

ACT 60 DNR/COLST Order Informed Consent Committee

Meeting Minutes – August 24, 2011

Attendees:

Dr. Harry Chen, Commissioner VDH
Dixie Henry, Senior Policy Advisor VDH
Bessie Weiss, AAG, VDH
Joyce Brabazon, VDH
Jackie Majoros, Long Term Care Ombudsman
Madeleine Mongan, Vermont Medical Society
Peter Cobb Director, VAHHA
Jill Olson, VAHHS
Patrice Knapp, VPQHC
Avril Cochran, VPQHC
Dr. Robert Macauley, Clinical Ethics FAHC
Sally Bliss RN, Clinical Ethics FAHC
Cindy Bruzzese, Vermont Ethics Network
Laura Pelosi, Vermont Health Care Association
Christine Scott, Mayo Healthcare
Lori Collins, Deputy Commissioner DVHA

Absent: Angela Means VNA, Vicki Loner, Deputy Commissioner DVHA, Dr. Susan Wehry Commissioner DAIL

Minutes: Joyce Brabazon

Agenda:

Dr. Harry Chen introduced himself and stated the legislative charge of the committee:

- To study and create criteria to be used for developing rules concerning individuals who are giving informed consent for a DNR/COLST order
- To make recommendations to VDH on which individual or individuals, who are not the patient, the patient's agent, or the patient's guardian, but are a family member or a person with a known close relationship to the patient, are permitted to give informed consent;
- Parameters for deciding how to determine who is the appropriate person to be giving informed consent;
- A process for accessing a hospital's internal ethics protocols when there is disagreement over who is the appropriate person to give informed consent; and
- A process for examining the patient's wishes as expressed in an advanced directive and the DNR/COLST.

Dr. Chen then had everyone go around the room to introduce themselves. He set out the timeline for the Committee stating that a report is due to the Vermont Health Access Oversight Committee on December 1, 2011 and that rulemaking needs to be undertaken in order for the rule to be effective March 1, 2012. Dr. Chen then turned the meeting over to Dixie Henry who facilitated the meeting.

Several questions were posed to the committee for consideration:

- What gaps, if any, should be addressed by the rules?
- Why are rules from VDH being sought as a solution to address those gaps?
- Is there any other direction that should be considered?
- Who should be authorized to give or withhold consent when there is no agent or guardian designated?

Group Discussion:

Cindy Bruzzese started the conversation stating that there is a public perception that someone's spouse is automatically the person designated. She said this works when there is no controversy. However, communication is not always good among family members; there can be disagreement, or no clear decision maker. It is not clear who has real authority to make decisions. Who among the family members is the best choice to make decisions for the patient when there is no advanced directive and no clear goals? It can be very confusing.

If there is a guardian or agent, the decision-making process is clearly outlined based upon a patient's wishes. For those who are not a guardian or agent, the decision-making process is not clear in current law. Only 30% of the population has designated a health care agent. There are no guidelines for the other 70% about giving informed consent. We don't want to be overly restrictive in developing rules with who can give consent but want some guidelines.

Dixie Henry said that a couple of our statutes establish a tier system when there is no advanced directive in place. She referred to the Uniform Anatomical Gifts Act and Disposition of Remains. Dixie asked whether we should look at an existing tier pattern?

Dr. Macauley responded that conversations don't always happen with the person at the top of the hierarchy. A patient might not talk with his wife but instead talk with his fishing buddy. The wife may be less informed. The hierarchy puts the person closest to the patient in the position of making a decision contrary to what their own wishes might be. Giving informed consent is fundamentally different than disposition of remains. How structured do we make these hierarchies? Who really knows the patient? These questions never got answered and have been outstanding for some time.

Today physicians might recommend to the patient that they have a DNR/COLST order. If the family is present, how does FAHC make that decision?

Dr. Macauley stated that they focus on the decision, not the decision maker. The family is asked to talk about the patient, describe who they are, and what would they want. The decision goes beyond just DNR orders. We focus on the patient's goals not the individual's goals. There are all kinds of family motivations; we take the individual person out of it. Ideally consensus is reached, but if not we focus on those that seem to be speaking for the patient. Initially, we go along with the person who wants the most because we can always fall back.

