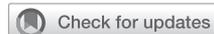*Brief Methodological Report*

A Tool to Assess Patient and Surrogate Knowledge About the POLST (Physician Orders for Life-Sustaining Treatment) Program

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Abstract

Context. It is especially important that patients are well informed when making high-stakes, preference-sensitive decisions like those on the Physician Orders for Life-Sustaining Treatment (POLST) form. However, there is currently no way to easily evaluate whether patients understand key concepts when making these important decisions.

Objectives. To develop a POLST knowledge survey.

Methods. Expert ($n = 62$) ratings of key POLST facts were used to select items for a POLST knowledge survey. The survey was administered to nursing facility residents ($n = 97$) and surrogate decision-makers ($n = 112$). A subset ($n = 135$) were re-administered the survey after a standardized advance care planning discussion to assess the scale's responsiveness to change.

Results. The 19-item survey demonstrated adequate reliability ($\alpha = 0.72$.). Residents' scores (x = 11.4, standard deviation 3.3) were significantly lower than surrogate scores (x = 14.7, standard deviation 2.5) ($P < 0.001$). Scores for both groups increased significantly after administration of a standardized advance care planning discussion ($P < 0.001$). Although being a surrogate, age, race, education, cognitive functioning, and health literacy were significantly associated with higher POLST Knowledge Survey scores in univariate analyses, only being a surrogate ($P < 0.001$) and being white ($P = 0.028$) remained significantly associated with higher scores in multivariate analyses.

Conclusion. The 19-item POLST Knowledge Survey demonstrated adequate reliability and responsiveness to change. Findings suggest the survey could be used to identify knowledge deficits and provide targeted education to ensure adequate understanding of key clinical decisions when completing POLST. J Pain Symptom Manage 2019;57:1143−1150. © *2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words
Physician Orders for Life-Sustaining Treatment, advance care planning, palliative care, nursing home

Advance care planning (ACP) is the process of discussing goals, values, and preferences for future medical care with patients and their family members.[1] The

Physician Orders for Life-Sustaining Treatment (POLST) form is used to document the outcomes of ACP discussions as medical orders that are actionable

throughout the health care system. POLST is designed for patients with serious life-limiting medical conditions who are at risk for life-threatening clinical events[2] and contains medical orders reflecting preferences for cardiopulmonary resuscitation (CPR), medical interventions including hospitalization and ventilation, antibiotics, and artificial nutrition. These preferences are elicited during conversations with health care providers that should include both education and discussion about the patients' medical condition.[3] Research suggests that POLST orders do guide treatment decisions, as medical treatments provided are largely consistent with POLST orders.[4]

It is especially critical that patients are well informed when making high-stakes, preference-sensitive decisions like those on POLST.[5–7] However, there is currently no way to easily evaluate whether patients understand key concepts when making these important decisions. In an earlier study, POLST knowledge was assessed using hypothetical scenarios.[8] However, this approach raised concerns about the readability of items and the possibility that low health literacy in residents and surrogates and/or undetected mild cognitive impairment in residents contributed to higher rates of discordance. A brief survey to evaluate POLST knowledge could have applications both in the clinical setting to identify knowledge deficits for targeted education and in research to evaluate the effects of interventions.

The goal of this study was to develop a survey to assess information identified by experts as important when making POLST decisions and to evaluate the properties of this survey after pilot testing. Survey testing was conducted with a subset of participants participating in a larger, ongoing study of POLST decision quality (NR015255).

Methods

This study was conducted in Indiana after review and approval by the Indiana University Institutional Review Board. The Indiana version of POLST became available for use following the passage of the Indiana POST (Physician Orders for Scope of Treatment) Act in July 2013. The National POLST Paradigm, a nonprofit organization that establishes POLST program quality standards, endorsed the Indiana POST program in April 2017 as meeting all program and form standards.[2,9]

Knowledge Survey Development

The knowledge survey was developed by a multidisciplinary research team with expertise in palliative and end-of-life care following an established approach used in decision quality assessment.[6,10] POLST patient and provider educational materials were reviewed by the research team to generate an initial list of salient facts about POLST with a focus on four content domains: choices (options that are available), benefits of choices, harms/risks of choices, and the decision situation (e.g., recognition of decision, urgency). Salient facts were identified specific to each category of treatment decisions (CPR, medical interventions, antibiotics, and artificial nutrition) and POLST generally. The goal was to identify 3–6 items per decision category to minimize participant burden.

A convenience sample of 62 experts was identified through the National POLST Paradigm[2] and were sent a survey that asked them to 1) rate the importance of 41 salient facts (1 = not important to 4 = extremely important); 2) indicate if each item was accurate (yes/no); 3) share if there were any salient facts about the POLST form missing from the initial list; 4) provide feedback about the wording of the items; and 5) rate items within each category of treatments as first, second, or third most important. The research team used this information to narrow the list of facts and generate survey items that were further reviewed for readability, accuracy, and clarity, drawing from their experiences with research, education, and practice. These items were used to create the POLST Knowledge Survey.

