

Advance Directive Accessibility Study

A Report by the Commissioner of Health to the Vermont General Assembly

January 15, 2005

Introduction

In the Spring of 2004, the General Assembly enacted and the Governor signed into law H.752, which became designated Act 162: *An Act Relating to Advance Directives for Health Care, Pain Management, and Long-term Care*. Section 2 of Act 162 requires the department of Health to “conduct a study and develop a plan to create and maintain a registry identifying individuals who have executed an advance directive.” The study shall include consideration of the following:

- (1) Secure access: The registry should be maintained in a secure database that provides authorized health care providers, health care facilities, residential care facilities, funeral directors, and crematory operators immediate access to the registry at all times;
- (2) Consolidation with organ donor registry: The study should consider how the registry might be consolidated with the anatomical gift registry authorized by section 5248 of Title 18;
- (3) Revocation and amendments: All individuals entered in the registry would have the right to revoke or amend the advance directive as provided in chapter 111 of Title 18;
- (4) Content filed in the Registry: The study should consider whether a copy of an individual’s advance directive or other means of determining the contents of an individual’s advance directive should be filed in and accessible through the registry;
- (5) Funding the Registry: The commissioner of Health is authorized to secure grants from public and private sources to conduct the study, to fund the registry, and to receive and disburse funds which are assigned, donated, or bequeathed to the department to cover the costs of the registry;
- (6) Notation on driver’s license: The department of Health in consultation with the department of Motor Vehicles shall determine a method of indicating on an individual’s motor vehicle license or identity card that the individual has an advance directive.

Finally, Act 162 requires that the commissioner of Health submit a report of the study to the general assembly by January 15, 2005.

Study Plan

The plan for the study was to convene a group of interested and knowledgeable stakeholders and to work with that committee in three phases:

Phase 1: Identify the needs and desired features for a Vermont advance directive registry. In this phase, we considered the features specifically mentioned in Act 162 including: security and access by health care providers; consolidation with the anatomical gift registry; ability to revoke or amend the advance directive once registered; content of the registry; funding; and methods for using drivers licenses to indicate having an advance directive.

Phase 2: Review existing advance directive registries. A few other states and jurisdictions have developed web-based registries. Given the time and money typically needed to develop, test, and implement new information systems, we wanted to explore how Vermont could take advantage of these existing systems and of the experience gained from operating them. For example, if an existing registry had most of the features and met most of the requirements we defined in Phase 1, then perhaps Vermont could transfer the technology or even subscribe to the system. This would be a far more cost-effective approach than to develop a new system from scratch.

Phase 3: Propose an implementation plan for a Vermont registry. Since the charge of Act 162 was to develop a plan to create and maintain a Registry, the study did not dwell on the relative merits of a Registry as a policy option or on other related issues addressed in Act 162 (e.g., pain management). Instead the focus of the committee's work was to develop a feasible plan to implement a Registry within a relatively short period of time.

Stakeholders were identified and were invited to participate on the study committee by William Apao, the director of the division of Health Surveillance in the department of Health, who chaired the study committee. During the Fall 2004, 23 individuals participated in three committee meetings, or served as consultants to the committee. Participants represented a variety of constituents including elderly people, people with disabilities, physicians, hospitals, and the legal community. The committee included representatives from two hospitals, several state agencies (departments of Health, Aging and Independent Living, and Motor Vehicles), the office of the Attorney General, Vermont Medical Society, Vermont Legal Aid, Vermont Health Care Association, and the Vermont Ethics Network. In addition, committee staff met with experts in palliative care and advance directive registries at Dartmouth Hitchcock Medical Center. A complete list of participants appears at the end of this report as Appendix A.

Phase 1: Desired Features of the Registry

The study committee discussed how a Vermont advance directive registry should operate from the perspectives of people registering advance directives and of people who need to access advance directives once they are registered. The committee identified the following as desired features.

1. Ease of use: The Registry must be easy to use by providers and depositors.
 - a. Providers:
 - Providers must be able to quickly search the Registry for an individual record (person), determine if the individual has a directive on file and if so what type of directive (e.g., durable power of attorney, living will, organ donation), and be able to view or print them without having to wade through a long text form.
 - Staff at hospitals and other health care providers must be able to easily and quickly access, view, or print a directive.
 - Advance directives should be accessible by out of state providers.
 - b. Depositors:
 - There should be a variety of ways for people to register their advance directives to make the process simple and convenient, irrespective of where they live or their level of technological sophistication. Depending upon an individual's need for assistance, the process might range from working with a lawyer, notary, or hospital clerk to working on one's own at home to complete standard paper forms and mailing them to a deposit site or even completing them online.
 - People should be able to contact people who are trustworthy, credible, and easily accessible in order to learn about advance directives, to get assistance, and to get answers to their questions.
 - When individuals submit their advance directives to the Registry, they should receive confirmation of the registration along with a written explanation of security and confidentiality protections, and instructions on how to access, revise, update, or delete records.
2. Security and confidentiality: The Registry should have a Statement of Purpose which makes it clear that it is intended as a tool for quickly and efficiently sharing advance directives with those who need it. However, measures must be taken to protect confidentiality and to ensure appropriate access to the Registry.
 - a. There should be policies and safeguards in place to ensure that health care providers access only their own patients' directives.
 - b. The registrant should have some measure of control over who has access to his or her record.

