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## Ethical Documentation at the End of Life

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**Ethical Documentation at the End of Life**

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## **Introduction**

Patient autonomy is a basic tenant of ethical decision making in medicine (AMA Opinion 9.12). Individuals who are unable to participate in decision making at the end of life present a unique challenge to delivering ethical patient-centered care. To ensure patient autonomy is upheld, providers are encouraged to use healthcare directives<sup>3, 4</sup> to guide clinical decision-making. Healthcare directives are designed to uphold patient autonomy by indicating the desired scope of care at the end of life. While a particular type of healthcare directive, the advance care directive, is widely accepted, there are two common issues concerning its use: interpretation and accessibility. Issues with advance care directives have been largely circumvented by a new method of documentation: the physician order for life sustaining treatment (POLST). In addition to a review of the ethical issues pertaining to healthcare directives, this paper will outline a multi-methodological study proposal developed with support from the Lindmark Fellowship in Ethics.

### ***Legal & Ethical Interpretation of Healthcare Directives***

While the intent of advanced care directives is to protect patient autonomy, inadequate interpretation of these documents by providers and surrogate decision makers<sup>5</sup> compromises patient autonomy.

Burkle, Mueller, Swetz, Hook, & Keegan (2012) used the following scenarios in their study which highlighted the interpretation problems with advanced care directives:

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<sup>3</sup> Healthcare directive is broadly construed to include a variety of documentation types concerning care at the end of life including: advanced care directives, power of healthcare attorney, and physician orders for life sustaining treatment (POLST).

<sup>4</sup> See Appendices A and B to compare popular forms of healthcare directives.

<sup>5</sup> Surrogates make healthcare decisions on behalf of the patient. Surrogate decision making can assumed by next of kin or an individual pre-appointed by the patient.

Scenario I: A 65-year-old patient with well-controlled hypertension arrives to the emergency department (ED) complaining of "chest pain". Shortly following arrival to the unit, he falls into ventricular fibrillation, is apneic and requiring mask ventilation. The patient has signed an advance directive stating a wish to "pass away in peace". Should the provider intubate the patient?

Scenario II: A 68-year-old patient with hypertension, diabetes, end stage renal disease on dialysis and acute lymphocytic leukemia arrives to the ED. His heart stops beating. The patient completed and signed an advance directive indicating "Do not resuscitate" (DNR) / "Do not intubate" (DNI) during a recent visit with his oncologist. Should the provider begin resuscitation?

When presented with scenario II, 73 percent of providers would honor the advanced directive while only 45 percent of providers would honor the healthcare directive in scenario I (Burkle et al., 2012). The willingness of providers to follow healthcare directives in some circumstances but not others reflects the ambiguity surrounding their interpretation and calls into question their ethical and legal utility.

In scenarios I and II, the scope of questioned medical intervention was the same but the wording of the healthcare directive was different. While instructions for DNR/DNI (scenario II) are straightforward, phrases like, "pass away in peace" (scenario I) are ambiguous and require interpretation. Interpretation of unclear healthcare directives is not only a legal concern but can present an ethical dilemma. For example, 68 percent of providers indicated they would withhold life-sustaining treatment for the individual in scenario I, as letting him die of cardiac arrest would not honor his wish to "pass away in peace" (Burkle et al., 2012). However, the likelihood of surviving CPR in hospital is only

eight percent for people over 65—statistically, the “peaceful death” would have been intervention, as CPR can cause significant post-delivery pain and traumatic blood loss from internal hemorrhage (AHA, 2012). A panel recommendation published in the American Medical Association’s Journal of Ethics advised, “...when [healthcare directives] create more ethical ambiguity than they resolve, it is appropriate to set them aside” (Lawrence & Brauner, 2009, p. 573). Ambiguous wording exemplifies a case where providers can ethically ignore the orders of a healthcare directive, as patient autonomy cannot be upheld when patient preferences are unclear. While the ambiguous healthcare directive has little ethical utility in decision-making, it still carries legal weight.

In 2007, a patient in a Florida nursing home was found unresponsive. Staff had difficulty obtaining any vitals and her healthcare directive stated, “In the event of terminal illness, the patient is DNR/DNI” (Scheible v Morse Geriatric, p. 1). The patient was certainly not “terminally ill” but was not responsive. Medical staff decided to resuscitate the resident and admit her to the hospital where she later died. The family of the resident filed a wrongful life suit. Due to the ambiguity of the resident’s healthcare directive, the jury found medical staff was not liable for her death but the institution had to pay punitive damages. Scheible v. Morse (2008) and similar wrongful life rulings have set an unusual precedent while adding a layer of confusion to the degree of interpretability afforded to providers.

