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

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Executive Summary

In 2012, The Conversation Project (TCP), in collaboration with the Institute for Healthcare Improvement (IHI), launched a public campaign dedicated to encouraging people to talk about their wishes for end-of-life care with their loved ones, before a health care crisis occurs. The aim of The Conversation Project is that everyone's end-of-life care wishes are "expressed and respected."

As TCP's work to engage the public in "having the conversation" gained increasing national attention, it became clear that health care organizations would need to be "ready" to respond to this activated public in a reliable way — that is, to have systems in place to receive patients' wishes, to record them in the health record, and to respect them by providing care aligned with patients' stated wishes. Thus, IHI's "Conversation Ready" work began in 2012 with a group of end-of-life care experts and ten Pioneer Sponsor organizations participating in a one-year Conversation Ready initiative. At the conclusion of the year of work, the teams and faculty synthesized their learning into five principles of what it means to be "Conversation Ready." IHI launched a subsequent nine-month Collaborative in 2014 to build on the initial learning, with the aim of developing reliable processes for health care organizations to engage patients in conversations about their wishes for end-of-life care, steward that information, and then respect those wishes at the appropriate time.

Based on this work, IHI developed a detailed framework built on five core principles to help organizations begin the process of becoming Conversation Ready. This white paper describes the Conversation Ready framework, the changes associated with the framework's five principles that can be implemented to improve end-of-life care, examples of changes tested by organizations, and suggested measures to guide improvement.

Overview

In 2012, The Conversation Project (TCP), in collaboration with the Institute for Healthcare Improvement (IHI), launched a public campaign dedicated to encouraging people to talk about their wishes for end-of-life care with their loved ones, before a health care crisis occurs. TCP was built on the premise that, too often, people die in circumstances and surroundings they would not choose.

The aim of The Conversation Project is that everyone's end-of-life care wishes are "expressed and respected." In order to accomplish this aim, TCP created a website that provides free tools to support end-of-life conversations and an opportunity for education and shared storytelling. The tools include the *Conversation Starter Kit* (translated into various languages), *How to Talk to Your Doctor*, and the *Pediatric Starter Kit*.[1] Additionally, TCP engages deeply with communities, employers, and faith leaders to learn more about how best to reach people where they "live, work, and pray."

As TCP's work to engage the public in "having the conversation" gained increasing national attention, it became clear that health care organizations would need to be "ready" to respond to this activated public in a reliable way — that is, to have systems in place that actively engage with patients about their wishes, retain that information in a reliable way, and then use that information at the appropriate time. Thus began IHI's "Conversation Ready" work. In 2012, IHI convened a group of end-of-life care experts and ten Pioneer Sponsor organizations (see Appendix A) and launched the one-year Conversation Ready initiative. Together, this group committed to exploring what it means for a health care organization to be Conversation Ready — what that entailed, where to start, and how to know whether changes were leading to improvement.

For one year, the Pioneer Sponsors continued work already in progress at their organizations and innovated new ways of becoming Conversation Ready. Their engagement signaled an awareness of changing patient demographics, changing financial models, and the vast extent of the work at hand, as well as a deep commitment to patient-centered care.

At the conclusion of the year of work, the teams and faculty synthesized their learning — after reviewing the work already completed and the work that teams still needed to pursue — into five principles of what it means to be Conversation Ready: Engage, Steward, Respect, Exemplify, and Connect. (Initially, the Pioneer Sponsors referred to the key aspects of this work as Receive, Record, and Respect. Ultimately, however, the Conversation Ready teams decided that "Receive" was too passive and that the full breadth of work represented in the Exemplify and Connect principles was not sufficiently included.)

This white paper explains the development of the five Conversation Ready principles and associated changes and measures. The five principles reflect an expanded and more active role for health care providers, require providers to engage in their own personal conversations about their wishes regarding end-of-life care, and call for heightened sensitivity to diverse cultural contexts that may influence end-of-life care preferences. Together these five principles provided a framework for the first iteration of a "change package," which included examples of the changes that the Pioneer Sponsor teams tested within each of the principles, along with known best practices reported in the literature or directly to IHI staff. The ultimate goal is, for each of the five principles, to define a set of key process changes (a "change package") that will lead to improvement in the specified aim, along with associated measures to guide improvement.

The Need to Improve End-of-Life Care: Consider the "Allergy Analogy"

Imagine that an 80-year-old woman with a known medication allergy comes to your health system for care, but the medications allergy field in her electronic health record is blank, or has a "Y" (for "Yes") indicating that she does have an allergy, but provides no further information about specific medications to which she is allergic. She is admitted to your hospital four times in a six-month period, without further clarification of this allergy field in her record. When she is admitted a fifth time for pneumonia, she is administered the very medicine to which she is allergic. You would label this as a serious medical error with a significant risk of harm, and you would seek to change the system to prevent future recurrence of this error and thereby improve the safety and quality of care.

Now imagine that the same 80-year-old woman has severe emphysema. Despite her frequent and significant encounters with your health care system, and the context of her advanced serious illness and older age, no one on the health care team makes a real effort to encourage her to designate a health care proxy (a surrogate medical decision maker), no one asks what matters most to her when it comes to her end-of-life care, and no one documents her wishes in her electronic health record. Her condition is so advanced that none of her health care providers would be surprised if she became so sick that intubation was considered, and none would be surprised if she died within a year. However, none of them discusses these possibilities with her or documents her end-of-life care preferences. During her admission for pneumonia, she becomes sicker and loses capacity to communicate her preferences. She is intubated and eventually dies on a ventilator in the intensive care unit after a week, with her family arguing about what kind of care she would have wanted.

For this patient, the lack of advance care planning could lead to one of two possible outcomes: 1) at best, simply by chance, her care was consistent with what mattered most to her, but her family suffered unnecessary anxiety and stress because her wishes were unclear; or 2) at worst, not only did her family suffer unnecessarily, but the system may actually have harmed her. Imagine that the system did know what mattered most to her, which was to stay at home, maximizing quality of life, having time with family, and minimizing time in health care institutions, even if that meant she wouldn't live as long. In that situation, the care she received was not only inappropriate but was also disrespectful, depriving her of the opportunity to have a death with dignity, completing her life in the ways that mattered most to her.

Sadly, the experience described in this story is not an anomaly. End-of-life care across the United States is fraught with shortcomings, challenges, and lost opportunities. Just as the 1998 Institute of Medicine report, *To Err Is Human*, laid bare the deficiencies in the overall quality and safety of medical care, the 2014 Institute of Medicine report, *Dying in America*, is a call to action for health systems that provide end-of-life care. The report delineates the myriad problems with end-of-life care and makes recommendations about potential solutions in key areas, including patient-centered end-of-life care, clinician-patient communication, and professional education for physicians and nurses in palliative care and hospice.[2]

Because the end of life is often unpredictable, it is important to plan ahead, especially when we know a patient is at increased risk of getting sick or dying. This is known as the process of advance care planning. The available data suggest that advance care planning ensures that health care providers systematically and reliably elicit patients' preferences about their end-of-life care, and respect those preferences when the time comes.[3]

For certain patient populations, advance care planning is particularly important. The risk of harm is elevated and more apparent in patients with serious illness or older age. As a consequence of their conditions, such patients have an increased risk of death, and may also have an increased risk of potentially harmful events such as hospitalization, loss of capacity, loss of independence, or loss of identity. In these populations, failure to conduct appropriate advance care planning could be considered negligent, resulting in unnecessary suffering and harm (as illustrated in the "Allergy Analogy"). If a system conducts advance care planning, but does not use it to appropriately inform care at the end of life — that is, recommending treatments that are not consistent with the patient's stated wishes and goals of care — that, too, could be considered harm. Among patients with serious illness or older age, advance care planning is an essential element of good care.

