



Advance Directive Registries: A Policy Opportunity

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The most critical health care decisions facing patients and families are often made under the most difficult of circumstances—in emergencies, or when patients are not able to speak for themselves. When patients are unable to communicate their own wishes for treatment, and have not made them known to family or physicians in advance, it is up to family and physicians to make and carry out medical decisions on their behalf. These decisions may or may not comport with the patient's own wishes.

Advance directives offer a solution for these situations by providing family members with a better understanding of the patient's preferences for treatment—and/or appointing someone familiar with their preferences to make decisions on their behalf. But in order for advance directives to be effective, health care providers need to know they exist and have ready access to them. One way to accomplish this is through statewide electronic registries of advance directives.

This paper discusses advance directives available under Michigan law, models for state and regional advance directive registries, and approaches for encouraging their use.

Current Michigan Law

In Michigan there are four major instruments patients can use to express their wishes for medical decision-making in the event of an emergency or incapacitation: durable power of attorney, living will, do-not-resuscitate declaration, and request for organ donation. Because organ donation is the only advance directive recorded in a Michigan statewide registry, the task of informing physicians and hospitals of other directives falls to patients and their advocates.

- 1. Durable Power of Attorney for Health Care:** In a durable power of attorney for health care, the patient appoints a proxy, or "patient advocate," who is empowered to make health care decisions in the event the patient is incapacitated. When signing the power of attorney, patients are allowed, but not required, to list their preferences to instruct the patient advocate. When signed, the power of attorney is legally binding but can be revoked by the patient at any time.
- 2. Living Will:** A living will is a statement describing the medical decisions the patient wants made on his or her behalf. It differs from the durable power of attorney because it does not require a proxy. Living wills are not binding under Michigan law and may not ensure the patient's preferences are met.

The Center for Healthcare Research & Transformation (CHRT) sponsors research and public information to promote evidence-based care delivery, improve population health, and expand access to care. Housed at the University of Michigan, CHRT is a nonprofit partnership between U-M and Blue Cross Blue Shield of Michigan to test the best ideas for improving the effectiveness and efficiency of the health care system.

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3. **Do-Not-Resuscitate Declaration (DNR):** A DNR is a request that a patient not be resuscitated if breathing or heartbeat ceases. It is legally binding and can be made by the patient or by a patient advocate holding the patient's durable power of attorney.
4. **Organ Donation:** Patients can express their desires regarding organ donation in statements of durable power of attorney, living wills, or by adding their names to the [Michigan Organ Donor Registry](#). If a patient enrolls in the Michigan Organ Donor Registry, no family or patient advocate consent is required unless specifically requested by the patient. The registry is maintained by [Gift of Life Michigan](#) in conjunction with the Michigan Secretary of State.

For more detailed information on advance directive options available in Michigan, visit the [State Bar of Michigan website](#).

Statewide Models for Advance Directive Registries

Every state has a registry for organ donation but only Arizona, California, Idaho, Louisiana, Maryland, Montana, Nevada, North Carolina, and Vermont currently record other forms of advance directives. (Washington State's Living Will Registry was closed on July 1, 2011 as a result of state funding reductions.)

Arizona (2005): The Arizona Advance Directive Registry is maintained by the Arizona Department of State. The registry accepts living wills, medical power of attorney, or mental health power of attorney. When registered the patient is issued a password which allows access to the registry. The patient must share this password in order for patient advocates, family members, physicians and hospitals to access the registry. While the registry eliminates the need for a patient to provide health care providers with a copy of an advance directive the patient or proxy is still required to actively share the password.

California (1995): The Advance Health Care Directive Registry is run by the California Secretary of State. It accepts health care power of attorney, and living wills. Forms must be submitted by mail and there is a \$10 filing fee. Physicians and legal representatives may request access.

Idaho (2007): The Idaho Secretary of State maintains the Health Care Directive Registry and accepts living wills, and power of attorney for health care. The registry is free to use and accessible to both patients and physicians online.

Louisiana (1991): The Louisiana Secretary of State maintains the oldest registry in the United States. It only accepts living wills and charges a \$20 filing fee. The names of registrants are publicly available on the Secretary of State's website along with the registry number and date of entry. Physicians and health care facilities can request access to the registry.

Maryland (2005): The Maryland Secretary of State, Division of State Documents, maintains an advance directive registry. It accepts living wills, health care power of attorney, physician orders for life-sustaining treatment, and request for anatomical gift. The forms must be mailed or submitted in person. There is a \$10 fee for registration and amendments. Access to the registry is given to physicians and anyone designated by the registrant.

Montana (2006): The Office of Consumer Protection maintains the End-of-Life Registry which records living wills, and power of attorney for health care. Forms must be mailed to the registry and access is available online to both registrants and physicians. The Montana legislature included a mandate for public outreach and education when it created the registry.

