



The POLST Quality and Research Toolkit (PQRsT)

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The POLST Quality and ReSearch Toolkit (PQRsT)

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Introduction:

This toolkit is intended as a resource for anyone who is interested in doing research or quality improvement work with POLST paradigm programs or forms. The project was generously funded by Judy Citko, JD and the California Coalition for Compassionate Care. The project included

1. A comprehensive literature search for published POLST research articles
2. Contacting each research article to request copies of their instruments and research materials (if they still existed)
3. Organizing these materials along with 'user guides' to provide easy access to existing materials and prevent users from having to 'start from scratch'.

I am happy to report that all authors that I contacted were responsive and helpful in providing their materials, with some authors searching through archive boxes to look for materials over 10 years old. While some very old materials were regrettably no longer available, not a single author refused to have his or her work represented in the toolkit!

Note on terminology– many different acronyms!

POLST paradigm forms are known by different names in different states, including MOLST, MOST, POST, LaPOST, and TPOPP. For simplicity, we will use the term POLST when referring in general to POLST paradigm forms or programs. When we are referring to a specific program or form, we will use the actual name. We have left the original language intact as much as possible in each instrument to acknowledge all the hard work that went into creating them and the creators generosity in allowing us to use them.

Notes on modification:

It is understood that you will need to adapt these instruments to your program and specific objectives, and you should feel free to change terminology to fit your state/program needs (e.g. changing POLST to MOLST, etc.) Note that some of the instruments have been used successfully in research. None of the instruments have been formally 'validated' - a process that involves psychometrics and studying the actual performance of the instrument to prove that it really measures what it measures. Ironically, POLST could be considered an instrument for measuring patient preferences and has also not been formally validated, as that turns out to be quite difficult to do. However, if you are planning on using one of the instruments for research, it is helpful to be able to say that the instrument has previously been used successfully in other research projects. If you want to compare your results to the researchers results, you should try to make as few modifications to the instrument as possible so that you are asking the same question the same way.

Suggestions for getting off on the right track

- 1.) Be as clear as possible about why you are doing this study. This means having a clear question or questions that you want to answer, and a fairly clear idea of what the results will look like when you collect them. This sounds obvious and simple, but it's actually the hardest part. Too often people are

doing research or quality work because it is expected. The best researchers are those who need the results and already have an idea of how they will use them.

- 2.) Because it is difficult to envision results before you get them, the best practice is to pilot test your study, compile the results, and informally analyze them. You will be surprised at how much this process helps you identify questions that, while they make sense, yield useless or difficult to summarize data. It can be disastrous to recognize this after you've collected all your data.
- 3.) Another approach is to get input from people who have experience doing research in the area that you are interested in. The National POLST Paradigm Program (www.polst.org) is a great resource that can connect you with researchers and experts who can help you design your project and use the results effectively.
- 4.) Expect obstacles and don't let them discourage you. Obstacles are inherent to research, and no project is ever perfect. While often frustrating they are always opportunities to learn and some actually turn out to be important results. For example, a trainee of mine had a study that he really wanted to do, but every time he presented his ideas he encountered vigorous objections. Instead of giving up, he decided to study why people objected so strongly to his proposed project and ended up with results that were not only publishable, but are helping him re-design his project in a way that is more likely to succeed.

Instrument A

Title: POLST Quality Improvement Chart Review Form

Designer: Susan Hickman, PhD. Please credit her in any publications and public presentations.

Suitable for Quality Improvement? Yes, as is.

Suitable for research? Yes. Many of the questions have been used in previous research studies.

Description of Instrument: This basic form is designed to get POLST information that is readily available by reviewing medical or nursing facility records. It was specifically designed as a starting place for facilities that wanted to look at how well they are doing using POLST.

How to use:

Step 1: Modify the form to suit your purposes. You may want to modify the form so that it includes a 'patient ID' section if you are working with paper. Other questions may not fit your state as this was designed to match Oregon or California's POLST form. You should decide whether you really need each item – do you need to record the name of the signing physician (item 8d)? Unless you are planning some education or feedback to signing physicians perhaps you do not need to record their names. Only keep items that you have a planned use for or believe may be important to have even though you are not sure what to do with them.

Similarly, you may add items that are missing or that address questions that you are trying to answer. You may find items in other instruments elsewhere in the toolkit and want to include them and that is fine.

Step 2: Select which charts you will review. You may wish to review all the charts in your facility, however, if you have a lot of charts, you may not need to examine all of your charts. See the FAQ section on 'Sampling'. In general, as long as you choose charts in a random fashion (for example, by choosing numbers out of a hat) reviewing enough charts so that you get to review 30 POLST forms may be enough for most QA purposes.

Step 3: Review the charts and record the data. You will need to tabulate your results in a paper or software spreadsheet or statistical software program.

Step 4: Analyze the results. Some of the results that you will get from this survey include:

1. What % of your patients/residents have a POLST form in their chart?
2. How much time has elapsed since the POLST was completed?
3. How often is each order section completed and with what orders?
4. Who (RN, SW, MD) is discussing POLST with whom (patient, surrogate, etc.)?
5. How often was the form not properly signed and dated by an appropriate health professional?
6. How often is there evidence that the POLST form was reviewed or more than one form present?

This information can be very helpful in ensuring that POLST is being used consistently and appropriately in your institution and can identify who may be in need of more education. It doesn't measure the quality of the conversations that ensure that POLST orders properly represent patient preferences—that is very difficult to measure!

**POLST QUALITY IMPROVEMENT:
CHART REVIEW**

1. Presence of POLST Form:

a. Is a POLST Form present?

☐ No ☐ Yes (go to question 2)

b. If NO, why not? ☐ new admission ☐ resident refused

☐ unknown ☐ other _____

IF NO POLST, PROCEED TO NEXT CHART

2. POLST form description:

a. Number: Is there more than one POLST form present?

☐ No ☐ Yes. If yes, why? _____

BASE REST OF RESPONSES ON MOST RECENT FORM IN CHART

b. Format: ☐ original pink form ☐ photocopy ☐ fax ☐ other _____

c. Version: ☐ California ☐ Oregon ☐ other _____

d. Location: ☐ Front of chart ☐ Protective sleeve ☐ MD Orders

☐ special AD section ☐ other _____

e. Length of time to POLST completion:

Date of admission: _____

Date POLST form signed by patient/surrogate: _____

Date POLST form signed by MD: _____

3. Section A--Resuscitation orders:

a. Is a Resuscitation Order marked?

☐ No ☐ Yes. If yes, what is marked?

☐ Resuscitate ☐ Do Not Resuscitate

b. Are there any modifications to this section?

☐ No ☐ Yes. If yes, describe. _____

4. Section B--Medical Interventions:

a. Is a Medical Order marked?

☐ No ☐ Yes. If yes, what is marked?

☐ Comfort Measures Only

☐ Limited Additional Interventions

☐ Full Treatment

b. Are other instructions provided about Medical Interventions?

☐ No ☐ Yes. If yes, describe. _____

c. Are there any modifications to the Medical Interventions orders?

☐ No ☐ Yes. If yes, describe. _____

6. Section C—Antibiotics:

a. Is an Antibiotics order marked?

☐ No ☐ Yes. If yes, what is marked?
☐ No antibiotics
☐ Determine use or limitation when infection occurs
☐ Use antibiotics

b. Are other instructions provided about Antibiotics?

☐ No ☐ Yes. If yes, describe. _____

c. Are there any modifications to the Antibiotics orders?

☐ No ☐ Yes. If yes, describe. _____

7. Section D—Artificially Administered Nutrition:

a. Is an Artificial Nutrition order marked?

☐ No ☐ Yes. If yes, what is marked?
☐ No artificial nutrition by tube.
☐ Defined trial period of artificial nutrition
☐ Long-term artificial nutrition

b. Are other instructions provided about Artificially Administered Nutrition?

☐ No ☐ Yes. If yes, describe. _____

c. Are there any modifications to the Artificially Administered Nutrition orders?

☐ No ☐ Yes. If yes, describe. _____

8. Summary of Medical Condition and Signature:

a. Discussed with:

☐ Patient/resident ☐ health care representative ☐ court-appointed guardian
☐ spouse ☐ parent of minor ☐ other _____ ☐ blank

b. Summary of Medical Condition:

☐ patient wishes ☐ specific medical diagnosis ☐ physician orders
☐ vague medical information ☐ blank ☐ other _____

c. Physician/Nurse Practitioner signature: ☐ blank ☐ signed

d. Name of Physician/Nurse Practitioner: _____

- ☐ Facility medical director
- ☐ Community PCP
- ☐ Hospital MD/NP
- ☐ Unknown
- ☐ Other _____

e. Phone number: ☐ blank ☐ present

f. Patient/Surrogate signature: ☐ blank signed

9. Modifications to POLST form:

- ☐ None ☐ Yes. If yes, how?
- ☐ bar code ☐ organizational logo ☐ words crossed out ☐ patient identifier
- ☐ other _____

10. POLST form review:

- ☐ No ☐ Yes.

If yes, what was the outcome of the most recent review?

- ☐ no change ☐ voided/new form completed ☐ voided/no new form

11. Other issues noted: _____

Instrument B

Title: LaCrosse Advance Directive Study II Instrument

Designer: Bud Hammes, PhD. Please cite the manuscripts listed below in any publications and public presentations.

Suitable for Quality Improvement? Yes, as is.

Suitable for research? Yes, not validated, but has been used successfully in publications:

- Hammes BJ, Rooney BL, Gundrum JD. A comparative, retrospective, observational study of the prevalence, availability, and specificity of advance care plans in a county that implemented an advance care planning microsystem. J Am Geriatr Soc. 2010 Jul;58(7):1249-55.
- Hammes BJ, Rooney BL. Death and end-of-life planning in one midwestern community. Arch Intern Med 1998;158:383–390.

Description of Instrument: This instrument was designed to track advance care planning (including POLST, Advance Directive documents) and related clinical outcomes (hospitalization, location of death, receipt of life-sustaining treatments, etc.). Data is collected from the decedent's POLST form, Advance Directive, death certificate, and electronic medical record. The instrument allowed the investigators to comprehensively describe the prevalence of advance care planning in their region and whether patients who died received care consistent with their preferences.

How to use: This instrument is an excellent way for a health system to evaluate advance care planning practices among their patients. LaCrosse Wisconsin is unusual in that almost all health care is provided by a single integrated health system with an electronic medical record. The investigators gathered subjects by requesting the death certificates of all the people who died in the region during a particular time frame. They then gathered the POLST, Advance Directive, and clinical information about them from the electronic medical records. This approach would be much, much more difficult without an integrated electronic medical record.

First, you should obtain a list of all the patients who died in your institution for a particular time frame. States have different policies and rules about obtaining death certificates, and you will have to contact your local state Vital Records department to inquire about getting this information. Having subjects' name, date of birth, date of death, and social security number can help you to obtain the right death certificates.

If you are doing research see FAQ QX on 'Do I need IRB approval?' Although people who have died are not considered human subjects (and therefore Institutional Review Boards don't oversee research involving decedents), you will probably need a description of your research and a determination from an IRB that what you are doing does not require IRB approval.

The results you get allow you to answer the question of whether advance care planning is 'working' in your institution. You will see what proportion of patients who die have an advance directive or POLST in your records, and for patients who die in your institution, you can see whether the care they received was consistent with those documents.

Please Credit Bud Hammes, PhD et al.

LACROSSE ADVANCE DIRECTIVE STUDY II INSTRUMENT

ID# _ _ _

Eligibility criteria

≥ 18 years of age	Yes	No
Live in La Crosse County	Yes	No
Die at/under the care of a health care facility	Yes	No
Mentally capable 15+ years	Yes	No

Facility	Record reviewed
Long-term care facility patient	
<input type="checkbox"/> Bethany St. Joseph Care Center <input type="checkbox"/> Hillview Care Center <input type="checkbox"/> St Joseph Nursing Home <input type="checkbox"/> Bethany Riverside <input type="checkbox"/> Onalaska Care Center <input type="checkbox"/> Mulder's Nursing Home <input type="checkbox"/> Lakeview Nursing Home	Yes NA
Medical facility	
<input type="checkbox"/> Gundersen Lutheran <input type="checkbox"/> Franciscan Skemp	Yes
Hospice	
<input type="checkbox"/> Gundersen Lutheran <input type="checkbox"/> Franciscan Skemp	Yes NA
Homecare	
<input type="checkbox"/> Gundersen Lutheran <input type="checkbox"/> Franciscan Skemp	Yes NA
Reviewed death certificate	Yes
Request charges	Yes
Data entered	Yes

Description of death:

POLST DATA COLLECTION FORM

1. Location of POLST form

☐ None ☐ Nursing Home ☐ Hospital ☐ Homecare/hospice files

2. Orders on the POLST form at time of death.

TREATMENT CATEGORY	CHECK BOX	Written Orders	Date of Order
Resuscitation		DNR/DNAR	
		Full Code	
Medical interventions		Comfort Measures Only/Hospitalize only if comfort measures fail/Supportive Care Only	
		Limited/Advanced Treatments	
		Full Treatment/Aggressive Treatment	
Antibiotics		No antibiotics	
		No IM/IV antibiotics	
		Antibiotics	
Artificial Nutrition and Hydration		No artificial nutrition or hydration	
		Limited trial for _____ days	
		Artificial nutrition and hydration	

3. Who was involved in the development of the POLST?

☐ Patient ☐ Health Care Agent ☐ Court-appointed Guardian ☐ Other

ADVANCE DIRECTIVE DATA COLLECTION FORM AT LOCATION OF DEATH

1. Location of Death:

- ☐ Hospital ☐ Nursing Home ☐ Home ☐ Inpatient Hospice ☐ Other

2. What, if any, **advance directive** forms are present in the chart? (Check all that apply)

- ☐ Advance directive/living will (circle type used and indicate date of document)
- ☐ Power of attorney for health care (POAHC) ____/____/____ Date
 - ☐ Addendum to POAHC ____/____/____ Date
 - ☐ Statement of Treatment Preference form ____/____/____ Date
 - ☐ Wisconsin Statutory POAHC ____/____/____ Date
 - ☐ Wisconsin Declaration to Physicians or
other Living Will ____/____/____ Date
- ☐ Designated Decision-maker (named by resident) ____/____/____ Date
- ☐ Legal Guardian ____/____/____ Date
- ☐ Other (describe) _____ ____/____/____ Date
- ☐ No form present

3. Was the Power of Attorney activated? ☐ Yes ☐ No ____/____/____ Date
(GL CWS/POA form, NH with POA form)

FROM NON-DEATH FACILITY

4. Was an advance directive located at the nursing home (if a hospital death) or at the hospital (if a nursing home or home death?)

- ☐ Yes ☐ No ☐ DNA Date of this directive ____/____/____

Continued

5. Document all **treatment preferences** in the table below. (See advance directive)

Agent authority to admit me to a nursing home or community-based residential facility for the purpose of long-term care: <input type="checkbox"/> Yes <input type="checkbox"/> No	Agent authority to order the withholding or withdrawal of feeding tube and IV hydration: <input type="checkbox"/> Yes <input type="checkbox"/> No
RESUSCITATION (preferences, not orders) <input type="checkbox"/> Check if from dictated note <input type="checkbox"/> I do want cardiac resuscitation <input type="checkbox"/> I do not want cardiac resuscitation <input type="checkbox"/> I want CPR under certain circumstances as MD recommends <input type="checkbox"/> No preference indicated	LOSS OF ABILITY TO RELATE TO SELF, OTHERS AND ENVIRONMENT <input type="checkbox"/> I do not want CPR <input type="checkbox"/> I do not want antibiotics <input type="checkbox"/> I do not want a feeding tube, artificial hydration and nutrition <input type="checkbox"/> No preference indicated
PAIN AND SYMPTOM CONTROL IF EFFORTS TO PROLONG LIFE ARE STOPPED <input type="checkbox"/> I want to be kept comfortable even if it risks my dying sooner <input type="checkbox"/> No preference indicated	HOSPITALIZATION <input type="checkbox"/> I do want _____ <input type="checkbox"/> I do not want _____ <input type="checkbox"/> No preference indicated
GOAL OF TREATMENT: <input type="checkbox"/> From dictated note <input type="checkbox"/> Prolong Life <input type="checkbox"/> Comfort measures only	
IF I AM CLOSE TO DEATH: <input type="checkbox"/> I want feeding tubes/artificial nutrition and hydration. <input type="checkbox"/> I want tube feedings only as my physician recommends <input type="checkbox"/> I do not want feeding tubes/artificial nutrition and hydration <input type="checkbox"/> No preference indicated <input type="checkbox"/> I want any other life support that may apply <input type="checkbox"/> I want life support only as my physician recommends <input type="checkbox"/> I want NO life support <input type="checkbox"/> No preference indicated	IF I AM PERMANENTLY UNCONSCIOUS/PERISTENT VEGETATIVE STATE: <input type="checkbox"/> I want to receive tube feeding <input type="checkbox"/> I want tube feeding only as my physician recommends <input type="checkbox"/> I do not want tube feeding <input type="checkbox"/> No preference indicated <input type="checkbox"/> I want any other life support that may apply <input type="checkbox"/> I want life support only as my physician recommends. <input type="checkbox"/> I want NO life support <input type="checkbox"/> No preference indicated

Continued

Please Credit Bud Hammes, PhD et al.

KIDNEY DIALYSIS <input type="checkbox"/> I do want kidney dialysis <input type="checkbox"/> I do not want kidney dialysis <input type="checkbox"/> No preference indicated	VENTILATOR SUPPORT <input type="checkbox"/> I do want ventilator support <input type="checkbox"/> I do not want ventilator support <input type="checkbox"/> No preference indicated.
ANTIBIOTICS <input type="checkbox"/> I do want antibiotics <input type="checkbox"/> I do not want antibiotics <input type="checkbox"/> No preference indicated	TRANSFUSION <input type="checkbox"/> I do want transfusion <input type="checkbox"/> I do not want transfusion <input type="checkbox"/> No preference indicated

CHART REVIEW – INTERVENTIONS AT DEATH FOR HOSPITAL DEATHS OR FOR HOSPITALIZATIONS IN THE LAST 30 DAYS OF LIFE --- DATA COLLECTION FORM

1. Use of life-sustaining treatments during the **LAST HOSPITALIZATION (within 30 days of death)**

Done	TREATMENT PROVIDED	Dates/Times of occurrences
<input type="checkbox"/> Yes <input type="checkbox"/> No	Resuscitation (CPR, mouth-to-mouth, electro-cardioversion, etc.):	1) _____ 2) _____
<input type="checkbox"/> Yes <input type="checkbox"/> No	EMS assistance -indicate treatments provided: 1) _____ 2) _____	1) _____ 2) _____
<input type="checkbox"/> Yes <input type="checkbox"/> No	Emergency Department Visit without hospitalization-indicate treatments provided: 1) _____ 2) _____	1) _____ 2) _____
<input type="checkbox"/> Yes <input type="checkbox"/> No	Hospitalization:	Date of admitt _____ Date of disch _____
<input type="checkbox"/> Yes <input type="checkbox"/> No	Critical Care stay:	Date of admitt _____ Date of disch _____
<input type="checkbox"/> Yes <input type="checkbox"/> No	Surgery: type/description	1) _____ 2) _____
<input type="checkbox"/> Yes <input type="checkbox"/> No	Transfusion:	1) _____ 2) _____
<input type="checkbox"/> Yes <input type="checkbox"/> No	Intubation:	1) _____ 2) _____
<input type="checkbox"/> Yes <input type="checkbox"/> No	Ventilator/Respirator: Or <input type="checkbox"/> CPAP/BiPAP	Date placed: _____ Date removed: _____
<input type="checkbox"/> Yes <input type="checkbox"/> No	Dialysis: (If pt on dialysis prior to 30 days of death, record approx start month/year or # years on dialysis. If pt stops dialysis within 30 days of death, record date ended dialysis.)	Date started: _____ OR _____ yrs Date ended: _____

Continued

Please Credit Bud Hammes, PhD et al.

<input type="checkbox"/> Yes <input type="checkbox"/> No	Antibiotics:	Date/time started: _____ Date/time ended: _____
<input type="checkbox"/> Yes <input type="checkbox"/> No	Non-oral nutritional support (eg. Feeding Tubes or tpn):	Date placed: _____ Date removed: _____

2. Code status order at:

	Date	Time
Admission:		
At death:		

HOSPITAL

- ☐ Full Code
- ☐ PDNR (DNR with comfort measures only)
- ☐ ODNR/DNI – (DNR + limited TX on POLST)
- ☐ ODNR – (DNR + full treatment on POLST)

3. Who made decisions about the patient's treatment during this hospitalization?

- ☐ Patient ☐ Health Care Agent ☐ family (other than health care agent)
- ☐ Court-appointed Guardian ☐ Other: _____
- ☐ Don't know who made decisions

4. DATE OF DEATH: _____ TIME OF DEATH: _____

CHART REVIEW – INTERVENTIONS AT DEATH FOR NON-HOSPITAL DEATHS --- DATA COLLECTION FORM

1. Use of life-sustaining treatments during the last 30 days of life:

Done	TREATMENT PROVIDED	Dates/Times of occurrences
<input type="checkbox"/> Yes <input type="checkbox"/> No	Resuscitation (CPR, mouth-to-mouth, electro-cardioversion, etc.):	1) _____ 2) _____
<input type="checkbox"/> Yes <input type="checkbox"/> No	Dialysis: (If pt on dialysis prior to 30 days of death, record approx start month/year or # years on dialysis. If pt stops dialysis within 30 days of death, record date ended dialysis.)	Date started: _____ OR _____ yrs Date ended: _____
<input type="checkbox"/> Yes <input type="checkbox"/> No	Antibiotics:	Date/time started: _____ Date/time ended: _____
<input type="checkbox"/> Yes <input type="checkbox"/> No	Non-oral nutritional support (eg. Feeding Tubes or tpn):	Date placed: _____ Date removed: _____
<input type="checkbox"/> Yes <input type="checkbox"/> No	Patient transported to the hospital in the last 30 days of life: <input type="checkbox"/> Admitted to hospital <input type="checkbox"/> Admitted to inpatient hospital (make sure this/these hospitalization(s) are reviewed)	Date transported/returned _____ Date transported/returned _____

2. Code status at death/Changes in Code status in the last 30 days:

	Date	Time
<input type="checkbox"/> Full Code <input type="checkbox"/> DNR		
<input type="checkbox"/> Full Code <input type="checkbox"/> DNR		
<u>At death:</u> <input type="checkbox"/> Full Code <input type="checkbox"/> DNR		

Continued

Please Credit Bud Hammes, PhD et al.

3. Who made decisions about the patient's treatment during the last 30 days?

- ☐ Patient ☐ Health Care Agent ☐ family (other than health care agent)
- ☐ Court-appointed Guardian ☐ Other: _____
- ☐ Don't know who made decisions

4. DATE OF DEATH: _____ TIME OF DEATH: _____

Please Credit Bud Hammes, PhD et al.

DEATH CERTIFICATE DATA COLLECTION FORM

1. Zip Code of residence: _____

2. Date of Death: _____ Date of Birth: _____

3. Gender: ☐ Male ☐ Female 4. Race: ☐ white ☐ Black (African American)
☐ Hispanic ☐ Asian (Hmong)
☐ Other: _____

4. Marital status: ☐ married ☐ widow ☐ single ☐ divorced

5. Location of Death:

- ☐ Hospital
 - ☐ Gundersen Lutheran
 - ☐ Franciscan Skemp
- ☐ Nursing facility
 - ☐ Bethany St. Joseph Care Center
 - ☐ Hillview Care Center
 - ☐ St Joseph Nursing Home
 - ☐ Bethany Riverside
 - ☐ Onalaska Care Center
 - ☐ Mulder's Nursing Home
 - ☐ Lakeview Nursing Home
- ☐ Home
- ☐ Other _____

6. Highest grade completed: _____
(record total # years)

7. Immediate cause of death: _____

8. Other significant conditions: _____

Please Credit Bud Hammes, PhD et al.

MEDICAL EXPENSES LAST 1 & 6 MONTHS OF LIFE
DATA COLLECTION FORM

ONE MONTH PRIOR TO DEATH → DATE: _____ TO _____

SIX MONTHS PRIOR TO DEATH → DATE: _____ TO _____

	Medicare Part A Hospital services	Medicare Part B Clinic services	TOTAL
Last 1 month			
Last 6 months			

Instrument C

Title: NY MOLST Quality Chart Review

Designer: Pat Bomba, MD. Please credit her in any publications and public presentations.

Suitable for Quality Improvement? Yes, with modification to fit your state.

Suitable for research? Yes, while not validated this has been used extensively in NY state.

Description of Instrument: This 1-page form supports quick completion of chart reviews using check boxes. It allows any institution (hospital, nursing home, hospice, etc.) to make a quick assessment of how MOLST is being used. Instrument D, the NY MOLST Quality Chart Review is a complementary instrument designed for state or regional programs to assess their state's use of MOLST across multiple facilities or institutions.

How to use:

Step 1: Modify the form to suit your purposes. You may want to modify the form so that it includes a 'patient ID' section if you are working with paper. Other questions may not fit your state as this was designed to match New York's MOLST form. However, this form can be modified to work with any POLST paradigm form. While this form is very concise, you should still make sure whether you really need each item. Only keep items that you have a planned use for or believe may be important to have even though you are not sure what to do with them.

Similarly, you may add items that are missing or that address questions that you are trying to answer. You may find items in other instruments elsewhere in the toolkit and want to include them and that is fine.

Step 2: Select which charts you will review. You may wish to review all the charts in your facility, however, if you have a lot of charts, you may not need to examine all of your them. See the FAQ section on 'Sampling'. In general, as long as you choose charts in a random fashion (for example, by choosing numbers out of a hat) reviewing enough charts so that you get to review 30 MOLST forms may be enough for most QA purposes.

Step 3: Review the charts and record the data. You will need to tabulate your results in a paper or software spreadsheet or statistical software program.

Step 4: Analyze the results. Some of the results that you will get from this survey include:

1. What % of your patients/residents have a MOLST form in their chart?
2. In what form (fax, photocopy, original) is MOLST present?
3. Does the person have any advance directives?
4. How often is each order section completed and with what orders?
5. How often was the form properly signed and dated by an appropriate health professional and the patient/surrogate?
6. How often is there evidence that the MOLST form was appropriately reviewed?

This information can be very helpful in ensuring that MOLST is being used consistently and in compliance with state laws. It may help you identify who may be in need of more education.



Review Date: _____

MOLST QUALITY CHART REVIEW

MOLST QUALITY AUDIT TOOL: ACCURACY OF FORM COMPLETION

We are collecting data to evaluate the accurate completion of the MOLST form throughout the community. To achieve a consistent evaluation process, we are requesting that this tool be used to audit completion of the MOLST forms. Thank you for your support.
Please return copies of completed audit forms to: Patricia Bomba M.D., 165 Court Street, Rochester, NY 14647.

PLEASE ANSWER ALL QUESTIONS TO THE BEST OF YOUR ABILITY

General	MOLST Form Present:	<input type="checkbox"/> No If present: <input type="checkbox"/> Original Pink Form <input type="checkbox"/> Photocopy <input type="checkbox"/> Fax <input type="checkbox"/> Other _____
	Facility type: (Check all that apply)	<input type="checkbox"/> Hospital <input type="checkbox"/> Nursing Home <input type="checkbox"/> Hospice <input type="checkbox"/> PACE <input type="checkbox"/> Assisted Living <input type="checkbox"/> Enriched Housing <input type="checkbox"/> Adult Home <input type="checkbox"/> Physician Office
	Location of form:	<input type="checkbox"/> Front of Chart <input type="checkbox"/> Protective Sleeve <input type="checkbox"/> MD Orders <input type="checkbox"/> Special Section <input type="checkbox"/> Other _____
	Has the form been modified in any way?	<input type="checkbox"/> No <input type="checkbox"/> If Yes: <input type="checkbox"/> Bar Code <input type="checkbox"/> Words Crossed Out <input type="checkbox"/> Patient Identifier <input type="checkbox"/> Logo <input type="checkbox"/> Other _____

MOLST SECTION RESUSCITATION INSTRUCTIONS AND ADVANCE DIRECTIVES

A	Resuscitation orders:	<input type="checkbox"/> DNR <input type="checkbox"/> Full CPR <input type="checkbox"/> No orders
B	DNR (CPR) consent of patient: (Check all that apply)	<input type="checkbox"/> Patient/Resident Signature <input type="checkbox"/> Verbal Consent <input type="checkbox"/> Date <input type="checkbox"/> Witness Signature OR
		<input type="checkbox"/> HCA/Surrogate Signature (pt <u>lacks</u> capacity) <input type="checkbox"/> Verbal Consent <input type="checkbox"/> Date <input type="checkbox"/> Witness Signature <input type="checkbox"/> Supplemental Documentation Form is attached (patient <u>lacks</u> capacity)
C	Physician signature for section A & B: (Check all that apply)	<input type="checkbox"/> Physician Signature <input type="checkbox"/> Date <input type="checkbox"/> Physician License# <input type="checkbox"/> Physician Phone/Pager#
D	Does the person have any Advance Directives?	<input type="checkbox"/> None <input type="checkbox"/> Health Care Proxy <input type="checkbox"/> Living Will <input type="checkbox"/> Other written or oral advance directive If yes, is a copy in the chart? <input type="checkbox"/> Yes <input type="checkbox"/> No

ORDERS FOR OTHER LIFE-SUSTAINING TREATMENT AND FUTURE HOSPITALIZATIONS

E	Additional Treatment Guidelines:	<input type="checkbox"/> None Checked Interventions <input type="checkbox"/> Limited Medical <input type="checkbox"/> MD Signature & Dated <input type="checkbox"/> Comfort Measures Only <input type="checkbox"/> No Limitations
	Other orders or Instructions: (Review each of the subsections and check if completed)	<input type="checkbox"/> None Checked <input type="checkbox"/> Antibiotics <input type="checkbox"/> Additional Intubation and Ventilation Instructions <input type="checkbox"/> MD Signature & Dated <input type="checkbox"/> Future Hospitalization/Transfer <input type="checkbox"/> Other instructions <input type="checkbox"/> Artificially Administered Fluids and Nutrition <input type="checkbox"/> Consent Signature & Dated

RENEW/ REVIEW INSTRUCTIONS

F	Review of MOLST form	Is the patient identifier on the MOLST Renew/Review section? <input type="checkbox"/> Yes <input type="checkbox"/> No
		Has the MOLST form ever been reviewed? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
		If yes, how many times?
		Appropriate physician signatures? <input type="checkbox"/> Yes <input type="checkbox"/> No

ADDITIONAL COMMENTS

Instrument D

Title: NY MOLST Facility Questionnaire

Designer: Pat Bomba, MD. Please cite with any future work:

Bomba PA, Caprio TC, Gillespie SM, Richardson K. Community Implementation of the Medical Orders for Life-Sustaining Treatment (MOST) to improve Advance Care Directives. J Am Geriatric Soc 55(4) Supplemt:S44, April 2007.

Suitable for Quality Improvement? Yes, with modification to fit your state.

Suitable for research? Yes.

Description of Instrument: This 1-page form was designed to allow a state or regional program to survey a broad range of end-users. It allows a POLST paradigm program to assess the penetrance of the program in multiple settings (hospice, LTC, hospital, etc.) across the state. Instrument C, the NY MOLST Quality Chart Review is a complementary instrument designed for facilities to assess how well they are doing individually with MOLST.

How to use:

Step 1: This survey could be completed by paper (mailed survey), converted to web-based (e.g. Survey Monkey) or by telephone completion. It would be best completed by an administrator at the facility or his or her designee. You should modify the form to suit your purposes. Some questions may not fit your state but it can be modified to work with any POLST paradigm program. While this form is very concise, you should still make sure whether you really need each item. Only keep items that you have a planned use for or believe may be important to have even though you are not sure what to do with them. Similarly, you may add items that are missing or that address questions that you are trying to answer.

Step 2: Select who you will survey. This form was designed to survey broadly in a region and examine MOLST use in hospice, long-term care, hospital, and other end-user facilities. You may wish to survey all of your end-users, hospitals (for example) only, or, if you have a lot of end-users, you may not need to survey all of them. See the FAQ section on 'Sampling'. In general, as long as you choose facilities in a random fashion (for example, by choosing numbers out of a hat) surveying enough facilities so that you get 15-30 responses total may be enough for most QA purposes.

Step 3: Call the facilities and record the data. For some facilities, you may not find someone who is willing or able to answer your questions—that is expected; just do the best you can. You will need to tabulate your results in a paper or software spreadsheet or statistical software program.

Step 4: Analyze the results. Some of the results that you will get from this survey include:

1. What % of facilities in your region are using MOLST and for how long?
2. For those who aren't using MOLST, are they planning to use it and what are the barriers?
3. What educational interventions and training materials has the facility employed, and for whom?
4. Who is the MOLST 'champion' at your facility?
5. What additional forms do they use to ensure patient preferences are followed?
6. Who does advance care planning in that facility?



Date: _____

MOLST FACILITY QUESTIONNAIRE

Thank you in advance for completing this brief survey on Medical Orders for Life-Sustaining Treatment (MOLST). We are gathering information from facilities to evaluate the spread of the MOLST program throughout the community. This will enable us to collect and report quality data during the MOLST Pilot sponsored by the New York State Department of Health. This is an essential step in advancing the MOLST form and program statewide.

GENERAL MOLST INFORMATION

Facility Name:	
Facility Address/City/Zip:	
Facility Type:	<input type="checkbox"/> Hospice <input type="checkbox"/> LTC <input type="checkbox"/> Hospital <input type="checkbox"/> Homecare <input type="checkbox"/> Other _____
Have you implemented MOLST in your facility?	<input type="checkbox"/> Have not implemented <input type="checkbox"/> < 6 months <input type="checkbox"/> 6 mo.- 1 year <input type="checkbox"/> 1-2 years <input type="checkbox"/> >2 years
If you have <i>not</i> implemented - When are you planning to implement MOLST in your facility?	<input type="checkbox"/> < 3 months <input type="checkbox"/> < 6 months <input type="checkbox"/> 6 mo.- 1 year <input type="checkbox"/> 1-2 years <input type="checkbox"/> Not planning What are the barriers? _____
Has your facility included use of the MOLST form within your current advance directives/DNR policy? <input type="checkbox"/> Yes <input type="checkbox"/> No	What forms do you use to ensure patient wishes are followed regarding life sustaining treatments? (Please check all that apply) <input type="checkbox"/> NYS Health Care Proxy <input type="checkbox"/> DNR <input type="checkbox"/> MOLST <input type="checkbox"/> Living Will <input type="checkbox"/> Facility Form
Who typically does advance care planning with patients/residents? (Please check all that apply)	<input type="checkbox"/> Physician <input type="checkbox"/> NP/ PA <input type="checkbox"/> Social Service <input type="checkbox"/> Nursing <input type="checkbox"/> Care Managers

MOLST IMPLEMENTATION AND TRAINING

How widely is MOLST implemented in your facility?	<input type="checkbox"/> Entire Facility <input type="checkbox"/> Specific Department <input type="checkbox"/> Specific Unit/Floor <input type="checkbox"/> None _____ If specific departments/units, which ones? _____
What percent of the facility <i>has</i> MOLST already been implemented?	<input type="checkbox"/> 0-25% <input type="checkbox"/> 26-50% <input type="checkbox"/> 51-75% <input type="checkbox"/> 76-99% <input type="checkbox"/> 100%
What is the total percent of the facility that MOLST <i>is planned to be implemented</i>?	<input type="checkbox"/> 0-25% <input type="checkbox"/> 26-50% <input type="checkbox"/> 51-75% <input type="checkbox"/> 76-99% <input type="checkbox"/> 100%
How have you implemented MOLST in your facility? (Please check all that apply)	<input type="checkbox"/> Training seminar <input type="checkbox"/> Facility communications <input type="checkbox"/> Provide professional educational material <input type="checkbox"/> Mandatory curriculum <input type="checkbox"/> Web/Online training <input type="checkbox"/> Provide patient/resident educational material
What training materials are you using? (Please check all that apply)	<input type="checkbox"/> MOLST conference training materials <input type="checkbox"/> Web download materials <input type="checkbox"/> Facility materials <input type="checkbox"/> Other _____
Who is being trained? (Please check all that apply)	<input type="checkbox"/> All Staff <input type="checkbox"/> Physician <input type="checkbox"/> NP/ PA <input type="checkbox"/> Nurses <input type="checkbox"/> Social Workers <input type="checkbox"/> Care Managers <input type="checkbox"/> Secretaries <input type="checkbox"/> Clergy <input type="checkbox"/> Admissions <input type="checkbox"/> Other _____
Who is the MOLST "champion" or point person for your facility?	Name: _____ Email Address: _____

Additional information on the MOLST program can be found at www.compassionandsupport.org. Send all completed Questionnaire's to:

Patricia Bomba, MD Chair - MOLST Community Implementation Team Patricia.Bomba@lifethc.com
165 Court Street 3rd Floor Rochester, New York 14647

Instrument E

Title: NC MOST Health Care Provider Survey

Designer: Anthony Caprio, MD and Ellen Roberts, MPH, PhD. Please cite this reference in any work you do:

Caprio AJ, Rollins VP, Roberts E. Health care professionals' perceptions and use of the medical orders for scope of treatment (MOST) form in North Carolina nursing homes. J Am Med Dir Assoc. 2012 Feb;13(2):162-8.

