

Digitalization of Advance Care Planning

A Massachusetts State-wide and National Landscape Analysis

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Executive Summary

Most Americans want to die at home; yet only 24% do.ⁱ Much of existing efforts in Massachusetts target this need by increasing public and clinician practice of advance care planning. However, the current landscape of ACP is complex, fragmented and often siloed. ACP documents may be completed in numerous settings. Storage locations are similarly diverse. Thus, only 33% of those who have completed an AD have a valid document scanned into their medical record, and when they do, the locations are often variable.ⁱⁱ Unsurprisingly, it can be difficult to locate the appropriate information in a timely manner. Studies show that less than 2% of individuals who have ADs have access to them when needed.ⁱⁱⁱ And at the time when ACP documents may be needed most—during transfer to acute care settings—only 26% of individuals with ACP documents already filled out had them accessed.^{iv}

This project examines how Massachusetts (MA) could use technology to innovate ways for providers and patients to reliably share Advance Care Planning (ACP) documents electronically and improve ability of clinicians, emergency medical services, and other caregivers to quickly and reliably identify a person's wishes and care preferences. The methodology includes (1) a landscape analysis of ACP documentation in MA, (2) statewide analysis of ACP digitalization, (3) 22 semi-structured interviews, (4) an RFI with 9 responses, and (5) a focus group of 15 patients.

This report highlights focus areas where digital health solutions could ensure that all health care professionals are aware of available ACP documentation, can easily locate relevant information, and that providers – especially of emergency medical services - are able to honor these wishes of our patients.

Key findings from the research include:

- In **Massachusetts**, most centers use scanned documents into electronic health records with variable or poorly measured rates of digitalization.
- **Nationally**, 19 States have digital ACP solutions. 16 have advance directive registries or equivalents. Oregon highlights a long-standing program that rests upon a strong legal basis and funding mechanism alongside incremental implementation. Maryland's experience teaches us that concurrent outreach and education is crucial to success.
- A **patient and family focus** group revealed that ACP document storage location is highly variable and mostly on paper. Several had personal experiences with documents not being honored or not found. They concluded that a stronger infrastructure is a crucial component.
- An **RFI** highlighted several potential solutions including a centralized registry,
- Special consideration must be given to timely, reliable, and integrated storage and retrieval processes, relevant content, incremental implementation, cost, and ways of measuring impact.

Acknowledgements

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Introduction

Most Americans want to die at home; yet only 24% do.^v Much of existing efforts in MA target this need by increasing public and clinician practice of advance care planning. *Advance care planning* (ACP) is the process of planning for one's medical future so that an individual's values, goals, and preferences are taken into account when that person loses the ability to speak for him or herself. However, the current landscape of ACP remains complex, fragmented and often siloed.

ACP documents may be completed in numerous settings - primary care, acute, sub-acute settings; nursing home or residential care settings; as part of estate planning in law offices' in consultation with a pastor' and at home around the kitchen table or on a computer. Storage locations are similarly diverse – from consumer-facing web sites and apps, existing online registries, physical or 'virtual' safety deposit boxes, to the front of refrigerator doors, scanned into EHRs, in patient's paper records or even in the files of a church. Thus, 33% of those who have completed an AD have a valid document scanned into their medical record, and when they do, the locations are often variable.^{vi}

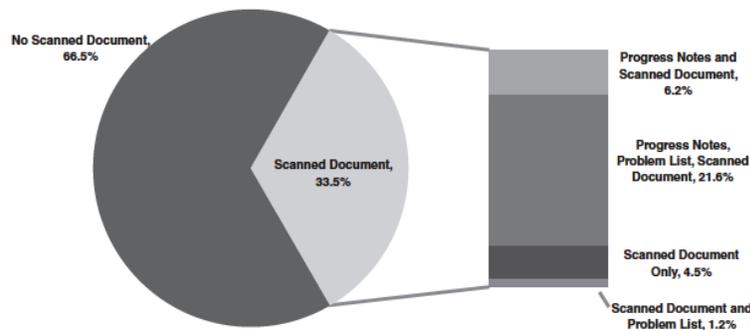


FIG. 1. All patients with any ACP documentation: Location of documentation in the EHR (n = 30,566 patients).^{vii}

Unsurprisingly, it can be difficult to locate the appropriate information in a timely manner. Studies show that less than 2% of individuals who have ADs have access to them when needed.^{viii} And at the time when ACP documents may be needed most—during transfer to acute care settings—only 26% of individuals with ACP documents already filled out had them accessed.^{ix}

Therefore, ACP must be readily and easily accessible. ACP must also be reliable. Providers must have confidence that the ACP forms, including the Massachusetts Orders for Life-Sustaining Treatment (MOLST), accurately reflect a patient's current values and preferences and that forms are valid. There is a clear need to develop systems to ensure that all health care professionals are aware of available ACP documentation, can easily locate relevant information, and that providers – especially of emergency medical services—are able to honor these wishes.

