



"Conversation Ready": A Framework for Improving End-of-Life Care

(Second Edition)



AN IHI RESOURCE

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AUTHORS:

Lauge Sokol-Hessner, MD: Associate Director of Inpatient Quality, Beth Israel Deaconess Medical Center

Angela Zambeaux: Director, IHI

Kevin Little, PhD: Principal, Informing Ecological Design, LLC, and IHI Faculty

Lauren Macy: Improvement Advisor, IHI

Kate Lally, MD, FAAHPM: Attending Physician, Dana Farber

Cancer Institute

Kelly McCutcheon Adams, MSW, LICSW: Senior Director, IHI

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For more than 25 years, the Institute for Healthcare Improvement (IHI) has used improvement science to advance and sustain better outcomes in health and health systems across the world. We bring awareness of safety and quality to millions, accelerate learning and the systematic improvement of care, develop solutions to previously intractable challenges, and mobilize health systems, communities, regions, and nations to reduce harm and deaths. We work in collaboration with the growing IHI community to spark bold, inventive ways to improve the health of individuals and populations. We generate optimism, harvest fresh ideas, and support anyone, anywhere who wants to profoundly change health and health care for the better.

The ideas and findings in these white papers represent innovative work by IHI and organizations with whom we collaborate. Our white papers are designed to share the problems IHI is working to address, the ideas we are developing and testing to help organizations make breakthrough improvements, and early results where they exist.

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Executive Summary

The resilience of the human body and spirit, the science of modern health care, and the efforts of health care professionals have resulted in a larger number of patients living with increasingly complex illnesses for longer periods of time. As the number of seriously ill patients has risen, so too has the scrutiny of end-of-life care. Stories about poor end-of-life care have become unfortunately familiar to health care professionals, patients, and families. Beyond its effects on patients, poor end-of-life care can have negative impacts on the bereaved family, the involved health care professionals, and, more broadly, society when such care leads to distrust of the health care system and rising costs.

To address these challenges, the Institute for Healthcare Improvement (IHI) and The Conversation Project launched a public engagement campaign in 2012 to ensure that every person's end-of-life care wishes are expressed and respected. In addition to the public-facing campaign, IHI convened a group of clinical experts to begin to explore what it would mean for the health care system to be "Conversation Ready": prepared to reliably receive, record, and respect patients' end-of-life care wishes.

Respectful end-of-life care is concordant with patients' stated goals, values, and preferences — in other words, honoring what matters most to them at the end of life. Goal-concordant care is pursued through the process of advance care planning (ACP), which strives to both ensure that patients (or their surrogate medical decision makers) understand their diagnosis, prognosis, and treatment options, and health care professionals understand what matters most to their patients. ACP also involves shared decision making to ensure that health care professionals make care recommendations that are sensitive to what matters most to patients, and that patients (or their surrogates) always have the opportunity to make informed care decisions.

This white paper — the product of several years of work with dozens of diverse health care organizations and hundreds of health care professionals — presents IHI's Conversation Ready approach to help health care organizations and clinicians provide respectful end-of-life care that is concordant with patients' stated goals, values, and preferences. The paper is designed to be relevant whether you are a leader in a large hospital, a social worker in the community, a doctor in a clinic, or a palliative care nurse in a skilled nursing facility.

The white paper:

- Defines five interconnected Conversation Ready principles;
- Calls out the consequences of inadequate advance care planning and disrespectful care as forms of preventable harm;
- Guides readers through an in-depth examination of the concepts that underlie the Conversation Ready work and the factors that contribute to unreliable advance care planning;
- Encourages taking a systems perspective to build more reliable processes for advance care planning and providing respectful care at the end of life; and
- Provides recommendations about where and how to begin, including examples of changes other organizations have tried and suggested measures.

Introduction

Ms. Jones has abdominal cancer. Despite her having received cancer care for many months, no one from her health care team has asked about her care-related goals, values, or preferences. When she asks her doctor how serious the cancer is, he replies, "You're not dying from it." Soon after, she gets sick, is admitted to the hospital, and is found to have a malignant bowel obstruction. She is told she needs emergency surgery or that she may die.

Ms. Jones's family requests to see the doctor, but he is unavailable. Instead, one of his colleagues reviews the patient's medical record and speaks with the family, telling them, "This cancer is not curable." This is the first time Ms. Jones and her family have heard this. They are shocked and upset.

Ms. Jones agrees to the surgery but suffers complications and never regains consciousness. After she has lost the capacity to speak for herself, it becomes clear that no one is certain what she would have wanted in a situation like this. She dies in the intensive care unit a few days later. Months pass and Ms. Jones's family still thinks about this daily.

Stories like this one are upsetting, as we imagine the pain and suffering Ms. Jones and her family endured. Perhaps even more concerning is that such stories are familiar to many of us, and that extensive data demonstrate that many aspects of end-of-life care are suboptimal. Regardless of whether physical harm to Ms. Jones could have been prevented despite her advanced incurable malignancy, her care team could have better communicated to ensure she had the opportunity to live out her life in the ways that mattered most to her. Had her care team been aware of her goals, values, and preferences, they may have made different recommendations about her care (for example, a primarily palliative approach rather than emergency surgery). Ms. Jones and her family were unaware that her cancer was not curable; had they known, they might have chosen a different course of care.

What Matters Most

In the context of Conversation Ready, the terminology "what matters most" (WMM) refers to an individual's goals, values, and preferences for end-of-life care. The "what matters" concept was first introduced by Susan Edgman-Levitan and Michael J. Barry, who encouraged health care professionals to ask their patients, "What matters to you?" in addition to "What is the matter?" 2

History and Evolution of Conversation Ready

In 2012, in partnership with IHI, The Conversation Project launched a public engagement initiative to ensure that every person's wishes for end-of-life care are expressed and respected. Through awareness-building campaigns, free and simple resources, as well as community engagement, The Conversation Project strives to normalize and facilitate conversations about end-of-life care.

During the early months of The Conversation Project, an important question arose: When the initiative is successful and people begin to express their end-of-life care wishes reliably and openly, what do health care systems need to do to be ready to respect those wishes — to receive an

activated and engaged public? To explore this question and begin to define what a health care system needs to do to become "Conversation Ready," IHI convened a group of innovative health care organizations later that year, aptly named the Pioneer Sponsors. Whereas The Conversation Project works with the public — with individuals, communities, employers, financial planners, and faith communities — the Conversation Ready initiative works with health care organizations and health care professionals across the continuum of care.

