Policy Barriers to Advanced Illness Care Models
Exploring the Obstacles to Implementing Innovative Clinical Models
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About C-TAC

The Coalition to Transform Advanced Care (C-TAC) is a nonpartisan, not-for-profit alliance of over 140 national healthcare stakeholders. We are dedicated to the goal that all Americans with advanced illness receive comprehensive, high-quality, person-centered care that is consistent with their goals and values, and honors their dignity.

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OVERVIEW

Americans are living longer than ever before. In 2015, the average 65-year old could expect to live another 19.4 years. But longer life also brings a greater prevalence of chronic illness. In 2015, 65 percent of Medicare beneficiaries over the age of 65 had two or more chronic conditions, often resulting in advanced illness.

While the U.S. health care system handles acute medical issues quite well, it is poorly equipped to provide appropriate care for people with advanced illness. Such patients typically receive care that is uncoordinated and treatments they do not want or benefit from. As a result, they often have a burdensome and costly health care experience. Palliative care, which focuses on improving quality of life, has been shown to improve outcomes and reduce cost by better aligning treatment with patients’ goals and values. However, access to such care is limited, particularly in the community or home, where people and their families would prefer to receive it.

Seeking to address this gap, clinicians and payers have implemented a number of innovative models to deliver care that better reflects patients’ goals and values. The Coalition to Transform Advanced Care (C-TAC) developed this report to highlight innovative models of care designed to provide people with advanced illness with palliative care in a community setting; the report will also review the policy barriers such models face and outline recommendations to address those policy barriers.

This report is based on information from published and presented findings, interviews, and a survey sent to industry experts (see Appendix A). It is also based on the years of experience that C-TAC and its members have in implementing such models.

*Advanced illness* occurs when one or more chronic conditions become serious enough to affect a person’s general health and functioning. In this situation, curative treatment begins to lose its effect and the focus of care needs to shift towards comfort. This situation continues to the end of life, typically 1-2 years.

*Palliative Care* is person- and family-centered care that optimizes the quality of life by anticipating, preventing, and treating suffering. Palliative care addresses physical, mental, emotional, social, and spiritual needs and facilitates patient autonomy, access to information, and choice. It is provided by a specialty-trained interdisciplinary team of doctors, nurses, social workers, chaplains, and other specialists who work together to provide people with an additional layer of support. It is appropriate at any age and at any stage in a serious illness; is not restricted by prognosis, and can be provided along with curative treatment.
The key findings of this report are:

- **Payment and Supporting Interdisciplinary Team Care** - Medicare’s current fee-for-service (FFS) payment model does not cover the full range of medical, psychosocial, and spiritual supports people living with advanced illness need, nor all the members of an interdisciplinary team (IDT) to deliver them. This discourages the full use of such teams to deliver needed care.

- **Upfront investment** - Current payment models, even new ones such as Accountable Care Organizations (ACOs), that enable groups of practitioners to coordinate care and share in any savings, typically do not allow for upfront funding for investment in program infrastructure. This makes launching new programs challenging, especially for smaller and rural health systems.

- **Rules for the provision of services** - Medicare Conditions of Participation (COPs) govern home health and hospice agencies but are outdated and siloed. This impedes the delivery of coordinated services to people at home and prevents the adoption of new innovations in home-based care.

- **Restrictive eligibility requirements for the Medicare Hospice Benefit** - Current eligibility requirements for the Medicare Hospice Benefit (MHB) force beneficiaries to forgo disease-directed care. This makes clinicians and patients reluctant to consider hospice until late in an illness, resulting in delayed or missed hospice admissions.
SYSTEM REFORM

Despite the political tensions over health care, virtually all stakeholders agree on the need to provide more efficient, coordinated, person-centered and community-based care to those with advanced illness. A major focus of delivery system reform is the FFS payment system which has traditionally paid for specific tasks or procedures and thus established financial incentives geared more towards the volume, rather than the quality, of care. The current payment system has also rewarded institutional rather than community-based care. The result is a disjointed system of misaligned incentives, where people are shuttled between practitioners and clinical settings with poor communication and little awareness of their goals and values.\(^5\)

In response, the Centers for Medicare & Medicaid Services (CMS) implemented ACOs, a new type of payment model, authorized by the Affordable Care Act in 2010. Though the type of ACOs varies by Medicare and health plan, they are all entities created by a group of health care providers that agree to coordinate care for a population of patients. The theory is that by improving coordination and collaboration, the ACO can not only improve health outcomes and reduce the number of transitions between care settings, but also produce savings by reducing unnecessary utilization of inpatient services.\(^6\) An ACO that also participates in the Medicare Shared Savings Program (MSSP)—and meets all of its quality benchmarks—can share in all or part of any savings if the population’s cost of care is less than the established threshold.\(^7\) A key distinguishing feature of ACOs are their degree of financial risk. Some ACOs share in both savings and in losses, others share to a lesser degree in savings and not all in losses.

