C-TAC
COALITION TO TRANSFORM
ADVANCED CARE

Evidence-Based Best Practices for Improving State-Level C-TAC ACT^{SM} Index Results

ADVANCE CARE PLANNING

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PRODUCED IN COLLABORATION WITH

DISCERN
HEALTH

CONTENTS

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- **Discern Health:** Theresa Schmidt, Alexis Malfesi, Emily Schutz, and Tom Valuck
- **C-TAC:** David Longnecker, Bill Hannon, Lou Gagliano, and Marian Grant

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Subject Matter Experts Consulted

C-TAC and Discern thank the following national subject matter experts for their feedback on our approach and findings. These individuals offered guidance on key project questions, shared articles for inclusion in the literature search, identified potential key informants for Phase III interviews, and reviewed draft versions of this report.

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EXECUTIVE SUMMARY

Project Goals

The Coalition to Transform Advanced Care (C-TAC) partnered with Discern Health (Discern) to support its continued efforts to build the Advanced Care Transformation Index^{SM} (ACT Index), which C-TAC developed to assess the state of advanced illness and end-of-life care in the United States. In this project, Discern conducted research to identify evidence-based best practices that states can implement to improve performance on one of the ACT Index measures, Advance Care Planning (ACP).

Act Index Measure: Advance Care Planning

The ACT Index offers a single composite measure that allows policymakers, regulators, healthcare providers, communities, and consumers to assess the overall performance of the advanced illness care movement through measured change over time. ACP is a component measure of the ACT Index and captures the percentage of Medicare fee-for-service (FFS) beneficiaries with a 2017 claim for at least one of the two ACP Current Procedural Terminology (CPT) codes, 99497 and 99498.

The practice of ACP is rooted in the understanding the values, goals, and preferences of the individual. A care team works with the patient, their designated decision maker, and family to make decisions and sometimes prepare documents to ensure that care is concordant with their wishes. ACP can increase patient and family satisfaction with care and reduce the costs associated with unwanted care or unnecessary treatment.[1,2,3,4.5]

Methods

Discern worked with C-TAC to apply a mixed-method research strategy to identify evidence-based actions to increase ACP at the state level and improve performance on the ACT Index ACP measure. This three-phased approach included:

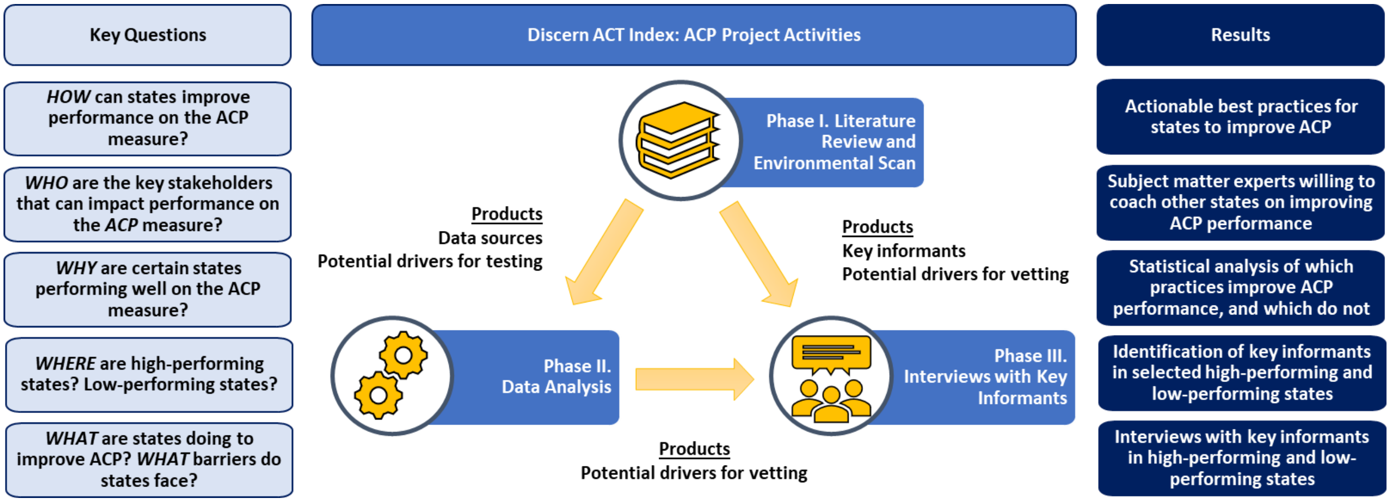
- Phase I. Literature Review and Environmental Scan
    - Review of peer-reviewed publications and grey literature to surface evidence on ACP drivers that may be actionable at the state level as well as other relevant factors that might impact the use of ACP, such as demographic or socioeconomic factors
- Phase II. Data Analysis
    - Operationalization of key drivers identified in the literature review, data aggregation, and statistical analysis to assess the association of driver variables and controls with the 2017 rates of ACP at the state level
- Phase III. Interviews with Key Informants
    - Facilitation of six stakeholder interviews to identify best practices for increasing ACP and barriers to widespread use of ACP. We interviewed stakeholders in Hawaii, the highest performing state on the ACP Act Index Measure. We also interviewed

stakeholders in Louisiana, a lower-performing state and an outlier (i.e., rates of ACP were lower than our statistical model predicted)

  - Leveraging key informant interviews to identify four potential Regional ACT Index Coach candidates. C-TAC is recruiting Regional ACT Index Coaches to champion efforts to improve the quality of care for those with advanced illness and support grassroots change at the local level

As shown in **Figure E1** below, we adopted an agile approach to managing this research process, using findings from each phase to inform the execution of subsequent phases. After creating the initial draft of this report, we requested review from subject matter experts who provided additional input into the report contents and presentation.

Figure E1. Three-Phased Research Methodology to Identify ACP Best Practices



Findings

Best practices to improve rates of ACP at the state-level (and the ACP ACT Index measure), have implications for stakeholders across the healthcare spectrum and beyond the healthcare industry. While cultural, political, and structural barriers to ACP may detract from provider and patient engagement in discussions about end-of-life care, there are clear actions that states and stakeholder organizations can take to promote awareness and address reluctance to participate in ACP.

Our analysis of publicly available data and interviews with key informants largely reinforced findings surfaced in the literature review and environmental scan. Such findings provide context and inform the future landscape of providers, patients, families, and others as they engage in ACP discussions.

Table E1 (next page) lists the categories of best practices that states can take to improve performance on the ACP ACT Index measure, the specific state-level drivers, the number of reviewed articles and studies that described drivers in each category, whether a variable based on each driver was included on one of the final statistical models, the number of interviews that referenced each driver, and specific best practices noted in the literature or interviews.

Table E1. Surfaced Best Practices to Improve ACP Performance

Driver Category	State-Level Drivers	Literature Review Studies	Variable Included in Final Statistical Model	Interviews	Specific Best Practices
Patient Engagement, Education, and Resources	Patient Education	25	-	3	• Develop culturally tailored materials to support provider discussions; integrate faith-based elements • Develop multi-modal engagement and education strategies to invite person and family participation • Use storytelling as a component of interventions
	Public Education	6	-	3	• Conduct outreach in non-healthcare as well as healthcare settings • Leverage social media in public awareness campaigns
Communication and Accessibility	Communication	16	-	2	• Make materials available in multiple languages
	Accessibility	12	Primary care physician visits per decedent	1	• Recognize racial and economic disparities in ACP and consider social determinants of health when designing programs • Provide resources to patients that are easy to use and access
	Palliative Care	6	-	1	• Encourage development and use of palliative and hospice programs
Provider Education and Tools	Provider Education	35	Availability of Online ACP Resources Legal Information, or Forms for Providers	6	• Educate providers early in their careers • Conduct regional training programs and training within specific care settings (e.g., skilled nursing facilities) • Create educational programs for clinicians and healthcare organizations on the value of ACP and how to have meaningful conversations • Reinforce primary care practitioner use of ACP, but also train other types of providers, including long
	Provider Tools	40		2	• Post provider tools on the state website • Offer standardized tools and resources to help providers facilitate conversations, including resources on person-centered care and inclusive language and best practices content
Quality Improvement and Accountability	Quality Improvement Initiatives	5	-	4	• Leverage principles of change management, including identifying champions and gaining buy-in from leadership • Track performance, benchmark with peers
	Care Team Collaboration	21	-	2	• Implement "top of license" practice, engaging front-office staff or medical assistants to participate in elements of ACP
	Incentives	5	Medicare Advantage (MA) Penetration	3	• Encourage health plans to cover ACP and promote provider use of ACP documents • Offer incentives for providers to have ACP conversations via reimbursement or quality bonuses
Technology and Infrastructure Redesign	Interoperability Frameworks	3	-	3	• Leverage technology (e.g. health information exchange and other interoperability frameworks) to ensure access to completed ACP documents (e.g., advance care plans, portable medical orders [POLST], advance directives) at point of care
	Infrastructure	8	-	6	• Dedicate organizational resources to establish ACP policies and offer ongoing education • Integrate ACP practice into workflow and operations
	Electronic Health Record (EHR) Standardization	11	-	2	• Program billing codes into EHRs; consider incorporating templates and clinical decision support tools
Coalition Building and Community Outreach/ Engagement	Community Partnerships	7	Medicare Advantage Plan Quality	6	• Build state and local coalitions that include government agencies, multiple types of healthcare providers, faith-based organizations, legal experts, community organizations, philanthropic organizations, and insurers • Offer resources for health plans that describe the quality and financial benefits of ACP and improving the quality of their MA offerings
State Policies and Regulations	Policy	17	Person- and Family-Centered Care Policies	2	• Promote the use of POLST and standardized forms (e.g., the National POLST form, effective standardized advance directives) • Develop state policies that support family caregivers, aligning policies with national and global efforts

About C-TAC

The Coalition to Transform Advanced Care (C-TAC) is a national, nonpartisan, not-for-profit (501c3) alliance of over 140 national healthcare stakeholders based in Washington, DC. C-TAC is 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. For more information, visit TheCTAC.org.

About Discern Health

Discern Health is a research and advisory services firm that works with clients across the private and public sectors to better define and measure value in health care. Discern has been involved in quality and value-based purchasing projects since its founding in 2004. Discern's focus is enhancing the value of healthcare services through quality-based payment and delivery models. These models align performance with incentives by rewarding doctors, hospitals, suppliers, and patients for working together to improve health outcomes and healthcare processes, while lowering total costs. For more information, visit discernhealth.com.

BACKGROUND

The Coalition to Transform Advanced Care (C-TAC) is a not-for-profit organization that believes that all Americans should have access to high-quality, person-centered advanced illness care that aligns with their personal goals and values. In 2017, C-TAC launched the Campaign to Transform Advanced Care, which is a national campaign focused on policy change, support for family caregivers, and community organizing to help achieve this vision.[6]

C-TAC partnered with Discern Health (Discern) to support its continued efforts to build the Advanced Care Transformation Index^{SM} (ACT Index), which C-TAC developed to assess the state of advanced illness and end-of-life care in the United States. This report discusses Discern's work with C-TAC to identify best practices that states can implement to improve performance on one of the ACT Index measures, Advance Care Planning (ACP).

ACT Index

The ACT Index offers a single composite measure that allows policymakers, regulators, healthcare providers, communities, and consumers to assess the overall performance of the advanced illness care movement through measured change over time. While the index initially captured performance at the national level, C-TAC adapted the composite for state-level use in 2018 to allow for state-to-state comparisons and highlight opportunities for improvement.[7]

Each of the ACT Index measures was carefully selected by C-TAC, invited stakeholders, and serious illness experts to capture key facets of advanced illness care as they evolve. Selected ACT Index measures are reviewed and approved by an independent steering committee. Some of the measures in the ACT Index are fully specified and in use in accountability programs for various entities (such as the Hospice Quality Reporting Program), while others are measures of population health that have not been tested and validated for use in payment or other accountability programs for specific populations.

As of 2020, the ACT Index includes 37 measures that address five key domains relevant to advanced illness and end-of-life care: care, caregiving, communication, community, and cost.[8] The index uses data from patient and family surveys, as well as publicly-available data on payer claims, costs, hospital readmissions, and home health visits.[9] In its current published state, the ACT Index provides state and national-level data on each of the 37 measures, the scores for which are rolled into the ACT Index composite. Continued use of the index and its component measures provide the public, providers, and policy-makers data to inform evidence-based decision making and track progress over time.[10] Learn more about the ACT Index at https://www.thectac.org/evaluating-progress/.

Value of Advance Care Planning

ACP was selected as an ACT Index measure because it captures a process that has the potential to improve the experiences of individuals during periods of serious or sudden illness when their decision-making capacity is lost, as well as at the end of their lives, while reducing out-of-pocket and system-wide healthcare costs that might otherwise be incurred from unwanted or unnecessary treatment.

