physician orders for life-sustaining treatment paradigm®

Oregon POLST Registry

2011

Oregon POLST Registry Annual Report

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Executive Summary

The Oregon POLST Registry completed its second full year of operation in 2011. The Registry is contractually operated by the Oregon Health & Sciences University (OHSU) Department of Emergency Medicine for the Oregon Health Authority.

The Registry receives and processes between 3500-4500 POLST forms per month. In 2011, the Registry received and processed over 45,000 forms (includes both Registry-ready and Not Registry Ready forms) and at the end of 2011, there were more than 70,000 POLST Registrants. There were more than 600 calls to the Emergency Communication Center requesting POLST forms from the Registry with over 200 forms found and POLST orders provided to emergency departments, EMS and hospital acute care units. An additional 2000 calls to the Registry office generated nearly 150 additional, non-urgent, POLST form requests.

This year we implemented a number of Registry innovations, collaborations and gains in efficiency. The revised Oregon 2011 POLST form was integrated into the Registry. Staffing was modified and workflow streamlined, allowing us to decrease the time from receipt of a form to activation in the Registry. Working with the Providence Health System, we successfully completed a pilot project for electronic submission of POLST forms. Working with the Oregon Health Authority, we obtained electronic files of Oregon death certificate, allowing archival of Registrants known to be deceased.

Statewide education both to "users" and to "senders" is critical to the success of the Oregon POLST Registry. The Oregon POLST Registry provides education about the Oregon POLST Registry to EMS, Emergency Departments and the Emergency Communication Center. The OHSU Center for Ethics in Health Care and the Oregon POLST Task Force provide educational materials and programs to the health professionals and organizations that complete, sign and transmit POLST forms to the Registry. Both the Registry team and the Center for Ethics in Health Care have provided educational materials and traveled around the state.

We are pleased to provide this report highlighting the second full year of Oregon POLST Registry operations and would like to give a special thank you to our partners, the Oregon Health Authority and the Center for Ethics in Health Care and above all to the staff of the Registry and the Emergency Communication Center who make this possible.

Terri Schmidt, MD, MS

Director, Oregon POLST Registry

Introduction and Background: POLST and the Oregon POLST Registry

The Physicians Orders for Life Sustaining Treatment (POLST) Paradigm was initiated in the mid-1990s in Oregon with the intent of converting patient preferences regarding life sustaining treatments into signed, portable medical orders able to be honored across care settings, including emergency care. POLST utilization across the country has ballooned. As of May, 2012, 14 states have endorsed "POLST Paradigm" programs and 29 states are developing POLST programs. The National POLST Paradigm Task Force has created criteria for developing, endorsed and mature programs which can be found at www.polst.org. The effectiveness of the POLST Paradigm is demonstrated in the evaluation studies summarized at http://www.ohsu.edu/polst/resources/research+references.htm.

POLST forms are completed by a physician, nurse practitioner, or physician assistant based on a conversation with the patient or the legally authorized representative. When the form is signed by an authorized provider, the orders are valid. The form is intended to stay with the patient in order to direct care in an emergency, however, a 2004 study with Oregon Emergency Medical Services (EMS) providers indicated that the form can be difficult to locate in an emergency, with 25% of respondents indicating that the last time they expected to find a POLST, they were unable to do so[1]. Identification of this potential barrier initiated the development and implementation of the Oregon POLST Registry.

Conceived as an electronic backup for the original POLST form in emergency situations, the Oregon POLST Registry collects signed POLST forms, scans and enters the form and its content in a database. This database is then searchable by trained Emergency Communications Specialists within the OHSU Emergency Communication Center (ECC), a 24/7 call center

housed in the Department of Emergency Medicine. These specialists receive telephone calls from EMS, emergency departments and acute care units, search the Registry and, if a match is found between the patient and a form, provide the POLST orders to the caller. They may also fax a copy of the form to an emergency department or hospital (see Appendix A).

The Oregon POLST Registry was philanthropically funded and piloted in 2008 and 2009 through a partnership between the OHSU Center for Ethics in Health Care, the OHSU Department of Emergency Medicine and Clackamas County EMS. On July 1, 2009, as a part of House Bill 2009, the Oregon POLST Registry was designated as *the* POLST Registry for the State, and on December 3, 2009, the Registry was expanded to statewide operation. House Bill 2009 also mandated submission of completed POLST forms to the Registry unless the patient chooses to opt out. Completion of a POLST form has always been and remains completely voluntary.

The Oregon POLST Registry is funded by the Oregon Health Authority, administratively overseen by Dr. Ritu Sahni, State EMS Medical Director, advised by the Oregon POLST Registry Advisory Committee (PRAC), and operated contractually by the OHSU Department of Emergency Medicine. The Registry team would like to acknowledge the efforts of Dr. Sahni, Michael Harryman, Interim EMS and Trauma Director, and Sarah Apodaca, who provides administrative support for Registry and PRAC efforts.

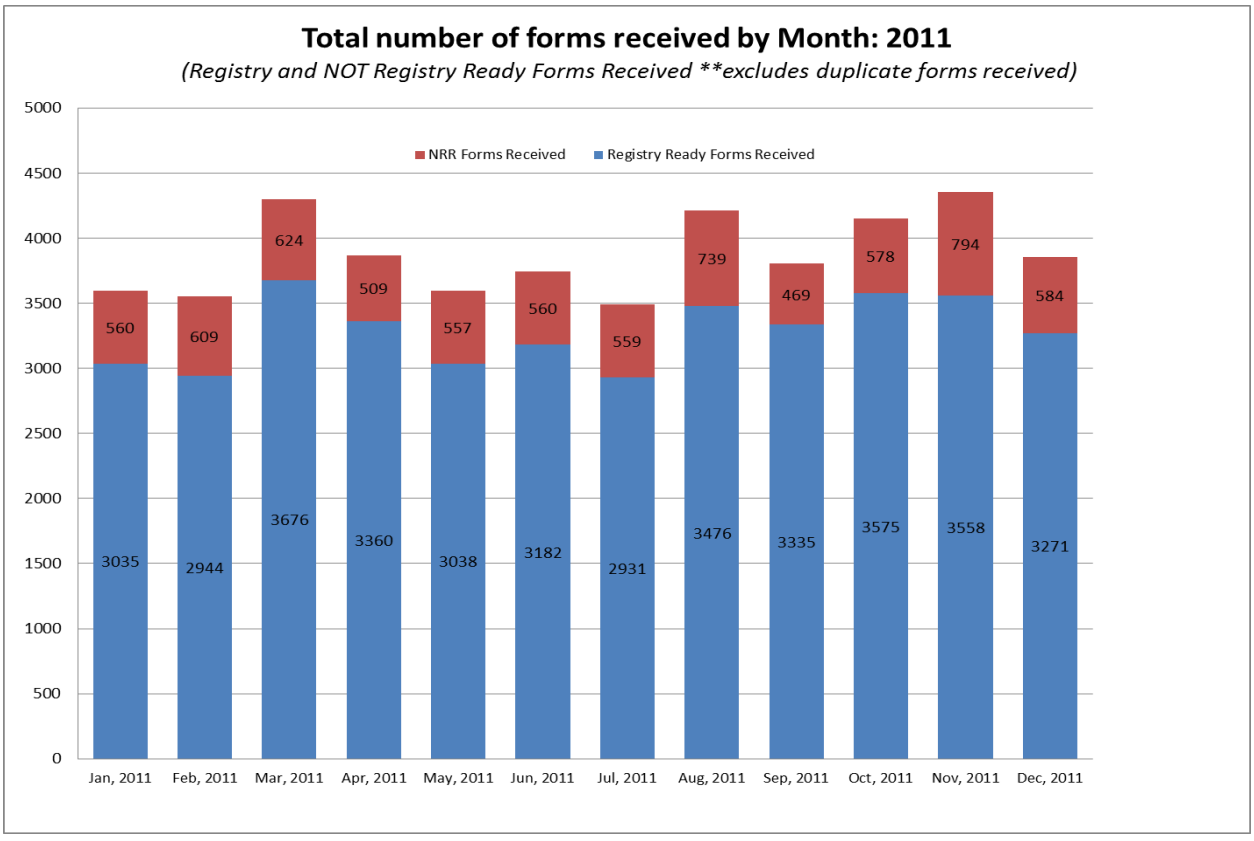
Education and outreach related to the POLST Registry for EMS and other emergency health care professionals are managed by the POLST Registry staff, while education and outreach related to POLST or the POLST Paradigm are managed and coordinated by the Center for Ethics in Health Care, the National POLST Paradigm Task Force and the Oregon POLST Task Force.

