# VALIDATING THE PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST) ALGORITHM

By

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## A THESIS

Presented to the Department of Public Health & Preventative Medicine and the Oregon Health & Science University School of Medicine in partial fulfillment of the requirements for the degree of

Master of Public Health

March 2011

Department of Public Health and Preventive Medicine

School of Medicine

Oregon Health & Science University

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## ACKNOWLEDGMENTS

Thank you to my colleagues, family, and friends for their support and assistance in completing this project. Special thanks to Dana Zive, Craig Newgard, Terri Schmidt, John McConnell, Jenny Cook, Sherrie Forsloff, Susan Tolle, Alex Hunt, the Oregon POLST Registry team, the OHSU Center for Ethics, and the Emergency Communication Specialists for their efforts and commitment to the success of this project and the Oregon POLST Registry.

## ABSTRACT

*Background*: The POLST form is a portable medical order documenting treatment preferences for those with advanced illness or chronic disease. In 2009, Oregon created an electronic registry, The Oregon POLST Registry, available 24 hours a day for emergency personnel to access these orders in cases where the original form cannot be found. An algorithm was devised based on expert opinion to determine whether or not the patient on the scene had a form in the Registry. The objectives of this study were (1) to determine if any patients did have orders in the Registry that were not released to them during a call; (2) explore the creation of an algorithmic model for matching patients; (3) to validate the current algorithm.

*Methods*: Medical records for all patients believed to have a POLST (as determined by a call made to the POLST Registry) between 12/3/2009 and 7/31/2010 were compared to all POLST registrants who had an active form in the Registry through probabilistic linkage to determine if the patients truly did have a POLST form in the Registry at the time of the call. Classification and Regression Tree (CART) modeling was then performed to determine if an alternative to the algorithm would result in higher sensitivity and specificity.

*Results*: 180 records were analyzed and probabilistic linkage revealed 3 "missed matches" in addition to the 29 known matches. The current algorithm is estimated to have 90.6% sensitivity (95%CI: 75.0%-98.0%), 100% specificity (95%CI: 97.5%-100%), and 98.3% accuracy (95% CI: 95.2%-99.7%). CART modeling produced two trees of interest—one that optimized specificity and another that optimized sensitivity. However, no single model outperformed the current algorithm in both facets. CART identified the three most important variables for discriminating between patients—last name, DOB, and SSN. Validation of the call log revealed that search processes varied greatly and the information searched was not comprehensive of what was available at the scene.

*Conclusions*: The current algorithm is specific and highly sensitive. While 3 "missed matches" were found, no "false matches" were identified. Further standardization of search processes (i.e., initiating each search by asking for the 3 most important variables and POLST ID) may improve efficiency and better allow the Oregon POLST Registry to be replicated by other states.

### **INTRODUCTION**

As technology continues to advance around life-prolonging medical treatments, health professionals continue to seek new ways to ensure that patients' treatment preferences are being honored. Previous methods have included use of an advance directive or Do Not Resuscitate orders. Advance directives allow people who can no longer express their preferences to retain control over their medical care by specifying their values and choices in advance and naming someone to make medical decisions once they are no longer able to do so. In 1991, medical ethics leaders in Oregon recognized that advance directives were insufficient in relaying patients' preferences consistently (See Appendix A for more information on the shortcomings of advance directives). Under the direction of the Center for Ethics in Health Care at Oregon Health & Science University (OHSU), stakeholder health care organizations created a portable medical orders document based on a patient's preferences for life-sustaining treatment (Dunn et al., 1996). This document, originally called the Medical Treatment Coversheet, was evaluated and renamed the Physician Orders for Life-Sustaining Treatment (POLST) form prior to its release for use in Oregon in 1995 (Center for Ethics in Health Care, Oregon Health & Science University, 2008).

Now one of the most widely used and studied paradigms to express patient wishes for medical care in the last chapter of life, POLST is a national model for honoring patient treatment preferences, with more than 30 states and communities currently using or in the process of adopting POLST or POLST-like programs. The POLST paradigm is designed for patients with serious, chronic illness. In addition to an order 'for or against' attempted resuscitation, the form documents the patient's preference for one of three

levels of treatment: Comfort Measures Only, Limited Interventions, or Full Treatment. It also allows choices about antibiotics and artificial nutrition (Appendix B). Since the development of the POLST form, ongoing research and continuing education processes with health care professionals and organizations have allowed the form to improve and evolve (See Appendix C for more information on POLST paradigm history and research) (Center for Ethics in Health Care, Oregon Health & Science University, 2008).

POLST recently evolved with the creation of an electronic registry. The Oregon POLST Registry is the first and only collection of POLST forms with (a) mandated form submission from signers and (b) 24/7 access to POLST form orders for emergency medical personnel. On July 1, 2009, the State of Oregon enacted legislation that mandates the signer of a POLST form (physician, nurse practitioner or physician assistant) to submit a completed form to the Oregon POLST Registry unless the patient specifically opts out of the Registry. Completion of a POLST form is always voluntary and nothing in the legislation mandates that any person have one.

The Registry was developed, built, and piloted at OHSU using philanthropic and grant support. On December 3, 2009, The Oregon POLST Registry became available statewide for EMS and hospitals to access POLST form information 24 hours a day, through the Emergency Communication Center (ECC) housed in OHSU's Department of Emergency Medicine. In the development of the Registry and its processes, it was known that the correct match of form information to the patient being treated was critical. To prevent the provision of incorrect medical orders to Registry callers, the algorithm implemented to identify patients based on information provided from the scene was inherently conservative.

Often on the scene of an emergency, limited identifying information about a patient is available. A group of experts used available data from the POLST form to create a highly-specific algorithm. In the algorithm, different pieces of demographic information are weighted to ensure that a patient's POLST orders are only released if there is enough information present to confirm the patient on the scene matches their POLST in the Registry. Since the number of patients with POLST forms in the Registry is growing, there is an increasing chance that the known demographics on the scene are not exclusive to a single person in the Registry. A better understanding of how the existing demographic information facilitates the match of patients to their POLST form in the Registry is necessary to evaluate the current algorithm and ensure best practice.

With the current algorithm, each of the demographic variables that are available to search in the Registry are assigned point values according to their specificity to an individual. These variables include: POLST ID# (an ID assigned at the time of submission and provided unique to each registrant), full first name, partial first name, full last name, partial last name, and the last four digits of social security number (SSN), date of birth (DOB), age, and gender. When emergency personnel call to access the Registry, operators at the OHSU Emergency Communication Center search the database according to the demographic information they receive from the caller. Points are accumulated as information is received that matches a registrant. If a high enough point level is accumulated that record becomes accessible for the operator to disseminate the appropriate orders. In cases where more than one record fits the known information, the operator will not disseminate the orders without the addition of a discriminating piece of information (Appendix D).

The current research proposed to (a) use probabilistic linkage of demographic information from EMS or hospital charts of patients for whom a form was not found to determine the absolute and relative number of patients who were in the POLST Registry but were not matched to their form at their call (i.e., missed matches); (b) to explore the creation of an algorithmic model for matching patients with their POLST form in the Registry using binary recursive partitioning; and (c) to validate the current algorithm by comparing sensitivity and specificity of the current algorithm with the new prediction model. Accomplishing these aims will suggest improvement or validate the matching system currently in place.