Attorneys Lynch, Mathes, and Sawick (2008) suggest providers should be allowed some flexibility when caring for patients with healthcare directives, “Dogmatic adherence to the text of advance directives merely trades one problem for another and would promote neither patient autonomy nor the best interests of patients, and therefore must be avoided” (Lynch et al., 2009, p. 159). However, as medical ethicist and physician, Dr.

Ferdinando Mirarchi, notes, “providers do not adequately understand how to interpret healthcare directives, specifically a type of healthcare directive called the advanced care directive” (Mirarchi, Costello, Puller, Cooney, & Kottkamp, 2012, p. 519).<sup>6</sup>

Conducted in 2012, the TRIAD III study, a large ( $n = 786$ ) multispecialty and multistate provider survey, reported 77 percent of internists, 74 percent of family physicians, and 80 percent of emergency medicine physicians incorrectly interpreted advanced care directives (Mirarchi et al., 2012). However, providers are not alone in their misinterpretation of advanced care directives—patients’ families also have difficulty. Ditto and colleagues (2001) took a group of patients and their appointed healthcare decision makers and split them into groups. Patient-decision maker pairs in the control group (Group 1) did not create an advanced directive while pairs in the experimental group (Group 2) completed an advanced directive and discussed it in each other’s presence. The decision-making surrogates from both groups were then presented with four fictional scenarios that required mechanical preservation of life. The surrogates’ decisions were then revealed to the patients, who indicated whether the decisions of the surrogate accurately reflected their wishes. Both surrogate groups were only 30 percent accurate in their decision and there was no statistically significant difference between groups—suggesting advanced directives did not aid surrogates in decision-making (Ditto et al., 2001).

The inability of surrogates and providers to accurately interpret advanced care directives suggests they do not aid in ethical decision-making at the end of life, as patient

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<sup>6</sup> Advanced care directives are a sub-type of healthcare directive that may or may not offer situation-specific treatment guidelines and are part of the American Bar Association’s Healthcare decision making toolkit for attorneys and clients. They are recognized as legal documents by all 50 states and the federal government.

autonomy is not reliably upheld. Furthermore, the legal enforceability of these documents discourages flexibility on behalf of providers.

### **Access**

Both patients and providers have difficulty accessing advanced directives—Americans who identify as non-white have lower advanced directive completion rates than their white counterparts while providers have difficulty finding advanced directives in patients' electronic medical records (Kelley, Wenger, & Sarkisian, 2010).

#### ***I. Patient Access***

In 1990, Congress passed The Patient Self-Determination Act (PSDA). Aimed at encouraging the widespread use of advanced directives, it requires health care organizations that report Medicare or Medicaid beneficiaries to ask patients whether they have advanced directives, to promote advanced directives, and include advanced directives in medical records. Unfortunately, the PSDA's goal, to achieve nationwide advanced care planning, has not been realized in the 25 years since its inception. Advanced directive completion rates are low—26.4 percent of Americans have filed an advanced directive (Rao, Anderson, Lin, & Laux, 2014). Of Americans who have an advanced directive, those identifying other than white are relatively underrepresented: Korean 5.4 percent, Latino non-White 23 percent, White non-Latino 68 percent (Kelley, Wenger, & Sarkisian, 2010; Ko & Berkman, 2012). This has been identified as a serious ethical issue, as it suggests non-white Americans are unable to exercise autonomy to the same degree as their white peers (ACP Ethics Manual 6<sup>th</sup> Edition, 2012; AMA Opinion 9.121, 2005).

Patient's accurate understanding their health is vital, as informed patients make informed decisions. Volandes et al. (2008) identified a group of Latino patients with mixed scores on the Rapid Estimate of Adult Literacy in Medicine (REALM) scores—a test for

assessing health literacy. Patients were given an oral description of the natural disease progression of dementia. Patients were then asked whether they would favor palliative or aggressive care at the end of life if diagnosed with dementia. Individuals with low health literacy scores opted for more aggressive care while those with higher health literacy scores selected palliative care. After giving their initial preferences, the patients viewed a video detailing the progression of dementia and were asked again whether they favored aggressive or palliative care. After viewing the video, there was no relationship between health literacy score and care preference (Vollandes, et al., 2008). Therefore, better communication between providers and patients of different health literacy backgrounds is vital to ensure patients have an accurate understanding of their condition and realize the importance of planning ahead.