CMS has also encouraged the clinician community to develop and propose alternative payment models (APMs). Here, Medicare would consider different methods of reimbursement for providers to treat people with a specific clinical condition as part of an episode of care. Potential new APMs, authorized under the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA), are a means of addressing barriers in current payment systems that make it financially infeasible to deliver higher-quality care in innovative ways. If approved, such new models, many of which may apply to various types of provider organizations, could ultimately replace the traditional FFS system. C-TAC\(^8\) and the American Academy of Hospice and Palliative Medicine (AAHPM)\(^9\) have each proposed APMs that are designed to increase access to community-based palliative care and address some of the financing problems seen in providing interdisciplinary care. PTAC recommended both models to the Secretary of Health and Human Services in March 2018.

However, while such payment reforms are important, they do not fully address all the policy barriers that prevent innovative community-based models of care from expanding beyond local or single settings. This report briefly outlines three models for treating advanced illness and the policy barriers they face. The models represent
a range of organizations and payment types and include a hospice that provides community-based palliative care on an FFS basis (Four Seasons), a risk-bearing multispecialty ACO practice (ProHEALTH), and a health plan (Aetna). Combined, they reflect a range of new structures that demonstrate how payment and delivery reform could proceed. They were selected based on a literature review and a survey C-TAC sent to 30 industry experts soliciting their views. The survey results demonstrated a surprising degree of consensus (see appendix A). Appendix B provides additional information on other advanced illness models that were also considered for this report.
KEY CARE DELIVERY MODELS

Four Seasons’ Compassion for Life Program

Overview

Four Seasons Compassion for Life, incorporated in 1979, is a non-profit organization that provides hospice and palliative care services in eleven predominately rural counties in Western North Carolina. There, an aging population has chronic care needs that go beyond the medical to include social supports and services.\textsuperscript{10} In 2014, Four Seasons was a recipient of a $9.6 million Center for Medicare & Medicaid Innovation (CMMI) Award focused on expanding community-based palliative care, improving patient outcomes, improving patient and family satisfaction, while reducing healthcare costs. With this grant the community-based palliative care model was scaled across numerous counties in Western North Carolina and upstate South Carolina covering 21 counties, with the addition of two large hospitals, 52 nursing facilities, and two new clinics. The goals of this grant are to reduce hospitalizations in this population by 10 percent, hospital deaths by 15 percent and total health care costs by $25 million over three years.\textsuperscript{11}

Design

Participants who enroll in the Four Seasons’ program receive community-based palliative care from an interdisciplinary team that is intended to supplement the regular, disease-modifying care provided by their primary practitioners.\textsuperscript{12} The services offered by Four Seasons include medical care focused on symptom management, quality of life, psychosocial support, coordination with community-based resources, advance care planning, and spiritual support. Participants also receive care coordination to ensure clinical follow-up as they change settings. The program provides educational opportunities to patients, family, the community, and practitioners through weekly palliative care clinics, presentations in the community, and webinars. The program also emphasizes participant, family, and provider education on topics that range from health counseling to the benefits of palliative care. Finally, the program coordinates efforts with local social service providers such as the Council on Aging, food banks, shelters, and counseling services to meet some of the social and practical needs of participants struggling in the community.\textsuperscript{13}

Four Seasons’ program is built around an IDT of physicians, nurse practitioners (NP), physician assistants (PA), registered nurses (RN), social workers (SW), chaplains, and administrative support staff. This team delivers palliative care services across the continuum of care settings including hospitals, clinics, private residences, nursing homes, and assisted living facilities. Ideally, this care is intended to provide an alternative to unexpected visits to the emergency room/hospital.\textsuperscript{14}
The model focuses on Medicare FFS beneficiaries with a life-limiting condition and a prognosis of three years or less. Participants are identified with a clinical assessment and screening tool developed by Four Seasons that determines physical limitations and social determinants of health. Referrals can come from clinicians or can be initiated by participants themselves. Once enrolled, participants are kept in the program until they are discharged, transition to a hospice, or die. Participants may be discharged if they no longer require palliative care services, if they have met their care plan goals, or if they have asked to be discharged.

Of the 2,482 participants that entered the program as of April 2017, approximately 48% came from hospitals, 29% from nursing facilities, 20% from home, and 2% from a clinic. Many were homebound and unable to visit their primary care practitioners in an acute crisis. The most common diagnoses were cancer, heart failure, chronic obstructive pulmonary disease (COPD), and dementia.

