



LEGISLATIVE RESEARCH SERVICES

Alaska State Legislature
Division of Legal and Research Services
State Capitol, Juneau, AK 99801

(907) 465-3991 phone
(907) 465-3908 fax
research@legis.state.ak.us

Memorandum

TO: Representative Lindsey Holmes
FROM: Tim Spengler, Legislative Analyst
DATE: December 21, 2011
RE: Advanced Health Care Directive Databases
LRS Report 12.095

You wanted to know which states have a centralized electronic database for residents to register their advanced health care directives. You also were interested in the approximate costs of these programs.

As you know, an advanced health care directive (AHD) is a legal document in which an individual indicates how he or she wants to be treated in the event of becoming severely ill or incapacitated with no chance of recovery. Advanced health care directives are typically divided into two types, as follows:

- 1) A **living will** is a document in which an individual states the kind of health care he or she wants in a specific circumstance.
- 2) A **health care proxy** is a document in which an individual names a close friend or relative who will make the final decisions regarding the care of that individual in the event he or she becomes incapacitated.

We identified eleven states with statutes mandating the creation of a centralized electronic database (registry) specifically for AHDs.¹ Those states are Arizona, California, Idaho, Maryland, Montana, Nevada, North Carolina, Oklahoma, Vermont, Virginia, and Washington. Of these, eight have AHD registries in place; Maryland and Oklahoma have yet to implement a registry, while Washington ceased funding its program in June of 2011, as a cost cutting measure.

Half of the state registries are managed by the secretary of state's office (the equivalent of Alaska's lieutenant governor's office), while other states place this responsibility with the department of health. Seven of the states with registries created and maintain their own database. Vermont, on the other hand, uses a private outside agency, the United States Living Will Registry, to manage its online database.²

The estimated startup costs for creating an AHD registry ranged from \$25,000 to \$100,000, while ongoing expenses were estimated at between \$15,000 and \$35,000 annually. Startup costs usually include the building of a database as well as public education and outreach efforts. Ongoing costs typically include personnel expenses (generally a portion of an IT and/or program position) as well as general clerical costs. Table 1, on the following page, disaggregates program expenses for the states from which we were able to identify cost estimates.

In 2007, the Council of State Governments (CSG), Committee on Suggested State Legislation, recommended that states consider establishing registries for advanced health care directives. We include CSG's model legislation on AHD registries as Attachment B. Additionally, the New York Online Access to Health (NOAH) publishes a document with numerous links to information on advance directives in each state, which may be of interest to you. This NOAH resource can be accessed at <http://noah-health.org/en/rights/endoflife/adforms.html>. We also include, as Attachment C, an in-depth *question and*

¹ Table 1 on the following page includes the relevant statutory citations for each of these 11 states. We also include copies of these statutes as Attachment A. While we conducted a thorough review, there may be additional states with AHC registry laws but worded such that our Lexis and Westlaw queries did not identify them.

² The US Living Will Registry is an independent organization that electronically stores advanced directives and donor information for individuals and for states. Until recently, Nevada and Washington also used this resource. Vermont's AHD coordinator, Sharon Goldwin (802-865-7748), is happy to discuss her state's (very positive) experience with the US Living Will Registry.

answer document regarding North Carolina's AHD registry, which includes information on how the state set up its program, the goals of the registry, cost and registration figures, and much more programmatic information.

Table 1: States with Advanced Health Care Directive Database Laws and Estimated Program Costs					
State	Statutory Citation	Status of Database	Estimated Costs		
			Startup	Annual	Fee for users
Arizona	A.R.S. 36-3291 <i>et seq.</i>	Operational since 2004.	\$25,000	\$25,000-\$30,000	Free to residents
California	Cal. Prob Code 4800	Operational since 2008.		No response	
Idaho	IC 39-4515	Operational since 2006.	Unavailable	\$20,000-\$25,000	Free for residents
Maryland	Md. Code Ann., Health 5-624	Law passed in 2006 but the state has yet to implement		Not applicable	
Montana	MCA 50-9-501	Operational since 2008	\$100,000	\$15,000	Free for residents
Nevada	NRSA 449.920	Operational since 2008.	\$50,000	\$15,000-\$20,000	Free for residents
North Carolina	GSNC 130a-465	Operational since 2002.	\$75,000	\$25,000	\$10 registration
Oklahoma	63 Okl. St. § 3102.1	Registry has not yet gone into effect		Not applicable	
Virginia	CV § 54.1-2994.	Operational since 2008.	No cost ^(a)	\$15,000	Free for residents
Vermont	18 VSA 9719	Operational since 2007.	\$50,000	\$35,000	Free for residents
Washington	RCW 70.122.130	Program started in 2008 and shut down in June 2011 due to funding restrictions		Costs were unavailable	

Notes: (a) Unival and Microsoft set up Virginia's registry at no cost to the state.
Sources: Lexis and Westlaw searches and correspondence with state authorities.

We hope this is helpful. If you have questions or need additional information, please let us know.