Another common barrier to access of advanced directives is their literary complexity—the literacy level of traditional advanced care directives exceeds that of high school yet the National Assessment of Adult Literacy Assessment identified individuals for whom English is a second language are more likely to be below the national literacy benchmark (NAAL, 2003; Sudore et al., 2007). To assess whether advanced directive completion rates would shift in response to making the documents easier to read, Sudore and colleagues (2007) redesigned the traditional advanced care directive with informative graphics and questions of a fifth grade reading level. Presenting both forms to a group of individuals with mixed English language proficiency (40 percent of the group had limited English proficiency), the simpler form was preferred by 73 percent of participants. After a six-month follow up, 19 percent of participants had completed an advanced directive compared to zero percent at the beginning and of the newly completed directives, and 95



percent of completed directives were the simpler form (Sudore et al., 2007). Access to quality health care at the end of life can be improved by uncomplicating language barriers in documentation.

## ***II. Physician Access***

At the end of life, transfer of care between facilities is common—45 percent of dying patients relocate during the last months of life (Menec, Nowicki, Blandford & Veselyuk, 2009). Frequent provider changes are associated with poor healthcare directive adherence, as new providers often fail to intercept complete documentation (Vawter & Ratner, 2010). Electronic medical record (EMR) use was thought to help eliminate problems associated with the physical transfer of records between institutions of care. However, incompatibility between multi-vendor software can prevent electronic transfer (FDA, 2010).

Ultimately, it is the responsibility of the patient to secure and supply the provider with an advanced directive. Consider the following clinical case by Tulskey (2005):

Mr. N presented to the hospital and a diagnostic test confirmed an aggressive colon cancer. His provider asked if he wanted to indicate DNR/DNI status, Mr. N said he was working with a lawyer to draft his advanced directive. A month later, Mr. N was admitted to the hospital for abdominal distention and pain. An X-ray revealed his cancer was progressing. When asked about DNR/DNI status, Mr. N said he “was not keen on the idea of tubes” but he was still unsure about his DNR/DNI status. A week later, Mr. N was deteriorating quickly and required surgery at an out-of-system hospital, during which he was intubated. Following surgery, he was transferred to his primary hospital and fell into cardiac arrest. Mr. N’s son was upset to see him intubated but his daughter believed Mr. N would have wanted life support. The son,

feeling he was not being listened to, physically inserted himself between Mr. N and the code team. Mr. N's physician was unable to determine the code status indicated by Mr. N prior to surgery because the institutions did not have compatible software. After the family lawyer was contacted and the advance directive (which indicated DNR/DNI) procured, the code team removed intubation and Mr. N died shortly (Tulsky, 2005, p. 359).

The above clinical experience was used by Tulsky (2005) to exemplify the manifestation of a pervasive clinical problem—poor communication between patients, providers, and families at the end of life. The physician could not follow DNR/DNI orders because the patient had not consented to DNR/DNI specifically but indicated he was “working on them,” the family was divided about how to proceed with no clear decision making surrogate, and the advance directive was not incorporated into the patient's medical record due to a software compatibility error.

#### **POLST Paradigm – A documentation system for better interpretation?**

Providers turn to healthcare directives to guide care decisions at the end of life. Consulting a patient's healthcare directive to ensure the care received matches care desired is considered essential to providing ethical care. However, when providers have difficulty interpreting healthcare directives, patient autonomy is not realized and ethical care is compromised. To better facilitate ethical decision-making at the end of life, a group of Oregon physicians developed a novel end of life document: the physician orders for life sustaining treatment (POLST). POLST documentation was designed to circumvent traditional interpretive and access barriers associated with advanced directives (Castillo et al., 2011). It is one page in length, indicates DNR/DNI status, is a medical order, and does

not allow open-ended responses. A statewide study of Oregon POLST registrants who died in nursing homes reported care received matched care desired in 100 percent of cases (n = 180) (Tolle, Tilden, Nelson, & Dunn, 1998). Another study of end-of-life care administered to geriatric patients in Oregon revealed desired life preserving and/or palliative care approaches documented in POLST agreed with realized care in over 83 percent of all cases (Lee et al., 2000). Oregon's commitment to no-nonsense end of life documentation has inspired other health systems to embrace a similar approach.

