Quality Palliative Care**

**January 2017 – July 2019/\$828,000**

This grant supports the National Coalition for Hospice and Palliative Care for the development, stakeholder endorsement, dissemination and implementation of the Community-Based Practice Guidelines for Quality Palliative Care. The Guidelines are available [HERE](#).

**(Contract) Discern Health: Health Benefits Design**

**November 2016 – July 2018/\$137,980**

Discern Health will produce a paper that evaluates innovation in health benefits design and its impact on the accessibility and affordability of high-quality, community-based serious illness care. For this project, Discern Health will conduct a landscape scan of benefits design models relevant to serious illness care, interview key stakeholders, and develop a conceptual framework for benefits designs that will promote access to serious illness care programs. The report is available [HERE](#).

**(#5255) University of Washington, Cambia Palliative Care Center of Excellence: Measurement Framework for Serious Illness Care  
October 2016 – March 2018/\$252,959**

This grant supports the Cambia Palliative Care Center of Excellence, part of the University of Washington, to lead a number of activities that will result in guiding principles and a measurement framework for population-based payment and delivery models that care for people with serious illness. A special issue of the Journal of Palliative Medicine, which includes 11 papers generated for this project, is available [HERE](#).

**(Contract) Discern Health: Data Availability and Alignment  
October 2016 – October 2017/\$166,000**

This project will produce a paper that identifies the data needed to support care delivery, quality measurement, value-based payment, and monitoring and evaluation; assesses the state of currently available data resources (federal datasets, electronic health records, patient-reported outcomes, repositories and clinical registries) to address those needs; reviews efforts underway to standardize data requirements; and identifies critical gaps in serious illness data moving forward. The paper is available [HERE](#).

**(#5393) American Academy of Hospice and Palliative Medicine: Planning for a Comprehensive Clinical Registry for High-Need Patients  
October 2016 – October 2017/\$471,191**

This grant was made to explore and define strategic options for integrating existing clinical registries (or developing a new one) to advance quality care for the nation's high-need patients with chronic conditions and functional limitations. A paper about a potential future registry is available [HERE](#).

**(#5467) Health Affairs: Health Affairs Serious Illness and End-of-Life Thematic Issue  
August 2016 – January 2018/\$845,945**

This grant was made to support the publication and dissemination of a thematic issue featuring peer-reviewed papers on key policy issues pertaining to serious illness and end-of-life care. The themed issue is available [HERE](#).

**(#5550) Center to Advance Palliative Care: Value-Based Contracting Incubator  
August 2016 – February 2019/\$850,000**

With this grant, the Center to Advance Palliative Care will create a "business incubator" to help community-based serious illness programs thrive under alternative payment models. The expected outcome is to develop, pilot, refine and spread the Payment Accelerator, which will train 200 serious illness programs to manage financial risk. Training materials and tools are available [HERE](#).



**(#5465) Pew Charitable Trusts: End-of-Life Quality Measure Convening  
July 2016 – March 2017/\$91,500**

The Moore Foundation partnered with Pew Charitable Trusts and Discern Health to convene leaders working in end-of-life/serious illness care to identify a small number of priority performance measures for specific settings of care, based on the environmental scan of measures created by Discern. A report about the convening is available [HERE](#).

**(#5304) National Academy of Sciences, National Academy of Medicine:  
Roundtable on Quality of Care for People with Serious Illness  
May 2016 – May 2019/\$250,000**

This grant supports the National Academy of Medicine to convene an expert roundtable on quality care for people with serious illness. The proceedings for the first workshop (“Integrating the Patient and Caregiver Voice into Serious Illness Care”) are available [HERE](#); the proceedings for the second workshop (“Models and Strategies to Integrate Palliative Care Principles into Serious Illness Care”) are available [HERE](#); and the proceedings for the third workshop (“Financing and Payment Strategies to Support High-Quality Care for People with Serious Illness”) are available [HERE](#). The foundation made a separate grant to support an April 2018 workshop focused on implementation of quality measures for community-based serious illness programs; the proceedings from that fourth workshop are available [HERE](#).

**(#5353) Discern Health: Advanced Care Measurement Framework  
March 2016 – March 2017/\$94,800**

Discern Health was commissioned to conduct an environmental scan of payment models related to advanced care. The report is available [HERE](#). Discern Health also conducted an environmental scan of performance measures in support of an end-of-life quality measures convening activity conducted in collaboration with Pew Charitable Trusts (see above).

