SERIOUS ILLNESS COMMUNICATION PROJECT

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The figure below illustrates the overall study design we will use for the Serious Illness Conversation Guide (SICG in the diagram) study. Details of participant identification can be found in section 3.0 (pg 8-10).
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1.0 INTRODUCTION

1.1 Overview

The purpose of the study is to evaluate the impact of implementing a “Serious Illness Conversation Guide” to guide patient/family-clinician discussions and planning about end-of-life care decisions. The goal of the intervention is to improve achievement of patient care priorities and peacefulness at the end of life for patients with serious and life-threatening illness and their families. We hypothesize that patients whose physician is trained to use and adheres to the elements of the Serious Illness Conversation Guide will demonstrate enhanced consistency between documented key priorities and care received, and will experience greater peace in the final month of life; similarly, their families will experience higher satisfaction with care. This project is funded by Partners Healthcare and gifts from the Margaret T. Morris Foundation and the Charina Endowment Fund.

1.2 Background and Rationale

Dana-Farber strives for excellence in all areas of patient care, including excellent end-of-life care. Unfortunately, the evidence about quality of care at end-of-life shows that there are deficiencies that can be addressed. Our aim at DFCl is to be at the forefront of providing excellent, state-of-the-art disease-directed treatment as well as excellent end-of-life care and advance care planning. These two goals are not mutually exclusive; both can be achieved at the same time. If end-of-life care is not optimal, it has many negative consequences including unnecessary suffering, family stress, prolongation of the dying process, high costs, underutilization of hospice care, physician burnout, and patient mistrust of the health care system. Most Americans wish to die at home and to avoid heroic measures, yet most die in an institutional setting, including hospitals and nursing homes (1), and 20% die in intensive care units (2). The transition of death from home to institutional settings over the past forty years has been promoted by the advent of new medical technologies. While these remarkable technologies can be life-saving for certain patients, for many others, these aggressive therapies may simply prolong the dying process and extend suffering. In addition, many patients who die in institutional settings die with under-treated pain and dyspnea (3, 4). Although the use of hospice for the care of the terminally ill has increased ten-fold from 158,000 patients in 1985 to over 1.56 million in 2009 (5), the average length of stay in hospice has decreased over the same time period. Fifteen percent of hospice patients are referred in their last week of life, where benefits to the patient and family may be limited (5, 6). In one recent study, the median length of hospice stay for patients with lung cancer was 4 days (7).

We propose a systematic approach, based on best practices and existing evidence, for clinicians to discuss and document, in an accessible format, critical end-of-life goals and values. While it is often difficult to plan for situations that have a high level of uncertainty, clinicians can give patients with limited life expectancy (prognosis of less than one year) some idea of what to expect. However, clinicians need training on how to have these discussions and how to effectively deal with patient and family emotional responses to these difficult conversations. While advance care plans should encourage patients to express individual preferences and concerns in an open-ended manner (8, 9), certain key information should be ascertained and communicated to all clinicians in an electronic format, especially given the multiple care transitions that patients encounter. This key information, including the patient’s understanding of
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prognosis, fears, goals for treatment, and willingness to tolerate suffering, is not currently readily accessible in the medical record.

We have developed, piloted, and refined a Serious Illness Conversation Guide program, based on an extensive literature review (see Background Document, attached in Appendix A), as well as a quality improvement initiative in which oncologists in GI and Neurooncology at DFCI were supported in conducting early values and goals discussions with their patients. We evaluated the success of this intervention by examining the proportion of 160 patients whose physician documented values and goals in the ACP module before this intervention (<4%) and those who did after the QI intervention (>90%). Following these quality-improvement interventions, we received extensive feedback from the clinicians about their experiences in conducting and documenting these discussions; this feedback informed our development of our checklist and our training program. Clinicians found it feasible to conduct these early discussions. However, we found that there was considerable variation in the documentation clinicians provided about their conversations, and that key areas of such conversations were not included in clinician documentation (e.g., prognosis was included in 42%, information preferences in 7%, goals in 15%, fears in 2%, function in 8%, and tradeoffs in 13%). These findings suggest that oncologists will benefit from additional structure and training in conducting high-quality discussions about end-of-life care goals in order to meet national consensus standards.

The aim of the Serious Illness Conversation guide is to provide clinicians with an evidence-based structure for eliciting and documenting this vital information and to help open the door for patients, families, and clinicians to reflect on and talk about end-of-life issues in an ongoing way. Our hypothesis is that adherence to this guide will enhance patient understanding and allow control over their own decisions, relieve burdens of decision-making on family members, and achieve a state of peace as patients approach the end of life. This conversation guide is designed to support clinicians in conducting the most optimal conversation (patients should have the opportunity to understand where they stand in their illness, to articulate concerns about the future, to express their goals, and to share their wishes about medical care and family involvement) at the right time (in the outpatient setting, before a crisis), with the right people (family, key clinicians) present or included, guided by the right clinician (the person who knows the patient and his/her medical situation best).

2.0 OBJECTIVES
This protocol is a pilot intervention study; we plan to train clinicians and assess the feasibility and impact of the Serious Illness Conversation Guide program.

The main objectives of the study are:
- To identify and achieve patient health care goals, and improve peace at the end of life for patients with serious and life-threatening illness.
- To produce a proven, effective, Serious Illness Conversation Guide (SICG), for use by clinicians, to guide end-of-life conversations and care planning with patients and families.

Primary Aim 1: Enhanced goal-consistent care
Hypothesis: Patients whose physician is trained to use and adheres to the Serious Illness Conversation Guide will receive care that is more consistent with their key life priorities during
the last week and the last 3 months of life than patients whose physician is not trained to use the Serious Illness Conversation Guide.

**Primary Aim 2: Peace**

**Hypothesis:** Patients whose physician is trained to use and adheres to the Serious Illness Conversation Guide will be more likely to report being at peace in the final 3 months of life than patients whose physician is not trained to use the Serious Illness Conversation Guide. Secondary outcomes of the study can be found in the table below.

**Table 1. Primary and Secondary Specific Aims**

<table>
<thead>
<tr>
<th>Aim</th>
<th>Hypothesis</th>
<th>Time Frame</th>
<th>Measurement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Primary Outcomes</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Specific aim 1.1: Enhanced goal-consistent care</td>
<td>Patients whose physician is trained to use and adheres to the <em>SICG</em> will receive care that is more consistent with their key life priorities during the last week and the last 3 months of life than patients whose physician is not trained to use the <em>SICG</em>.</td>
<td>7 days after SICG*; 2 months after enrollment**; every 2 months</td>
<td>Self-designed “Life priorities” web survey; “Family Perception” survey</td>
</tr>
<tr>
<td>Specific aim 1.2: PEACE</td>
<td>Patients whose physician is trained to use and adheres to the <em>SICG</em> will be more likely to report being at peace in the final 3 months of life than patients whose physician is not trained to use the <em>SICG</em>.</td>
<td>Baseline; 7 days after SICG*; 2 months after enrollment**; every 2 months</td>
<td>PEACE questionnaire (Prigerson) web survey</td>
</tr>
<tr>
<td><strong>2. Process Measures: Patient-derived aims</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specific aim 2.1: Therapeutic Alliance</td>
<td>Patients whose physician is trained to use and adheres to the <em>SICG</em> will rate patient-clinician therapeutic alliance higher following the conversation than patients whose physician is not trained to use the <em>SICG</em>.</td>
<td>Baseline; 7 days after SICG*; 2 months after enrollment**; every 2 months</td>
<td>Modified Human Connection Scale (Mack 2009) by web survey</td>
</tr>
<tr>
<td>Specific aim 2.2: Anxiety</td>
<td>Patients whose physician is trained to use and adheres to the <em>SICG</em> will have lower anxiety after the conversation than patients whose physician is not trained to use the <em>SICG</em>.</td>
<td>Baseline; 7 days after SICG*; 2 months after enrollment**; every 2 months</td>
<td>GAD-7 anxiety scale by web survey</td>
</tr>
<tr>
<td>Specific aim 2.3: Depression</td>
<td>Patients whose physician is trained to use and adheres to the <em>SICG</em> will not have worse depression after the conversation than patients whose physician is not trained to use the <em>SICG</em>.</td>
<td>Baseline; 7 days after SICG*; 2 months after enrollment**; every 2 months</td>
<td>PHQ-9 depression scale by web survey</td>
</tr>
<tr>
<td>Specific aim 2.4: Quality of Communication</td>
<td>a) Patients whose physician is trained to use and adheres to the <em>SICG</em> will report more and higher-quality conversations with their loved ones about their wishes than patients whose physician is not trained to use the <em>SICG</em>.</td>
<td>Baseline; 7 days after SICG*; 2 months after enrollment**; every 2 months</td>
<td>Self-designed “Quality of Communication with family” web survey</td>
</tr>
<tr>
<td></td>
<td>b) Patients whose physician is trained to use and adheres to the <em>SICG</em> will report more and higher-quality conversations with their doctor about their wishes than patients whose physician is not trained to use the <em>SICG</em>.</td>
<td>Baseline; 7 days after SICG*; 2 months after enrollment**; every 2 months</td>
<td>“Quality of Communication with Clinician” by web survey</td>
</tr>
</tbody>
</table>
| Specific aim 2.5: | Patients will find the use of the *SICG* by their physician | 7 days after SICG*; | Self-designed “Patient
<table>
<thead>
<tr>
<th>Pt Acceptability*</th>
<th>acceptable.</th>
<th>2 months after enrollment**</th>
<th>acceptability” web survey</th>
</tr>
</thead>
</table>

### 3. Secondary Outcomes: Family-derived aims

- **Specific aim 3.1: Quality of Death**
  - Families of patients whose physician is trained to use and adheres to the SICG will rate the patient’s quality of life at end-of-life better than families of patients whose physician is not trained to use the SICG.
  - 6 to 12 weeks after patient death
  - Modified QODD administered by phone or in person by social worker/fellow

- **Specific aim 3.2: Quality of Communication with Patient**
  - Families of patients whose physician is trained to use and adheres to the SICG will report more and higher-quality conversations with the patient than families of patients whose physician is not trained to use the SICG.
  - Baseline; every 2 months
  - Self-designed “Quality of Communication with Patient” web survey

### 4. Process Measures: Clinician-derived aims (volunteer clinicians only)

- **Specific aim 4.1: MD Acceptability**
  - a) Clinicians will find the use of the SICG acceptable.
  - After first SICG; end of study
  - “Clinician acceptability” paper survey
  - b) Clinicians will not find the use of the SICG overly time-consuming.
  - After every SICG conversation
  - “Post-conversation form” paper survey

- **Specific aim 4.2: MD Prognostic Communication**
  - Clinicians who are trained to use the SICG will communicate more specific prognostic information, compared to untrained clinicians.
  - After every SICG conversation
  - “Post-conversation form” paper survey

- **Specific aim 4.3: MD Attitudes**
  - Clinicians who are trained to use the SICG will have improved attitudes about having end-of-life conversations, compared to untrained clinicians.
  - Enrollment; immediately after training*; end of study
  - Self-designed “Clinician Attitudes” paper survey

- **Specific aim 4.4: MD Confidence**
  - Clinicians who are trained to use the SICG will have improved confidence in carrying out end-of-life conversations, compared to untrained clinicians.
  - Enrollment; immediately after training*; end of study
  - Self-designed “Clinician Confidence” paper survey

### 5. Process Measures: System improvement

- **Specific aim 5.1: Documentation**
  - a) Clinicians who are trained to use the SICG will document patient priorities more often and more completely than untrained clinicians.
  - End of study
  - Chart reviews
  - b) Clinicians who are trained to use the SICG will complete more SICG components with their patients by 4 months before death than untrained clinicians.
  - End of study
  - Chart reviews
  - c) Patients whose physician is trained to use and adheres to the SICG will be more likely to have a completed HCP than patients of untrained clinicians.
  - End of study
  - Chart reviews

- **Specific aim 5.2: Feasibility**
  - Use of the SICG is feasible.
  - After every SICG not completed
  - # completed/assigned; “Post-conversation form”

- **Specific aim 5.3: Performance of the Surprise Question screening process**
  - The Surprise Question is a feasible and successful screening tool to identify patients at high risk of death within a year.
  - After two years of patient screening
  - Analysis of patients about whom the Surprise Question was asked

### 6. Secondary Outcomes: Resource use

- **Specific aim 6.1: Aggressiveness**
  - Patients whose physician is trained to use and adheres to the SICG will have more use of hospice and less
  - After death
  - Palliative Care Quality Indicators—chart
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<table>
<thead>
<tr>
<th>of care</th>
<th>aggressive care at end-of-life than patients whose physician is not trained to use the SICG.</th>
<th>review</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specific aim 6.2: Place of Death</td>
<td>Patients whose physician is trained to use and adheres to the SICG will be more likely to die at home than patients whose physician is not trained to use the SICG.</td>
<td>After death</td>
</tr>
<tr>
<td>Specific aim 6.3: Cost of care</td>
<td>Patients whose physician is trained to use and adheres to the SICG will incur lower costs of care at end-of-life than patients whose physician is not trained.</td>
<td>After death</td>
</tr>
</tbody>
</table>

* Intervention group only
**Control groups

3.0 RESEARCH SUBJECT SELECTION
The subjects of this study will be the clinicians (physicians, nurse practitioners, and physician’s assistants) conducting the conversations, their patients with high-risk cancer, and a friend or family member of the patient.

**Clinicians:**
Clinicians who care for patients with selected high-risk cancers will be asked to volunteer for this pilot study. We plan to invite all DFCI physicians, nurse practitioners, and physician’s assistants in the following disease centers: breast oncology, gastrointestinal oncology, head and neck oncology, genitourinary oncology, leukemia program, lymphoma program, melanoma, neuro-oncology, sarcoma, and thoracic oncology. We plan to accrue 50-60 clinicians. If more clinicians volunteer, we will allow more to be enrolled in the study. We will enroll clinicians over a three-month period and accrue their patients over a year. The initial group of clinicians will be recruited from DFCI and its satellite clinics; DFCI Gynecology-Oncology specialists will be excluded from the study, as there is an on-going trial investigating communication about end-of-life in this population. We plan to begin with four smaller disease centers at DFCI (Sarcoma, Head and Neck, Neurooncology, and Melanoma) and expand to other disease centers in phases. Once our initial implementation in these disease centers is operational (i.e., we are able to successfully recruit, randomize, and train clinicians; recruit and enroll patients and family members; and remind clinicians to conduct SICG conversations), we will phase-in additional disease centers. Milford and South Shore will be added last.

**Patients:**
Patients over 18 are eligible. Patients must speak English, have the ability to consent, and have a friend or family member who consents to be available to answer surveys every two months and after patient death (see definition of friend/family member below). Adult patients of all races and ethnic backgrounds, as well as all religious preferences, are eligible. Obstetric patients will be excluded. Since this is a preliminary trial, which relies intensively on the clinician’s communication skills about a culturally-complex topic, we believe that relying on interpreters, who do not have experience with these conversations, and who have been shown to be unreliable translators of emotionally-difficult material (10, 11), might expose patients and their families to greater stress and distress. Therefore, we request that all non-English-speaking patients be excluded from this phase of the research study. We are also beginning to develop culturally-appropriate versions of the conversation guide for other key populations, which we intend to test in a subsequent study.
We anticipate enrolling 476 patients, split among the 3 study arms (trained clinicians, non-trained clinicians, and non-volunteer clinicians). Each clinician will have 5-40 enrolled patients, depending on the disease center. Patients will be selected in the same manner, regardless of their physician’s participation or randomization assignment.

Patients with the following cancers will be screened: breast, gastric, intestinal, esophageal, pancreatic, biliary, colorectal, hepatocellular, head and neck, renal, bladder, prostate, AML, ALL, lymphoma, melanoma, glioblastoma multiforme (GBM), other brain tumors, sarcoma, and lung. These cancers were chosen because they are high-risk cancers and they represent a population of patients who would benefit from early discussions of end-of-life values and goals. All adult outpatients who receive their primary oncology care at DFCI will be screened for eligibility. Since this is a RCT of a quality improvement intervention, we will allow disease centers to customize their identification of patients, since they have the most knowledge about patient prognoses.

All patients with high mortality diagnoses (e.g., hepatocellular, biliary gastric, unknown primary, esophageal, pancreatic, intestinal, and glioblastoma multiforme), will be eligible after their 4th clinic visit. This will allow time for the clinician-patient relationship to be established, and will help assure that these patients plan to receive ongoing care at DFCI. For the patients with high mortality diagnoses eligible after 4 visits, a CORIS roster will produce a weekly list of patients who have an appointment with the enrolled clinicians, and meet the eligibility criteria based on ICD-9 code. For example, all patients with ICD-9 code 191: “Malignant neoplasm of the brain” with 4 visits will be screened for eligibility for the study by reviewing their LMR notes for the diagnosis of GBM. For all other diagnoses, the study coordinator will attend disease center clinical meetings where patients are discussed and will ask the MD or NP to identify patients by asking the question “Would you be surprised if this patient died this year?” If the answer to this question is “no,” the patient will be eligible to participate in the study if they meet other study requirements. Patient identification for each of the cancers is summarized in the table below.

<table>
<thead>
<tr>
<th>Disease center/cancer</th>
<th>ID criteria</th>
<th>Patient Identification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neuro: GBM</td>
<td>4 visits</td>
<td>CORIS report: codes 191, 192, 239.6 + chart review “GBM”</td>
</tr>
<tr>
<td>Neuro: other brain tumors</td>
<td>Surprise</td>
<td>Review patient list at weekly meeting</td>
</tr>
<tr>
<td>Unknown primary</td>
<td>4 visits</td>
<td>CORIS report: code 199, 239.9</td>
</tr>
<tr>
<td>Metastatic disease</td>
<td>4 visits</td>
<td>CORIS report: codes 196, 197, 198 + chart review</td>
</tr>
<tr>
<td>GU: Renal</td>
<td>Surprise</td>
<td>Review patient list at weekly meeting</td>
</tr>
<tr>
<td>GU: Bladder</td>
<td>Surprise</td>
<td>Review patient list at weekly meeting</td>
</tr>
<tr>
<td>GU: Prostate</td>
<td>Surprise</td>
<td>Review patient list at weekly meeting</td>
</tr>
<tr>
<td>Thoracic: Lung</td>
<td>Surprise</td>
<td>Review patient list at weekly meeting</td>
</tr>
<tr>
<td>GI</td>
<td>Surprise</td>
<td>Review patient list with individual MDs</td>
</tr>
<tr>
<td>Melanoma</td>
<td>Surprise</td>
<td>Review patient list at weekly meeting</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>Surprise</td>
<td>Review patient list at weekly meeting</td>
</tr>
<tr>
<td>Head and Neck</td>
<td>Surprise</td>
<td>Review patient list at weekly meeting</td>
</tr>
<tr>
<td>Hem Malig: Leukemia</td>
<td>Surprise</td>
<td>Review patient list with individual MDs</td>
</tr>
</tbody>
</table>
Breast  Surprise  Review patient list at bi-monthly meeting
Lymphoma  Surprise  Review patient list with individual MDs

**Friends/Family Members:**
The definition we are using for “friend or family member” is given here; the terms “friend or family member” used in the rest of this protocol document refer to this definition. Patients will identify a friend or family member who may be able to participate in the study. This person should be the patient’s Health Care Proxy (HCP), or a close friend or family member who is involved in helping the patient think about decisions related to their health care, even if they have not been legally appointed as Health Care Proxy. The friend or family member does not have to be local or need to attend clinic appointments with the patient (see section 4.0 for consent procedures). The friend or family member needs to be available to answer surveys by email or postal mail, and by phone. The friend or family member must be over 18, speak English, and have the ability to provide consent. Adults of all races and ethnic backgrounds, as well as all religious preferences, are eligible.

