

ACT 60 DNR/COLST Order Informed Consent Committee

Meeting Minutes – October 26, 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
Jill Olson, VAHHS
Dr. Robert Macauley, Clinical Ethics FAHC
Sally Bliss RN, Clinical Ethics FAHC
Cindy Bruzzese, Vermont Ethics Network
Merle Edwards Orr, DAIL
Avril Cochran, VPQHC
Stephanie Beck, DVHA
Sheila Burnham

Absent: Madeleine Mongan, Vermont Medical Society, Peter Cobb Director, VAHHA, Laura Pelosi, Vermont Health Care Association, Tom Paquette, VNA, Christine Scott, Mayo Healthcare, Lori Collins, Deputy Commissioner DVHA, Vicki Loner, Deputy Commissioner DVHA, Angela Means, VNA

Minutes: Joyce Brabazon

Welcome and Introductions – Dr. Chen. Dr. Chen asked the committee for comments or changes to the 9/28/2011 minutes. Dixie Henry noted that the minutes would be corrected to reflect Avril Cochran was present and not absent. There were no further comments and the minutes were approved.. Dr. Chen thanked Dixie Henry, Bessie Weiss and the workgroup for their work on the draft rule and thanked all who forwarded their comments.

Agenda:

Dixie Henry facilitated the meeting. Dixie thanked Cindy Bruzzese for collecting comments and integrating them into one document. Laura Pelosi, Peter Cobb and Avril Cochran had concurred via e-mail on the comments. Dixie stated that the committee is under a significant timeline and the goal today is to get through the comments on the rule, identify areas where we can reach consensus and on areas where there is not consensus, begin the rulemaking process and put the rule out for comment. The proposed rule needs to be filed in time for the ICAR meeting on 11/14/2011 in order to be effective 3/1/2012.

Dixie began with page 1 of the rule and reviewed the definitions. Dixie reiterated that the definitions in statute control. Dixie asked whether there were comments on the definition

for Surrogate. Cindy Bruzzese said that a surrogate may not just be one person, it could be persons. A group of people could provide substituted judgment such as a family.

Dr. MacAuley said this jumps ahead to the heart of the matter – what is the thought process? He stated he felt we are shifting and adding a layer of bureaucracy and that the focus is not on the decision maker but on the decision. He said this is a big philosophical issue.

Trinka Kerr said the statute is talking about the person and not the decision. Bessie Weiss read the statute. Dixie said we could come back to the definition but that the rule has to stay within the framework of the statutory authority. Cindy Bruzzese said the statute contains reference to both multiple and singular. Dr. MacAuley stated it says individuals and that it is a big burden to place on one individual. He said he would hate to be forced to make one person amongst family members the decision maker. Cindy Bruzzese asked Dr. MacAuley how this works in practice. Is there a note put in the chart that reflects a conversation or would he have a person sign an order? Dr. MacAuley said patients do not sign orders so neither would a surrogate. He responded that they put a document in the chart that indicates how they arrived at the decision.

Dixie stated that the proposed form has a place for a person to sign and the name of the surrogate. Cindy Bruzzese said she gets questions about what needs to be put on the form. Dixie said a recurring theme is the right to provide informed consent and the right to revoke and that someone needs to be designated so there is someone to go to if need to revoke. Dr. MacAuley suggested naming one person on behalf of the family.

Cindy Bruzzese said that if there is consensus, it works for her but need to work out when there is not consensus. Jackie Majoros said it is important to have one person ultimately named as surrogate. Have to keep in mind we are not just talking about FAHC.

Avril Cochran and Jill Olson said they agreed with Dr. MacAuley and Cindy Bruzzese. Sally Bliss said she worries about people other than the patient if an agent is not named. She said it is a big leap for one person to make the decision. It may be one person but if not, it is important for us to pursue a collective decision

Dixie asked for comments on page 3. Dixie said that the long form was updated after Attachment A. Cindy Bruzzese said she had no experience with updates to the long form. Dixie said we'll compare the long form and Attachment A.