Despite this, significant gaps persist when it comes to patients and their families making sure that end-of-life care wishes are known, understood, and correctly documented. One 2013 study quantified these gaps:[4]

> Before hospitalization, most patients (76.3 percent) had thought about end-of-life (EOL) care, and only 11.9 percent preferred life-prolonging care; 47.9 percent of patients had completed an advance care plan, and 73.3 percent had formally named a surrogate decision maker for health care. Of patients who had discussed their wishes, only 30.3 percent had done so with the family physician and 55.3 percent with any member of the health care team. Agreement between patients' expressed preferences for EOL care and documentation in the medical record was 30.2 percent. Family members' perspectives were similar to those of patients.

This study demonstrates gaps at each step of the process: patients first consider their preferences regarding end-of-life care; then share their thinking with family, in legal documents, and with their providers. Providers are often reluctant to initiate conversations about end-of-life care, so the health record regularly fails to capture the true wishes of patients. Even when such information is documented in the record, clinicians often don't notice it. Furthermore, wishes captured in legal documents are not always translated into actionable medical orders, leaving health care providers uncertain about what actions to take in a medical crisis. Each of these gaps represents an area ripe for improvement.

A 2011 survey conducted by the California HealthCare Foundation quantifies these gaps. The researchers found that 82 percent of respondents said it is important to put their wishes in writing, but only 23 percent had actually done it. Additionally, nearly 80 percent said that they definitely or probably would want to talk with a doctor about end-of-life care, but only 7 percent had had such a conversation.[5] Responses to The Conversation Project survey conducted in 2013 (conducted by Kelton, with more than 2,000 respondents over age 18 in the United States) indicated that although more than 90 percent of Americans think that it is important to talk about their and their loved ones' end-of-life care wishes, fewer than 30 percent have had that conversation.[6]

Certainly, patients and their families have a responsibility to proactively communicate about their end-of-life care wishes, but health care systems must share this responsibility. Even when institutions agree that advance care planning is an important part of preventing harm to their patients, many lack the systems and skills necessary to reliably record patient preferences, make this information accessible at the point of care, and provide care aligned with the documented preferences.

So, what will it take to close these gaps? This question became the focus of IHI's Conversation Ready Health Care Community.

The Conversation Ready Health Care Community

As the initial year of Conversation Ready work with Pioneer Sponsors was ending, IHI formed a Collaborative called the Conversation Ready Health Care Community to continue this learning. The nine-month Collaborative ran from February through October 2014 and engaged 15 new teams. Seven of the original Pioneer Sponsors also participated; the Collaborative faculty included representatives from four of the Pioneer Sponsor organizations.

We adapted the IHI Breakthrough Series Collaborative model for this work.[7] The Conversation Ready Collaborative change package was less mature and less complete than is typical for IHI Collaboratives; when the Conversation Ready Collaborative began, we were still in the process of developing and testing the change package. Also, two of the three Learning Sessions were virtual rather than all three being conducted in person. Ideally, the Collaborative would have lasted longer than nine months to give the teams more time to test changes and learn from these tests. (Collaboratives are usually 12 to 18 months in duration and have more in-person shared learning time to accelerate results.)

Of the 22 teams participating in the Collaborative (see Appendix A), 21 were from the United States and one team represented three boards (regions) in the Scottish Government Health Department. The 21 US teams were geographically dispersed, with great variation in organization size (from single hospitals to multi-site health care systems with multiple hospitals and additional services like hospice and visiting nurse services); and there was one Area Agency on Aging.

The goal of the nine-month Collaborative was to develop reliable processes for each of the five Conversation Ready principles. The documented wishes for care should reflect unique patient preferences and issues, beyond a mere "problem list" of diagnoses and symptoms. The system changes needed to achieve this goal involve many components: communication, care planning, patient-centered care, cultural competence, staff engagement, and information systems configured to manage the necessary data.

IHI faculty advised participating organizations that true cultural transformation in this area would likely take many years, depending on the organization and scope of work. Thus, faculty guided organizations to be realistic about what could be accomplished within the nine-month period, while also planning additional improvements in the future beyond the Collaborative. It takes time to successfully change a large complex system, beginning in a targeted part of the organization and then spreading throughout. Participating teams were asked to start improvement efforts in an area of their organization where commitment, resources, and alignment with institutional strategy already existed. Participants learned the basics of using the Model for Improvement[8] as a method for their improvement work, and they set aims that spanned the nine months of the Collaborative. Aim setting presented challenges because the specific changes were largely untested and the degree of improvement possible was not known.

Based on the lessons and insights from the 22 Collaborative teams, combined with learning gained during the Pioneer Sponsor year, IHI developed a detailed framework to help organizations begin the process of becoming Conversation Ready. This framework is described in the remainder of this paper.

Getting Started

IHI has identified three tasks to start Conversation Ready work: **collect baseline data, set an aim, and identify a subpopulation**.

Collect Baseline Data and Understand the Current Process: Chart Review of the Last 20 Patient Deaths

Teams getting started in this work should complete a patient chart review of the last 20 deaths in their hospital or system. (Detailed instructions are provided in Appendix B.) The purpose of the chart review is to understand what percentage of these patients had documentation (in some written form like an advance directive or a clinician's progress note) in the chart of: 1) their health care proxy (desired surrogate medical decision maker), and 2) "What matters?" to them (i.e., their preferences and wishes) regarding care at the end of life.

Because teams participating in the Collaborative represented a variety of types of organizations, as well as different states and countries, with considerable variation in government regulations, each team had to make a determination about what counts as documentation of proxy and "What matters?" (i.e., a phrase derived from Michael Barry and Susan Edgman-Levitan,[9] which has provided a powerful framing for how we understand patients' end-of-life care wishes and overall care goals).

"What matters?" documentation might include documents that clarify patient wishes about care received (e.g., a living will), documents that translate those wishes into actual medical orders (e.g., DNR [Do Not Resuscitate], POLST/MOLST [Physician/Medical Orders for Life-Sustaining Treatment]), and provider documentation of key conversations on this topic with patients and their families.