We hypothesize that the number of patients matched to their POLST form in the Registry is lower than the number of true matches and that the current algorithm will match the new model in sensitivity, specificity, and accuracy.

#### **METHODS**

All calls to the Registry made between 12/3/2009 and 7/31/2010 were considered for analysis (See Figure 1 for a depiction of the population of interest). Calls came from: Emergency Medical Services (EMS), Emergency Departments (ED), or Acute Care Units (ACU). Descriptive analysis was used to describe the availability of variables in the Registry and what was searched on with respect to the outcome of whether or not the POLST was available in the Registry (SAS version 9.2 ; SAS Institute Inc., Cary, NC).



Figure 1: Sample Population. Calls to the Registry can be for patients that (1) do not have a POLST form, (2) have a POLST form but it is not in the Registry, or (3) have a POLST form in the Registry. This study will only allow us to discern whether or not the patient had a POLST form in the Registry. There is currently no method of tracking whether or not a person has a POLST form; since submission of POLST forms is mandatory unless a patient opts out, it is believed that the longer the Registry is around, the more accurate it will become as a reflection of how many POLST forms are out there and whether or not a patient has a form.

### **PROBABILISTIC LINKAGE**

A call log within the Registry tracks each call and all searches made by the emergency communication specialist within that call. It is of interest to note that EMS callers likely have less available demographic information to provide to emergency communication specialists compared to ED and ACU callers because they are in an outof-hospital setting. At the end of each call, emergency communication specialists complete a form where they provide information about the caller (i.e. what EMS agency or hospital they represent and whether they are EMS, ED or ACU). The demographic information that makes up the *Charts* dataset was collected from the medical records departments of EMS agencies and hospitals that called the registry. The demographic information received from callers was treated as the "gold-standard" of that patient's information. The *Charts* dataset was then compared to a dataset of all registrants who had an active POLST form in the Registry at any point between 12/3/2009 and 7/31/2010 (*Registry* dataset). Probabilistic linkage (LinkSolv v.5.0; Strategic Matching, Inc., Morrisonville, NY) was used to compare these two datasets and determine which patients had a matching POLST form in the Registry that was not found at the time of the call ("missed matches", see Figure 2).



Figure 2: Two by Two Table. "Matched" refers to whether or not enough demographic information was available at the scene of the emergency for the POLST orders to be released. "POLST in Registry" refers to whether or not the patient at the scene actually had a POLST form in the Registry. Information on whether or not a match was made (and what demographic information was available at the scene) was obtained from the Registry call log. Information regarding whether or not a person actually had a POLST form in the Registry was ascertained through probabilistic linkage by comparing demographics of the EMS or hospital chart for each patient with demographics of registrants.

Probabilistic linkage is a method used to link patient care records from two

different settings when unique identifiers are not available. It has been used and validated to match EMS and trauma registry records (Clark & Hahn, 1999; Newgard, 2006) as well as to match EMS records to hospital records (Dean et al, 2001; Waien, 1997). When records from different care settings can be linked up, a more complete picture of the care and outcomes are achieved (Newgard, 2006). In the current study, no single unique identifier was available to match patients believed to have a POLST to their POLST form in the Registry. Based on the available information, probabilistic linkage was selected as a viable method to identify those patients believed to have a POLST but not matched to their form at the time of the crisis based on that limited demographic profile.

In probabilistic linkage, common variables between two datasets were used to create cumulative probabilities of a true match versus non-match. Additive weights of a match (positive weight) and non-match (negative weight) were calculated for every value within every match variable. Variables with less common values and values that help to identify individual patients had higher discriminatory power. The "reliability" of each variable represented the probability of a variable not agreeing for a known match. The relationship between reliability and discriminatory power was used to calculate odds of a match, which was then log transformed to an additive weight of agreement, or weight of disagreement, depending on whether or not the records matched on the variable (Newgard, 2006). For records with missing data for a given variable, no weight was generated for the variable. This allowed missing variables to neither penalize nor inflate the odds of a match. Multiple passes (iterations of the linkage analysis using different blocking variables) were performed to ensure all "missed matches" would be found and different blocking variables (variables used to restrict the analysis to records with exact matches in both datasets on the blocking variables) were used for each pass to decrease computer processing time. All potential matches with a positive cumulative match weight were reviewed manually in order to determine if they were in fact a true match. All available demographic variables were considered in the linkage analyses (first name, last name, date of birth, age, gender, last four digits of Social Security Number, address). A more detailed explanation of probabilistic linkage can be found in the literature (Blakely & Salmond, 2002; Clark, 2004; L. J. Cook, Olson, & Dean, 2001; Dean et al., 2001;

Waien, 1997). A more detailed explanation of how linkage was performed in this analysis can be found in Appendix E.

#### **CART ANALYSIS**

Once all true matches and non-matches were identified, we used Classification and Regression Tree (CART) modeling to create a classification model based on what information was available in the Registry at the time of the search. CART analysis is ideal for creating cut-points based on large number of predictor variables while allowing for misclassification costs to be specified *a priori* (Adams et al., 2007). The variables used in the CART analysis were restricted to those which had the ability to discriminate between patients (i.e. gender was not included because at any given point during the sample period, members of both gender had active forms in the Registry). These variables included: date of birth, last name, first name, address, city, county, last four digits of SSN, zip code, and state. CART analysis started with the selection of the single best predictor for separating patients into registrants and non-registrants (done by binary recursive partitioning). For each of these subgroups, the best predictors for further subdividing the groups were selected until further "splits" would not improve accuracy. Each variable was considered at each decision point, regardless of whether or not it had been used previously in the tree (Newgard, Lewis, & Tilman Jolly, 2002).

Misclassification costs and tree complexity parameters were selected *a priori* to generate a practical decision tree with adequate sensitivity and specificity. The sensitivity and specificity of the decision tree were then calculated by cross-validation (Geisser, 1975; Stone, 1974). Cross-validation uses a randomly selected subset of the study sample called the "learning sample" (about 90% of the original sample) to create a tree in a manner identical to that used to create the original model. This tree is then used to classify the

outcomes in the excluded sample of calls (about 10% of the original sample). This 10% is the validation set. The procedure was repeated several times until every call was excluded once from the "learning sample" (Newgard, Lewis, & Tilman Jolly, 2002).

CART analysis handled missing variables by using a different variable that most closely resembled the missing variable in its ability to make a similar decision split in the data at that point in the tree (i.e., a "surrogate" variable). Because of this, missing values did not require withdrawal of the patient and missing values did not detract from the integrity of the model (Dean et al., 2001). Variable importance was also calculated for each of the final models. This consisted of a normalized score ranging from 0 - 100 which represented how frequently each variable was used as a primary or surrogate "splitter." Variable importance varied between models depending on the misclassification costs assigned *a priori*. Models created through CART analysis were then compared to the current algorithm with respect to accuracy, sensitivity, and specificity.

#### CALL LOG VALIDATION

Additionally, we analyzed a sub-sample of 21 audio records from the call log to determine if the demographic information provided by the caller matched the searches made by the emergency communication specialist. We listened to each of the 21 audio records and recorded what demographic information was provided by the caller, without prior knowledge of what was recorded in the call log. The call log (searches made by emergency communication specialists) was then compared to the audio transcript for accuracy, sensitivity, and specificity. Kappa statistics were calculated to assess agreement between the two methods.

