



ACP
DECISIONS

Advance Care Planning Decisions

A Special Report for Healthcare Executives

Implementing an ACP Program that Reduces Costs Without Compromising Care

Angelo Volandes, MD, MPH, President, ACP Decisions

Aretha Delight Davis, MD, JD, Executive Director, ACP Decisions



Advance Care Planning Decisions

www.acpdecisions.org
info@acpdecisions.org

ACP is intended to be an ongoing person-centered, family-oriented and documented conversation.

Implementing an ACP Program that Reduces Costs Without Compromising Care

Overview

Advance care planning (ACP) is a decision-making process that supports people at any age or stage of health in receiving medical care that is aligned with their values, goals and priorities. To accurately reflect an individual's preferences, ACP is intended to be an ongoing person-centered, family-oriented, and documented conversation.

The intent of ACP is to prevent painful, unwanted, and potentially ineffective interventions. When done well, it can lead to improved quality of care, decreased decisional conflict, and an increased likelihood that a patient will have their preferences about end-of-life decisions honored.

ACP is a process, not an end product, such as an advance directive legal document. While an advance directive is a component of ACP, having one does not necessarily mean that ACP has occurred. A drawback of advance directives are their questionable stability as time passes — meaning whether the decisions or specific wishes made at one point in time still apply later, when those decisions must be made. ACP is a strategy designed to overcome the shortcomings of advance directives.

In recognition of the value of the ACP process, the Centers for Medicare and Medicaid Services (CMS) began paying for this service in 2016. This decision followed the recommendation of the American Medical Association (AMA), a wide range of stakeholders, and most Americans. A Kaiser Health Tracking Poll in 2015 found that 89 percent of the public favors doctor-patient discussions of end-of-life care issues.

Limitations of Current ACP Interventions

Although there is more and more evidence to support the significant contribution to patient autonomy and enhanced quality and access to care at the end of life, ACP discussions are not happening for most people. The same Kaiser Health Tracking Poll that found overwhelming support for end-of-life discussions also found that only 17% of people reported ever discussing end-of-life care with their doctor.



ONLY 17% of people reported ever discussing end-of-life care with their doctor.



ONLY 37% of U.S. adults had completed an advance directive between 2011–2016.

Many U.S. healthcare systems have implemented programs to improve access to ACP and advance directives; however, there is little evidence to show these programs are carrying out people's wishes regarding the care they receive at the end of life — or even encouraging people to participate. One review of studies published from 2011 to 2016 found that only 37% of U.S. adults had completed an advance directive.

To avoid the pitfalls of most ACP initiatives, an integrated ACP approach is necessary.

Patient activation begins with decision tools that educate and inform patients and families.

The rates of documented ACP discussions may not be any better — in one study, only 37% of patients with advanced cancer had this crucial conversation before death. Unfortunately, even when the documents are completed, they are often not available or adhered to at the time they are needed.

There are several reported reasons why a focus on only advance directive completion does not work.

While data show that ACP models improve multiple outcomes for seriously ill patients, there is limited data regarding which program design works best. Many institutional ACP initiatives focus on a single stakeholder, such as clinicians, or a program, such as documentation. Furthermore, although several evidence-based, patient-facing tools and goals-of-care conversation trainings are available, they are often tested and implemented in isolation despite evidence that an integrated ACP system is needed.

A systematic review published in Palliative Medicine found that one ACP trial, known as the SUPPORT study, was ineffective in meeting any of its goals to improve the communication process, outcomes, or cost reductions. The authors conjectured that there was a lack of standards for the ACP intervention which led them to conclude that the structure and carry-through of an ACP program is essential to positive outcomes.

Comprehensive ACP as a Solution

Narrow approaches to ACP are unlikely to influence complex healthcare systems. To avoid the pitfalls of most ACP initiatives, an integrated ACP approach is necessary. One that addresses the four primary stakeholders: patients, providers, healthcare systems, and communities.



ONLY 37% of patients with advanced cancer had this crucial conversation before death.



“Improving the quality and availability of medical and social services for patients and their families could not only enhance quality of life through the end of life, but may also contribute to a more sustainable care system.”