A 2017 consensus panel defined ACP as follows:

> "(1) Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.
>
> (2) The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.
>
> (3) For many people, this process may include choosing and preparing another trusted person or persons to make medical decisions in the event the person can no longer make his or her own decisions."[11]

Prior research has shown that ACP improves experience of care for patients and families. When compared to patients who did not receive ACP services, patients who engaged in ACP reported increased satisfaction with the information provided to them in the hospital, how much they were listened to by their providers, and their involvement in decision-making.[12,13] Studies have shown that ACP can also improve goal concordant care and reduce post-traumatic stress, depression, and anxiety in family members and caregivers of individuals with serious illness.[14,15] Patients who participate in ACP conversations are also more likely to be admitted to hospice earlier, and longer hospice stays are associated with better quality of life.[16]

Advance care planning improves the value of care and increases quality of care and outcomes while decreasing costs to patients and the healthcare system.

Research also suggests that ACP may reduce hospitalizations and unwanted procedures. These studies associate increased ACP with lower rates of patient ventilation, resuscitation, intensive care unit admissions, and hospitalization rates.[17,18] Additionally, ACP can help identify which procedures are unwanted and reduce unnecessary treatment, leading to a decrease in costs in the 12 months prior to a patient's death.[19]

ACT Index Advance Care Planning Measure

The ACT Index ACP measure captures the percentage of Medicare beneficiaries using two ACP Current Procedural Terminology (CPT) codes and is calculated using Medicare fee-for-service (FFS) claims data. In 2016, the Centers for Medicare & Medicaid Services (CMS) added CPT codes 99497 and 99498 to the Medicare Physician Fee Schedule (PFS), making voluntary ACP a reimbursable service for Medicare beneficiaries under the PFS and the Hospital Outpatient Prospective Payment

System (OPPS).[20] As discussed further below, while ACP is appropriate for individuals at any age or stage of health, the ACT Index ACP measure only captures Medicare FFS beneficiaries.

Before the introduction of these CPT codes, physicians could only bill for ACP discussions that occurred during an introductory "Welcome to Medicare" appointment for new beneficiaries.[21] CMS defines voluntary ACP as "a face-to-face service between a physician (or other qualified health care professional) and a patient discussing advance directives with or without completing relevant legal forms." These codes are described in **Table 1**.

Table 1. Medicare Billing Codes for ACP

Billing Code	Description
99497	"Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; first 30 minutes, face-to-face with the patient, family member(s), and/or surrogate."[22]
99498	"Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; each additional 30 minutes."[23]

CPT 99497 reimburses providers for up to 30 minutes of ACP with the patient and their family member or caregiver with a minimum discussion length of 16 minutes. CPT 99498 reimburses the provider for an additional 30 minutes of ACP discussions. Providers who can perform ACP services are health care professionals using a team-based approach to include "physicians, nonphysician practitioners (NPPs) and other staff under the order and medical management of the beneficiary's treating physician."[24]

Providers can bill for ACP services using the new Medicare billing codes on the same day or a different day as most other appointments where they provide other evaluation and management (E/M) services. The CPT codes can also be used "during the same service period as transitional care management services or chronic care management services and within global surgical periods." There is no limit on the number of times a provider can bill for ACP services in a year, as a patient's wishes may change if their health status changes.[25]

Providers are prohibited from reporting codes 99497 and 99498 on the same date of service as certain critical care services.[26] Advance care planning discussions are only covered with no cost to a patient during their Annual Wellness Visit (AWV); if these discussions occur in any other context, the patient will be responsible for paying Medicare Part B copays for the service.[27] These limitations are discussed in more detail below.

Providers can furnish ACP services in facility and non-facility settings, as there are no place-of-service limitations for providers.[28] A 2019 study of 2016 and early 2017 Medicare claims and Census Bureau data found that in 2016, internists billed Medicare for the most ACP claims (65%), followed by family physicians (22%), gerontologists (5%), and oncologists/hematologists (0.3%). The study also found that most patients with ACP claims were female, over age 85, enrolled in hospice, and died in the study year.[29,30]

An ACP conversation may include discussion of advance directives (AD) but completing an AD is not a requirement to bill for the ACP service. ADs are legal documents that specify the types of medical care a person would like to receive if they are unable to make the decision.[31] Under the Medicare ACP codes, providers can bill for end-of-life planning discussions with or without the creation of an AD.[32] **Table 2** below describes ADs and other types of ACP documents that may be generated as a result of the ACP process.

Table 2. Types of Documents That May Result from ACP

Document	Description
Advance Care Plan	Expression of the person's wishes written by the person.[33]
Advance Directive	According to the National Cancer Institute (NCI), an AD is a "legal document that states a person's wishes about receiving medical care if that person is no longer able to make medical decisions because of a serious illness or injury."[34]
Living Will	The American Cancer Society (ACS) defines a living will as "a legal document used to state future health care decisions only when a person becomes unable to make those decisions or choices on their own. The living will is only used at the end of life if a person is terminally ill… or permanently unconscious."[35] A living will describes the types of life-sustaining treatments a person would or would not like to receive; including dialysis, tube feeding, life support, etc.[36] A living will is a common type of advance directive.[37]
Medical Power of Attorney	ACS defines medical power of attorney as a document in which a person names a proxy to make healthcare decisions on their behalf if they become unable to do so. A physician must certify that the patient is unable to make their own decisions.[38] A medical power of attorney is a common type of advance directive.[39]
POLST (portable medical orders)	According to National POLST, "The POLST form is a portable medical order communicating patient treatment wishes to other providers, including emergency personnel, when the patient lacks capacity to speak for him/herself."[40] POLST forms are created by providers after discussion with patients. The acronym was popularized as "Physician Orders for Life-Sustaining Treatment", but National POLST has updated the term to "portable medical orders" because the use of POLST extends beyond physicians, and "life-sustaining treatment" may be value-laden and less descriptive of what is included.

Limitations to Measuring Advance Care Planning

Limitations to Billing for ACP under Medicare

Measuring the rate of ACP using CPT codes has several limitations. First, ACP conversations shorter than 16 minutes are not reimbursable using the Medicare CPT billing codes, and some providers may find it difficult to integrate ACP discussions of this length into their clinical workflows.[41] CMS suggests that providers bill to a different E/M service code if the ACP conversation is shorter than 16 minutes, "provided the requirements for billing the other E/M service are met."[42] Therefore, some ACP services may be captured through E/M codes beyond the 99497 and 99498 CPT billing codes, and would not be counted towards the ACT Index measure score.

Further, Medicare reimbursement alone may not be high enough to incentivize providers to have ACP discussions; physicians are reimbursed about $80 for the first 30 minutes of ACP discussions and $75 for an additional 30 minutes.[43]

Place-of-service limitations affect the ability to use "incident-to" billing, which is required for non-providers to bill for ACP services. "Incident-to" billing requires that a supervising physician must be available in person to participate in the service as needed and address questions.[44,45] For example, if ACP is performed in a hospital by a social worker, nurse, or chaplain, then the services cannot be billed to Medicare.

As noted above, Medicare beneficiaries do not have to pay for ACP discussions that occur during their yearly Medicare Wellness Visits, but they are responsible for paying Medicare Part B copayments if the ACP discussions happen at any other time.[46] This may dissuade patients from having ACP discussions during non-wellness appointments.

Limitations of the ACP ACT Index Measure

The ACP Index measure is presented as a proxy for the relative levels of ACP from state to state. By its definition, the ACP measure does not capture all ACP conversations that may occur. For example, the ACP Index measure captures the percent of traditional FFS Medicare beneficiaries who receive ACP services in a state and does not account for Medicare Advantage (MA) beneficiaries.

Not all ACP services are billed and, conversely, not all ACP codes reflect high quality ACP, documentation, or goal concordant care.

Conversely, conversations related to ACP may occur with medical staff or non-medical professionals who are not covered by (or eligible for) the billing codes included in the measure. The measure also does not capture the quality of the ACP conversations that occur, whether they result in advance directives or POLST completion, or whether the care that patients ultimately receive is concordant with the wishes they discuss in ACP conversations and express in the documents they complete.

Finally, these ACP data are relatively new, as the CPT codes went into effect in 2016. Some of the observed increases in ACP since 2016 may be due to providers improving their awareness of and ability to capture the new ACP CPT codes. From 2016 to 2017, C-TAC found that the number of Medicare beneficiaries with ACP claims increased by approximately 70% and the number of providers billing for ACP services increased by about 48%.[47] Of note, billing for ACP remains low across states, with the US national value of the 2017 Medicare FFS beneficiaries with ACP at 2.12% (See **Appendix A: State Interview Considerations** for more information).

About this Report

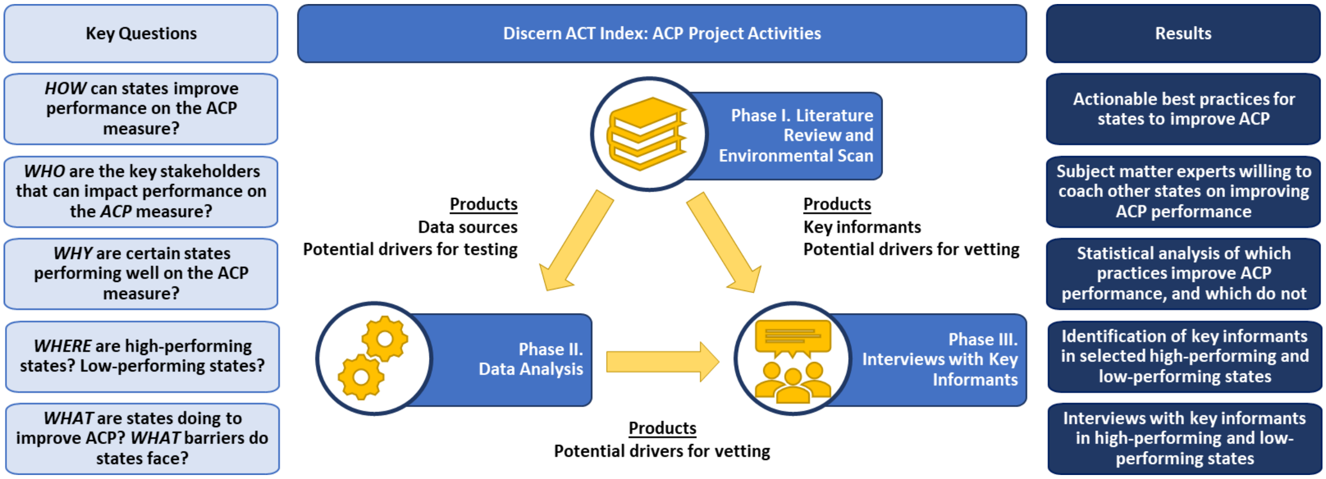
Discern applied a mixed-method research strategy to identify evidence-based actions to increase ACP at the state level and improve performance on the ACP measure. This report summarizes the methodology and findings from Discern's analysis. This report also includes recommendations and considerations for future research to support states and local change agents in increasing ACP.

METHODS

Discern used a three-pronged approach to identify and validate best practices for improving ACP at the state level and answer key questions about state performance on the ACT Index measure. The following three phases were conducted from February through August 2019 and are described in **Figure 1** below:

- Phase I. **Literature Review and Environmental Scan:** find existing evidence on potential drivers of ACP
- Phase II. **Data Analysis**: test the impact of these drivers on state-level ACP performance
- Phase III. **Interviews with Key Informants:** validate and expand on analytic results

Figure 1. Three-Phased Research Methodology to Identify ACP Best Practices



Each phase was designed to inform the execution of subsequent phases. Discern leveraged the results from the literature review and environmental scan to identify potential data sources and variables to test during the data analysis phase. The results from the first two phases were used to identify interviewees for Phase III and to develop the discussion guide used to facilitate interviews with selected key informants.

The three phases each produced results addressing key research questions identified at the onset of the project. Cumulative results include identified actionable state-level best practices to improve ACP, statistical evidence of the impact of identified best practices on ACP performance, barriers and considerations for implementing best practices, and a list of subject matter experts in high-performing states willing to coach others to improve ACP.

Phase I. Literature Review and Environmental Scan

Discern conducted a literature review and environmental scan to identify potential "driver measures" of state-level performance on the ACP ACT Index measure. For the purposes of this project, a driver measure is a practice or policy that may result in an increase in ACP and can be assessed at the state level. We also sought evidence for population or state characteristics that might contribute to higher or lower rates of ACP. We used this information to inform our selection of potential variables to include in our data analysis. See *Phase II. Data Analysis* for more information about our approach to statistical analysis of potential drivers of ACP.

Discern developed a search strategy to find evidence related to ACP from peer-reviewed journal articles and studies as well as grey literature, such as white papers, government publications, press releases, news articles, fact sheets, and website posts. We used the reference lists from highly relevant articles to identify additional sources through a "snowball" approach. As relevant articles were identified, Discern considered new key terms and sources to best capture the ACP universe. **Table 3** outlines the sources and search terms used to conduct the literature review and environmental scan.

