

# A Comprehensive Approach to Eliciting, Documenting, and Honoring Patient Wishes for Care Near the End of Life: The Veterans Health Administration's Life-Sustaining Treatment Decisions Initiative

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**Background:** There is an emerging consensus that clinicians should initiate a proactive “goals of care conversation” (GoCC) with patients whose serious illness is likely to involve decisions about life-sustaining treatments (LSTs) such as artificial nutrition, ventilator support, or cardiopulmonary resuscitation. This conversation is intended to elicit the patient's values, goals, and preferences as a basis for shared decisions about treatment planning. LST decisions are often postponed until the patient is within days or even hours of death and no longer able to make his or her goals and preferences known. Decisions then fall to surrogates who may be uncertain about what the patient would have wanted.

**Life-Sustaining Treatment Decisions Initiative (LSTDI):** The Veterans Health Administration's Life-Sustaining Treatment Decisions Initiative (LSTDI) was designed to ensure that patients' goals, values, and preferences for LSTs are elicited, documented, and honored across the continuum of care. The LSTDI includes a coordinated set of evidence-based strategies that consists of enterprisewide practice standards for conducting, documenting, and supporting high-quality GoCCs; staff training to enhance proficiency in conducting, documenting, and supporting GoCCs; standardized, durable electronic health record tools for documenting GoCCs; monitoring and information technology tools to support implementation and improvement; a two-year multifacility demonstration project conducted to test and refine strategies and tools and to identify strong practices; and a program of study to evaluate the LSTDI and identify strategies critical to improving care for patients with serious illness.

**Conclusion:** The LSTDI moves beyond traditional advance care planning by addressing well-documented barriers to goal-concordant care for seriously ill patients.

There is an emerging consensus that clinicians should initiate a proactive “goals of care conversation” (GoCC) with patients whose serious illness is likely to involve decisions about life-sustaining treatments (LSTs) such as artificial nutrition, ventilator support, or cardiopulmonary resuscitation (CPR).<sup>1–4</sup> The purpose of this conversation is to elicit the patient's values, goals, and preferences as a basis for shared decisions about treatment planning. Heretofore, LST decisions have often been postponed until a crisis occurs, the patient is within days or even hours of death, and is no longer able to make his or her goals and preferences known.<sup>5–7</sup> Decisions then fall to surrogates who may be uncertain about what the patient would have wanted.<sup>8,9</sup>

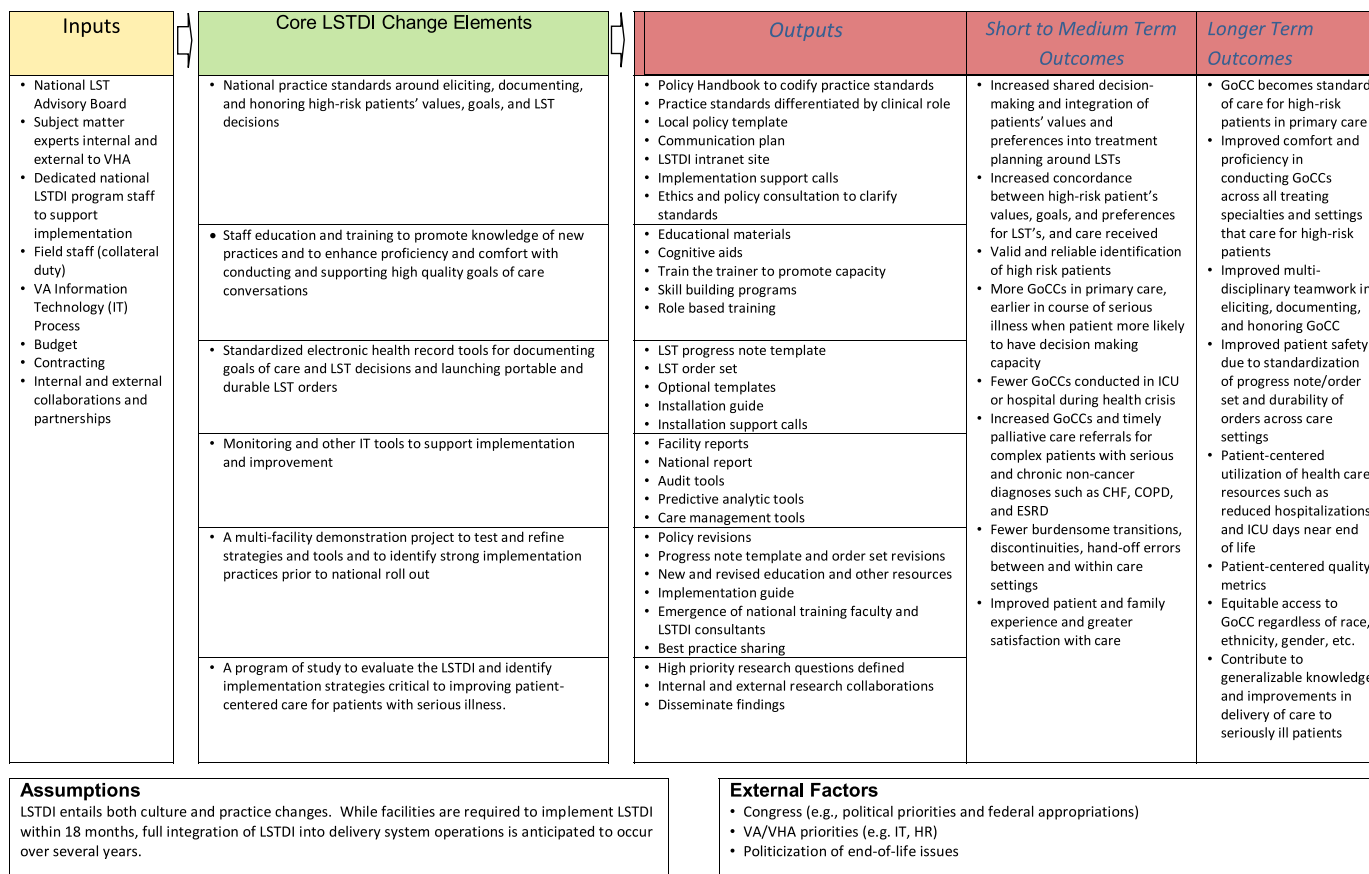
There are many reasons why GoCCs are not yet the standard of care. Proactively identifying appropriate patients is impeded because of prognostic uncertainty and the lack of valid and reliable tools to provide decision support.<sup>2,10</sup> Even when patients are identified, a GoCC may not be initiated because of provider fears about engendering anxiety or hopelessness, uncertainty about the best timing for a GoCC, or other clinical demands that take precedence.<sup>11</sup>