We anticipate enrolling 476 friends/family members, split among the 3 study arms (trained clinicians, non-trained clinicians and non-volunteer clinicians). Friends/family members will be selected in the same manner, regardless of the patient’s physician’s participation or randomization assignment.
Fig. 2: Patient selection

IDENTIFYING PATIENTS APPROPRIATE FOR SICC STUDY

- List of MD teams
- Which type of cancer?
  - GI
    - Lung
    - Melanoma
    - Sarcoma
    - Head and Neck
    - AML, ALL
    - Renal
    - Bladder
    - Prostate
    - Breast
    - Other brain tumors
  - GBM
    - Unknown primary
  - 4th visit scheduled
  - MD/NP answers NO to “Surprise” question
  - Study coordinator obtains list of patients with upcoming visits via CORIS
  - Study coordinator obtains patient list from disease center
  - Study coordinator calls to explain study and invite participation

Legend:
- Eligibility criteria
- Study process
- Cancer/disease center

PATIENT ELIGIBLE IF over 18, speaks English, FLUS.
4.0 RESEARCH SUBJECT ENTRY

Clinicians:
The study investigators (SDB, REB, and MMAH) will present to each eligible Medical Oncology disease center group to explain the purpose and background of the study, and to encourage physician, NP, and PA participation. During the presentation, clinicians who are interested in participating in and volunteer for the research study will be allowed to enroll and be consented by the study coordinator, as described in section d below. Following the presentation, clinicians who did not volunteer to participate during the disease center presentation will receive an email from the study investigators, inviting them to consider participating (see Appendix B for recruitment email).

a. When clinicians respond ‘no’, the study coordinator will send them a follow-up email thanking them for considering participation, and notifying them that we will be inviting their patients to participate, in an effort to better understand patients’ advance care planning experiences and preferences.

b. When clinicians are uncertain, the study coordinator will contact them to address any questions or concerns.

c. When clinicians do not respond to the first email, the study coordinator will send a second email. If the clinicians do not respond to the second email, the study investigators (REB, SDB, or MMAH) will follow up with a phone call or in-person request.

d. When clinicians agree to consider participating, the study coordinator will schedule to meet the clinician at his/her office at a convenient time to discuss the consent form and enrollment (see Appendix C for informed consent form). The written consent form will explain the background and purpose for the research study; and describe in detail what participation entails, including the amount of time spent in training and coaching, and on responding to surveys. The consent form will explain randomization into trained or non-trained arm, and the opportunity for non-trained clinicians to receive training at study completion. The consent form will also inform the clinician of the benefits of participating in the study. The consent form will then describe how the clinician’s patients will be identified and enrolled in the study, and how those patients will be flagged as requiring a SICG conversation. The consent form will state that patients of physicians who do not enroll in the study will also be invited to participate. Finally, the consent form will outline the potential minimal risks to the clinician, patient, and friend or family member, and the procedures for discontinuing participation in the study, should the clinician wish to do so. The study coordinator will explain the research study in detail, review the informed consent form, and encourage questions. If the clinician agrees to participate, they will then be asked to sign the informed consent document. After signing the document, they will be asked to answer the “Clinician Confidence” and “Clinician Attitudes” baseline surveys, described further below.

e. For physicians who work with a nurse practitioner/physician’s assistant in an exclusive relationship (i.e., the physician-NP/PA pair only work with each other), their collaborating NP/PA will be eligible to enroll in the study as well and will be consented in the same fashion as the physicians. The nurse practitioners who work with more than one physician will be excluded from the study as they will contaminate the randomization of physicians.

Volunteer clinicians will then be randomized, using a SAS program, half into the intervention group, and half into a standard care group. The intervention group will receive training in using the SICG and ongoing coaching (see section 5.3 below for detailed description). Volunteers in
the standard care group will provide usual care, and will be able to receive the same training and coaching after completion of the study. In addition, patients of the clinicians who did not volunteer for the intervention (approximately 25-30 clinicians) will serve as a second control group. They will receive usual care.

**Patients:**
Patients will be recruited in the same manner, independent of their physician’s participation or randomization assignment. Eligible patients will receive a letter inviting them to participate in the research study. The letter (found in Appendix B) will briefly describe the study, what participation entails, and how patients were identified, and will invite patients who are not interested to call the study staff or to send in the opt-out card to opt-out of the study. The study coordinator will call patients who do not contact the study staff within 10 days of the recruitment letter to ask them to consider participating. The study coordinator will call the patient a maximum of 3 times to attempt the recruitment phone call: two calls leaving a voice message, and one call not leaving a voice message. During the recruitment phone call (see Appendix B for phone call script), the study coordinator will review the study and informed consent form, including the need for a friend or family member to participate in the study, ask eligibility questions, and encourage questions. If the patient is interested in participating in the study, the study coordinator will ask the patient to identify a friend or family member who might be willing to participate in the study. This person should be the patient’s Health Care Proxy (HCP), or a close friend or family member who is involved in helping the patient think through decisions about their health care, even if they have not been legally appointed as Health Care Proxy. The study coordinator will obtain contact information, including address, for the friend or family member, and ask the patient to inform this friend or family member that the study staff will be sending them a letter about the study.

The study coordinator will then arrange to meet the patient at their next clinic appointment to give the patient an opportunity to review the study and written consent form in detail, and to consider participating (see Appendix C for informed consent form). The study coordinator will call the patient 1-2 days before their appointment to remind the patient to meet the study coordinator at the clinic to review the informed consent.

At the consent visit, the study coordinator will give the patient a paper copy of the informed consent form to review. The written consent form will describe how the patients were identified for the study. The consent form will then explain the background and purpose for the research study and describe in detail what participation entails, including the amount of time spent responding to surveys and the need for a friend or family member to participate. Finally, the consent form will inform the patient of the potential benefits and minimal risks of participating in the study, and the procedures for discontinuing participation in the study, should the patient wish to do so. The study coordinator will read the consent document with the patient in a private area of the clinic waiting room. If the patient wishes to participate, they will then be asked to sign the written consent form.

After signing the consent form, intervention-arm patients will be given a one-page preparation letter for their SICG conversation with their clinician (see Appendix E). After signing the form, all patients will be asked to complete the pre-visit survey of demographic and baseline measures, described further below. If patients do not want to participate, they will
be thanked for their time. The same process will occur for all patients, whether their doctor is a trained volunteer, non-trained volunteer, or non-volunteer. Patients will not know whether their physician is in the intervention, standard care, or secondary control group.

If at any point during recruitment, the patient states that he/she is not interested in participating in the study, the study coordinator will ask the patient if he/she would be willing to say why he/she is not interested in participating. We are interested in this information so that we can describe the patient population in our trial.

**Friend or Family Member:**
Friends/family members will be recruited in the same manner, independent of the patient’s physician’s participation or randomization assignment. Eligible friends/family members, who were identified by a participating patient, will receive a letter inviting them to participate in the research study. The letter (found in Appendix B) will briefly describe the study, what participation entails, and how friends/family members were identified, and will invite friends/family members who are not interested to call the study staff or to send in the opt-out card to opt-out of the study. The study coordinator will call friends/family members who do not contact the study staff within 10 days of the recruitment letter to ask them to consider participating. The study coordinator will call the patient a maximum of 3 times to attempt the recruitment phone call: two calls leaving a voice message, and one call not leaving a voice message. During the recruitment phone call (see Appendix B for phone call script), the study coordinator will review the study and informed consent form, ask eligibility questions, and encourage questions. If the friend/family member is interested in participating in the study, the study coordinator will arrange to meet the friend/family member at the patient’s next clinic appointment (or a time more convenient for the friend/family member) to give the friend/family member an opportunity to review the study and written consent form in detail, and to consider participating (see Appendix C for informed consent form). The study coordinator will call the friend/family member 1-2 days before their appointment to remind the friend/family member to meet the study coordinator at the clinic to review the informed consent. For friends/family members who say during the recruitment phone call that they cannot come to DFCI and prefer remote consent, we will conduct remote consent as described further below.

The written consent form will describe how the patients and friends/family members were identified for the study. The consent form will then explain the background and purpose for the research study and describe in detail what participation entails, including the amount of time spent responding to surveys. Finally, the consent form will inform the friend or family member of the potential benefits and minimal risks of participating in the study, and the procedures for discontinuing participation in the study, should the friend or family member wish to do so. The study coordinator will read the consent document with the friend or family member in a private area of the clinic waiting room. If the friend or family member wishes to participate, they will then be asked to sign the written consent form. After signing the form, the friend or family member will be asked to complete the baseline survey, described further below.

If the friend/family member asks to consent remotely, the study coordinator will send a copy of the consent form in the mail to the friend/family member, along with a self-addressed, stamped envelope. When the friend/family member has received the consent form in the mail, the study
coordinator will call the friend/family member and review the consent form with the friend/family member on the phone (see Appendix B for remote consent phone call script). If the friend/family member is interested in participating, they will be asked to sign the consent document, and return it to the study coordinator in the enclosed envelope. Once received, the study coordinator will sign the document and send a copy back to the friend/family member. Only once both the friend/family member and the study coordinator have signed the consent form will the friend/family member be asked to complete the baseline survey.

If at any point during recruitment, the friend/family member states that he/she is not interested in participating in the study, the study coordinator will ask the friend/family member if he/she would be willing to say why he/she is not interested in participating. We are interested in this information so that we can describe the population in our trial.
The flowchart below is a visual summary of the patient and family member recruitment described above.
5.0 STUDY DESIGN AND METHODS

5.1 Design/Study Type
The pilot study is a prospective, cluster-randomized controlled trial of a quality improvement intervention at clinics within DFCI.

5.2 Selection of Instruments
All instruments used in this study can be found in Appendix D; their selection is described below.

1. Primary Outcomes
The goal of this study is to improve patient-clinician discussions about end-of-life care to enhance the likelihood that patients will receive the medical care that they want at the end of life. Our key hypothesis is that patients who have a discussion with a clinician who has been trained to use the Serious Illness Conversation Guide will receive care that is more consistent with their key life priorities during the last week and the last 3 months of life than patients whose physician has not been trained to use the Serious Illness Conversation Guide. There is no existing “gold standard” for measurement of concordance between patient wishes and care provided at the end of life; validated measures of this critical construct do not exist (12-17). Thus, we have extensively reviewed the existing literature, interviewed patients, and used this information to design a “Life Priorities” survey (to be administered to the patient) and a “Family Perception” survey (to be administered to the friend or family member). The Life Priorities survey will evaluate patient priorities before death and the extent to which those priorities are being achieved; and the Family Perception survey will examine the extent to which the friend or family member understands the patient’s priorities while the patient is living, and the extent to which those priorities were achieved in the last week and last 3 months of the patient’s life. The last administration of the Life Priorities before patient death will be used as the primary outcome. If there is not a Life Priorities survey completed in the last 3 months of life, we will use the survey completed closest to death. We plan to test the reliability of the Life Priorities Survey as part of this study. To do so, we will conduct a test/re-test of the Life Priorities Survey 10 days apart for 20 patients. The 20 patients will be randomly selected from the 3 study arms: Intervention, Primary Control, and Secondary Control. For a patient who is selected for the test/re-test process: after he/she completes his/her already scheduled Life Priorities Survey (as part of the usual study protocol), the study coordinator will call the patient to provide information about the test/re-test and to ask if the patient would verbally consent to filling out a second iteration of the Life Priorities Survey in 10 days. The patient may refuse participation, in which case we will randomly select another patient. Once we receive the test/re-test Life Priorities Surveys for 20 patients, we will compare patient responses to evaluate internal consistency. We will validate Family Perception survey data through a systematic chart review that will code available medical record data to capture information about achievement of patient priorities. The DFCI Survey and Data Management Core has collaborated with us in refining the Life Priorities survey, which is also being pilot-tested in a separate but related study (Advance Care Planning Preoperative Checklist, PI: Z. Cooper).

Our second hypothesis is that patients who have a discussion with a clinician who has been trained to use the Serious Illness Conversation Guide will be more likely to report being at peace in the final 3 months of life than patients whose physician has not been trained to use the Serious
Illness Conversation Guide. The PEACE scale, or the “Peace, equanimity and acceptance in the cancer experience” scale, will be used to measure patient peacefulness at the end of life. The PEACE instrument contains 2 subscales, ‘Peaceful acceptance of Illness’ and ‘Struggle with Illness’. The ‘Peaceful acceptance of Illness’ subscale will be used as the main outcome; it is an ordinal variable which ranges from 5 to 20, with 5 being the least peaceful acceptance and 20 being the most peaceful acceptance (18). This scale was developed for cancer populations, and is easy to administer. The psychometric properties are established: the 12-item PEACE scale Cronbach’s alpha is 0.85, ‘Struggle with Illness’ subscale Cronbach’s alpha is 0.81 and ‘Peaceful acceptance of Illness’ subscale Cronbach’s alpha is 0.78 (18). PEACE measures peaceful awareness, which is correlated with better quality of life at end-of-life (19). In a study of 280 advanced cancer patients, peacefully aware patients had lower rates of psychological distress and higher rates of advance care planning (e.g., completing do-not-resuscitate [DNR] orders, advance care planning discussions with physicians) than those who were not peacefully aware (19).

2. Family-derived aims
Although symptom management is crucial during the end-of-life period, there is consensus that the quality of dying and death is defined by more than simply pain control. Thus, interventions designed to improve quality of end-of-life care need to measure the many aspects of the end-of-life experience. The Quality of Dying and Death (QODD) instrument is a validated tool administered to families after patient death and is used to measure the quality of care provided at end-of-life to the patient (20-22). This tool has been used to document gains in a quality improvement intervention (23). Recently, this scale was reduced to a set of 17 items to minimize respondent burden and simplify analyses aimed at identifying domains underlying the dying-and-death experience (24). We have also abstracted key items from two additional validated scales to tap into areas not covered in the QODD. The FAMCARE scale is a validated instrument to measure family satisfaction with advanced cancer care. It can be administered to family members after the patient’s death (25). The Toolkit of Instruments to Measure Care at the End of Life (TIME) includes the After-death Bereaved Family Member Interview, a validated tool that measures the quality of end-of-life care provided to patients and their families (26).

3. Patient-derived aims
The patient measures we intend to collect include: Modified Human Connection Scale, GAD-7 anxiety scale, PHQ-9 depression scale, and Curtis’s Quality of Communication scale. We have also designed “Patient acceptability” and “Quality of Communication with family” instruments because there are no available validated tools to measure these constructs. The DFCI Survey and Data Management Core has reviewed all of our self-designed measures.

The Human Connection Scale measures therapeutic alliance between the clinician and patient. This is a critical construct in clinical care in general, but is particularly relevant to our study because of concerns that discussions about end-of-life issues will harm the physician-patient (or clinician-patient) relationship. We plan to use a modified version of The Human Connection Scale. Responses range from 16 to 64, with a higher THC score indicating a greater therapeutic alliance between the physician and patient (27). The Human Connection Scale is a valid and reliable measure of therapeutic alliance between advanced cancer patients and their physicians (27). The psychometric properties of this scale are established: its internal consistency is high (Cronbach’s alpha= 0.90). We modified the scale to remove items that duplicated those
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contained in the Quality of Communication scale (described below). The major unique elements in the Human Connection Scale relate to how much patients like, trust and respect their physician. Permission was granted from Dr. Mack in October, 2011 to use this scale. In addition, Dr. Bernacki discussed the modifications to the scale and the reasons for doing so with Dr. Mack in person and the potential for alteration of psychometric properties of this instrument. We determined that the benefits of deleting the repetitive questions outweighed the risk of the potential altered psychometric properties.

Patient anxiety represents a critical, but under-addressed challenge to effective end-of-life discussions. Fears associated with death are intrinsic to being human and the confrontation with a life-threatening illness is likely to heighten this anxiety to levels that may become overwhelming to patients, and certainly contribute to poor quality of life and suffering. One quarter to one half of all patients with advanced cancer experience significant anxiety symptoms, while 2-14% have anxiety disorders (28-30). Thus, attention to and assessment of anxiety is important in our intervention. The GAD-7 is a widely-used, easy to administer, and well-validated scale that measures anxiety in both general populations and in cancer patients. The anxiety scale ranges from 0 to 21, with higher scores indicating more anxiety (31). The psychometric properties are well established: reliability (Cronbach’s alpha is 0.92), test-retest stability ($r_{icc} = 0.81-0.96$), sensitivity (ROC=0.95) and specificity (ROC=0.84) are excellent. High scores on the GAD-7 are associated with more physician visits, more disability days and worse functional impairment (32, 33).

Many physicians fear discussing end-of-life with their patients because they fear it will ‘take away hope’. However, most patients prefer open and honest communication about their illness (34) and are able to discuss their illness without significant depression or loss of hope (35). We will measure our intervention’s effect on patient depression scores to evaluate the impact of this structured discussion on depression. PHQ-9 is a widely-used, easy-to-administer, and well-validated tool for the diagnosis of the presence and severity of depression (36). It is appropriate for general populations as well as cancer populations. The psychometric properties are well established: reliability (Cronbach’s alpha is 0.86-0.89), test-retest stability ($r_{icc} = 0.83$), sensitivity (ROC=0.92) specificity (ROC=0.76) and factor validity (factor loadings=0.69-0.81) are excellent (37, 38). It has been validated with diagnostic interviews, functional status, disability days and health care use (39). After interventions to improve depression and anxiety, both the GAD-7 and PHQ-9 scores decline (38, 40, 41).

Patients and families identify good communication as an essential feature of quality end-of-life care. In a study to determine the factors considered important at the end of life by patients and their families, researchers found that pain and symptom management, communication with one’s physician, preparation for death, and the opportunity to achieve a sense of completion are important to most patients (13, 42). Therefore, being able to assess and measure patient perception of the quality of communication is essential to measure the effectiveness of our intervention. “Quality of Communication” (QOC) is 13-item questionnaire that measures the quality of end-of-life communication in two scales: a six-item "general communication skills" scale and a seven-item, "communication about end-of-life care" scale (43). The general communication skills scale correlates more strongly with the general communication items while the communication about end-of-life care scale correlates more strongly with items addressing an
end-of-life topic. The psychometric properties include: good factor convergence (values >0.63) and discrimination (values different >0.25), high percent of variance explained (69%), and good internal consistency (Cronbach’s alpha is 0.79) (43). The quality of communication scale has been used to determine whether a disease-specific planning process can improve surrogate understanding of goals of patients with life-limiting illnesses for future medical treatment (44). It has also been used to evaluate (45, 46) and improve (47) quality of end-of-life care communication in patients with severe COPD or chronic heart failure (CHF).

