Who Decides if the Patient Cannot and There is No Advance Directive: Research and Recommendations on Clinical Practice, Law and Policy:

ABA Commission on Law and Aging

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A. Introduction

The overall goal of this project was to examine how health care decisions are made in critical care settings, for patients who lack capacity and have nothing in writing naming a person as health care surrogate. The project included a review of existing laws, a national survey of health care providers, and convening a round table of national experts.

Because most adults in the United States have no advance directives, the vast majority of health care decisions for patients with diminished capacity are made by someone-- usually a relative or close friend-- who has not been named by the patient, under state surrogate consent statutes. No research had examined how these laws affect clinical medical practice, if at all, especially in high pressure critical care hospital settings, and what processes physicians use — or should use — to identify the authorized decision-maker and secure consent for a course of treatment.

With funding from the Retirement Research Foundation, the ABA Commission on Law and Aging examined that very question in partnership with the Society for Hospital Medicine (SHM) and the Society for Critical Care Medicine (SCCM). The research objectives were to:

- (1) gain valuable information on how physicians address treatment decisions concerning the growing number of patients lacking decisional capacity who need a surrogate but have no advance directive or court-appointed guardian; and
- (2) produce and actively promote informed recommendations for clinical practice, education, policy and law.

The project consisted of three elements:

- development and implementation of a survey of critical care and hospital physicians on decision making practices for patients lacking decisional capacity who have no appointed surrogate;
- (2) a review of selected hospital policies on surrogate decision-making and development of model provisions;
- (3) convening of a consensus roundtable of practitioners and experts from multiple disciplines to produce action recommendation on practice, education, policy and law; and

In addition to the principal investigator David Godfrey, J.D., and co-investigator Charlie Sabatino, J.D., from the American Bar Association, the project team included designated representatives from SHM and SCCM, sociologist consultant Dr. Susan Shapiro, Ph.D., from the American Bar Foundation, and medical research consultant Dr. Neil Wenger, M.D., from the UCLA Department of Medicine. A background literature review was conducted by Teresa Yao, a JD/MSW candidate at Washington University in St. Louis.

Explanation of terminology Limitations of the Data and Findings

Throughout this report, the terminology of "surrogate" or "default surrogate" will be used interchangeably to refer to decision-makers or potential decision-makers for incapacitated patients who have not appointed a person in writing through a health care power of attorney, appointment of a surrogate or proxy or by oral designation, and who also have no court appointed guardian or conservator with health decisions authority.

At the center of the issues addressed in this report is the goal of respecting the real people whose individuality, values, goals, culture, and preferences are at stake. The term "patient" does not adequately capture that humanity; however, it is used throughout the report to distinguish these individuals from all the other parties engaged in the decision-making process.

The report's copious references to health care providers and health care decisions should be understood in the context of critical care and end-of-life decisions for persons who lack decisional capacity.

The findings may not represent the overall practice of medicine. As described under the header "Respondents" below, a total of 527 members of the Society for Critical Care Medicine and Society for Hospital Medicine responded to the survey. The response rate was a low 1.3%. And the sample was limited to members of the two professional associations. Response was entirely voluntary and reflected a self-selected sample of critical care clinicians and hospitalists.

The membership of the Societies surveyed represent health care providers specializing in critical and hospital care, and likely do not represent the views of the full spectrum of health care professionals.

Additional review of the data did not reveal any meaningful variation in the findings based on demographics of the respondents. The goal of this project was to look at the general responses from the sample, and not to focus on differences based on the demographics of the respondents. Differences based on demographics would have little, if any, impact on the global recommendations. We felt that there was a very real risk of the overall message getting lost in demographic data details and have chosen not to focus on those differences.

B. Survey

Methodology

A survey comprised of 10 substantive questions, six optional narrative explanation questions, and 8 background or demographic questions was developed over a period of several months in early 2016. Development of the survey was led by staff from the Commission on Law and Aging in collaboration with representatives of the Society of Hospital Medicine (SHM), the Society of Critical Care Medicine (SCCM), UCLA Department of Medicine and the American Bar Foundation. The survey was created in and all data were collected via the online Qualtrics survey platform. The questions were first reviewed and edited by members of the planning team, with a focus on clarity of the questions and answers. Team members and other volunteers then tested the online survey – submitting comments, and suggestions

for further edits. Cognitive pre-testing was then conducted one-on-one with five volunteer testers from SCM, SHM and other volunteers. The goal of the cognitive testing was to assess the clarity of the questions and answers and the level of comfort respondents had with the survey. Additional edits were made based on this feedback. To protect the anonymity of respondents, the survey platform was set to not identify individual respondents. To prevent multiple responses from the same person, the platform was set to accept only one response from an IP address. Respondents could return to partially completed surveys within 30 days and resume at the question they had left off. Respondents could move forward or backward and change answers prior submitting the survey. In compliance with study guidelines from the medical societies, respondents could skip any question, or submit a partially completed survey, resulting in differing numbers of responses from question to question.

Respondents

The survey was sent to 40,239 email addresses of members of the two participating medical societies. The Society of Hospital Medicine (SHM) sent the survey request to 28,884 people and the Society for Critical Care Medicine (SCCM) emailed the survey request to 11,355 members. The survey link was included in a cover email sent from an officer of the associations. Reminders were sent via email, social media, and other communication tools. The survey instrument was circulated by the Societies in early August 2016 with a due date the end of August. The due date was then extended until the end of September, and the Associations were asked to do additional outreach to encourage responses. A total of 527 responses were received, for a 1.3% response rate. SCCM reported 5,277 members opened the email (out of 11,355 emails sent by SCCM.) SCCM reported that 447 recipients clicked the link to open the survey. Similar data is not available from SHM. While a 1.3% response rate is low, it was nevertheless productive in data and insight generated. The Societies and other sources say this is an expected response rate for a voluntary survey from this sample profile of health care providers.

The membership of these Associations are primarily physicians, but also includes related professionals. Responses were received from 45 states, the District of Colombia, and 35 responses were from outside of the United States. Ten or more responses were received from 18 states, the top three being California (37), Pennsylvania (32), and New York (29).

Seventy-Five percent of respondents identified their professional field – of those:

- 80% were physicians,
- 11% were physician assistants or nurse practitioners, and
- 6% were registered nurses.

The median years of experience of respondents (using 5-year increments from 0 to 25) fell in the 16 to 20 years category, although the single highest frequency category (the mode) was 26 years or more, with over a quarter of respondents.

The majority of respondents (64%) worked in hospitals with 250 to 999 beds, followed by 22% in hospitals with 100 to 249 beds. A large majority of the hospitals were teaching

facilities with 50% being university based and 32% community-affiliated, and most were non-profit (77%).