### RESULTS

A total of 230 calls were made to the Registry between 12/3/2009 and 7/31/2010. For each of the calls where the caller's institution (EMS agency or hospital) was recorded (207 calls), the institution was contacted and a request was made for the demographic information pertaining to the patient believed to have a POLST. For 196 calls, the institution responded to the request and supplied demographic information for the 180 calls for which it was available (Figure 3). For the 16 calls for which demographic information was not available, the institution being contacted responded that they had no record of caring for a patient with the name and DOB provided; it is suspected that an error in recording the caller's institution was made at the time of the call in these instances.



Figure 3: Breakdown of the Sample. Numbers in red constitute calls that were not matches and numbers in green represent calls that were matches. 2 of the calls were classified as "Other" and excluded from the sample. These included a test call from an EMS agency and a call from a hospital where the EMS unit who transported the patient called moments before; in this case, only the first call was included in the sample. For 207 calls, at the time of the call, the name of the institution who requested the POLST form was recorded in the call log and the charts from these patients were requested. 21 of the original 230 calls did not have a record of what EMS agency or hospital was calling and were unable to be followed up on. Information was received on a total of 180 patients where contact information was available (87%); for 11 charts, the caller did not respond to the chart request, and 16 of the charts were unable to be located by the EMS agency or hospital listed in the Registry as the caller.

These 180 cases formed the primary sample. The median age of patients in the sample was 83 years (range 5 months – 104 years), 42.8% of the patients were male, and 52.8% of the patients were female (gender was missing for the remaining 4.4%). The percent of missing data for each of the demographic variables in the Registry is listed in Table 1. Fourteen different EMS agencies and 25 different hospitals were represented in the 207 calls with contact. For the 180 charts received, 93 came from EMS and 87 were from hospitals (Table 1).

 Table 1: Descriptive information from the Charts Dataset (N = 180). EMS: Emergency Medical Services; ACU:

 Acute Care Unit; ED: Emergency Department. Not recorded calls came from Hospitals but no distinction was made been ACU or ED.

Demographics	Percent of Sample
Age (median (range))	83 (5 months -104 years)
Male	42.8%
Female	52.8%
Variable	Percent Missing
Last Name§	0.0%
First Name	0.0%
Middle Initial	60.0%
Address	3.3%
City	5.0%
State	10.0%
Zip	3.9%
DOB	0.0%
SSN	21.7%
Gender	4.4%
County	8.3%
Caller	Percent of Sample
EMS	51.7%
ACU	15.0%
ED	22.8%
Not recorded	10.5%

\$There was 1 record with a last name recorded as missing due to the inability to retroactively determine whether or not it had been present in the Registry at the time of the call.

#### PROBABILISTIC LINKAGE

Probabilistic linkage identified 40 potential missed matches. Manual review of these matches revealed that 3 of them were in fact "missed matches." The majority of the potential missed matches were found to be registrants who had a POLST form submitted to the Registry on the day of or after the call (n=34). Of those 34, 23 of the patients had their form signed after the call or on the day of the call; 2 of those patients had their form signed and submitted prior to the call, but it had not been entered by the Registry until after the call; 9 of those patients had their form signed before the call, but it was not received by the Registry until after the call (Table 2). The final 3 potential missed matches were non-matches. Utilizing the results of the linkage as a "Gold Standard," the specificity of the current algorithm was estimated to have 90.6% sensitivity (95%CI: 75.0%-98.0%), 100% specificity (95% CI: 97.5%-100%), and 98.3% accuracy (95% CI: 95.2%-99.7%). Additionally, the positive predictive value was 100% and the negative predictive value was 98%.

Status of POLST Form	Frequency
Patient's form was signed and submitted prior to the call but was not entered until after the call	2
Patient's form was signed before the call but submitted after the call	9
Patient's form was signed and submitted after the call or on the day of the call	1 23

Table 2: Status of POLST form for non-matches. Status and frequency of patients who were identified through probabilistic linkage as having an active POLST form in the Registry during the sample period but not during the time of their call.

### **CART ANALYSIS**

The CART analysis was conducted using 9 discriminating variables that were collected from the chart review and also routinely recorded in the Oregon POLST Registry. No single model was found that could surpass or meet the sensitivity and specificity of the current algorithm. Two models are reported here, the model that optimized specificity (High Specificity Model; Figure 4) and the model that optimized sensitivity (High Sensitivity Model; Figure 5). In both models "Last name" was the main effect. The surrogate variables used for "Last Name" were "DOB" and "First name."



Figure 4: High Specificity Model



Figure 5: High Sensitivity Model

The importance of each variable in terms of differentiating between a "true match" and a "true non-match" for both models is listed in Table 3. The importance of each variable was determined by its use as a primary splitter and then its utility as a surrogate predictor. Surrogate variables were only generated for variables that when used as a splitter had missing data.

Variable	High Specificity Tree	High Sensitivity Tree	First Surrogate (Second Surrogate)
Date of birth	100.00	100.00	n/a
Last name	56.68	85.07	Date of birth (First name)
Last four SSN	48.20	0.00	Date of birth
Address	9.09	0.00	n/a
First name	7.54	11.62	n/a
City	0.00	0.00	n/a
State	0.00	0.00	n/a
Zip code	0.00	0.00	n/a
County	0.00	0.00	n/a

#### Table 3: Variable Importance.

§ Date of birth was used as a surrogate variable for Last four SSN only in the High Specificity Tree.

In the High Specificity Model (Figure 4), 3 of the 9 variables (Date of Birth, Last Name, and Last four SSN) were strong in their ability to differentiate between "matches" and "non-matches" matches, while, City, State, Zip code and County had very poor discriminative ability and were not used in the model. At Node 2, DOB was used as the surrogate variable for splitting by SSN. The sensitivity of the learning sample for the High Specificity Tree was estimated at 34.4% (95%CI: 18.6-53.2%) and the specificity 93.9% (95%CI: 88.8-97.2%). A more detailed explanation of the model can be found in Appendix F.

In the High Sensitivity Model, 2 of the 9 variables (Date of Birth and Last Name) were strong in their ability to differentiate between "matches" and "non-matches" matches, while last four SSN, Address, City, State, Zip code and County had very poor discriminative ability and were not used in the model. The sensitivity of the learning sample for the High Sensitivity Tree was estimated at 96.9% (95%CI: 83.8-99.9%) and

the specificity 65.5% (95%CI: 57.3-71.1%). A more detailed explanation of the model can be found in Appendix G.

#### CALL LOG VALIDATION

The purpose of the call log validation was to determine if what was said on the telephone by the emergency medical personnel was correctly searched by the ECC communication specialist. Each variable that can be searched on and can contribute to a match weight using the current algorithm was analyzed separately and results are reported in Table 4 (2 x 2 tables are in Appendix H).