There is no state-wide system that exists in MA, and most of the efforts at individual health facilities are fragmented. This kind of undertaking has never been done before in MA and thus is different from previous work in improving ACP in the state, which has largely focused on increasing the *number of conversations* about patients' wishes in the event of serious illness.

State-wide initiatives elsewhere in the US and individual organizations within this state have years of experience in ensuring proper documentation, storage, and retrieval of ACP documents, which can inform the policies most appropriate for MA to adopt. The experience of other states such as Oregon, New York, and West Virginia have shown significant improvements in concordance of care with patient wishes, cost-savings, and anecdotal evidence of improved provider satisfaction, meeting the quadruple aim of health in the field of palliative care. Ultimately, our aim in more effective ACP digitalization is to ensure that people's care preferences are known, respected, and shared with loved ones and with care providers when they are needed most.

Research Methods

This report was based on multiple components including semi-structured interviews, a focus group, a request for information (RFI), stakeholder engagement, public meetings, and a literature review. An outline of the approach was created by a stakeholder group convened in the spring of 2017, with an expectation that some of the methodology may be fluid based on the needs of the group. Specifically, this included:

A **background literature review** of academic, policy, and legal literature. The initial literature review included a search of 4 databases: MEDLINE®, Google Scholar, Hollis, and the National Conference of State Legislatures. The searches were conducted in an iterative manner during June-November 2017 to retrieve articles related to the digitalization of advance care planning documents in any of the 50 states of the United States. Initial search terms included “advanced care planning digitalization”, “MOLST registry”, “POLST registry”, “living will registry”, and “advance directive documentation”. No specific key words were required as inclusion criteria. A small number of original studies exist on this subject so we incorporated a bottom-up search strategy and retrieved articles from medical, legal, and policy journals, as well as from Federal and State documents. During the semi-structured interviews, we encountered several other unpublished state-specific documents (N=7) which were shared by the interview subjects. A single reviewer evaluated the relevance of retrieved articles (n=28), and recorded the main findings of each study in a table. Inclusion criteria were relevance to the subject and age of the article less than 5 years old, given the pace of this field of health information technology and the turnover in policy documents. All information was obtained lawfully and where private documents were shared, all parties involved ensured maximal protection of confidentiality.

A **RFI** was sent out to 41 organizations and stakeholders in August, 2017. 9 responses were received. These responses were reviewed independently by our team and the results were compiled into a shared spreadsheet where team members had reviewed key themes from each response.

We conducted **semi-structured interviews** with 22 organizations and stakeholders from various states and across MA. In the statewide analysis, interviewees were identified based on states that had an existing ACP digitalization solution. All interviewed individuals were either academic palliative care physicians or registry employees who played a central role in the creation and/or continued implementation of a state's electronic solution. In the MA analysis, we first approached Pat Noga from the MA Health and Hospital Association to identify a group of leaders from representative hospitals across the state with known solutions on ACP documentation. We identified individuals to maximize regional diversity and differences in size of hospitals. A set of questions was drafted through group consensus and feedback amongst the primary project team. I conducted all interviews in-person, over voice over internet protocol (VoiP) systems, or over phone. All interviewees were asked at least the core set of questions with flexibility in additional questions. All responses were recorded and tabulated into a spreadsheet.

We convened one **focus group** on October 18th, 2017 with 9 individuals from the Beth Israel Deaconess Medical Center (BIDMC) through their Patient and Family Advisor Focus Group, and 5 facilitators. We selected individuals who have already completed the ACP creation process, for themselves and/or for a loved one. We did not exclude based on whether they had any knowledge or experience with electronic storage or retrieval of these documents. All individuals signed an agreement to share information and the conversation was recorded.

One **public meeting** on December 7th, 2017 at the Blue Cross Blue Shield of MA, attended by 42 individuals.

Legal counsel from Suffolk Law School professor and legal literature review and co-drafting of a tentative house bill and senate bill, in the case of establishing a registry.

Results

Massachusetts Landscape

Most centers in MA use scanned documents (e.g. MOLST, advance directives) into electronic health records (EHRs) with variable or poorly measured rates of digitalization. These scanned documents are most often stored in a media folder within the EHR, often with other non-ACP related scanned documents. Some centers have searchable PDF functions or organized folders but with variable reliability.

