



April 2015

ADVANCE DIRECTIVES

Information on Federal Oversight, Provider Implementation, and Prevalence

Accessible Version

GAO Highlights

Highlights of [GAO-15-416](#), a report to congressional requesters

Why GAO Did This Study

Advance directives, such as living wills or health care powers 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. Many individuals receive medical care from Medicare and Medicaid funded providers during the last 6 months of life, and may benefit from having advance directives that specify treatment preferences. According to IOM, advance directives are most effective when part of a comprehensive approach to end-of-life care called advanced care planning.

GAO was asked to review information related to advance directives. This report examines (1) how CMS oversees providers' implementation of the PSDA requirement; (2) what is known about the approaches providers use and challenges they face to inform individuals about advance directives; and (3) what is known about the prevalence of advance directives and how it varies across provider types and individuals' demographic characteristics. To do this work, GAO reviewed CMS documents and survey data reported by state survey agencies into CMS's Certification and Survey Provider Enhanced Reporting system about covered providers' implementation of the PSDA requirement. GAO also conducted a literature review of peer reviewed articles and federal government reports. In addition, GAO interviewed CMS officials and stakeholders representing providers and individuals likely to benefit from advance directives.

View [GAO-15-416](#). For more information, contact Vijay D'Souza at (202) 512-7114 or DsouzaV@gao.gov.

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What GAO Found

The Centers for Medicare & Medicaid Services (CMS) oversees providers' implementation of the advance directive requirement in the Patient Self Determination Act (PSDA) to maintain written policies and procedures to inform individuals about advance directives, and document information about individuals' advance directives in the medical record by providing guidance and monitoring covered providers. Covered providers include hospitals, nursing homes, home health agencies (HHAs), hospices, and Medicare Advantage (MA) plans that receive Medicare and Medicaid payments. CMS, an agency within the Department of Health and Human Services (HHS), provides operations manuals, memoranda, and model documents to these providers to inform them about the advance directive requirement and describe how the agency will monitor providers' implementation. Because individual states are responsible for administering contracts with and providing guidance to Medicaid managed care plans, also specified in the PSDA, CMS ensures that the contracts include the advance directive requirement, but does not issue guidance to these plans. To monitor providers' implementation of the advance directive requirement, CMS primarily relies on other entities. CMS enters into agreements with state survey agencies to periodically survey and report data, which CMS collects, on deficiencies related to advance directives for hospitals, nursing homes, HHAs, and hospices. CMS also relies on accrediting organizations to survey providers that participate in the Medicare program through accreditation and subsequently make recommendations to CMS regarding providers' participation in Medicare. In addition, CMS reported reviewing MA and Medicaid managed care plans' contracts to determine that they include the advance directive requirement.

Approaches used to inform individuals about advanced directives vary by type of provider, but providers face similar challenges, according to stakeholders interviewed and literature GAO reviewed. For example, hospitals, nursing homes, HHAs, and hospices inform individuals about advance directives during the admission process, while MA plans and Medicaid managed care plans inform individuals during enrollment. Challenges in informing individuals about advance directives include discomfort talking about end-of-life issues and lack of staff time for such discussions. Providers may address these challenges by using leading practices, such as patient education or population specific materials.

Many adults have advance directives, but estimated prevalence varies by provider type and an individual's demographic characteristics. In 2013, 47 percent of adults over the age of 40 had an advance directive, according to the Institute of Medicine (IOM) report, *Dying in America*. However, the prevalence of individuals with advance directives varies by type of provider and demographic characteristic. For example, a National Center for Health Statistics report found that 88 percent of discharged hospice patients had advance directives in 2007 compared to 65 percent of nursing home patients in 2004. Studies GAO reviewed found that individuals who were older, white, had higher education or incomes, or were women were more likely to have advance directives than others.

HHS provided technical comments on a draft of this report, which were incorporated as appropriate.

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April 29, 2015

The Honorable Bill Nelson
Ranking Member
Committee on Commerce, Science, and Transportation
United States Senate

The Honorable Johnny Isakson
United States Senate

The Honorable Mark Warner
United States Senate

Advance directives—such as living wills or health care powers 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.¹ Many individuals receive medical care during the last 6 months of life that may involve making difficult decisions about life sustaining treatment, which underscores the importance of planning for medical care at the end of life. For example, 69 percent of Medicare beneficiaries that died in 2009 experienced a hospitalization in the last 90 days of life.² A recent Institute of Medicine (IOM) report noted that an advance directive may be a useful component of a comprehensive approach to end-of-life care, called advance care planning, which includes discussions about end-of-life treatment preferences and documenting those preferences.³ In addition to written statements about preferred medical care, an advance directive may be used to identify an agent to make medical decisions on the individual’s behalf if necessary.

¹A health care power of attorney is a document that identifies a health care agent as decision maker for the patient, and under state law, typically becomes operative when a patient is medically determined as unable to make decisions.

²See Teno, et al., “Change in End-of-Life Care for Medicaid Beneficiaries,” *Journal of the American Medical Association*, vol. 309, issue 5 (2013).

³IOM (Institute of Medicine). *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. (Washington, D.C.: The National Academies Press, 2015).

Beginning in the 1970s, public concerns over an individual's right to determine his or her own health care led to state legislative efforts to encourage the use of advance directives, according to a 2008 Department of Health and Human Services (HHS) report.⁴ In 1990, similar federal efforts resulted in what is commonly referred to as the Patient Self Determination Act (PSDA), which, as amended, requires six types of Medicare and Medicaid funded providers—hospitals, nursing homes, hospices, home health agencies (HHAs), health maintenance organizations, and Medicare Advantage (MA) organizations (hereafter collectively referred to as covered providers)—to maintain written policies and procedures to inform those they serve about advance directives, and document information about individuals' advance directives in the medical record.⁵ The Centers for Medicare & Medicaid Services (CMS)—the agency within HHS that administers Medicare and oversees Medicaid—is responsible for ensuring covered providers' implementation of the PSDA requirement.

You asked us to review CMS's oversight of covered providers' implementation of PSDA regarding advance directives, related information on providers' practices, and the prevalence of individuals with advance directives. In this report, we examine: (1) how CMS oversees providers' implementation of the PSDA requirement to maintain written policies and procedures to inform individuals about advance directives and document advance directives, and providers' implementation of these policies and procedures; (2) what is known about the approaches providers use and challenges they face to inform individuals about advance directives and document advance directives; and (3) what is known about the prevalence of advance directives, and how they vary across provider types, individuals' demographic characteristics, and over time.

To examine CMS's oversight of covered providers' maintenance of written policies and procedures, and providers' implementation of these policies and procedures, we reviewed relevant laws, regulations, and CMS

⁴See HHS, *Advance Directives and Advance Care Planning: A Report to Congress* (Washington, D.C.: August 2008).

⁵Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, §§ 4206 and 4751, 104 Stat. 1388, 1388-115, and 1388-204 (codified, as amended, at 42 U.S.C. 1395cc (f) (Medicare) and 1396a (w) (Medicaid)).

documents and data. We also conducted interviews with CMS officials and stakeholders, including officials that represent each of the six types of covered providers, and two organizations representing individuals likely to benefit from advance directives, including older individuals and those near the end of life.⁶ In addition, we reviewed data in the Certification and Survey Provider Enhanced Reporting (CASPER) system, which CMS uses to retain data regarding deficiencies, including those related to advance directives, identified during surveys of providers that must meet certification standards for participation in Medicare. Such providers include nursing homes, HHAs, and hospice care providers. To collect CASPER data, CMS enters into agreements with state survey agencies to conduct provider surveys and report survey results into the CASPER system.⁷ However, a substantial portion of certain covered providers, particularly hospitals, are certified for participation in Medicare through accrediting organizations, and full survey data for these providers are generally not included in the CASPER system.⁸ The CASPER system does however, contain full survey data from a relatively small number of providers—hospitals, HHAs, and hospices—accredited through accrediting organizations, which are included in our analysis. To assess the reliability of the CASPER data, we reviewed data documentation, discussed the data with CMS officials, and examined the data for consistency and unusually high and low values. We determined that the data were sufficiently reliable for our purposes.