- c. The system should include administrative tools for monitoring who has accessed each record.
3. Content of Registry record: What information should be filed in the Registry?
 - a. Two parts to the Registry record:
 - A “cover sheet” with limited data that would be keyed into the system and would be used to search for records: e.g., name, address, agent, check boxes to indicate the type of directives on file, and where the paper copies of the directives are located.
 - A digital copy (scanned .pdf file) of the advance directive. We would promote the use of a standard form (e.g., the Vermont Ethics Network forms), but any valid form could be scanned and stored.
 - b. Most depositors will file both parts of the record. However, there should also be an option to file only the cover sheet, but not a copy of the advance directive itself.
 - c. The Registry will not retain paper copies of advance directives; original forms will be returned to depositors.
 - d. *Do Not Resuscitate* (DNR) orders would not be filed in the Registry at this time. Based on a review of likely DNR scenarios (e.g., emergency response situations), we concluded that services such as education or hospice, or a standardized method for DNR identification (e.g., a bracelet) would be more effective than an advance directive Registry to ensure that DNR orders are followed. In addition, some members of the committee felt that DNR orders did not constitute advance directives because they are medical orders, signed by physicians. Nevertheless, the potential for the appropriate use of the Registry for DNR orders should be reconsidered at some future time, especially with regard to EMS field responses outside of medical facilities.
4. Revising and deleting directives
 - a. Depositors must be able to revise, update, and delete directives.
 - b. Updated directives would replace earlier versions: But the Registry will store only the most recent version to prevent possible confusion.
 - c. A valid directive is still “legal” whether or not it is filed in the Registry. Similarly, an updated “paper” directive would be the controlling document even if the Registry version had not been replaced.

5. Application development strategy

- a. Should be “scaleable”: In the interest of developing the Registry quickly, the first version may not have all the desired features and functionality, but should be designed so that enhancements could be made in the future.
- b. Explore options to “fast-track” development by adapting or transferring technology developed in other states, or by coordinating with other Vermont initiatives or registries.

6. Funding and Governance

- a. No registration fee: The committee believes that charging a fee to register an advance directive, even a nominal fee, may discourage use of the Registry and create two classes of people with advance directives: those who can afford to register and those who can't.
- b. Start up funding: Explore the possibility of funding the initial development and implementation of the Registry system through existing or renewed federal grants. One possible source of funds may be the department of Health's Comprehensive Cancer Grant from CDC if the Registry is selected as a priority project.
- c. Funding for on-going maintenance, administration, and enhancements: The committee suggests that annual operational costs should come from state general funds unless or until other stable funding is secured.
- d. Options for governance: The Registry should be sponsored by an agency or a partnership of agencies with credibility, stature, and state-wide coverage. The sponsor(s) should be able to acquire stable funding for the Registry, to provide technical support and manage enhancements to the Registry software application, to promote the Registry and educate the public about its services. The sponsor(s) should not be directly involved in the provision of health care. Two organizations that have been mentioned as possible sponsors are the department of Health and the Vermont Ethics Network.

Phase 2: Review existing advance directive registries

The committee next turned to a review of existing Registries in light of the desired features we identified in Phase 1. Dr. Fran Brokaw made available to the committee a study entitled *Making A Difference in Vermont: State Reform of Advance Care Planning* (Bakitas, Brokaw, Brown, Drayton, and Rice, 2004) that was conducted as part of a health policy course at Dartmouth College. The report included a review of four electronic advance directive registries:

- North Carolina registry (<http://www.secretary.state.nc.us/ahcdr/>)

- Choices Bank in Missoula, MT (<http://www.choicesbank.org/>)
- A commercial registry (www.uslivingwillregistry.com)
- A website that supports completing and storing electronic advance directives on line (<http://www.tortuga.com/ihd/midbio2/>)

Committee members and health department staff visited and reviewed each of the registry websites. Each had strengths and weaknesses, but we concluded that the Choices Bank registry was the most promising as a model for Vermont: it had most of the features we wanted for a Vermont registry; the web pages were attractive and well-designed; it had good protections for security and confidentiality, and the registration process was simple and clear.

In addition, preliminary findings of an evaluation of Choices Bank are encouraging and reflect the success of the system to date to increase the use of and improve access to advance directives:

- 42% of Choices Bank registrants indicated that they had not previously completed an advance directive prior to depositing an advance directive into the Choices Bank.
- Users' confidence that they and other key health care decision makers (e.g., agents, family members, and doctors) could locate their advance directive at any time increased from about 39% before using Choices Bank to about 90% after using Choices Bank.
- 97% of depositors reported being Very to Extremely Satisfied with the Choices Bank services.

In order to address specific questions raised by the committee about Choices Bank, we had a phone conference with Susan Hancock, the project director of Choices Bank, and Lily Tuholske, Executive Director of Life's End Institute in Montana. In addition, three members of the committee met with Dr. Brokaw and Dr. Ira Byock, Director of Palliative Medicine at Dartmouth Hitchcock Medical Center. Dr. Byock formerly practiced in Missoula, Montana and was instrumental in the development of Choices Bank. Below is a summary of the main findings from those discussions as they relate to the desired features for a Vermont Registry.

1. Ease of Use

Below is a description of the Choices Bank deposit process -- i.e., how individuals complete and submit advance directives to the Registry. This addresses the features identified in 1b above:

Step 1: Depositors take their completed advance directive to one of the 17 Choices Bank deposit locations in Western Montana.