Conversation Ready Pioneer Sponsors

- Beth Israel Deaconess Medical Center (Massachusetts)
- Care New England Health System (Rhode Island)
- Contra Costa Regional Medical Center (California)
- Henry Ford Health System (Michigan)
- Mercy Health (Ohio)

- North Shore–Long Island Jewish Health System (New York)
- Qulturum, Jönköping County Council (Sweden)
- St. Charles Health System (Oregon)
- UPMC (Pennsylvania)
- Virginia Mason Medical Center (Washington)

Contributing Sponsor

· Gundersen Health System (Wisconsin)

When the Conversation Ready initiative began in 2012, IHI recognized that in addition to the excellent work in this field by many colleagues, there remained opportunities to support a broad range of health care organizations — especially beyond acute care settings — that care for diverse patients and communities. There was also an opportunity to focus more deeply on those who experience health care inequities.

IHI sought to apply a systems-thinking approach and use improvement science methods to achieve the Conversation Ready goals. This initial work led to the publication in 2015 of the IHI White Paper, "Conversation Ready": A Framework for Improving End-of-Life Care.³ The paper described the work of the Pioneer Sponsors in 2012 and 2013 and the initial Conversation Ready Collaborative in 2014, and laid out five principles — Engage, Steward, Respect, Exemplify, and Connect — to guide organizations' work to become Conversation Ready.

These five principles formed the core of IHI programs that reached hundreds of health care professionals in 2015 and 2016. In April 2015, IHI offered an in-person training followed by virtual trainings in June and November 2017, as well as national presentations in 2016, 2017, and 2018. In addition, IHI conducted two Conversation Ready Breakthrough Series Collaboratives⁴ concurrently with public engagement campaigns, both of which involved several in-person Learning Sessions and monthly reporting of data and learning:

- The Speak(easy) Howard County Conversation Ready Collaborative (2016–2017) in Maryland, funded by the Horizon Foundation, engaged both health care organizations and faith communities. This Collaborative helped expand our thinking beyond acute care settings.
- The Conversation Ready Massachusetts Collaborative (2017–2018), funded by the Gordon and Betty Moore Foundation, engaged teams from across the state and across the spectrum of health care organizations. This Collaborative furthered the learning beyond acute care

settings and helped us delve deeper into the Connect principle through the identification of multiple change ideas and associated tests.

The work to date has revealed several key lessons, which are explored in more detail in this paper:

- Sharing real-life examples storytelling, as with Ms. Jones's case is a powerful way to continually ground individuals, teams, and organizations, making the work tangible and actionable. Stories can be at the level of the individual, the patient-provider interaction, and the health care teams and organizations as they experience change and challenges.
- The failure to respect patients' wishes regarding end-of-life care can lead to harm including
 emotional, psychological, socio-behavioral, and financial harm meaning that poor end-oflife care is a safety issue.
- What matters most to patients at the end of life should be reliably respected, no matter their health status. The Conversation Ready work focuses on individuals with serious illness those with an increased risk of mortality whose illnesses cause them to suffer negative impacts on their function or quality of life, and/or significantly burden their caregivers because 1) the stakes are higher with such patients, 2) the consensus about the need for action with such populations is broader, and 3) it is important to be strategic when encouraging resource-limited health care organizations and strained health care professionals to change.
- For a health care organization to become Conversation Ready, it should consider the work
 from two perspectives: 1) system-level design, such as electronic health record functionality
 and the concept of population health management; and 2) individual patient-professional
 interactions. This paper contains guidance on how to approach improvement from both
 perspectives.
- The Conversation Ready principles help organizations conceptualize key aspects of the work; they are useful when considering how to approach individual patient-professional interactions, as well as when developing systems designed to better support advance care planning.
- Each health care organization benefits significantly from developing its own internal capacity for improvement, and changes are more likely to be effective and sustainable if they are locally designed or adapted.

Advance Care Planning

Although there are many components to optimal end-of-life care — including symptom management, psychosocial support, help with the logistics of care transitions across the continuum, and bereavement support after a loss — one of the most complex components is ensuring that care is respectful. Respectful end-of-life care is pursued through the process of advance care planning (ACP).

Advance care planning is defined as "a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals, and preferences during serious and chronic illness."⁵

Fundamentally, advance care planning is about honoring patients' right to decide what care they receive, also known as patient self-determination. The optimal advance care planning process will

vary depending on the needs and contexts of the patient, his or her family, the health care team, and the system in which they work. Importantly, the process is often iterative and recursive, reflecting both its complex nature and the fact that patients' conditions and what matters most to them at the end of life may change over time.

ACP includes several key components:6

- Identifying a surrogate medical decision maker;
- Sharing difficult news, such as a new diagnosis or a serious prognosis;
- Understanding "what matters most" in the context of the patient's life (which can also be conceptualized as "data about the patient as a person");
- Discussing treatment options, including palliative care and hospice;
- Anticipating medical emergencies (including cardiac arrest, respiratory failure, etc.);
- Communication and coordination among the patient, family, surrogate medical decision maker, and any involved health care professionals; and
- The use of a shared decision-making process that draws on all of the above components to ensure that, when appropriate, the health care team makes an informed recommendation about which plan of care is most aligned with the patient's wishes, and that there is always an opportunity for questions and discussion, allowing all parties to feel confident that informed decisions are being made and that the patient's wishes are being respected. Shared decision making helps avoid the undesirable extremes of paternalism (when health care professionals make decisions without input from patients or families) and unguided autonomy (when patients or families make decisions without input from health care professionals).

When properly conducted, ACP has considerable benefits: better quality of life, care that is more consistent with patient preferences, and improved bereavement outcomes for the family. Importantly, for those who fear that having end-of-life care conversations will take away hope, the preponderance of evidence indicates that people experience no increased depression, anxiety, or hopelessness as a result of such conversations. Even if attempts to engage patients in the ACP process do not always lead to specific decisions, they may be an important way of building trust and relationships among patients, families, and health care professionals, and may also be helpful for making future decisions. ACP is thus recommended for all patients with serious illness.⁷

Preventable Harm Resulting from Disrespectful End-of-Life Care

Unfortunately, when ACP is absent, inadequate, or improperly performed, it can lead to care that is not concordant with a patient's goals, values, and preferences — in other words, disrespectful care. In such situations, patients can suffer significant, preventable physical and non-physical harm. Physical harm — such as organ damage or physical injury — can occur naturally as a result of serious illness itself, sometimes even when the best available treatments are provided.