Furthermore, providers may lack training in needed communication skills, adding to their reluctance to proactively initiate GoCCs.<sup>12</sup>

Documentation of GoCCs in the electronic health record (EHR) is also problematic. Patient preferences are difficult to document in ways that will be consistently understood by others and may not be available at the point of care when needed.<sup>13</sup> Furthermore, preferences documented in an advance directive are not treatment orders, thus limiting their utility in guiding medical decision making. State-based Physician Orders for Life-Sustaining Treatment (POLST) were developed to translate patients' LST preferences into portable medical orders for use by first responders in the community,<sup>14,15</sup> but many health care systems do not have durable orders (that is, orders that do not need to be rewritten every time the patient changes care setting or location of care) in the EHR that follow the patient from location to location within the system.

Advance directives and the POLST paradigm are important but imperfect solutions to the problem of eliciting, documenting, and honoring patients' values, goals, and LST decisions. Comprehensive practice change requires a multipronged approach that addresses multiple barriers to best practice simultaneously and on a systems level. The

Logic Model: Life-Sustaining Treatment Decisions Initiative (LSTDI)



**Figure 1:** The LSTDI Logic Model summarizes expected outcomes associated with the initiative and the inputs, activities, and outputs that will lead to these outcomes. VHA, Veterans Health Administration; VA, US Department of Veterans Affairs; CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease; ESRD, end-stage renal disease; HR, human resources.

Veterans Health Administration's (VHA) Life-Sustaining Treatment Decisions Initiative (LSTDI)<sup>16</sup> was designed to do this. In this article we describe the details of our approach, with special emphasis on resources that can be used outside of the US Department of Veterans Affairs (VA) system.

## THE LIFE-SUSTAINING TREATMENT DECISIONS INITIATIVE

The LSTDI is intended to address known gaps in the care of seriously ill patients through an interrelated and coordinated set of evidence-based strategies fortified by hands-on implementation support that includes the following elements:

1. Clear enterprisewide practice standards for conducting, documenting, and supporting high-quality GoCCs
2. Staff training to enhance proficiency in conducting, documenting, and supporting GoCCs
3. Standardized, durable EHR tools for documenting GoCCs
4. Monitoring and information technology tools to support implementation and improvement
5. A multifacility demonstration project to test and refine strategies and tools and to identify strong implementation practices
6. A program of study to evaluate the LSTDI and identify implementation strategies critical to improving care for patients with serious illness

The LSTDI Logic Model (Figure 1) summarizes expected outcomes associated with the initiative and the inputs, activities, and outputs that will lead to these outcomes. We now describe each of the elements in detail.

### Practice Standards

Practice standards for GoCCs were defined in a VHA handbook (Handbook 1004.03) and published on January 11, 2017.<sup>17</sup> The two key practice standards are (1) practitioners are required to initiate proactive GoCC with seriously ill patients (or the patient's surrogate) prior to writing LST orders, and (2) practitioners are required to document these conversations and decisions, using the national standardized VHA LST progress note template and order set.

To ensure that the development of Handbook 1004.03, and the LSTDI as a whole, was informed by expert input, the VHA National Center for Ethics in Health Care (NCEHC) engaged relevant clinical and operational stakeholders and subject matter experts (SMEs) through a sequence of multidisciplinary work groups that included VA and academic affiliate members. These groups, which convened between roughly 2005 and 2012, reviewed the state of the science in advance care planning and care of seriously ill patients, including the literature on improving communication with patients and families near the end of life.

Then, after a multiyear iterative VHA drafting and review process, a draft policy was submitted in May 2015 for formal review and approval by all VHA clinical and administrative program offices and the VA Office of General Counsel, as well as review for bargaining by the major unions representing VHA employees.

In February 2013 NCEHC also convened a VHA advisory board to help promote the successful implementation of the policy initiative. Through this process, NCEHC cultivated champions to enculturate staff and veterans about required practice changes, engage providers and others in LST education, and anticipate and address barriers. The advisory board's collective insights into systemwide implementation of other complex initiatives helped to ensure that policy requirements reflected the realities of clinical and administrative work flows. When the final policy was issued by the VHA Under Secretary for Health (Handbook 1004.03),<sup>17</sup> facilities were given 18 months to implement practice changes across all VA sites of care.