**Evidence**

The program recently completed the final year of implementation and CMMI is now working on a full program evaluation. Initial limited data has explored various aspects of the program:

- An analysis of all CMMI Four Seasons study participant transition outcomes from point of entry showed that 32% came from smaller hospitals (<300 beds), followed by 17% from larger hospital systems, and 22% from home or a clinic.
- Hospice transition was highest among those referred from home or the clinic, followed by nursing facilities, smaller hospitals, and larger hospitals. Palliative care deaths and discharges were higher in larger hospitals and re-enrollment in palliative care after previous discharge took place for 18% of discharged participants.
- In regard to disease profiles, the most prevalent diagnoses were neurological disorders (35%), followed by cardiovascular (16%), pulmonary (14%), and cancer (13%). The highest symptom burden was among those diagnosed with cancer or pulmonary disease, 45% and 37% respectively, of participants having two or more moderate-to-severe symptoms.
- Patients had poor functional status with 87% with a Palliative Care Performance Scale (PPS) of ≤ 60% and 94% with a PPS of ≤ 70%.

**Payment**

As with many community-based palliative care programs, Four Seasons’ program has struggled to recoup its total costs under the traditional FFS system. First, FFS rates are generally lower for the rural areas where Four Seasons operates. This financial challenge is compounded by the fact that staff spend significant unbillable time
traveling to and from each participant’s home. Second, Four Seasons’ team-based care includes services by clinical staff that cannot bill under Medicare: RNs, SWs, and chaplains. This means that Four Seasons must have a disproportionately higher number of billable practitioners, such as physicians and advance practice nurses, to make up for the RNs, Licensed Clinical Social Workers (LCSW), and chaplains that cannot bill. Maintaining this staffing balance is particularly difficult in a rural setting. In 2016, Four Seasons initiated a pilot palliative care telemedicine project as part of the CMMI award utilizing a combined approach of remote patient monitoring (via the TapCloud application) and videoconferencing in rural counties. This pilot telemedicine project significantly enhanced the services that the palliative care team was able to provide and demonstrated this model was feasible, usable and acceptable in a palliative care population of 100 patients and caregivers. Moreover, qualitative interviews with patients, caregivers, and providers demonstrated overwhelmingly positive experiences with the telemedicine model.

The CMMI grant has enabled Four Seasons to expand its community-based palliative care program, provide team-based care, and collect data. Beyond FFS reimbursement and the CMMI grant, the Four Seasons’ program is supported through a combination of external funding sources: research grants, community donations, and revenue from the operations of a thrift store. The result is a patchwork of funding streams that makes its long-term sustainability difficult for Four Seasons and complicates replication for others. The path to financial sustainability for Four Seasons after 2017 is unclear, but is likely to rely on the development of a Medicare-approved APM for community-based palliative care.

**ProHEALTH Home-Based Palliative Care**

**Overview**

ProHEALTH is a large multispecialty medical group in the New York metropolitan area with more than 1,000 medical practitioners in 230 locations serving over one million patients. The practice is part of Optum, a large national health care delivery organization. As is the case with most large provider organizations, ProHEALTH has a number of contractual arrangements with health plans. For example, it participates in a number of shared savings programs with different payers and also delivers home-based palliative care to enrollees of two local Medicare Advantage (MA) plans in return for a per-member-per-month payment. Finally, ProHEALTH also runs an ACO that is part of the MSSP that has approximately 32,000 members.

ProHEALTH’s home-based palliative care program serves patients with advanced illness or multiple chronic conditions. This includes patients in their last year of life as well as many with serious illness and other burdensome symptoms leading to multiple avoidable hospital admissions. The ProHEALTH team manages pain and other symptoms, leading conversations around goals of care, documenting participant treatment
preferences, and providing psychosocial support for patients and their family caregivers. The average daily census for ProHEALTH’s home-based palliative care program is 1,500 people, serving approximately 2,000 participants annually. Approximately half are in enrolled under MA and the other half in FFS under the ACO or other shared savings health plan arrangements.24

Design

ProHEALTH focuses on homebound and frail elders, individuals with advanced heart failure, COPD, metastatic cancer, or severe dementia as well as those on home oxygen. The program originally relied on practitioner referrals, but now relies on a proprietary algorithm that uses health plan and Medicare claims data to identify high-cost, high-need patients.25 Once identified, the patient’s primary care practitioner is notified and, if the practitioner does not opt out, the patient is asked to sign a consent form and enrolled in the program. As of 2016, no participant has opted out of the program.26 Participants have their total costs and health care utilization tracked with a particular focus on emergency room utilization and hospital admission rates. Other key measures include symptom measurement and management, the use of hospice and length of stay in that program. Overall, ProHEALTH’s ACO generated savings of $4 million annually.27

This home-based palliative care program is delivered by an IDT consisting of four physicians, ten RNs, four NPs and four SWs; an additional data analyst and five administrative staff provide program support. ProHEALTH provides at least one house call and two telephone calls per month to each participant with additional contact on an as-needed basis. Participants have 24/7 telephone support as well as access to team members through a telemedicine app that enables them and their family members to have a virtual visit with any team member as needed. The IDT reviews cases on a biweekly basis to see who may be appropriate for referral to hospice; the team also holds a quarterly review to discuss which participants may be transitioned to usual care or a less intense telephone-based case management system.28

One way that the team-based approach used by ProHEALTH differs from that of Four Seasons and others is that it has volunteers who are considered members of the team and provide supportive services and friendly conversation. They may join participants during chemotherapy treatments if the person wants company and does not have available friends or family. Volunteers do not provide any medical care and the relationship is managed by the participant.