Step 2: Trained staff at the deposit location review the advance directive to make sure it is complete, legible, signed and dated, and witnessed by two people, one of

whom can be a notary public. The documents are also checked to make sure they are health care, not financial, documents. This staff person asks the depositor to complete a *Deposit & Release Form*. This form can be downloaded from the Web site and completed in advance. This form allows the Choices Bank to release the advance directive to health care providers. It also is the form used to collect identifying information that will be used to search through the database. The depositor also chooses between two levels of privacy (see section below on Security and Confidentiality). Finally, the staff person photocopies the advance directive and gives it to the depositor to take home, as well as a receipt for the original advance directive that explains what will happen next. The entire deposit process usually takes less than 15 minutes.

Step 3: The original advance directive and *Deposit & Release Form* are mailed to the central office where they are scanned and entered into the secure Choices Bank website.

Step 4: Within two weeks of the deposit, a Choices Bank Depositor Kit is mailed to the depositor. This kit includes the original advance directive, two wallet cards with the confidential access code, instructions for reviewing the advance directive online, and information about updating it in the future.

2. Security and confidentiality

Levels of privacy: Choices Bank recognizes that some people wish to control who will have access to their advance directives. Others want their advance directives available to a wider circle of people. Therefore, they created a choice of two privacy levels to meet the needs of both groups: the Standard Privacy level allows anyone with the depositor's social security number, birth date, and mother's maiden name to view their advance directive; the Higher Privacy level requires the confidential access code. In the latter case, the depositor shares the access code with whomever they choose and thereby controls who can view their advance directive.

Both privacy levels serve to restrict access to the advance directive. In either one, health care providers and anyone to whom wallet card information is given can view the advance directive. Individuals choose one of the two privacy levels during the deposit process but can change levels at a later date. By having this choice, depositors can exert some control over access to their records -- a desired feature for a Vermont Registry (feature 2b).

To further protect the privacy and the integrity of a depositor's advance directive, it is scanned and stored as a read-only PDF (portable document format) file, which cannot be modified in any way (feature 3a). If a depositor wishes to make changes to an advance directive, he/she must complete and deposit a more recently signed advance directive or a revocation form (features 4a and 4b).

Internal protections of confidentiality and security: Choices Bank adopted several measures to ensure that a depositor's privacy is respected and protected while their documents are being processed. Every member of the staff at the location where a deposit is made has signed a confidentiality agreement with strict penalties for non-compliance. Each person has also been trained in the deposit process, privacy issues, and procedures for properly handling confidential documents. Completed deposit materials and advance directives are temporarily stored, if necessary, in a secure location and promptly transferred to Choices Bank Central in a secure manner.

Choices Bank Central is located in a restricted access area closed to the public. If a deposit package is not actively being processed, it is temporarily stored in a locked location. Once processing is complete, original deposit materials are returned by mail to the depositor along with the Depositor Kit. Choices Bank Central does not make or retain any paper copies of the documents (feature 3c). Only specific, trained employees have access to the database, and their access is password protected. The computer server that stores the information is located in a locked facility with access restricted to specific individuals.

In addition, Choices Bank has implemented measures to protect their Web site from loss, misuse, and unauthorized alteration of any registered information. Information transmitted via the Internet (e.g., directives scanned at a remote deposit site) is encrypted using the Secure Sockets Layer protocol similar to that used by banks. They periodically conduct preventive maintenance on their web site, check for viruses, and back up all data. If their computers ever crashed, the system could be restored from back ups.

Access by health care providers and measures to prevent abuse: Every person who deposits an advance directive in the Choices Bank is issued a wallet card that contains their name and access code which they or others who have the access code can use to view their advance directive on the website. In the best case scenario for access to records by health care providers (feature 1a), a depositor would give his or her doctor the wallet card; then the doctor would use the access code to retrieve and view the advance directive on the Web site. The entire process would take only a few minutes. In addition, health care providers and medical records department staff have been issued their own user accounts and passwords which allows them to search the Choices Bank database in case the wallet card is not readily available. Any single piece of identifying information -- name, address, birth date, social security number, driver's license number, mother's maiden name -- can be used as search criteria.

To prevent misuse of the information (feature 2a), the first time a health care provider accesses the Choices Bank database to search for an advance directive, the statement below appears and must be agreed to before the system will allow access to the search engine.

I agree to use my Choices Bank-issued user name and password only to locate my own advance directive or that of patients for whom I am directly providing medical care. I understand that:

- *Individuals' advance directives are private documents.*
- *Access to my patients' advance directives via my user name and password issued by the Choices Bank is a privilege accorded me due to my clinical responsibilities.*
- *I am responsible for any access achieved using my assigned user name and password since these constitute my electronic signature.*
- *It is my responsibility to protect the confidentiality of my user name and password.*

The privilege of access to Choices Bank information can be revoked if it is used in a manner inconsistent with my professional role. You will only be asked to agree to this policy the first time you use your user name and password.

Finally, the system also has the capability to monitor whoever has searched the database and when (feature 2c).

3. Content of Registry record

Choices Bank manually keys the following fields into the system: first name, last name, middle name or initial, address (including city, state, and zip), birth date, social security number, driver's license number, mother's maiden name, the date the advance directive was signed, and the security level chosen. The advance directive form is scanned as a .pdf file and linked to the record containing the identifier fields (feature 3a).

Currently, the Choices Bank system does not include a field for the type of directives deposited (durable power of attorney, terminal care, organ donation, etc.) as a means of quickly identifying and accessing an individual's directives without having to scroll through a lengthy text document. This has not been a problem in their system because most people use the relatively short standard form. However, the system could be adapted to have links to separate forms (if each directive is scanned into a separate file), or to separate sections within a single form.