The LSTDI—and the ethics and policy that ground it—represents a significant culture change aimed at improving care by improving care planning. To accomplish this, Handbook 1004.03 introduces the concept of “high-risk patients” (Sidebar 1) for whom GoCCs are appropriate, clarifies which providers are responsible for GoCCs, and defines specific “triggering events” (Sidebar 2) for initiation of GoCCs, such as prior to writing a do-not-attempt-resuscitation (DNAR) or do-not-resuscitate (DNR) order. It requires providers to cover specific topics as part of GoCCs and to document GoCCs and the resulting LST plan using a standardized progress note template and LST order set. Finally, the policy specifies that LST orders are durable; that is, they will not be automatically discontinued at discharge or when the patient crosses care settings within the VHA but will remain in effect until they are modified based on a change in the patient's LST plan.

#### Sidebar 1. Select Life-Sustaining Treatment Decisions Initiative Definitions

**Goals of Care Conversation.** A goals of care conversation (GoCC) is undertaken between a health care practitioner and a patient or surrogate for the purpose of determining the patient's values, goals, and preferences for care, and, based on those factors, making decisions about whether to initiate, limit, or discontinue life-sustaining treatments (LSTs). Other health care team members may contribute to the GoCC as specified in VHA Handbook 1004.03.

**High-Risk Patient.** For the purposes of this policy, a high-risk patient is a patient who is considered to be at high risk for a life-threatening clinical event because he or she has a serious life-limiting medical condition associated with a significantly shortened lifespan. High-risk patients are patients about whom the practitioner would not be surprised if the patient experienced a life-threatening clinical event within the next one to two years. In addition to clinical judgment as a basis for identifying these patients, objective criteria may be used to make this determination.

**Life-Sustaining Treatment.** A life-sustaining treatment (LST) is a medical treatment that is intended to prolong the life of a patient who would be expected to die soon without the treatment (for example, artificial nutrition and hydration, mechanical ventilation).

**Life-Sustaining Treatment Progress Note.** An LST progress note is a health record progress note that documents a GoCC and the resulting

LST plan using a nationally standardized Computerized Patient Record System (CPRS) progress note template.

**Life-Sustaining Treatment Order Set.** The LST order set is a nationally standardized CPRS order set for documenting orders to limit or not place limits on one or more LSTs. Orders documented in the LST order set will not expire or automatically discontinue based on dates, time frames, or patient movements (for example, admission, discharge, transfer) but will remain in effect unless they are modified based on a revised LST plan.

#### **Sidebar 2. Triggering Events for Initiating a Goals of Care Conversation**

##### **High-Risk Patients Without Active LST Orders and/or LST Progress Notes (adapted from VHA Handbook 1004.03, Section 5b(2)(a)):**

###### **When clinically appropriate, including the following:**

- In primary care/home-based primary care (for example, within six months after coming under the care of the PCP as a high-risk patient, or at the earliest opportunity if the prognosis is less than six months)
- Upon admission to an inpatient unit
- Upon admission to a community living center
- Upon palliative care consultation
- Prior to referral to hospice
- Prior to initiating or discontinuing a treatment intended to prolong the patient's life when the patient would be expected to die soon without the treatment

##### **High-Risk Patients With Active LST Orders and/or LST Progress Notes (adapted from VHA Handbook 1004.03, Section 5b(2)(b)):**

###### **When clinically appropriate, including the following:**

- If there is evidence that the orders no longer represent the patient's preferences
- Prior to a procedure involving general anesthesia, initiation of hemodialysis, cardiac catheterization, electrophysiology studies, or any procedure that poses a high risk of serious arrhythmia or cardiopulmonary arrest

##### **All Patients (adapted from VHA Handbook 1004.03, Section 5b(2)(c)):**

###### **When clinically appropriate, including the following:**

- Prior to writing DNAR/DNR orders or other orders to limit LST, including SAPO
- At any patient encounter when the patient (or surrogate) expresses a desire to make or change decisions about limiting or not limiting LSTs in the patient's current treatment plan
- At any patient encounter when the patient (or surrogate) presents with SAPO for LST, unless the patient already has LST orders in CPRS that are consistent with the SAPO.

LST, life-sustaining treatment; VHA, Veterans Health Administration; PCP, primary care provider; DNAR, do-not-attempt-resuscitation order; DNR, do-not-resuscitate order; SAPO, state-authorized portable orders; CPRS, Computerized Patient Record System.

In addition, Handbook 1004.03 and the LST progress note reflects the VA's long-standing regulatory requirement that facilities either obtain a special guardian for health care or follow the process for multidisciplinary committee review of LST treatment recommendations for high-risk patients who lack capacity and have no surrogate.<sup>18</sup> Finally, to help ensure that a patient's VHA LST orders can be communicated to non-VA clinicians who provide care to veterans in the community, the VHA has a dedicated policy—VHA Handbook 1004.04, *State-Authorized Portable Orders (SAPO)*—on the steps required to align a veteran's VHA LST orders and state-authorized portable orders, such as POLST, MOLST (Medical Orders for Life-Sustaining Treatment), and POST (Physician Orders for Scope of Treatment).<sup>19</sup>

The LSTDI includes policy implementation support to VA medical facilities, including an LSTDI intranet site, an

implementation guide, and an annotated policy template to ensure that each local VA facility policy not only aligns with Handbook 1004.03 but is tailored to appropriately reflect local nomenclature and work flow. The NCEHC also provides ongoing policy interpretation to address technical questions and ethics consultation to help resolve value uncertainty or conflict related to care of these high-risk veterans. A twice monthly NCEHC implementation support call addresses policy questions and enables problem solving and sharing of strong practices between medical centers nationwide.