Suitable for Quality Improvement? Yes, with modification to fit your state.

Suitable for research? Yes, although there may be an updated version available with future publications.

Description of Instrument: This written survey was designed to be completed by mail. Its purpose is to describe health care professionals' experiences and attitudes towards North Carolina's new MOST form. The survey is being undertaken at an early stage of MOST implementation to identify health professional's degree of buy-in and their concerns about the program. The results of the statewide survey are not yet published, but the survey was based on face-to-face interviews with health professionals using Toolkit Instrument F, the NC MOST Provider Interview described in the Caprio et al 2012. The survey should prove very useful in designing and guiding statewide educational efforts.

How to use:

Step 1: Modify the form to suit your purposes. Some questions may not fit your state as this was designed to match North Carolina's MOST form. Only keep items that you have a planned use for or believe may be important to have even though you are not sure what to do with them. Similarly, you may add items that are missing or that address questions that you are trying to answer. If you make a lot of changes to the survey, we recommend that you pilot test it with a small (10-15) group to ensure that it gets you the results you need.

Step 2: Select who you will send the survey to. The survey is designed for clinicians who use the MOST form. If you are a POLST paradigm program you may wish to survey your entire state or region. If you are a hospital or a nursing facility you may wish to only survey your clinicians. If you have a lot of clinicians, you may not need to survey them all. See the FAQ section on 'Sampling'. In general, as long as you choose clinicians in a random fashion (for example, by choosing numbers out of a hat) and get a decent response rate to your survey (30-50%+ for QA and 50-75%+ for research) and survey enough clinicians so that you get to 30 usable responses (more for research), that may be enough for most QA purposes.

Step 3: There is a well described methodology for mailed surveys that is beyond the scope of this toolkit, but you should include a copy of your POLST paradigm form and a self-addressed, stamped envelope and plan on doing more than one mailing. It also helps to have as much institutional support as you can muster to encourage busy people to complete your survey.

Step 4: Analyze the results. Some of the results that you will get from this survey include:

1. Respondents' familiarity and experience with MOST.
2. Respondents' beliefs about how and when to use MOST.
3. Respondents' beliefs about how using MOST might impact communication.
4. Concerns about and barriers to MOST.

Survey Code _____

**Documenting Patient Goals and Preferences:
Understanding the Experiences of Physicians and Nursing Home Staff**

NC MOST Health Care Provider Survey

University of North Carolina-Chapel Hill

IRB Study #

Principal Investigator: Anthony J. Caprio, MD

Co-Investigators: Tori Rollins, BS; Laura Hanson, MD, MPH; Ellen Roberts, MPH, PhD

Study Contact telephone number: 919-966-5945 ext. 281

Study Contact email: acaprio@med.unc.edu

The purpose of this research study is to learn about your experience using standardized forms to document and communicate patient goals and preferences for medical care if a patient becomes seriously ill or is dying. We are also interested in learning different ways in which physicians, nurses, and other health care professionals can communicate more effectively with families about making medical decisions for a loved one in a long-term care facility (nursing home). You are being asked to be in the study because you regularly care for older adults in a long-term care facility (nursing home).

Please review the enclosed study information fact sheet. If you agree to participate in this research study, please complete the following survey by checking the appropriate box or boxes. You should complete this survey before your interview.

1.) Please describe your role as a health care professional:

- ☐ Physician
 - ☐ Nurse Practitioner
 - ☐ Nurse
 - ☐ Social Worker
 - ☐ Nursing Home Administrator
 - ☐ Other _____
-

2.) How do you describe your racial or ethnic identity? (Check all that apply)

- ☐ Hispanic or Latino
- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ Black or African American
- ☐ White or Caucasian

3.) Are you familiar with the Medical Orders for Scope of Treatment (MOST) form?

- ☐ NO
- ☐ YES

Please read the following brief description of the MOST form and see the enclosed sample form:

Medical Orders for Scope of Treatment (MOST) form is an optional, bright pink, portable medical order used in North Carolina to document patient preferences for end-of-life care. Section A of the MOST form elicits instructions for cardiopulmonary resuscitation. Section B of the MOST outlines the scope of medical treatment for a patient who is not experiencing cardiopulmonary arrest. This section of the MOST form outlines 3 types of care: *Full Scope of Treatment*, *Limited Interventions*, and *Comfort Measures*. The MOST form also allows patients to specify their wishes for other medical treatments if they are seriously ill or dying, including orders to provide or withhold antibiotics, and medically-administered fluids or nutrition.

4.) Have you used the MOST form in clinical practice? [Check all that apply]

- ☐ **NO**, I have never used the MOST form in my clinical practice
- ☐ **YES**, I have completed a MOST form with a patient/family
- ☐ **YES**, I cared for a patient who had a completed MOST form, but I did not personally complete the form

5.) When would you consider using the MOST form? [Check all that apply]

- ☐ At the time of nursing home admission
- ☐ During routine care planning meetings
- ☐ After change in health status
- ☐ After a hospitalization
- ☐ With Hospice enrollment
- ☐ When asked by the patient or family
- ☐ When asked by other staff
- ☐ Other _____

6.) When do you believe is the *most important* time to complete the MOST form?

[Select one]

- ☐ At the time of nursing home admission
- ☐ During routine care planning meetings
- ☐ After change in health status
- ☐ After a hospitalization
- ☐ With Hospice enrollment
- ☐ When asked by the patient or family
- ☐ When asked by other staff
- ☐ Other _____

7.) When do you believe it is *appropriate* to complete a MOST form? [Check all that apply]

- ☐ Only after a physician has a specific discussion about goals of care and medical treatments with the patient/family
- ☐ After a nurse practitioner has a discussion about goals of care and medical treatments with the patient/family
- ☐ After a social worker has a discussion about goals of care and medical treatments with the patient/family
- ☐ Based on a patient's living will or other prior written directives, but in the absence of a discussion with the patient or family
- ☐ Based on medical judgment about prognosis and appropriate treatment, but in the absence of a discussion with the patient or family
- ☐ Other _____

Survey Code_____

8.) How often do you have to review and renew (sign) a MOST form? [Check all that apply]

- ☐ Annually
- ☐ Whenever the patient is admitted or discharged from a health care facility
- ☐ Whenever there is a substantial change in clinical status
- ☐ Whenever treatment preference change
- ☐ Other_____

9.) What is the best way to use the MOST form during discussions with patients or their families?

[Check one]

- ☐ I would ask the patient or family to review the form before our discussion
- ☐ I would use the form during our meeting to discuss goals and treatments
- ☐ I would use the form after our discussion to document treatment decisions
- ☐ I would give the form to someone else to review with the family
- ☐ Other_____

10.) What are some of the barriers that might prevent you from using the MOST form?

[Check all that apply]

- ☐ Time-consuming
- ☐ Redundant (duplicate paperwork)
- ☐ Too vague
- ☐ Difficult to match resident goals with a particular scope of treatment
- ☐ Concerned about liability or responsibility
- ☐ Other_____

11.) Please use the following scale to rate how the MOST form might change communication about a patient's goals and treatment preferences:

Improve a lot ----- Improve Somewhat ----- Worsen Somewhat ----- Worsen a lot ----- No Effect

Communication	Improve a lot	Improve somewhat	Worsen somewhat	Worsen a lot	No effect
Between physicians and/or nurse practitioners					
Between physicians and nursing staff					
With an on-call or covering physician					
Between hospital and nursing home					
Between physicians and patients/families					

Survey Code_____

12.) What is your greatest concern about the use of the Medical Orders for Scope of Treatment (MOST) form in clinical practice? [Select one]

- ☐ Takes too long to complete
- ☐ Undermines patient autonomy
- ☐ Forms will get lost
- ☐ Forms will not be filled-out properly
- ☐ Patients/families will not understand the forms
- ☐ Physicians will not follow the instructions on the forms
- ☐ No concerns
- ☐ Other_____

Instrument F

Title: NC MOST Provider Interview

Designer: Anthony Caprio, MD and Ellen Roberts, MPH, PhD. Please cite this reference in any work you do:

Caprio AJ, Rollins VP, Roberts E. Health care professionals' perceptions and use of the medical orders for scope of treatment (MOST) form in North Carolina nursing homes. J Am Med Dir Assoc. 2012 Feb;13(2):162-8.

Suitable for Quality Improvement? Possibly, but this is a supplement to Instrument E that is very specific to the investigators' research questions.

Suitable for research? Yes.

Description of Instrument: This face to face interview guide was designed to supplement a written survey (Toolkit Instrument E NC MOST Health Care Provider Survey). Its purpose is to qualitatively elicit health care professionals' approach to discussing section B, Scope of Treatment and to elicit any other experiences or comments about MOST. The investigators' results are described Caprio et al 2012. The responses should prove very useful in designing educational efforts.

How to use:

Step 1: Modify the interview to suit your purposes. Since this was designed as a supplement to Instrument E, it has only 2 questions with the investigators' research questions in mind. Unless you have the same question, you may want to use their question as a good example of how to construct a qualitative question(s) of your own. We recommend that you pilot test your new questions with a small (3-4) group of your target audience to ensure that it gets you the results you need.

Step 2: Select who you will interview. The interview is designed for clinicians who have used the MOST form. Because face-to-face interviews are very time consuming to arrange, conduct, and analyze, the numbers will be necessarily be smaller. For example, the published study included 11 interviews total. Because of this, it's important to try to interview people who can really speak well on behalf of your target audience. Some people are good interview subjects, others are not, and if you've got the choice it's better to interview people who do well in interviews. If your goal is quality and dissemination, you could select people in positions to influence others.

Step 3: There is a well described methodology for qualitative research that is beyond the scope of this toolkit, but you should consider recording your interviews. It is better to start with more open ended questions like 'tell me about the last time you completed a MOST form with a patient'. More specific questions you are interested in can be included as 'probes' like the investigators have done here.

Step 4: Analyze the results. Qualitative questions like the question in this survey are good for learning how different people think about a complex topic like 'how do you describe the different scope of treatment options in section B?'. The purpose is not to be able to generalize (this is how people do it in our state) but to describe (these are some of the different ways people might do it in our state). If done properly, you'll learn about things you had not even thought of and learn to better understand how your target audience thinks about the topics you discuss. This could particularly helpful in designing meaningful educational interventions.

Section B of the MOST form tries to address the overall scope of medical care. Specifically, it mentions a “Full Scope of Treatment,” “Limited Additional Interventions,” and “Comfort Measures.” How might you introduce and discuss this section of the MOST form with patients or families?

Probes:

- A. How would you explain “Full Scope of Treatment, Comfort Measures, and Limited Additional Interventions (as outlined in Section B of the MOST form)?”
- B. How do you explain the difference between these 3 “scopes” of treatment?
- C. Is any one level particularly difficult to explain? Why?
- D. How do you relate these “scopes” of treatment to care for a nursing home patient?
- E. How does this section relate to a patient’s goals of care?

Clarification:

- The MOST form needs to be completed with the assistance of a health professional. That person should explain the various sections of the MOST to the patient or their family
- How should that health professional (doctor, nurse practitioner, physician assistant or other qualified/trained professional engaged in advance care planning in nursing homes) explain Section B of the MOST to a patient or to the patient’s family?
- Relate the response to how you would explain Section B in the nursing home setting

[SUMMARIZE FREE RESPONSE]

Do you have any final comments about the MOST form?

Probes:

- A. On survey question 12 I see that you marked –X- as your greatest concern about the use of the MOST form. Can you tell me why that is your greatest concern?
- B. On survey question 10 I see that you marked –X- as a barrier that might prevent you from using the MOST form. Can you tell me more about that?

[RECORD FREE RESPONSE]

Instrument G

Title: Michigan POLST Chart Review Form

Designer: Jane Dinnen, RN. Please credit her in any publications and public presentations.

Suitable for Quality Improvement? Yes, with modifications to fit your state.

Suitable for research? Not yet.

Description of Instrument: This basic form is designed to get POLST information that is readily available by reviewing medical or nursing facility records. It is similar to Toolkit Instrument A but has been simplified to fit on two pages. It is a starting place for facilities that want to look at how well they are doing using POLST.

How to use:

Step 1: This form is a good illustration of how a more extensive form (Instrument A) can be modified to be simpler to meet the user's specific needs. So you should also feel free to modify this form to suit your purposes. You should decide whether you really need each item and feel free to add items that are missing or that address questions that you are trying to answer. You may find items in other instruments elsewhere in the toolkit and want to include them and that is fine.

Step 2: Select which charts you will review. You may wish to review all the charts in your facility, however, if you have a lot of charts, you may not need to examine all of your charts. See the FAQ section on 'Sampling'. In general, as long as you choose charts in a random fashion (for example, by choosing numbers out of a hat) reviewing enough charts so that you get to review 30 POLST forms may be enough for most QA purposes.

Step 3: Review the charts and record the data. You will need to tabulate your results in a paper or software spreadsheet or statistical software program.

Step 4: Analyze the results. Some of the results that you will get from this survey include:

1. What % of your patients/residents have a POLST form in their chart?
2. How often is each order section completed and with what orders?
3. What other orders are being added?
4. Who (RN, SW, MD) is discussing POLST with whom (patient, surrogate, etc.)?
5. How often was the form not properly signed and dated by an appropriate health professional and patient/surrogate?
6. Does the person have an advance directive or a guardian?
7. How often is there evidence that the POLST form was reviewed?

This information can be very helpful in ensuring that POLST is being used consistently and appropriately in your institution and can identify who may be in need of more education. It doesn't measure the quality of the conversations that ensure that POLST orders properly represent patient preferences—that is very difficult to measure!

MICHIGAN POLST CHART REVIEW DATA COLLECTION FORM

1. Is a POLST form present? ☐ Yes ☐ No

If yes, describe: ☐ original pink form ☐ photocopy ☐ fax ☐ other

2. Where is the form located? ☐ Front of chart ☐ Protective sleeve ☐ MD Orders
☐ special AD section ☐ other _____

3. Which version of the form is being used? ☐ Original ☐ _____

4. Resident month and year of birth: _____month _____ year

5. Resuscitation orders: ☐ Resuscitate ☐ Do Not Resuscitate ☐ blank

6. Medical Interventions: ☐ Comfort Measures Only ☐ Limited Interventions
☐ Full Treatment ☐ blank

7. Are additional orders provided about medical interventions? ☐ Yes ☐ No

If so, what: _____

8. Antibiotics: ☐ No antibiotics ☐ Determine use of limitation of antibiotics when infection occurs
☐ Use antibiotics if life can be prolonged ☐ blank

9. Are additional orders provided about antibiotics? ☐ Yes ☐ No

If so, what: _____

10. Artificially administered fluids and nutrition:

☐ No artificial nutrition by tube ☐ Defined trial period
☐ Long term artificial nutrition by tube ☐ blank

11. Are additional orders provided about artificially administered fluids and nutrition? ☐ Yes ☐ No

If so, what: _____

12. Discussed with: ☐ Patient ☐ health care representative
☐ court-appointed guardian ☐ parent of minor ☐ other _____ ☐ blank
13. Is anything written in the sections requesting the basis for orders/medical condition information?
☐ yes (If yes, check below all that apply to the orders) ☐ no
☐ patient wishes ☐ specific medical diagnosis ☐ physician orders
☐ vague medical information ☐ other _____
14. Signature line contains:
☐ physician signature _____ (date signed) ☐ nurse practitioner signature _____ (date signed) ☐ no signature
☐ other health care provider signature ☐ patient/surrogate signature
15. Is there a phone number for the physician/nurse practitioner? ☐ yes ☐ no
16. Has the form been modified in any way? ☐ yes ☐ no
If so, how? ☐ bar code ☐ organizational logo ☐ words crossed out ☐ patient identifier
☐ other _____
17. Does the POLST form contain a patient/resident/surrogate signature? ☐ yes ☐ no
18. Has the POLST form ever been reviewed? ☐ yes _____ times ☐ no
If yes, what was the outcome of the most recent review?
☐ no change ☐ voided/new form completed ☐ voided/no new form
19. Who prepared the POLST form? ☐ staff member ☐ MD/NP ☐ family member
☐ patient/resident ☐ unknown person _____ ☐ blank
20. Did the person have an advance directive? ☐ yes ☐ no ☐ blank
21. Did the person have a court-appointed guardian? ☐ yes ☐ no ☐ blank
22. Other issues noted: _____

Instrument H

Title: California POLST Quality Chart Review

Designer: ?

Suitable for Quality Improvement? Yes, with modifications to fit your state.

Suitable for research? Not yet.

Description of Instrument: This basic form is designed for high-volume chart audits in nursing facilities, hospices, or hospitals. 10 chart reviews can be documented per page. The purpose of the form is to assure appropriate quality in completing POLST forms.

How to use:

Step 1: Modify the form to meet your needs. See the list of results below in Step 4. You may want to track additional information (for example, should you track the % of charts that have a POLST form or the date the POLST form was completed?). Even though the form is ultra-concise, you should make sure you really need each item and feel free to add items that are missing or that address questions that you are trying to answer. You may find items in other instruments elsewhere in the toolkit and want to include them and that is fine.

Step 2: Select which charts you will review. You may wish to review all the charts in your facility, however, if you have a lot of charts, you may not need to examine all of your charts. See the FAQ section on 'Sampling'. In general, as long as you choose charts in a random fashion (for example, by choosing numbers out of a hat) reviewing enough charts so that you get to review 30 POLST forms may be enough for most QA purposes.

Step 3: Review the charts and record the data. You will need to tabulate your results in a paper or software spreadsheet or statistical software program.

Step 4: Analyze the results. The specific results that you will get from this survey include:

1. What % of your patients/residents have the correct name and date of birth on their POLST form?
2. What % of the time is the date of POLST completion noted?
3. Who are the POLST forms being discussed with?
4. Does the physician sign and date the form?
5. Does the patient/surrogate sign the form?
6. Do the orders in sections A and B correlate (see opposite side of instrument H)?
7. What orders are marked in sections A, B, and C?
8. Is the health care providers contact information present?

This form is designed to review a lot of charts quickly. The quality metrics listed above provide measures of whether POLST completion is being appropriately documented, and how POLST forms are being completed. Because it is so simple, this process could be repeated periodically with samples of charts to track quality over time.

Facility Name: _____

Quality Assurance/Improvement Audit

Chart	Name/ DOB Correct Yes/No	Date Form Prepared is Noted Yes/No	POLST Discussed with:	Physician Signed Yes/No	Physician Dated Yes/No	POLST Signed by:	Section A Correlates with Section B Yes/No	Section A, B, & C Choices	Health Care Provider's Contact Info Present Yes/No
#1			<input type="checkbox"/> Patient <input type="checkbox"/> Decisionmaker <input type="checkbox"/> Parent <input type="checkbox"/> Conservator <input type="checkbox"/> Other: _____			<input type="checkbox"/> Patient <input type="checkbox"/> Decisionmaker <input type="checkbox"/> Parent <input type="checkbox"/> Conservator		<input type="checkbox"/> CPR <input type="checkbox"/> DNR <input type="checkbox"/> Comfort <input type="checkbox"/> Limited <input type="checkbox"/> Full <input type="checkbox"/> No tube <input type="checkbox"/> Trial <input type="checkbox"/> Long-term	
#2			<input type="checkbox"/> Patient <input type="checkbox"/> Decisionmaker <input type="checkbox"/> Parent <input type="checkbox"/> Conservator <input type="checkbox"/> Other: _____			<input type="checkbox"/> Patient <input type="checkbox"/> Decisionmaker <input type="checkbox"/> Parent <input type="checkbox"/> Conservator		<input type="checkbox"/> CPR <input type="checkbox"/> DNR <input type="checkbox"/> Comfort <input type="checkbox"/> Limited <input type="checkbox"/> Full <input type="checkbox"/> No tube <input type="checkbox"/> Trial <input type="checkbox"/> Long-term	
#3			<input type="checkbox"/> Patient <input type="checkbox"/> Decisionmaker <input type="checkbox"/> Parent <input type="checkbox"/> Conservator <input type="checkbox"/> Other: _____			<input type="checkbox"/> Patient <input type="checkbox"/> Decisionmaker <input type="checkbox"/> Parent <input type="checkbox"/> Conservator		<input type="checkbox"/> CPR <input type="checkbox"/> DNR <input type="checkbox"/> Comfort <input type="checkbox"/> Limited <input type="checkbox"/> Full <input type="checkbox"/> No tube <input type="checkbox"/> Trial <input type="checkbox"/> Long-term	
#4			<input type="checkbox"/> Patient <input type="checkbox"/> Decisionmaker <input type="checkbox"/> Parent <input type="checkbox"/> Conservator <input type="checkbox"/> Other: _____			<input type="checkbox"/> Patient <input type="checkbox"/> Decisionmaker <input type="checkbox"/> Parent <input type="checkbox"/> Conservator		<input type="checkbox"/> CPR <input type="checkbox"/> DNR <input type="checkbox"/> Comfort <input type="checkbox"/> Limited <input type="checkbox"/> Full <input type="checkbox"/> No tube <input type="checkbox"/> Trial <input type="checkbox"/> Long-term	
#5			<input type="checkbox"/> Patient <input type="checkbox"/> Decisionmaker <input type="checkbox"/> Parent <input type="checkbox"/> Conservator <input type="checkbox"/> Other: _____			<input type="checkbox"/> Patient <input type="checkbox"/> Decisionmaker <input type="checkbox"/> Parent <input type="checkbox"/> Conservator		<input type="checkbox"/> CPR <input type="checkbox"/> DNR <input type="checkbox"/> Comfort <input type="checkbox"/> Limited <input type="checkbox"/> Full <input type="checkbox"/> No tube <input type="checkbox"/> Trial <input type="checkbox"/> Long-term	
#6			<input type="checkbox"/> Patient <input type="checkbox"/> Decisionmaker <input type="checkbox"/> Parent <input type="checkbox"/> Conservator <input type="checkbox"/> Other: _____			<input type="checkbox"/> Patient <input type="checkbox"/> Decisionmaker <input type="checkbox"/> Parent <input type="checkbox"/> Conservator		<input type="checkbox"/> CPR <input type="checkbox"/> DNR <input type="checkbox"/> Comfort <input type="checkbox"/> Limited <input type="checkbox"/> Full <input type="checkbox"/> No tube <input type="checkbox"/> Trial <input type="checkbox"/> Long-term	
7			<input type="checkbox"/> Patient <input type="checkbox"/> Decisionmaker <input type="checkbox"/> Parent <input type="checkbox"/> Conservator <input type="checkbox"/> Other: _____			<input type="checkbox"/> Patient <input type="checkbox"/> Decisionmaker <input type="checkbox"/> Parent <input type="checkbox"/> Conservator		<input type="checkbox"/> CPR <input type="checkbox"/> DNR <input type="checkbox"/> Comfort <input type="checkbox"/> Limited <input type="checkbox"/> Full <input type="checkbox"/> No tube <input type="checkbox"/> Trial <input type="checkbox"/> Long-term	
#8			<input type="checkbox"/> Patient <input type="checkbox"/> Decisionmaker <input type="checkbox"/> Parent <input type="checkbox"/> Conservator <input type="checkbox"/> Other: _____			<input type="checkbox"/> Patient <input type="checkbox"/> Decisionmaker <input type="checkbox"/> Parent <input type="checkbox"/> Conservator		<input type="checkbox"/> CPR <input type="checkbox"/> DNR <input type="checkbox"/> Comfort <input type="checkbox"/> Limited <input type="checkbox"/> Full <input type="checkbox"/> No tube <input type="checkbox"/> Trial <input type="checkbox"/> Long-term	
#9			<input type="checkbox"/> Patient <input type="checkbox"/> Decisionmaker <input type="checkbox"/> Parent <input type="checkbox"/> Conservator <input type="checkbox"/> Other: _____			<input type="checkbox"/> Patient <input type="checkbox"/> Decisionmaker <input type="checkbox"/> Parent <input type="checkbox"/> Conservator		<input type="checkbox"/> CPR <input type="checkbox"/> DNR <input type="checkbox"/> Comfort <input type="checkbox"/> Limited <input type="checkbox"/> Full <input type="checkbox"/> No tube <input type="checkbox"/> Trial <input type="checkbox"/> Long-term	
#10			<input type="checkbox"/> Patient <input type="checkbox"/> Decisionmaker <input type="checkbox"/> Parent <input type="checkbox"/> Conservator <input type="checkbox"/> Other: _____			<input type="checkbox"/> Patient <input type="checkbox"/> Decisionmaker <input type="checkbox"/> Parent <input type="checkbox"/> Conservator		<input type="checkbox"/> CPR <input type="checkbox"/> DNR <input type="checkbox"/> Comfort <input type="checkbox"/> Limited <input type="checkbox"/> Full <input type="checkbox"/> No tube <input type="checkbox"/> Trial <input type="checkbox"/> Long-term	

Audit Completed by: _____

Date: _____

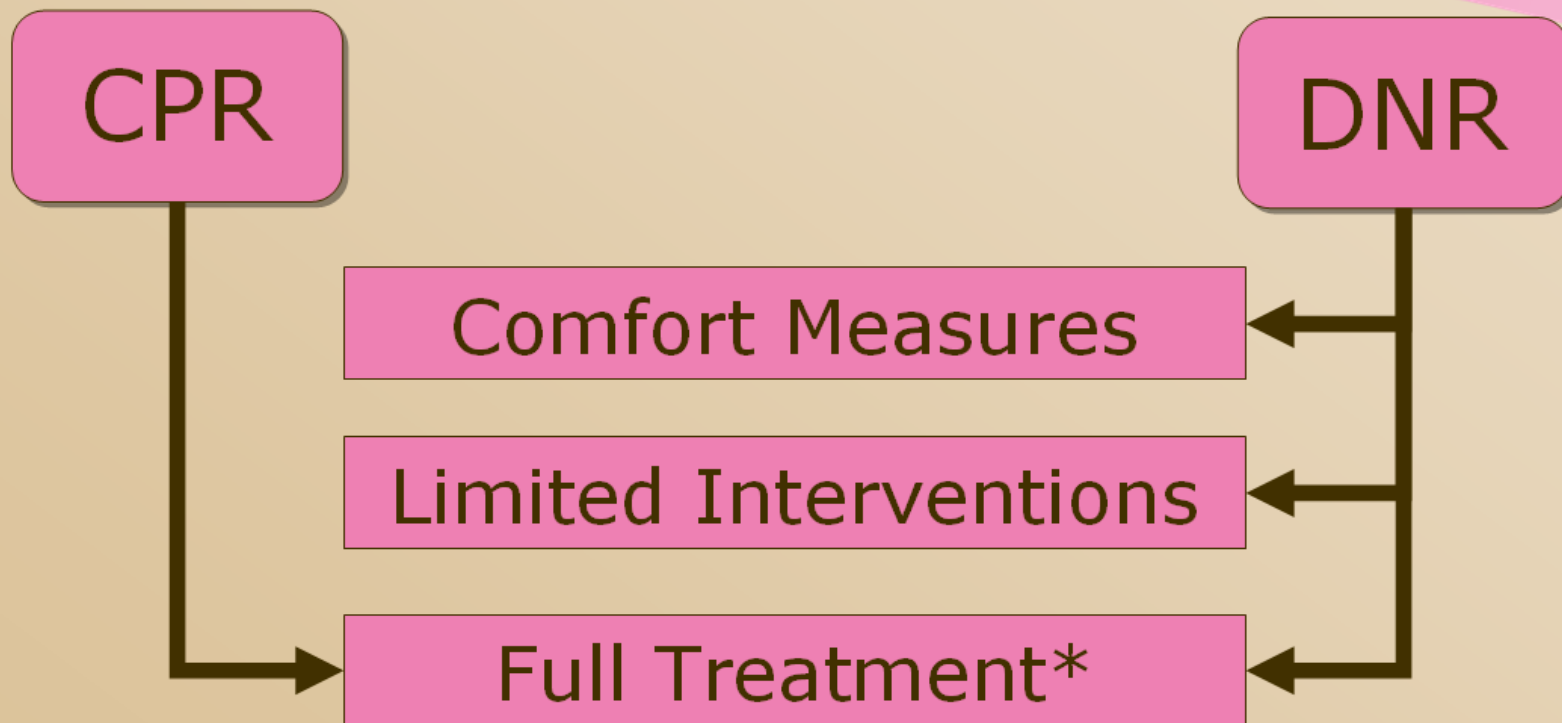
Audit Reviewed with SNF staff? Yes No

Date: _____

SNF Staff Name/Title: _____

SNF Staff Name/Title: _____

Diagram of POLST Medical Interventions



*Consider time/prognosis factors under "Full Treatment"
"Defined trial period. Do not keep on prolonged life support."

Instrument I

Title: Oregon Nursing Home and Hospice Telephone Survey

Designer: Susan Hickman, PhD. Please credit her in any publications and public presentations.

Suitable for Quality Improvement? Yes, modified to fit your state.

Suitable for research? Yes.

Description of Instrument: This form is designed for POLST paradigm programs to get information about how POLST is being used in nursing homes and hospice programs by means of a telephone survey. The survey should be completed by an administrator or knowledgeable designee. It includes a short section on how the hospice/facility is using POLST, any problems they've encountered, and a 9 question measure of attitudes towards POLST.

How to use:

Step 1: Modify the form to suit your purposes. Decide whether you really need each item and keep items that you have a planned use for or believe may be important to have even though you are not sure what to do with them. That said, if you want to assess POLST attitudes, I would recommend keeping the 9 questions (items 6-14) about attitudes together as Dr. Hickman has been using this group of 9 questions and has shared them with others. At some point you may want to compare your regions' results to others and having the same questions asked the same way maximizes this opportunity. Similarly, you may add items that are missing or that address questions that you are trying to answer. You may find items in other instruments elsewhere in the toolkit and want to include them and that is fine.

Step 2: Select which hospices and/or nursing homes you will survey. You may wish to survey all of them, or just a cross-section. See the FAQ section on 'Sampling'. In general, as long as you choose programs/facilities in a random fashion (for example, by choosing numbers out of a hat) ensuring that you get to review 15-30 programs and/or facilities total may be enough for most QA purposes.

Step 3: Call the programs/facilities and record the data. For some, you may not find someone who is willing or able to answer your questions—that is expected, just do the best you can. You will need to tabulate your results in a paper or software spreadsheet or statistical software program.

Step 4: Analyze the results. Some of the results that you will get from this survey include:

1. How they document patient preferences and medical orders for life-sustaining treatments.
2. What proportion of patients they are using POLST for (this is often the most useful question).
3. What proportion of them have POLST policies.
4. Who usually initiates advance care planning with patients/residents.
5. Attitudes about POLST including whether it works in preventing unwanted hospitalization, is respected by EMS, and is working in that community.

Since nursing facilities and hospices are 'early adopters' of POLST paradigm forms, this survey is well suited to measuring early program success.

ATTENTION: IF YOU USE THIS SURVEY, PLEASE CREDIT SUSAN HICKMAN, PhD hickman@iupui.edu

Date: _____

Oregon Nursing Home and Hospice Telephone Survey

We understand that hospice programs/nursing facilities across Oregon use many different forms to document patient treatment preferences and guide care. We are interested in learning more about advance care planning within your program/facility and your attitudes towards the POLST (Physician Orders for Life-Sustaining Treatment) Program.

1. What forms are used to document patient/resident wishes for life-sustaining treatment?
[READ LIST]

YES	NO	FORM [Check all that apply]
		State Advance Directive
		Program specific form for advance planning
		Any other form (describe)

2. What forms do you use to record medical orders regarding life-sustaining treatments? [READ LIST]

YES	NO	FORM [Check all that apply]
		Program specific form for physician orders
		DNR/Full Code (in medical records)
		POLST Program (IF YES, GO TO #3: IF NO, SKIP TO #4)
		Any other form (describe)
		No system

3. How long has your program used the POLST form? [read choices]

- ☐ Less than 6 months
- ☐ 6 months to less than 1 year
- ☐ 1 – 2 years
- ☐ 2 or more years

- b. How many current patients have POLST forms? [read choices]

- ☐ None
- ☐ Less than half
- ☐ About half
- ☐ More than half
- ☐ Nearly all or all

- c. Does your program/facility have a policy, formal or informal, that every patient/resident must be offered a POLST form?

- ☐ No
- ☐ Yes

- d. Are you aware of any problems related to the use of the POLST program in your hospice/nursing facility?

- ☐ No
- ☐ Yes

IF YES, please describe: _____

4. Who usually initiates advance care planning with patients/residents? (check all that apply)

- ☐ Physician/Nurse Practitioner
- ☐ Social Services staff
- ☐ Nursing staff
- ☐ Director
- ☐ Pastoral Care
- ☐ Other (describe) _____

5. Approximately what is the current patient census in your program/facility? _____

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

I'd like you to rate the next set of questions I ask you on a scale of 1 – 5 with 1 = strongly disagree and 5 = strongly agree.

6. _____ The POLST form provides clear instructions about a patient's/resident's treatment preferences.
7. _____ The POLST form is useful in preventing unwanted hospitalization.
8. _____ The POLST for is useful in preventing unwanted resuscitation by EMS.
9. _____ The POLST form reliably express patient/resident treatment preferences.
10. _____ The POLST form is not working in my community.
11. _____ I feel more comfortable knowing what to do when a POLST form is available.
12. _____ The POLST form helps ensure patient/resident treatment preferences are honored.
13. _____ Having a POLST form makes treating patients/residents more complicated.
14. _____ The POLST form serves as a helpful mechanism for initiating a conversation about treatment preferences.

Note: For hospice programs, use the term "patients." For nursing facilities and other long-term care settings, use the term "residents."

Instruments J and K

Title: California POLST Nursing Home Surveys 1 and 2

Designer: Neil Wenger, MD, MPH. Please cite this article in any future work:

Wenger NS, Citko J, O'Malley K, Diamant A, Lorenz K, Gonzalez V, Tarn DM. Implementation of physician orders for life sustaining treatment in nursing homes in California: evaluation of a novel statewide dissemination mechanism. J Gen Intern Med. 2013 Jan;28(1):51-7.

Suitable for Quality Improvement? Yes, modified to fit your state.

Suitable for research? Yes.

Description of Instrument: These surveys produced research quality data about POLST utilization in skilled nursing facilities to assess the effectiveness of a major grass roots effort promoting POLST use in California. The surveys were not done in isolation, but as follow up to an extensive educational outreach. They are mailed surveys addressed to the nursing home administrator or knowledgeable designee.

How to use:

Step 1: Modify the form to suit your purposes. Versions 1 and 2 are very similar and you should choose which items you want to use from each. Version 2 includes a question 'does your SNF require completion of POLST as a condition of admission?' A 'yes' response to this identifies an improper practice as POLST completion can be offered but not required as a condition for admission. Decide whether you really need each item and keep items that you have a planned use for or believe may be important to have even though you are not sure what to do with them. Similarly, you may add items that are missing or that address questions that you are trying to answer. You may find items in other instruments elsewhere in the toolkit and want to include them and that is fine.

Step 2: Select which nursing facilities you will survey. You may wish to survey all of them, or just a cross-section. See the FAQ section on 'Sampling'. In general, as long as you choose facilities in a random fashion (for example, by choosing numbers out of a hat) and get a decent response rate to your survey (30-50%+ for QA and 50-75%+ for research) and survey enough facilities so that you get to 30 usable responses (more for research), that may be enough for most QA purposes. Dr. Wenger's article describes the sampling strategy they used to ensure that their sample was representative of the entire region—a higher standard needed for research purposes.