There were no comments to pages 6 and 10. Page 11, Section 8 was new. Dr. MacAuley had suggested language to include emancipated minors as having the right to consent. There were no comments to page 12.

Page 13: DNR based on consent versus futility and right of patients to revoke. Dixie asked if anyone had concerns or comments. Dr. MacAuley spoke about medical ethics and that futility is not based on patient decision.

Jackie Majoros said she was not sure what she thought about it; whether patient decision should be overridden. Jackie said there is a right to refuse and consent to treatment. Dixie said this is in our current law and rule. Dixie proposed leaving it the way it is. Cindy Bruzzese asked for clarification. Dixie suggested taking out the parenthetical otherwise leaving the language the same. Dr. MacAuley said we need to make sure patients are informed regarding the declaration. Sally Bliss remembered somewhere in the rule there is mention of responsibility to inform.

Page 14 regarding EMS personnel. Dixie said we have not heard conscious versus capacity as being confusing for EMS personnel. Dr. MacAuley said he would be extremely surprised if EMS personnel listened to a refusal of someone who was inebriated.

Dixie commented on part D Surrogate Consent for DNR or COLST. To specify as DNR Or COLST and the form is entitled DNR/COLST.

Dr. MacAuley said the focus needs to be on the patient and the decision the patient would have made and who can articulate it. Dr. MacAuley understood naming a surrogate for purposes of revocation. Merle Edwards-Orr suggested the line reflect the patient, someone speaking for the patient, the decision made. He said identifying the person is important. He said multiples make sense in a hospital setting. In the community, it is fuzzy. He asked how this would work in the broader community.

Dr. Chen suggested switching the order – decision and someone to sign for decision. There was a discussion regarding D(2) “The surrogate(s) shall be ...” Cindy Bruzzese wanted clarification. She said to her this described an agent. Merle Edwards Orr suggested inserting the language, “In the presence of a clinician.” Dr. MacAuley suggested using capacity in an all or nothing way. He suggested considering the language, “and the patient did not lack capacity for identifying a surrogate.”

Cindy Bruzzese discussed the language “exhibited special care and concern” and its order in the priority. Is there knowledge of the patient’s goals and values? Someone could have care and concern without knowledge of patient’s values. Cindy suggested listing this language after the fact.

Page 15, #3: Cindy Bruzzese said this gets back to the whole philosophical discussion. Dixie asked if everyone was in agreement, what more would the rule need to say. Dr. MacAuley said that everyone doesn’t have to reach consensus, only those that want to be the surrogate. The way the rule is structured excludes a lot of people – those not the surrogate. Dixie said we are trying to identify who needs to reach consensus. Dr. MacAuley suggested language such as surrogate determined by those seeking to participate in the decision making process. Dr. Chen said to determine by consensus these that fit criteria 1 and 2.

Cindy Bruzzese said we are only asking them to make one decision regarding end of life decisions. Dixie responded that we can take down their comments and then will put this out for comment during the rulemaking process. Dr. MacAuley commented that the way

it is structured everyone does not have to agree, only the people who get votes are the ones that want to be surrogate themselves. Jackie Majoros asked what the point of the language is. Dixie responded, trying to reach consensus and to define what this group looks like. Jackie Majoros asked if there was a difference between people who want to participate in the process but don't want to serve but their information and values are helpful. Dr. MacAuley said a consensus of those eligible and seeking to participate in the decision making process. Dixie expressed concern that this expands it out. She saw tension between many people involved and writing it in way that ended up in more disagreement. Dr. Chen suggested same criteria but take out willing to serve. Cindy Bruzzese said I'm struggling with whether there has to be one decision maker talking to family members about what they would want. Once you get to the decision, identifying the decision maker is easy. Cindy said she was struggling with the order and how we have these conversations with families. Jackie Majoros said that when talking about this last week we discussed family members making decision in consultation with clinician. Not imagining eight people in a room deciding on a surrogate; envision it would be sitting down with the clinician. Jill Olson asked whether the language precluded the process Cindy Bruzzese and Dr. MacAuley were prescribing. Want to make sure that does not happen. Dixie said she did not worry too much about the language for when people are in agreement. Dixie suggested moving onto #4 when people cannot reach consensus, then what?