Table 3. ACP Sources, Search Terms, and Driver Measures

Sources	Search Terms
• PubMed • Google Scholar • Key stakeholder organization websites: ○ American Academy of Hospice and Palliative Medicine (AAHPM) ○ Area Agencies on Aging ○ Association of American Retired Persons (AARP) ○ Center to Advance Palliative Care (CAPC) ○ Compassionate Choices ○ Conversation Project ○ Docubank ○ MyDirectives ○ National Academy for State Health Policy (NASHP) ○ National Coalition of Hospice and Palliative Care (National Consensus Project) ○ National Hospice and Palliative Care Organization (NHPCO) ○ National POLST ○ Respecting Choices ○ The Conversation Project ○ Vital Decisions ○ WiserCare	• Advance directives • Advance care planning • Advance medical planning • Medical power of attorney • Health care power of attorney • Advance directive adherence • Resuscitation orders • Do-not-resuscitate (DNR) orders • Right to die • Death with dignity • State Health Planning and Development Agencies • End-of-life decision-making • Shared decision-making • Five Wishes • Living well (at the end of life) • POLST • MOLST • Religiosity • Financial end-of-life planning

To ensure consistent information was captured from each relevant publication, Discern developed a framework for coding that included article metadata, drivers surfaced, and mentions of publicly available data that could potentially be leveraged to inform the second phase of the project, data analysis. **Table 4** describes each element in our literature review framework and provides an example entry for one article.

Table 4. Literature review framework for ACP Index measure

Element	Example
Publication Type	Journal article
Title	The Influence of Culture on End-of-Life Decision Making
First Author	Karen Bullock
Journal or Publication	Journal of Social Work in End-of-Life & Palliative Care
Year Published	2011
DOI or Hyperlink to Publication	https://doi.org/10.1080/15524256.2011.548048
Abstract	In their research, scholars have documented racial and ethnic differences in end-of-life care preferences, which have translated into cultural barriers. However, few studies have explained the racial differences. In the present study, focus groups with semi-structured follow-up interviews were utilized to elicit explanations for variance in decision making in a sample of Black and White community-dwelling residents. Participants identified specific cultural beliefs, values, and communication patterns that can be used to promote cultural competency among practitioners who provide care to the seriously ill or those at the end of their lives.
Driver Measures Tested and Supporting Evidence	Cultural competence training; provider education led to improved conversations regarding end-of-life care preferences
Potential State-Level Driver Measures	Provider education
Potential Demographic Variables	Race/ethnicity
Other Key Findings	Cultural roles often play an important factor in end-of-life decision-making
Publicly Available Data Sources to Leverage for Phase II: Data Analysis	None identified

Literature Search Results

Using the search terms and sources in **Table 3**, Discern initially identified over 15,000 articles published in the last ten years. Discern excluded over 10,000 articles after removing the following from our results:

- Duplicate articles;
- Foreign or international studies with no direct link to ACP driver measures that would be actionable in the U.S.;
- Studies focusing on the an out-of-scope population (e.g., neonatal, pediatric, etc.);
- Condition-specific studies; and

- Studies that did not relate to ACP (e.g., shared-decision making studies without a link to serious illness or end-of-life care planning).

Approximately 1,200 studies were identified as being potentially informative to the ACP ACT Index project. Discern selected articles for additional review that provided information on driver measures, potential control variables, and promising data sources. Ultimately, we identified 180 relevant articles that reported on 95 potential driver measures. See *Findings: Literature Review and Environmental Scan* for more information on the driver measures surfaced during this phase of the project.

Phase II. Data Analysis

In partnership with the C-TAC team, Discern collected data for 50 states and the District of Columbia to test potential actionable state-level drivers of ACP identified through the literature review and environmental scan. Discern used Ordinary Least Squares (OLS) regressions to test whether identified drivers had a relationship with the percent of Medicare FFS beneficiaries that received ACP services in 2017. The OLS regression is a statistical method for estimating the parameters in a linear equation to identify associations among independent and dependent variables.

Discern's approach to data analysis is described below.

Identification and Selection of Variables for Testing

Dependent Variable

Discern tested five potential dependent variables constructed from available data to determine whether identified drivers had a relationship with rates of ACP at the state level:[1]

- Percent Total Traditional Medicare FFS Beneficiaries with ACP (2017)
- Percent Total Traditional Medicare FFS Beneficiaries with ACP (2016)
- Percent Total Traditional Medicare FFS Beneficiaries with ACP (Average of 2016 and 2017)
- ACP services per beneficiary (2017)
- ACP services per provider (2017)

In collaboration with C-TAC, Discern selected *Percent Total Traditional Medicare FFS Beneficiaries with ACP (2017)* as the primary dependent variable. 2017 was the most recent year for which data are available for all 50 states and the District of Columbia. Further, relying on data from 2016, either on its own or included in an average, could cause skewed results. Because ACP CPT codes were included for the first time in the 2016 PFS, physicians and other providers eligible for Medicare reimbursement for ACP services may not have been using the CPT code consistently in 2016.

Discern did not select ACP services per beneficiary or ACP services per provider as the dependent variable because relying on these data could also skew results. The average ACP services per provider

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[1] Discern used 2016 and 2017 Medicare FFS claims data provided by C-TAC (numerator) as well as 2016 and 2017 traditional Medicare FFS claims data (denominator) reported by the Kaiser Family Foundation (KFF) to calculate the five tested dependent variables.

could be higher in rural or remote areas because there are fewer providers. The average ACP services per beneficiary does not accurately depict performance around the C-TAC ACP ACT Index measure, because there is no upper limit to the number of services a single beneficiary receives, and this number may be related to a person's health condition.

Independent and Control Variables

Discern selected ten drivers from a list of over 95 potential drivers of ACP identified through the literature review and environmental scan. Discern and C-TAC used the criteria described in **Figure 2** to prioritize driver measures.

Figure 2. Criteria for Selection of Driver Measures for Statistical Analysis

Driver Selection Criteria

- ✓ **Evidence:** Strong evidence in the literature to support a link to increased ACP utilization
- ✓ **Impact:** Deemed actionable at the state level with a potentially substantial impact on state ACP rates
- ✓ **Feasibility:** Feasible for data collection and analysis at the state level

The following potential drivers of ACP met the selection criteria to be tested:

1. State policies related to ACP, including living wills state law requirements (i.e., the number of witness signatures required for states to recognize a living will)
2. POLST adoption level within a state
3. POLST Program maturity (e.g., POLST has become standard of care in the state for appropriate patient populations)
4. The presence of statewide AD and/or POLST registries
5. Availability of online provider education resources, tools, and forms
6. Availability of online patient education resources, tools, and forms
7. Five Wishes state requirements (e.g., whether Five Wishes forms were recognized by the state, or if additional documentation beyond the forms was required)
8. Respecting Choices/Honoring Choices training and faculty
9. Medicaid reimbursement for ACP services
10. MA penetration

Discern identified and collected state-level data for 29 independent variables, which represented various operational definitions of the ten driver measures listed above. Discern also leveraged publicly available datasets aggregated by C-TAC to test an additional 25 independent variables that suggested potential ACP drivers outside of those surfaced during the literature review and environmental scan. As discussed in the *Data Analysis: Statistical Tests and Model Selection* section, we found statistical evidence for five state-level drivers of ACP from among the 54 variables tested: availability of online provider ACP educational resources, legal information, and forms; Medicare Advantage penetration; Medicare Advantage plan quality; access to primary care; and availability of person- and family-centered care policies.

To account for socio-demographic factors that might impact ACP or explain or change the impact of the drivers on ACP, Discern also tested six primary control variables:

1. Gender
2. Race/ethnicity
3. Religiosity (i.e., importance of religion)
4. Population density
5. Education (i.e., percent of the population with at least a Bachelor’s degree)
6. Age (i.e., percent of the population 65 years or older)

Additional controls were identified, but several were eliminated due to multicollinearity with the primary controls we tested (see *Data Analysis: Statistical Tests and Model Selection* below for more information). For example, the education variable was correlated with income, so we included education because it had a stronger statistical relationship with ACP.

Statistical Tests and Model Selection

The statistical tests conducted are shown in **Figure 3.**

Figure 3. Statistical Tests to Inform Identification of State-Level ACP Best Practices

Discern first used a correlation matrix, which is a table showing correlation coefficients between variables, to determine whether any of the independent variables or control variables were highly correlated with each other to inform regression testing and assess multicollinearity.

Discern then performed an OLS regression in Stata/IC 14.2 (https://www.stata.com/stata14/) for each of the independent variables, including most control variables, to test relationships with the dependent variable. Discern also ran several OLS regressions with different combinations of independent and control variables to identify drivers with the strongest positive relationships with the primary dependent variable.

Using these tests, Discern and C-TAC selected two models to inform driver identification based on goodness of fit, state-level actionability, plausibility (i.e., having a plausible relationship with ACP), the strength of the relationships between the independent variables and the dependent variables, and the level of statistical significance.

Discern used a Y-hat test to identify the predicted ACP values for each state. The Y-hat value is the predicted value of the "y" or dependent variable in a regression equation. This test can also be used to determine the level of improvement in an independent variable that is needed to gain a certain outcome; in this case, improvement in rates of ACP.

The results from Discern's analyses are described in the *Findings: Data Analysis* section.

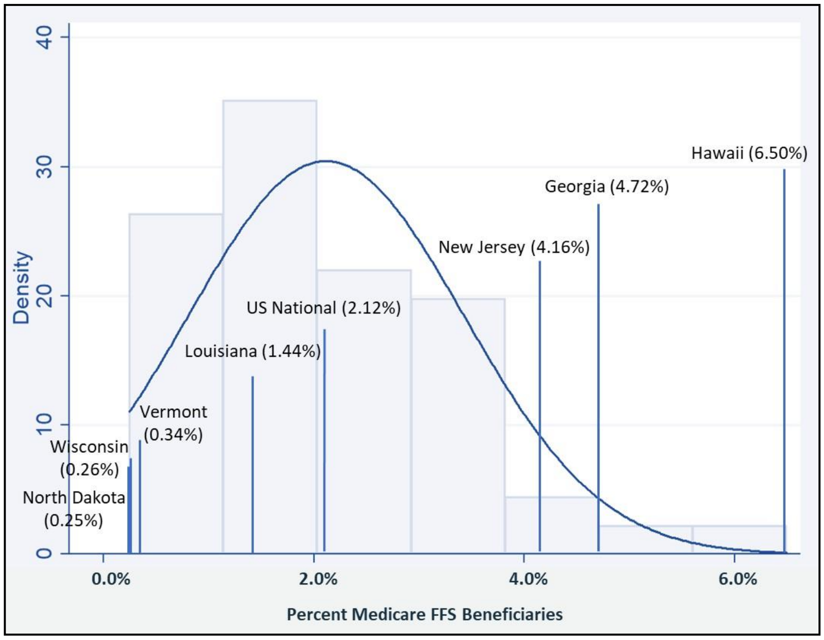
Phase III. Interviews with Key Informants

Discern conducted six interviews with key informants in two states, Hawaii and Louisiana, to learn more about ACP from a "boots-on-the-ground" perspective, identify additional state-level drivers of ACP, and provide context to the findings from the literature review/environmental scan and data analysis phases.

State Selection

Discern worked with C-TAC to identify states of focus for the interview phase. Discern considered state performance on the *Percent Total Traditional Medicare FFS Beneficiaries with ACP (2017)* measure, regional variation, and outliers from the data analysis phase (large difference between predicted and actual performance) to recommend the high-priority states to target for interviews. Data informing the factors underlying Discern's recommendations for state selection are detailed in **Appendix A: State Interview Considerations**.

Figure 4: Distribution of 2017 ACP State Rates



Discern and C-TAC selected Hawaii, the highest performer on the ACP measure, and Louisiana, a lower performer and "outlier" observation where predicted performance was higher than actual, for interviews. See **Figure 4** for the overall distribution of 2017 ACP state rates with the highest performing three states, the lowest performing three states, and Louisiana highlighted.

Key Informant Identification and Outreach

Discern identified subject matter experts (SMEs) and organizations active in ACP in Hawaii and Louisiana for interviews, focusing on stakeholders that could best assess contributors to state-level performance and implementation of best practices.

Organizations prioritized for interviewee identification included:

- State agencies;
- Local areas agencies on aging;
- State provider associations (e.g., hospital, hospice/palliative, nursing home, home health);
- Organizations that developed state ACP resources;
- Leaders in state MA plans; and
- Universities and university medical centers.

For organizations for which there was more than one SME identified, Discern reached out to all SMEs at that organization to try to schedule an interview when all individuals were available. Discern conducted outreach to SMEs via email and/or phone and followed the initial outreach with at least two follow-up messages before selecting other stakeholders for interviews.

Discern conducted formal interviews with the key informants listed in **Table 5**.

