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Report of the Study Committee on Informed Consent for a Do Not Resuscitate Order or Clinician Order for Life-Sustaining Treatment

Report to the Legislature on **Act 60**
November 30, 2011

VERMONT
AGENCY OF HUMAN SERVICES
DEPARTMENT OF HEALTH

108 Cherry Street
PO Box 70
Burlington, VT 05402
healthvermont.gov

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Introduction

This report is submitted to the Vermont Health Access Oversight Committee, the Chair of the House Committee on Human Services, and the Chair of the Senate Committee on Health and Welfare, as required by Act 60 (2011) Section 11.

Committee charge

The Study Committee was created by Act 60 (2011) to study criteria to be used for rules concerning individuals who are giving informed consent for a do-not-resuscitate order (DNR) or a clinician order for life-sustaining treatment (COLST) issued pursuant to 18 V.S.A. § 9708(b), but who are not the patient, the patient's agent, or the patient's guardian.

Committee members

The Committee was convened and chaired by the Commissioner of Health. As provided in Act 60, the members of the committee were representatives of the Commissioners of Vermont Health Access and Disabilities, Aging, and Independent Living; the Vermont Medical Society, the Vermont Ethics Network, the Vermont Association of Hospitals and Health Systems, Vermont Program for Quality in Health Care, the Hospice and Palliative Care Council of Vermont, the Vermont Center for Independent Living, Vermont Area Agencies on Aging, Vermont Assembly of Home Health and Hospice Agencies, and the Vermont Health Care Association; and the long term care ombudsman and the state health care ombudsman.

Committee Recommendations

The Committee met on August 24, September 28, October 26 and November 16, 2011. The minutes of the meetings and other information relating to the Committee's work is posted on the Health Department website at:

http://healthvermont.gov/vadr/dnr-colst/index.aspx

In addition, interested members of the Committee met with staff of the Department of Health on October 19 to work on the proposed rule. Because Act 60 requires the rule to be effective by March 1, 2012, the Health Department initiated the rulemaking process in early November. The proposed rule was presented to the Interagency Committee on Administrative Rules on November 14 and subsequently filed with the Secretary of State. A public hearing is scheduled on January 6, 2012 at 1 p.m. at the Health Department, 108 Cherry Street, Burlington in Room 3B. Comments may be submitted through January 13, 2012. Information about the proposed rule, and an opportunity to file comments electronically, are available on the Health Department website at:

http://healthvermont.gov/admin/public_comment.aspx

I. Committee Recommendations for DNR/COLST Rules:

The Committee discussed the specific elements for selecting a surrogate to provide informed consent for a DNR or COLST order and the specific wording of the proposed rule. In addition, the Committee reviewed and reached consensus on modifications to the DNR/COLST form, including adding the patient's name to each page, adding a certification statement when the informed consent is provided by a surrogate, and moving the instructions to the last page so that the DNR or COLST order is prominently indicated on the first page. The Committee also reviewed and discussed more specific provisions relating to DNR identification that are included in the proposed rule.

In many areas, the Committee reached consensus and the proposed rule reflects that consensus. In other areas, however, the Committee did not reach consensus and the proposed rule contains provisions that should elicit comments to further explore those topics prior to adoption of the final rule. The Committee discussions with respect to the four specific areas identified in Act 60 for consideration are summarized below.

(1) which individual or individuals who are not the patient, the patient's agent, or the patient's guardian, but who shall be a family member of the patient or a person with a known close relationship to the patient, are permitted to give informed consent for a DNR or COLST order.

The Committee reviewed and discussed how other states have addressed surrogate consent for health care and also existing provisions in Vermont law such as those relating to consent for organ donation and disposition of remains. Several of the Committee members discussed their experiences with situations where surrogate consent for a DNR or COLST order would be appropriate. The Committee reached consensus that a specific hierarchy of family members should not be specified in the rule. Rather, the Committee conclusion was that the family member or friend best informed as to the patient's values and wishes would be the preferred person to provide informed consent for a DNR or COLST order. The proposed rule seeks to capture this consensus in the provisions in section IX.D.2. The proposed rule provides as follows:

2. The surrogate shall be:
- *a. A person designated by the patient[1] by personally informing the clinician; or*
- *b. If the patient has not designated a surrogate, or if the surrogate designated by the patient is not reasonably available or is not willing to serve,*
  - *i. a family member of the patient or a person with a known close relationship to the patient; and*

[1] The Committee recommended adding this provision, even though the patient could choose to appoint an agent through an advance directive. This provision would allow the patient to designate a surrogate in those circumstances where the patient chooses not to appoint an agent. The immediately preceding provision in the proposed rule, not quoted here, makes clear that if the patient has appointed an agent, then there may not also be a surrogate.

> *ii. willing to provide informed consent for a DNR or COLST order for the patient in accordance with the patient's known wishes and values; and*
> *iii. willing and available to engage in consultation with the patient's clinicians.*

The proposed rule as drafted does not establish a preference for one family member, such as a spouse or sibling, to have priority over another family member, such as a grandniece, or over a close friend. The Committee consensus was that it is the knowledge of the patient's values and wishes and willingness to honor them that are essential qualities for a person to serve as a surrogate to provide informed consent for a DNR or COLST order.

The Committee, however, did not reach a consensus on whether a single individual should serve as surrogate or whether multiple individuals should be authorized to provide informed consent for the DNR or COLST order. The language in Act 60 uses both the singular and the plural, so the intent of the legislation was not clear to all Committee members. The proposed rule anticipates a single individual will serve as surrogate and it is expected that the proposed rule language will elicit comments that will further inform the final rule.