Evidence

A recent study of participants in the ACO portion of this home-based palliative care program compared 82 patients who died during the study period and for whom ProHEALTH had continuous claims data. This group was compared with 569
similar ACO patients who did not participate in the program but would have been candidates if ProHEALTH had had the capacity to reach out to them for enrollment. The research showed that the home-based palliative care program produced significant cost-savings, fewer hospitalizations, and increased use of hospice during the last months of life:

- While the ProHEALTH home-based palliative care model cost approximately $400 per participant per month during the final three months of life, the cost per participant was $12,000 lower for the 82 participants in the home-based palliative care program. The cost per participant for those in the study was $20,420 per month, compared to $32,420 per month for patients who received usual care in the control group;
- The at-home death rate for the 82 participants was 87%, compared with a national average of 24%;
- There was a 35% increase in hospice enrollment and 240% increase in the median length of stay in hospice compared to the control group.

**Payment System**

ProHEALTH’s home-based palliative care program focuses primarily on participants who are part of the organization’s risk-based ACO. This means that as long as certain quality indicators are met, ProHEALTH is reimbursed by Medicare on an FFS basis for the covered services that it provides but can recoup a share of the savings if the participant’s care costs less than expected. ProHEALTH can then use these savings to pay for services that Medicare FFS does not traditionally cover, such as social and spiritual supports and nonbillable IDT members.

The program also serves a small proportion of Medicare participants who are in traditional FFS and are not part of the ACO. For these participants, ProHEALTH must subsidize the nonmedical costs of the program that cannot be billed directly to Medicare. Given the difficulties in obtaining reimbursement for many aspects of the program under traditional Medicare FFS payments, ProHEALTH has not been able to expand the home-based palliative care services model to more than a few of the FFS patients outside the ACO. For example, telehealth is also a key feature of the ProHEALTH program, but many of the virtual encounters would not be reimbursable under current Medicare payment regulations.

**Aetna’s Compassionate Care Program**

**Overview**

Under its Compassionate Care Program (ACCP), Aetna implemented case management for a group of commercial and Medicare enrollees with advanced illness
and expanded access to hospice services for some commercial members; Aetna targeted members from both its private and MA plans. The goal of the program, which has been in place since 2004, is to provide comprehensive case management to people living with advanced illness and their families to improve their quality of life and other outcomes.31

**Design**

Aetna identified eligible enrollees using a proprietary algorithm and predictive model including claims data.32 Under the ACCP, Aetna nurses, supported by social workers, provided care management, needs assessment, care coordination, advance care planning, and symptom assessment primarily through telephonic support. In practices with value-based arrangements, Aetna had embedded case managers that could work on a one-on-one basis with enrollees. In either case, the key to the program was selection and training of the case managers who developed highly personal relationships of trust with the participants; in both telephonic and in-person case management, clinicians and Aetna-trained nurses worked closely to facilitate access to private practitioners for additional symptom management when needed. The number and frequency of interactions with program participants were determined largely by participant need.33

At the same time, Aetna made a number of changes related to hospice for its commercial members. For the commercial health benefits, Aetna loosened eligibility for its hospice benefit and allowed commercial members to receive hospice care and disease-directed care concurrently as long as they had a prognosis of 12 months or less. Previously, members had to give up disease-directed care and have a prognosis of 6 months or less in order to enter hospice, which are the enrollment criteria of the MHB. Furthermore, commercial enrollees also became eligible for 15 days of community-based respite care as well as a bereavement service. MA enrollees are not eligible for these modified hospice benefits as the MA program does not cover hospice.

Selection and training of case managers is a key part of the success of the ACCP. The case management relies on the development of highly personal relationships that cannot be duplicated by just using the right script or decision tree. Whether through telephonic support or through the use of embedded case managers, utilization of hospice more than doubled for ACCP private-pay enrollees and increased by one-quarter for Medicare beneficiaries. Scaling the case management elements of the program, however, has been more difficult.34 The program currently serves approximately 7,700 individuals each year from the commercial side and about 6,000 individuals enrolled in the MA program.35
Evidence

A study in 2009 looked at 4,325 commercial and MA enrollees in Aetna’s CCP who died in 2005 and 2006. All received intensive case management with hospice eligibility requirements that were liberalized for some of the commercial enrollees. Compared with enrollees who died prior to 2004, a higher percentage of ACCP participants used hospice; the median length of stay in hospice increased for both groups of commercial enrollees. At the same time, other important indicators of quality of care, such as emergency room utilization and days spent in the intensive care unit, also showed a significant reduction.