Three out of 22 centers that we surveyed have ACP modules in their EHR, i.e., a separate functional unit within the EHR that allows for ACP-specific activities such as code status history, advance care planning notes, and a repository for scanned ACP documents. However, these modules are not standardized or interoperable, even between centers that share the same EHR company. One ACP modules we encountered was home-grown and two were customized through EPIC. An example of an ACP module from the Partners System is shown below.

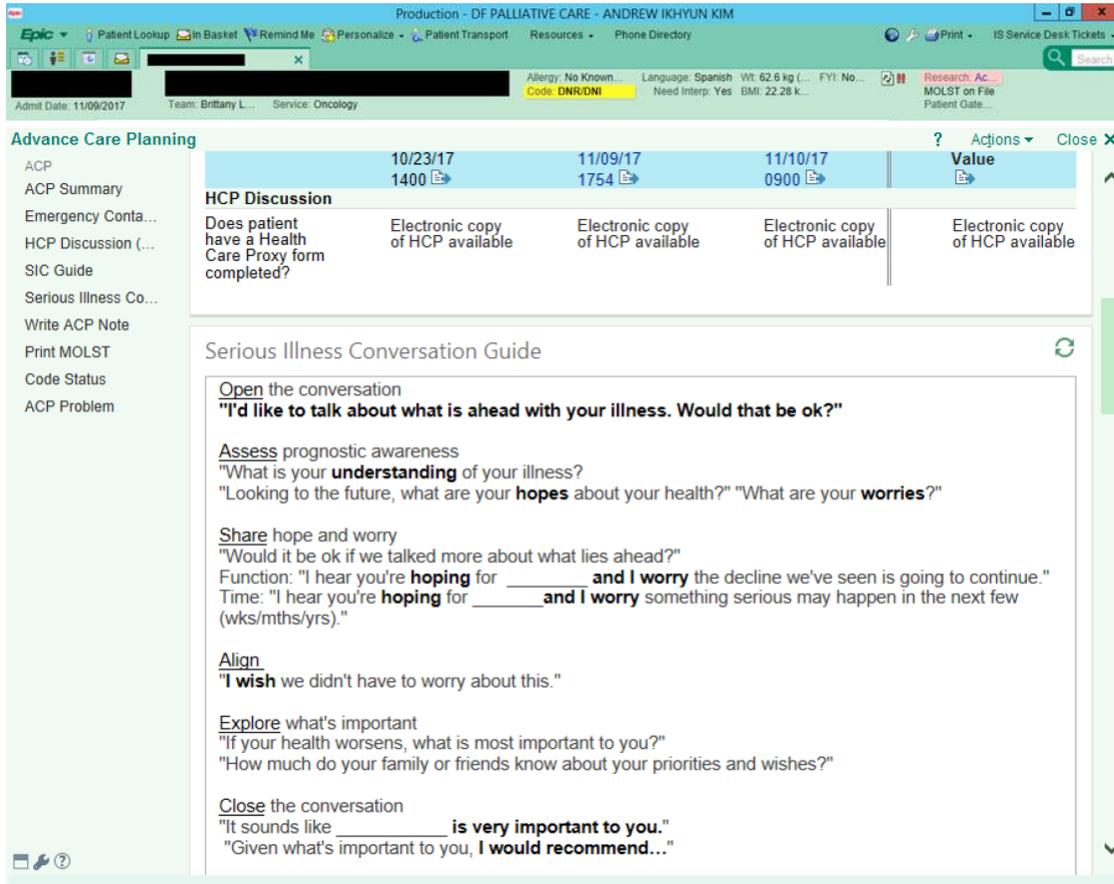


Figure 2: Example ACP Module

Of the 22 centers evaluated, we highlight four models that exemplify the range of digital solutions for ACP in MA. We evaluate these models across three axes: (1) is there the capability of digital storage, (2) is there an organization structure for easy storage/retrieval, and (3) is there sufficient utilization?

Atrius – As a pioneer accountable care organization (ACO) in 2012, Atrius identified multiple initiatives to meet the triple aim of health, and identified one as high risk patients. Under this category, they led multiple initiatives including ACP training in 2012, MOLST training in 2013, hospice in 2014, and palliative care in 2015. During this program, they also utilized a digital solution of an ACP module that allows for easy documentation and retrieval of the initiation, discussion, and completion stages of ACP in the EHR. Overall, they currently have 90+% of all

patients with a health care proxy (HCP) in the EHR and 75%+ of high risk pts with MOLST in the EHR. Given these impressive outcomes, our interview subject stated, “We feel pretty set about how documentation works.”