#4. Dixie asked what about access to hospital ethics committees? The law requires we include it in the rule. Cindy said that nursing homes do not have ethics committees. Home health agencies have ethics committees. Hospitals have ethics committees and some have relationships with nursing homes but usually in connection with a patient going back and forth. Cindy said there are liability issues for hospitals.

Jill Olson said she did not read the statute that way; she did not read protocols as requiring that. She said hospitals agreed to share the protocols, not share the ethics committees. Dixie asked what would be shared; is it a written document? Dixie asked what is the internal ethics protocol? Jill said it is written out; it is how they do things. Jill said hospitals are not offering up their ethics committees for use by other facilities. Dr. MacAuley responded the language does not say local hospital. If understand protocol that way could distribute FAHC's protocol. Dixie said she did not think the language in the Act was clear about how to get the protocol. Dr. Chen asked Dr. MacAuley if posting their protocols online would work? Sally Bliss asked how does posting protocols resolve disputes? Dr. MacAuley responded that this area is problematic; don't have an ethics structure. Jill Olson suggested something linked to the statute around protocol. She suggested collecting protocols that exist as examples. Sally Bliss said there is nothing in the protocols on how to resolve disputes or pick a surrogate. There is nothing to meet the requirements of #4. Jill asked if the information would be of any use to people? Jackie Majoros said she did not think the legislature thought residential care homes were going to just use ethics protocols. Dr. MacAuley said the spirit of that one sentence is not achievable right now; but if we can get by with the letter of the law for now. Jill Olson expressed she never thought people would interpret this language in that way. She said the solution cannot be that hospital ethics committees take this on nor does VAHHS think that is required. She said she was not proposing a solution. Dixie said we would write

language for the proposed rule. Merle Edwards-Orr asked whether the solution was to go to court? Cindy Bruzzese asked if there was a way somewhere in the language to take into account as identifying the surrogate, that the decision piece is a component? Dixie said we have a limited charge from the legislature and we will work within those parameters. Cindy Bruzzese asked what does substituted judgment do to choose a surrogate?

Dr. MacAuley said the form was also a big issue. Dr. MacAuley was concerned about the certification section. He said there were philosophical issues. He asked why the physician certifies? He asked what would happen if someone forgot to sign this section? Would this still be a valid COLST? He said we are ramping up the “officialness” with the certification. Jackie Majoros said that a person is not signing this section, just certified by clinician. Dixie said as back up, a surrogate could sign on the first page for a DNR. Dr. MacAuley said people will fill out the form incorrectly. He said guaranteed there will be DNR orders based on surrogate consent signed on page 1 and blank on page 3. There was a discussion about the certification and the various places where signatures are required. Jill Olson said there are two separate orders. Dixie said it was a different question whether it should be on the form and if so where on the form. Dr. MacAuley proposed as a compromise, adding language on the bottom of page 1, “By signing this form, I certify that the person named above

Dixie suggested including less certification language and fewer places to sign. She said if folks want to send us their comments to do so by tomorrow, 10/27/2011.

Bessie Weiss discussed particular parts of the statute that were not extended to surrogates. Bessie discussed immunity and that surrogates do not have immunity. Immunity is only extended to agents and guardians acting in good faith. Bessie said surrogates need to be added to that section. The second part pertained to access to medical records. She said surrogates will not be able to access medical records under HIPAA, only agents and guardians can. Dixie suggested talking about these two areas next time. Dixie said the committee did not address DNR identification. Cindy Bruzzese said she did not think EMS currently honors this identification now. Dixie said that EMS is not bound by an Advance Directive. She asked, is a bracelet not an expression of a patient’s wishes? We are talking about people who don’t go through the process. Sally Bliss said no, do not honor. This does not reflect an informed decision. Cindy Bruzzese said she has been doing a lot of education with people and that you cannot write your own order.