Step 3: There is a well described methodology for mailed surveys that is beyond the scope of this toolkit, but you should include a copy of your POLST paradigm form and a self-addressed, stamped envelope and plan on doing more than one mailing. It also helps to have as much institutional support as you can muster to encourage busy people to complete your survey.

Step 4: Analyze the results. Some of the results that you will get from this survey include:

1. The use of POLST in the facility
2. POLST education
3. Barriers to POLST
4. Confidence in POLST
5. Some questions about the facility

Survey about POLST

1. Has your SNF ever admitted a resident who already had a completed POLST form?
☐ Yes
☐ No → ***Skip to question 4***
☐ Don't know → ***Skip to question 4***
2. Does your SNF have a specific place in the medical record to put the POLST?
☐ Yes
☐ No
☐ Don't know
3. Approximately what percentage of the residents admitted to your SNF in the past 30 days had a completed POLST form upon admission?
 %
☐ Don't know
4. Has a POLST form ever been completed for a resident after admission to your SNF?
☐ Yes
☐ No → ***Skip to question 7***
☐ Don't know → ***Skip to question 7***
5. Who usually initiates discussion about POLST with the resident or resident's family?
Choose one answer Nurse
☐ Physician
☐ Social services
☐ A dedicated team → Who? _____
☐ Other staff: _____
☐ All different people initiate POLST documents
6. Is there a "champion" for POLST within the SNF, for example someone for whom advocating for POLST is part of their job responsibilities?
☐ Yes → What is this person's job title? _____
☐ No
7. Approximately what percentage of the residents in your SNF currently have a POLST form?
 %
☐ Don't know
8. Does your SNF have a formal policy on how to complete and adhere to POLST forms?
☐ Yes
☐ No
☐ Don't know
9. Have SNF staff ever received education about POLST?
☐ Yes
☐ No → ***Skip to question 12***

10. What aspects of POLST education have been completed at your SNF?

Respond Yes or No for each item

	<u>Yes</u>	<u>No</u>
a. General orientation about POLST	_____	_____
b. Teaching about having the POLST conversation	_____	_____
c. Role play or case discussion about POLST	_____	_____
d. Distribution of written material about using POLST	_____	_____

Other: _____

11. Approximately what percentage of the SNF staff have received education about POLST?

_____ %
 _____ Don't know

12. Has your SNF encountered any of the following problems with POLST?

Respond Yes or No for each item

	<u>Yes</u>	<u>No</u>
a. Translating the POLST into SNF medical record orders	_____	_____
b. Interpreting the POLST to make treatment decisions	_____	_____
c. Getting physicians to participate in completion of POLST	_____	_____
d. Getting physicians to sign a POLST form	_____	_____
e. Following the orders contained in the POLST	_____	_____
f. Getting EMS to follow the orders contained in the POLST	_____	_____
g. Receiving the original POLST back from other facilities	_____	_____
h. Family disagreement with POLST content	_____	_____

Other: _____

If "Yes" to any of the above, please describe: _____

13. Would your SNF benefit from any assistance in the use of the POLST?

Respond Yes or No for each item

	<u>Yes</u>	<u>No</u>
a. Educational program for staff	_____	_____
b. Example policy for handling POLST	_____	_____

Other: _____

Now a few questions about your views about POLST. For each of the following items please indicate if you Strongly agree, Agree, are Neutral, Disagree or Strongly disagree:

	<u>Strongly Agree</u>	<u>Agree</u>	<u>Neutral</u>	<u>Disagree</u>	<u>Strongly Disagree</u>
14. The value of POLST makes it worth the extra effort.	_____	_____	_____	_____	_____
15. I feel confident that this SNF can honor a POLST ordering comfort care.	_____	_____	_____	_____	_____
16. In this SNF, a POLST would be useful for many patients who do not have one.	_____	_____	_____	_____	_____

Now some questions about your SNF

17. Approximately what proportion of total days are covered by the following insurance?

Post acute Medicare	_____	%
Medicaid	_____	%
Private pay	_____	%
Other:	_____	%
	1 0 0	%

18. Over the past month, on average, what percent of your SNF beds were filled?

_____ %

19. What is the primary language of the residents in your SNF?

English	_____	%
Spanish	_____	%
Other:	_____	%
Other:	_____	%
	1 0 0	%

20. Does your SNF accept residents who are receiving care under the Medicare hospice benefit?

_____ Yes	_____ No	_____ Don't know
-----------	----------	------------------

Who completed this survey?

Name: _____

Title: _____

Telephone #: _____ - _____ - _____

CA POLST Nursing Home Survey II

1. Has your SNF ever admitted a resident who already had a completed POLST form?
☐ Yes
☐ No → ***Skip to question 4***
☐ Don't know → ***Skip to question 4***
2. Does your SNF have a specific place in the medical record to put the POLST?
☐ Yes
☐ No
☐ Don't know
3. Approximately what percentage of the residents admitted to your SNF in the past 30 days had a completed POLST form upon admission?
 %
☐ Don't know
4. Has a POLST form ever been completed for a resident after admission to your SNF?
☐ Yes
☐ No
☐ Don't know
5. Is there a “champion” for POLST within the SNF, for example someone for whom advocating for POLST is part of their job responsibilities?
☐ Yes → What is this person's job title? _____
☐ No
6. Approximately what percentage of the residents in your SNF currently have a POLST form?
 %
☐ Don't know
7. Does your SNF have a formal policy on how to complete and adhere to POLST forms?
☐ Yes
☐ No
☐ Don't know

8. Does your SNF require completion of POLST as a condition of admission?

_____ Yes
_____ No

9. Have SNF staff received education about POLST?

_____ Yes
_____ No → *Skip to question 12*

10. What aspects of POLST education have been completed at your SNF?

Respond Yes or No for each item

	<u>Yes</u>	<u>No</u>
a. General orientation about POLST	_____	_____
b. Teaching about having the POLST conversation	_____	_____
c. Role play or case discussion about POLST	_____	_____
d. Distribution of written material about using POLST	_____	_____

Other: _____

11. Approximately what percentage of the SNF staff have received education about POLST?

_____ %
_____ Don't know

12. Would your SNF benefit from any assistance in establishing procedures for POLST?

Respond Yes or No for each item

	<u>Yes</u>	<u>No</u>
a. Educational program for staff	_____	_____
b. Example policy for handling POLST	_____	_____

Other: _____

13. Has your SNF encountered any of the following problems with POLST and if so, how often?

Please provide one answer to each item

Problem with POLST	Very Often	Often	Occasionally	Rarely	Never
Interpreting the POLST to make treatment decisions					
Getting physicians to participate in completion of POLST					
Getting physicians to sign a POLST form					
Physicians signing blank POLST forms					
Following the orders contained in the POLST					
Getting EMS to follow orders contained in the POLST					
Receiving the original POLST back from other facilities					
Family disagreement with POLST content					
Family signed POLST although resident has capacity					
POLST does not match the resident's advance directive					
Family changed POLST to be inconsistent with resident's previously expressed wishes					
Receiving incomplete or incorrect POLST from another facility					
Other:					

14. Questions about POLST are now on the California MDS as of October 2010. Did your SNF change its approach to POLST in response to POLST appearing on the MDS?

☐ Yes → How? _____
☐ No → How? _____
☐ Don't know

Now a few questions about perceptions about POLST. For each of the following items please indicate if you Strongly agree, Agree, are Neutral, Disagree or Strongly disagree:

	<u>Strongly Agree</u>	<u>Agree</u>	<u>Neutral</u>	<u>Disagree</u>	<u>Strongly Disagree</u>
15. POLST is collected on the MDS so every resident should have a POLST	_____	_____	_____	_____	_____
16. POLST is sometimes completed for residents for which it is not appropriate	_____	_____	_____	_____	_____
17. I feel confident that this SNF can honor a POLST ordering comfort care	_____	_____	_____	_____	_____
18. In this SNF, a POLST would be useful for many patients who do not have one	_____	_____	_____	_____	_____

Some questions about your SNF

19. Over the past month, on average, what percent of your SNF beds were filled?
_____ %

20. What is the primary language of the residents in your SNF?

English	_____ %
Spanish	_____ %
Other: _____	_____ %
Other: _____	_____ %
	1 0 0 %

21. Does your SNF accept residents who are receiving care under the Medicare hospice benefit?
_____ Yes _____ No _____ Don't know

Thank you

Please place this survey in the enclosed envelope and mail

Instrument L and M

Title: Oregon Nursing Facility Chart Review Short and Long Versions

Designer: Susan Hickman, PhD. Please cite these studies in any future work:

Hickman SE, Nelson CA, Perrin NA, Moss AH, Hammes BJ, Tolle SW. A comparison of methods to communicate treatment preferences in nursing facilities: traditional practices versus the physician orders for life-sustaining treatment program. J Am Geriatr Soc. 2010 Jul;58(7):1241-8.

Hickman SE, Nelson CA, Moss AH, Tolle SW, Perrin NA, Hammes BJ. The consistency between treatments provided to nursing facility residents and orders on the physician orders for life-sustaining treatment form. J Am Geriatr Soc. 2011 Nov;59(11):2091-9.

Suitable for Quality Improvement? Probably too extensive for QI purposes, but the items are excellent.

Suitable for research? Yes.

Description of Instrument: These chart review forms were designed to collect research data for a study examining whether POLST forms were effective in guiding life-sustaining treatments for patients in nursing facilities. Both forms are long and require some skill on the part of the chart reviewer to correctly complete the review. They are both more suitable for research but some of the items may be of use for QI purposes.

Description of selected Short Version items:

- Item 3, Preferences: this item asks the reviewer to identify and describe any documented discussions about treatment preferences.
- Items 4-6: these items assess who is making medical decisions and the presence of other advance care planning documents.
- Item 7: Indicates if the patient had treatment PREFERENCES documented for a long list of medical treatments.
- Item 8-10: Indicates whether the patient had ORDERS, including POLST orders, for life sustaining treatments in the chart.
- Item 11: Documents whether the patient received any of 13 different life sustaining treatments.
- Item 12: Documents any changes in life sustaining treatment orders.

Additional items form the Long Version:

- Items 1-7: Patient demographic information.
- Items 8-20: Items from the DHS Minimum Data Set including who is responsible for patient, Advance Directive orders present, selected diseases that may be present, special treatments that may have been received, indicators assessing consciousness, memory, cognitive skills, depression/anxiety/sad mood, activities of daily living, and pain symptoms.
- Item 26: Documents reasons why patient received treatment different from LST preferences or orders.
- Item 27: Documents symptoms and symptom management medications in the last week of life.

Oregon NURSING HOME CHART REVIEW Short Version

1. Today's date _____
2. What is the reason for this chart review?
 - ☐ regular review
 - ☐ change in status (indicate type of change):
 - ☐ hospice admission
 - ☐ discharge to home
 - ☐ discharge to hospital
 - ☐ other _____

NURSING FACILITY PREFERENCES, ORDERS, & LIFE-SUSTAINING TREATMENTS

3. PREFERENCES: Have any discussions occurred at the nursing home regarding **treatment preferences**?
 - ☐ yes
 - ☐ no

If yes, describe:

Date of Discussion	Staff involved? Identify.	Patient/family involved? Identify.	Was surrogate authorized? If so, describe role.

- a. Where is this documented? _____
- b. Who documented the discussion? _____
- c. Length of discussion
 - ☐ 0-15 min.
 - ☐ 15-30 min.
 - ☐ 30-45 min
 - ☐ no time listed
- d. What was discussed? Please describe treatment preferences or plans.

4. Who is making decisions at this point in time?
 - ☐ Patient
 - ☐ Healthcare Agent
 - ☐ Legal Guardian
 - ☐ Designated Decision-maker
 - ☐ Next of Kin
 - ☐ Other: _____

5. What, if any, **advance directive** forms are present in the chart? (Check all that apply)

- ☐ Advance directive/living will (circle type used and indicate date of document)
- ☐ LaCrosse Respecting Choices POAHC _____/_____/_____ Date
 - ☐ Addendum to POAHC _____/_____/_____ Date
 - ☐ Statement of Treatment Preference form _____/_____/_____ Date
 - ☐ Wisconsin Statutory POAHC _____/_____/_____ Date
 - ☐ Wisconsin Declaration to Physicians OR
other Living Will _____/_____/_____ Date
 - ☐ Designated Decision-maker (named by resident) _____/_____/_____ Date
 - ☐ Legal Guardian _____/_____/_____ Date
 - ☐ Other (describe) _____/_____/_____ Date
 - ☐ No form present

6. Were any documents created since admission to nursing home? ☐ yes ☐ no

- a. If yes, what type of document was completed? _____
- b. Date? _____
- c. Certification of provider signing document _____

7. Document all **treatment preferences** in the table below. (See advance directive).

<p>IF I AM CLOSE TO DEATH:</p> <p><input type="checkbox"/> I want feeding tubes/artificial nutrition and hydration.</p> <p><input type="checkbox"/> I want tube feedings only as my physician recommends</p> <p><input type="checkbox"/> I do not want feeding tubes/artificial nutrition and hydration</p> <p><input type="checkbox"/> No preference indicated</p> <p><input type="checkbox"/> I want any other life support that may apply</p> <p><input type="checkbox"/> I want life support only as my physician recommends</p> <p><input type="checkbox"/> I want NO life support</p> <p><input type="checkbox"/> No preference indicated</p>	<p>IF I AM PERMANENTLY UNCONSCIOUS/PERISTENT VEGETATIVE STATE:</p> <p><input type="checkbox"/> I want to receive tube feeding</p> <p><input type="checkbox"/> I want tube feeding only as my physician recommends</p> <p><input type="checkbox"/> I do not want tube feeding</p> <p><input type="checkbox"/> No preference indicated</p> <p><input type="checkbox"/> I want any other life support that may apply</p> <p><input type="checkbox"/> I want life support only as my physician recommends.</p> <p><input type="checkbox"/> I want NO life support</p> <p><input type="checkbox"/> No preference indicated</p>
<p>KIDNEY DIALYSIS</p> <p><input type="checkbox"/> I do want kidney dialysis</p> <p><input type="checkbox"/> I do not want kidney dialysis</p> <p><input type="checkbox"/> No preference indicated</p>	<p>VENTILATOR SUPPORT</p> <p><input type="checkbox"/> I do want ventilator support</p> <p><input type="checkbox"/> I do not want ventilator support</p> <p><input type="checkbox"/> No preference indicated.</p>
<p>RESUSCITATION (preferences, not orders)</p> <p><input type="checkbox"/> I do want cardiac resuscitation</p> <p><input type="checkbox"/> I do not want cardiac resuscitation</p> <p><input type="checkbox"/> I want CPR under certain circumstances as MD recommends</p> <p><input type="checkbox"/> No preference indicated</p>	<p>LOSS OF ABILITY TO RELATE TO SELF, OTHERS AND ENVIRONMENT</p> <p><input type="checkbox"/> I do not want CPR</p> <p><input type="checkbox"/> I do not want antibiotics</p> <p><input type="checkbox"/> I do not want a feeding tube, artificial hydration and nutrition</p> <p><input type="checkbox"/> No preference indicated</p>

ANTIBIOTICS <input type="checkbox"/> I do want antibiotics <input type="checkbox"/> I do not want antibiotics <input type="checkbox"/> No preference indicated	TRANSFUSION <input type="checkbox"/> I do want transfusion <input type="checkbox"/> I do not want transfusion <input type="checkbox"/> No preference indicated
PAIN AND SYMPTOM CONTROL IF EFFORTS TO PROLONG LIFE ARE STOPPED <input type="checkbox"/> I want to be kept comfortable even if it risks my dying sooner <input type="checkbox"/> No preference indicated	HOSPITALIZATION <input type="checkbox"/> I do want _____ <input type="checkbox"/> I do not want _____ <input type="checkbox"/> No preference indicated
Agent authority to admit me to a nursing home or community-based residential facility for the purpose of long-term care: <input type="checkbox"/> Yes <input type="checkbox"/> No	Agent authority to order the withholding or withdrawal of feeding tube and IV hydration: <input type="checkbox"/> Yes <input type="checkbox"/> No
OTHER PREFERENCES 	

8. Are there any **medical order forms or orders** for life-sustaining treatments in the chart?

A. If yes, what type of orders?

☐ Wisconsin DNR order form/bracelet _____/_____/_____ Date

☐ POLST (Please document orders found on POLST below)

a. Is document signed? ☐ yes ☐ no

b. Is document dated? ☐ yes ☐ no

If yes, date signed: _____/_____/_____ Date

c. Is there a resident/surrogate signature on back? ☐ yes ☐ no

d. What parts of document have been completed?

☐ A ☐ B ☐ C ☐ D ☐ E

☐ Standard order form? ☐ yes ☐ no

If yes, describe: _____

☐ Other order form? ☐ yes ☐ no

If yes, describe: _____

9. MEDICAL ORDERS RE LIFE-SUSTAINING TREATMENT: Document all **medical orders** written in the chart in the table below.

TREATMENT CATEGORY	CHECK BOX	WRITTEN ORDERS	DATE OF ORDER
Resuscitation		DNR/DNAR	
		Full Code	
Other Orders			

10. POLST ORDERS RE LIFE-SUSTAINING TREATMENT: Document all **POLST** orders in the table below.

TREATMENT CATEGORY	CHECK BOX	WRITTEN ORDERS	DATE OF ORDER
A. Resuscitation		DNR/DNAR	
		Full Code	
B. Medical Interventions		Comfort measures only....allow a natural death to occur	
		Do not hospitalize	
		Limited/advanced treatments	
		Full treatment	
C. Antibiotics		No antibiotics	
		No IM/IV antibiotics	
		Antibiotics	
D. Artificial Nutrition and Hydration		No artificial nutrition or hydration	
		Limited trial for ____ days	
		Artificial nutrition and hydration	

11. TREATMENTS: Document **life-sustaining treatments** below.

TREATMENT PROVIDED	Dates of occurrences	Treatments Provided & Other Relevant Information
Resuscitation	1) _____ 2) _____	
EMS visit with/without transport (indicate treatments provided by EMS)	1) _____ 2) _____ 3) _____ 4) _____	1) _____ 2) _____ 3) _____ 4) _____
Emergency Department Visit without hospitalization	1) _____ 2) _____ 3) _____ 4) _____	1) _____ 2) _____ 3) _____ 4) _____
Hospitalization:	1) _____ 2) _____	
Surgery:	1) _____ 2) _____	
Transfusion:	1) _____ 2) _____ 3) _____ 4) _____	
Intubation:	1) _____ 2) _____ 3) _____ 4) _____	
Dialysis:	1) _____ 2) _____ 3) _____ 4) _____	
Antibiotics:	1) _____ 2) _____ 3) _____ 4) _____	
Feeding Tubes:	1) _____ 2) _____ 3) _____ 4) _____	
IV Fluids:	1) _____ 2) _____ 3) _____ 4) _____	
Chemotherapy	1) _____ 2) _____ 3) _____ 4) _____	
Ventilator/Respirator	1) _____ 2) _____ 3) _____ 4) _____	

Nursing Home Follow-up

12. While at nursing home has there been any **change regarding life-sustaining treatment orders**? ☐ yes ☐ no

- a. If yes, who initiated the conversation?
- b. Who was involved in the discussion?
- c. Who made the decisions?
- d. How many days after admission did the orders change?
- e. Please describe change in treatment orders.

ELIGIBILITY SCREENING FOR CHART REVIEW

1. Is the resident age 65 and over? ☐ yes ☐ no (If no, do not include in sample)

2. Was resident originally admitted to the facility a minimum of 90 days earlier?

NOTE: Mark “yes” if the resident was temporarily at the hospital 90 days earlier but was a resident prior to this date.

☐ YES

○ If yes, indicate date of admission_____

☐ NO

○ If no, do not include in sample

3. What is the resident’s current payment source?

☐ Medicare per diem (if yes, do not include in sample)

☐ Medicaid per diem

☐ Medicare ancillary part A

☐ Medicare ancillary part B

☐ self or family pays full per diem (private pay)

☐ other

IF RESIDENT MEETS ALL ELIGIBILITY SCREENING CRITERIA COMPUTER PROGRAM WILL DIRECT DATA COLLECTOR TO FULL CHART REVIEW

IF RESIDENT DOES NOT MEET ALL ELIGIBILITY SCREENING CRITERIA, COMPUTER PROGRAM WILL RECORD AND PROMPT DATA COLLECTION TO MOVE TO NEXT CHART FOR ELIGIBILITY REVIEW

DEMOGRAPHICS

1. At the time of chart review, subject was: ☐ Living ☐ Deceased _____ (Date of death)
2. Today's date _____ (*computer will generate*)
3. Date chart review should begin _____ (*computer will generate based on either date of death or today's date*)
4. Age in years _____
5. Gender
☐ Female ☐ Male
6. Race/Ethnicity:
☐ White ☐ African American/Black ☐ Native Hawaiian/Pacific Islander
☐ Asian ☐ American Indian/Alaskan Native ☐ Hispanic ☐ Other ☐ not available
7. Education
☐ No Schooling ☐ 8th Grade/less ☐ 9 – 11th grades ☐ high school
☐ Technical or trade school ☐ some college ☐ Bachelor's degree ☐ graduate degree
☐ not available

MINIMUM DATA SET VARIABLES

TAKE FROM MOST RECENT MDS ASSESSMENT CONTAINING VARIABLE

8. Type of MDS assessment(s) reviewed and date (mark all that apply)
 - ↑ Admission Assessment _____
 - ↑ Annual Assessment _____
 - ↑ Significant Change in status assessment _____
 - ↑ Quarterly review assessment _____
 - ↑ Significant correction of prior quarterly assessment _____
 - ↑ None of the above

9. Responsibility/legal guardian as noted on the initial/full MDS (check all that apply) *COMPUTER LINK TO ITEM 20*

- ☐ Legal guardian ☐ other legal oversight ☐ durable power of attorney/health care
☐ durable power of attorney/financial ☐ family member responsible ☐ patient responsible for self
☐ none of the above

10. Advance Directives as noted on initial/full MDS (check all that apply) *COMPUTER LINK TO ITEM 20*

- ☐ Living Will ☐ Feeding restrictions ☐ Do not hospitalize ☐ other treatment restrictions
☐ Do not resuscitate ☐ medication restrictions ☐ Organ Donation ☐ None of the above

11. Disease Diagnoses noted on the MDS

ENDOCRINE/METABOLIC/NUTRITIONAL		Hemiplegia/hemiparesis	
Diabetes mellitus		Multiple sclerosis	
Hyperthyroidism		Paraplegia	
Hypothyroidism		Parkinson's disease	
HEART/CIRCULATION		Quadriplegia	
Arteriosclerotic heart disease (ASHD)		Transient ischemic attack (TIA)	
Cardiac dysrhythmias		Traumatic brain injury	
Congestive heart failure		PSYCHIATRIC/MOOD	
Deep vein thrombosis		Anxiety disorder	
Hypertension		Depression	
Hypotension		Manic Depression (bipolar)	
Peripheral vascular disease		Schizophrenia	
Other cardiovascular disease		PULMONARY	
MUSCULOSKELETAL		Asthma	
Arthritis		Emphysema/COPD	
Hip fracture		SENSORY	
Missing limb		Cataracts	
Osteoporosis		Diabetic retinopathy	
Pathological bone fracture		Glaucoma	
NEUROLOGICAL		Macular degeneration	
Alzheimer's disease		OTHER	
Aphasia		Allergies	
Cerebral palsy		Anemia	
Cerebrovascular accident (stroke)		Cancer	

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Dementia other than Alzheimer's disease		Renal failure	
		NONE OF THE ABOVE	

12. Special Treatments

- | | |
|--|---|
| <input type="checkbox"/> Chemotherapy | <input type="checkbox"/> Ventilator or respirator |
| <input type="checkbox"/> Dialysis | <input type="checkbox"/> Alzheimer's/dementia special care unit |
| <input type="checkbox"/> IV Medication | <input type="checkbox"/> Hospice care |
| <input type="checkbox"/> Tracheostomy care | |
| <input type="checkbox"/> Transfusions | |

13. Consciousness

- | | |
|-----------------------------------|---------------------------------------|
| <input type="checkbox"/> Comatose | <input type="checkbox"/> not comatose |
|-----------------------------------|---------------------------------------|

14. Memory—short term

- | | |
|------------------------------------|---------------------------------------|
| <input type="checkbox"/> memory OK | <input type="checkbox"/> some problem |
|------------------------------------|---------------------------------------|

15. Memory—long term

- | | |
|------------------------------------|---------------------------------------|
| <input type="checkbox"/> memory OK | <input type="checkbox"/> some problem |
|------------------------------------|---------------------------------------|

16. Memory/recall ability

- | | |
|---|---|
| <input type="checkbox"/> current season | <input type="checkbox"/> that he/she is in a nursing home |
| <input type="checkbox"/> location of own room | <input type="checkbox"/> NONE OF THE ABOVE are recalled |
| <input type="checkbox"/> staff names/faces | |

17. Cognitive skills for daily decision-making

- ☐ Independent
- ☐ Modified independence
- ☐ Moderately impaired
- ☐ Severely impaired

18. Indicators of depression, anxiety, or sad mood.

0 = not exhibited in last 30 days

1 = indicator of this type exhibited up to five days a week

2 = Indicator of this type exhibited daily or almost daily (6, 7 times a week)

INDICATORS	0	1	2
a. Resident made negative statements			
b. Repetitive questions			
c. Repetitive verbalizations			
d. Persistent anger with self or others.			
e. Self-deprecation			
f. Expressions of what appear to be unrealistic fears			
g. Recurrent statements that something terrible is about to happen			
h. Repetitive health complaints			
i. Repetitive anxious complaints/concerns			
j. Unpleasant mood in morning			
k. Insomnia/change in usual sleep pattern			
l. Sad, pained, worried facial expressions			
m. Crying, tearfulness			
n. Repetitive physical movements			
o. Withdrawal from activities of interest			
p. Reduced social interaction			

19. Activities of Daily Living Self-Performance (over last 7 days)

- ☐ independent ☐ limited assistance ☐ Supervision
☐ extensive assistance ☐ full dependence ☐ Activity did not occur during prior 7 days

20. Pain symptoms

a. Frequency with which resident complains or shows evidence of pain

- ☐ (0) No pain ☐ (1) pain less than daily ☐ (2) Pain Daily

b. Intensity of pain

- ☐ (1) mild pain ☐ (2) Moderate pain ☐ (3) Times when pain is horrible or
 excruciating

END OF MDS DATA—RETURN TO FULL CHART FOR THE REMAINING ITEMS

PREFERENCES, ORDERS, & LIFE-SUSTAINING TREATMENTS

21. What, if any, **advance directive** forms are present in the chart? (check all that apply)

- ☐ Advance directive/living will (circle type used)
 - ☐ Five wishes
 - ☐ LaCrosse Respecting Choices form
 - ☐ Wisconsin Declaration to Physicians
 - ☐ West Virginia state form
 - ☐ Oregon Advance Directive
- ☐ facility form—patient/surrogate wishes for treatment
- ☐ Designated Power of Attorney for health care (person named by resident)
- ☐ WVA health care surrogate appointment (identified by MD)
- ☐ other (describe) _____
- ☐ No form present

NOTE: COMPUTER WILL
PROMPT RA IF PRIOR MDS
DATA SUGGESTS
ALTERNATIVE DECISION-
MAKER OR ADVANCE
DIRECTIVE ARE PRESENT

22. If the resident has an advance directive/living will form in their chart, what are their preferences?

DO NOT CHECK FOR PHYSICIAN/NP ORDERS:

<p>IF I AM CLOSE TO DEATH:</p> <ul style="list-style-type: none"> <input type="checkbox"/> I want feeding tubes/artificial nutrition and hydration. <input type="checkbox"/> I want tube feedings only as my physician recommends <input type="checkbox"/> I do not want feeding tubes/artificial nutrition and hydration <input type="checkbox"/> No preference indicated <input type="checkbox"/> I want any other life support that may apply <input type="checkbox"/> I want life support only as my physician recommends <input type="checkbox"/> I want NO life support <input type="checkbox"/> No preference indicated 	<p>IF I AM PERMANENTLY UNCONSCIOUS/PERISTENT VEGETATIVE STATE:</p> <ul style="list-style-type: none"> <input type="checkbox"/> I want to receive tube feeding <input type="checkbox"/> I want tube feeding only as my physician recommends <input type="checkbox"/> I do not want tube feeding <input type="checkbox"/> No preference indicated <input type="checkbox"/> I want any other life support that may apply <input type="checkbox"/> I want life support only as my physician recommends. <input type="checkbox"/> I want NO life support <input type="checkbox"/> No preference indicated
<p>IF I HAVE ADVANCED PROGRESSIVE ILLNESS/TERMINAL CONDITION AND/OR CANNOT INTERACT MEANINGFULLY:</p> <ul style="list-style-type: none"> <input type="checkbox"/> I want tube feedings 	<p>IF I AM EXPERIENCING EXTRAORDINARY SUFFERING:</p> <ul style="list-style-type: none"> <input type="checkbox"/> I want to receive tube feedings <input type="checkbox"/> I want tube feedings only as my physician recommends

<input type="checkbox"/> I want tube feedings only as my physician recommends <input type="checkbox"/> I do not want tube feedings <input type="checkbox"/> No preference indicated <input type="checkbox"/> I want any other life support that may apply <input type="checkbox"/> I want life support only as my physician recommends <input type="checkbox"/> I want NO life support <input type="checkbox"/> No preference indicated.	<input type="checkbox"/> I do not want tube feeding <input type="checkbox"/> No preference indicated <input type="checkbox"/> I want any other life support that may apply <input type="checkbox"/> I want life support only as my physician recommends <input type="checkbox"/> I want NO life support <input type="checkbox"/> No preference indicated
KIDNEY DIALYSIS <input type="checkbox"/> I do want kidney dialysis <input type="checkbox"/> I do not want kidney dialysis <input type="checkbox"/> No preference indicated	VENTILATOR SUPPORT <input type="checkbox"/> I do want ventilator support <input type="checkbox"/> I do not want ventilator support <input type="checkbox"/> No preference indicated.
RESUSCITATION (preferences, not orders) <input type="checkbox"/> I do want cardiac resuscitation <input type="checkbox"/> I do not want cardiac resuscitation <input type="checkbox"/> I want CPR under certain circumstances as MD recommends <input type="checkbox"/> No preference indicated	SURGERY OR INVASIVE DIAGNOSTIC TESTS <input type="checkbox"/> I do want surgery or invasive diagnostic tests <input type="checkbox"/> I do not want surgery or invasive diagnostic tests <input type="checkbox"/> No preference indicated
ANTIBIOTICS <input type="checkbox"/> I do want antibiotics <input type="checkbox"/> I do not want antibiotics <input type="checkbox"/> No preference indicated	TRANSFUSION <input type="checkbox"/> I do want transfusion <input type="checkbox"/> I do not want transfusion <input type="checkbox"/> No preference indicated
PAIN AND SYMPTOM CONTROL IF EFFORTS TO PROLONG LIFE ARE STOPPED <input type="checkbox"/> I want to be kept comfortable even if it risks my dying sooner	HOSPITALIZATION <input type="checkbox"/> I do want _____ <input type="checkbox"/> I do not want _____
OTHER <input type="checkbox"/> I do want _____ <input type="checkbox"/> I do not want _____	OTHER <input type="checkbox"/> I do want _____ <input type="checkbox"/> I do not want _____

23. Are there any **medical order forms or orders** for life-sustaining treatments in the chart?

(check all that apply)

- ☐ POLST/POST form (see box to right)
- ☐ facility medical order form (must require MD or NP and be called an order)
- ☐ WVA DNR order form
- ☐ WI DNR bracelet
- ☐ Form and other orders present
- ☐ No form but other orders present
- ☐ No form, no orders present
- ☐ other (describe) _____

IF POLST FORM IS PRESENT:

- a. Is there a resident/surrogate signature on back? ____ yes ____ no
- b. Who was it discussed with?
 - ____patient/resident
 - ____health care representative
 - ____Court-appointed guardian
 - ____ Spouse
 - ____ Other _____
- c. Is there a physician/nurse practitioner signature? ____ yes ____ no

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24. ORDERS RE LIFE-SUSTAINING TREATMENT: Document all medical orders written on the POLST/POST form or in the medical chart in the table below. The date may precede the 90 day review period but if orders are still in effect, record below. Be sure to provide the date of the order. If the orders change, complete additional ORDERS form. *Computer will generate additional orders form if required.*

TREATMENT CATEGORY	Written Orders	Date of Order	Check if change in orders during 90 day review
Resuscitation	↑ DNR/DNAR		
	↑ Full Code		
Medical interventions	↑ Comfort Measures Only/Hospitalize only if comfort measures fail/Supportive Care Only		
	↑ Do Not Hospitalize		
	↑ Limited/Advanced Treatments		
	↑ Full Treatment/Aggressive Treatment		
Antibiotics	↑ No antibiotics		
	↑ No IM/IV antibiotics		
	↑ Antibiotics		
Artificial Nutrition and Hydration	↑ No artificial nutrition or hydration		
	↑ Limited trial for _____ days		
	↑ Artificial nutrition and hydration		

25. LIFE-SUSTAINING TREATMENTS AND INTERVENTIONS PROVIDED DURING 90 DAY REVIEW: RECORD EACH TIME TREATMENT OR INTERVENTION OCCURS AND PROVIDE ADDITIONAL INFORMATION AS INDICATED

The ACCESS computer program for data collection will cue the data collection for each recorded treatment, requesting date information and other relevant information.

TREATMENT PROVIDED	DATE STARTED/PROVIDED	ADDITIONAL INFORMATION
↑ Resuscitation	1) _____ 2) _____	1) Did resident survive? ↑ yes ↑ no 2) Did resident survive? ↑ yes ↑ no
↑ Hospitalization:	1) _____ 2) _____ 3) _____ 4) _____	1) Date returned (computer will calculate length of stay) _____ (_____ days) 2) Date returned _____ (_____ days) 3) Date returned _____ (_____ days) 4) Date returned _____ (_____ days)
↑ Dialysis:	1) _____ 2) _____	1) _____ (Date stopped) 2) _____ (Date stopped)
↑ Transfusion:	1) _____ 2) _____ 3) _____ 4) _____	1) Purpose: _____ 2) Purpose: _____ 3) Purpose: _____ 4) Purpose: _____
↑ Intubation:	1) _____ 2) _____ 3) _____ 4) _____	1) Outcome: _____ 2) Outcome: _____ 3) Outcome: _____ 4) Outcome: _____
↑ Surgery:	1) _____ 2) _____ 3) _____ 4) _____	1) Purpose of surgery _____ 2) Purpose of surgery _____ 3) Purpose of surgery _____ 4) Purpose of surgery _____
↑ Antibiotics:	1) _____ 2) _____ 3) _____ 4) _____	1) Purpose of antibiotics _____ 2) Purpose of antibiotics _____ 3) Purpose of antibiotics _____ 4) Purpose of antibiotics _____
↑ Feeding Tubes:	1) _____ 2) _____ 3) _____ 4) _____	1) _____ (Date stopped) 2) _____ (Date stopped,) 3) _____ (Date stopped) 4) _____ (Date stopped)

↑ IV Fluids:	1) _____ 2) _____ 3) _____ 4) _____	1) _____ (Date stopped) 2) _____ (Date stopped) 3) _____ (Date stopped) 4) _____ (Date stopped)
↑ Chemotherapy	1) _____ 2) _____ 3) _____ 4) _____	1) _____ (Date stopped) 2) _____ (Date stopped) 3) _____ (Date stopped) 4) _____ (Date stopped)
↑ Ventilator/Respirator	1) _____ 2) _____ 3) _____ 4) _____	1) _____ (Date stopped) 2) _____ (Date stopped) 3) _____ (Date stopped) 4) _____ (Date stopped)

NOTE: The ACCESS computer program will identify treatment deviations (e.g, orders for no artificial nutrition and hydration but feeding tube was used) and prompt the data collector to explore each discrepancy and identify the reason for it.

