Proposal for “Express Your Wish” (Advance Health Care Directive) Registry

The Problem

Advanced Health Care Directives, Resuscitative Measures, and Powers of Attorney cannot be retrieved promptly enough for decision making in urgent care. The current Advanced Health Care Directive Registry relies on paper documents to be faxed or mailed and processing and turnaround times at the California Secretary of State’s Office remain in the 48-65 hour range. As a result, emergency and intensive care physicians make decisions that do not fulfill the wishes of incapacitated patients.

Background

Many Californians complete documents concerning end of life care, including Advanced Health Care Directives, Resuscitative Measures, and Durable Powers of Attorney. These documents provide guidance to critical care physicians in determining treatment measures and the authority of substitute decision makers. Unfortunately, these documents are often filed with the patient’s attorney or general practitioner. As a result, the inability to retrieve these documents can lead to medical paralysis, or worse, critical care physicians may perform treatments that the patient did not wish for.

Currently, the California Secretary of State’s Office maintains an Advanced Health Care Directive Registry under the direction of California Probate Code § 4800. However, this registry is not responsive to critical care requests because it relies on paper documents, and critical care physicians are unable to provide adequate care in times of need.

a. Evidence of the Problem:

Medicare spends approximately $55 billion dollars a year to care on people during the last two months of their lives. Approximately 18-20 percent of Americans spend their last days in the intensive care unit and these last days are often uncomfortable, expensive, and unwanted.

Accordingly, State governments want clear legal proof that a surrogate decision maker is acting with the full authority of the patient and as desired by the patient in his or her advanced directive. Legal standards concerning the authority of Next of Kin to make decisions differ among the states between (1) no presumption on the wishes of the patient, (2) only if the patient is certified as end stage/terminal or permanently unconscious, or (3) best interests as is the case in California.

These statutory limitations placed on decision-making authority leads to ethical and practical paralysis in the critical care setting, where a medical provider may attempt or
fail to ascertain the Next of Kin without a clear indication that the patient has made his or her wishes known.\(^1\)

The current Advanced Health Care Directive Registry maintained by the California Secretary of State hosts 4,320 directives with 450 directives filed annually. Through 2013 however, there has only been an average of one request per year. In 2013, the Secretary of State’s office saw a dramatic uptick as it received 93 requests for information. The office is currently seeking to create an online registration system under the California Business Connect Project. The project is currently in the procurement stage and is scheduled for full implementation in June 2016. However, it is unclear whether this system will include procedures for expedited identification of registrants and retrieval of documents.

b. Law on the Subject:

The Uniform Health-Care Decisions Act of 1993 (not adopted in California) governs inconsistencies presented when patient mobility requires usage of advanced directives across states. However, the UHCP does not provide for online registry.

SB 1857 (Watson, 1994) required the SOS to establish a central registry for power of attorney for health care or a Natural Death Act declaration. This legislation was repealed by the Health Care Decisions Law.

AB 891 (Alquist, 2000) established the Health Care Decisions Law, which also governs advance health care directives.

AB 2445 (Canciamilla, 2004) required the SOS to issue an Advance Health Care Directive Registry identification card to any person who registers in the existing Advance Health Care Directive Registry.

AB 1676 (Richman, Nation, 2005) directed the Secretary of State to work with the State Department of Health Services and the office of the Attorney General to develop information about end of life care and post information at the Advance Health Care Directive Registry website.

AB 113 (2012) amended the Budget Act of 2012 to increase the appropriation for the Secretary of State by $2 million under the California Business Connect Project to address business filing backlogs.

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\(^1\) Arvind Venkat, MD, FACEP, Julianna Becker, BA, The Effect of Statutory Limitations on the Authority of Substitute Decision Makers on the Care of Patients in the Intensive Care Unit: Case Examples and Review of State Laws Affecting Withdrawing or Withholding Life-Sustaining Treatment, J Intensive Care Med January 17, 2012 0885066611433551
California’s Current System

Healthcare providers in California are protected from liability for complying with an Advanced Healthcare Directive under the current system. Healthcare providers are also protected from liability for refusing to comply with an Advanced Healthcare Directive due to a personal belief.

The California Attorney General’s Office is responsible for developing the forms and standards for the system and maintains a website with resources for people interested in registering in the system.\(^2\)

The California Secretary of State’s Office is responsible for maintaining the registry, intake and processing forms and releasing the forms to authorized persons that requested documents from the registry, including medical professionals or others designated by the registrant.\(^3\)

From site-inspection, it appears that the Secretary of State may have little or no resources devoted to this registry. This and other non-business-filing registries share an office and a public help desk queuing system for all inquiries.