To examine what is known about the approaches providers use and challenges they face informing individuals about advance directives and documenting advance directives, we conducted a literature review of peer reviewed articles and selected federal government reports published from

⁶We interviewed officials from the American Hospital Association, American Health Care Association, National Association for Home Care and Hospice, National Hospice and Palliative Care Organization, Excellus BlueCross and BlueShield Association, American Geriatrics Society, and Mt. Sinai School of Medicine Center to Advance Palliative Care.

⁷The Social Security Act directs HHS to enter into agreements with state health agencies or other appropriate agencies when determining whether health care entities meet federal standards. Social Security Act §1864(a) (codified at 42 U.S.C. § 1395aa (a)). State survey agencies conduct most surveys to determine a provider's compliance with federal requirements. A state survey agency may be the state health agency or other appropriate state medical agency responsible for establishing and maintaining health standards for certain institutions in which health care may be provided in a particular state.

⁸In 2012, 88 percent of hospitals, 36 percent of HHAs, and 31 percent of hospices were certified to participate in the Medicare program through accreditation.

2009 through 2014. Using search terms including “advance directive” and “living will,” we identified 297 studies from our search of social science research and medical bibliographic databases, including MEDLINE and ProQuest, and selected 125 studies for in-depth review based on their relevance to our objectives.⁹ For each of the studies that we reviewed, we identified how a particular type of covered provider informs patients about advance directives; how the provider documents whether a patient has an advance directive; challenges related to these activities; and how these challenges can be addressed. In addition, our work was informed by IOM’s 2015 *Dying in America* report,¹⁰ a key source of information on end-of-life care. We also interviewed stakeholders representing covered providers and individuals likely to benefit from an advance directive, and supplemented these interviews with information from CMS about how the agency oversees managed care plans.

To examine what is known about the prevalence of advance directives and how this varies across provider types, individuals’ demographic characteristics, and over time, we relied on the same literature review of peer reviewed articles and selected federal government reports published from 2009 through 2014. For each of the studies relevant to this objective, we identified the prevalence of individuals with an advance directive within the general population, within provider types, by demographic characteristics, and how the prevalence has changed over time.¹¹ In addition, we identified statistical data from four studies: (1) *Dying in America*, IOM; (2) “Completion of Advance Directives Among U.S. Consumers,” *American Journal of Preventive Medicine*; (3) “Use of Advance Directives in Long-Term Care Populations,” *National Center for Health Statistics Data Brief*; and (4) “Advance Directive Completion by Elderly Americans: A Decade of Change,” *Journal of the American*

⁹We excluded research focused on children or non-U.S. populations, studies published outside the United States, and articles that were not research based.

¹⁰IOM, *Dying in America*.

¹¹We summarized information from the literature review that may have defined advance directives differently from each other or more broadly than the PSDA. For example, some studies included medical orders in their definitions of advance directives, such as “do-not-resuscitate” or physicians orders for life sustaining treatment, which can be used in conjunction with or instead of advance directives to translate an individual’s general preferences for medical treatment into specific actionable medical orders. However, our summaries did not include information that focused exclusively on medical orders.

Geriatrics Society.¹² To assess data reliability, we reviewed information about each study including its source (e.g., peer reviewed journal), methodology, and the sample size upon which the study's estimates were based. To the extent that comparable information was available, we also compared the study's estimates with other published work to determine whether the findings were reasonable. On the basis of this assessment, we determined that the data were sufficiently reliable for our purposes. In addition, we analyzed CMS data from the CASPER system on the number of nursing home patients with advance directives from 2004 to 2014. As previously noted, we assessed the reliability of the CASPER data and determined that the data were sufficiently reliable for our purposes.

We conducted this performance audit from June 2014 to April 2015 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

PSDA, Advance Directives, and Advance Care Planning

As amended, the PSDA requires Medicare and Medicaid funded hospitals, nursing homes, hospices, HHAs, and managed care plans—including MA and Medicaid health maintenance organizations—to maintain written policies and procedures related to advance directives. Among other things, the policies and procedures maintained by covered providers are required to specify that the provider will: (1) provide written

¹²IOM, *Dying in America*, see Tompson, et al., 2013, survey conducted by the Associated Press, National Opinion Research Center, Center for Public Affairs Research; Rao, Jaya K., Lynda A. Anderson, Feng-Chang Lin, et al., "Completion of Advance Directives Among U.S. Consumers," *American Journal of Preventive Medicine*, vol. 46, issue 1 (2014): 65-70; Jones, Adrienne L., Abigail J. Moss and Lauren D. Harris-Kojetin, "Use of Advance Directives in Long-Term Care Populations," *National Center for Health Statistics Data Brief*, no. 54 (Hyattsville, Md.: National Center for Health Statistics, January 2011); and Silveria, Maria J., Wyndy Wiiala and John Piette, "Advance Directive Completion by Elderly Americans: A Decade of Change," *Journal of the American Geriatrics Society*, vol. 62 (2014): 706-710.

information to all adult individuals receiving medical care by or through the provider on their rights under state law to make decisions concerning medical care, including the right to execute an advance directive; and (2) document in the medical record whether the individual has an advance directive.

The PSDA defines an advance directive as a written instruction, such as a living will or durable power of attorney for health care, recognized under state law (whether statutory or as recognized by the courts of the state) and relating to the provision of such care when the 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 procedures, or to identify an agent to make medical decisions on the individual's behalf if necessary. The most common forms of advance directives are living wills and health care powers of attorney.

During the last 6 months of life, many individuals receive care from one or more covered providers, including hospitals and nursing homes, and having an advance directive that specifies an individual's treatment preferences to covered providers in preparation for difficult medical decisions that may arise at the end of life may be useful. According to the IOM, advance directives are most effective when used as part of advance care planning, which may involve multiple, in-depth discussions with family members, legal and financial counsel, and healthcare providers,¹³ and may also include the formulation of medical orders. The IOM also reported 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, such as an advance directive, helps to ensure that medical treatment given at the end of life is consistent with an individual's preferences.

¹³Medicare reimburses for a one-time initial preventive physical examination that may include end-of-life planning.

Covered Providers and CMS Oversight

The six provider types covered by the PSDA provide or arrange for Medicare or Medicaid health care services in multiple settings for individuals of varying demographics. For example, nursing homes generally provide care in an institutional setting to older individuals who have chronic conditions, such as congestive heart failure, while hospices generally deliver palliative care in an institutional, home, or home-like setting to critically ill individuals of various ages who are close to the end of life. The characteristics and distribution of individuals enrolled in MA and Medicaid managed care also have similarities and differences. For example, individuals enrolled in MA may be disabled or elderly (over the age of 65), and individuals enrolled in Medicaid managed care may include adults who are also disabled and elderly. However, in 2013, CMS reported that half of the Medicaid population was children in comparison to Medicare in which 83 percent of beneficiaries were over age 65. In addition, while most individuals enrolled in Medicare are not enrolled in a managed care plan, over 70 percent of individuals enrolled in Medicaid are enrolled in some form of Medicaid managed care, according to CMS. However, the distribution of individuals enrolled in Medicaid across various demographic groups—disabled, elderly, adults, and children—varies widely by state.