Data from the subsequent research showed similar results for the MA enrollees in the ACCP. Researchers found an:

• 82% hospice election rate (versus the national average of 49 percent);
• 82% decrease in acute days versus a separate FFS control group;
• 88% decrease in intensive care unit days versus a separate FFS control group;
• 80% reduction in emergency room use;
• A high level of member and family satisfaction;36
• A $12,000 per member average cost reduction compared to the FFS average control group.37

Payment System

ACCP is financed by the health plan as a care management service for its members and their families. Similar to other risk-based payment models, the program primarily uses nurses as case managers supported by social workers and leverages physician resources in an oversight role. Because it is funded by the MA plan that receives a per-member, per-month payment from Medicare, it is able to include services beyond what FFS or other payment structures pay for. The overall savings of the program helps to fund these additional services and costs. Health plan-based programs have some flexibility in what benefits they can offer yet face some regulatory limitations—particularly MA plans, which until recently could not provide nonmedical services like non-skilled personal care or disease-modifying services once someone has elected hospice.
POLICY RECOMMENDATIONS AND SOLUTIONS

Current policy barriers significantly hinder the ability of health plans and providers to implement, sustain, and expand the scope of models such as the three outlined here. Particular plans and providers may find innovative solutions to work around these barriers, but ultimately policies must be changed in order for this type of care to be more widely available or expanded nationally. The following is a description of significant policy barriers and potential ways to address them.

Payment and Financing

As these three examples demonstrate, the traditional Medicare FFS reimbursement system does not fully support efforts to transform the current delivery system into one that delivers high-quality, home-based palliative care to people with advanced illness. In order to facilitate these new approaches, alternative payment models must address two critical gaps. First, they must support the use of the full IDT that is a key part of delivering comprehensive palliative care. Second, they must support the upfront investment that health care systems need to make to implement the new delivery models.

Supporting Interdisciplinary Team Care

Quality care for advanced illness requires the ability to call on members of a full IDT: physicians and nurses to manage the medical care, social workers to address psychosocial and behavioral health issues, case managers and coordinators for transitions of care, and chaplains for spiritual and existential concerns. Some programs also include pharmacists, physical and occupational therapists, and ancillary therapists as part of the care team. Trained community members, such as lay navigators, may also be part of the team, as is the case with the University of Alabama’s Cancer Navigator Program.¹⁸

However, current Medicare billing guidelines only reimburse for activities performed by certain members of the medical team: physicians, NPs, PAs, and physical and occupational therapists.³⁹ Pharmacists and SWs can occasionally bill “incident to” physicians in certain situations; SWs with an MSW degree and licensure as a LCSW can bill for mental health counseling services. However, this type of counseling often falls outside of the typical palliative care SW encounters described here; SWs who are not LCSWs cannot bill for their services, even though they perform vital psychosocial services as part of an IDT. There is no Medicare reimbursement for other social work services, nurses, case managers, or chaplains. This is one reason why only one of the three models reviewed in this report, Four Seasons, included a chaplain—and then only part-time. Programs hoping to use the
full complement of an IDT currently have to seek additional organizational or private funding and such opportunities are limited.

There are a number of potential approaches to fund the use of a full IDT focused on care for people with advanced illness. The most straightforward would be for an APM with capitated payments to providers. In that way, the providers would have the flexibility to support the right balance of IDT staff and services to deliver the care needed. The APMs proposed by C-TAC and the AAHPM would make the range of IDT services more widely available through the use of capitated payments.  

Another approach would be for CMS to initiate rulemaking that expands the list of Medicare practitioners that can be reimbursed under FFS. Along those lines, it is worth noting that the bipartisan The Patient Choice and Quality Care Act of 2017 would add SWs to the group of practitioners that can be reimbursed for advance care planning conversations. However, while it is possible to see extending situations where SWs could bill for their services, it is unlikely that Medicare could ever cover chaplain services, for instance, as these fall far outside the medical care Medicare has traditionally been required to cover.

**Upfront Investment**

At present, only well-resourced health organizations that care for a large number of people, and have significant cashflow, can afford to implement such new models. As one insurance industry expert noted, the biggest barrier to implementation of innovative models is often the large start-up costs such as hiring the IDT staff and program development including health information technology (HIT) systems. CMS appears to recognize this and has created a new ACO investment model that allows for spending on infrastructure, such as the expansion of HIT systems to include a patient portal and/or data warehouse capabilities; it also allows for the hiring of staff such as nurse case managers, executives, or project directors to oversee the implementation of care coordination efforts. This is the kind of upfront investment that may allow organizations like the ProHEALTH model to expand their effective services to all advanced illness patients with Medicare FFS coverage. These upfront incentives will also likely be particularly important for rural ACOs, areas with low ACO penetration, and existing ACOs that are planning on taking on greater financial risk.