Table 5. Completed Interviews with Key Informants in Hawaii and Louisiana[2]

Organization	Key Informants
HAWAII	
Kōkua Mau: "Kōkua Mau is the leader of Hawaii's statewide movement related to hospice care, palliative care, end-of-life care, and advance care planning and serves as the umbrella organization and central hub for local individuals and entities in these fields. Kōkua Mau does not provide clinical care but instead leverages partners' innovative work to effect greater community change."[48]	**Jeannette Koijane** (Executive Director) **Hope Young** (Advance Care Planning Coordinator)
Hawaii Medical Service Association (HMSA): "HMSA is the most experienced health plan in the state of Hawaii, covering more than half of the state's population... Headquartered on Oahu with centers statewide to serve [its] members, HMSA is an independent licensee of the Blue Cross and Blue Shield Association."[49]	**Rae Seitz** (Medical Director)- not speaking on behalf of HMSA.
Hawaii Pacific Health Medical Center: "Hawaii Pacific Health provides a variety of comprehensive inpatient, outpatient, and same-day services."[50] The palliative care team at Hawaii Pacific Health includes physicians, nurses, social workers, and chaplains that address the physical, emotional and spiritual needs of patients. Palliative care services provided at Hawaii Pacific Health include care coordination, shared decision-making, specialty medical care, and ACP.[51]	**Emese Somogyi** (Medical Director, Palliative Care)
LOUISIANA	
LaPOST Coalition: The LaPOST Coalition is a network of Louisiana healthcare professionals raising awareness about the Louisiana Physician Orders for Scope of Treatment (LaPOST) document.[52]	**Susan Nelson** (Chairwoman of LaPOST and System Chair, Palliative Medicine and Medical Director of Post-Acute Care at Oschner Health System)

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[2] Affiliations current as of August 2019

Organization	Key Informants
Ochsner Health System: Ochsner Health is Louisiana's largest non-profit, academic, healthcare system. Ochsner provides coordinated clinical and hospital patient care connected electronically for patients across the region at Ochsner's 40 hospitals and more than 100 health centers and urgent care centers.[53]	**Shannon Wentz** (Assistant Vice President for Palliative Care at Ochsner Health System)
Louisiana Health Care Quality Forum (LHCQF): "The Louisiana Health Care Quality Forum is a private, not-for-profit organization dedicated to reshaping health care. Led by a volunteer Board of Directors, the Quality Forum serves as a neutral convener, bringing providers, purchasers, payers and consumers together to drive improvements in health care quality, safety and value for Louisiana residents".[54] "The Quality Forum adopted the Louisiana Physician Orders for Scope of Treatment (LaPOST) program as one of its initiatives in 2010."[55]	**Cindy Munn** (CEO)
Louisiana-Mississippi Hospice and Palliative Care Organization (LMHPCO): The LHPCO is a 501(c)(3) non-profit, educational corporation dedicated to improving the quality of hospice and palliative services in Louisiana and Mississippi. LMHPCO achieves its mission through research, professional education, public awareness, and advocacy.[56]	**Jamey Boudreaux** (Executive Director)

Interviewing Key Informants

With input from C-TAC, Discern developed a discussion guide to facilitate semi-structured interviews with key informants, included in Appendix B: Key Informant Discussion Guide. The discussion guide outlines interview goals and expectations to provide structure, ensuring that the most critical questions were addressed consistently across interviewees, and flexibility, allowing the interviewer to effectively probe deeper on key topics of interest. The goals for the interviews were to:

- Identify best practices for improving the ACP measure that are actionable at the state-level;
- Surface evidence that identified best practices have been effective in improving ACP; and
- Identify local or state groups that are instrumental to change in this area.

Discern Vice President Theresa Schmidt facilitated the six 60-minute interviews with selected key informants. At least one other Discern staff member was present during the interviews to support notetaking. In addition to the goals noted above, the interviews also identified barriers to both ACP itself and implementation of best practices.

FINDINGS

Literature Review and Environmental Scan

After reviewing relevant literature, Discern identified 95 potential driver measures of ACP for further exploration. Prominent themes across drivers included provider and patient education, particularly around culturally-tailored ACP interventions, the use of Electronic Health Record (EHR) tools to facilitate ACP and improve capture of ACP billing codes, and state and federal policies designed to promote ACP and AD utilization.

Identified Driver Measures

Discern's literature review and environmental scan surfaced drivers that are actionable at the state level and have implications for stakeholders across the healthcare landscape. Discern organized identified state-level drivers of ACP into the following seven categories:

1. **Patient Engagement, Education, and Resources** includes the provision of patient education materials as well as public awareness and education campaigns
2. **Communication and Accessibility** captures drivers addressing communication, accessibility, and palliative care concepts, more broadly
3. **Provider Education and Tools** includes the provision/creation of provider educational materials and other tools to support providers in the facilitation of ACP
4. **Quality Improvement and Accountability** includes drivers related to quality improvement initiatives, care team collaboration, and other incentives to promote ACP
5. **Technology and Infrastructure Redesign** includes technology and infrastructure needed to drive ACP, such as state AD or POLST registries, health information exchange (HIE), interoperability frameworks, or standardized EHR tools to facilitate ACP and capture ACP billing codes
6. **Coalition Building and Community Outreach/Engagement** includes drivers related to establishing and strengthening community partnerships to support ACP and educating community stakeholders
7. **State Policies and Regulations** includes policies and regulations with the potential to drive rates of ACP at the state level

These seven categories impact patients, providers, health plans, community organizations, and policymakers/regulators, as shown in **Figure 5**.

Figure 5 State-Level Drivers of ACP with an Impact on ACP Stakeholders

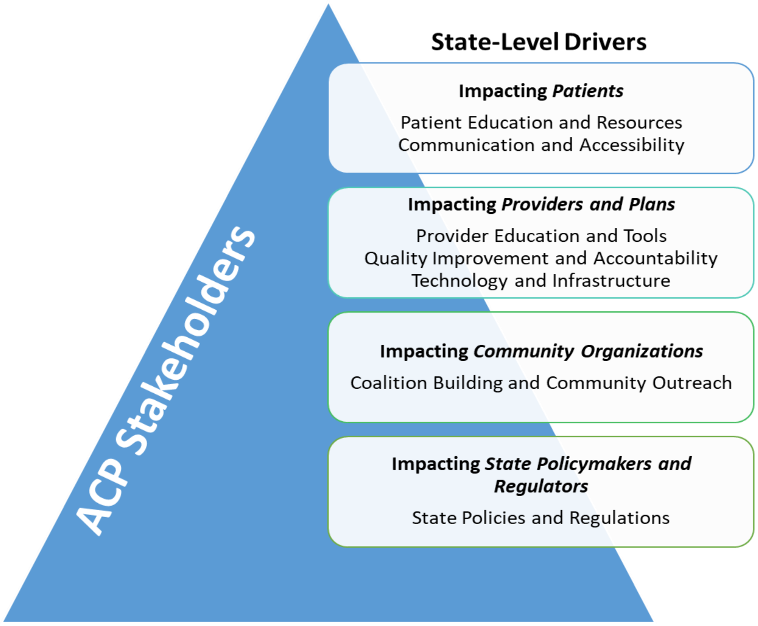
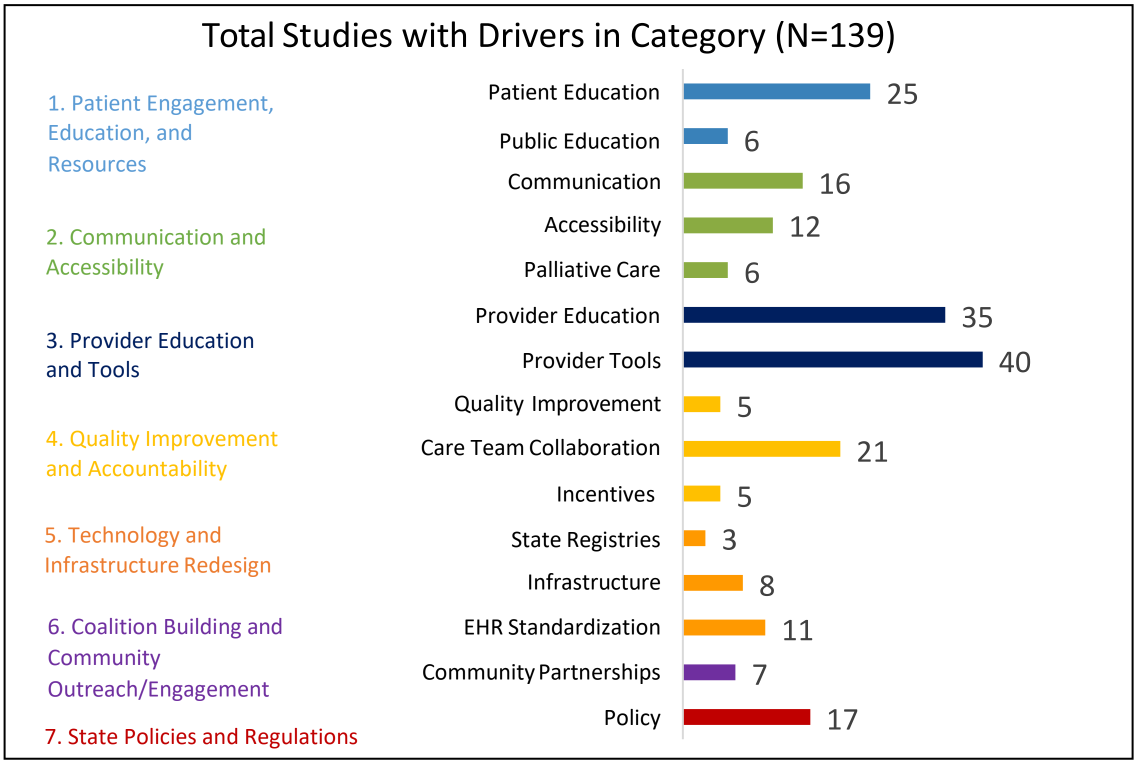


Figure 6 below shows the total number of peer-reviewed studies and other grey literature articles that address each identified state-level ACP driver. Drivers are grouped by their driver category, as indicated by the colors in the bar chart and the table below.

Figure 6. Total Articles or Studies with Evidence of State-Level ACP Drivers*



*Some studies discussed multiple drivers or drivers in multiple categories.

Each ACP driver category is explored in greater detail below. While the literature generally did not analyze state-level drivers of ACP, the categories below have clear implications for state-level practice.

Patient Engagement, Education, and Resources

Providing educational materials that discuss ACP and are targeted to patients can improve rates of ACP at the state-level. Studies indicate that educational materials presented through different media, such as video vignettes demonstrating end-of-life care decision-making conversations, online resources, or story-telling based interventions delivered by providers are effective in promoting ACP conversations.[57,58,59] For instance, one study found that hypothetical video vignettes successfully motivated older adults to engage in ACP with their providers.[60] Other studies recommend that states and community-based organizations sponsor public education and public interest campaigns that leverage tools like social media to promote awareness of ACP.[61,62]

Communication and Accessibility

Research suggests that strengthening communication between patients and providers and making information about ACP and end-of-life care decision-making accessible to patients can improve rates of ACP. One study found that patients with greater trust in their physicians were more likely to engage in ACP.[63] A study of ACP implementation found that some patients prefer nursing staff to initiate ACP conversations because of their closer personal relationships. This study also found that patients preferred having ACP planning discussions with providers who know them, their families, and their medical history.[64] Another study found that patients with greater social support, including support from their care team, were more willing to complete ADs.[65] That study recommended that healthcare professionals assist older adults in planning end-of-life care. Providers can also reach patients for ACP in a variety of ways, from the office visit to facilitating ACP conversations telephonically.[66]

Multiple studies identified the provision of culturally-tailored ACP information as an effective way to encourage ACP conversations, making materials more accessible to patients and their families.[67,68,69,70,71] Cultural-tailoring may include integrating faith-based elements into ACP educational materials or translating materials in different languages for non-English speaking patients and families. Another study underscored the importance of easy-to-read and understand materials to improve accessibility.[72]

Provider Education and Tools

Provider education and tools were discussed in 35 and 39 of the reviewed studies respectively. Many resources and tools for providers are available (including, but not limited to, those used as examples in this section).

