

ACT 60 DNR/COLST Order Informed Consent Committee

Meeting Minutes – November 16, 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
Trinka Kerr, Health Care Ombudsman
Dr. Robert Macauley, Clinical Ethics FAHC
Sally Bliss RN, Clinical Ethics FAHC
Cindy Bruzzese, Vermont Ethics Network
Avril Cochran, VPQHC
Peter Cobb, Director VAHHA
Laura Pelosi, Vermont Health Care Association
Madeleine Mongan, Vermont Medical Society
Stephanie Beck, DVHA

Absent: Jill Olson, VAHHS, Merle Edwards Orr, DAIL, Tom Paquette, VNA, Christine Scott, Mayo Healthcare, Angela Means, VNA, Joyce Lemire, Senior Solutions

Minutes: Joyce Brabazon

Welcome and Introductions – Dr. Chen thanked the Committee members for their active participation and noted that this process had an aggressive timeline based upon the legislation in Act 60. He reported that the draft rules were submitted and passed by the Interagency Committee on Administrative Rules (ICAR). Comments are welcomed on the rule. Dr. Chen noted that the Study Committee's report is due to the legislature on December 1, 2011 and that the main purpose of today's meeting was to review the draft report and make changes and/or suggestions to it. Dr. Chen stated he would welcome continuing participation by a voluntary workgroup to continue the discussions so that the work group might further define issues on this complex topic. Dr. Chen turned the meeting over to Dixie Henry.

Agenda:

Dixie Henry facilitated the meeting. Dixie asked for approval of the October 26, 2011 minutes. There were no objections and the minutes were approved as drafted. The next order of business was to review the draft study report due to the legislature on December 1, 2011. Dixie told the committee that she tried to capture succinctly the work of the committee, noting where the committee could reach consensus and where it could not. Dixie led the committee through review of the draft report.

Committee's charge - Dixie told the group that the language for this paragraph was taken directly from Act 60.

Committee members - Dixie stated that the language in this paragraph was taken from Act 60 as well.

Review of Committee Recommendations: Dixie told the committee that the information on the public hearing would be included in the final version of the report. and that VDH is continuing to work on the link to this information on the website and will include the proposed rule once it has been filed.

The draft report includes the requirements for the Study Committee recommendations as specified in Act 60. The Committee discussed the draft report and the comments from Merle Edwards-Orr, sent November 15, 2011 (who was unable to attend). Merle indicated that he did not feel the report contained a discussion of how the surrogate would actually be selected in circumstances where there are several eligible individuals and that he did not sense that the committee reached consensus on that point.

Cindy Bruzzese said that the language in the proposed rule is singular and that she thought the overall goal was plural; that multiple individuals could provide informed consent. Cindy stated that the statute uses both the singular and the plural. Cindy stated she did not think there was consensus in the Committee whether only a single surrogate or multiple individuals can be the surrogate.

Dixie Henry agreed that Act 60 that references both the singular and the plural in relation to who can provide informed consent.

Cindy Bruzzese asked whether it was more important to reach consensus about the decision or more important that one (1) person make that decision.

Dixie said she wanted to achieve clarity for describing the Committee's recommendation for the report. Dixie said she could report that the committee did not reach consensus on whether one individual or multiple individuals serve as surrogate.

Jackie Majoros said that she thought she would address when a surrogate follows the wishes expressed in an advance directive. She said we should recognize the provisions in the Advance Directive statute.

Dixie suggested that perhaps we could add a footnote regarding subsection 1 to state clearly that if an agent is appointed then there is no authority for a surrogate to provide consent.

Sally Bliss asked about using the term "substituted judgment" in the proposed rule. Dixie said she had proposed a definition in the initial draft but that comments from Madeleine Mongan pointed out that the term did not fully reflect the range of the provisions in § 9711. Jackie Majoros suggested that the clarifying that the use of the term "substituted judgment" in the rule is intended to reflect the decision-making standard of § 9711. The Committee agreed.

Dixie moved onto the section of the report dealing with use of hospital ethics protocols. This section of the rule contains language that puts hospitals on notice there might be a request for access to their ethics protocols for people that are not their patients. She indicated she expected to receive comments on this language and that it may change in the final rule. .