Dr. Chen said that we don't want to make the current process less efficient. He said that end of life decisions are happening all over the state now. Facilities without an ethicist on staff may have a committee. He said we don't want to upset a process that is working now. There is a tension between structure and leaving unstructured.

Jill Olson agreed the risk is to upset processes that are working well now.

Jackie Majoros said that decisions are made all over Vermont and not just at FAHC. The hierarchy in statute is too rigid and nursing homes do not follow it. This is too rigid and does not really work. A lot of times decisions are not well made or smooth. She is not sure they reflect the individual. She has thought the current COLST form allows for someone other than a guardian or agent to provide consent.

Dixie Henry said that the current form is based on another form and was intended for guardians, agents or parents to consent to decisions to provide or withhold care. It was never intended to create an authorization to consent. The DNR statute does contain the language: "or other individual giving informed consent for the DNR", but this should be someone specifically authorized by law.

Dr. Macauley stated the majority of decision-making happens outside existing legal authorities.

Madeleine Mongan referred to a treatise regarding the right to die that had been provided by Bob Orr. The treatise summarizes the state of the law across the nation. It looks at the common law interpretation of incompetence and surrogate decision making for clinical determinations.

Substituted judgment is the standard used, if that can't work the best interests standard is used. There is no reported case law in Vermont.

Dixie Henry asked whether there was consensus on barriers to be addressed in rule? What has been done in the past to address unclear laws and public expectations that don't match up with the law?

Dixie also asked whether we are looking to change the system or by rule, authorize the existing system?

Dr. Macauley said he would be ok with authorizing the way it works now.

Jackie Majoros didn't agree and suggested that guidance is needed on who can make decisions and how. She can't count how often people are looking at best interests versus substituted judgment.

The statute backs up that an agent cannot contravene the patient's values. It would be great to take the same criteria verbatim out of the statute for the rule: If the decision-maker is not an agent, this is still how you make the decision.

Jackie Majoros said this is an opportunity to educate people about how these decisions are made. She expressed concern that we may not be prescriptive enough.

Cindy Bruzzese said that the COLST form is the best kept secret and that information needs to be disseminated. People need to be educated about how these decisions need to be made. We have processes for guardianship and advanced directives. What do we expect to do with this rule to fill the gap for the 70% of people other than what we have already done?

Dixie Henry said that inside facilities folks can use their own form but that outside of the facility, the VDH form must be used upon discharge or transport.

Dr. Macauley said the challenge with the COLST form is that it is so black and white that people don't know what to do with it. It is difficult for physicians to bear the moral responsibility of putting it in black and white.

Cindy Bruzzese said health care providers want something quick and easy. The advance directive is seen by some as ineffective because patients change their mind. COLST is more binding. A huge amount of education is needed around how to make people feel more comfortable with topics. This is an ongoing process. The message needs to be consistent and ongoing. Rulemaking could provide more tools for the delivery of a consistent message.

Peter Cobb said that as close as we can get to a prescriptive menu for telling people what to do would be useful. Madeleine Mongan responded that this proposal is a good place to start but that it needs to be simple and straightforward.

Elements of a rule should include:

- 1) Who is the family or known close friend?
- 2) How to pick a family member or members over a friend or vice versa and who makes that choice?
- 3) How to decide who the best surrogate is by who knows the patient best or judge by default, individual physician or ethics committee? Many decisions are made in real time by a clinician, medical team or ethicist.

Dr. Macauley said there is a lot of precedent for a two tier approach. He would like this group to focus on how.

A question posed to Dr. Macauley was who do they go to for informed consent for any procedure if the patient cannot provide the consent – if not end of life? He said that for every question that comes up, it depends on how emergent the situation is. There may be a discussion with the medical team to determine who knows the patient best if there's a conflict they would convene the ethics committee.

Laura Pelosi said that process may be true for hospitals but she is not sure the system is that robust for all providers.

Dr. Chen said there may be a way of allowing long term care facilities to access hospital ethic's committees.

An important question to be asked is who shouldn't be contacted to make an informed decision since a lot of people put their spouse's name on that line. Who should be contacted if the hierarchy does not work well? Should the rule consider which family member, which friend? Pursuant to statute we are to establish criteria for identifying who should be the family member or other person.

Dr. Chen said the question is should we have a list? Usually go to the spouse first.

