



February 2019

# ADVANCE CARE PLANNING

## Selected States' Efforts to Educate and Address Access Challenges

# GAO Highlights

Highlights of [GAO-19-231](#), a report to congressional requesters

## Why GAO Did This Study

Many individuals receive medical care for a serious or life-limiting condition during the last months of life, which may involve making difficult decisions about life-sustaining treatment. Advance care planning helps ensure that physicians, families, and friends have documentation outlining individuals' wishes under these circumstances.

GAO was asked to identify issues related to completing and accessing advance care planning documents. This report describes, among other things, (1) the challenges individuals and providers face completing and accessing the documents, and (2) selected states' strategies for improving individuals' and providers' understanding of and access to advance care planning documents.

GAO reviewed documents and interviewed officials from national stakeholder organizations involved in advance care planning or aging issues, and conducted a literature review of relevant articles published from January 2012 to April 2018 in peer-reviewed and other publications. In addition, GAO interviewed officials from state agencies and stakeholder organizations in California, Idaho, Oregon, and West Virginia. GAO selected those four states because they were active in encouraging advance care planning and had registries for completed documents that were in different stages of development.

The Department of Health and Human Services, states, and stakeholders provided technical comments on a draft of this report, which GAO incorporated as appropriate.

View [GAO-19-231](#). For more information, contact Carolyn L. Yocom at (202) 512-7114 or [YocomC@gao.gov](mailto:YocomC@gao.gov).

February 2019









## ADVANCE CARE PLANNING

### Selected States' Efforts to Educate and Address Access Challenges

## What GAO Found

Advance care planning documents—including advance directives and physician orders for life sustaining treatment (POLST)—allow individuals to express their wishes for end-of-life care. Advance directives, which include living wills and health care power of attorney, provide direction regarding care when an individual becomes incapacitated. POLST documents are appropriate for seriously ill individuals whose health status indicates the need for medical orders to be documented in their medical records.

### Types of Advance Care Planning Documents

	What type of document	Who should have the document	Who completes the document	What the document communicates
<b>Advance directives</b>	Legal document 	All competent adults 	Individual 	General treatment wishes (if incapacitated) 
<b>Physician orders for life sustaining treatment (POLST)</b>	Medical orders 	Any seriously ill or frail individuals (regardless of age) 	Health care provider 	Specific medical orders 

Source: GAO analysis of National POLST Paradigm information. | GAO-19-231

Stakeholders from national organizations and officials in the four states GAO selected to review cited several challenges—affecting both individuals and health care providers—related to the use of advance care planning documents. In particular, they noted a lack of understanding about how to complete the documents and how to initiate conversations about advance care planning. They also cited challenges related to the difficulty of ensuring access to completed documents when needed, such as in an emergency situation.

Officials from state agencies and stakeholder organizations in the four selected states reported pursuing various strategies to improve understanding of advance care planning documents by conducting education efforts for individuals and providers. In addition, the states utilized strategies to improve access to completed documents, such as improving the electronic exchange of information between health records and a state registry, which is a central repository intended to improve access to the documents. Further, stakeholder officials reported strategies related to the acceptance of out-of-state advance care planning documents; all four selected states had statutory provisions that address the validity of documents executed in another state.

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## Abbreviations

CMS	Centers for Medicare & Medicaid Services
CPR	cardiopulmonary resuscitation
EHR	electronic health record
EMS	emergency medical services
HHS	Department of Health and Human Services
MIPS	Merit-based Incentive Payment System
POLST	physician orders for life-sustaining treatment

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February 21, 2019

### Congressional Requesters

Many individuals receive medical care for a serious or life-limiting condition during the last 6 months of life that may involve making difficult decisions about life-sustaining treatment. Advance care planning helps ensure that physicians, families, and friends have documentation outlining individuals' wishes under these circumstances. Advance care planning documents include advance directives and physician orders for life-sustaining treatment (POLST) forms. Advance directives, such as living wills or health care power of attorney, specify—consistent with applicable state law—how individuals want medical decisions to be made for them should they become unable to communicate their wishes. POLST forms—typically used for seriously ill or frail individuals—instruct health care providers which specific medical actions, such as cardiopulmonary resuscitation (CPR), to take or not to take in the event of a medical emergency.<sup>1</sup>

Some blank advance care planning documents can be downloaded from state government or other websites to be voluntarily completed by individuals or by health care providers after consultation with the individual or their representative. Completed documents may be added to an individual's medical records or, depending on the state, stored in a state registry, which is a central repository of advance care planning documents intended to facilitate individuals' and providers' access to these documents when needed. Depending on the state, and how and where advance care planning documents are stored, providers and others may not be aware that the documents exist or have access to them when needed; as a result, providers may not follow individuals' documented wishes for end-of-life care. Also, state laws vary in what is considered a valid advance directive and POLST form, and whether these documents can be used in a state other than the state in which the document was executed. Although advance directives and POLST forms have been available for at least 20 years and 15 years, respectively, there is still interest in the strategies used at the state-level to help promote the

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<sup>1</sup>According to the National POLST Paradigm, POLST originally stood for physician orders for life-sustaining treatment, but states can refer to POLST forms by various names, such as medical orders for life-sustaining treatment or clinician orders for life-sustaining treatment.

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voluntary completion of these documents, and strategies to provide access through medical records or a state registry to help ensure the documents are readily available to individuals and providers. At the federal level, several agencies within the Department of Health and Human Services (HHS) play a role in providing or collecting information on advance care planning, including the Centers for Medicare & Medicaid Services (CMS), which provides incentives to encourage use of electronic health records.

You asked us to identify issues and states' strategies related to completing and accessing advance care planning documents.<sup>2</sup> In this report, we describe

1. state-level advance care planning information available online, and which states have registries for completed documents;
2. challenges individuals and providers face in completing and accessing advance care planning documents; and
3. selected states' strategies for improving individuals' and providers' understanding of and access to completed advance care planning documents.

To describe the state-level advance care planning information available online, and which states have registries of completed documents, we reviewed reports and studies by national organizations, including the American Bar Association Commission on Law and Aging, and the National POLST Paradigm.<sup>3</sup> We also conducted searches of informational websites provided by state governments and non-government

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<sup>2</sup>In this report, we use the term "state" to refer to the 50 states and the District of Columbia.

<sup>3</sup>For example, we reviewed the American Bar Association Commission on Law and Aging, *Links to State-Specific Advance Directive Forms, Updated June 2018*, accessed September 19, 2018, [https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2018-Inks-to-st-sp-cifc-advnc-drctv-frms.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/2018-Inks-to-st-sp-cifc-advnc-drctv-frms.pdf). We also reviewed the National POLST Paradigm's state map; see National POLST Paradigm, *Programs in Your State*, accessed September 6, 2018, <http://polst.org/programs-in-your-state/>. The National POLST Paradigm is an organization that was developed to improve the quality of patient care by creating a system that identifies patients' wishes regarding medical treatment and communicates and respects them by creating portable medical orders. Advance directives also exist for individuals with mental illness; however, we did not focus on these documents for our report.

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organizations operating within each state for available advance care planning information, including documents.<sup>4</sup>

To describe the challenges individuals and providers face in completing and accessing advance care planning documents, we reviewed documents and interviewed officials from six national stakeholder organizations involved with advance care planning or aging issues: Aging with Dignity; the American Bar Association Commission on Law and Aging; the Coalition to Transform Advanced Care; the National Hospice and Palliative Care Organization; the National POLST Paradigm; and the Pew Charitable Trusts, which administered a project on improving end-of-life care. We also conducted a literature review of relevant articles published in peer-reviewed and other publications from January 2012 to April 2018. We identified publications through a search of bibliographic databases, including AgeLine, MEDLINE, and Scopus, using terms such as “advance directive,” “POLST,” and “documentation.” Of the 253 citations we reviewed, we determined there were 92 relevant articles. We reviewed the 92 articles for information related to advance care planning, including prevalence of advance care planning documents, as well as challenges to access and voluntary and informed completion of documents. We also reviewed relevant GAO and other reports. In addition, we reviewed documents and interviewed officials from federal agencies that play a role in providing or collecting information on advance care planning, including CMS, the Office of the National Coordinator for Health Information Technology, and the National Institutes of Health’s

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<sup>4</sup>Government websites included those operated by state government agencies that discuss government efforts, activities, or other information relevant to residents of that state. Non-government websites included those operated by organizations—including nonprofit organizations and associations—that provide information related to advance care planning for that state. For example, in Colorado, the Colorado Advance Directives Consortium, a non-government organization, administers a website that provides information on advance care planning. Although some national organizations—such as the National Hospice and Palliative Care Organization—and advance care planning companies also offered state specific advance care planning documents, we focused our work on state-level websites.