Once the team identifies the percentage of the 20 reviewed patient charts that include documentation of proxy and "What matters?" they can estimate — to the extent possible in a chart review exercise — the percentage of these patients that received end-of-life care that seemed to align with their wishes. The faculty for the Collaborative provided some guidance to teams on how to estimate this information, but ultimately left it up to each organization to determine the method that worked best for them. This method is far from perfect; the ability to accurately judge the actions of clinicians working in complex systems of care who intend the best for their patients is inherently limited by the retrospective, document-based approach. Charts are usually incomplete with respect to documentation of what matters to the patient, and extrapolating from limited data can lead to inaccuracy. Nonetheless, this review is a valuable starting point because it can provide teams with anecdotes and suggest opportunities for improvement that motivate their work. A team must work together to determine the criteria for their chart review so that the data are meaningful to and understood by them.

The following is a sample of results from this chart review: "When we completed our chart review of the most recent 20 deaths, 60 percent had documentation of a proxy decision maker and 50 percent had documentation of 'What matters?' (using available advance directives and physician notes). Of the 10 patients who had this latter documentation, 60 percent received care that seemed, based on team review, to align with what was expressed in documentation of what mattered to them."

The death chart review, although rudimentary, provides a starting point for teams to understand their current state with regard to engaging, stewarding, and respecting patients' end-of-life care wishes. In the Collaborative, many stories resulting from the chart review described excellent patient-centered care, although often the stories revealed care that was not patient-centered and, at worst, actually contrary to the stated mission, vision, and values of the organization. These stories illustrated situations in which care was given without knowledge of what mattered most to the patients or, in some cases, against patients' documented wishes. These rudimentary data and stories enabled teams to start talking about experiences in their own organizations, and to consider the subpopulation on which to focus their work during the nine-month Collaborative. In some cases, the data pointed toward a particular disease state or geographical care location that would be a good focus for testing initial improvements.

In addition to exploring whether end-of-life care that was provided aligned with patients' stated preferences for end-of-life care, the chart review exercise enabled teams to understand their processes for gathering and storing end-of-life care information. One organization in the Collaborative learned that the majority of nurses were skipping questions about end-of-life care wishes in their admission assessment because they did not feel comfortable talking with patients about end-of-life care. Another organization learned that the advance directive question was only triggered in their electronic health record (EHR) if a "Yes" answer was given to the question, "Does the patient have a proxy?" To understand their current systems, some teams created formal workflow diagrams after observing their processes at work. Many organizations surfaced staff confusion about the basic terminology (e.g., proxy, advance directive, durable power of attorney for health care, living will, will), which at times led to workarounds like skipping EHR screens to avoid well-meaning processes that were in place.

Set an Aim and Identify a Subpopulation

After completing the death chart review, teams should set an aim with measurable, time-specific goals ("how good, by when") and select a subpopulation on which to focus their improvement work. Most organizations will identify numerous opportunities and populations for which the Conversation Ready principles are applicable. However, IHI strongly encourages teams to focus their initial work on just one pilot site and/or one pilot population, and not try to tackle all five principles at the same time. A focused start prevents teams from becoming overwhelmed.

Below are some sample aims created by faculty for the IHI Conversation Ready Health Care Community to help teams think about their own aims.

- By October 31, 2014, Loma Alta Hospital will have a field in the electronic health record (EHR) that stores scans of advance directive documents along with flagged clinician notes about pertinent conversations with patients about end-of-life care goals. We will test scanning and flagging processes on unit 5W before broader testing of the new EHR field on other units. Additionally, we will convene a meeting with local faith leaders by July 2014 to increase mutual understanding of end-of-life care issues and increase collegial relationships, as evidenced by increased communication among hospital staff and faith leaders when patients are nearing the end of their lives. We will track these advances qualitatively at the start, through discussions with hospital social workers and chaplains.

- Stony Hill Nursing Care Center will conduct Conversation Groups (in which participants discuss their own wishes regarding end-of-life care, and/or develop a plan to have a conversation with a friend or loved about their wishes) with 75 percent of nursing staff by October 31, 2014, with particular attention to night and weekend shifts. Additionally, a

monthly chart review will be used to verify that 80 percent of residents who have changed level of care within the Center have a documented note about end-of-life care wishes, and copies of advance directives will be present in the chart. Each month, we will meet with two families of residents who have died to discuss alignment of end-of-life care with residents' wishes and their own experience of care as loved ones.

- Marietta Valley Medical Center will focus initial Conversation Ready Health Care Community participation in the SICU and MICU with all patients who have had a prior admission to these units in the last three months. Goals (by October 31, 2014): 1) the percentage of patients with documented power of attorney (DPOA) will increase from 37 percent to 75 percent; and 2) random monthly chart review of patients who have died on these units will show that 75 percent have documentation of a goals-of-care discussion, and 50 percent have documentation of alignment of patient wishes with care received at time of death. We will conduct two qualitative interviews monthly with MICU and SICU patients, as able (and families, as needed), who met readmission criteria to confirm/deny alignment of patients' wishes with the plan of care and to discuss their experience while hospitalized.

Below are examples of identifying a subpopulation of patients using specific health characteristics.

- During ICU rounds, use the question, "Would it surprise you if this patient died within a year?"[10] Those patients for whom the response is, "No, it would not surprise me," are counted in the pilot population.

- Focus on patients with stage IV heart failure (using New York Heart Association criteria), metastatic cancer, or stage IV or V chronic kidney disease.

- Focus on patients age 85 or older with three or more admissions in the last 180 days.

In the Collaborative, examples of identifying a subpopulation within specific sites of care included dialysis units, oncology units, acute care of the elderly units, skilled nursing facilities, and hospices. Some organizations focused on subpopulations that were solely determined by health characteristics, others by specific sites of care, and others used a hybrid of the two. Considering the principles of population health management may help organizations identify the subpopulations most in need of advance care planning.

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

The five Conversation Ready principles (see Figure 1) provide the framework for teams undertaking this work. The Conversation Ready principles are discussed here in greater detail, along with examples of specific changes that teams participating in the IHI Collaborative tested for each principle.

Figure 1. The Five Conversation Ready Principles
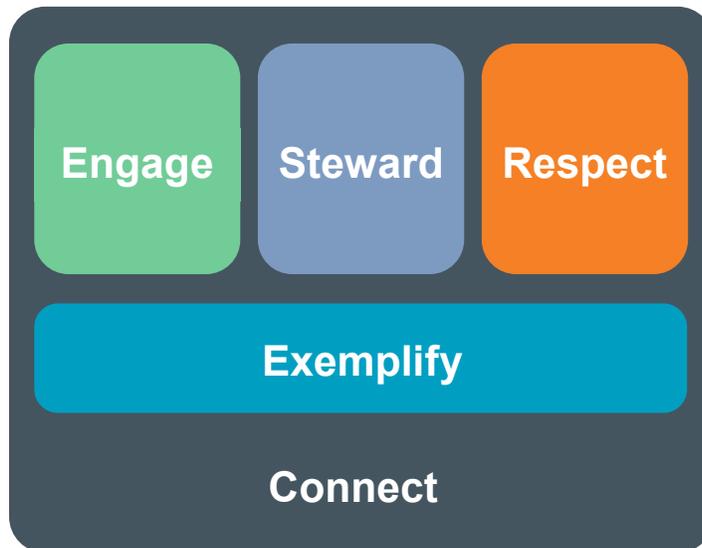
1. ***Engage*** *with patients and families to understand what matters most to them at the end of life*

   This principle signifies a proactive and ongoing engagement with patients and their families to understand what matters most to them about care at the end of life. This activity has been likened to talking with patients about tobacco use and then engaging them in smoking cessation after assessing readiness. Ideally, the conversation occurs proactively (i.e., well in advance of a medical crisis), although it may be necessary to engage in end-of-life care conversations during a medical crisis.