4. Revising and deleting directives

As a security measure, advance directives in Choices Bank are stored as read-only PDF files which cannot be altered. Therefore, to revise or update an advance directive, the depositor must complete and submit a more recently signed advance directive. Directives on file can be deleted by submitting a revocation form (features 4a and 4b).

5. Application development strategy

As a way to “fast-track” the development of a Vermont Registry (feature 5b), the committee staff engaged Choices Bank management in discussions of possible options for adapting or transferring the Choices Bank system to Vermont. The option that we found most attractive was to contract with Choices Bank to develop, host, and maintain a “Vermont Choices Bank” on their server in Montana. They would modify their web screens so that they would appear in every way to be a Vermont registry rather than a Montana registry. They would also incorporate enhancements and special features (e.g., a “cover sheet only” option – feature 3b) that do not currently exist in their system. These Vermont features could be implemented with the first version of the Vermont registry, or with future versions as we gain more experience and identify and prioritize enhancements (feature 5a)¹.

There are several advantages of this development strategy. First, we can exploit current web technology. The physical location of the web server does not affect the operation of the registry, and would not be important to users as long as they access a *Vermont* Choices Bank through a Vermont “portal”. Second, with this development strategy, Vermont can quickly, cost-effectively, and with relatively little risk develop a registry with nearly all of the desired features the committee identified. Third, we can avail ourselves of the training, outreach and marketing, consulting, and technical expertise of people who have been operating a successful registry for over two years.

6. Funding and Governance

Unlike some other registries, Choices Bank does not charge a registration fee. They decided not to charge a fee partly for the same reason that the study committee recommended against charging a fee (feature 6a): that it could present a barrier and discourage use of the Registry. Even though Choices Bank promotes its services to only one county in Montana, it has more advance directives on deposit than the North Carolina state registry which started at about the same time but charges a fee. Choices Bank staff also pointed out that, if a fee were charged, they would need an accounting system for keeping track of payments and would also have to deal with problems such as bad checks, credit card numbers that don’t process correctly, etc.

If not through fees, how should a Vermont Registry be funded? Act 162 authorizes the commissioner of health “to secure grants from public and private sources to conduct the study, to fund the registry, and to receive and disburse funds which are assigned, donated, or bequeathed to the department to cover the costs of the registry”. Therefore, the commissioner is exploring possible funding using existing or renewed federal grants such as department of Health’s Comprehensive Cancer Grant from CDC if the Registry is selected as a priority project (feature 6b). Since

¹ As examples of enhancements, the committee envisioned an interface between the Registry and death certificates to purge records of people who have died; or an interface with hospital systems so that the Registry is automatically searched as part of the inpatient admission process.

most federal grants, this one included, have a fixed duration, grant funding would be most appropriate for the initial development and implementation of the Registry system. For on-going operations of the Registry (maintenance, administration, and future enhancements), the committee recommends funding from state general funds unless or until other stable funding is secured (feature 6c).

The committee notes that public funding of an advance directive registry could be justified by the potential for avoidance of unnecessary health care costs. Based on national figures, 30% of Medicare expenditures are attributable to the 5% of beneficiaries who die each year, resulting in per-capita spending on decedents that is six times as great as for non-decedents². End-of-life care consumes 10% to 12% of all health care expenditures and 27% of Medicare expenditures³. A 10% savings in medical costs during the last year of life would amount to approximately \$10 billion per year and almost \$4.7 billion for Medicare alone⁴.

While originally developed to enhance patient control and to provide better care at the end-of-life, advance directives can also be a means to avoid unwanted and costly medical procedures at the end of life. In a study of Medicare patients at tertiary care hospitals, patients who had advance directives had a 52% reduction in length of stay (10 vs. 21 days), and a 68% reduction in mean hospital charges for their terminal hospitalizations (\$30,478 vs. \$95,305)⁵. In the same study, patients with *prior* advance directives experienced significantly lower hospital charges than those completed as an inpatient. In another study of patients who died in a terminal hospitalization, hospital costs for those with advance directives were 38% less than those without advance directives⁶.

Monetary savings are not the only justification for public funding and support of the operations of an advance directive Registry. Fostering patient self-determination and improved communication, especially in times of medical crisis, and in all medical care settings, are worthy goals of public policy and financial support.

Phase 3: Proposal to implement a Vermont advance directive registry

- Contract with Choices Bank to customize, host, and maintain the Vermont Advance Directive Registry

² Hogan, C., et al. 2001. "Medicare beneficiaries' costs of care in the last year of life." *Health Affairs* 20 (4): 188-95

³ Lubitz, J.D.; Riley, G.F. 1993. "Trends in Medicare payments in the last year of life." *New England Journal of Medicine* 328 (15): 1092-6

⁴ Emanuel, E. 1996. "Cost savings at the end of life: what do the data show?" *Journal of the American Medical Association* 275 (24): 1907-14

⁵ Chambers, C.V. et al. 1994. "Relationship of advance directives to hospital charges in a Medicare population." *Archives of Internal Medicine* 154 (5): 541-7

⁶ Weeks, W.B., et al. 1994. "Advance directives and the cost of terminal hospitalization." *Archives of Internal Medicine* 154 (18): 2077-83

The committee finds that the Choices Bank registry (a) is a well-designed system with a good track record and is the best of all the existing registries we reviewed, (b) has nearly all the features desired for a Vermont registry, and (c) is willing to customize their system (screens, fields, forms, colors), add features to meet our specific needs, and share with us their expertise in operating a registry. By building on an existing system, the state of Vermont assumes very little risk while developing a *Vermont Choices Bank* more quickly and at less cost than if we were to develop a new system.