In order to participate in the Medicare or Medicaid programs, covered providers must comply with applicable federal standards, including PSDA requirements.¹⁴ CMS is responsible for oversight of providers' compliance with PSDA requirements and does so through both state survey agencies and accrediting organizations.

CMS enters into agreements with state survey agencies to conduct oversight activities of covered providers. Specifically, four of the six covered provider types—hospitals, nursing homes, HHAs, and hospices—must demonstrate their compliance with federal standards to a state survey agency. These agencies conduct surveys of covered providers—observations, interviews, and document/record reviews—that assess compliance with applicable requirements for Medicare and/or Medicaid participation. The survey process covers multiple standards. For example, there are about 200 quality and safety standards for nursing

¹⁴When Medicaid services are furnished through provider types that must be certified for Medicare, standards must be met for both. Of the covered provider types, nursing homes are the only type that may participate solely in Medicaid, although most participate in both Medicaid and Medicare.

homes that range from determining the prevalence of pressure sores and use of restraints to documenting the posting of an individual's bill of rights.

However, in some cases, particularly for hospitals, accrediting organizations provide primary oversight. Specifically, hospitals, HHAs, and hospices that choose to undergo accreditation by an accrediting organization, rather than certification from a state agency, must demonstrate to the accrediting organization their ability to meet the standards of accreditation, including PSDA standards. The accreditation organization subsequently recommends to CMS certification of providers meeting such standards. The processes that accrediting organizations use to certify providers for Medicare participation are subject to CMS review and approval.¹⁵ In addition, under agreements with CMS, state survey agencies annually survey a sample of accredited providers to verify the results of surveys conducted by the accrediting organizations, and assess the organizations' ability to monitor providers' compliance with federal standards.¹⁶

The two remaining covered provider types—MA and Medicaid managed care plans—must contract with CMS or individual states to participate in the Medicare or Medicaid programs. Specifically, under MA, CMS contracts with private health plans to provide covered services to individuals who enroll in an MA plan, while under Medicaid managed care, individual states contract with private health plans to cover medical services; however, both MA and Medicaid managed care plans are prospectively paid a per person, or capitated, payment.¹⁷

¹⁵See 42 U.S.C. §§ 1395x (e), 1395bb.

¹⁶In 2012, state survey agencies conducted 332 surveys of accredited providers, which represented 3 percent of accredited hospitals and 2 percent of accredited HHAs and hospices. In addition, state survey agencies also conduct complaint investigations for serious complaints concerning accredited providers.

¹⁷For MA plans, the capitated payment is in addition to any applicable monthly premium paid by the enrollee, according to CMS officials.

CMS Oversees Covered Providers' Implementation of the Advance Directive Requirement by Providing Guidance and Monitoring Implementation

CMS Provides Guidance to Help Covered Providers Implement the Advance Directive Requirement to Maintain Written Policies and Procedures

CMS develops and disseminates guidance through operations manuals, memoranda, or model documents to five of the six covered provider types—hospitals, nursing homes, HHAs, hospices, and MA plans—to inform these providers of the requirement to maintain written policies and procedures about advance directives and to describe how the agency will monitor providers' implementation. For example, CMS issues operations manuals specific to five provider types that describe the advance directive requirement and how each of these providers is required, in accordance with federal regulations, to maintain and provide each patient with written notice of the provider's policies related to advance directives. These operations manuals also describe how the providers are required to maintain policies related to documentation of an individual's advance directive in the individual's medical record. CMS shares oversight of Medicaid managed care plans, the sixth covered provider type, with individual states. CMS is responsible for approving managed care contracts to ensure that they conform to advance directive requirements in federal regulation, and states are responsible for administering these contracts, including providing guidance to plans and ensuring that plans comply with contractual requirements, according to CMS officials.¹⁸ As a result, CMS does not issue guidance to Medicaid managed care plans.

¹⁸Although CMS relies on states to administer their Medicaid programs within broad federal parameters, CMS must approve each program, including its care delivery system (fee for service or managed care). CMS provides technical assistance to states and issues guidance to states regarding operational issues related to the Medicaid program, including managed care contract requirements. For example, CMS issued a memo to state Medicaid directors to inform them that CMS would not approve managed care contracts that contained certain payment requirements.

CMS also provides an operations manual to four covered provider types—hospitals, nursing homes, HHAs, and hospices—to help these providers understand the standards state survey agencies will use during surveys to monitor the providers’ implementation of the advance directive requirement. Covered provider types may use this information to ensure that survey standards are met. In addition, CMS’s guidance informs the standards that accrediting organizations use during surveys to monitor accredited providers’ implementation of the advance directive requirement, because these standards must be approved by CMS as meeting or exceeding the Medicare standards. Guidance in the operations manual describes to state survey agencies and covered providers the activities and documents that may be observed and reviewed during surveys. For example, the operations manual indicates that state survey agencies may review the provider’s policies, examine an individual’s medical records for documentation that required information was provided to the individual, and whether or not the individual has an advance directive; or conduct interviews with other individual patients and provider staff to understand how the provider’s policies are implemented. One stakeholder we spoke with that represented HHAs reported that the survey process described in the operations manual demonstrates the importance that CMS places on advance directives.

Additionally, CMS issues memoranda available to state survey agencies and four of the six covered provider types—hospitals, nursing homes, HHAs, and hospices—that contain clarifications and new or revised guidance related to the advance directive requirement. For example, in September 2012, a CMS memorandum notified state survey agencies that CMS had updated its guidance regarding how survey agencies should assess nursing home compliance with the advance directive requirement and encouraged survey agencies to share the information with providers. Further, in October 2013, a CMS memorandum to state survey agencies clarified nursing homes’ cardiopulmonary resuscitation (CPR) policies in the context of an individual’s advance directive.¹⁹ According to the memorandum, nursing homes must provide CPR to all individuals in their care unless an individual’s advance directive specifies otherwise, and may not establish or implement facility-wide “no CPR” policies. The memorandum instructs state survey agencies to examine

¹⁹CPR refers to any medical intervention used to restore circulatory and/or respiratory function that has ceased.

nursing home policies and individuals' medical records to ensure that no such policy has been established or implemented. A stakeholder that represented nursing home providers reported that the memoranda and updated survey guidance for nursing home providers clarified and reinforced CMS's expectations for nursing homes' policies related to advance directives, and demonstrated CMS's focus on providing oversight in this area.

In addition to the guidance that CMS provides to MA plans—the fifth provider type—through the Medicare Managed Care Manual (chapter 4 entitled, “Benefits and Beneficiary Protections”), CMS also provides MA plans with model documents used to inform enrollees about advance directives to demonstrate how plans are to implement the guidance in the manual. For example, the model document contains the exact wording that the plans must use to inform individuals enrolled in MA plans about their right to formulate an advance directive. MA plans are required to provide this document, called an Evidence of Coverage, to each individual at initial enrollment and each year thereafter. According to CMS officials, MA plans are not permitted to modify the language in the model document unless otherwise instructed by CMS. Officials also reported that CMS annually reviews the policies and procedures in the model document and, when necessary, updates them to ensure that they reflect current laws and CMS policies. CMS relies on states to provide guidance to Medicaid managed care plans—the sixth provider type—because states are responsible for administering contracts with these plans.