Similar Law in Other States

- **Nevada**: “End of Life Lockbox” launched 2008 – administered by Secretary of State; developed in conjunction with the U.S. Living Will Registry to build and host the website.
- **Washington**: Launched November 6, 2007; administered by Dept. of Health; developed in conjunction with the U.S. Living Will Registry to build and host the website following a competitive bid process; free to participants.
- **Vermont**: Launched 2007; administered by Dept. of Health; developed in conjunction with the U.S. Living Will Registry to build and host the website.

Other states maintaining advanced directive registries include Arizona, California, Idaho, Louisiana, Maryland, Montana, and North Carolina. Non-governmental registries also exist, including the Rochester Regional Health Information Organization (RHIO) in New York. Four health insurance exchanges in Michigan currently operate such registries. And Texas includes an identifying mark on state issued identification cards noting the existence of advanced health care directives.

Liability

Health care providers are protected from liability for complying with an Advanced Healthcare Directive. Health care providers are protected from liability for refusing to comply with an Advanced Healthcare Directive due to a personal belief.

\(^2\) [http://oag.ca.gov/consumers/general/adv_hc_dir](http://oag.ca.gov/consumers/general/adv_hc_dir)
\(^3\) [http://www.sos.ca.gov/ahcdr/](http://www.sos.ca.gov/ahcdr/)
c. Prior Attempts to Address the Problem:

The timing of the original enabling legislation and the legislative history strongly suggest that the legislature responded to the Terri Schiavo case in Florida. The case involved a protracted legal conflict between family members, resulting in 15 years of litigation before a court order resulted in feeding tubes being removed under protest from other family members. AB 1676 (Richman, Nation, 2005) and the other prior legislation conceived of a system that would help to ease or reduce litigation around these decisions, yet the systems established to this point do not move quickly enough to avoid certain avoidable harms or loss to the healthcare system. A legal framework exists to guide the courts through contentious litigation but speed and ease of access have not been addressed.

d. Views of the Parties of Interest:

No one contacted has expressed an opinion other than support for this project. The likeliest points of contention are anticipated to involve funding issues, and the operation and capability of the registry system.

3. Alternative Solutions:

4. Preferred Solution:

Creation of a secure and safe web-based portal that allows the public the power to store their Advanced Health Care Directives and Power of Attorney forms online. This could also include documentation about the patient’s values history if the express statements of the other documents leave room for doubt. Health care providers (e.g. emergency department or ICU physicians) will have access to the website but could only access documents with a code on the patient’s driver’s license, a valid ID, or other official card, as well as the doctor’s Medical Board of California license number. If someone found the patient’s ID they could not access the portal without a Medical Board license number. All entries into the system would be logged to prevent fraud. Once accessed, health care providers could obtain the information they need to treat their patients according to each person's specialized wishes.

The website would allow individuals to upload their own specialized documents, and would also offer templates for patients to fill out their own end of life care. The DMV and DOH websites would each have links to the Express Your Wish Registry website and toolbox. Current law requires that end of life documents be signed by two witnesses or be notarized. Patients will likely have to print out the forms, and either mail them to the registry which would then upload them, or upload them directly at their lawyer or doctor’s office. They may also upload them on their own if they have the ability to do so. Once the forms have been uploaded to the system, the patient will be mailed a card, or be able to print out a card, on which will be a code that must be used to access the documents. Records would be kept on the website showing who has accessed and viewed
Disciplinary action would be used as a tool to ensure that physicians do not tamper with their patients' files.

The Express Your Wish Registry's website would look and operate similar to the Donate Life California Donor Registry. That website allows people to sign up to become organ donors, and holds their names in a state wide on-line registry. It is run by California's four federally designated non-profit organ procurement organizations, and has already registered almost 10,000,000 people. Since this website has been so successful, it is only logical to model the Wish Registry website after it.

The Express Your Wish Registry website could be administered by a number of lead agencies, including the Secretary of State, the Department of Health, and Covered California, and could be funded through a variety of means, including private donations, hospitals whose physicians have signed up with the registry, and state contributions. The Secretary of State’s Office would be a logical choice because it is accustomed to important filings of legal documentation such as business organizations. However, the Secretary of State may be considered primarily as a business-oriented agency. The Department of Health may be a logical administrative choice because members of the public seeking to interface with the state government concerning their health care wishes, would likely turn to that department. Covered California may be preferable because it avoids the cons of both departments while currently maintaining an online health care interface for consumers seeking to purchase insurance. However, due to its recent roll-out, there may be concerns of development and effectiveness. Currently, four health care exchanges in Michigan offer such registries.