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National Institute on Aging.<sup>5</sup> Finally, we reviewed documents and interviewed officials in four states—California, Idaho, Oregon, and West Virginia. We selected the four states because they were active in encouraging the use of advance care planning and had registries for completed advance care planning documents that varied in type or stage of development, based on our literature review and interviews with national stakeholder organizations. The officials we interviewed or obtained information from included those from state agencies, such as the state agency responsible for emergency medical services (EMS), and other non-governmental stakeholder organizations that were involved in advance care planning activities (state stakeholder organizations).<sup>6</sup> The perspectives of the officials from the national stakeholder organizations and those interviewed in the selected states are not generalizable, but provided us with valuable insight on the challenges individuals and providers face in completing and accessing advance care planning documents.

To describe selected states' strategies for improving the understanding of advance care planning documents and information, and access to completed documents, we reviewed documents and interviewed officials from state agencies and state stakeholder organizations in our four selected states. Specifically, for each state, we interviewed officials representing EMS providers and the state registry (registries for advance directives, POLST forms, or both). We also reviewed selected states' statutes related to advance care planning documents, reviewed articles

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<sup>5</sup>CMS administers the Medicare program, which has requirements related to advance care planning for Medicare providers, and also established incentive programs for electronic health records (EHR) for Medicare providers. The Office of the National Coordinator for Health Information Technology is the principal federal entity charged with coordination of nationwide efforts to implement and use health information technology and the electronic exchange of health information. We also contacted officials in two other HHS agencies—the Centers for Disease Control and Prevention and the Administration for Community Living—for background information on advance care planning and on the prevalence of advance care planning documents. The Administration for Community Living, in consultation with its stakeholders, developed principles that it uses to inform policy discussions and enhance its programs and services related to serious illness among older adults and individuals with disabilities, including those who are considering advance directives.

<sup>6</sup>We contacted the following state stakeholder organizations: Coalition for Compassionate Care of California, the Idaho Health Continuum of Care Alliance (formed through a merger between the Idaho Association for Home Care & Hospice and the Idaho Quality of Life Coalition), Oregon Health Decisions, Oregon POLST Coalition, Oregon Health and Sciences University (which operates the technical aspects of the state's POLST registry), and the West Virginia Center for End-of-Life Care.



from our literature review, and reviewed documents and interviewed officials from national stakeholder organizations, CMS, and the Office of the National Coordinator for Health Information Technology.









We conducted this performance audit from October 2017 to February 2019, in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

## Background

### Advance Directives and POLST Forms

Decisions about end-of-life care are based on an individual's personal beliefs and values. Advance care planning documents, including advance directives and POLST forms, allow individuals to express their wishes for end-of-life care. These documents serve different purposes depending on an individual's stage of life or health condition. (See fig. 1.)

**Figure 1: Types of Advance Care Planning Documents**

	What type of document	Who should have the document	Who completes the document	What the document communicates
<b>Advance directives<sup>a</sup></b>	Legal document 	All competent adults 	Individual 	General treatment wishes (if incapacitated) 
<b>Physician orders for life sustaining treatment (POLST)<sup>b</sup></b>	Medical orders 	Any seriously ill or frail individuals (regardless of age) 	Health care provider <sup>c</sup> 	Specific medical orders 

Source: GAO analysis of National POLST Paradigm information. | GAO-19-231

<sup>a</sup>Advance directives—which include living wills and health care power of attorney—are recognized under state law, and provide information regarding provision of care when an individual is

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incapacitated. Advance directives may be completed in consultation with an attorney and as part of conversations with loved ones about an individual's wishes.

<sup>b</sup>The National POLST Paradigm recognizes 13 different names for POLST, including medical orders for life sustaining treatment and clinician orders for life-sustaining treatment. According to the National POLST Paradigm, the POLST decision-making process and resulting medical orders are intended for patients who are considered to be at risk for a life-threatening clinical event, because they have a serious life-limiting medical condition, which may include advanced frailty.

<sup>c</sup>Health care providers authorized to sign the POLST form may include physicians, nurse practitioners, or physician assistants, depending on the state. Health care providers complete the POLST form in consultation with the seriously ill or frail individual or their health care agent.

According to a report by the Institutes of Medicine, advance care planning documents are most effective when used as part of broader advance care planning efforts, which may involve multiple, in-depth discussions with family members and health care providers.<sup>7</sup> The report also stated that multiple discussions at various stages of life are needed, with greater specificity as an individual's health deteriorates, because an individual's medical conditions and treatment preferences may change over time. Therefore, a comprehensive approach to end-of-life care, rather than any one document, helps to ensure that medical treatment given at the end of life is consistent with an individual's preferences.

## Advance Directive

An advance directive is a written instruction recognized under state law and relating to the provision of health care when an individual is incapacitated. For example, an advance directive may be used to record an individual's wish to receive all available medical treatment, to withdraw or withhold certain life-sustaining treatments, or to identify an agent to make medical decisions on the individual's behalf if necessary. The most common advance directive documents are living wills and health care power of attorney.

### Life-Sustaining Treatment

Life-sustaining treatment means the use of available medical machinery and techniques, such as heart-lung machines, ventilators, and other medical equipment and techniques, that may sustain and possibly extend life, but which may not by themselves cure the condition.

Source: American Bar Association. | GAO-19-231

- **Living will.** A living will is a written expression of how an individual wants to be treated in certain medical circumstances. Depending on state law, a living will may permit an individual to express whether they wish to be given life-sustaining treatment in the event they are terminally ill or injured, to decide in advance whether they wish to be provided food and water via intravenous devices (known as tube feeding), and to give other medical directions that affect their health care, including at the end of life. A living will applies to situations in which the decision to use life-sustaining treatments may prolong an individual's life for a limited period of time and not obtaining such

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<sup>7</sup>Institute of Medicine of the National Academies, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (Washington, D.C.: 2015).

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treatment would result in death. Having a living will does not mean that medical providers would deny medications and other treatments that would relieve pain or otherwise help an individual be more comfortable.

- **Health care power of attorney.** A health care power of attorney is a document that identifies a health care agent—also called a health care proxy—as the decision maker for the patient. Under state law, the health care power of attorney typically becomes operative when an individual is medically determined as unable to make decisions. Most commonly, this situation occurs either because the individual is unconscious or because the individual’s mental state is such that they do not have the legal capacity to make decisions. As with living wills, the process for validly executing a health care power of attorney depends on the state of residence. The health care power of attorney may be designated by using a model form in state statute or it may be drafted specifically for an individual by a lawyer. Similar to the living will, medical providers will make the initial determination as to whether an individual has the capacity to make their own medical treatment decisions.

Most adults in the United States do not have an advance directive. According to a 2017 study, about 37 percent of adults had an advance directive.<sup>8</sup> However, the proportion of individuals with an advance directive can vary by demographic group. See appendix I for more information related to the prevalence of advance directives.

## POLST Form

POLST forms differ from advance directives in that they are medical orders used to communicate an individual’s treatment wishes, and are appropriate for individuals with a serious illness or advanced frailty near the end-of-life.<sup>9</sup> For these individuals, their current health status indicates the need for medical orders. In the event of a medical emergency, the POLST form serves as an immediately available and recognizable medical order in a standardized format to aid emergency personnel.<sup>10</sup> Following the POLST form orders, emergency personnel can honor the

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<sup>8</sup>Yadav, Kuldeep 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 (2017).

<sup>9</sup>In addition, do-not-resuscitate or allow-natural-death documents function similarly to POLST forms, but do not include all of the information included in POLST forms.

<sup>10</sup>POLST forms are typically printed on bright, colored paper so they are recognizable to providers, such as emergency personnel who might be the first to respond in a medical emergency.

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individual's treatment wishes as communicated to and documented by the individual's health care provider.<sup>11</sup> See appendix II for information on the types of information included on a POLST form.

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### Information on Completing and Storing Advance Care Planning Documents

Both government and non-government organizations, such as state agencies or the National POLST Paradigm, provide individuals and providers information on how to access or download blank advance care planning documents through their websites and education campaigns. For Medicare and Medicaid providers, the Patient Self Determination Act requires certain providers participating in these programs—such as hospitals and nursing homes—to maintain written policies and procedures to inform individuals about advance directives, and document information about individuals' advance directives in their medical records.<sup>12</sup> Once the advance care planning documents are completed, individuals and providers can access them through various systems. For example, an individual may have their advance directive or POLST form in their electronic health record (EHR), which can be accessed by their provider or other medical personnel in the event that the individual has a medical emergency. In addition, advance directives can be stored in a lawyer's office or in an individual's home; these documents would have to be found and transported to the medical setting if needed. Some states have registries (either electronic or paper-based) for advance directives or POLST forms, whereby individuals and providers can access the registry and obtain the necessary documents.