26. REASONS FOR TREATMENT DEVIATIONS

Treatment Discrepancy #1: Describe and date _____

CHECK ALL REASONS THAT APPLY

- | | |
|------------------------|--|
| ↑ None noted | ↑ patient changed mind |
| ↑ family changed mind | ↑ Orders written after treatment started |
| ↑ MD/NP changed order | ↑ Condition changed |
| ↑ Orders not consulted | ↑ Other |

↑ No information provided

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Treatment Discrepancy # 2: Describe and date _____

CHECK ALL REASONS THAT APPLY

- | | |
|---|---|
| <input type="checkbox"/> None noted | <input type="checkbox"/> patient changed mind |
| <input type="checkbox"/> family changed mind | <input type="checkbox"/> Orders written after treatment started |
| <input type="checkbox"/> MD/NP changed order | <input type="checkbox"/> Condition changed |
| <input type="checkbox"/> Orders not consulted | <input type="checkbox"/> Other |

☐ No information provided

Treatment Discrepancy #3: Describe and date _____

CHECK ALL REASONS THAT APPLY

- | | |
|---|---|
| <input type="checkbox"/> None noted | <input type="checkbox"/> patient changed mind |
| <input type="checkbox"/> family changed mind | <input type="checkbox"/> Orders written after treatment started |
| <input type="checkbox"/> MD/NP changed order | <input type="checkbox"/> Condition changed |
| <input type="checkbox"/> Orders not consulted | <input type="checkbox"/> Other |

☐ No information provided

SYMPTOMS AND SYMPTOM MANAGEMENT IN THE LAST WEEK

THE DATA IN THIS SECTION SHOULD BE EXTRACTED FROM THE LAST SEVEN DAYS OF THE CHART REVIEW ONLY, REGARDLESS OF WHETHER RESIDENT IS LIVING OR DECEASED

27. Review chart notes and orders for symptoms and symptom management interventions in the week prior to the date of the chart review. Start with the last day of the chart review as Day 7. *Note: The computer will enter the corresponding dates automatically and cue RA to look for interventions when symptoms are reported as well as vice versa.*

SYMPTOMS & Interventions	DAY 7 X/X/XX	DAY 6 X/X/XX	DAY 5 X/X/XX	DAY 4 X/X/XX	DAY 3 X/X/XX	DAY 2 X/X/XX	DAY 1 X/X/XX
DRY MOUTH/LIPS							
Mouth care							
DYSPNEA/SOB							
Oxygen							
Suctioning							
CONSTIPATION							
Increased activity							
Increased fluids							
Dietary interventions							
Medication							
AGITATION							
Review/adjust meds							
Emotional support							
RESTLESSNESS							
Activities as tolerated							
FATIGUE							
Allow resident to remain in bed							
ANXIETY							
Emotional support							
FEARFULNESS							
Emotional support							
TEARFULNESS/CRYING							
Emotional support							

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MOANING							
Pain assessment*							
YELLING							
Pain assessment*							
DEPRESSION							
Emotional support							
LOSS OF APPETITE							
Diet as tolerated							
DROWSINESS							
Review/adjust meds							
Allow resident to remain in bed							
RESTRICTED TO BED							
Positioning for comfort							
Foley catheter							
OTHER:							
Hospice care							
Communicate with family about status							
*Pain (record highest level of pain documented each day and level of pain if available—note scale used)							
no description							
vague description							
mild							
moderate							
Horrible or excruciating							
Level of pain							
___ 0 – 5 scale							
___ 0 – 10 scale							

When the RAs enter a number for a pain assessment, the computer will prompt them to indicate what scale was used to generate the number (0 – 5 or 0 – 10)

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28. What pain and psychotropic medication did the resident receive over the past seven days? Record total amount per day for last week of chart review. Start with the last day of the chart review as Day 7. *Note: The computer will enter the dates automatically.*

MEDICATION	DAY 7 X/X/XX	DAY 6 X/X/XX	DAY 5 X/X/XX	DAY 4 X/X/XX	DAY 3 X/X/XX	DAY 2 X/X/XX	DAY 1 X/X/XX
acetaminophen (APAP)							
Oral							
Rectal							
acetaminophen and codeine							
Oral							
acetaminophen and hydrocodone (Vicodin)							
Oral							
morphine (Roxanol)							
Oral							
IM/IV/SubQ							
fentanyl (Duragesic)							
IM/IV/SubQ							
Patch							
hydromorphone (Dilaudid)							
Oral							
IM/IV/SubQ							
oxycodone							
Oral							
Antidepressant; Specify: _____							

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Oral							
Anxiolytic; Specify: _____							
Oral							
Antipsychotic; Specify: _____							
Oral							
Other; Specify: _____							
RT: _____							
Other; Specify: _____							
RT: _____							
Other; Specify: _____							
RT: _____							

Instrument N

Title: California Skilled Nursing Facility Interview Guide

Designer: Catherine McGregor, RN, MSN, FNS, Sutter Auburn Faith Hospital. Please credit her in any publications and public presentations.

Suitable for Quality Improvement? Yes, edited to suit your state.

Suitable for research? No.

Description of Instrument: This interview guide is designed for face-to-face interviews with one or more nursing facility personnel involved with POLST at their facility. The interview helps the interviewer understand how POLST is working in that facility and what challenges and resources are present. The data collected is all free text, so aggregating it would be challenging unless you devised a systematic way of answering each question, however I think the intent of this instrument is to guide planned POLST education that a skilled POLST educator would then provide to personnel at the facility. It would also be a good preliminary step to learn more about how POLST is and is not working in your community before embarking on a more structured QA or QI activity.

How to use:

Step 1: Modify the form to suit your purposes. The questions are fairly specific so if you are worried about people being willing to speak up you could start with a more open-ended question such as ‘tell me about your experiences with POLST here’. Since these items were devised with specific educational objectives in mind, you may not need all the questions and may have others that you want to add. You may find items in other instruments elsewhere in the toolkit and want to include them and that is fine.

Step 2: Set up your face-to-face interview. This could be with an administrator or director of nursing or with a group of interested or selected personnel from the facility.

Step 3: Conduct your interview or focus group.

Step 4: Review the results. As noted, if you do these interviews at multiple facilities you may have some difficulty in aggregating the responses. It’s probably more important that you take away ideas about what needs improvement and what is working well, or important lessons or examples from each interview that will improve your educational interventions.

Some of the results that you will get from this survey include:

1. Who in the facility is a (potential) POLST champion?
2. What are the facilities’ policies and procedures for POLST?
3. What is the facilities experience with POLST?
4. How well educated and knowledgeable are the respondents about POLST?
5. What do the respondents find challenging about POLST?
6. How is POLST working between the facility and EMS?

Name of Staff Person: _____ **Date:** _____

Title: _____

SNF Name: _____

1. How long has your facility been using POLST?
2. Who would you say is the person with the most knowledge about POLST within your SNF (title)?
3. Does your SNF have a formal policy related to POLST? May I have a copy?
4. Has there been any POLST education for staff at the SNF? If so, please describe.
5. Have you admitted residents who have already had completed POLST forms?
6. What hospitals do residents with POLST forms come from?
7. When and how does a POLST form get introduced and completed?
8. Who is responsible for initiating the POLST conversation? Who participates in the conversation?
9. Who is responsible for completing the POLST form with the resident?

Please Credit Catherine E. McGregor, RN, MSN, FNS, Sutter Auburn Faith Hospital

10. Which physician signs the POLST form (e.g., medical director or patient's primary care physician)?
11. How do you determine whether a resident has capacity to sign the POLST form?
12. How do you determine who signs the POLST form if the resident lacks capacity?
13. What do you do with a completed POLST form? Where is it kept?
14. How do you keep track of POLST forms when a resident is transferred?
15. When is a POLST form reviewed and updated?
16. Are there any aspects of POLST that have been challenging for your staff or residents?
17. What EMS providers does your facility use?
18. Do the EMS staff know about POLST?
19. Have you experienced any issues with EMS staff regarding POLST?

Instrument O

Title: California POLST Assisted Living Survey

Designer: Neil Wenger, MD, MPH. Please credit him in any future work.

Suitable for Quality Improvement? Yes, modified to fit your state.

Suitable for research? Yes. A more refined version may be available from Dr. Wenger.

Description of Instrument: This telephone survey is the only instrument designed specifically for assisted living facilities. It was designed to produce research quality data about POLST utilization to assess the effectiveness of a major grass roots effort promoting POLST use in California. The survey was not done in isolation, but as follow up to an extensive educational outreach. It is a telephone survey addressed to the assisted-living administrator or knowledgeable designee.

How to use:

Step 1: Modify the form to suit your purposes. Note that RCFE stands for ‘residential care facilities for the elderly’. Decide whether you really need each item and keep items that you have a planned use for or believe may be important to have even though you are not sure what to do with them. Similarly, you may add items that are missing or that address questions that you are trying to answer. You may find items in other instruments elsewhere in the toolkit and want to include them and that is fine.

Step 2: Select which assisted living or residential care facilities you will survey. You may wish to survey all of them, or just a cross-section. See the FAQ section on ‘Sampling’. In general, as long as you choose facilities in a random fashion (for example, by choosing numbers out of a hat) and survey enough facilities so that you get 20-30 usable responses, that may be enough for most QA purposes.

Step 3: Call the programs/facilities and record the data. For some, you may not find someone who is willing or able to answer your questions—that is expected; just do the best you can. You will need to tabulate your results in a paper or software spreadsheet or statistical software program.

Step 4: Analyze the results. Some of the results that you will get from this survey include:

1. Awareness of POLST
2. Previous education about POLST for staff
3. Location of POLST in the facilities
4. Whether residents are completing POLST before or after coming to the facility
5. Proportion of residents who have a POLST
6. Interest in having future education about POLST
7. Some demographic questions about the facility

(Draft) CA POLST Assisted Living Survey

1. Have you heard of Physicians Order for Life Sustaining Treatment (POLST)?

____ Yes
 ____ No → ***Skip to question 10***

2. Have your staff ever received education about POLST?

____ Yes
 ____ No → ***Skip to question 6***

3. Approximately what percentage of the RCFE staff have received education about POLST?

____ %
 ____ Don't know

4. What aspects of education about POLST did your staff receive?

Respond Yes or No for each item

	<u>Yes</u>	<u>No</u>
a. General orientation about POLST	____	____
b. What to do with a POLST document in the RCFE	____	____
c. What to do with the POLST when the patient travels to a medical appointment	____	____

Other: _____

5. Who provided the education for the RCFE staff?

____ Don't know

6. Does your RCFE have a specific place to keep a copy of the POLST?

____ Yes
 ____ No
 ____ Don't know

7. Has your RCFE ever had a resident who had completed a POLST form before admission?

- ☐ Yes
☐ No → ***Skip to question 9***
☐ Don't know → ***Skip to question 9***

8. Approximately what percentage of the residents admitted to your RCFE in the past 3 months had a completed POLST form upon admission?

%
☐ Don't know

9. Approximately what percentage of the residents in your RCFE currently have a POLST form?

%
☐ Don't know

10. Would your RCFE benefit from any assistance in establishing procedures for POLST?

Respond Yes or No for each item

	<u>Yes</u>	<u>No</u>
a. Educational program for staff	<input type="checkbox"/>	<input type="checkbox"/>
b. Example policy for handling POLST	<input type="checkbox"/>	<input type="checkbox"/>

Other: _____

Some questions about your facility

11. How many residents are there in your RCFE? ____

12. Does your RCFE have a hospice waiver?

- ☐ Yes
☐ No
☐ Don't know

13. What is the primary language of the residents in your RCFE?

English	<input type="text"/> <input type="text"/> %
Spanish	<input type="text"/> <input type="text"/> %
Other: _____	<input type="text"/> <input type="text"/> %
Other: _____	<input type="text"/> <input type="text"/> %
	1 0 0 %

Instrument P

Title: Michigan POLST Program Partner Survey

Designer: Jane Dinnen, RN. Munson Medical Center. Please credit her in any future work.

Suitable for Quality Improvement? Yes, edited to suit your state.

Suitable for research? No.

Description of Instrument: This instrument was designed to survey partners in a statewide POLST initiative about their experience using POLST in nursing facilities. The 7 questions can be answered briefly but there is also room for comments, so it could be used to gather both quantitative and qualitative data. I think it was designed to be administered over the telephone or face-to-face. The 7 questions primarily address whether POLST is used and useful in that nursing facility.

How to use:

Step 1: Modify the form to suit your purposes. You may not need all the questions (several of the questions may be redundant) and may have others that you want to add. You may find items in other instruments elsewhere in the toolkit and want to include them and that is fine. You might want to ask specifically about barriers or challenges.

Step 2: Select which nursing homes you will survey. You may wish to survey all of them, or just a cross-section. See the FAQ section on 'Sampling'. In general, as long as you choose facilities in a random fashion (for example, by choosing numbers out of a hat) ensuring that you get to review 15-30 facilities total may be enough for most QA purposes.

Step 3: Call the facilities and record the data. Interviews could be with an administrator or director of nursing. For some, you may not find someone who is willing or able to answer your questions—that is expected; just do the best you can. You will need to tabulate your results in a paper or software spreadsheet or statistical software program.

Step 4: Review the results. The qualitative data will be difficult to aggregate but it's probably more important that you take away ideas about what needs improvement and what is working well, or important lessons or examples from each interview that will improve your educational interventions.

Some of the results that you will get from this survey include:

1. What % of patients have POLST form.
2. Is POLST useful in guiding treatment decisions and preventing unwanted resuscitation or hospitalization.
3. Could we conduct a chart review of a random sample of your patients?
4. In respondents' experience, have POLST forms been honored?

Michigan POLST Program Partner Survey

Please credit Jane Dinnen, RN, Munson Medical Center

POLST/ECF Partner Questions

1. What percentage of your patients do you believe have a POLST form?

_____ %

Comment: _____

2. Is it useful in guiding treatment decisions inside your facility?

☐ Yes ☐ No

Comment: _____

3. Is it useful in guiding/initiating end of life care treatment decisions?

☐ Yes ☐ No

Comment: _____

4. Is it useful in preventing unwanted resuscitation?

☐ Yes ☐ No

Comment: _____

5. Is it useful in preventing unwanted hospitalization?

☐ Yes ☐ No

Comment: _____

6. May we conduct a chart review of a random sampling of your pts?

☐ Yes ☐ No

Comment: _____

7. In your experience, have pt's POLST forms been honored?

☐ Yes ☐ No

Comment: _____

Michigan POLST Program Partner Survey

Please credit Jane Dinnen, RN, Munson Medical Center

Chart Review questions

Age

Track percentage of pts choosing various options

Limiting hospitalization, limiting ICU care

Forms signed?

Does pt have advance directive?

POLST consistent w/ advance directive?

Was pt POLST honored?

Instrument Q

Title: Washington POLST Nursing Facility Project

Designer: Judy Meyers, RN, PhD et al. Please cite the following reference in any future work:

Meyers JL, Moore C, McGrory A, Sparr J, Ahern M. Physician orders for life-sustaining treatment form: honoring end-of-life directives for nursing home residents. J Gerontol Nurs. 2004 Sep;30(9):37-46.

Suitable for Quality Improvement? Yes, modified to fit your state.

Suitable for research? Yes.

Description of Instrument: Dr. Meyers generously provided a lot of her research materials in hard-copy form. She and her colleagues did a very thorough evaluation of POLST in several nursing facilities in Washington state. Combining interviews with staff, patients and families, and chart review, she was able to demonstrate that, even though the program was very new in the state, it was working fairly well. This article is (so far) the only published evaluation of whether POLST orders match patient preferences, which is the question we all want answered. I've decided to group several instruments and interview guides together and will try to summarize what's here:

- Appendix A: Interview with Nursing Home Contact Person. These interviews could be completed in person or by phone. The interviewer begins by reading the verbal consent script (see Toolkit item KK). The questions are designed for free text answers to be recorded either by hand or by audio-recording. Because a small number of facilities were involved in this study, it was not difficult to compile afterwards. Question 4 is somewhat leading, it might be better to ask 'How is POLST introduced to patients in your facility?' and leave 'how do you ensure informed consent?' for a follow-up probe question.
- Appendix B: Interview guide for nursing home residents/legal surrogates. This also includes the informed consent script (see Toolkit item KK). This started as an 8 question guide but was shortened to just 2 questions after pilot testing!
- Appendix C: Chart Review Tool for Nursing Homes. This chart review requires a knowledgeable, probably clinically or research trained reviewer because the reviewer must determine whether informed consent process was followed, whether patients received care consistent with their wishes, and whether POLST appeared to follow the patient across treatment settings.

In addition, Dr. Meyers also provided copies of her Project Recruitment Letter (Toolkit Item JJ), her consent form (Toolkit item KK), and a summary of her project that she provided to stakeholders to report her findings (Toolkit item LL).

Appendix A

Interview with Nursing Home Contact Person

Read verbal consent script

1. When use of the POLST form was introduced to your facility, what sort of training did you receive?
2. What training did the staff of this facility receive?
3. Was it clear to you, and in the training that your staff receives, that use of the POLST is optional?
4. When POLST is used in your facility, what measures are taken to ensure that the informed consent process is honored?
5. What policies and procedures, related to use of the POLST, do you have in place? (Ask them if they would be willing to have a copy of their policies and procedures related to the POLST mailed to Crystal Moore, EWU, 203 Senior, 526 5th St., Cheney, W A 99004)
6. What types of problems or issues have you encountered in utilizing the POLST?

Appendix B

Interview guide for Nursing Home Residents/Legal Surrogates

Read informed consent script.

1. What are your end-of-life wishes?
2. How was the POLST (show them a copy of the form) introduced to you?

Appendix C

Chart Review Tool for Nursing Homes

1. Is there evidence that the informed consent process was followed? Yes No

Comments: (E.g., evidence of care conference with discussion of EOL issues.)

2. Is there evidence that the resident's wishes were honored? Yes No

Comments: (E.g. congruence between AD and boxes marked on POLST, feeding tube placements or antibiotics?)

3. Was the POLST reviewed appropriately? Yes No

Comments: (E.g. within 14 days of admission and/or with each significant change in the resident's condition?)

4. Is there evidence that the POLST form is portable across health care settings? Yes/No

Comments: (E.g. on the back of the form there is evidence of resident transfer(s) with the form.)

Instrument R

Title: Oregon Emergency Medical Services Survey

Designer: Terri Schmidt, MD, MS et al. Please cite this reference in any future work.

Schmidt TA, Hickman SE, Tolle SW, Brooks HS. The Physician Orders for Life-Sustaining Treatment program: Oregon emergency medical technicians' practical experiences and attitudes. J Am Geriatr Soc. 2004 Sep;52(9):1430-4.

Suitable for Quality Improvement? Yes, modified to fit your state.

Suitable for research? Yes.

Description of Instrument: This written survey is for to be completed by EMTs and Paramedics and has been successfully used for research projects in Oregon and California. This is the only instance of one state using another's survey, but hopefully with this Toolkit it will not be the last. The Oregon study (ref above) was used this survey to demonstrate that POLST did change emergency management for patients and that most EMTs found it useful. The survey includes 5 sections:

1. demographic information about the EMTs
2. experiences with the POLST form
3. most recent experience with a specific POLST form
4. attitudes about POLST
5. feedback on the form itself

How to use:

Step 1: Consider modifying the form to suit your purposes. If you are doing research you may want to keep the individual sections intact as much as possible—this survey has proven itself in multiple projects and would facilitate comparison to other states' data. See also Toolkit Instrument S the NY EMT MOLST Survey which asked different but equally useful questions. Decide whether you really need each item and keep items that you have a planned use for or believe may be important to have even though you are not sure what to do with them. You may also add items that are missing or that address questions that you are trying to answer. You may find items in other instruments elsewhere in the toolkit and want to include them and that is fine.

Step 2: Select which EMTs you want to survey. You may wish to survey all of them, or just a cross-section. See the FAQ section on 'Sampling'. In general, as long as you choose EMTs in a random fashion (for example, by choosing numbers out of a hat) and get a decent response rate to your survey (30-50%+ for QA and 50-75%+ for research) and survey enough EMTs so that you get to 30 usable responses (more for research), that may be enough for most QA purposes.

Step 3: There is a well described methodology for mailed surveys that is beyond the scope of this toolkit, but you should include a self-addressed, stamped envelope and plan on doing more than one mailing. It also helps to have as much institutional support as you can muster to encourage busy people to complete your survey.

Step 4: Analyze the results.

POLST EMS SURVEY

Please indicate your response by placing a check before your choice or writing in your answer. Your responses will be kept confidential.

First, we would like to ask a few questions about you and your experience as an EMT:

1. What is your certification level? ☐ EMT Basic ☐ EMT intermediate ☐ Paramedic
2. What is your age? ☐ 18 –25 yrs ☐ 26 - 34 yrs ☐ 35 – 44 yrs ☐ 45 – 54 yrs ☐ 55yrs+
3. What is your gender? ☐ female ☐ male
4. How many years have you been an EMT at your current level?
 ☐ less than 1 year ☐ 1-5 years ☐ 6 – 10 years ☐ 11-15 years ☐ 15 years +
5. Do you work as part of a 9-1-1 system? ☐ yes ☐ no
6. How many hours a week do you work/volunteer in your *primary* EMS role? _____ hours
7. Do you transport patients? ☐ yes ☐ no
8. Please use the attached sheet to identify your agency's ID number. (We will use this information to assess the average calls per day for your agency.) Primary position agency # _____.

Next, we would like to know about your personal experience with the POLST form:

9. Have you received any education about the use of POLST (Physician Orders for Life Sustaining Treatment) form?
 ☐ yes _____ formal (class or reading materials) _____ informal (from peers) _____ other
 ☐ no
10. To your knowledge, is the POLST form used in your community? ☐ yes ☐ no
11. Have you ever treated a patient with a completed POLST form?
 ☐ yes _____ patients in the last month (please estimate #)
 ☐ no (if, no skip to question 14)
12. Have you ever treated a pediatric patient (under age 18) with a filled-out POLST form? ☐ yes ☐ no
 If yes, was the POLST helpful in making treatment decisions? ☐ yes ☐ no

13. Please answer the following questions based on the most recent patient you treated who had a POLST form:

a. Where was this patient located at the time you responded to the call?

- ☐ Private home ☐ Residential Care/Assisted Living Facility ☐ Foster home ☐ Nursing facility
☐ Other (please specify) _____

b. Did you have any difficulty locating this patient's POLST form? ☐ yes ☐ no

If yes, please describe _____

c. Where was this patient's POLST form located?

- ☐ front of chart ☐ refrigerator ☐ wallet card in wallet

☐ provided by family member ☐ other , please specify _____

REMINDER: Please answer the following questions based on the most recent patient you treated who had a POLST form:

d. Was this patient's POLST form filled out appropriately? ☐ yes ☐ no *If no, what was wrong?*

☐ no signature ☐ conflicting orders ☐ sections A or B not marked

☐ other, please specify _____

e. Did the POLST form change the treatment plan from treatments that would otherwise have been given to this patient?

☐ yes ☐ no *If the plan of treatment changed, in what way(s) did it change?* _____

f. Was this patient's POLST form over-ridden? ☐ yes ☐ no *If yes, by whom?*

☐ patient ☐ family member ☐ durable power of attorney over health care

☐ other, please specify _____

g. Was this case typical of situations in which the POLST form is present? ☐ yes ☐ no

Now we would like to know your opinions about POLST:

Please indicate whether you agree or disagree to the statements below using the following scale. Place the number that best represents your beliefs in the space provided.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

14. _____ The POLST form provides clear instructions about patient's preferences.
15. _____ The POLST form is useful in determining which treatments to provide when a patient has no pulse and is apneic.
16. _____ The POLST form is useful in determining whether or not to transport a patient to the hospital.
17. _____ The POLST form does NOT reliably express patient wishes.
18. _____ The POLST form is useful in determining what treatments to provide a patient who currently has a pulse and is breathing.
19. _____ The POLST form is not working in my community.
20. _____ I feel more comfortable knowing what to do when a POLST form is available.
21. _____ The POLST form has made difficult decisions easier for me.
22. _____ I wish that more patients in my area had a POLST form.
23. _____ Sometimes having a POLST form makes treating patients more complicated.

Please Credit Terri Schmidt, MD, MS et al, Oregon Health & Science University

Finally, please provide feedback about the POLST form:

24. Are there barriers to the use of the POLST form in your community? ☐ Yes ☐ No *If yes please explain:*
25. What problems, if any, have you seen with the POLST form in the field (*answer only if you have had first hand experience with the POLST form in the field*)?
26. In what ways, if any, has the POLST program been helpful to you in the *field* (*answer only if you have had first hand experience with the POLST form in the field*).

THANK YOU FOR YOUR TIME.

PLEASE RETURN BY JULY 17, 2002

Instrument S

Title: New York MOLST Emergency Medical Technician Survey

Designer: Stanley Sam, MD et al. Please cite this reference in any future work.

Sam S, Pekmezaris R, Nouryan CN, Tan R, Conrardy A, Ward MF, Schwalberg A, Vij B, Silverman H, Guzik HJ, Lesser ML, Wolf-Klein GP. Survey of emergency medical services professionals' experience with advance directives and medical orders for life-sustaining treatment. J Am Geriatr Soc. 2011 Dec;59(12):2383-4.

Suitable for Quality Improvement? Yes, modified to fit your state.

Suitable for research? Yes.

Description of Instrument: This written survey is to be completed by EMTs and Paramedics and has been successfully used for a research project in New York City and Long Island. The authors used this survey to show that there were significant knowledge deficits among EMTs (MOLST had only been in place for a few years at the time of the survey) and that younger EMTs were less likely to honor MOLST DNR orders than those with 6 or more years of experience.

How to use:

Step 1: Consider modifying the form to suit your purposes. If you are doing research you may want to keep the survey intact as much as possible—this survey has proven itself and would facilitate comparison to the NY data. See also Toolkit Instrument R the Oregon Emergency Medical Services Survey which asked different but equally useful questions. Decide whether you really need each item and keep items that you have a planned use for or believe may be important to have even though you are not sure what to do with them. You may also add items that are missing or that address questions that you are trying to answer.

Step 2: Select which EMTs you want to survey. You may wish to survey all of them, or just a cross-section. See the FAQ section on ‘Sampling’. In general, as long as you choose subjects in a random fashion (for example, by choosing numbers out of a hat) and get a decent response rate to your survey (30-50%+ for QA and 50-75%+ for research) and survey enough subjects so that you get to 30 usable responses (more for research), that may be enough for most QA purposes.

Step 3: There is a well described methodology for mailed surveys that is beyond the scope of this toolkit, but you should include a self-addressed, stamped envelope and plan on doing more than one mailing. It also helps to have as much institutional support as you can muster to encourage busy people to complete your survey.

Step 4: Analyze the results. Some of results include:

1. Demographic information about the EMTs, including their own preferences for resuscitation.
2. Experiences with family members trying to reverse a DNR order, and attitudes toward CPR and DNR orders.
3. Experiences with MOLST and out of hospital DNR orders
4. Two scenarios asking the question ‘what would influence your decision to initiate CPR/to transfer the patient to the hospital’.
5. Attitudes toward and familiarity with MOLST

NY EMT POLST/MOLST Survey

Abbreviations:

MOLST=Medical Orders for Life-Sustaining Treatment **POLST**=Physician Orders for Life-Sustaining Treatment

EOL=End of Life **AD**=Advance Directives **EMT B**= BASIC **EMT-I**=Intermediate **EMT CC**=Critical Care

DNR=Do Not Resuscitate **DNI**= Do Not Intubate

1. What is your EMT status? (check all that apply)

☐ EMT-B ☐ EMT-CC ☐ EMT-I ☐ EMT-Paramedic ☐ Other_____

2. What EMT organization(s) are you affiliated with? (check all that apply)

☐ Police Dept. ☐ Fire Dept. ☐ EMT ☐ Paramedic ☐ Nassau EAB ☐ Hatzolah ☐ NSLIJ ☐ Other_____

3. How are you employed?

☐ Volunteer ☐ Paid ☐ Both ☐ Other_____

4. What is the highest level of education you have completed?

☐ High School ☐ High school equivalency degree ☐ College ☐ Masters ☐ MD ☐ PhD ☐ Other_____

5. How many years have you been an EMT?

_____Years

6. Please indicate your gender.

☐ Male ☐ Female

7. Please indicate your age.

_____Years

8. What religion are you?

☐ Buddhist ☐ Catholic ☐ Hindu ☐ Jewish ☐ Muslim ☐ Protestant ☐ Atheist
☐ Other_____

9. How religious are you?

☐ Not at all ☐ Not very ☐ A little ☐ Somewhat ☐ Very religious

10. How important is it to you to ascertain a patient's end of life care preferences prior to initiating emergency treatment. (i.e. a need to secure airway via intubation or CPR)?

☐ Not important ☐ Some what important ☐ Neutral ☐ Important ☐ Very important

11. At your current age, do you personally wish to be resuscitated in the event of a cardiac or respiratory arrest?

☐ No ☐ Probably Not ☐ Not sure ☐ Probably ☐ Definitely

12. When you reach age 85, would you wish to be resuscitated in the event of a cardiac or respiratory arrest?

☐ No ☐ Probably not ☐ Not sure ☐ Probably ☐ Definitely

13. Have you ever felt you had to initiate and continue CPR in a patient who clearly had a DNR order because a family member/health care proxy requested it?

☐ Never ☐ Rarely ☐ Sometimes ☐ Frequently ☐ Very frequently

14. In some situations, I believe that a “slow code” is justified.

☐ Never ☐ Rarely ☐ Sometimes ☐ Frequently ☐ I don't know what that means

15. What importance does your supervisor place on looking/asking for advance directives on patients?

☐ Irrelevant ☐ Minor ☐ Neutral ☐ Important ☐ Essential

16. I would perform CPR on all patients rather than wasting time trying to find a DNR/MOLST/POLST document.

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

17. It is the ER attending/staff responsibility to sort out the patient/family wishes regarding DNR/MOLST/POLST.

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

18. In the field, when arriving at the scene of a cardiac arrest, for which patient age group would you be most likely to seek advance directive documentation?

☐ Under 20 ☐ 21-40 ☐ 41-60 ☐ 61-80 ☐ Over 80 ☐ All ages

19. In the field, when arriving at the scene of a cardiac arrest, in what patient setting would you be most likely to seek advance directive documentation?

☐ Private residence ☐ Public setting ☐ Doctor's office ☐ Assisted Living ☐ Nursing facility ☐ All settings

20. Have you ever heard of the MOLST document?

☐ Yes ☐ No ☐ Don't know

21. NY State law requires that all EMT's get on-line MOLST/POLST training and get a certificate.

☐ Yes ☐ No ☐ Don't know

22. Have you had formal training about the MOLST/POLST document?

☐ Yes ☐ No ☐ Don't know

23. How many times have you been presented with the MOLST/POLST document in an emergency situation?

☐ Never ☐ 1-5 ☐ 6-10 ☐ 11-20 ☐ over 20

24. A photocopy of the MOLST/POLST document is as good as the original.

☐ Yes ☐ No ☐ Don't know

25. Have you ever been asked to honor an out-of-hospital DNR/advance directive?

☐ Yes ☐ No ☐ Don't know

→ If yes, by whom?

☐ Spouse ☐ Sibling ☐ Children ☐ Friend ☐ Neighbor ☐ Self ☐ Other_____

26. It is difficult to find advance directive documents while at the scene of a cardiac arrest.

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

27. You arrive at the home of a person on the floor in cardiac arrest. A MOLST/POLST indicating DNR and DNI is presented. Which of the following factors would influence your decision to initiate CPR? (Check all that apply)

- | | |
|--|--|
| <input type="checkbox"/> Age of the patient | <input type="checkbox"/> Perceived quality of life of the patient prior to arrival |
| <input type="checkbox"/> Gender of the patient | <input type="checkbox"/> Knowledge of terminal disease in the patient |
| <input type="checkbox"/> Presence of family member in the room | <input type="checkbox"/> All of the above |
| <input type="checkbox"/> Environmental surroundings of the patient | <input type="checkbox"/> none of the above |

28. You arrive at the home of a 62 year old male patient with advanced COPD who is having difficult breathing but denies pain. His low-flow oxygen is working properly. A MOLST/POLST indicating comfort measures only, and Do Not Transfer is presented. Which of the following factors would influence your decision to transfer the patient to the hospital? (Check all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Age of the patient | <input type="checkbox"/> Gender of the patient |
| <input type="checkbox"/> Presence of family member in the room | <input type="checkbox"/> Environmental surroundings of the patient |
| <input type="checkbox"/> Perceived quality of life of the patient prior to arrival | <input type="checkbox"/> Knowledge of terminal disease in the patient |
| <input type="checkbox"/> All of the above | <input type="checkbox"/> None of the above |

29. I feel comfortable in honoring the MOLST/POLST document.

- ☐ Yes ☐ No ☐ Don't know

30. Have you been asked not to resuscitate a patient in the absence of a formal advance directive document? (e.g. MOLST/POLST, out-of-hospital DNR?)

- ☐ Yes ☐ No ☐ Don't know

→ **If yes, in what setting.** (check all that apply)

- ☐ Private residence ☐ Public setting ☐ Doctor's office ☐ Assisted Living ☐ Nursing facility ☐ All settings

→ **If yes, by whom** (check all that apply)

- ☐ Spouse ☐ Sibling ☐ Children ☐ Friend ☐ Neighbor ☐ Self ☐ Other _____

31. What color is the MOLST/POLST document?

- ☐ Yellow ☐ Red ☐ Purple ☐ Pink ☐ White ☐ Green

32. NY State grants immunity from lawsuits to health care workers and EMTs who honor the wishes expressed in a MOLST/POLST document.

- ☐ True ☐ False ☐ Don't know

33. Which of the following is NOT part of the MOLST/POLST document? (check all that apply)

- | | |
|--|--|
| <input type="checkbox"/> Resuscitation | <input type="checkbox"/> Pain medications |
| <input type="checkbox"/> Power of attorney | <input type="checkbox"/> Artificial Nutrition |
| <input type="checkbox"/> Intubation | <input type="checkbox"/> Artificial hydration with IV fluids |
| <input type="checkbox"/> Antibiotics | <input type="checkbox"/> Hospitalization |

34. I would look for the MOLST/POLST form (check all that apply)

- ☐ On the back of bedroom door ☐ Next to the phone ☐ In the medicine cabinet ☐ On the refrigerator door

THANK YOU FOR YOUR PARTICIPATION!

Instrument T

Title: New York MOLST EMS Quality Assurance Project

Designer: Pat Bomba, MD. Please credit her in any future work.

Suitable for Quality Improvement? Yes, modified to fit your state.

Suitable for research? No.

Description of Instrument: This very concise survey is designed to be completed by EMTs in the field as they are working and completing their patient care records (PCR) – one survey for one EMT and one patient. The survey includes a descriptive summary of the QA/QI program. You should also check out Dr. Bomba’s website, www.compassionandsupport.org and her supporting materials:

- Toolkit Instrument FF: Sample MOLST Survey Cover Letter
- Toolkit Instrument GG: Sample MOLST Implementation Plan
- Toolkit Instrument HH Sample MOLST EMS Pilot Results Letter

How to use:

Step 1: Getting buy-in from Emergency Medical Services Leadership. This is obviously critical, as the EMTs will be providing the data and it is their work which is being assessed. Since the program is voluntary, getting buy in from EMS programs is more likely to be effective than recruiting individual EMTs.

Step 2: Educating EMTs about MOLST. A major educational effort is needed to ensure that EMTs understand MOLST, understand why it is important, and are aware of the QA program and what they need to do to complete and submit the forms.

Step 3: There needs to be infrastructure to receive and review the submitted forms, aggregate the data, and provide feedback to each participating EMS group. It will be helpful to establish benchmarks and decide beforehand with EMS leaders how they want to receive feedback, what they plan to do with it, and how long the project will continue. In particular, there needs to be consensus on how to handle cases where MOLST was not followed. Without consistent and reliable feedback and follow up QA programs fizzle.

Step 4: Follow up with participating EMS groups to find out what they are doing with the data, if they require further education, etc. See Dr. Bomba’s EMS Pilot Results Letter, Toolkit Instrument HH.