POLST Knowledge Survey Administration
Nursing Facility Residents and Surrogate Participants. The POLST Knowledge Survey was administered to a sample of nursing facility residents and surrogate decision-makers for incapacitated nursing facility residents as part of an ongoing study. The data in this article were collected between August 25, 2016, and August 15, 2018. Potential participants were identified based on who had signed the POLST form on file (resident or surrogate). Eligibility criteria for residents included aged 65 years and older; a minimum length of stay of 60 days; and signed POLST form in the medical chart. Eligibility criteria for surrogates included adult aged 18 years and older; served as surrogate decision-maker for an incapacitated nursing facility resident aged 65 years or older with a minimum length of stay of 60 days; and signed the POLST form on file as the resident's representative. All potential participants had to achieve a score of 22 or more on the Telephone Interview for Cognitive Status.[11] Informed consent was verified using a teach-back method with up to three attempts to ensure the participants understood the information provided.[12] Resident and surrogate participants were provided with a $50 gift card as compensation for participation.

Procedures. Chart reviews were conducted to assess study eligibility at 23 participating Indiana nursing

facilities where POLST is used.[13] A list was created of all potentially eligible participants, and a random sample was selected. Nursing facility staff were asked to review the list of potential participants and omit anyone who was potentially inappropriate due to illness, cognitive decline, or psychosocial concerns.

Research assistants (RAs) were introduced to residents by nursing facility staff, and consenting residents were interviewed in person at the nursing facility. When a surrogate had signed the POLST form, a packet containing study information was mailed to surrogates one week in advance of a call from the RA. Surrogates had the ability to opt out of the study without talking to the RA by leaving a voicemail message. If the surrogate was interested in participation, verbal consent was obtained. The POLST Knowledge Survey was administered by a trained RA as part of the overall study. Other data collected and presented in this manuscript include the date of the existing POLST form on file, participant characteristics, and health literacy. For survey development purposes, the POLST Knowledge Survey was administered a second time to a subset of participants after completing the Respecting Choices Advanced Steps POLST Facilitation interview,[14] a central part of the parent-study data collection methods.

Data Collection Instruments
Telephone Interview for Cognitive Status. Scores on the 11-item Telephone Interview for Cognitive Status[11] range from 0 to 41. Scores between 21 and 25 detect mild impairment, and scores less than 21 detect moderate to severe impairment.

POLST Form. The resident's POLST form was reviewed to obtain the date of POLST completion. Time since completion was calculated by subtracting the date of the interview from the date the form was signed by the treating practitioner.

Participant Characteristics. Participants self-reported age, gender, race, and educational attainment as part of the interview.

Health Literacy. Three self-report questions assessed health literacy. The items are rated on a 5-point Likert scale ranging from 1 (extremely) to 5 (not at all). Health literacy is the average of items assessing confidence, understanding, and need for help. Scores range from 0 to 4, with higher scores reflecting greater problems with reading.[15–17]

POLST Knowledge Survey. The pilot version of the survey comprised 22 items (18 true/false questions and four multiple-choice items). Items were grouped together into five subscales: 1) General POLST knowledge, 2) Resuscitation, 3) Medical Interventions, 4) Antibiotics, and 5) Artificial Nutrition. There was one correct response per item, and possible scores range from 0 to 22. Responses of "I do not know/I am not sure" were considered incorrect. See Appendix for the pilot version of the POLST Knowledge Survey.

Respecting Choices Advanced Steps Interview. A structured advance care planning facilitation approach designed to support values-based, informed decisions about POLST. Certified facilitators are trained to explore understanding of current diagnoses, elicit values, and discuss the risks, benefits, and alternatives of life-sustaining medical interventions documented on POLST.

Analysis. Analysis was performed using the SAS software, version 9.4. Descriptive statistics were computed to describe the sample and item characteristics. Acceptability was assessed by the number of participants who discontinued the survey or skipped items, and feasibility was assessed by the number of participants who discontinued participation. Item difficulty was assessed by the percent of participants who selected the correct response, with lower rates reflecting increased difficulty. Cronbach's alpha was calculated for the overall survey and for each subscale to evaluate the reliability/internal consistency. Pearson's Chi-square tests were used to compare resident and surrogate responses, and the *t*-test was used to compare pre- and post-test scores as a test of discriminant validity. A linear regression model was fitted to the data to identify predictors of higher scores. Cluster-robust standard errors for the estimated parameters of the latter model were used to account for the potential association among study participants from the same nursing facility, who may be more likely to have similar knowledge based on facility approach to POLST completion than residents from different facilities. Ignoring this fact would lead to biased standard error estimates, and, therefore, invalid *P*-values. Factor analysis was not performed as each individual question was designed to measure knowledge of POLST facts, rather than to identify latent constructs.

Results
Development of the POLST Knowledge Survey
Sixty-two experts participated in the POLST facts review process. Experts included physicians (15, 24.2%), nurses (20, 32.3%), social workers (11, 17.7%), chaplains (2, 3.2%), educators (3, 4.8%), and others (11, 17.7%). A majority of experts (46/62 or 74%) complete POLST with patients "sometimes" or "often."

Summary statistics were calculated for each of the 41 salient POLST facts. Ratings exhibited minimal range in scoring on a scale of 1 (not important) to 4 (extremely important). The lowest rated fact had an average rating of 2.56, and the highest rated fact had an average rating of 3.93 (see Supplemental Table 1 for ratings and rankings). An item addressing the purpose of POLST (item 5) was added as a result of open-ended suggestions by participant experts.