Respondent Demographics:

The survey respondents were 57% male and 43% female. The survey link was sent to the members of the Society for Hospital Medicine (SHM) who report that 60% of their members are male and 40% female and the Society for Critical Care Medicine (SCCM) with a membership that is 60.5% male and 39.4% female. The survey respondents were about 3% more female than the overall potential sample. About 93.3% of respondents practice in the United States. The two Societies average 93.7 of their members practicing in the United States (SHM 99.1% US, SCCM 88.37% US.)

Specialty or Primary Practice Areas:

The two associations collect specialty or practice areas in different categories. When the survey was being developed representatives from the Societies had difficulty agreeing on a list of practice areas or specialties. This should have been a red flag that the two groups differ widely in how they categorize practice areas or specialty.

Of the survey respondents:

Critical care 56.0%

Hospital medicine 34.6%

Internal medicine 20.0%

Surgery 12.1%

All other areas were below 10%.

Members of the Society for Hospital Medicine:

Medicine 46.2%

Adult Hospital Medicine 14.4%

Not Specified 28.2%

All others less than 10%

Society for Critical Care Medicine (multiple specialties are collected for many members):

Internal Medicine 36.38%

Critical Care Internal Medicine 23.6%

Pediatrics 22.47%

Surgery 16.90%

Critical Care Pediatrics 14.20%

Anesthesiology 12.5%

Pulmonary Diseases 12.31%

Critical Care Surgery 11.21%

All others less than 10%

Survey Results

The survey had two main parts, the first focusing on hypothetical decision scenarios and the second eliciting information about the respondents' experience in encountering these kinds of scenarios.

Decision Scenario Questions

Spouse and child at the bedside:

 Patient, age 87, has a terminal condition, and a decision needs to be made about a DNR / DNAR order. Spouse and adult child are at the hospital. With whom do you discuss treatment options and seek consent?

Where close family are available-- specifically, the patient's spouse and child-- a small majority of respondents (55.4%) would discuss treatment options and seek consent from both the spouse and adult child, while 44.6% selected the spouse alone. No one selected the adult child exclusively. The prevailing law for consent in most states designates the spouse to provide consent. Despite the prevailing legal authority of the spouse, the results suggest a practice of seeking group consensus, at least with immediate family.

 Same case, but spouse and adult child disagree. You have tried unsuccessfully to reach consensus. From whom would you seek consent? (check all that apply)

In the above situation where the spouse and child disagree on a course of treatment and consensus is not possible, 91% of respondents said they would frequently rely on the spouse's consent, although over one-third (35%) would frequently choose "whoever appears to know the patient's wishes best." The frequency of each option was rated independently, so the percentages of respondents who chose "frequently" do not add up to 100%. See TABLE 1. In addition, over a quarter (26%) reported

that they would frequently consult an ethics committee or consultant, and 19% would consult risk management or the legal department.

TABLE 1

Question	Frequently		Sometimes		Rarely		Never		Total
The spouse	90.76%	383	6.40%	27	0.95%	4	1.90%	8	422
The adult child	6.60%	26	42.89%	169	27.41%	108	23.10%	91	394
Whoever appears to know the patient's wishes best	35.11%	138	24.17%	95	13.74%	54	26.97%	106	393
Whoever you feel supports the best medical option	7.95%	31	20.77%	81	21.03%	82	50.26%	196	390
Seek guidance from an ethics committee or consultant.	26.44%	110	37.26%	155	26.44%	110	9.86%	41	416
Seek guidance from risk management, or legal department.	18.45%	74	32.17%	129	34.41%	138	14.96%	60	401

• Adult children in disagreement:

 Same case, but there is no spouse and the conflict is among the three adult children, with two favoring DNR / DNAR and one against. You have tried unsuccessfully to reach consensus. What would you do? (Check all that apply)

In the scenario where there is no spouse and an irreconcilable conflict exists among three adult children over a decision regarding DNR / DNAR, only 14% of respondents reported that they would frequently accept consent from a majority of children, while a majority (60%) favored seeking guidance from an ethics committee or consultant. See TABLE 2. Twenty states provide that, in the case of such disagreements among surrogates of equal level, the physician should accept the decision of the majority. Looking just at the data from the states with majority rule, there were 267 responses. Of these, less than 7% of respondents said that they would frequently accept consent from the majority of the adult children. By contrast, 49%

¹ The language in most of the statutes is that the health care provider "shall accept consent from the majority," implying that this is a requirement, but there is seldom if ever a legal action to enforce these laws. See ABA Commission on Law and Aging, Default Surrogate Consent Statutes,

https://www.americanbar.org/content/dam/aba/administrative/law aging/2014 default surrogate consent stat utes.authcheckdam.pdf

said they would <u>never</u> accept consent from the majority of the adult children, indicating that a "majority rule" approach to dispute resolution among surrogates is not a generally accepted clinical practice among the respondents.

TABLE 2

Question	Frequently		Sometimes		Rarely		Never		Total
Accept consent from the two children favoring DNR because they constitute a majority	13.91%	53	22.57%	86	27.03%	103	36.48%	139	381
Accept consent from whichever side you feel supports the best medical option	3.96%	15	20.32%	77	26.39%	100	49.34%	187	379
Accept consent from whomever you feel best knows the patient's wishes	26.87%	104	27.13%	105	17.83%	69	28.17%	109	387
Seek guidance from an ethics committee or consultant.	59.67%	250	24.58%	103	12.17%	51	3.58%	15	419
Seek guidance from risk management, or legal department.	43.83%	174	27.71%	110	19.90%	79	8.56%	34	397

• Adult child versus close friend:

Same case, but conflict is between Patient's only adult child and a close friend familiar with Patient's values. You have tried unsuccessfully to reach consensus. What would you do? (Check all that apply)

In this variation of this scenario, the irreconcilable conflict is between an adult child and a close friend of the patient familiar with the patient's values. A large majority chose "frequently" for accepting consent from the adult child (80%) versus only 0.5% for the close friend. However, over one-third (36%) chose frequently for seeking guidance from an ethics committee or consultant. This predominant reliance on close family versus non-family is consistent with the hierarchical preference dictated in the majority of state statutes. However, it raises concerns where the close friend relationship may be more significant from the incapacitated patient's point-of-view, such as a long term non-martial relationship.

• The unrepresented patient:

Same case, but there are no relatives or friends willing to discuss treatment options or give consent. How often would you? (Check all that apply.)