The price for hospitals to sign up their physicians to use the service will be offset by the expenses the hospital will save as a result of a dissipation of expensive and unnecessary end of life care, as well as protracted legal procedures, such as a patient’s Next of Kin proving the patient’s best interests. Due to concerns regarding budgeting for the proposal however, it is important that the possibility of a fee (with an attached income-based exemption) be considered to assist in funding the program. Moreover, it is important to note that, although there will be similarities between the two, the Express Your Wish Registry will be a separate entity from the California Donor Registry.

Currently, the Washington State Living Will Registry is funded through the State General Fund. For the 2007-2009 fiscal years, $363,426 was allocated in the biennial budget for the registry. The allotment has funded one staff position, while the remainder of the budget funds the registry contract and marketing efforts. As of October 2008, Washington’s Department of Health had spent approximately $146,000 for registry start-up costs and marketing. The capacity allotted for was 3,500 participants. Through scaling the model, it is expected that costs will reduced per participant as usage increases. Due to California’s population size, it is expected that the cost will be higher than that of Washington’s program.4

4 Using estimates based upon the Washington model, capacity could reach approximately 19,300 participants.
Visual Representation of the System

Rapid Identification of Registrant

The Express Your Wish Registry would provide a number of benefits but for the system to operate effectively, rapid identification is key for maximum benefits to be realized by the patient and the healthcare system. To this end, a state issued identification card (and/or healthcare system provider or insurance card) could include a small identifying mark similar to the Donate Life California, Organ and Tissue Donor Registry and/or radio frequency identification devices or data using existing magnetic strip technology to alert healthcare providers that the incapacitated patient is a registrant. A practical suggestion would be a blue “wish” dot with the caduceus symbol, often identified with medical care.

Visual Representation of the State Issued Identification Card Mark

Each license would include a small mark, approximately 3/8ths of an inch in diameter, near or adjacent to the pink ‘donor’ dot printed on current identification cards.

Sample A: 

Sample B:
a. Groups/Parties for and Against:

California Medical Association – supported prior legislation – likely to provide clarity and guidance for end of life care decisions in a way that contains costs through voluntary treatment decisions

Coalition for Compassionate Care – working group believes they will support

California Alliance of Retired Americans – working group believes they will support

California Chapter of Physicians for a National Health Plan – working group believes they will support

California Health Professional Student Alliance – working group believes they will support

CA Restaurant Association – supported prior legislation – in context of debates prior to PPACA healthcare reform, this was seen as one part of a solution to comprehensive healthcare reform without higher costs for employers while helping to contain costs in the system

Drug Policy Alliance Network – Supported prior legislation

CA Dialysis Council – Supported prior legislation

CA Nurses Association – Opposed some prior legislation, likely because of concerns related to liability and duties – working group believes they will support

CA SOS Bruce MacPherson – Opposed – may oppose mandates on their planned California Business Connect Program.

b. Strategy:

Develop of coalition of health care providers, health care insurance providers and concerned members of the public to support the bill and establish rules for an updated program.

Meet with Information Technology personnel in integrated health systems (e.g. Kaiser Permanente, Sutter) to examine how their systems ensure compliance with doctor-patient confidentiality.

c. Realistic Outcome: Passage in amended form due to wide range of alternatives available and details involved.
5. Additional Documentation:

   a. Draft of bill language, regulatory language, or complaint: Attached.

Section 4800-4806 is amended to read

4800. (a) The Secretary of State shall establish a registry system through which a person who has executed a written advance health care directive may register in a central information center, information regarding the advance directive, making that information available upon request to any health care provider, the public guardian, or the legal representative of the registrant. A request for information pursuant to this section shall state the need for the information.

(b) On and after January 1, 2016, the Secretary of State shall establish and maintain the Advance Health Care Directives Registry on the Internet website of the Secretary of State. The registry must include, without limitation, in a secure portion of the website, an electronic reproduction of each advance directive or other document listed in Subsection (e). The electronic reproduction must be capable of being viewed on the website and downloaded, printed or otherwise retrieved by a person.

(c) On and after January 1, 2016, the Secretary of State shall establish a process for submission of applications, personal information and documents to the Advance Health Care Directives Registry either by electronic submission or submission of paper documents.

(d) A person who wishes to register an advance directive must submit to the Secretary of State:
   (1) An application in the form prescribed by the Secretary of State;
   (2) A copy or electronic reproduction of the advance directive or other documents listed in Subsection (e); and
   (3) The fee, if any, established by the Secretary of State pursuant to Subsection (n).