Pilot Testing of POLST Knowledge Survey

During the study timeframe included in this article, 97/212 (45.2%) of eligible residents and 112/427 (26.2%) of eligible surrogate decision-makers participated in the study. See Table 1 for participant characteristics.

Acceptability. All participating residents and surrogates completed the full the POLST Knowledge Survey.

Feasibility. There were missing data on only two items. These items were missed by fewer than 1% of participants.

Item Difficulty. Item difficulty was assessed by identifying the percent of residents and surrogates who selected the correct response. The most difficult item on the survey assessed knowledge about the approximate number of people with serious illness who survive after having CPR. Only 20.6% of residents and 24.7% of surrogates selected the correct multiple-choice option. The easiest item on the survey assessed knowledge about the consequences of an untreated infection. An overwhelming majority of residents (95.9%) and surrogates (98.2%) knew that an untreated infection could result in death. The three antibiotics questions were answered correctly by over 80% of resident and surrogate decision-makers, suggesting the items were too easy and do not discriminate well between low and high levels of POLST knowledge[18] so they were dropped, resulting in a 19-item survey.

Reliability-Internal Consistency. Reliability was assessed by the computation of a Cronbach's coefficient alpha for the overall survey tool. The Cronbach's alpha coefficient was $\alpha = 0.67$. When the antibiotics subscale questions were removed, the Cronbach's coefficient alpha increased to 0.72 (See Supplemental Table 2 for more information).

POLST Knowledge Survey Scores. Resident POLST Knowledge Survey scores ranged from 2 to 19 with an average score of 11.4 (standard deviation = 3.3) and a median score of 11. Surrogate POLST

Table 1
Characteristics of Participating Residents and Surrogates

Characteristic	Resident ($n = 97$)	Surrogate ($n = 112$)	P-value
Age, mean (range)	80.1 (65.0, 101.7)	62.7 (43.0, 81.0)	<0.0001
Gender, n (%)			0.5291
Male	28 (28.9)	28 (25.0)	
Female	69 (71.1)	84 (75.0)	
Race, n (%)			0.0110
Nonwhite	22 (22.7)	11 (9.8)	
White	75 (77.3)	101 (902)	
Ethnicity, n (%)			0.0983
Non-Hispanic	94 (96.9)	112 (100.0)	
Hispanic	3 (3.1)	0	
Schooling, n (%)			<0.0001
Grade school or less	4 (4.1)	0	
Some high school/technical school	13 (13.4)	1 (0.9)	
High school/technical school graduate	36 (37.1)	23 (20.5)	
Some college	26 (26.8)	39 (34.8)	
College graduate	12 (12.4)	27 (24.1)	
Some graduate/professional school	2 (2.1)	4 (3.6)	
Graduate or professional degree after college	4 (4.1)	18 (16.1)	
Telephone Interview for Cognitive Status score, mean (±SD)[a]	29.1 (±4.2)	35.7 (±2.7)	<0.0001
Health Literacy, mean (±SD)[b]	1.6 (±0.7)	0.9 (±0.7)	<0.0001
Relationship to resident, n (%)			
Spouse	n/a	10 (8.9)	
Adult child		74 (66.1)	
Sibling		5 (4.5)	
Other (friend, grandchild, niece/nephew, etc.)		23 (20.5)	
Time elapsed (in months) since POST completed	13.0 (0.0, 41.0)	15.5 (2.0, 43.0)	0.1015

POST = Physician Orders for Scope of Treatment.
[a]Scores range from 0 to 41 and measure global cognitive functioning; scores between 21 and 25 detect mild impairment, and scores less than 21 detect moderate to severe impairment.[11]
[b]Scores range from 0 to 4, with higher scores reflecting greater problems with reading.[15–17]

Table 2
POLST Knowledge Survey Item Characteristics (Percent of Correct Response and Chi-square Test Results Between Residents and Surrogates)