MOLST

New York EMS QA/QI Program

History:

MOLST began as a community wide collaborative effort to develop a method that would ensure that patient wishes were known and honored across the health care system at the end of life. Through the efforts of many individuals and groups, a pilot program was created that included legislation that allowed the MOLST form to replace the currently accept NYS DOH DNR form. The MOLST not only addresses the issue of DNR but also gives direction to providers regarding different modalities of care for patients. These directions are actual medical orders given by a licensed physician that can be followed by all health care providers.

Objectives:

There are two distinct objectives to be measured in this phase of the MOLST program.

- 1) Is the MOLST form identified and available?
- 2) Is the MOLST form being followed?

(As an addition to item 1, a tool to identify the facility that MOLST was found should be used to help quantify the saturation of the form.)

Method:

As part of a pilot study, data gathered for MOLST will be a voluntary participation program. Providers receiving the education on the use of MOLST will be informed on the importance of data and encouraged to participate in this program.

- 1) Electronic Patient Charting
 - a. A data collection point can be added to the electronic patient charting program.
 - i. This data collection point will identify:
 1. Was a MOLST form identified?

2. Was the MOLST form complete?
3. What type of facility was the patient picked up from, i.e. home, assisted living, extended care facility, office, hospital?
4. Was the MOLST honored?
 - a. if not why –
 - i. not applicable (condition of patient did not warrant use of MOLST)
 - ii. conflict with people on scene
 - iii. medical control
 - iv. other

2) Paper Patient Charting

- a. An additional survey form would be filled out and forwarded to a central reporting location. (form attached)

- 3) All Patient Care Reports (100%) that identify the use of MOLST in decision making regarding care of the patient will be reviewed by the Regional QA program.



NYS MOLST PILOT PROJECT QA SURVEY

PCR Number _____ Date _____

Patient Pick Up: ☐ Hospital ☐ Home ☐ Assisted Living ☐ Long Term Care
☐ Hospice ☐ Other

Name and Address of Facility

Was MOLST identified? ☐ Yes ☐ No

Was MOLST complete? ☐ Yes ☐ No

Was MOLST honored? ☐ Yes ☐ No

If answer above was No why –

- ☐ Patient condition not applicable
- ☐ Conflict on scene with patient/family
- ☐ Medical Control
- ☐ Other

Comments

EMT # _____

Instrument U

Title: New York Hospital Anonymous Employee Survey

Designer: Vo et al. Please cite this reference in any work you do:

Vo H, Pekmezaris R, Guzik H, Nouryan C, Patel C, Vij B, Tai J, Wolf-Klein G. Knowledge and attitudes of health care workers regarding MOLST (Medical Orders for Life-Sustaining Treatment) implementation in long-term care facilities. Geriatr Nurs. 2011 Jan-Feb;32(1):58-62.

Suitable for Quality Improvement? Yes, with modification to fit your state.

Suitable for research? Yes, with some modifications.

Description of Instrument: This written survey was designed to measure knowledge and attitudes about MOLST in physicians, nurses, and social workers in long term care facilities operated by North Shore-LIJ Health System in New York state. The surveys were distributed in paper form and completed and collected at staff meetings. Although the published research deals with long term care, the survey is targeted to hospital-based clinicians.

How to use:

Step 1: Modify the form to suit your purposes. Only keep items that you have a planned use for or believe may be important to have even though you are not sure what to do with them. Similarly, you may add items that are missing or that address questions that you are trying to answer. That said, I would encourage you to keep the sections 1 and 2(end-of-life experience and attitudes) of this instrument as intact blocs if feasible. Another recommendation is to avoid asking respondents about DNR and POLST in the same item, e.g. item 1:

1. How often in the last 12 months have you been asked to **fill out** or administer a ~~DNR or~~ POLST?
- | | | | | |
|-------|---------------|----------------|-------------|-----------|
| Never | 1 to 10 times | 11 to 20 times | 21-30 times | >30 times |
|-------|---------------|----------------|-------------|-----------|

Step 2: Select who you will send the survey to. The survey is designed for clinicians who use the MOLST form. If you are a POLST paradigm program you may wish to survey your entire state or region. If you are a hospital or a nursing facility you may wish to only survey your clinicians. If you have a lot of clinicians, you may not need to survey them all. See the FAQ section on 'Sampling'. In general, as long as you choose clinicians in a random fashion (for example, by choosing numbers out of a hat) and get a decent response rate to your survey (30-50%+ for QA and 50-75%+ for research) and survey enough clinicians so that you get to 30 usable responses (more for research), that may be enough for most QA purposes.

Step 3: This survey could be mailed or you could follow the researchers practice of handing out the surveys at staff meetings. The latter practice got them a 35% response rate. They must have kept careful track of how many surveys they distributed in order to calculate the response rate.

Step 4: Analyze the results. Some of the results that you will get from this survey include:

- EOL Experience including with MOLST and talking to patients and families
- EOL Attitudes about MOLST, whose responsibility is it to discuss MOLST, and whether patients have the right to refuse life-sustaining treatment.
- EOL Training including professional experience, and demographics. This section is actually includes only 1 question about training and might be better labeled 'EOL Demographics'.

NY Hospital Employee Anonymous Survey

Please complete this voluntary, anonymous, and completely confidential survey to aid researchers and staff to assess palliative care needs in XXX Hospital. This information will be used as aggregated data only. By completing and returning the form to DR XXX, principal investigator, you are giving consent to participate. If you desire more information, contact Dr XXX at: Dr XXX@xxx.com.

Abbreviations: POLST=Physician Orders for Life-Sustaining Treatment, EOL=End of Life, AD=Advance Directives

Part 1: EOL Experience

1. How often in the last 12 months have you been asked to **fill out** or administer a DNR or POLST?
Never 1 to 10 times 11 to 20 times 21-30 times >30 times

2. How many times in the last 12 months have you been asked to **honor** a DNR or POLST **in the hospital setting**?
Never 1 to 10 times 11 to 20 times 21-30 times >30 times

3. How often in the last 12 months have you been asked to **ignore** an existing DNR, POLST, or another advance directive by a surrogate decision maker or family member?
Never 1 to 10 times 11 to 20 times 21-30 times >30 times

4. How often in the last 12 months have you **met** with a family member regarding EOL decisions?
Never 1 to 10 times 11 to 20 times 21-30 times >30 times

5. How often in the last 12 months have you **met** with a patient regarding EOL decisions?
Never 1 to 10 times 11 to 20 times 21-30 times >30 times

6. A POLST form must be signed by a physician to be valid. True False Don't Know

7. A POLST form must be pink to be valid. True False Don't Know

Part 3: EOL Training

- ## Table of Contents

Instrument V

Title: Wisconsin Hospital Chart Review Form

Designer: Bud Hammes, PhD. Please cite these studies in any future work:

Hickman SE, Nelson CA, Perrin NA, Moss AH, Hammes BJ, Tolle SW. A comparison of methods to communicate treatment preferences in nursing facilities: traditional practices versus the physician orders for life-sustaining treatment program. J Am Geriatr Soc. 2010 Jul;58(7):1241-8.

Hammes BJ, Rooney BL, Gundrum JD. A comparative, retrospective, observational study of the prevalence, availability, and specificity of advance care plans in a county that implemented an advance care planning microsystem. J Am Geriatr Soc. 2010 Jul;58(7):1249-55.

Suitable for Quality Improvement? Probably too extensive for QI purposes, but the items are excellent.

Suitable for research? Yes.

Description of Instrument: This chart review provides a comprehensive look at advance care planning, patient preferences, and receipt of life-sustaining treatment during and after hospitalization. It was designed to collect research data for studies examining whether POLST forms were effective in guiding life-sustaining treatments for patients in nursing facilities. Since most life-sustaining treatments occur in the hospital, this form was used to capture data when these patients were hospitalized. The form is long and requires some skill on the part of the chart reviewer to correctly complete the review. It is more suitable for research but any of the items may be of use for QI purposes.

Description of selected items:

- Item 7, Reason for hospitalization and discharge disposition
- Item 9, Preferences: this item asks the reviewer to identify and describe any documented discussions about treatment preferences.
- Items 10: these items assess who is making medical decisions and the presence of other advance care planning documents.
- Item 11: Indicates if the patient had treatment PREFERENCES documented for a long list of medical treatments.
- Item 12: Indicates whether the patient had ORDERS, including POLST orders, for life sustaining treatments in the chart.
- Item 13: Documents whether the patient received any of 13 different life sustaining treatments.
- Item 14: Documents whether there are any orders for life-sustaining treatments in the community at discharge.
- Item 15: Documents POLST orders at discharge.

OR HOSPITAL CHART REVIEW FORM

1. Today's Date _____

2. Age in Years _____

3. Gender

☐ Female

☐ Male

4. Race/Ethnicity:

☐ White

☐ African American/Black

☐ Native Hawaiian/Pacific Islander

☐ Asian

☐ American Indian/Alaskan Native

☐ Hispanic

☐ Other

☐ not available

5. Education

☐ No Schooling

☐ 8th Grade/less

☐ 9 – 11th grades

☐ High School

☐ Technical/trade school

☐ some college

☐ Bachelor's degree

☐ Graduate degree

☐ not available

6. Discharge destination

☐ Bethany St. Joseph's

☐ Bethany Riverside

☐ Hillview

☐ St. Joseph's

☐ Onalaska Care

☐ Mulders

☐ Lakeview

☐ Rolling Hills

☐ Morrow Home

7. Admission/Discharge:

a. Primary reason for hospitalization _____

b. Reason for discharge to nursing home

☐ rehabilitation

☐ long term care

☐ other _____

c. Is this a new discharge to a nursing home? ☐ yes ☐ no

d. Did the resident have a POLST at admission to the hospital? ☐ yes ☐ no

If the resident had a POLST at admission, was the POLST changed at
discharge? ☐ yes ☐ no ☐ not applicable

8. Primary service admitted to: _____

Discharge Service: _____

Date of admission _____ Date of Discharge _____

HOSPITAL PREFERENCES, ORDERS, & LIFE-SUSTAINING TREATMENTS

9. PREFERENCES: Is there evidence of a discussion about **treatment preferences** in the chart at discharge: ☐ yes ☐ no

If yes, describe:

Date of Discussion	Staff involved? Identify.	Patient/family involved? Identify.	Was surrogate authorized? If so, describe role.

a. Where is this documented? _____

b. Who documented the discussion? _____

c. Length of discussion

☐ 0-15 min. ☐ 15-30 min. ☐ 30-45 min ☐ no time listed

d. What was discussed? Please describe treatment preferences or plans.

10. a. What, if any, **advance directive** forms are present in the chart? (Check all that apply)

- ☐ Advance directive/living will (circle type used and indicate date of document)
 - ☐ LaCrosse Respecting Choices POAHC _____/_____/_____ Date
 - ☐ Addendum to POAHC _____/_____/_____ Date
 - ☐ Statement of Treatment Preference form _____/_____/_____ Date
 - ☐ Wisconsin Statutory POAHC _____/_____/_____ Date
 - ☐ Wisconsin Declaration to Physicians or other Living Will _____/_____/_____ Date
- ☐ Designated Decision-maker (named by resident) _____/_____/_____ Date
- ☐ Legal Guardian _____/_____/_____ Date
- ☐ Other (describe) _____/_____/_____ Date
- ☐ No form present

b. Who is making decisions at this point in time?

- ☐ Patient
- ☐ Healthcare Agent
- ☐ Legal Guardian
- ☐ Designated Decision-maker
- ☐ Next of kin
- ☐ Other: _____

11. Document all **treatment preferences** in the table below. (See advance directive)

<p>IF I AM CLOSE TO DEATH:</p> <p><input type="checkbox"/> I want feeding tubes/artificial nutrition and hydration.</p> <p><input type="checkbox"/> I want tube feedings only as my physician recommends</p> <p><input type="checkbox"/> I do not want feeding tubes/artificial nutrition and hydration</p> <p><input type="checkbox"/> No preference indicated</p> <p><input type="checkbox"/> I want any other life support that may apply</p> <p><input type="checkbox"/> I want life support only as my physician recommends</p> <p><input type="checkbox"/> I want NO life support</p> <p><input type="checkbox"/> No preference indicated</p>	<p>IF I AM PERMANENTLY UNCONSCIOUS/PERISTENT VEGETATIVE STATE:</p> <p><input type="checkbox"/> I want to receive tube feeding</p> <p><input type="checkbox"/> I want tube feeding only as my physician recommends</p> <p><input type="checkbox"/> I do not want tube feeding</p> <p><input type="checkbox"/> No preference indicated</p> <p><input type="checkbox"/> I want any other life support that may apply</p> <p><input type="checkbox"/> I want life support only as my physician recommends.</p> <p><input type="checkbox"/> I want NO life support</p> <p><input type="checkbox"/> No preference indicated</p>
<p>KIDNEY DIALYSIS</p> <p><input type="checkbox"/> I do want kidney dialysis</p> <p><input type="checkbox"/> I do not want kidney dialysis</p> <p><input type="checkbox"/> No preference indicated</p>	<p>VENTILATOR SUPPORT</p> <p><input type="checkbox"/> I do want ventilator support</p> <p><input type="checkbox"/> I do not want ventilator support</p> <p><input type="checkbox"/> No preference indicated.</p>
<p>RESUSCITATION (preferences, not orders)</p> <p><input type="checkbox"/> I do want cardiac resuscitation</p> <p><input type="checkbox"/> I do not want cardiac resuscitation</p> <p><input type="checkbox"/> I want CPR under certain circumstances as MD recommends</p> <p><input type="checkbox"/> No preference indicated</p>	<p>LOSS OF ABILITY TO RELATE TO SELF, OTHERS AND ENVIRONMENT</p> <p><input type="checkbox"/> I do not want CPR</p> <p><input type="checkbox"/> I do not want antibiotics</p> <p><input type="checkbox"/> I do not want a feeding tube, artificial hydration and nutrition</p> <p><input type="checkbox"/> No preference indicated</p>
<p>ANTIBIOTICS</p> <p><input type="checkbox"/> I do want antibiotics</p> <p><input type="checkbox"/> I do not want antibiotics</p> <p><input type="checkbox"/> No preference indicated</p>	<p>TRANSFUSION</p> <p><input type="checkbox"/> I do want transfusion</p> <p><input type="checkbox"/> I do not want transfusion</p> <p><input type="checkbox"/> No preference indicated</p>
<p>PAIN AND SYMPTOM CONTROL IF EFFORTS TO PROLONG LIFE ARE STOPPED</p> <p><input type="checkbox"/> I want to be kept comfortable even if it risks my dying sooner</p> <p><input type="checkbox"/> No preference indicated</p>	<p>HOSPITALIZATION</p> <p><input type="checkbox"/> I do want _____</p> <p><input type="checkbox"/> I do not want _____</p> <p><input type="checkbox"/> No preference indicated</p>
<p>Agent authority to admit me to a nursing home or community-based residential facility for the purpose of long-term care:</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p>	<p>Agent authority to order the withholding or withdrawal of feeding tube and IV hydration:</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p>

OTHER PREFERENCES

12. ORDERS RE LIFE-SUSTAINING TREATMENT: Document all **medical orders** written in the medical chart in the table below.

TREATMENT CATEGORY	CHECK BOX	WRITTEN ORDERS	DATE OF ORDER
Resuscitation/ Medical Intervention	<input type="checkbox"/>	Full Code	
	<input type="checkbox"/>	O-DNR	
	<input type="checkbox"/>	O-DNR/DNI	
	<input type="checkbox"/>	P-DNR	
Other Orders (specify)	<input type="checkbox"/>		
	<input type="checkbox"/>		
	<input type="checkbox"/>		
	<input type="checkbox"/>		
	<input type="checkbox"/>		
	<input type="checkbox"/>		

13. TREATMENTS: Document **life-sustaining treatments** below.

TREATMENT PROVIDED	Date(s) of occurrences	Treatments Provided & Other Relevant Information
Resuscitation:	1) _____ 2) _____	
EMS visit with/without transport (indicate treatments provided by EMS):	1) _____ 2) _____ 3) _____ 4) _____	1) _____ 2) _____ 3) _____ 4) _____
Emergency Department Visit without hospitalization (indicate treatments provided in ED):	1) _____ 2) _____ 3) _____ 4) _____	1) _____ 2) _____ 3) _____ 4) _____
Hospitalization:	1) _____ 2) _____	
Surgery:	1) _____ 2) _____	
Transfusion:	1) _____ 2) _____ 3) _____ 4) _____	
Intubation:	1) _____ 2) _____ 3) _____ 4) _____	
Dialysis:	1) _____ 2) _____ 3) _____ 4) _____	
Antibiotics:	1) _____ 2) _____ 3) _____ 4) _____	
Feeding Tubes:	1) _____ 2) _____ 3) _____ 4) _____	
IV Fluids:	1) _____ 2) _____ 3) _____ 4) _____	
Chemotherapy:	1) _____ 2) _____ 3) _____ 4) _____	
Ventilator/Respirator:	1) _____ 2) _____ 3) _____ 4) _____	

14. At discharge are there orders for life-sustaining treatment out in the community?

☐ yes ☐ no

If yes, what type of orders?

☐ Wisconsin DNR order form/bracelet _____/_____/_____ Date

☐ POLST (Please document orders found on POLST below)

a. Is document signed? ☐ yes ☐ no

b. Is document dated? ☐ yes ☐ no

If yes, date signed: _____/_____/_____ Date

c. Is there a resident/surrogate signature on back? ☐ yes ☐ no

d. What parts of document have been completed?

☐ A ☐ B ☐ C ☐ D ☐ E

15. POLST ORDERS AT DISCHARGE

TREATMENT CATEGORY	CHECK BOX	WRITTEN ORDERS	DATE OF ORDER
A. Resuscitation	<input type="checkbox"/>	DNR/DNAR	
	<input type="checkbox"/>	Full Code	
B. Medical Interventions	<input type="checkbox"/>	Comfort measures only....allow a natural death to occur	
	<input type="checkbox"/>	Do not hospitalize	
	<input type="checkbox"/>	Limited/advanced treatments	
	<input type="checkbox"/>	Full treatment	
C. Antibiotics	<input type="checkbox"/>	No antibiotics	
	<input type="checkbox"/>	No IM/IV antibiotics	
	<input type="checkbox"/>	Antibiotics	
D. Artificial Nutrition and Hydration	<input type="checkbox"/>	No artificial nutrition or hydration	
	<input type="checkbox"/>	Limited trial for _____ days	
	<input type="checkbox"/>	Artificial nutrition and hydration	

Instruments W

Title: California POLST Hospital Survey

Designer: Neil Wenger, MD, MPH et al . Please cite this article in any future work:

Wenger NS, Citko J, O'Malley K, Diamant A, Lorenz K, Gonzalez V, Tarn DM. Implementation of physician orders for life sustaining treatment in nursing homes in California: evaluation of a novel statewide dissemination mechanism. J Gen Intern Med. 2013 Jan;28(1):51-7.

Suitable for Quality Improvement? Yes, modified to fit your state.

Suitable for research? Yes.

Description of Instrument: This written survey was designed to produce research quality data about POLST utilization in California hospitals to assess the effectiveness of a major grass roots effort promoting POLST use. The surveys were not done in isolation, but as follow up to an extensive educational outreach. They are mailed surveys addressed to the hospital administrator or knowledgeable designee.

How to use:

Step 1: Modify the form to suit your purposes. Decide whether you really need each item and keep items that you have a planned use for or believe may be important to have even though you are not sure what to do with them. Similarly, you may add items that are missing or that address questions that you are trying to answer. You may find items in other instruments elsewhere in the toolkit and want to include them and that is fine. You may want to add questions about the hospital itself, or that information is often available in the America Hospital Association's published Hospital Guide.

Step 2: Select which hospitals you will survey. You may wish to survey all of them, or just a cross-section. See the FAQ section on 'Sampling'. In general, as long as you choose hospitals in a random fashion (for example, by choosing numbers out of a hat) and get a decent response rate to your survey (30-50%+ for QA and 50-75%+ for research) and survey enough hospitals so that you get to 20-30 usable responses (more for research), that may be enough for most QA purposes.

Step 3: There is a well described methodology for mailed surveys that is beyond the scope of this toolkit, but you should include a self-addressed, stamped envelope and plan on doing more than one mailing. Making follow up phone calls to make sure you are sending your survey to the right person and encouraging them to complete the survey also makes sense. Offering them the option of completing the survey over the phone (while they are looking at a copy of the paper survey) should improve your response rate.

Step 4: Analyze the results. Some of the results that you will get from this survey include:

1. POLST policy and procedures and availability
2. POLST education
3. How emergency department and inpatient physicians would treat a POLST form
4. Likelihood of completing POLST on a patient with a hospital DNR order d/c'ing to a nursing facility.
5. Any problems with POLST they've encountered
6. Interest in further education

CA POLST HOSPITAL SURVEY
Please Credit Neil Wenger, MD, MPH

1. Does your hospital have a formal policy on how to complete and follow POLST forms?
 ____ Yes → ***Whom might we contact to obtain a copy of the policy?***
 ____ No
2. Are blank (pink or other) POLST forms available in your hospital to complete with patients?
 ____ Yes
 ____ No
3. Usually in hospitals, a particular department or area “owns” specific interventions or aspects of care. In your hospital, who “owns” the POLST? _____
 ____ No one department or area
 ____ Don’t know
4. Have hospital staff received education about POLST?
 ____ Yes ____ No → ***Skip to question 6***
5. Describe the hospital education about POLST, types of materials used and who conducted the education: _____

6. Has your hospital ever admitted a patient who already had a completed POLST?
 ____ Yes ____ No ____ Don’t know
7. If a patient presents to the Emergency Department with a POLST containing a DNR order and suffers a cardiopulmonary arrest in the ED, how would the ED physicians respond? (***Choose one answer***)
 ____ Respect the POLST as a physician order and withhold CPR
 ____ Consider the POLST as information about patient preferences to be combined with other information in deciding whether to initiate CPR.
 ____ Physicians will choose whether to initiate CPR according to their individual practice.
 ____ I don’t know.
 ____ This hospital has no Emergency Department.
8. If a patient is admitted to your hospital with a completed POLST that contains physician orders concerning resuscitation, how would the attending physician regard the POLST? (***Choose one answer***)
 ____ Copy the POLST resuscitation order into the hospital admission orders.
 ____ Consider the information in the POLST as information about patient preferences to be combined with other information in deciding what orders to write.
 ____ Physicians will handle the POLST according to their individual practice.

Continues on back →

_____ I don't know.

9. If a patient admitted to your hospital enters the hospital with a completed POLST, what would the healthcare team do with the POLST document? (**Choose one answer**)

- _____ Place the original POLST into the medical record
- _____ Place a copy/Scan the POLST into the medical record and return the original to the patient
- _____ Not incorporate the POLST into the medical record because it is not a hospital document.
- _____ Physicians will handle the POLST differently on various hospital units.
- _____ Physicians will handle the POLST according to their individual practice.
- _____ I don't know.

10. A patient is admitted to the hospital from home and during the hospitalization decided with her physicians that care should be comfort-oriented and should not include resuscitation. A DNR order is placed in the hospital chart. The patient will be discharged to a SNF.

What is the likelihood, from 0 to 100%, that on discharge to the SNF, the patient would have a POLST form created capturing her decisions? _____ %

11. Has your hospital encountered any problems with POLST forms?

_____ No

_____ Yes → ***Please describe below***

12. Would your hospital benefit from any assistance in the use of the POLST?

_____ No

_____ Yes → ***Please describe below***

_____ Educational program for staff

_____ Example policy for completing and/or following POLST documents

_____ Other: _____

THANK YOU

Instrument X

Title: Hospice Telephone Survey

Designer: Susan Hickman, PhD. Please cite the manuscript listed below in any publications and public presentations.

Suitable for Quality Improvement? Yes, as is.

Suitable for research? Yes, not validated, but has been used successfully in publications before:

- Hickman SE, Nelson CA, Moss AH et al. Use of the Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Program in the Hospice Setting. Journal of Palliative Medicine 2009, February; Volume 12, Number 2: 133-141

Description of Instrument: This short survey is designed to be administered over the phone to hospice administrators or their designees. This survey allows POLST Programs to assess POLST use in hospice in their state or region. The last page of the survey, requesting permission to do on-site chart reviews, may not be necessary for your project.

How to use: The most important question is 3b:

b. How many current patients have POLST forms? [read choices]

- ☐ None
- ☐ Less than half
- ☐ About half
- ☐ More than half
- ☐ Nearly all or all

This allows you to quantify POLST penetrance in your state or region, which you might report to stakeholders like this: “80% of the hospice programs in our state report using POLST with more than half of their patients”.

The second most important question is 3d:

d. Are you aware of any problems related to the use of the POLST program in your hospice?

- ☐ No
- ☐ Yes

If YES, please describe: _____

This question allows you to identify problems with POLST that can help you design education and outreach programs. A common concern for hospice programs in new POLST Paradigm states has been emergency personnel who were not familiar with POLST and therefore would not honor the orders.

OR Hospice Telephone Survey

We understand that hospice programs across Oregon use many different forms to document patient treatment preferences and guide care. We are interested in learning more about advance care planning within your hospice program and your attitudes towards the POLST (Physician Orders for Life-Sustaining Treatment) Program.

1. What forms are used to document patient wishes for life-sustaining treatment? [READ LIST]

YES	NO	FORM [Check all that apply]
		Oregon Advance Directive
		Program specific form for advance planning
		Any other form (describe)

2. What forms do you use to record medical orders regarding life-sustaining treatments? [READ LIST]

YES	NO	FORM [Check all that apply]
		Program specific form for physician orders
		DNR/Full Code (in medical records)
		POLST Program (<i>IF YES, GO TO #3: IF NO, SKIP TO #4</i>)
		Any other form (describe)
		No system

3. How long has your program used the POLST form? [read choices]

- ☐ Less than 6 months
- ☐ 6 months to less than 1 year
- ☐ 1 – 2 years
- ☐ 2 or more years

b. How many current patients have POLST forms? [read choices]

- ☐ None
- ☐ Less than half
- ☐ About half
- ☐ More than half
- ☐ Nearly all or all

c. Does your program have a policy, formal or informal, that every patient must have a POLST form?

- ☐ No ☐ Yes

d. Are you aware of any problems related to the use of the POLST program in your hospice?

- ☐ No ☐ Yes

IF YES, please describe: _____

4. Who usually initiates advance care planning with patients? (check all that apply)

- ☐ Physician/Nurse Practitioner
- ☐ Social Services staff
- ☐ Nursing staff
- ☐ Director
- ☐ Pastoral Care
- ☐ Other (describe)_____

5. What is the current patient census in your program? _____

6. What is your current average length of stay (approximately)? _____

1	2	3	4	5
Strongly disagree		Neutral		Strongly agree

I'd like you to rate the next set of questions I ask you on a scale of 1 – 5 with 1 = strongly disagree and 5 = strongly agree.

7. _____ The POLST form provides clear instructions about a patient's treatment preferences.

8. _____ The POLST form is useful in preventing unwanted hospitalization.

9. _____ The POLST for is useful in preventing unwanted resuscitation by EMS.

10. _____ The POLST form reliably express patient treatment preferences.

11. _____ The POLST form is not working in my community.

12. _____ I feel more comfortable knowing what to do when a POLST form is available.

13. _____ The POLST form helps ensure patient treatment preferences are honored.

14. _____ Having a POLST form makes treating patients more complicated.

15. _____ The POLST form serves as a helpful mechanism for initiating a conversation about treatment preferences.

We will be requesting permission to conduct on-site chart reviews at a small number of programs over the next few months. These programs will be selected based on geographic location, size, and the type of advance care documents used. If your program is selected, a letter will be sent to the Program Director in advance of a telephone call, requesting permission to conduct the chart review.

[skip if speaking with Director]: Would it be OK if we told your Director we spoke with you about this topic? If you agree, your name will be recorded on a separate sheet of paper that will be destroyed after chart review data collection is complete. Would it be okay for us to use your name?

☐ Yes (enter name here)_____

☐ No

Thank you very much for your time. We greatly appreciate your help in better understanding advance care planning in Oregon.

RECORD THE FOLLOWING:

Program Name _____

City _____

Instrument Y

Title: Hospice Chart Review Form

Designer: Susan Hickman, PhD. Please cite these studies in any future work:

Hickman SE, Nelson CA, Perrin NA, Moss AH, Hammes BJ, Tolle SW. A comparison of methods to communicate treatment preferences in nursing facilities: traditional practices versus the physician orders for life-sustaining treatment program. J Am Geriatr Soc. 2010 Jul;58(7):1241-8.

Hickman SE, Nelson CA, Moss AH, Tolle SW, Perrin NA, Hammes BJ. The consistency between treatments provided to nursing facility residents and orders on the physician orders for life-sustaining treatment form. J Am Geriatr Soc. 2011 Nov;59(11):2091-9.

Suitable for Quality Improvement? Probably too extensive for QI purposes, but the items are excellent.

Suitable for research? Yes.

Description of Instrument: This chart review provides a comprehensive look at advance care planning, patient preferences, and receipt of life-sustaining treatment, and symptoms/symptom management in the final week for patients enrolled in hospice. It was designed to collect research data for studies examining whether POLST forms were effective in guiding life-sustaining treatments for patients in nursing facilities after they discharged to hospice care. The form is long and requires some skill on the part of the chart reviewer to correctly complete the review. It is more suitable for research but any of the items may be of use for QI purposes.

Description of selected Short Version items:

- Item 7 and 8, duration of hospice care and hospice diagnosis.
- Item 9, Preferences: this item assesses who is making medical decisions and the presence of other advance care planning documents.
- Items 10: Indicates if the patient had treatment PREFERENCES documented for a long list of medical treatments.
- Item 11-12: Indicates whether the patient had ORDERS, including POLST orders, for life sustaining treatments in the chart.
- Item 13: Documents whether the patient received any of 13 different life sustaining treatments.
- Item 14: Documents the reasons for discordance between treatment preferences and treatment received.
- Item 15 and ?28: Documents symptoms and symptom management medications received in the last 7 days of life.

DEMOGRAPHICS

1. Today's date _____

2. Client's age in years _____

3. Client's gender

☐ Female

☐ Male

4. Client's Race/Ethnicity:

☐ White

☐ African American/Black

☐ Native Hawaiian/Pacific Islander

☐ Asian

☐ American Indian/Alaskan Native

☐ Other

☐ not available

5. Place of death

☐ home

☐ hospital

☐ in-patient hospice

☐ foster home/RCF/ALF

☐ Nursing facility as resident

☐ Nursing facility as hospice admission

☐ other_____

☐ not available

6. The client was cared for by (check all that apply):

☐ Spouse/partner

☐ Other family member

☐ Paid caregiver

☐ Friend

☐ None

7. Length of stay in hospice: Total # of days in hospice

Admission date(s)_____

Discharge date(s)_____

Date of death_____

Please Cite: Hickman SE et al. J Pall Med. 2009; 12(2):133-141

8. Primary Diagnosis (check one only)

<input type="checkbox"/>	Cancer	<input type="checkbox"/>	Neurological Disease	<input type="checkbox"/>	Renal Disease/Failure
<input type="checkbox"/>	Heart Related Disease	<input type="checkbox"/>	Dementia	<input type="checkbox"/>	Liver Disease/Failure
<input type="checkbox"/>	Respiratory Related Disease	<input type="checkbox"/>	Stroke	<input type="checkbox"/>	Other

PREFERENCES, ORDERS, & LIFE-SUSTAINING TREATMENTS

9. What, if any, **advance directive** forms are present in the chart? (check all that apply)

- ☐ Advance directive/living will (circle type used)
 - ☐ Oregon Advance Directive
 - ☐ Other state advance directive
- ☐ facility form—patient/surrogate wishes for treatment
- ☐ Designated Power of Attorney for health care (person named by client)
- ☐ other (describe) _____
- ☐ No form present

10. If the client has an advance directive/living will form in their chart, what are their preferences?

DO NOT CHECK FOR PHYSICIAN/NP ORDERS:

IF I AM CLOSE TO DEATH:

- ☐ I want feeding tubes/artificial nutrition and hydration.
- ☐ I want tube feedings only as my physician recommends
- ☐ I do not want feeding tubes/artificial nutrition and hydration
- ☐ No preference indicated

- ☐ I want any other life support that may apply
- ☐ I want life support only as my physician recommends
- ☐ I want NO life support
- ☐ No preference indicated

IF I AM PERMANENTLY UNCONSCIOUS/PERISTENT VEGETATIVE STATE:

- ☐ I want to receive tube feeding
- ☐ I want tube feeding only as my physician recommends
- ☐ I do not want tube feeding
- ☐ No preference indicated

- ☐ I want any other life support that may apply
- ☐ I want life support only as my physician recommends.
- ☐ I want NO life support
- ☐ No preference indicated

<p>IF I HAVE ADVANCED PROGRESSIVE ILLNESS/TERMINAL CONDITION AND/OR CANNOT INTERACT MEANINGFULLY:</p> <ul style="list-style-type: none"> <input type="checkbox"/> I want tube feedings <input type="checkbox"/> I want tube feedings only as my physician recommends <input type="checkbox"/> I do not want tube feedings <input type="checkbox"/> No preference indicated <input type="checkbox"/> I want any other life support that may apply <input type="checkbox"/> I want life support only as my physician recommends <input type="checkbox"/> I want NO life support <input type="checkbox"/> No preference indicated. 	<p>IF I AM EXPERIENCING EXTRAORDINARY SUFFERING:</p> <ul style="list-style-type: none"> <input type="checkbox"/> I want to receive tube feedings <input type="checkbox"/> I want tube feedings only as my physician recommends <input type="checkbox"/> I do not want tube feeding <input type="checkbox"/> No preference indicated <input type="checkbox"/> I want any other life support that may apply <input type="checkbox"/> I want life support only as my physician recommends <input type="checkbox"/> I want NO life support <input type="checkbox"/> No preference indicated
<p>KIDNEY DIALYSIS</p> <ul style="list-style-type: none"> <input type="checkbox"/> I want kidney dialysis <input type="checkbox"/> I do not want kidney dialysis <input type="checkbox"/> No preference indicated 	<p>VENTILATOR SUPPORT</p> <ul style="list-style-type: none"> <input type="checkbox"/> I want ventilator support <input type="checkbox"/> I do not want ventilator support <input type="checkbox"/> No preference indicated.
<p>RESUSCITATION (preferences, not orders)</p> <ul style="list-style-type: none"> <input type="checkbox"/> I want cardiac resuscitation <input type="checkbox"/> I do not want cardiac resuscitation <input type="checkbox"/> I want CPR under certain circumstances as MD recommends <input type="checkbox"/> No preference indicated 	<p>SURGERY OR INVASIVE DIAGNOSTIC TESTS</p> <ul style="list-style-type: none"> <input type="checkbox"/> I want surgery or invasive diagnostic tests <input type="checkbox"/> I do not want surgery or invasive diagnostic tests <input type="checkbox"/> No preference indicated
<p>ANTIBIOTICS</p> <ul style="list-style-type: none"> <input type="checkbox"/> I want antibiotics <input type="checkbox"/> I do not want antibiotics <input type="checkbox"/> No preference indicated 	<p>TRANSFUSION</p> <ul style="list-style-type: none"> <input type="checkbox"/> I want transfusion <input type="checkbox"/> I do not want transfusion <input type="checkbox"/> No preference indicated

PAIN AND SYMPTOM CONTROL IF EFFORTS TO PROLONG LIFE ARE STOPPED <input type="checkbox"/> I want to be kept comfortable even if it risks my dying sooner	OTHER <input type="checkbox"/> I want _____ <input type="checkbox"/> I do not want _____
OTHER <input type="checkbox"/> I want _____ <input type="checkbox"/> I do not want _____	OTHER <input type="checkbox"/> I want _____ <input type="checkbox"/> I do not want _____

11. Are there any **medical order forms or orders** for life-sustaining treatments in the chart?

(check all that apply)

- ☐ POLST form (see box to right) _____ →
- ☐ facility medical order form (must require MD or NP and be called an order)
- ☐ Form and other orders present
- ☐ No form but other orders present
- ☐ No form, no orders present
- ☐ other (describe) _____

IF POLST FORM IS PRESENT:

a. Is there a client/surrogate signature on back?

___ yes ___ no

b. Who was it discussed with?

___ client/client

___ health care representative

___ Court-appointed guardian

___ Spouse

___ Other _____

c. Is there a physician/nurse practitioner signature?