### **Staff Education and Training**

Education and training of clinical teams that care for seriously ill patients across a range of specialties and settings is essential to achieving proactive, goal-concordant care. Our strategy cultivates both the knowledge and skills necessary to identify appropriate patients and to plan for, conduct, and document GoCCs across treating specialties, irrespective of care location. We developed educational materials to help staff understand the ethical basis for the LSTDI, build the skills required to proactively identify high-risk patients, and document patients' values, goals, and LST decisions. We created materials in varied formats, including videos, online modules, podcasts, and avatar-based simulation. These materials enable individual or team-based learning, address distinct learning styles, and are scalable to clinicians' time constraints. Key learning is reinforced through cognitive aids, such as pocket cards, that clinicians use in the clinical environment. Medical center executive leadership is responsible for ensuring that staff are trained and they may elect to use any of the provided resources or those they develop themselves.

Proactive identification of high-risk patients is a critical component of LSTDI training. Valid and reliable methods to identify seriously ill patients at high risk of a life-threatening event are a work in progress. For instance, by some estimates, the "surprise question" (for example, "Would you be surprised if your patient died within the next one or two years?") is insensitive, missing a significant percentage of high-risk patients who could benefit from a GoCC.<sup>20–22</sup> To better ensure that the right patients are identified at the right time, we train teams to use a combination of screening approaches, including the Care Assessment Need (CAN) score, which is a predictive analytic risk assessment tool (see "Monitoring," page 15); an adaptation of the surprise question ("Would you be surprised if the patient experienced a life-threatening clinical event in the next one to two years?"); and clinical judgment. We do not use EHR alerts or automatic reminders to flag patients with high CAN scores or to remind providers to consider the surprise question because alerts



are so ubiquitous that they are often overlooked. Our approach is to nudge practice change through training and ready access to tools that assist in identifying high-risk patients.

Building clinicians' communication skills in conducting GoCCs with seriously ill patients is another central objective of the LSTDI training strategy. To this end, in 2017 we launched train-the-trainer programs to expand our internal capacity to improve critical communication skills among clinicians across the VHA. Trainers are selected by their facilities, attend a 2.5-day course, and are responsible for delivering training in their home facilities using nationally standardized curricula.

Two GoCC skills training programs are offered by clinician-educators who have attended the national train-the-trainer program. The first targets physicians, advanced practice nurses, and physician assistants who are authorized to make shared decisions with patients and surrogates about LST plans and write LST orders. Developed in partnership with VitalTalk,<sup>23</sup> this program consists of five interactive modules on delivering serious news, assessing the patient's understanding of his or her illness and prognosis, eliciting the patient's goals and values, discussing GoCC and LST decisions, and communicating recommendations for a treatment plan based on the patient's priorities. The training modules can be delivered in one block or in a series of one-hour sessions across several weeks.

The second program is for nurses, social workers, psychologists, and chaplains who care for patients with serious illness. During this face-to-face, day-long training, participants learn key communication skills for engaging patients and families, assisting them in exploring patients' values, and responding to their emotions, consistent with the VitalTalk-based GoCC training for practitioners. Participants also learn strategies for assessing the patient's understanding of his or her illness, providing information about services and treatments within their scope of practice, and ensuring handoffs to practitioners for shared decision making about LSTs and other medical interventions. The training includes short didactic segments, video demonstrations, and communication skills practice exercises. Given the importance of multidisciplinary teamwork in reducing burdens on practitioners, particularly in primary care, the course includes a module to help teams develop strategies and identify team members' roles in identifying high-risk patients, preparing patients and families for these discussions, ensuring that these discussions occur and are appropriately documented, and engaging in team-based quality improvement.

NCEHC also offers monthly teleconferences to VA trainers to provide a forum for problem solving and sharing best practices in teaching communication skills to clinicians. Education and training resources may be accessed from the LSTDI website.<sup>24</sup>