But *preventable* physical harm can occur if a patient's care is not aligned with what they would have wanted to receive. For instance, if a patient chooses to pursue a course of treatment but does not understand that it involves a high risk of harm and a low risk of benefit — and, had they known that, they would not have chosen to pursue the treatment — they may suffer needless physical harm from the treatment, such as a prolonged length of stay in the hospital and physical debilitation.

Beyond physical harm, there is increasing recognition of the prevalence and importance of *non-physical* harm, including emotional, psychological, socio-behavioral, and financial harm. As with physical harm, non-physical harm can occur naturally as a result of serious illness itself, but *preventable* non-physical harm can occur if patients are not treated the way that they would want.

For example, the patient who suffered a prolonged length of stay in the hospital and physical debilitation may be angry they were not better informed about the risks; they may suffer worsened anxiety and depression along with their physical ailments; they may be distrustful of (and wary of returning to) the professional and/or hospital where the harms occurred; and they may incur additional cost as a result of their prolonged hospital stay and debilitation. In situations like these, the harms are not just a result of the medical treatments themselves; they're also a result of the disrespectful interaction between the health care system and the patient: the failure to ask the patient about what mattered most to them and to ensure they had the opportunity to make an informed decision.

The concept that disrespect experienced by patients and families in the course of health care can lead to non-physical harm has been the subject of recent work, including at Beth Israel Deaconess Medical Center, a Conversation Ready Pioneer Sponsor. ^{8,9,10} Disrespect can take many forms, including when care does not accord with patients' stated wishes. ⁸ The prevalence of disrespect is not well defined, but non-physical harm appears to be even more prevalent among the seriously ill than in the general population. ¹⁰ The degree to which such effects are attributable to low-quality care or disrespectful interactions with the health care system — versus the serious illnesses themselves or the patients' medical treatments — is unclear and represents an important area for future research.

In the context of serious illness, harm resulting from the illness and its treatments — assuming the treatments are appropriately administered and concordant with the patient's wishes — is not preventable. But harm resulting from substandard or disrespectful care — including inadequate advance care planning — may be preventable. For instance, in the example of Ms. Jones above, we can imagine that because of the lack of prognostic awareness — which is a reflection of inadequate advance care planning and is fundamentally disrespectful inasmuch as it represents a withholding of known information — the family might suffer non-physical harm. They may feel guilty for not having asked more questions earlier in the course of care, or they may lament the lost opportunity to talk about what mattered most to her at the end of life, possibly choosing a different course of care such as hospice at home.

In addition to the harm suffered by the patient and family, health care professionals may experience moral distress when advance care planning is absent. The emotional and ethical challenges of caring for seriously ill patients can be exacerbated in cases when what matters most to a patient is not known or documented. In some cases, if a patient's wishes are documented but not known to their surrogate medical decision maker, the care team may still experience moral distress if they must choose between respecting a patient's documented wishes and the wishes of the surrogate decision maker.

Becoming Conversation Ready: Taking a Systems Perspective

While many recognize the need to improve the way health care systems guide patients and families through serious illness, reduce episodes of harm, and ensure individuals' end-of-life care wishes are respected, this is not simple to do. Although the vast majority of patients develop a serious illness prior to their death, such as organ failure, a terminal illness, or frailty, rather than dying

suddenly without a preceding serious illness, few organizations routinely or systematically identify such patients. ¹³ Most health care organizations do not have adequate systems in place to reliably support advance care planning for patients, particularly those with serious illness, much less improve it.

Health care organizations seeking to become Conversation Ready often face several system-level challenges.

- Many health care organizations have little to no familiarity with, or infrastructure for, advance care planning. Numerous barriers to ACP exist, including a lack of the necessary knowledge, attitudes, and skills on the part of health care professionals, patients, and their families to feel comfortable with discussing serious illnesses and preferences about end-of-life care; a perceived lack of time to have such conversations; inadequate health information systems for managing the ACP process; poor coordination among members of the health care team; and poorly developed or non-existent feedback loops to drive iterative improvement. 14,15,16,17,18
- Transitions in care often introduce risks of discontinuity to patients with serious illness, especially those who are near the end of life. Such patients may receive care in an outpatient clinic, inpatient settings (including emergency departments, medical floors, or intensive care units), rehabilitation or nursing facilities, or in their homes. Even within the same health system, information about patients' illnesses, treatments, and end-of-life care wishes may not reliably accompany them as they transition between various care settings. This discontinuity may contribute to harm.
- Defining "error" and "harm" with respect to end-of-life care may vary depending on what matters most to each patient. One of the most unique aspects of end-of-life care is that, for some patients, the ultimate goal may be to allow death rather than prevent it. This is in contrast to most other situations in health care where we strive to prevent death. In the context of serious illness, what is considered an error depends entirely upon a patient's goals, values, and preferences at the end of life. In some situations, failing to attempt to sustain life is an error, 19 whereas in others, attempting to sustain life is an error. The prevalence of such errors is difficult to determine, 21 but may be significant. 22,23 Such errors may be perceived as examples of disrespect: failures to respect patients' goals, values, or preferences.

To avoid such errors and the subsequent harms, rather than striving to prevent death as the default goal, health care must focus on identifying and respecting patients' wishes in an iterative fashion so that care is provided in accordance with what matters most to each patient. For many health care organizations, this shift in perspective is a prerequisite to the recognition of preventable non-physical harm, and as such may need to be part of their system-level work.

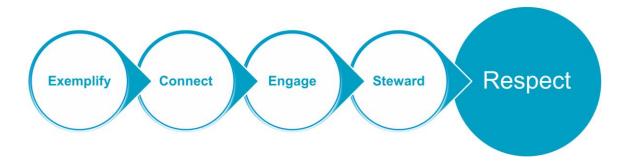
Despite the many challenges, improvements are possible. Adopting a systems perspective is critical. Health care organizations that objectively scrutinize their own performance will likely find that while some patients are receiving optimal advance care planning, others are not. Such variation fundamentally represents unreliable care processes: groups of related actions performed to fulfill patient and family care needs that are poorly designed, organized, or executed.

Conversation Ready Vision and Principles

IHI's vision of high reliability for the process of advance care planning can be conceptualized as health care organizations striving to become "Conversation Ready": ready to reliably guide all patients and families throughout the context of serious illness to ensure that their wishes for end-of-life care are respected.