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<sup>11</sup>The National POLST Paradigm has established National POLST Paradigm standards and endorsed state POLST programs that meet those standards; however, there is no national POLST form. Policies related to POLST forms are dictated by states, and each state may require different information, access, portability, and storage of POLST forms, according to HHS.

<sup>12</sup>For more information on Patient Self Determination Act requirements and implementation, see GAO, *Advance Directives: Information on Federal Oversight, Provider Implementation, and Prevalence*, [GAO-15-416](#) (Washington, D.C.: April 29, 2015).

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## Websites Related to Advance Care Planning Were Available for All States; About One Quarter of States Had Registries for Completed Documents

We found websites related to advance care planning for every state; however, the amount of information on these websites varied. In addition, about a quarter of states had registries to provide access to completed advance directives, POLST forms, or both.

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## For All States, Advance Care Planning Information, Such as Blank Documents, Was Available Online

For all states, either government or non-government websites provided information, which could include blank documents, on advance care planning for individuals and providers within the state. However, the amount of available information about advance care planning varied by state. The information available online varied from having an advance care planning document available to download, to extensive information on advance care planning.<sup>13</sup> For example, in Mississippi, the State Board of Medical Licensure provided a POLST document that could be downloaded from its webpage with no additional information. In contrast, California—through its state attorney general’s website—offered a blank advance directive document that could be downloaded, as well as additional information on advance directives, including

- who should fill out particular types of advance care planning documents, and the importance of filling out these documents; and
- other resources, including brochures or information packets detailing advance care planning and other relevant documents.

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<sup>13</sup>Informational websites in the 51 states might or might not include blank advance care planning documents as part of the information the websites provide to individuals. For example, Arizona’s POLST webpage included information explaining their POLST form, but did not include a blank copy of their POLST form.

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About One-Quarter of States Had Registries for Completed Advance Directives, POLST Forms, or Both

To give providers, individuals, or both access to completed advance care planning documents, about one-quarter of states (14) had active registries (either electronic or paper-based) of completed advance directives, POLST forms, or both, as of November 2018. (See fig. 2.) Specifically,

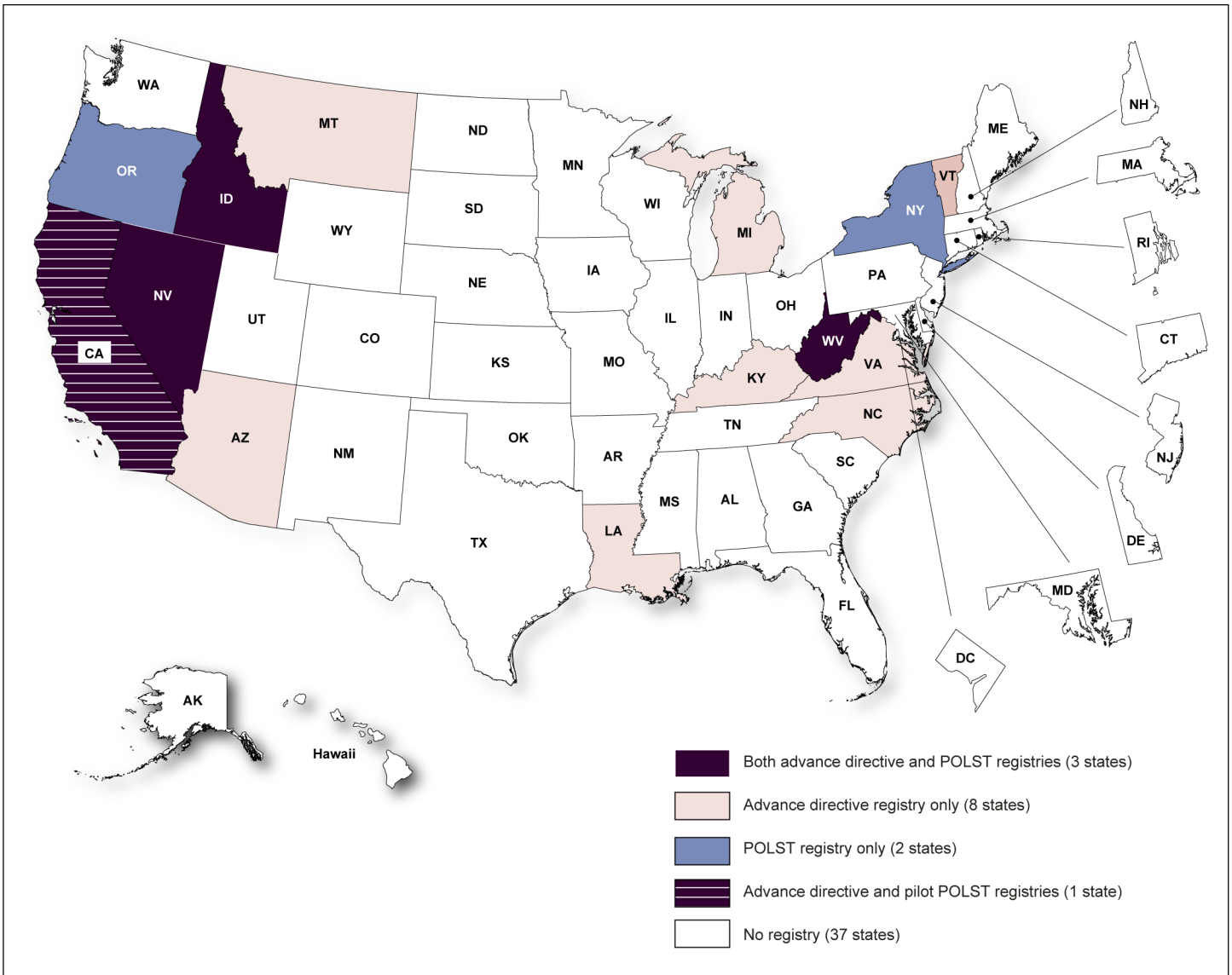
- 3 states had active registries for both completed advance directives and POLST forms,
- 8 states had active registries solely for completed advance directives;
- 2 states had active registries solely for completed POLST forms,
- 1 state had an active registry for completed advance directives and was piloting registries for completed POLST forms,<sup>14</sup> and
- 37 states did not have active registries for either advance directives or POLST forms.<sup>15</sup>

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<sup>14</sup>In October 2015, the California legislature authorized a pilot program for an electronic registry (POLST eRegistry). The law requires use of non-state funds to develop the POLST eRegistry pilot and to evaluate its effectiveness. The pilot program is testing the development and implementation of POLST eRegistries in two community settings, the city of San Diego and Contra Costa County; these two pilots began operating in 2016. These pilot registries were intended to enable the submission, storage, and retrieval of POLST forms across participating care settings with the goal of demonstrating feasibility, functionality, quality, and acceptability of the registries to inform and support the development of statewide electronic access to POLST forms.

<sup>15</sup>As of November 2018, some of the 37 states were in the process of developing state registries to store completed advance directives, POLST forms, or both.

**Figure 2: State Advance Care Planning Registries, November 2018**



Sources: GAO (data); Map Resources (map). | GAO-19-231

**Notes:**

Washington previously supported a registry for living wills, but, as of November 2018, did not have an active state registry.

According to an official from the West Virginia Center for End-of-Life Care, as of November 2018, West Virginia's registry did not receive new advance care planning documents through online submissions. However, providers could access completed documents in the registry by calling the registry's phone number during business hours or by fax.

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As of November 2018, some states were in the process of developing state registries to store completed advance care planning documents.

The 14 states with active registries varied in how they administered them. Some states' registries were administered through state agencies or by contracting with an outside organization. For example, in Oregon, the state contracted with a large health system in the state to operate the technical aspects of the state's POLST registry, while in Vermont, the Department of Health administered the state's registry with technical support from a private national document registry company. For other states—such as New York, Virginia, and West Virginia—the state registries were administered through non-government organizations in collaboration with state agencies.

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## Challenges to Advance Care Planning Include Understanding the Types of Documents and Ensuring Access to Completed Documents

Based on our interviews with officials from national stakeholder organizations, state agencies and stakeholder organizations in selected states, and articles we reviewed, we identified two broad challenges to advance care planning: (1) a lack of understanding about advance care planning, including how to initiate conversations about advance care planning and how to complete and follow advance care planning documents; and (2) ensuring access to completed documents. In addition to these two broad challenges, the officials we interviewed identified challenges related to resources and the portability of advance care planning documents.

Individuals and providers may struggle with how and when to initiate advance care planning conversations. We previously reported that providers identified informing individuals about advance care planning as a challenge due to reluctance to talk about end-of-life issues.<sup>16</sup> In addition, officials from both national and state stakeholder organizations identified challenges to providers properly counseling their patients about advance care planning, either to avoid discussing death and dying with their patients, or because of their own uncertainties regarding the timing of when to hold such discussions.<sup>17</sup> In addition to challenges related to having advance care planning conversations, individuals and providers may not understand that filling out the document is voluntary or how to

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<sup>16</sup>See [GAO-15-416](#).

