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## ADVANCE CARE PLANNING AND ADVANCE DIRECTIVES

Policy options to ensure patients' wishes are known at the time that decisions are made and followed by family and health practitioners

### Issue Summary

Advance care planning is a process where individuals express their wishes about health care and ensure that in cases where that person cannot express their own wishes, others are able to do so.<sup>1</sup> An important piece of this process is a conversation where the individual and his or her family learn about options and discuss their preferences. Following this conversation and to ensure their wishes will be followed, it is important that individuals record their decisions in a variety of documents, including instructional directives and proxy directives.<sup>2</sup>

Instructional Directives are those that give direction to guide decisions about future care.<sup>3</sup> These are designed to communicate a patient's values, goals, and specific treatment wishes to those that are forced to make difficult decisions on the patient's behalf. Examples of instructional directives are living wills, Do-Not-Resuscitate Orders (DNR Orders), Medical Orders for Scope of Treatment (MOST forms, in other states referred to as POST or POLST forms), CPR Directive, and Five Wishes. Depending on context, many of these documents may be referred to alone or together as a patient's advance directive.

Proxy Directives are documents that formally appoint a decision-maker for instances where a patient is unable to make or express decisions for themselves. These documents are formal legal documents called durable medical powers of attorney. The individual appointed as decision-maker may be referred to as the patient's agent, surrogate decision-maker, or proxy decision-maker. In some states, there are laws appointing a default decision-maker if the person has not chosen one or if that person is unavailable.<sup>4</sup> In Colorado, the default proxy statute requires a number of interested individuals to decide by consensus on a person to be the proxy in this situation.<sup>5</sup>

Crucial to these important documents having the effect that the patient intended is that the health practitioner and family know of the documents, that the documents are available when they are needed,

<sup>1</sup> National Institute on Aging, "Advance Care Planning," Text, *National Institute on Aging*, (February 23, 2012), <https://www.nia.nih.gov/health/publication/advance-care-planning>.

<sup>2</sup> CDC, "Advance Care Planning: Ensuring Your Wishes Are Known and Honored If You Are Unable to Speak for Yourself." (Centers for Disease Control and National Association of Chronic Disease Directors, 2012), <http://www.cdc.gov/aging/pdf/advanced-care-planning-critical-issue-brief.pdf>.

<sup>3</sup> J. M. Teno et al., "Do Advance Directives Provide Instructions That Direct Care? SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment," *Journal of the American Geriatrics Society* 45, no. 4 (April 1997): 508–12.

<sup>4</sup> "Default Surrogate Consent Statutes" (American Bar Association, June 2014), [http://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2014\\_default\\_surrogate\\_consent\\_statutes.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.authcheckdam.pdf).

<sup>5</sup> C.R.S. §§ 15-18.5-101 to 103. Available at: <http://www.lexisnexis.com/hotttopics/colorado?source=COLO;CODE&tocpath=1A53PZKP1KIDJWC3L,2FTOM1UFJS9VWOMOC,3Q3BISDE6PRSLVOPM;1WZHYZPO10FHKWWPK,2QRWSJMHKGSJL9ISL,3XWTSSTU4XO4Z50HK;1T2RBWFU29N3J8ZNJ,2D366BQOHEJXB4B7M,3BWGZ87YSW8KTXESJ&shorthead=no>

and that the document be as current as possible.<sup>6</sup> In Colorado, there are a number of laws that have been passed with the intent of increasing the legal authority of advance directive documents.

However, issues remain around the knowledge of and availability of these documents at crucial times. One possible policy option to increase the availability of these documents at critical times is the creation of a statewide registry of advance directives where individuals can store their directives and from where health practitioners can access the directives in cases where the individuals needs care but cannot express decisions about that care. State registries are active in a number of states and there have been past efforts to create such a registry in Colorado.

### **Advance Care Planning: The Basics**

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Advance care planning is a process where individuals express their wishes about health care and ensure that in cases where that person cannot express their own wishes, others are able to do so.<sup>7</sup> An important piece of this process is a conversation where the individual and his or her family learn about options and discuss their preferences. Following this conversation and to ensure their wishes will be followed, it is important that individuals record their decisions in a variety of documents, including instructional directives and proxy directives.<sup>8</sup>

Three vital tasks in advance care planning are (1) appointing a surrogate decision-maker, (2) ensuring family, caregivers, and the surrogate understand the individual's wishes for treatment and the individual's values and attitudes about life, death and dying, and (3) engaging in conversation about wishes for treatment.<sup>9</sup>

*Appointing a surrogate decision-maker* – In cases where a patient is unable to make or express decisions about their own care, it's important that a person be available and ready to make those decisions. Many people assume that if they are unable to make decisions that their spouse or other family member would be able to make decisions, but that is not always the case. In Colorado, if a proxy is needed and a person fails to appoint a decision-maker, the proxy will be chosen by a number of interested persons. Research has shown the importance of the proxy in ensuring the patient's wishes are observed. In particular, for a proxy to be effective, he or she must be readily available and needs to be an effective advocate.<sup>10</sup> The process of proxy decision-making requires regular communication between proxy and health provider, as the goals of care change and the patient's condition changes.