How the Registry Works

Form Submission and Entry

In 2011, the Oregon POLST Registry received 45,783 Oregon POLST forms (Figure 1, excludes duplicate forms received). The Registry receives Oregon POLST forms through fax, eFax, mail, and electronically through secure file transfer. Forms are received from many sources, including but not limited to health systems, nursing homes, hospices, clinics, long term care facilities, hospitals, individual providers, and patients who are identified as Registrants.

Figure 1: Monthly receipt of forms in 2011



The first step in the Registry process is to *validate* the POLST form for Registry inclusion (see Appendix B for process). During validation, the form is checked for patient's full name, birth date, signature of an authorized professional (MD, DO, NP, or PA with a valid Oregon license),

section A resuscitation orders. The opt-out box is also reviewed to confirm that the patient has not requested that the form not be included in the Registry. The Registry does not keep or enter any forms if a patient has opted out.

In late 2010, a review was added to assure that there were not conflicting orders in Sections A and B. The Registry returns forms that request "Attempt Resuscitation" in Section A and provide "Comfort Measures Only" in Section B.

Once the form is validated, an electronic version is created. This electronic version is imported into the Registry and a Registry ID is assigned to the patient. This number is a unique patient identifier and the same number is used for any revised forms submitted for the same patient. If a form received belongs to a person already registered, their original Registry ID is used for entering the updated information, and the earlier form is archived. The form content is then abstracted and manually entered into the Registry. At this point, the form is not yet searchable, and is in a "pending" status. The final step is a review and verification of the form content and scanned form by a second team member (i.e., the person who enters the form does not review it). Once reviewed and confirmed to be accurate, the form is "activated" for searching. Only the most recent valid form is available for searching, viewing, and release by the ECC staff.

The Registry is contractually obligated to process and enter forms within 10 business days of Registry receipt. Throughout 2011, this validation and entry process took an average of 4.2 calendar days (median: 3.5 calendar days). This "lag time" was consistently reduced throughout the latter half of 2011. In December, 2011, the mean time to entry from receipt was only 1.5 calendar days (median: 1.4 calendar days).

Once forms are entered, confirmation packets are created and sent to Registrants for whom a mailing address is available. The confirmation packet includes notification the form was received and entered, along with information about the orders that were on their form. The packet also includes Registry contact information for questions, corrections, or concerns. Finally, for new registrants, the packet includes POLST stickers and a magnet that includes the Registrant's name and Registry ID number. In 2011, the Registry prepared and mailed more than 34,000 packets.

Not Registry Ready Forms

When a form does not contain all required elements, the form is deemed "Not Registry Ready" (NRR). In 2011, 15.6% of all received forms (n=7,142) were NRR. About 2/3 of these forms were missing one or more of the required pieces of information and the remainder were illegible. To resolve NRR form issues, each is assigned a NRR ID number, and resolution is attempted with the sender of the form by faxing with a coversheet noting the concern. On some occasions, the staff may attempt one phone call it get the information. Using these processes in 2011 produced 2,200 additional Registry-ready forms; 30% of previously NRR forms were able to be entered into the Registry.

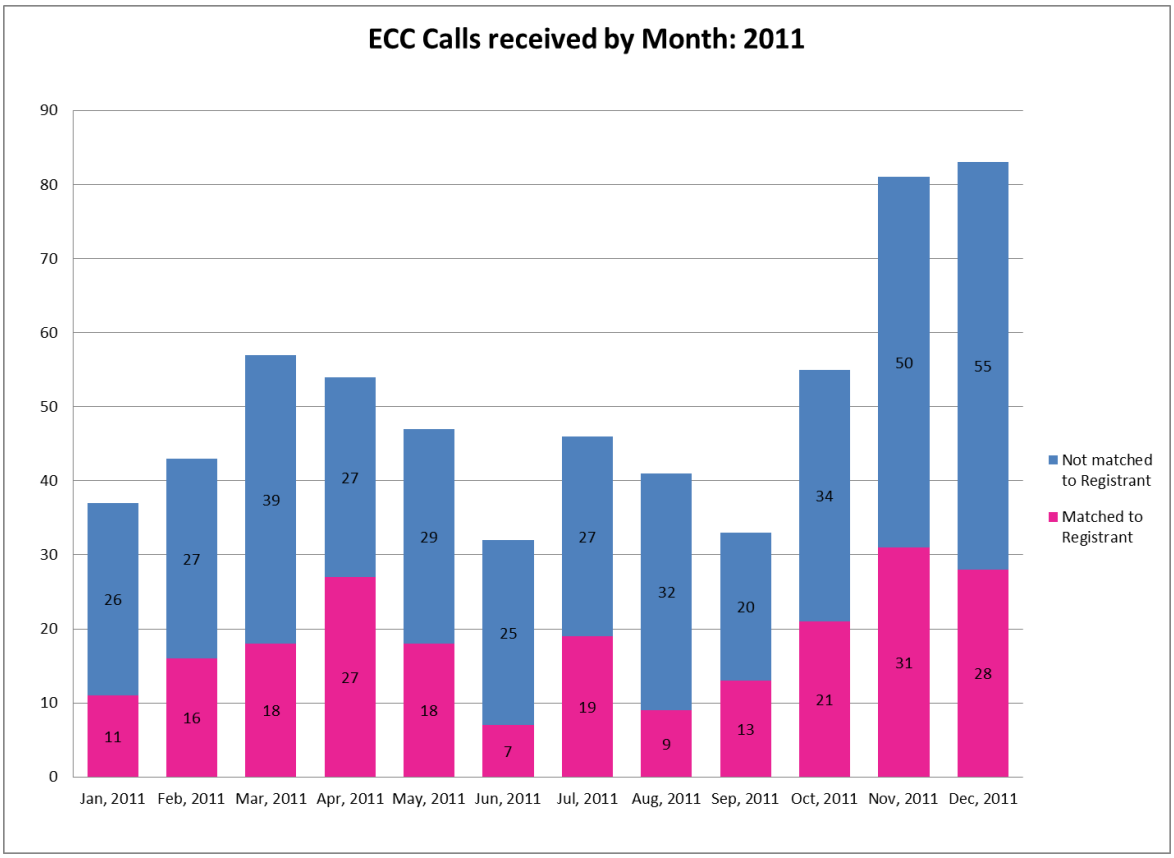
Both the Oregon POLST Task Force and the PRAC review the information regarding Not Registry Ready forms and develop strategies to reduce the number of NRR forms. Some of the strategies have been built into the development of an electronic POLST form (ePOLST).

Utilization

EMS, emergency departments (EDs), and hospital acute care units are able to access the POLST Registry using a toll-free non-public direct telephone line to the ECC. In 2011, the ECC

received 609 calls for Registry forms. Forms were found and released for 218 Registrants (match rate of 36%, Figure 2). In 2011, EDs were the most frequent callers (n=334, 54% of all calls), followed by EMS (n=180, 30% of all calls) and acute care units. (n=95, 16% of all calls). Acute care unit calls generated the highest match rate to the Registry at 44%. The ED match rate was 35% while 34% of calls from EMS generated a match.

Figure 2: ECC Calls and Matches by Month (2011)



The Oregon POLST Registry office staff also process a large number of non-urgent POLST form requests. Following a strict release of information protocol, callers to the Registry office who are requesting forms, form information, or Registrant information are required to submit proof that the patient is in their care or that they have a legal right to access or update patient information.

In April 2011, the Registry implemented enhanced tracking mechanisms for all non-urgent calls and POLST form requests. From April-December 2011, the Registry office received over 2,000 calls, including nearly 150 requests for POLST forms. The office receives approximately 200 calls per month, and POLST requests have been increasing throughout the year. Calls not related to the Registry (e.g. POLST education and patient questions) are referred to the OHSU Center for Ethics in Health Care. Policy questions may also be referred to the Oregon POLST Task Force (see Appendix C).

Year in Review

The Oregon POLST Registry works to remain flexible and scalable, allowing for process changes to improve the system overall. In 2011, the Registry underwent changes both physically and in its management and staffing.

Staffing Model

In the spring of 2011, the Registry staffing model was modified to include the hiring of an Operations Specialist, along with a reduction in the student worker staff and hours (see Table 1), and an increased utilization of volunteers. The staff moved into a new central office. These changes resulted in both efficiency and productivity gains, as well as a management model allowing for increased communication, and appropriate escalation and resolution of Registry issues.