Finally, in this decision scenario there are no relatives or friends available or willing to discuss treatment options or give consent, over half the respondents would frequently seek a second physician's opinion (55%) or seek guidance from an ethics committee or consultant (58%). Close behind, 45% would frequently seek guidance from hospital risk management or its legal department. The option of going to court for a guardianship was a frequently chosen by a substantial minority (39%), while the option of making a decision by oneself was frequently chosen by only 10.5% of respondents. See TABLE 3. Most state laws do not provide a clear path for decision-making in this situation². The response rates in states that do have laws on this issue, though generally unfavorable, were too small to draw any conclusions about the impact of the law in those states.

TABLE 3

Question	Frequently		Sometimes		Rarely		Never		Total
Seek the opinion of a second physician.	55.25%	221	24.75%	99	14.00%	56	6.00%	24	400
Seek guidance from an ethics committee or consultant.	58.19%	238	24.45%	100	14.18%	58	3.18%	13	409
Seek guidance from hospital risk management, or legal department.	45.23%	180	29.40%	117	18.09%	72	7.29%	29	398
Seek court-ordered guardianship.	39.29%	156	26.70%	106	24.69%	98	9.32%	37	397
Make a decision yourself, abiding by professional ethics and standards.	10.53%	42	21.80%	87	29.07%	116	38.60%	154	399

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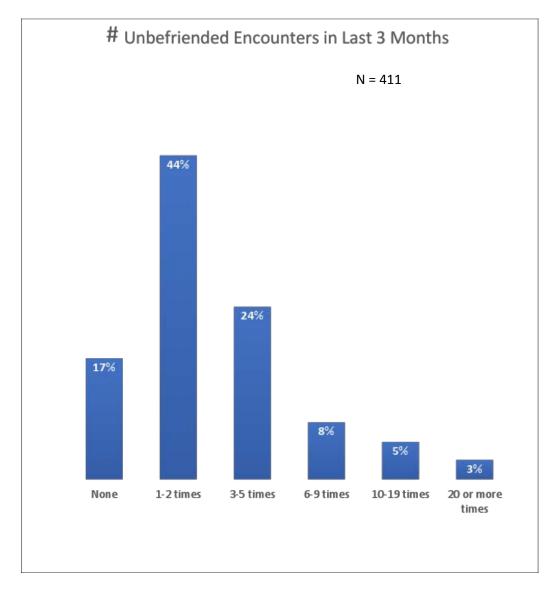
² See Table 3 below for a summary of state laws on health care decision making for patients who do not have readily identifiable family or friends.

Practice Experience Questions

• Frequency in the last three months of encountering patients, other than in emergencies, who did not have family or friends to review treatment options or grant consent:

These patients are sometimes referred to as unrepresented or unbefriended. The median response fell in "1 to 2 times" in the last three months, but the range of answers was significant, with nearly 17% having no encounters with unrepresented patients and nearly 8% having 10 or more encounters. See TABLE 4.

TABLE 4

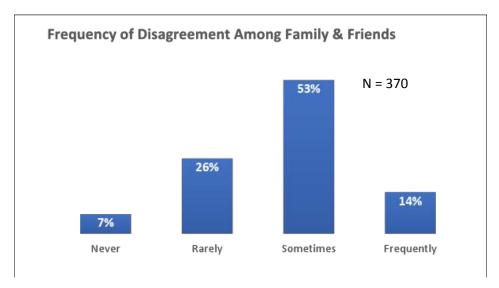


A variation of this question utilizing a scale from "never" to "frequently" produced relatively similar results with 17% reporting that they never encounter this situation; 58% rarely; 21% sometimes; and 3% frequently.

• Frequency of encountering a patient who lacks capacity and an appointed decision-maker where there was disagreement among family or friends concerning treatment options:

A majority (53%) answered that "sometimes" they encountered disagreement among family or friends, followed by "rarely" (26%), "frequently" (14%) and "never" (7%). See TABLE 5.

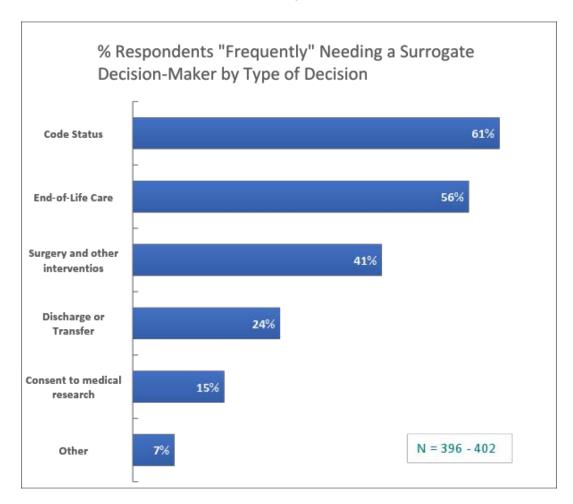
TABLE 5



• Frequency of cases needing a default surrogate decision by type of decision:

Code status received the highest proportion of "frequently needed" responses (61%), followed by end-of-life care decisions (56%); surgery and other interventions (41%); discharge/transfer decisions (24%); medical research consent decisions (15%); and lastly, other (7%). See TABLE 6.

TABLE 6



Respondents' awareness of the existence of a written policy on health care
decision making for patients who do not have a written advance directive in the
respondent's primary hospital:

Nearly half (47%) reported having such a policy, while 14% said none exists, although a significant proportion (39%) were unsure whether one existed.

• Respondents' awareness of any laws in one's state that designate a default surrogate decision-maker:

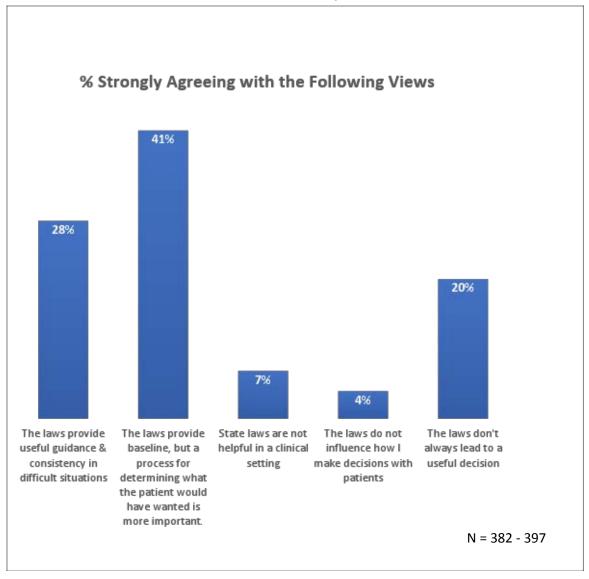
Over two-thirds reported awareness of such laws (68%). In the states that actually have such laws, 71% of respondents in those states reported awareness of the laws. In the states without such a law, 55% of respondents in those states nevertheless reported awareness of such a law in their state, indicating a significant gap between the law and knowledge of the law.