			Positive Predictive	Negative Predictive	
Variable	Specificity	Sensitivity	Value	Value	Карра
Last name	na†	100%	100%	na†	na†
First name	na†	95.20%	100%	0.0%	0
Middle Initial	87.5%	80.0%	66.7%	93.3%	0.63
Birth month	100%	88.2%	100%	66.7%	0.74
Birth day	100%	88.2%	100%	66.7%	0.74
Birth year	100%	82.4%	100%	57.1%	0.64
PID	100%	100%	100%	100%	1
Last 4 SSN	93.8%	80.0%	80.0%	93.8%	0.74
Gender	50.0%	30.8%	50.0%	30.8%	< 0

#### Table 4: Call Log Validation Results

+ Calculation was unable to be done because all searches were available on the scene.

Perfect agreement between the call audio and searches was found with regards to PID. Additionally, sensitivity was highest for "Last name" and "First name" (100% and 95%, respectively) and specificity was 100% for "Birth month", "Birth day", and "Birth year". Of note, the variable "last name" was always searched and always searched correctly. "First name" was available and searched in 20/21 calls.

#### **MODEL COMPARISONS**

Table 5 shows a direct comparison between the current algorithm, the High Specificity Tree, and the High Sensitivity Tree. The current model is superior in sensitivity, specificity, and accuracy. The most costly misclassification ("false match") has never occurred with the current model.

Model	Sensitivity (95%Cl)	Specificity (95%Cl)	Accuracy (95%Cl)
Current Algorithm	90.6% (75.0-98.0%)	100% (97.5%-100%)	98.3% (95.2-99.7%)
High Specificity Tree	34.4% (18.6-53.2%)	93.9% (88.8-97.2%)	83.3% (77.1-88.5%)
High Sensitivity Tree	96.9% (83.8-99.9%)	65.5% (57.3-71.1%)	71.1% (63.9-77.6%)

**Table 5: Model Comparisons** 

### DISCUSSION

The current algorithm has high specificity and sensitivity, exceeding the models created from the CART modeling. From our sample, three "missed matches" were found using the current algorithm; affirming that the number of patients being matched to their POLST form in the Registry is lower than the number of "true matches." CART modeling was able to produce a tree with a higher estimate for sensitivity than the current algorithm (96.9% vs. 90.6%), but with overlapping confidence intervals (83.8-99.9% and 75.0-98.0%, respectively) meaning it is not certain which model yields higher sensitivity. The High Sensitivity model produced by CART also suffered from inadequate specificity (65.5%) which is significantly less than the current model (95%CI: 57.3-71.1% vs. 97.5-100%).

The CART modeling performed was limited in that each variable was assessed individually for its availability in the Registry. Another limitation, specific to binary recursive partitioning, is that subjects are not allowed to re-enter the tree once excluded. This differs from the current algorithm, where all active registrants are considered with every search. Additionally, in the real-time search methods currently employed, multiple variables can be searched together (i.e. a last name of "Smith" can be searched with a year of birth of 1920 in the current algorithm) but with CART modeling they could only be assessed independently. These results underscore the importance of the dynamic search process utilized in the current algorithm. The ability of the operator to combine search terms, and repeat searches in new ways appears to yield a higher accuracy rate (98.3% (95%CI: 95.2-99.7%)) compared to either the High Specificity Model (83.3% (95%CI: 77.1-88.5%)) or the High Sensitivity Model (71.1% (95%CI: 63.9-77.6%)).

CART modeling did identify the three most important variables for discriminating registrants to determine a match: last name, DOB, and SSN. These three variables were utilized most often when creating the trees and separated the patients most effectively. While last name and DOB are two pieces that are required to be on a POLST form prior to submission to the Registry, SSN is not currently required. Despite voluntary submission of this variable, in the *Registry* dataset utilized for linkage, SSN was lacking for 24% of registrants. When SSN was not available from the *Charts* dataset (for 21.67% of cases), CART utilized DOB as a surrogate variable. However, a shortcoming of the CART model was that when SSN was available in the Charts dataset, but not in the Registry for known matches, that known match was "missed" by the High Specificity Model. Thus, since SSN is not a required element of the Registry, in current practice, SSN is ideally not searched to exclude the possibility of a match, but rather only to provide further evidence for one. Our findings support this current practice.

Three "missed matches" from the current algorithm were identified. Two of the three missed matches were due to name mismatches - the first name searched did not match the first name in the Registry. In one case, it appears that alternative spelling was the issue, while in the other it appears that the middle name of the registrant was searched instead of the first name. The third match was missed because the year of birth searched did not match the birth year recorded in the Registry. The nature of the current analysis does not inform as to whether the search error was due to inaccurate information on the scene or a mistake by the operator searching the Registry in these cases.

Currently, there is no standard practice for communication specialists searching the Registry with regards to what terms they should request, what terms they should search, and what order they should do these things. Incorporating the variables identified by CART as those most important in discriminating matched and un-matched calls into a standardized protocol may help improve the efficiency of current practice. It is recommended that emergency communication specialists be trained to ask for POLST ID number first, followed by last name and date of birth, and then last four digits of SSN. Prioritizing which information is asked for will add structure to these emergent calls, and allow for more comprehensive evaluation of the current algorithm in the future.

Interestingly, our study found that 32 patients believed to have a POLST form at the time of their call did not have an active form in the Registry but did have a form in the Registry at a later date. Nine of those patients had a POLST form signed prior to their call, but submitted afterwards to the Registry and 23 of those patients had a POLST form signed on or after the day of their call with subsequent submission to the Registry.

Continued research is necessary to determine if calls made to the Registry prompted completion and or submission of a POLST form for these patients.

Future research is also warranted to examine the efficiency (i.e., time required) of the search process. Creating an efficient and standardized search process will not only benefit users and registrants of the Oregon POLST Registry, but will facilitate the translation of this model Registry to other states looking to develop similar systems. The POLST program is one of the most widely used and studied paradigms to express patient wishes for the last chapter of life. With more than 30 states and communities adopting POLST or POLST-like programs, POLST has become a national model for honoring patient treatment preferences near the end of life. Overall, our study validates the current algorithm being used to match registrants to their form in the Registry and proposes that continued research seek to evaluate the efficiency and standardization of search processes to further enhance utilization of the POLST paradigm.

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#### **APPENDIX** A: Shortcomings of Advance Directives

A review of the efficacy of methods available to guide clinician care at the end of life prior to introduction of the POLST paradigm.

# I. Advance directives are ineffective in ensuring patients' end-of-life wishes are carried out.

Advance directives alone do not ensure that patient preferences are honored. Danis et al (1991) conducted a prospective study of 126 competent nursing home residents and 49 surrogates of incompetent residents to assess treatment preferences with regards to hospitalization, artificial ventilation, surgery, and artificial nutrition. Patients and surrogates were interviewed at the beginning of the study to record preferences in advance directives. Over the course of two years, 96 measureable events were recorded and the level of care given to the patient was compared to that indicated in their advance directive. Results illustrated that the presence of an advance directive did not assure that the requested level of care was given. More aggressive care occurred 6% of the time and was attributed to unanticipated surgery or artificial ventilation; less aggressive care occurred 19% of the time and was characterized by the withholding of cardiopulmonary resuscitation or hospitalization. Danis and colleagues attributed the ineffectiveness of advance directives to inattention to treatment preferences listed and lack of consideration for patient autonomy (Danis et al., 1991).