Four core principles form the foundation of a Conversation Ready health system, all leading to the fifth and most important principle: Respect for what matters most to each individual at the end of life (see Figure 1). Taken together, the Conversation Ready principles lay out a practical, sequential framework to approach many different aspects of advance care planning.

Figure 1. Conversation Ready Principles



Exemplify

Health care professionals who practice and model the behaviors they are encouraging their patients and families to undertake — such as having conversations about what matters most to them at the end of life with their own selected surrogate medical decision maker — are more likely to appreciate the importance of and difficulty inherent in those activities. They may thereby more effectively encourage their patients and families to do the same. Exemplify also has important linkages to Connect (see below), as the lifelong process of personal reflection and examination of our biases can be powerful ways to develop cultural curiosity and humility.

Connect

Appreciating the context of patients' lives (and that of their loved ones) — recognizing that socioeconomic status, racial identity, religion, ethnic heritage, educational history, primary language, cultural background, sexual orientation, gender identity, and many other factors shape perspectives and interactions — and attending to one's own biases are critical prerequisites to building trust. Without this foundation, it is difficult or impossible to understand and support patient and family decisions or behaviors. Health care professionals who have exemplified the work may be better able to develop awareness of their own biases.

By acknowledging and managing their own discomfort with having conversations about end-of-life care, health care professionals may find they are able to more effectively connect with patients and their families. Cultural perspectives on death are powerful factors in any interaction about end-of-life care and ignoring them impairs clinicians' ability to respect what matters most to each patient.

The Potential Impact of Bias on End-of-Life Care

Health care professionals' own beliefs and biases about death, about what constitutes quality of life, and about the role of autonomy in decision making can alter how clinicians talk about patients' medical conditions and treatment options. Although the term "bias" is often assumed to have a negative connotation, biases can also be positive. Furthermore, all of us have biases; some bias is a normal part of being human. The key is to recognize our biases — especially those that are implicit or automatic — and reflect on whether they are constructive or destructive. Clinicians have a responsibility to ensure that their own biases don't interfere with care and treatment recommendations and that they support patient self-determination. The foundation of the unwritten contract of trust with patients is that clinicians must always focus on what is right for patients.²⁴

Engage

Passive approaches to ACP, such as waiting for patients and families to reach out to discuss goals, values, and preferences or to inquire about treatment options, are inadequate. Just as health care professionals are not passive about addressing the topics of smoking cessation, obesity, substance abuse, and safety in their patients' homes, so too are they called on to be proactive about knowing what matters most to their patients at the end of life. Engage is closely interwoven with Steward (see below) because together these two principles create the back-and-forth process by which critical information about end-of-life care wishes is obtained, stored, accessed, and reviewed with patients and families throughout the care continuum.

Steward

Collecting information from patients and families on end-of-life care goals, values, and preferences and then handling that information with reverence — by consistently capturing, storing, maintaining, and retrieving it — is critical to the overall reliability and integrity of the ACP process. The presence and quality of information that can be stewarded depends on the effectiveness and reliability with which patients and families are engaged.

The "allergy analogy" is one way to think about the ideal state for Steward: In today's health care environment, patients are reliably asked if they have any allergies, and their responses are then reliably entered into their electronic health record (EHR) so that this information is available at all future points of care. Additionally, clinicians would not tolerate an allergy field (in the electronic record) simply denoting "Y" for "Yes, this patient has an allergy" with no further information, yet often the extent of information clinicians have about ACP documents such as health care proxies begins and ends with a "Y" or an "N."

Health care professionals have become so accustomed to the reliability of the allergy information documentation process that if a patient's allergy information remained unaddressed in the medical record after the patient received care over a period of time, this would likely be considered a medical error. In a future state, we aspire to have similar reliability in the documentation and availability of ACP information. EHR systems and the associated workflows will likely need to be refined to realize this vision.

Respect

The four previous principles all lead to the fifth and most important: Respect for what matters most to each individual at the end of life. Respectful end-of-life care is concordant with patients' stated goals, values, and preferences for what matters most to them at the end of life.

Conversation Ready Principles in Action

Here are examples of how some health care organizations participating in the Conversation Ready Collaboratives have begun their work.

• Baystate Health, an integrated health care system that serves more than 800,000 people throughout western New England, participated in the 2017–2018 Conversation Ready Massachusetts Collaborative. Their initial aim was to have a documented health care proxy on file in the EHR for 95 percent of the patients in their pilot unit by April 30, 2018. In addition, they aimed to get 50 percent of patients older than age 70 on the same unit with a documented what matters most (WMM) conversation in the EHR. They experienced early success and learned that turnover in nursing staff could negatively affect their ability to continue to improve. By identifying and engaging several clinical champions, they worked to motivate more staff to participate in having WMM conversations and documenting them.

The Baystate team also experienced senior leadership transitions during their time as participants in the Collaborative. But the team was still able to achieve documented improvements because they had developed leadership-related skills in their Conversation Ready champions (so that these champions could lead the work on their own, without requiring senior leaders to do so) and they had made WMM conversations standard practice. They expanded their aim in August 2017 to include documented WMM conversations with individuals seen by their outpatient services. After the conclusion of the Conversation Ready Collaborative, Baystate joined the IHI-led Age-Friendly Health Systems initiative and continue to work toward improving care for all older adults. As a result of their focus on improvement, Baystate increased the number of documented goals-of-care conversations, reduced readmissions, and realized a cost savings.

- Winter Growth is a community-based provider of services for older adults and an assisted living facility in Howard County, Maryland. As a participant in the Speak(easy) Howard Collaborative in 2016–2017, they sought to have completed WMM questionnaires with 100 percent of their cognitively capable patients by July 2017. In December 2016, they had engaged 100 percent of their population to have a discussion about choosing a health care proxy. Once they achieved this goal, the team sought to make changes to their workflow to have conversations with each incoming resident about their end-of-life care wishes and choosing a health care proxy.
- Boston Senior Home Care, also a participant in the Massachusetts Collaborative, wanted to engage Chinese-speaking elders in end-of-life care discussions. In order to better understand the cultural factors for these patients, they partnered with the Chinese American Coalition for Compassionate Care. The Coalition provided training and guidance to help the Boston Senior Home Care team begin to engage their patients. A key focus was on finding an appropriate interpretation of the WMM concept in order to have clear and respectful conversations with Chinese-speaking elders in the Boston Senior Home Care housing complexes.