Respondents' opinion of laws regarding health care decision-making when there
is nothing in writing naming a person to make health care decisions and the
patient lacks capacity:

Responses from all respondents (including those from states without default surrogate laws) indicated a relatively positive view of these laws with the most frequent view garnering "strong agreement" being: they "provide a baseline process for determining what the patient would have wanted" (41%).

Twenty-eight percent viewed these laws as providing useful guidance and consistency in difficult situations. Smaller numbers strongly agreed with less favorable views – not helpful (7%), do not influence how I make decisions (4%), and the laws don't always lead to a useful decision (19%). While smaller in number, they indicate a wide diversity of views. See TABLE 6.

TABLE 6



C. Review of Health Care Decision Making Policies

Institutional Policies

Hospital policies were collected in two ways: through a review of approximately 130 hospital websites and as part of the online survey.

In the internet search for hospital policies, we found that there are two varieties of hospital policies on health care decision making: consumer policies and internal staff policies.

The consumer polices document the health care provider's obligations under federal law³ to ask patients if they have an advance health care directive and inform patients of the right to have an advance directive. Consumer policies were found on about 1/3rd of the 130 hospital websites examined. At the expert round table, it was pointed out that virtually every hospital needs to have a consumer policy to comply with federal law and certification requirements.

While the most common element of the consumer policies is a recitation of the requirement under federal law that all patients be informed of the right to create an advance directive and to be asked at the time of admission if the patient has an advance directive, some of the consumer policies went farther and offered advice on how to create an advance directive under state law.

Internal staff policies direct staff on what to do with advance directives and what process to follow when no advance directives exist and a patient is unable to make health care decisions. These policies proved very difficult obtain. A review of about 130 hospital websites located just one internal policy posted online and publicly available.

Polices were also requested as part of the online survey. Respondents were asked to email or fax the policies. This request was sent to over 40,000 email addresses of members of the two participating medical societies. Policies were also requested from attendees at the round table. In the end, we collected only seven internal staff policies that addressed the key issues for this project, despite the fact that 47% of respondents to the survey reported being aware of a policy on health care decision making at the hospital they practice in.

Comments at the round table and off the record comments from physicians and other health care providers indicated that this type of policy is generally considered confidential, proprietary and internal. Reluctance to disclose may be related to potential liability concerns. Despite assurances that the policies would be redacted of identifiable information, and commented on only collectively or in summary, few providers who were aware of the policies were willing to share them with the researchers. Input from the round table showed that larger medical centers are more likely to have formal policies and processes in place to respond to requests for help with health care decision making issues.

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³ If the hospital receives payment from Medicare or Medicaid -The Patient Self Determination Act, Pub. L. No. 101-508, §§ 4206 & 4751, 104 Stat. 1388 (codified at 42 USC §§ 1395cc(f), 1396a(w) (1994)).

The seven documents received were from hospital policy or operations manuals and staff training materials. Some were a single policy, others were a collection of several policies on advance directives, POLST⁴, seeking emergency guardianship, or seeking guidance from the ethics committee. All provided some overview of the relevant state laws. A couple included detailed decision trees, describing the flow of health care decision making citing relevant policies, procedures and laws. Some addressed the elements of informed consent. All failed to address a process for identifying surrogates, other than referring to the priority order in state law.

Given the inability to collect a critical mass of hospital policies for review, development of a model policy was not possible. However, a prominent theme voiced in the expert round table was that a Tool Kit for surrogate decision-making best practices would be most valuable. It could provide strategies, options, and best practices for care teams to: ascertain the existence of advance directives, possible surrogates, and informants; engage surrogates effectively in the decision-making process; problem solve and mediate disagreements among surrogates; and develop a person-centered process of decision-making for unrepresented patients.

Supplementing the largely unsuccessful review of hospital policies was: (a) a review of state laws providing for default surrogates where no one has been appointed by the patient; and (b) a review of the literature specifically addressing decision-making for unrepresented patients.

Review of State Law

Over the past 40 years 40 states have passed statutes regarding health care decision making for patients who lack capacity and have nothing in writing naming a person to make health care decisions for them. A detailed comparison chart of state default surrogate laws is available at https://www.americanbar.org/content/dam/aba/administrative/law_aging/state-health-care-power-of-attorney-statutes.authcheckdam.pdf. For purposes of the analysis below, specialized consent statutes for singular types of decisions such as code status or medical research consent are not included. Each state falls into one of three general categories: (1) Hierarchy, (2) Authorized surrogates but no hierarchy, and (3) No statutory provision.

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⁴ POLST stands for "Physician Orders for Life Sustaining Treatment," which are medical orders for patients with advanced illness, based on the patient's goals of care, that address cardiac resuscitation and other critical care decisions. There are several variations of the name across the states.

Table 7
State Default Surrogate Statutes for Health Decisions

States and (number of survey		es provides hiera ogate decision-m	Authorized surrogates but no	No general default surrogate consent statute	
responses)	Hierarchy	Includes "close friend"	Majority rule	hierarchy	
AL (5)	X				
AK (1)	X	X	X		
AZ (11)	X	X	X		
AR (4)	X				
CA (37)					X
CO (9)				X	
CT (10)	X				
DE (3)	X	X			
DC (2)	X	X			
FL (20)	X	X	X		
GA (10)	X	X			
HI (3)				X	
ID (0)	X				
IL (23)	X	X	X		
IN (10)	X				
IA (4)	X		X		

KS (0)				X
KY (6)	X		X	
LA (13)	X			
ME (3)	X	X	X	
MD (21)	X	X		
MA (14)				X
MI (17)	X			
MN (9)				X
MS (1)	X	X	X	
MO (13)				X
MT (2)	X		X	
NE (2)				X
NV (0)	X		X	
NH (0)	X	X	X	
NJ (15)				X
NM (8)	X	X	X	
NY (29)	X	X		
NC (17)	X	X	X	
ND (2)	X	X		
OH (14)	X		X	
OK (2)				X

OR (4)	X	X	X		
PA (32)	X	X	X		
RI (1)					X
SC (4)	X				
SD (0)	X	X			
TN (10)	X	X			
TX (26)	X				
UT (9)	X	X	X		
⁵ VT (2)					X
VA (10)	X	X	X		
WA (17)	X				
WV (3)	X	X			
WI (12)					X
WY (1)	X	X	X		
39 states + DC have Statutes	38	23	19	2	11

Hierarchy statutes provide a list of potential health care decision makers, or surrogates. The list generally lists legal next of kin first and expands from there. In 38 states, the statute prescribes that the highest person available and willing to make health care decisions becomes the surrogate. If, for example, the patient is married, the spouse becomes the surrogate, if there is no spouse, you look to the patients' children who are

⁵ Vermont has a new law, effective January 1, 2018, not reflected in this chart. It creates a default surrogate hierarchy covering most but not all end-of-life decisions. It includes close friend and requires consensus among surrogates of equal rank. 2016 Vermont Laws No. 136 (S. 62).

legal adults (frequently referred to as adult children), if there are none, you ask the patients' parents, and so on through the family tree. Some hierarchy statutes include close friends or other provisions for persons with no identifiable family by blood or marriage. Some statutes limit the degree of relationship to the patient for a surrogate, others say the "nearest next of kin."