*Ensuring family, caregivers, and the surrogate understand the individual's values and attitudes about life, death and dying* – While many discussions of advance care planning focus on specific treatments, it is equally important that the individual's values and attitudes be shared as part of the process. Some suggest that patients' preferences depend less on treatment specifics than on treatment outcomes.<sup>11</sup> Patients regularly weigh the burdens of treatment against the possible outcomes. As such, part of the advance care planning process includes discussion of patient values that might inform decisions about treatment options.

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<sup>6</sup> CDC, "Advance Care Planning: Ensuring Your Wishes Are Known and Honored If You Are Unable to Speak for Yourself."

<sup>7</sup> Aging, "Advance Care Planning."

<sup>8</sup> CDC, "Advance Care Planning: Ensuring Your Wishes Are Known and Honored If You Are Unable to Speak for Yourself."

<sup>9</sup> Ibid.

<sup>10</sup> Joan M. Teno et al., "Role of Written Advance Directives in Decision Making: Insights from Qualitative and Quantitative Data," *Journal of General Internal Medicine* 13, no. 7 (July 1998): 439–46, doi:10.1046/j.1525-1497.1998.00132.x.

<sup>11</sup> Terri R. Fried et al., "Understanding the Treatment Preferences of Seriously Ill Patients," *New England Journal of Medicine* 346, no. 14 (2002): 1061–1066.

*Engaging in conversation about wishes for treatment* – Researchers and advocates agree that for advance care planning to be effective, it must be a process, not just a collection of documents.<sup>12</sup> On researcher noted that “as patients die, the patient, family, and health care provider often negotiate a transition in the goals of care,” moving from extending life to patient comfort.<sup>13</sup> During these difficult decisions, it’s important that the health provider and decision-maker understand not just the patient’s values, but also the patient’s wishes for treatment. Advance directive documents are an important part of communicating treatment wishes.

The above-listed factors are vital to effective advance care planning as a process, but to give full effect to the decisions made, they must be documented. Advance care documents generally fit into one of two broad categories: instructional directives and proxy directives.<sup>14</sup>

*Instructional Directives* – Instructional directives are documents that give direction about future care. Many people first think of living wills in this category; this is appropriate as they were, historically, the only documents available. *Living wills* emerged in the 1960s when medical science had transformed end of life care with ventilators and other machines capable of prolonging life, “even for patients whose chances of survival were vanishingly small.”<sup>15</sup> Traditionally, living wills include more “poetic” language that might be hard to implement when faced with specific treatment decisions. Further, conditional statements such as “If my death is imminent” can present challenges as to determining when the document’s terms go into effect.<sup>16</sup>

With the difficulties of using living wills in specific treatment situations, new directives have emerged that provide more specific treatment decisions. Countering the trouble with living wills, modern *advance directives* can be easier to apply in specific situations (However, the specificity can be harder to apply in vague or unpredictable situations).<sup>17</sup> Research has suggested that modern health care directives are especially helpful for physicians treating patients with whom they have no prior relationship.<sup>18</sup> In one study, patients’ judgment about the proper course was compared to the judgment of physicians working in hospital settings, where they might encounter the individuals in an emergency or end of life situation. With the documents, the accuracy of these physicians’ judgments compared to the patient’s judgment significantly increased.

Some instructional directives are even more specific, in particular *Colorado’s CPR Directives* and *MOST forms*. CPR directives are used to specifically refuse cardiopulmonary resuscitation in the event of cardiac arrest. These documents do not include other provisions, but in the specific instance where they apply, emergency personnel and health providers must comply with the refusal. Similarly, MOST forms detail specific medical interventions and whether the patient wishes them to be performed. The MOST is a medical order, meaning it must be completed by a physician and must be complied with in the specific treatment situations in the form.

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<sup>12</sup> Teno et al., “Role of Written Advance Directives in Decision Making.”

<sup>13</sup> Ibid.

<sup>14</sup> Teno et al., “Do Advance Directives Provide Instructions That Direct Care?”