- Adapt the Choices Bank process for depositing an advance directive to meet Vermont-specific needs and preferences

Multiple Deposit Sites: We would enlist partner agencies throughout Vermont to serve as “deposit sites” where trained staff would be available to answer questions and to assist depositors with the technical aspects of completing the directive forms as well as a cover sheet with a deposit and release form. They would also review completed forms to make sure they are valid: i.e., properly completed, dated, signed, and witnessed. These deposit sites could include hospitals, nursing homes, and the department of Health’s 12 district offices.

Registry Administrator: Completed forms would be mailed from deposit sites to a central “registry administrator” in Vermont who would scan the forms and use the Choices Bank web site to electronically send the scanned files to Montana where the forms would be posted on the Vermont Choices Bank web server. The registry administrator would mail back to the depositor the Choices Bank Depositor Kit: the original advance directive, wallet cards and other ways to signify having an advance directive (e.g., driver’s license stickers), instructions for reviewing the advance directive online, and information about updating, revising, and deleting it. The registry administrator will also offer telephone assistance through a 1-800 number.

Direct Mail option: Individuals could choose to prepare their own directives and mail completed forms (including the cover sheet) directly to the registry administrator rather than going through deposit sites. This may be more convenient for some depositors. However, we would encourage depositors to work with deposit sites to ensure that directives are completed correctly. Invalid forms that are not checked before being sent to the registry administrator would have to be mailed back to depositors for corrections.

Forms: We would promote the use of the Vermont Ethics Network advance directive form and make it widely available as a paper form, or in electronic form which could be downloaded from the website. However, any valid advance directive (i.e., signed, witnessed, dated, etc.) in any form would be acceptable and could be scanned and deposited.

- Secure access and protections of confidentiality

Another benefit of having Choices Bank host the Vermont registry is that our system will be protected by the same security measures that protect the Montana system. These are described more fully above but include:

- ✓ Two levels of privacy are offered so that depositors can control who has access to their advance directives⁷.
- ✓ Directives are scanned as read-only PDF (portable document format) files which cannot be modified or tampered with.
- ✓ Staff at both deposit sites and the registry administrator agency are trained on the deposit process, privacy issues, and handling practices for confidential documents.
- ✓ The server at Choices Bank Central is in a locked facility with access restricted to specific individuals.
- ✓ Information transmitted via the Internet is SSL encrypted.
- ✓ Preventive maintenance of the web site, including virus checks and data back ups, is conducted regularly.
- ✓ Depositors and anyone with specific personal information about the depositor can access his or her advance directives on the web. In addition, health care providers and medical records staff have been issued their own user ID's and passwords and can search the Choices Bank database provided that they first agree to a statement concerning their professional responsibilities and conditions for using the Registry.
- ✓ The system can track whoever has searched the database and when.

- Costs and Funding

The first year start-up costs for Vermont Choices Bank and subsequent on-going costs are estimated as follows:

First year: approx. \$52,000

- a. Registration (\$25,000): Essentially, this is a licensing fee that allows Vermont to use the Choices Bank their software, server, and technical support.

⁷ Vermont may elect to offer a “cover sheet only” option in addition to, or in lieu of, the higher level of security which requires the individual’s access code.

- b. Customization (\$6,000): to modify screens, change colors, and incorporate small functional changes to the system to meet our needs.
- c. Training (\$15,000): for staff at the registry administrator agency and deposit sites on the deposit process, confidentiality practices, sending files to Montana, etc.
- d. Promotional and marketing materials (\$5,000)
- e. Record maintenance (\$1,200): estimated for 1000 records @ \$.10/record/month)

Subsequent years: approx. \$11,000 annually

- a. Annual registration renewal (\$9,500)
- b. Record maintenance (\$1,200): estimated for 1000 records @ \$.10/record/month)

Staff costs: approx. \$15-20,000 annually

This would pay for a half time administrative assistant at the registry administrator agency. We expect that staff costs at deposit sites will be absorbed as in-kind contributions given that the time and work required of staff at deposit sites will be minimal.

The committee recommends against charging an advance directive deposit or registration fee lest some people be discouraged from using the Registry. In addition, collecting fees would require an accounting system and would create a burden on the agency acting as registry administrator. Instead, the committee recommends that the commissioner of Health explore using existing or renewed federal grants to fund the initial deployment of the Vermont Choices Bank (\$52,000). For on-going operations of the Registry (maintenance, administration, and future enhancements) after the first year (estimated \$26,000-31,000 including staffing costs), the committee recommends funding from state general funds unless or until other stable funding is secured.

- Governance

The committee discussed at length who or what agency should sponsor the Vermont advance directive registry and be responsible for local administrative functions including: scanning and sending files to Montana for posting, mailing depositor kits to depositors, answering questions from the public and deposit sites, and conducting outreach, promotion, training, etc. Some committee members proposed that the Vermont Ethics Network (VEN) would be the appropriate choice given their leadership in education about ethics in health care and end of life care issues. VEN

would be the Vermont equivalent of the Life's End Institute which is the sponsoring agency of Choices Bank.

Other committee members, however, pointed out possible advantages of having the department of Health be the local sponsor: accountability, a fiscal infrastructure, greater opportunities for finding stable funding, technical support, credibility, stature, and state-wide coverage. Furthermore, the public is familiar with, and has a generally favorable opinion of, the department of Health.

Both Dr. Byock and Choices Bank staff recommended that VEN be the local sponsor rather the department of Health because of the public perception that advance directives can be used to limit health care at end of life. Any agency involved or perceived to be involved in the provision of health care might be viewed by the public as having a conflict of interest and should not be the local sponsor. This is similar to the reason why an individual's health care provider cannot sign as a witness on the advance directive.