The majority of the hierarchy statutes offer some statutory guidance for resolving disputes between surrogates of the same degree in the form of sanctioning consent from a majority of authorized surrogates of the same class. A prime example is the case of multiple adult children who are not in agreement. If a majority agree, the provider can, in theory, rely on their decision. The last resort for resolving conflict in every state is guardianship or conservatorship.

Table 8

Dispute Resolution Provisions in Default Surrogate Laws

Majority Rule (20 States)	Alaska, Arizona, Florida, Illinois, Iowa, Kentucky, Louisiana, Maine, Mississippi, Montana, Nevada, New Hampshire, New Mexico, North Carolina, Ohio, Oregon, Pennsylvania, Utah, Virginia, Wyoming
Ethics Committee	Delaware, Maryland 16 Del. Code § 2507(b)(9) the attending physician or an individual [in the surrogate list] may refer the case to an appropriate committee of the health-care institution for a recommendation in compliance with this chapter, and the attending physician may act in accordance with the recommendation of the committee or transfer the patient in accordance with [transfer rules]. Maryland Code, Health-Gen. § 5-605(b) the attending physician or an individual [in the surrogate hierarchy] shall refer the case to the institution's patient care advisory committee, and may act in accordance with the recommendation of the committee or transfer the patient in accordance with [transfer rules]. A physician who acts in accordance with the recommendation of the committee is not subject to liability for any claim based on lack of consent or authorization for the action
Provider selects surrogate	Tenn. Code Ann. § 68-11-1806(c) the patient's surrogate shall be identified by the supervising health care provider and documented in the current clinical record of the institution or institutions at which the patient is then receiving health care. The patient's surrogate shall be an adult who has exhibited special care and concern for the

patient, who is familiar with the patient's personal values, who is reasonably available, and who is willing to serve.

W. Va. Code, § 16-30-8(b)

- (1) Where there are multiple possible surrogate decision-makers at the same priority level, the attending physician or the advanced nurse practitioner shall, after reasonable inquiry, select as the surrogate the person who reasonably appears to be best qualified. The following criteria shall be considered in the determination of the person or entity best qualified to serve as the surrogate:
- (A) Whether the proposed surrogate reasonably appears to be better able to make decisions either in accordance with the known wishes of the person or in accordance with the person's best interests;
- (B) The proposed surrogate's regular contact with the person prior to and during the incapacitating illness;
- (C) The proposed surrogate's demonstrated care and concern;
- (D) The proposed surrogate's availability to visit the incapacitated person during his or her illness; and
- (E) The proposed surrogate's availability to engage in face-to-face contact with health care providers for the purpose of fully participating in the decision-making process;
- (2) The attending physician or the advanced nurse practitioner may select a proposed surrogate who is ranked lower in priority if, in his or her judgment, that individual is best qualified, as described in this section, to serve as the incapacitated person's surrogate. The attending physician or the advanced nurse practitioner shall document in the incapacitated person's medical records his or her reasons for selecting a surrogate in exception to the priority order provided in subsection (a) of this section.

A dozen state statutes provide guidance for making health care decisions when the patient does not have readily identifiable family or friends to make health care decisions. The state by state variations in these laws reflect the overall challenge of helping this patient group.

Table 3

Non-Judicial Decision-Making for Unrepresented Patients

Attending physician in some combination with an ethics committee and/or 2 nd physician	Alabama Arizona Arkansas Georgia (DNR only) Louisiana New York Tennessee Texas
Social worker selected by the facility & ethics committee if forgoing life prolonging care	Florida
Attending physician w/ multidisciplinary team review	CA (for nursing home residents only)
Attending physician	North Carolina Oregon
Anyone specified by regulation	West Virginia
Member of the clergy	Texas (Texas has two statutory provisions)

Literature Review

To enhance understanding of the background and published research, a literature review was conducted looking at published articles on healthcare decision-making for incapacitated individuals lacking surrogates or advance directives. The result is an annotated bibliography of articles on health care decision making for persons who have no document naming a person to make health care decisions. The search included legal research journals, medical journals and social work journals. The literature review provides an overview of the landscape of published research on the challenge of health care decision making in the absence of advance care planning. The annotated bibliography from the literature review is available at https://www.americanbar.org/content/dam/aba/administrative/law_aging/rrf_annotated_bibliography_literature_review.authcheckdam.pdf.

The Challenge of Unrepresented Patients

In the early stages of development and testing of the survey questions the term "unbefriended" was used and quickly became problematic. The majority of health care providers were unsure of the meaning of the term, and those that were familiar generally disliked the term. We changed the wording in the survey questions to patients who lack capacity and have no readily identifiable family or friends. The terminology generated considerable discussion at the Round Table, again with great disagreement on the term that should be used to describe persons without identifiable family or friends to help with health care decisions. It was agreed that we would use the term unrepresented, or the longer description. Other researchers are using the term 'solos" as in adults who are aging solo. While it is agreed that these patients are a small fraction of patients, it is also agreed that patients without family or friends require a disproportionate share of resources.

In the landmark report by Karp and Wood (2003) for the ABA, bioethicist Nancy Dubler describes these individuals as:

"the single greatest category of problems we encounter...These are the most vulnerable patients because no one cares deeply if they live or die. That is not to say that staff are not concerned to do what is right and in the best interest of the patient, but no one's life will be fundamentally changed by the death of the patient." (p. 1)

Scope of the Problem: There are no precise data on the size of this population, and the nature of the sample for this project did not lend itself to generalized projections. One study reported that in the intensive care units, 16% of those individuals admitted and 20% who died lacked both decision-making capacity and a surrogate (White, et al., 2006; White et al., 2007). Three to four percent of long-term care residents are thought to be unrepresented (Karp & Wood, 2003). The size of the problem will likely increase as Baby Boomers age: more than 10 million of this group live alone, and 20% are childless (Redfoot, et al., 2013). Extrapolations using these estimates suggest more than 25,000 ICU patients and 56,000 long-term care residents who are unrepresented (Pope, 2017). The Gerontological Society of America published a report in 2017 predicting the population at risk of not having family available. Looking at data from a Rand Corporation study, researchers concluded that 6.6% of US adults age 55 and older have no living spouse or children, and 1% lack a spouse, children, siblings or parents (Margolis and Verdery 2017.) In real numbers 6.6% of the US population is age 55 and older is about 8.3 million people, 1% of the population is about 835,000 adults in this high-risk group. It is important to note, that those numbers do not account for persons who have family, and choose not to associate with them.