Studies indicate that targeted provider training on ACP, palliative care, legal issues, and cultural- and disability-competence can improve ACP conversations.[73,74,75,76,77] In particular, educating providers early in their careers or in medical school may be effective for encouraging engagement in ACP.[78,79,80] Some organizations have developed resources that can be used in provider education. For example, tools from the Conversation Project have been used effectively in nursing and medical student education and increased their abilities to have end of life conversations.[81,82] Another study found that the most successful interventions to facilitate the completion of advance directives combined computer, video, and discussion elements.[83] This study also found that decision aids helped to improve patients' knowledge of advance directives and increased the rate of advance directive completion and ACP discussions.[84] Researchers recommend that non-primary care providers, such as ICU providers or surgeons, also learn how to facilitate ACP discussions.[85,86]

Provider tools are useful to support ACP discussions with patients and families. In addition to the Conversation Project resources referenced above, standardized POLST forms (e.g., the National POLST Form), video decision-aids, Respecting Choices resources, Five Wishes resources, the Serious Illness Conversation Guide, and infographics are some tools that may help providers facilitate challenging conversations about end-of-life care.[87,88,89,90,91,92,93] Providers can also consider other interventions to reach patients. For example, one study demonstrated that group visits for ACP, which include discussion with other patients and peer-based learning, can help patients document their preferences about future care.[94] Another study of 118 adults 65 years or older found that documentation of decision-maker preferences for patients that participated in an ACP group visit increased from 39% to 81% from baseline to three-month follow-up.[95]

Quality Improvement and Accountability

Leveraging principles of effective change management and healthcare quality improvement initiatives can be applied to efforts to improve the rate of ACP with state-level impacts. Identifying clinicians to champion ACP interventions to spread change from the bottom-up while gaining buy-in from executive leadership has been shown an effective technique for promoting ACP-focused interventions.[96,97]

Studies have shown that building in accountability for ACP interventions using financial incentives for providers or patients can also improve rates of ACP.[98,99,100] For instance, one study found that more than 51,000 employees of a large health system and their insured relatives participated in a health plan incentive program that compensated participants for engaging in ACP discussions with their providers. Of those who participated, more than 80% rated the experience as helpful or very helpful.[101]

Technology and Infrastructure Redesign

Ensuring that clinicians and provider organizations have the appropriate technology and infrastructure to execute ACP conversations may be critical to increasing rates of ACP at the state level. Integrating ACP documentation templates and clinical decision support prompts into EHRs can streamline the facilitation of ACP conversations and remind providers to have these discussions with their patients.[102,103,104,105] Having the administrative infrastructure to capture ACP billing codes is also key to improving rates of ACP, particularly in smaller practices or nursing homes with fewer resources.[106,107] One survey of 43 skilled nursing facility (SNF) providers found that systems-based infrastructure factors, like lack of a centralized document location, inconsistent documentation habits, and lack of time were barriers to ACP documentation.[108]

Coalition Building and Community Outreach/Engagement

Building strong multi-stakeholder, statewide coalitions may improve state performance on the ACP Act Index measure. States have leveraged models such as Respecting Choices to effectively promote ACP awareness. For instance, Honoring Choices Minnesota, an ACP program based on Respecting Choices, brought together eight large healthcare systems in the metropolitan area. In the five years after adopting the program, the number of hospitalized individuals age 65 or older with ADs in the EHR increased by almost 54%.[109] Likewise, the Massachusetts Department of Health included the Conversation Project's Conversation Starter Kit in its educational brochure.[110]

Including stakeholders outside of the healthcare industry is also important to coalition building; research indicates that partnering with legal experts and other community-based organizations can improve the frequency and quality of ACP discussions, as well as patient satisfaction with ACP.[111,112,113]

State Policies and Regulations

Implementing policies and regulations can catalyze change across a state to increase rates of ACP. Policies that set legal penalties for ignoring ADs or that require certain practitioners to have ACP conversations with terminally ill patients may impact state performance on the ACP ACT Index measure.[114,115] A systematic review of ACP literature found that policy reforms that include incentives for providers and encourage a multidisciplinary approach may help to overcome some existing barriers.[116] One study concluded that barriers to ACP in Maryland, such as lack of patient familiarity with ADs, could be addressed through policy interventions or through state sponsorship of public health advocacy campaigns.[117]

All 50 states and DC have POLST programs, and 23 programs (24 states) have been endorsed by National POLST (formerly the National POLST Paradigm).[118] Among these programs, however, there is variation in the forms used and information captured, and stakeholders have called for greater standardization on the end of life options included. Some states have passed legislation to establish POLST guidelines, remove legal barriers, or offer immunity provisions from liability related to POLST use; but legislation can also create new barriers by too narrowly prescribing form language, intended populations, and processes and, therefore, may not be beneficial for ACP or supportive of the national POLST movement.[119,120]

Other Key Findings

In addition to describing potentially actionable drivers of ACP, many included studies examined the relationships between demographic and other variables on the implementation or utilization of ACP. While these factors are not themselves actionable at the state level, they can play a role in state performance on the ACP ACT Index measure. Additionally, many of the drivers that are actionable might be implemented in different ways and with different content considering these findings. For example, educational programming that is tailored to specific religious traditions may be a more effective driver in areas with a large religious population than generic programming.

- **Age:** Older adults are more likely to engage in ACP than younger individuals.[121,122] In a survey of 1,195 Maryland adults, researchers found that 14% of those without ADs believed that they were “too young or healthy to need one.”[123] Provider age is also associated with rates of ACP; another study found that older providers were more likely to engage patients in ACP discussions.[124]
- **Socioeconomic Status:** Socioeconomic factors such as income and education affect engagement in ACP discussions. Researchers found that individuals who obtained a higher level of education are more likely to participate in ACP in the palliative care context.[125] Further, surrogate decision-makers with lower incomes and low education levels are less likely to have AD documentation for their patients with chronic illness.[126] Home ownership and higher net worth are also associated with higher rates of health-related planning. Data from the Wisconsin Longitudinal Study indicate that low rates of ACP among individuals with low or negative assets “are largely accounted for by the fact that they are less likely to execute a will, an action that triggers health-related preparations.”[127]
- **Gender:** Studies suggest that women are more likely to have ACP conversations than men.[128] Women are also more likely to have ADs.[129,130]
- **Health/Functional Status:** Research suggests that those with poorer health or functional status, or those who had previous experience managing a serious illness or health condition, are more likely to engage in end-of-life planning.[131] One study found that patients with experience in end-of-life decision-making were also more likely to possess a living will or a healthcare proxy than those without those experiences.[132] Another study found that “older

adults who received hospital, nursing home, or home health/hospice care were more likely to complete advance directives."[133]

- **Race/Ethnicity:** Research shows that ACP is more common among white populations.[134,135] Several of the studies also found that African Americans are much less likely to complete ADs than white Americans.[136,137] As ACP has become more common, this gap has narrowed[138,139], and one study found that the gap was eliminated when controlling for financial disparities.[140] Provider race or ethnicity may also impact ACP; one study found statistically significant differences between personal and professional attitudes towards advance directives of white and black nursing students: "Black/African-American students were less likely to give consent to the attending physician to allow natural death (AND) and were less comfortable with the nurses' role in facilitating ADs in end-of-life care."[141]
- **Religiosity:** Studies suggest that individuals' religiosity or spirituality may impact likelihood of engaging in ACP conversations.[142,143] People who identify as being more religious or spiritual may be less willing to participate in discussions about planning for end-of-life care.[144]

Data Analysis

Discern and C-TAC identified statistical evidence to support five potential actionable drivers that have relationships with ACP via two selected OLS regression models (Model A and Model B) described below. **Table 6** defines these drivers.

Table 6. Actionable State-Level Drivers of ACP Identified During OLS Regression Testing

Driver	Year	Definition
Availability of Online ACP Resources Legal Information, or Forms for Providers	2019	Discern researched state health department and state government websites to identify whether the state offered online ACP resources, legal information, or forms geared toward providers. This variable was coded as yes/no and indicates whether the state made at least one ACP resource or form available. We did not assess the quality or efficacy of the forms.
Person- and Family-Centered Care Policies (composite indicator)[145]	2016	This is a composite measure that considers state policies related to supporting family caregivers of individuals needing Long-Term Services and Supports (LTSS). States can score up to 5.5 points on the measure. The three components considered include: 1. State policies on financial protection for spouses of Medicaid beneficiaries who receive home and community-based services (up to 2 possible points) 2. State assessment of family caregiver needs (up to 2.5 possible points), and 3. Whether the state passed Caregiver Advise, Record, Enable (CARE) Act legislation signed into law (1 possible point) This measure is used in the AARP State LTSS Scorecard.
Primary Care Physician (PCP) Visits per Decedent[146]	2014	This Dartmouth Atlas indicator assesses the average number of visits by primary care physicians (including those specializing in family practice, internal medicine and pediatrics) during the last 6 months of life for beneficiaries with one of nine chronic conditions who were enrolled in traditional (fee-for-service) Medicare and died during the measurement period.

Driver	Year	Definition
Medicare Advantage (MA) penetration[147]	2017	Discern used MA penetration data from 2017 from Kaiser Family Foundation (KFF). KFF calculates MA penetration by dividing the number of MA enrollees by the total number of Medicare beneficiaries in each state.
Medicare Advantage (MA) Plan Quality[148]	2016	This U.S. News & World Report measure assesses the percentage of a state's Medicare Advantage enrollees whose plans have at least a 4-star rating (out of a possible 5 stars) from the Centers for Medicare & Medicaid Services.

Regression Model Results

Discern and C-TAC selected two regression models suggesting that the measures in **Table 6** above have a positive relationship with the dependent variable, *Percent Total Traditional Medicare FFS Beneficiaries with ACP (2017)*. Discern ran both regression Model A and Model B with and without the control variable, percent of each state's population that is female.

MA Plan Quality and *MA Penetration* were tested together and independently, but ultimately not included in the same final regression model. When both variables were included together in the same regression along with the *Percent Female* control variable, *MA Quality* (β=0.016, p<.18) and *MA Penetration* (β=0.014, p<.29) had weaker relationships with the dependent variable than when only one of the variables was included in the regression. Discern also observed similar results when both *MA Plan Quality* (β=0.017, p<.18) and *MA Penetration* (β=0.015, p<.25) were included in the same regression without the *Percent Female* control variable.

Table 8 describes summarizes the variables included and results from each of the final regression models. More details for each of these models follow. The primary difference between Model A and Model B is the inclusion of the *MA Plan Quality* variable in Model A and the *MA Penetration* variable in Model B.

Table 8. Summary of Results for Regression Models A and B

Variables	Model A		Model B	
	Without Control	With Control	Without Control	With Control
Availability of Online ACP Resources, Legal Information, or Forms for Providers	β=0.005 p<.10	β=0.004 p<.22	β=0.006 p<.06	β=0.005 p<.13
Person- and Family-Centered Care Policies	β=0.002 p<.17	β=0.002 p<.15	β=0.002 p<.16	β=0.002 p<.13
Primary Care Physician Visits per Decedent	β=0.004 p<.00	β=0.003 p<.00	β=0.003 p<.00	β=0.003 p<.00
MA Plan Quality	β=0.020 p<.11	β=0.020 p<.11	Not included	Not included
MA Penetration	Not included	Not included	β=0.019 p<.15	β=0.017 p<.18
Percent Female	Not included	β=0.291 p<.13	Not included	β=0.278 p<.15

A higher β value indicates a **stronger positive** relationship with the dependent variable
A smaller p value indicates a more **significant** relationship with the dependent variable

The following Figures illustrate the results from Models A and B, including the regression equation and a chart of the actual and predicted values of each state. As displayed in **Figure 7**, The results from Model A (no control variables) show that *Provider Education, Person- and Family-Centered Care Policies, PCP Visits per Decedent*, and *MA Plan Quality* have positive relationships with the ACP. *PCP Visits per Decedent* had relationship with the dependent variable with the highest significance (β=0.004, p<.01).

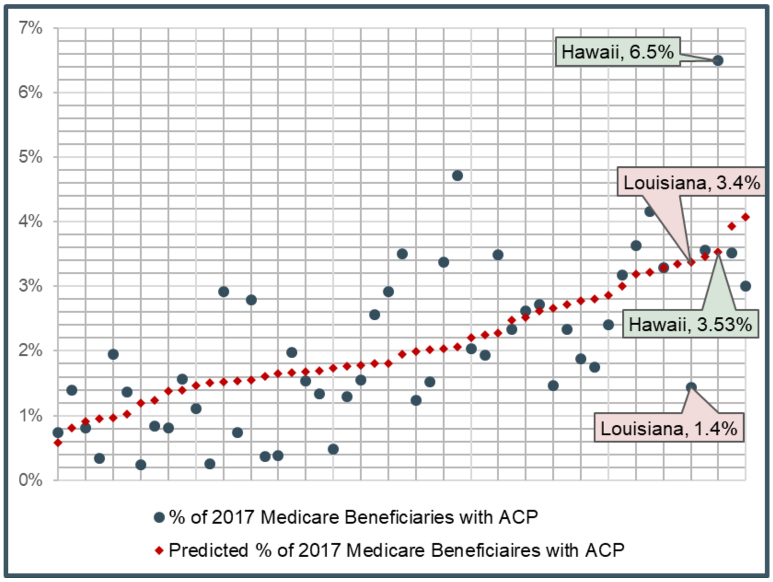
Figure 7. OLS Regression Model A (No Control Variables)

Adjusted R-Squared: 0.379 | AIC: -317.0 | BIC: -307.3

EQUATION:

$$Y_i = \beta_1(\text{Provider Education})i + \beta_2(\text{Person-and Family-Centered Care})_i + \beta_3(\text{PCP Visits per Decedent})_i + \beta_4(\text{Medicare Quality})_i - 0.0342(\text{Intercept}) + \varepsilon i$$

Variable	Beta Coefficient	P-value
Provider Education	0.00524	0.101
Person- and Family-Centered Care	0.00190	0.173
Primary Care Physician (PCP) Visits per Decedent	0.00361	0.000
Medicare Quality	0.01960	0.107



The results from Model B (no control variables) in **Figure 8** show that *Provider Education, Person- and Family-Centered Care Policies, PCP Visits per Decedent*, and *MA Penetration* have positive relationships with the dependent variable, indicating that they may be drivers of ACP performance at the state level. As with Model A (no control variables), *PCP Visits per Decedent* had the relationship with the dependent variable with the highest significance (β=0.003, p<.01).

