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## 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 responsiveness of the scale 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 < .001). Scores for both groups increased significantly following administration of a standardized advance care planning discussion (p < .001). Although being a surrogate, age, race, education, cognitive functioning, and health literacy were significantly associated with higher

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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.

### Keywords

Physician Orders for Life Sustaining Treatment; advance care planning; palliative care; nursing home

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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 healthcare system. POLST is designed for patients whose treating practitioner would not be surprised if they died within the next 12 months (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 following pilot testing. Survey testing was conducted with a subset of participants participating in a larger, on-going study of POLST decision quality (NR015255).

### Methods

This study was conducted in Indiana following 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 in order 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 in order 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 paper was 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 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 or older with a minimum length of stay of 60 days; and signed the POLST form on file as the resident representative. All potential participants had to achieve a score of 22 or more on the Telephone Interview for Cognitive Status (TICS) (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 includes 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 model (14), a central part of the parent-study data collection methods.

### Data Collection Instruments

**Telephone Interview for Cognitive Status (TICS) (11).**—Scores on the 11-item Telephone Interview for Cognitive Status (TICS) range from 0–41. Scores between 21 and 25 detect mild impairment and scores less than 21 detect moderate to severe impairment.

**POLST Forms.**—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). Scores range from 0–4, with higher scores reflecting greater problems with reading. Healthy literacy is the average of confidence, understanding and help (15–17).

**POLST Knowledge Survey.**—The pilot version of the survey was comprised of 22 items (18 true/false questions and 4 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 – 22. Responses of “I don’t know/I am not sure” were considered incorrect. (See Appendix for the pilot version of the POLST Knowledge Survey.)

**Respecting Choices Advanced Steps.**—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 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 in order to identify predictors of higher scores. Cluster-robust standard errors for the estimated parameters of the latter model were used in order 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 paper, 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 was 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 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 compared to 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 model.<sup>14</sup> Resident scores improved from 11.1 prior to the Advanced Steps discussion to 14.3 ( $p < 0.001$ ) after the Advanced Steps discussion and surrogate scores improved from 14.8 before the Advanced Steps discussion to 17.8 after the Advanced Steps discussion ( $p < 0.001$ ).

**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 following 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. Even though 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 co-variables, there may be differences in decision-making processes for nursing home residents 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 a majority of 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 make the tool more generalizable (9).

### **Limitations.**

Research on the informed consent process suggests that knowledge degrades over time (24), so it is possible 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, though knowledge about how the available treatment options are relevant to one’s current health condition is certainly important and may influence treatment preferences (10). Additionally, 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 due to 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.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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**Table 1.**

Characteristics of participating residents and surrogates.

	Resident (n=97)	Surrogate (n=112)	p-value
<b>Age, mean(range)</b>	80.1 (65.0, 101.7)	62.7 (43.0, 81.0)	<.0001
<b>Gender, n (%)</b>			0.5291
Male	28 (28.9%)	28 (25.0%)	
Female	69 (71.1%)	84 (75.0%)	
<b>Race, n (%)</b>			0.0110
Non-White	22 (22.7%)	11 (9.8%)	
White	75 (77.3%)	101 (90.2%)	
<b>Ethnicity, n (%)</b>			0.0983
Non-Hispanic	94 (96.9%)	112 (100.0%)	
Hispanic	3 (3.1%)	0	
<b>Schooling, n (%)</b>			<.0001
Grade school or less	4 (4.1%)	0	
Some HS/technical school	13 (13.4%)	1 (0.9%)	
HS/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%)	
<b>Telephone Interview for Cognitive Status score, mean (<math>\pm</math>SD)<sup>A</sup></b>	29.1 ( $\pm$ 4.2)	35.7 ( $\pm$ 2.7)	<.0001
<b>Health Literacy, mean (<math>\pm</math>SD)<sup>B</sup></b>	1.6 ( $\pm$ 0.7)	0.9 ( $\pm$ 0.7)	<.0001
<b>Relationship to resident</b>			
Spouse	n/a	10 (8.9%)	
Adult child		74 (66.1%)	
Sibling		5 (4.5%)	
Other (friend, grandchild, niece/nephew, etc.)		23 (20.5%)	
<b>Time elapsed (in months) since POST completed</b>	13.0 (0.0, 41.0)	15.5 (2.0, 43.0)	0.1015

<sup>A</sup> Scores range from 0–41 and measure global cognitive functioning; scores between 21 and 25 detect mild impairment and scores less than 21 detect moderate to severe impairment (11).

<sup>B</sup> Scores range from 0–4, 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
<b>General POLST Knowledge</b>				
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%	<.0001
5. What do you think the POST tells health care providers? (multiple choice)	68.0%	92.9%	81.3%	<.0001
<b>Cardiopulmonary Resuscitation</b>				
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%	<.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%	<.0001
11. Do you think use of a ventilator/breathing tube could happen after CPR? (y/n)	55.7%	90.2%	74.2%	<.0001
<b>Medical Interventions</b>				
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%	<.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%	<.0001
<b>Antibiotics</b>				
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%	<.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
<b>Artificial nutrition</b>				
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

Note: "Don't know/unsure" was counted as incorrect. Bolded response options reflects the correct response to the survey question. Antibiotics items are highlighted in grey as these items were removed from the final scale.

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**Table 3.**

Unadjusted and adjusted associations between POLST Knowledge Survey scores and participant characteristics.

Covariates	Univariable regression results				Multivariable regression results			
	$\beta^A$	95% CI		P value	$\beta^A$	95% CI		P value
Surrogate participant	3.3507	2.5093	4.1921	<.0001	2.1047	0.9574	3.2520	0.0003
Age	-0.1164	-0.1485	-0.0842	<.0001	-0.0252	-0.0680	0.0177	0.2491
Gender: female	0.2418	-1.0319	1.5156	0.7098	0.3403	-0.9466	1.6273	0.6042
Race: white	2.0455	0.6842	3.4067	0.0032	1.2975	0.1439	2.4511	0.0275
Education: at least high school	2.8685	1.6999	4.0371	<.0001	0.6087	-0.4647	1.6822	0.2663
Cognition <sup>B</sup>	0.2898	0.2231	0.3566	<.0001	0.0451	-0.0577	0.1478	0.3903
Health literacy <sup>C</sup>	-1.0659	-1.5055	-0.6263	<.0001	-0.1285	-0.7110	0.4539	0.6654
Time since POST completion	-0.0233	-0.0735	0.0268	0.3615	-0.0314	-0.0740	0.0112	0.148

<sup>A</sup> Mean difference in POLST Knowledge Survey Scores for each unit increase of the corresponding covariate

<sup>B</sup> Cognition was measured by the Telephone Interview for Cognitive Status (11).

<sup>C</sup> Health literacy was measured using a composite score (15–17).