General physical and mental health function will be measured by the SF-12 V2 health survey (48). It consists of 12 items (varying response options) and provides scores for both overall physical and mental health. In two samples of the general USA population, R squares greater than .90 were found between the physical & mental component scores of the SF-12 and the SF-36, demonstrating that the shorter SF-12 accurately captures these dimensions. Two week test-retest reliability is 0.89 & 0.76 for physical and mental, respectively.

Patients and families feel that religion and spirituality are important in end-of-life care. The Brief R-Cope – short form is a 6-item measure, 3 of each that assess positive religious/spiritual methods of coping (PRC) and dealing with life stressors, and negative religious/spiritual methods of coping (NRC) that are representative of religious struggle when dealing with life stressors. Each 3-item group represents the items with the highest factor loadings on the positive and negative subscales of the longer Brief R-Cope. Exploratory & confirmatory factor analyses across several samples have repeatedly shown that a 2-factor structure underlies this measure. In a recent review of all studies between 2005 – 2010 using this measure, the median internal consistency coefficient was 0.92 for PRC and 0.81 for NRC (49). Evidence of concurrent validity illustrates that the PRC subscale is positively correlated to psychological well-being, behavior coping, acceptance, happiness and self-esteem (correlations range from 0.20 – 0.66) while NRC is correlated with anxiety, depression, negative affect and pain (correlations range from 0.26 – 0.69). In addition, we have also included a 1-item measure developed by Pargament and his colleagues that assesses the overall role that religious/spiritual beliefs play in coping.

As the presence or absence of pain can affect coping with illness and decisions, pain will be assessed using the pain item(s) from the European Organization for the Research and Treatment of Cancer Quality of Life Questionnaires (50-53). For these questions, respondents are asked to indicate how often they experience pain on a 4-point scale ranging from “not at all” to “very much”. All EORTC-QLQ measures must meet evidence-based gold-standard criteria for psychometric validity and reliability. As such, patients who self-report different levels of pain have been rated by their physicians as experiencing different levels of pain and this has differentiated between patients in different stages of their disease.

4. Clinician-derived aims
Physician barriers appear to be more common than patient barriers to end-of-life communication (54, 55). Surveys of physician-reported barriers to completing advance directives identified time constraints, lack of understanding about Advance Care Planning (ACP), and discomfort with the process (56, 57). Several studies describe physician reluctance to address ACP as a major barrier to introducing ACP and research on ACP, suggesting that interventions that support physicians in addressing this topic with patients may be of particular importance (58, 59). Therefore, we
intend to measure the intervention’s effect on clinicians. We have designed “Clinician acceptability,” “Clinician Confidence,” and “Clinician Attitudes” surveys based on national surveys used to evaluate a national sample of medical students, residents, and attending physicians’ attitudes about end-of-life care, as well as the Harvard Medical School Center for Palliative Care’s national faculty development program (60). The chosen items show good convergent and discriminate validity (61). Some of these items have also been used and modified in a survey of hematology-oncology fellows’ training in palliative care (62).

5. Time for completion of surveys and duration of study
The estimated total time required for patients to complete all the measures proposed is approximately 30 minutes. Based on a one year prognosis, we expect each patient to complete 7 assessments. We anticipate each subject to be followed for 6-24 months, although we do not know for certain given patient prognoses are variable. The estimated total time required for families to complete all the measures proposed is approximately 20 minutes. Based on a one year prognosis for the patient, we expect each friend or family member to complete 7 assessments. We anticipate each subject to be followed for 6-24 months, although patient prognoses are variable. The estimated total time required for clinicians to complete all the measures proposed is approximately 10 minutes. We anticipate each clinician to complete 3 assessments, and to be followed for 12-24 months.

5.3 Description of Intervention
We have developed, piloted, and refined a Serious Illness Conversation Guide, based on an extensive literature review, as well as a quality improvement initiative in which oncologists in GI and Neuro-oncology were supported in conducting early values and goals discussions with their patients. We evaluated the success of this intervention by examining the proportion of 160 patients whose physician documented values and goals in the ACP module before this intervention (<4%) and those who did after the QI intervention (>90%). Following these quality-improvement interventions, we received extensive feedback from the clinicians about their experiences in conducting and documenting these discussions; this feedback informed our development of our checklist and our training program. Clinicians found it feasible to conduct these early discussions. However, we found that there was considerable variation in the documentation clinicians provided about their conversations, and that key areas of national consensus about the content of such conversations (e.g., prognosis (42%), information preferences (7%), goals (15%), fears (2%), function (8%), and tradeoffs (13%)) were not included in clinician documentation.

We developed the Serious Illness Conversation Guide (SICG) (see appendix E for intervention tools) to help clinicians structure their discussions about end-of-life issues to assure that key topics are addressed in a sensitive and appropriate manner. The conversation guide interview that grew out of our previous QI project is a structured and individualized process for clinicians to use when caring for patients with a serious illness who can expect illness complications, frequent hospitalizations, significant decline, and/or death due to their disease. Such changes in health will require an exploration of patients’ goals and related treatment decisions. This discussion includes the development of a specific plan based on decisions the patient is likely to face in the future. During these discussions, a trained clinician explores what patients know about their
disease, aims to gain an understanding of the patients’ values, and develops an understanding of
the risks that patients would or would not want to take. Beta-testing of the conversation guide has shown that it takes approximately 15 to 20 minutes to administer. We have tested the SICG initially with palliative care fellows, then with general internists, neurologists, cardiologists, and oncologists. We hired an actor to serve as a standardized patient and gave the physician a brief overview of the intent of the SICG, then recorded the conversation between the standardized patient and physician (see Appendix F for 2 example transcripts). We then conducted a semi-structured interview to obtain feedback on the use of the Guide (see Appendix G for semi-structured interview questions). The behavioral intervention that grew out of this preliminary work and that we will use in this study is described in detail below.

Training Program—see Appendix H for training materials

1. Initial Training
The initial training program for clinicians randomized into the intervention arm will be 2.5 hours. Physicians and their collaborating NPs/PAs, if eligible, will attend. Clinicians will be asked to read “Letting Go” by Atul Gawande and to review the SICG prior to the session. The two project directors (REB and SDB) will lead the training session, drawing on their years of expertise teaching palliative care courses to clinicians. The project will be introduced and the SICG shared (see below for a description of the items included in the guide; see Appendix E for the SICG). A brief didactic session on “Challenges in discussing advance care planning/values and goals” will include strategies on how to find time to perform the SICG, maintain hope, deal with uncertainty regarding prognosis and variability in patient preferences, assess psychological readiness of patient for end-of-life planning, and determine appropriate timing of the discussion. Trained actors will serve as standardized patients and all participants will have an opportunity to practice using the SICG during the training. The clinicians will be observed by palliative care/communication specialists and given feedback on their performance. They will also have the opportunity to reflect on which competencies they felt they have mastered, and which they feel they still need to work on. The training session will also include training on documenting results of the conversations into the Advance Care Planning module of the Longitudinal Medical Record (LMR). We anticipate holding approximately 5-10 sessions with 6 participants each for training, although this will depend on how many clinicians enroll in the trial. At the close of the study, the same 2.5 hour training will be available for the volunteers that were randomized to the non-training arm.

2. Ongoing Coaching
In addition, ongoing group coaching and training will be available from SDB or REB for routine and difficult patient encounters. Clinician-participants of these coaching sessions will identify a learning goal based on their experiences using the SICG and present challenges from their discussions with recent patients. Videotaping or audiotaping an encounter for discussion with the coach is optional, but will be encouraged to enhance learning. The coach will identify common themes and learning goals and then facilitate group discussion of approaches to challenges presented, including use of mini-role play or skill practice. The session will end with a summary of take-away points. We are integrating principles and successful practices gained from 30 years of teaching physicians about improving end-of-life discussions in award-winning national programs (SDB) and consultation from coaching experts. We will keep records of the number of
coaching sessions and the number of clinicians who attend them, so we can determine how much of the effect of the intervention is due to the initial training versus coaching.

3. **“Real-Time” Feedback**

We will also provide “in the moment” individual coaching for clinicians. Clinicians will be able to contact an email inbox to request coaching/debriefing on a distressing or urgent case; one of the investigators will respond within 24-48 hours for urgent or distressing cases (up to 72 hours on weekends). In-the-moment coaching will be by telephone or in person. We will collect data on how often the email inbox is emailed, and how often the Palliative Care team is paged regarding patients enrolled in the study, so we can determine how much of the effect of the intervention is due to the initial training versus real-time feedback.

The **Serious Illness Conversation Guide**

The following are the critical items we will coach health care providers to discuss with identified patients: understanding of prognosis, information preferences, goals, fears and worries, views on impaired function and tradeoffs, and degree of family involvement in decisions.

a. Understanding of prognosis: Physicians should encourage patients and families to engage in discussion (16, 63); patient understanding of prognosis is key to good discussions. Physicians should provide patients with information about prognosis to the degree desired by the patient.

b. Information preferences: Understanding the patient’s preferences for information and for involvement in decision-making is essential in tailoring the approach used with the patient’s wishes. Physicians underestimate patient desire for information about end-of-life issues (64-66) and most patients prefer to have as much information as possible. However, not all patients want information about prognosis; patients should be asked how much information they want about what is likely to be ahead with their illness. Since patients vary in the extent to which they want to be involved, want their family members involved, and want their clinicians involved in decisions, information about these preferences is essential. While shared decision-making is an ideal for some patients, others prefer strong guidance from the physician and others prefer to be guided by their families’ wishes (64-66). In addition, because key end-of-life decisions are often made by the patient’s surrogate, understanding of the patient’s preferences about who the patient wants as their surrogate and how they view the surrogate’s role are important.

c. Patient goals: While patient goals are clearly important, these are often not elicited by the physician or are completed in a variable fashion (67-69). A focus on patient goals allows the physician to tailor recommendations to the patient to address what is most important. Furthermore, focusing on goals tends to help the patient feel a sense of hope, direction, and control, which are antidotes to the helplessness and despair that can arise as part of the grieving process associated with a serious illness.

d. Fears: Patient desire for information about the future is often the greatest unmet need at end-of-life (63). Fears about future suffering are a major component of patient distress (70, 71); understanding the nature of these fears can allow the clinician to provide appropriate reassurance, and to tailor treatment plans with the patient that address patient concerns. The physician may delegate this question to a social worker to discuss if available.
e. Impaired function: Patients view impairments in functions differently and make different choices based on these views (8). An opportunity to express views of unacceptable functional states helps guide decision-making in different circumstances.

f. Tradeoffs: Patients may view time in the hospital, invasive procedures, or treatments differently, particularly when weighing these against the value of time at home or feeling well. Allowing patients to reflect on the tradeoffs that might be necessary to achieve different outcomes promotes good decision-making (72-74).

g. Family involvement: Patients vary in how much they want their own values, as opposed to those of family members, to determine care at the end of life (75, 76). Family understanding of goals and preferences is associated with better outcomes (77). Some patients may need help from clinicians in engaging family members in these critical discussions.

**Documentation:**
A new electronic Advance Care Planning module, available through Partners Applications from the Start menu of all Partners computers, has been created to allow documentation of the SICG components by clinicians. Access to this module will be granted to all DFCI clinicians. Clinicians in the intervention arm will be trained to enter data from their conversation with intervention patients into the “Values and Goals” section of the module, which includes each question of the SICG, in a combination of checkbox and free text fields. Each question is on its own screen, with the possibility of saving one screen at a time, and saving incomplete forms and returning later to complete or update. The module also keeps track of the history of documentation, with the latest entry showing up first on the home screen of the “Values and Goals” tab. Please see Appendix I for the content and a screen shot of the module.

**5.4 Data Collection**
To assess the effectiveness of the SICG discussion, both quantitative and qualitative data will be collected. A summary table of measures used for evaluation is provided below. The primary outcome of the study will be patient receipt of care aligned with their key priorities at the end of life. Surveys that will be used for data collection can be found in Appendix D. The measures are further described below.
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<td>Baseline, 7d post-SICG*, 2 months after enrollment**, q 2 mths</td>
<td>PHQ-9</td>
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<td>Quality of communication w clin.</td>
<td>Process</td>
<td>Baseline, 7d post-SICG*, 2 months after enrollment**, q 2 mths</td>
<td>Quality of Communication w Clinician</td>
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<td>Quality of communication w fam.</td>
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<td>Quality of Communication w Family</td>
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<td>Process</td>
<td>Q 2 mths after enrollment</td>
<td>Patient acceptability</td>
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<td>Q 2 mths after visit, 6 to 12 weeks after death</td>
<td>Family perception</td>
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<td>2° Outcome</td>
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<td>Perception of communication</td>
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<td>Palliative Care Quality Indicators</td>
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<td>Cost of Care</td>
<td>Outcome</td>
<td>End of study</td>
<td>TSI, DFCI</td>
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### Retrospective review

1. Answer to "surprise question" ("Would you be surprised if this patient died within a year?" Y or N)
2. Date of Birth
3. Gender
4. Ethnicity
5. Disease Center
6. Name of clinician who answered the surprise question about the patient
7. Type of clinician (MD/NP/PA) who answered the surprise question about the patient
8. List of visit dates to Dana-Farber
9. Date of death (if applicable)
10. Stage of cancer
11. Date of cancer diagnosis

<table>
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<th>Process</th>
<th>After two years of patient screening</th>
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*For intervention arm only

**For control arms

**Measures of Aggressive Care:** surgeries in last month of life; procedures/treatments in last month of life:
- ICU admission, CPR, intubation, tracheostomy, BIPAP, AICD firing, chemotherapy, radiation therapy, surgery (including VAD), dialysis, antibiotics, artificial nutrition, feeding tubes, embolizations, ERCP, stent placement, MRI, CT scans, line placements.
1. Clinician Measures
After each SICG conversation conducted, we will ask the intervention-arm clinician to note the amount of time required to conduct the conversation; as well as what prognostic estimates, if any, were conveyed to the patient (see “Post-conversation form” survey in Appendix D). When a Checklist conversation for an intervention-arm patient does not occur, we will ask the clinician for the reasons that the SICG was not completed (see “Post-conversation form” in Appendix D). After the first SICG conversation by each clinician, and at the end of the study, we will collect data about acceptability of the intervention (see “Clinician acceptability” survey in Appendix D). At enrollment, following the training, and at the end of the project, we will measure physician confidence in and attitudes about caring for patients at the end of life, and the effectiveness of the training and coaching sessions.

2. Patient Measures
The primary outcome (enhanced goal-consistent care) will be measured by the “Life Priorities” instrument (see Appendix D), which will be collected within one week after a SICG conversation for intervention patients, and every 2 months for all patients. We will then compare the patients’ life priorities to the patient’s care experience at the end of life through chart review, as well as the family’s perception of the patient’s achievement of key goals. The last administration of the Life Priorities will be used as the primary outcome. If there is not a Life Priorities survey completed in the last 3 months of life, we will use the survey completed closest to death. Patients will also be surveyed about acceptability of the intervention, self-assessed peacefulness (PEACE), therapeutic alliance with clinicians, and perceptions of the amount and quality of communication with clinician, health care agent, and family. Depression and anxiety will also be measured (PHQ-9 and GAD-7). All patient measures will be collected every 2 months to ensure being able to detect changes over time; except for acceptability, which will be measured once, within 7 days after the SICG from intervention patients only, and at month 2 for control patients.

3. Family Measures
Friends/family members will be surveyed every two months about the amount and quality of communication with the patient about advance care planning and about their perception of the patient’s life priorities (see Appendix D). Six to twelve weeks following the patient’s death, a social worker and/or palliative care fellow will administer the last survey of the study to the friend/family member by phone or in person, based on the friend/family member’s preference. This survey includes a modified form of the Quality of Dying and Death instrument (QODD), additional questions from validated scales that tap into areas not covered in the QODD, and questions about the friend/family member’s perceptions of the patient’s achievement of self-identified goals using an adaptation of the Life Priorities measure (see Appendix D).

4. Chart reviews
Chart reviews will be conducted evaluating aggressiveness of care, place of death, documentation in the LMR advance care planning module, and completion of health care proxy. Aggressiveness of care measures will include: ICU admission, procedures/treatments in last month of life, including CPR, intubation, tracheostomy, BIPAP, AICD firing, chemotherapy in last 2 weeks of life, radiation therapy, dialysis, antibiotics, artificial nutrition, feeding tubes, embolizations, ERCP, stent placement, MRI, CT scans and line placement.

5. Cost Data
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Costs of medical care delivered within the BWH/DFCI care system will be evaluated for all patients. In particular, we will examine costs of aggressive care in the last month of life.

6. Claims Data
In order to most accurately evaluate overall costs of care, we will request claims data on a subset of patients from BCBS (with patient consent), to examine overall costs of medical care between onset of SICG conversation and patient death, allowing us to examine costs of hospital, outpatient, ED, hospice and other settings of care. In addition, claims data will provide us with reliable information on days spent in hospice.

7. Retrospective Review of Screening process (Surprise Question)
In order to evaluate the performance of the surprise question, we will conduct a retrospective review of the patients screened for entry into the study. We will conduct a survival analysis; determine the hazard ratio for patients for whom the answer to the surprise question was “no;” determine the sensitivity, specificity, positive predictive value, and negative predictive value of the Surprise Question in predicting mortality for oncology patients (within six months and within one year); and determine if specific patient or clinician characteristics correlate with the accuracy of the Surprise Question.

5.5 Description of Study Process
5.51 Instrument Administration
Clinicians:
“Clinician Attitudes” and “Clinician Confidence” will be self-administered on paper survey at three different time points. At enrollment, after having signed the informed consent form, all volunteer clinicians will be asked to self-administer the surveys, which will take 5-10 minutes to complete. For oncologists, the number of patients for whom the oncologist is named as the “primary oncologist” will be obtained from CORIS Business Objects and will be recorded. The number of patient deaths for each clinician in the two years prior to enrollment will also be obtained and recorded through CORIS Business Objects. At the end of the training session, intervention-arm clinicians will self-administer the surveys on paper, along with a feedback form on the appropriateness of the training session. Finally, all volunteer clinicians will self-administer the paper surveys at the end of the study.
The Post-conversation form will be placed on the front of the patient chart, along with a copy of the SICG, reminding the intervention-arm clinician to conduct a SICG discussion with their patient at that visit. Intervention-arm clinicians will be trained to self-administer the left side of the paper survey after conducting at SICG conversation with their patient. If a SICG conversation does not happen at that visit, intervention-arm clinicians will be trained to self-administer the right side of the paper survey. The study coordinator will work with clinic staff to place the survey on the appropriate patient charts, and to collect the completed surveys on a daily basis. Reminders will be sent by email if surveys are not returned.