Partners – Partners had a pre-existing system with an ACP module but given its transition to EPIC as an EHR a few years ago, it has been re-building a customized system with its EPIC team. At the time of conversation, they have been utilizing an in-banner, easily accessed and auto-populated ACP module that includes code status history, scanned ACP documents, ACP-related notes, and the Serious Illness Conversation Guide.

Baystate – Baystate Health uses CERNER (CIS) with a capacity for scanning ACP documents into an “advanced directives central folder.” However, according to our interview, the subfolders are often confusing and there hasn’t been a strong method of holding providers accountable to document these forms in an organized and easily-accessible manner. Currently, they are working on a PVIX platform to increase interoperability within their system, and they are starting a pilot with Cake and Vital Decisions.

Cambridge Health Alliance (CHA) – CHA’s experience of ACP digitalization seems representative of the majority of centers in MA. There has been a capacity for scanning ACP documents into the EHR but they are lumped together with other unrelated scanned media documents ranging from outside health records to photos of skin lesions, making old ACP documents challenging to find. Even when discovered, their validity becomes difficult to ascertain. Finally, variable rates of scanning of documents—it is provider dependent—makes it unlikely for “end-users” to consistently look for the documents.

Institution	Scanned Documents	ACP Module	Utilization
<u>Atrius</u>			<u>High risk patients:</u> 90%+ HCP 75%+ MOLST
Partners			Inpatient and Outpatient
<u>Baystate</u>		Partial Folder	Planning Pilot
Cambridge Health Alliance			Variable

Rather than tabulate all 19 states in low resolution, we highlight two States that teach us key lessons about design and implementation of a digital ACP solution.

State cases: Oregon and Maryland

Oregon:

Oregon has one of the longer standing ACP registries, established in 2008 with philanthropic funding and a pilot at the Oregon Health Sciences University (OHSU). The registry, however, has longer-standing roots from a task force created in 1991. A key component of implementation was a 2009 House Bill establishing funding, legal basis, and resources for the registry. They also implemented many state-wide outreach and education efforts to ensure high utilization and reliability of the system. Finally, the state recently launched the capability for ePOLST, which allows for the form to be filled and signed digitally by patients and providers, and automatically integrated into the registry. Key components and outcomes are highlighted below.

Input: ePOLST system, scanned documents, and faxed documents.

Output: Phone calls (53.2 seconds)

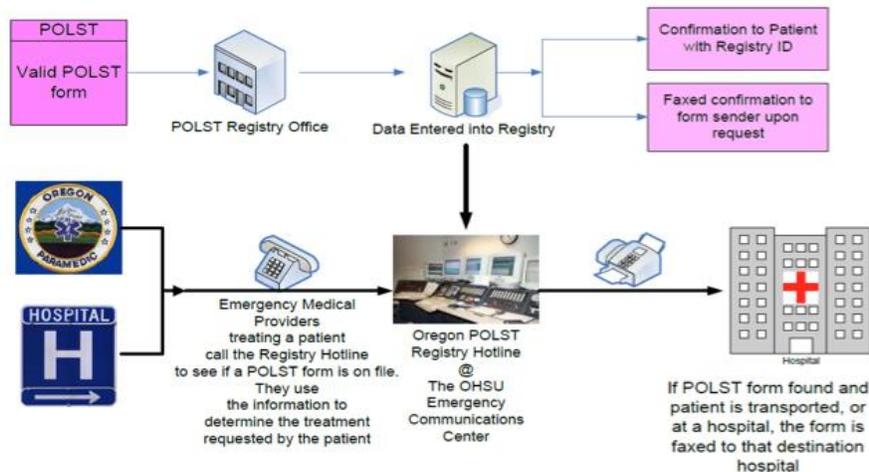


Figure 4: Oregon’s Centralized Registry Process ^{xi}

Volume: 3,500-5,000 uploads/mo; 108-165 calls/month; 42.8% match rate.

Financial: Set-up costs of \$250,000 funded by a grant from the health authority. Annual operating budget in 2015 was \$380,000.

Technology: Vynca created with EPIC integration.

