

Draft Minutes
Advanced Health Care Directive Registry Constituent Meeting
September 23, 2008

Purpose: This meeting was convened for the purpose of soliciting input from various constituent groups concerning the potential business models for a state-sponsored Advanced Health Care Directive Registry. This meeting is not required by statute, regulations, executive order, or any other legally binding document. Attendees will receive no compensation for their participation and will continue in an advisory capacity at their own discretion.

I. An overview of the enabling legislation was provided. The creation of the Advanced Healthcare Directive Registry is not required of VDH until sufficient funds are garnered for its operation. These funds can be obtained through gifts, contributions, grants, etc.

II. The required emergency regulations are being promulgated and should become effective September 25, 2008. The process of promulgating final regulations will then commence.

III. There are 4 discussion points for the implementation of Virginia's Advanced Directive Registry that need input from the various constituencies present: Technology, Funding, Governance, and Barriers

A. Technology – there are 4 options for obtaining the necessary software for the registry:

1. VDH builds the product
 - a. High costs are estimated for in-house development that can be upward of \$1 mil.
 - b. VDH cannot solicit funds from key stakeholder such as the hospital association and nursing home associations due to the regulatory aspect of the agency.
2. Contract with a current Advanced Directive Registry vendor (ASP model) that would host and maintain the registry (e.g., US Living Will Registry)
 - a. Need RFP to allow purchase
 - b. Would need a bridge loan to implement, then charge a cost-based fee for registration of consumer's information on the registry;
 - c. Would require
 - i. use of the VA's Public Procurement Process
 - ii. assurance that registry contents belongs to VA, not vendor
3. Partner with Senior Navigator, a 501(c)(3) corporation that currently supplies electronic information and referral services primarily to the older citizens of the Commonwealth.
4. Accept a 'donated' product
 - a. Available through the Secretary of Technology
 - b. Leverage IT partner to provide base code to host in VA
 - c. Examples are Microsoft and Google
 - i. May not have ability to customize to meet statutory requirements, i.e., scanning, security, etc.
 - ii. May not allow for scanning of document, which must be notarized

- B. Funding – no state monies were appropriated for this initiative.
1. If VDH chose to charge citizens for registering their information, the charge must be cost-based.
 2. Outside funding sources necessary for implementation
 - a. Use of bridge loans could be problematic; i.e., purchasing a product vs. a service
 3. The states of North Carolina and California charge a consumer fee for registering. Each state charges a fee of \$10.00.
 4. Staff was asked to research the availability of grants

C. Governance Options

1. Hosted by VDH
2. Hosted by a unique 501(c)(3) entity, under contract with VDH
 - a. Governing body would be determined by the Advanced Directive constituency
 - b. Allows for the possibility of deductible donations
 - c. Allows for a more transparent organization than a proprietary or hospital based organization
3. Hosted through an agreement with an existing 501(c)3
 - a. Arizona has such a partnership
 - b. Senior Navigator expressed interest
 - c. Staff requested to contact Virginia Health Care Foundation

D. Barriers – may prevent successful use of system

1. The statute requires that Advanced Directive requests be notarized, which is currently not required by hospitals when filing one on behalf of their patient.
2. Registration fee may preclude access by those that need registration the most
3. System must be easily accessible by anyone needing to use the system, ex. Medical staff
4. Documents must be reviewed for completeness prior to entry into the registry or the entry is meaningless
5. Unique consumer identification, not based on SS# to prevent ID Theft
6. Interface with deaths in VA to clear records and save storage space
 - a. Yearly notice is invaluable tool
7. System needs a meaningful indexing system as legal system uses various nomenclature for end of life decision making
8. Prohibition of surrogate filing may be problematic
9. Registry must be inclusive
 - a. Not target a segment of the population, e.g., elderly
 - b. Include university students, ethnic groups, VA Veterans
 - c. Become pro forma service for clients by the legal profession

IV. Other suggestions

1. Health care system must have buy-in
2. Tanner Smith (Troutman Sanders) is the Va. Spokesperson for National Advanced Directive Day
3. National Advanced Directive Day is April 16, 2009

V. Next steps - VDH Staff will

1. Develop a list of questions and research programs in other states for possible business model options
2. Work with Secretary of Technology in locating any potential software partners
3. Ask OAG clarification on legal interpretation of declarant, does it allow surrogates?
3. Solicit VHCF for possible grant or willingness to participate as a 501(c)3 partner

Attendees expressed an interest in continuing their participation and it was determined that the next meeting be scheduled after staff had completed sufficient research on business model options that a substantive discussion could take place.

Having no further business the meeting was adjourned.