“Clinician acceptability” will be self-administered by intervention-arm clinicians on a paper form, immediately following the first clinician-patient discussion using the SICG, and at the end of the study. The study coordinator will work with clinic staff to place these forms on the patient chart at appropriate times for each intervention-arm clinician.

Patients:
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REDCap (Research Electronic Data Capture) will be used to collect and store all patient information and survey answers. REDCap is a secure, web-based, HIPAA-compliant application hosted by the Partners HealthCare Research Computing, Enterprise Research Infrastructure & Services (ERIS) group, designed to support data capture for research studies, providing: 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources (78).

At the time of consent, the study coordinator will administer a computer-based REDCap survey using an iPad in a private area of the clinic waiting room, which will contain the following demographic and baseline measures: age, gender, race/ethnicity, religion/spirituality, health literacy, PEACE, Modified Human Connection Scale, GAD-7, PHQ-9, and Quality of Communication with Clinician and Family. Administering the baseline survey with the patient will minimize missing data, and will ensure that patients are familiar with the survey tool, which will be used for follow-up measures as well. After baseline measures have been collected, the study coordinator will inform the intervention-arm patient’s physician that the patient is enrolled and consented for the study, and that a SICG conversation should take place.

For intervention patients, within 1 week after the patient has had their first SICG discussion with their clinician, the study coordinator will email the patient a link to a new REDCap web survey that will include the first follow-up measures: Patient acceptability, Life priorities, PEACE, Modified Human Connection Scale, GAD-7, PHQ-9, and Quality of Communication with Clinician and Family. In order to minimize missing data, the patients will be given several options for completing the survey: they can self-administer the web survey, request a phone-administered survey if they have difficulty completing the web survey, complete a paper version of the survey, or request in-person administration in clinic. This survey will be emailed to the patient within 3 days of the SICG visit, and the patient will be asked to complete it within 7 days of receipt. Patients will be able to save their answers and exit the survey before completing, and then come back to the survey later to complete, so as not to be required to complete the survey in one sitting.

Finally, every 2 months after enrollment and until patient death, the study coordinator will email all patients a new link to a REDCap web survey, containing the follow-up measures: Life Priorities, PEACE, Modified Human Connection Scale, GAD-7, PHQ-9, Quality of Communication with Clinician and Quality of Communication with Family. This survey will be administered in the same way as the surveys above.

If patients do not answer their surveys when they receive the first email, we will use the following protocol to attempt to obtain responses: email with survey link, second email with survey link, call and leave voice message, call and leave voice message, send letter with paper copy of survey. The letter we will send with the survey can be found in Appendix D.

If patients continually do not answer their surveys, we will consider them lost-to-follow up after 6 months, or 3 unanswered surveys.

Families:
After the patient has been enrolled and before their first visit with their clinician, the study coordinator will ask the registered friend or family member to complete the “Quality of Communication with Patient” REDCap web survey. This survey will be administered in the
same way as the patient survey every 2 months. This survey will take approximately 10 minutes to complete.

Every 2 months thereafter, the REDCap survey will also include the “Family Perception” survey, asking the friend or family member to indicate what they believe the patient’s priorities are. This will allow us to detect if increased communication between patient and family member is associated with a change in perception of the patient’s priorities on the part of the friend or family member.

If friends/family members do not answer their surveys when they receive the first email, we will use the following protocol to attempt to obtain responses: email with survey link, second email with survey link, call and leave voice message, call and leave voice message, send letter with paper copy of survey. The letter we will send with the survey can be found in Appendix D.

If friends/family members continually do not answer their surveys, we will consider them lost-to-follow up after 6 months, or 3 unanswered surveys.

Six to twelve weeks after the patient’s death, a Social Worker or a Fellow in the Department of Psychosocial Oncology and Palliative Care at the Dana-Farber Cancer Institute will administer the modified Quality of Dying and Death and the “Family Perception” questionnaire by phone or in person to the registered friend or family member. This survey will take approximately 60 minutes to complete. One or two Social Workers and one or two Fellows will be trained by the study coordinator for 1.5 hours on how to administer the survey. The study coordinator will be trained by Dr. Curtis or colleagues (developers of the survey) and by Sue Morris, the Bereavement Coordinator at DFCI, on how to administer to the modified Quality of Dying and Death. The surveys will be audio-taped. This will be done to provide feedback to the SICG structure, as long as the friend or family member provides written consent in their informed consent form and verbal consent on the day of the questionnaire.

5.52 Intervention Administration
The intervention will be executed in the manner described below. This section summarizes the sequential flow of the intervention steps, details of which can be found in other sections of this protocol document, as noted below:

1. The project leadership team will attend a staff meeting for each of the targeted DFCI disease centers to introduce and summarize the project, and to encourage the physicians and nurse practitioners to consider participating. At these meetings, disease center teams will have the opportunity to customize the study processes to best fit into their current work flow. Clinicians who are interested in participating in the study will be allowed to enroll during this presentation.

2. The study coordinator will then email individual clinicians who did not volunteer at the presentation to invite them to consider participating in the study, as described above in section 4.0.

3. Physicians who are interested in participating in the study will be enrolled and consented, as described above in section 4.0. A SAS program will assign each volunteer physician to either the intervention arm or the standard care arm. Nurse practitioners and physician’s assistants who work exclusively with the volunteer physicians will be enrolled and consented in the manner described above in section 4.0.
4. For every 10 physicians enrolled in the intervention arm, training sessions will be scheduled at a time most convenient for the majority of physicians and their nurse practitioners/physician’s assistants. The training sessions, 2.5 hours each, will be conducted in the manner described above in section 5.3 by the study investigators REB and SDB. Coaching sessions will occur on a monthly basis and will be recommended to all physicians and nurse practitioners in the intervention arm.

5. The study coordinator will attend the disease center staff meeting weekly to obtain a list of patients appropriate for the study. The clinicians from each disease center will use the eligibility criteria described above in section 3.0 to identify the appropriate patients from the disease center’s schedule. Using this list and the schedule of upcoming visits, the study coordinator will send a letter to patients and invite them to call the study coordinator or send in the opt-out postcard if they are not interested in participating, as described above in section 4.0. The study coordinator will call patients who do not respond to the letter within 10 days to ask them to consider participating in the study.

6. The study coordinator will consent patients and friends/family members as described above in section 3.0, then give the patient an information packet about the study.

7. Intervention-arm clinicians will be reminded by email before the patient’s first clinical visit after enrollment and consent to conduct and document the SICG. The study coordinator will also place the Serious Illness Conversation Guide and Post-conversation form on the patient chart as an additional reminder to the clinician. Clinicians will have discretion about when to complete the SICG, and whether to complete it in one visit, or over multiple visits. They will be trained to continue the discussion until the conversation guide has been completed. The individual physician may delegate the conversation to be completed by the NP/PA, if the NP/PA is trained. Completion of conversation elements by physician, NP, and PA will be considered equivalent. All Checklist items must be documented in the patient’s ACP module to be considered complete.

8. A random selection of 20% of conversations will be audio-taped. This will be done to assure fidelity to the SICG structure, as long as the clinician and patient provide written consent in their informed consent form and verbal consent on the day of the conversation.

9. After the patient’s visit with their physician, the study coordinator will send intervention arm patients the “Family Communication Guide” (see Appendix E) to help patients talk about their illness with their family.

10. The study coordinator will obtain the paper survey completed by the intervention-arm physicians at the SICG visit. If a SICG conversation occurred and the “Time and prognosis” survey was completed, the study coordinator will begin patient follow up within one week after the visit (intervention patients only), as described above in section 5.51. If the SICG conversation did not occur and the “Reasons for not completing the SICG” survey was completed, the study coordinator will enter these data into the patient’s file and remind the physician at the patient’s next visit to conduct a SICG conversation.

11. Follow-up for standard care and secondary control group patients will begin approximately 40 days after enrollment, and continue every 2 months thereafter.

12. Patients will be followed every 2 months, as described above in section 5.51, until patient death or up to 2 years. At that time, the study coordinator will note the date of death in the patient’s file and discontinue scheduled follow-up surveys. The study coordinator will then abstract the patient’s chart, including conversations documented in the ACP module, and contact the patient’s friend or family member 6-12 weeks after patient death to complete the QODD survey, as described above in section 5.51.
5.53 Special Concerns
This project involves no use of drugs or devices. There is no risk of physical injury associated with participation in this project. While there is psychological risk, as intervention-arm patients will be interviewed regarding their treatment preferences in advanced illness, they will be interviewed by their own clinician. In order to minimize risk, we will use standardized actors at the training and all intervention-arm clinicians will receive real-time feedback to enhance competencies in conducting these discussions. In addition, follow-up coaching sessions will be conducted for all intervention-arm clinicians. The first coaching session will be conducted approximately one month after the initial training and monthly thereafter. We will also audiotape a small portion of the conversations, if the patient and clinician agree, for quality control. An outpatient palliative care appointment will be available for patients who cannot be served by training or coaching of the primary clinician. These may include special difficult circumstances such as challenging family situations, patient or family members with psychiatric disorders, or any situation when the clinician needs specialist level palliative care expertise for a patient. In order to monitor the clinician response to the project, we will create an internal advisory group, comprised of MDs and NPs who are using the SICG, to provide us with feedback and suggestions about the process throughout the trial. We will invite members of the existing DFCI Advance Care Planning Advisory Group and other clinicians who volunteer for the trial to be part of this advisory group.

5.54 Compensation
Patients and friends/family members will not receive remuneration. Volunteer clinicians will receive a $150 Phantom Gourmet gift certificate to local area restaurants.

5.6 Adverse Reactions and Their Management
5.61 Reporting Adverse or Unanticipated Events
The investigators do not anticipate needing to remove a subject from the study and subjects may decline, as per standard policies and procedures. If a circumstance arose where the investigators were concerned about a subject’s safety as a result of the study, the subject would be removed from the study. The proposed research will comply with the regulations set forth in 45 CFR Part 46, Protection of Human Subjects. All staff involved in the project are educated on the protection of human research participants. All personnel involved in the proposed protocol have been educated regarding HIPAA regulations and fully understand their responsibility to safeguard the personal health information of every participant involved in the research.

5.62 Anticipated Reactions
We expect that a patient whose physician is trained and adheres to the elements of the Serious Illness Conversation Guide will be more likely than patients who do not receive the intervention to have their values and goals about end-of-life care honored, and to experience greater peacefulness in the final month of life; similarly, their families will experience higher satisfaction with care. We believe that both patients and physicians will find the use of the Checklist acceptable. Finally, we anticipate that patient anxiety will be lessened and that the therapeutic alliance between patient and clinician will be strengthened.

The risks to patients and family members involved in this project are primarily that they may find discussions with their clinicians about end-of-life issues distressing. Currently, these conversations about patient values and goals at end-of-life often occur late in life, if at all. In
clinicians learning a new communication skill, there is a risk that they will not be adept when first using it. Even if clinicians are adept at conducting these conversations, some patients and family members may experience talking about the future as upsetting. However, previous researchers have examined emotional responses to discussions about end-of-life care and found that patients are not more depressed, anxious, or traumatized by these questions, and that they are subsequently at greater peace (16).

5.6.3 Reaction Management
We will minimize patient distress by asking patients, as part of the SICG, how much information they want about their prognosis (which is often the most distressing issue), and training oncologists to tailor their conversations to the level of information desired. In addition, for patients who experience significant distress related to these conversations, expert back-up and support will be available through both the Palliative Care Program and the Psychosocial Oncology Program at DFCI. If a subject is distressed, the following psychologists and social workers who are not involved in the study can be contacted:

Phil Higgins, MSW 617-525-9778
Karen Fasciano, PhD 617-632-4724
Amanda Moment, MSW 617-525-9786

Additionally, we will monitor responses to the PHQ-9 measure of depression daily, as patient survey responses come in. If the patient answers “Nearly every day” to the question, “Thoughts that you would be better off dead, or of hurting yourself,” and/or if the total score for depression on the PHQ-9 is 20 or above (considered “severe depression”), and/or if the total score for anxiety on the GAD-7 is 15 or above (considered “severe anxiety”), and/or if the patient reports high levels of intolerable pain at 8 or above (on a scale of 1-10), we will notify the patient’s NP or physician immediately by pager or phone.

6.0 STATISTICAL ANALYSIS
The objective of this study is to evaluate, in patients with serious and life-threatening illness, if the SICG is better than usual care at helping patients achieve health care goals, as well as improving peacefulness at the end of life. The design will be a cluster-randomized design, in which patients will be nested within clinicians (clusters). One-half of the oncologists will be randomized to the SICG and one-half of the oncologists will be randomized to standard care. All primary and secondary endpoints discussed below will be measured at the patient level.

6.1 Primary and secondary endpoints
There will be two primary endpoints and two secondary endpoints. In describing the endpoints, we also describe the associated aims and hypotheses.

Primary Specific aim 1: Do patients whose physician is trained to have a conversation using the Serious Illness Conversation Guide (SICG) demonstrate enhanced consistency between documented values and goals and care received in the final 3 months and final week of life? (Enhanced goal-consistent care)
Hypothesis: Patients whose physician is trained to use and adheres to the SICG will demonstrate enhanced consistency between documented patient values and goals and care received versus standard care.
Measurement: Life priorities.
Time point: preferences indicated on the last survey before death or the end of the study, whichever comes first.
Primary endpoint (main outcome): The patient will rank 3 goals as their top three priorities. The outcome for a patient will be a score of 0,1,2,3, corresponding to the number of these top three goals that are met in the last week and 3 months of life.

Primary Specific aim 2: Do patients whose physician is trained to have a conversation using the SICG have greater peacefulness in the final 3 months of life? (PEACE)
Hypothesis: Patients whose physician is trained to use and adheres to the SICG will report greater peacefulness in the final month of life.
Time point: One month post-baseline.
Measurement: PEACE administered questionnaire
Primary endpoint: The ‘Peaceful acceptance subscale’ will be used as the main outcome, which is an ordinal variable which ranges from 5 to 20, with 5 being the least peaceful acceptance and 20 being the most peaceful acceptance.

Secondary (Patient-Derived) Specific aim 1: Is use of the SICG associated with a better patient-clinician alliance? (Therapeutic Alliance)
Hypothesis: Patients whose physician is trained to use and adheres to the SICG will rate patient-clinician therapeutic alliance higher following the conversation.
Time point: One month post-baseline.
Measurement: The Human Connection Scale (THC), Mack 2009 (27)
Primary endpoint: The Human Connection Scale will be used as the main outcome, which ranges from 16 to 64, with a higher THC score indicating greater a therapeutic alliance between the physician and patient.

Secondary (Patient Derived) Specific aim 2: Does use of the SICG reduce patient anxiety? (Anxiety)
Hypothesis: Patients whose physician is trained to use and adheres to the SICG will have lower anxiety following the conversation.
Time point: One month post-baseline.
Measurement: GAD-7 anxiety scale
Primary endpoint: The GAD-7 anxiety scale will be used as the main outcome, which is an ordinal variable which ranges from 0 to 21, with higher scores indicating more anxiety.

6.2 Sample size and statistical power or precision associated with the sample size.
To have sufficient power to test the hypotheses of interest, we will enroll 50 oncologists who on average each see approximately 8.5 patients with serious and life-threatening illness per year. In this cluster-randomized design, one-half (twenty-five) of the oncologists will be randomized to the SICG and one-half of the oncologists will be randomized to standard care. There are 2 primary aims. In order to preserve an overall Type I error rate of 5% with 80% power, the hypotheses for the two primary aims will be tested at a Type I error rate of 2.5% (Bonferroni correction for multiple testing). There are also two secondary (Patient Derived) Aims, and each of these (more exploratory) aims will be tested at a Type I error rate of 5%. Here, we discuss the power calculation for each aim.

Power Calculation:

Primary Specific aim 1: Do patients whose physician is trained to have a conversation using the Serious Illness Conversation Guide (SICG) demonstrate enhanced consistency between
documented values and goals and care received in the final 3 months and final week of life? (Enhanced goal-consistent care)

**Power Calculation:** Based on previous data, the SD of ‘number of these high priority goals met’ is conservatively estimated to be 1.35, and we expect the average ‘number of these high priority goals met’ to be at least .6 point higher with the SICG (a clinically important increase based on prior studies). The two arms will be compared using a robust generalized estimating equations (GEE) Wilcoxon rank-sum type score test (79) for ordinal categorical data; this approach does not assume normality of the outcome, and accounts for a possible cluster effect of patients within clinician. This aim relies on patients dying; we expect to follow each patient for at least one year from randomization, or until death if less than 1 year from randomization. Further, we expect the 1-year survival rate to be approximately 40%. Thus, conservatively, we will have 0.6*200=120 evaluable patients per arm for this aim. Using the GEE Wilcoxon rank-sum score test with a 2-sided type I error rate of 2.5% and 200 evaluable patients per arm, we have over 80% power to detect an average 0.6 point higher average score in the SICG arm. In this power calculation, an intra-cluster (clinician) correlation coefficient (ICC) of approximately 0.1 has been assumed, as is (conservatively) commonly used in this type of cluster randomization study (80).

**Primary Specific aim 2:** Do patients whose physician is trained to have a conversation using the SICG have greater peacefulness in the final 3 months of life? (PEACE)

**Power Calculation:** Based on previous data (18) the SD of the ‘Peaceful acceptance subscale’ is conservatively estimated to be 3.3 (‘conservatively’, since this is the largest SD found in Mack et al, 2008), and we expect the average score to be at least 1.3 point higher with the SICG (again, a clinically important increase based on prior studies). The two arms will be compared using the GEE Wilcoxon rank-sum score test accounting for clustering of patients within clinician. Using a GEE Wilcoxon rank-sum score test with a 2-sided type I error rate of 2.5% and 200 evaluable patients per arm, we have over 80% power to detect a 1.3 point higher average ‘Peaceful acceptance subscale’ in the SICG arm, assuming the ICC=0.1.

**Secondary (Patient Derived) Specific aim 1:** Is use of the SICG associated with a better patient-clinician alliance? (Therapeutic Alliance)

**Power Calculation:** Based on previous data (27) the SD of the THC is conservatively estimated to be 10. The two arms will be compared using the GEE Wilcoxon rank-sum score test, accounting for clustering of patients within clinician. Using the GEE Wilcoxon rank-sum score test with a 2-sided type I error rate of 5% and 200 evaluable patients per arm, we have over 80% power to detect a 3.7 point higher average THC in the SICG arm, assuming the ICC=0.1.

**Secondary (Patient Derived) Specific aim 2:** Does use of the SICG reduce patient anxiety? (Anxiety)

**Power Calculation:** Based on previous data (31) the SD of the GAD-7 anxiety score is conservatively estimated to be 3.8. The two arms will be compared using the GEE Wilcoxon rank-sum score test, accounting for clustering of patients within clinician. Using the GEE Wilcoxon rank-sum type score test with a 2-sided type I error rate of 5% and 200 evaluable patients per arm, we have over 80% power to detect 1.4 point lower average GAD-7 anxiety score in the SICG arm, assuming the ICC=0.1.