<sup>15</sup> Ibid.

<sup>16</sup> Ibid.

<sup>17</sup> Fried et al., “Understanding the Treatment Preferences of Seriously Ill Patients.”

<sup>18</sup> K. M. Coppola et al., “Accuracy of Primary Care and Hospital-Based Physicians’ Predictions of Elderly Outpatients’ Treatment Preferences with and without Advance Directives,” *Archives of Internal Medicine* 161, no. 3 (February 12, 2001): 431–40.

*Proxy Directives* – Proxy directives are the legally binding documents in which a patient names a surrogate decision-maker. The most common form (and most legally authoritative) of these documents is the medical durable power of attorney. This document affords the named proxy a broad range of authority to respond to patient issues according to their understanding of the patient’s values (but cannot override some documents). These documents can include a variety of limitations on the proxy’s authority.

For these (many) documents to be truly successful, the document must be as current as possible to reflect the individual’s condition and goals, the treating health provider (and others) must know of the documents, and the health provider must adhere to the patient’s wishes.<sup>19</sup>

*Current to reflect wishes and condition* – The American Bar Association (and the American Academy of Estate Planning Attorneys) offer an easy to remember guide to when advance directive documents should be reviewed – The 5 Ds:

- Death (of a friend or family)
- Divorce
- (new) Diagnosis
- Decline (in health)
- Decade<sup>20</sup>

The 5 Ds are a helpful guide because they emphasize the number of factors that might impact the decisions reflected in advance directive documents. The first two (death and divorce) emphasize the changes that might happen requiring a change in proxy. The last three (diagnosis, decline, and decade) point to factors that could have significant impacts on a patient’s values and desires for treatment.

*Treating health provider must know of the documents* – It is perhaps obvious to state that for a document detailing the patient’s wishes to be effective it must be made known to the treating physician. However, this is an important point that must be considered when completing the ACP process. For the MOST form, which can include vital instructions in cases of emergency, the Colorado Consortium on Advance Directives recommends that individuals place the form on the refrigerator, by the bed, and by the phone in the kitchen.<sup>21</sup> These are the locations that emergency personnel are trained to look in emergencies. When not at home, the consortium recommends that individuals carry a paper copy of the form with them at all times.

Posting the two-page MOST form on a refrigerator or carrying it at all times is perhaps possible, but it is unlikely that individuals will wish to carry paper copies of the variety of forms included in the ACP process. Therefore, it is important the individuals take steps to make their advance directive documents known. In Larimer County, it is recommended by the ACP Team at the Health District of Northern Larimer County that individuals take copies of their forms to all hospitals in the area, regardless of whether the individual has previously been a patient. Most hospitals can open a patient record to import

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<sup>19</sup> CDC, “Advance Care Planning: Ensuring Your Wishes Are Known and Honored If You Are Unable to Speak for Yourself.”

<sup>20</sup> Randi Siegel, “The ‘5 D’s’ for Reviewing Clients’ Advance Directives,” *American Academy of Estate Planning Attorneys*, September 10, 2012, <http://www.aaepa.com/2012/09/5-ds-reviewing-clients-advance-directives/>.

<sup>21</sup> “Getting the Most out of the Medical Orders for Scope of Treatment Process and Form” (Colorado Advance Directives Consortium, April 2015), <http://coloroadvancedirectives.com/wp-content/uploads/2014/07/1-MOST-Booklet-REV-2015.pdf>.

the advance directive so that in case of need the documents are available. However, the patient must be sure to update records if documents change or if a new facility opens.

(For other options for improving access to records, see below)

*Health provider must adhere to the patient's wishes* – Even with an advance directive in hand, treating providers regularly face challenges with adhering to the patient's wishes. As noted above, some documents are vague and difficult to apply in clinical settings.<sup>22</sup> Alternatively, some documents are too specific to apply in unclear or changing situations. Several writers have noted the difficulty for physicians in knowing whether the treatment decisions are “triggered.”<sup>23</sup> For example, how is a physician to know when a stated condition of “hopeless” has occurred?

### **Advance Care Planning at the Health District of Northern Larimer County**

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In 2016, the Health District of Northern Larimer County was awarded a grant by the Colorado Health Foundation to greatly increase the number of individuals in the community that have participated in advance care planning.<sup>24</sup> This team has partnered with UHealth's Aspen Club, Colorado Health Medical Group, the Palliative Care Team at UHealth, Associates in Family Medicine, Columbine Health Systems, the Larimer County Office on Aging and the Sharing the Care Campaign to complete this mission.