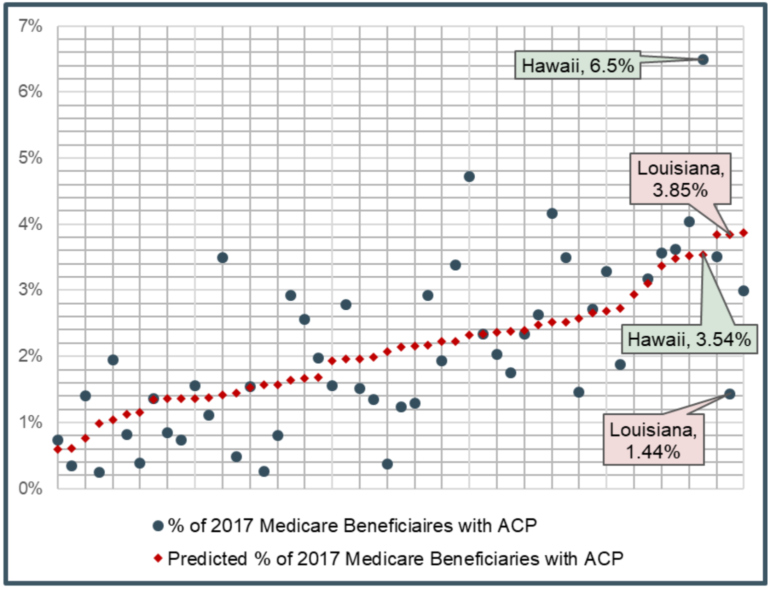
Figure 8. OLS Regression Model B (No Control Variables)

Adjusted R-Squared: 0.373 | AIC: -316.5 | BIC: -306.8

EQUATION:

$$Y_i = \beta_1(\text{Provider Education})i + \beta_2(\text{Person-and Family-Centered Care})_i + \beta_3(\text{PCP Visits per Decedent})_i + \beta_4(\text{MA Penetration})_i - 0.0250(\text{Intercept}) + \varepsilon i$$

Variable	Beta Coefficient	P-value
Provider Education	0.00607	0.055
Person- and Family-Centered Care	0.00198	0.157
Primary Care Physician (PCP) Visits per Decedent	0.00345	0.000
MA Penetration	0.01870	0.146



As shown in **Figure 9 and Figure 10**, when controlling for the percent of a state's population that is female, the coefficients for each of the independent variables in both Model A and Model B remain positive with p-values less than 0.25, meaning that there is approximately a 25% probability (or less) that the observed relationship between the variable and the percent of the Medicare population with ACP occurred due to chance. The *PCP Visits per Decedent* variable continues to have the most significant relationship with the dependent variable (p<.01).

Figure 9. OLS Regression Model A (Control Variable)

Adjusted R-Squared: 0.397 | AIC: -317.6 | BIC: -306.0

EQUATION:

$$Y_i = \beta_1(\text{Provider Education})i + \beta_2(\text{Person-and Family-Centered Care})_i + \beta_3(\text{PCP Visits per Decedent})_i + \beta_4(\text{Medicare Quality})_i + \beta_5(\text{\% Female})_i - 0.1770(\text{Intercept}) + \varepsilon i$$

Variable	Beta Coefficient	P-value
Provider Education	0.00398	0.220
Person- and Family-Centered Care	0.00201	0.145
Primary Care Physician (PCP) Visits per Decedent	0.00321	0.001
Medicare Quality	0.01900	0.114
% Female (control)	0.29100	0.131

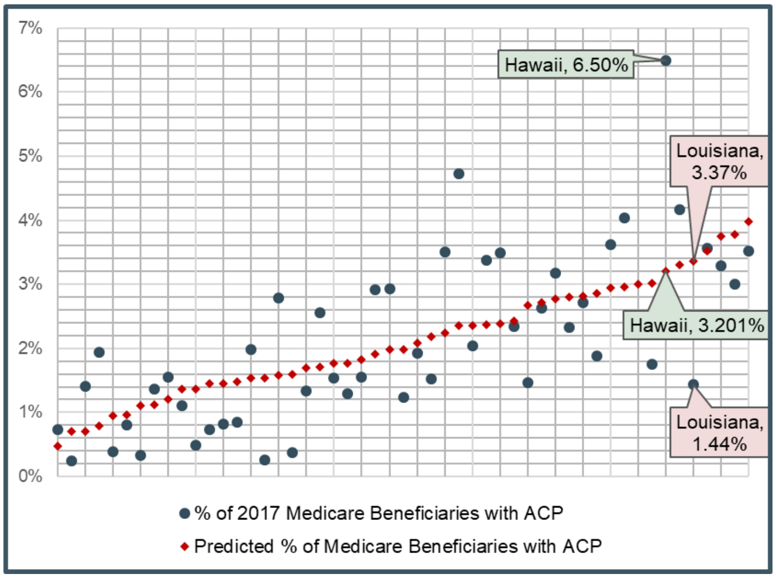


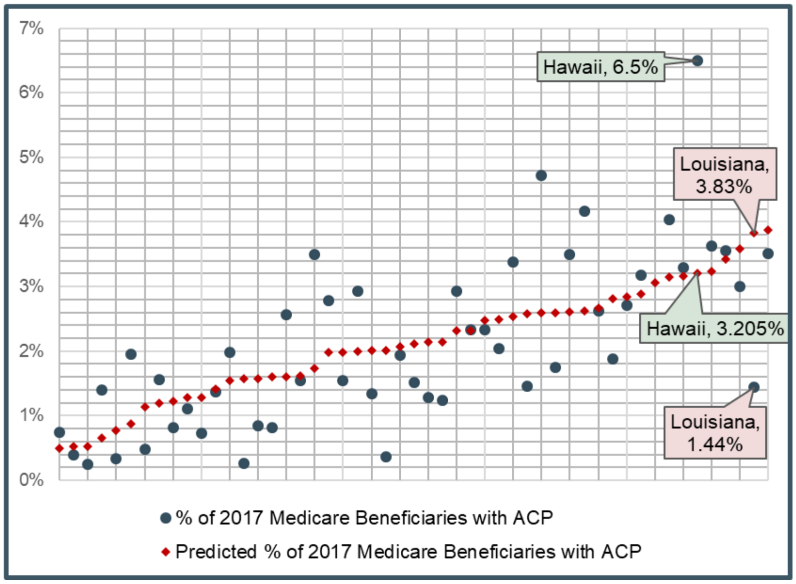
Figure 10. OLS Regression Model B (Control Variable)

Adjusted R-Squared: 0.388 | AIC: -316.8 | BIC: -305.2

EQUATION:

$$Y_i = \beta_1(\text{Provider Education})i + \beta_2(\text{Person-and Family-Centered Care})_i + \beta_3(\text{PCP Visits per Decedent})_i + \beta_4(\text{MA Penetration})_i + \beta_5(\text{\% Female})_i - 0.1620(\text{Intercept}) + \varepsilon i$$

Variable	Beta Coefficient	P-value
Provider Education	0.00485	0.131
Person- and Family-Centered Care	0.00209	0.133
Primary Care Physician (PCP) Visits per Decedent	0.00309	0.001
MA Penetration	0.01710	0.180
% Female (control)	0.27800	0.152



Implications for States

Results from the selected regression models suggest that the following have a relationship with increased rates of ACP at the state level:

- The availability of provider educational materials (Availability of Online ACP Resources Legal Information, or Forms for Providers)
- State policies that support the family caregivers of people needing LTSS (*Person- and Family-Centered Care Policies*)
- Increased engagement with primary care physicians (*Primary Care Physician [PCP] Visits per Decedent*)
- Higher MA penetration (*MA Penetration*)
- Better MA plan quality (*MA Plan Quality*)

To address these drivers, states can consider posting educational materials geared toward providers online in easily accessible formats. States should ensure that such resources are visible to providers and that providers know how to use the resources to promote ACP discussions with their patients.

Results from the analysis also indicate that there is a stronger relationship between higher scores on the *Person- and Family-Centered Care Policies* composite measure and higher rates of ACP planning. This would suggest that states with more robust policies supporting family caregivers have a higher percent of Medicare beneficiaries with ACP. States could implement policies relevant to the three component metrics (financial protection for spouses of Medicaid beneficiaries who receive home and community-based services, assessment of family caregiver needs, and CARE Act legislation) to support family caregivers and potentially improve performance on the ACP ACT Index measure.

States can also provide resources or implement programs that promote ACP in the primary care setting, given that results indicate that an increase in primary care physician visits is associated with higher rates of ACP at the state level. States could make efforts to increase primary care physician visits, more broadly.

Results suggest that states with a higher percent of Medicare beneficiaries enrolled in MA versus traditional Medicare have higher rates of ACP. Further, the *MA Plan Quality* metric results indicate that states with higher quality MA plan also have higher ACP rates. Of note, when these two variables are included together in the same model, each tends to moderate the effect of the other. This suggests that an increase in the percent of beneficiaries on MA plans is associated with an increase in ACP only when those plans are high quality. This is especially interesting because the ACP Index measure only includes Medicare FFS beneficiaries. One hypothesis is that as providers are encouraged or incentivized to perform ACP by high quality MA plans, they also increase their delivery and coding of ACP for FFS beneficiaries.

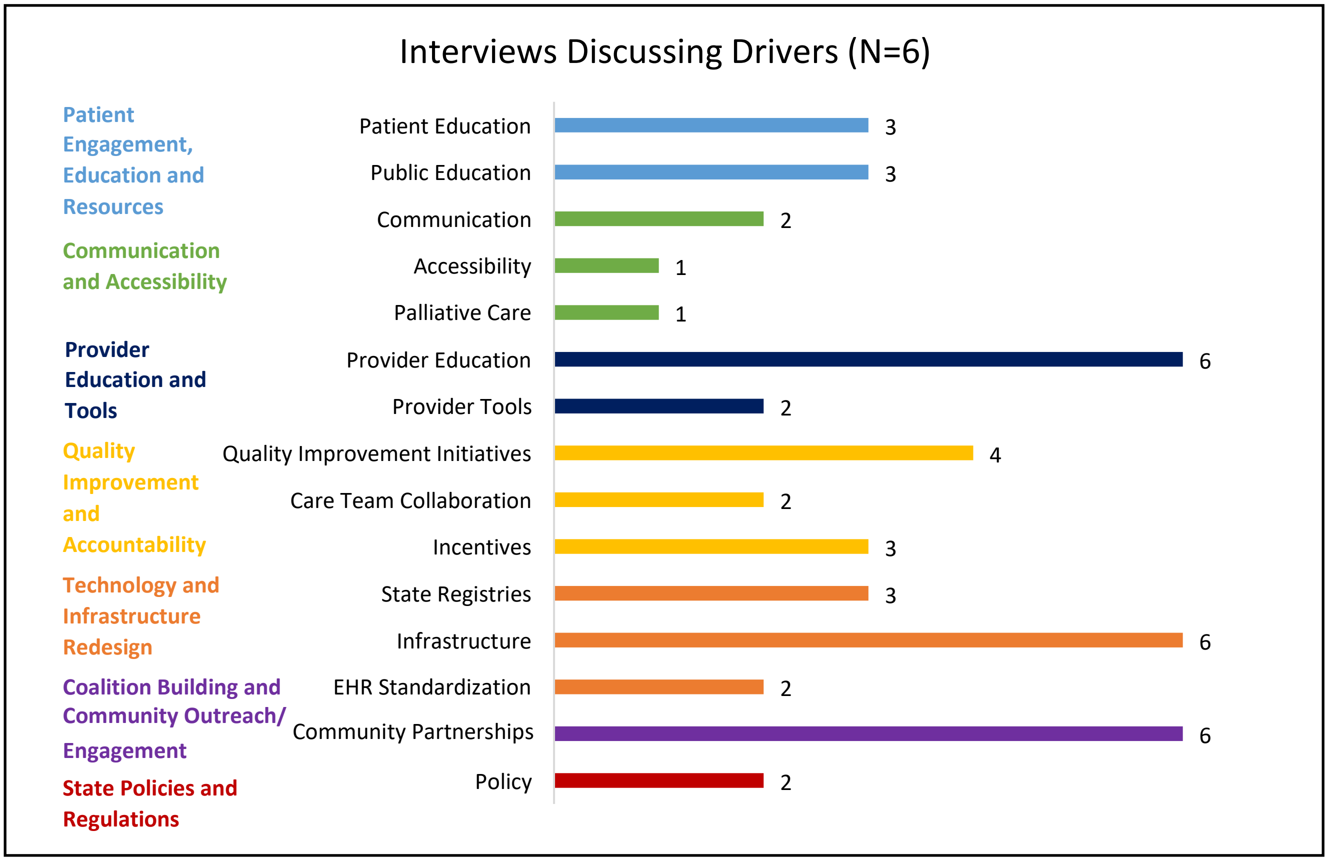
To capitalize on this relationship, states could engage commercial plans and consumers in activities that encourage ACP and give consumers the information they need to promote MA enrollment in high quality plans. States could also develop resources for commercial plans around improving plan quality, focusing on the delivery of and payment for ACP services. However, it should be noted that because the ACP ACT Index measure only captures Medicare FFS beneficiaries, increased MA penetration could impact the denominator in the ACP measure.