We will allow for 6% unevaluability due to patient dropout or death, meaning a total of 426 patients (213 per group) will be accrued at an estimated accrual rate of 425 patients per year;
accrual should be completed in approximately 1 year. Given that each patient must be followed for at least one month, we expect the study to be open at least 1 year and 1 month.

Secondary Specific aim 3 (Clinician Derived): Does the clinician feel more skilled in 'Discussing end-of-life issues with my patients' (1-7 Likert Scale with higher being more skilled) AFTER participating in this study than BEFORE participating in this study.

Power Calculation: Based on previous data the SD of the likert score is conservatively estimated to be 1.1.

We expect to have at least 40 clinicians participate in the survey on each arm (intervention or control). For a given arm, using a paired Wilcoxon signed rank test, we will we have over 80% power to detect an average 0.75 point increase in the Likert Score.

We will also compare the two arms using a 'difference in differences' analysis. For this power calculation, we expect the difference in the control group to be approximately 0. The paired differences in the two arms will be compared using a Wilcoxon rank-sum test. Using the Wilcoxon rank-sum test with a 2-sided type I error rate of 5% and 40 clinicians per arm, we have over 80% power to detect an 0.82 average increase in the Likert score in the SICG arm (versus 0 in the control arm).

Secondary Specific aim 4 (Patient Derived): Estimate reliability of the Life Priorities Survey in two surveys given 10 days apart on the same patient. In particular, we are interested in the Life Priority 'Be Independent' and the agreement of being ranked among the patient’s top 3 priorities in the two surveys.

Power Calculation: The Kappa coefficient will be used to measure the reliability of the two surveys given 10 days apart on the same patient. The power calculations for Kappa depend on the provenance of the outcome and the percent of times it is among the patient’s top 3 priorities. Based on previous data, we expect approximately 30% of patients to rank 'Be Independent' among their top 3 priorities.

Using the Landis and Koch (1977) scale, a Kappa coefficient of at least .8 is considered 'Almost perfect agreement,' whereas a Kappa coefficient of at least 0.4 is considered moderate agreement. In this exploratory aim, we would like to be able to test for at least moderate agreement (null of Kappa=0.4) versus almost perfect agreement (alternative of Kappa=0.8).

Using Wald test for the Kappa coefficient for a 2 x 2 table with 2-sided type I error rate of 5% and 20 patients, we have over 80% power to test the null that Kappa=0.4 versus the alternative that Kappa is at least 0.8.


6.3 Stratification factors and intervention allocation plan for randomized studies.
The oncologists will be stratified by disease center or satellite facility. There will be 8 strata, corresponding to the disease centers (Breast, Gastrointestinal, Genitourinary, Hematologic Malignancies, Thoracic, Grouped disease centers (Sarcoma, Head & Neck, Melanoma, Neuro-Oncology)) and 2 satellite facilities (Milford and South Shore). The disease centers with a low number of physicians were grouped (Sarcoma, Head & Neck, Melanoma, Neuro-Oncology).
Within strata, one-half of the oncologists will be randomized to the SICG and one-half of the oncologists will be randomized to standard care.

6.4 Stratification factors and their impact on design
The GEE statistical methods described in the power calculations (and described below in the analysis section) will take into account the stratification (disease center) and clustering (clinicians) variables in the analysis.

6.5 Early stopping rules
For primary Aims 1 and 2, the trial will be monitored for possible early stopping due to a large intervention effect using a Haybittle-Peto approach (80). Specifically, one interim GEE Wilcoxon rank-sum score test will be performed after approximately 50% of the total patients are enrolled, which should occur approximately 6 months after baseline and 213 patients. In order to stop the study at this point in favor of the SICG arm, the P-value for GEE Wilcoxon rank-sum score test must be <0.001. The power calculations in section 6.2 take into account the possibility of one interim analysis. The stopping rule for this study will be used as a guideline rather than as a hard-and-fast rule. Any final decision will also consider additional endpoints such as differences in complications and process measures. If the findings of the interim analysis are in favor of stopping the trial due to beneficial effect of the SICG, the research study would be stopped. We note here that we used a simpler conservative interim analysis approach (Haybittle-Peto) because the less conservative approaches (e.g., O’Brien-Fleming) require independent increments of data, but the data will not likely come to us in independent increments because of the cluster randomized design (81).

6.6 Definition of and allowance in design for unevaluable/ineligible participants
We expect at most 5% of the patients to die prior to the 1 month post-baseline surveys. Thus, these patients will be un-evaluable. It is also possible that a small percentage (1%) of patients will dropout of the study by 1 month post-baseline. Together, the 5% death rate and 1% dropout rate at one month give the 6% unevaluability rate at 1 month discussed at the end of section 6.2. As discussed above, at an estimated accrual rate of 425 patients per year, accrual should be completed in approximately 1 year. Given that each patient must be followed for at least one month, we expect the study to be open at least 1 year and 1 month. We expect a proportion of patients will survive beyond one year, and plan to follow patients for up to 2 years.

6.7 Analysis plan
This study is a pilot RCT in 2 arms, with randomization at the cluster (clinician) level, and the outcomes being measured at the patient (individual) level. Since this is a randomized trial with stratification prior to randomization, we expect the demographic characteristics and other possible confounders (age, disease severity, etc) to be similar in the two groups. However, since randomization is at the cluster-level, and there are 50 total clusters, there is a slightly greater chance that characteristics will not balance out than if randomization was done at the patient level. Prior to evaluating the effect of the intervention, the demographic characteristics of test arms will be compared by the Rao-Scott chi-square (accounting for stratification by disease center and clustering by oncologist) for discrete variables, and by the GEE Wilcoxon rank-sum score test for ordered categorical variables and continuous variables square (accounting for stratification by disease center and clustering by oncologist) (80).
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If, as expected, there are no differences in demographic or other confounders, the primary outcomes across arms will be compared using the GEE Wilcoxon rank-sum score test for ordered categorical variables and continuous variables square (accounting for stratification by disease center and clustering by oncologist) (80).

If baseline differences are found among the 2 arms with respect to important confounders (such as age, race, comorbidities), the GEE Wilcoxon rank-sum test will incorporate propensity weights. In particular, to conduct the propensity score adjustment, we will use a logistic regression model to calculate the propensity (probability) of being in the SICG or control groups based on all the possible confounders, and then weight each subject in the GEE Wilcoxon score test based on the inverse propensity of being in one of the 2 treatment groups (82).

This study will not address whether it is the SICG itself, or the SICG in conjunction with training and intensive clinician support. We will collect how often we are emailed and paged regarding patients, as well as the number of coaching sessions, and will report this data. Using this data in a secondary analysis, we will perform a regression analysis with an additional covariate corresponding to the number of coaching sessions. This will allow us to explore if the number of coaching sessions attended affects outcomes in patients in the intervention arm.

Also in a secondary analysis, we will compare patients of non-volunteers in the study as a secondary comparison group. Patients of non-volunteer physicians as well as patients of physicians randomized to the standard care arm will not get the SICG. However, volunteers and non-volunteer physicians will have different characteristics in how they discuss advance care planning with their patients. Further, it is possible that there will be a placebo effect in the randomized study. Therefore we will include patients of non-volunteers in the study as a secondary comparison group in a secondary analysis. We will not combine these patients with those randomized to the non-trained physician group (even though neither get the SICG), but instead will include them as a third group in the analysis. In this secondary analysis, we will perform pairwise comparisons between patients from non-volunteer physicians and the two randomized study arms, with each comparison performed at alpha=0.05 (since this is a secondary analysis). We will use a propensity adjusted analysis as described above to account for possible confounding when comparing the three arms. To keep the scope of the project achievable, we plan to accrue approximately 50 patients of non-volunteer physicians; though we will enroll more if more are available. We expect there to be approximately 25 non-volunteer physicians, and we will accrue approximately two patients from each of these non-volunteer physicians. With 50 patients of non-volunteer physicians, we will still have sufficient power to detect meaningful differences. For example, for Primary Specific aim 2 (PEACE), using a GEE Wilcoxon rank-sum score test with a 2-sided type I error rate of 5% and 200 evaluable patients in the SICG arm and 50 evaluable patients in the non-volunteer physician arm, we have over 80% power to detect a 1.8 point higher average ‘Peaceful acceptance subscale’ in the SICG arm, assuming the SD=3.3 and ICC=0.1.

6.8 Handling of missing data in the analysis
If data at 1 month post-randomization are missing for patients who die or dropout, we will use established methods for conducting GEE analyses with random or non-random missing data (83). If the outcome data appear to be missing at random (MAR), we will get unbiased tests and regression estimates using modified GEE (84) in which the data at both baseline and 1 month are modeled as outcomes. Modified GEE (MGEE) produces unbiased tests and parameters estimates.
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when follow-up data is MAR. If the data are MAR, then patients with better (or worse) outcome are seen more often at 1 month. SAS Proc GLIMMIX will be used to obtain the MGEE estimates. If dropouts appear non-random, i.e., subjects who are in the poorest health are more likely to drop out, pseudo-likelihood estimating equations will be used (83).

If a clinician drops out before randomization occurs, he/she will be replaced. If a clinician drops out after randomization, but patients and family members are evaluable, we will perform an intent-to-treat analysis for that patient. If a patient and/or family member are not evaluable, we will use all available data that are observed on that patient/family member, and use multiple imputation, in which that unevaluable data will be 'predicted' from the available data using regression methods via Proc MI in SAS version 9.3 (which is a new, flexible version of multiple imputation for both continuous and categorical variables). Multiple imputation is a state-of-the-art approach in statistics. These patients with imputed data will be analyzed as randomized (for intent-to-treat for many studies, an outcome such as survival is available; for our study, the outcome may not be available, so we will use multiple imputation). In particular, the missing responses will be imputed from the observed responses on the survey as well as other observed relevant patient and family characteristics.
7.0 REFERENCES


8.0 APPENDICES

Appendix A: Background document—see attached PDF
Clinician recruitment email:

Dear colleagues,

We are writing to ask you to consider participating in an intervention study to test the effectiveness of *The Serious Illness Conversation Guide*. This innovative project is designed to strengthen the physician-patient relationship and enhance conversations clinicians have with patients with high-risk cancer about their goals and values. We have developed a checklist to guide physicians and other health care professionals in conducting effective discussions of end-of-life values and goals with seriously ill patients and their families. Checklists have been shown to enhance compliance with quality standards and to result in improved clinical outcomes in a variety of settings.

We are evaluating the impact of this intervention on patient, family, clinician, and health system outcomes by conducting a **cluster-randomized controlled quality improvement intervention trial**. We will be recruiting medical oncologists and nurse practitioners from the Dana-Farber Cancer Institute to participate in the study. Clinicians will be randomized into a non-training arm or a training arm with follow-up coaching, which will prepare clinicians to effectively use the checklist. Clinicians will then be asked to conduct end-of-life discussions with their patients, following the structured format outlined in the checklist. Clinicians not trained initially will continue to provide care as usual for the duration of the study; they will then have the opportunity to be trained to use the checklist after the study has concluded.

We would be extremely grateful for your consideration of this study, which is a high-priority initiative of DFCI. All clinicians who volunteer will receive remuneration in the form of a $150 gift card to a local restaurant. If you are interested in participating, please email the study staff at [communicationchecklist@dfci.harvard.edu](mailto:communicationchecklist@dfci.harvard.edu) or call us at 617-632-6055. If we do not hear from you within 2 weeks of this email, we will follow up with another email. If you choose not to volunteer for this study, we will still be inviting your patients to participate, in an effort to better understand patients’ advance care planning experiences and preferences.

Thank you for considering this request. We really hope you can join us for this exciting project.

* Susan Block, MD  
  Chair  
  Department of Psychosocial Oncology and Palliative Care  
  Dana-Farber Cancer Institute  
  Professor, Harvard Medical School  

* Rachelle Bernacki, MD MS  
  Director of Quality Initiatives  
  Department of Psychosocial Oncology and Palliative Care  
  Dana-Farber Cancer Institute
Patient recruitment letter: sent by mail to all patients identified as potentially eligible for study

Dear (patient name),

I am writing to ask you to consider participating in a research study at Dana-Farber Cancer Institute about how doctors communicate with their patients. I got your name through your oncologist, Dr. __________, who has been invited to participate in this study.

This research study is evaluating communication between doctors and their patients with serious illness, and between those patients and their friends or family. We are interested in learning if doctors can learn and use a structured approach to talking about values and goals with patients, and if that affects how patients talk with friends and family about their illness. Some patients with serious illnesses may have strong values and beliefs about how they would like to receive care and to be treated during their illness. The structured approach we are testing in this research study will hopefully help doctors and patients to be on the same page when it comes to future care for the patient, by raising questions that may otherwise be difficult for doctors and patients to talk about.

We are asking you to take part in this research study because you have one of the illnesses we are studying and have an appointment scheduled to see your oncologist at Dana-Farber. Participation in this study includes completing surveys (by e-mail or postal mail) approximately every 2 months about your health and your communication with your doctor and your family. Each survey would take about 30 to 45 minutes to complete. You would be in the study for up to 2 years.

If you are NOT interested in participating in this study, please call the study staff at 617-632-6055 or send in the enclosed postcard, and we will no longer contact you. If we do not hear from you within 10 days of this letter, we will call you to ask you to consider participating.

If you have any questions about this study, please call the study staff at 617-632-6055.

Sincerely,

Rachelle Bernacki, MD MS
Project Director, Serious Illness Communication Project

Jenna Ogden, Nate Pertsch, and Maribel Valenzuela
Research Assistants, Serious Illness Communication Project
Patient recruitment phone call script:

Hi, my name is ___________ and I’m calling from a research study about how doctors communicate with their patients. May I speak to __________ please?
If unavailable, ask “When would be a better time for me to call?” and note response in patient record.

Good morning/afternoon Mr/Ms_____________. My name is ______________ and I’m calling about a research study at the Dana-Farber Cancer Institute about how doctors communicate with their patients. I got your name through Dr_________ who was invited to participate in our study. I’d like to take a few minutes to talk to you about the study and ask if you are interested in participating, and ask you some questions to see if you are eligible. Is it OK for me to talk to you about this now?

If YES, continue below.
If NO, ask “When would be a better time for me to call?” note response in patient record.
If NOT INTERESTED, say “Thank you for your time today. We will no longer be contacting you about this study.” Note response in patient record.

First, can you please tell me, what is your preferred language?

1. English⇒continue script below
2. Spanish⇒ask question a.
3. Other: ______⇒ask question a.
   a. What is your level of comfort with speaking English?
      i. Perfectly comfortable⇒continue script below
      ii. Very comfortable⇒continue script below
      iii. Somewhat comfortable⇒thank patient for their time and say “You are not eligible to be in this study”
      iv. Not at all comfortable⇒thank patient for their time and say “You are not eligible to be in this study”

I am going to give you a summary of the research study now over the phone. If you choose to participate, I will give you all of this information in writing at your next appointment here at Dana-Farber, and we will review it together then. Feel free to stop me at anytime if you have any questions.

We are doing this research study to find out if doctors can learn and use a structured approach to talking about values and goals with patients. Some patients may have strong values and beliefs about how they would like to receive care and to be treated during their illness. The approach we are testing in this research study will hopefully help doctors and patients to be on the same page when it comes to future care for the patient, by raising questions that may otherwise be difficult for doctors and patients to talk about.
We are asking you to take part in this research study because you have one of the illnesses we are studying and have an appointment scheduled to see your oncologist at Dana-Farber.

It will take you up to 2 years to complete this research study. During this time, we will ask you to answer 7 to 13 study surveys by email or postal mail, whichever you prefer, in addition to your regularly-scheduled appointments with your doctor. In these surveys, we will ask you some questions about your general health and well-being, quality of life,
mental health, emotional health, mood and your relationship with your doctor and friends or family.

We’re also interested in how talking with your doctor may affect how you talk with friends and family about your illness. We will therefore ask you to identify one friend or family member who may be able and willing to participate in the study along with you. This should be your Health Care Proxy, or a close friend or family member who is involved in helping you think about decisions related to your health care, even if you haven’t legally appointed them as your Health Care Proxy. We will call them to ask them similar questions.

Many doctors from Dana-Farber have been asked to participate in this research study, including your doctor. The doctors have been assigned by chance (like a coin toss) into one of two groups: one group has been trained to use this new approach to communication (this is the intervention group), and the other group will continue to provide care as usual (this is the standard care group). You or your doctor cannot choose your study group. Your doctor has an equal chance of being assigned to the intervention group or the standard care group. It is possible that your doctor is not assigned to the intervention group. In addition, some doctors did not agree to participate in this study, and they will continue to provide care as usual (this is the control group). You will not know which group your doctor is in, but your doctor will know since there is no way to hide it from them. Either way, your doctor will continue to care for you as he or she normally would.

Do you have any questions about the study at this time?

Would you be interested in meeting with me to learn more about this research study?
If YES, continue below.
If NO, ask “May I ask why?” and note reason in patient record. Say “Thank you for your time today. We will no longer be contacting you about this study.”

Great! Thank you for agreeing to meet with me.

1) What is a second phone number we could use to reach you?
Note number in patient record.

2) How would you like to receive the surveys for this study?
   1. Email: ________
   2. Postal mail: _____
   3. Phone
   4. In person

3) What is your email address?

4) What is your mailing address?

As I mentioned earlier, we will need to ask a friend or family member some questions for this study. This person can be your health care proxy or a close friend or family member who is involved in helping you think about decisions related to your health care, even if you
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haven’t legally appointed them as your Health Care Proxy. They do not have to be local or need to attend clinic appointments with you. They will need to come to DFCI once to review and sign the informed consent document. They will need to be available to answer surveys by email and by phone. They must be over 18, speak English, and have the ability to provide consent.

A Health Care Proxy (HCP or Durable Power of Attorney [DPOA]) is a legal document that allows you to appoint someone you trust to make decisions for you if you become unable to communicate those decisions yourself. This person is then called your proxy or surrogate decision maker.

5) Do you have a Health Care Proxy?
   0. No ➔ skip to 7
   1. Yes ➔ continue to 6

6) Is this the person you would like to take part in this study?
   0. No ➔ continue to 7
   1. Yes ➔ provide details below, skip question 7

   Full name:  
   Relationship:  
   Phone number:  
   Email address:  
   Postal Address:  

7) Who would you like to be the person we enroll in this study? This should be a close friend or family member who is involved in helping you think about decisions related to your health care, even if you haven’t legally appointed them as your Health Care Proxy.

   Full name:  
   Relationship:  
   Phone number:  
   Email address:  
   Postal Address:  

The next step in enrolling in this research study is to meet with me to learn more about the study and review the informed consent form. This meeting will take 45 minutes to an hour.

We can do this before your next appointment at Dana-Farber, if that works for you. When would you like us to meet?

   Date: __/__/____  Time:________ Location:________

Can I answer any other questions for you right now?

If you have any questions at any point, please do not hesitate to call me. The study phone number is 617-632-6055.
Dear friend/family member name,

I am writing to ask you to consider participating in a research study at Dana-Farber Cancer Institute about how doctors communicate with their patients. I got your name from patient name, who is participating in this study.