Conversation Ready Change Ideas

Below we demonstrate how the Conversation Ready principles can work together to promote improvement of two key aspects of advance care planning — selecting a surrogate medical decision maker and eliciting what matters most at the end of life — using some specific examples of changes tested and associated measures. The examples reflect specific change ideas for the Conversation Ready principles that health care organizations participating in the Collaboratives developed and tested.

To date, change ideas for Exemplify, Engage, and Steward have been the focus of the most testing, learning, and measurement. Organizations have been exploring how to develop and test change ideas related to the principles of Connect and Respect, including early tests using the Respect Measurement Tool (see Appendix B) to prompt learning conversations for provider teams.

IHI encourages other health system teams to test these change ideas in their own organizations to see if they result in improvements, and to develop their own ideas.

Select a Surrogate Medical Decision Maker			
Conversation Ready Principle and Rationale	Changes Ideas and Organizations That Tested Them	Measures to Consider	
Exemplify Encourage staff who will be helping patients identify a surrogate medical decision maker to do so for themselves, so they can learn what is involved in the process.	 Create a video of staff describing the importance of appointing a health care proxy and talking about their end-of-life care wishes — University of Kansas Hold a "Take Your Health Care Proxy to Dinner" raffle where staff who bring in their proxy forms are entered in a drawing for dinner at a local restaurant — Erie County Medical Center Through an interactive large group format, teach all internal medicine residents about the importance of a health care proxy and coach them through completing their own (if they so choose) — Beth Israel Deaconess Medical Center Incorporate into new staff orientation a staff training on how and why to have their own conversations — Brockton Visiting Nurses Association, Inc. 	Percent of staff who participate in the session/training Percent of staff who have identified a health care proxy	
Connect Encourage staff to explore what might be challenging for some patients when selecting a surrogate, and make recommendations about how they might most effectively connect and build trust with their patients.	 Train interpreters to be prepared for advance care planning conversations with patients — Contra Costa Regional Medical Center Host a cultural competency speaker to help inform staff and facilitate discussions around how different cultures may identify a surrogate — Brockton Visiting Nurses Association, Inc. Engage experts in the field, such as the Chinese American Coalition for Compassionate Care — Boston Senior Home Care 	Percent of staff who participate in such sessions Comfort level of patients in having these conversations	
Engage Identify which patients should be engaged in identifying a surrogate (i.e., the subpopulation, see Measures column), including when and where. Coach the involved health care professionals on how to engage patients (e.g., suggest what words they might use).	 Include Honoring Choices Massachusetts "Who's Your Agent?" Program Toolkit in patient admission packets and patient waiting areas — Lahey Clinic Use case managers and nurses who are working in the community (elder services agency) to ask about and document proxy information — Elder Services of Merrimack Valley Design and implement an interdisciplinary process in a primary care clinic to encourage all patients to identify a health care proxy and complete a proxy form — Beth Israel Deaconess Medical Center 	Percent of patients in the subpopulation who are asked if they have identified a health care proxy Percent of patients in the subpopulation without an identified health care proxy who are then engaged in a conversation with a health care professional to identify a proxy	
Steward Identify what information about surrogate medical decision makers will be stewarded, as well as when, where, and how; then coach the involved health care professionals.	 Train unit secretaries to scan advance directives into EPIC in such a way that they are easily located by other health care professionals — Penn Medicine Build scanning of completed health care proxy forms into the interdisciplinary workflow that creates them — Beth Israel Deaconess Medical Center Call patients individually who indicated having a health care proxy at the time of admission but could not provide the completed form — Brockton Visiting Nurses Association, Inc. 	Percent of patients with health care proxy documented in the electronic health record	

Elicit What Matters Most (WMM) at the End of Life for Each Patient ²⁵			
Conversation Ready Principle and Rationale	Changes Ideas and Organizations That Tested Them	Measures to Consider	
Exemplify Encourage the staff who will be engaging patients in conversations about what matters most (WMM) at the end of life to plan their own WMM conversation with their family, to better understand what having such discussions is like.	 Include a wellness incentive to watch advance care planning video for health spending account contribution — Providence Health System Host a "Day of Conversation" event annually — University of Pittsburgh Medical Center Review The Conversation Project Starter Kit²⁶ materials at staff orientation — Erie County Medical Center Host provider workshops with showings of "Being Mortal" — St. Jude Medical Center 	Percent of staff who participate in such sessions Percent of staff who indicate having had a WMM conversation with their family	
Connect Encourage health care professionals to explore the benefits and challenges of talking about what matters most (WMM) with their patients, and how they might most effectively connect and build trust with their patients around the topic.	 Host multi-pronged symposia, panels, and workshops for faith leaders in the community and two-way training between clergy and clinicians to learn about faith traditions and medical care at the end of life — Henry Ford Health System Tailor advance care planning outreach to underserved and underrepresented populations — Henry Ford Health System Host "Lunch and Learn" sessions with local clergy to promote community engagement around The Conversation Project Starter Kits and to provide education about palliative care — St. Charles Health System 	Percent of staff who participate in such sessions Comfort level of patients in having these conversations	
Engage Identify which patients should be engaged in what matters most (WMM) conversations (i.e., the subpopulation, see Measures column) as well as when and where that engagement will occur. Coach the involved health care professionals on how to best engage patients in such conversations (e.g., what questions to ask).	 Focus on patients with cancer who are undergoing chemotherapy, or patients with advanced lung disease who are attending a pulmonary rehabilitation class — St. Jude Medical Center Define "seriously ill patients" as those who have a reasonable chance of dying in the next 12 months, using a variety of methods, for example: surprise question²⁷ (e.g., would you be surprised if this patient died within the next 12 months?), clinical criteria (e.g., metastatic solid organ cancer), or high scores on mortality models (such as Levine Score²⁸ = 42% and Gagne Score²⁹ = 47%) Create new workflows in the inpatient palliative care department to engage patients in the subpopulation that need a life care planning conversation — Kaiser Permanente San Jose Medical Center Integrate the Conversation Nurse³⁰ as part of inpatient palliative care team to have conversations with patients, or use home care admissions nurses to have goals-of-care conversations, or develop role play to train accountable care organization (ACO) nurse care managers to have goals-of-care conversations — Care New England Use Senior Emergency Room Care Coordinator to proactively talk with elders in the emergency department about end-of-life care wishes — Winter Park Memorial Hospital 	Percent of patients in the subpopulation who are asked if they have articulated WMM Percent of patients in the subpopulation without WMM articulated who were engaged in a conversation by a health care professional to articulate WMM Percent of staff who indicate they are confident in having WMM conversations with patients	