Gunderson Health System in La Crosse, Wisconsin is particularly noteworthy and has been lauded as a model for incorporation of healthcare directives into routine care and electronic medical records. Eighty five percent of Gunderson patients have healthcare directives—all accessible in patient's electronic medical records. Gunderson's program, Respecting Choices, uses a succinct POLST-like document to identify DNR/DNI status, state care goals, and appoint a surrogate decision maker. Similar to Oregon's approach, Respecting Choices care plans are recognized as a physician order and are incorporated into the electronic medical record. Furthermore, Gunderson is proactive—requiring providers to update patients' Respecting Choices care plans during routine clinical visits and in the event of a change in medical status (e.g. severe to critical)—ensuring the record on file is always up to date.

The Respecting Choices program was introduced with a widespread two-year campaign promoting discussion regarding end of life documentation between patients, family, and providers. Prior to the program's start, 15 percent of patients in the Gunderson health system had some type of advanced care planning compared with 85 percent of the population after the program's trial-period, during which providers complied with

patient's healthcare directives in 98 percent of cases (Hammes et al., 2010). Additionally, an analysis of the electronic medical records of recently deceased Gunderson patients revealed 96 percent of patients had a form of healthcare directive and 98 percent of directives were updated within 11 months before death (Jennings, Kaebnick, & Murray, 2005). Gunderson's success with POLST like documentation has sparked discussion on a national level. Yet, challenges to comprehensive care planning remain.

While considered a healthcare directive by the American Bar Association, there exist several legal barriers to POLST's widespread use and adoption as a legal document. In 2007, the POLST Paradigm National Taskforce examined laws in all 50 states and identified three common barriers to implementing a national POLST system. Satisfying state-specific statutory specifications on what constitutes an acceptable end of life document is the first barrier. For example, five states require extensive information for a form to qualify as end of life documentation while two states require an individual with DNR/DNI status to wear a physical bracelet indicating this status (Hickman, Sabatini, Moss, & Nester, 2008). A second potential barrier includes laws in 15 states that require one to have a pre-existing medical condition before one can obtain DNR/DNI status. The final roadblock to national POLST adaptation includes witnessing requirements in 12 states, which would necessitate the signature of up to two individuals in addition to the physician and patient signatures (Hickman et al., 2008). While there are significant legal challenges to the adoption of a national POLST program, Oregon and Wisconsin have successfully implemented statewide POLST initiatives and serve as case studies to determine whether POLST forms enhance the ability of providers to make ethical decisions at the end of life.

The primary difference between a POLST and an advanced directive is the scope and presentation of information. While advanced directives were created to ensure maximum patient autonomy by dictating care in a broad set of circumstances, their variable specificity forces practitioners to interpret patient wishes in unpredictable clinical circumstances—often incorrectly. As demonstrated in Oregon and Wisconsin, POLST documentation takes the reverse approach and is both highly specific in terms of what lifesaving measures are appropriate and can be appropriated to a variety of clinical situations, allowing providers to determine a course of care that aligns with patient desires. In the context of ethical end of life decision-making, POLST documentation facilitates clinical decisions that remove problematic interpretation and extend patient autonomy into the end of life.

### **Conclusion**

Preserving patient autonomy of care is at the core of ethical clinical care (AMA Opinion 9.12). When individuals are unable to self-direct care at the end of life, practitioners are encouraged to consult end of life documentation to ensure patient wishes are respected. To address issues with traditional forms of documentation, POLST forms have a simple design—promoting clarity and accessibility. However, understanding provider opinion of both old and new end of life documents is important in assessing the documents' utility in ethical clinical decision-making. Therefore, future research attempting to identify provider opinion of end of life documentation should have a special focus on whether healthcare providers believe documentation aids the delivery of ethical care and whether providers view certain forms of documentation as superior conduits for patient-centered decision-making. The study proposed in this paper is a step towards

answering important questions on a regional level by interviewing the creators of Respecting Choices and assessing provider opinion in Central Minnesota—where providers are free to choose from a variety of different documentation methods.