Item	Residents (*n* = 97) % Correct	Surrogates (*n* = 112) % Correct	Total (*n* = 209) % Correct	*P*-value
General POLST Knowledge				
1. Do you think the POST is a medical order that the doctor needs to sign? (y/n)	50.5%	66.1%	58.9%	0.0227
2. Do you think everyone is required to have a POST, even if they do not want on? (y/n)	40.2%	37.5%	38.8%	0.6888
3. Can the POST form ever be changed? (y/n)	70.1%	91.1%	81.3%	0.0001
4. Do you think the POST form is based on what the doctor thinks is best, and that it does not matter what the patient or surrogate prefers/thinks? (y/n)	63.9%	89.3%	77.5%	<0.0001
5. What do you think the POST tells health care providers? (multiple choice)	68.0%	92.9%	81.3%	<0.0001
Cardiopulmonary Resuscitation				
6. Do you think CPR or cardiopulmonary resuscitation works best if a patient is healthy and has no illness? (y/n)	71.1%	76.8%	74.2%	0.3519
7. About how many people with serious illness do you think survive after having cardiopulmonary resuscitation? (multiple choice)	20.6%	35.7%	28.7%	0.0161
8. Do you think a "Do not attempt resuscitation" or DNR order means staff will let a patient die a natural death without attempting resuscitation? (y/n)	66.0%	92.0%	79.9%	<0.0001
9. Do you think brain damage could happen after CPR? (y/n)	73.2%	83.9%	78.9%	0.0577
10. Do you think CPR causes a higher risk of cancer? (y/n)	75.3%	94.6%	85.6%	<0.0001
11. Do you think use of a ventilator/breathing tube could happen after CPR? (y/n)	55.7%	90.2%	74.2%	<0.0001
Medical Interventions				
12. Do you think a ventilator/breathing tube works best when a patient's lungs are healthy? (y/n)	62.9%	75.9%	69.9%	0.0410
13. The POST includes the option to select comfort measures. What do you think is the goal of the comfort measures order on POST? (multiple choice)	55.7%	92.0%	75.1%	<0.0001
14. If a patient has an order for comfort measures, when do you think he or she would be sent to the hospital? (multiple choice)	52.6%	69.6%	61.7%	0.0114
15. The POST includes the option to select full treatment. Do you think the goal of full treatment is to prolong life by all medically effective means? (y/n)	62.9%	86.6%	75.6%	<0.0001
Antibiotics				
16. If a patient has an untreated infection, could it result in death? (y/n)	95.9%	98.2%	97.1%	0.3128
17. Do you think antibiotics are free of side effects? (y/n)	80.4%	98.2%	90.0%	<0.0001
18. Do you think antibiotics are sometimes needed to reduce symptoms of discomfort for infections? (y/n)	86.6%	90.2%	88.5%	0.4181
Artificial Nutrition				
19. A feeding tube is a tube placed in the stomach to feed people who cannot eat on their own. Do you think patients with advanced dementia would likely benefit from a feeding tube? (y/n)	48.5%	50.9%	49.8%	0.7250
20. Do you think patients who are dying would likely benefit from a feeding tube? (y/n)	54.6%	77.7%	67.0%	0.0004
21. Do you think patients with a problem that will likely get better would benefit from a feeding tube? (y/n)	75.3%	93.8%	85.2%	0.0002
22. Do you think feeding tubes can cause discomfort at the end of life? (y/n)	71.1%	76.8%	74.2%	0.3519

POLST = Physician Orders for Life-Sustaining Treatment; POST = Physician Orders for Scope of Treatment.
"Don't know/unsure" was counted as incorrect. Antibiotics items are highlighted in gray as these items were removed from the final scale.

Knowledge Survey scores ranged from 6 to 19 with an average score of 14.7 (standard deviation = 2.5) and a median score of 15. Table 2 includes information about the average resident and surrogate performance on each survey item (see Supplemental Tables 3 and 4 for additional information about the mean and median scores). Surrogates scored higher on the full survey than residents (mean difference = 3.4, *P* < 0.001) and also scored higher on most items.

Responsiveness to Change. A subset of 135 participants were administered the POLST Knowledge Survey before and after a facilitated ACP discussion using the Respecting Choices Advanced Steps interview.[14] Resident scores improved from 11.1 before the Advanced Steps interview to 14.3 ($P < 0.001$) after the Advanced Steps interview and surrogate scores improved from 14.8 before the Advanced Steps interview to 17.8 after the Advanced Steps interview ($P < 0.001$).

Predictors of POLST Knowledge Survey Scores. Linear regression analysis was performed to assess predictors of POLST Knowledge Survey scores. In bivariate analyses, gender and time since POLST completion were not significantly associated with POLST Knowledge Survey scores, but being a surrogate, age, race, education, cognitive functioning, and health literacy were significant. In multivariate analyses, only race (white: $P = 0.028$) and being a surrogate rather than a resident ($P < 0.001$) remained significantly associated with higher POLST Knowledge Survey scores (see Table 3).

Discussion

In this survey development and pilot study, standardized methods were used to develop a POLST Knowledge Survey.[6,10] The resulting 19-item survey is designed to assess knowledge about key preference-sensitive decisions on resuscitation, medical interventions, and artificial nutrition identified by experts as important to the POLST decision-making process. On average, residents were able to correctly answer 60% of the items and the surrogates were able to correctly answer 78% of items. The scale demonstrated adequate reliability[19,20] and scores for both residents and surrogates significantly improved after a facilitated ACP conversation to elicit values-based, informed decisions, suggesting the survey is sensitive to change.

Participant characteristics including being a surrogate, age, race, education, cognitive functioning,

and health literacy were associated with POLST Knowledge Survey scores in univariate analyses. However, only being a surrogate and white race were significantly predictive of higher scores in multivariate analyses, raising questions about whether race is a proxy for an unmeasured variable such as communication disparities.[21] Overall, residents had lower scores on the POLST Knowledge Survey than surrogates. Although participating residents passed a thorough cognitive screen and informed consent verification process as part of the study enrollment procedures and factors such as education were included as covariates, there may be differences in decision-making processes for nursing home residents. These differences may be related to mild cognitive impairment or chronic disease, including the efficiency of deliberative processes involved in consciously analyzing information.[22]

The high proportion of correct answers to most items suggests that most decision-makers were well informed. However, some gaps were apparent. Only a small number of participants (20%) correctly responded that "not very many" nursing facility residents survive CPR, a finding consistent with prior research.[23] Also, most participants believed incorrectly that the POLST form was required even if unwanted, despite the fact that use is voluntary per Indiana law. These are two areas in which future POLST educational efforts for residents, surrogates, and health care providers should focus. In contrast, questions about antibiotic use were answered correctly by nearly all participants and were therefore removed from the final measure because of their failure to enhance the tool's ability to differentiate between participants' POLST knowledge.[1, 18] Several states have dropped a specific antibiotics section from their version of POLST, so this change may also make the tool more generalizable.[9]