## Documentation

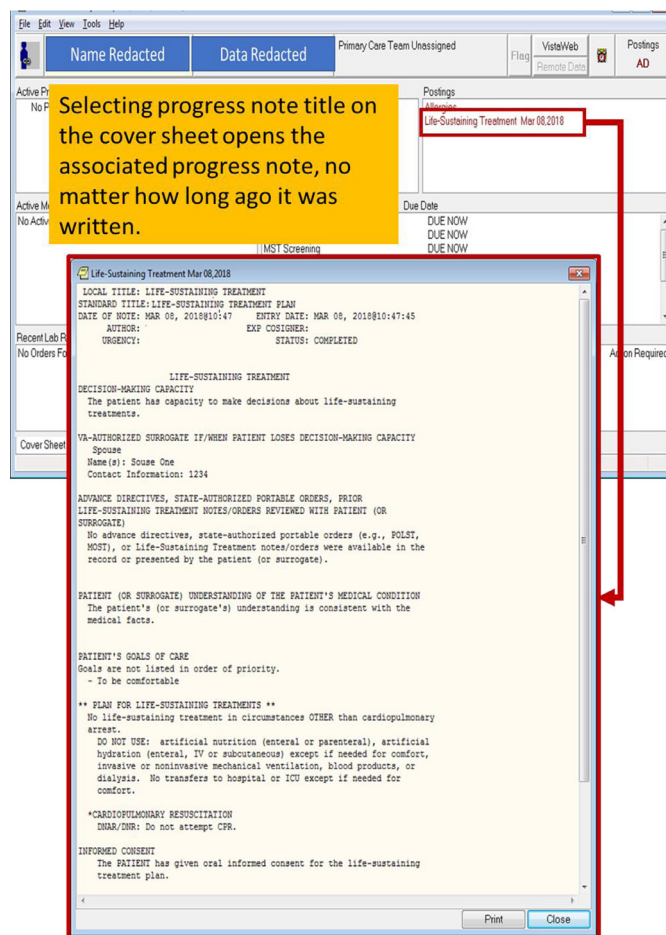
In 2013 the Agency for Healthcare Research and Quality called for improved documentation of patients' GoCCs, observing that poor documentation practices can result in confusion among staff, inaccurate communication with families, and mistakes in code situations.<sup>25</sup> To address this gap, we developed a national, standardized LST progress note title template and an LST order set to document the patient's goals and LST decisions in the EHR.<sup>26</sup> They are mandated for use in VA medical centers, outpatient clinics, nursing homes, and home care clinics.

Completed LST progress notes are easy to find and are accessed from the EHR cover sheet or from a tab containing all progress notes (Figure 2). They may be viewed within and across levels of care (inpatient, outpatient, nursing home) and across VA facilities. While previous progress notes related to LSTs were scattered in the patient's record and thus difficult to find, the new process makes the most recent note highly visible on the cover sheet. The unique, mandated progress note title also makes it more easily discoverable when searching records at remote facilities across the VA enterprise. This standardized note title is also expected to make it easier for community providers to locate these notes when they are given broader access to VA EHRs.

The progress note captures vital information about the patient's goals and LST decisions through a mix of checkboxes and text fields. The progress note template was developed through extensive review by SMEs, usability testing with VA's Human Factors Laboratory, and pilot testing by clinicians within our four VA demonstration sites. Specifically, cognitive testing was conducted with physicians, advanced practice nurses, and RNs to ensure that the language on the template was understood by those who document GoCC notes and orders, as well as by those who inform, interpret, and carry them out. In addition, providers conducted simulated GoCC with "patients" and "family members" and then documented the conversations using the progress note template. Documentation time was recorded. Providers were interviewed following each simulation to learn about their experience and to identify opportunities for improvement. Modifications and retesting occurred until providers reported that the time required to document was not burdensome. Documentation time diminished with practice (often down to a couple of minutes) and was less than the time required for documenting a GoCC using free-text entry.

The template fields consist of the patient's capacity to make LST decisions, the patient's surrogate, whether documents reflecting the patient's wishes were available and reviewed (for example, advance directive, POLST), the patient's (or surrogate's) understanding of his or her condition and prognosis, the patient's goals of care (for example, to be cured, to prolong life, to be comfortable, to achieve life goals specified in his or her own words), the plan for use

## Life-Sustaining Treatment (LST) Note Opening



**Figure 2:** A screen shot of an LST note opening from the Computerized Patient Record System (CPRS) cover sheet is shown.

of CPR and other LSTs, and who gave consent for the LST plan. Pop-up boxes provide information about specific topics (for example, order of surrogacy) when needed. At each facility's discretion, a menu of related consults and a link to a comfort care order set may be built into the template.

On the basis of negotiation during the policy concurrence process, four sections of the template must be filled in to complete the template: patient's decision-making capacity, goals of care, treatment preferences in the event of cardiopulmonary arrest, and informed consent. The other four sections (authorized surrogate, review of related documents such as advance directives, patient/surrogate understanding of the patient's condition/prognosis, and plan for life-sustaining treatments in circumstances other than cardiopulmonary arrest) are currently optional. If a practitioner begins an LST progress note, it cannot be edited by others before signature, but addenda can be added, as needed.

The LST progress note allows clinicians to automatically launch and populate LST orders based on treatment decisions that are documented within the note. For example, documenting a decision not to attempt CPR in the

event of cardiopulmonary arrest launches a DNAR/DNR order. This functionality reduces the risk of transcribing errors and speeds the documentation process for practitioners. The LST order set was modeled after the portable LST orders authorized in many states and is used to document limits to a range of LSTs, including CPR, mechanical ventilation, artificial nutrition, artificial hydration, and others (for example, dialysis, blood products). The order set can be used to limit transfers to the hospital or the ICU and to indicate whether the patient would accept a time-limited trial of LSTs. The orders may be written in any VHA care setting (for example, outpatient, inpatient, nursing home) and are viewable and durable across VHA settings—that is, they will not expire or automatically discontinue based on dates, time frames, or patient movements (for example, admission, discharge, transfer) and will remain in effect until they are modified based on changes in the patient's goals or decisions.