While our statistical analysis supports the above preliminary conclusions, assessing the relationship between variables measured at the state level as opposed to the patient level presents methodological challenges. Even if two variables have a statistical relationship, it is harder to attribute a causal relationship because it is unknown whether the same individuals who have the characteristic represented by one of the control variables or independent variables have also received ACP services. See *Project Limitations* for more information on the research limitations of this project.

Interviews with Key Informants

Interviews with key informants in both Hawaii and Louisiana helped validate the initial results from the literature review and statistical analysis and surfaced barriers to ACP and best practices for promoting ACP that are actionable at the state level. **Figure 11** below summarizes which of potential state-level drivers of ACP were discussed during the interviews and notes the number of interviewees who mentioned each topic. We organized these into the driver categories identified during the literature review and environmental scan.

Figure 11. Summary of State-Level ACP Drivers Discussed During Interviews with Key Informants



Best Practices for and Barriers to Facilitating ACP

While the topics discussed during the interviews align with the state-level drivers of ACP identified during the literature review and environmental scan phase of this project, the key informants in Hawaii and Louisiana provided real-world examples of how states can successfully implement interventions and accelerate improvement on the ACP ACT Index measure. The interviews also provided more information about barriers to implementing, and scaling initiatives focused on increasing or improving ACP conversations, and how to overcome challenges.

Hawaii was the highest performing state, performing much higher than predicted by Models A and B. In three of our four models, Louisiana's performance was predicted to be higher than Hawaii, but the state ranked 34th in its actual rate of ACP. Given these results, it is notable that there were similarities in the best practices and barriers mentioned by informants in both Hawaii and Louisiana. However, the state government and local payers both played collaborator roles in Hawaii, whereas the same support does not seem to have historically been available in Louisiana. **Appendix C: Key Informant Interview Highlights** includes insights from each of the six interviews with key informants in Hawaii and Louisiana.

Patient Engagement, Education, and Resources

Interviewees in both Hawaii and Louisiana shared best practices for educating patients about ACP and engaging them in ACP conversations. One helpful resource that key informants in Hawaii recommended that providers use with their patients is the collection of online visual decision aides that ACP Decisions, an advance care planning advocacy and education organization, produced on a range of end-of-life care topics. HMSA, one of the largest health plans in Hawaii, worked with ACP Decisions to produce the videos in different languages and supplied hospitals, hospices, and skilled nursing facilities an iPad with the ACP Decisions videos pre-loaded. When this program was discontinued, some of the larger practices purchased their own subscriptions to the videos, but many did not. According to one interviewee, the videos that were provided to her health system were not widely used by providers and some patients were resistant to using the videos to inform their decisions.

In Louisiana, key informants recommended that providers leverage the online resources available for download from the Louisiana Health Care Quality Forum. Resources include an ACP implementation guide, FAQ fact sheet, and LaPOST (the Louisiana POLST form). LaPOST also disseminated public service announcements around National Decisions Day (April 16, 2019) to raise community awareness of ACP.

Several interviewees mentioned that resources created for patients were not sufficient to explain and increase ACP. These resources must be coupled with meaningful discussions with providers, peers, and other influencers (such as spiritual counselors, attorneys, or financial planners).

> “Education by itself doesn't change behavior. You also have to have proper preparation and follow-up"

Communication and Accessibility

Key informants also provided recommendations around improving communication with patients about ACP and making ACP information more accessible. Kōkua Mau, a non-profit advocacy organization at the center of advance care planning efforts in Hawaii, conducts outreach and ACP conversations in the community: at churches, workplaces, and community centers. Kōkua Mau recently partnered with the Hawaii Department of Motor Vehicles to deliver ACP education to people in the waiting room. The Kōkua Mau ACP Coordinator, who implements Kōkua Mau’s story-telling based ACP program, is also a notary, so she can streamline the execution of AD and POLST documents that are recognized by the state. Kōkua Mau also emphasized the importance of developing palliative care programs and integrating ACP into palliative care settings.

Interviewees echoed the literature review findings that social determinants of health are a factor in ACP engagement. Key informants in both states also shared that many cultures do not feel comfortable discussing ACP and end-of-life issues and may have a general distrust of the healthcare system and fear being “cheated out of care.” People may also hold superstitions about openly discussing ACP (noted specifically for Louisiana).

Interviewees suggested that it is essential for providers to use person-centered tactics to build strong relationships with patients and encourage open ACP conversations. One informant from Louisiana suggested that provider communication with patients should begin with an in-depth assessment of social determinants; patient, family, and cultural values; the way decisions are made each family; and the expectations that each patient and their family may have. Another Louisiana interviewee recommended that providers "flip the script" when discussing challenging topics like end-of-life care with their patients. She emphasized the importance of talking about what can be offered as opposed to what is not going to be offered to a patient.

> "What we build here is what we'll be consuming in the not-so-distant future. We ***need*** to create language that is more inclusive."

Another interviewee noted that providers may use language that separates them from older adults or patients with advanced illness. Using inclusive language can help ease provider reluctance to engage patients in conversations about end-of-life care planning.

Provider Education and Tools

Providers must be well-educated on conducting ACP conversations in order to effectively engage patients in shared discussions about end-of-life care planning. As a part of Hawaii's HMSA initiative around the ACP Decisions video resources, HMSA provided one- to four-hour trainings for providers so that they would not only have the ACP tools at their disposal but know how to use them effectively.

The Louisiana Health Care Quality Forum conducts statewide provider trainings in targeted areas of Louisiana to educate healthcare professionals, faith-based organizations, and social workers about ACP in partnership through the LaPOST Ready Campaign. Similarly, Hawaii Pacific Health Medical Center in Hawaii leverages an internal ACP champion to deliver full day workshops to staff several times a year and has built clinical decision support tools for providers into its EMR (see *Technology and Infrastructure Redesign* below).

Key informants stressed the importance of reaching medical school students early in their careers to teach and reinforce ACP. One interviewee recommended that nursing schools, allied health schools, and medical schools prioritize palliative care in their curriculum. This is also an opportunity for standardization of educational materials, such as integrating best practices content into facilitated ACP modules, and ACP forms so that professionals can more easily implement what they learn if they practice in different settings or regions than where they were initially trained.

One challenge for the ACP movement in Louisiana has been sustaining momentum. Spreading the use of ACP required ongoing education and reinforcement following the passage of POLST legislation. In addition to education for new clinicians, consistent outreach to practitioners is needed to reinforce the importance of ACP and for succession planning and developing the future leaders of the movement. One interviewee described a program to educate providers in communities across the state and identify local champions willing to present on the topic in their regions. Likewise, in provider organizations with frequent staff turnover, such as skilled nursing facilities, ongoing education is needed to ensure all staff are included. This challenge was noted in both Hawaii and Louisiana.

Quality Improvement and Accountability

Best practices for change management in healthcare organizations can be applied to efforts to improve ACP at the state level. Interviewees emphasized using small tests of change (e.g., Plan-Do-Study-Act) to implement ACP interventions with lasting effects. To engage others in participating in such targeted quality initiatives, key informants recommended that states and other organizations identify clinicians and other change agents to champion ACP and promote adoption. The LaPOST Ready Campaign uses training sessions as an opportunity to recruit local champions to lead grassroots ACP efforts. Because most organizations undertaking change initiatives will face some resistance, one key informant suggested that organizations identify "early adopters" to champion the change and persuade those who may be neutral to the change to support it.

Stephanie Anderson and Carole Montgomery from Respecting Choices recommend that organizations align ACP initiatives with other strategic priorities (e.g., patient experience, patient safety, readmissions reductions, etc.) so that staff are more encouraged to engage "rather than thinking of ACP as another thing to do."

While support from the bottom up is necessary to execute quality improvement initiatives, one informant from Hawaii also noted that it is important to get leadership buy-in. HMSA was successful in implementing several quality improvement ACP-focused initiatives because they were able to garner support from executive leadership, which helped to encourage participation from the top-down.

Building accountability (including financial) for quality with quality improvement initiatives is one way to promote ACP. HMSA used provider incentives to increase rates of ACP among their members. In 2010, HMSA developed a value-based payment model in which its hospital partners were paid a bonus based on the quality of care provided. To determine this bonus, HMSA implemented quality pay-for-performance (P4P) measures (e.g., patient safety, avoiding hospital-acquired infections, etc.). One of the P4P measures used to determine the quality bonus was an end-of-life composite, which included ACP components. In 2013, HMSA implemented another quality metric around ACP aimed at primary care providers.

Using financial incentives for providers to engage in ACP conversations with their patients helped to improve rates of ACP in Hawaii before the CPT codes were added to the PFS in 2016. As of 2018, Advance Care Planning is one of the measures included in HMSA's pay for performance program for patients covered under commercial insurance and Medicare Advantage.[149]

Two major health plans in Hawaii reimburse for ACP, which "makes a huge difference in promoting ACP for the Hawaii population."

Stakeholders support incentives for ACP conversations, and payers can also use incentives to encourage providers to access ACP documents once they are completed. However, incentives for AD or POLST completion are problematic because they may lead to pressure on patients that undermines the "voluntary" nature of completing these documents.[150] Likewise, including POLST completion as a measure of quality in programs may have unintended consequences, such as encouraging providers to complete POLST forms at less appropriate times that may not result in achieving goal-concordant care.[151]

While financial incentives are useful for promoting ACP, if they are not enticing enough, barriers to ACP will persist. One key informant noted that most physicians do not use the ACP billing codes because they do not spend enough time on ACP conversations to be able to use the codes, or do not have enough time to have meaningful conversations with their patients. To address lack of resources to conduct ACP, one interviewee suggested that organizations leverage top-of-license practices and the skills of the entire care team to encourage staff at healthcare organizations to participate in facilitating ACP discussions with patients. According to one interviewee, a Hawaii organization used their medical billing/front office staff to walk patients through the ACP Decisions videos before handing the patient over to the provider to finish the ACP conversation and complete necessary documentation.

Technology and Infrastructure Redesign

Integrating the ACP billing codes into organizations' EHRs and either leveraging an HIE/interoperability framework or establishing a statewide online registry may encourage providers to both engage patients in ACP conversations and document those discussions. The Louisiana Health Care Quality Forum works with Vynca, an ACP technology solutions company, to manage a statewide electronic LaPOST registry. The Forum has integrated ACP and AD documents with EHRs so that the documents are completed online and are able to be extracted by authorized healthcare professionals. Ryan Van Wert, Vynca CEO, shared that making easy access to ACP documents available within EHRs is important: "accessing documents in an easy-to-find single location within an EHR can streamline version control and improve integration into clinical workflows." In February, 2020, Oschner became the first health system to join Louisiana Health Care Quality Forum and Vynca in their collaboration to manage the registry.[152]

The Louisiana Health Care Quality Forum embedded educational materials for patients and providers into the EHR-integrated forms so that these resources are available to use as the documents are completed. The Louisiana Health Care Quality Forum also offered free installation to organizations that agreed to participate in Louisiana's state registry efforts. One barrier to developing the state registry has been a lack of coordination between LaPOST and the Secretary of State office in Louisiana, which currently houses hard copies of ADs and ACP documents.

Hawaii Pacific Health hired a dedicated staff person in the quality department to develop organizational ACP practices, build the information system, oversee and conduct staff training, and track quality improvement activities. Tracking these initiatives is key; to effectively scale change initiatives, interviewees recommended that organizations collect data early and rely on evidence to inform decision-making. Hawaii Pacific Health has integrated ACP billing codes into its EMR system and embedded clinical decision support tools to help providers in ACP conversations.

Technology vendors are also supporting ACP redesign beyond Hawaii and Louisiana. For example, MyDirectives has partnered with Humana to offer a single sign on to the MyDirectives digital advance care platform so members can create advance care plans without additional credentialing.[153] United Healthcare, in partnership with AARP, is also offering digital ACP powered by MyDirectives.com to its Medicare Supplement audience who are AARP members.[154] Jeff Zucker, CEO of AdVault and MyDirectives, suggests that stakeholders should promote the use of ACP platforms that "support the communication between payers and providers to create a true ecosystem, allow for confirmation by the Health Care Agent (proxy) as to willingness to serve, and provide security and privacy consistent with the requirements of HITRUST certification." Above all, these platforms should ensure that each individual's voice is heard.