Elicit What Matters Most (WMM) at the End of Life for Each Patient ²⁵						
Conversation Ready Principle and Rationale	Conversation Ready Principle and Rationale Changes Ideas and Organizations That Tested Them Measures to Consider					
	 Have staff person who is getting the patient settled into the inpatient room ask whether the patient has an advance directive and collects that information; escalates: to an advance care planning volunteer for longer conversation if interested, to a nurse/case manager if complex illness or new diagnosis, to provider if life-limiting illness — Presbyterian Healthcare Systems Develop role plays and educational materials for staff to practice with colleagues and receive feedback before engaging patients — Milford Regional Medical Center 					
Steward Identify what information about what matters most (WMM) will be stewarded, as well as when, where, and how; then coach the health care professionals who will be involved in that work.	 Change the Nursing Admission Assessment Form to capture advance directive information — St. Peter's Health Partners and Ellis Medicine Make advance directive question a mandatory field in the electronic health record — Reid Medical Center Establish one place in the electronic health record (EHR) where information is kept: the Advance Directive Note Type — Virginia Mason Medical Center Work with IT to develop new advance directive field in home care medical record — Care New England Train unit secretaries to scan advance directives into the EHR in such a way that they are easily located by other health care professionals — Penn Medicine Streamline organization of EHR so that goals-of-care information is available two clicks from landing page rather than four — University of Kansas Medical Center Create Advance Care Planning Summary form that goes through "information reconciliation" process (like medication reconciliation) — NHS Lothian, Scottish Government Health Department Share patient stories from the last month during the team meeting to highlight the importance of documenting WMM — Broad Reach Hospice and Palliative Care 	Percent of patients with WMM documented in the electronic health record				

Getting Started with Conversation Ready

Conduct a Death Chart Review

One way for organizations to learn about their ACP systems and thereby better focus their improvement efforts is to conduct a Death Chart Review, to collect baseline data and gain an understanding of what percentage of patients had documentation of 1) their health care proxy (surrogate medical decision maker) and 2) what matters most to them regarding end-of-life care.

First, it is important to identify which patients will be the focus of the review, for instance, those who die in an emergency department, or on an inpatient unit, or at home. Then, the Death Chart Review includes identifying the following items for each of the last 10 to 20 patients who died in that care setting:

- The circumstances of the death (e.g., traumatic, sudden, prolonged, expected) and the presence of any serious illnesses (e.g., cancer, dementia, heart failure)
- Documentation of legally authorized surrogate medical decision maker (e.g., durable power of attorney for health care, health care proxy)
- Evidence of other advance directives (e.g., living wills) and whether or not they could be accessed and understood
- Documentation of what matters most to the patient at the end of life
- Documentation of provider and patient conversation(s) about end-of-life care wishes (or with surrogate decision maker, if the patient is not able to participate)
- Evidence of POLST-type form(s)

Gathering Death Chart Review information and sharing it with the health care professionals who are involved in ACP processes that support these patients can be extremely powerful and can build will for improvement by identifying areas where the system works reliably and areas where it falls short. However, data collection alone is not sufficient; involving professionals in conversations about the data — sharing, listening, and questioning — provokes deeper learning about the systems within which they work and helps focus initial efforts.

Improve Your ACP System Using the Model for Improvement

Once organizations have an understanding of the current performance of their ACP systems, they can begin to identify opportunities to improve those systems. IHI uses the Model for Improvement to guide and accelerate improvement efforts.³¹ Organizations may choose to use this model or another improvement approach already in use in their health systems.

Below are Conversation Ready examples for the Model for Improvement's three questions.

1. What are we trying to accomplish? (Set an Aim)

Develop an **aim statement** that is time specific, measurable, and defines the specific population of patients that will be affected (how much to improve, by when, and for whom).

It is important to align Conversation Ready improvement efforts with the organization's overall strategic priorities and to have organizational leadership support for the work.

Conversation Ready example:

Home Health VNA and Hospice's Death Chart Review revealed that in early 2017, only 40% of their new patients had a documented surrogate decision maker. After discussion, the organization's project team decided that during the intake process for new patients, 100% of patients (or their families) should have a surrogate medical decision maker (proxy) documented in the medical record.

The team thus developed this **aim statement**: By March 2018, 100% of patients starting with Home Health VNA who live in Massachusetts will have a health care proxy documented in the medical record.

2. How will we know that a change is an improvement? (Establish Measures)

As teams test changes, measures tell them whether the changes are leading to improvement.

- **Process measures:** How well is each part of the system or steps in a workflow performing? These measures can be early indicators of improvement in your outcome.
- Outcome measures: The measures you ultimately want to affect, often linked to the aim.
- Balancing measures: Are changes made to improve the outcome unintentionally impacting other areas in the system?

Conversation Ready example:

The Home Health VNA project team developed the following measures:

- Process:
 - Percent of new Home Health VNA patients who are asked if they have identified a health care proxy
 - Percent of patients who say "Yes" to having a proxy, whose proxy information is then documented in the electronic health record
- Outcome: Percent of patients whose proxy, diagnostic understanding, and WMM are articulated and documented as indicated by the scores on the Respect Measurement Tool (see Appendix B)
- · Balancing: Amount of time to perform intake for a new patient, as reported by the involved staff

3. What change can we make that will result in improvement? (Test Changes)

Once the aim and measures are established, teams generate and prioritize changes to test that they believe could result in improvement. A change idea is a specific, actionable idea that is an actual change to the current process. Test change ideas using small-scale **Plan-Do-Study-Act (PDSA)** cycles. Each new PDSA cycle begins with the learning from the prior cycle.

Conversation Ready example:

The project team tested several changes:

- Exemplify and Connect: The team planned and then conducted an optional, one-hour breakfast session with frontline health care professionals using <u>The Conversation Project Starter Kit and Proxy Kit</u>. The team repeated the breakfast session, inviting more staff members to attend based on interest from staff working in billing, scheduling, external relations, and human resources.
- Engage and Steward: The team used weekly huddles to coach the care team on how to ask patients if they've chosen a proxy, and how to record the answers in the electronic health record. Through iterative PDSA cycles, the team recognized a need to embed some coaching on these topics in the process of new employee onboarding.