The Case for Comprehensive Advance Care Planning

The potential benefits of ACP are numerous:

- 

Care that is aligned with preferences.
- 

Reduced misunderstandings and conflict between medical staff & families.
- 

Fewer interventions of limited clinical value.
- 

Earlier access to Palliative Care.
- 

Reduced emergency hospital admissions.
- 

Reduced anxiety & depression experienced by bereaved caregivers.
- 

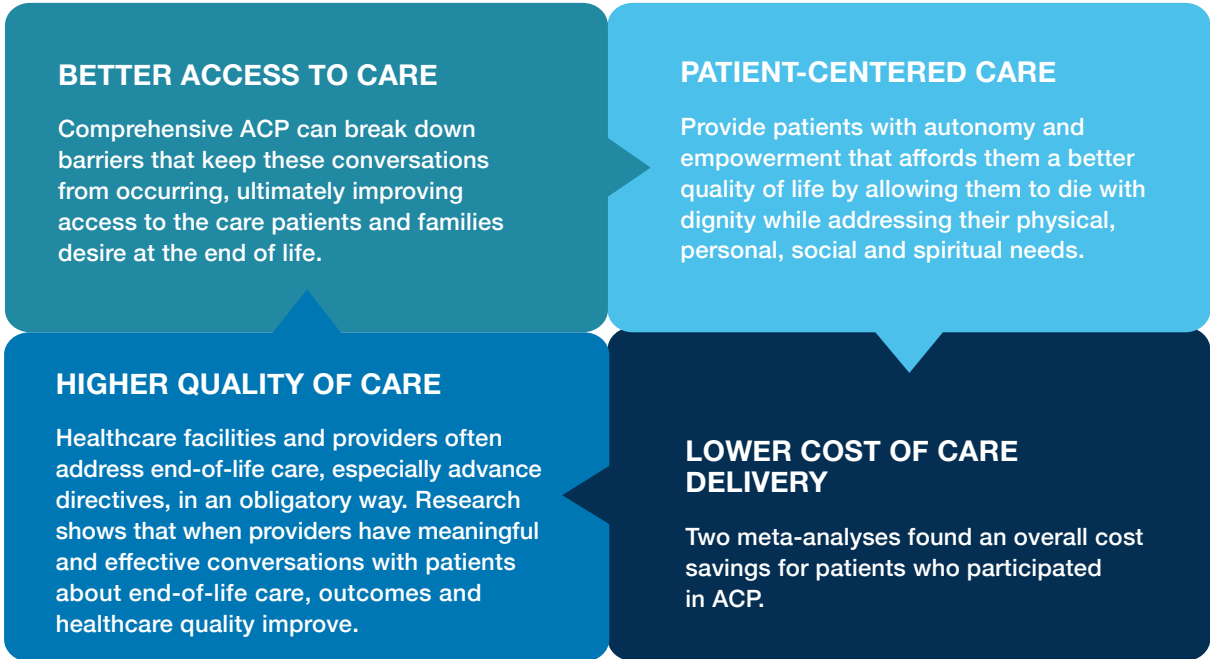
Fewer hospital deaths.
- 

Better use of resources at end of life.

To achieve these benefits, it is crucial that ACP is comprehensive and meets patient values wherever barriers and challenges exist. In *Dying in America*, a consensus report from the Institute of Medicine (IOM), a committee of experts concludes “improving the quality and availability of medical and social services for patients and their families could not only enhance quality of life through the end of life, but may also contribute to a more sustainable care system.”

How can ACP contribute to a more sustainable care system?

By meeting four key outcomes:



All four of these outcomes can be achieved with a comprehensive ACP program that seeks to balance each outcome – meaning one outcome cannot occur at the expense of another. For example, reducing costs of end-of-life care should not compromise quality of care.



How to Implement a Comprehensive ACP Program in 4 Steps

1 Patient care is a challenging task that requires not only a holistic view of patients, but also an understanding of the family, social, legal, economic, and institutional circumstances surrounding them, especially as they approach end of life. Patients need to understand the value of ACP and demand time with their clinical team to discuss their wishes – greater public education is necessary to drive this demand.

2 Transforming a healthcare system focused on curing disease to one focused on congruence with patient values presents unique challenges. An effective ACP program will address the primary stakeholders and meet the four key outcomes for a sustainable care system. This requires a multi-faceted approach.

3 There are 4 steps to implementing a comprehensive ACP program at the institutional level. Rather than taken sequentially, **these steps should be viewed as “pillars”**, supporting patient-centered, cost-effective ACP – each one as important as the other.