The role of volunteers trained to respect confidentiality in the Registry was increased, with seven volunteers working with the Registry in 2011. Volunteers aided in the preparation of confirmation packets and the production of educational materials. The volunteer program

attracts area students and individuals interested in the POLST Registry and its impact on patients. The Registry also supports the OHSU Emergency Communications Center through a subcontract for call center services and a maintenance contract with the Registry's architect and developer. Based on direct dollars received, each POLST form received cost $6.88.

Table 1: 2011 Oregon POLST Registry Staffing

Position	# in role	FTE
Data Entry Specialist (Student Worker)	4-9	2
Temp Research Assistant	2	1.1
Operations Specialist	1	0.8
Operations Manager	1	1
Project Liaison	1	0.5
Sr. Manager, Operations and Research	1	0.4
Director	1	0.13
TOTAL	**11-16**	**6.13**

Registry System Upgrades

The Oregon POLST form is a dynamic document. The Oregon POLST Task Force released a new Oregon POLST form in 2011 (See Appendix D). Changes were substantial – the antibiotics section of the 2009 form was removed, the opt-out box and patient/surrogate signature were moved to the front of the form. A major set of Registry system upgrades was completed in June 2011 after the adoption of this new version of the POLST form. A project team from the Registry gathered feedback from staff and Emergency Communication Center users to assist in the design and creation of the new form by the Oregon POLST Task Force. Prior to 2011, the Registry utilized the framework of only the 2009 version of the POLST form, as it had been determined that the language changes between previous versions of forms could still be encompassed by a singular, current version of the POLST. Due to the number of substantive changes to the 2011 version of the Oregon POLST form, it was determined that a 2011 specific form was needed within the Registry.

Through the staff feedback process, updates were prioritized for the Registry system. These upgrades helped lead to major efficiency gains in Registry operations during 2011. How information is displayed in the Registry system to the Emergency Communications Specialists was modified for ease, and improvements in coding and reporting were also completed during this system upgrade.

Electronic Manual of Operations (eMOO)

This year also saw the release of the Registry's electronic Manual of Operations (eMOO). The eMOO contains protocols for all data entry processes and Registry operations. The eMOO is a searchable document that includes flow diagrams, Registry protocols, department policies, "how-to" guides, and guiding principles. The eMOO is used for reference as well as in conjuncture with the Registry's new training manual, "The Guide to Mastering OPR Operations." The Registry staff training curriculum and performance metrics were also reassessed in 2011, resulting in revised staff benchmark reporting and the inclusion of peer-based training for new staff.

Special Projects

The Oregon POLST Registry continues to collaborate to support the use of POLST and the Registry across the State. In 2011, the Registry worked with the National POLST Paradigm Task Force to develop electronic submission standards in concert with electronic POLST utilization within electronic health or medical records (EHRs and EMRs), as well as expanding its use of external data.

Providence ePOLST Pilot

In the spring of 2011, the Oregon POLST Task Force was approached by Providence Health Systems with a request to build an electronic version of the POLST form. The Task Force approved development and subsequent pilot testing of an ePOLST (electronic POLST form) by Providence. The pilot project allowed Providence clinics statewide to implement an ePOLST form developed within their EMR, GE Centricity™.

Starting in summer of 2011 Providence and the Registry began testing the electronic submission processes and links between the Providence GE Centricity™ System and the Registry. The Registry team's goal for the pilot project was to develop a generalized, translatable set of process standards that can be used to connect the Registry to a variety of EHR and EMR systems. This pilot was successful, and currently Providence clinics submit all POLST data electronically. In comparing electronically received ePOLST data to faxed clinic data, we were able to ascertain that more than 3 times as many forms are received from the Providence system using the electronic direct submission method as compared to faxing, and all forms received electronically are received in a valid, "Registry-ready" state.

Pilot project timeline & highlights

- January-April 2011. Providence requested to develop an ePOLST form
- June 2011. An ePOLST form developed by Providence was submitted and approved for use by the Oregon POLST Task Force.
- July 2011. POLST Registry Advisory Committee notified of the Providence ePOLST pilot project
- July 25, 2011. Providence clinics statewide launch the ePOLST pilot project.
- 7/25/11-8/19/2011. Providence performed a dual submission process where forms were sent electronically, and via FAX to the Registry office.
- 8/19/2011. Providence discontinued faxing of POLST forms, and began submitting them via secure email only.

- May-October 2011. Registry staff developed a set of technical standards for the electronically submitting POLST forms to the Registry.
- October 2011. sFTP transfer of ePOLST records from Providence to the Registry began.
- Spring of 2012. Anticipated completion of Pilot testing. The Registry intends to adopt the developed electronic submission processes as a standard of practice.
- The Registry and Providence continue to keep system security and PHI protection as priorities.
- There are no concerns regarding the security of the transfer processes.
- ePOLST forms are printed on white paper, and placed in a pink envelope
- The Providence pilot was reviewed and concluded by the PRAC and the Oregon POLST Task Force in April and May 2012

EMS and Providence's ePOLST Form

- At the statewide EMS conference a copy of the Providence ePOLST form and envelope were available for viewing.
- In December 2011 Providence and the Registry jointly sent a mailing to EMS agencies statewide notifying them of the pilot project in process.
- The EMS community has not expressed any concerns over the new ePOLST form & pink envelope

Participation in the Development of EMR Standards for POLST

To promote rapid location of POLST orders within health systems and promote compatibility with The Oregon POLST Registry interface the Oregon POLST Task Force and the Registry staff secured support for the National POLST Paradigm Task Force in the development of Guidelines for EMR vendors (see Appendix E).

Availability of Death Certificate Data

The Registry contract calls for ongoing review and matching of death certificate data from Oregon Vital Statistics with the Registry to effectively "archive" Registrant data for those known to be deceased. In 2011, Oregon Vital Statistics and the Oregon POLST Registry were able to develop and implement a process to securely and electronically transmit this data. Using 2009-2011 death records, the Registry was able to identify over 12,000 registrants known to be

deceased. At the end of 2011, the developer initiated a feature allowing the "mass archive" of Registrants identified to be deceased. A very conservative "match" process was used to avoid over identification (false positive) of Registrants for archiving. This process was successfully implemented in 2012 and quarterly archives will continue.

Education and Outreach

The Center for Ethics in Health Care at OHSU coordinates the educational and outreach training for the Oregon POLST program. Upon the creation of the Oregon POLST Registry, training activities for Emergency Medical Services (EMS), and Emergency Department & acute care units became a responsibility of the Oregon POLST Registry since the Registry was developed to help improve timely access to POLST orders for these health care groups. The Registry also coordinates and administers training for the OHSU Emergency Communications Center (ECC) whose staff responds to emergent POLST requests.

POLST Education and Outreach

The Center for Ethics in Health Care is responsible for the education of health care professionals statewide about the proper and effective use of the POLST Program including education about the Oregon POLST Registry. The educational programs of the Center for Ethics are funded entirely by private philanthropy and play a critical role in the success of the Oregon POLST Registry by educating signers (physicians, NPs and PAs) and their staff about the POLST Program and the Registry. The high volume of submissions to the Registry every month, from every county in Oregon is due to ongoing and intensive education that is sponsored by the Center for Ethics and the Oregon POLST Task Force. Developing educational videos, slides and materials (with private funding) that can be used to reach health care professionals in every

hospice program, long term care facility and hospital and health system is a key role of the Center for Ethics. In 2009 the Center secured funding and the Oregon POLST Task Force created the Oregon POLST Registry video (explaining how the Registry should be used by both callers and senders). In 2011 the Center secured funding and the Oregon POLST Task Force wrote the script for the *POLST in Action in Oregon* video with the goal of further enhancing the skills of health care professionals throughout Oregon. Both videos can be viewed at the polst.org web site. The Center for Ethics not only develops POLST educational materials but trains leaders around the state in how to use them at both regional and statewide conferences. For example, 456 health care professionals from 52 cities joined the Center in June for the statewide Palliative Care Conference and were taught about advances in the POLST Program and given current information about the Registry.

EMS

In the first full year of Oregon POLST Registry operations (2010), training focused primarily on broad outreach to EMS throughout the State, informing them of Registry services and access. During 2011, the Registry staff focused primarily on evaluation of current EMS training opportunities and venues, Registry access and utilization by EMS agencies, and areas or agencies where focused training is needed (low utilization) or requested. The Registry tracks caller location throughout the State and uses that information to help to determine areas where there is a need for education. Identification of EMS focus areas is ongoing - four primary urban, suburban and rural locations have been identified for additional training during 2012.