<sup>17</sup>Providers misunderstanding the distinctions between advance directives and POLST forms was also noted by national stakeholders and articles as contributing to improper counseling of patients on how to complete the documents.



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complete and follow the advance care planning document, according to officials from national stakeholder organizations and officials in the four selected states.<sup>18</sup> Officials from national stakeholder organizations and articles we reviewed noted that challenges with voluntarily completing advance care planning documents can arise when there are language or cultural barriers to understanding these documents.<sup>19</sup> When individuals or providers do not understand the information being requested in advance care planning documents, it can affect whether an individual's wishes for care are accurately represented. A state agency official in one state identified challenges in ensuring EMS providers understand the appropriate actions to take when they encounter a document that is different from a traditional POLST form. For example, the state official noted that EMS providers might assume that individuals who have a wallet card on their person do not want CPR when the card actually indicates that the individual has completed an advance directive or POLST form to express their care wishes.<sup>20</sup> This could result in treatment that does not match the individual's expressed wishes.

Once advance care planning documents are completed, additional challenges exist to ensuring that providers have access to these documents when needed, such as in an emergency situation. Officials from the national stakeholder organizations, state agencies, and state stakeholder organizations we interviewed identified challenges related to accessing advance directives and POLST forms stored in EHRs. Specifically, stakeholders identified challenges related to EHR interoperability, such as where a provider in one health system cannot access advance care planning documents recorded in an EHR at a

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<sup>18</sup>According to the executive director of the National POLST Paradigm, a POLST form should be voluntarily completed by health care providers. The official noted that one state, Maryland, requires a POLST form to be completed in certain situations—such as admissions into home health agencies, assisted living programs, nursing homes, and hospice facilities. As a result, Maryland's POLST program does not conform with all National POLST Paradigm requirements.

<sup>19</sup>We reported on challenges related to advance directive completion specific to Latinos or African Americans, such as language barriers, lack of trust in health care providers, or fears that advance directives may prevent them from getting the care they wanted to receive. See [GAO-15-416](#), 18.

<sup>20</sup>Some states provide wallet cards to individuals with advance care planning documents so EMS providers and family members know the individual has completed such a document. The National Institute on Aging notes that individuals might want to carry a wallet card indicating that they have an advance care planning document and where they keep the document.

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different health care system.<sup>21</sup> While interoperability is not limited to advance care planning documents, the challenges associated with accessing advance care planning documents in EHRs can affect providers' abilities to honor an individual's wishes in an emergency if they do not have ready access to the documents.<sup>22</sup> For example, when emergency providers cannot readily access advance care planning documents in another health system's EHR, the providers might not be aware of and provide treatment inconsistent with the wishes of someone they are treating in the emergency room. National stakeholder officials also noted challenges due to a lack of standardization in EHR systems. For example, one national stakeholder official noted that EHR systems in health care facilities do not always have standardized processes for storing advance care planning documents—that is, one health care facility might enter advance directive information into a physician's notes section of the EHR, while another might have a specific tab in the EHR for advance directives. Due to the lack of standardization, providers might not be able to find an individual's advance care planning document, and consequently provide treatment inconsistent with the individual's expressed wishes.

In addition to challenges related to understanding and accessing advance care planning documents, officials from the national stakeholder organizations, state agencies, and state stakeholder organizations we interviewed identified other challenges related to resources and portability of advance care planning documents.

- State agency officials told us that the lack of dedicated resources for advance care planning efforts, such as maintaining a registry, can be challenging. For example, an Idaho official stated that, due to resource constraints within the Secretary of State's Office—which administers its Health Care Directive registry—the office does not

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<sup>21</sup>EHR interoperability refers to the ability of EHR systems to exchange electronic health information through their own system or with other health systems, and process the information without special effort on the part of the user, such as a health care provider.

<sup>22</sup>We previously reported on nonfederal efforts related to interoperability and challenges associated with these efforts. See GAO, *Electronic Health Records: Nonfederal Efforts to Help Achieve Health Information Interoperability*, [GAO-15-817](#) (Washington, D.C.: Sept. 16, 2015).

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have the personnel to maintain the registry at current document submission rates.<sup>23</sup>

- National stakeholder officials discussed challenges with states' legal structures for accepting advance care planning documents—that is, the portability of documents across state lines. For example, an individual might fill out an advance directive or POLST form in one state, but become ill in another state where these documents may not be valid.

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## Various Strategies Used in Selected States to Improve Individuals' and Providers' Understanding of and Access to Advance Care Planning Documents

In our four selected states—California, Idaho, Oregon, and West Virginia—state agencies and state stakeholder organizations pursued various strategies to improve individuals' and providers' understanding of advance care planning documents, as well as to improve their access to completed advance care planning documents.

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## Selected States Used Education and Training to Increase Understanding of the Need for and Use of Advance Care Planning Documents

Officials from state agencies and stakeholder organizations in our selected states described efforts to educate individuals about the importance of advance care planning and train providers on the use of advance care planning documents.

### Educating Individuals

To address individuals' lack of understanding of advance care planning, state agency officials and stakeholders in our selected states used strategies to inform them about the purpose of the documents and how to fill them out. The following are some examples of these efforts.

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<sup>23</sup>In addition to adding the documents to the registry, the Idaho official stated it takes time to consistently review documents currently in the system for duplication and remove documents for individuals who are deceased.

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- **Oregon.** The Oregon POLST Coalition used its relationship with stakeholder groups in the state—a large health system, and the state health authority—to educate individuals about POLST forms. These efforts included online videos and brochures intended to improve individuals’ voluntary and informed completion of the documents.
  - **West Virginia.** The West Virginia Center for End-of-Life Care—which administers the state’s advance care planning registry—collaborated with the West Virginia Network of Ethics Committees and a national organization to conduct public education presentations and webinars.<sup>24</sup>

For three of our selected states, educational efforts also included making information about advance care planning available in other languages. For example, in California, Idaho, and Oregon, POLST forms and other information on advance care planning are available in Spanish.<sup>25</sup> Articles we reviewed stated that providing culturally sensitive documents that communicate how to fill out the documents could help improve voluntary and informed completion of advance care planning documents.<sup>26</sup>

## Training Providers

Officials from state agencies and state stakeholder organizations in all four selected states reported conducting provider training, which included working with EMS and hospital providers to train them on advance care planning documents, such as how to use advance directives and POLST forms and when to conduct end-of-life care conversations. The following are examples of these efforts.

- **California.** A state stakeholder organization in California conducted train-the-trainer sessions to educate providers about POLST forms, so the providers could subsequently conduct community training events. The organization also published decision aids for providers and individuals to help facilitate advance care planning conversations. The

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<sup>24</sup>One national stakeholder also noted that some states have pursued advance directive education through other methods such as providing information about advance directives to individuals renewing their driver’s licenses.

<sup>25</sup>In California, the POLST form is available in multiple languages other than Spanish, and in Oregon, the advance directive document is also available in languages other than Spanish.

<sup>26</sup>For example, see Sudore, Rebecca L., et al., “Effect of the PREPARE Website vs an Easy-to-Read Advance Directive on Advance Care Planning Documentation and Engagement among Veterans, a Randomized Clinical Trial,” *Journal of the American Medical Association: Internal Medicine*, vol. 177, no. 8 (2017): 1102-1109.

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organization, which focused on POLST education and training, noted that it holds periodic conference calls with previous session participants to provide ongoing support and continue discussions about advance care planning.

- **Idaho.** The state—through collaborations with stakeholder organizations in Idaho—focused on improving advance care planning through education efforts. Specifically, the state collaborated with stakeholder organizations to conduct trainings on locating and understanding advance care planning documents. In addition, the organizations created EMS protocols related to accessing individuals' wishes during emergencies. An Idaho official noted that successful advance care planning education and outreach within the state has led to a large increase in the number of advance care planning documents submitted to the state's registry.<sup>27</sup>
- **Oregon.** State stakeholder organizations conducted provider training on advance directives and POLST forms. For example, an organization that focused on improving advance care planning education in the state developed an initiative, which included educational materials and training programs, to improve patient understanding of filling out and updating advance directives through health care organizations and provider training. Further, according to an official from the state health authority, POLST information is included in the curriculum for all medical education in the state ranging from emergency medical technicians to physicians.
- **West Virginia.** The West Virginia Center for End-of-Life Care created training manuals, led EMS training webinars, and provided other online education materials to improve provider education about using POLST forms and related protocols in the field.