Strategies for Decision-Making: Leading interventions to address decision-making for the unrepresented include: preventing older adults without potential surrogates (sometimes also known as "adult orphans") from becoming unrepresented by executing advance directives, better capacity assessments, more diligent searching for surrogates, increasing the rate of advance care planning, and more flexible default surrogate laws (Pope, 2012; Pope 2015; AGS, 2017).

Models to Address the Problem: The American Geriatric Society (2017) recently published its revised position statement on decision-making for unrepresented adults. AGS recommends uniform legal standards on the unrepresented to be adopted by all states; safeguards against *ad hoc* approaches to decision-making; and institutional committees, such as ethics committees, to synthesize all available evidence about patients, including cultural and ethnic factors, before decisions are made (AGS, 2017).

Various institutions or organizations have adopted preferred models or approaches to address decision-making on behalf of unrepresented persons. These include:

- Allowing attending physicians to make decisions, supported by ethics committees when requested (San Francisco General Hospital: Isaacs & Brody, 2010);
- Seeking court-appointed guardians for "urgent but not emergent medical treatment" (Milton S. Hershey Medical Center: Volpe & Steinman, 2013);
- Appointing multi-disciplinary teams whose members include individuals directly involved in caring for the patient, as well as someone to represent the patient's interests (California Hospital Association, 2015);
- Convening multi-disciplinary committees <u>not</u> including members of the patient's primary treatment team, to consider physician recommendations to withhold or withdraw life-sustaining treatment, subject to approval of the chief of staff (Department of Veterans Affairs, 2009);
- Consulting ethics committees to identify a surrogate decision-maker or "facilitate sound decision-making" (American Medical Association, *Code of Medical Ethics*).

Strengths and weaknesses to the various models have been advanced (Pope, 2015; Pope, 2012). "We want a decision-making process that is accessible, quick, convenient, and cost-effective" (Pope, 2015, p. 186). In addition, person-centered mechanisms have been advocated that incorporate the safeguards of expertise, independence from conflicts of interest, and careful deliberation emphasizing the least restrictive alternatives (Karp & Wood, 2003).

D. Round Table of Practitioners and Experts

The expert round table, convened March 17, 2017, was the capstone of the project. With an overall goal of 15 to 20 attendees, we sought a balance of expertise among the attendees. Round table participants consisted of a balanced team of ABA Commission on Law and Aging facilitators, health care law experts, bio-ethicists, policy experts from several foundations focused on elder care, and physicians from SCCM, SHM and academic medical ethics departments. Participants included seven persons with MD degrees; seven persons with law degrees—including the two ABA project investigators; two persons with PhDs; and two persons with MSWs. Nine attendees were female, ten were male, at least one person with a disability, two persons who are African American, one person who is Asian and one person who is openly gay.

The round table participants all had the benefit of reviewing the results of the survey, policy and literature review, and legal background. The purpose of the round table was to interpret and respond to the survey, policy and literature review through the collective experience and knowledge of the round table participants, with the goal being to clarify findings and develop recommendations for health-care decision-making policy and practice for persons lacking decisional capacity and with no appointed surrogate. The following section summarizes the cumulative themes, findings, and recommendations of the round table and project as a whole.

E. Findings and Recommendations

- A. **Absence of Appointed Proxies.** A large proportion of decisions at or near the end of life for patients lacking decisional capacity are made by surrogates who have not been appointed by the patient. This poses significant challenges to making decisions that reflect the patient's values, goals, culture, and preferences.
 - A majority of survey respondents (56%) reported that they "frequently" need surrogate decision-makers for decisions about end-of-life care, especially decisions about code status.
 - Health care providers generally work with any interested family or friends who appear at the bedside.
 - Health care providers seldom have easy access to any record of the patient's advance care planning history or advance directive documents, if they exist.

Recommendations:

A-1. Reliance of

A-1. Reliance on health decision surrogates who have not been chosen by the individual patient can and should be minimized in health care delivery. One solution is a radically longitudinal strategy of embedding advance care planning, and especially appointment of a proxy, in every stage and venue of health care. This should include incorporating the question of who the patient wants as a decision-maker if incapacitated as part of every medical history questionnaire, wellness check-up, onset of new illness, or admission to a facility, and ensuring it is documented.

- A-2. Electronic health record vendors can and should make an advance care planning field prominent and easily accessible as a standard component in all EHR systems.
- A-3. Oral appointment of a health care surrogate by means of the patient personally informing the supervising health care provider should be recognized in the advance directive laws of all states. Only 12 states currently recognize oral appointments.⁶

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⁶ Alaska Sta. §13.52.010(a) and 13.52.030(c) (West 2017); Ark. Code Ann. §§20-6-105; Cal. Prob. Code §§4623 and 4711 (West 2017); 16 Del. Code §2507(b) (West 2017); Fla. Stat. Ann. §§765.101(1) and 765.101(11)(a) (West

- B. **Default Surrogate Law Shortcomings**. While most states have default surrogate legislation for health care decisions, these laws inadequately reflect or support sound person- and family-centered decision-making.
 - Thirty-nine states plus the District of Columbia have default surrogate laws applicable to all or most health care decisions. Most of the state laws specify a hierarchy of authorized decision-makers, starting with spouse and descending through some degree of next-of-kin. They focus on identifying whom health care providers can legally rely upon to give or withhold consent.
 - In contrast to the hierarchical model, health professionals generally focus less on who has priority authority to make the decision but rather on how the decision is made among reasonably available surrogates, seeking consensus where possible or at least acceptance of a decision as appropriate, based on the patient's values, goals, culture, and preferences to the extent they can be ascertained. The process does not necessarily need someone to be identified as the authorized decision-maker. This process reflects the legal standard of decision-making referred to as substituted judgment.
 - A second model of default surrogate law in two states (CO & HI) defines a set of interested persons but does not dictate a hierarchy. Health care providers must make reasonable efforts to locate as many interested persons as practicable and notify them of the need for a decision-maker, but the burden is on the interested persons to come to consensus around identifying the decision-maker. Like the first model, this one focuses on decision-maker identification, but places that burden on interested parties, rather than focusing on a process of active engagement and collaborative decision-making.
 - A third model of default surrogate law in two other states (TN & WV) authorizes the supervising health care provider to select the best suited surrogate under specified circumstances and criteria. As with the other models, their focus on identifying the surrogate inadequately reflects clinical practice. Moreover, round table experts noted that being named as the surrogate responsible for making a difficult health decision can be an extremely stressful burden on that individual.
 - Avoiding disputes that tear families and friends apart emotionally, is also a major higher-level consideration of health care providers in these circumstances. As one participant in the Round Table put it, "We want the family to survive the death of the patient."