___ yes ___ no

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2. ORDERS REGARDING LIFE-SUSTAINING TREATMENT: Document all medical orders written on the POLST/POST form or in the medical chart in the table below. The date may precede the 90 day review period but if orders are still in effect, record below. Be sure to provide the date of the order. If the orders change, complete additional ORDERS form.

TREATMENT CATEGORY	Written Orders	Date of Order	Check if change in orders during 90 day review
Resuscitation	<input type="checkbox"/> DNR/DNAR		
	<input type="checkbox"/> Full Code		
Medical Interventions	<input type="checkbox"/> Comfort Measures Only/Hospitalize only if comfort measures fail/Supportive Care Only		
	<input type="checkbox"/> Do Not Hospitalize		
	<input type="checkbox"/> Limited/Advanced Treatments		
	<input type="checkbox"/> Full Treatment/Aggressive Treatment		
Antibiotics	<input type="checkbox"/> No antibiotics		
	<input type="checkbox"/> No IM/IV antibiotics		
	<input type="checkbox"/> Antibiotics		
Artificial Nutrition and Hydration	<input type="checkbox"/> No artificial nutrition or hydration		
	<input type="checkbox"/> Limited trial for _____ days		
	<input type="checkbox"/> Artificial nutrition and hydration		

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13. LIFE-SUSTAINING TREATMENTS AND INTERVENTIONS PROVIDED DURING 90 DAY REVIEW: RECORD EACH TIME TREATMENT OR INTERVENTION OCCURS AND PROVIDE ADDITIONAL INFORMATION AS INDICATED

TREATMENT PROVIDED	DATE STARTED/PROVIDED	ADDITIONAL INFORMATION
<input type="checkbox"/> Resuscitation	1) _____ 2) _____	1) Did patient survive? <input type="checkbox"/> yes <input type="checkbox"/> no 2) Did patient survive? <input type="checkbox"/> yes <input type="checkbox"/> no
<input type="checkbox"/> Hospitalization:	1) _____ 2) _____ 3) _____ 4) _____	1) Date returned (computer will calculate length of stay) _____ (_____ days) 2) Date returned _____ (_____ days) 3) Date returned _____ (_____ days) 4) Date returned _____ (_____ days)
<input type="checkbox"/> Dialysis:	1) _____ 2) _____	1) _____ (Date stopped) 2) _____ (Date stopped)
<input type="checkbox"/> Transfusion:	1) _____ 2) _____ 3) _____ 4) _____	1) Purpose: _____ 2) Purpose: _____ 3) Purpose: _____ 4) Purpose: _____
<input type="checkbox"/> Intubation:	1) _____ 2) _____ 3) _____ 4) _____	1) Outcome: _____ 2) Outcome: _____ 3) Outcome: _____ 4) Outcome: _____
<input type="checkbox"/> Surgery:	1) _____ 2) _____ 3) _____ 4) _____	1) Purpose of surgery _____ 2) Purpose of surgery _____ 3) Purpose of surgery _____ 4) Purpose of surgery _____
<input type="checkbox"/> Antibiotics:	1) _____ 2) _____ 3) _____ 4) _____	1) Purpose of antibiotics _____ 2) Purpose of antibiotics _____ 3) Purpose of antibiotics _____ 4) Purpose of antibiotics _____
<input type="checkbox"/> Feeding Tubes:	1) _____ 2) _____ 3) _____ 4) _____	1) _____ (Date stopped) 2) _____ (Date stopped,) 3) _____ (Date stopped) 4) _____ (Date stopped)

TREATMENT PROVIDED	DATE STARTED/PROVIDED	ADDITIONAL INFORMATION
<input type="checkbox"/> IV Fluids:	1) _____ 2) _____ 3) _____ 4) _____	1) _____ (Date stopped) 2) _____ (Date stopped) 3) _____ (Date stopped) 4) _____ (Date stopped)
<input type="checkbox"/> Chemotherapy	1) _____ 2) _____ 3) _____ 4) _____	1) _____ (Date stopped) 2) _____ (Date stopped) 3) _____ (Date stopped) 4) _____ (Date stopped)
<input type="checkbox"/> Ventilator/Respirator	1) _____ 2) _____ 3) _____ 4) _____	1) _____ (Date stopped) 2) _____ (Date stopped) 3) _____ (Date stopped) 4) _____ (Date stopped)

14. REASONS FOR TREATMENT DEVIATIONS

Treatment Discrepancy #1: Describe and date _____

CHECK ALL REASONS THAT APPLY

- | | |
|---|---|
| <input type="checkbox"/> None noted | <input type="checkbox"/> Patient changed mind |
| <input type="checkbox"/> Family changed mind | <input type="checkbox"/> Orders written after treatment started |
| <input type="checkbox"/> MD/NP changed order | <input type="checkbox"/> Condition changed |
| <input type="checkbox"/> Orders not consulted | <input type="checkbox"/> Other |

☐ No information provided

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Treatment Discrepancy # 2: Describe and date _____

CHECK ALL REASONS THAT APPLY

- | | |
|---|---|
| <input type="checkbox"/> None noted | <input type="checkbox"/> Patient changed mind |
| <input type="checkbox"/> Family changed mind | <input type="checkbox"/> Orders written after treatment started |
| <input type="checkbox"/> MD/NP changed order | <input type="checkbox"/> Condition changed |
| <input type="checkbox"/> Orders not consulted | <input type="checkbox"/> Other |
-
- ☐ No information provided

Treatment Discrepancy # 3: Describe and date _____

CHECK ALL REASONS THAT APPLY

- | | |
|---|---|
| <input type="checkbox"/> None noted | <input type="checkbox"/> Patient changed mind |
| <input type="checkbox"/> Family changed mind | <input type="checkbox"/> Orders written after treatment started |
| <input type="checkbox"/> MD/NP changed order | <input type="checkbox"/> Condition changed |
| <input type="checkbox"/> Orders not consulted | <input type="checkbox"/> Other |
-
- ☐ No information provided

SYMPTOMS AND SYMPTOM MANAGEMENT IN THE LAST WEEK OF LIFE

THE DATA IN THIS SECTION SHOULD BE EXTRACTED FROM THE LAST SEVEN DAYS OF THE CHART REVIEW ONLY

15. Review chart notes and orders for symptoms and symptom management interventions in the week prior to the date of the chart review. Start with date of death as Day 7 and work backwards. Enter dates in top line of table below.

SYMPTOMS Interventions	DAY 7 / /	DAY 6 / /	DAY 5 / /	DAY 4 / /	DAY 3 / /	DAY 2 / /	DAY 1 / /
AGITATION							
Review/adjust meds							
Emotional support							
ANXIETY							
Emotional support							
COMATOSE							
CONFUSION/DELERIUM							
CONSTIPATION							
Increased activity							
Increased fluids							
Dietary interventions							
Medication							
DEPRESSION							
Emotional support							
Medication							
DROWSINESS							
Review/adjust meds							
Allow resident to remain in bed							
DRY MOUTH/LIPS							
Mouth care							
DYSPNEA/SOB							
Oxygen							
Suctioning							
FATIGUE							

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SYMPTOMS INTERVENTIONS	DAY 7 / /	DAY 6 / /	DAY 5 / /	DAY 4 / /	DAY 3 / /	DAY 2 / /	DAY 1 / /
Allow resident to remain in bed							
FEARFULNESS							
Emotional support							
LOSS OF APPETITE							
Diet as tolerated							
Medication							
MOANING							
Pain assessment*							
TEARFULNESS/CRYING							
Emotional support							
WEAKNESS							
YELLING							
Pain assessment*							
Medication							
RESTRICTED TO BED							
Positioning for comfort							
Foley catheter							
OTHER:							
Communicate with family about status							
*Pain (record highest level of pain documented each day and level of pain if available—note scale used)							
Unable to report							
no description							
vague description							
mild							
moderate							
severe							
Level of pain							
___ 0 – 5 scale							
___ 0 – 10 scale							

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28. What pain and psychotropic medication did the resident receive in the last 7 days of life?? Record total amount per day for last week of chart review. Start with the date of death as Day 7 and work backwards.

MEDICATION	DAY 7 / /	DAY 6 / /	DAY 5 / /	DAY 4 / /	DAY 3 / /	DAY 2 / /	DAY 1 / /
acetaminophen (APAP)							
Oral							
Rectal							
acetaminophen and codeine							
Oral							
acetaminophen and hydrocodone (Vicodin)							
Oral							
Non-Steroidal Anti-inflammatory Drugs (NSAIDs)							
Oral							
morphine (Roxanol or MS Contin)							
Oral							
IM/IV/SubQ							
fentanyl (Duragesic)							
IM/IV/SubQ							
Patch							
hydromorphone (Dilaudid)							
Oral							
IM/IV/SubQ							
Oxycodone Hydrochloride (Oxycontin)							
Oral							

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MEDICATION	DAY 7 / /	DAY 6 / /	DAY 5 / /	DAY 4 / /	DAY 3 / /	DAY 2 / /	DAY 1 / /
Antidepressant 1--Specify:							
Oral							
Antidepressant 2--Specify:							
Oral							
Anxiolytic 1--Specify:							
Oral							
Anxiolytic 2--Specify:							
Oral							
Antipsychotic--Specify:							
Oral							
Anti-Seizure--Specify:							
Route:							
Other--Specify:							
Route:							
Other--Specify:							
Route:							
Other--Specify:							
Route:							
Other--Specify:							
Route:							

Instrument Z

Title: California POLST Knowledge Pre-Survey

Designer: Catherine McGregor, RN, MSN, FNS, Sutter Auburn Faith Hospital. Please credit her in any publications and public presentations.

Suitable for Quality Improvement? Yes, but note that the correct answers may be different depending on your state.

Suitable for research? Not yet.

Description of Instrument: This is a quiz designed as a pre-test administered prior to a POLST education intervention.

Notes:

I believe that the correct answers are:

1. True
2. True
3. True
4. True
5. True
6. False, CPR is not equally effective in all people.
7. True, California's form expressly prohibits combining CPR with any order other than Full treatment, but this is not the case in every state.
8. True
9. True
10. True
11. False. There are circumstances where an Advance Directive would supercede POLST – for example a patient could have a POLST order for Full Treatment and subsequently be found to be in a persistent vegetative state. If the patient had an Advance Directive stating s/he did not want life sustaining treatments under that specific circumstance, it would be appropriate to follow the Advance Directive.
12. False. In this case, it would probably be appropriate to follow the POLST form as it was completed more recently.

I recommend adding questions that are specific to your state or that you intend to address in your educational intervention, and you should make sure that the correct answers to the pre-test are included in your educational intervention explicitly.

CA POLST KNOWLEDGE PRE-SURVEY

Please answer True (T) or False (F) to the following questions:

- T or F The POLST form should be kept in a safe, locked location.
- T or F A patient with decision-making capacity may change his/her POLST choices and complete a new POLST form.
- T or F POLST gives instructions for care that all health care providers are to respect.
- T or F In order for a POLST form to be valid, a nurse or a doctor must sign it, along with the patient or their decision maker.
- T or F CPR is performed when a person is unconscious, and their heart and breathing have stopped.
- T or F CPR is equally effective in all people.
- T or F A person who has chosen Do Not Attempt Resuscitation in Section A of the POLST form may not select Full Treatment in Section B.
- T or F A person who has chosen CPR in Section A of POLST must select Full Treatment in Section B.
- T or F A POLST form on any color paper is valid.
- T or F Every adult should have a POLST form.
- T or F POLST does not replace an Advance Health Care Directive.
- T or F If a patient's POLST form and Advance Health Care Directive conflict, the POLST form is what should always be followed.
- T or F A patient has a completed and actionable POLST dated 4/11/2009 indicating DNR and an Advance Health Care Directive dated 3/2/2000 indicating "I wish life prolonging measures". The Advance Health Care Directive is the document you follow because it is a legal document.

Name: _____

9/20/2012

Instrument AA

Title: North Carolina Advance Care Planning Survey

Designer: Tae Joon Lee, MD et al. Please cite the following reference in any future work:

Lee T, Cao Q, Hayes S, Austin P, Zafar M, Newman R. "Increasing Residency Training of Goal-oriented Treatment Options in Patients with Life-Limiting Illnesses" Journal of the American Geriatrics Society 60(supplement 4): S43-44 April 2012

Suitable for Quality Improvement? Yes, with revisions to fit your state.

Suitable for research? Yes.

Description of Instrument: This paper based questionnaire was designed to evaluate the impact (on knowledge and attitudes) of an educational intervention for Family Medicine Resident Physicians and Geriatric Fellows at East Carolina University. It combines some questions to test the residents' knowledge, questions about their attitudes about advance care planning and questions about their experiences talking to patients about advance directives. See Dr. Lee's results, presented at the American Geriatric Society, in Toolkit Instrument II.

Notes:

1. The correct answer is "very few, less than 10%". However if you include all patients, not just those with advanced illness, the number is closer to 17%.
2. Less than 10% of patients with un-witnessed arrest survive CPR.
3. The intended answer is no, there is no evidence that antibiotics improve comfort for patients with pneumonia. Note that not having evidence is not quite the same thing as being untrue, but this is probably also true in most cases.
4. The correct answer is no.
5. This item asks the residents which advance care planning documents they've been exposed to.
6. This may vary by state. In my state, there is no category 'majority of parents and reasonably available adult children' and the order is as follows: Legal Guardian, Attorney in fact with power to make health care decisions, Parent or Guardian if the patient is a minor, Spouse, Majority of adult children, and an individual with an established relationship with the patient who is acting in good faith and can reasonably convey the wishes of the patient.
7. To 12. These items address the residents own preferences for life-sustaining treatment and whether they personally have advance directives.
13. I think there is a typographical error here. I am not sure of Dr. Lee's intent. It seems like he is asking the residents if they are interested in having a MOST form or an Advance Directive for themselves. Most residents are young and/or healthy and should not have a MOST form.
14. And 15 ask about the residents' experiences talking to patients and families about advance directives.

I recommend adding questions that are specific to your state or that you intend to address in your educational intervention, and you should make sure that the correct answers to the pre-test are included in your educational intervention explicitly.

MOST Form - Advance Directives Educational Intervention Project Survey - Residents:

You are being invited to participate in a **research** study titled "Increasing Understanding of Goal-oriented Treatment Options and the MOST Form in Patients with Life-Limiting Illnesses" being conducted by Dr. Cao, a faculty physician at East Carolina University in the Department of Family Medicine. The goal is to survey as many in-training family medicine residents and geriatric fellows as possible. The survey will take approximately 3 minutes to complete. It is hoped that this information will assist us to better understand residents and fellows' knowledge and attitude about discussing goals of care with patients at the end of life. The survey is anonymous, so please do not write your name. Your participation in the research is **voluntary**. You may choose not to answer any or all questions, and you may stop at any time. There is **no penalty for not taking part** in this research study. Please call Dr. Cao at 252-744-2597 for any research related questions or the Office for Human Research Integrity (OHRI) at 252-744-2914 for questions about your rights as a research participant.

1. How many patients with advanced illnesses who get CPR in the hospital survive and leave the hospital?

- ☐ Almost all (more than 90%)
- ☐ About half (50%)
- ☐ Very few (less than 10%)

2. How many patients with un-witnessed cardiac arrest survive CPR?

- ☐ About half (50%)
- ☐ About a quarter (25%)
- ☐ Less than 10%

3. If pneumonia is not treated with antibiotics, does this increase the discomfort level for patients with advanced dementia?

- ☐ Yes
- ☐ No

4. Does tube feeding eliminate the risk of aspiration pneumonia for patients with advanced dementia?

- ☐ Yes (If so, how? _____)
- ☐ No (If no, why not? _____)

5. Which end-of-life planning tool(s) do you know about? (Check all that apply)

- ☐ Do Not Resuscitate (DNR) order
- ☐ Health Care Power of Attorney (HCPOA)
- ☐ Advance Directive
- ☐ Medical Orders for Scope of Treatment (MOST)
- ☐ None of the above

6. If a patient cannot make medical decisions on his/her own, in which order can the following individuals make decisions?

- ☐ ___ Spouse
- ☐ ___ Majority of patient's reasonably available parents and adult children
- ☐ ___ An individual with an established relationship with the patient who is acting in good faith and can reliably convey the wishes of the patient
- ☐ ___ Legal Guardian
- ☐ ___ Parent or guardian if patient is a minor
- ☐ ___ Majority of patient's reasonably available adult siblings
- ☐ ___ Attorney-in-fact with power to make health care decisions

7. If you get close to the end of your life and get an infection (for example pneumonia or a skin infection) what treatment makes the most sense to you?

- ☐ Treat the infection with whatever is needed to cure the infection - even if ICU (Intensive Care Unit) treatment is needed
- ☐ Determine at the time if treatment should be given
- ☐ Do not treat the infection, because treating it would only prolong my suffering

8. If you are unable to eat or drink because of being near the end of your life from a terminal illness, would you want intravenous (IV) fluid?

- ☐ Yes, I would want IV fluid to keep me alive as long as possible, even if I'm unconscious
- ☐ Yes, I would want IV fluid, but only if it makes me more comfortable; not to prolong my life
- ☐ No, I would not want IV fluid

9. If you are unable to eat or drink because of being near the end of your life from a terminal illness, would you want tube feeding?

- ☐ Yes, I would want tube feeding to keep me alive as long as possible, even if I'm unconscious
- ☐ Yes, I would want tube feeding, but only if it makes me more comfortable; not to prolong my life
- ☐ No, I would not want tube feeding

10. If you have a cardiopulmonary arrest, do you wish CPR or intubation?

- ☐ Definitely yes, just keep me alive by all means
- ☐ Probably yes, if I still have a chance to preserve my basic life style
- ☐ Maybe, however, life-prolonging treatment can be withdrawn if there is low probably survival rate
- ☐ Maybe, however, life-prolonging treatment can be withdrawn if there is a permanent and severe functional impairment
- ☐ Maybe, however, life-prolonging treatment can be withdrawn if there is a permanent and severe cognitive impairment
- ☐ Definitely not
- ☐ I do not know

11. If you knew you only had 6 months to live, what would be your preference?

- ☐ Spend last weeks or so in the hospital to get all treatments as possible
- ☐ Spend last weeks or so in the hospital to be comfortable only
- ☐ Stay at home with family, but will go to hospital only for simple treatments such as IV hydration or/and antibiotics
- ☐ Stay at home with family, avoid hospital
- ☐ Go to an inpatient hospice facility

12. Have you had an advance directive?

- ☐ Yes, my family knows about it
- ☐ No, but I thought about it
- ☐ Yes, but I have not discussed with my medical providers
- ☐ No, I do not want to talk about it

13. Are you interested in having MOST form filled or having your advanced directives discussed with your providers after this section?

☐ Yes (1)

☐ No (2)

14. What kind questions were you asked when you discussed advance directives with patients/families?

15. What discouraged you from discussing advance directives with patients/families?

Instrument BB

Title: Kansas Missouri TPOPP Coalition Survey

Designer: Regina (Gina) Johnson, MSN, BSN, RN, Center for Practical Bioethics. Please credit her in any publications and public presentations.

Suitable for Quality Improvement? Yes, edited to suit your state.

Suitable for research? No.

Description of Instrument: Kansas' TPOPP (Transportable Physician Orders for Patient Preferences) Program has undertaken a broad-ranging dissemination plan that includes creating a coalition of partner organizations (hospitals, long term care, hospice and home care, EMS, private practice, assisted living, etc.) This survey is designed to gather information from participating partners and is collected electronically using the REDCap system, which stands for Research Electronic Data Capture (see www.project-redcap.org for details). This survey is designed for recruitment purposes. An accompanying survey (Toolkit Instrument CC Kansas TPOPP Implementation Plan Survey) serves as an electronic checklist for recommended policies and procedures to assure quality across institutions in this statewide implementation.

Survey

My institution or organization plans to be a participant in the Transportable Physician Orders for Patient Preferences (TPOPP) Coalition. (If yes, please enter the name of your institution.)

☐ Yes ☐ No

Please enter the name of your institution or organization

Please check the type of institution or organization:

- ☐ Acute Care
- ☐ LTC
- ☐ SNF
- ☐ Home Care
- ☐ Hospice
- ☐ EMS
- ☐ Medical Practice
- ☐ Assisted Living
- ☐ Other

Institutional or Organizational Champions:

To implement TPOPP, the TPOPP team suggest each institution or organization identify key individuals known as "Champions" to lead the way. These "Champions" may be in the role of a physician, nurse, social worker, chaplain, or administrative partner to shepherd TPOPP through the policy approval process. If your institution or organization has identified your champion(s) please provide their contact information below.

I have identified champions to lead this coalition at my institution.

☐ Yes
☐ No

Champion Name 1

Title

☐ MD
☐ RN
☐ NP
☐ PA
☐ SW
☐ Chaplain
☐ Other

Phone

Email

Champion Name 2

Title

☐ MD
☐ RN
☐ NP
☐ PA
☐ SW
☐ Chaplain
☐ Other

Phone

Email

I have not had the opportunity to identify our champions, but I plan to have champion(s) identified by:

(Please enter date in the following format:
01/22/2012)

Institutional or Organizational Program Coordinator:

Identification of a Program Coordinator is not required but highly recommended by the TPOPP team. A Program Coordinator may be a champion or champions listed above or it may be a separate individual who is a physician, nurse, social worker, chaplain, or administrative personnel. The role of the Program Coordinator will be to ensure TPOPP is part of the standardized practices and policies within your institution or organization. They will be instrumental in quality improvement activities and capturing TPOPP data at your institution or organization once TPOPP is implemented.

I have identified a TPOPP Program Coordinator at my institution.

- ☐ Yes
☐ No

My Program Coordinator has been identified as one of my champion(s). Please identify which champion(s) has been identified or if the Program Coordinator IS NOT one of the champions.

- ☐ Champion 1
☐ Champion 2
☐ Champion 1 and Champion 2
☐ Is Not One of the Champions

Name

Title

- ☐ MD
☐ RN
☐ NP
☐ PA
☐ SW
☐ Chaplain
☐ Other

Phone

Email

I plan to have a TPOPP Program Coordinator identified at my institution by:

(Please enter date in the following format:
01/22/2012)

Executive Level Feasibility:

To implement TPOPP, the TPOPP team suggest each institution or organization obtain executive level approval in support of the TPOPP coalition prior to implementation.

Has support for participation in the TPOPP coalition been formally addressed at the executive level committee at your institution?

- ☐ Yes
☐ No

I plan to have the TPOPP Program formally addressed at the executive level committee at my institution by:

(Please enter date in the following format:
01/22/2012)

Identification of Community Partners:

As part of the implementation of TPOPP, the TPOPP team suggest each institution or organization identify 5 key Community Partners. Identification of your Community Partners will allow the TPOPP team to contact those partners to formally introduce them to the Bi-State TPOPP Coalition and to offer education and training on TPOPP. Your Community Partners may be acute care institutions, long term care institutions, skilled nursing facilities, home care, hospice, or EMS providers.

I have identified our primary (top 5) community partners for our institution.

- ☐ Yes
☐ No
☐ I don't know my community partners

I plan to have community partners identified by:

(Please enter date in the following format:
01/22/2012)

Community Partner Name 1

Type of Community Partner 1

- ☐ Acute Care
☐ LTC
☐ SNF
☐ Home Care
☐ Hospice
☐ EMS

Contact Name

Community Partner Phone Number

Community Partner Email

Community Partner Fax

Community Partner Name 2

Type of Community Partner 2

- ☐ Acute Care
☐ LTC
☐ SNF
☐ Home Care
☐ Hospice
☐ EMS

Contact Name

Community Partner Phone Number

Community Partner Fax

Community Partner Email

Community Partner Name 3

Type of Community Partner 3

- ☐ Acute Care
☐ LTC
☐ SNF
☐ Home Care
☐ Hospice
☐ EMS

Contact Name

Community Partner Phone Number

Community Partner Fax _____

Community Partner Email _____

Community Partner Name 4 _____

Type of Community Partner 4

- ☐ Acute Care
- ☐ LTC
- ☐ SNF
- ☐ Home Care
- ☐ Hospice
- ☐ EMS

Contact Name _____

Community Partner Phone Number _____

Community Partner Fax _____

Community Partner Email _____

Community Partner Name 5 _____

Type of Community Partner 5

- ☐ Acute Care
- ☐ LTC
- ☐ SNF
- ☐ Home Care
- ☐ Hospice
- ☐ EMS

Contact Name _____

Community Partner Phone Number _____

Community Partner Fax _____

Community Partner Email _____

Electronic Medical Record

As a partner in the TPOPP Bi-State Coalition, the TPOPP team is determining how each institution will be able to track their TPOPP data for quality improvement and evaluation. We would appreciate you letting us know if you have access to an EMR and what type.

Does your institution have an EMR?

☐ Yes

☐ No

Name of EMR

Instrument CC

Title: Kansas Missouri TPOPP Implementation Plan Survey

Designer: Regina (Gina) Johnson, MSN, BSN, RN, Center for Practical Bioethics. Please credit her in any publications and public presentations.

Suitable for Quality Improvement? Yes, edited to suit your state.

Suitable for research? No.

Description of Instrument: Kansas' TPOPP (Transportable Physician Orders for Patient Preferences) Program has undertaken a broad-ranging dissemination plan that includes creating a coalition of partner organizations (hospitals, long term care, hospice and home care, EMS, private practice, assisted living, etc.) This survey is designed to gather information from participating partners and is collected electronically using the REDCap system, which stands for Research Electronic Data Capture (see www.project-redcap.org for details). This survey serves as an electronic checklist for recommended policies and procedures to assure quality across institutions in this statewide implementation. An accompanying survey (Toolkit Instrument BB Kansas TPOPP Coalition Survey) is designed for recruitment purposes.

Notes:

1. This survey necessarily includes items specific to Kansas' TPOPP program and will need to be heavily revised to suit your state's needs.
2. In addition to serving as a quality assurance and a measure of progress, the survey outlines a comprehensive step-by-step strategy for integrating TPOPP into an institution's patient care policies and procedures.
3. From my perspective, the survey is designed to best meet the needs of a large institution with enough manpower to dedicate several people's time to revising policies, meeting with stakeholders, etc. I could see it seeming intimidating to small organizations and I suspect as this project evolves the survey will be redesigned to meet the differing needs of smaller organizations.
4. However, it also may be appropriate for smaller organizations to simply reply 'no' to the items that don't fit with them and the size of the organization could then be taken into account when analyzing the data.

Survey

Please complete the survey below.

Thank you!

POLICIES AND PROCEDURES

- 1) Our policies recognize that TPOPP is an out of hospital order set for code status and level of intervention orders which are to be honored at the point of care. Consideration to include language of Common Law and Constitutional law principles, which require health care providers to respect a patient's known wishes. Example, Idaho: "any authentic expression of a person's wishes should be honored." Has a statement been included in the hospital's Resuscitation status policy.

☐ Yes
☐ No
- 2) For patients who reside in Missouri, the TPOPP form may need to be accompanied by a purple OHDNR form in order to be fully compliant with the MO out of hospital DNR law. Is this needed at your institution?

☐ Yes
☐ No
- 3) Has your hospital implemented appropriate policy and procedures specific for TPOPP?

☐ Yes
☐ No
- 4) Our TPOPP policies crosswalk with other policies on advance directives, EOL, Resuscitation Status, handling of OHDNR orders, and cross walk with medical staff/ NP/ and PA bylaws to include notation regarding TPOPP where necessary.

☐ Yes
☐ No
- 5) Our policies recognize that TPOPP is an out of hospital order set and the intervention orders are to be honored at

☐ Yes
☐ No
- 6) Please check that the following committees have reviewed and approved the policies referenced above:

☐ Ethics Committee
☐ Code Blue / Rapid Response
☐ Critical Care
☐ Emergency Services
☐ Transitions of Care
☐ End of Life Care Committee
☐ Performance Improvement
☐ ECMS
☐ Other, please list
- 7) Our implementation plans address direct admissions from the community of those patients who have a TPOPP form presented on admission.

☐ Yes
☐ No
- 8) Our implementation plans address processing the forms on admission, where they will be scanned or placed in the hospital record, and all staff know where to access TPOPP forms.

☐ Yes
☐ No
- 9) Our implementation plans address the return of the TPOPP form to patient or legal representative at discharge

☐ Yes
☐ No
- 10) Our implementation plans addresses patients entering our ER with a TPOPP form in hand.

☐ Yes
☐ No

- 11) Our implementation plans address processing the forms in the ER where they will be scanned or placed in the hospital record, and all staff will know where to access the forms. ☐ Yes ☐ No
- 12) Our implementation plans address the return of the TPOPP form to patient or legal representative at discharge? ☐ Yes ☐ No
- 13) Our implementation plans have addressed how to reconcile updated TPOPP forms. ☐ Yes ☐ No
- 14) Our implementation plans have addressed how to translate TPOPP orders into a hospital order set that would include but not limited to the following: Code Status, Level of Intervention ☐ Yes ☐ No
- 15) Our implementation plans have addressed which patients will be targeted for the TPOPP discussion? ☐ Yes ☐ No
- 16) Our implementation plans have addressed which providers will have the TPOPP conversation with the patients and/or POA. ☐ Yes ☐ No
- 17) Our implementation plans have included the person who will: order, process, and maintain the forms for our institution. ☐ Yes ☐ No
- 18) Our implementation plans have included the person who will process forms to the nursing care areas, ER, etc. ☐ Yes ☐ No

GOAL RECONCILIATION

19) Our implementation plans include goal reconciliation and addresses:

- ☐ Did patient have TPOPP form on admission?
- ☐ If so, did it change during admission?
- ☐ All forms were scanned into the system or entered into the Medical Record
- ☐ Did the patient leave the hospital with their form?
- ☐ Other

Educational Plan

- 20) Our implementation includes an educational plan for key stakeholders, as well as, institutional wide education and training. ☐ Yes
☐ No
- 21) All key stakeholders have been trained and ready to launch. ☐ Yes
☐ No
- 22) As part of the institutional commitment, TPOPP education and training will be included in employee training for all front line health care providers. ☐ Yes
☐ No

Jane Dinnen, RN
Advance Care Planning Coordinator
Munson Medical Center
1105 Sixth St
Traverse City, MI 49684
231-935-6176
jdinnen@mhc.net

POLST Metrics:

- # ECF pts w/ DNR &/or comfort measures only
- # ECF pts w/ a POLST in our ER, ICU, hosp bed & why
- # ECF pts transferred to MMC w/ POLST, without POLST
- # ECF transfers w/ POLST who die at MMC
- # ECF transfers w/o POLST who die at MMC
- Avg LOS of ECF transfers w/ & w/o POLST

- # Hospitalists writing POLST
- # Intensivists writing POLST
- # Primary Providers writing POLST
- #MMC pts transferred to ECF w/ POLST

ECFs using POLST for at least 50% of residents

Reasons POLST *not* used?

- Corporate policy
- Internal form
- Concern about form
- Difficulty obtaining physician's signature
- Other

What would need to change to start using the POLST

- Facility policy & procedures
- Change in the form itself
- Other

When POLST is used:

who believe POLST form reliably expresses resident wishes

- POLST form used to guide care
- EMTS consults POLST when pt is transferred
- POLST form consulted in the hospital

Who typically prepares the POLST form _____

POLST usage in the Field

Please credit Jane Dinnen, RN, Munson Medical Center
Michigan Nursing Facility Telephone Permission Script

My name is Lesli.

I am a research intern from Munson Medical Center's Advance Care Planning Department.

I am calling about a region-wide quality improvement project focused on the POLST that we are doing for the task force that is trying to have POLST be available throughout all of Michigan.

I am calling to speak w/ _____, whom I understand to be responsible for POLST in your facility. May I speak w/ her/him? Or leave a message for her?

When speaking w/ the person responsible for POLST:

The survey involves a brief telephone interview that will take about 5 minutes.

We are interested in learning more about the use of this bright pink medical order form. We are trying to assess

- **How widely it is used**
- **How it is used by your staff**
- **And any barriers you may experience**

Would you be willing to answer a few questions now or at a later time about your experience w/ the POLST program?

If no

OK – I understand. Is there anyone else with whom we might speak?

If so: Great is s/he available?

If not: Thank you for your time. I will not contact you again.

If yes:

Thank you. Have I called at a convenient time? (If not, arrange a time to call back later. If yes, proceed w/ the POLST nursing facility telephone survey.)

###

November 2006

Director of Quality Improvement/Performance Improvement
Facility
Address
City, New York Zip

Dear Director of Quality Improvement/Performance Improvement,

On behalf of the Medical Orders for Life-Sustaining Treatment (MOLST) Community Implementation Team for Monroe and Onondaga Counties, I am seeking your assistance to ensure the success of the MOLST Pilot Project.

We are collecting data to evaluate the accurate completion of MOLST forms throughout the community. We encourage all hospitals, long-term care facilities, PACE programs, home care and hospice agencies in Monroe and Onondaga Counties to participate in this performance improvement process.

To achieve a consistent evaluation process, we ask that you use the enclosed MOLST Quality Chart Review tool for audit completion of MOLST forms. The suggested process is based on responses to a recent community survey.

Community consensus is that 30 charts should be reviewed, with the option to review more in larger facilities. You should use a process to select the records for review that will accurately represent your facility. Please share with us the method used to identify the charts for MOLST review, including specifics such as timeframe, condition, facility unit, etc.

Please choose one of the suggested methods for selection of records and provide pertinent details:

☐ All new admissions (e.g., admission to the ICU in the last 20 days or to a nursing home in the last six weeks)

☐ All individuals who choose a Do Not Resuscitate (DNR) order

☐ All deaths

☐ Other

(If "Other," please describe the representative sample of the institution where you are using MOLST.)

The enclosed MOLST Quality Chart Review tools are coded for each facility; however, confidential individual data will *not* be released. Facility-type community data will be aggregated and used to track our progress in achieving a target benchmark. Our goal is to provide feedback to each participating facility that compares individual facility performance with community performance and the target benchmark.

Two target community benchmarks have been set:

1. A ninety percent accuracy rate for DNR orders (Sections A, B, C and F)
2. A ninety percent accuracy rate for Life-Sustaining Treatment orders (Section E)

If the target has been achieved, then the next review could be incorporated into the facility's performance improvement processes, as appropriate. If the target has not been achieved, it is recommended the review should be repeated monthly until target performance has been achieved.

Please review the MOLST forms your facility has on record, complete the enclosed MOLST audit tools along with this letter and return them to me within one week of receipt.

Thank you for your time in participating in the MOLST performance improvement process and your commitment to improving care of individuals with advanced progressive chronic illness.

If you have any comments or questions, please contact me at (585) 238-4514 or email me at patricia.bomba@lifethc.com.

Sincerely yours,

Patricia A. Bomba MD

Patricia A. Bomba M.D., F.A.C.P.
Vice President and Medical Director, Geriatrics
Chair, MOLST Community Implementation Team for Monroe and Onondaga Counties



EMS MOLST Implementation

This is a one page summary of the suggested steps and/or processes to implement MOLST in any County or Region in New York State. This is not meant to discuss the detail of each step, as that is outlined elsewhere. Rather, this may serve as a template or guideline for the implementation of MOLST for EMS, 911, and first responders in New York State. It represents our work in Monroe County and may be applicable in entirety or in part to other regions/counties.

1. Create a multi-disciplinary team to look at the feasibility of MOLST. At a minimum, The EMS members of this team should consist of the System EMS Medical Director, Regional EMS Council Chair or designee and County EMS Coordinators. 911 centers, law enforcement and fire agencies should also be considered.
2. REMAC and the Regional Council should be advised of the beginning of the process and be updated frequently as to the progress of the feasibility project.
3. REMAC and REMSCO should approve the implementation of MOLST in their area.
4. A specific protocol shall be approved by REMAC related to MOLST in the field which shall include the appropriate utilization of Medical Control if necessary. Current protocols do exist in Monroe County.
5. Training is the key component to the success of the project and it may be useful to review training already developed for EMS and first responders elsewhere in the State. Training should be geared to the different levels of emergency response (first responders, 911 operators, police and the separate levels of EMT's).
6. Quality assurance programs need to be reviewed/adjusted to include appropriate MOLST encounters in the pre-hospital setting. This QA information is useful in guiding future training and gauging success.
7. Training of medical control physicians in MOLST is essential.
8. Include EMS Regions where possible to limit confusion. Implementation by Region instead of by county simplifies training, roll-out, system-wide QAI and protocol development.
9. Use works developed elsewhere to reduce the effort of developing training, protocols, QAI. The information will need local tweaking; however, much of it is applicable across NYS.
10. Create a "contact list" of people who may have done this elsewhere and are willing to provide information and guidance as an area looks to implement MOLST



EMS and MOLST Pilot Results

The MOLST Pilot is a success.