(2) how decisions regarding who is the appropriate person to be giving informed consent for a DNR or COLST order are to be made, which shall include at a minimum the protection of a patient's own wishes in the same manner as set forth in 18 V.S.A.§9711.

The section above discusses how the proposed rule addresses how to choose the appropriate person to provide informed consent. With respect to the protection of the patient's own wishes, the Committee agreed that the provisions in 18 V.S.A. § 9711 appropriately protect the patient's wishes and recommended that standard be incorporated into the rule. The use of the term "substituted judgment" in the proposed rule is intended to reflect the decision making standards of section 9711. The proposed rule incorporates provisions of section 9711, including requirements that the surrogate: 1) be willing to

provide informed consent in accordance with the patient's known wishes and values; and 2) prohibiting the surrogate from considering their own wishes and values in making a decision regarding informed consent for a DNR or COLST order for the patient.

(3) the use of a hospital's internal ethics protocols when there is a disagreement over who is the appropriate person to give informed consent for a DNR or COLST order.

The Committee was not able to reach consensus regarding access to a hospital's internal ethics protocols. The intent of the provision was not clear to all members. The Committee discussed whether the internal ethics protocols alone would provide assistance to individuals seeking to resolve a disagreement over who would be the appropriate surrogate and whether the provision was intended to apply to patients who are not admitted to the hospital. The Committee also discussed whether the hospital's ethics committee may be useful in helping the surrogate reach the decision about whether to provide informed consent for a DNR or COLST order and whether it should not be limited to helping decide which individual or individuals should provide surrogate consent.

The Committee discussed whether hospital ethics committee consultations would be available in all areas of the state and whether a hospital ethics protocol alone would be of any real value in the absence of an ethics consultation. The Committee also discussed the probability that, at least for some hospitals, providing the ethics protocols or consultation, especially for non-patients, may be something they have not done before.

The proposed rule contains a provision that would require the hospital to provide access to the internal ethics protocols and to offer an ethics consultation when there is a disagreement over the appropriate surrogate for a patient receiving treatment in the hospital. The proposed rule also contains a provision that if a patient is not receiving treatment in a hospital, then the hospital in the geographic service area for the residence of the patient must provide access to its internal ethics protocol under those

circumstances. This latter provision would allow, but not require, the hospital to offer an ethics consult. These provisions are in Section IX.D.4. of the proposed rule. Comments on the proposed rule may provide further insight and guidance in this area for the final rule.

(4) an examination of the relationship between the wishes expressed in an advance directive and the DNR or COLST order.

The Committee recognized that Vermont law allows a principal to express their wishes and values for health care in an advance directive, without appointing an agent. The Committee agreed that, in those circumstances, the wishes expressed in an advance directive should be considered by the surrogate in providing informed consent to a DNR or COLST order to the same extent as an agent or guardian is required to honor the patient's wishes, as provided in 18 V.S.A. § 9711. The proposed rule reinforces those requirements, as discussed in Section (2) above.

II. Statutory Recommendations

Although not specifically requested, the Committee identified two areas that it recommends the legislature address as soon as possible and a third area that should be given further consideration for legislative action.

A. Immunity

The law does not currently provide immunity for a surrogate who provides informed consent for a DNR or COLST order in good faith. Immunity is provided for agents or guardians in similar circumstances and should be extended to surrogates if the benefits for patients of this authority are to be realized.

In Section 13 of Act 60, as follows:

> Sec. 13. 18 V.S.A. § 9713 is amended to read:
> § 9713. IMMUNITY
> (a) No individual acting as an agent or guardian shall be subjected to criminal or civil liability for making a decision in good faith pursuant to the terms of an advance directive, or DNA order, or COLST order and the provisions of this chapter.

The Committee urges the legislature to consider amending this section as soon as possible to include immunity for a surrogate to the same extent it applies to an agent or guardian.

B. Surrogate Access to Patient Health Information

Additionally, in 18 V.S.A. § 9711(e), there is specific authorization for an agent or guardian to receive health information relating to the patient/principal. There is, however, no specific provision that would authorize surrogates to receive the information they would need to provide informed consent for a DNR or COLST order. The law should be very clear that health care providers have the authority under state law to share the relevant health care information for the informed consent for a DNR or COLST order with surrogates to the same extent that information may be shared with agents and guardians. As with the immunity provision, the lack of specific authority in this area may prevent the benefits of surrogate consent from being realized. The Committee urges the legislature to consider amending this section as soon as possible to include access to the patient's health information for a surrogate to the same extent it applies to an agent or guardian.

C. Surrogate Consent for Other Health Care Decisions

Finally, the Committee notes that the limited provision for a surrogate to provide informed consent for a DNR or COLST order for a patient without an agent appointed in an advance directive or a guardian may create confusion, as there is no corresponding provision for a surrogate to provide informed consent for any other type of health care decision. Many states have enacted laws for surrogate consent that are not limited to DNR or COLST orders. The Committee recommends that the legislature consider enacting legislation to authorize surrogate consent in broader areas of health care in the near future.

Conclusion

The Committee carefully considered the topics required by Act 60 and consulted with the Health Department in the development of the proposed rule for a surrogate to provide informed consent for a DNR or COLST order. The formal rulemaking process is underway and the opportunity for public comment may provide further information and insights into these issues prior to adoption of the final rule.

With respect to the recommended further legislative action, the Committee urges immediate consideration of extending the immunity and access to health information provisions for surrogates. The Committee encourages further consideration of expanding surrogate consent to other health care decisions beyond informed consent for DNR and COLST orders.