The committee noted that the role of sponsor and the role of local administrator do not have to reside in the same agency. Therefore, the committee recommends that the department of Health and VEN should together develop a governance proposal that would take advantage of the strengths of each organization and the assets each could bring to the project. For example, the department of Health could be the fiscal agent for the contract with Choices Bank and subcontract with VEN to be the registry administrator agency. The department of Health's 12 district offices could be the first deposit sites which would provide immediate statewide coverage for the registry. As the registry administrator, VEN would be responsible for scanning and sending files, maintaining relations with depositors, and conducting outreach, promotion, training, etc. Both agencies could provide a link to Vermont Choices Bank from their respective web sites.

- Organ Donation and Coordination with Department of Motor Vehicles

Act 162 charges the study committee to “consider how the registry might be consolidated with the anatomical gift registry authorized by section 5248 of Title 18”; and charges the department of Health to consult with the department of Motor Vehicles to “determine a method of indicating on an individual's motor vehicle license or identity card that the individual has an advance directive.”

The committee spent parts of two meetings discussing these issues, and committee staff continued those discussions and vetted proposals with a committee member who represented the department of Motor Vehicles. Currently, Vermonters can signify their willingness to donate organs on their driver's license or identity card issued by the department of Motor Vehicles. However, that information is not captured in a registry, nor in any database managed by the department of Motor Vehicles. In 2002, the Vermont General Assembly passed legislation directing the departments of Health and Motor Vehicles to develop an anatomical gift registry.

This registry would be a place to store and retrieve an individual's written statements of preferences about anatomical gifts. It would be used by organ procurement organizations when discussing organ or tissue donations with families of potential donors. Although no funding was provided to develop and operate the anatomical gift registry, the department of Health was authorized to accept grants and donations for that purpose. The department did receive a \$10,000 donation from the Center for Donation and Transplant which was used to fund a study to review best practices, and to determine how to develop and operate a Vermont registry. That study concluded that it would cost about \$85,000 annually to operate such a registry.

The study committee's proposal for an advance directive registry offers a cost-effective solution for also developing an anatomical gift registry: organ donation can be a form of advance directive. As an advance directive, it can be deposited, scanned, and posted on the Vermont Choices Bank web site and accessed by organ procurement organizations.

Anticipating this, Vermont Ethics Network has drafted a new standard advance directive form which includes organ donation in addition to durable power of attorney and terminal care (a draft copy of the form is included as Appendix B). The organ donation portion of the standard advance directive form could be completed in the same way and with the same support services available for completing any other advance directive. However, since most people decide whether or not to become an organ donor when they renew their driver's license, the committee considered how the license renewal process could provide an opportunity for people to complete an anatomical gift or other advance directive.

The committee recommends the following: When people go to the department of Motor Vehicles offices to renew their license or to apply for an identity card, they would be informed about organ donation and other advance directives (e.g., a brochure). If interested, they would be given a copy of the Vermont Ethics Network form to complete. The form would be reviewed and witnessed by Motor Vehicles staff as it would be at a deposit site. However, depositors would be responsible for mailing the form to the central registry administrator. That step could be simplified by making available self-addressed envelopes. The registration process would proceed as described above. As part of the Depositor Kit that is mailed back to the depositor by the registry administrator, we would include a sticker that would be placed on the license or identity card. The sticker would signify that the person has an organ donation or other advance directive⁸.

There are several benefits of treating organ donation as a form of advance directive. First, the state gains an organ donor registry at the same time it develops an advance directive registry at far less than the anticipated annual cost for an organ donor

⁸ Some members of the committee disliked the idea of a sticker because it might not get applied or could peel off. When the department of Motor Vehicles renegotiates its contract for printing licenses, we may wish to add checkboxes for advance directives similar to the current organ donor checkbox.

registry of \$85,000. Second, Motor Vehicle offices become quasi-deposit sites for advance directives and the license renewal process becomes an outreach opportunity that will eventually reach nearly all Vermont adults. Thirdly, organ procurement organizations become a stakeholder in the advance directive registry, and a possible source of funding for the registry.

Summary

The study committee proposes to contract with Choices Bank to customize, host, and maintain a Vermont version of Choices Bank. The proposal addresses each of the study considerations specified in Act 162:

1. **Secure access:** Choices Bank has adopted several measures that protect the security of the system and confidentiality of individual documents, but also allow fast but appropriate access by health care providers and others authorized by depositors.
2. **Consolidation with organ donor registry:** The Choices Bank model is “neutral” with respect to what constitutes an advance directive. Organ donation can be treated as an advance directive and deposited into the advance directive registry. Authorized organ procurement organizations would be able to access organ donation information in the Vermont Choices Bank registry just as other health care providers.
3. **Revocation and amendments:** As a security measure, Choices Banks stores electronic copies of advance directives in a format that cannot be modified. However, depositors can amend or revoke their advance directive by completing and submitting a more recently signed advance directive, or a revocation form.
4. **Content filed in the Registry:** In most cases, an electronic scanned copy (.pdf file) would be stored in the Registry and would be accessible for viewing and printing by the depositor, health care providers, or others authorized by the depositor. The Vermont registry will also consider offering a “cover sheet only” option. In this option, the depositor’s record would not include a copy of the advance directive, but only a notation that one exists and where it could be located.
5. **Funding the Registry:** The committee recommends that the commissioner of Health explore using existing or renewed federal grants to fund the initial deployment of the Vermont Choices Bank (estimated at \$52,000). For on-going operations of the Registry (maintenance, administration, and future enhancements) after the first year (estimated \$26,000-31,000), the committee recommends funding from state general funds unless or until other stable funding is secured.
6. **Notation on driver’s license:** An individual who deposits an advance directive into the registry would be mailed a Depositor Kit from the registry administrator. The Kit would include a sticker that would be placed on the license or identity card signifying that the person has an organ donation or other advance directive.