See the Conversation Ready Change Ideas section (above) for specific changes tested by health care organizations participating in the Conversation Ready Collaboratives. See Appendix A for suggested Conversation Ready Measures and Appendix B on Measuring Respect.

Conclusion

The continued learning over six years of work has driven not only the growth of the Conversation Ready content, such as developing specific change ideas and measures, but also a deeper understanding of disrespect and non-physical harm. In addition, in partnership with hundreds of health care professionals engaged in this work, IHI has gained a better understanding of the ways in which the Conversation Ready principles (Exemplify, Connect, Engage, Steward, and Respect) work together to make the care of patients with serious illness and near the end of life more respectful.

While much progress has been made, much work remains:

- Most testing has occurred with the Exemplify, Engage, and Steward principles, less so with Connect and Respect. This has been partly strategic: many organizations discovered their organizations had little to no familiarity with, or infrastructure for, ACP, so Exemplify, Engage, and Steward felt like natural starting places. We encourage organizations to take on the complex topic of Connect as their approaches to the concepts of unconscious bias and health care equity evolve.
- Assessing the outcome of Respect is challenging, but critical to this work. The Respect Measurement Tool (see Appendix B) requires more development and testing, but has demonstrated promise and may promote more productive conversations between care teams and families about the patient's experience.
- Most of the Conversation Ready work to date has focused on increasing the proportion of
 patients who have chosen a surrogate medical decision maker (proxy) and/or expressed what
 matters most to them at the end of life. While these are foundational places to start, many
 other components of ACP need exploration and testing.

For many health care organizations, the vision of high reliability of advance care planning — becoming Conversation Ready — may seem daunting. Indeed, providing reliably respectful care to patients with serious illness and near the end of life is among the most complex challenges in modern health care. Yet, every organization will be able to find opportunities for improvement and can begin, one change at a time. Each test of change (including those that fail), however small, helps improve a health care organization's culture with regard to end-of-life care. We invite and encourage others to join us in the quest to become Conversation Ready.

Appendix A: Conversation Ready Measures

This appendix includes suggested measures for three of the Conversation Ready principles: Exemplify, Engage, and Steward. (There are no suggested measures for Connect because this work is primarily at an exploratory stage. See Appendix B for suggested measures for Respect.) IHI recommends that organizations begin their Conversation Ready work by first selecting a smaller subpopulation of individuals for whom there is no disagreement about the need to better align patient and family wishes for end-of-life care with the care actually delivered.

A Caution about Measures

With regard to end-of-life care, be particularly careful when considering measures about document completion (such as POLST forms), outcomes such as disposition (e.g., discharge to home versus hospice), and cost. Some patients may not be ready to transition to hospice when it is first mentioned as an option, and if clinicians push them to do so — because the measure of success is the percentage of patients discharged to hospice — we may injure patient trust and cause more harm than good.

While it's not wrong to measure the percentage of patients discharged to hospice to learn about current systems, a more nuanced measure focuses on ensuring that a high proportion of the subpopulation of patients who have a life expectancy of less than six months are aware that hospice is an option, and that when hospice is consistent with what matters most to that subset of patients, we have specifically recommended hospice to them. Such measures keep the focus on conversations and what matters most to patients, rather than the specific decisions they end up making.

Exemplify Measures

The measure as written is a cumulative measure. Use of cumulative measures is trickier than current month measures, as you need to keep a roster of staff (for the denominator) and then continue to check off the number of staff who meet the conditions over time.

Conversation Ready Principle	Measure Name	Proposed Definition	Data Collection Plan	Goal
Exemplify this work in health care professionals' own lives so that they understand the benefits and challenges	Percent of staff with Conversation Ready education	Numerator = count of staff who have had Conversation Ready education as defined by your organization Denominator = count of staff who were eligible for Conversation Ready education	Each quarter, count the number of staff who have had Conversation Ready education (numerator) and the number of staff who were eligible for Conversation Ready education (denominator).	100%

Engage Measures

Conversation Ready Principle	Measure Name	Proposed Definition	Data Collection Plan	Goal
Engage with patients and families to understand what matters most (WMM) to them at the end of life	Percent of patients in the subpopulation who are asked if they have a health care proxy identified	Numerator = count of patients in the subpopulation who are asked if they have a health care proxy identified Denominator = count of patients in the subpopulation	At the start of each calendar month, review the previous month's data and report the total number of patients in the subpopulation (denominator) and total number of patients in the subpopulation whom you asked if they have a health care proxy identified (numerator).	100%
	Percent of patients in the subpopulation who are asked if they have articulated WMM	Numerator = count of patients in the subpopulation who were asked if they have articulated WMM Denominator = count of patients in the subpopulation	At the start of each calendar month, review the previous month's data and report the total number of patients in the subpopulation (denominator) and total number of patients in the subpopulation whom you asked if they have articulated WMM (numerator).	100%
	Percent of patients in the subpopulation without a health care proxy identified who are then engaged by staff in a conversation to identify a proxy	Numerator = count of patients in the subpopulation without a health care proxy who engage with staff to identify health care proxy Denominator = count of patients in the subpopulation without a health care proxy identified	At the start of each calendar month, review the previous month's data and report the total number of patients in the subpopulation who do not have a health care proxy identified (denominator) and total number of patients in the subpopulation without a proxy identified AND who staff then engaged in a conversation to identify a proxy (numerator).	100%
	Percent of patients in the subpopulation without WMM articulated who are then engaged by staff in a conversation to articulate WMM	Numerator = count of patients in the subpopulation without WMM articulated who engage with staff to articulate WMM Denominator = count of patients in the subpopulation without WMM articulated	At the start of each calendar month, review the previous month's data and report the total number of patients in the subpopulation who do not have WMM articulated (denominator) and total number of patients in the subpopulation who do not have WMM articulated AND who staff then engaged in a conversation to articulate WMM (numerator).	100%

Notes

- Each organization needs to define what documentation will constitute an adequate attempt to have captured what matters most (WMM).
- If a patient answers "No" to the question about having a health care proxy, staff might ask a follow-up question like, "When would be a good time to identify that person and complete the form?" This helps initiate open-ended interaction with the patient, with the goal of documenting a proxy at some

point (but not pushing to do so in the first interaction). Staff who ask the follow-up question should have training and access to documents to engage further with the patient.