The durability of LST orders and ease of access to GoCC documentation reduces the burden on patients and the health care team of repetitive discussions held solely because the patient moved from one care location

to another. With this approach, clinicians are trained to revisit goals and LST decisions when clinically appropriate, such as when the patient's health declines, when there is a medical crisis such as hospital admission, or when there are indications that the patient's goals or preferences may have changed. Updates to the patient's LST plan can be documented with an addendum or a new LST progress note, readily viewable on the EHR cover sheet. Clear and accessible documentation of the patient's goals and LST decisions also reduces the risk of handoff-related communication failures—a leading cause of medical errors.<sup>27</sup> A sample LST progress note template and LST order set are available.<sup>28</sup>

In addition to using the LST progress note, each facility is required to develop a progress note for use by nurses, social workers, and others on the health care team to document discussions with patients or surrogates about the patient's values, goals, and preferences, or by practitioners when shared decisions about LSTs have not yet been made. A sample template for this note has been provided, a common note title has been recommended (“Goals & Preferences to Inform Life-Sustaining Treatment Plan”), and facilities have been advised to make it accessible from the EHR cover sheet. Final decisions about title, template, and placement are determined at each facility.

A monthly NCEHC support call addresses technical issues related to the installation and use of the EHR tools.

## Monitoring

Monitoring is an often overlooked component of policy implementation. Monitoring is the systematic collection of data on specified indicators to provide stakeholders with data on the degree to which progress has been made in achieving objectives. How monitors are used is ethically relevant. Monitors should be used to inform, understand, and improve—not police, punish, or coerce. To reduce activation of a compliance mind-set we emphasize the ethical basis of LSTDI in all communication related to GoCC monitoring.

To support facility champions during the first 18 months of LSTDI implementation, we developed a Web-based facility monitoring report linked to health factors (data elements) in the LST progress note template. The reports are updated daily from the VA's Corporate Data Warehouse (CDW) and provide a count of initial (first occurrence of a GoCC for a distinct veteran) and total GoCCs documented using the LST progress note by quarter and location (inpatient, outpatient, or nursing home). Currently, LST reports register a total of 54,371 new GoCCs with distinct veterans and a total of 63,965 GoCC conversations (that is, initial GoCC plus updates or changes to the patient's goals and LST decisions). The latter figure underestimates the true total, as it is based on clinicians who update the LST plan on a new progress note template. Updates documented on the addendum to the progress note are excluded because free text is not standardized in the CDW. We provide a count

of “total conversations” in the facility report to reinforce the concept that GoCCs are not one-time events, but rather an iterative communication process that should be revisited—particularly when a patient has a chronic illness with a long and declining trajectory. The reports also allow users to drill down further to treating specialties (inpatient), clinics (outpatient), providers, patients, date of encounter(s), and risk scores for each patient.

In addition, the reports provide graphics to track GoCCs by quarter and location—a feature designed to help facilities ensure that GoCCs are being initiated earlier in the patient's course of illness (that is, during outpatient care, rather than following hospitalization). The report also provides a pie chart that shows the distribution of CAN scores at the time of the patient's initial GoCC. The CAN score is a predictive analytic tool, developed with veteran health data that represents the estimated probability of hospitalization or death within a specified time frame of 90 days or one year. The CAN score is expressed as a percentile from 0 (lowest risk) to 99 (highest risk) and is an indicator of how a given veteran compares with other individuals in terms of likelihood of hospitalization or death.<sup>29</sup>

When practices are more firmly rooted following the 18-month implementation period, which ended on July 11, 2018, denominator data based on CAN scores within diagnostic groupings will be introduced to better understand penetrance among high-risk groups and as a basis for targeted improvement. In this next phase of implementation, we will introduce facility reports that monitor rates of GoCC among veterans who have died and the elapsed time between GoCC and death, with greater elapsed time indicating higher quality. VA facilities also currently have access to a national summary report that allows comparisons within regional networks and nationally.

A key outcome of LSTDI is that GoCCs will be conducted earlier in the course of serious illness, when a patient is more likely to have decision-making capacity—ideally in an outpatient setting, such as primary care, with clinicians the patient knows well. GoCC training emphasizes the importance of multidisciplinary teamwork to ensure that the patient's primary care provider is not shouldering the entire burden for this process (see “Training”). Information technology can support an efficient and effective team-based work flow with respect to GoCC. To this end, in 2016 we partnered with the VA Office of Analytics and Business Intelligence to develop a GoCC tool within the Patient Care Assessment System (PCAS). PCAS is a national VA Web-based application that helps primary care teams identify patients who require improved care coordination, or augmented services based on risk characteristics. The GoCC tool within PCAS helps teams identify, manage, and track completion of GoCCs with their high-risk patients and includes the following functionalities: an automatically generated list of veterans on the team's panel who are at highest risk (based on CAN score) and for whom GoCCs should

be prioritized; the ability to manually add other veterans to the list; a table that provides a snapshot of high-risk veterans' status with respect to completion of a GoCC, along with information about upcoming appointments; and the ability to assign, schedule, and manage tasks associated with a GoCC across the patient's health care team (for example, identifying and scheduling patients, preparing patients and families for the discussion, sending the patient education materials, discussing values and goals, making shared decisions about LST, helping patients identify a health care agent through an advance directive, consulting for new services).

### Demonstration Project

A two-year demonstration project was inaugurated to establish proof of concept (that is, feasibility and practical potential) and to ensure that materials and approaches were value-added, consistent with LSTDI goals and objectives, and useful to clinicians caring for patients with serious illness. Four VA health care systems participated: two medium (80,000 to 150,000 enrolled) and two large facilities (at least one site with more than 150,000 enrolled patients, at least one site with an integrated health record database across two facilities). All sites provide inpatient, outpatient, and home care services and have outpatient primary care clinics at locations separate from the primary medical center(s). Three sites have on-site extended care facilities and hospice beds.