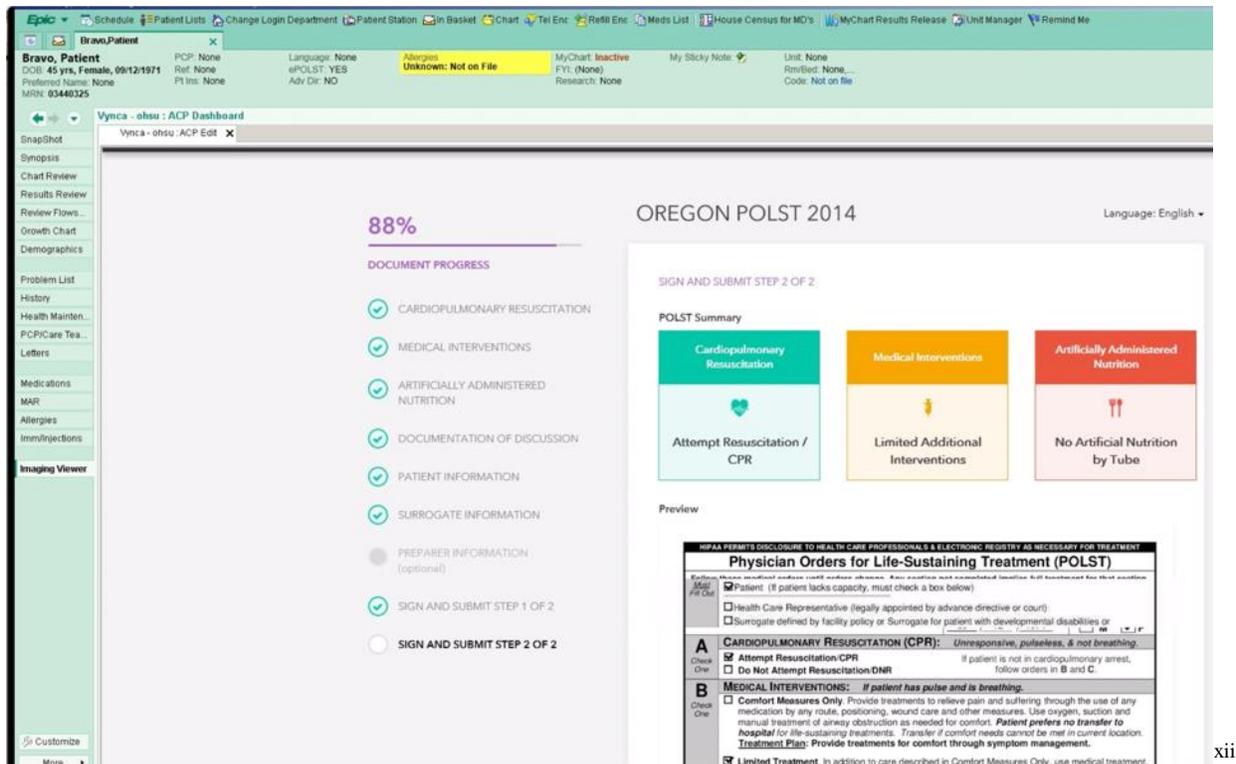


Figure 5: Oregon’s ePOLST system with EPIC integration.

Overall, our interviews with Oregon’s key leaders yielded a few important lessons. First, setting up a strong legal basis with specific stipulation on ongoing funding is crucial for a registry’s longevity and success. Second, starting off with a small pilot at a single health center helped work out challenges before scaling up. Third, a concurrent outreach effort to ensure high utilization ensured both reliable input and output. The significant mismatch rate is mostly due to absent ACP documents in the registry (e.g. emergency personnel queries for an individual who has not filled something out), rather than flaws in the match algorithm. Therefore, a key component of making sure that end-users continue to use the system is to ensure that there is a sufficient yield when querying a system.

Maryland

Maryland has had, to quote one of the interview subjects, “a long history of discussion and short history of action.”^{xiii} They first launched their advance directive registry using MyDirectives, funded by a \$30,000-\$40,000 grant. However, they had no statewide campaign or outreach efforts to use MyDirectives. The launch had been focused on consumer-side uploads without a strong effort on provider-side uploads. It also lacked the ability to upload *existing* paper directives. Therefore, “everything is empty,” said one stakeholder from Maryland. Though they do not have the exact utilization numbers, they are very low.

Content: MyDirectives; any scanned document

Input: Multiple existing registries, mostly consumer-side. Includes MyDirectives and US Living Will Registry.

Output: Provider only query through Web-based portal

Volume: Low

Financial: \$30,000-\$40,000 set-up costs from grant.

Technology: A shift from MyDirectives to a home-grown record locator via CRISP

Moving forward, new regulations under House Bill 0188, Maryland has now established a legal basis for state registries, funds for educational outreach to improve utilization, and a provision that a witness is not required for an electronic advance directive if the declarant's identity has been authenticated. Moreover, (CRISP) would create a home-grown record locator that allows a centralized mechanism to query multiple existing registries. Their major lesson-learned was to secure consistent funding and to implement a strong outreach program concurrently with a digital solution.