• Can you modify work so that the follow-up questions are **always** asked?

Steward Measures

Conversation Ready Principle	Measure Name	Proposed Definition	Data Collection Plan	Goal
Steward information about end-of-life care goals, values, and preferences as reliably as we do allergy information	Percent of patients with a health care proxy documented in the electronic health record (EHR)	Numerator = count of patients in the subpopulation who have health care proxy documented in the EHR Denominator = count of patients in the subpopulation	At the start of each calendar month, review the records from the previous month and report the total number of patients in the subpopulation (denominator) and total number of patients in the subpopulation who have a health care proxy documented in the EHR (numerator).	100%
	Percent of patients who have WMM documented in the electronic health record (given local definition of WMM)	Numerator = count of patients in the subpopulation who have WMM documentation in the EHR Denominator = count of patients in the subpopulation	At the start of each calendar month, review the records from the previous month and report the total number of patients in the subpopulation (denominator) and total number of patients in the subpopulation who have WMM documented in the EHR (numerator).	100%

Notes

- While documentation of health care proxy and WMM information in the EHR is not sufficient for reliable stewardship, integration of this information into the EHR appears to be practically necessary. Most organizations need many months to identify and achieve changes to the EHR that require IT effort. Don't let this barrier stop you. You still have an opportunity to test changes to electronic records; for example, the project team can identify EHR fields and screen layouts on paper, test different configurations, and summarize recommendations for IT.
- Where changes to the EHR are concerned, having an IT person as part of your team pays big dividends. It helps you deploy the Steward measures more quickly and effectively

Appendix B: Measuring Respect

In addition to developing measures for the Conversation Ready principles of Exemplify, Connect, Engage, and Steward, it is also important to try to measure Respect. We are still learning about this area of work, as are many organizations in this field. We have found it useful to measure Respect from two perspectives.

Patient and Family Perspective

Measuring Respect requires asking patients about what respectful care means to them. For patients who have lost the capacity to speak for themselves or who have died, it is reasonable to ask their family or other surrogate medical decision maker (although it may be difficult to determine whether they know enough to answer accurately on behalf of the patient).

Accordingly, consider several approaches:

- Conversations with patients and families, including those living with serious illness, for instance, this resource from Healthcare Improvement Scotland: <u>Person-Centred Health and Care: Real-time and Right-time evaluation report</u>
- Measures of shared decision making, for instance, the <u>collaboRATE™ instrument</u> that asks patients (or families) to rate their answers to three simple questions (e.g., using a 1-to-5 rating scale):
 - 1. How much effort was made to help you understand your health issues?
 - 2. How much effort was made to listen to the things that matter most to you about your health issues?
 - 3. How much effort was made to include what matters most to you in choosing what to do next?
- Post-mortem surveys or conversations with families, for instance, the National Hospice and Palliative Care Organization's <u>Family Evaluation of Palliative Care</u>, which includes the following questions:
 - At any time while the patient was receiving palliative care, did the doctor or another member of the medical care team do anything with respect to end-of-life care that was inconsistent with the patient's previously stated wishes?
 - While the patient was receiving palliative care, how often did the medical care team treat him/her with respect?
 - While the patient was receiving palliative care, how well did the medical care team do at providing care that respected his/her wishes?

Health Care Professionals Perspective

Asking professionals to reflect on whether they are providing respectful care may be a powerful, if limited, way to drive improvement. The Conversation Ready Respect Measurement Tool (see below) asks health care professionals to score the degree to which six key elements of advance care planning were addressed with a given patient.

While still in the early stages of testing, the tool is intended to help organizations quickly understand and learn about how well they are respecting patients' wishes at the end of life and prompt valuable conversations with patients, family members, and health care professionals.

Teams can use the tool as a basis for reflection and conversation about their provision of respectful care. The tool provides a structured way to conduct inquiry — allowing teams to consider care from multiple dimensions and surface opportunities to improve. In addition, teams might track the total scores over time as a rough indicator of overall provision of respectful care.

Organizations can use the Respect Measurement Tool retrospectively (to review records of patients who have died, to identify and understand system-level problems and focus future improvement work) and prospectively (to identify care gaps with patients who are still alive and provide more respectful care while there is still time to do so).

Conversation Ready Respect Measurement Tool

Element of Advance Care Planning	Score Criteria			Score
	0	1	2	
Appropriate involvement of health care proxy Involvement of legal surrogate medical decision maker (proxy when patient lacks capacity, guardian if appointed by court) and others (as defined by patient preferences)	No evidence, unable to assess Or Inappropriate involvement of others	Some involvement but incomplete Or Insufficient evidence to determine with confidence (e.g., patient was never asked who should be involved)	Reliably appropriate involvement of others, supported by evidence	
Patient and family understanding of diagnosis and prognosis Prognostic understanding does not have to include quantitative knowledge of life expectancy	No evidence, unable to assess Or Misunderstanding of diagnosis and/or prognosis	Limited understanding Or Insufficient evidence to determine with confidence	Complete understanding, supported by evidence	
3. Patient and family understanding of range of treatment options, given medical condition Includes awareness that the patient can seek a second opinion, be referred to specialty care, add palliative care, or learn more about hospice	No evidence, unable to assess Or Misunderstanding of treatment options	Limited understanding Or Insufficient evidence to determine with confidence	Complete understanding, supported by evidence	
4. Care team understanding of what matters most to the patient at the end of life Complex topic, can take many forms; fundamentally, who is the patient as a person and what are their priorities for care at the end of life	No evidence, unable to assess Or Misunderstanding of what matters most (e.g., due to premature closure)	Missed opportunity to discuss with patient directly or surrogate Or Insufficient evidence to determine with confidence	Complete understanding, supported by evidence; the patient's voice is clearly heard	
5. Appropriate combination of Elements 1 through 4 Elements 1 through 4 were appropriately combined and health professionals made appropriate care recommendation(s)	No evidence, unable to assess Or Inappropriate care recommendation(s)	Missed opportunity to discuss with patient or surrogate Or Insufficient evidence to determine with confidence	Complete process, supported by evidence	
Appropriate plan of care in case of emergency and appropriate use of MOLST	No evidence, unable to assess Or Inappropriate plan, or inappropriate use of MOLST	Missed opportunity to discuss with patient or surrogate Or Insufficient evidence to determine with confidence	Complete discussion and planning, supported by evidence	
			Total Score	

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