Limitations

Research on the informed consent process suggests that knowledge degrades over time,[24] so it is possible

Table 3
Unadjusted and Adjusted Associations Between POLST Knowledge Survey Scores and Participant Characteristics

	Univariable Regression Results			Multivariable Regression Results		
Covariates	β^a	95% CI	*P*-value	β^a	95% CI	*P*-value
Surrogate participant	3.3507	2.5093 to 4.1921	<0.0001	2.1047	0.9574 to 3.2520	0.0003
Age	−0.1164	−0.1485 to −0.0842	<0.0001	−0.0252	−0.0680 to 0.0177	0.2491
Gender: female	0.2418	−1.0319 to 1.5156	0.7098	0.3403	−0.9466 to 1.6273	0.6042
Race: white	2.0455	0.6842 to 3.4067	0.0032	1.2975	0.1439 to 2.4511	0.0275
Education: at least high school	2.8685	1.6999 to 4.0371	<0.0001	0.6087	−0.4647 to 1.6822	0.2663
Cognition[b]	0.2898	0.2231 to 0.3566	<0.0001	0.0451	−0.0577 to 0.1478	0.3903
Health literacy[c]	−1.0659	−1.5055 to −0.6263	<0.0001	−0.1285	−0.7110 to 0.4539	0.6654
Time since POST completion	−0.0233	−0.0735 to 0.0268	0.3615	−0.0314	−0.0740 to 0.0112	0.148

[a]Mean difference in POLST Knowledge Survey scores for each unit increase of the corresponding covariate.
[b]Cognition was measured by the Telephone Interview for Cognitive Status.[11]
[c]Health literacy was measured using a composite score.[15−17]

that participants were more knowledgeable at the time the POLST form was completed. Interestingly, the length of time since POLST completion was not predictive of knowledge. Another limitation is that it was not possible to include questions specific to the resident's medical condition, although knowledge about how the available treatment options are relevant to one's current health condition is certainly important and may influence treatment preferences.[10] In addition, we did not include residents or surrogates in the development of the survey, so it is possible that the survey items do not reflect information valued by lay people in making POLST decisions.[10] Not all items rated by experts as important were included in the survey because of challenges in creating clear survey items and concerns about length, so there may be facts important to POLST decision-making that are not reflected in the final survey.

Conclusions

The POLST Knowledge Survey was developed using an established approach for measuring knowledge in the context of assessing decision quality.[10] The survey demonstrates acceptability, reliability, and responsiveness to change. Most nursing facility residents and surrogate decision-makers demonstrated adequate knowledge about key POLST decisions on a newly developed POLST Knowledge Survey. This survey has the potential to be useful in future research studies to evaluate educational interventions as well as in clinical practice to assess knowledge and identify gaps in knowledge as part of a POLST conversation.

Disclosures and Acknowledgments

References

1. Rietjens JAC, Sudore RL, Connolly M, et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. Lancet Oncol 2017;18:543–551.

2. The National POLST Paradigm, 2019. Available from www.polst.org. Accessed March 26, 2019.

3. Wennberg JE, Fisher ES, Skinner JS. Geography and the debate over Medicare reform. Health Aff (Millwood) 2002; (Suppl Web Exclusives):W96–W114.

4. Hickman SE, Keevern E, Hammes BJ. Use of the physician orders for life-sustaining treatment program in the clinical setting: a systematic review of the literature. J Am Geriatr Soc 2015;63:341–350.

5. Sepucha K, Ozanne E, Silvia K, Partridge A, Mulley AG Jr. An approach to measuring the quality of breast cancer decisions. Patient Educ Couns 2007;65:261–269.

6. Sepucha KR, Levin CA, Uzogara EE, et al. Developing instruments to measure the quality of decisions: early results for a set of symptom-driven measures. Patient Educ Couns 2008;73:504–510.

7. Sepucha K, Ozanne EM. How to define and measure concordance between patients' preferences and medical treatments: a systematic review of approaches and recommendations for standardization. Patient Educ Couns 2010; 78:12–23.

8. Hickman SE, Hammes BJ, Torke AM, et al. The quality of POLST decisions: a pilot study. J Palliat Med 2017;20: 155–162.

9. Hickman SE, Critser R. National standards and state variation in physician orders for life-sustaining treatment forms. J Palliat Med 2018;21:978–986.

10. Sepucha KR, Fowler FJ. Measuring decision quality: Where we stand today. Informed Medical Decisions Foundation, 2013. Available from http://cdn-www.informed medicaldecisions.org/imdfdocs/Measuring_DQ_Sepucha_ Fowler.pdf. Accessed October 4, 2018.

11. Brandt J, Spencer M, Folstein M. The telephone interview for cognitive status. Neuropsychiatry Neuropsychol Behav Neurol 1988;1:111–117.

12. Sudore RL, Landefeld CS, Williams BA, et al. Use of a modified informed consent process among vulnerable patients: a descriptive study. J Gen Intern Med 2006;21: 867–873.

13. Hickman SE, Sudore RS, Torke AM, et al. Use of the physician orders for scope of treatment program in Indiana nursing homes. J Am Geriatr Soc 2018;66:1096–1100.

