

VERMONT2007

Implementation of an Advance Directive Registry

Report to the Legislature on **Act 55**
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Executive Summary

This report is submitted pursuant to Sec. 10 of Act 55 (2005), which requires the commissioner of health to submit an annual report describing the status and utilization of the advance directive registry and educational efforts undertaken to inform Vermonters about the registry and advance directives.

I. Status of Rulemaking.

The Department of Health initiated the rulemaking process pursuant to the Administrative Procedure Act in February 2006 and held a public hearing on March 21, 2006. The proposed rules addressed the criteria and forms required by 18 V.S.A. § 9719, including one optional form of an advance directive with an explanation of choices and responsibilities, a form for clinician orders for life sustaining treatment, the use of experimental treatments and a model DNR form. During the course of the year, meetings were held with the Attorney General's Office, Legislative Council and stakeholders to revise the final proposed rules and the forms required by 18 V.S.A. § 9719. The final rule and forms were approved by LCAR in December 2006 and became effective on January 8, 2007.

II. Development and Implementation of the Registry

In January 2006, the Department of Health awarded a contract to U.S. Living Will Registry to develop and host the Vermont Advance Directive Registry. The registry is designed to receive advance directives submitted by principals by mail or facsimile. Advance directives will be scanned and posted in the Vermont Advance Directive Registry web-accessible database. Health care providers will have special access to the registry through the web or through 24/7 telephone access. Principals may submit changes to an advance directive, such as amendments, suspensions or revocations, which will also be scanned and recorded in the registrant's electronic file.

The registry has undergone testing by the Department of Health and review by stakeholders since September 2006. Following the effective date of the rule, principals may submit advance directives to the registry. The forms and instructions for submitting an advance directive to the registry are available on the Department of Health website.

III. Project Educational Efforts

Provider education - During September and October 2005, informational briefings for health care providers were held through Vermont Interactive Television explaining the key provisions of Act 55. To ensure wide range coverage, presentations were delivered to provider audiences to educate them on their obligations, use of registry, forms and registration process.

Public education and promotion- The rule, including applicable forms and related information about the registry and advance directives is now available to the public on the Department of Health website. Beginning in early 2007, the Vermont Ethics Network, through a grant provided by the Department of Health, will be holding community workshops, community fairs through hospitals, senior centers and clinics statewide to educate the public about Act 55 and to promote and encourage people to execute and register their advance directive.

Introduction

In September 2005, the General Assembly enacted and the Governor signed into law H. 115, which became designated Act 55: *An Act Relating to Advance Directives for Health Care*. In accordance with Section 10 of Act 55, the commissioner of health is required to submit a report on or before January 15 of each year 2006, 2007 and 2008 to the chairs of the following committees: the house and senate committees on judiciary, the house committee on human services, and the senate committee on health and welfare. The report shall describe the status and utilization of the registry established by Act 55 and educational efforts undertaken to inform Vermonters about the registry and advance directives. This report describes the status and utilization of the registry including rulemaking, development of the registry and educational efforts to inform Vermonters and the medical community about Act 55.

The Department of Health worked throughout 2006 on the rulemaking and the design and testing of the registry in consultation and collaboration with a variety of stakeholders and input from the public and the medical community.

1 Status of Rulemaking

18 V.S.A. § 9719 requires the Department of Health to develop and maintain an Advance Directive Registry and to promulgate rules and specific forms, including at least one optional form of an advance directive with explanation of choices and responsibilities, a form for Clinician Orders for Life Sustaining Treatment (COLST), the use of experimental treatments, a model DNR Order, DNR identification, revocation of DNR identification and consistent statewide emergency medical standards for DNR Orders and advance directives for patients and principals in all settings.

The Department of Health initiated the rulemaking process pursuant to the Administrative Procedure Act in February 2006. In March 2006, notice of the proposed rule was published in newspapers and posted on the Department of Health website for public comment. A public hearing was held on March 21, 2006. The proposed rules addressed the criteria and forms required by 18 V.S.A. § 9719, including one optional form of an advance directive with an explanation of choices and responsibilities, a form for clinician orders for life sustaining treatment, the use of experimental treatments and a model DNR form. The Department filed final proposed rules on July 20, 2006.

During the course of the year, meetings were held with the Attorney General's Office, Legislative Council and stakeholders to revise the final proposed rules and the forms required by 18 V.S.A. § 9719. The final rule and forms were approved by LCAR in December 2006 and became effective on January 8, 2007.

The Department of Health's Legal Counsel appeared briefly before the Legislative Committee on Administrative Rules (LCAR) on August 30, 2006 mainly to say that the Department of Health would be working with a number of agencies, organizations, and individuals to revise the final proposed Advance Directives Rule to comply more closely with legislative mandate and intent. Since then, Department of Health staff has consulted frequently with representatives of the Vermont Ethics Network, the Vermont Medical Society, the Vermont Legal Aid Society, Vermont Protection & Advocacy, the Vermont Association of Hospitals and Health Systems, the Attorney General's Office, Legislative Council, and other interested individuals. The results of that consultation and collaboration were filed with LCAR on December 4, 2006. The rule was reviewed and approved at the LCAR hearing held on December 13, 2006. In accordance with filing procedures, the rule became effective on January 8, 2007.