Appendix A
Advance Directive Accessibility Study
Participant List

Name	Affiliation
Apao, William	VT Department of Health
Benvenuto, Michael	Director, Senior Citizens Law Project, Vermont Legal Aid, Inc.
Brokaw, Frances MD	Dartmouth Hitchcock Medical Center
Byock, Ira MD	Dartmouth Hitchcock Medical Center
Campbell, John	VT Ethics Network
Davis, Betsy RN, MPH	Retired VNA educator, Fletcher Allen Health Care Board, VT Ethics Network Board, and COVE Boards
Dempsey, Bob	VT Department of Health
Fishell, Kenneth	Community member
Frank, Cathy L.	VT Ethics Network, Board of Directors Chair
Hofstetter, Peter	CEO, Northwestern Medical Center
Majoros, Jackie JD	LTC Ombudsman VT Legal Aid
Manz, Dan	VT Department of Health
McDonnell, Sharon MD	CDC researcher and Medical Epidemiologist
Mongan, Madeleine JD	VT Medical Society – Dir. Of Government Relations
Morgan, Wendy JD	VT Office of the Attorney General
Olson, John	VT Department of Health
Orr, Robert D. MD	Director Clinical Ethics Fletcher Allen Health Care/UVM College of Medicine
Rainwater, Tuck	COVE/Sirotkin& Necrason
Reardon, Mildred A. MD	Area Health Education Center, President
Senecal, Joan	VT Department of Aging and Independent Living
Shriver, Mary	President, VT Health Care Association
Snyder, Linda	Vermont Department of Motor Vehicles
Williams, Xenia	Washington County Mental Health Services

Appendix B: Vermont Advance Directive For Health Care

Prepared by the Vermont Ethics Network

EXPLANATION AND INSTRUCTIONS

- *You have the right to give instructions about what types of health care you want or do not want.*
- *You also have the right to name someone else to make health care decisions for you when you are unable to make them yourself.*
- *You may do either of these by telling your family or your doctor, but it is generally better for you and your family if you write down your wishes.*
- *You may use this form in its entirety or you may use any part of it. For example, if you simply want to choose an agent in **Part One**, you may do so and go directly to **Part Five** to sign this in the presence of appropriate witnesses.*
- *You are also free to use a different form as long as it is properly signed and witnessed.*

Part One of this form lets you name a person as your “agent” to make health care decisions for you if you become unable to make your own decisions. You may also name alternate agents. You should choose as your agent (and alternates) people you trust, who are going to be comfortable making what might be hard decisions on your behalf. They should know you and be guided by your values in making choices for you.

You should notify your agent and alternates that you have named them, and they need to agree to act as your agent if asked to do so. Your agent does not have authority to make decisions for you until you are unable to make your own decisions.

If you do not appoint an agent, and then become unable to make your own decisions, someone will be found to make health care decisions for you.

Part Two of this form lets you state **Treatment Wishes**. Choices are provided for you to express your wishes about having, not having or stopping treatment necessary to keep you alive under certain circumstances. Space is also provided for you to write out any additional or specific wishes based on your values, health condition or beliefs.

Part Three of this form lets you express your wishes about **organ or tissue donation**.

Part Four is for you to express your wishes about autopsy and funeral arrangements.

Part Five of this form is for signatures. You must sign and date the form in the presence of two witnesses. The following persons may not serve as witnesses: your agent and alternate agents; your spouse or partner; your heirs; your doctor (or doctor's employee); an employee or the owner of the residential care facility where you live; or any person to whom you owe money.

You should give copies of the completed form to your agent and alternate agents, to your physician, your family and to any health care facility where you reside or at which you are likely to receive care. You should keep a list of those who have copies in case you revoke or revise the document in the future. You have the right to revoke all or part of this advance directive for health care or replace this form at any time. If you do revoke it, all old copies should be destroyed.

*You may wish to read the booklet **Taking Steps** that includes worksheets to help you think about and discuss different choices and situations with your agent or loved ones. You may also use this section to nominate a guardian of your person, should someone need to be appointed at some future time to make decisions for you. Also, if you have a specific illness or condition and wishes that relate to it, this is a good place to note that.*

Advance Directive

MY NAME _____ DATE OF BIRTH _____ S.S # _____

ADDRESS _____

CITY _____ STATE _____ ZIP _____

Part One: Appointment of My Health Care Agent

I appoint _____

ADDRESS _____

TEL. (DAY) _____ (EVENING) _____

CELLPHONE _____ EMAIL _____

as my Health Care Agent to make any and all health care decisions for me, *except to the extent that I state otherwise in this document.*

If this health care agent is unavailable, unwilling or unable to do this for me, I appoint _____ to be my **Alternate Agent**.

ADDRESS: _____

TEL. (DAY) _____ (EVENING) _____

CELLPHONE _____ EMAIL _____

(Use additional sheet to appoint additional agents or alternates.)

Others who can be consulted about medical decisions on my behalf include:

Those who should not be consulted include:

Your agents should have been notified that you appointed them, they should understand your wishes and they should agree to make health care decisions for you when you can no longer make them for yourself.