14. Respecting Choices Advanced Steps. Available from www.respectingchoices.org. Accessed October 4, 2018.

15. Sarkar U, Schillinger D, Lopez A, Sudore R. Validation of self-reported health literacy questions among diverse English and Spanish-speaking populations. J Gen Intern Med 2011;26:265–271.

16. Chew LD, Griffin JM, Partin MR, et al. Validation of screening questions for limited health literacy in a large VA outpatient population. J Gen Intern Med 2008;23: 561–566.

17. Chew LD, Bradley KA, Boyko EJ. Brief questions to identify patients with inadequate health literacy. Fam Med 2004; 36:588−594.

18. Lee CN, Wetschler MH, Chang Y, et al. Measuring decision quality: psychometric evaluation of a new instrument for breast cancer chemotherapy. BMC Med Inform Decis Mak 2014;14:73.

19. Kline P. The handbook of psychological testing, 2nd ed. London: Routledge, 2000.

20. Devellis RF. Scale develeopment: Theory and applications. Los Angeles: Sage, 2012.

21. Johnson KS. Racial and ethnic disparities in palliative care. J Palliat Med 2013;16:1329−1334.

22. Peters E, Hess TM, Vastfjall D, Auman C. Adult age differences in dual information processes: implications for the role of affective and deliberative processes in older adults' decision-making. Perspect Psychol Sci 2007;2:1−23.

23. Heyland DK, Frank C, Groll D, et al. Understanding cardiopulmonary resuscitation decision-making: perspectives of seriously ill hospitalized patients and family members. Chest 2006;130:419−428.

24. Lavelle-Jones C, Byrne DJ, Rice P, Cuschieri A. Factors affecting quality of informed consent. BMJ 1993;306:885−890.

Appendix

POLST Knowledge Survey

Survey Questions	Response Options
General POLST	
1. Do you think the POST is a medical order that the doctor needs to sign?	No **Yes** Don't know
2. Do you think everyone is required to have a POST, even if they do not want one?	**No** Yes Don't know
3. Can the POST form ever be changed?	Missing No **Yes** Don't know
4. Do you think the POST form is based on what the doctor thinks is best, and that it does not matter what the patient or surrogate prefers/thinks?	**No** Yes Don't know
5. What do you think the POST tells health care providers?	The patient is on hospice **What to do or not do in an emergency** Don't know
Cardiopulmonary Resuscitation	
6. Do you think CPR or cardiopulmonary resuscitation works best if a patient is healthy and has no illness?	No **Yes** Don't know
7. About how many people with serious illness do you think survive after having cardiopulmonary resuscitation?	Almost everyone About half **Not very many** Don't know
8. Do you think a "Do not attempt resuscitation" or DNR order means staff will let a patient die a natural death without attempting resuscitation?	Missing No **Yes** Don't know
9. Do you think brain damage could happen after CPR?	No **Yes** Don't know
10. Do you think CPR causes a higher risk of cancer?	**No** Yes Don't know
11. Do you think use of a ventilator/breathing tube could happen after CPR?	No **Yes** Don't know
Medical Interventions	
12. Do you think a ventilator/breathing tube works best when a patient's lungs are healthy?	No **Yes** Don't know
13. The POST includes the option to select comfort measures. What do you think is the goal of the comfort measures order on POST?	To order all available treatment **To focus on managing symptoms like pain** Don't know
14. If a patient has an order for comfort measures, when do you think he or she would be sent to the hospital?	Whenever there is a medical problem **Only when he or she could not be kept comfortable** Never-it means do not hospitalize Don't know
15. The POST includes the option to select full treatment. Do you think the goal of full treatment is to prolong life by all medically effective means?	No **Yes** Don't know
Antibiotics	
16. If a patient has an untreated infection, could it result in death?	No **Yes** Don't know
17. Do you think antibiotics are free of side effects?	**No** Yes Don't know
18. Do you think antibiotics are sometimes needed to reduce symptoms of discomfort for infections?	No **Yes** Don't know
Artificial Nutrition	
19. A feeding tube is a tube placed in the stomach to feed people who cannot eat on their own. Do you think patients with advanced dementia would likely benefit from a feeding tube?	**No** Yes Don't know

Continued

Survey Questions	Response Options
20. Do you think patients who are dying would likely benefit from a feeding tube?	**No** Yes Don't know
21. Do you think patients with a problem that will likely get better would benefit from a feeding tube?	No **Yes** Don't know
22. Do you think feeding tubes can cause discomfort at the end of life?	No **Yes** Don't know

POLST = Physician Orders for Life-Sustaining Treatment; POST = Physician Orders for Scope of Treatment.
"Don't know/unsure" was counted as incorrect. Bolded response options reflect the correct response to the survey question. Antibiotics items[16–18] are shaded to indicate these items were removed after pilot testing.