To assess field utilization, MOLST was reviewed as part of EMS Prehospital Care Report (PCR). **There have been no untoward consequences and no major issues with MOLST.** The positive attributes and benefits outweigh any potential risks. No new cases have appeared since the QI Audit.

Trained professionals know how to read it and understand its intent. To achieve success, 100% of ALS providers, including major ambulance companies, Monroe Ambulance and Rural Metro, and 100% of Rochester Fire Department have been trained. More than 90% of facilities contract with these 2 major companies. Training is available on the ETIN system. Similarly, extensive training has occurred in Onondaga Counties.

MOLST is well-recognized. EMS is seeing the MOLST serve as the DNR in increasing numbers of encounters. In August 2007, Monroe Ambulance implemented a new electronic record format. MOLST was added as an option in the drop down box as an alternative to the DNR form. This was a voluntary documentation and no focused attention or training was done. Prior to the December 2007 meeting when SEMAC and SEMSCO unanimously voted to endorse MOLST for approval at the statewide level, the presence of a MOLST form was documented 8 times. Subsequently, presence of the MOLST form was documented 100 times.

Recommendation:

- At its December 2007 meeting, New York State Emergency Medical Advisory Committee (SEMAC) and the State EMS Council (SEMSCO) unanimously:
 - voted to endorse MOLST for approval at the statewide level
 - encouraged the Commissioner to promote widespread adoption of the MOLST Program
- New York State amends the public health law, in relation to demonstration programs for alternative forms for nonhospital orders not to resuscitate and make the MOLST permanent and statewide. MOLST could then be used in the community as DNR and DNI throughout New York State and will facilitate appropriate treatment by emergency medical services (EMS) personnel.
- Training is critical and it is recommended that new counties assure adequate EMS training using the standardized EMS tools, education, implementation and QA/QI plans created by the MOLST Community Implementation Team.



Qing Cao, MD, HRSA1-K01 HP20471 Geriatric Academic Career Award. The investigators retain full independence in the conduct of this research

Increasing Residency Training of Goal-oriented

Tae Joon Lee, Qing Cao, Stella Hayes

East Carolina University

Abstract

Objectives: For many patients with life-limiting illnesses, defining and discussing goals of future medical care (advance care planning) are very important. This study measures the effects of education to the in-training residents of family medicine (FM) and internal medicine (IM) residency programs at East Carolina University (ECU).

Design: Based on the results of the informal assessment of need from the residents and faculty, educational materials were developed. These included discussion of advance care planning, MOST (POLST) form, FIVE WISHES, healthcare power of attorney, and living will. A 2-hour education and discussion session was given to all in-training FM and IM residents at ECU. Pre- and post-tests were administered to measure their medical knowledge as well as attitudes toward advance care planning.

Results: A total of 70 pre-test and 53 post-test scores were analyzed. Overall knowledge improved with the educational sessions (74.9% vs 90.5% correctly answered pre- and post-test, respectively). Also, the residents' own attitude toward advance care planning changed favoring less aggressive care at the end-of-life (EOL).

Conclusions: Educational sessions significantly impacted residents' knowledge and attitude about advance care planning and EOL care.

Background

- ❑ Most seriously ill patients are not able to make decisions at the end of life
- ❑ Surrogate decision maker to patient concordance about treatment preferences is often poor
- ❑ Improvement of surrogate understanding of patient preferences has the potential to improve both patient and surrogate outcomes
- ❑ Structured, facilitated patient-surrogate conversations are associated with improved surrogate understanding of patient wishes.
- ❑ Resident physician training in discussion of goal-oriented treatment options is not standardized.

Sample Educational Material

Goals of Care:

Life-prolonging: Prolong life at any cost

Includes: All potentially indicated treatments, CPR, mechanical ventilation, ICU

Basic medical: Maintain physical, mental function

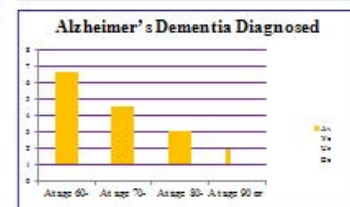
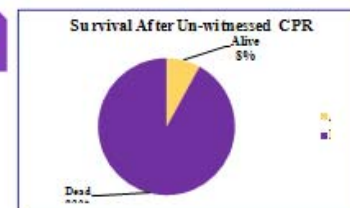
Includes: Hospitalization, IVF, antibiotics

Excludes: CPR, mechanical ventilation, ICU

Comfort: Maximize comfort, alleviate suffering

Includes: Treatments to relieve symptoms

Excludes: CPR, mechanical ventilation, ICU, Hospital unless for symptom control



Age (yr)	Patients with In-Hospital CPR number (percent)	Survival to Hospital Discharge percent (95%CI)
65-69	63,299 (14.6)	22.2 (21.9-22.6)
70-74	84,353 (19.4)	20.9 (20.6-21.1)
75-79	98,263 (22.6)	19.1 (18.9-19.3)
80-84	91,471 (21.1)	17.0 (16.8-17.3)
85-89	62,530 (14.4)	15.1 (14.8-15.4)
>=90	34,069 (6.9)	12.2 (11.9-12.6)
Admitted from a SNF		
Yes	10,924 (2.5)	11.5 (10.9-12.1)
No	423,061 (97.5)	18.5 (18.4-18.6)

Methods

- ❑ Based on the results of the informal assessment of need from the residents and faculty, 2-hour educational materials were developed.
- ❑ These included discussion of advance care planning, MOST (POLST) form, FIVE WISHES, healthcare power of attorney, and living will.
- ❑ Pre- and post-tests were administered to measure their medical knowledge as well as attitudes toward advance care planning.

September 29, 2000

Dear Nursing Home Representative,

This letter is to follow up on your participation in the 8/10/00 training session for use of POLST and to provide you with information related to the evaluation study of the form.

First, thank you for coming. The RENEW group found the sessions to be informative and productive. It is exciting to see so many people and groups working toward common goals.

Second, we would like to clarify that you should **not** make your own copies of POLST. In order to keep track of how many forms are going where, it is important that all POLSTs come from the central source, i.e. the Providence Center for Faith and Healing. Therefore, when you need more copies of the POLST, please call 509-474-3008.

Third, we would like to provide you with more information related to the evaluation study and ask for your assistance in collecting some of our data. The evaluation study will be conducted in three phases. The purpose of the first research phase is to provide the Department of Health and Human Services preliminary data regarding how well the implementation of POLST is progressing in the nursing home setting. The time line for the first phase is 9/15/00-12/15/00. During that time, we will be collecting information related to how many POLSTs are in use in your facility. In December, we will be requesting permission from your facility to do chart review on a random sample of resident charts which contain a POLST to ensure that the form was completed utilizing informed consent procedures and that there is evidence in the chart that the form accurately reflects patients wishes. We would also like the opportunity to interview a few of the residents who have opted to complete POLST.

Phase two of the research will occur from 1/15/01-3/15/01 and will involve more chart review, interviews with administrators, staff, and patients, collection of your facility's policies and procedures related to POLST, and a review of the facility's training process related to educating staff about the use of POLST. Finally, phase three will include much of the same phase two activities, only with larger sample sizes. We hope to conduct the research for phase three from 3/15/01-3/31/02.

This project is large in scope, and we need your help to ensure its success. We realize how busy you are, and we want to keep your participation in the data collection process manageable. To begin our work for phase one, we are asking your help with the following:

1. **Please identify a representative from your staff that will be the contact person for the research project.** We are hoping that this person would be knowledgeable about your facility and would be involved with implementation of POLST pilot. We will be contacting this person from time to time to gather information about the implementation of the project. Once this person is identified, could you please fax his/her name and phone number: attention Crystal Moore (Eastern Washington University) at 509-359-6475. Once we receive this information, we will be in contact with your representative.
2. **If you agree to help us with the evaluation, please write a letter addressed to Judy Meyers giving us permission to conduct the research in your facility.** For your convenience, we have included a model letter that you can use. Judy's address is listed on the letter. It would be helpful for us to have this letter as soon as possible so that the research can officially get underway.
3. **Please keep a log of residents in your facility who have a POLST in their charts.** We have included a tracking form that you can use for this purpose. It would be ideal if the selected representative could be the "keeper of the form" so that he/she would be the most familiar with what is happening with POLST in your facility. This tracking form asks for the resident's medical record number, the date that POLST appeared in this resident's chart, and who initiated the completion of POLST. If a resident is transferred to your facility with a POLST, you can indicate that on the form. This will allow us to keep track of how many POLSTs are in your facility and will facilitate the process of chart review. We ask for medical record numbers because we want to keep the resident anonymous on this form.

We realize we are asking quite a bit of you, but we also realize how important this research is to the success of the POLST pilot. We thank you for all that you have done to help implement this project. We are in this together, working toward the common goal of ensuring quality of end-of-life care. If you have any questions or comments, please do not hesitate to contact any of us.

With sincere thanks,

Crystal Moore, PhD, MSW
EWU
509-359-6425

Judy Meyers, PhD, RN
ICNE
509-324-7282

Melissa Ahern, PhD
WSU
509-358-7982

Appendix E

Verbal Consent Script

For physicians, nursing home administrators, and nursing home staff

Hello, my name is _____, and I am working with the research team that is responsible for evaluation of the pilot of the POLST form. Our records indicate that you received copies of the POLST form and information about using it. I'd like to ask your help with our evaluation. I would like to ask you a few questions regarding your experience with the POLST form. Your participation should take about 30 minutes. (If the participant indicates a willingness to participate, then continue with the remainder of the consent process.)

This research project has been reviewed and approved by the Institutional Review Board at Washington State University and Eastern Washington University. If you have any questions or concerns about this research project, you can contact the WSU IRB at (509) 335-9661. These data will be kept confidential. I will not record your name on the interview form, but rather will use a number to identify the interview for our records. Your participation is completely voluntary. You are free to not answer any questions you may find objectionable, and may withdraw from participating at any time, just by letting me know you would like to end the interview.

The interview poses minimum risk to you but there are two potential concerns. Making end of life decisions with patients can be difficult and the interview may be emotionally troubling. Also, the researchers are obligated by Washington State Law to report incidents of abuse or neglect.

Are there any questions about the program that I can answer for you at this time?

(Answer questions.) Would you like to participate in this project?

Appendix F

POLST Evaluation Study

Consent Form

Dear Resident (or legal surrogate for health care decision making),

You are cordially invited to participate in a research study designed to evaluate the usefulness and safety of the Physician Orders for Life Sustaining Treatment (POLST) form. You have been identified as a resident who has completed a POLST with your physician. The POLST research group will be using what you tell us to do a better job with the POLST form. This work is part of an effort to improve end of life care for everyone.

We expect that our interview will take about 30 minutes to an hour of your time. The interview will be audio-taped and the interviewer will take notes during the interview. The audio-tapes will not have your name on them, only the code number. One list that matches your name with the code number will be kept in a locked cabinet and only the three researchers listed below will have access to the list. The tapes will be kept in a separate locked cabinet. The list and the audio-tapes will be destroyed after three years. Your name will not be identified in the final research report.

Participating in this interview is entirely voluntary. You may, at any time, change your mind and refuse to participate. There will be no consequences for you, whether you choose to participate or not. Because the POLST form deals with end of life decision making, there is some risk that this interview will be troubling for you. If needed, nursing or social service staff will be available to talk about concerns that you might have. If you have any questions regarding this study or the interview, please contact any of the researchers listed below. Thank you for participating.

Sincerely,

Judy L. Meyers, RN, PhD
509-324-7282

Crystal Moore, MSW, PhD
509-359-6425

Melissa Ahern, MBA, PhD
509-358-7982

Consent Statement

I have read the above comments and agree to participate in this research study. I understand that I will be interviewed and asked about my experience with completing the POLST form. If I have concerns, or change my mind prior to participating, I will notify a staff person who will inform the researcher(s) of my desire to not participate. I also understand that during the interview, I can refuse to answer any question, or stop the interview at any time. I understand that if I have questions or concerns regarding this project, I can contact any of the researchers involved or the Washington State University Institutional Review Board at 509-335-9661.

Resident (or legal surrogate)_____ Date_____

Physicians' Orders for Life Sustaining Treatment (POLST) Evaluation Project

Phase I Preliminary Report

Prepared by: Judy Meyers, Crystal Moore, Melissa Ahem, Alice McGrory, and Jennifer Sparr

DO NOT REPRODUCE WITHOUT PERMISSION OF J. MEYERS

The purpose of this exploratory research was to evaluate use of the POLST in 25 nursing homes in the pilot area of Spokane and Whitman Counties. The pilot implementation began on August 1, 2000. These data were collected during January 2001.

Phase I of the evaluation study was a preliminary examination of the following questions:

1. With use of the POLST, are health care providers and nursing home staff complying with policies related to informed consent?
2. What type of training did nursing home staff receive regarding use of the POLST?
3. Is the content of current POLST forms consistent with nursing home residents' current choices about end-of-life care?
4. Does use of the POLST make residents' wishes more portable to ensure that wishes are not lost as residents move from setting to setting?
5. In the pilot area, how widely is POLST being used in nursing homes?
6. Have Emergency Medical Services encountered the POLST in the field?
7. Do health care providers have problems using POLST? If so, what is causing these problems and how can the problems be resolved?

Population and Sample

Of the 25 nursing homes in Spokane and Whitman Counties who participated in training related to use of the POLST, six granted permission for the evaluation study to be conducted at their facilities. These six were Royal Park, Riverview, St. Joseph's Care Center, Beverly- Palouse Hills,

the Waterford, and Cheney Care Center. Contact people included Directors of Nursing, social workers, and administrators. Charts of all nursing home residents who currently have POLST forms in the participating nursing homes were reviewed, and all available residents who have POLSTs, or their legal surrogates, were interviewed.

Of the six participating nursing homes, two (Cheney Care Center and The Waterford) had no POLST forms in use; the remaining four facilities (Royal Park, Riverview, St. Joseph's, and Palouse Hills) were found to have a total of 21 valid POLST forms currently in use. The breakdown of the total number is as follows: Royal Park (n=4); Riverview (n=1); St. Joseph's (n=6); Palouse Hills (n=10).

To assess how often Emergency Medical Services encounter the form in the field, EMS coordinators in Spokane and Whitman counties were asked to track the number of POLSTs encountered in the field during the pilot period.

Setting

The participating nursing homes were the six facilities that granted permission to study use of the POLST in their facilities. Five of the six (Royal Park, Riverview, St. Joseph's, and The Waterford) are located in Spokane County; one (Palouse Hills) is located in Whitman County.

Procedures

Numerous attempts were made to gain permission to conduct the evaluation study in the 25 identified nursing homes. Six letters of permission were signed, granting permission for research to be conducted at that facility. IRB approval was obtained at both Washington State University and Eastern Washington University.

Contact persons at each of the six participating nursing homes were contacted by a research assistant in order to determine the number of current POLSTs being used and to coordinate times for chart review and resident interviews. Contact persons were also told that a research assistant would be contacting them for an interview. One research assistant performed telephone interviews of contact persons from each of the six participating nursing homes. For each interview, the Verbal Consent Script was read, and the Interview with Nursing Home Contact Person was utilized (Appendix A). The interviewer took detailed notes during the interview, transcribed these, and identified major themes.

Chart review was performed in each of the facilities that reported having POLSTs currently in use. Charts of all residents bearing valid POLSTs were reviewed, utilizing the Chart Review Tool (Appendix C). One research assistant conducted all audio taped resident interviews, after determining resident competence for interview, reading consent forms, and obtaining written consent (Appendix B). One resident gave verbal consent due to physical limitations that prevented him from signing. In the event that a legal surrogate had signed the POLST for the resident, an audio taped telephone interview of that legal surrogate was performed. All available residents and legal surrogates were interviewed. The recorded interviews were transcribed, and the interviewer identified major themes.

EMS coordinators were given a questionnaire (Appendix D) to distribute to EMS personnel, that was to be completed when a POLST form was encountered in the field . Personnel were instructed to complete a questionnaire whenever they encountered a POLST form. The completed questionnaire was then to be faxed to the EMS coordinator.

Instrumentation

Data were gathered via interviews and chart review. Open-ended telephone and personal interviews utilized two interview guides. One was for nursing home contact persons, see Appendix A. The other was for nursing home residents, see Appendix B. Interviews with nursing home residents or their legal surrogates were audiotaped. For chart review, the research assistants utilized the Chart Review Tool in Appendix C. The principal researchers developed the Interview Guides used for the nursing home contact persons and the residents/legal surrogates, consent scripts for interviews, consent forms, and the Chart Review Tool.

Interview with Nursing Home Contact Person

Description

The interview with nursing home contact persons was designed to determine what methods of training and education of nursing home personnel had been used, what informed consent processes were specified, what policies and procedures related to POLST use were specified, and problems with using the POLST form. Six open-ended questions were designed to elicit this information.

Validity/Reliability

The contact persons interviewed were individuals who were identified previously by the principal researchers as (1) being familiar with the POLST pilot project and (2) being responsible for tracking POLST use in their respective facilities. All interviews were conducted by telephone by a single research assistant, who took notes during the interviews, and transcribed the audiotapes

Interview Guide for Nursing Home Residents

Description

The interview with nursing home residents was designed to elicit information regarding the congruency of residents' end of life wishes as stated with their POLST forms, and issues of informed consent. Two open-ended questions were developed for the purpose of gleaning this information.

Validity/Reliability

Audio taped interviews were completed on all residents who were POLST users, were deemed competent, and were able to communicate. Nurses on duty were asked to evaluate residents' cognitive abilities to understand interview questions and to communicate adequately for audiotaping purposes. Only residents whose signature appeared on the POLST were considered for interviews. For those residents who were incompetent, legal surrogates whose signature appeared on the POLST were interviewed by audiotaped telephone interviews. A single research assistant performed all resident and legal surrogate interviews.

Chart Review Tool

Description

The Chart Review Tool was designed to evaluate the following: (1) whether the informed consent process was followed, (2) whether residents' wishes were honored, (3) whether appropriate review had occurred, (4) whether there was evidence of transport across settings, and (5) whether there was congruence with an existing advance directive. A five-question form was developed to elicit this information.

Validity/Reliability

The research assistants who performed chart review met with each other and Crystal Moore, co-principal investigator, to discuss inclusion and operational criteria for coding responses. All charts that contained a valid POLST form were determined to be eligible for review. For chart review purposes, a valid POLST form was one for which the resident was currently residing in the nursing home, and for whom the POLST form bore signatures of both physician and resident/legal surrogate. Operational criteria included the following:

- 1) evidence that the informed consent process was followed (e.g., documentation of discussion in care conference or progress notes, and/or checks in Part E of the POLST).
- 2) evidence that the resident's wishes were honored (e.g., congruence between the advance directive and boxes marked on the POLST, or evidence that medical care was congruent with POLST directions for antibiotics or artificially administered fluids and nutrition).
- 3) evidence that the POLST was reviewed appropriately (within the appropriate period of time of admission, with significant change in resident health status, or with resident treatment preference change)
- 4) evidence that the POLST was portable across health settings (e.g., documentation of resident transfers with the form on Part G on the back of the form) .
- 5) evidence that the POLST was congruent with the resident's advance directive (if advance directive exists, a copy is attached, and care directives are the same as those indicated on the POLST form)

Limitations in reliability of the chart review performed for this study include variations in reviewers' evaluations that required subjective judgments regarding levels of medical intervention. This bias was limited in that all three of the chart reviewers are registered nurses enrolled in

graduate study and engaged in frequent discussion regarding operational criteria to minimize any variation in interpretation.

EMS Questionnaire

Description

The EMS questionnaire was developed in consultation with an EMS coordinator from Spokane County. The questionnaire was developed to assess: 1) Was the POLST readily available to the EMS professional? 2) Was the form helpful for initial EMS response? 3) Was the form completed appropriately? 4) Were the orders on the form followed by the EMS professional? 5) Did the form accompany the patient if the patient was transferred?

Validity/Reliability

EMS personnel attended an in-service on the POLST form and the data collection procedure. In addition, they were asked to complete the questionnaire immediately after responding to a call in which the POLST was present in order to increase the reliability of the reported data.

Results

Chart Review

Chart review showed that informed consent procedures were followed in 76% of cases (n=16), as indicated by a check in Part E of the POLST, and/or documentation in care conference notes, social services notes, nurses' notes, or physicians' progress notes. Five charts lacked evidence of informed consent procedures, with four of these lacking any documentation of discussion of end-of-life issues or completion of Part E of the POLST. One chart indicated in a care conference note that the resident had changed her preference from "DNR" to "Resuscitate," which was not reflected on the POLST.

POLST Chart Review Data

Number of charts-21	<u>YES</u> No. (%)	<u>NO</u> No. (%)	<u>(N/A)</u> No. (%)
1. Is there evidence that the informed consent process was followed?	16 (76%)	5 (24%)	0
2. Is there evidence that the resident's wishes were honored?	19 (90.5%)	2 (9.5%)	0
3. Was the POLST reviewed appropriately?	19(90.5%)	2 (9.5%)	0
4. Is there evidence that the POLST is portable across health care settings?	1(100%)	0	20 (95%)*
5. Is the POLST congruent with the patient's advance directive?	12 (57%)	0	9 (43%)**

* Resident had not required transport since POLST initiated

** Resident had no advance directive

The POLST form was universally congruent with existing advanced directives (only 12 patients had an advance directive). Also, in 19 of 21 cases (90.5%), evidence showed that residents' treatment wishes had been honored, as indicated by appropriateness of medical interventions and congruence with other advanced directives, including living wills. There were two cases where residents' wishes were not reflected in the POLST. One involved placement of a feeding tube when the POLST clearly indicated "no feeding tube." The other involved a clear departure from the resident's wish in that her decision to be resuscitated was not reflected on her POLST form.

The POLST was reviewed appropriately in 90.5% of cases (n=19). Since all of the POLSTs had been initiated in current facilities within the five months preceding the review, most residents had not experienced a significant change in condition, and the time frame was such that the form had not come up for institutional review.

Similarly, there was little evidence that addressed how often POLST is portable across health care settings, since 20 of 21 residents had not been transferred since the POLST had been

initiated. The POLST form did successfully follow one patient who was transferred to an acute care facility and then re-admitted to the nursing home. This patient's POLST was appropriately reviewed at the acute care facility and upon readmission to the nursing home. All of the POLSTs studied were initiated at the nursing home in which the resident resided. In other words, no POLST forms transferred with the patient into the facility.

Resident/Legal Surrogate Interviews

Personal or telephone interviews were performed with eight residents/legal surrogates, representing nine of the 21 POLST users (one individual was the legal surrogate for two POLST users). The remainder of POLST users was not interviewed because of communication or cognitive limitations, unavailability, or refusal to participate; legal surrogates were interviewed on the basis of availability.

One research assistant performed all of the (audio taped) resident/legal surrogate interviews. After reading the informed consent script, written consent for the interview was obtained. Two questions were asked: 1) what are your end-of-life wishes? 2) How was the POLST first introduced to you? The interviewer took notes during the interviews, and POLST form indications regarding end-of-life wishes and evidence of informed consent were noted for each interviewee. The interviews were transcribed, and pertinent themes were identified. These included:

- ◆ the POLST is more detailed than previous advanced directives
- ◆ the POLST adequately reflects end-of-life wishes contained in advance directives
- ◆ the POLST seems to be more binding in that it is a physician's order
- ◆ the POLST was introduced by nursing home social worker, nurse, or resident's physician (or interviewee unable to recall)

- ◆ the POLST was explained adequately to residents/legal surrogates
- ◆ the POLST is being used to replace previous advance directives in facility, and must be filled out
- ◆ residents/legal surrogates feel that there is adequate discussion of end-of-life wishes with the use of the POLST
- ◆ the POLST is long
- ◆ the POLST could be made simpler
- ◆ Some vagueness exists about terms such as "comfort measures," or cases when antibiotics are for comfort as opposed to treatment, etc.

The POLST appears to have accurately described the end-of-life wishes of the interviewee in all cases, except one. In that case the interviewee was unable to understand the question. All of the interviewees indicated they had adequate informed consent prior to signing the POLST, as indicated by discussion of end-of-life issues with physicians, social workers, or nurses at the facility. Chart reviews, of those interviewed, further indicated that informed consent procedures had been followed .

It should be noted that one nursing home (Palouse Hills) is requiring that advance directives be replaced by the POLST and that the POLST be offered to every resident upon admission. This explains the higher number of POLSTs in that facility.

Contact Person Interviews

A single research assistant interviewed six contact persons from each of the participating nursing homes, utilizing the Interview with Nursing Home Contact Person as a guide (Appendix A).

Notes taken during the interview were transcribed by the researcher. Below is information obtained regarding each question.

1: When use of the POLST form was introduced to your facility, what sort of training did you receive?

- ◆ Training by Sally Denton (Director of Nursing Services at St. Joseph's who developed model policies and procedures for POLST implementation in the nursing home setting)
- ◆ Meetings with DSHS
- ◆ Training by researchers

2: What training did the staff of this facility receive?

- ◆ None
- ◆ Training by Sally Denton (Director of Nursing Services at St. Joseph's who developed model policies and procedures for POLST implementation in the nursing home setting)
- ◆ Training by contact person

3: Was it clear to you, and in the training that your staff receives, that use of the POLST form is optional?

- ◆ N/A- no training
- ◆ Yes

4: When POLST is used in your facility, what measures are taken to ensure that the informed consent process is honored?

- ◆ N/A- none used

- ◆ Discussion with clients by staff
- ◆ Discussion with doctor, family, resident, and staff together
- ◆ Review of form and chart by contact person

5: What policies and procedures, related to the use of the POLST, do you have in place?

- ◆ None
- ◆ Policy and procedures developed by Sally Denton and DSHS
- ◆ Policy and procedures developed by agency staff

6: What types of problems or issues have you encountered in utilizing the POLST?

- ◆ Accessibility of physician to have conversation and sign form
- ◆ Accessibility of primary care physician to sign form
- ◆ Resistance of physician to have conversation and sign form
- ◆ Portability of the form
- ◆ Ability of the client to sign own form
- ◆ Accessibility of surrogate to sign form
- ◆ Accessibility to the POLST forms
- ◆ Decision making rights when patient and power of attorney disagree
- ◆ Time taken to complete form
- ◆ Complexity of form - confusing to clients
- ◆ Incorrectly completed forms
- ◆ Lack of need for the form

EMS Questionnaire

EMS personnel encountered no POLST forms during the pilot period. Hence, there are no results to report on this aspect of the study.

Conclusions and Recommendations

In evaluating the results presented in this preliminary report, it is important to consider the small sample size employed and lack of a comparison group. For example, are the results pertaining to documentation of compliance with informed consent for the POLST typical when compared to documentation of informed consent for other procedures in the nursing home setting? In order to develop of fuller understanding of POLST implementation in the nursing home setting, a larger sample representing more nursing homes should be examined.

Clearly, there is a need for further study related to the implementation of the POLST form . Specifically, increased efforts and resources need to be invested to involve other nursing homes in the evaluation process. Based upon these preliminary findings, there appears to be a need for more training of nursing home personnel related to the appropriate use of the form in that setting. Training related to POLST implementation should also be provided to other stakeholder groups. These include hospice personnel, home health care professionals, and health care providers in the acute care setting. All stakeholders must be involved to fully actualize the positive impact that the POLST form can have on end-of-life care.

Towards validating Physician Orders for Life Sustaining Treatment (POLST)

Funding Agency: *OHSU Foundation 24620*

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Final Protocol Date: *March 21, 2011*

Protocol Revision Dates: *March 21, 2011*

1.0 Abstract: “End-of-life decision making in the United States is often poorly implemented with patients receiving care inconsistent with preferences...” concluded a recent evidence based review. The Physician Orders for Life Sustaining Treatment (POLST) Program augments traditional methods for advance care planning like living wills and health care proxies by transforming life-sustaining treatment preferences into actionable medical orders that can be followed by emergency medical technicians and other health professionals in times of crisis and transition. Early evidence is promising--data suggest that POLST is effective in influencing the care that patients receive in nursing facilities, and that the forms are acceptable to hospice professionals and emergency medical technicians. Hailed as a ‘next generation’ advance directive POLST has caught the attention of communities around the country seeking to improve end-of-life care. Despite all this, there are critical gaps in our understanding of POLST: First and foremost it is unknown how well completed POLST form orders represent patients’ actual treatment preferences. This pilot study will take the necessary first step in addressing this gap by developing a methodology for ascertaining patients’ treatment preferences that can be used to validate the POLST form. This will be accomplished by 1) Obtaining POLST users’ treatment preferences, understanding of the POLST form, and feedback on POLST through telephone interviews. 2) Testing the feasibility of two methods for eliciting patient treatment preferences that can be used establish construct validity of POLST. This pilot study of up to 30 POLST users will provide preliminary data to strengthen an NIH R21 application for a larger-scale validation study of the POLST Paradigm. It will also provide patient-derived information to improve, better use, and better understand the Oregon POLST form and to improve POLST education. The long term goal of this line of research is to improve the clinical and research tools available for advance care planning, to improve our understanding of how to skillfully use these tools, and to consequently improve the care of patients with life-threatening illnesses by ensuring that the care they receive at the end of their lives reflects their well-informed preferences.

2.0 Background / Rationale:

Americans have embraced the right of seriously ill patients to make their own choices about whether they receive life-sustaining treatment. How to actually do this in end-of-life situations, however, has proved difficult, especially when the patient is too sick to make his or her own decisions.(Ditto, Jacobson et al. 2006) Traditional advance directives were developed as a practical means for ensuring that the end-of-life care patients receive is aligned with their treatment preferences, either in the form of a statement of those preferences(Emanuel and Emanuel 1989) (‘living will’), by designating a trusted person as a health care proxy, or both. Although traditional advance directives can be an important tool to assist those facing the end of life, a 2007 evidence-based review concluded that end-of-life decision making in the United States is often poorly implemented with patients receiving care inconsistent with preferences, a poor match of aggressive care with prognosis, undue suffering, and wasted resources.(Wilkinson, Wenger et al. 2007) The Physician Orders for Life Sustaining Treatment (POLST) Program augments traditional methods like living wills and health care proxies by transforming life-sustaining treatment preferences into medical orders that can be followed by emergency medical technicians, nursing facility staff, and other health professionals in times of crisis and transition. The centerpiece of the POLST Program is the POLST form, a brightly colored form with medical orders indicating preferences about cardiopulmonary resuscitation (CPR) status, medical interventions including hospitalization and intensive care, antibiotic use, and artificial nutrition by feeding tube (see Appendix A). POLST differs from traditional advance directives in several key respects—unlike an advance directive, POLST is not suitable for healthy adults. Because the form contains actionable and specific medical orders, POLST is intended for seriously medically ill or frail patients who could need decisions about life sustaining treatment made at any time. The form is designed to be completed and signed by a health professional who discusses the different options with

the patient or the patient's surrogate decision maker when the patient lacks decision-making capacity and the health professional must sign the orders for them to become actionable. Data from Oregon, West Virginia, and Wisconsin suggest that POLST forms are effective in influencing the care that patients receive in nursing facilities(Hickman, Nelson et al. 2010) (Tolle, Tilden et al. 1998), in elder care settings(Lee, Brummel-Smith et al. 2000), and by Emergency Medical Services(Schmidt, Hickman et al. 2004), and that the forms are viewed as useful and effective by hospice professionals(Hickman, Nelson et al. 2009) and emergency medical technicians.(Schmidt, Hickman et al. 2004) POLST programs are becoming increasingly common and currently exist in varying degrees of development in part or all of 33 US states including New York and California in 2009.(Center for Ethics in Health Care 2010) POLST has been heralded as the 'next stage in honoring patient preferences'.(Meier and Beresford 2009) Despite all this, there are critical gaps in our understanding of POLST: First and foremost **it is unknown how well completed POLST form orders represent patients' actual treatment preferences.** As the necessary first step in addressing this gap, **the goal of this study is to develop a methodology for ascertaining patients' treatment preferences that can be used to validate the POLST form.** We propose a telephone survey of Oregon POLST users to test methods for measuring patient preferences that can be used to study POLST. These surveys will include in-depth interviews to ensure that the telephone surveys are not introducing bias or missing important elements.

This study will provide us with preliminary data and experience necessary to take the next step: a larger-scale validation study of POLST. It will also provide patient-derived information to improve and better use the Oregon POLST form and to improve POLST education. The long term goal of this line of research is to improve the clinical and research tools available for advance care planning, to improve our understanding of how to skillfully use these tools, and to consequently improve the care of patients with life-threatening illnesses by ensuring that the care they receive at the end of their lives reflects their well-informed preferences.

Significance:

The Prevalence of Needing Advance Care Planning is High: Everyone dies. Death follows a trajectory—sometimes a precipitous or more gradual decline, sometimes an up and down course of hospitalizations, recoveries, and uncertainty, and sometimes a gradual decline in frailty.(Lunney, Lynn et al. 2003; Gill, Gahbauer et al. 2010) In each of these situations treatment decisions must be made—ideally taking into account the patient's values, goals, and preferences.(Steinhauser, Christakis et al. 2000; Ferrell, Connor et al. 2007) Data from the US Health and Retirement Study found that among 3,746 adults 60 or older who died between 2002 and 2006, 42.5% needed to make decisions about treatable life-threatening conditions before they died, but 70.3% of these people lacked decision-making capacity.(Silveira, Kim et al. 2010) Extending these data to the US population – for the 1.91 million persons aged 60 or older who died in 2007 *approximately 570,000 Americans die each year needing to make decisions about their treatment but lacking decision making capacity.* In the Health and Retirement Study two-thirds of such decedents had some type of advance directive, suggesting that advance care planning can play an important role in helping to guide these decisions.

The need will only increase: The oldest old (persons 85 years and older) are the fastest growing segment of the elderly population.(Meyer 2001) As the proportion of Americans who die at an advanced age increases and the proportion of Americans who die outside the hospital likewise increases(Flory, Yinong et al. 2004) the importance of advance care planning will only increase as will the need to better understand advance care planning and to do it more effectively.

Unfortunately Public Policy for Advance Care Planning remains too driven by reactionary

politics: The public and legislators take an active interest in advance care planning as illustrated by the failed attempt to incorporate reimbursement for advance care planning conversation into the Affordable Health Care Act(Connolly 2009), the subsequent ‘death panel’ media storm(Rutenberg and Calmes 2009), and the recently passed New York Palliative Care Information Act. The latter requires physicians who treat patients with a terminal illness or condition to offer them or their representatives information about prognosis and options for end-of-life care, including aggressive pain management and hospice care.(Brody 2010) It would be seem preferable for policy efforts to be driven more by data than by fears and partisan politics.