The Oregon POLST Registry Project Liaison, along with the Registry Medical Director, provides most emergency health care professional outreach and education. In 2011, two articles appeared

in the State Trauma and EMS newsletter and a direct mailing was sent to all Oregon EMS and Fire agencies regarding the Providence ePOLST pilot project, described in an earlier section of this report.

Conferences

The following conferences included Registry or Registry-related presentations:

- Rural Aspects of EMS at Timberline Lodge
- State EMS Conference in Salem
- Statewide Palliative Care Conference in Portland
- National POLST Paradigm Conference in San Diego California

Topics included information on how to access the Registry on scene, Registry-based Research, and Registry utilization throughout the State. Direct training to EMS was provided at the Timberline and State EMS conference. At the 2011 Statewide Palliative Care Conference, we focused on general networking with individuals who work with both EMS and Emergency Departments.

Emergency Departments and Acute Care Units

In order to protect patient confidentiality, the ECC will only fax POLST forms to registered and secure fax numbers. In 2011, the Registry faxed information regarding the Registry and how to access it every ED in Oregon and to any additional acute care fax numbers that were registered. Each Oregon hospital was called, soliciting any additional acute care fax numbers (e.g., ICU or ICU-like units) they wished to register, in an effort to improve the ECC's ability to send POLST forms to hospitals requesting them emergently or receiving prehospital patients with POLST orders that may impact their care.

Emergency Communications Center (ECC)

The Registry staff was also able to utilize EMS feedback collected during a research project that concluded in spring of 2011 to identify process improvements for the ECC. An improved, more robust training module for ECC staff was developed and was launched in spring 2012. The ECC staff also received training in fall of 2011 on a new efficiency module that allows for direct electronic fax transmission of POLST forms from the Registry to known Emergency Department and acute care unit fax numbers.

Research Activities

The second full year of Registry operations saw the completion of several research projects, including publication and presentation of findings, as well as the development and initiation of new proposals and analyses.

The first Registry-related study, *A New Electronic POLST Registry: Utilization, Impact on Care, and Dissemination*, had two distinct aims – an analysis of patterns of POLST completion from registered forms signed between 12/3/09 and 12/2/10 (the first year of Registry operations), as well as assessing the POLST form's impact on medical care in a crisis. Analysis for the first aim was completed by Dr. Erik Fromme in spring, 2011 and results from 25,142 registered POLST forms were presented at two conferences (Society of General Internal Medicine by Erik Fromme and Statewide Palliative Care Conference by Dana Zive), and published in the Journal of the American Medical Association in January, 2012 as a research letter. A manuscript ("*When resuscitation is not the most important question: Scope of treatment in advanced illness and*

frailty.") has also been submitted for publication. The analysis described the registered population (85.9% age 65 or older, 61% Female, and 40.4% residing in a rural area) and indicated that while the majority of patients' POLSTs included a Section A order for Do Not Resuscitate (72.1%), only half of these forms indicated an order for "Comfort Measures Only" in Section B, bolstering the argument that DNR does not mean "Do Not Treat," and that DNR status should not be used to infer patient wishes regarding care in other circumstances[2].

The second aim of this study was also completed in spring, 2011 and focused on interviews with patients (and/or their surrogates) treated by EMS providers who utilized the Registry between 9/1/10 and 3/31/11 as well as the EMS providers who retrieved POLST orders from the Registry for these patients. Interviews were completed with 11 patients/surrogates and 24 EMS providers. While just over half of patients or surrogates were aware their form was in the Registry (55%), the majority were aware they or their loved one had a POLST form (73%). The majority reported that they felt their or their loved one's wishes had been honored (73%). An additional 18% were not sure about the role of POLST, but felt treatment wishes were honored. The EMS interviews helped to elucidate the effectiveness of the Registry system, providing operations and logistic suggestions to improve efficiency. The EMS respondents indicated that they were prompted to call the Registry because they saw a Registry sticker or magnet (35%) or because someone at the scene of the emergency indicated a POLST form existed, but it could not be located (30%). These findings have been presented by Dr. Terri Schmidt at the 2001 Annual Meeting of the National Association for EMS Physicians and by Ms. Zive at the 2011 Statewide Palliative Care Conference, and have been submitted for publication.

The second Oregon POLST Registry study completed in 2011, "*Validating the POLST Algorithm*," was focused on testing the search methodology used to "match" caller-provided details with a registered person and their POLST form. For this study, calls to the Registry between 12/3/09 and 7/31/10 were reviewed. Calls, both those generating a "match" or release of Registry-contained POLST orders as well as those yielding no "match" were screened, and a manual Registry search was performed to assess whether "missed" matches or "false" matches had occurred. While no false matches were identified, there were 3 "missed" matches. For these cases, a patient's form was in the Registry but was not released because the personal information provided was not enough to confirm a match. No algorithmic model developed was able to outperform the current algorithm in specificity or sensitivity. Of note, of patients not "matched" at the time of the call, many had a form submitted to the Registry within two weeks of the initial call, indicating that a call to the Registry may actually prompt form completion. These results have been accepted for publication in the Journal of the American Geriatrics Society and are currently in press[3]. The work was performed by Elizabeth Olszewski as her Master of Public Health thesis project.

Research projects still underway include the study titled, "*Validating a Process to Assess Patient Preference and Physician Orders for Life-Sustaining Treatment*." This study focuses on user understanding of the POLST form, attempting to validate the POLST by assessing whether orders recorded on the form are reflective of patient wishes expressed through responses to scenario-based interviews at a set time after POLST form completion. Results from this study are expected in late 2012.

A number of new research proposals were submitted to the Oregon POLST Registry and the POLST Registry Advisory Committee in 2012. Approved studies include 1) "*Survival, Demographics, and Location of Death of Oregon POLST Registry Decedents,"* and 2) "*The Impact of an Electronic Registry for End of Life Decisions on Emergency Department and EMS Patient Care*." The first study, proposed by Ms. Zive and Drs. Fromme, Schmidt, Tolle, and Sahni, aims to asses association(s) between patients' POLST orders and their location of death. Analyses will include review of changes in POLST forms in proximity to death and cause of death. Analysis is expected to be complete in fall, 2012.

The second study is being completed by investigators from the Center for Policy and Research in Emergency Medicine (Drs. Craig Newgard and Derek Richardson, along with Dr. John McConnell and Ms. Zive), and focuses on data linkage between the Oregon POLST Registry, the Oregon Trauma Registry, the Oregon Statewide EMS Database, the Oregon Hospital Discharge Database, and a local epidemiologic registry of out of hospital cardiac arrest patients. This study is evaluating the impact of the POLST Registry on both pre-hospital and in-hospital care for patients in Oregon, focusing on patients with out-of-hospital cardiac arrest, trauma, and patients admitted to hospitals between 1/1/10 and 12/31/10. Results from this study are expected in late 2012.

Finally, potential collaborative research utilization of data from the Oregon POLST Registry was included in several grant proposals submitted in 2011, including a large community/ hospital/EMS project submitted to the Center for Medicare and Medicaid Innovation Center as well as a trauma study, *Improving Prehospital Triage to Identify Traumatic Brain Injury in Older Adults Taking Anti-coagulants and Platelet Inhibitors*, submitted to the Centers for

Disease Control and Prevention. Both of these studies are authored by Dr. Newgard of the OHSU Center for Policy and Research in Emergency Medicine.

Research utilization of the Oregon POLST Registry is supported by statute. All proposals requesting Oregon POLST Registry Data are reviewed by the POLST Registry Advisory Committee and approved or denied by the State Public Health Institutional Review Board (IRB), as well as the IRB of a researcher's home institution. The confidentiality of individual patients is always protected. In 2011, a standardized research request form was generated by the State of Oregon, streamlining the process of research requests (appendix F). Key Registry staff are also participating in grant activities through the Center funded by The Retirement Research Foundation. In June 2012, the Center will release a report on the creation and development of POLST registries.