Supplemental Table 1
Expert Ratings and Rankings of POLST Facts

POLST Fact	N	Extremely Important	Very Important	Somewhat Important	Not Important	Ranking*	Item number
General POLST Knowledge							
The POLST form should be based on patient preferences.	61	57 (93.4%)	4 (6.6%)	0 (0.0%)	0 (0.0%)	1	4
You can change your POLST at any time in the future if you change your mind about treatments.	61	48(78.7%)	10 (16.4%)	3 (4.9%)	0 (0.0%)	2, 3	3
Having a POLST form is voluntary. You get to choose whether or not to have a POLST form.	61	33 (54.1%)	20 (32.8%)	7 (11.5%)	1 (1.6%)	—	2
The POLST form is a physician order.	61	39 (63.9%)	14 (23.0%)	5 (8.2%)	3 (4.9%)	—	1
Your preferences may change over time.	61	34 (55.7%)	20 (32.8%)	7 (11.5%)	0 (0.0%)	—	3
The POLST form should be reviewed whenever a patient has a major change in their health.	60	41 (68.3%)	14 (23.3%)	5 (8.3%)	0 (0.0%)	—	3
You may not be able to tell us if you change your mind about your treatment in the future.	59	19 (32.2%)	25 (42.4%)	12 (20.3%)	3 (5.1%)	—	—
Cardiopulmonary Resuscitation							
CPR works best if you are healthy with no illness.	61	41 (67.2%)	13 (21.3%)	6 (9.8%)	1 (1.6%)	1	6
If you select DNR, staff will not attempt to restart your heart if your heartbeat or breathing stops.	60	38 (63.3%)	21 (35.0%)	1 (1.7%)	0 (0.0%)	2	8
One possible side effect of CPR is brain damage from a lack of oxygen.	59	31 (52.5%)	20 (33.9%)	6 (10.2%)	2 (3.4%)	3	9, 10
If you survive CPR, you will go to the hospital and be admitted to the ICU.	58	38 (65.5%)	11 (19.0%)	8 (13.8%)	1 (1.7%)	3	11
About three of every 100 nursing home residents survive CPR.	60	32 (53.3%)	17 (28.3%)	8 (13.3%)	3 (5.0%)	—	7
CPR stands for cardiopulmonary resuscitation.	60	16 (26.7%)	24 (40.0%)	14 (23.3%)	6 (10.0%)	—	6
DNR stands for do not resuscitate.	58	24 (41.4%)	24 (41.4%)	8 (13.8%)	2 (3.4%)	—	
If you select CPR, staff will attempt to restart your heart by pushing on your chest if your heartbeat or breathing stops.	60	39 (65.0%)	16 (26.7%)	4 (6.7%)	1 (1.7%)	—	
You may have damage to your ribs or internal organs from CPR.	61	27 (44.3%)	22 (36.1%)	8 (13.1%)	4 (6.6%)	—	
Medical Interventions							
A ventilator/breathing tube works best when your lung problem can be fixed.	59	35 (59.3%)	16 (27.1%)	8 (13.6%)	0 (0.0%)	1	12
The comfort measures option means that you will not go to the hospital unless it is needed to keep you comfortable.	60	50 (83.3%)	8 (13.3%)	2 (3.3%)	0 (0.0%)	2	13, 14
Full treatment option means it is okay to use a breathing tube and the ICU if needed.	60	47 (78.3%)	8 (13.3%)	5 (8.3%)	0 (0.0%)	—	15
The goal of full treatment is to try to extend your life.	60	31 (51.7%)	18 (30.0%)	9 (15.0%)	2 (3.3%)	—	15
You may need to go to the hospital to be kept comfortable.	59	14 (23.7%)	29 (49.2%)	14 (23.7%)	2 (3.4%)	—	14
The goal of comfort care is to focus on managing symptoms like pain.	60	45 (75.0%)	12 (20.0%)	3 (5.0%)	0 (0.0%)	—	14
It may not be possible for you to live without the breathing tube once it is put in.	60	39 (65.0%)	17 (28.3%)	4 (6.7%)	0 (0.0%)	3	
Limited additional interventions mean that you will go to the hospital for some treatments if needed. You will not go to the ICU.	60	35 (58.3%)	17 (28.3%)	7 (11.7%)	1 (1.7%)	—	
Hospitals provide some treatments you cannot get in the nursing home.	60	11 (18.3%)	25 (41.7%)	21 (35.0%)	3 (5.0%)	—	
Antibiotics							
Antibiotics can reduce symptoms of discomfort for some infections.	57	24 (43.9%)	27 (47.4%)	5 (8.8%)	0 (0.0%)	2	18
Untreated infections can result in death.	57	19 (33.3%)	22 (38.6%)	14 (24.6%)	2 (3.5%)	—	16
A side effect of some antibiotics can be stomach upset.	57	11 (19.3%)	23 (40.4%)	20 (35.1%)	3 (5.3%)	—	17
The use of antibiotics can lead to antibiotic resistant germs that are very hard to treat.	57	16 (28.1%)	24 (42.1%)	13 (22.8%)	4 (7.0%)	—	17
It is possible to provide comfort to someone with pneumonia without antibiotics.	58	42 (72.4%)	11 (19.0%)	5 (8.6%)	0 (0.0%)	1, 3	
Antibiotics treat infections and, in some cases, may extend life.	57	21 (36.8%)	26 (45.6%)	10 (17.5%)	0 (0.0%)	—	
You may need to go to the hospital to receive some antibiotics.	57	24 (43.9%)	20 (35.1%)	9 (15.8%)	3 (5.3%)	—	

(Continued)