The demonstration sites were authorized to implement a draft form of Handbook 1004.03 and were supported by NCEHC staff who provided both on-site and virtual technical assistance. In the first year, sites established LSTDI advisory boards to oversee implementation and submit ongoing feedback to NCEHC. Advisory boards were multidisciplinary and represented key clinical stakeholder groups involved in caring for patients with serious illness across the continuum of care, as well as the members from ethics, quality improvement, education, and facility leadership. During the first year, this group was responsible for drafting the facility's LST policy, establishing and executing a staff education plan, and installing and testing the LST progress note and order set prior to use. By January 2015 all facilities began new processes, including use of the LST progress note and order set for documenting GoCCs. Throughout, advisory boards were responsible for monitoring implementation, submitting feedback to NCEHC on all materials and processes related to the initiative, and implementing multiple iterative changes to the EHR and other processes and materials based on consensus feedback from all sites.

Recommendations from demonstration sites resulted in changes to the draft national policy—in some cases to make process requirements more flexible (for example, time frames for completing GoCCs), and in others, to make them more explicit (for example, the role of nurses, so-

cial workers, and other team members in GoCC-related processes). Each site was asked to review change proposals from other sites, and when there was disagreement (for example, about changes in language within the LST note template), compromises were made to maximize utility and mutual understanding across facilities and to promote processes supportive of overarching goals. All the materials now available nationally were informed by or are a direct outgrowth of the lessons learned and strong practices generated during the demonstration project. The demonstration project resulted in the emergence of a cadre of champions who continue to support national rollout as training faculty and consultants to VA facilities implementing new LSTDI practices.

### Evaluation

Evaluation is critical to informing and improving implementation of the LSTDI and to establishing an evidence base for its overall effectiveness and the relative effectiveness of each of its elements. We have identified both short- and long-term outcomes that we expect to result from the LSTDI (see [Figure 1](#)), including goal-concordant care for seriously ill veterans. Goal concordance has been an elusive outcome to measure, particularly using the type of administrative data generally available through the EHR in most health care systems. However, because of the VHA's mandated practice standards, including use of the standardized note title and associated LST health factors (computerized data elements that capture patient information for which no standard code exists) stored in VA's CDW, we will be able to quantitatively evaluate whether medical orders align with the patient's goals and LST decisions—and do so over the illness trajectory so long as changes are documented in a new progress note. Follow-up chart reviews will be necessary to establish whether the LST plan was implemented as documented.

As LSTDI matures, we anticipate that GoCCs will occur more often in outpatient settings, earlier in the patient's illness trajectory, and across a range of serious chronic illnesses such as congestive heart failure, metastatic cancer, chronic obstructive pulmonary disease, end-stage renal disease, and serious neurological disorders. We believe that the LSTDI offers an approach to achieving goal-concordant care for patients with serious illness that may be adaptable to health care institutions beyond VHA. Rigorous evaluation and research can help substantiate this hypothesis.

Early evaluation of the LSTDI is ongoing, starting with an analysis of the 6,300 GoCCs conducted during the four-site demonstration project. Evaluation aims include describing patient, provider, and facility characteristics associated with GoCCs; assessing variability in patient goals and LST decisions based on variables such as the patient's decision-making capacity and diagnosis; and providing a preliminary assessment of the LSTDI's impact on outcomes such as location of death, early consultation with palliative



care, intensity and cost of health care utilization, and surrogate satisfaction with end-of-life decision making. We are also conducting in-depth qualitative interviews with key informants at the demonstration sites and nationally to understand how implementation of the LSTDI is being sustained and spread now that direct, one-to-one NCEHC support has ended. Interim reporting of strong practices will be disseminated to inform national rollout.

A four-year study has been funded through the VA's Quality Enhancement Research Initiative to examine implementation of practices to promote GoCCs in home-based primary care and nursing homes. In addition, comparative effectiveness and randomized control studies are currently being developed with other research collaborators. We will report results of all this work in future publications.

## CONCLUSION

The LSTDI is designed to improve the quality of care received by veterans with serious illness by ensuring that their goals, values, and preferences for LSTs are elicited, documented, and honored across the continuum of care. The LSTDI moves beyond traditional advance care planning by addressing well-documented barriers to goal-concordant care for seriously ill patients. It establishes standards and robust support with the goal that all VHA patients whose condition places them at risk for a life-threatening clinical event in the next one to two years are given the opportunity to discuss their diagnosis and prognosis and identify their goals and values as a basis for establishing or modifying a plan and actionable medical orders to direct the use of LSTs in their care. With more than nine million enrolled veterans, the VHA represents the largest health care organization in the United States and is well positioned to evaluate population-based outcomes related to this initiative. We look forward to the results of ongoing research.