Focus Group Summary

A focus group of a Patient and Family Advisory Group (PFAC) at the BIDMC revealed several important lessons from the patient and family perspective. Of the 9 individuals in attendance for the 1.5 hour discussion, all of the individuals had recently gone through the advance care planning and documentation process for themselves and/or for a loved one.

The conversation began with three unifying experiences that resonated with most participants. First, most felt that “people still dance around the issue,” and wished that doctors and social workers would talk more openly about advance care planning. Second, all felt that no matter one’s situation in life, ACP is relevant to everybody, whether as patient, advocate, or caregiver. Third, no one felt that they had a good sense of where the documents went and how they were accessed.

“I just went through MOLST with mother. I always wondered where it goes. Just like my health care proxy. How I know they have it? Is it just with the state?” – Ms. T, Focus Group Participant

Some key questions and answers are highlighted below:

What happens after you fill out an advance care planning form? Where do you keep these documents?

- Lawyer’s office
- File cabinet at home. Told the family where it is. It is not with my doctor
- “With my sister’s transfer to hospital by ambulance, I had to re-fill it”

- Fridge
- Glove compartment
- HCP and AD to doctors at BIDMC. Scanned into EMR
- Copies at home and with doctor
- Paper copies at home for parents in a file cabinet. Family knows where it is

Overall theme: Storage location is highly variable and mostly on paper. Several had personal experiences with documents not being honored or not found.

“However, if I am in an ambulance, how are they going to access that information? Especially with HIPAA? How will they have access to my records?” – Mr. J, Focus Group Participant

Have you talked about it with a physician and does he/she have a copy?

Yes	2
No	2
Unsure	5

Other Key Issues

Other key issues that the participants raised during the conversation include:

- **HIPAA/Privacy**
 - How do you ask people to put their most sensitive information where they are not certain about the security?
- **Underlying issues are not addressed**
 - How do you know whether the core of your conversation and wishes is communicated?
 - Once the infrastructure is in place, we need to make sure that there is education and resources to help patients and families to navigate this infrastructure.
- **Access to electronic documents**
 - What about electronically challenged individuals?
 - What about different languages?
 - What about vulnerable populations?
 - What about Understanding of terminologies?
- **Flexibility and Updating**
 - Need the ability to change their mind if circumstances change
 - Need a place for patients to access to ensure that updates are confirmed and accurate
- **Reliability**
 - How do we trust the document?
 - Patients need to know where it goes
- **Automation and control**
 - Every year we renew our health insurance; perhaps we should automatically revisit to confirm or change our preferences.

- **How do we measure success?**
 - Concordance of care with patient wishes
 - For the health care proxy, they need assurance that they made the right decision
 - Capture rate: # of documents filled out
 - % of HCP
 - % of ADs
 - % of people who have held conversations

*“The document is not the solution. The word ‘infrastructure’ set this in place for me. It’s like we need to create highways before training people to drive, to make sure that **people get where they need to go.**” – Mrs. N, Focus Group Participant*

Request for Information Summary

Full text of RFI responses available at:

http://mehi.masstech.org/sites/mehi/files/documents/2018-MeHI-01%20Revised%208-4-17_0.pdf

Full summary slides of RFI responses available at:

<http://mehi.masstech.org/sites/mehi/files/documents/L.%20STUNTZ%20Overview%20MeHI%20and%20RFI%20responses.pptx>

Key Points are highlighted below:

- **Technology can facilitate adoption and usage but, by itself, is insufficient; we must also**
 - Ensure robust public outreach and education program
 - Create an environment of trust
 - Enable patients and providers to have and document conversations
 - Ensure reliability of documentation
- **Need a single source of truth, accessible to all stakeholders**
 - Ease of access regardless of place of care
 - Consumers able to share with clinicians AND designated family/caregivers
- **Any solution must address:**
 - Disparities (no internet, unfamiliarity with technology, etc.)
 - Privacy and security concerns
- Version control is an important consideration

Technology Recommendations

- Be readily accessible by the entire health and care ecosystem
 - Maintain accurate patient and provider identities and relationships
 - Have standard forms and processes; patient index; databases
- Co-exist with other systems across the healthcare landscape