Supplemental Table 1
Continued

POLST Fact	N	Extremely Important	Very Important	Somewhat Important	Not Important	Ranking*	Item number
Artificial Nutrition							
Feeding tubes work best when you are healthy and need it for just a short time.	59	34 (57.6%)	16 (27.1%)	9 (15.3%)	0 (0.0%)	1	20, 21
Feeding tubes do not work as well for people who are frail and need long-term feeding tubes.	58	44 (75.9%)	10 (17.2%)	3 (5.2%)	1 (1.7%)	—	21
It is generally best to stop tube feedings during the dying process.	59	40 (67.8%)	14 (23.7%)	5 (8.5%)	0 (0.0%)	—	20, 22
Feeding tubes do not work well in people with advanced dementia.	57	45 (78.9%)	10 (17.5%)	2 (3.5%)	0 (0.0%)	—	19
Hand feeding can keep people alive and maintain personal contact.	59	39 (66.1%)	15 (25.4%)	4 (6.8%)	1 (1.7%)	2	
Even with a feeding tube, food/fluid/saliva may still get into your lungs.	59	49 (83.1%)	8 (13.6%)	2 (3.4%)	0 (0.0%)	3	
You can decide on a trial of a feeding tube for a period of time.	59	33 (55.9%)	20 (33.9%)	5 (8.5%)	1 (1.7%)	—	
You can have a feeding tube long-term if eeded and wanted.	58	23 (43.1%)	22 (37.9%)	9 (15.5%)	2 (3.4%)	—	
Feeding tubes can extend life for some patients.	59	22 (37.3%)	23 (39.0%)	12 (20.3%)	2 (3.4%)	—	

POLST = Physician Orders for Life-Sustaining Treatment; POST = Physician Orders for Scope of Treatment.
*Participants were asked to rank the top three items in each category.

Supplemental Table 2
Cronbach Coefficient for Each Item With the Overall POLST Knowledge Survey Score Raw and Standardized

Cronbach Coefficient Alpha With Deleted Variable

Deleted Variable	Raw Variables		Standardized Variables	
	Correlation With Total	Alpha	Correlation With Total	Alpha
A01	0.128504	0.716573	0.135123	0.723325
A02	0.131136	0.716103	0.137726	0.723097
A03	0.398526	0.690366	0.401242	0.699237
A04	0.367371	0.692395	0.372172	0.701949
A05	0.419039	0.688579	0.428496	0.696676
A06	0.195843	0.708321	0.189622	0.718525
A07	0.206892	0.707556	0.209716	0.716738
A08	0.386417	0.691087	0.389168	0.700366
A09	0.314637	0.697355	0.312451	0.707457
A10	0.358652	0.694865	0.358739	0.703195
A11	0.360265	0.692678	0.375323	0.701656
A12	0.246348	0.703802	0.238861	0.714130
A13	0.385590	0.690335	0.387962	0.700478
A14	0.342631	0.693953	0.347866	0.704200
A15	0.271309	0.701205	0.278603	0.710542
A19	0.271165	0.701742	0.268057	0.711497
A20	0.269977	0.701544	0.270594	0.711268
A21	0.221486	0.705305	0.223100	0.715543
A22	0.234502	0.704703	0.225415	0.715335

Supplemental Table 3
Mean Scores on the POLST Knowledge Survey

Knowledge Survey 1 (Pre-RCAS Interview)	Residents (n = 97) Mean (±SD)	Surrogates (n = 112) Mean (±SD)	Overall (n = 209) Mean (±SD)
General POLST Knowledge	2.9 (±1.2)	3.8 (±1.0)	3.4 (±1.2)
Resuscitation	3.6 (±1.3)	4.7 (±1.0)	4.2 (±1.3)
Medical Interventions	2.3 (±1.1)	3.2 (±0.9)	2.8 (±1.1)
Artificial Nutrition	2.5 (±1.0)	3.0 (±1.0)	2.8 (±1.0)
Total	14.0 (±3.6)	17.6 (±2.6)	15.9 (±3.6)
Total with 19 items	11.4 (±3.3)	14.7 (±2.5)	13.2 (±3.3)

POLST = Physician Orders for Life-Sustaining Treatment; RCAS = Respecting Choices Advanced Steps.
Score potential range (min, max): General POLST Knowledge (0, 5), Section A (0, 6), Section B (0, 4), Section C (0, 3), Section D (0, 4), Total (0, 22), and Total with 19 items (0, 19).

Supplemental Table 4
Median Scores on the POLST Knowledge Survey

Knowledge Survey 1 (Pre-RCAS Interview)	Residents ($n = 97$) Median (min, max)	Surrogates ($n = 112$) Median (min, max)	Overall ($n = 209$) Median (min, max)
General POLST Knowledge	3.0 (0, 5)	4.0 (0, 5)	4.0 (0, 5)
Resuscitation	4.0 (0, 6)	5.0 (2, 6)	4.0 (0, 6)
Medical Interventions	2.0 (0, 4)	3.0 (0, 4)	3.0 (0, 4)
Artificial Nutrition	3.0 (0, 4)	3.0 (1, 4)	3.0 (0, 4)
Total	14.0 (2, 22)	18.0 (7, 22)	17.0 (2, 22)
Total with 19 items	11.0 (2, 19)	15.0 (6, 19)	14.0 (2, 19)

POLST = Physician Orders for Life-Sustaining Treatment; RCAS = Respecting Choices Advanced Steps.
Score potential range (min, max): General POLST Knowledge (0, 5), Section A (0, 6), Section B (0, 4), Section C (0, 3), Section D (0, 4), Total (0, 22), and Total with 19 items (0, 19).