4 Pillars to Launching a Comprehensive ACP Program



The pillars to supporting patient-centered, cost-effective ACP



Resource for patient activation:

[ACP Decisions](#)

PATIENT ACTIVATION

This step involves helping patients and surrogates better understand the medical system and their options for care. It also promotes enhanced communication between patients and clinicians as well as with designated surrogates and family. Patient activation begins with decision tools that educate and inform patients and families. Patients are often unaware of what ACP is or why they should prioritize these conversations. High-quality clinician-patient communication is a critical component of this step.

All individuals who have capacity should have the opportunity to actively participate in their healthcare decision making. The conversation should be ongoing to ensure that patients' goals and needs are met. Advance directive documents are just one step and should not supersede allowing patients to make informed decisions as conditions change.



Resources for clinician training:

[Center to Advance Palliative Care](#)

[Coalition for Compassionate Care of California](#)

[CSU Institute for Palliative Care](#)

[Vital Talk](#)

CLINICIAN TRAINING

This step involves preparing clinicians and healthcare systems to document ACP conversations and enact patients' preferences for care. Resource allocation for multi-disciplinary clinician training will increase the number of ACP specialists as well as expand the knowledge base for all clinicians.

Since clinicians often bear the responsibility of informing patients about their prognosis, exploring treatment options, and helping formulate preferences based upon a risk-benefit analysis and their values, better clinician training around these conversations is necessary. While physician endorsement of ACP is important, many clinicians are not

prepared nor have the time to follow-through on all ACP conversations. Training across several different disciplines to create an integrated workflow of ACP communication from physicians to front desk staff may be needed.

Professional education and development can occur in person, via webinar, or be self-taught through apps, and may include role-play or simulations. It can be provided and promoted by educational institutions, professional societies, accrediting organizations, state regulatory agencies, academic medical centers, and teaching hospitals.

3

HEALTH SYSTEM IMPLEMENTATION

Health systems should deliver comprehensive quality improvement ACP initiatives that are person- and family-centered. As recommended by the IOM, the initiatives need to be “integrated, person-centered, family-oriented, and consistently accessible care near the end of life be provided by health care delivery organizations and covered by government and private health insurers.”

To be adequately processed by the health system, ACP care should be supported through EHR technology to ensure follow-through, transparency, and accountability. An EHR with dedicated ACP tabs or face page locations are critically important for documentation and finding ACP information with actionable medical orders when needed. Templates and guidelines that help clinicians properly document informed patient wishes are vital to ensuring that appropriate value-reflective individual choices are honored.

Resources for health system implementation:

[CMS Reimbursement](#)

[EHR Systems and Documentation](#)

[Providence Institute for Human Caring](#)

[State Advance Directives](#)

4

COMMUNITY ENGAGEMENT

To catalyze educational efforts, there must be a robust conversation about ACP within the larger community. Part of this effort includes engaging communities to understand the limits of medicine.

This community may include public health and other governmental agencies, community- and faith-based organizations, civic leaders, consumer groups, healthcare organizations, professional societies, payers, and employees. Faith-based organizations and group social settings may represent excellent non-clinical sites in which to engage in ACP conversations. Working collaboratively, these groups can share successful strategies that may work for organizations throughout the community.

Public awareness campaigns need to be supplemented by evidence-based decision tools which help bridge the gap in understanding the role of ACP in medical care and informing patients about their medical options. To meet the needs of populations with lower health literacy or limited language proficiency, these tools should be adapted into various languages or learning formats. Outreach efforts should be adapted to media and other channels that will reach all audiences, including underserved populations.

Resources for community engagement implementation:

[The Conversation Project](#)

[PREPARE](#)

How ACP Decisions Can Help

Limited resources are a reality in today's healthcare environment. While including all four pillars within a comprehensive ACP program is the goal, patient activation using the ACP Decisions Video Library is a great starting point. Patient and clinician-centered tools have the largest evidence base, and more resource-intensive EHR support and community engagement can be initiated over time.

The ACP Decisions Video Library consists of over 200 video support tools in 17 different languages. The offerings address a range of issues and fall under three categories: Video Decision Aids, Free Standing Educational Videos, and Caregiver Videos.

Over ten years of research shows that patients make better-informed decisions after watching a relevant ACP Decisions video because they see procedures and interventions with their own eyes and can thoughtfully review video content at their own pace. Data from a statewide implementation in Hawaii have shown that using the ACP Decisions Video Library leads to an increase of ACP documentation, a decrease in hospital death rates, an increase in hospice referrals, and a decrease in costs in the last month of life.