References

1. Schmidt, Terri A, Hickman, S. E., Tolle, S. W., & Brooks, H. S. (2004). The Physician Orders for Life-Sustaining Treatment Program: and Attitudes. Journal of the American Geriatrics Society, 52, 1430-1434.
2. Fromme E, Zive D, Schmidt T, Olszewski E, Tolle S. POLST Registry Do-Not-Resuscitate Orders and Other Patient Treatment Preferences Journal of the American Medical Association. 2012;307(1):34-35
3. Olszewski E, Newgard C, Zive D, Schmidt T, and McConnell K.J. Validation of Physician Orders for Life-Sustaining Treatment: Electronic Registry to Guide Emergency Care (in press at Journal of the American Geriatrics Society)

Members of the POLST Registry Advisory Committee

Position	Member
Public (3)	Jane Baumgarten
Public (1)	Open
Public (2)	Patty Brost
Public (4)	Jan Campbell
Long-Term Care	Margaret Carley JD, RN
EMT	Doug Kelly, EMT-P
Hospital	Laura Matthews
EMS and Trauma Systems Program Designee	Ritu Sahni, MD, MPH
Supervising MD for EMTs	Terri Schmidt, MD, MS
Hospice	Sheila Sund, MD
Health Professional	Susan Tolle, MD

2011 Oregon POLST Registry Staff

Student workers: April Iman, Erin Watson, John Trihn, Kaidden Kelly, Kaitlin Gath, Katelynd Orolin, Michael Tran, Mindy Mariano, Nancy Le, Natalia Smiley, Noah Axe , and Stefan Alexander

Volunteers: Colleen Campbell, Journey Rippner, Marina Dubistov, Pete Stuve, Reagan Wilkinson, Sarah Buchanan, Stephen Rogitz (Jan-May 2011)

Research Assistants: Elizabeth Olszewski, Hanna Nelson, Galit Zwirner, Stephen Rogitz (May 2011)

Operations Manager: Brittany Tagliaferro-Lucas

OPR Project Liaison: Jenny Cook

Sr. Manager, Operations and Research: Dana Zive

Director: Terri Schmidt

Glossary of terms

Glossary	
Terms in this report	**Definition**
Registry Forms or Registry Registrants:	Forms or registrants recorded in the Registry only, not all those received by the Registry office.
Not Registry Ready (NRR):	Forms received that are missing information to make them eligible for the Registry.
Not Registry Ready (NRR-REO) - REQUIRED ELEMENTS ONLY:	Forms received that are missing any one or more of the REQUIRED data elements: First or Last Name, DOB, Signature, Date signed, Section A orders
Not Registry Ready (NRR) - Registry Unusable Only:	Forms received that are unable to be entered into the Registry but are still valid POLST orders. Includes copies that are illegible, copies that are too dark or too light, etc.
Active Forms:	Forms in the Registry that are ready to be searched.
Archived Forms:	Forms in the Registry that are no longer valid. These have been removed from searches.
Pending Forms:	Valid forms in the Registry that have been entered but have not been "activated" (double-checked to ensure accuracy, the last step before a form becomes searchable).
Active Registrants:	Registrants with searchable, active forms who are not known to be deceased and have not opted out.
Archived Registrants:	Registrants known to be deceased or those who have opted out of the Registry. Forms from these registrants are not searchable for healthcare professionals.
Updated Forms:	An updated form is one received for a patient already in the Registry, but with a more recent date.
Forms Received:	All forms received by the Registry, including NRR but excluding duplicate submissions
Forms Created/Entered:	All forms entered into the Registry in a given timeframe but not necessarily searchable for healthcare professionals. This may include forms received in the previous month.

2011 Registrant Profile

Table 1: 2011 New vs. Updated Registrants

Registrant	*Count*	*%**
Update	2,898	8.1%
New	33,008	91.9%

A *new* (above) registrant was a patient who had one or more POLST forms submitted to the Registry for the first time in 2011, while *updates* are those who were already in the Registry before 2011 but had a new form added in 2011.

Table 2: Status of all Registrants (regardless of date added) at end of 2011

Status	*Count*	*%**
Archived	3,041	4.3%
Active	67,294	95.7%

An *archived* (above) Registrant is one whose information is no longer searchable in the Registry. This primarily happens when a patient passes away or opts out of the Registry. *Active* Registrants are those whose information is searchable in the Registry. Over 12,000 Registrants have been archived in 2012 through matches with death certificates.

Table 3: All Registrants by Gender at end of 2011

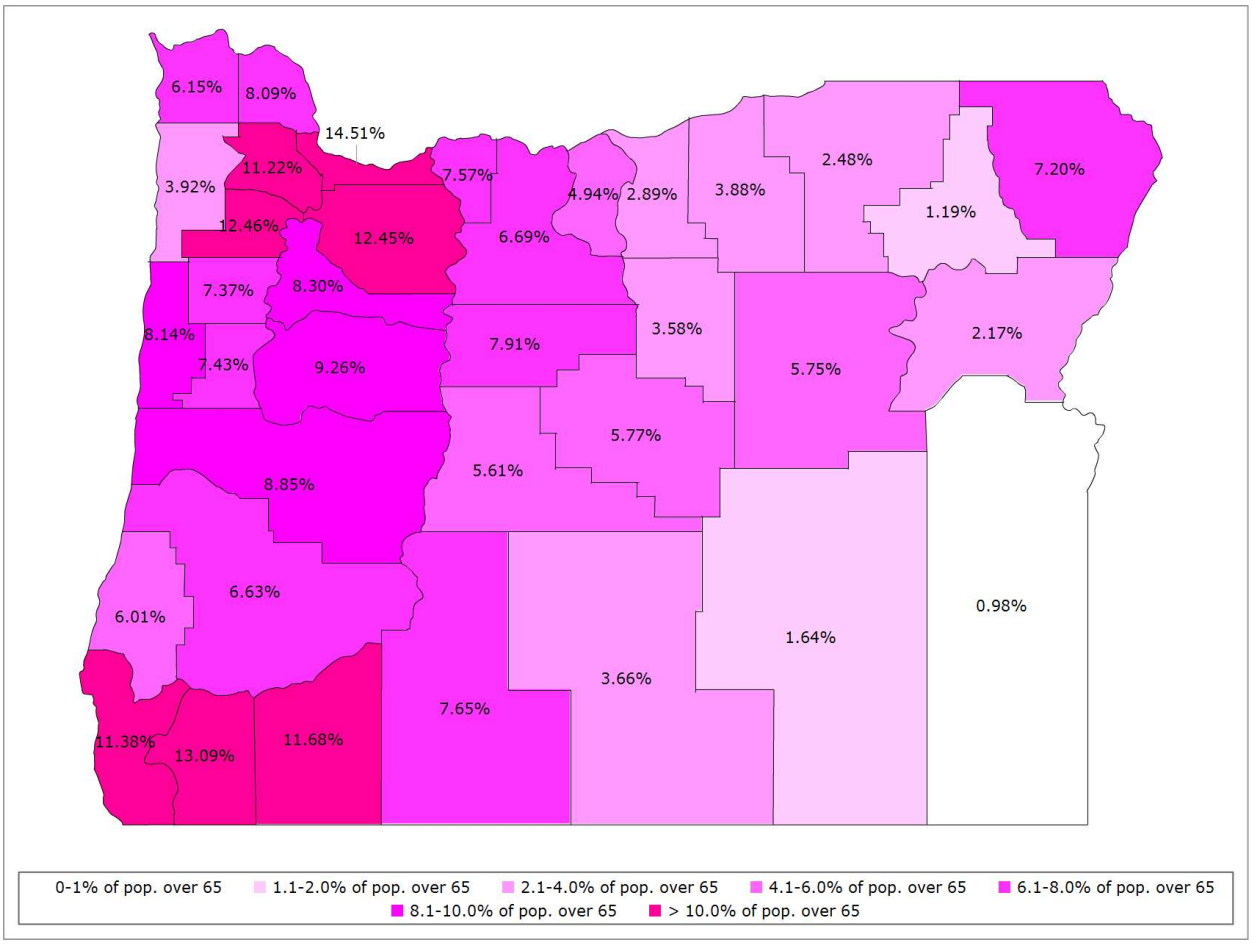
Gender	*Count*	*%**
Unknown	6,177	8.8%
Male	25,096	35.7%
Female	39,062	55.5%

Gender (above) is not a required element on a POLST form, and gender was not indicated for 6,177 (8.8%) of these Registrants.

Table 4: Geographic Distribution of NEW 2011 Registrants, in alphabetic order (County of Residence). Includes 2010 Census Population and Population over the age of 65.