The team's mission is to help “adults to feel comfortable discussing their end-of-life wishes, understand their medical care options and express their values with their loved ones and medical providers, and ensuring that medical directives are available when they are needed.” By working with individuals, the ACP team facilitates conversations and helps those individuals document their preferences.

The team is also looking to work directly with health providers to increase awareness and increase ACP completion with their patients.

### **Colorado Legal Landscape of Advance Care Planning**

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Colorado has a number of provisions in its law affirming the rights of patients to make decisions about their treatment or about their refusal of treatment. The Colorado Patient Autonomy Act, passed in the 1970s, was the first law and since that time a number of provisions have been added and sections amended. Colorado's law allows for the creation of medical durable powers of attorney (appointing a proxy health decision-maker), the authority of powers of attorney created in other jurisdictions, the authority of advance directive documents, and specifically for CPR Directives and Medical Orders for Scope of Treatment.

**C.R.S. 15-14-503 – 509 – Colorado Patient Autonomy Act** – This act, passed in 1979, positively affirms the right of a patient to accept or reject medical treatment and spells out rights and requirements with regard to medical durable powers of attorney.

**C.R.S. 15-14-506 – Medical Durable Power of Attorney** – This code defines the medical durable power of attorney, which authorizes an agent to act on behalf of a principal in consenting to or refusing treatment. These documents may contain any number of exceptions, conditions, or limitations that might be used to guide the decision-making process of the agent in a case where the patient lacks decision-making capacity.

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<sup>22</sup> Teno et al., “Role of Written Advance Directives in Decision Making.”

<sup>23</sup> Henry S. Perkins, “Controlling Death: The False Promise of Advance Directives,” *Annals of Internal Medicine* 147, no. 1 (2007): 51–57.

<sup>24</sup> “Larimer Advance Care Planning Team,” *Health District of Northern Larimer County Advance Care Planning Team*, 2016, <http://www.larimeradvancecare.org/>.

These individuals who are authorized to make decisions are made immune from civil or criminal liability for executing their powers in good faith.

**C.R.S. 15-14-509** – Interstate effect of medical durable power of attorney – The laws regarding powers of attorney and their creation vary from state to state. This section attempts to encourage other states’ courts to give effect to medical durable powers of attorney created in Colorado. Further, it states that similar instruments created in other states can be presumed to comply with Colorado’s laws, giving them effect.

**C.R.S. 15-18 – The Colorado Medical Treatment Decision Act** – This Act affirms the rights of patients to make decisions about their future care and for those decisions to have effect in cases where the patient does not have decisional capacity. This section primarily details provisions around living wills and when they can apply (and when a living will can be challenged by others if the patient is incapacitated)

**C.R.S. 15-18.5 - Proxy Decision-Makers for Medical Treatment and Surrogate Decision-Makers for Health Care Benefit Decisions** – This code section spells out the authority of proxy decision-makers appoint via a durable power of attorney to make health decisions in cases where the patient lacks decisional capacity. Further, when a proxy decision-maker is not already appointed, a proxy may be chosen by consensus of a variety of “interested persons,” who include “the patient’s spouse, either parent of the patient, any adult child, sibling, or grandchild of the patient, or any close friend of the patient.”

**C.R.S. 15-18.5** – Directive Relating to Cardiopulmonary Resuscitation – CPR Directives are directives documenting a patient’s refusal of CPR for patients in cardiopulmonary arrest. These orders must be complied with by emergency medical personnel, health care providers, and health facilities when the directive is “apparent and immediately available.”

**C.R.S. 15-18.7** – Directives Concerning Medical Orders for Scope of Treatment (MOST) – Medical Orders for Scope of Treatment are medical orders that must be complied with by health practitioners, facilities, and emergency personnel. These orders are created by medical professionals following discussions with the patient about options and the patient’s choices to accept or refuse life-sustaining treatment. The standardized form is similar to the POST and POLST form used in other states.

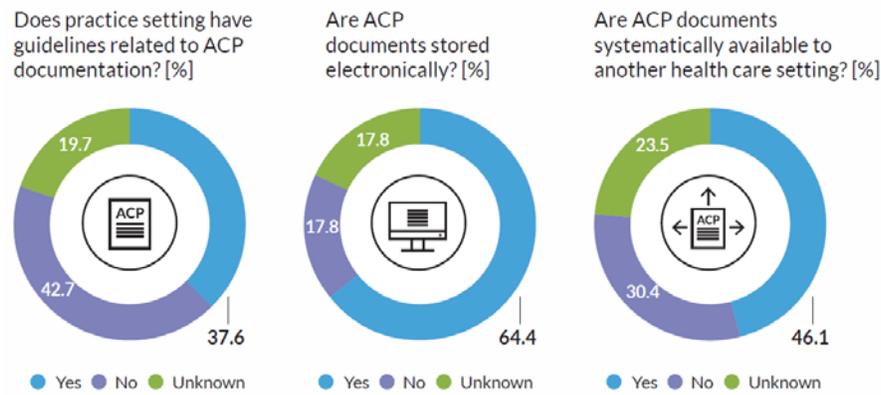
### **How to record Advance Directives and get them into “play”**