Nevada (2008): In Nevada, [livingwilllockbox.com](#) is an online, statewide registry maintained by the Nevada Secretary of State. Patients can submit a living will or durable power of attorney to the registry, which is accessible to qualified health care providers. Health care providers can access the registry directly without patient consent, eliminating the need or responsibility for patients to share specific information with their doctors.

North Carolina (2002): North Carolina’s Advance Health Care Directive Registry accepts both living wills and durable power of attorney documents. It is run by the North Carolina Department of Secretary Of State. Health care providers can access the registry directly without patient consent, eliminating the need or responsibility for patients to share specific information with their doctors. Registrants are also issued a card with their information for reference.

Vermont (2007): The Vermont Department of Health’s Advance Directive Registry accepts both living wills and durable power of attorney documents. Health care providers can access the registry directly without patient consent, eliminating the need or responsibility for patients to share specific information with their doctors. Registrants are also issued an ID number so they can access their directives.

Washington (2008): Prior to July 1, 2011, when state funding reductions resulted in its closure, the Washington State Living Will Registry (WSLWR) accepted health care directives, durable powers of attorney for health care, mental health advance directives, and physician orders for life sustaining treatment. The registry was run by the Washington State Department of Health. Health care providers could access the registry directly without patient consent, eliminating the need or responsibility for patients to share specific information with their doctors. Registrants were also issued an ID number so they could access their directives.

Non-governmental Registries

Some private non-profit health information exchanges (HIEs), such as the [Rochester Regional Health Information Organization](#) (RHIO) in New York, include a registry of advance directives as part of a larger electronic medical record system. While many health insurance exchanges receive state funding, they are designed to serve specific regions, not entire states.

Currently, there are four operational health insurance exchanges in Michigan: [Great Lakes HIE](#) (previously called Capital Area RHIO), [Michigan Health Connect](#) (MHC), [my1HIE](#), and [Jackson Community Medical Record](#) (JCMR). Two additional HIEs, [Southeast Michigan Health Information Exchange](#) and [Upper Peninsula Health Care Network](#), are in the process of being implemented.

Merits of an Advance Directive Registry

States promote advance directives as a useful tool for health care planning. However, Morrison et al. found that only 26 percent of hospital patients with advance directives had the directives recognized.¹

States with registries have noted the advantages to be:

- Provide “Peace of mind, knowing that your choices are secure and will be available to your family and doctors even if you become ill away from home.” – VT Department of Health
- “Your attending physician has access to an exact copy of your written health care instructions” – WA State Department of Health
- “Relieve your family from having to make stressful health care decisions” – WA State Department of Health

¹ The Inaccessibility of Advance Directives on Transfer From Ambulatory to Acute Care Settings R. Sean Morrison, Ellen Olson, Kristan R. Mertz, Diane E. Meier JAMA. 1995;274(6):478-482.

Also, a registry can:

- Be designed so that advance directives are vetted when submitted by patients. For example, Michigan requires that a durable power of attorney for health care meets certain requirements i.e. dating and witness signatures. Either automated or staff checks could ensure that advance directives that these requirements are met.
- Facilitate annual reminders being sent to encourage patients to update their entries and provide information about relevant changes in the law.

Education and Outreach

There are multiple methods that states carry out to educate the public about the registry. The most common method of outreach and education is workshops. These seminars generally include presentations and Q&A sessions along with handouts that participants can take home. Workshops on advanced directives and registries are held as a standalone topic or as part of a greater event focusing on end of life and health care planning. The Arizona Secretary of State Office for example, sends state employees to senior centers and community centers to conduct education workshops. Other states such as Montana have simply added advance directive registries to existing events targeted at seniors.

Several states outsource education efforts to non-profits and other organizations. For example, Vermont issues grants to non-profit organizations that hold workshops for seniors. This is a useful strategy when state agencies experience staffing limitations.

Arizona and many other states have also used more traditional paid media efforts such as newspaper and TV ads. These media campaigns often use the Attorney General's Office, which already have consumer information campaigns, and simply expand those efforts to include advance directive registries. Advertising campaigns have been cut back or eliminated in most states however as a result of state budget restrictions.

Conclusion

The advantages of statewide advance directive registries are obvious for patients and families: they provide peace of mind and allow patients' wishes to be known when they cannot speak for themselves. And by allowing physicians access to patients' advance directives, registries also enhance the ability of the physician to provide care that is patient-centered. However, establishing advanced directive registries and encouraging their use is not without challenges given current state budget constraints.

There are a number of alternatives for establishing advance directive registries, following successful models in other states. Registries can be established by state departments, non-governmental entities such as health insurance exchanges, or built on existing statewide frameworks. In Michigan, this could take the form of expansion of the Michigan Organ Donor Registry or the [Michigan Health Information Network](#).

Advance directive registries can help improve patient care and modernize health care systems. Such systems merit consideration as part of any new health information technology investment.

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