**(#5217) Center to Advance Palliative Care: Developing Payment Models to  
Support Palliative Care  
January 2016 – January 2017/\$150,000**

This grant supports the Center to Advance Palliative Care in convening private health insurance plans to refine effective strategies and address ongoing challenges. The expected outcome is to deliver tools, training and technical assistance to support payers in improving access to palliative care. The Serious Illness Strategies framework is available [HERE](#).

## **Workforce**

### **(#8001) LeadingAge: Home Care Profession Training Standards in California October 2018 – October 2019/\$76,000**

This grant supports a white paper that will provide recommendations on establishing training standards and on ways to support a sustainable and skilled home care profession in California. The white paper is targeted toward state policymakers, home care agencies, health care provider associations, labor groups, consumer organizations and other interested stakeholders, and will be available in late 2019.

### **(#8038) Center for Health Care Strategies: Helping States Support Families Caring for an Aging America November 2018 – March 2020/\$156,862**

This grant supports a multi-state learning collaborative to develop new models and strategies to support family caregivers. Publications highlighting promising practices and lessons in supporting family caregivers will be available in early 2020.

### **(#7003) Health Affairs: Thematic Issue on Strengthening the Workforce for Community-Based Serious Illness Care December 2017 – December 2019/\$1,000,000**

This grant supports the publication and dissemination of a thematic issue featuring peer-reviewed papers on the topic of building a workforce to deliver high-quality, community-based serious illness care. The thematic issue will be published in June 2019.

### **(#6903) Massachusetts General Hospital: Addressing the Needs of the Home-Based Health and Personal Assistance Direct Care Workforce November 2017 – May 2019/\$1,053,899**

This grant supports the generation of policy and practice recommendations to strengthen the personal assistance direct care workforce and maximize their role as part of the interdisciplinary health and personal care workforce serving individuals with serious illness in the community. Two white papers and targeted recommendations should be completed by summer of 2019.

### **(#6939) University of California, San Francisco: Recommendations for Strengthening the Health Care Workforce for Community-Based Serious Illness Care October 2017 – April 2019/\$600,000**

This grant supports development and dissemination of recommendations that strengthen the workforce that provides care in the community for people with serious illness. A series of papers and recommendations for strengthening the health workforce should be completed by early 2019.

**(#5551) Coalition to Transform Advanced Care: Respecting Choices Advance Care Planning (ACP) Online Training Modules**

**July 2017 – July 2019/\$260,078**

Funding through this grant supports Respecting Choices to develop, test and disseminate a three-module online curriculum that will provide guidance to physicians and other health care providers to start advance care planning conversations with patients while they are healthy, prior to a health crisis. The curriculum is available [HERE](#).

**(#6419) University of North Carolina at Chapel Hill, The Cecil G. Sheps Center for Health Services Research: Improving Primary Care Clinicians' Communication Skills in Dementia Palliative Care**

**May 2017 – May 2019/\$512,241**

This grant supports the development, evaluation and dissemination of a video-based toolkit for dementia-specific communication skills aimed at assisting primary care clinicians in advanced care planning for patients with dementia and their families. The toolkit should be completed by August 2019.

**(#5968) University of California, Davis Health System: Family Caregiving Institute**

**February 2017 – February 2021/\$5,000,000**

This grant was made to support the Betty Irene Moore School of Nursing to launch a Family Caregiving Institute to support health and wellbeing for persons with chronic and serious illness, and their family caregivers. The anticipated activities of this grant include establishing caregiver competencies, advancing support and resources for caregivers, and developing a professional workforce to train and support caregivers.

**(#5532) University of Louisville Research Foundation: Palliative Care Certification Program for Social Workers**

**October 2016 – December 2019/\$367,961**

This grant helps support a role delineation study and certification program in palliative care for social workers. The expected outcome, a certification program for social workers is now taking registrations for the test in 2019. Information is available [HERE](#).

**(#5395) Brigham and Women's Hospital: Capacity Development for Large-Scale Implementation of the Serious Illness Care Program**

**October 2016 – October 2019/\$1,485,000**

This grant was made to support coaching of health care systems to implement serious illness communications training skills. The expected outcome is the development of a health system infrastructure to support clinicians to have better, earlier and more conversations about serious illness with patients. The pilot training program began the spring of 2018.

**(#5394) Massachusetts General Hospital: Aging Patients and Health Professionals – New Roles in a Changing Health System  
August 2016 – August 2018/\$1,899,487**

Funding through this grant will support research on how best to organize interprofessional teams to care for older adults including the quality and cost implications of various team models. Manuscripts are under review and planned for dissemination.