As noted above, in Colorado, a patient’s wishes and choices must be documented in a variety of different forms: durable medical power of attorney, advance directive (living will), CPR directive, and medical order for scope of treatment (MOST). Health providers must comply with the patient’s wishes in these documents, but only if the documents are accessible, and in the case of CPR Directives and MOST the documents must be “*apparent and immediately available.*”

Making these documents readily available and accessible is an important step in the Advance Care Planning process. Electronic Health Records are the seemingly obvious location for health providers to store advance directive documents, but implementation has thus far been a challenge. In a survey of Colorado health providers and practices about advance care planning, while many ACP documents are stored electronically (64.4%), less than half responded that the ACP documents were available in other health settings.<sup>25</sup> This is supported by stories of a lack of EHR interoperability across the health community.

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<sup>25</sup> “Advance Care Planning – Perspectives from Colorado Health Care Providers” (Colorado Health Foundation., 2015), <http://www.coloradohealth.org/WorkArea/DownloadAsset.aspx?id=8227>.



Most settings do not have guidelines related to ACP documentation. ACP documents are stored electronically in 64% of practice settings, although only 46% are able to provide ACP documents with another health care setting.

Figure 1 - Colorado Provider and Practice Demographics<sup>26</sup>

As noted previously, in Larimer County it is recommended that patients take their documents to health providers across the community, including those where the patient has never received care. The need for an advance directive document can happen in any location, so this is a key way to make them available.

### Statewide Registries for Advance Directive Documents

In an effort to make advance directive documents more widely available when they are needed, at least 10 states have created statewide registries.<sup>27</sup> These states are Arizona, California, Idaho, Louisiana, Maryland, Montana, Nevada, North Carolina, and Vermont (and Washington, whose registry may have closed due to funding). These registries vary in their operation and which forms are included.

**Example: Vermont Advance Directive Registry<sup>28</sup>** – The state of Vermont offers a statewide registry of advance directives that is operated by a contractor, [www.uslivingwillregistry.com](http://www.uslivingwillregistry.com).<sup>29</sup> The state’s registry is administered by the Department of Health and as of June, 2016 reports that it contains approximately 32,000 “registrations,” though it is unclear if this number is the total number of documents or registrants.

Registrants in Vermont can file the directive documents with the registry or can simply register a description of the physical location of the documents.<sup>30</sup> Providers (or others) can gain access to a Vermont registration by using one of three methods. First, by logging into the registry using a registrant’s ID number, which registrants are instructed to carry with them on a special wallet card. Second, by calling the registry’s toll-free number and going through various steps to confirm that the caller is a provider. Third, health providers

<sup>26</sup> Ibid.

<sup>27</sup> “Advance Directive Registries: A Policy Opportunity” (Center for Healthcare Research and Transformation, September 2011), [www.chrt.org/document/advance-directive-registries-a-policy-opportunity/](http://www.chrt.org/document/advance-directive-registries-a-policy-opportunity/).

<sup>28</sup> “Vermont Advance Directive Registry,” accessed August 17, 2016, <http://healthvermont.gov/vadr/>.

<sup>29</sup> “U.S. Living Will Registry - State Registries,” accessed August 17, 2016, <http://liv-will1.uslivingwillregistry.com/state.html>.

<sup>30</sup> “Vermont Advance Directive Registry Policies and Procedures” (Vermont Department of Health, 2016), [http://healthvermont.gov/vadr/documents/AD\\_policies\\_procedures.pdf](http://healthvermont.gov/vadr/documents/AD_policies_procedures.pdf).

can go through an application process to create a registry account that provides access to the registry in a searchable format.<sup>31</sup>

To ensure health provider compliance, Vermont requires that providers first (except in emergencies) attempt to determine whether a patient without capacity has an advance directive in effect.<sup>32</sup> If an advance directive is found, the providers must then comply by the advance directive to the best of their ability.