## **Study Proposal**

### ***I. Purpose***

While there exists ample data supporting the use of end of life documentation to guide healthcare providers in ethical clinical decision-making at the end of life, documentation practices are ultimately determined individually by healthcare providers. In Minnesota, organizations like Honoring Choices MN are producing educational material to help patients engage their families and providers in discussions about end of life care planning. Respecting Choices, La Crosse, Wisconsin's version of community directed end of life education, resulted in widespread end of life care planning. La Crosse has a healthcare system dominated by one medical group yet there are a wide variety of medical groups in Central Minnesota. In the absence of a central infrastructure for implementing community-wide end of life planning, the success of Honoring Choices MN is dependent on collective cooperation from healthcare providers. Therefore, it is important to characterize provider attitudes towards end of life care planning in order to determine whether there is a common desire for the widespread use of end of life documentation in Minnesota.

This study is designed to assess whether providers in central Minnesota believe health care directives aid in ethical decision-making at the end of life, and to examine the clinical utility of these documents with reference to the often-opposing ethical, medical, and legal challenges presented to health care providers while determining care at the end of life. In addition, this study

will explore how Gunderson's Respecting Choices paradigm upholds ethical decision-making at the end of life, as it respects patient autonomy.

## ***II. Methodology***

To assess whether providers in central Minnesota believe health care directives aid in ethical decision-making at the end of life, I have created an online survey instrument (Appendix A) for healthcare providers in central Minnesota.

Health care providers (MD, DO, NP, PA, CRNA, CNS) in Central Minnesota are eligible to participate in the survey and will be identified from publicly listed electronic contact information. Participants will be contacted via email with a link to the survey instrument, which is attached in Appendix A.

Additionally, I propose interviewing the creators of Respecting Choices at Gunderson Health Care System in La Crosse, WI, who have successfully engaged 94% of their patient population in some form of end of life documentation (Appendix B). Interviews will be semi-structured and conducted in person (for questions, see Appendix B). Individuals who are currently employed at Gunderson Health and have either authored or coauthored a manuscript in an academic journal concerned with the design, implementation, and development of the Respecting Choices Program<sup>®</sup> will be solicited for an interview.

Survey responses will be numerically sorted from Likert-type questions. A regression analysis using statistical software will be performed on the data garnered from the online provider survey to identify broad trends for multiple variables. Correlational analysis will be performed to further characterize trends. Interviews will be transcribed and thematically coded. Provider and interview responses will be used to determine if

providers believe healthcare directives assist in ethical decision-making and if healthcare providers view a certain form of end of life documentation as superior.

The College of St. Benedict and St. John's University Institutional Review Board approved this study in late summer 2015. See Appendix C for informed consent procedures.



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## Appendix A Provider Survey



### Ethical Documentation at the End of Life (2.0)

Please answer the following background information I-VI

**I. In the state of Minnesota, I am a licensed: (please select one)**

- Medical Doctor (M.D.)
- Doctor of Nursing Practice (D.N.P.)
- Doctor of Osteopathy (D.O.)
- Doctor of Nurse Anesthesia Practice (D.N.A.P.)
- Physician Assistant (P.A.)
- Clinical Nurse Specialist (C.N.S.)
- Nurse Practitioner (N.P.)
- Other

**II. I practice: (please select one)**

--select---

**III. I identify with the following sex/gender:**

--select--

**IV. I have served as a medical provider for: (please select one)**

--select--

**V. Of the following end of life documentation forms, I am familiar with: (you may select more than one)**

- Advanced Care Directive (AD)
- Physician Orders for Life Sustaining Treatment (POLST)
- Living will
- MN Health Directive (MN Statute 145C)
- None of these

**VI. Of the following end of life documentation forms, I prefer: (please select one)**

- Advanced Care Directive (AD)
- Physician Orders for Life Sustaining Treatment (POLST)
- Living will
- MN Health Directive (MN Statute 145C)
- I have no preference
- I prefer another form of documentation

Please select the "Next" button to begin the survey.