National stakeholder organizations we interviewed and articles we reviewed also noted that increasing the quality of the advance care planning conversations between providers and their patients is an important aspect of successful advance care planning efforts. One strategy to improve the advance care planning conversations is to

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<sup>27</sup>According to the official, the total number of documents in the registry more than doubled from about 17,000 in 2013 to about 36,000 documents as of October 2018.

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conduct the conversations over multiple visits, according to national stakeholders and articles.<sup>28</sup>

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### Selected States’ Strategies to Improve Access to Completed Documents Included Interoperability between Electronic Health Records and Registries

Officials from state agencies and stakeholder organizations in our selected states utilized strategies to improve access to current advance care planning documents, including better interoperability between EHRs and a state registry, and access to completed documents stored in registries.

### Access in Electronic Health Records

Officials from state agencies and stakeholder organizations identified strategies to improve providers’ access to advance care planning documents stored in an EHR and to ensure the EHR has the most current copy of the document. One strategy used in Oregon enabled information sharing between EHR systems and the state’s electronic registry of completed POLST forms, allowing providers access to the most current POLST forms, according to state officials. Certain EHR systems—including those in three large health systems in the state—are interoperable with the state’s electronic POLST registry using bidirectional technology, meaning that the systems are coded in a way that they can seamlessly exchange information with each other.<sup>29</sup> This allows providers to receive updated POLST forms from the registry upon the individual’s admission to the hospital. It also updates the POLST forms in the registry when changes are made in the EHR by the provider in the hospital. The Oregon officials described another strategy taken within a large health system in the state, which allows providers to quickly know whether a patient has an advance directive in an EHR by using a tab in the medical record indicating that the documents are in the EHR. Stakeholder organizations identified other strategies for increasing access to

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<sup>28</sup>See, for example, Barocas, Joshua A., et al., “Advance Directives among People Living with HIV: Room for Improvement,” *AIDS Care*, vol. 27, no. 3 (2015), 370-377. In 2016, Medicare began covering advance care planning conversations as a separate service provided by physicians and other health professionals, such as nurse practitioners.

<sup>29</sup>According to Oregon registry officials, although this bidirectional system is available to all health systems in the state, some health systems may not have the EHR capabilities to integrate with the registry. For all health systems, they also noted that the registry is always available by phone and fax.

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completed advance care planning documents, such as standardizing information.<sup>30</sup> For example, one national stakeholder organization noted that advance care planning documents could be in a standardized location within an EHR to help providers find these documents more easily.

Another strategy used in our selected states is the use of a health information exchange to facilitate access to advance care planning documents.<sup>31</sup> According to a West Virginia stakeholder organization, using the state's health information exchange allowed West Virginia to easily provide authorized individuals with direct access to completed advance care planning documents—both advance directives and POLST forms—in its registry.<sup>32</sup>

## Access to Registry Information

Officials from state agencies and stakeholder organizations also developed strategies to improve access to completed advance care planning documents in their state registries. All four selected states used registries to facilitate access to completed advance care planning documents: two states (Idaho and West Virginia) had registries for both advance directives and POLST forms, one state (California) had an advance directive registry and was piloting an electronic POLST registry in two communities, and the remaining state (Oregon) had a POLST registry.<sup>33</sup> Officials in these states reported strategies to facilitate access through their registries. Below are examples of these strategies.

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<sup>30</sup>CMS provided incentive payments to eligible providers who reported certain measures through its Medicare EHR Incentive Programs (meaningful use program), which started in 2011. At certain points in the program, measures related to advance care planning were optional measures. Beginning in 2019, CMS will provide incentive payments through the Merit-based Incentive Payment System (MIPS). See appendix III.

<sup>31</sup>A health information exchange is an entity that oversees or facilitates the secure and timely exchange of health information among a diverse group of stakeholders within and across regions, according to nationally recognized standards.

<sup>32</sup>For more information on health information exchanges, see Office of the National Coordinator for Health Information Technology, *Electronic End-of-Life and Physician Orders for Life-Sustaining Treatment (POLST) Documentation Access through Health Information Exchange (HIE)* (July 2018).

<sup>33</sup>California's registry for advance directives was paper-based. According to an official from the Office of the Secretary of State, from January 1995 to October 2018, the paper-based advance directive registry had 7,187 registrations on file with the California Secretary of State.

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- **California.** To test whether partnering with a health information exchange organization would provide benefits to the state’s POLST eRegistry uptake and expansion, one of the two California communities chosen to pilot the POLST eRegistry was led by a health information exchange. The other community selected for the pilot was led by a for-profit commercial service. According to a California EMS official, using the health information exchange allowed advance care planning documents to be exchanged quickly between ambulances and hospitals.<sup>34</sup>
  - **West Virginia.** West Virginia’s registry used the state-wide EMS structure, enabling EMS providers to access the information in an individual’s POLST form while en route to an emergency call. The medical director at the EMS state office noted that EMS providers could call one of its five medical command centers, which could access the registry online to “pre-screen” individuals, to determine if there was a valid advance care planning document on file. EMS providers then received the individual’s information from the medical command center.<sup>35</sup> According to an official involved with the state registry, authorized individuals—i.e., individuals with a registry-issued username and password—could also directly view registry documents.<sup>36</sup>
  - **Oregon.** State officials reported using an opt-out strategy for the submission of POLST forms to the state’s registry to help ensure that the information in the registry was current. That is, the state has a legislative mandate for providers to submit all POLST forms to the state’s POLST registry unless the patient elected to opt out of the submission.<sup>37</sup> According to Oregon stakeholders, Oregon attributes the widespread use and adoption of the registry to this strategy. One article noted that, in Oregon, successful access to POLST forms through the registry by EMS providers influenced the treatment of

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<sup>34</sup>According to a state EMS official, usage of a health information exchange in the pilot county allowed it to advance in the registry pilot program faster than the other pilot county in the program.

<sup>35</sup>This feature was not available for parts of 2018 while the registry was offline and transitioning to a new health information exchange.

<sup>36</sup>West Virginia also offers wallet cards detailing individuals’ advance care planning information, including name, address, date of birth, and registry contact information.

<sup>37</sup>In contrast, West Virginia utilized a voluntary opt-in registry strategy, which requires individuals to provide the registry with their permission to list their advance care planning documents in the registry and to release the documents to treating health care providers.



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individuals.<sup>38</sup> Oregon officials and stakeholders told us that they have not experienced many challenges related to administering its POLST registry and providing access to completed POLST forms, because they leveraged their existing centralized EMS system and created a state administered registry that is interoperable and available to all health systems within the state. Oregon officials stated that the state's registry success is largely attributable to the fact that it was designed to meet the access and workflow needs of both EMS providers in the field and acute care providers.

At the federal level, to support state registry efforts, in February 2016, CMS published a State Medicaid Director letter alerting states to the availability of federal Medicaid funding for the development of and connection to public health systems, such as registries.<sup>39</sup> A July 2018 report by the Office of the National Coordinator for Health Information Technology noted that end-of-life care advocacy groups should consider working with State Medicaid Directors to apply for CMS funding to pilot POLST registries.<sup>40</sup> According to CMS, as of October 2018, one state, Louisiana, received approval to fund an electronic registry for advance directives.<sup>41</sup>

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<sup>38</sup>Schmidt, Terri A., et al., "The Oregon Physician Orders for Life-Sustaining Treatment Registry: A Preliminary Study of Emergency Medical Services Utilization," *The Journal of Emergency Medicine*, vol. 44, no. 4 (2013): 796-805.

<sup>39</sup>State Medicaid Letter 16-003 expands the scope of expenditures eligible for the 90 percent matching rate and supports the goals of "Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap," version 1.0. (Feb. 29, 2016).

<sup>40</sup>Office of the National Coordinator for Health Information Technology, *Electronic End-of-Life and Physician Orders for Life-Sustaining Treatment (POLST) Documentation Access through Health Information Exchange (HIE)*, (July 2018).

<sup>41</sup>According to CMS, Colorado was approved for funding for a consent registry to support information sharing of consents and disclosures across providers, which will potentially integrate with other patient-directed registries, including advance directives.

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Additional Strategies Used in Selected States Address Resource Needs for Advance Care Planning Registries and the Portability of Documents.

Officials from state agencies and stakeholder organizations in our selected states discussed the importance of having adequate funding and staff resources to administer their registries. For example, according to an Oregon stakeholder organization, dedicated state funding for the state's registry allows multiple benefits, such as continuous availability of the registry for individuals and providers. Oregon POLST officials stated that in order to ensure access to individuals' POLST forms between health systems within a state, they believe POLST registries should be state funded and administered. According to the Office of the National Coordinator for Health Information Technology report and a West Virginia registry official, the state's registry, which received state-funding from 2009 until 2017, functioned as a central source of information on individuals' wishes, which were recorded in documents such as advance directives and POLST forms and alleviated multiple access issues.<sup>42</sup> However, officials involved in receiving and providing registry services reported challenges when the registry did not receive state funding in 2018. As a result, online access to advance directives and POLST forms through the registry was discontinued.<sup>43</sup> In California, officials involved with the POLST eRegistry pilot stated that one goal of the pilot project was to identify potential plans for sustainable funding of a registry.