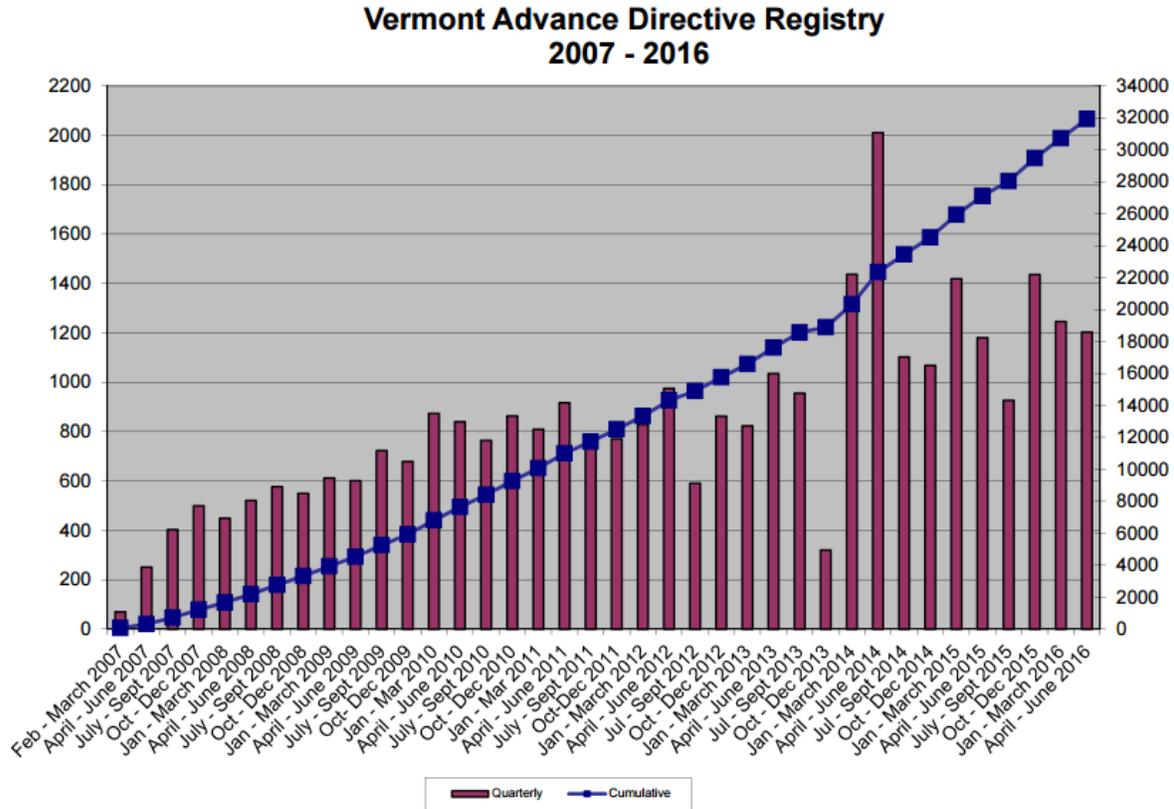


Figure 2 Data Snapshot: Vermont Registrations<sup>33</sup>

## SB15-125 – Statewide Registry for Advance Directives

**Bill Sponsors:** Senate – Steadman (D)  
**Committee:** Senate State, Veterans, and Military Affairs  
**Bill History:** 02/09/2015 – Postponed Indefinitely

**Bill Summary:** This bill would have created a statewide advance directive registry within Colorado Department of Public Health and Environment, recording powers of attorney, CPR Directives, MOST forms, declarations as to medical treatment, living wills, or forms

<sup>31</sup> “Provider Access to the Registry - Vermont Advance Directives(VADR)- Vermont Department of Health,” accessed August 17, 2016, <http://healthvermont.gov/vadr/access.aspx>.

<sup>32</sup> Vermont Laws, Title 18, Chapter 231 § 9709, at: <http://legislature.vermont.gov/statutes/section/18/231/09709>

<sup>33</sup> <http://healthvermont.gov/vadr/>

properly executed in other states on these issues. The registry would have been a website with specific privacy protections, allowing individuals to grant access to others and allowing health providers to gain access. County clerks would record documents and submit them to the state registry.

The fiscal note noted that to perform this task the state would most likely contract with a national vendor that already does this. Most likely would have been <http://www.uslivingwillregistry.com/>

**Fiscal Note:** \$81,505 in first year, including approximately \$50,000 for state personnel and \$24,000 for registry contract.