2. ***Steward*** *information about each patient's end-of-life care wishes as reliably as we do allergy information*

   Knowing, confirming, and documenting patients' end-of-life care wishes is as important as knowing, confirming, and documenting their allergies. Just like allergy information, information about end-of-life care wishes should be readily accessible in patients' health records. Many health care systems have existing processes to prompt providers to ask patients if they have a proxy and/or advance directive, but often there is no means to document additional information beyond a "Yes/No" response — and no place within the health record to reliably record additional information. Dr. Lachlan Forrow, director of ethics and palliative care programs at Beth Israel Deaconess Medical Center, who served on the IHI Conversation Ready faculty, pushed Collaborative teams to see that providing care without

engaging patients in conversations about end-of-life care wishes and delivering care inconsistent with patients' stated wishes were on a par with medical errors.

3. ***Respect*** *people's wishes for care at the end of life by partnering to develop a patient-centered plan of care*

Nothing is gained if patients' wishes are known and recorded, but then ultimately not considered in developing an end-of-life care plan. In some care locations and in some health care crises, the span of time between engaging patients and families in end-of-life care conversations and respecting those wishes can be extremely short. However, in other locations such as primary care, community agencies, and public outreach efforts, there could be a considerable amount of time between initial engagement in such conversations and needing to act to respect those wishes. Recognizing that wishes often change over time, processes must support not only accessing this information, but also easily updating and maintaining it. Furthermore, simply accessing the information is not sufficient; health care providers must then use the information in the process of shared decision making with patients and their families to develop care plans that are truly patient-centered.

4. ***Exemplify*** *this work in our own lives, so that we fully understand the benefits and challenges*

This principle embodies "walk the walk" and encourages all providers to "have the conversation" with their own families and loved ones about end-of-life care wishes. Through IHI's work, we gained increased confidence that this is an important starting point with organizations involved in Conversation Ready work — not just a "nice to have" but, in many cases, essential to achieving their aims. Undertaking this work in one's own life can help surface any personal challenges that might interfere with encouraging one's patients to "have the conversation" and can also build confidence about the importance of doing so, along with empathy about the challenges. Much like wearing an "I voted" or "I gave blood" sticker, there is a pride in being able to say, "I had the conversation," and then, "Here's why I hope you will, too."

5. ***Connect*** *in a manner that is culturally and individually respectful of each patient*

The fifth, and perhaps most important, principle encompasses the other four principles since they all need to be conducted through this lens. Providers can fall short of their aim of providing patient-centered end-of-life care if they do not account for cultural influences — religious, ethnic, socioeconomic, educational, and geographic — that impact how a patient approaches end-of-life care. This area of work is vital for becoming Conversation Ready, yet it may not be a natural starting point for teams. Organizations will likely want to begin their work on the other principles in order to be more effective in the Connect principle.

Testing Changes for the Five Conversation Ready Principles

The Conversation Ready Collaborative teams approached this work from different starting points. Although we are not ready to be prescriptive about sequence (i.e., to say, "First do this, then do that"), Table 1 presents the most promising changes for each principle that evolved from IHI's Conversation Ready Collaborative change package, along with examples for each and Collaborative organizations that tested these changes.

Table 1. Examples of Promising Changes for the Five Conversation Ready Principles

Promising Changes	Examples (and Organization Testing the Change)
Principle: **Engage with patients and families to understand what matters most to them at the end of life**	
Identify and segment patients.	• Create new workflows in the inpatient palliative care department to identify the subpopulation of patients that need a life care planning conversation, and engage them in that conversation. (Kaiser Permanente San Jose Medical Center) • Use a structured template for ward rounds to first identify patients and then document their wishes. (NHS Lothian, Scottish Government Health Department) • Conduct a Senior Assessment during internal medicine outpatient visits to introduce POLST (Physician Orders for Life-Sustaining Treatment) discussions. (St. Jude Medical Center)
Develop and use materials and tools that help care teams conduct and document end-of-life care conversations with patients and their families.	• Revise health care proxy materials and outreach using patient and family advisors. (Beth Israel Deaconess Medical Center) • Use the TCP *Conversation Starter Kit* and advance directive packet with hospitalized patients enrolled in COPD (Chronic Obstructive Pulmonary Disease) Education Program. (Renown Health) • Develop a conversation template tool for nurses and medical providers; the tool has disease-specific trajectories on the back of the template to enable patients to locate themselves on the trajectory. (The University of Kansas Hospital)
Creatively use staff to operate at "top of license."	• Use a designated Conversation Ready Nurse to see palliative care referrals for whom the primary need is to identify and clarify end-of-life wishes. (Care New England) • Use case managers and nurses in community work (elder services agency) to ask about and document proxy information; proxy information is required by some skilled nursing facilities when patients are discharged from the hospital. (Elder Services of Merrimack Valley)
Train staff to be more effective at facilitating end-of-life care conversations.	• Train staff using Gundersen Lutheran Respecting Choices® model.[11] (Erie County Medical Center) • Create new four-hour training program for staff around advance directives, decision making, and POLST. (Penn Medicine)
Create upstream community engagement.	• Hold large-scale public events to raise awareness ("A Little More Conversation" with Elvis theme). (Knoxville Academy of Medicine) • Have public "Deciding Over Dinner" event. (Reid Hospital) • Develop community class: "Your Life, Your Choices." (Virginia Mason Medical Center)
Principle: **Steward information about each patient's end-of-life care wishes as reliably as we do allergy information**	
Understand the current fields in the electronic health record (EHR) to identify opportunities to capture and store end-of-life care information in the system.	• Fully understand advantages and limitations of current EHR system to guide design of new system. (Beth Israel Deaconess Medical Center) • Resolve pathway issues in EHR when steps did not go in expected sequence or direction. (Winter Park Memorial Hospital)
Create an architecture for the health record that accounts for entry, storage, and retrieval.	• Add advance care planning page to home-grown EHR. (Beth Israel Deaconess Medical Center) • Make advance directive question a mandatory field in EHR. (Reid Hospital) • Use features in Soarian Clinical to give all clinicians access to advance directive history. (St. Peter's Health Partners/Ellis Medicine) • Establish one place in record where information is kept: the Advance Directive Note Type. (Virginia Mason Medical Center)