CMS Monitors Covered Providers' Implementation of the Advance Directive Requirement

CMS's activities to monitor covered providers' implementation of the advance directive requirement vary across the six covered provider types and include periodic surveys, contract reviews, and the collection of certain related data. CMS enters into agreements with state survey agencies to conduct most surveys. Specifically, under agreements with CMS, state survey agencies periodically survey four of the six provider types—hospitals, nursing homes, HHAs, and hospices.²⁰ Survey frequencies for each provider type are determined by statute or CMS

²⁰CMS monitors the performance of state survey agencies that assess covered providers on behalf of CMS. Specifically, CMS conducts validation surveys of prior state agency surveys to verify their accuracy. In addition, CMS assesses the agencies' performance to identify areas for improvement.

policy.²¹ For example, the frequency of nursing homes, HHAs, and beginning in 2015, hospice standard surveys is statutorily determined and must occur, on average, every year for nursing homes and every 3 years for HHAs and hospices.²² The frequency of hospital standard surveys is determined by CMS and should occur, on average, every 3 years. According to CMS officials, state survey agencies follow up with providers to correct deficiencies found during surveys, and may work with CMS to impose enforcement actions,²³ such as civil monetary penalties and termination, on providers that do not correct deficiencies in a timely manner.

Through state survey agencies, CMS retains data regarding deficiencies related to advance directives identified during surveys of hospitals, nursing homes, HHAs, and hospices. The data—which, according to CMS officials, the agency uses for enforcement actions—indicate that the rate of noncompliance with the advance directive requirement among these four covered provider types in 2012 and 2013 was less than 3 percent for the providers surveyed in each given year. For example, about 2 percent of the 14,161 nursing homes that were surveyed in 2013 had a deficiency related to the advance directive requirement. Deficiencies related to the advance directive that were identified during surveys of the four provider types included providers' failure to inform individuals about advance directives, including failure to provide individual patients with written information about the providers' policies regarding advance directives. Providers also failed to accurately document an individual's advance directive in the medical record. Surveyors based their findings on observations, medical record reviews, and interviews

²¹See CMS, Survey and Certification Group, Center for Clinical Standards and Quality, *Quality Assurance for the Medicare & Medicaid Programs*, FY 2014 MPD, p. 4, March 7, 2014 (CMS's annual mission and priority document).

²²See 42 U.S.C. §§ 1395i-3(g)(2)(A), 1396r(g)(2)(A) (nursing homes); 42 U.S.C. § 1395bbb(c) (home health agencies); and Pub. L. No. 113-185, § 3(a), 128 Stat. 1952, 1968 (codified at 42 U.S.C. § 1395x (dd)(4)(C)) (hospices).

²³Accrediting organizations also follow up with providers to correct deficiencies found during surveys, and notify CMS of any immediate jeopardy situations they identify, as well as of any adverse action taken against a provider's accreditation. In such cases, CMS directs the state survey agency to conduct a complaint or full survey of the provider. Accredited providers found to be noncompliant may be subject to oversight by a state survey agency until the provider can achieve substantial compliance or has its Medicare agreement terminated by CMS if it cannot achieve substantial compliance within a reasonable timeframe.

with provider staff, and noted that a provider's failure to ensure that individuals have an opportunity to formulate complete and accurate directives has the potential to cause harm to individuals who may receive treatment or have treatment withheld when their exact treatment preferences are not known. In addition, accrediting organizations—through findings from periodic surveys of providers that would include findings related to providers' compliance with the advance directive requirement—may recommend to CMS whether accredited providers should maintain their certification.²⁴

In addition to the survey process for hospitals, nursing homes, HHAs, and hospices, CMS reviews contracts from the two remaining covered provider types—MA plans and Medicaid managed care plans. Specifically, CMS reviews MA and Medicaid managed care plan contract provisions addressing compliance with applicable requirements, including the advance directive requirement. According to CMS officials, each MA plan must annually renew its contract with CMS indicating that it will comply with Medicare laws and regulations, which includes the advance directive requirement. Although the MA plan's contract application indicates that CMS may conduct monitoring activities, such as on-site visits to the plan's facilities to verify the plan's compliance with Medicare requirements, CMS does not currently conduct such activities related to the advance directive requirement. CMS officials told us that current audits of MA plans are focused on outcome based measures, such as plans' coverage determinations, which would not indicate noncompliance with the advance directive requirement.²⁵

For Medicaid managed care plans, CMS officials reported that CMS staff review contracts between the plan and individual states prior to implementation of a new plan contract or when revisions are made to an existing approved contract to ensure that the contract addresses

²⁴CMS receives limited survey data from accrediting organizations regarding deficiencies identified during surveys of accredited providers. However, in contrast to survey data reported to CMS by state survey agencies, CMS does not use survey data reported by accrediting organizations for the purposes of enforcement actions against noncompliant providers.

²⁵According to CMS officials, CMS collects data through the Healthcare Effectiveness Data and Information Set specific to MA special needs plans in accordance with CMS's expectation that these plans conduct and document advance care discussions with enrollees.

provisions related to advance directives. CMS staff use a contract review checklist that includes the regulatory language related to the advance directive requirement when conducting their review. For example, staff are to indicate on the review checklist whether the contract under review requires that the plan maintain written policies and procedures on advance directives for all adult individuals receiving medical care by or through the plan. However, CMS does not currently have data on the extent to which Medicaid managed care plans' contracts address the advance directive requirement. Although CMS recently began electronically collecting contract review data, the data will indicate the extent to which plans' contracts address advance directive requirements, but not the extent to which plans' implementation is in compliance with the contractual provisions. CMS does not conduct audits of Medicaid managed care plans to monitor implementation or identify noncompliance with contractual provisions. CMS officials reported that this is because individual states are legally responsible for monitoring the Medicaid managed care plans with which they contract.

Approaches Used to Inform Individuals about Advance Directives Vary by Provider Type, but Providers Face Similar Challenges

Providers use various approaches to inform individuals about their right to have an advance directive, either as part of the admission or the enrollment process depending on the type of covered provider, according to CMS and stakeholder officials, and the limited amount of information found in the literature about certain types of providers. For example, four of the provider types—hospitals, nursing homes, HHAs, and hospices—provide individuals with information about their right to formulate an advance directive during the admission process, according to interviews with stakeholder officials representing these provider types and 10 studies.²⁶ In contrast, MA plans and Medicaid managed care plans provide written information to individuals on their right to formulate an advance directive during the enrollment process, according to stakeholders we interviewed. MA plans provide individuals enrolling in the plan with a model document developed by CMS—the Evidence of Coverage—to inform individuals about their right to have an advance directive, according to CMS officials. Medicaid managed care plans also

²⁶For example, see Rich, Shayna E., Ann L. Gruber-Baldini, Charlene C. Quinn, and Sheryl I. Zimmerman, "Discussion as a Factor in Racial Disparity in Advance Directive Completion at Nursing Home Admission," *Journal of the American Geriatrics Society*, vol. 57 (2009): 146-152; and Van Lueven, Karen A., "Advanced Care Planning in Health Service Users," *Journal of Clinical Nursing*, vol. 21(2010): 3126-3133.

provide written information at the time of enrollment, according to a stakeholder official that represented a Medicaid managed care plan.

Providers' approaches also vary in the extent to which they each discuss information about advance directives with individuals, according to the literature and stakeholder officials. Specifically, hospital staff do not generally discuss advance directives with individuals during the admission process, as five stakeholders, including officials representing three provider types and individuals close to the end of life, and six studies noted.²⁷ By contrast, staff for three other covered provider types—nursing homes, HHAs, and hospices—nurses, social workers, or case managers generally discuss advance directives during the admissions process as part of one or more advance care planning discussions with individual patients, according to the findings from four studies and five stakeholders.²⁸ However, information on the extent to which MA and Medicaid managed care plan providers discuss advance directives with individuals enrolled in the plans is more limited. Specifically, we did not identify any peer reviewed studies in our literature review that addressed MA and Medicaid managed care plans. In addition, although a stakeholder representing both an MA plan and Medicaid managed care plan told us that while the stakeholder's plans require their providers to discuss advance directives with individual enrollees during an initial health assessment and during annual visits with their physicians, not all plans take a similar approach.