**Proponents** (with registered lobbyists)

- Boulder County
- Mental Health America of Colorado

**Opponents** (with registered lobbyists)

- Colorado Society of Osteopathic Medicine

**Other methods of increasing access and/or availability of ACP documents**

- *Private Registries* – There are a number of private entities offering registries for advance care planning documents. The largest, U.S. Living Wills Registry, is used by several states to facilitate the states’ exchanges. However, private individuals in other states (including Colorado) can register their documents with it, for a fee. Currently a registration costs \$59 for five years and comes with a wallet card and other materials to help others gain access to the registry. One challenge with private registries is that providers may not be able to access every registry or might question the validity of the private registry. However, they offer one method of storing documents in a secure yet accessible location.



Figure 3 U.S. Living Wills Registry, a private advance directive registry at [www.uslivingwillregistry.com](http://www.uslivingwillregistry.com)

- *Smartphone apps/other personal tech solutions* – There are a number of apps available for smartphones that serve as storage for ACP documents. The American Bar Association Commission on Law and Aging has created a smartphone app called My Health Care Wishes Pro.<sup>34</sup> This app allows for the storage of any documents for any number of friends or family. The app is low-cost (\$3.99) and is a convenient method for individuals to readily store their own documents or documents of those close to them. Like private registries, smart phone apps present unique challenges, including providers (or others) not knowing how to access the apps and not being able to verify the accuracy of the documents.
- *Wallet Cards and Driver’s License Icons* – Many registries include a wallet card that will allow the registrants to carry their registry information for ease of access in an emergency. In Ohio, applicants

<sup>34</sup> “My Health Care Wishes Pro on the App Store,” *App Store*, accessed August 17, 2016, <https://itunes.apple.com/us/app/my-health-care-wishes-pro/id554946247?mt=8&ign-mpt=uo%3D4>.

for a drivers license are asked if they wish for their license to include an icon indicating that they have a living will or advance directive.<sup>35</sup>

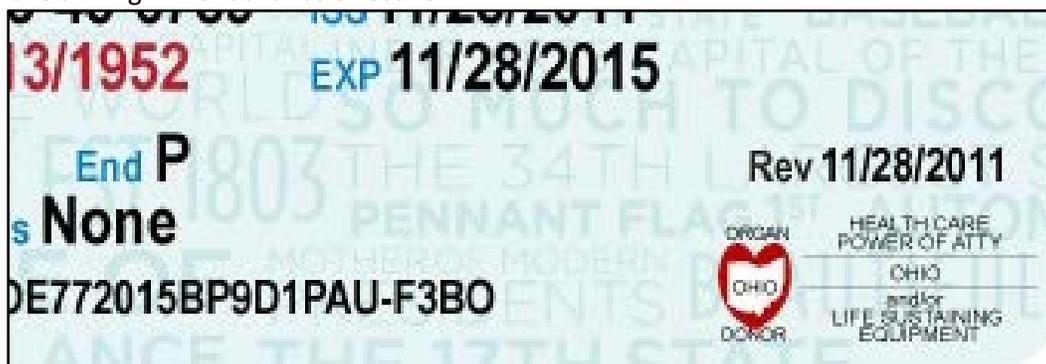


Figure 4 Ohio License Sample Showing the Licensee has a Power of Attorney or Other Health Directive.

## Discussion

### Important considerations in the design and implementation of an Advance Directive Registry

- How would this information be available in emergency situations?
- What privacy protections need to be put in place?
- If a directive is registered with the state's registry, but other directives (made earlier or later) exist outside the registry, what sort of procedure would be in place to ensure the most recent directive has priority? Is there some good way to recall other outstanding directives previously distributed?
- Who has access to a patient's directives?

### Arguments in support of an Advance Care Registry

- Patients who complete Advance Care Planning documents can better ensure that their documents are available and accessible to those that need them. Especially for patients with completed ACP documents but who require treatment outside their home area, the documents can be accessed anywhere.
- With increased availability of advance directives by registration in a state-sponsored registry, treating physicians could better understand patient wishes and values, which leads to medical decision-making that is better aligned with the patient's intent.
- Updating ACP documents (should be relatively often – see the 5 D's discussed above) become easier when all documents are easily stored in one place. This reduces the risk of providers encountering multiple (potentially contradictory) versions of advance directives.
- Statewide registry could increase awareness of advance care planning among patients and providers across the state. There are a number of organizations around the state ramping up efforts to increase awareness of advance care planning and to encourage more people to complete them. A statewide advance directive registry would complement these efforts both in effectiveness of the documents and in increasing statewide awareness among the general population and health providers.