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## REFERENCES

1. Bernacki RE, Block SD American College of Physicians High Value Care Task Force. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA Intern Med.* 2014;174:1994–2003.
2. Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life.* Washington, DC: National Academy of Sciences, 2015.
3. Berlinger N, Jennings B, Wolf SM. *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life.* 2nd ed. New York City: Oxford University Press, 2013.
4. National Quality Forum. *Safe Practices for Better Healthcare—2010 Update: A Consensus Report.* 2010. Accessed Jul 6, 2018. <http://www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=25689>.
5. Kim SY, Karlawish JH, Caine ED. Current state of research on decision-making competence of cognitively impaired elderly persons. *Am J Geriatr Psychiatry.* 2002;10:151–165.
6. Raymont V, et al. Prevalence of mental incapacity in medical inpatients and associated risk factors: cross-sectional study. *Lancet.* 2004 Oct 16-22;364:1421–1427.
7. Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med.* 2010 Apr 1;362:1211–1218.
8. Vig EK, et al. Surviving surrogate decision-making: what helps and hampers the experience of making medical decisions for others. *J Gen Intern Med.* 2007;22:1274–1279.
9. Schenker Y, et al. I don't want to be the one saying 'We should just let him die': intrapersonal tensions experienced by surrogate decision makers in the ICU. *J Gen Intern Med.* 2012;27:1657–1665.
10. Smith AK, White DB, Arnold RM. Uncertainty—the other side of prognosis. *N Engl J Med.* 2013 Jun 27;368:2448–2450.
11. Walling A, et al. Evidence-based recommendations for information and care planning in cancer care. *J Clin Oncol.* 2008 Aug 10;26:3896–3902.
12. Tulsky JA, et al. A research agenda for communication between health care professionals and patients living with serious illness. *JAMA Intern Med.* 2017 Sep 1;177:1361–1366.
13. Yung VY, et al. Documentation of advance care planning for community-dwelling elders. *J Palliat Med.* 2010;13:861–867.
14. Bomba PA, Kemp M, Black JS. POLST: an improvement over traditional advance directives. *Clev Clin J Med.* 2012;79:457–464.
15. National POLST Paradigm. Home page. Accessed Jul 6, 2018, 2018. <http://polst.org>.
16. US Department of Veterans Affairs National Center for Ethics in Health Care. *The Life-Sustaining Treatment Decisions Initiative.* 2018. Accessed Jul 6 <https://www.ethics.va.gov/LST.asp>.
17. US Department of Veterans Affairs, Veterans Health Administration. *Life-Sustaining Treatment Decisions: Eliciting, Documenting and Honoring Patients' Values, Goals and Preferences.* VHA Handbook 1004.03. Jan 11, 2017. Accessed Jul 6, 2018. [http://www.va.gov/vhapublications/ViewPublication.asp?pub\\_ID=4308](http://www.va.gov/vhapublications/ViewPublication.asp?pub_ID=4308).

18. Cornell Law School, Legal Information Institute. 38 CFR 17.32—Informed Consent and Advance Care Planning [62 FR 53961, Oct 17, 1997.] Jul 1, 2007. Accessed Jul 6, 2018. <https://www.law.cornell.edu/cfr/text/38/17.32>.
19. US Department of Veterans Affairs, Veterans Health Administration. State-Authorized Portable Orders (SAPO). VHA Handbook 1004.04. Oct 25, 2012. Accessed Jul 6 2018. [https://www.ethics.va.gov/docs/policy/vha\\_1004\\_04\\_state\\_auth\\_port\\_ordrs\\_2012\\_10\\_25.pdf](https://www.ethics.va.gov/docs/policy/vha_1004_04_state_auth_port_ordrs_2012_10_25.pdf).
20. Moss AH, et al. Utility of the “surprise” question to identify dialysis patients with high mortality. *Clin J Am Soc Nephrol*. 2008;3:1379–1384.
21. Moss AH, et al. Prognostic significance of the “surprise” question in cancer patients. *J Palliat Med*. 2010;13:837–840.
22. Downar J, et al. The “surprise question” for predicting death in seriously ill patients: a systematic review and meta-analysis. *CMAJ*. 2017 Apr 3;189:E484–E493.
23. VitalTalk. Home page. Accessed Jul 6, 2018. <http://www.vitaltalk.org>.
24. US Department of Veterans Affairs, National Center for Ethics in Health Care. Resources for Clinical Staff Caring for High-Risk Patients: Life-Sustaining Treatment Decisions Initiative. Accessed Jul 6, 2018. <https://www.ethics.va.gov/LST/ClinicalStaffResources.asp>.
25. Dy S. Ensuring documentation of patients’ preferences for life-sustaining treatment: brief update review. In: *Making Health Care Safer II: An Updated Critical Analysis of the Evidence for Patient Safety Practices*. Rockville, MD: Agency for Healthcare Research and Quality; 2013, 320–324. AHRQ Publication No. 13-E001-EF.
26. US Department of Veterans Affairs, National Center for Ethics in Health Care. Implementing New Practices: Resources for Health Care Facilities: Life-Sustaining Treatment Decisions Initiative. Accessed Jul 6, 2018. <https://www.ethics.va.gov/LST/ImplementationResources.asp>.
27. Starmer AJ, et al. Changes in medical errors after implementation of a handoff program. *N Engl J Med*. 2014 Nov 6;371:1803–1812.
28. US Department of Veterans Affairs, National Center for Ethics in Health Care. LST Progress Note Template—Entire Text. Jan 4, 2018. Accessed Jun 23, 2018. [https://www.ethics.va.gov/LST/LST\\_Template\\_Text.pdf](https://www.ethics.va.gov/LST/LST_Template_Text.pdf).
29. Wang L, et al. Predicting risk of hospitalization or death among patients receiving primary care in the Veterans Health Administration. *Med Care*. 2013;51:368–373.