

Neil Samuel Ghiso Fellowship Final Report/Summary of Activities

Student: Andrew Ikhyun Kim

Mentor: Lachlan Forrow

Summary

We worked with the Executive Office of Elder Affairs, Massachusetts e-Health Institute, and the Coalition on Serious Illness Care on a national and state-wide landscape analysis of digitalizing advance care planning documents. This included over 20 semi-structured interviews, a request for information with 9 responses, a focus group, and a literature review, culminating in policy recommendations to the state and a presentation at a public forum. Ultimately, we hope that these findings may help the state create a more reliable infrastructure for access to advance directives when patients need them most. And ultimately, we hope that these improvements may ensure that all individuals' wishes may be honored at crucial moments in their life.

Details Methods and Activities:

Given the changes in stakeholder needs, we ended up shifting the methods slightly from the original study. We conducted a mixed methods policy study involving 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. Search terms included “advanced care planning digitalization”, “. 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 During the semi-structured interviews, we encountered several other unpublished state-specific documents (**N=7**) which were shared by the interview subjects.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=34**), 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 on August, 2017. 9 responses were received. These responses were reviewed independently by 5 members of our team. The results were compiled into a shared spreadsheet where team members had reviewed key themes from each response. The final results were then shared and discussed at the December 7th, 2017 public meeting.

We conducted **semi-structured interviews** with 24 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 15 individuals from the Beth Israel Deaconess Medical Center (BIDMC) through their Patient and Family Advisor Focus Group. 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.

One **stakeholder engagement meeting** on November 7th, 2017.

One **public meeting** on December 7th, 2017. Blue Cross Blue Shield of MA. Attended by 60+ individuals.

Legal counsel from Suffolk Law School professor and legal literature review. Drafted a house bill and senate bill for presentation to the legislative process.

Results/Deliverables

Attached you will find a copy of the presentation given at the Dec. 7th Public Meeting. You may also find the recording of the meeting here: <http://mehi.masstech.org/support/electronic-sharing-advance-care-planning-acp-documents>

Attached you will also find a draft house bill for presentation to legislature.