Peter Cobb commented that a hierarchy, for all its weaknesses, is better than not having one. We need to know who knows the patient's wishes the best, not the patient the best. A good faith standard should be built into the rule. The substituted judgment standard should lead the way not who leads the way.

Jill Olson said not sure it is a list of people so much as how to make decisions.

Sally Bliss said that they try to listen to everyone to understand more about that patient. This helps to put a picture together of the patient. If there is no time in an emergent situation, then have to act in good faith. There should be a two-tiered approach:

- How, not who- if emergent situation, discretion to medical team to designate surrogate; if conflict, ethics mechanism such as an ethics committee (may be true for hospitals but not whole spectrum of providers)
- Can treat over objection (not sure what this means or what the context was?)

There was consensus amongst the committee that the substituted judgment standard be used as a framework for this rule. The guardian statute has substituted judgment standard; compare both. Although the guardian statute has another hoop to jump through.

There should be access to hospital ethics internal protocols if there is disagreement. What about for a patient who lives at home and has a DNR/COLST or a residential facility or long term care facility? No reason why the committee shouldn't be available but whether they can be available due to hospital liability concerns is unknown. Some hospitals consult; some do not. There are questions as to whether they can do so.

Jill Olson said at this point in time she could not speak on behalf of her members on the resource or liability issue.

The good faith provision should carry over for the decision in real time to the ethics committee. This is a good goal but not practical? We don't want to create a false sense that the situation is resolved. The current infrastructure is not amenable but this is something to work towards.

A question was asked about who has ethics committees and how often they might meet? Cindy Bruzzese has information on this that she will disseminate to the committee. She will also check with the committee chair about the current practice on consulting with long term care and residential facilities.

Dixie Henry noted that the DNR/COLST form contains distinct pages for the DNR and the COLST although they are combined into one form. The legislation required a joint form. A question posed was whether, as the conversation moves forward should we separate them or keep them together?

Dr. Macauley strongly argued that the committee should not separate them. If we separate the two forms we stress DNR exceptionalism. As it is we don't ask patients to sign any orders except for this.

Dr. Chen said that together they are more complicated and it might be worthwhile to think about renaming the form to something that resonates more with people..

Dr. Macauley responded that by splitting the forms up we narrow the conversation about advanced care planning. If the two forms are together, it provides an opportunity to have a broader conversation.

Jackie Majoros said that lumping them together confuses patients.

Jill Olson said the issue may not be separating the forms but instead maybe focus on looking at how the forms work?

Cindy Bruzzese suggested some administrative changes to the form such as having the patient's name also appear on the second page and that there is redundancy on the third page with the number of times a physician has to sign.

Next Steps:

- Future committee meetings are scheduled for:
 - September 28
 - October 26
 - November 16
- A report to the Vermont Health Access Oversight Committee is due December 1, 2011

- Jackie Majoros will looking into the differences in the substituted judgment standard within the Advanced Directive and the Guardianship statutes
- Madeleine Mongan and Bessie Weiss will research decision makers in other states and default surrogates. Madeleine and Bessie will bring forward information from the ABA charts to the group. Bessie will also contact Wendy Morgan for a file she put together on default surrogates.
- Cindy Bruzzese will provide the committee with links to the VEN Handbook, Surrogate Decision Making, Taking Steps, and forms
- Jackie Majoros, Cindy Bruzzese and Madeleine Mongan agreed to work on or review a rough draft of the rule
- It was suggested that Gail Falk who previously was with the Office of Public Guardian be included in the committee or June Bascom.
- Emails for committee members are as follows:
 - Harry.chen@ahs.state.vt.us
 - Dixie.henry@ahs.state.vt.us
 - Bessie.weiss@ahs.state.vt.us
 - Joyce.brabazon@ahs.state.vt.us
 - jmajoros@vtlegalaid.org
 - mmongan@vtmd.org
 - vahha@comcast.net (Peter Cobb)
 - jill@vahhs.org
 - patricek@vpqhc.org
 - avrilc@vpqhc.org
 - Robert.macauley@vtmednet.org
 - Sally.bliss@vtmednet.org
 - vtethicsnetwork@sillcondairy.net (Cindy Bruzzese)
 - lpelosi@vhca.net
 - cscott@mayohc.org
 - Lori.collins@ahs.state.vt.us
 - means@vnacares.org
 - Victoria.loner@ahs.state.vt.us
 - Susan.wehry@ahs.state.vt.us