A randomized, controlled trial was conducted by Schneiderman et al in 1992 to determine the effects of advance directives treatment in the hospital setting. Patients in the experimental group were offered an advance directive (California Durable Power of Attorney) while patients in the control group were offered nothing. Monitoring of hospital admissions was conducted to ensure that the advance directive document was available in the medical record of patients at hospitalization. Several outcomes were assessed, including psychosocial, health outcomes, medical treatments, and charges. No significant difference for any of these variables was seen between the experimental and control groups. The authors concluded that advance directives did not appear to have any effect of treatment received upon hospitalization (Schneiderman, Kronick, Kaplan, Anderson, & Langer, 1992).

A more recent study examined the records of 160 older adults who died in a community hospital to examine the utilization of advance directives and the impact it had on health care decisions. Results illustrated that the presence of an advanced directive did not appear to impact where the person was treated, the use of life-sustaining treatments, or the initiation of palliative care (Dobbins, 2007).

In emergency situations, advance directives are inadequate. Emergency Medical Services (EMS) requires signed medical orders before it can deviate from protocols, which generally require attempted cardiopulmonary resuscitation, intubation, and transfer to an acute care hospital. In states where legislation has been put in place authorizing EMS to act on advance directives in the pre-hospital setting, a 1998 study found that only 28% had acted on an advance directive without medical control (Partridge, Virk, Sayah, & Antosia, 1998). EMS providers attributed their lack of action on advance directives to the fear of legal consequences, the moral issue of withholding care, and uncertainty in patient's wishes from the advance directive. EMS providers are unable to effectively implement advance directives in a pre-hospital setting due in legal and documentation ambiguities (Partridge, Virk, Sayah, & Antosia, 1998).

# **II.** Inaccessibility of advance directives during acute hospitalization events can render them useless.

The inaccessibility of advance directives during an acute hospitalization event leads to unwanted treatment (Morrison, Olson, Mertz, & Meier, 1995). A retrospective chart review of geriatric admissions over 3 years at a teaching hospital was reviewed for advance directive documentation and the following treatment course. Only 26% of patients whom had advance directives had those wishes recognized during their hospitalization. In a sub-group of those having advance directives and whom were also judged incompetent at the time of their admission, 26% had their directive recognized. However, when directives were recognized, 86% of the time they changed the course of treatment. While advance directives are important vehicles of expressing patient wishes, their inaccessibility prevents them from being recognized in an acute hospitalization scenario.

# **III.** The lack of public education about end-of-life care treatment options can cause discordance in surrogate's interpretation of patient's wishes.

In general, advance directives work well to identify who should speak on the patient's behalf in the event of catastrophic illness; however, they are less effective in ensuring patients with advanced chronic diseases get care consistent with their wishes (Ditto et al., 2001; Shalowitz, Garrett-Mayer, & Wendler, 2006; Silveira, 2000).

A review of studies conducted measuring surrogate-patient agreement on treatment preferences found that overall, 32% of the time surrogates did not correctly predict patient preferences (Shalowitz, Garrett-Mayer, & Wendler, 2006). Interestingly, in both studies were the surrogate was selected by the patient in those were it was assigned (next of kin) results were the same. Additionally, in studies where discussion between the patient and surrogate was controlled for, no significant difference was found in agreement on treatment based on prior conversation.

The agreement of patient-surrogate pairs was not improved when the surrogate was provided with the patient's advance directive (Ditto et al., 2001). Four-hundred and one elderly patients and their self-appointed surrogates were randomized to five different intervention groups: (1) surrogates predicted patient wishes without any aid; (2) surrogates predicted patient wishes after reviewing a value based advanced directive; (3) surrogates predicted patient wishes after reviewing a value based advanced directive and discussing the contents with the patient; (4) surrogates predicted patient wishes after reviewing a scenario based advance directive; (5) surrogates predicted patient wishes after reviewing a scenario based advance directive and discussing it with the patient. Results of the study illustrated that none of the interventions (2-5) improved accuracy of surrogate predictions compared to the control group (1). Surrogates do not consistently make decisions that reflect patient's wishes with regards to end of life treatment.

The general public lacks understanding of end-of-life care treatments (Silveira, 2000). A cross-sectional survey of adult patients in clinics across Oregon was conducted to determine the level of knowledge with regards to end-of-life treatment and to analyze whether or not knowledge was related to prior experience in dealing with these issues. Higher knowledge of end-of-life treatment was found to be associated with being a surrogate for health care decisions, but not with personal illness experience, death or illness of a loved one, or the authoring of an advance directive. The misunderstandings surrounding medical options for end-of-life treatment are a major shortcoming in current methods of advance care planning.

#### IV. Advance directives are not widely used.

A 1995 study examined the characteristics of people are have an advance directive, are interested in having an advance directive, and those with no interest in advance directives. A random sample of patients (n=160) from three clinics were administered a 10-item survey to determine the patients knowledge and interest in advance directives. Despite 95% of the participants indicating an interest in advance directives, only 16% had completed an advance directive. The authors concluded that multiple barriers exist to completing advance directives and few characteristics were found to discriminate between those completed advance directives and those who did not (Gilligan & Jensen, 1995).

In 2009 a study surveyed 306 patients about their use and opinions of advance directives. The majority of these patients (73.9%) indicated that they thought it was important to discuss health care wishes with their physician, but only 15.9% indicated that they had done so. Similarly, 86.9% indicated that they believed it was important to discuss health care wishes with their family, but only 60.1% reported having done that. Of those surveyed, 25.2% indicated that they had a durable power of attorney and 14.7% had living wills. Researchers concluded that while patients believe it is important to communicate their end-of-life wishes, many fail to do so (Clements, 2009).

Advance directives were intended to allow patients to direct their life-prolonging treatment preferences, yet decades of experience demonstrates that statutory advance directives alone are insufficient to allow patients and families control over end-of-life. A new model addressing the short comings of advance directives is necessary to ensure that patient's end-of-life wishes are being honored.
# **APPENDIX B:** Example POLST Form