Promising Changes	Examples (and Organization Testing the Change)
Principle: **Respect people's wishes for care at the end of life by partnering to develop a patient-centered plan of care**	
Create workflows to support entry and retrieval of end-of-life care information.	• Send completed POLST forms to Health Information Management for earlier scanning into EHR. (Kaiser Permanente San Jose Medical Center) • Train unit secretaries to scan advance directives into Epic and update header so documents can be located. (Penn Medicine)
Identify patients needing end-of-life care.	• Create Advance Care Planning Summary form and go through "information reconciliation" process (like medication reconciliation). (NHS Lothian, Scottish Government Health Department) • Use "Ceiling of Treatment" tools to guide patient/provider conversations about desired treatment courses for different disease pathways. (NHS Lanarkshire, Scottish Government Health Department)
Access and affirm known end-of-life care wishes.	• Ask unit secretaries to access advance directives prior to family meetings. (Mohawk Valley Health System)
Maintain an end-of-life care plan across organizational boundaries.	• Develop MOLST guidelines and educational materials. (Beth Israel Deaconess Medical Center) • Add Life Care Planning order to home health referral for patients discharged from hospital so follow-up happens with a trained facilitator. (Kaiser Permanente San Jose Medical Center)
Principle: **Exemplify this work in our own lives, so that we fully understand the benefits and challenges**	
Prioritize and segment staff for engagement through their own advance care planning.	• Train staff to go through their own personal conversation processes before engaging clients. (Elder Services of Merrimack Valley)
Provide the right tools at the right time.	• Hold annual "Talk Turkey" Day for staff before Thanksgiving to sign up for a health care proxy and bring materials to their holiday celebrations to promote end-of-life care conversations. (Beth Israel Deaconess Medical Center) • Host annual "Day of Conversation" for staff. (UPMC)
Principle: **Connect in a manner that is culturally and individually respectful of each patient**	
Recognize the effects of different cultural influences, and connect with communities and leaders to help smooth the path.	• Engage pastors, elders, faith leaders, and neighbors in community conversations. (Erie County Medical Center) • Have multi-pronged symposia, panels, and workshops for faith leaders in the community, and conduct two-way training between clergy and clinicians to learn about faith traditions and medical care at the end of life. (Henry Ford Health System)
Explore the role of disparities in other aspects of Conversation Ready work.	• Tailor advance care planning outreach to underserved and underrepresented populations (e.g., African-American elders). (Henry Ford Health System)

Conversation Ready Measures

Measures of progress toward becoming Conversation Ready are still in development. The death chart review was the main outcome measure used in the IHI Collaborative, indicating 1) whether or not patients had designated a health care proxy, and 2) whether or not patients had documentation of "What matters?" to them at the end of life. The teams in the Collaborative began their work with a death chart review to gather baseline data; some teams repeated the review three times during the Collaborative, using their designated subpopulation, to help them assess early improvement efforts.

While the death chart review is retrospective, it did help surface stories and aided organizations' understanding of gaps in processes that needed to be improved. However, our experience in the Collaborative suggests that teams should be cautious about using the death chart review as the only measure of performance. There are substantial limitations to using only chart review to guide improvement efforts, and more information is needed to understand the nuances of whether or not your organization has reliable processes to help you ultimately respect your patients' wishes for end-of-life care.

Beyond the outcome data yielded by the death chart review, to try to understand the alignment of care provided with patients' wishes for end-of-life care, IHI developed suggested process measures for the Engage and Steward principles (see Table 2).

Table 2. Process Measures for the Engage and Steward Conversation Ready Principles

Measure	Proposed Definition	Sampling Plan
Engage *with patients and families to understand what matters to them at the end of life*		
Percent of patients in subpopulation who are asked if they have determined a legal surrogate	Numerator: Count of patients in subpopulation who are asked if they have determined a legal surrogate Denominator: Count of patients in subpopulation	At the start of each calendar month, review the evidence from the previous month and report the total number of patients in your subpopulation whom you've engaged (denominator) and total number of patients in your subpopulation whom you've engaged AND asked about determination of a legal surrogate (numerator).
Percent of patients in subpopulation who are asked if they have documented "What matters?" (WM) information	Numerator: Count of patients in subpopulation who are asked if they have documented WM Denominator: Count of patients in subpopulation	At the start of each calendar month, review the evidence from the previous month and report the total number of patients in your subpopulation whom you've engaged (denominator) and total number of patients in your subpopulation whom you've engaged AND asked if they have documented WM (numerator).
Percent of patients in subpopulation *without* legal surrogate, who are then engaged in conversation to identify legal surrogate	Numerator: Count of patients in subpopulation without legal surrogate who engage with staff to identify legal surrogate Denominator: Count of patients in subpopulation without legal surrogate	At the start of each calendar month, review the evidence from the previous month and report the total number of patients in your subpopulation whom you've engaged who did not have a legal surrogate (denominator) and total number of patients in your subpopulation whom you've engaged who did not have a legal surrogate AND were asked about identifying a legal surrogate (numerator).
Percent of patients in subpopulation *without* articulated "What matters?" (WM) information, who are then engaged in conversation to document WM	Numerator: Count of patients in subpopulation without articulated WM who engage with staff to document WM Denominator: Count of patients in subpopulation without articulated WM	At the start of each calendar month, review the evidence from the previous month and report the total number of patients in your subpopulation whom you've engaged who did not have WM articulated (denominator) and total number of patients in your subpopulation whom you've engaged who did not have WM articulated AND were asked about WM (numerator).
Steward *information about each patient's end-of-life care wishes as reliably as we do allergy information*		
Percent of patients with legal surrogate identified in your information system	Numerator: Count of patients in subpopulation you have engaged who have legal surrogate identified in your information system Denominator: Count of patients in subpopulation you engage	At the start of each calendar month, review the records from the previous month and report the total number of patients in your subpopulation whom you've engaged (denominator) and total number of patients in your subpopulation whom you've engaged AND who have a legal surrogate identified in your information system (numerator).
Percent of patients with "What matters?" (WM) documentation in your information system (given local definition of WM)	Numerator: Count of patients you engage in subpopulation who have WM documentation in your information system Denominator: Count of patients in subpopulation you engage	At the start of each calendar month, review the records from the previous month and report the total number of patients in your subpopulation whom you've engaged (denominator) and total number of patients in your subpopulation whom you've engaged AND who have WM documented in your information system (numerator).

These process measures assume that it is important to know whether or not patients have proxy and "What matters?" information accessible in their health records and, if not, whether improvements are being made in processes for gathering and storing this information. The Collaborative teams had varying levels of engagement and success in using these process measures and in repeating the outcome measure exercise of the death chart review. For example, a team engaged in an EHR redesign to support documentation and retrieval of patient end-of-life care wishes would not see outcome measure changes in the nine-month span of the Collaborative.

We began the Collaborative without defined measures for the Exemplify and Connect principles. During the Collaborative, Elder Services of Merrimack Valley (ESMV) developed some custom measures for the Exemplify principle:

- Percent of staff introduced to the Conversation Ready work

- Percent of staff with "Five Wishes"[12] document completed

- Percent of staff with documented legal proxy

Although these measures gave ESMV the ability to track their progress, there is still much to be learned about effective measures for the Exemplify principle. Concerns about employee privacy and the degree to which an employer has access to such private information are important to consider.