The Bottom Line

No matter what steps your organization takes, a well-designed comprehensive ACP program will help your patients with the complex issues they face in modern medicine and encourage them to take charge of their end-of-life care. These actions can reduce healthcare costs while preserving patient dignity and quality of care. ■

Would you like to learn more? Contact us!

support@acpdecisions.org

www.acpdecisions.org





Implementing an ACP Program that Reduces Costs Without Compromising Care

About the Authors

Angelo Volandes, MD, MPH



Angelo E. Volandes is a physician, researcher, and Associate Professor at Harvard Medical School and co-Founder of Nous Foundation (d/b/a ACP Decisions). He is an internationally recognized expert on the use of video decision support tools, decision science, and ethics. He leads an internationally recognized group of innovators and video artists who create video support tools to better inform patients about their options for medical care. Dr. Volandes' work has been featured in major publications and national media and he is the author of *The Conversation: A Revolutionary Plan for End-of-life Care*. He received his undergraduate degree from Harvard, a medical degree from Yale, and a Masters of Public Health from Harvard.

Aretha Delight Davis, MD, JD

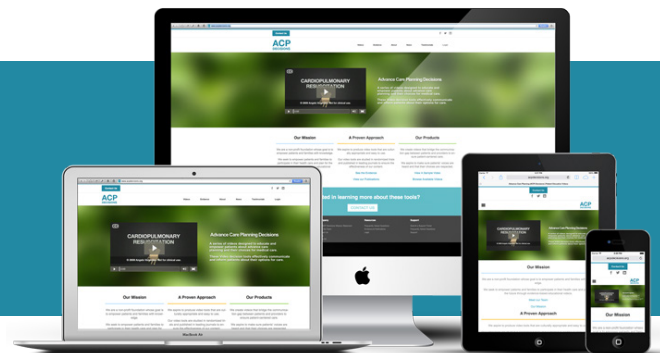


Aretha Delight Davis is a physician, lawyer, and co-Founder of Nous Foundation (d/b/a ACP Decisions) and serves as its Executive Director. She has had a long-standing interest in applying her legal skills for vulnerable populations within the healthcare system to promote more patient-centered care. Prior to her medical career, Dr. Davis was a practicing attorney who advocated on behalf of Medicaid recipients and the uninsured as well as represented individuals and corporations in corporate criminal matters. She received her undergraduate degree from Harvard, a law degree from the University of Pennsylvania, and a medical degree from Harvard.

About ACP Decisions

ACP Decisions is a mission-driven healthcare technology nonprofit that provides shared decision-making principles and evidence-based video support tools for patients and their families, so they can make informed decisions about end-of-life care. Our technology platform and video support tools help health systems, insurers, and hospitals improve the quality of end-of-life care while reducing its associated costs.