The space below is to identify your doctor or health care provider (optional).

PRIMARY CARE PHYSICIAN _____

ADDRESS _____ TELEPHONE _____

OTHER HEALTH CARE PROFESSIONAL _____

ADDRESS _____ TELEPHONE _____

It is encouraged that you and your doctor discuss this document.

MY NAME _____ DATE OF BIRTH _____ S.S # _____

Part Two: Treatment Wishes

Please express your preferences that follow by initialing or checking the statements. You may initial more than one choice. Draw a line through any statement you do not agree with. If you do nothing, your agent or others such as family members and doctors treating you will assume you want them to decide for you. If you do not state a preference for withholding or withdrawing artificial food (tube feeding) and hydration, your agent may not have authority to withhold or withdraw it, without a court order, if you are being treated in a New York or New Hampshire hospital.

_____ A. My Choice is to Limit Treatment—

(Initial or check those statements below that you agree with)

- _____ 1. I do not want to be kept alive if I am so sick that I will die within a relatively short time (I cannot get better and have only weeks, days or hours left to live).
- _____ 2. I do not want to be kept alive if I become unconscious or unaware of my surroundings and most doctors agree that I will never regain consciousness.
- _____ 3. I do not want to be kept alive if I become unable to think or act for myself (and won't get better).
- _____ 4. I do not want to be kept alive if the likely risks and burdens of treatment would outweigh the expected benefits. (For example: I will be in pain, or I will be unable to do things for myself, or the costs of caring for me will be beyond my willingness to pay.)
- _____ 5. If it is possible that I might recover with treatment and *more time is needed* to determine if I can get better or not, I wish my medical team to start the necessary treatments to keep me alive. If, over time, these treatments do not improve my chances of living or my physical condition, I wish to have life-sustaining treatment stopped.
- _____ 6. If any of the situations I have initialed above occur, and if I am also unable to swallow enough food and water to stay alive, I *do* want food and water to be given to me by vein or by feeding tube.
- _____ 7. If any of the situations I have initialed above occur, and if I am also unable to swallow enough food and water to stay alive, I *do not* want food and water to be given to me by vein or feeding tube, however, I will accept medication for pain and agitation via an I-V line.
- _____ 8. Other specific instructions are as follows:

_____ B. My Choice is to Sustain Life—I want to be kept alive as long as possible through any means possible regardless of my condition or awareness.

MY NAME _____ DATE OF BIRTH _____ S.S # _____

Specific Care Wishes Near the End of My Life

- _____ If it becomes clear to my doctor, my agent and those caring for me that I am dying, I want palliative care for my pain, worries, nausea and other conditions that bother me. I want sufficient **pain medication** even though it may hasten my death.
- _____ I want **hospice care** when I am dying, if possible and appropriate.
- _____ I prefer to **die at home**, if this is possible.

Spiritual and Other Care Concerns

I am of the _____ faith. Below is the contact information (if known).
Church, Synagogue, or Worship Center:

_____ ADDRESS _____

LEADER _____ PHONE # _____

Other people to notify if I have a life-threatening illness:

The following items or music or readings would be a comfort to me:

Part Three: Specific Instructions about Organ Donation

I want my agent (if I have appointed one), family, friends and all who care about me to follow my wishes about organ donation if that is an option at the time of my death. *It is strongly encouraged that you talk with your family and your health care agent about your wishes regarding organ donation.* (Initial below all that apply.)

_____ I do **not** wish to be an organ donor.

_____ I wish to donate the following organs and tissues:

_____ any needed organs

_____ major organs (heart, lungs, kidneys, etc.)

_____ tissues such as skin and bones

_____ eye tissue such as corneas

_____ I desire to donate my body to research or educational programs. (Note: you will have to make your own arrangements through a Medical School or other program.)

_____ If an **autopsy** is suggested for any reason, I give my permission to have it done.

MY NAME _____ DATE OF BIRTH _____ S.S # _____

Part Four: My Wishes for Burial or Disposal of My Remains Following My Death

(Initial below all that apply.)

_____ A funeral followed by a burial in a casket at the *following location, if possible (please tell us where the burial plot is located and whether it has been pre-purchased):*

_____ Cremation and my ashes buried or distributed as follows:

_____ A low cost alternative to a traditional funeral.

_____ Funeral arrangements as determined by my agent or family.

I have made pre-need contract arrangements with the following Funeral Service:

NAME _____

ADDRESS _____ TEL. _____

Part Five: Signed Declaration of Wishes

SIGNED _____ DATE _____

The witnesses below confirm the signature of the maker of this document and that it is being signed by that person as a free and voluntary act. Appointed agents, family members, health care providers and anyone to whom you owe money may not be witnesses.

WITNESS (AND ADDRESS) _____

WITNESS (AND ADDRESS) _____

If the maker is a current patient or resident in a hospital, nursing home or residential care home, the following *additional witness* confirms the maker's capacity, understanding, and freedom from undue influence (Hospital Explainer or Long-term-care Ombudsman or clergy, attorney, probate court designee):

NAME _____ TITLE/POSITION _____

ADDRESS _____ DATE _____

Important!

Please check below the people and locations that will have a copy of this document:

____ Vermont Advance Directive Registry (anticipated available by 2006)

____ Health care agent

____ Alternate health care agent

____ Family members: (name and address of all who have copies)

NAME _____ ADDRESS _____

____ MD

NAME _____ ADDRESS _____

____ Hospital(s) NAME _____

____ Other individuals or locations: *(use additional sheet if needed)*

NAME _____ ADDRESS _____