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^{2017);} Haw. Rev. Stat. §327E-3 and §327E-5 (2017); Md. Health-Gen. Code Ann. §5-602(d)(1) (West 2017); Miss. Code Ann. §§41-41-205(1) and 41-41-211 (West 2017); N.M. Stat. Ann. §§24-7A-2(A) and 24-7A-5 (West 2017); Tenn. Code Ann. §§68-11-1803 and –1806 (West 2017); Utah Code Ann. §§75-2a-103 and -107 (2017); Vt. Stat. Ann. tit. 18, § 9731(C)(1) (2017).

- Health care providers appear to give weight to the hierarchical order of authority in simpler situations involving the decision of a spouse versus children, or that of family members versus non-family; but they do not rely on the prescribed hierarchical order in more complicated or non-traditional family circumstances. Instead, they focus on the process of decision-making as described above and on giving the greatest voice to the person who cares for the patient and best knows the patient's values, goals, history, and prior decisions.
- Hierarchical default surrogate laws are especially ill-adapted to address patients whose significant relationships fall outside the nuclear family model, particularly the LGBT community, couples in long term, committed, non-marital relationships, and individuals who no longer have biological or marital family available. Recent research released by Pew Research says that 42% of adults in the United States do not have a spouse or partner.⁷
- Hierarchical default surrogate laws also do not account for cultural differences that may, for example, rely on the eldest family member, or community elder, or eldest male family member to make major decisions.
- Awareness of default surrogate laws is reportedly fairly high with over two-thirds
 of survey respondents reporting awareness. But, in looking at just those states
 without such a law, 55% of respondents nevertheless reported awareness of such a
 law in their state, so depth of knowledge is questionable.
- A large minority of survey respondents (41%) strongly agreed with the statement that these laws provide a baseline process for determining what the patient would have wanted; but other responses and the round table discussion demonstrated a wide range of opinion about their usefulness, and a general agreement that they have limited impact as presently written.

Recommendations:

B-1. Law and policy makers should be encouraged to adopt more flexible models for selecting a health care surrogate. The strict hierarchal model most commonly used too often fails to reflect the realities of clinical care or cultural differences in our society. Health care default surrogacy laws should recognize the involvement of all reasonably available interested persons in the decision-making process for patients, giving presumptive priority voice to spouses or domestic partners and adult children. Presumptive priority of surrogates should be flexible to give greater weight to interested persons who have exhibited

⁷ "The share of Americans living without a partner has increased, especially among young adults" Richard Fry, Pew Research Center, October 2017. Available at <a href="http://www.pewresearch.org/fact-tank/2017/10/11/the-share-of-americans-living-without-a-partner-has-increased-especially-among-young-adults/?utm_source=Pew+Research+Center&utm_campaign=a2b9bd68d5-EMAIL CAMPAIGN 2017 10 11&utm_medium=email&utm_term=0 3e953b9b70-a2b9bd68d5-399798357

- special care and concern for the patient, who are familiar with the patient's personal values, and who are reasonably available toy act as surrogate
- B-2. Health care providers, law and policy makers should enhance supported decision-making resources for persons with partial decision-making abilities to enable these persons to make their own heath care decisions.
- B-3. Decision-making should be structured as a person and family-centered discussion with relevant interested persons to clarify the medical facts and options and to determine how decisions will be made that are consistent with the patient's explicit preferences to the extent known, and otherwise in accord with the patient's values, priorities and preferences, inferred from past knowledge of or experience with the patient. The best interest of the patient, defined to the extent possible by the patient's values, priorities, and preferences, always guides the process, along with a recognition of the well-being of those close to the patient.
- B-4. The family or other interested persons involved in the decision-making process should be assisted by health professionals trained to facilitate person- and family-centered decision-making along with relevant decision aids or tools that help improve understanding of treatment options.
- C. **Dispute Resolution.** Default surrogate laws for health decisions do not provide useful means for dealing with disagreement among surrogate decision-makers.
 - Of the 40 state statues, 20 allow health care providers to rely on the decision of a majority where there is disagreement among surrogates of the same rank, such as adult children. Survey respondents and roundtable experts overwhelmingly describe majority rule as an undesirable solution to handling disagreements among surrogates of the same rank.
 - A second model for dispute resolution contained in two states' statutes (DE & MD) is referral to and reliance on the recommendation of an ethics committee. A consensus view of the expert round table is that while ethics committees can play a valuable role in improving policy and practice, committees are seldom quick, nimble, or qualified enough to play a meaningful role in real-time, bedside decisions. Round table experts viewed trained ethics consultants, mediators, or palliative care teams as far more effective in helping address surrogates' concerns and resolve disputes.
 - The respondents consistently told us that carefully facilitated meetings with a trained and accessible facilitator are an essential in resolving conflict among surrogates, or family and close friends regarding health care decisions, allowing

for clear communication of information and an opportunity to all questions and concerns to be heard.

• While resort to the courts for appointment of a guardian or authority to make a decision is available as a last resort in all states, the consensus view among round table experts is that the judicial process is far too slow, cumbersome, expensive, and emotionally detrimental for all involved.

Recommendations:

- C-1. Health care providers should make use of trained professionals to facilitate meetings among surrogates or family members in conflict over the course of care. Health care providers should train a broad spectrum of facilitators as needed to accommodate the need for this assistance. Facilitators may be ethics consultants, mediators, palliative care team or ethics committee members.
- C-2. The use of facilitated meetings to resolve conflicts should be factored into changes in laws and policies.
- C-3. Where judicial review is necessary, legislators and the courts should ensure that expedited proceedings are available to respond flexibly to the decision-making needs of the situation.
- D. **Unrepresented Patients.** A small proportion of incapacitated patients have no readily identifiable family or friends to serve as surrogates, so called unrepresented or unbefriended patients. These are the hardest cases in which to construct decision processes that respect the patient's values, dignity and rights.
 - While only 3% of survey respondents reported that they "frequently" encounter incapacitated patients with no family or friends to serve as surrogates, 20% reported that they "sometimes" encounter this situation. Only 17% report that they never encounter this situation. While these patients are a small percentage of adults, the consensus at the round table was that this population consumes a disproportionate share of resources.
 - Health care providers are too often ill-equipped to do a meaningful investigation of the patient's social history to identify family or friends, caregivers, and others who may know the patient and be able to participate in decision-making or offer insight into the patient's values, goals, priorities, and preferences.