To learn more, visit
acpdecisions.org
or contact us at
support@acpdecisions.org



- 1 Detering, Karen, and Maria J Silveira. "Advance Care Planning and Advance Directives." UpToDate, Wolters Kluwer, 30 Oct. 2017, www.uptodate.com/contents/advance-care-planning-and-advance-directives.
- 2 Gurman, Andrew W. "AMA on Medicare's Proposed Plan to Cover Advance Care Planning." AMA, American Medical Association, 9 July 2015, www.ama-assn.org/content/ama-response-medicares-proposed-plan-cover-advance-care-planning.
- 3 DiJulio, Bianca, et al. "Kaiser Health Tracking Poll: September 2015." KFF.org, The Henry J. Kaiser Family Foundation, 30 Sept. 2017, www.kff.org/health-costs/poll-finding/kaiser-health-tracking-poll-september-2015/.
- 4 Yadav, K N, et al. "Approximately One In Three US Adults Completes Any Type Of Advance Directive For End-of-life Care." *Health Affairs*, vol. 36, no. 7, 1 July 2017, pp. 1244–1251., doi:10.1377/hlthaff.2017.0175.
- 5 Silveira, M J, et al. "Advance Directive Completion by Elderly Americans: a Decade of Change." *Journal of the American Geriatrics Society*, vol. 62, no. 4, 2 Apr. 2014, pp. 706–10., doi:10.1111/jgs.12736.
- 6 Wright, A A, et al. "Associations between End-of-life Discussions, Patient Mental Health, Medical Care near Death, and Caregiver Bereavement Adjustment." *JAMA*, vol. 300, no. 14, 3 Oct. 2008, pp. 1665–73., doi:10.1001/jama.300.14.1665.
- 7 Silveira, M J, et al. "Advance Directive Completion by Elderly Americans: a Decade of Change." *Journal of the American Geriatrics Society*, vol. 62, no. 4, 2 Apr. 2014, pp. 706–10., doi:10.1111/jgs.12736.
- 8 Institute of Medicine of the National Academy of Sciences. "Dying in America: Improving Quality and Honoring Individual Preferences Near the End-of-life. <http://www.nationalacademies.org/hmd/~/media/Files/Report%20Files/2014/EOL/Report%20Brief.pdf>
- 9 Sudore, Rebecca L., and Terri R. Fried. "Redefining the 'Planning' in Advance Care Planning: Preparing for End-of-life Decision Making." *Annals of Internal Medicine*, vol. 153, no. 4, 17 Aug. 2010, pp. 256–261., doi: 10.1059/0003-4819-153-4-201008170-00008.
- 10 Fagerlin, A, and C E Schneider. *Enough. The Failure of the Living Will*. 2nd ed., vol. 34, Institute of Society Ethics and the Life Sciences, 2004, pp. 30–42, Hastings Center Report.
- 11 Detering, Karen, and Maria J Silveira. "Advance Care Planning and Advance Directives." UpToDate, Wolters Kluwer, 30 Oct. 2017, www.uptodate.com/contents/advance-care-planning-and-advance-directives.
- 12 Klingler, Corinna, et al. "Does Facilitated Advance Care Planning Reduce the Costs of Care near the End-of-life? Systematic Review and Ethical Considerations." *Palliative Medicine*, vol. 30, no. 5, May 2016, pp. 423–433., doi: 10.1177/0269216315601346.
- 13 Detering, Karen, and Maria J Silveira. "Advance Care Planning and Advance Directives." UpToDate, Wolters Kluwer, 30 Oct. 2017, www.uptodate.com/contents/advance-care-planning-and-advance-directives.
- 14 Institute of Medicine of the National Academy of Sciences. "Dying in America: Improving Quality and Honoring Individual Preferences Near the End-of-life. <http://www.nationalacademies.org/hmd/~/media/Files/Report%20Files/2014/EOL/Report%20Brief.pdf>

References continued on the following page.

- 15 Kim, Oliver, et al. "Advance Care Planning: Tying a Community Perspective to the National Conversation." Center for Healthcare Research & Transformation, 22 Aug. 2016, www.chrt.org/publication/advance-care-planning-tying-community-perspective-national-conversation/.
- 16 D. William Molloy MRCP, et al. "Systematic Implementation of an Advance Directive Program in Nursing Homes." *JAMA*, vol. 283, no. 11, 15 Mar. 2000, pp. 1437–44., doi:doi:10.1001/jama.283.11.1437.
- 17 Klingler, Corinna, et al. "Does Facilitated Advance Care Planning Reduce the Costs of Care near the End-of-life? Systematic Review and Ethical Considerations." *Palliative Medicine*, vol. 30, no. 5, May 2016, pp. 423–433., doi: 10.1177/0269216315601346.
- 18 Dixon, J, et al. "The Economic Evidence for Advance Care Planning: Systematic Review of Evidence." *Palliative Medicine*, vol. 29, no. 10, Dec. 2015, pp. 869–84., doi:doi: 10.1177/0269216315586659.
- 19 Institute of Medicine of the National Academy of Sciences. "Dying in America: Improving Quality and Honoring Individual Preferences Near the End-of-life. <http://www.nationalacademies.org/hmd/~/media/Files/Report%20Files/2014/EOL/Report%20Brief.pdf>
- 20 Hendricks, D, et al. "Church-Based Health Promotion Focused on Advance Care Planning and End-of-life Care at Black Baptist Churches: A Cross-Sectional Survey." *Journal of Palliative Medicine*., Feb. 2016, pp. 190–4., doi:10.1089/jpm.2015.0319.
- 21 El-Jawahri, Areej, et al. "Randomized, Controlled Trial of an Advance Care Planning Video Decision Support Tool for Patients With Advanced Heart FailureClinical Perspective." *Circulation*, vol. 134, no. 1, 5 July 2016, pp. 52–60., doi:10.1161/CIRCULATIONAHA.116.021937.
- 22 El-Jawahri, Areej, et al. "A Randomized Controlled Trial of a CPR and Intubation Video Decision Support Tool for Hospitalized Patients." *Journal of General Internal Medicine*, vol. 30, no. 3, Aug. 2015, pp. 1017–1080., doi:10.1007/s11606-015-3200-2.