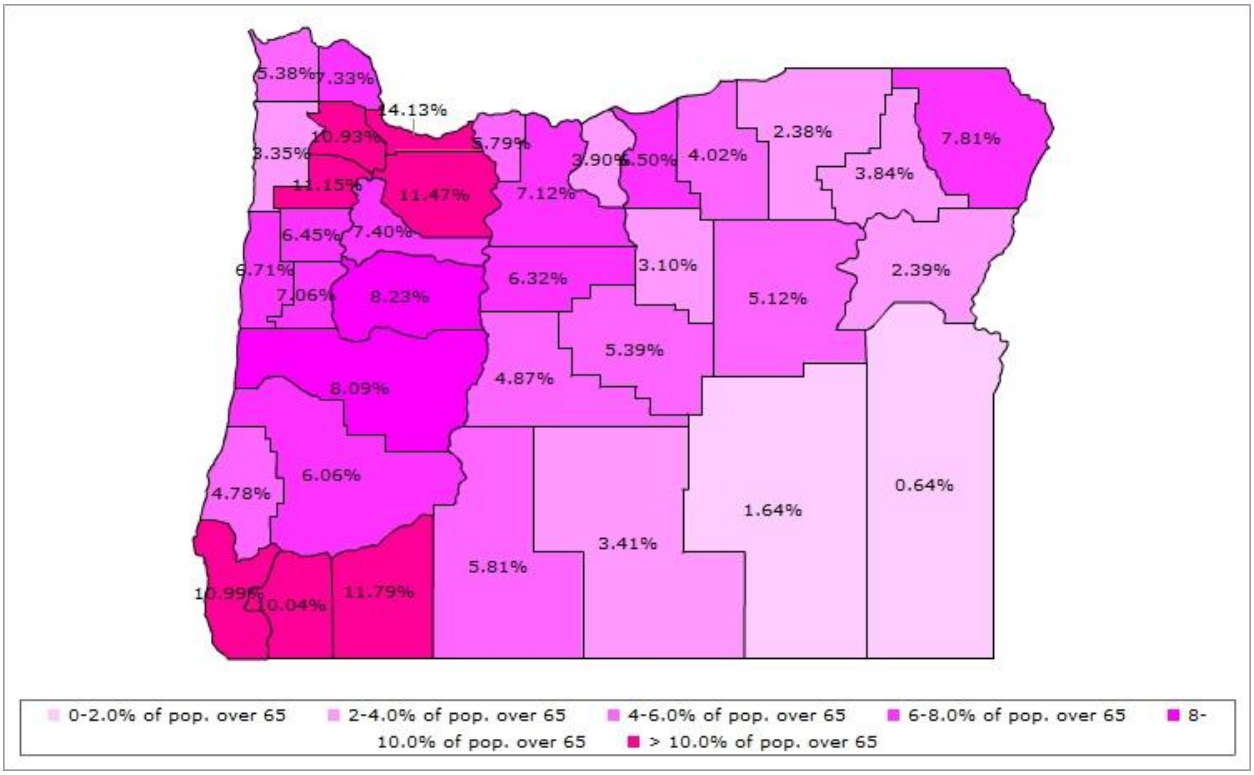
County	New 2011 Registrants	2010 Population (Census)	2010 Population over the age of 65 (Census)
Baker	45	16134	3549
Benton	353	85579	10269
Clackamas	3073	375992	51135
Clatsop	181	37039	6148
Columbia	275	49351	6860
Coos	318	63043	13491
Crook	125	20978	4196
Curry	382	22364	6262
Deschutes	700	157733	23502
Douglas	750	107667	22610
Gilliam	4	1871	415
Grant	41	7445	1757
Harney	6	7422	1403
Hood River	98	22346	2816
Jackson	2288	203206	35764
Jefferson	128	21720	3323
Josephine	955	82713	18445
Klamath	441	66380	11351
Lake	21	7895	1611
Lane	2428	351715	52757
Lincoln	353	46034	9989
Linn	752	116672	17967
Malheur	13	31313	4697
Marion	1733	315335	40678
Morrow	22	11173	1419
Multnomah	5715	735334	77210
Polk	423	75403	11160
Sherman	4	1765	385
Tillamook	104	25250	5277
Umatilla	128	75889	9638
Union	43	25748	4300
Wallowa	58	7008	1626
Wasco	142	25213	4437
Washington	3106	529710	52971
Wheeler	8	1441	419
Yamhill	661	99193	13292

Figure 3: Active Registrants, by County, as of 12/31/11* (includes only registrants over the age of 65 with known County of residence and with form(s) signed on or after 12/3/09).

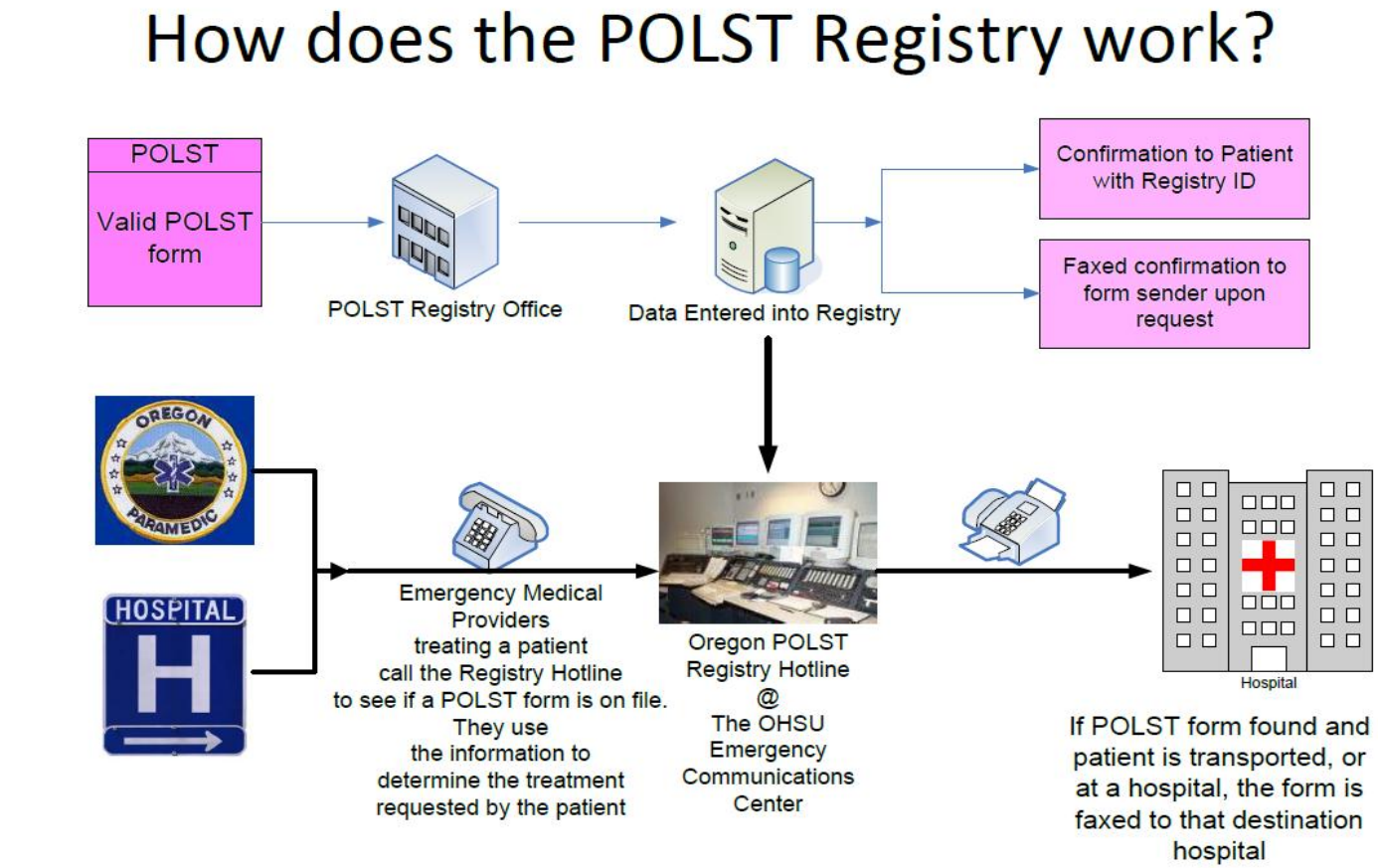


*Includes Registrants archived in 2012 due to death certificate matching projects

Figure 4: Current Active Registrants, by County, as of 5/31/12 (includes only registrants over the age of 65 with known County of residence and with form(s) signed on or after 12/3/09). All Registrants matched to death records in 2012 have been removed.