Such incentives, although necessary, would likely not be sufficient for ACOs with a high percentage of individuals with advanced illness. Any models for that population will also need new palliative care APMs that are designed to provide sufficient upfront investment and reimbursement for full palliative care services.
Rules for the Provision of Services

Conditions of Participation

COPs are a set of minimum health and safety standards that providers and suppliers of health services must comply with in order to qualify for Medicare certification and reimbursement. COPs specify, and therefore limit, the types of care for which a Medicare-certified agency can be reimbursed. For instance, the hospice COPs limit the type of in-home nursing services hospice nurses can provide. That usually means such nurses cannot perform direct personal care such as wound management. If a patient needs additional nursing services, a hospice must engage a home health agency to bring in additional nursing resources. In addition, COPs apply to all Medicare beneficiaries served by the certified organization even though the organization may care for different patient populations with different needs. An organization can be certified to provide more than one kind of service, but certifications are expensive to gain and to maintain.

The barriers created by COPs make the arrangement of services logistically complicated and impede the continuity in team-based care that people with advanced illness and their families need. Providers can seek Medicare waivers to the COPs for demonstration models, but that is administratively impractical should such programs become more widespread.

One solution would be to add a new COP for home-based palliative care programs, as has been done with other added programs over time. However, doing so would be a substantial and lengthy undertaking. Medicare would have to develop rules around the organizational requirements and patient care, as well as identify what constitutes core services, how the provider would get paid, and what constitutes covered services and licensed professional services. This would clarify the scope of practice and the type of services that would be required for providers of such programs, but would contribute to yet another siloed type of care in the home setting.

Another option would be for the existing COPs to be revised to accommodate new and innovative home-based models such as the palliative care ones described here. For example, the Medicare home health COP could be modified to permit agencies to provide services covered by Medicare, but falling outside the scope of the home health benefit; another example is to allow Medicare-certified agencies to provide supportive services to beneficiaries not receiving Medicare home health benefits or other skilled care. This would allow Medicare home health agencies to provide care as long as required resources, skills, and patient protections were met across the state license categories. By doing so, the current requirement that COPs apply to all Medicare beneficiaries served by the certified organization would be removed, without changing the requirement that COPs apply where Medicare-covered services are provided.
Overall, such a federal change would provide a more flexible approach by allowing organizations with existing state licenses to extend the services they can perform under those licenses. It also recognizes that many types of organization have the capabilities to offer in-home services that fill gaps in care—while continuing to ensure that there are appropriate patient protections and oversight requirements in place for Medicare-covered services.

In practice, modifying the federal COPs involves some challenges. It would require Medicare to initiate rulemaking that could trigger opposition from agencies that have developed an infrastructure around a particular set of home-based services and may view new palliative care programs as competition. And once any federal COPs would be modified, there would then need to be subsequent work at the state level, as most states also license home health or hospice agencies there.

**Hospice Admissions Criteria**

Although the profile of people who would benefit from hospice services has changed dramatically since the MHB was established in 1982, the enrollment criteria have not changed to keep pace. Hospice was designed to primarily provide home care for cancer patients at a time when there were few disease-modifying treatments available. If remission from cancer was not possible in the 1980s, then there was little else medically to do, and the requirement that people forgo further disease-modifying treatment did not mean giving up much.

Today, a significant number of treatments can improve the quality of life for people living with cancer and other illnesses, even in the later stages. Many of these treatments are clearly disease-directed, but some—like blood transfusions, radiation, and certain chemotherapies—are also palliative. Requiring that hospice patients forgo such treatment removes interventions that could improve the trajectory of their disease; it could also deny them treatment that provides significant palliation and improved quality of life. Evidence shows that having to forego such disease-directed treatment often makes physicians and patients reluctant to consider hospice until very late in an illness.

Therefore, extending the MHB to allow for concurrent disease-modifying treatment, as was done by Aetna’s CCP, could help people enroll in hospice sooner and reap more of the benefits. It was with this goal in mind that CMMI launched the Medicare Care Choices Model (MCCM) in 2016. This model is for a select group of beneficiaries who are hospice eligible but do not want to give up disease-modifying treatment. It provides reimbursement for a slimmed-down package of hospice services to patients with advanced cancer, heart failure, COPD, or HIV living at home. Medicare continues to pay for any disease-modifying treatment, but also provides a per-beneficiary, per-month fee of $400 to the participating hospice. This gives patients access to a hospice IDT and helps with care coordination and symptom management, although with less frequent in-home follow-up than typical hospice care.
Preliminary results suggest that MCCM enrollees find this appealing and that clinicians believe it makes for a smoother and earlier transition to hospice.\textsuperscript{50} CMMI is authorized to make cost-effective components of a demonstration program a permanent part of the Medicare program or to expand the number of demonstration sites if the demonstration is found to be successful. MCCM’s full results will become available after 2022, although CMS could expand the demonstration project or change the eligibility criteria before then based on early evidence of cost effectiveness. The MHB could also be changed through legislation. In addition, CMMI could also create a wholly new demonstration that tests the effect of allowing enrollees in MA to access concurrent hospice and disease-directed care.