We have not yet developed measures for the Connect principle. However, we identified several preliminary steps to inform potential measures for this principle:

- Identify prevalent cultural and religious groups;

- Develop strategies to engage prevalent cultural and religious groups in the Conversation Ready work;

- Engage patient and family advisors from prevalent cultural and religious groups as members of project teams; and

- Create advance care planning materials in the top prevalent non-English languages spoken and read by patients in the health system.

Lessons Learned

IHI is fortunate and grateful to have had committed, creative, innovative organizations engaged with us in the Conversation Ready work. The fundamental components of this work are not new — a 1991 federal law in the US mandated that health care organizations ask patients if they have an advance directive and educate them as needed. What is new about IHI's Conversation Ready work, however, is the focus on developing a *reliable set of processes* for going beyond a checkbox about whether or not a patient has an advance directive. A checkbox does not ensure that the documents are understood, available, and being used appropriately.

The overall scope of work required for a hospital or health system to become Conversation Ready is large; changing IT systems, for example, is especially time- and energy-consuming. The five Conversation Ready principles span many interconnected processes and departments, both within and outside of health care. The work ranges from the technical (e.g., changing electronic health

record platforms) to the existential (e.g., providers understanding their role in these processes and examining their own perspectives on death). It is exciting to see organizations engage, steward, and respect patients' wishes regarding end-of-life care, which is the ultimate in patient-centered care. It is also important to be forthright about the scope — and, therefore, the challenges — of the work at hand.

Although testing of the Conversation Ready framework is still in early stages, IHI has identified some key lessons learned from its two years of work:

- Don't try to tackle all five Conversation Ready principles at the same time. Some teams worked on two to three interconnected principles at once, but it's too much to take on all five.

- Consider the Exemplify principle as a good foundational base for launching the work. This gives staff time to process their own fears, concerns, and barriers, and to strengthen their understanding of the importance of the work and their commitment to it.

- Link the Conversation Ready work to other strategic priorities like reducing readmissions.

- Start with a subpopulation/pilot unit to make this work manageable and to gain experience. IHI encouraged teams to identify a population for whom there is strong agreement within the organization about their need for end-of-life care planning (for example, patients over age 85 with multiple admissions), so as to leverage the power of consensus.

- Use the death chart review as a starting point for understanding what advance care planning data are collected and the general prevalence of such data, and to identify stories about end-of-life care that may create a sense of urgency and a reason for action.

- Recognize the limitations of the death chart review. It is very difficult to accurately judge whether the care provided was congruent with the patient's wishes, given that detailed and up-to-date information about the patient's wishes is often missing from the chart. Furthermore, those providing care in what become the last moments of a patient's life do not have the benefit of knowing what is going to happen. Judging their attempts to take care of the patient may be premature without more information. These limitations must be considered when conducting a death chart review and reporting the results, in order to avoid alienating well-intentioned providers.

- Realize that the Engage, Steward, and Respect principles are sequenced in time from the patient perspective (though not necessarily from the standpoint of how a team sets about improving them). Note that the time span of engaging, stewarding, and respecting a person's end-of-life care wishes can range from days to decades.

- Understand the financial implications of this work. For example, reducing unwanted care and reducing readmissions as a result of improved end-of-life care processes may lead to reduced revenue for health care organizations.

- Define what "proxy" and documentation of "What matters?" mean in your setting. Regulations as well as local culture and preferences must be accounted for. Examples of proxy documentation include health care proxy forms and durable power of attorney for health care documents. Examples of documenting "What matters?" include advance directives and living wills, The Conversation Project's *Conversation Starter Kit*, clinician notes of conversations, and the "Five Wishes" document.

- Engage patients and families in co-designing processes that improve the "workflow" (from Engage to Steward to Respect).

- Recognize that the Steward work is a substantial undertaking. It cannot be separated from the challenging IT issues that most health care organizations face. Even when an electronic health record (EHR) module can be deployed to store documented end-of-life care information, this typically entails substantial IT resources. It also requires persistent management coaching and feedback to make sure these new EHR features are used appropriately and reliably.

Examples of Progress in Becoming "Conversation Ready"

Kaiser Permanente San Jose Medical Center, San Jose, California

This Collaborative team's subpopulation was hospitalized patients 75 years old and older with a Do Not Resuscitate (DNR) order, but no POLST (Physician Order for Life-Sustaining Treatment); and patients 85 years old and older with congestive heart failure, end stage renal disease, dementia, or stage IV cancer. Patients in the subpopulation were identified for a facilitated Life Care Planning conversation (using the Respecting Choices® model developed by Gundersen Lutheran). Figure 2 below shows their data for the Engage process measure (as defined in the Measures section above): the percent of patients in the subpopulation without articulated "What matters?" (WM) information, who are then engaged in conversation to document WM. While monthly patient counts were small and variable, the run chart increased the team's degree of belief that changes to workflow drove more conversations about "What matters?" to their patients.

Figure 2. Kaiser Permanente San Jose Medical Center: Percent of Patients in the Subpopulation Engaged in a Conversation to Document "What Matters?" Information (March through October 2014)
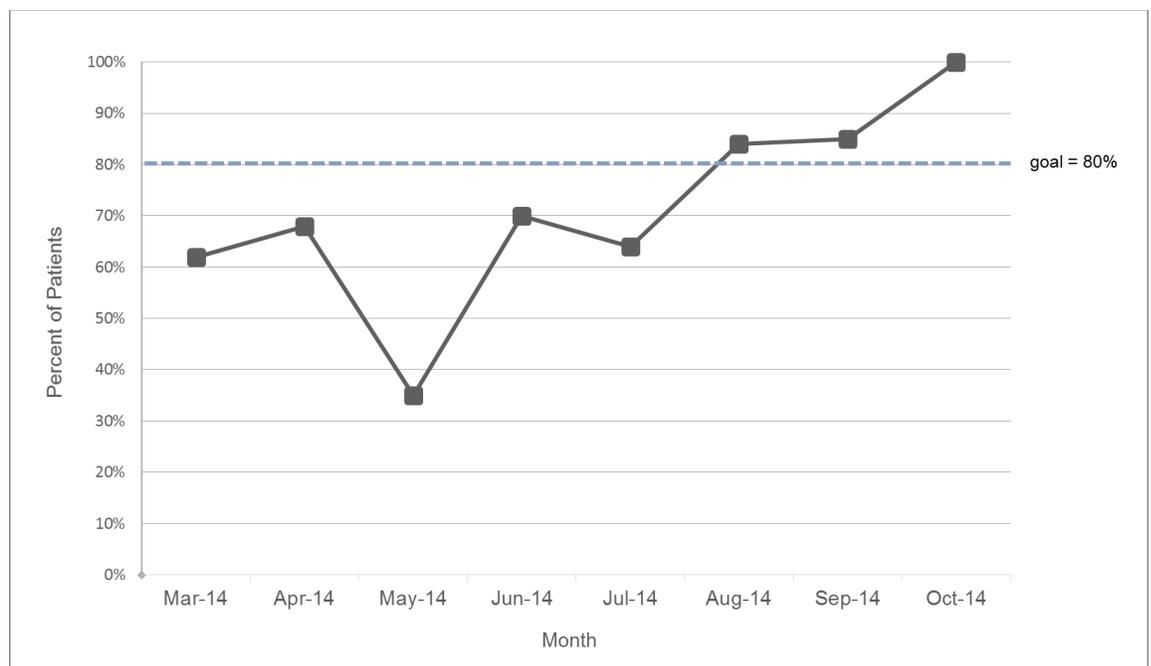
Care New England/Kent Hospital, Warwick, Rhode Island