²⁷For example, see Baughman, Kristin R., Julie Aultman, Susan Hazelett, Barbara Palmisano, et al., "Managing in the Trenches of Consumer Care: The Challenges of Understanding and Initiating the Advance Care Planning Process," *Journal of Gerontological Social Work*, vol. 55, (2012): 721-737; and Wagner, Glenn J., Deborah Riopelle, Jillisa Sleckart, et al. "Provider Communication and Patient Understanding of Life-Limiting Illness and Their Relationship to Patient Communication of Treatment Preferences." *Journal of Pain and Symptom Management*, vol. 39 no. 3 (2010): 527-534.

²⁸According to three studies and two stakeholders representing nursing home providers and seniors, staff in nursing homes, HHAs, or hospices have generally received some training on advance directives, are expected to discuss these issues with patients, and/or take the time to have these discussions with patients and their families. For example, see Krok, Jessica, Debra Dobbs, Kathryn Hyer and LuMarie Polivka-West, "Nurse Managers' Perspectives of Structural and Process Characteristics Related to Residents' Advance Directives in Nursing Homes," *Applied Nursing Research*, vol. 24 (2011): 45-50. Three stakeholders—representing HHAs, hospices, and seniors—also told us that nursing home or hospice patients generally have health conditions or are of an age that places them close to the end of life, so these providers may prioritize such discussions.

Covered providers generally document whether an individual has an advance directive either in paper medical records or in an electronic health record, according to the limited information in the literature and the stakeholder officials we interviewed.²⁹ Specifically, each stakeholder official we spoke with and six studies we reviewed found that all six covered provider types document individuals' advance directives using either paper medical records or electronic health records,³⁰ and some of these sources indicated that providers may also keep a copy of individuals' directives in these records if such documents are available.³¹

Providers face similar challenges in informing individuals about advance directives and documenting them, according to the literature and stakeholder officials. The challenges to informing individuals about advance directives include discomfort talking about end-of-life issues, confusion about which staff should have the discussions with individuals, and lack of staff time to have the discussions. Specifically, 18 studies found and five stakeholder officials representing providers and seniors confirmed that providers, individual patients, or both are often uncomfortable talking about end-of-life issues, in some cases even when

²⁹The PSDA requires that providers document in an individual's medical records whether the patient has an advance directive if that information is known by providers, but does not require that the medical record contain a copy of any advance directives.

³⁰Electronic health records are viewed by HHS and others as a necessary step toward the goals of improved quality, efficiency, and patient safety. The Health Information Technology for Economic and Clinical Health Act, part of the American Recovery and Reinvestment Act of 2009, provides incentives to certain hospitals and professionals receiving Medicare or Medicaid funding to adopt meaningful use of electronic health records. See Pub. L. No 111-5, div. A, tit XIII, 123 Stat. 115, 226-279 and div. B, tit IV, 123 Stat. 115, 467-496 (2009). Hospitals and professionals demonstrate meaningful use by reporting certain mandatory measures and also must report a set of optional measures that they may choose from a menu. An optional meaningful use measure for certain hospitals is to record advance directives for patients 65 years or older. See GAO, *Electronic Health Record Programs: Participation Has Increased, but Action Needed to Achieve Goals, Including Improved Quality of Care*, [GAO-14-207](#) (Washington, D.C.: March 6, 2014).

³¹For example, see Blechman, Jennifer A.; Norman Rizk, Marguerite M. Stevens, and Vyjeyanthi S. Periyakoil, "Unmet Quality Indicators for Metastatic Cancer Patients Admitted to Intensive Care Unit in the Last Two Weeks of Life," *Journal of Palliative Medicine*, vol. 16, no. 10 (2013): 1285-1289.

an individual is close to the end of life.³² For example, 9 studies found that physicians often do not communicate poor prognoses with individuals, in part, due to their discomfort to do so, which can deprive individuals of the opportunity to understand that they are nearing the end of life and the opportunity to discuss their advance care preferences in that context.³³ Three studies also found confusion about which staff—nurses, social workers, or physicians—should have discussions to inform individuals about advance directives,³⁴ although most individuals prefer to have these discussions with their physicians, according to 3 other studies.³⁵ In addition, 10 studies found that physicians may either not have the time or do not spend the time discussing end-of-life issues with individual patients.³⁶ Two stakeholders that represented managed care plans and seniors also noted the time constraints physicians face when discussing advance directives with individual patients.

Other challenges that providers face informing individuals about advance directives are associated with individuals' lack of understanding about advance directives and challenges informing certain demographic groups about them, according to the literature. Specifically, 13 studies found that many individuals lack an understanding about advance directives, assume incorrectly that these documents are expensive or require attorneys, or have difficulty understanding complex medical information

³²For example, see Fu, Siqing; F. Diane Barber, Aung Naing, Jennifer Wheeler, et al., "Advance Care Planning in Patients With Cancer Referred to a Phase I Clinical Trials Program: The MD Anderson Cancer Center Experience," *Journal of Clinical Oncology*, vol. 30, no. 23 (2012): 2891-2896.

³³For example, see de Caprariis, Pascal J., Alex Carballo-Dieiguez, Sarah Thompson, and Claudia Lyon, "Advance Directives and HIV: A Current Trend in the Inner City," *Journal of Community Health*, vol. 38 (2013): 409-413.

³⁴For example, see Burgess, Mary; Stephen Cha, and Ericka E. Tung, "Advance Care Planning in the Skilled Nursing Facility: What Do We Need for Success?" *Hospital Practice*, vol. 39, no. 1 (2011): 85-90.

³⁵For example, see Clements, John M., "Patient Perceptions on the Use of Advance Directives and Life Prolonging Technology," *American Journal of Hospice & Palliative Medicine*, vol. 26, no. 4 (2009): 270-276.

³⁶See, for example, Tunzi, Marc; "Advance Care Directives: Realities and Challenges in Central California," *The Journal of Clinical Ethics*, vol. 22, no. 3 (2011): 239-248.

included in some advance directive forms.³⁷ Thirteen studies also identified challenges specific to Latinos or African Americans, such as language barriers, lack of trust in health care providers, or fear that advance directives may prevent them from getting the care they want to receive.³⁸

In addition to the challenges with informing individuals about advance directives, providers face similar challenges documenting this information, such as errors in individuals' medical records and challenges related to access or updates to advance directives, according to the literature and stakeholder officials. Specifically, nine studies found errors in individuals' records related to advance directives, such as lack of documentation about advance directives that should have been included in the records—in one case despite the fact that individuals had recently discussed directives with providers.³⁹ In addition, five studies reported challenges related to access to this information, such as challenges identifying where a copy of individuals' directives may be located or concerns that information about directives may not be transferred with individuals if they are moved from one provider to another; for example, from a nursing home to a hospital.⁴⁰ Similar concerns about access to documents were reiterated by four stakeholders we interviewed that represented providers and seniors. Two stakeholders representing nursing homes and managed care plans reported that providers face difficulties ascertaining in the documentation whether individuals had recently reviewed or updated their directives, or if the directives in individuals' records were current.