2 Development and Implementation of the Registry

On January 18, 2006, the Department of Health issued a Request for Proposals to develop and host an advance directive registry for Vermont. We received four proposals, and selected the proposal from U.S. Living Will Registry (USLWR). This vendor has successfully operated a web-based advance directive registry in several states for over ten years. USLWR proposed to customize their existing registry and provide web-hosting services for Vermont.

Once the contract was executed, work began immediately to adapt the USLWR system to meet Vermont needs. A preliminary registry design was presented to stakeholders on July 6, 2006. Modifications were made and the registry was ready for testing by September 1, 2006. The applicable forms, including the Registration Agreement, Locator form, Authorization to Change and Provider Notification forms were prepared as part of the rule and are posted on the Department of Health website.

The registry operates as follows:

- A prospective registrant completes the Registration Agreement form and mails or FAX's it along with a copy of their advance directive to the Vermont Advance Directive Registry c/o USLWR. If they prefer, registrants can send a description of the physical location of copies of their advance directive in lieu of the advance directive itself.
- The registry will scan the advance directive (or Locator form), and post it in a web-accessible database along with identifying information from the Registration Agreement.
- The registry will send a confirmation letter to the registrant along with a registration number, instructions for accessing their documents at the registry website, a wallet card, and stickers to affix to a driver's license or insurance card. Registrants are instructed to share the registration number from the wallet card

- with anyone who should have access to their advance directives (e.g., agent, family members, or physician). With this number, anyone may access a person's advance directive.
- Health care providers will have special access to the registry enabling them to search the registry on-line for a specific person's advance directive using that person's registration number. If the registration number is not readily available, providers can search using other identifying information (name and date of birth). Providers also may search the registry through telephone access 24 hours a day and seven days a week
 - Any changes and notices of changes to an advance directive (amendments, suspensions, revocation) reported to the registry will also be scanned and recorded in the registrant's electronic file.
 - Registrants will be contacted annually by the registry to confirm that their contact information and advance directives are up to date.
 - Registrations, as well as changes to documents, are free of charge and will remain in effect until the registrant dies or terminates the registration.

The Department of Health is in the process of finalizing the content of registry web access and once completed the registry will be accessible to both registrants and providers through the Department of Health web site. The web site will include "public" pages with information about advance directives, anatomical donations, the registry, forms and resources, as well as a link to the secure database where advance directives may be accessed and viewed.

The registry has been tested internally by Department of Health staff and has been made available for review by stakeholders since September 2006. Many of the registry operational procedures, forms, instructions and agreements were adopted as part of the Advance Directives for Health Care rule and are available on the Department of Health web site.

3 Project Educational Efforts

3.1 Provider briefings on Act 55

In September and October of 2005 the Vermont Medical Society, the Attorney General's Office and the Vermont Ethics Network (VEN), with input and support from the Vermont Association of Hospitals and Health Systems, Vermont Health Care Association (representing nursing homes) and the Vermont Assembly of Home Health Agencies, held informational briefings through Vermont Interactive Television explaining the key provisions of Act 55. These briefings were mainly intended for the provider community and covered provider obligations as well as the implementation of the Advance Directive Registry.

In addition, VEN and the Department of Health delivered several presentations about the registry to provider audiences:

- July 6, 2006 -- meeting with stakeholders to discuss proposed Registry access and operational procedures with the registry vendor, US Living Will Registry.
- June 9, 2006 -- the ExCEL (Excellent Care Near the End of Life) annual meeting at Lake Morey. ExCEL includes hospitals, Vermont Program for Quality in Health Care, and the Hospice and Palliative Care Council.
- September 14, 2006 -- Department of Disabilities, Aging and Independent Living Advisory Committee.
- September 26, 2006 -- Vermont Ethics Network Board meeting which included several non-member representatives from Vermont and New Hampshire health care facilities.

Finally, as providers are enrolled and issued registry accounts, additional provider briefings will be delivered particularly for hospitals and hospital staff. The briefings will instruct providers on their obligations, how to use the registry, policies and procedures, forms and the registration process. This same information will also be available on the Department of Health web site.

3.2 Public Education and Promotion

Information about the registry and advance directives will be available to public agencies and the general public on the Department of Health web site. In addition, the Department of Health has awarded a grant to the Vermont Ethics Network (VEN) to help educate the public about Act 55 and promote advance directives and the registry through educational materials and community fairs. VEN will be scheduling community workshops through hospitals, senior centers and community clinics in Winter and Spring of 2007. A goal of this project is to promote the registry as a vehicle to assist people in storing and sharing their advance directives.