\section*{Issues in Need of Further Exploration: State Barriers}

Although not the focus of this report, the survey C-TAC sent to industry experts confirmed that state policies create additional barriers for programs, especially those that operate in multi-state metropolitan areas or regionally. These barriers are outlined below, although the solutions for them need additional research and development.

\subsection*{Organizational Licensure}

As with the federal COPs, current state licensure rules for home-based interdisciplinary care limit models like ProHEALTH and Four Seasons from providing care to the full range for those with advanced illness. Even in the absence of changing federal COPs, there is variability across states regarding which types of people hospices can enroll in palliative care, as opposed to hospice services. Specifically, some states limit hospices to caring for only those with a prognosis of six months or less, while others allow hospices to care for those with a prognosis of up to a year.\textsuperscript{51} The latter broader population is more appropriate for advanced illness programs. In addition, current state licensure requirements of traditional home-based services such as home health, hospice, and private duty nursing effectively prevent multispecialty medical groups from providing these services. Changing this system, however, would require a complicated and long-term state-based effort.

\subsection*{Clinician Licensure}

Clinicians must be licensed by each state in which they provide patient care. This can be a challenge for programs that span multiple states, as the licensing process is increasingly expensive due to the requirement of additional elements, such as criminal background checks. There is a move towards interstate licensing compacts, in which states agree to accept the licenses from other participating states; however, these are currently limited to certain disciplines and also vary by state. For example, the physician compact states differ from those in the nursing compact.\textsuperscript{52} The increasing use of telehealth for patient follow-up may hasten the effort to create a broad interstate licensure compact.\textsuperscript{53}
Varying state licensing policies also limit the scope of practice for SWs and NPs. For example, only 22 states allow NPs to practice to the full extent of their training and certification. The remaining states bar those health care professionals from providing services, such as prescribing medications, that they have been trained and certified to do.

Creating greater uniformity in licensure policies across states for all regulated members of the IDT would remove inefficiencies and ensure that clinicians are able to practice at the top of their professional skills and training. However, this would also require a coordinated state-by-state effort.

**Conclusion**

Despite its many strengths, the current healthcare system does not have the flexibility to provide the necessary range of medical and supportive services for people with advanced illness, especially in community-based settings. People with advanced illness often encounter poorly coordinated care in settings not of their choosing; some experience unnecessary and occasionally unwanted care. Fortunately, the recent shift to value-based care provides many opportunities to adopt innovative ideas and programs to ensure that the care provided reflects patients’ goals, values, and care needs. Several models developed through Medicare demonstrations and in the private sector show considerable promise. Yet, for all these innovations, policy barriers still hinder the development, sustainability, and expansion of such programs.

This report has highlighted successful care models that treat people with advanced illness, identified the policy problems that these models encounter, and proposed solutions to address them. Policymakers should use these suggestions as a guide as they continue to transform the U.S. health care delivery system.
Appendix A – Model Survey Overview

Survey of Model Experts

Background

In order to better understand specific aspects of the key models and the policy barriers they encountered, C-TAC sent a survey to 30 industry experts. Seventeen of them filled out the survey and C-TAC conducted a phone interview using the survey’s questions with an additional industry expert. Respondents included the clinical or organizational leaders representing some of the models, and other industry experts from key palliative care or policy organizations.

The Survey

The survey included 15 questions, all but one of which were open-ended. The first question named eight existing models of care—pre-selected for being particularly innovative—and asked respondents to identify which, if any, they were most familiar with. (Respondents were also allowed to write in additional models.) Respondents were then asked a series of questions about the model they selected, including barriers encountered implementing the model, the effect of those barriers on the model’s sustainability, the ability of the model to be expanded, and whether the policy barriers affected any other aspects of the chosen model. The survey then sought to find out whether these policy barriers were ones that the model could overcome and, if so, at what cost. The survey also had a question on the model’s payment structure, whether that payment supported all the clinical elements of the model, and, if not, what would be added if further funding were available. The survey then raised questions about the respondent’s federal policy priorities and their assessment of the federal and state policy opportunities for the model. Respondents were also asked for the one state or federal regulatory change they would make if they could.

Survey Findings

The analysis of the responses showed consensus. Most respondents named payment as the key policy barrier, both to the model they were most familiar with and to other models they knew about. Most respondents also reported the additional problems in obtaining reimbursement for the full range of services these models offered and for the interdisciplinary team delivering them. Several pointed out the limitations of the Medicare Hospice Benefit and others discussed the challenges of how Conditions of Participation limited the smooth delivery of home-based services between current Medicare-approved agencies. Those with experience with multi-state programs also raised issues around the variability there.