This research study is evaluating communication between doctors and their patients with serious illness, and between those patients and their friends or family. We are interested in learning if doctors can learn and use a structured approach to talking about values and goals with patients, and if that affects how patients talk with friends and family about their illness. Patients with serious illnesses may have strong values and beliefs about how they would like to receive care and to be treated during their illness. The structured approach we are testing in this research study will hopefully help doctors and patients to be on the same page when it comes to future care for the patient, by raising questions that may otherwise be difficult for doctors and patients to talk about.

Every patient who participates in this research study must have a friend/family member participate alongside them. We are asking you to take part in this research study because your friend/family member indicated you as possibly available to participate in this research study. Participation in this study includes completing surveys (by e-mail or postal mail) approximately every 2 months about your communication with your friend/family member. Each survey would take about 15 minutes to complete. You would be in the study for up to 2 years.

If you are NOT interested in participating in this study, please call the study staff at 617-632-6055 or send in the enclosed postcard, and we will no longer contact you. If we do not hear from you within 10 days of this letter, we will call you to ask you to consider participating.

If you have any questions about this study, please call the study staff at 617-632-6055.

Sincerely,

Rachelle Bernacki, MD MS
Project Director, Serious Illness Communication Project

Jenna Ogden, Nate Pertsch, and Maribel Valenzuela
Research Assistants, Serious Illness Communication Project
Hi, my name is ___________ and I’m calling from a research study about how doctors communicate with their patients. May I speak to _______ please?
If unavailable, ask “When would be a better time for me to call?” and note response in family member record.

Good morning/afternoon Mr/Ms ___________. My name is ___________ and I’m calling about a research study at the Dana-Farber Cancer Institute about how doctors communicate with their patients. I got your name from your _____ (relationship to patient) who is participating in our study. I’d like to take a few minutes to talk to you about the study and ask if you are interested in participating, and ask you some questions to see if you are eligible. Is it OK for me to talk to you about this now?

If YES, continue below.
If NO, ask “When would be a better time for me to call?” note response in family record.
If NOT INTERESTED, say “Thank you for your time today. We will no longer be contacting you about this study.” Note response in family record.

First, can you please tell me, what is your preferred language?
4. English → continue script below
5. Spanish → ask question a.
6. Other: ______ → ask question a.
   a. What is your level of comfort with speaking English?
      i. Perfectly comfortable → continue script below
      ii. Very comfortable → continue script below
      iii. Somewhat comfortable → thank patient for their time and say “You are not eligible to be in this study”
      iv. Not at all comfortable → thank patient for their time and say “You are not eligible to be in this study”

I am going to give you a summary of the research study now over the phone. If you choose to participate, we will set up a time to meet, preferably at your friend/family member's next appointment at Dana-Farber, and I will give you all of this information in writing and we will review it together then. Feel free to stop me at anytime if you have any questions.

We are doing this research study to find out if doctors can learn and use a structured approach to talking about values and goals with patients. Patients may have strong values and beliefs about how they would like to receive care and to be treated during their illness. The approach we are testing in this research study will hopefully help doctors and patients to be on the same page when it comes to future care for the patient, by raising questions that may otherwise be difficult for doctors and patients to talk about.

We are asking you to take part in this research study because your friend or family member has one of the serious illnesses we are studying, and indicated you as possibly available to participate in this research study by answering survey questions about your communication with your friend or family member.
It will take you up to 2 years to complete this research study. During this time, we will ask you to answer 7 to 13 study surveys by email or postal mail, whichever you prefer. Keeping in touch with you helps us look at the long-term effects of the standard communication approach we are teaching doctors to use as part of the study. If your friend or family member dies during the course of the study, we will call you approximately 6-12 weeks later to ask you some final questions about your communication with them and the care they received.

Many doctors from Dana-Farber have been asked to participate in this research study, including your friend/family member’s doctor. The doctors have been assigned by chance (like a coin toss) into one of two groups: one group has been trained to use this new approach to communication (this is the intervention group), and the other group will continue to provide care as usual (this is the standard care group). You, your family member/friend, or their doctor cannot choose their study group. Your family member's/friend's doctor has an equal chance of being assigned to the intervention group or the standard care group. It is possible that your family member's/friend's doctor is not assigned to the intervention group. In addition, some doctors did not agree to participate in this study, and they will continue to provide care as usual (this is the control group). You will not know which group your family member's/friend's doctor is in, but their doctor will know since there is no way to hide it from them. Either way, their doctor will continue to care for your family member/friend as he or she normally would.

Do you have any questions about the study at this time?

Would you be interested in meeting with me to learn more about this research study? If YES, continue below.

If interested in participating, but cannot meet at DFCI, say “Ok, I can send you the consent form so you can review and sign it, then send it back to us. I'll include a stamped return envelope you can use.” Obtain postal address, then continue below.

If NO, ask “May I ask why?” and note reason in family record. Say “Thank you for your time today. We will no longer be contacting you about this study.”

Great! Thank you for agreeing to meet with me.

1) What is a second phone number we could use to reach you?
Note phone number and type in family record.

2) How would you like to receive the surveys for this study?
   1. Email: ____________
   2. Phone
   3. Mail
   4. In person

3) What is your mailing address?
The next step in enrolling in this research study is to meet with me to learn more about the study and review the informed consent form. This meeting will take 45 minutes to an hour.
We'd like to do this at your friend/family member’s next appointment at Dana-Farber. Would this work for you?
Yes → Date:__/__/____ Time:________ Location:_______
No → When would be a good time for you to meet me at Dana-Farber? Date:__/__/____
Time:________ Location:_____

Can I answer any other questions for you right now?

If you have any questions at any point, please do not hesitate to call me. The study phone number is 617-632-6055.
Family member remote consent phone script:

Hi, my name is ____________ and I’m calling from the Dana-Farber Cancer Institute. May I speak to family member name please?

I’m calling on behalf of Dr. Rachelle Bernacki at Dana-Farber Cancer Institute, about the research study about how doctors communicate with their patients. Did you receive your copy of the consent document I sent you?
Yes → continue below
No → Would you like to give me a call when you receive the document? My phone number is 617-632-6055. If you don’t mind, I’ll call in about a week if I haven’t heard from you.

Do you have some time now so we can go over the consent form and discuss your participation?
Yes → continue below
No → When would be a better time to call? Note in family record.

I’ll review the consent form with you, then give you a chance to ask questions, if you have any. You can also speak with the study doctor, if you’d like. When we’re finished reviewing the form, you can sign it if you are interested in participating. Feel free to stop me at any time to ask questions. Please have the consent form handy as I read through it with you.

Review “family member consent form”, giving friend/family member opportunities to ask questions.
Now that we’ve finished reviewing the consent form, do you have any questions?

Are you interested in participating in this study?
Yes → Say “Great, thank you for agreeing to participate. Please sign and date the consent form on page 9. Then you can put the consent form in the envelope we included, and send it back to us. I’ll sign the form, and send a copy back to you. I’ll send you the first survey after I have signed the consent form.”

No → say “May I ask why?” and note response in family record.
NO, I do not wish to participate in the Serious Illness Communication Project.

Dr. Rachelle Bernacki
Dana-Farber Cancer Institute
450 Brookline Avenue
SW 411
Boston, MA 02215

Print Name: ____________________________
Signature: _____________________________

NO, I do not wish to participate in the Serious Illness Communication Project.

Dr. Rachelle Bernacki
Dana-Farber Cancer Institute
450 Brookline Avenue
SW 411
Boston, MA 02215

Print Name: ____________________________
Signature: _____________________________

NO, I do not wish to participate in the Serious Illness Communication Project.

Dr. Rachelle Bernacki
Dana-Farber Cancer Institute
450 Brookline Avenue
SW 411
Boston, MA 02215

Print Name: ____________________________
Signature: _____________________________

NO, I do not wish to participate in the Serious Illness Communication Project.

Dr. Rachelle Bernacki
Dana-Farber Cancer Institute
450 Brookline Avenue
SW 411
Boston, MA 02215

Print Name: ____________________________
Signature: _____________________________
Appendix C: Informed consent forms (patient, clinician, family member)

See attached documents:
Patient Consent 120814 CLEAN.doc
Clinician Consent 120814 CLEAN.doc
Family Consent 120814 CLEAN.doc
Appendix D: Survey instruments

Below are the Word-document versions of all survey instruments. We have included screenshots of the REDCap web surveys as examples.

Patient Measures:

1. Patient Baseline Measures—At written consent visit

Thank you for participating in this study. Please complete the survey below by selecting the answer that best reflects the way you feel. Read each question and its answers carefully, then answer each question to the best of your ability. You will find instructions for answering questions throughout the survey. Read these before continuing to the next section.

If you cannot complete the survey today, please click on the "Save and Return later" button. You will receive a code. Please write this code down, and use it to complete the survey at a later date. If you have any questions, please contact the study staff at 617-632-6055.

Thank you!

Therapeutic Alliance (Modified Human Connection Scale):

We would like to ask about your relationship with your doctor. Thinking about your oncologist who is associated with this study, please answer the following questions by selecting the most appropriate answer.

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How much do you like your doctor?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. To what extent do you feel comfortable asking your doctor questions?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. How open-minded do you feel your doctor is?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. How much do you trust your doctor?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. How much do you respect your doctor?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. How often does your doctor offer hope?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. How often does your doctor ask how you are coping with your illness?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

Quality of communication with clinician:

We would like to know, in as much detail as possible, how good the doctor taking care of your cancer (your oncologist associated with this study) is at talking with you about your illness and the type of care you would want if you become sicker or too sick to speak for yourself. We know that many people think very highly of their doctors. To help us improve communication between doctors and their patients, please be critical.

Rate your doctor on a scale of 0 to 10, where 0 means your doctor is the very worst you could imagine, and 10 means your doctor is the very best you could imagine. If your doctor does not do the particular task, select the circle for “Doesn’t do.”
When talking with your doctor about important issues like becoming very ill, how good is he/she at:

<table>
<thead>
<tr>
<th></th>
<th>Very worst</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>Very best</th>
<th>Doesn’t do</th>
</tr>
</thead>
<tbody>
<tr>
<td>8. Using words that you can understand.</td>
<td>0 1 2 3 4 5 6 7 8 9</td>
<td>10 N/A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Looking you in the eye.</td>
<td>0 1 2 3 4 5 6 7 8 9</td>
<td>10 N/A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Including your loved ones in decisions about your illness and treatment.</td>
<td>0 1 2 3 4 5 6 7 8 9</td>
<td>10 N/A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Answering all your questions about your illness and treatment.</td>
<td>0 1 2 3 4 5 6 7 8 9</td>
<td>10 N/A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Listening to what you have to say.</td>
<td>0 1 2 3 4 5 6 7 8 9</td>
<td>10 N/A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Caring about you as a person.</td>
<td>0 1 2 3 4 5 6 7 8 9</td>
<td>10 N/A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Giving you his/her full attention.</td>
<td>0 1 2 3 4 5 6 7 8 9</td>
<td>10 N/A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Talking with you about your feelings concerning the possibility that you might get sicker.</td>
<td>0 1 2 3 4 5 6 7 8 9</td>
<td>10 N/A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Talking to you about the details concerning the possibility that you might get sicker.</td>
<td>0 1 2 3 4 5 6 7 8 9</td>
<td>10 N/A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Talking to you about how long you might have to live.</td>
<td>0 1 2 3 4 5 6 7 8 9</td>
<td>10 N/A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Involving you in the decisions about the treatments that you want if you get too sick to speak for yourself.</td>
<td>0 1 2 3 4 5 6 7 8 9</td>
<td>10 N/A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. Asking about the things in life that are important to you.</td>
<td>0 1 2 3 4 5 6 7 8 9</td>
<td>10 N/A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Respecting the things in life that are important to you.</td>
<td>0 1 2 3 4 5 6 7 8 9</td>
<td>10 N/A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. Asking about your spiritual or religious beliefs.</td>
<td>0 1 2 3 4 5 6 7 8 9</td>
<td>10 N/A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. Respecting your spiritual or religious beliefs.</td>
<td>0 1 2 3 4 5 6 7 8 9</td>
<td>10 N/A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. Overall, how would you rate this doctor’s communication with you?</td>
<td>0 1 2 3 4 5 6 7 8 9</td>
<td>10 N/A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

24. In your opinion, how comfortable is your doctor with talking about end-of-life care?
0 = “not at all comfortable” and 10 = “extremely comfortable”

How often does your doctor:

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Usually</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>25. explain things about the course of your illness in a way you can understand?</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26. show respect for what you have to say?</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. spend enough time with you?</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
To what extent do you think your clinician understands:

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>To a slight extent</th>
<th>To some extent</th>
<th>To a large extent</th>
</tr>
</thead>
<tbody>
<tr>
<td>28. ...your understanding of where you are with your illness?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>29. ...how much information you would like about what is likely to be</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>ahead?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30. ...your most important personal goals, if your health situation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>worsens?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>31. ...your fears and worries about the future?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>32. ...what abilities are so critical to your life that you would not</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>want to live without them?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>33. ...what you would be willing to go through for the possibility of</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>gaining more time?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**PEACE:**

Now we would like to ask what you think and feel about your health. For these questions, please indicate the extent to which the statement describes how you feel by clicking the corresponding button.

The answer choices for these questions are “not at all,” “to a slight extent,” “to some extent,” and “to a large extent.”

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>To a slight extent</th>
<th>To some extent</th>
<th>To a large extent</th>
</tr>
</thead>
<tbody>
<tr>
<td>34. To what extent are you able to accept your diagnosis?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>35. To what extent would you say you have a sense of inner peace and</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>harmony?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>36. Do you feel well loved now?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>38. To what extent do you feel a sense of inner calm and tranquility?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>39. To what extent do changes in your physical appearance upset you?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>40. To what extent does worry about your illness make it difficult for</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>you to live from day to day?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>41. To what extent do you feel that it is unfair for you to get ill</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>now?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>42. To what extent do you feel that your life, as you know it, is now</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>over?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>43. To what extent do you feel angry because of your illness?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>44. To what extent do you think your illness has beaten you down?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>45. To what extent do you feel ashamed of, or embarrassed by, your</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>current condition?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>46. To what extent do you feel emotionally numb about your illness?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

**Tradeoffs:**

47. If you could choose, would you prefer:
   - a course of treatment that focused on extending life as much as possible, even if that meant more pain and discomfort, OR
   - a plan of care that focused on relieving pain and discomfort, even if that meant not living as long?
### Anxiety:
Over the last 2 weeks, how often have you been bothered by the following problems? Please select the answer that best corresponds to how often this has happened in the last 2 weeks. The answer choices for these questions are “not at all,” “several days,” “more than half the days,” and “nearly every day.”

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>48. Feeling nervous, anxious or on edge</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>49. Not being able to stop or control worrying</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>50. Worrying too much about different things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>51. Trouble relaxing</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>52. Being so restless that it’s hard to sit still</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>53. Becoming easily annoyed or irritable</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>54. Feeling afraid as if something awful might happen</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

### Depression:
Over the last 2 weeks, how often have you been bothered by the following problems? Please select the answer that best corresponds to how often this has happened in the last 2 weeks. The answer choices for these questions are “not at all,” “several days,” “more than half the days,” and “nearly every day.”

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>Several Days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>55. Little interest or pleasure in doing things.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>56. Feeling down, depressed or hopeless.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>57. Trouble falling or staying asleep, or sleeping too much.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>58. Feeling tired or having little energy.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>59. Poor appetite or overeating.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>60. Feeling bad about yourself, or that you are a failure, or have let yourself or your family down.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>61. Trouble concentrating on things, such as reading the newspaper or watching television.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>62. Moving or speaking so slowly that other people could have noticed. Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>63. Thoughts that you would be better off dead, or of hurting yourself.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
64. If you had any of these problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people? *If you have not had any of these problems, please select “Not applicable.”*

- Not difficult at all
- Somewhat difficult
- Very difficult
- Extremely difficult
- Not applicable

*A Health Care Proxy (HCP) or Durable Power of Attorney (DPOA) is a legal document that allows you to appoint someone you trust to make decisions for you if you become unable to communicate those decisions yourself. This person is then called your proxy or surrogate decision maker.*

65. Do you have a Health Care Proxy (HCP) or Durable Power of Attorney (DPOA) for medical care?
- Yes
- No

66a. If yes: How long has this person been your HCP or DPOA? *If you do not know, please estimate.*

- 0 to 2 months
- 3 to 6 months
- 6 months to 2 years
- More than 2 years

**Quality of communication with family:**
This next set of questions is about how much you talk with your friend/family member about your illness. For these questions, we are asking about the friend or family member who is enrolled in the study with you.

<table>
<thead>
<tr>
<th>How often do you talk with your friend/family member about the following issues:</th>
<th>Never</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very frequently</th>
</tr>
</thead>
<tbody>
<tr>
<td>66. Your quality of life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>67. Your personal goals?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>68. The abilities that are important to you?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>69. Your fears and worries about the future?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>70. Medical treatments you would want?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>71. Medical treatments you would not want?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

72. Overall, how helpful to you has it been to discuss these issues with your friend/family member?
- Not at all helpful
- A little helpful
- Somewhat helpful
- Very helpful
Extremely helpful
We do not discuss these issues

73. To what extent do you feel your friend/family member understands what you would want if you couldn’t talk for yourself?
- Not at all
- To a slight extent
- To some extent
- To a large extent

74. How much emotional support do you receive from your friend/family member?
- Much less than I want/need
- A little less than I want/need
- About the right amount
- A little more than I want/need
- A lot more than I want/need

75. Have you had any conversations with your oncologist associated with this study about your goals and wishes for your future care?
- Yes, go to 77
- No, go to Functional Status and Pain

76. How much did talking with your doctor help you talk with your friend/family member about your goals and wishes for your future care?
- Not at all
- A little
- Moderately
- Very much
- Extremely

<table>
<thead>
<tr>
<th>How much did the discussion(s) with your doctor:</th>
<th>Made things much worse</th>
<th>Made things slightly worse</th>
<th>No change</th>
<th>Made things slightly better</th>
<th>Made things much better</th>
</tr>
</thead>
<tbody>
<tr>
<td>77. Change the quality of conversations with your friend/family member?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>78. Help you get support from your friend/family member?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Functional status and pain:
This next set of questions asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. For each of the following questions, please select the one circle that best describes your answer.

79. How would you define your current health status?
- Relatively healthy and not seriously ill
- Relatively healthy, but terminally ill
80. What is your estimate of how much time you are likely to live?
- More than a year
- Several months to a year
- Several weeks to a month
- Days to weeks
- Other, please specify: ______________

81. In general, would you say your health is:
- Excellent
- Very good
- Good
- Fair
- Poor

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

82. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf?
- Yes, limited a lot
- Yes, limited a little
- No, not limited at all

83. Climbing several flights of stairs?
- Yes, limited a lot
- Yes, limited a little
- No, not limited at all

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

84. Accomplished less than you would like?
- Yes
- No

85. Were limited in the kind of work or other activities?
- Yes
- No

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

86. Accomplished less than you would like?
- Yes
- No
87. Did work or other activities less carefully than usual?
   • Yes
   • No

88. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?
   • Not at all
   • A little bit
   • Moderately
   • Quite a bit
   • Extremely

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks...