Recognizing that 70 percent of referrals to their new palliative care program entailed clarification of end-of-life wishes, the Care New England/Kent Hospital site initially focused on developing the role of an inpatient Conversation Nurse to work with patients and families to clarify and document their wishes. Because this pilot was successful, the hospital then added two more inpatient Conversation Nurse positions and also spread this improvement to the standard work of their home care and hospice admission nurses. They focused on educating all home-based RNs to facilitate end-of-life care conversations with their patients, and as a result have documented an advanced directive for 50 percent of home-based palliative care patients (with baseline of 25 percent). They are currently expanding these efforts into the larger community, working with both an insurer and a large statewide primary care group to develop an at-home palliative care program focused on encouraging family meetings to discuss end-of-life care wishes and delivering home-based care consistent with those wishes.

Virginia Mason Medical Center, Seattle, Washington

At Virginia Mason Medical Center, the initial Conversation Ready work focused on their Acute Care of the Elderly unit. An initial death chart review was conducted for 22 patients; of those, two had a surrogate decision maker noted in their charts and one also had an advance directive. Fifty percent of the patients on the unit had cognitive impairment. At the time of admission, all patients were asked whether or not they had a durable power of attorney for health care (DPOA-H) and an advance directive. Forty-one percent said yes, but less than ten percent of these documents were available in the electronic health record. Following improvement efforts, 100 percent of patients were asked on admission about DPOA-H and advance directives, and 100 percent of those who already had these key documents then had them scanned in real time into the EHR.

The team identified a social worker champion for this process and, one year later, 80 percent of patients in the hospital had an identified DPOA-H and some kind of advance directive. Key changes the team implemented include establishing an enduring location in the EHR related to end-of-life care planning to document patients' wishes, goals, values, and preferences. Also, an internal medicine champion has focused on increasing patient and provider satisfaction in having these conversations, providing the information, and referring patients to the community class, "Your Life, Your Choices." At the end of the Collaborative, a death chart review was repeated for the last 30 in-hospital deaths. All 30 patients had DPOA-H and end-of-life wishes documented. The team assessed that the end-of-life care provided was congruent with documented wishes for 29 of these patients, and for one patient the DPOA-H deviated slightly from the documented wishes.

Reid Hospital, Richmond, Indiana

Through their Conversation Ready work, Reid Hospital learned that questions about end-of-life care documentation in their electronic health record were not correctly sequenced, which made it possible for some information to be missed. Changes in the EHR were implemented to increase the reliability of the process of the admission nurse asking patients and their families about a health care proxy and advance directive, and documenting these in the EHR.

The subpopulation for the team's pilot work included any patient identified as at high risk for readmission and having two or more of the following positive risk factors:

1. Long-term care resident;

2. End-stage or terminal illness; and/or

3. Diagnosis of heart failure, diabetes, chronic obstructive pulmonary disease, or HIV/AIDS.

At the start of their work, when the team began monitoring the reliability of asking patients in this subpopulation about advance directives, an average of 86.9 percent of patients were asked; following the changes to the EHR as described above, the average rose to 98.7 percent.

Beth Israel Deaconess Medical Center, Boston, Massachusetts

The team at BIDMC had a comprehensive approach to their Conversation Ready work over two years (that included the initial Pioneer Sponsors work and the subsequent Collaborative), with emphasis on working upstream, revamping their EHR, and revising staff educational materials and documentation forms. They have a strong internal team of interdisciplinary Conversation Ready partners (who lead specific improvement efforts, spread the word with peers, and provide education), as well as internal and external websites about the work, which provide helpful information for patients and providers.[13]

Components of their work include the following:

- Capture and share stories and data about end-of-life care and advance care planning to create a sense of urgency, focus improvement efforts where they are needed most, and begin a cultural transformation.

- Partner with colleagues to test and refine ideas, and to make the work sustainable and scalable.

- Craft and iteratively refine the vision, and communicate it widely throughout the institution through numerous meetings, presentations, and forums to build awareness and consensus.

- Focus on three key elements of advance care planning:

  o Health care proxies, including a data-driven initiative to improve rates of proxy completion in a primary care clinic (see Figure 3 below);

  o "Conversations," including training providers how to discuss "code status" with patients admitted to the hospital, and developing a longitudinal communication skills training program for internal medicine residents; and

  o MOLST (Medical Orders for Life-Sustaining Treatment), including writing institution-wide guidelines and developing educational materials for patients, families, and providers.

Figure 3. Beth Israel Deaconess Medical Center: Percent of Patients Needing a Health Care Proxy Completed Who Have a Completed Proxy on Discharge (July 2014 through April 2015)
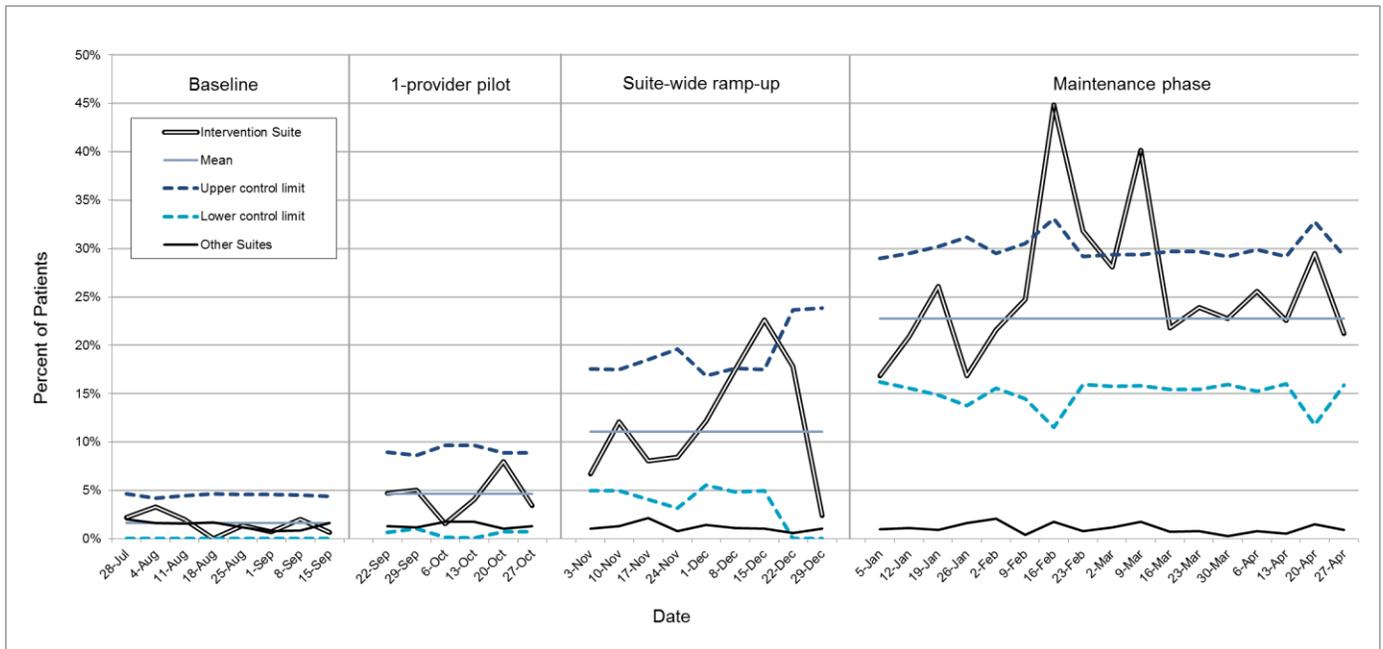
Note: Average weekly volume in the intervention suite is ~230 patients. On average ~144 patients need a proxy, so a 20 percent rate is ~29 new proxy forms per week.