HIPAAPERMITSDIGCLOSURE TO HEALTH CARE PROFESSIO	WALS & ELECTRONIC REGISTRY AS NECESSARY FOR TREATMENT			
Physician Orders	Last Name/First/Middle Initial			
for Life-Sustaining Treatment (POLST)	Address			
First follow these orders, then contact physician, NP, or PA. These	City / State / Zip			
medical orders are based on the person's current medical condition and preferences. Any section not completed does not	Date of Birth (mm/dd/yyyy) Last 4 SSN Gender			
invalidate the form and implies full treatment for that section.	MF			
. CARDIOPULMONARY RESUSCITATION (CPI	R): Person has no pulse and is not breathing.			
	ot Attempt Resuscitation/DNR (Allow Natural Death)			
When not in cardiopulmonary arrest, follow orders in B. C and D.				
the state of the second se				
MEDICAL INTERVENTIONS: Person has pu B Comfort Measures Only Use medicatio				
measures to relieve pain and suffering Us	n by any route, positioning, wound care and other se oxygen, suction and manual treatment of airway			
obstruction as needed for comfort. Patient	profers no transfer to hospitality ite-sustaining treatment. Transfer f			
comfort needs cannot be met in current location.	1			
	es care described above. Use medical treatment, IV fluids			
and cardiac monitor as indicated. Do not use in	unbation, advanced airway interventions, or mechanical			
venhiation. May consider less invasive airwa Avoid intensive care	sy support (e.g. CPAP, BiPAP). Transfer to hospital Final cated.			
	ove. Use inhubation, advanced airway interventions,			
	over Use minibation, advanced airway interventions,			
Additional Orders:	acates. Harbor Amospian Hucates. Includes mensive care.			
and the second se				
C ANTIBIOTICS				
🖂 🔄 No antibiotics. Use other measures to rel				
Determine use or limitation of antibiotics	s when infection occurs.			
<ul> <li>Use antibiotics if medically indicated.</li> </ul>				
Additional Orders:				
ARTIFICIALLY ADMINISTERED NUTRITION:	Abraw offer feed by month if feerible			
D ARTIFICIALLY ADMINISTERED NUTRITION:	Always offer food by mouth it feasible.			
Defined trial period of artificial nutrition	her telas			
Long-term artificial mutrition by tube.	by tube.			
Additional Orders:				
Additional Orages:				
E REASON FOR ORDERS AND SIGNATURES	The second se			
My signature below indicates to the best of my knot	wledge that these orders are consistent with the person's current			
medical condition and preferences as indicated by d				
	Surrogate for patient with developmental disabilities or significant mental health condition (Note: Special requirements for completion, See reverse side.)			
Construction of the second sec	ontation (voir: special requiring as completion, see reverse side.)			
Print Primary Care Professional Name				
Cruit Cranary Care Processinal Name	Office Use Only			
Print Signing Physician / NP / PA Name and Phone Number				
( )				
Physician / NP / PA Signature (mendatory) Det				
ORIGINAL TO ACCOMPANY PERSON IF TRANSFE	RRED OR DISCHARGED, SUBMIT COPY TO REGISTRY			

CENTER FOR ETHES IN HEALTH CARE, Origon Health & Science University, 3181 See Jackson Park Rd, U305-86, Portland, OR 97239-3098 (503) 494-3965

HIPAAPERMITS DISCLOSURE TO HEALTH CARE PROFESSI	ONALS & ELECTRONIC REDISTRY AS NECESSARY FOR TREATMENT		
Information for Person Named on this Form	Person's Name (print)		
	staining treatment in your current state of health. It can be it any time if your preferences change. If you are unable to make i your preferences as best understood by your surrogate.		
Signature of Person or Surrogate			
Signature Name (print)	Relationship (write "self" if patient)		
alor tul			
Opt Out Check box if you do not want this for	m included in the electronic POLST registry.		
Contact Information			
Surrogate (optional) Relationship	Phone Number Address		
	1		
Health Care Professional Preparing Form (optional) Prepa	are Title Phone Number Date Prepared		
PA's Supervising Physician	Plene Number		
Directions for He	alth Care Professionals		
Sending to POLST Registry (Reguired unless 4) • For the POLST Registry, the following information on the other side of the form <u>must</u> be completed: • Person's full name	stowals at http://www.ohse.edu/polst/programs/docs/guidance.pdf Opt Out* box is checked)  • Send a copy of <u>both</u> sides of this POLST form to the POLST Registry. • FAX or eFAX: (503) 418-2161 Date/		
<ul> <li>Date of birth</li> <li>Section A</li> <li>Physician / NP / PA Signature and date signed</li> </ul>	or • Mail: Oregon POLST Registry Date// Mail Code: CDW-EM 3181 SW Sam Jackson Park Road Portland, OR 97239		
Reviewing POLST This POLST should be reviewed periodically and if: • The person is transferred from one care setting or care leve • There is a substantial charge in the person's health status, • The person's treatment preferences charge.	PUT REGISTRY ID STICKER HERE:		
Volding POLST • A person with capacity, or the valid surrogate of a person w • Draw line through sections A through E and write "VOID" in • Send a copy of the voided form to the POLST Registry as a • If included in an electronic medical record, follow voiding p	hove (Required).		
www.point.org or at pointgolau.edu.	Ethics in Haddh Care. Information on the POLST program is available online at ERRED OR DISCHARGED, SUBMIT COPY TO REGISTRY		

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June 2009

## **APPENDIX C:** A Review of the POLST Paradigm.

#### I. The origins of the POLST Program.

The POLST form originated as the Medical Treatment Coversheet (Dunn et al., 1996). The document was designed and tested through health professional focus groups. In testing the document, these professionals were asked to describe their treatment approach to three hypothetical scenarios twice—one time using the MTC document and the other time without it. A comparison of responses for each professional was made against the most medically appropriate treatment approach (determined by an expert panel). Results showed that professional utilizing the MTC compared to those who were not saw changes in treatment decisions that were consistently related to providing or withholding treatment that was consistent with patient wishes.

The name of the document was changed to "Physician Orders for Life-Sustaining Treatment (POLST)" and pilot testing began in nursing homes (Center for Ethics in Health Care, Oregon Health & Science University, 2008). The success of focus groups and pilot studies led the POLST form to be released for use throughout Oregon. A prospective one-year study began at this time to examine the effect of this new document in nursing homes.

Nursing home patients with a POLST universally received the level of care requested with respect to cardiopulmonary resuscitation orders in Oregon (Tolle, Tilden, Nelson, & Dunn, 1998). A prospective cohort of nursing home residents (n=180) with POLST forms indicating a DNR preference and transfer from facility only for comfort measures were followed for 1 year. At the end of 1 year, no patient had received CPR. Only 13% of patients were hospitalized during the study period and 85% of all

hospitalizations were because comfort measures could not be adequately met at the patient's current facility. POLST orders were 100% effective in expressing patients DNR wishes and largely effective in preventing unwanted life-extending treatments.

## **II.** Continued research reaffirms the efficacy of the POLST paradigm.

ElderPlace participants in Portland, OR who utilized a POLST received desired care consistently (Lee, Brummel-Smith, Meyer, Drew, & London, 2000). The charts of 54 patients who died in 1997 were reviewed for concordance with POLST orders. Care was consistent with patient preferences in 91% of cases for CPR; 84% of cases for IV fluids; 94% of cases for feeding tubes; 86% of cases for antibiotic use; 46% of cases for medical interventions. The degree to which care received by patients in their last two weeks of life matched patient wishes as recorded on a POLST form was found to be higher than agreement previous research has shown with advance directives.

In Washington, the POLST paradigm was found to be effective in a pilot study of nursing home residents (Meyers, Moore, McGrory, Sparr, & Ahern, 2004). Chart reviews of 21 patients with a POLST found concordance with patient wishes and the written orders in 19 cases. When the patient also had an advance directive, orders on the POLST were found to match wishes expressed in that document. These pilot-study findings suggest that the POLST form effectively conveys nursing home patient's end-of-life wishes.

The POLST paradigm is widely effective in ensuring end-of-life wishes are met in the hospice setting (Hickman et al., 2009). A cross-sectional study assessed the use of POLST in hospice programs in Oregon, Wisconsin, and West Virginia through telephone survey. A sub-sample of POLST programs in each of the three states further analyzed outcomes for POLST patients via a chart review. POLST was found to be widely utilized

in hospice programs in Oregon (100%) and Washington (85%), but only regionally in Wisconsin (6%). Attitudes towards the POLST program were overwhelmingly positive, with 97% of hospice workers believing that it helped prevent unwanted CPR and 96% believing it played a significant role in instigating end-of-life planning conversations. CPR orders were respected in 100% of charts reviewed and preference for all treatment orders was honored in 98% of cases. The POLST program effectively relayed patient's wishes in the hospice care setting.