³⁷For example, see Gutierrez, Karen M., "Advance Directives in an Intensive Care Unit: Experiences and Recommendations of Critical Care Nurses and Physicians," *Critical Care Nursing Quarterly*, vol. 35, no. 4 (2012): 396-409.

³⁸See, for example, Jonnalagadda, Sirisha, Jenny J. Lin, Judith E. Nelson, et al. "Racial and Ethnic Differences in Beliefs About Lung Cancer Care." *CHEST*, vol. 142, no. 5 (2012):1251–1258.

³⁹For example, see Resnick, Helaine E., Susan Hickman, and Gregory L. Foster, "Documentation of Advance Directives Among Home Health and Hospice Patients: United States, 2007," *American Journal of Hospice & Palliative Medicine*, vol. 29, no. 1 (2012): 26-35.

⁴⁰For example, see Sharma, Rashmi K. and Sydney M. Dy, "Documentation of Information and Care Planning for Patients with Advanced Cancer: Associations with Patient Characteristics and Utilization of Hospital Care," *American Journal of Hospice & Palliative Medicine*, vol. 28, no. 8 (2011): 543-549.

Providers may better address challenges to inform individuals about advance directives and document them by using leading practices, according to the literature and stakeholders. Some of the leading practices for informing individuals about advance directives include patient education, materials tailored for specific groups, or an iterative advance care planning process. For example, one study using the Respecting Choices program—an advance care planning model developed by Gunderson Health System that includes multiple stages of care planning involving patients, providers, and communities—demonstrated that a provider using patient education and staff training efforts can increase the extent to which individuals understand and complete advance directives.⁴¹ In addition, 12 studies suggested that providers use materials designed for specific groups, such as videos, for those with low literacy or information developed for those with specific medical conditions that can help individuals better understand and communicate their preferences with providers.⁴² Eleven studies and four stakeholders that represented providers and individuals nearing the end of life also suggested using an iterative advance care planning process, such as a process that would start with community education about advance directives, continue with increasingly specific discussions with providers as an individual’s health deteriorates, and culminate with the completion of increasingly specific documents, such as advance directives or medical orders, as an individual nears the end of life.⁴³ Fifteen studies noted the importance of such planning when individuals are diagnosed with a major illness or impending loss of decision-making

⁴¹An intervention using the Respecting Choices advance care planning program, developed by the Gunderson Health System in La Crosse, Wis., demonstrated increases in patient understanding about advance directives, and provider follow up to ensure that directives are discussed with patients and information is entered in patients’ medical records. See Boettcher, Iris, Rozanne Turner and Linda Briggs. “Telephonic Advance Care Planning Facilitated by Health Plan Case Managers,” *Palliative and Supportive Care* (published online June 9, 2014): 1-6.

⁴²For example, see Schellinger, Sandra; Abbey Sidebottom, and Linda Briggs, “Disease Specific Advance Care Planning for Heart Failure Patients: Implementation in a Large Health System,” *Journal of Palliative Medicine*, vol. 14, no. 11 (2011): 1224-1230.

⁴³For individuals with deteriorating health conditions that place them close to the end of life, one study and two stakeholders representing seniors and managed care plans suggested that advance directives be supplemented with medical orders, such as physician orders for life sustaining treatment or “do-not-resuscitate” orders, that instruct providers to take specific medical actions.

capacity so that the individuals can communicate their preferences with providers before they are unable to do so.⁴⁴

Providers may also use leading practices to better address challenges to documenting information about advance directives in order to help ensure the accuracy and the accessibility of this information in an individual's medical record, according to the literature and stakeholder officials. For example, five studies found that using specific documentation methods, such as spreadsheets or electronic health record systems, can improve the accuracy—including quantity and quality—of the information about advance directives maintained in individuals' medical records.⁴⁵ Six studies also suggested that providers adopt electronic health record systems that, in addition to indicating whether individuals have an advance directive, could contain copies of the directives to ensure that individuals' preferences are more easily accessible to providers and families, especially for individuals that may transfer from one provider to another.⁴⁶

⁴⁴See, for example, Lawrence, James F., "The Advance Directive Prevalence in Long-Term Care: A Comparison of Relationships between a Nurse Practitioner Healthcare Model and a Traditional Healthcare Model," *Journal of the American Academy of Nurse Practitioners*, vol. 21 (2009): 179-185.

⁴⁵For example, see Bakerjian, Debra; Alice Bonner, Carol Benner, Cheryl Caswell, et al., "Reducing Perceived Barriers to Nursing Homes' Data Entry in the Advancing Excellence Campaign: The Role of LANEs (Local Area Networks for Excellence)," *Journal of the American Medical Directors Association*, vol. 12, no. 7 (2011): 508-517.

⁴⁶See, for example, Ahluwalia, Sangeeta C., Fukai L. Chuang, Anna Liza M. Antonio, Jennifer L. Malin, et al., "Documentation and Discussion of Preferences for Care Among Patients With Advanced Cancer," *Journal of Oncology Practice*, vol.7, no.6 (2011): 361-366.

Many Adults Have Advance Directives, but the Prevalence Varies by Provider Type, Demographics, and Over Time

Many adults in the United States have advance directives. In 2013, about 47 percent of adults over the age of 40 had an advance directive, according to IOM's report *Dying in America*.⁴⁷ In addition, an earlier nationally representative survey that included younger adults age 18 and older found that an estimated 26 percent of this population had an advance directive during the 2009 and 2010 time period.⁴⁸

The prevalence of individuals with advance directives varies by the type of provider that individuals are served by—hospitals, nursing homes, HHAs, and hospices—according to the literature. For three of these four provider types (hospice, nursing homes, and HHAs), a 2011 National Center for Health Statistics report found that 88 percent of discharged hospice patients in 2007 had advance directives, compared to 65 percent of nursing home patients in 2004, and 28 percent of HHA patients in 2007.⁴⁹ (See fig. 1.) Among the four covered provider types for which information was available, our analysis of 12 studies found that hospital patients were least likely to have advance directives and that hospice patients, who are by definition close to the end of life,⁵⁰ were the most likely to have advance directives as compared with nursing home and HHA patients.⁵¹ We did not find peer reviewed studies in our literature

⁴⁷IOM, *Dying in America*, see Tompson, et al., 2013, telephone survey conducted from February 21 through March 27, 2013, among a nationally representative sample of 1,019 American adults aged 40 and older, 125.

⁴⁸See Rao, Anderson, Lin, et al. "Completion of Advance Directives," 65-70. Information is from 7,946 adults 18 years or older that participated in nationally representative HealthStyles surveys in 2009 and 2010.