Next Steps

The IHI Conversation Ready Collaborative lasted nine months, and many teams were just hitting their stride when the Collaborative ended in October 2014. IHI has been fortunate to remain actively connected with some teams and are additionally connected with teams represented on the Conversation Ready faculty. The most important next steps are the following:

- Continue to test the change package in many different settings;

- Deepen experience with a measurement strategy to develop a parsimonious and practical set of indicators to drive improvement; and

- Deepen exploration of the Connect principle, including how to get started, identify the most high-leverage changes, and determine ways to effectively engage cultural (religious, ethnic, etc.) leaders.

Conclusion

Aging Baby Boomers, changes in US health care payment incentives, and increased professional and public attention to end-of-life care planning are important factors driving the need for health care providers and organizations to become Conversation Ready. To be successful, the relevant technical, cultural, and management actions must be aligned. Early testing of the Five

Conversation Ready Principles framework has given IHI confidence that this alignment can be achieved through improved processes to reliably respect patients' wishes for end-of-life care.

To become truly Conversation Ready — and to deliver care that is truly patient-centered — health care organizations need to commit to stewarding end-of-life wishes, and implement standardized practices to make stewardship effective and reliable for every patient. Future work in this area needs to include further testing and refinement of the five Conversation Ready principles, identifying additional best practices for each principle, and embedding this work in the broader context of population health management.

Appendix A: IHI Conversation Ready Participants

Pioneer Sponsors in the IHI Conversation Ready Initiative (2012-2013)

- 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–LIJ Health System (New York)
- St. Charles Health System (Oregon)
- UPMC (Pennsylvania)
- Virginia Mason Medical Center (Washington)
- Contributing Sponsor: Gundersen Health System (Wisconsin)

IHI Conversation Ready Health Care Community (Collaborative) Members (2014)

- Beth Israel Deaconess Medical Center (Massachusetts)
- Care New England Health System (Rhode Island)
- Elder Services of Merrimack Valley (Massachusetts)
- Erie County Medical Center (New York)
- Geisinger Health System (Pennsylvania)
- Henry Ford Health System (Michigan)
- Kaiser Permanente San Jose Medical Center (California)
- Knoxville Academy of Medicine (Tennessee)
- Mercy Health (Ohio)
- Mohawk Valley Health System (New York)
- North Shore–LIJ Health System (New York)
- Penn Medicine (Pennsylvania)
- Reid Hospital (Indiana)
- Renown Health (Nevada)

- Scottish Government Health Department (Scotland)

- St. Charles Health System (Oregon)

- St. Jude Medical Center (California)

- St. Peter's Health Partners/Ellis Medicine (New York)

- The University of Kansas Hospital (Kansas)

- Vidant Health (North Carolina)

- Virginia Mason Medical Center (Washington)

- Winter Park Memorial Hospital (Florida)

Appendix B: Instructions for Chart Review of the Last 20 Patient Deaths

Getting Started with "Conversation Ready": Collect Baseline Data and Understand the Current Process

Health care providers and organizations beginning their work to become "Conversation Ready" — that is, engaging patients and their families in conversations about end-of-life care wishes and establishing processes that enable providers to reliably respect these wishes — need to first understand their current processes. Completing a patient chart review of the last 20 deaths in the hospital or health system provides some useful baseline data about current practices and processes.

The purpose of the review is to understand what percentage of these patients had documentation (in some written form like an advance directive or a clinician's progress note) in the chart of: 1) their health care proxy (desired surrogate medical decision maker), and 2) "What matters?" to them (i.e., their preferences and wishes) regarding care at the end of life.

Although this method is rudimentary, the review serves as a valuable starting point because it can provide teams with anecdotes and suggest opportunities for improvement that motivate their work. A team must work together to determine the criteria for their chart review so that the data are meaningful to and understood by them.

1. **Review the charts of the last 20 patients who died in your setting.**

As you review the charts, note evidence of the following:

- Advance directive documents are accessible and can be understood by the care team (i.e., not just a "Yes/No" notation that the patient has an advance directive);

- Documentation of provider and patient conversation(s) — or conversation(s) with a surrogate decision maker, if the patient is not able to participate — about "What matters?" to the patient regarding end-of-life care wishes;

- Location of death;

- Whether patient received life-sustaining treatment;

- A few details about the patient's medical history and situation immediately prior to death; and

- The presence of indicators about whether the care the patient received was aligned with their documented end-of-life care wishes.

Consider including representatives from the involved clinical services in the review, to understand their perspectives on the care provided and to engage them in the work.

2. **For each patient chart attribute reviewed, quantify what you learned from this review.**

For example, for the 20 patient charts reviewed:

-   85 percent of charts reviewed had documented surrogate decision maker

-   65 percent of charts reviewed had accessible advance directive

-   50 percent of charts reviewed had documented provider and patient discussions about end-of-life care wishes

-   Of the patients for whom there was documentation of directive/end-of-life care wishes:

    o   50 percent had indicators that the care received was consistent with the patient's end-of-life care wishes

    o   30 percent had indicators that the care received was not consistent with the patient's end-of-life care wishes

    o   20 percent did not have enough information to indicate either way

3. **Briefly document two stories gleaned from the review that illustrate current end-of-life care processes (to help build will among colleagues and create a clearer picture of reasons to engage in work).**

For example:

-   Mr. S had a note in his patient chart that an advance directive existed, but it was not accessible in the patient chart. There was no documentation of discussions with providers about end-of-life care goals, and the care team was not able to determine alignment of care goals and Mr. S's end-of-life care wishes.

-   Ms. W had an accessible advance directive and detailed notes about end-of-life care goals in her patient record, and she was transferred to an inpatient hospice unit in apparent alignment with her wishes.

Information from the review can be used to guide team conversations about setting an aim, selecting a subpopulation, and identifying the best location for pilot testing. Additionally, this information can help build will when discussing work with colleagues.

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