Recent research continues to support the validity of the POLST program, finding that the form is effective in documenting orders beyond cardiopulmonary resuscitation and that treatment preferences are followed when a lesser degree of treatment is indicated (Hickman et al., 2010). A retrospective cohort study of 1711 nursing facility residents was undertaken to study life-sustaining treatment orders and related treatments. Results illustrated that those residents with POLST forms were significantly more likely to have documentation of orders beyond cardiopulmonary resuscitation than residents without POLST (98% compared to 16.1%). Additionally, patients with POLST forms indicating orders for comfort measures only treatment were significantly less likely to receive medical interventions that those residents with POLST orders indicating full treatment, residents with DNR orders, or residents with full resuscitation orders. These results indicate that the POLST form is effective in communicating treatment preferences and documenting specific levels of care.

# **III. POLST impacted the scope of treatment provided by EMTs and First Responders.**

In 1999, the POSLT task force recognized that EMS and first responders would be instrumental in ensuring patient's wishes were honored in a crisis event. In order for emergency personnel to honor this document, a change in the Oregon Medical Board's scope of practice for EMTS's/First Responders was proposed. The new language empowers EMTs to withhold treatment when specified by medical orders that indicate patient preference. The approved language reads:

An Oregon-certified First Responder or EMT, acting through standing orders, shall respect the patient's wishes including life-sustaining treatments. Physician supervised First Responders and EMTs shall request and honor life-sustaining treatment orders executed by a physician, nurse practitioner or physician assistant if available. A patient with life-sustaining treatment orders always requires respect, comfort and hygienic care (Oregon Administrative Rules, ORS 682.245)

In 2008, reports expressed that when asked to consider the last time they would've expected a POLST form on a scene, EMS personnel were unable to locate a form 25% of the time, thus creating a potential barrier to the honoring of patients end of life wishes (Terri A Schmidt, Hickman, Tolle, & Brooks, 2004). A random sample of Oregon emergency medical technicians were asked to complete an anonymous survey regarding their experiences and perceptions of POLST. Responses from 572 EMTs indicated that the POLST form changed the course of treatment in 45% of cases where it was present. Most EMTs (75%) indicated that the POLST form gave clear instructions on patients' wishes. The POLST was believed to be most useful when a patient was in cardiopulmonary arrest (93% of EMTs agreed) and less useful when the patient had a

pulse and was breathing (63% of EMTs agreed). Overall, the POLST form is an effective tool in the pre-hospital setting for disseminating patient's wishes when it is available.

## IV. An electronic Registry was created to facilitate access to POLST orders.

The demonstrated concern over not finding patient's POLST forms sparked the initiative to create an electronic Registry which would store copies of all POLST forms and be accessible to EMS in the event that the original form could not be located. Under the direction of Terri Schmidt, M.D., funding from the Greenwall Foundation and private philanthropy, a collaboration began between the Oregon POLST Task Force, the OHSU Center for Ethics in Health Care, and the OHSU Department of Emergency Medicine (Center for Ethics in Health Care, Oregon Health & Science University, 2008). Design of the electronic Registry was completed in December 2008 and system training and testing began in early 2009. On May 26, 2009, a pilot-phase in Clackamas County began. On July 1, 2009, state legislation was passed that partnered the Registry with the Department of Human Services and the Oregon Health Authority facilitating statewide expansion of the Registry (Oregon Administrative Rules, Ch. 595, Sec. 1184, 2009).

On December 3, 2009, The Oregon POLST Registry became available 24/7 for EMTs to access on the scene, emergency departments and acute care units when the original POLST form cannot be located. In addition to housing POLST information in an easy to use database, the Registry also houses copies of each active POLST form that can be faxed to hospitals for consultation once a patient arrives. Unless a patient notes specifically on their POLST form that they do not want to be included in the Registry (by checking an "opt out box") signers are required to submit the form to the Registry. Completing the form is voluntary and nothing in the legislation has changed that.

## **APPENDIX D:** Current Algorithm

Table D-1: Points Assigned to Demographic Variables.

Field/category:	Points/score	
Registry ID #		4
Last name		4
First name		3
Partial Last name		3
Partial first name		2
SSN		2
DOB		2
Partial DOB		1
Age		1
Gender		1

- A MINIMUM score of 6 is needed before you can view POLST data.
  - A score of 6 **DOES NOT** guarantee a match but should produce narrow list of potential Registrants. To confirm a match you must have:
    - Only one Registrant listed with a score of 6 or higher AND at least 3 pieces of available identifying information to confirm
    - If more than 1 Registrant matches with a score of 6 or higher one of these 2 criteria must be met as well:
      - at least 4 pieces of available identifying information match
      - A Registry ID number is found and confirmed after initial match
- Any score under 6 will allow you to view a list of Registrants who MIGHT match your search criteria
  - More criteria MUST be entered into the search screen before you can view the potential Registrant.

## **APPENDIX E:** Expanded Methods, Probabilistic Linkage

Probabilistic linkage was done to compare the *Charts* dataset to a dataset of all registrants whom had an active POLST form in the Registry at any point between 12/3/2009 and 7/31/2010 (*Registry*). Specifically, the goal of linkage was to utilize a complete demographic profile for a patient believed to have a POLST and compare that to the demographics of registrants who had an active POLST for in the Registry at the time of the call in order to see if additional matches could be found. Since the goal was to find additional matches, all known matches were removed from both datasets, leaving 151 records in *Charts* and 23,257 in *Registry*.

The Oregon POLST Registry is unique in that it is dynamic and constantly changing. In order to determine which registrants had an active POLST form in the Registry at any point during our sample, we restricted these registrants to those that had forms created before 8/1/2010. Since it was

implausible to run linkage 180 different times to restrict each dataset of registrants to those in the Registry at the time of the specific call, the registrants who matched forms through the linkage were manually reviewed. This manual review not only determined if the form found in the Registry matched the patient from the scene, but also

## Figure E-1: Variables used in Probabilistic Linkage

- First name
- Last name
- Last initial
- Middle initial
- Date of birth
- Gender
- Last four digits of SSN
- Street number
- Street name
- Apt/Unit/Space/Box number
- City
- State
- Zip code

determined whether or not that form was active—i.e. "searchable"—by the emergency communications operator at the time of the call.

Fourteen variables were utilized in linkage (Figure E-1). These were all of the variables that were present in both the *Charts* and *Registry* datasets. Prior to linkage, both datasets were reviewed extensively to make sure that data in similar fields was coded in the same way—i.e. Mount Angel was written as "Mount Angel" in both datasets and not "Mount Angel" in one and "Mt. Angel" in the other. To minimize labor, coding conventions from the Registry Manual of Operations v11.1 were utilized in the creation of the *Charts* dataset.

Once the data was in the linkage program, variables that overlapped in

information were adjusted for so that match probabilities would not be falsely inflated. The variables "city" and "street" were down-weighted because the variable "zip code" contained more specific and overlapping information. The linkage program calculated the degree to which those two variables provided the same information, and adjusted the

 
 Table E-1: Error Assigned to Variables
 Variable Error First name 0 - 1 typo Last name 0 - 1 typo No error Last initial Middle initial No error Date of birth +/- 1 Gender No error Last 4 SSN No error Street number +/- 1 Street name 0-2 typos Apt/Unit/Space/Box +/- 1 City 0-1 typo No error State Zip code No error

match weight accordingly. The variable "last initial" was down-weighted based on the more specific variable "last name."