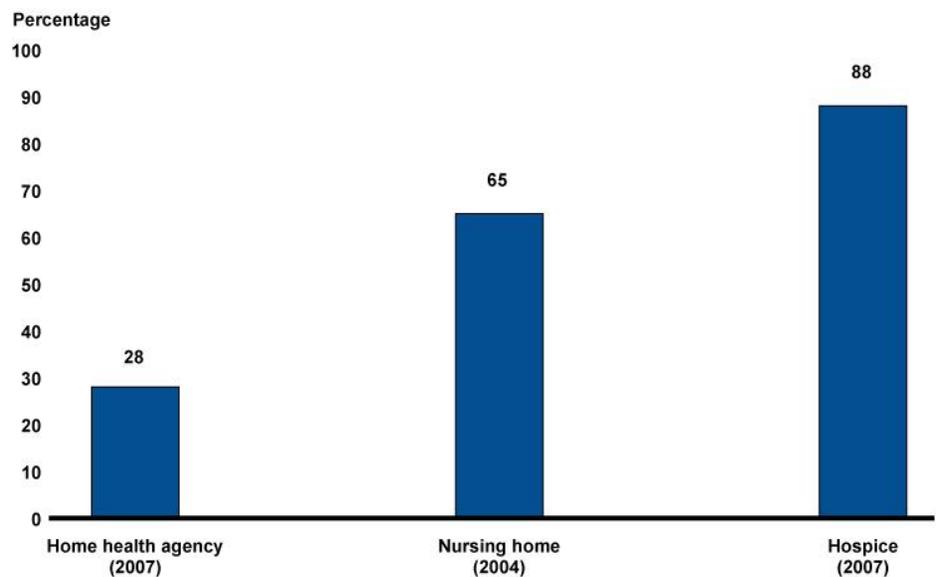
⁴⁹Nursing home data are from the 2004 National Nursing Home Survey resident file, and HHA and hospice data are from the 2007 National Home and Hospice Care Survey current patient and discharge files. Prevalence includes home health care and nursing home patients on the provider's roster the night before the interview, and hospice patients formally discharged from the provider during a designated 3-month reference period prior to the month of the interview, including both live and dead hospice discharges, which may represent episodes of care rather than the number of patients. See Jones, Moss and Harris-Kojetin, "Use of Advance Directives."

⁵⁰Two physicians must certify that an individual is likely to live only 6 months or less due to deteriorating medical conditions in order for that individual to receive Medicaid or Medicare funding for hospice services.

⁵¹For example, see Karches, Kyle E., Grace S. Chung, Vineet Arora, David O. Melzer and Farr A. Curlin, "Religiosity, Spirituality, and End-Of-Life Planning: A Single-Site Survey of Medical Inpatients," *Journal of Pain and Symptom Management*, vol. 44, no. 6 (2012): 843-851.

review on the prevalence of those with advance directives among individuals enrolled in MA and Medicaid managed care plans, although these individuals may also be served by the other four covered provider types.

Figure 1: Estimated Percentage of Patients with Advance Directives Served by Home Health Agency, Nursing Home, and Hospice Providers, 2004 and 2007



Source: Data from the National Center for Health Statistics, 2011. | GAO-15-416

Note: Nursing home data are from the 2004 National Nursing Home Survey resident file, and home health agency and hospice data are from the 2007 National Home and Hospice Care Survey current patient and discharge files. Prevalence includes home health care and nursing home patients on the provider's roster the night before the interview, and hospice patients formally discharged from the provider during a designated 3-month reference period prior to the month of the interview, including both live and deceased hospice discharges, which may represent more than one episode of care rather than number of patients.

In addition to variations by provider type, the prevalence of advance directives also varies among individuals based on certain demographic characteristics, such as medical conditions including chronic and life threatening diseases, according to the literature. For example, in 2010, individuals 18 years of age and older with chronic diseases were more likely than those without such diseases to have advance directives, with an estimated 33 percent and 22 percent prevalence, respectively.⁵² (See

⁵²See Rao, Anderson, Lin, et al. "Completion of Advance Directives," 65-70.

fig. 2.) A total of 20 studies found that individuals with certain medical conditions were more likely to have advance directives than healthier individuals. In general, certain medical conditions—such as diabetes, malignancies, renal dysfunction, dementia, or declining health—increased the likelihood that individuals had advance directives, according to the literature.⁵³

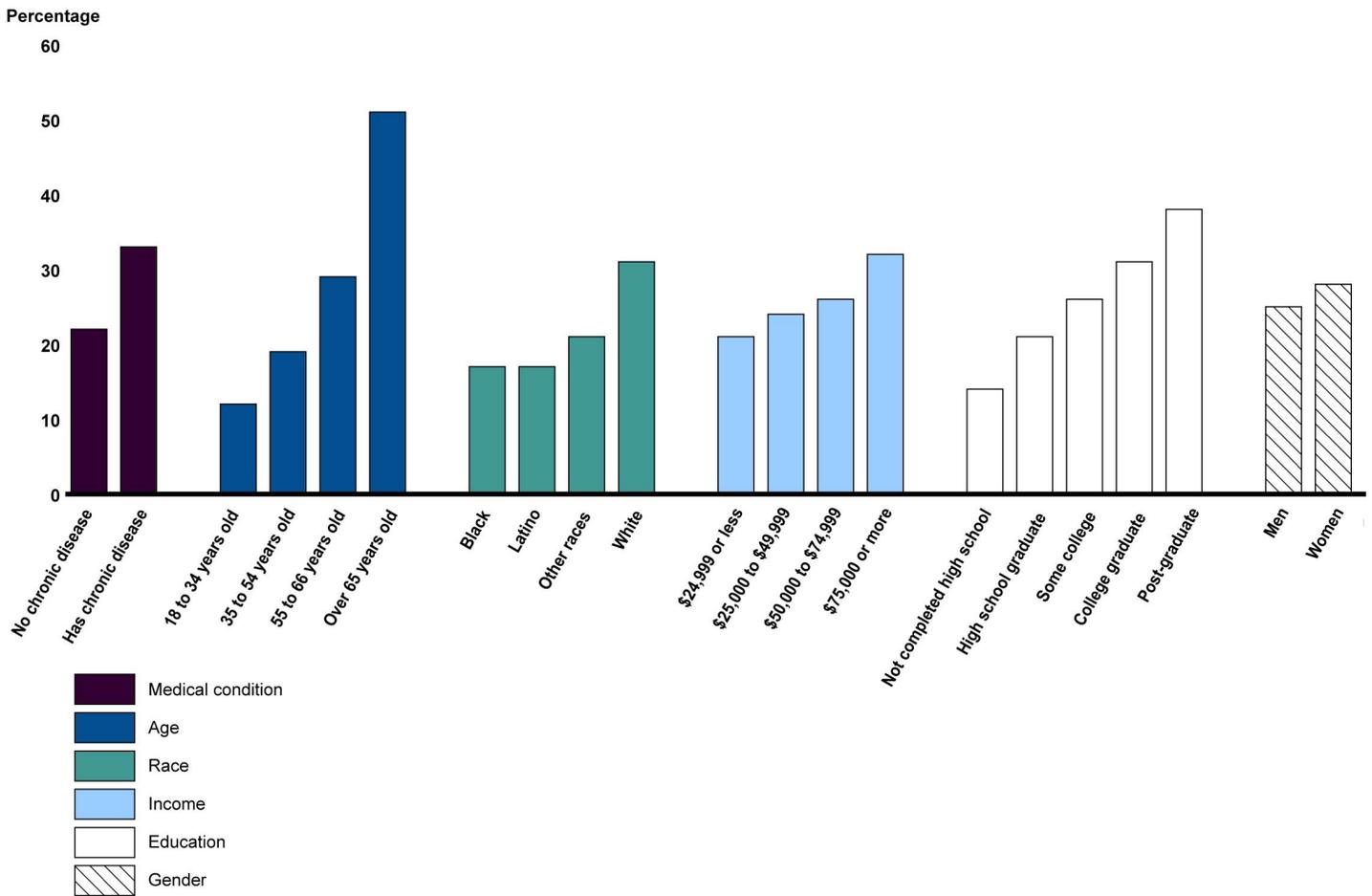
The prevalence of advance directives also varies by age, race, income, education, and gender, according to the literature. Older individuals were more likely to have advance directives than younger individuals. For example, a 2009 and 2010 nationally representative survey found that an estimated 51 percent of individuals 65 years of age and older had advance directives, while among individuals 18 to 34 years old, an estimated 12 percent had advance directives.⁵⁴ The survey also indicated that an estimated 31 percent of whites compared to an estimated 17 percent of African Americans or Latinos had advance directives. In addition, this study found that an estimated 32 percent of individuals with incomes of \$75,000 or more had advance directives in comparison to an estimated 21 percent of those with incomes under \$25,000. Similarly, prevalence among individuals with post-graduate educations compared to those who had not completed high school was an estimated 38 percent and an estimated 14 percent, respectively, according to the study. Women were also more likely to have advance directives than men, an estimated 28 percent versus 25 percent, according to the study. In addition to this study, 36 studies found variations in the prevalence of advance directives by age, race, income, education, or gender.⁵⁵

⁵³For example, see Hirschman, Karen B., Katherine M. Abbott, Alexandra L. Hanlon, Janet Prvu Bettger, et al., “What Factors Are Associated With Having an Advance Directive Among Older Adults Who Are New to Long Term Care Services?” *Journal of the American Medical Directors Association*, vol. 13 (2012): 82e7-82e11.