Next >>

Page 1 of 2



## Ethical Documentation at the End of Life (2.0)

### 15 Item Survey

For questions 1-10, indicate your agreement with the statement by selecting a value. If the statement does not apply to your practice, please select N/A.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A
1. It is important that I talk with my patient's about creating health care directives.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I frequently make decisions concerning patient welfare at the end of life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Discussion of a health care directive would produce a more collaborative relationship between me and my patient.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. When determining a course of care for a patient at the end of life, I ultimately respect the family's decision.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. In a catastrophic situation, I would have greater confidence in my treatment decisions if guided by a health care directive.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Health care directives represent an unwarranted extension of the law into the practice of medicine.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. A health care directive would reduce family discord over decisions to withhold treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I would worry less about legal consequences of limiting treatment if I were following a health care directive.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. In the event of an acute medical emergency, I could easily find a patients' health care directive.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. I do not have time during clinical visits to complete a health care directive with a patient.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. My religious beliefs influence the course of treatment I propose for my patient's at the end of life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. The training and experience of providers gives them greater authority than patients in decisions about withholding "heroic" treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Discussion of a health care directive would produce a more adversarial relationship	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

between me and my patient.

14. Health care directives facilitate ethical decision making at the end of life.



15. I would be hesitant to follow a health care directive aged more than:

16. Which of the following influences your decisions MOST in providing end of life care for a patient unable to make decisions. (please select one)

If you wish to provide further feedback, please feel free to do so in the text box below. (optional)

<< Previous

Submit

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## **Appendix B**

*The following is a list of potential questions for interviews with the creators of Respecting Choices at Gunderson Health Systems.*

### **General**

What individuals of the allied health team are best suited to fill out AD's with patients?

An unparalleled 98% of people in La Crosse have some form of health care directive. Why do you believe the community was so receptive to the program?

What was the initial response of Gunderson providers to Respecting Choices? How has provider opinion changed with the program's evolution?

What is a critical factor in the successful integration of Respecting Choices into a healthcare organization?

Part of your model involves reaching out to the community (e.g. interfaith leaders, social clubs, etc.) Why did you move the discussion outside a clinical setting?

I understand individuals connected with Respecting Choices have pushed both lawmakers and private industry to compensate physicians for completing healthcare directives with patients. How important is provider reimbursement for healthcare directive discussion going forward?

### **Ethics**

What is the role of family in determining care at the end of life?

Have you encountered an instance where a provider's personal values are in disagreement with the course of treatment outlined in a patient's health care directive? How was it resolved?

Do providers have an ethical obligation to ensure their patients have some type of end of life documentation? Why/why not?

How do health care directives enable providers to make ethical decisions at the end of life?

### **Cultural Considerations**

When you created Respecting Choices, how important was it to create a document that was accessible to individuals of varying language comprehension?

Expectations for who determines care at the end of life can vary by culture. How can this be addressed through end of life care planning?

### **Legal Considerations**

Should providers feel health care directives extend them a certain degree of legal protection? Why/why not?

### **Comparative**

When considering the clinical utility of an ideal end of life planning document, which of the following is a top consideration (e.g. time spent in clinic to fill out the document, Lexile score, thoroughness, etc.)



## **Appendix C**

*Electronic informed consent introduced to survey participants prior to entering survey and informed consent document presented before conducting interviews concerning the Respecting Choices Program at Gunderson Health Systems.*

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### **COLLEGE OF ST. BENEDICT/ST. JOHN'S UNIVERSITY**

#### **Ethical Documentation at the End of Life**

##### **INTRODUCTION**

You are invited to be in a research study about provider opinion on ethical documentation at the end of life. This study is being conducted by: James Pathoulas (Student, St. John's University) and Jennifer Kramer, Ph.D.(Associate Professor, College of St. Benedict/St. John's University) You were selected as a possible participant, as you are a certified healthcare provider practicing in central Minnesota. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

##### **BACKGROUND and PROCEDURES**

The purpose of this study is to determine provider opinion concerning the: ethics, clinical utility, and legal/professional implications of health care directives. If you agree to be in this study, we would ask you to complete an anonymous survey that would take ten to fifteen minutes to complete.

##### **RISKS/BENEFITS**

This study has no known risks. There are no direct benefits to you from participating in this study. While your participation in this research may not benefit you personally, it will help us better understand provider opinion of health care directives including the barriers providers face in determining care at the end of life.

##### **CONFIDENTIALITY**

Data is collected anonymously using a computer program called Forms Manager. No names, e-mail addresses, or computer IP addresses, will be captured when you submit your completed survey. The records of this study will be kept private. Research records will be kept in a password secure document. Only the researchers will have access to the records. In any reports or public presentations, no information will be included that would make it possible to identify participants.

##### **VOLUNTARY NATURE OF THE STUDY**

Your participation in this research study is completely voluntary. You may stop participating at any time by closing your browser window without penalty or costs of any kind. Your decision whether or not to participate will not affect your current or future relations with the College of Saint Benedict or Saint John's University.