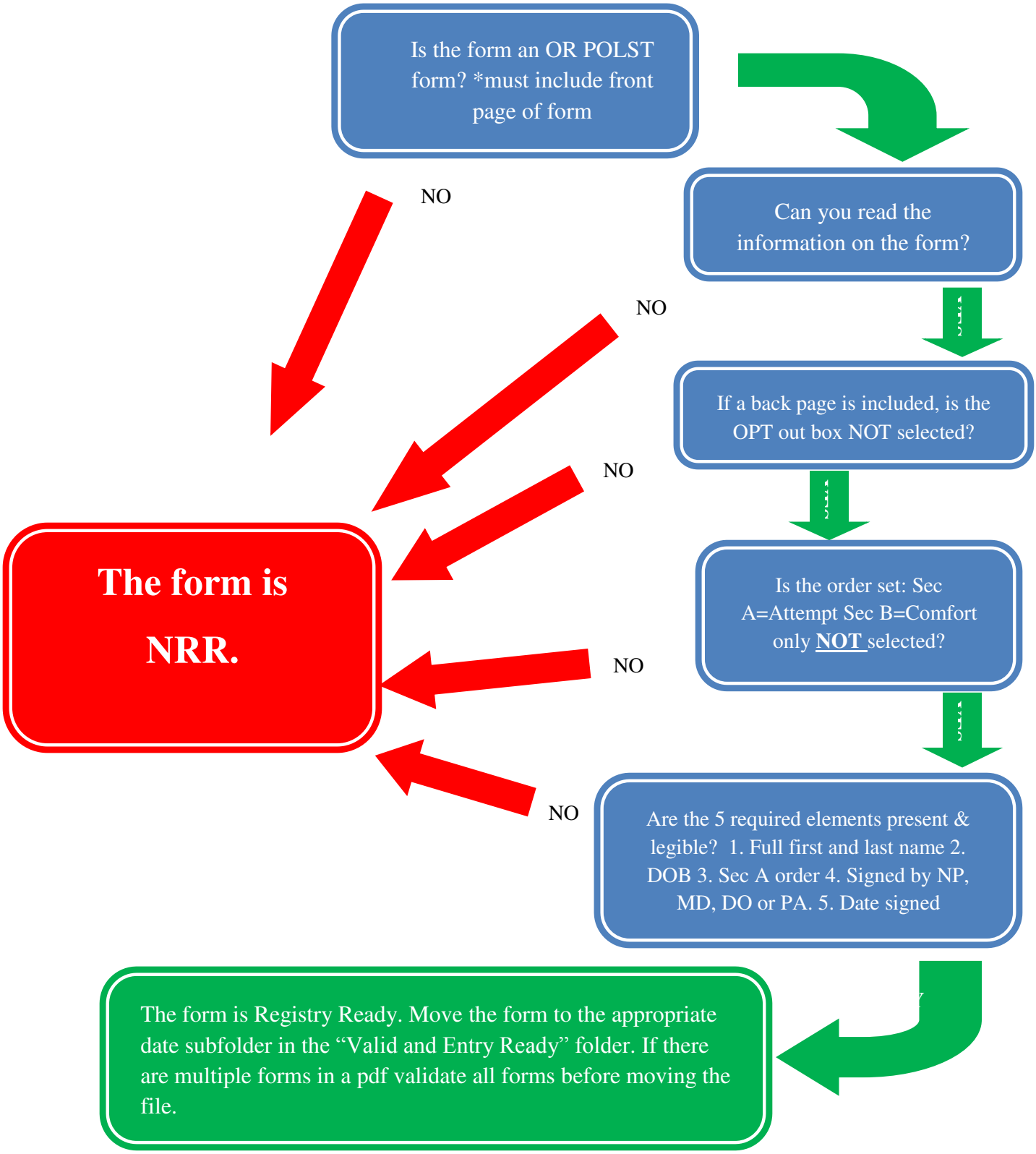


Appendix A: Registry Overview

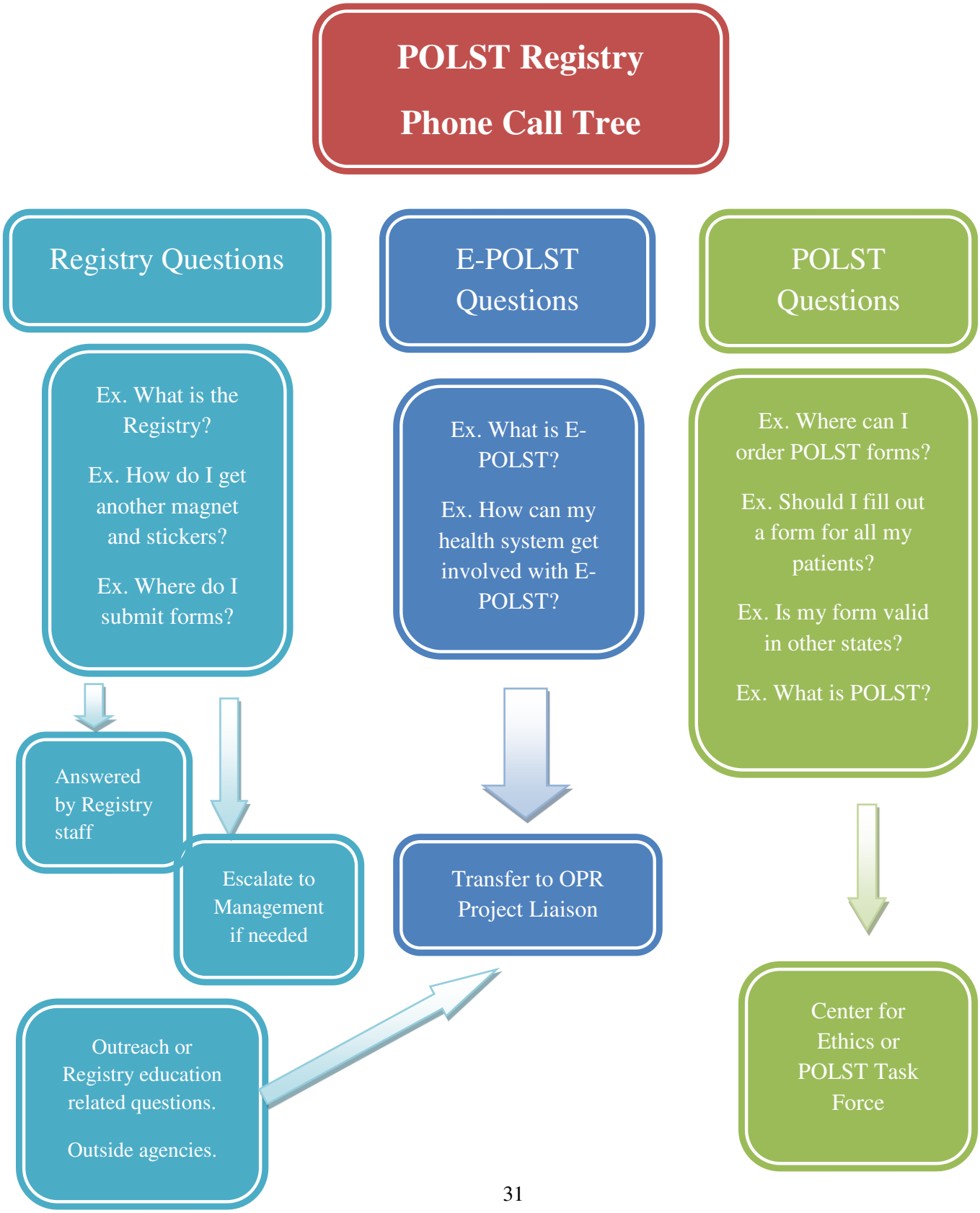


POLST
physician orders for life-sustaining treatment paradigm®
Oregon POLST Registry

Appendix B: Validation



Appendix C: POLST Registry Question Forwarding Plan



Appendix D: 2011 Oregon POLST Form

HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS & ELECTRONIC REGISTRY AS NECESSARY FOR TREATMENT

Physician Orders for Life-Sustaining Treatment (POLST)

Follow these orders until orders change. These medical orders are based on the patient's **current** medical condition and preferences. Any section not completed does not invalidate the form and implies full treatment for that section. With significant change of condition new orders may need to be written.
Guidance for Health Care Professionals. http://www.ohsu.edu/polst/programs/documents/Guidebook.pdf.