Regarding acceptance of out-of-state advance care planning documents—that is, the portability of documents across state lines—we found that all four selected states have statutes that address the validity of advance care planning documents executed in another state. To ensure individuals' wishes are honored, according to an American Bar Association official, states need to engage in efforts to develop processes

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<sup>42</sup>Office of the National Coordinator for Health Information Technology, *Electronic End-of-Life and Physician Orders for Life-Sustaining Treatment (POLST) Documentation Access through Health Information Exchange (HIE)*, (July 2018).

<sup>43</sup>According to a registry official, individuals and providers continued to submit over 1,000 documents per month to the registry by mail, e-mail, or fax to the West Virginia registry. In addition, as of November 2018, the registry received funding from West Virginia University. This funding allowed the registry to continue most functions, including providing information to providers and individuals through a call-in number; phone and fax access to registry documents; and document submissions through mail, e-mail, and fax. However, the registry did not allow new documents to be uploaded electronically. According to the West Virginia registry official, the registry will resume online document submission and online access to registry documents once the registry has completed its transition to the new health information exchange system—the Chesapeake Regional Information System for our Patients. As of November 2018, the registry had not completed the transition, but the transition was anticipated to occur in early 2019.

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and protocols that will allow advance care planning documents to be accepted between states. While the states' language varies, all selected states allow use of out-of-state documents. Under Idaho's statute, out-of-state documents that substantially comply with Idaho's requirements are deemed to be compliant with Idaho's statute. California's, Oregon's, and West Virginia's statutes note that out-of-state documents executed in compliance with that state's laws are valid within their states. For more information on the states' statutes related to advance care planning, see appendix IV.

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## Agency and Third Party Comments

We provided a draft of this report to the Department of Health and Human Services. HHS provided technical comments, which we incorporated as appropriate. We also provided relevant information from the draft report to state officials and stakeholders in each of the four selected states in our review (California, Idaho, Oregon, and West Virginia), and to one national stakeholder organization (the National POLST Paradigm), and incorporated their technical comments, as appropriate.

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We are sending copies of this report to the appropriate congressional committees, the Secretary of Health and Human Services, the Administrator of the Centers for Medicare & Medicaid Services, the National Coordinator for Health Information Technology, the National Institute on Aging, and other interested parties. In addition, the report will be available at no charge on the GAO website at <http://www.gao.gov>.

If you or your staff have any questions about this report, please contact me at (202) 512-7114 or [yocomc@gao.gov](mailto:yocomc@gao.gov). Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this report. GAO staff who made key contributions to this report are listed in appendix V.



Carolyn L. Yocom  
Director, Health Care

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*List of Requesters*

The Honorable Susan M. Collins  
Chairman, Special Committee on Aging  
United States Senate

The Honorable Tammy Baldwin  
United States Senate

The Honorable Shelley Moore Capito  
United States Senate

The Honorable Johnny Isakson  
United States Senate

The Honorable Amy Klobuchar  
United States Senate

The Honorable Mark R. Warner  
United States Senate

# Appendix I: Information on the Extent to Which Individuals Have Advance Directives

Officials from the National Institutes of Health’s National Institute on Aging, the Centers for Disease Control and Prevention’s National Center for Health Statistics, and representatives of national stakeholder organizations identified specific surveys and a comprehensive national study of the prevalence of individuals who have completed advance directives. Table 1 provides information from selected research on the prevalence of advance directives. Table 2, below, shows the percentage of individuals age 65 and older responding to the Health and Retirement Survey who reported having a living will or power of attorney in 2012, 2014, and 2016.<sup>1</sup>

**Table 1: Selected Research on Prevalence of Advance Directives**

Title	Source	Description	Information on prevalence
Approximately One In Three US Adults Completes Any Type Of Advance Directive For End-Of-Life Care	Kuldeep N. Yadav, Nicole B. Gabler, Elizabeth Cooney, Saida Kent, Jennifer Kim, Nicole Herbst, Adjoa Mante, Scott D. Halpern and Katherine R. Courtright, <i>Health Affairs</i> 36, no.7 (2017):1244-1251	Systematic review of 150 studies with 795,909 people in the studies published in the period 2011–2016 to determine the proportion of U.S. adults with a completed living will, health care power of attorney, or both.	About 37 percent of adults had an advance directive. <sup>a</sup>
QuickStats: Percentage of Residential Care Community Residents with an Advance Directive, by Census Division—National Study of Long-Term Care Providers, 2016	National Center for Health Statistics, <i>National Study of Long-Term Care Providers</i> , 2016	The biennial National Study of Long-Term Care Providers monitors trends in the supply, provision, and use of the major sectors of paid, regulated long-term care services. Survey data are collected on the residential care community and adult day services sectors, and administrative data on the home health, nursing home, and hospice sectors.	In 2016, about 78 percent of residents in residential care communities had an advance directive documented in their files. <sup>b</sup>

<sup>1</sup>The Health and Retirement Survey is a longitudinal panel survey of a representative sample of more than 26,000 Americans over the age of 50, sponsored by the National Institute on Aging and the Social Security Administration, and conducted by the University of Michigan every 2 years. We previously reported on the prevalence of people with different characteristics who had advance directives. See [GAO-15-416](#).

**Appendix I: Information on the Extent to Which  
Individuals Have Advance Directives**

<b>Title</b>	<b>Source</b>	<b>Description</b>	<b>Information on prevalence</b>
Serious Illness in Late Life: The Public's Views and Experiences	Bianca DiJulio, Liz Hamel, Bryan Wu, Mollyann Brodie, The Henry J. Kaiser Family Foundation, (2017)	The Kaiser Family Foundation conducted a large scale nationally representative telephone survey of 2,040 adults in order to better understand people's expectations about later life and efforts they have taken to plan for if they become seriously ill.	Ninety-seven percent of people over the age of 18 thought it was important to have their wishes for medical care documented in case of serious illness, but 34 percent had documented them. A higher percentage of people age 65 and older documented their wishes, but there was still a gap: 96 percent thought it was important, 58 percent had a written document.
Low Completion and Disparities in Advance Care Planning Activities Among Older Medicare Beneficiaries	Krista L. Harrison, Emily R. Adrion, Christine S. Ritchie, Rebecca L. Sudore, and Alexander K. Smith, JAMA Internal Medicine, December 2016, vol. 176, no. 12	Using data from the National Health and Aging Trends Study, a longitudinal cohort study using a nationally representative sample of community-dwelling Medicare beneficiaries age 65 and older. Analysis used a random one-third sample of 2015 participants.	About 52 percent of participants age 65 and older had an advance directive and about 50 percent had a health care power of attorney.

Source: GAO selected research. | GAO-19-231

<sup>a</sup>According to the article, approximately 81 percent of populations covered in the analyzed studies were age 65 and older.

<sup>b</sup>This study defined "advance directive" as including POLST forms.

**Table 2: Survey Respondents Age 65 and Older Who Reported Having a Living Will or Power of Attorney**

<b>Percentage of respondents</b>	<b>2012</b>	<b>2014</b>	<b>2016</b>
Have a living will	47	52	54
Have power of attorney	48	55	58
Have both a living will and power of attorney	39	46	49

Source: GAO analysis of the Health and Retirement Survey. | GAO-19-231

Notes: The Health and Retirement Survey is a longitudinal panel survey of a representative sample of more than 26,000 Americans over the age of 50, sponsored by the National Institute on Aging and the Social Security Administration, and conducted by the University of Michigan every 2 years.

In all three survey years, over 99 percent of the respondents age 65 and older answered one or both questions.

# Appendix II: Types of Information Found on a POLST Form

Physician orders for life-sustaining treatment (POLST) forms are different in each state, and the order of the sections or the options within a section may differ.<sup>1</sup> However, according to the National POLST Paradigm, POLST forms cover the same information. Information about the forms, including sections on cardiopulmonary resuscitation (CPR), medical interventions, artificially administered nutrition, and signatures, is provided below.<sup>2</sup>

## Section A: Cardiopulmonary Resuscitation

This section only applies when the individual is unresponsive, has no pulse, and is not breathing. This is similar to a do-not-resuscitate order, but the individual only has a do-not-resuscitate order when they do not want CPR. The POLST form allows individuals to clearly show they do want CPR. If this is left blank, the standard protocol is for emergency personnel to provide CPR if medically indicated. (See fig. 3.)