- Standards-based (agree on common code sets / terminology)
- Allow integration with acute and ambulatory EHRs, HIEs
- Have both provider-facing and consumer facing components
 - Consumers: Educate patients about need for ACP & help make informed decisions
 - Providers: Collect and update ACP information/documents and find in EHR
- Be flexible and adaptable to future changes
 - Able to be used on any device (phone, tablet, PC)
 - Accessible from social media
 - Integrated with mobile health devices

Suggested Solutions

- Central eRegistry (repository)
 - Single point of storage and access for ACP documents
 - Operated by the state *OR*
 - Privately-managed and operated technology platform
- Public-private partnership
 - Private: stores, manages and maintains ACP documents on behalf of state
 - State: supports core registry functions
- Internet-based centralized statewide registry for MOLST/POLST
 - Internet, not EHR-system, dependent
 - Future: build out complete AD registry
- Online tool for ACP planning
 - Co-developed, state-run cloud portal to host documents
- Web-based application with:
 - patient-facing interface
 - databases, and
 - interface for information exchange

Emerging Themes

The Storage and Retrieval Process

In the storage and retrieval process, the most important factors from our research seem to be (1) timeliness, (2) reliability, and (3) integration into workflow.

Timely Retrieval

Across our nation-wide analysis speed and match rate were variable. In an interview with ED physician, Kei Ouchi, he proposed a three-tiered approach to retrieval incorporating an appropriate trade-off between speed and detail. For emergent DNR/DNI situations, an

appropriate speed is <1 min and the only detail required is a reliable code status designation. As situations decrease in urgency, the level of detail of wishes may appropriately increase.

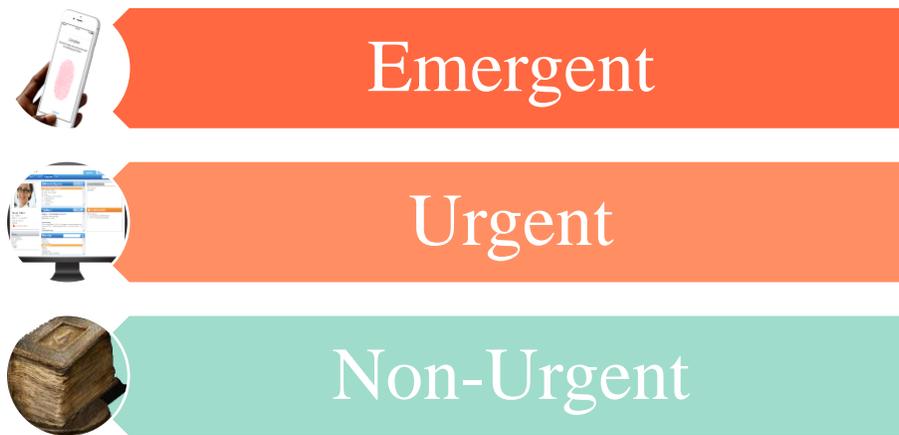


Figure 6: Three levels of timely retrieval and detail in ACP documents

Moreover, integration of electronic documentation into the workflow of a health provider, alongside effective outreach and education efforts can have a drastic impact on documentation rates. For example, in a study highlighted in Figure 7 below, a simple EMR intervention that integrated AD documentation into a clinic workflow drastically increased % documentation from 1% to almost 80%. Similarly, as we learned from Atrius, Oregon, and Maryland, outreach and training to document is crucial for adequate utilization of digital solutions.