**(#5282) Yale University School of Medicine: Clinician and Patient Training in Patient Priority Care  
June 2016 – December 2019/\$806,126**

This grant supports the development and dissemination of training materials for patients and clinicians to develop care plans that are concordant with patient goals and preferences. Training materials are available [HERE](#).

**(#5291) VitalTalk: Training Clinicians to Have End-of-Life Conversations  
May 2016 – May 2019/\$6,657,673**

This work is a coordinated effort between three organizations with the goal of creating a “one-door” portal for health systems and clinicians seeking training to improve clinicians’ communication skills pertaining to end-of-life values, goals and care options. The Communications Skills Pathfinder site is now available [HERE](#). This effort is being led by VitalTalk in collaboration with Ariadne Labs (#5391) and the Center to Advance Palliative Care (#5389). Qualitative findings from the study are available [HERE](#).

**(#5317) University of California, San Francisco Medical Center: IMPACT ICU Training of Nurses to Discuss Palliative Care  
May 2016 – December 2017/\$222,500**

This grant supported dissemination of training for bedside nurses to lead palliative care communication for their patients in Intensive Care Units. A set of nine high-quality videos are available along with downloadable materials to facilitate group and individual learning [HERE](#) on the VitalTalk website.

**Public Education**

**(#5313.01) University of California, San Francisco School of Medicine: PREPARE Advance Directive Website Sustainability Planning  
December 2018 – December 2021/\$550,000**

This grant supports refinements to materials, dissemination and sustainability planning of the PREPARE website. The project team will complete updates and refinements to the PREPARE website and advance care planning tools, develop a business plan to promote the sustainability of PREPARE, and disseminate the PREPARE website and tools. States’ advance directive forms and other tools are available on the PREPARE website [HERE](#).

**(#6472.01) Twin Cities Public Television – Television Documentary on Preparing for Aging**

**February 2018 – June 2020/\$750,000**

This grant supports the production and distribution of a television documentary about preparing for aging. The program will focus on Americans' readiness for old age, specifically the planning and decisions that should be made by persons and their families well before a medical crisis or life-limiting diagnosis. The documentary should be broadcast in early 2020.

**(#6913) Tides Center, The National POLST Paradigm: National POLST Paradigm Form Quality Assurance Review**

**November 2017 – May 2019/\$205,510**

This grant was made to support the creation of a National POLST Paradigm Form and Form guideline document, as well as a recorded webinar presenting the two pieces, with the goal of improving the quality of care for patients who are seriously ill or frail. The documents should be published along with the webinar by late 2019.

**(#5290) Henry J. Kaiser Family Foundation: Promoting Public Education and Behavior Change About Serious Illness**

**May 2016 – May 2019/\$3,660,000**

This three-year grant was made to improve public understanding of serious illness issues and the importance of preparing for the last stage of life and provides for a steady stream of news coverage on relevant topics that will be distributed through Kaiser Health News. The grant also provides for the conduct of a public opinion survey (see description below under surveillance system).

**(#5313) University of California, San Francisco School of Medicine (UCSF): UCSF/PREPARE Advanced Directives Website**

**May 2016 – May 2019/\$650,000**

This grant supports the enhancement and dissemination of the UCSF PREPARE website with advance directive instructions and forms applicable to all states. States' advance directive forms are available on the PREPARE website [HERE](#).

**(#5289) Institute for Healthcare Improvement: Advance Care Planning – Outreach to the Public through Community Partners**

**May 2016 – May 2019/\$1,262,298**

This grant supports The Conversation Project, a project of the Institute for Healthcare Improvement, to refine and spread educational messages and tools around end-of-life planning to new audiences. Learnings from community partnerships should be disseminated in early 2019.

## **Model Programs**

**(#8039) George Washington University, School of Nursing: A Learning Collaborative to Improve Care for Patients with Chronic Kidney Disease  
October 2018 – October 2020/\$2,396,286**

This grant supports an 18-month pilot program to implement palliative care best practices at 15 dialysis clinics that care for 2,000 patients with chronic kidney disease. The project aims to improve the experiences and outcomes of care for these patients, particularly through the achievement of goal-concordant care. National dissemination of the results, including through an article in a peer-reviewed journal, will occur in late 2020.