However for traditional Advance Directives the data are decidedly mixed. In contrast to the Health and Retirement Study, other surveys have found that advance directive completion rates among chronically ill individuals in the community are at most 1 in 3, suggesting that the people who should have them are only slightly more likely to complete advance directives than the general population.(Knaft, Nielsen et al. 2005; Perry, Swartz et al. 2005; Wilkinson, Wenger et al. 2007) However data also demonstrate that systematic efforts to promote advance care planning can succeed—in LaCrosse, Wisconsin, a community that implemented an advance care planning ‘microsystem’ was able to get 90% of decedents to complete an Advance Directive before they died(Hammes, Rooney et al. 2010). Some studies question whether advance directives are effective in influencing care(Teno, Lynn et al. 1994; Tulsky, Fischer et al. 1998), particularly in the hospital and intensive care unit care where, in theory, they should have their greatest impact.(Kass-Bartlemes, Hughes et al. 2003) Conversely, data from the AHEAD study of oldest old found that having a living will was associated with lower probability of dying in a hospital for nursing home residents and people living in the community (OR = .35 and .65, respectively).(Degenholtz, Rhee et al. 2004) For proxies, a systematic review found that while they inaccurately predicted patient preferences one third of the time, family member proxies were still more accurate than patients’ physicians.(Shalowitz, Garrett-Mayer et al. 2006)

POLST evidence is more positive, but much more limited. A total of 11 papers report empirical data about POLST in the medical literature.(Dunn, Schmidt et al. 1996; Tolle, Tilden et al. 1998; Lee, Brummel-Smith et al. 2000; Demanelis and Moss 2002; Hickman, Tolle et al. 2004; Meyers, Moore et al. 2004; Schmidt, Hickman et al. 2004; Hickman, Nelson et al. 2009; Resnick, Foster et al. 2009; Hammes, Rooney et al. 2010; Hickman, Nelson et al. 2010) They describe POLST use in the nursing home (6 studies), hospice (2), elder-care (1), emergency (1) and community (community decedents, 1). Studies have addressed POLST utilization: 13.3% of nursing homes (used POLST forms at all) in a 2004 national sample; 71% of Oregon nursing homes (used POLST in at least half of their residents) in 2002; 67% of decedents in LaCrosse Wisconsin who died in 2007-8 had a POLST form at the time they died; in a 2007 sample POLST was widely used in hospices in Oregon (100%) and West Virginia (85%) but only regionally in Wisconsin (6%). Studies have addressed the effects of POLST: a cohort study of 1711 residents in 90 nursing facilities in Oregon, Wisconsin, and West Virginia found that POLST users were more likely to have orders about life-sustaining treatment preferences beyond CPR than non-POLST users (98.0% vs. 16.1%, $P<.001$) and that POLST users with orders for Comfort Measures Only were less likely to receive medical interventions (e.g., hospitalization) than residents with POLST Full Treatment orders ($P=.004$), residents with Traditional DNR orders ($P<.001$), or residents with Traditional Full Code orders ($P<.001$).(Hickman, Nelson et al. 2010) This finding highlights another key difference between POLST and other Advance Directives – POLST allows patients to assert a preference not to be hospitalized and not to receive intensive care—thus avoiding two places where advance directives have proven unable to influence care.(Kass-Bartlemes, Hughes et al. 2003) Another study of POLST showed that Emergency Medical Technicians can correctly interpret the orders on the form and will follow POLST orders.(Schmidt, Zechnich et al. 1998)

While these studies of POLST are encouraging, they are mostly confined to nursing home or hospice populations, and have not been designed to detect or test limitations of POLST. Does POLST augment traditional advance directives? Is it the ‘next wave’ of advance care planning? It is impossible to say because POLST has not been studied with anywhere near the scrutiny of traditional advance directives.(Schneiderman, Pearlman et al. 1992; Emanuel, Emanuel et al. 1994; Alpert, Hoijtink et al. 1996; Schwartz, Merriman et al. 2004) Optimism surrounding POLST could be based on the fact that it is newer and less studied and so its limitations are not yet known. As more and more states adopt POLST as public policy, we can’t afford to wait any longer to critically study POLST and answer key questions like whether POLST form orders accurately reflect patient preferences. There is an urgent need to better understand the form, its limitations, and how it is best designed and used.

POLST information can be rapidly disseminated and acted upon. The POLST task force provides a potent means to disseminate new knowledge. The task force maintains key contacts in most US states, the POLST.org website, and ongoing statewide education efforts like those going on in Oregon, Wisconsin, West Virginia, and California (see Appendices D,E,F for education examples). This knowledge will have immediate application in teaching the public how to use POLST, teaching health professionals to better use POLST, and in revising the POLST form so that becomes progressively easier to use and better reflects the range of options patients want.

Preliminary Work. The POLST Registry represents the full spectrum of POLST users, the most comprehensive data ever made available for research activities. Since December 3, 2010 health care providers’ who complete a POLST form are mandated to enter it into a Registry unless the patient opts out. This data allows us to identify both individual and aggregate information about recorded patient wishes as well as demographic information of POLST form holders. As of July 31, 2010 there were 22,446 active forms in the Oregon POLST registry. POLST orders for Cardiopulmonary Resuscitation (CPR)) and Medical Interventions are listed in Table 1.

Table 1: Frequencies of POLST orders in the Oregon POLST registry as of July 31, 2010:

If no pulse/ not breathing	n	%	If has a pulse and is breathing	n	%
No CPR	16444	73.3	Comfort only	8218	37.2
			Limited treatment	7072	32.0
			Full treatment	1043	4.7
Yes CPR	6002	26.7	Comfort only	181	0.8
			Limited treatment	1225	5.5
			Full treatment	4364	19.7
Total	22446	100%		22103	100%

As table 1 illustrates, POLST registrants use POLST to indicate a spectrum of treatment wishes with 37% wanting the lowest level of care and 19.7% wanting the highest. The mean age of registrants is 77.7 years (SD = 13.2) and the median age is 81 at the time their form is signed by a clinician. Only 10 percent of registrants are 60 years or younger, and 10 percent are 91 years or older. 62.1% of registrants are women.

3.0 Objectives:

The objective of this pilot study is to obtain preliminary data to strengthen an NIH R21 application. The specific aims of this protocol are:

Specific Aim 1: To determine POLST users' treatment preferences, understanding of the POLST form, and feedback on POLST through telephone interviews.

Specific Aim 2: To test the feasibility of two methods for eliciting patient treatment preferences that can be used to establish construct validity of POLST: 1) Assessing POLST preferences by telephone and 2.) Measuring treatment preferences using the Life Sustaining Treatment Preferences Questionnaire

4.0 Study Population: Up to thirty (n=30) men and women age 18 or older who are signers (either as the patient or the surrogate decision maker) on valid POLST forms submitted to the Oregon POLST Registry with 7 days of being signed. Valid POLST forms are those with the following: 1.) physician assistant, or nurse practitioner signature, 2.) date, 3.) name and date of birth of the patient, and 4.) response to (at a minimum) section A for cardiopulmonary resuscitation.

Human Subjects Involvement, Characteristics and Design: The object of this study is to invite patients/surrogates who have recently completed a POLST form to participate in a voluntary telephone interview, in order to understand their treatment preferences and understanding and experience of POLST completion. We are defining 'recent' as within 1-2 weeks for having completed a POLST form and 1-2 months for completing the telephone interview. We will use the POLST Registry to identify Oregon patients and/or surrogates who have recently (within two weeks) completed a POLST form. We will use the date the form was signed as indicating the date of completion. If the patient signs his or her form, we will attempt to contact, consent, and enroll the patient for an interview about his or her preferences. If the form is signed by a surrogate rather than the patient, we will attempt to contact, consent, and enroll the surrogate for an interview about the patient's preferences. Prior to contacting the patients whose POLST form is sent from a hospice program or nursing care facility we will contact the hospice or nursing care facility to ensure that the patient is still alive and to seek guidance about whether the patient or his or her surrogate should be invited to participate. For appropriate patients we will use the demographic information on the POLST form (name, address, date of birth, gender, last 4 social security number, primary care professional, signing professional name and telephone number, and surrogate name and relationship to patient) combined with white pages and internet based search to

locate the patient/surrogate directly, or through the primary care professional or POLST signing professional. Approximately 30 patients/surrogates will be recruited to participate in telephone interviews lasting approximately 30 minutes. Subjects can refuse further participation at any time.

Recruitment and Informed Consent: Prior to initial telephone contact, subjects will receive a letter describing the study along with a blank POLST form and a copy of the informed consent document. This letter will contain both a phone number they can call and a stamped self-addressed envelope post-card that the patient/surrogate that can be returned to the study team if they do not wish to be contacted. Patient/surrogates who have not expressed their dissent will be contacted by telephone 1 week after the mailing is received and informed consent will be obtained from the patient/surrogate (interview subject) over the telephone.

5.0 Inclusion/Exclusion Criteria:

Inclusion criteria:

- Signer of a valid POLST form submitted within 7 days of being signed.
- English speaking
- Provides telephone consent to participate
- Able to participate in a telephone interview (e.g. not too hard-of-hearing)

Exclusion criteria:

- Returns the ‘opt-out’ postcard indicating s/he does not wish to participate
- Unable to pass cognitive function screen: Prior to asking more in-depth questions about POLST and treatment preferences we will ask patients to pass a cognitive screen. We will administer the ‘Short portable mental status questionnaire’ (Pfeiffer E, 1975). Subjects who get more than 4 questions wrong (or more than 5 questions wrong for subjects with high school level education or less) will be thanked for answering demographic questions but not questioned further. These scores correlate with moderate cognitive impairment or worse. We will use the cognitive function screen on patients but not surrogates as surrogate decision makers who recently signed a POLST form are much less likely to have significant cognitive impairment. In either case we will offer to stop the interview if the subject (patient or surrogate) starts to sound either tired or confused as the interview progresses.

6.0 Methodology:

Structured Telephone Interviews: Data will be gathered through structured telephone interviews with patients and/or legal surrogates as soon as possible following POLST completion. Surveys will be conducted by research personnel (Ms. Olszewski and Dr. Fromme) who are both experienced interviewers. Interviews will cover the following domains:

- Patient/surrogate preferences as rendered on the POLST form and the Life Support Preferences Questionnaire.
- Context in which POLST was completed and current interview takes place: location (home, nursing facility, assisted living), enrollment in hospice, education, age, race/ethnicity, health status, etc. (see telephone interview script for specifics)
- POLST completion factors: Do you know what we’re talking about when we say ‘POLST’ form—the pink form? Do you remember signing your POLST? When was the last time you reviewed your POLST? Where were you when your POLST form was completed? What was happening to you that caused those taking care of you to complete the POLST? Who reviewed the form with you and how long had you known that person or people? What occurred at the

time of that review? Did they discuss your prognosis, or what is likely to happen with your illness? Did the provider make a recommendation? Did the provider invite and answer questions? How long did the provider spend with you? Was this the first time they talked to you about the form? Who else was present? Did their presence influence your decision making?

- Accounting for discordance: In cases where the patient's preferences differ from the orders on their POLST Registry form, it is important to distinguish between discordance caused by changes in preference and discordance caused by error. Why do you think your wishes are different now? Were your wishes incorrectly recorded at the time of POLST completion? Have your wishes changed since you filled out the form originally? Why? Did the person helping you complete the POLST influence you to record something other than your own wishes?
- Cognitive interviewing open-ended and probe questions. Cognitive interviewing is a technique for evaluating sources of response error in questionnaires by inquiring into the cognitive processes, overt and hidden, of the respondent (Willis 2005). In this study the function of the cognitive interview questions is threefold: 1) To ask the patients/surrogates about the thinking that underlies their treatment choices to understand the mental construct that informs their preferences. 2) To probe their responses for misunderstandings that constitute additional response error. 3) To get users understanding and feedback on POLST.

7.0 Study Procedures and Schedule of Events:

Day 0-14: POLST form signed by clinician

Day 0-14: receive signed POLST form in registry, use internet search of white pages to locate telephone number; mail letter and opt-out postcard to POLST address

Day 7-21: call telephone number, invite patient/surrogate to participate in telephone interview within 7 days.

Day 7-30: complete telephone interview

8.0 Time line and Milestones:

We hope to be able to begin interviews in May 2011 and begin the first round of analyses in June 2011. We anticipate completing interviews by January 2012 and final analyses by June 2012.

9.0 Biostatistical Considerations: This is primarily a qualitative study using cognitive interviewing methods to obtain pilot and preliminary data for a larger NIH funded proposal. Because of the small sample size statistical analysis will be limited—calculating response and participation rates, demographics, concordance of POLST orders with stated preferences, and frequencies of patient responses to close-ended questions. Cognitive interviews will be recorded and analyzed using the qualitative approach described by Willis.(Willis 2005)

9. ETHICAL AND REGULATORY REQUIREMENTS

9.0 Protocol Review

The protocol and informed consent procedure for this study must be reviewed and approved in writing by the OHSU and Oregon State Institutional Review Boards (IRB) prior to any patient being registered on this study.

9.1 Informed Consent (only if applicable)

Telephone informed consent will be obtained from all patients, or the legally authorized representative of the patient, participating in this trial, as stated in the Informed Consent section of the case of Federal Regulations, Title 21, Part 50.

9.3 Human Subjects Considerations

Protection of Human Subjects: The protocol for the proposed research will be reviewed by two Institutional Review Boards: The OHSU Office of Integrity and the Oregon State Department of Health and Human Services IRB. Each patient/surrogate will be provided an opportunity for informed consent and can refuse continued participation at any time.

Risks to Human Subjects

Sources of Materials: Materials will come from the patients' POLST form(s) in the electronic POLST Registry, from telephone interviews with the patient/surrogate, and from in-person interviews with the patient/surrogate. Both the telephone interviews and in-person interviews will be audio-recorded. The in-depth interviews will be transcribed.

Potential Risks: The potential risks of the telephone and in-depth interview are similar. In both cases, patients/surrogates will be asked to consider scenarios that they could find distressing. Some may experience fatigue during the telephone or in-depth interview and will be offered the opportunity to pause and complete the interview at a later time. Distressed subjects will also be offered a call-back from study PI Erik Fromme or CI Terri Schmidt who are both board certified Palliative Care physicians.

Adequacy of Protection Against Risks: Like our current POLST Registry study, this study protocol will be reviewed and approved by Institutional Review Boards at Oregon Health and Science University and the Oregon State Department of Health and Human Services. The interviewer will be alert for signs of fatigue or emotional distress with the questions. If the participant becomes distressed at the nature of the questions, the interview will be terminated and resources for support offered. The interview can be stopped and continued at another time if the participant becomes fatigued. The risk of breaching confidentiality will be minimized by identification by code numbers and by securing all data collected in locked files in areas with limited staff access. Data will be stored anonymously. Participant information (names, addresses, phone numbers) will be stored separately and in a locked cabinet. The risk of interviewing a patient/surrogate who is cognitively impaired will be addressed using a cognitive screening procedure at the beginning of the interview.

Potential Benefits of the Proposed Research to Human Subjects and Others: All of the subjects in this study will have recently completed a POLST form and may benefit from going over the form again. For patients/surrogates who have concern about the wishes recorded on their POLST form, we will inform them of the options they have to (1) void that form in the Oregon POLST Registry and (2) how to complete a new form and how to proceed with either of these options.

Importance of the Knowledge to be Gained: The proposed study will examine a practice change in advance care planning that is relatively understudied but increasingly used. As more and more states (now over 30) adopt POLST programs it is critically important to try to

understand the strengths and limitations of the form as well as we understand traditional Advance Directives. This study will generate important information about the POLST form that will help guide changes in the form, public education about the form, and health professional training. In addition, this study will yield preliminary data, instruments, and data about methods that will be used to undertake a fully powered validation study of POLST.

Data and Safety Monitoring Plan: Data provided by the POLST Registry will be maintained in an encrypted format on a secure computer (accessed only by authorized research staff and not in a shared network directory) and reported only in aggregate (no protected health information included) and any identifiers will be destroyed after use in identifying subjects. Data collected in the course of interviews will be maintained in a secured and encrypted database. Patients will be identified by a third-party identifier, not directly associated with any protected health information. No identifiers will be maintained in the research-de-identified dataset for analysis, although certain relevant dates will be included (date POLST form was signed, etc). Individual identifying data will not be reported. Audio recordings and interview transcripts (if recordings are transcribed) will be saved on a secured computer with access limited to only appropriate staff and will be destroyed upon completion of the project. The telephone interview recordings will be periodically reviewed by Dr. Fromme will review a 20% (n = 6) sample to ensure data accuracy and that the research assistant is paying attention to patient/surrogate fatigue and emotional distress and offering to allow them to stop or take a break.

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Instrument NN

Title: California POLST Minimum Data Set Questions

Designer: Neil Wenger, MD, MPH. Please credit him in any future work:

Suitable for Quality Improvement? Yes, modified to fit your state.

Suitable for research? Yes, especially if you are planning to add POLST questions to your states Minimum Data Set.

Description of Instrument: The Minimum Data Set is collected by all Medicare and Medicaid certified nursing homes in the United States. The data are clinical variables that assess each patient's functional capacity, symptoms, diagnoses, treatments, and demographics. While there are a common set of variables collected by every state, there is a section, called Section S, where states are allowed to add variables that will be collected only in that State. In California, POLST advocates have been able to add questions about POLST to section S. In addition to being able to track how many nursing homes have POLST, their POLST orders, signer and Advance Directive information, investigators will be able to look at that information in the context of the comprehensive information contained in the Minimum Data Set and possibly link it to other databases such as Medicare. This will provide extraordinarily complex data about POLST utilization and how different POLST orders correlate with diagnoses, functional status, etc, etc. These data provide outstanding quality metrics in addition to research grade data.

How to use:

From listening to the National POLST Task Force attendees, getting questions added to your state's Minimum Data Set may not be feasible in all states, and the process requires getting permission both from the correct state Department of Health & Human Services agency and the blessing of National Centers for Medicare and Medicaid Services. Many states do not utilize section S, which is generally used to do case mix adjustment-based reimbursement. Therefore states that are not currently using section S may automatically reject a request to add POLST questions because it would require additional resources.

At the February 14, 2013 meeting, it was proposed that these questions be added to the national Minimum Data Set. Some attendees raised the concern that nursing facilities would interpret the presence of the POLST questions as an indication that residents SHOULD have a POLST form and would begin offering them to residents who were not POLST appropriate, such as a younger patient rehabbing from orthopedic surgery. The decision was to wait until the California data were analyzed to see if this problem materialized before proceeding nationally.

If you are interested in exploring adding POLST questions to your state's Minimum Data Set, I strongly encourage you to contact the National POLST Task Force Chair who can advise you and connect you with the appropriate contacts in California if necessary. Mailing Address: National POLST Paradigm Task Force, Oregon Health & Science University, Center for Ethics in Health Care, 3181 SW Sam Jackson Park Road, Mail Code: UHN-86, Portland, Oregon 97239. Phone: 503-494-3965. Fax: 503-494-1260

Section S		California
S9040A	California POLST	
Enter Code	Does resident have a California POLST form in chart?	
<input type="checkbox"/>	0. No	
<input type="checkbox"/>	1. Yes	
S9040B	CA- Item selected in California POLST Section A	
Enter Code	1. Attempt resuscitation/CPR	
<input type="checkbox"/>	2. Do not attempt resuscitation/DNR	
<input type="checkbox"/>	9. Not completed	
S9040C	CA- Item selected in California POLST Section B	
Enter Code	1. Comfort measures only is checked	
<input type="checkbox"/>	2. Limited additional interventions is the only box checked	
<input type="checkbox"/>	3. Limited additional interventions AND "Transfer to hospital only if comfort needs cannot be met in current location" are BOTH checked	
<input type="checkbox"/>	4. Full Treatment is checked	
<input type="checkbox"/>	9. Not completed	
S9040D	CA- item selected in California POLST Section C	
Enter Code	1. No artificial means of nutrition, including feeding tubes	
<input type="checkbox"/>	2. Trial period of artificial nutrition including feeding tubes	
<input type="checkbox"/>	3. Long term artificial nutrition including feeding tubes	
<input type="checkbox"/>	9. Not completed	
S9040E	CA- POLST Section D - Signature of Physician	
Enter Code		
<input type="checkbox"/>	0. No	
<input type="checkbox"/>	1. Yes	
S9040F	CA- POLST Section D - Signature by Patient or Decisionmaker	
Enter Code		
<input type="checkbox"/>	0. No	
<input type="checkbox"/>	1. Yes	
S9040G	Discussed with in California POLST Section D	
Enter Code	1. Patient	
<input type="checkbox"/>	2. Legally Recognized Decisionmaker	
<input type="checkbox"/>	9. Not completed	
S9040H	California POLST Section D- Advance Directive:	
Enter Code	1. Advance directive available and reviewed	
<input type="checkbox"/>	2. Advance directive not available	
<input type="checkbox"/>	3. No advance directive	
<input type="checkbox"/>	9. Not completed	

Users Guide/Frequently Asked Questions:

Q1: I want to do a POLST Paradigm quality improvement project, can you recommend a good starting place?

A1: Congratulations! The answer depends whether you want to look at state level, evaluating your state's POLST Paradigm program, or a institutional level, evaluating how your facility, hospital, or institution is using POLST. See Q2 (state) and Q3 (institution) below for details.

Q2: Can you recommend a good starting place for evaluating our state's POLST Paradigm Program?

A2a: If you are a new program, it may make sense to start by keeping track of POLST education that is offered, and, if possible, how many people attend. You can do that on a spreadsheet or word document table. Toolkit Instrument Z, the California POLST Knowledge Pre-Survey offers a way to assess whether people attending an educational session have learned enough.

Another approach would be to assess your coalition efforts. The Kansas-Missouri TPOPP Coalition has provided the instruments they've used to build their coalition and assess its progress in Toolkit Instruments BB and CC.

A2: At the state level, you could start with a telephone survey that asks facilities how often they use the POLST form with their patients. The instrument is included in the Toolkit and titled 'Instrument I OR Nursing Home and Hospice Telephone Survey' The most important question is:

a. How many current patients have POLST forms? [read choices]

- ☐ None
- ☐ Less than half
- ☐ About half
- ☐ More than half
- ☐ Nearly all or all

These results will allow you to tell stakeholders what % of nursing homes use report using POLST forms, and the % of nursing homes that report using POLST forms in at least ½ of their residents. This is probably the best measure to track growth of developing POLST programs in the most succinct manner.

Q3. Can you recommend a good starting place for evaluating our institution's use of POLST?

A3: At a facility level, you could start with a simple chart review for all residents and complete the chart audit tool which is included in the Toolkit and titled 'Instrument A POLST Quality Improvement Chart Review Form'. The most important questions are:

1. Presence of POLST Form:

a. Is a POLST Form present?

- ☐ No ☐ Yes (go to question 2)

This lets you know how many of your residents have a POLST. Also:, and

e. Length of time to POLST completion:

Date of admission: _____

Date POLST form signed by patient/surrogate: _____

Date POLST form signed by MD: _____

This helps to verify that the form is valid because you are confirming that the POLST is signed and dated by the health professional as well as the patient/surrogate.

Q4: Do I need Institutional Review Board (IRB) approval to do this project?

A4: It depends on the purpose of your project. Institutional Review Boards are responsible for overseeing human subjects research. So if the purpose of your project is to answer a research question, or create and disseminate new knowledge, then you will need to get IRB approval. If the purpose of your project is to evaluate and/or improve the quality of your POLST program, or the use of POLST in your institution, then you do not need IRB approval. If you have already done a quality project and you wish to disseminate your findings to others outside your program or institution, then you should apply for IRB approval to use your quality data for research purposes because this extends beyond the scope of internal quality assurance or improvement. If you have both quality and research aims for your project, then you will need IRB approval. If you have never worked with an IRB before, we recommend that you contact the IRB and ask to speak with an analyst who can help you understand the steps and requirements. In particular, if you are doing research on human subjects, you will either need to obtain informed consent or justify why this is unnecessary. If, after reading this, you are not sure whether you need IRB approval to do your project, we strongly recommend that you contact your IRB and ask for them to help you make this determination. We have several IRB protocols included in the toolkit which may give you a place to start if you have never written one before.

Q5: I would like to evaluate whether the POLST forms in our institution are being filled out correctly according to patient/surrogate preferences, how can I do that?

A5: Figuring this out is very tricky and we don't recommend trying to do it on a large scale because there are a lot of complexities. Your best bet would be to review the approach taken by Meyers et al in Washington. Their materials are available in 'Instrument Q: Washington POLST Nursing Facility Project.' Other Toolkit Item MM is an IRB proposal for an ambitious research study that would address this question if cost were no object.

Q6: What is sampling?

A6: If you want to find out what a group of people think about an issue, you could ask all of them and tally the results – for example this is the approach used in voting. However it is not necessary to ask every single person in a group for their response in order to characterize how the group will respond – this is like the straw polls that predict the outcome of elections before the whole results are tallied. Making sure that you get enough responses to accurately characterize the entire group requires good sampling. In most cases, groups can be characterized by the responses of 20-30 members, but only if the members are chosen randomly. For example, if you did your straw poll prior to election and only polled

Democrats, you would conclude that the Democratic candidate was going to win. You would need to make sure that the sample you chose included a number of democrats and republicans and other voters that was close enough to the proportions of those parties in the whole state in order to accurately predict the outcome of the election in that state.

In the example I picked, you would be best off if you could put the names of everyone who voted in a hat and selected your sample at random from the pool of all available voters. Random selection can be achieved using a random number table, drawing from a hat, or a randomization program. Achieving a good sample that faithfully represents your entire population can be very difficult to do, because you do not always have access to everyone that you are interested in. Sometimes it's necessary to use what's called a 'convenience sample' – i.e. you survey the people who you have access to and will complete your survey. Often this is sufficient, especially for quality improvement work. You just need to make sure that you remember the limitations of this strategy so that you carry incorrect conclusions too far. In my election example, faulty sampling caused newspapers to prematurely declare that John Dewey, rather than Harry Truman was elected president of the United States.

POLST Quality and ReSearch Toolkit Literature Review

Last update: 1/24/2013

Year	Citation	Patient Population	Corresponding Author	Project Outcome
1997	Communicating Preferences for Life-Sustaining Treatment using a Physician Order Form. Authors: P Dunn, CA Nelson, SW Tolle, VP Tilden Journal of General Internal Medicine 12(1S) 102 April 1997	Nursing home residents	Patrick Dunn, MD (retired)	Unable to piece together instrument from old files.
1998	“A Prospective Study of the Efficacy of the Physician Order Form for Life” Authors; Susan Tolle MD Virginia Tilden, Christine Nelson, & Patrick Dunn MD Journal of American Geriatric Society 46:1097-1102.	Nursing home residents	Patrick Dunn, MD (retired)	Unable to piece together instrument from old files.
2000	“Physician Orders for Life-Sustaining Treatment (POLST); Outcomes in a PACE Program.” Authors: Melinda Lee MD, Kenneth Brummel-Smith MD, Jan Meyer, Nicholas Drew BS, and Maria London, MA Journal of the American Geriatrics Society 48(10):1219-1225, October 2000	Elder place residents, Chart Review	Melinda Lee MD	Materials no longer available.
2004	“The Physician Orders for Life-Sustaining Treatment Program: Oregon Emergency Medical Technicians’ Practical Experiences and Attitudes.” Authors; Terri Schmidt MD, Susan Hickman PhD, and Heather Brooks BS Journal of the American Geriatrics Society 52(9): 1430-34, September 2004	Mailed survey to EMT respondents	Terri Schmidt MD schmidt@ohsu.edu	Toolkit Instrument R
2004	“Physician Orders for Life-Sustaining Treatment Form Honoring End of Life Directives for Nursing Home Residents.” Authors: Judy Meyers PhD RN, Crystal Moore PhD MSW, Alice	Chart reviews Template analysis of interviews	Judy Meyers, RN, PhD judyandkenm@gmail.com	Toolkit Instrument Q

	McGrory RN, Jennifer Sparr MSW, & Melissa Ahern PhD MBA Journal of Gerontological Nursing 30(9):37-46 September 2004			
2004	“Use of Physician Orders for Life –Sustaining Treatment Program in Oregon Nursing Facilities: Beyond Resuscitation Status” Authors: Susan Hickman PhD, Susan Tolle MD, Kenneth Brummel-Smith MD, Margaret Murphy RN JD	Nursing homes, Telephone survey	Susan E. Hickman, PhD hickman@iupui.edu	Toolkit Instrument I
2004	“Nursing Home Participation in End-of-Life Programs: United States, 2004” Authors: Helaine E. Resnick, PhD, MPH, Gregory L. Foster, MPH, MA, and Susan E. Hickman.	Secondary data analysis	Susan E. Hickman, PhD hickman@iupui.edu	No instrument, n/a
2005	“Do not Hospitalize Orders in Nursing Homes: A Pilot Study” Authors: John Culbertson MD Cari Levi MD, Larry Lawhorne MD Jof A Medical Directors Association 6(1):22-26 Jan/Fed 2005	Online survey of AMDA Foundation Members	John Culbertson MD	Only mentions POLST in the discussion, n/a
2006	Withholding Resuscitation: A New Approach to Prehospital End-of-Life Decisions Authors: S Farber, J Shaw, J Mero & WH Maloney Annals of Internal Medicine 145(10): 788, November 2006	Letter to editor which mentions POLST	Stuart Farber, MD	n/a
2006	“Withholding Resuscitation: A New Approach to Prehospital End-of-Life Decisions Authors: Sylvia Feder MA,MICP, Roger Matheny MICP, Robert Loveless PhD EMT-D & Thomas Rea MD MPH. Annals of internal Medicine 144: 634-40 May 2, 2006	EMS personnel; Interviews Review medical incident reports	Sylvia Feder	Does not mention POLST, n/a
2007	“Community Implementation of the Medical Orders for Life-Sustaining Treatment (MOST) to improve Advance Care Directives” Authors; PA Bomba, TC Caprio, SM Gillespie, K Richardson Journal of the American Geriatrics Society 55(4) Supplemnt:S44, April 2007.	Nursing homes, hospitals, PACE; Mailed survey	Patricia A. Bomba, MD patricia.bomba@lifethc.com www.compassionandsupport.org	Toolkit Instrument D (plus Instruments C, T, and extras EE, FF, and GG)

2009	<p>“Nursing home participation in End-of-Life Programs: United States, 2004”</p> <p>Authors; Helaine Resnick PhD MPH, Gregory Foster MPH MA, & Susan Hickman PhD</p> <p>American Journal of Hospice & Palliative Medicine; 26(5): 354-360 Oct/Nov 2009</p>	This was a secondary data analysis project using data from the National Nursing Home Survey study	Helaine Resnick	n/a
2009	<p>"Use of the Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Program in the Hospice Setting"</p> <p>Authors: Susan E. Hickman, PhD, Christine A. Nelson, PhD, RN, Alvin H. Moss, MD, Bernard J. Hammes, PhD, Allison Terwilliger, MPH, RN, Ann Jackson, MBA, Susan W. Tolle, MD</p> <p>Journal of Palliative Medicine</p> <p>2009, February; Volume 12, Number 2: 133-141</p>	Hospice Programs in Oregon, Wisconsin, and West Virginia; Telephone Survey	Susan E. Hickman, PhD hickman@iupui.edu	Toolkit Instrument I
2009	<p>“Randomized Controlled Trial of SPIRIT: An Effective Approach to Preparing Africa-American Dialysis of Patients and Families for End of Life”</p> <p>Authors; Mi-Kyung Song, Sandra Ward, Mary Beth Happ, Beth Piraino, Hiedi Donovan, Anne-Marie Shields & Mary Connolly.</p> <p>Research in Nursing & Health 32(3): 260-73, June 2009</p>	Feasibility study of an intervention to promote conversations about end-of-life care.		POLST is mentioned only as something patients didn’t have access to. n/a
2010	<p>“Healthcare Professionals’ Perceptions of the North Carolina Medical Orders for Scope Treatment (MOST) Form in Long-Term Care.”</p> <p>Authors: V Rollins A Caprio & E Roberts.</p> <p>Journal of the American Geriatrics Society</p> <p>58 Sup:S91, April 2010</p>	Physicians, Nurse Practitioners & Social Workers; Survey and interviews	Anthony Caprio, MD ajcaprio@gmail.com	This is the abstract for the 2012 publication below. Toolkit Instruments E & F
2010	<p>“A Comparative, Retrospective, Observational Study of the Prevalence, Availability, and Specificity of Advance Care Plans in a County that Implemented an Advance Care Planning Microsystem"</p> <p>Authors: Bernard J. Hammes, PhD, Brenda L. Rooney, PhD, MPH, and Jacob D. Gundrum, MS</p> <p>Journal of the American Geriatrics Society</p>	Review: Death Certificates, identify use of POLST or Advance directives	Bernard J Hammes, PhD bjhammes@gundluth.org	Toolkit Instrument B

2010	"The POLST (Physician Orders for Life-Sustaining Treatment) Paradigm to Improve End-of-Life Care: Potential State Legal Barriers to Implementation" Authors: Susan E. Hickman, Charles P. Sabatino, Alvin H. Moss, and Jessica Wehrle Nester 2008, March; Volume 36: 119 - 140	This was a review of state legal policies.	Susan E. Hickman, PhD hickman@iupui.edu	n/a
2010	"A Comparison of Methods to Communicate Treatment Preferences in Nursing Facilities: Traditional Practices Vs. the Physician Orders for Life-Sustaining Treatment Program" Authors; Susan Hickman PhD, Christine Nelson PhD RN, Nancy Perrin PhD, Alvin Moss MD, Bernard Hammes PhD & Susan Tolle MD Journal of American Geriatrics Society. 58(7): 1241-48, July 2010	Nursing home residents Oregon, Wisconsin and West Virginia Chart Review	Susan E. Hickman, PhD hickman@iupui.edu	Toolkit Instruments L, M, V, and Y
2011	"Survey of Emergency Medical Services Professionals' Experience with Advance Directives and Medical Orders for Life-Sustaining Treatment" Authors; Sam Stanley MD, Renee Pekmezaris PhD, Christain Nouryan MA, Richard Tan BA, Anthony Conrady, MBA EMT-P, Brinder Vij MD, Harold Silverman, Howard Guzik MD, Martin Lesser PhD EMT, & Gisele Wolf-Klein MD Journal Am Geriatric Soc 59(12): 2383-2384, December 2011	EMS personnel Anonymous Mailed Survey	Gisele Wolf-Klein, MD gwolf@nshs.edu 718.470.7295 Chris Nouryan, MA CNouryan@NSHS.edu 516-465-3187	Toolkit instrument S
2011	"The Consistency Between Treatments Provided to Nursing Facility Residents and Order on the Physician Orders for Life-Sustaining Treatment Form" Authors; Susan Hickman PhD, Christine, Nelson PhD RN, Alvin Moss MD, Susan Tolle MD, Nancy Perrin PhD, & Bernard Hammes PhD. Journal Am Geriatric Soc 59(11): 2091-99, November 2011	Nursing home residents in OR, WI, and WV.	Susan E. Hickman, PhD hickman@iupui.edu	Toolkit Instruments L, M, V, and Y
2011	Knowledge and attitudes of health care workers regarding MOLST (Medical Orders for Life-Sustaining Treatment) implementation in long-term care facilities. Vo H, Pekmezaris R, Guzik H, Nouryan C,		Gisele Wolf-Klein, MD gwolf@nshs.edu 718.470.7295	Toolkit Instrument U

	Patel C, Vij B, Tai J, Wolf-Klein G. Geriatr Nurs. 2011 Jan-Feb;32(1):58-62.		Chris Nouryan, MA CNouryan@NSHS.edu 516-465-3187	
2012	<p>“Increasing Residency Training of Goal-oriented Treatment Options in Patients with Life-Limiting Illnesses”</p> <p>Authors; T Lee, Q Cao, S Hayes, P Austin, M Zafar & R Newman. Journal of the American Geriatrics Society 60(supplement4): S43-44 April 2012</p>	Family Medicine Residents; This abstract evaluated a 2 hour advance care planning educational intervention including MOST	Tae Joon Lee, MD leetae@ecu.edu	Toolkit Instrument AA and Poster II
2012	Health care professionals' perceptions and use of the medical orders for scope of treatment (MOST) form in North Carolina nursing homes. Caprio AJ, Rollins VP, Roberts E. J Am Med Dir Assoc. 2012 Feb;13(2):162-8. Epub 2010 Nov 3.	Survey and interview of physicians, nurses, and social workers	Anthony Caprio, MD ajcaprio@gmail.com	Toolkit Instruments E and F
2012	<p>POLST Registry Do-Not-Resuscitate Orders and Other Patient Treatment Preferences”</p> <p>Authors; Erik Fromme MD, Dana Zive MPH, Terri Schmidt MD, Elizabeth Olszewski MPH, & Susan Tolle MD JAMA 307(1): 34-35 January 4, 2012</p>	Review POLST registry forms	Erik Fromme MD fromme@ohsu.edu	n/a
2013	Implementation of Physician Orders for Life sustaining Treatment in Nursing Homes in California: Evaluation of a Novel Statewide Dissemination Mechanism Neil S. Wenger, MD, MPH, Judy Citko, JD, Kate O’Malley, RN, MS, Allison Diamant, MD, MSHS, Karl Lorenz, MD, MSHS4, Victor Gonzalez, BS1, and Derjung M. Tarn, MD, PhD. Journal of General Internal Medicine 2013 Jan;28(1):51-7	Mailed survey of skilled nursing facilities	Neil Wenger, MD NWenger@mednet.ucla.edu	Toolkit instruments J and K (as well as Instruments O and W)