(e) Information that may be received is limited to information or documents associated with the individual registrant:
   (1) the registrant's name,
   (2) social security number,
   (3) driver's license number,
   (4) state issued identification number or other individual identifying number established by law, if any,
   (5) address,
   (6) date and place of birth,
   (7) the registrant's an advance health care directive,
   (8) a values statement, questionnaire or other document supplementary to an advance health care directive,
   (9) registrant’s documentation executing a durable power of attorney,
   (10) a physician orders for life-sustaining treatment (“POLST”) form,
   (11) the name and telephone number of the agent and any alternative agent, and
   (12) an intended place of deposit or safekeeping of a written advance health care directive or other document.
(f) If the person satisfies the requirements of subsections (d) and (e), the Secretary of State shall:
(1) Make or transfer an electronic reproduction of the advance health care directive or other documents listed in Subsection (e) and post it to the registry and, if the person consents, a statewide health information exchange system.
(2) Assign a registration number and password to the registrant; and
(3) Provide the registrant with a registration card that includes, without limitation, the name, registration number and password of the registrant. Costs associated with issuance of the card shall be offset by the fee charged by the Secretary of State to receive and register information at the registry.

(g) The Secretary of State shall establish procedures for:
(1) The registration of an advance directive or other document listed in Subsection (e) that replaces an advance directive or other document listed in Subsection (e) that is posted on the Registry;
(2) The removal from the registry of an advance directive or other document listed in Subsection (e) that has been revoked following the revocation of the advance directive or other document listed in Subsection (e) or the death of the registrant; and
(3) The issuance of a duplicate registration card or the provision of other access to the registrant’s registration number and password if a registration card issued pursuant to this section is lost, stolen, destroyed or otherwise unavailable.

(h) Except as otherwise provided in this section, the Secretary of State shall not provide access to a registrant’s advance health care directive, personal information or other documents listed in Subsection (e) unless:
(1) The person requesting access provides the registration number and password of the registrant;
(2) The Secretary of State determines that providing access to the advance directive is in the best interest of the registrant;
(3) Access to the advance directive is required pursuant to the lawful order of a court of competent jurisdiction; or
(4) Access to the advance directive is requested by the registrant or the registrant’s personal representative.

(i) A provider of health care to the registrant may access the registrant’s advance directive only in connection with the provision of health care to the registrant.

(j) A registrant or the personal representative of a registrant may access the registrant’s advance directive for any purpose.

(k) The Secretary of State shall respond by the close of business on the next business day to a request for information made pursuant to Section 4717 by the emergency department of a general acute care hospital when the request is not made using the registry process described under this section.
(l) Information that may be released upon request may not include the registrant's social security number except when necessary to verify the identity of the registrant.

(d) When the Secretary of State receives information from a registrant, the secretary shall issue the registrant an Advance Health Care Directive Registry identification card indicating that an advance health care directive, or information regarding an advance health care directive, has been deposited with the registry.

(e) (m) The Secretary of State, at the request of the registrant or his or her legal representative, shall transmit the information received regarding the written advance health care directive to the registry system of another jurisdiction as identified by the registrant, or his or her legal representative.

(f) (n) The Secretary of State shall charge a fee to each registrant in an amount such that, when all fees charged to registrants are aggregated, the aggregated fees do not exceed the actual cost of establishing and maintaining the registry.

4801. The Secretary of State shall establish procedures to verify the identities of health care providers, the public guardian, and other authorized persons requesting information pursuant to Section 4800. No fee shall be charged to any health care provider, the public guardian, or other authorized person requesting information pursuant to Section 4800.

4802. The Secretary of State shall establish procedures to advise each registrant of the following:
(a) A health care provider may not honor a written advance health care directive until it receives a copy from the registrant or retrieved an electronic reproduction from the registry established under this Division.
(b) Each registrant must notify the registry upon revocation of the advance directive.
(c) Each registrant must reregister upon execution of a subsequent advance directive.

4803. Failure to register with the Secretary of State does not affect the validity of any advance health care directive.

4804. Registration with the Secretary of State does not affect the ability of the registrant to revoke the registrant's advance health care directive or a later executed advance directive, nor does registration raise any presumption of validity or superiority among any competing advance directives or revocations.

4805. Nothing in this part shall be construed to affect the duty of a health care provider to provide information to a patient regarding advance health care directives pursuant to any provision of federal law.

4806. (a) The Secretary of State shall work with the State Department of Health Services and the office of the Attorney General to develop information about end of life care, advance health care directives, and registration of the advance health care directives at
the registry established pursuant to subdivision (a) of Section 4800. This information 
shall be developed utilizing existing information developed by the office of the Attorney 
General.