Coalition Building and Community Outreach/Engagement

Statewide and regional coalition building, involving a wide range of community and stakeholder organizations, is one of the most-cited best practices across key informants in Hawaii and Louisiana. Hawaii has a strong, long-standing network of health plans, provider organizations, community-based organizations, advocacy organizations, and academic institutions that promote ACP. Many of the key ACP quality improvement initiatives in Hawaii involved stakeholders across this broad healthcare spectrum.

Louisiana is continuing to build its coalition of organizations interested in improving ACP in the state and across the South. LaPOST has partnered with community and faith-based organization leaders to carry the ACP message. The Louisiana Health Care Quality Forum, while not a government entity, works closely with the Louisiana Department of Health to manage state quality health IT initiatives with support from state funding, including initiatives around improving end-of-life care planning. Key informants in Louisiana noted that it is important to include stakeholders outside of the healthcare industry in coalitions to promote ACP for individuals with advanced illness, such as those from the finance industry and experts with legislative experience. Establishing coalitions can help pass key legislation to improve care and build a statewide infrastructure to develop educational and promotional materials to support implementation efforts.

As discussed above, informants in both states noted the importance of religion and culture in ACP conversations and decision-making. Engaging leaders from religious and faith-based organizations to promote understanding of ACP and, where possible, offer their support is one technique to bridge gaps in this arena. LaPOST's has worked with the Louisiana Conference of Catholic Bishops, and in 2017, that organization announced support for ACP and added links to an ACP toolkit from its homepage.[155] This toolkit includes resources for priests to integrate ACP information in the homily and include articles about ACP in the church bulletins.

One key principle of change management is building stakeholder support early in the process. Multiple organizations within a given state may have independently begun ACP-related projects. Therefore, engaging relevant organizations within and outside of health care early will help avoid duplicative efforts and encourage collaboration.

State Policies and Regulations

Hawaii and Louisiana passed POLST legislation in 2009 and 2010, respectively, authorizing statewide use of a standardized POLST form to streamline ACP discussions. [156,157] While the Hawaii Department of Health supports ACP initiatives, Kokua Mau has been the central strategic convener, leader, and coordinator of state-wide action to promote ACP.

Passing legislation in Louisiana has been challenging, given that the political environment makes it difficult to advance ACP policies and programs. Conservative groups have historically had a strong influence, advocated for laws being more "protective of life", and resisted policies that facilitate ACP and ADs. LaPOST worked for four years to promotes passage of the POLST legislation and has been working since its passage to build a statewide infrastructure to support improved coordination and communication among providers, patients, and the state regarding ACP documentation. LaPOST pushed for related legislation to expand POLST, as well. One interviewee shared that in 2012 (and again in 2014) Louisiana adjusted the surrogate decision-makers statute regarding the withdrawal and withholding of life-sustaining treatment to give more autonomy to the patient and his or her preferred caregiver or decision-maker.

POLST legislation may not benefit all states and patients, however, or functionally increase ACP. National POLST works with a variety of stakeholders to promote the adoption of POLST, including the development of state programs. In September 2019, they released a National POLST Form, created through consensus among programs and external stakeholders, that states can choose to use and guidance for aligning forms in states that currently require use of their own.[158] According to Executive Director Amy Vandenbroucke, this is critical because patients travel throughout the United States and should be able to have confidence that their wishes will be honored everywhere. Because implementing POLST generally does not require legislation, restrictive or overly specific state legislation can serve as a barrier for physicians honoring POLST forms from other states. According to Ms. Vandenbroucke, "the biggest challenge we have is getting state legislators and policymakers to recognize that this is a national program, not a state program. State legislation should not create barriers to using POLST for patients coming into—or leaving—their state." Using a standardized form that includes critical components can facilitate comprehensive ACP and help ensure that patient wishes are followed throughout the US.

Both Hawaii and Louisiana have check-boxes on their drivers' licenses related to advance directives, but neither has an active database for providers to search for the document, and it is unclear whether this has increased ACP. Other stakeholders have suggested that including a quick response (QR) code on drivers' licenses and/or insurance cards would be help providers connect more rapidly to electronically stored patient information at the point of care.

Identification of Regional ACT Index Coaches

Discern leveraged interviews with key informants to identify Regional ACT Index Coach candidates. C-TAC is recruiting Regional ACT Index Coaches to champion efforts to improve the quality of care for those with advanced illness and support grassroots change at the local level. The ideal ACT Index Regional Coach has been directly involved with implementing changes to advanced care delivery systems that have improved patient care and is willing to collaborate with a network of leaders in other states about their experiences. Coaches will coordinate with C-TAC to participate in meetings, webinars, potential publications, and conversations with others in this space as they are available.

Table 9 summarizes the individuals whom Discern and C-TAC approached regarding the coaching opportunity and who were interested in moving forward with next steps. Biographies for the potential Regional ACT Index Coaches are available in **Appendix C: Key Informant Interview Highlights**.

Table 9. Summary of Discern Outreach to Potential Regional ACT Index Coaches

Name	State	Position	Organization
Rae Seitz, MD	Hawaii	Medical Director	Hawaii Medical Service Association (HMSA, Blue Cross Blue Shield affiliate)
Cindy Munn, MHA	Louisiana	CEO	Louisiana Health Care Quality Forum
Jamey Boudreaux, MSW, M.DIV	Louisiana	Executive Director	Louisiana-Mississippi Hospice and Palliative Care Organization

DISCUSSION AND RECOMMENDATIONS

The C-TAC ACT Index is a useful tool to gauge the national state of advanced illness care. Because component measures, like the ACP ACT Index measure, are collected at the state level, states can use the ACT Index as a tool to target continuous quality improvement efforts to improve care for individuals with serious illness. Further, understanding a state's performance relative to other states can underscore opportunities for collaboration and alignment to move closer to achieving C-TAC's goals for improving the quality, accessibility, and affordability of care to individuals with advanced illness on a national scale. Best practices to improve rates of ACP at the state-level, and thus improve performance on the ACP ACT Index measure, have implications for stakeholders across the healthcare spectrum and beyond the healthcare industry.

Summary of Best Practices

While cultural, political, and structural barriers may detract from provider and patient engagement in ACP, there are clear actions that states, organizations, and coalitions can take to address reluctance to participate in ACP and promote awareness. Analysis of publicly available data and interviews with key informants in two select states validated findings surfaced in the literature review and environmental scan and provided context and color to what providers, patients, families, and others are experiencing on-the-ground, across the country as they engage in ACP discussions.

Figure 12 summarizes the best practices in each category that were supported by our qualitative and/ or quantitative results.

Figure 12: Best Practices within Each Category

Patient Engagement, Education, and Resources

- Develop culturally tailored materials to support provider discussions; integrate faith-based elements
- Develop multi-modal engagement and education strategies to invite person and family participation
- Use storytelling as a component of interventions
- Conduct outreach in non-healthcare as well as healthcare settings
- Leverage social media in public awareness campaigns

Communication and Accessibility

- Make materials available in multiple languages
- Recognize racial and economic disparities in ACP and consider social determinants of health when designing programs
- Provide resources to patients that are easy to use and access
- Encourage development and use of palliative and hospice programs

Provider Education and Tools

- Educate providers early in their careers
- Educate providers early in their careers
- Conduct regional training programs and training within specific care settings (e.g., skilled nursing facilities)
- Hold provider training programs on the value of ACP and how to have meaningful conversations
- Reinforce primary care practitioner use of ACP, but also train other types of providers, including long term care providers, oncologists, social workers, and others.
- Post provider tools on the state website
- Offer standardized tools and resources to help providers facilitate conversations, including resources on person-centered care and inclusive language and best practices content

Quality Improvement and Accountability

- Leverage principles of change management, including identifying champions and gaining buy-in from leadership
- Track performance, benchmark with peers
- Implement “top of license” practice, engaging front-office staff or medical assistants to participate in elements of ACP
- Encourage health plans to cover ACP and promote provider use of ACP documents
- Offer incentives for providers to have ACP conversations via reimbursement or quality bonuses

Technology and Infrastructure Redesign

- Leverage technology (e.g. health information exchange and other interoperability frameworks) to ensure access to completed ACP documents (e.g., advance care plans, portable medical orders [POLST], advance directives) at point of care
- Dedicate organizational resources to establish ACP policies and offer ongoing education
- Integrate ACP practice into workflow and operations
- Program billing codes into EHRs; consider incorporating templates and clinical decision support tools

Coalition Building and Community Outreach/Engagement

- Build state and local coalitions that include government agencies, multiple types of healthcare providers, faith-based organizations, legal experts, community organizations, philanthropic organizations, and insurers

- Offer resources for health plans that describe the quality and financial benefits of ACP and improving the quality of their MA offerings

State Policies and Regulations

- Promote the use of POLST and standardized forms (e.g., the National POLST form, effective standardized advance directives)
- Develop state policies that support family caregivers, aligning policies with national and global efforts
- Develop state policies that support family caregivers, aligning policies with national and global efforts

PROJECT LIMITATIONS

Limitations to this research project include those related to the availability and use of state-level data, the Medicare FFS billing codes for ACP, number and selection of interviewees, and funding limitations.

Discern's analysis used publicly available state-level data from multiple sources, which imposed limitations to the interpretation of the relationships among the independent, control, and dependent variables. Because data were assessed at the state-level, we could not capture variation within states. Our cross-sectional approach can identify associations between variables, but not causal relationships or patient-level relationships. Thus, state rates of independent and control variables may be associated with variation in state performance on the ACP measure, but we do not know whether the individuals who are included in those variables are the same individuals who have received ACP. These challenges could be mitigated in future research projects by using patient-level data and aggregating results to assess impact at the state level.

The analysis was also limited by the data available to inform the dependent variable, rate of ACP, as described earlier in the report. The Medicare FFS data only includes traditional Medicare claims, not MA claims. Further, many ACP conversations may not be documented by the Medicare FFS CPT ACP codes, 99497 and 99498. Providers may not be billing to those codes properly or billing other codes, professionals (clinical and non-clinical) may be having ACP conversations who are not eligible to bill for them, and some clinicians may be having very short conversations that do not meet billing criteria. Additionally, CPT codes do not capture the quality of ACP conversations, rate of ACP documentation, or whether patients receive care that aligns with their plan and/or wishes.

There is also a data lag: Discern only had access to 2016 and 2017 data for ACP. Further, not all data from other variables in the analysis were collected during the same time frame. To mitigate limitations related to consistent data, Discern used data within a three-year timeframe from variable to variable. However, this approach was itself limited because not all data are collected on an annual basis.

Additionally, given limitations in funding, Discern only interviewed key informants in two states and collected data for ten potential drivers of ACP. To make the best use of available resources, Discern used the following strategies:

- We leveraged datasets provided by C-TAC and scheduled interviews with multiple experts from the same organizations to gather information from as many different perspectives as possible.
- We reviewed a draft of this paper with national experts to validate and enhance the content before publishing the document.

CONCLUSIONS AND CONSIDERATIONS FOR FUTURE RESEARCH

Discern identified key drivers of the ACT Index measure ACP via by supplementing existing evidence from the literature with original quantitative and qualitive research. These drivers fell into the overarching categories of Patient Engagement, Education, and Resources; Communication and Accessibility; Provider Education and Tools; Quality Improvement and Accountability (including financial incentives); Technology and Infrastructure Redesign; Coalition Building and Community Outreach/Engagement; and State Policies and Regulations. We also generated interest for the ACT Index Coach program through our interviews with key informants. Finally, through the course of completing this project, we tested the three-pronged research strategy for identifying best practices.

While we believe this project identified the most salient drivers of ACP, C-TAC and other stakeholders have several opportunities to continue this research to identify actionable best practices that states and organizations can pursue to improve performance on the ACP ACT Index measure:

- Continue to interview key informants in additional states and talk with additional national experts who have worked across states to enhance the best practices library for this ACT Index measure.
- Use the information gathered from the interviews to develop case studies as an output to supplement conversations with key informants.
- Compile online resources developed by multiple organizations to support the best practices identified through this research project.
- Leverage a stakeholder network as a rich source of best practice information.
- Work with the broader advanced illness community to promote the effective translation of evidence and surfaced best practices into practice.
- In areas where interviews indicate promising interventions, but literature is scarce (e.g., accessibility of materials and interoperability), pursue additional research studies.
- Test additional independent variables to identify potential relationships with rates of ACP across states
- Acquire patient-level data, if possible, to more precisely identify relationships between potential drivers of ACP and performance on the measure.
- Develop or identify data sources that are more inclusive of ACP practices beyond the Medicare billing codes and/or that reflect the quality of ACP conversations and outcomes related to goal concordant care.
- Include promoting effective ACP as a tactic in the C-TAC moonshot to promote C-TAC’s goal of 12 million people with serious illness having high quality of life by 2030.

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