<table>
<thead>
<tr>
<th>Question</th>
<th>All of the time</th>
<th>Most of the time</th>
<th>A good bit of the time</th>
<th>Some of the time</th>
<th>A little bit of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you felt calm and peaceful?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Did you have a lot of energy?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Have you felt downhearted and blue?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>0</td>
</tr>
</tbody>
</table>

93. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?
   • All of the time
   • Most of the time
   • Some of the time
   • A little of the time
   • None of the time

94. Do you have any pain today?
   • Yes→ continue to 95
   • No→ skip to 97

95. On a scale of 1 to 10, how bad is your pain? 1 is very mild pain, and 10 is the worst pain you have ever felt.

96. Considering your illness and your current health, how acceptable is that level of pain to you?
   • Much better than I would be willing to accept
   • Better than I would be willing to accept
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- About what I can accept
- Worse than I am willing to accept
- Much worse than I am willing to accept

**Religion and Spirituality**

97. What is your religion? *Please select all that apply.*

- ☐ Protestant
- ☐ Catholic
- ☐ Jewish
- ☐ Born-again or Evangelical Christian
- ☐ Mormon/Latter-day Saints
- ☐ Muslim
- ☐ Buddhist
- ☐ Hindu
- ☐ Unitarian Universalist
- ☐ No religion
- ☐ Atheist
- ☐ Other religion (please specify:_______)

98. The following items deal with ways you’ve coped with a significant trauma or negative events in your life. There are many ways to try to deal with problems. The following items ask what part religion played in coping with these negative events. We want to know to what extent you did what the item says. Don’t answer on the basis of what worked or not - just whether or not you did it. Please try to make your answers as true FOR YOU as you can. The answer choices are “a great deal,” “quite a bit,” “somewhat,” and “not at all.”

<table>
<thead>
<tr>
<th>To deal with negative events in the past, how often or how frequently did you....</th>
<th>Not at all</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>99. Look for a stronger connection with God.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>100. Seek God’s love and care.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>101. Seek help from God in letting go of my anger.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>102. Try to put my plans into action together with God.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>103. Try to see how God might be trying to strengthen me in this situation.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>104. Ask forgiveness for my sins.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>105. Focus on religion to stop worrying about my problems.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>106. Wonder whether God had abandoned me.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>107. Feel punished by God for my lack of devotion.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Number</td>
<td>Question</td>
<td>Options</td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------</td>
<td>--------------------------------------------------------------------------</td>
<td>------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>108</td>
<td>Wonder what I did for God to punish me.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>109</td>
<td>Question God’s love for me.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>110</td>
<td>Wonder whether my church/faith community had abandoned me.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>111</td>
<td>Decide the devil made this happen.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>112</td>
<td>Question the power of God.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Health Literacy:**

113. How often do you have problems learning about your medical condition because of difficulty understanding written information?
   - Never
   - Occasionally
   - Sometimes
   - Often
   - Always

114. How confident are you filling out medical forms by yourself?
   - Extremely
   - Quite a bit
   - Somewhat
   - A little bit
   - Not at all

115. How often do you have someone (like a family member, friend, hospital/clinic worker or caregiver) help you read hospital materials?
   - Never
   - Occasionally
   - Sometimes
   - Often
   - Always

116. Typically, when medical decisions about your care are made, what role, if any, does your doctor(s) play in these? *Please select the 1 statement that best reflects the role your doctor played in making this decision.*
   - I make the decision with little or no input from my doctor(s).
   - I make the decision after considering my doctor(s) advice or opinions.
   - My doctor(s) and I make the decision together.
   - My doctor(s) make the decision after considering my opinion.
   - My doctor(s) make the decision with little or no input from me.

**Demographics**

117. Which of the following categories best reflects your total family income (i.e., income from all sources)?
   - Under $20,000
What kind of health insurance do you currently have? Please select all that apply.

- Medicare
- Medicaid
- Private insurance (such as Blue Cross-Blue Shield, Harvard Pilgrim, Tufts Health Plan)
- Mass Health
- No insurance → skip to 119

If “private insurance” selected: What type of health insurance plan is your private insurance?

- PPO
- HMO
- Unsure/Don’t know

What is the highest level of education you have completed?

- Less than high school
- High school
- Some college
- College graduate
- Graduate or Professional school

What is your current marital status?

- Legally married or registered domestic partners
- Living with a partner to whom you are not married
- In a serious relationship but not living with a partner
- Single
- Separated
- Divorced
- Widowed
- Other (Please specify): ____________

Please indicate who (if anyone) you live with: Please select all that apply.

- Self
- Partner/Spouse
- Roommate/Friend
- Dependent Children
  - If yes, specify number(s) ____________
  - If yes, specify age(s) ____________
- Group home/Residential
- Independent Child
- Dependent Adult
- Parent
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☐ Other *(please specify) ______________________

122. Do you consider yourself Hispanic or Latino/a?
   - No
   - Yes, Hispanic or Latino/a

123. What is your race? *Please select all that apply.*
   - ☐ American Indian or Native American
   - ☐ Asian
   - ☐ Black or African American
   - ☐ Native Hawaiian or other Pacific Islander
   - ☐ White
   - ☐ Other *(please specify): ______________________________________

We are working to improve our surveys and would very much appreciate your response to the following two questions:

124. Please choose the statement that best describes your experience filling out this survey:
   - ☐ The survey makes me very anxious.
   - ☐ The survey makes me somewhat anxious.
   - ☐ The survey does not make me anxious (at all).
   Other comments:

125. Please choose the statement that best describes your experience filling out this survey:
   - ☐ The survey gets me very down.
   - ☐ The survey gets me somewhat down.
   - ☐ The survey does not get me down (at all).
   Other comments:

Thank you for your time. If you have any questions about this study, please do not hesitate to call the study staff at 617-632-6055.
Example of what the Patient Baseline survey looks like on REDCap:
Think about how you try to understand and deal with major problems in your life. To what extent does each of the statements below reflect the way you cope? Please click on the circle that best corresponds to the way you cope.

The answer choices for these questions are:
- "Not" = Not at all
- "Some" = Somewhat
- "Quite" = Quite a bit
- "Great" = A great deal

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not</th>
<th>Some</th>
<th>Quite</th>
<th>Great</th>
</tr>
</thead>
<tbody>
<tr>
<td>I think about how my life is part of a larger spiritual force.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I work together with God as partners to get through hard times.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I look to God for strength, support and guidance in crises.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel that stressful situations are God’s way of punishing me for my sins or lack of spirituality.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I wonder whether God has abandoned me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I try to make sense of the situation and decide what to do without relying on God.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

To what extent is your religion involved in understanding or dealing with stressful situations in any way?
- Not involved at all
- Not very involved
- Somewhat involved
- Very involved
Thank you for participating in this study. Please complete the survey below by selecting the answer that best reflects the way you feel. Read each question and its answers carefully, then answer each question to the best of your ability. You will find instructions for answering questions throughout the survey. Read these before continuing to the next section.

If you cannot complete the survey today, please click on the "Save and Return later" button. You will receive a code. Please write this code down, and use it to complete the survey at a later date. If you have any questions, please contact the study staff at 617-632-6055.

During today’s survey, we will ask you questions about your health, your relationship with your doctor, and what you think and feel about your illness. Read each question, along with the responses.

**Therapeutic alliance:** same as baseline

**Quality of communication with clinician:** same as baseline

**Patient acceptability for Intervention-arm Patients**

Which clinician did you see during your most recent visit to Dana-Farber? Please select your clinician from this menu. [drop-down menu of Intervention clinicians]

During this visit, did your clinician communicate with you about how long you are likely to live with your disease?

- Yes
- No

If yes, what did he/she communicate to you about your prognosis, in terms of time?

- More than a year
- Several months to a year
- Several weeks to a month
- Days to weeks
- Other, please specify: ___________________

After your visit, how did your understanding about your prognosis change?

- No change
- My current prognosis is worse than I believed
- My current prognosis is better than I believed
- Not discussed

Did you receive the Family Communication Guide pamphlet at this visit?

- Yes
- No
- I don’t know
At this visit, you had a conversation with your clinician about your goals and wishes for your future care. Think about that conversation and answer the following questions. Please select the response that best corresponds to your answer.

<table>
<thead>
<tr>
<th>To what extent did this conversation increase or decrease...</th>
<th>Decreased a lot</th>
<th>Decreased a little</th>
<th>Neither increased nor decreased</th>
<th>Increased a little</th>
<th>Increased a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>your anxiety about your illness?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>your hopefulness about your quality of life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>your hopefulness about your life expectancy?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>your sense of peacefulness?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>your sense of control over your medical decisions?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>the closeness you have with your clinician?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

We are interested in what you think about specific parts of the conversation you had with your clinician about your goals and wishes for your future care. For each of the questions below, please select the circle that best reflects your response. If you did not talk about that specific part of the conversation, please select the circle for "Did not discuss."

Did you like the way this conversation was introduced?
- □ The conversation was not introduced.
- □ Disliked a lot
- □ Disliked a little
- □ Neither liked nor disliked
- □ Liked a little
- □ Liked a lot

How much did this conversation with your clinician increase or decrease your understanding of what your health may be like in the future?
- □ Decreased a lot
- □ Decreased a little
- □ Neither increased nor decreased
- □ Increased a little
- □ Increased a lot

How helpful was each of the following parts of the conversation in planning for the future?

<table>
<thead>
<tr>
<th>How helpful was it for your doctor to...</th>
<th>Not at all helpful</th>
<th>A little helpful</th>
<th>Somewhat helpful</th>
<th>Very helpful</th>
<th>Extremely helpful</th>
<th>Did not discuss</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ask about your understanding of where you are now with your illness?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>N/A</td>
</tr>
<tr>
<td>Ask about how much information you would want about what is likely to be ahead?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>N/A</td>
</tr>
<tr>
<td>Communicate your prognosis to you?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>N/A</td>
</tr>
<tr>
<td>Bring up your personal goals for the future?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>N/A</td>
</tr>
</tbody>
</table>
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<table>
<thead>
<tr>
<th>Question</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ask you about your fears and worries about the future?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ask you about the abilities that are so critical to your life that you would not want to live without them?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ask you about how much you would be willing to go through for the possibility of gaining more time?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ask you about how much your family knows about your priorities and wishes.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How much information did you get from this discussion?
- [ ] I received much more information than I wanted.
- [ ] I received a little more information than I wanted.
- [ ] I received the exact amount of information I wanted.
- [ ] I received a little less information than I wanted
- [ ] I received a lot less information than I wanted

How much information about what is likely to be ahead with your illness would you like from your physician?
- [ ] I want to be fully informed about everything
- [ ] I want to be informed of big picture, but not details
- [ ] I want some information, but only positive information
- [ ] I do not want any information about myself
- [ ] Other: __________________

What was your reaction to the doctor using a written guide or form during this conversation?
- [ ] Unsure/did not notice
- [ ] Disliked a lot
- [ ] Disliked a little
- [ ] Neither liked nor disliked
- [ ] Liked a little
- [ ] Liked a lot

Did you feel that your clinician had this conversation with you at the right time?
- [ ] It was the right time to talk about this
- [ ] It was too soon to talk about this, because it is too early in my relationship with my doctor
- [ ] It was too soon to talk about this, because I am too healthy at this time
- [ ] I wish my doctor had brought this up earlier
- [ ] Other, please specify: __________________

Overall, how worthwhile was it to talk about these issues with your clinician?
- [ ] Not at all
- [ ] Slightly
- [ ] Somewhat
- [ ] Very much
- [ ] Extremely
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Was a family member present during this conversation?

- Yes
- No

If yes, how helpful was it to have your family member present during this conversation?

- Not at all helpful
- A little helpful
- Somewhat helpful
- Very helpful
- Extremely helpful

If no, how helpful would it have been to have your family member present during this conversation?

- Not at all helpful
- A little helpful
- Somewhat helpful
- Very helpful
- Extremely helpful

What, if anything, have you done differently as a result of this conversation?

**OPEN ENDED**

**Patient Acceptability for Non-intervention patients:**

We want to ask you some questions about your conversations with your clinician who is associated with this research study.

Please select your clinician from this menu. *[drop-down menu of Non-intervention clinicians]*

Has your clinician communicated with you about how long you are likely to live with your disease?

- Yes
- No

If yes, what did they communicate to you about your prognosis, in terms of time?

- More than a year
- Several months to a year
- Several weeks to a month
- Days to weeks
- Other, please specify: ______________________

If yes, how did your understanding about your prognosis change?

- No change
- My current prognosis is worse than I believed
- My current prognosis is better than I believed
- Not discussed
Think about the most recent conversation you had with this clinician about your goals and wishes for your future care. Please select the response that best corresponds to your answer. If you have never discussed this with your clinician, please select the circle for “Have not had conversation.”

To what extent did this conversation increase or decrease…

<table>
<thead>
<tr>
<th></th>
<th>Decreased a lot</th>
<th>Decreased a little</th>
<th>Neither increased nor decreased</th>
<th>Increased a little</th>
<th>Increased a lot</th>
<th>Have not had conversation</th>
</tr>
</thead>
<tbody>
<tr>
<td>your anxiety about your illness?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>your hopefulness about your quality of life?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>your hopefulness about your life expectancy?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>your sense of peacefulness?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>your sense of control over your medical decisions?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>the closeness you have with your clinician</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
</tr>
</tbody>
</table>

How much did this conversation with your clinician increase or decrease your understanding of what might happen in the future?

- Decreased a lot
- Decreased a little
- Neither increased nor decreased
- Increased a little
- Increased a lot
- Have not had conversation

How much information did you get from this discussion?

- I received much more information than I wanted.
- I received a little more information than I wanted.
- I received the exact amount of information I wanted.
- I received a little less information than I wanted.
- I received a lot less information than I wanted.
- Have not had conversation

How much information about what is likely to be ahead with your illness would you like from your physician?

- I want to be fully informed about everything
- I want to be informed of big picture, but not details
- I want some information, but only positive information
- I do not want any information about myself
- Other: ________________

Did you feel that your clinician had this conversation with you at the right time?

- It was the right time to talk about this
- It was too soon to talk about this, because it is too early in my relationship with my doctor
- It was too soon to talk about this, because I am too healthy at this time
- I wish my doctor had brought this up earlier
- Other, please specify: ________________
Overall, how worthwhile was it to talk about these issues with your clinician?
- Not at all
- Slightly
- Somewhat
- Very much
- Extremely

Was a family member present during this conversation?
- Yes
- No

If yes, how helpful was it to have your family member present during this conversation?
- Not at all helpful
- A little helpful
- Somewhat helpful
- Very helpful
- Extremely helpful

If no, how helpful would it have been to have your family member present during this conversation?
- Not at all helpful
- A little helpful
- Somewhat helpful
- Very helpful
- Extremely helpful

What, if anything, have you done differently as a result of this conversation?

**PEACE (all patients): same as baseline**

**Tradeoffs questions (all patients): same as baseline**

**Life priorities (all patients):**

<table>
<thead>
<tr>
<th>Goal</th>
<th>Not important at all</th>
<th>Somewhat important</th>
<th>Important</th>
<th>Very important</th>
<th>Extremely important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live as long as possible, no matter what</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Sometimes, when people have serious illnesses they identify goals that they will try to achieve. These goals may be anything--attending the wedding of a family member/friend, waiting to see the birth of a grandchild, not being in pain or simply being able to walk up a flight of stairs without feeling breathless. Everyone’s goals are different; some people choose not to set goals at all. As you think about the future, what are your most important goals?

Please read all of the goals below and rate the importance of each goal on a scale from “Not important at all” to “Extremely important.”
Now, please rank-order your top-5 goals according to their importance to you. Please place the number 1 in the goal that is most important, and 5 in the goal that is least important; then fill in other numbers (2-4) to rank the other goals according to their importance to you. Because there are 10 total goals, some goals will not have a ranking.

- Live as long as possible, no matter what
- Be at home
- Be physically comfortable
- Be mentally aware
- Not be a burden
- Be independent
- Have my medical decisions respected
- Provide support for family
- Be spiritually and emotionally at peace
- Achieve particular life goal, please specify: ____________________

<table>
<thead>
<tr>
<th>Goal</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be at home</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Be physically comfortable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Be mentally aware</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not be a burden</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Be independent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have my decisions respected</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provide support for family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Be spiritually and emotionally at peace</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Achieve particular life goal, please specify: ________________</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In the last two months, to what extent have you been able to achieve the following goals:

<table>
<thead>
<tr>
<th>Goal</th>
<th>Not at all</th>
<th>To a slight extent</th>
<th>To some extent</th>
<th>To a large extent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living as long as possible, no matter what</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Remain at home</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Be physically comfortable</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Be mentally aware</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Be independent</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Have your medical decisions respected</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Provide support for family</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Be spiritually and emotionally at peace</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Achieve particular life goal, please specify</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Where would you choose to spend your last days of life?

- Hospital
- Nursing home
- Hospice or another palliative care facility
- My own home
- Another person’s home, such as a family member or friend
- Another place, please specify: __________
- Don’t know/not sure
Fears/worries: What are your biggest fears and worries about the future with your health? Please read the list below, then rank up to 5 fears/worries, where 1 means the fear/worry is extremely important and 5 means the fear/worry is somewhat important. Because there are more than 5 total possibilities, some will not have a ranking. If you have less than 5 fears/worries, please rank only those relevant to you. Please input a different number for each of the fears/worries that you choose.

- Pain
- Other symptoms
- Emotional distress
- Spiritual distress
- Concerns about meaning of my life
- Burdening family
- Ability to care for others (e.g., children, ill spouse)
- Other family concerns
- Loss of control
- Getting treatments I don’t want
- Loss of dignity
- Preparing for death
- Finances
- Other ______________

Unacceptable levels of Function: What abilities are so critical to your life that you can’t imagine living without them? Select all that apply.

- Being conscious
- Being able to talk
- Not being in pain or very uncomfortable
- Being myself
- Being able to care for myself, including toileting and feeding
- Being able to interact with others
- Other:_______________

Anxiety and depression (all patients): same as baseline

Quality of Communication with Family (all patients):
This next set of questions is about how talking with your doctor has influenced how much you talk with your family about your illness. For these questions, we are asking about the friend or family member who is enrolled in the study with you.

A Health Care Proxy (HCP or Durable Power of Attorney for medical care [DPOA]) is a legal document that allows you to appoint someone you trust to make decisions for you if you become unable to communicate those decisions yourself. This person is then called your proxy or surrogate decision maker.
Have you changed your HCP or registered a new HCP since the last survey?
- Yes, registered a new HCP
- Yes, changed who is my HCP
- No

Since the last survey, approximately how many conversations have you had with the following people about your goals and wishes for your future care?