(b) Links to the information specified in subdivision (a) and to the registry shall be 
available on the Web sites of the Secretary of State, the Department of Motor Vehicles, 
the State Department of Health Services, the office of the Attorney General, the 
Department of Managed Health Care, the Department of Insurance, the Board of 
Registered Nursing, and the Medical Board of California.

Section 4807 is added to the Probate Code

4807. On or before January 1, 2016 the Secretary of State shall to the extent practicable, 
pursuant to subdivision (a) of Section 4800, consult with health care service plan, 
specialized health care service plan, carriers, other providers of health insurance 
including the California Health Benefit Exchange, administrators of acute care hospitals 
or other entities that develop or deploy health information technology to integrate 
retrieval procedures and processes into health information technology platforms.

Section 4808 is added to the Probate Code

4808. On or before January 1, 2016 the Secretary of State shall consult with the 
Department of Motor Vehicles to develop and implement an addition to the design of 
drivers’ licenses or other identification cards pursuant to Division 6 of the Motor 
Vehicles Code to effectuate rapid identification of registrants with the Registry of 
Advance Directives for Health Care either by visual or electronic means.

Section 12820 is added to the Vehicle Code

12820. (a) On and after January 1, 2016, an application for an original or renewal 
driver’s license or identification card shall contain a space for the applicant to authorize 
the department to add a blue ‘wish’ dot with a ‘white caduceus symbol’ to each 
applicant’s driver license or identification card signifying enrollment in the California 
Secretary of State’s Advance Health Care Directive Registry. The application shall 
include check boxes for an applicant to mark either (A) Yes, print a blue ‘WISH’ dot 
with a ‘white caduceus symbol’ on my card or (B) No, not at this time.

(b) The department shall inquire verbally of an applicant applying in person for an 
original or renewal driver’s license or identification card at a department office as to 
whether the applicant wishes to enroll in the Advance Health Care Directive Registry. 
Failure or refusal to answer this question or check a box on the application form shall not 
be a basis for the department to deny an applicant a driver’s license or identification card. 
The department may direct the applicant to the California Secretary of State Advance 
Health Care Directive Registry Program for additional information.

(c) The following language shall be included with the question required by paragraph (a):
“Marking ‘Yes’ authorizes DMV to add a blue dot with a ‘white caduceus symbol’ to your license indicating enrollment in the California Secretary of State’s Advance Health Care Directive Registry. You must enroll in the Advance Health Care Directive Registry by contacting the California Secretary of State Registries Program or by visiting the Internet website at www.sos.ca.gov/ahcdr/. Only after DMV receives confirmation of your enrollment in the Advance Health Care Directive Registry and receives authorization provided on this form, may DMV add the blue dot to your license or identification card. If you wish to remove your name from the registry you must contact the California Secretary of State Registries Program (see back); DMV can remove the blue dot from your licenses but cannot remove you from the registry.”

**Item 0890-001-0001 of Section 2.00 of the Budget Act of 2012 is amended to read:**

Provisions:

5. Of the amounts appropriated in this item, $__________ shall be used for operational costs associated with implementation of “The Act”
The Express Your Wish Registry Act
FACT SHEET

PURPOSE

The Express Your Wish Registry Act expedites end of life/palliative care capabilities by directing the Secretary of State’s Office to develop and manage an online portal for filings of Advanced Health Care Directives, Resuscitative Measures, and Durable Powers of Attorney that may be accessed by emergency and intensive care physicians, and directing the Department of Motor Vehicles to include a blue “wish” dot with a white caduceus symbol on state-issued identifications noting that such documents have been filed.

BACKGROUND

Many Californians complete Advanced Health Care Directives, Resuscitative Measures, or Durable Powers of Attorney forms and file them with their attorneys or general practitioners. These documents provide guidance to health care providers about the patient’s wishes, and prevent paralysis in the medical care of severely ill patients.

EXISTING LAW

California law provides for an Advanced Health Care Directive registry maintained by the Secretary of State’s office. This registry allows individuals to file directive forms issued by the Attorney General’s office, which may then be accessed via physician email or fax requests. The turnaround time for requests is unknown, though a response is mandated by end of business the day following the request. An average of one request has been made annually through 2012.

SUMMARY

The Express Your Wish Registry Act directs the Secretary of State’s Office to develop and manage an online portal for filings of Advanced Health Care Directives, Resuscitative Measures, and Durable Powers of Attorney. Additionally, the Act directs the Department of Motor Vehicles to include a blue “wish” dot with a white caduceus symbol on state-issued identifications corresponding to the filings.

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