**(#7795) Research Foundation for Mental Hygiene: Case Studies for Integrating Behavioral Health and Serious Illness Care  
October 2018 – October 2020/\$366,775**

This grant supports the development and publication of 10 case studies of model programs that have successfully integrated behavioral health and serious illness care delivered in community-based settings. The project will produce publications, including the case studies, about how community-based serious illness programs can integrate the delivery of behavioral health care into their existing programs.

**(#7521) Stanford University: Pathways Project Evaluation  
October 2018 – December 2020/\$239,381**

This grant supports an external evaluation of a pilot program to implement evidence-based palliative care interventions at 15 dialysis clinics that care for 2,000 patients with chronic kidney disease. The evaluation will assess the extent to which the palliative care interventions were adopted by the pilot clinics and whether that led to improvements in patient-reported outcomes such as the quality of patient/clinician communication. Project deliverables include an evaluation report and an article for a peer-reviewed journal.

**(#6879) Duke University, Duke-Margolis Center for Health Policy: Identifying Strategies for How Accountable Care Organizations Can Improve Care for High-Need Patients in the Community  
November 2017 – May 2019/\$499,656**

This grant supports research about how accountable care organizations can best serve high-need patients living in the community, including completing a quantitative analysis of Medicare claims data and developing and disseminating six case studies. Publications should be completed by mid-2019.

**(#5397) Quality Insights: Planning for Palliative Care for Patients with Chronic Kidney Disease**

**October 2016 – December 2018/\$921,400**

This grant supports the development of an evidence-based set of best practices for delivering person-centered palliative care to patients with chronic kidney disease as well as a plan to pilot the program.

**(#5753) Coalition to Transform Advanced Care: Serious Illness Care Model Implementation Framework**

**November 2016 – November 2017/\$384,242**

With this grant, the Coalition to Transform Advanced Care developed a Care Model Implementation Framework (i.e., evidence-based interventions, such as care coordination, caregiver supports and telehealth that improve quality and/or reduce costs). The framework provides guidance to community-based organizations designing programs for people with serious illnesses. The framework is available [HERE](#).

**(#5662) Altarum Institute: Aggregating Care Plans to Manage Supportive Care Services for Elders**

**December 2016 – December 2019/\$1,497,000**

Through this funding, the Altarum Institute will develop a process and monitoring tool for measuring frail elders' supportive service needs and providing this information on an ongoing basis to leaders within a geographic community responsible for managing the supply of supportive services. A tool for aggregating care plans will be produced by the end of 2019.

**(Contract) Research Foundation for Mental Hygiene: High-Need Patients Model Programs Research**

**December 2016 – July 2018/\$129,241**

This project was undertaken to examine the dual systems of care under which our health system operates with regard to medical/surgical conditions and mental health conditions, and how these separate systems create barriers to effective integration of care for high-need, high-cost patients. A white paper will be produced from the research conducted and should be available by early 2019.

**(#6331) Stanford University: Development of an Evaluation Plan for End-Stage Renal Disease Redesign Project**

**April 2017 – May 2018/\$133,351**

This grant supports the development an external evaluation plan for a pilot to test an evidence-based set of best practices for delivering person-centered palliative care to patients with end-stage renal disease at three community-based sites (see the above grant to Quality Insights).

**(#6752) Icahn School of Medicine at Mount Sinai: National Palliative Care Research Center Career Development Awards Program**

**July 2017 – July 2020/\$1,738,636**

This grant was made to support the National Palliative Care Research Center's Career Development Awards program, as well as the annual retreat and symposium in 2019 and 2020.

**(#5398) Kathleen Kerr: Serious Illness Model Programs Research**

**June 2016 – June 2017/\$46,350**

This grant was made to conduct an environmental scan of existing community-based programs that provide support and care for people with multiple chronic conditions and functional limitations, including those near the end of life. The goal was to identify programs that possess core competencies including: provision of care concordant with patient goals; team-based approach; home-based care delivery; seamless care across settings; comprehensive care including curative, palliative and end-of-life care; and a central role for family caregivers. More in-depth profiles were created for eight of the most comprehensive programs. The report is available [HERE](#).

**Surveillance System**

**(#5392) Center to Advance Palliative Care: Registry of Community-based Serious Illness Programs**

**October 2016 – October 2019/\$1,627,982**

This grant was made to support the Center to Advance Palliative Care to expand its National Palliative Care Registry to include all service settings, thus enabling the field to monitor the prevalence of community-based serious illness programs. A national report on prevalence of such programs should be available by late