Patient Last Name:	Patient First Name	Middle Int.

Date of Birth: (mm/dd/yyyy)	Gender:	Last 4 SSN:
____ ____ ____	☐ M ☐ F	☐☐☐☐

Address: (street / city / state / zip)

A *Check One*

CARDIOPULMONARY RESUSCITATION (CPR): *Patient has no pulse and is not breathing.*

- ☐ **Attempt Resuscitation/CPR**
- ☐ **Do Not Attempt Resuscitation/DNR**

When not in cardiopulmonary arrest, follow orders in **B** and **C**.

B *Check One*

MEDICAL INTERVENTIONS: *If patient has pulse and/or is breathing.*

- ☐ **Comfort Measures Only** (**A**llow **N**atural **D**eath). Relieve pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. *Patient prefers no transfer to hospital for life-sustaining treatments. Transfer if comfort needs cannot be met in current location.* **Treatment Plan: Maximize comfort through symptom management.**
- ☐ **Limited Additional Interventions** In addition to care described in Comfort Measures Only, use medical treatment, antibiotics, IV fluids and cardiac monitor as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). *Transfer to hospital if indicated. Generally avoid the intensive care unit.* **Treatment Plan: Provide basic medical treatments.**
- ☐ **Full Treatment** In addition to care described in Comfort Measures Only and Limited Additional Interventions, use intubation, advanced airway interventions, and mechanical ventilation as indicated. *Transfer to hospital and/or intensive care unit if indicated.* **Treatment Plan: Full treatment including life support measures in the intensive care unit.**

Additional Orders: _____

C *Check One*

ARTIFICIALLY ADMINISTERED NUTRITION: *Offer food by mouth if feasible.*

- ☐ No artificial nutrition by tube.
- ☐ Defined trial period of artificial nutrition by tube.
- ☐ Long-term artificial nutrition by tube.

Additional Orders: _____

D

DOCUMENTATION OF DISCUSSION:

- ☐ Patient (Patient has capacity)
- ☐ Parent of minor
- ☐ Court-Appointed Guardian
- ☐ Health Care Representative or legally recognized surrogate
- ☐ Surrogate for patient with developmental disabilities or significant mental health condition (Note: Special requirements for completion. See reverse side.)
- ☐ Other_____

Signature of Patient or Surrogate

Signature: ***recommended***	Name (print):	Relationship (write "self" if patient):

This form will be sent to the POLST Registry unless the patient wishes to opt out, if so check opt out box ☐

E

SIGNATURE OF PHYSICIAN / NP/ PA

My signature below indicates to the best of my knowledge that these orders are consistent with the patient's current medical condition and preferences.

Print Signing Physician / NP / PA Name: ***required***	Signer Phone Number:	Signer License Number: *(optional)*

Physician / NP / PA Signature: ***required***	Date: ***required***	Office Use Only

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED. SUBMIT COPY TO REGISTRY

Appendix E: Electronic Health or Medical Record recommendations for POLST Forms

National POLST Paradigm Task Force: Recommendations for Electronic Health Records and Physicians Orders for Life Sustaining Treatment (POLST) Paradigm Forms

Preamble: The National POLST Paradigm Task Force has developed the following recommendations to foster the conversion from paper based state POLST Paradigm Forms to electronic POLST forms stored in a variety of Electronic Health/Medical (EMR) Systems. State specific e-POLST electronic templates are usually developed, approved and updated by state coalitions and/or state agencies. For more information on the POLST programs, go to www.POLST.org.

These recommendations specifically address recommendations for integrating the POLST Paradigm form into the EMR and do not address the important separate issues of storage or retrieval of advance directives and other types of advanced care planning records.

Recommendations:

1. The EMR system offers access to an external POLST form database and/or system via a secure, authenticated portal, interoperable data exchange standard or link— so that a state specific POLST Paradigm e-POLST document could be accessed while the health care professional is still working within the EMR system. We prefer no additional log on.

2. The EMR system has the ability to rapidly receive and accurately store and display the external document within that patients' EMR.

3. The POLST Paradigm forms will be in a unique POLST field/tab and can be accessed instantly preferably within one click. The tab can be marked with a yes or no box, so that the provider can see if a form exists before opening the tab.

4. State specific e-POLST electronic templates developed, approved and updated by state coalitions and/or state agencies and standards for wording and printing would be set and changed only by POLST coalitions and/or state agencies.

5. As POLST Paradigm updates occur, the EMR system accepts and stores the updated forms, form definitions [electronic templates].

6. The unique POLST Filed within the inpatient and outpatient EMR contain only POLST medical orders.

7. As allowed by state law or regulation, The EMR system should allow export of POLST paradigm forms to a regional or statewide database/system/register for storage and authorized access of forms; using accepted interoperability standards; when such a statewide or regional system exists.

Appendix F: Oregon Data Request Form

Data Request Form		
In order to request data from the EMS & Trauma Systems Program, complete the following information and submit electronically to: xxxxxxx@state.or.us. Should you have any questions you may contact: xxxxxxx at 971-673-xxxx.		
Purpose of Data Request		
A.	Describe the purpose for this data request:	
B.	Is the purpose of the request one of the following? Check all that apply:	
	☐	Public Health Activities
	☐	Health Care Operations (i.e. quality improvement, quality assurance, teaching, accreditation, development of clinical guidelines.)
	☐	Research – complete the following:
		Title of study:
		Principal Investigator:
		Has the study been approved by an IRB? ☐ Yes ☐ No
		If yes, provide a copy of the original and current IRB approvals. Note – additional review by the Public Health IRB may be necessary.
C.	How will your results be presented, published or otherwise disseminated?	
D.	Will you re-release the data to a third party? ☐ Yes ☐ No	
	If yes, describe the user access restrictions you will employ:	

REQUESTOR INFORMATION (Who is requesting the information?)	
Name:	
Title:	
Affiliation:	
Address:	

City/State/ZIP:	
Phone:	
Fax:	
E-mail:	

Will the data being requested be used by multiple authorized users?	☐ **Yes** ☐ **No**
If Yes, the Requestor is considered the overall responsible party. List authorized users below:	
Name(s):	
Title(s):	
Affiliation(s):	

Are you requesting a single data transfer or repeated data transfers as updates become available?	☐ Single ☐ Repeated

Describe the administrative, technical and physical safeguards you will use to protect the requested data set:

Provide a plan for the destruction of the data when the project is complete.

Description of Data Requested: OCHHP-EMS reserves the right to recode or combine certain variable ranges to protect confidentiality if record-level data or aggregate data with small cell sizes is requested.	
Data Set Name: Include data set description here or as attachment. .	
Are you requesting:	☐ Aggregated data

	☐ Record level
If record-level data:	Will records in the requested data be matched with data in any other data set either by the Requestor or Provider? ☐ Yes ☐ No
If yes, please describe:	
If record-level data:	Do you intend to contact persons identified in the data, their family or health care providers? ☐ Yes ☐ No
If yes, please describe:	
GEOGRAPHY	☐ State ☐ County (specify): ☐ Other: (e.g. ZIP Code, census tract, location, etc):
YEAR(S) / MOST RECENT:	
OTHER DATA ELEMENTS and SPECIFIED VALUE RANGES **(example: "Age" or "Ages 15-17 only")**	
List non-identifier variables in the data set:	List of variables: ☐ to be determined. (Variables must be identified prior to final approval and entering into data use agreement.)
If record-level data:	Are you requesting any of the following data elements? Check all that apply: ☐ Names ☐ Postal address information, other than town or city, State and ZIP code ☐ Any other geographic subdivision smaller than the state ☐ All elements of dates (except year) ☐ Telephone numbers ☐ Fax numbers ☐ E-mail addresses ☐ Social Security Number(s) ☐ Medical record number(s) ☐ Health plan beneficiary number(s) ☐ Account number(s) ☐ Certificate or license number(s) ☐ Vehicle identifiers and serial numbers, including license plate

	numbers ☐ Device identifiers and serial numbers ☐ Web universal resource locators (URLs) ☐ Internet protocol (IP) address numbers ☐ Biometric identifiers, including fingerprints and voiceprints ☐ Full face photographic images and any comparable images ☐ Any other unique identifying number, characteristic or codes

Preferred file format:	
Preferred manner of data transfer:	
Date data is needed:	

☐ Request is Approved	Data Use Agreement must be signed and dated prior to release of data.
☐ Request is Denied	Reason for denial:
Signature of person authorized to approve and printed name:	