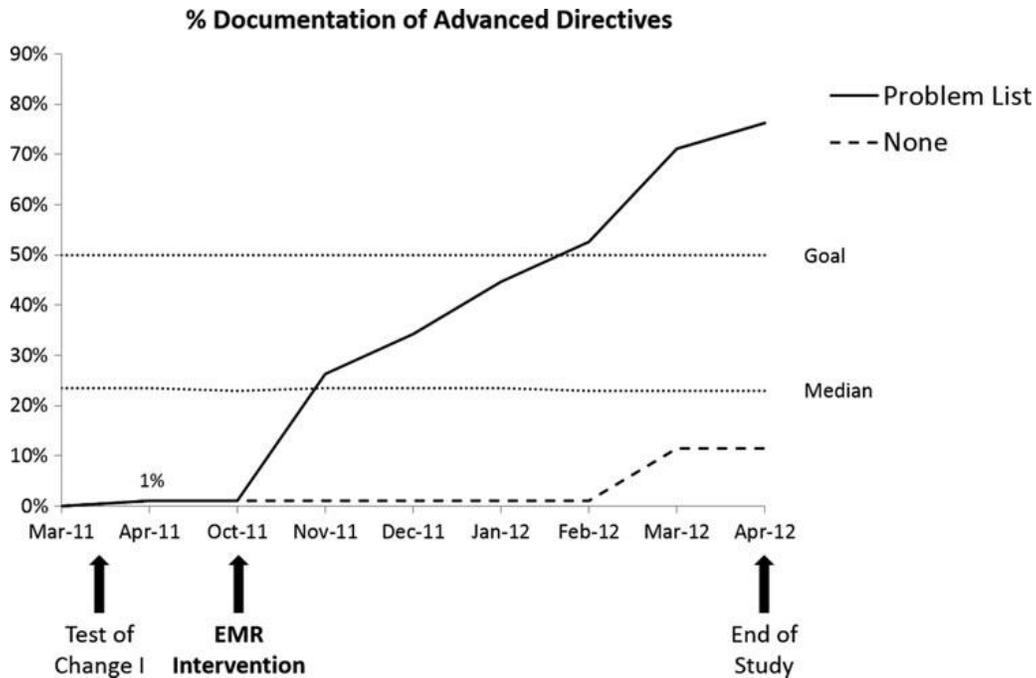


Figure 7: The effect of EMR intervention in documentation of ADs^{xiv}

Content relevance

According to surveys with end-users of ACP documents, they 74% needed to access ACP documents ≥ 1 time/week and 43% ≥ 5 times/week. Moreover, high visibility on the main screen of an EHR was crucial. The following is the ranking of relevance of specific ACP documents for end-users, and has been corroborated by our interviews with state and national registries.^{xv}

Relevance

- **Code Status (90%)**
- **Durable Power of Attorney for Health Care (78%)**
- **POLST/MOLST/POST (86%)**
- Living Will (37%)
- Values History (31%)
- Combined Directives (e.g. “Five Wishes”)

Incremental Implementation

Another recurrent lesson from our research was to create a **learning system** with data analytics for feedback. As one stakeholder from another State told us, the process could be a black box, but the measured outcomes and feedback mechanisms for improvement must be well-established.

Our focus group, other States, and RFI responders suggested several **core outcomes** to measure:

- Concordance/discordance with wishes
- Quality of life measures
- Hospice quality measures
- Match rates and utilization rates

The best way to ensure that this learning system is enacted is to implement in multiple stages (such as in Oregon’s experience). A corollary of this is the importance of **parsimony** to start – to begin with one form and a few sites, and then to expand once reliable.

Cost and Impact

Finally, we must consider the costs, funding mechanisms, and potential cost savings. Registries in others states have operational costs of \$100K (NY) to \$400K (WV), and a wide range of start-up costs. Most have funded their start-up costs with grants and operating costs through the State government.

Although incremental cost saving data has not been directly measured in other States, Oregon found that patients after ACP storage and appropriate access are six times less likely to die in acute care setting, with decreased rates of ventilator use and late hospice referrals. We can envision that cost savings for the system, though not the primary aim, may be a secondary benefit of a well-functioning digital ACP solution.

Discussion

Limitations of Analysis and Future Directions

This report is limited by the lack of quantitative data outcomes and collection. A further study analyzing current and projected costs and cost-savings, health outcomes, patient and family distress, and wish-concordant care would help inform a more targeted approach.

Moreover, interviews were limited to larger health provider networks and hospitals. More input from hospice homes, skilled nursing facilities, emergency medical services, and other potential users/creators of ACP documentation would provide a more rounded view. Moreover, community-based advance care planning efforts in MA, such as places of worship and library associations, were informally consulted but not interviewed for this analysis.

Implications of Findings

Overall, these findings suggest that a centralized registry may be a feasible and beneficial digital solution to the capture, storage, and retrieval of ACP documents. However, implementation must be done with careful consideration of cost, utilization, reliability of documents, prudence in pace of scaling up, and strong concurrent outreach.

Supplementary Materials

Supplement 1: Link to Dec. 7th Meeting

Resources and recordings from the December 7th Public Meeting are available at the link below:

<http://mehi.masstech.org/support/electronic-sharing-advance-care-planning-acp-documents>

About the meeting: Hosted at Blue Cross Blue Shield of Massachusetts, MeHI, EOEAA, and the Coalition engaged stakeholders and interested parties to react to presentations and panel discussion, and provide comments on how technology can best make electronic sharing of ACP documents a reality in Massachusetts.

Supplement 2: Excerpts from Proposed Bill

Below is the link to text from key components of the proposed bill drafted in conjunction with Suffolk Law Professor, Renee Landers, and with adaptation from Joseph Grant's publication in the Journal of Legislation.

<https://drive.google.com/open?id=0B4NIukUgIdrYZU9YRVVJcmE4MDQ>

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