

# Advance Care Planning: Why an Electronic Registry is Necessary for Success

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## Goals of Summer Project

Vynca is a medical start up company that provides an electronic solution to Advance Care Planning (ACP) ensuring that patients' end of life wishes are honored. My work with them this summer was to review the literature and create a 'White Paper' detailing the importance of ACP in medical care, the barriers to using ACP information, past attempts at creating Registries that house ACP documents, and what the key elements are for ensuring a successful registry.

## What is Advance Care Planning (ACP)?

Advance Care Planning (ACP) is a process where patients decide what kind of care they would like to receive when they can no longer make those decisions for themselves. Based on their values and beliefs, patients decide on their healthcare proxy and whether or not they would like CPR, artificial nutrition, mechanical ventilation, etc. These decisions are documented and stored for later access.

The following are commonly used ACP forms that help document patient's end of life (EOL) wishes:

- Medical Orders
  - MOLST (Medical Orders for Life Sustaining Treatment) and the related MOST, POST, and POLST
- Do Not Resuscitate (DNR)
- Advance Health Care Directives
  - Advance Directive
  - Living Will
  - Healthcare Proxy
- Goals of Care & Care Preference Documents
  - Patient Questionnaires
  - Medical Notes

The form is a 'MASSACHUSETTS MEDICAL ORDERS for LIFE-SUSTAINING TREATMENT (MOLST)' document. It includes sections for patient information, medical orders (A, B, C, D, E, F), and signatures. It is dated August 10, 2013, and page 1 of 2.

## Importance of ACP to Improve Quality of Care

ACP has been shown to greatly improve the quality of EOL care. Having ACP documented leads to fewer deaths in hospitals and more hospice use which leads to higher satisfaction, fewer concerns with care, and fewer unmet needs<sup>1,2</sup>.

ACP forms decrease unnecessary hospitalizations which provides better quality of care in line with patient preferences and also decreases cost<sup>3</sup>.

The quality of dying is also influenced by ACP. Patients with dementia were seen to have a 3x higher chance of having a better rating for emotional well being in the last week of their life if they had Advance Directives<sup>4</sup>.



## Barriers to Using ACP Forms

There is great need to access ACP documents, but physicians face barriers with being able to use this documentation. Common issues with using ACP documentation stem from problems locating it, lack of familiarity, and inadequate content. The current state of ACP documentation has led to a fragmented system where patients' wishes are incompletely gathered and recorded, and physicians face multiple barriers in acting on patients' wishes in times of emergency. Documents are filled out in one care setting and not accessible at other facilities where physicians many need to act on that information.

- 74% of ED Physicians need to access ACP documentation at least once per week<sup>5</sup>
- 31% of ED Physicians feel confident that they can find ACP documentation in the EMR<sup>5</sup>
- 55% of ED Physicians feel confident they could use the ACP documentation to care for patients<sup>5</sup>
- 15% of patients have no documentation of the use of end of life (EOL) treatment, and of those patients with documentation, only 30% of the time do the recorded preferences actually matches the patient wants<sup>6</sup>

## Past Attempts at ACP Registries

Many states have tried to create Registries that act as repositories for ACP forms to centrally store information to be accessed across the care continuum. Although this in theory answers the problem of physician accessibility to ACP information, a system with any weakness will ultimately collapse.

Past Registries like Idaho, Utah, and Washington's failed because they were not well thought out with the needs of its users in mind. Other Registries such as Oregon's was successful because it had all the necessary elements<sup>7</sup>.

	Idaho	Utah* prior to 2010	Washington	Oregon
Registry tied to local group or coalition	✓	✓	X	✓
Integrated into clinical care application	X	X	X	✓
Mandatory submission of completed forms via supporting legislation	X	X	X	✓
Easy access to data in emergency settings	X	X	X	✓
Electronic ACP forms	✓	X	✓	✓
Marketing and awareness	X	X	X	✓
Sustainable funding	X	X	X	✓

## Key Factors for ACP Registry Success

Companies such as Vynca have taken the successful components of past registries and acknowledged and avoided the downfalls of other attempts to create a comprehensive and easy to use electronic Registry solution that ensures patients EOL treatment choices are honored. Success depends on thoughtful technology as well as supporting factors that promote the continued success.

### Technology:

- Error free and complete forms
- Platform that ensures patients know what they are selecting
- Platform that fully encompasses ACP choices
- Secure Storage
- Form retrieval that quickly and accurately gets the user the patient's data
- A system built to accommodate different types of users
- Easy to use and quickly integrated into the healthcare continuum
- Ability to obtain metrics on how the system is being used

### Supporting the technology:

- Sustainable funding
- Marketing to increase awareness and adoption
- Stakeholder engagement
- Legislative mandates supporting the Registry

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## References

- Bischoff KE et al. Advance care planning and the quality of end-of-life care in older adults. *J Am Geriatr Soc* 2013;61:209-14.
- Teno JM et al. Family Perspectives on End-of-Life Care at the Last Place of Care. *JAMA*. 2004;291(1):88-93.
- Nakashima, Taeko et al. Are Hospital/ED Transfers Less Likely Among Nursing Home Residents *JAMDA*, Volume 18 , Issue 5 , 438 - 441
- Vanderpool A et al. Quality of Dying in Nursing Home Residents Dying with Dementia: Does Advanced Care Planning Matter? A Nationwide Postmortem Study. *Montazeri A, ed. PLoS ONE*. 2014;9(3):e91130.
- Lakin, JR et al. (2016). Emergency Physicians' Experience with Advance Care Planning Documentation in the Electronic Medical Record: Useful, Needed, and Elusive. *JOURNAL OF PALLIATIVE MEDICINE*. 19(6), 632 – 638
- Heyland DK et al. The prevalence of medical error related to end-of-life communication in Canadian hospitals: results of a multicentre observational study. *BMJ Qual Saf* 2016;25:671-679.
- Schmidt TA et al. Physician orders for life-sustaining treatment (POLST): lessons learned from analysis of the Oregon POLST Registry. *Resuscitation*. 2014;85:480-5.