Figure 3: Section on Cardiopulmonary Resuscitation

<b>A</b> <i>Check One</i>	<b>CARDIOPULMONARY RESUSCITATION (CPR):</b> <i>Unresponsive, pulseless, &amp; not breathing.</i>	
	<input type="checkbox"/> <b>Attempt Resuscitation/CPR</b>	If patient is not in cardiopulmonary arrest, follow orders in <b>B</b> and <b>C</b> .
	<input type="checkbox"/> <b>Do Not Attempt Resuscitation/DNR</b>	

Source: National POLST Paradigm. | GAO-19-231

Note: POLST elements and additional information on POLST are available on the National POLST Paradigm website, [www.polst.org](http://www.polst.org) (accessed Nov. 8, 2018).

## Section B: Medical Interventions

This section gives medical orders when CPR is not required, but the individual still has a medical emergency and cannot communicate. There are three options and a space for a health care professional to write in orders specific for the individual. Care is always provided to individuals. This section is for letting emergency personnel know what treatments the individual wants to have. (See fig. 4.)

<sup>1</sup>The National POLST Paradigm has established National POLST Paradigm standards and endorsed state POLST programs that meet those standards; however, there is no national POLST form. Policies related to POLST forms are dictated by states and each state may require different information, access, portability, and storage of POLST forms, according to the Department of Health and Human Services.

<sup>2</sup>Do-not-resuscitate or allow-natural-death documents function similarly to POLST forms, but do not include all of the information included in POLST forms.

1. **Full treatment.** The goal of this option is to provide all treatments necessary (and medically appropriate) to keep the individual alive. In a medical emergency, individuals want to go to the hospital and, if necessary, be put in the intensive care unit and on a breathing machine.
2. **Limited treatment / select treatment.** The goal of this option is to provide basic medical treatments. These individuals want to go to the hospital, but do not want to be put in the intensive care unit or on a breathing machine. They are okay with antibiotics and intravenous fluids.
3. **Comfort measures only.** The goal of this option is to focus on making the individual as comfortable as possible where they are. These individuals do not want to go to the hospital. If the individual's comfort cannot be taken care of where they are, transfer to the hospital may be necessary.

According to the National POLST Paradigm, in many states, if an individual chooses CPR—or leaves Section A blank—the individual is required to choose “Full Treatment” in Section B. This is because CPR usually requires intubation and a breathing machine, which are only options under “Full Treatment.” If an individual has a medical emergency, but does not want CPR, this is the section emergency personnel will look at to see whether the individual wants to go to the hospital or not (for Full Treatment and Limited Interventions: yes; for Comfort Measures Only: no). If the individual only has a do-not-resuscitate order, emergency personnel would take them to the hospital.



Figure 4: Section on Medical Interventions

<b>B</b> <i>Check One</i>	<b>MEDICAL INTERVENTIONS:</b> <i>If patient has pulse and is breathing.</i>	
	<input type="checkbox"/>	<b>Comfort Measures Only.</b> Provide treatments to relieve pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. <b><i>Patient prefers no transfer to hospital for life-sustaining treatments. Transfer if comfort needs cannot be met in current location.</i></b> <b><u>Treatment Plan:</u> Provide treatments for comfort through symptom management.</b>
	<input type="checkbox"/>	<b>Limited Treatment.</b> In addition to care described in Comfort Measures Only, use medical treatment, antibiotics, IV fluids and cardiac monitor as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). <b><i>Transfer to hospital if indicated. Generally avoid the intensive care unit.</i></b> <b><u>Treatment Plan:</u> Provide basic medical treatments.</b>
	<input type="checkbox"/>	<b>Full Treatment.</b> In addition to care described in Comfort Measures Only and Limited Treatment, use intubation, advanced airway interventions, and mechanical ventilation as indicated. <b><i>Transfer to hospital and/or intensive care unit if indicated.</i></b> <b><u>Treatment Plan:</u> All treatments including breathing machine.</b> <b><u>Additional Orders:</u> _____</b>

Source: National POLST Paradigm. | GAO-19-231

Note: POLST elements and additional information on POLST are available on the National POLST Paradigm website, www.polst.org (accessed Nov. 8, 2018).

### Section C: Artificially Administered Nutrition

This section is where orders are given about artificially administered nutrition (and in some states artificially administered hydration) for when the individual cannot eat. All POLST forms note that individuals should always be offered food by mouth, if possible. (See fig. 5.)

Figure 5: Section on Artificially Administered Nutrition

<b>C</b> <i>Check One</i>	<b>ARTIFICIALLY ADMINISTERED NUTRITION:</b> <i>Offer food by mouth if feasible.</i>	
	<input type="checkbox"/>	Long-term artificial nutrition by tube.
	<input type="checkbox"/>	Defined trial period of artificial nutrition by tube.
	<input type="checkbox"/>	No artificial nutrition by tube.
		<b><i>Additional Orders (e.g., defining the length of a trial period):</i></b> _____

Source: National POLST Paradigm. | GAO-19-231

Note: POLST elements and additional information on POLST are available on the National POLST Paradigm website, www.polst.org (accessed Nov. 8, 2018).

### Other Section: Signatures

- **Health care professional.** Since this document is a medical order, a health care professional is required to sign it in order for it to be valid. Which health care professionals can sign (e.g., physician, nurse practitioner) varies by state. The document has a statement saying

that, by signing the form, the health care professional agrees that the orders on the document match what treatments the individual said they wanted during a medical emergency based on their current medical condition.

- **Patient or surrogate.** According to the National POLST Paradigm, most states require the patient or the surrogate to sign this form. This helps to show the patient or surrogate was part of the conversation and agrees with the orders listed on the form.

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## Backside of a POLST Form

The backside of the POLST form has directions and information, usually for health care professionals. Other information it may have includes

- information on how to void a POLST form;
- contact information for surrogates; and
- information on who completed the POLST form.

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# Appendix III: Information on CMS's Promoting Interoperability Programs Related to Advance Care Planning Documents

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This appendix provides information about incentive programs provided by the Centers for Medicare & Medicaid Services (CMS) to encourage providers to use electronic health records related to advance care planning documents. CMS provided incentive payments to eligible providers who reported certain measures through its Medicare electronic health records (EHR) Incentive Program (meaningful use program), which started in 2011. At certain points in the program, measures related to advance care planning were optional measures. In 2017, eligible professionals (physicians) began reporting “promoting interoperability” measures through the Merit-based Incentive Payment System (MIPS).<sup>1</sup>

The American Recovery and Reinvestment Act of 2009 established the Medicare and Medicaid EHR Incentive Program. This program provided incentive payments for certain eligible providers—certain hospitals and physicians—that successfully demonstrated meaningful use of certified EHR technology and met other program requirements established by CMS.<sup>2</sup> The program was implemented in three stages—measures were established at each stage to promote the use of EHRs in the delivery of health care and to ensure that providers capture information in their EHRs consistently.<sup>3</sup> For example, one measure assessed whether providers have the technical capability in their EHRs to notify the provider of potential interactions among the patients’ medications and with patients’ allergies. In all three stages of meaningful use, providers had to report

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<sup>1</sup>The Medicare Access and CHIP Reauthorization Act of 2015 established MIPS, which affects provider payments beginning in 2019. With regard to CMS’s administration of the program, as of 2018, both the Medicare EHR Incentive Program and the MIPS performance category are known as CMS’s Medicare Promoting Interoperability Programs.

<sup>2</sup>The Department of Health and Human Services stated that the program began in January 2011, when initial registration started. The first incentive payments were made in May 2011. Starting in 2015, the program included payment adjustments for not meeting necessary requirements. In 2018, the programs were renamed the Medicare and Medicaid Promoting Interoperability Programs.

<sup>3</sup>Stage 1 was intended to promote the electronic capture of health information in a structured format and to encourage providers to use that information to track key clinical conditions. Stage 2 was to encourage continuous quality improvement at the point of care and placed a stronger emphasis on electronic health information exchange with other providers compared to stage 1. Stage 2 was modified to align measures with other quality reporting programs. Stage 3 was intended to improve health outcomes, such as using decision support tools or providing patient access to self-management tools.

certain mandatory or core measures, as well as on a set of optional or menu measures.<sup>4</sup>

The recording of advance directives was not included as a mandatory measure for eligible providers during any stage of meaningful use. For stages 1 and 2 of meaningful use (2011 through 2015) the recording of advance directives was an optional measure, meaning hospitals could choose to report it or could choose to report a different measure.<sup>5</sup> This optional measure for eligible hospitals was a yes/no measure of whether users could record whether a patient has an advance directive.<sup>6</sup> In October 2015, CMS released the stage 3 final rule that also modified elements of stage 2 reporting; this modification eased reporting requirements and aligned them with other quality reporting programs, according to agency officials.<sup>7</sup> For both modified stage 2 and stage 3 (2015 through 2017), the original advance directive measures were no longer included.<sup>8</sup> CMS noted that a goal for stage 3 measures was to include more advanced EHR functions, and one stage 3 measure

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<sup>4</sup>For more information on meaningful use, see *Health Information Technology: HHS Should Assess the Effectiveness of Its Efforts to Enhance Patient Access to and Use of Electronic Health Information*, [GAO-17-305](#) (Washington, D.C.: March 15, 2017).