### Concerns about Advance Directive Registries

- *Privacy* – Confidentiality issues are complicated with regard to advance care planning documents. The documents reflect very personal decisions and values, as well as a great deal of confidential information, such as social security numbers, physician names, birth dates and more. This information

<sup>35</sup> "State of Ohio BMV," accessed August 17, 2016, <http://www.bmv.ohio.gov/dl-other-living-will.aspx>.

should be kept confidential; however, ACP documents are ineffective if they cannot be readily accessed at the time of need. Some state registries allow only designated individuals to access the system, while others (like Vermont) allow any person to view registry information (with a registrant's ID). Options other than a large state database may be better suited to ensuring the confidentiality of information. Balancing ease of access to the documents with confidentiality needs could be a challenge, but other states have experience that could be learned from.

- *Government Intervention* – Some people are uncomfortable with government involvement with decisions around end-of-life care. During the debate of the Affordable Care Act, a provision that would have reimbursed physicians for advance care planning discussions became the source of the infamous “Death Panels” arguments. Government interests in reducing health costs raise the specter of reducing expensive end-of-life care for some. For some, these discussions and decisions should be kept between individuals, their families, and their care providers, not in a large government database.<sup>36</sup> In states with registries for advance directives, registration is optional, which could allay some of these concerns.
- *Burden on Physicians* - In Vermont, as part of the state's advance directive registry law, physicians are required to seek out advance directives for patients that lack capacity to make medical decisions. Some health providers might object to such a requirement even if a registry were easy and quick to receive information from. Such a requirement is not necessary for an advance directive registry to be effective (other states do not have a similar requirement), but it could encourage use of the registry.
- *Applicability in Emergencies* – Vermont's law requiring that health providers check for directives does not apply in emergency situations; this presents another challenge with a registry. Colorado law recognizes CPR Directives and MOST forms, which are frequently used by emergency personnel. It is recommended that these forms be kept printed in various locations in an individual's home, where emergency personnel are trained to look. While a state registry is intended to be a central location to collect advance care plan documents, there are some documents that should also be kept readily available for emergency situations. A registry for some documents and then printed copies for other documents might increase confusion by both patients and health professionals.
- *Budgets and Sustainability* – Washington State, in creating its registry in a contract with U.S. Living Will Registry in 2007, budgeted approximately \$360,000 for its first two years operation.<sup>37</sup> Washington's registry program then was ended following budget cuts in 2009 due to the recession.<sup>38</sup> The fiscal note attached to SB15-125 estimated that a Colorado statewide registry would cost approximately \$80,000 to operate in its first year – about 2/3 for state personnel and 1/3 for a contractor to implement the registry itself.<sup>39</sup> This funding would have come primarily from the Colorado General Fund, which is subject to a variety of budget pressures that might lead to a situation like that in Washington. If the registry were to be created then eliminated in a tight budget year, this could lead to some individuals being in a worse position than had the registry never existed.

## About this Summary

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<sup>36</sup> “The Living Truth about ‘Death Panels,’” *AEI*, accessed August 17, 2016, <https://www.aei.org/publication/the-living-truth-about-death-panels/>.

<sup>37</sup> “Living Will Registry: A Report to the Legislature” (Washington State Department of Health, January 2009), [http://app.leg.wa.gov/ReportsToTheLegislature/Home/GetPDF?fileName=Living%20Will%20Registry\\_92a07e21-6747-45eb-a8c8-f4f4988f1835.pdf](http://app.leg.wa.gov/ReportsToTheLegislature/Home/GetPDF?fileName=Living%20Will%20Registry_92a07e21-6747-45eb-a8c8-f4f4988f1835.pdf).

<sup>38</sup> “State Budget Cuts Endanger Registry for Living Wills,” *The Seattle Times*, March 28, 2009, <http://www.seattletimes.com/seattle-news/politics/state-budget-cuts-endanger-registry-for-living-wills/>.

<sup>39</sup> Pat Steadman, *SB15-125 - Statewide Registry For Advance Directives - 2015 Colorado Legislation | LegisPeak*, 2015, 15-, <http://legispeak.com/bill/2015/sb15-125>.

<b>Date:</b> August, 2016	<b>POLICY BRIEF</b> <b>ADVANCE DIRECTIVE POLICY</b>	Page 12
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This summary was prepared by Health District of Northern Larimer County staff to assist the Health District Board of Directors in determining whether to take an official stand on various health-related issues. The Health District is a special district of the northern two-thirds of Larimer County, Colorado, supported by local property tax dollars and governed by a publicly elected five-member board. The Health District provides medical, mental health, dental, preventive and health planning services to the communities it serves. For more information about this summary or the Health District, please contact Dan Sapienza, Policy Coordinator, at (970) 224-5209, or e-mail at [dsapienza@healthdistrict.org](mailto:dsapienza@healthdistrict.org).