Additional models that were identified in the survey included the following:

- Care New England/Integra
- Northwell Independence at Home
- Sharp Hospice Care
- Sutter Advanced Illness Model and
- University of Alabama at Birmingham Cancer Care Navigators

Because elements of these models, including the population served and the services provided, overlapped with other models, it was decided to choose an exemplary model for each payment category. Additionally, most of the policy barriers each model reported were the same ones across the other models.
## Appendix B – Overview of Additional Models Reviewed

Beyond the three models chosen, C-TAC identified additional models through its literature review and survey results. These are summarized briefly here:

### ADDITIONAL MODELS & POLICY BARRIERS

<table>
<thead>
<tr>
<th>Model</th>
<th>Population/Setting</th>
<th>Services</th>
<th>Results</th>
<th>Key Policy Barrier(s) Noted</th>
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| Care New England/Integra           | Complex care (high risk/high need) population cared for by integrated health system/ACO in RI. | Nurse care managers contact patients weekly, palliative care via IDTs integrated into all aspects of health system. | Improved transitions of care, decreased SNF readmissions, increased training of providers in primary palliative care, reduced utilization. | Payment model: Program successful in MSSP ACO structure but may not be as effective in payment systems that also include risk.  
Telehealth: This is limited for Medicare patients by rules that need to be updated. |
| Northwell Independence at Home     | Those with advanced illness, complex care or stable chronic conditions in integrated health system/payer organization in greater NYC/Long Island. | A defined palliative care bundle of services delivered telephonically and via team-based home visits. | Improvements in care effectiveness and efficiency and the patient’s experience, and reduced utilization. | Payment model: Home-based services have been supported by the Independence at Home pilot which now needs to be made a permanent Medicare program.  
Telehealth: limited for Medicare patients by rules that need to be updated. |
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<th>Services</th>
<th>Results</th>
<th>Key Policy Barrier(s) Noted</th>
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<tr>
<td>Sharp Hospice Care</td>
<td>Health plan patients at risk of hospitalization for decompensation, delivered by hospice organization in San Diego, CA, part of an integrated health system.</td>
<td>Community-based palliative care layered onto traditional care focused on home disease management and proactive psychosocial management.</td>
<td>Reduced hospital and total healthcare costs, dying in the hospital very low, lower cost last months of life, high patient satisfaction.</td>
<td>Payment model: Needs new payment structure—limited to financially at-risk population only. Need payment system for FFS.</td>
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<tr>
<td>Sutter Advanced Illness Model (AIM)</td>
<td>Patients with severe chronic illness not ready for hospice care, who are in clinical, functional, or nutritional decline, and who are high-level consumers of healthcare in an integrated health system in Northern CA.</td>
<td>Nurse-led/physician-guided interdisciplinary teams coordinate and deliver care that promotes patients and caregiver confidence and supports home-management of symptoms.</td>
<td>Reduced utilization, and increased patient and provider satisfaction.</td>
<td>Payment model: Needs new payment structure—When HCIA funding ended, Sutter was challenged to continue the program under current fee-for-service (FFS) structure. (Fully capitated contracts for a population subset provides a partial reimbursement mechanism.) Agency licensure: There are potential licensure barriers in providing home services, barriers that get magnified when programs are implemented through contracting partners, although integrated systems run into them too.</td>
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<tr>
<td>Model</td>
<td>Population/ Setting</td>
<td>Services</td>
<td>Results</td>
<td>Key Policy Barrier(s) Noted</td>
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<td>University of Alabama at Birmingham Cancer Care Navigators</td>
<td>Medicare patients with cancer cared for by UAB Health System Cancer Community Network in rural South.</td>
<td>Community Health Workers (lay navigators), integrated into cancer care team, provide support and coaching to patients across cancer continuum; hardware program to support actively engaged patients with a proactive, responsive, patient-centered infrastructure and IT system.</td>
<td>Decreased hospital utilization and EOL costs, increased hospice enrollment.</td>
<td>Payment model: Lack of reimbursement for lay navigators and potential issues with state regulations. Currently non-professionals such as lay navigators cannot bill for their services. Personnel licensure: Also, some states may have regulations regarding use of unlicensed health care personnel which could conflict or restrict the adoption of such a program more broadly.</td>
</tr>
</tbody>
</table>
Endnotes

12. Taylor et al, Feb 2017 HA blog post


27. ACL case study.


34. Interview with Randall Krakauer, MD. 2017.

http://www.chcf.org/-/media/MEDIA%20LIBRARY%20Files/PDF/PDF%20C/PDF%20ComplexCareManagementOverviewsGeneral.pdf


51. Citation forthcoming.

52. Citation forthcoming.