Next, error was built into some of the variables in order to allow for typos in either dataset. For example, the variable "city" was designated to match if it had 0 or 1 typo. Table E-1 shows each of the variables utilized in linkage and what error (if any was built into these terms).

In order to reduce processing time, the entire *Registry* dataset was

Pass #	Blocking Variable(s)
1	Date of birth
2	Gender and Last initial
3	Last 4 SSN
4	Zip code
5	Last name
6	City and First name

not compared to the entire *Charts* dataset for all variables for each record. Instead, "blocking variables" were created that required information from both datasets to be an exact match before the rest of the record was reviewed. For example, one blocking variable utilized was date of birth. When this "pass" was run, only those records in the *Registry* dataset with a date of birth exactly matching a date of birth for a record in the *Charts* dataset were considered in the review of other variables and in the assigning of match weights (Figure D-3). When a variable was used as a blocking variable, any built in error was disregarded and an exact match was necessary in order for the rest of the variables for that record to be reviewed. More than one blocking variable was used in 2 of the passes which meant that both of those variables in the *Charts* dataset had to have an exact match in the *Registry* dataset in order for the record to be further analyzed and a match weight assigned. The blocking variables utilized in each pass are listed in Table Z. Multiple (6) passes were run in order to ensure that an error in a matching record in a *Charts* blocking variable for one pass would be picked up in another—i.e. if there was an error in date of birth, while that match would not be found in pass 1, it should be picked up in another pass.

Finally, each of the passes were run and results from all 6 were compiled together to create a list of all possible matches. Any record from the dataset that had a positive match weight with a record in the *Registry* dataset was considered for manual review.

## **APPENDIX F:** High Specificity Model Detail Explanation

This model begins at Node 1 by splitting all 180 calls by the variable "Last name." At Terminal Node 1, it is noted that 69 of the calls are removed from further analysis and deemed "not matches." All 69 of these calls are correctly categorized as "not matches. At Node 2, 111 of the 180 calls are separated to be further analyzed. Of these 111 calls, 79 of them are "non-matches" and 32 of them are "true matches." These 111 calls were then split based on SSN. Terminal Node 2 illustrates that 38 of the calls did not match on SSN and are classified as "not matches." Of those 38 calls, 35 of them are correctly categorized as "not matches", while 3 of there are incorrectly categorized as such.<sup>1</sup> Node 3 listed 73 of the 111 calls as having a matching SSN in the Registry. Of these 73 calls, 29 of them were "true matches" while 44 of them were "non-matches." These 73 calls were further split by DOB. Terminal Node 3 shows that 10 of the 73 calls did not match on DOB. Of these 10, 9 were correctly categorized as "non-matches", while 1 was incorrectly categorized as such.<sup>2</sup> At Node 4, 63 of the 73 calls did match on DOB. Of these 63 calls, 35 of them were "non-matches" and 28 of them were "true matches." Finally, these 63 calls were split based on address. Terminal Node 4 shows that 43 of these calls did not match on address; of those 43, 26 were true "non matches" whereas 17 were incorrectly classified as such.<sup>3</sup> Terminal Node 5 shows that of those who did match on address, 9 were incorrectly classified as "true matches" while 11 were

<sup>&</sup>lt;sup>1</sup> Further analysis revealed that for 2 of the 3 calls that were "true matches", while the SSN was provided by the chart, it was not available in the Registry and thus did not match. For the 3<sup>rd</sup> call, the SSN listed in the Registry was different from what was received from that patients chart.

<sup>&</sup>lt;sup>2</sup> In this case, the DOB recorded in the Registry was different from what was from the patients chart. <sup>3</sup> Reasons behind address not matching for "true matches" were: address not available in the Registry, but available from the chart; address in the Registry different from the address provided on the chart; variation in how the same address was recorded in the Registry and listed on the chart (i.e. inclusion of SW vs. exclusion).

correctly classified as such. In summary, this model yielded 11 "true matches", 21 "missed matches", 9 "false matches", and 139 correct non-matches.

In the cross-validation sample (CARTs prediction of how the model would do on a completely new dataset), the sensitivity of the High Specificity Tree was 100% and the sensitivity was 0%. However, these Cross Validation results are believed to be inaccurate based on the small sample size. It is not realistic to expect that we would find no one in a separate analysis and have perfect specificity.

## **APPENDIX G:** High Sensitivity Model Detail Explanation

This model begins at Node 1 by splitting all 180 calls by the variable "Last name." At Terminal Node 1, it is noted that 69 of the calls are removed from further analysis and deemed "not matches." All 69 of these calls are correctly categorized as "not matches." At Node 2, 111 of the 180 calls are separated to be further analyzed. Of these 111 calls, 79 of them are "non-matches" and 32 of them are "true matches." These 111 calls were then split based on DOB. Terminal Node 2 indicates that 29 of the 111 did not match on DOB. Of these 29, 28 were correctly classified as "non matches", while 1 was incorrectly classified as such.<sup>4</sup> Terminal Node 3 contained 82 calls that did match on DOB. Of these 82 calls, 31 were correctly classified as "true matches", while 51 were incorrectly classified as such. In summary, this model yielded 31 "true matches", 1 "missed match", 51 "false matches", and 97 correct non-matches.

In the cross-validation sample (CARTs prediction of how the model would do on a completely new dataset), the sensitivity of the High Sensitivity Tree was 87.5% and the specificity was 64.9%.

<sup>&</sup>lt;sup>4</sup> In this case, the DOB recorded in the Registry was different from what was from the patient's chart.

# **APPENDIX H: Call Log Validation Analysis**

Table H-1: A: The variable was available on the scene and searched correctly; B: The variable was available on the scene and not searched or searched incorrectly; C: The variable was not available on the scene but searched; D: The variable was not available on the scene and not searched.

Key		Available or "+"	Available on the Scene	
Searched	"+"	Α	В	
Correctly	"_"	С	D	
Last Name		Available o "+"	n the Scene	
Searched	"+"	21	0	
Correctly	"_"	0	0	
First Name		Available on the Scene		
		"+"	"_"	
Searched	"+"	20	0	
Correctly	"_"	1	0	
Middle Initial		Available o "+"	"_"	
Searched	"+"	4	2	
Correctly	"_"	1	14	
Birth month		Available o "+"	Available on the Scene "+" "-"	
Searched	"+"	15	0	
Correctly	"_"	2	4	
Birth day		Available o "+"	Available on the Scene	
Searched	"+"	15	0	
Correctly	"_"	2	4	
Birth year		Available o "+"	Available on the Scene	
Searched	"+"	14	0	
Correctly	"_"	3	4	
•				

PID		Available on the Scene	
		"+"	"_"
Searched	"+"	1	0
Correctly	"_"	0	20
SSN		Available on the Scene	
		"+"	"_"
Searched	"+"	4	1
Correctly	"_"	1	15
Gender		Available on the Scene	
		"+"	"_"
Searched	"+"	4	4
Correctly	"_"	9	4