<sup>5</sup>CMS referred to these as “menu” measures.

<sup>6</sup>The measure required that more than 50 percent of all unique patients age 65 or older admitted to the eligible hospital have an indicator of an advance directive status recorded.

<sup>7</sup>According to agency officials, the advance directive menu measure was “topped out,” or was a measure that is no longer useful in gauging performance, because all those who reported on the measure were high performing on the measure. In addition, the measure was removed as part of efforts to reduce administrative burden to providers as it was considered duplicative, according to CMS officials.

<sup>8</sup>Advance care planning stakeholders provided comments to CMS on meaningful use measures. Comments included both support for having more robust measures regarding advance directives, and support of having fewer measures to ease the burden of reporting. For example, comments stated that a yes/no measure of whether an advance directive was in the EHR was not useful, but a measure requiring a copy of the advance directive in the medical record, and making sure it is updated, would be more beneficial to patients and their families with a first step of ensuring that advance directives are recorded in hospital and physician records.

addressed capturing and incorporating a broad range of data into the EHR, including advance directives.<sup>9</sup>

One national stakeholder organization recommended a measure to ensure that if there are any advance care planning documents in the medical record, that the documents be accessible to all health care providers. CMS noted that advance care planning directives can be included in the notes and is addressed by certification requirements applicable to EHRs.<sup>10</sup> Participants in these CMS programs must use certified EHR technology, which is technology that has been determined to conform to certification criteria developed by the Department of Health and Human Services' Office of the National Coordinator for Health Information Technology. The 2015 certified EHR technology criteria—the most recent edition—includes a criterion that relates to advance care planning documents.<sup>11</sup>

The Medicare Access and CHIP Reauthorization Act of 2015 established the Quality Payment Program, which consolidated components of three previously used payment incentive programs, including the Medicare EHR Incentive Program, into MIPS.<sup>12</sup> Under the MIPS program, which affects clinician payments beginning in 2019, participating clinicians will generally be assessed in four areas, one of which is the “promoting interoperability” performance category that aims to achieve the same

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<sup>9</sup>This stage 3 measure was a measure related to patient generated health data or data from a non-clinical setting. The measure addressed capturing, standardizing, and incorporating a broad range of data—including advance directives—into an EHR. In the stage 3 final rule, this measure was set out in conjunction with the corresponding certification criterion, Patient Health Information Capture.

<sup>10</sup>The Medicare Conditions of Participation require hospitals to have written policies and procedures addressing the patient's right to formulate advance directives and to ensure such directives are followed. In addition, providers are to document in the patient's medical record whether or not the individual has executed an advance directive. See 42 C.F.R. §§ 482.13(b)(3), 489.102(a)(2).

<sup>11</sup>The 2015 certified EHR technology criteria included one criterion—the patient health information capture certification criterion—that supports the capture of advance care planning documents in an EHR, and the ability for an EHR to access a POLST registry. For example, the 2015 patient health information capture certification criterion requires the EHR to properly identify health information for users, which could include labeling health information documents as advance directives.

<sup>12</sup>Pub. L. No. 114-10, § 101, 129 Stat. 87, 89 (2015).

objectives as the original meaningful use program.<sup>13</sup> MIPS-eligible clinicians report measures and activities to earn a score in the performance categories. Under the “improvement activities” performance category, one optional activity—advance care planning—covers items such as implementation of practices or processes to develop advance care planning that includes documenting the advance care plan or living will, and educating clinicians about advance care planning. Clinicians who meet the criteria for this activity can report this advance care planning activity to earn credit for the “improvement activities” performance category. Further, the advance care planning activity could earn bonus points in the “promoting interoperability” category, if the activity was conducted using certified EHR technology in 2017 and 2018.<sup>14</sup>

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<sup>13</sup>The four MIPS categories are quality, promoting interoperability, improvement activities, and cost. According to CMS, the “promoting interoperability” performance category was initially known as the “advancing care information” performance category under MIPS. In general, Medicare clinicians that are not participating in an advanced alternative payment model, and meet thresholds for Medicare charges or provide care to a certain number of Medicare patients per year, are included in MIPS.

<sup>14</sup>Further, CMS noted that the Medicare Promoting Interoperability program includes an objective for hospitals called “public health and clinical data registry reporting.” A measure under this objective is “clinical data registry reporting.” 42 C.F.R. § 495.24(c)(8). CMS stated that hospitals may meet this measure by submitting data to advance directive registries.

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# Appendix IV: Selected State Statutes Related to Advance Care Planning Documents

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Our four selected states—California, Idaho, Oregon, and West Virginia—had statutes with similar provisions that affected access to advance care planning documents; however, the statutes differed in the specificity of these provisions.<sup>1</sup> This appendix provides information on provisions related to (1) document execution requirements, such as signature and witness requirements; (2) the validity of other advance care planning documents; (3) provider objections to advance care planning directions; and (4) provider liability protections.

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## Document Execution Requirements

Statutes in the four selected states required advance care planning documents to contain specific elements for the documents to be valid. The document requirements included the following:

- **Signature requirements.** All four selected states required individuals or designated representatives to sign the advance care planning document for the document to be legally valid. In addition, California allows individuals to sign the documents with a digital signature.
- **Witness requirements.** Three of the states (California, Oregon, and West Virginia) have statutes that require at least one witness to be present during the completion of advance care planning documents for that document to be legally valid.<sup>2</sup> These states varied regarding the relationship the witness could have with the individual and number of required witnesses. For example, for advance care planning documents that were signed by witnesses, California required that at least one of the witnesses not be related to the individual by blood, marriage, or adoption, nor be entitled to any portion of the individual's estate upon the individual's death under an existing will. In contrast, according to state officials in Idaho, the state removed witness requirements from its advance care planning documents in 2012 to make the documents easier to complete.

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## Format of Advance Care Planning Documents

All four selected states' statutes contained model forms that could be used as a valid advance care planning document. All of the states contained provisions regarding the acceptance of documents other than

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<sup>1</sup>Advance care planning documents covered in these provisions included both advance directives and POLST forms, unless specifically noted.

<sup>2</sup>A notarized signature, without witnesses, may also be valid. For example, in Oregon, the advance care planning document may be witnessed and signed by two witnesses or notarized.

the forms set out in statute. A document other than the model form is valid if it includes required statutory elements (e.g., signature requirements). For example, in Idaho, the document must be substantially like the model form or contain the elements laid out in the statute.<sup>3</sup> In Oregon, the advance directive statute states that, except as otherwise provided, Oregon residents' advance directives must be the same as the statutory model form to be valid.<sup>4</sup>

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### Provider Objections to Advance Care Planning Directions

All four selected states' advance care planning statutes had provisions related to provider objections—the statutes address situations in which the provider is unable or unwilling to comply with advance care planning directions.<sup>5</sup> However, the statutes varied on the grounds for provider objection, the required steps to be taken, and the extent to which providers were responsible for taking those steps. For example, California's and Idaho's statutes allow providers to object on ethical and professional grounds; and California's, Idaho's, and West Virginia's statutes allow providers to object on reasons of conscience.<sup>6</sup> In addition, the four states' statutes specified the steps that providers or health systems must take after an objection is made. For example, all four selected states require that specified steps be taken with regard to transferring the individual to a provider that will honor their wishes. Further, California and Oregon explicitly require patient or health care representative notification as soon as provider objections are made.

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### Provider Liability Protections

All four states also had statutes that addressed the circumstances under which providers would not be subject to civil or criminal liability, or professional disciplinary action with regard to administering advance care planning documents and directions. The states' statutes varied with

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<sup>3</sup>With regard to existing directives and directives from other states, the Idaho statute is to be liberally construed to give effect to an authentic expression of the individual's prior wishes or health care directives.

<sup>4</sup>As noted above, the Oregon statute also states that a principal may execute an advance directive that is in a form that is substantially the same as the model form.

<sup>5</sup>The term "provider objection" is the terminology used in this report and is not necessarily the term used in the state statutes.

<sup>6</sup>The California statute allows a provider to decline to comply with an instruction or decision that requires medically ineffective health care or health care contrary to generally accepted health care standards.



regard to the actions that were covered under these liability provisions. For example, California's statute addresses situations in which a provider or institution either complied with or objected to the directions provided in advance care planning documents, while Idaho's, Oregon's, and West Virginia's statutes only addressed situations in which providers and other parties complied in good faith with the directions.

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# Appendix V: GAO Contact and Staff Acknowledgments

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## GAO Contact

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## Staff Acknowledgments

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