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⁸ 22% of the over 11,000 members of the Society for Critical Care Medicine practice pediatrics, anytime parents are guardians are present for a child, a surrogate is present. The narrative comments reflected that a lack of surrogate is seldom if ever a concern in pediatrics.

- Twelve states include provisions in their laws for non-judicial decision-making procedures for individuals with no authorized surrogate. Most use some combination of consultation with and concurrence of an ethics committee or multidisciplinary team, but all lack adequate testing and evaluation and are subject to criticism and challenge as having structural conflicts of interest.
- A handful of states allow the treating physician to make health care decisions, in absence of any other surrogate. Survey responses and comments at the Round Table generally indicated that doing so is inappropriate and should be avoided absent an emergency.

Recommendations:

- D-1. Development of a tool kit for working with patients without readily identifiable family or friends is needed. The tool kit should contain guidelines for searching effectively and creatively for family and friends; piecing together the patient's values history; implementing ethical and practical policies for supporting patient-centered decision-making, and understanding the applicability of existing laws. One example of a guideline is the *Clinical Ethics Consult Guideline*, *Algorithm for the Unbefriended*, developed by Nancy Dubler, LLB, Professor Emerita, The Albert Einstein College of Medicine/Montefiore Medical Center are attached as Exhibit C.
- D-2. Non-judicial processes for surrogate health care decision-making must be centered around conscientiously discerning the values, priorities, and preferences of the patient through processes that counteracts institutional conflicts of interest. To the extent that ethics committees are used in these matters, the composition of these committees should include non-employees and persons with disabilities.
- D-3. For cases that need judicial resolution, lawmakers need to be urged to create streamlined legal procedures for appointing a legal surrogate or determining the course of treatment for patients who are "unrepresented." The guardianship process in many jurisdictions to too time consuming to be useful for appointing a health care surrogate.
- E. **Research and Training.** Further research, demonstrations, tools, and training are needed to develop and support better person- and family-centered decision-making for patients lacking decisional capacity with no appointed surrogate.
 - Policies and procedures for decision-making for unrepresented patients need much more development and examination.
 - Related areas identified needing further research include how non-beneficial or "futile" care is addressed or not addressed in surrogate decision-making; the

- extent to which liability fears and risk management concerns effect the decision-making process; the impact of gender bias and LGBT discrimination in surrogate decision-making.
- At the round table the issue of standard or default treatment recommendations for certain illnesses are based on assumptions that the person would want to live longer or want to receive the same care as another person with different baseline health. For frail persons' this may not be the best care. Recommendations from health care professionals have a strong influence on health care decisions. An example the normal treatment recommendation for kidney failure is dialysis. For a 90-year-old person with dementia, dialysis may not be the best treatment option.

Recommendations:

- E-1. Further study is needed of the effectiveness of facilitation methods and resources intended to assist in surrogate health-care decision-making.
- E-2. Research should be undertaken to study practices and strategies used to make decisions for unrepresented patients in order to assess their effectiveness in honoring the values, preferences, rights, and culture of the patient. Focused research on the impact of decision making models on persons of varied cultural backgrounds should be included.
- E-3. Further study is needed to assess the effectiveness of dispute resolution strategies and resources in the context of health care decision-making by surrogates.
- E-4. Health care providers should develop standard recommendations of care that are flexible based on an understanding of the underlying values and health of the individual person.
- E-5. A new model of default surrogate law has emerged in Tennessee and West Virginia that authorizes an entity such as the supervising health care provider to select the best suited surrogate under specified circumstances and criteria. Research is needed to see how effective this model is.

F. Next Steps and Audiences to Be Reached

The project team hopes to reach several audiences for this information to improve health care decision making for older adults.

First are heath care providers. Over the coming months we will write and submit articles to medical and nursing journals, starting with our collaborators on the project, the Society for Critical Care Medicine and Society of Hospital Medicine. The articles will focus on the research findings, and promote the concepts of engaging ethics experts to resolve conflicts and for guidance on making health care decisions for patients who do not have readily available family and friends.

The next audience is social and human services professionals, including chaplains. A presentation on the research findings and recommendations was made to the 2016-2017 Health and Aging Policy Fellows Annual Leadership Retreat, in Washington, DC on September 8, 2017. The findings and core recommendations were enthusiastically received with many good questions and comments.

We will present a workshop at the American Society on Aging, Aging in America Conference, as part of a paired symposium, "Do Laws Influence Health Care Decision Making in Clinical Settings?" David Godfrey and Dr. Jeffrey Frank of SCCM will present the program in San Francisco, CA on March 28, 2018.

Lawyers and the legal community are the third major audience. Lawyers will use this on two fronts, to engage in better advance care planning, and in reforming laws on health care decision making. We will reach the legal community through articles in legal journals and presentations at continuing legal education events.

A presentation was made at the 2017 National Aging and Law Conference, as a brief report on data and findings, to an audience of lawyers and aging policy makers, October 27, 2017.

An article is being outlined for the National Academy of Elder Law Attorneys Journal.

One recommendation from the round table was a tool kit for better health care decision making. This will start with understanding current clinical practices and laws and then focus on resolving disputes and patients without readily available family and friends. It is clear from the survey data and the round table that the preferred clinical method of resolving disputes is through facilitated meetings aimed at reaching understanding, if not agreement are the preferred clinical practice. The tools for unrepresented patients will start with recent and soon to be released policy statements, protocols shared at the round table by lawyer-ethicist Nancy Dubler.

G. Unintended Outcomes or Findings

A few of things stood out from the data and round table experience.

- The percentage of health care providers who ask the next of kin for consent, exceeds the percentage of health care providers who are aware of laws in the state they practice in, directing them to do so. Many commentators have speculated that this was the case, this survey provides data to back up the belief.
- An early realization was that that clinicians are more focused on the process of decision-making and striving for agreement, or at least acceptance, of an appropriate decision, and the law is more focused on who can make decisions and the scope of authority.

•	The near total failure of statutory provisions on dispute resolution. We have solid data showing that concepts such as "majority rule" are not generally accepted clinical practice.