⁵⁴See Rao, Anderson, Lin, et al., “Completion of Advance Directives,” 65-70.

⁵⁵For example, see Alano, Gloria J., Renee Pekmezaris, Julia Y. Tai, Mohammed J. Hussain, Jose Jeune, et al., “Factors Influencing Older Adults to Complete Advance Directives,” *Palliative and Supportive Care*, vol. 8 (2010): 267-275.

Figure 2: Estimated Prevalence of Adults with Advance Directives Based on Demographic Characteristics, 2009 and 2010



Source: GAO analysis of data from "Completion of Advance Directives Among U.S. Consumers," *American Journal of Preventive Medicine*, 2014. | GAO-15-416

Note: Information is from 7,946 adults 18 years or older that participated in nationally representative HealthStyles surveys in 2009 and 2010.

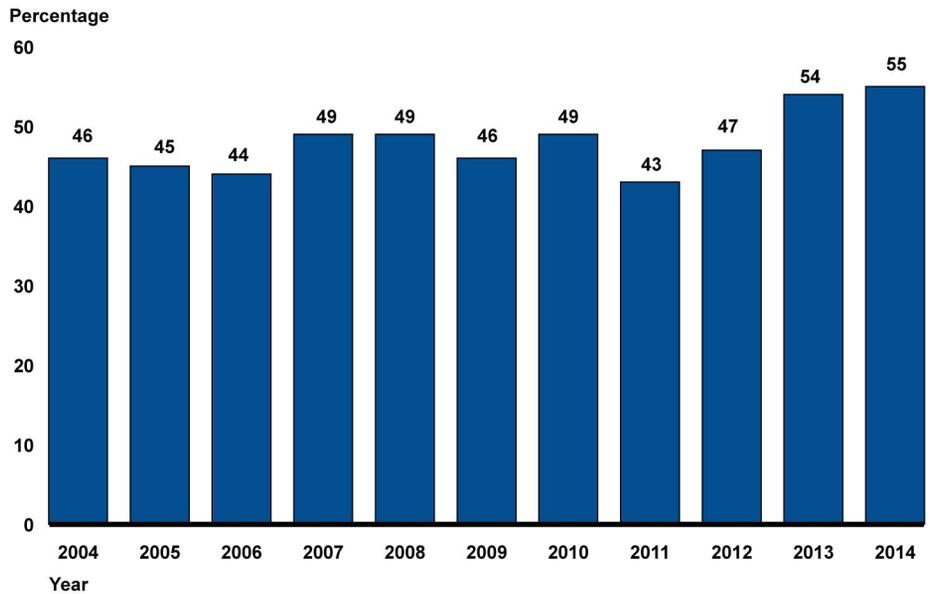
The prevalence of advance directives has been increasing over time, according to the literature and CMS data. For example, prevalence within the older population has increased over time, according to a study examining the prevalence of advance directives for those 60 years of age or older who died between 2000 and 2010. This study found that individuals 60 years of age and older who died during that period with an advance directive increased from an estimated 47 percent to

72 percent.⁵⁶ Available information on nursing home residents also shows an increase over time. Our analysis of CMS data found that the proportion of nursing home patients with advance directives has increased between 2004 and 2014. We found that the average percentage of nursing home patients who had an advance directive increased from 46 percent in 2004 to 55 percent in 2014, based on data from nursing homes that were surveyed during that time. (See fig. 3.) However, the percentage of nursing home residents having advance directives fluctuated over this period. Eight additional studies found increases in the prevalence of those with advance directives over time for a specific group, such as those from one state or type of provider.⁵⁷ Factors that may have contributed to the increasing prevalence of individuals with advance directives over time, according to the literature, include community education efforts and provider staff training.

⁵⁶Silveria, Wiitala and Piette, "Advance Directive Completion by Elderly," 706-710.

⁵⁷For example, see Hammes, Bernard J., Brenda L. Rooney and Jacob D. Gundrum, "A Comparative, Retrospective, Observational Study of the Prevalence, Availability, and Specificity of Advance Care Plans in a County that Implemented an Advance Care Planning Microsystem," *Journal of the American Geriatrics Society*, vol. 58 (2010): 1249-1255.

Figure 3: Prevalence of Advance Directives Among Nursing Home Patients, 2004 to 2014



Source: GAO analysis of Center for Medicare & Medicaid Services data. | GAO-15-416

Agency Comments

We requested comments on a draft of this product from HHS. HHS provided technical comments, which we incorporated as appropriate.

We are sending copies of this report to the appropriate congressional committees, the Secretary of Health and Human Services, and other interested parties. In addition, the report will be available at no charge on the GAO website at <http://www.gao.gov>.

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Vijay A. D'Souza
Director, Health Care

Appendix I: GAO Contact and Staff Acknowledgments

GAO Contact

Vijay A. D'Souza, (202) 512-7114, DsouzaV@gao.gov

Staff Acknowledgements

In addition to the contact named above, James C. Musselwhite Jr., Assistant Director; George Bogart; Kye Briesath; Leia Dickerson; Julianne Flowers; Jennel Lockley; Drew Long; and Vikki Porter made key contributions to this report.

Appendix II: Accessible Data

Data Table for Figure 1: Estimated Percentage of Patients with Advance Directives Served by Home Health Agency, Nursing Home, and Hospice Providers, 2004 and 2007

Provider	Percentage
Home health agency (2007)	28%
Nursing home (2004)	65%
Hospice (2007)	88%

Source: Data from the National Center for Health Statistics, 2011. GAO-15-416.

Data Table for Figure 2: Estimated Prevalence of Adults with Advance Directives Based on Demographic Characteristics, 2009 and 2010

Demographic	Percentage
No Chronic Disease	22%
Has Chronic Disease	33%
18 to 34 years old	12%
35 to 54 years old	19%
55 to 65 years old	29%
Over 65 years old	51%
Black	17%
Latino	17%
Other races	21%
White	31%
Income \$24,999 or less	21%
Income \$25,000 to \$49,999	24%
Income \$50,000 to \$74,999	26%
Income \$75,000 or more	32%
Not Completed High School	14%
High School Graduate	21%
Some College	26%
College Graduate	31%
Post-graduate	38%
Men	25%
Women	28%

Source: GAO analysis of data from "Completion of Advance Directives Among U.S. Consumers," *American Journal of Preventive Medicine*, 2014. GAO-15-416.

Data Table for Figure 3: Prevalence of Advance Directives Among Nursing Home Patients, 2004 to 2014

Year	Percentage
2004	46%
2005	45%
2006	44%
2007	49%
2008	49%
2009	46%
2010	49%
2011	43%
2012	47%
2013	54%
2014	55%

Source: GAO analysis of Center for Medicare & Medicaid Services data. GAO-15-416.

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