**CONTACTS AND QUESTIONS**

The researchers conducting this study are James Pathoulas and Jennifer Kramer, Ph.D. If you have questions, you may contact James Pathoulas and/or Jennifer Kramer, Ph.D., at [jtpathoulas@csbsju.edu](mailto:jtpathoulas@csbsju.edu) or [jskramer@csbsju.edu](mailto:jskramer@csbsju.edu), respectively. If you have additional questions you may also contact the CSB/SJU Institutional Review board chair, Robert Kachelski, Ph.D.: [irb@csbsju.edu](mailto:irb@csbsju.edu).

You may select “print screen” to save this form for your records, if you desire.

**STATEMENT OF CONSENT**

- I have read the above information.
- I have asked any questions I had and have received answers.
- I consent to participate in the research. I certify that I am a licensed health care provider (MD, DO, PA, DNP, NP) in the state of Minnesota
- By selecting “yes” and then submitting to enter the survey, I indicate my willingness to voluntarily take part in the study.

YES

<SUBMIT>

**COLLEGE OF ST. BENEDICT/ST. JOHN'S UNIVERSITY****Ethical Documentation at the End of Life****INTRODUCTION**

You are invited to be in a research study about provider opinion on ethical documentation at the end of life. This study is being conducted by: James Pathoulas (Student, St. John's University) and Jennifer Kramer, Ph.D. (Associate Professor, College of St. Benedict/St. John's University) You were selected as a possible participant, as you have authored or coauthored a publication concerning the Respecting Choices Program through Gunderson Health Systems and are a current employee of Gunderson Health Systems. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

**BACKGROUND and PROCEDURES**

The purpose of this study is to determine provider opinion concerning the: ethics, clinical utility, and legal/professional implications of health care directives. If you agree to be in this study, we would ask you consent to participate in an interview discussing the Respecting Choices Program. This interview will be conducted in person in La Crosse, WI and will be audio recorded. Broadly, questions will examine general information, ethics, uniqueness, and cultural considerations concerning the Respecting Choices Program. Following the interview, you will be provided with a transcript and are invited to redact any responses you so choose.

**RISKS/BENEFITS**

The study has one risk in that your responses are not confidential as you are being asked join this study due to your national reputation with Respecting Choices. However, participation may result in unforeseen complications affecting your professional reputation. To minimize the likelihood of this occurring, you will be given a transcript of this interview and are free to redact any response you wish. Benefits of participation include promotion of the Respecting Choices Program while contributing to a better understanding of how end of life documentation programs can be successfully executed and maintained.

**CONFIDENTIALITY**

Names will be collected as part of the study. Identifying information will not be removed from the transcripts once transcripts are codified. However, you will be provided with a transcript of your responses following the interview and are free to redact responses. Research records will be kept in a password-protected document and only the researchers will have access to the records. Audiotapes of the interview will be housed in a password-protected document until transcribed. Upon transcription, the audio recordings will be destroyed. Any publications or presentations of this work will not be confidential and will have your name associated with it.

**VOLUNTARY NATURE OF THE STUDY**

Your participation in this research study is completely voluntary. You may stop participating at any time without penalty or costs of any kind and will receive a transcript of this interview, the content of which you may selectively redact. Your decision whether or not to participate will not affect your current or future relations with the College of Saint Benedict or Saint John’s University.

**CONTACTS AND QUESTIONS**

The researchers conducting this study are James Pathoulas and Jennifer Kramer, Ph.D. If you have questions, you may contact James Pathoulas and/or Jennifer Kramer, Ph.D., at [jtpathoulas@csbsju.edu](mailto:jtpathoulas@csbsju.edu) or [jskramer@csbsju.edu](mailto:jskramer@csbsju.edu), respectively. If you have additional questions you may also contact the CSB/SJU Institutional Review board chair, Robert Kachelski, Ph.D.: [irb@csbsju.edu](mailto:irb@csbsju.edu) .

You will be given a copy of this form to keep for your records.

**STATEMENT OF CONSENT**

- I have read the above information.
- I have asked any questions I had and have received answers.
- I consent to participate in the research, knowing my participation is not confidential due to my nationally recognized involvement with Respecting Choices.

**Signature** \_\_\_\_\_ **Date** \_\_\_\_\_

**Printed name** \_\_\_\_\_