Cindy Bruzzese said she thought there was a misconception that the ethics committee focuses on the decision-maker and not the decision. She said that in reality, ethics consults focus more on the decision than the decision-maker. Cindy said there is a process about how ethics committees function; they are not a decider.

Dr. MacAuley said we went for a lot and it is clear this is not available in every jurisdiction. He said he was not sure what someone would get out of going to a local hospital for ethics protocols. He suggested creating a guide for community hospitals.

Cindy Bruzzese said there are two aspects to this: 1) the practicality of accomplishing the goal and 2) role of ethics committee to help make the decision to provide consent, not just to pick the decision maker.

Jackie Majoros said that she thought the decision of who would be the surrogate and whether to provide informed consent are two different decisions. Jackie said it was her interpretation that the legislature wanted the ethics protocols to help the family decide who the surrogate would be. She suggested there was some consensus that this is asking ethics committees to do something they may not have done before.

Dr. Chen suggested that the ethics committee would help the family make a decision which ultimately would be whether to provide informed consent. Cindy Bruzzese said the way she read it, the ethics committee was asked to help with both the decision and the decision maker. Dr. MacAuley responded that his comment was more about the process and access to ethics policies. Dixie read suggested language and said she is hoping for further comments and suggestions on this provision through the rule making process. The committee agreed.

Jackie Majoros suggested that (4) on page 6 of the draft report should be clear that the reference to an Advance Directive is for circumstances when no agent appointed.

Statutory Recommendations – Dixie said the report includes recommendations for further statutory change in three areas: immunity; surrogate access to patient health information; and expansion of surrogate consent to other health care decisions.

Dr. MacAuley suggested extending immunity to ethics committees offering advice and guidance for a patient not having a pre-existing relationship with a hospital. Dixie said this could be raised as something the committee might want to consider. Dixie said there is a conflict regarding access to health information and this is a flag for the committee to consider. The group agreed to include in the report a recommendation for the committee to consider an expansion of surrogate consent to other health care decisions.

Jackie Majoros suggested we should be emphatic about further legislative action regarding immunity and access to patient health information. Dixie suggested language that the legislature takes up further legislation as soon as possible to address the gap because with the gaps, the intent of Act 60 will not be fulfilled. The committee agreed that A. (Immunity) and B (Surrogate Access to Patient Health Information) were needed and that C. (Surrogate Consent for Other Health Care Decisions) was a bigger discussion and that the committee should identify this as an issue to be considered for future discussion.

Conclusion – Cindy Bruzzese asked whether the report should reflect the changes to the DNR/COLST form regarding certification and education as part of the work product of the committee. Dixie said she would include that on page 3 of the report. Cindy responded that she would anticipate comments about the form in the rulemaking proceeding.

Bessie Weiss asked whether the report should include comments on DNR Identification. Dixie said she would include a comment about this on page 3 under the work of the committee generally. Dr. MacAuley said EMS personnel honoring a refusal of a conscious patient's wishes is a Pandora's Box. He asked whether procedurally this should be brought up during the public comment period. Dixie responded that this is in the existing rule and not part of our charge, but could be raised through comments in the rule making process.

Dixie informed the committee that this was the last meeting. Dixie said she would finalize the report and then send it to the legislature.

Dixie asked if folks wanted to continue to meet as an informal work group to continue to discuss these topics. Peter Cobb said that it would be his preference to do this. Dixie said that this would be a separate track from rule making. She said she would be happy to schedule a few meetings. Folks agreed that Wednesdays work best.

Cindy Bruzzese stated that she could share the draft rule with hospital ethics committees and could collect their feedback.

Dixie said that she would work to put clarifying language on the website regarding the use of the form. Cindy Bruzzese responded that she could not find the listing on the VDH website regarding the DNR/COLST form and vendors that supply I.D.s. Dixie said she would work to clear this up and make the site more navigable.

Dixie reviewed the rule making process and explained the goal was to get to LCAR in early February. She then asked the committee members if anyone had anything else and there were no comments. Dixie thanked everyone for their participation.