<table>
<thead>
<tr>
<th>People</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any doctor?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your oncologist?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your friend or family member?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How much did talking with your doctor help you talk with your friend/family member about your goals and wishes for your future care?
- Not at all
- A little
- Moderately
- Very much
- Extremely

How much did the discussion(s) with your doctor:

<table>
<thead>
<tr>
<th>Effect</th>
<th>Made things much worse</th>
<th>Made things slightly worse</th>
<th>No change</th>
<th>Made things slightly better</th>
<th>Made things much better</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change quality conversations with your family member?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Help you get support from your friend/family member?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Since the last survey, how often have you talked with your friend/family member about the following issues:

<table>
<thead>
<tr>
<th>Issue</th>
<th>Never</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very frequently</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your quality of life?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your personal goals?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The abilities that are important to you?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your fears and worries about the future?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical treatments you would want?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical treatments you would not want?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Family:** How much does your family know about your priorities and wishes?
- Extensive discussion with family about goals and wishes
- Some discussion, but incomplete
- No discussion, but I plan to address these issues
- No discussion; I want help talking with family
- I want my clinician to talk with my family
- I do not want family informed
Overall, how helpful to you has it been to discuss these issues with your friend/family member?

- Not at all helpful
- A little helpful
- Somewhat helpful
- Very helpful
- Extremely helpful
- We do not discuss these issues.

To what extent do you feel your friend/family member understands what you would want if you couldn’t talk for yourself?

- Not at all
- To a slight extent
- To some extent
- To a large extent

How much emotional support do you receive from your family member?

- Much less than I want/need
- A little less than I want/need
- About the right amount
- A little more than I want/need
- A lot more than I want/need

Functional status and pain: same as baseline

We are working to improve our surveys and would very much appreciate your response to the following two questions:

126. Please choose the statement that best describes your experience filling out this survey:

☐ The survey makes me very anxious.
☐ The survey makes me somewhat anxious.
☐ The survey does not make me anxious (at all).

Other comments:

127. Please choose the statement that best describes your experience filling out this survey:

☐ The survey gets me very down.
☐ The survey gets me somewhat down.
☐ The survey does not get me down (at all).

Other comments:
3. Patient Follow-up Measures—Every 2 months after enrollment

Thank you for participating in this study. Please complete the survey below by selecting the answer that best reflects the way you feel. Read each question and its answers carefully, then answer each question to the best of your ability. You will find instructions for answering questions throughout the survey. Read these before continuing to the next section.

If you cannot complete the survey today, please click on the "Save and Return later" button. You will receive a code. Please write this code down, and use it to complete the survey at a later date. If you have any questions, please contact the study staff at 617-632-6055.

Therapeutic alliance: same as baseline

Quality of communication with clinician: same as baseline

PEACE: same as baseline

Tradeoffs: same as "extra" survey

Life priorities: same as "extra" survey

Anxiety and depression: same as baseline

Quality of communication with family: same as “extra” survey

Functional status and pain: same as baseline

Is there anything else you would like us to know? OPEN ENDED

We are working to improve our surveys and would very much appreciate your response to the following two questions:

128. Please choose the statement that best describes your experience filling out this survey:
   ☐ The survey makes me very anxious.
   ☐ The survey makes me somewhat anxious.
   ☐ The survey does not make me anxious (at all).
   Other comments:

129. Please choose the statement that best describes your experience filling out this survey:
   ☐ The survey gets me very down.
   ☐ The survey gets me somewhat down.
   ☐ The survey does not get me down (at all).
   Other comments:
That is the end of the questions for today’s survey. Thank you for your time. If you have any questions about this study, please do not hesitate to call the study staff at 617-632-6055.
We will send this letter to patients who have not responded to their survey after 2 email
tries and 2 phone call attempts:

Dear [patient name],

Thank you for your participation in the Serious Illness Communication Study at Dana-Farber
Cancer Institute. You may remember when you enrolled in [month of enrollment] that we
explained that we would send you a survey every 2 months to ask you follow-up questions. We
have attempted to send you your next survey, but have not received your response.

Please complete the enclosed survey and send back to us in the envelope provided. We greatly
appreciated your continued participation.

If you have any questions, please do not hesitate to call the study staff at 617-632-6055.

Best,

Jenna Ogden, Nate Pertsch, and Maribel Valenzuela Research Assistants
Serious Illness Communication Study
communicationchecklist@dfci.harvard.edu
617-632-6055

We will send this letter to patients/family members who have completed their 2 years in the
study:

Dear [patient/friend/family member],

We would like to express our sincerest gratitude for your participation in the Communication
Study at the Dana-Farber Cancer Institute. You were enrolled in the study on [month and year of
enrollment visit] and have now completed all study requirements. You will no longer be
receiving surveys from us.

The information you have shared with us has been incredibly valuable. We are so grateful for
your time and effort in filling out our surveys, and your contribution is very meaningful to our
study and to the larger goal of improving care for patients with cancer and their families.

If you have any questions or comments, please contact a member of our research team by phone
at 617-632-6055 or by email at communicationstudy@dfci.harvard.edu.

We thank you again for your important contributions.

Sincerely,

Names and titles
Serious Illness Communication Project
Dana-Farber Cancer Institute
450 Brookline Avenue
Friend/Family Member Measures:

1. Friend/Family Member Baseline Measures—At consent

Thank you for participating in this study. Please complete the survey below by selecting the answer that best reflects the way you feel. Read each question and its answers carefully, then answer each question to the best of your ability. You will find instructions for answering questions throughout the survey. Read these before continuing to the next section.

If you cannot complete the survey today, please click on the "Save and Return later" button. You will receive a code. Please write this code down, and use it to complete the survey at a later date. If you have any questions, please contact the study staff at 617-632-6055.

Demographics/relationship

1) What is your relationship to your friend or family member (the person who is enrolled in this study with you)?
   I am her/his:
   [Drop-down menu with options]: Parent, Sibling, Spouse/Partner, Uncle/Aunt, Close Friend, Child, Other (please specify:______________)

2) What is your date of birth?

3) What is your gender?
   1. Male
   2. Female

4) Do you consider yourself Hispanic or Latino/a?
   0. No
   1. Yes, Hispanic or Latino/a

5) What is your race? Please check all that apply.
   1. American Indian or Native American
   2. Asian
   3. Black or African American
   4. Native Hawaiian or other Pacific Islander
   5. White
   6. Other (please specify): __________________________

6) What is the highest level of education that you have completed?
   1. Less than high school
   2. High school
   3. Some college
   4. College
   5. Graduate or Professional school

7) How many years have you known your friend or family member? (If less than 1 year please say “0”.)

A Health Care Proxy (HCP or Durable Power of Attorney [DPOA]) is a legal document that allows a person to appoint someone they trust to make decisions for them if they become unable
Serious Illness Communication Project
3/4/2015
to communicate those decisions themselves. This person is then called their proxy or surrogate
decision maker.

8) Do you know who your friend or family member’s surrogate decision maker or Health Care
Proxy is?
   0. No, I don’t know
   1. Yes, it is me
   2. Yes, it is someone else: ________________
   3. They do not have one.

Quality of Communication with Patient
We’d like to ask you about how much you talk with your friend or family member about certain
aspects of their illness.

<table>
<thead>
<tr>
<th>How often do you talk with your friend/family member about the following:</th>
<th>Never</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very frequently</th>
</tr>
</thead>
<tbody>
<tr>
<td>9. His/her quality of life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. What his/her personal goals are?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. The abilities that are important to him/her?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. His/her fears and worries about the future?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. Medical treatments he/she would want?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. Medical treatments he/she would not want?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

15. Overall, how helpful to you has it been to discuss these issues with your friend/family
member?
   ☐ Not at all helpful
   ☐ A little helpful
   ☐ Somewhat helpful
   ☐ Very helpful
   ☐ Extremely helpful
   ☐ We do not discuss these issues.

16. To what extent do you feel you understand what your friend/family member would want if
   he/she could not talk for him/herself?
   ☐ Not at all
   ☐ To a slight extent
   ☐ To some extent
   ☐ To a large extent

17. How did you complete this survey?
   ☐ Self on computer/tablet
   ☐ Self on paper
   ☐ Study staff on computer tablet
   ☐ Study staff on phone
   ☐ Other, please specify
Friend/Family member Follow up Survey--Sent same day as corresponding patient follow-up survey

Thank you for participating in this study. Please complete the survey below by selecting the answer that best reflects the way you feel. Read each question and its answers carefully, then answer each question to the best of your ability. You will find instructions for answering questions throughout the survey. Read these before continuing to the next section.

If you cannot complete the survey today, please click on the "Save and Return later" button. You will receive a code. Please write this code down, and use it to complete the survey at a later date. If you have any questions, please contact the study staff at 617-632-6055.

1. Since the last survey, approximately how many conversations have you had with your friend or family member about his/her end-of-life healthcare concerns and preferences?
   - 0
   - 1
   - 2
   - 3
   - 4 or more

<table>
<thead>
<tr>
<th>Since the last survey, how often have you talked with your friend/family member about the following:</th>
<th>Never</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very frequently</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. His/her quality of life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. What his/her personal goals are?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. The abilities that are important to him/her?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. His/her fears and worries about the future?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. Medical treatments he/she would want?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. Medical treatments he/she would not want?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

8. Overall, how helpful to you has it been to discuss these issues with your friend/family member?
   - Not at all helpful
   - A little helpful
   - Somewhat helpful
   - Very helpful
   - Extremely helpful
   - We have not discussed these issues.

9. To what extent do you feel you understand what your friend/family member would want if he/she could not talk for him/herself?
   - Not at all
   - To a slight extent
   - To some extent
   - To a large extent
Family Perception of Life Priorities

Sometimes, when people have serious illnesses they identify goals that they will try to achieve. These goals may be anything--attending the wedding of a family member/friend, waiting to see the birth of a grandchild, not being in pain or simply being able to walk up a flight of stairs without feeling breathless. Everyone’s goals are different; some people choose not to set goals at all. Now we would like you to think about your friend or family member and her or his goals.

Please read all of the goals below and rate the importance of each goal to your friend or family member on a scale from “Not important at all” to “Extremely important.”

<table>
<thead>
<tr>
<th>Goal</th>
<th>Not important at all</th>
<th>Somewhat important</th>
<th>Important</th>
<th>Very important</th>
<th>Extremely important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live as long as possible, no matter what</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Be at home</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Be physically comfortable</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Be mentally aware</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Not be a burden</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Be independent</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Have my decisions respected</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Provide support for my family</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Be spiritually and emotionally at peace</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Achieve particular life goal, please specify:</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Now, please rank-order the top 5 goals according to their importance to your friend or family member. Please place the number 1 in the goal that is most important to your friend or family member, and 5 in the goal that is least important to your friend or family member; then, please fill in other numbers (2-4) to rank the other goals according to their importance to your friend or family member. Because there are 10 total goals, some goals will not have a ranking.

☐ Live as long as possible, no matter what
☐ Be at home
☐ Be physically comfortable
☐ Be mentally aware
☐ Not be a burden
☐ Be independent
Serious Illness Communication Project
3/4/2015

☐ Have my medical decisions respected
☐ Provide support for family
☐ Be spiritually and emotionally at peace
☐ Achieve particular life goal, please specify: ______________________

Is there anything else you would like us to know?
OPEN ENDED

How did you complete this survey?
☐ Self on computer/tablet
☐ Self on paper
☐ Study staff on computer tablet
☐ Study staff on phone
☐ Other, please specify
An example of what the family online survey looks like:

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>How would you like to ask you about how much you talk with your friend or family member about certain aspects of their illness.</td>
<td></td>
</tr>
<tr>
<td>The answer choices for these questions are on a scale of 1 to 5, where</td>
<td></td>
</tr>
<tr>
<td>1 = Greatly decreased</td>
<td></td>
</tr>
<tr>
<td>2 = Slightly decreased</td>
<td></td>
</tr>
<tr>
<td>3 = No change</td>
<td></td>
</tr>
<tr>
<td>4 = Slightly increased</td>
<td></td>
</tr>
<tr>
<td>5 = Greatly increased</td>
<td></td>
</tr>
<tr>
<td>Since starting this study, how has the amount you talk with your friend or family member about the following topics changed?</td>
<td></td>
</tr>
<tr>
<td>4) The role of a Health Care Agent or Health Care Proxy</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>5) Who should be your friend or family member’s health care agent or proxy</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>6) How your friend or family member wishes to live the remainder of their life</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>7) What your friend or family member would like to be able to achieve</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>8) What capabilities are important to your friend or family member</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>9) Your friend or family member’s fears</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>10) Your friend or family member’s future goals</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>11) Medical treatments your friend or family member would want</td>
<td>1 2 3 4 5</td>
</tr>
</tbody>
</table>
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Upon learning of a patient’s death, we will send the friend/family member the following letter in the mail:

Dear __________.

We were very sorry to learn about _____’s recent death. Please accept our sincerest sympathies for your loss. Our thoughts are with you and your family during this difficult time.

Our warmest condolences,

The Serious Illness Communication Project Team at Dana-Farber

If we cannot get a hold of the friend/family member to schedule the final interview after 5 phone-call attempts (including 2 voice messages) over a 3-month period, we will send the friend/family member the following letter:

Dear ______ [friend/family member]____.

We were so saddened to hear about your (RELATIONSHIP TO PATIENT, PATIENT FULL NAME)’s death.

We would like to express our condolences to you and your family. We also want to convey our sincere gratitude for your participation and for your (RELATIONSHIP TO PATIENT)’s participation in the Communication Study at the Dana-Farber Cancer Institute. You were enrolled in the study on [month and year of enrollment visit]. You may remember that when we spoke in [month of recruitment call], we mentioned that we would contact you if your friend/family member died to ask you some final questions.

The information you have shared with us has been incredibly valuable, and I am writing to ask that you consider completing one more survey. This final survey asks some questions about your (RELATIONSHIP TO PATIENT)’s experience and your experience at the end of HIS/HER life. If you are willing to follow-up with us during this difficult period, we would greatly appreciate your time. Your perspectives on your friend/family member’s experiences would be invaluable to us as we continually attempt to improve care.

If you are interested in completing the last survey of the study, please contact a member of our research team by phone at 617-632-6055 or by email at communicationchecklist@dfci.harvard.edu. If you contact us, we will then schedule a time to complete the survey.

We know that this letter may find you at a difficult time. The study is entirely voluntary, and we completely understand if you choose not to do the survey. Please let us know if you would prefer that we no longer try to get in touch.

We thank you again for your important contributions.
3. Family interview—6 to 12 weeks after patient death  

[This interview will be scheduled with the family member ahead of time]

Hi, this is____, may I please speak to _____?

Hi____, this is______, from the research study about how doctors communicate with their patients at Dana-Farber. When we last spoke, we scheduled this time to do the final survey for the project. As you may remember, this will take about 45 minutes to an hour and many of the questions are very personal and may be difficult. Is now still a good time?

If yes--> continue.  
If no--> schedule a new time.

If at any point you want to take a break, or pause and start back again later, let me know. If there are any questions you’d like to skip, that’s completely fine as well, just let me know.

Family Perception of Life Priorities Achieved

The first questions may sound familiar to you, as they are similar to ones we’ve been asking on the follow up surveys throughout the study.

Sometimes, when people have serious illnesses, they identify goals that are important to them. These goals may be anything – attending the wedding of a family member/friend, waiting to see the birth of a grandchild, not being in pain, or simply being able to walk up a flight of stairs without feeling breathless. Everyone’s goals are different; some people choose not to set goals at all.

Consider your friend or family member’s illness and quality of life in the last 3 months/last week of life. To what extent did your friend or family member achieve the following in the last 3 months/last week of life? The answer choices are on a scale of 1 to 5, where 1 means that your friend or family member did not achieve this goal at all, and 5 means they achieved this goal very much.

<table>
<thead>
<tr>
<th>Not at all</th>
<th>To a slight extent</th>
<th>To some extent</th>
<th>To a large extent</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the last 3 months/last week of life, to what extent did your friend/family member....</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Achieve the goal of living as long as possible, no matter what | 1 | 2 | 3 | 4
---|---|---|---|---
Remain at home | 1 | 2 | 3 | 4
Be physically comfortable | 1 | 2 | 3 | 4
Be mentally aware | 1 | 2 | 3 | 4
Be independent | 1 | 2 | 3 | 4
Have her/his medical decisions respected | 1 | 2 | 3 | 4
Provide support for family | 1 | 2 | 3 | 4
Be spiritually and emotionally at peace | 1 | 2 | 3 | 4
Achieve particular life goal, please specify | 1 | 2 | 3 | 4

[Each of these items will be asked for the last 3 months of life and afterwards will be asked for the last week of life.]

**Hospice:**

The next few questions are general questions about your friend or family member’s care at the end of his/her life.

Where did your friend or family member die?

Was your friend or family member enrolled in hospice during their illness?
0. No ➔ skip to question 3
1. Yes ➔ continue to question 2

Was your friend or family member in hospice at home?
0. No ➔ where were they in hospice? _______ How many days? _______days
1. Yes ➔ how many days were they at home with hospice? _______days

**Care during the last month of life:**

The next few questions are about your friend or family member’s last month of life.

During your friend or family member’s last month of life...

How many days was your friend or family member in a nursing home/other facility? _____days

How many days was your friend or family member in a hospital? _____ days

How many times did he/she go to the emergency department? _____visits

Now I’m going to read you a list of different treatments and procedures. Please answer “yes” if your friend or family member received this treatment or procedure during the last month of life or “no” if your friend or family member did not receive this treatment or procedure during the last month of life. [If yes, ask when and “Was there a discussion of the risks/benefits of this treatment or procedure?,” “Was there a discussion of the alternatives to this treatment or procedure?” and “Was there a discussion of the eventual discontinuation of this treatment or procedure?” If the answers to any of these follow up questions is “yes,” then the friend/family member will be asked: “Can you please tell me more about that discussion?”]

- Surgery; If yes, when? _______ weeks before death
- Chemotherapy; If yes, when? _______ weeks before death
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- Radiation therapy; If yes, when? ________ weeks before death

- MRI; If yes, when? ________ weeks before death
- CT scans; If yes, when? ________ weeks before death
- Line placements; If yes, when? ________ weeks before death
  - A line placement is when a tiny tube is placed in a vein for drug therapy or for kidney dialysis. Examples would be a PICC line in the arm, or a Hickman in the chest, or a Port in the chest, or a central line in the neck.

Now I’m going to read a different list of treatments and procedures. For this list, please answer “yes” if your friend or family member ever received this treatment or procedure or “no” if your friend or family member never received this treatment or procedure: [If yes, ask when and “Was there a discussion of the risks/benefits of this treatment or procedure?,” “Was there a discussion of the alternatives to this treatment or procedure?” and “Was there a discussion of the eventual discontinuation of this treatment or procedure?” If the answers to any of these follow up questions is “yes,” then the friend/family member will be asked: “Can you please tell me more about that discussion?”]

- CPR; if yes, when? ________(month)
- Tracheostomy; if yes, when? ________(month)
  - A tracheostomy is a surgical procedure to create an opening through the neck into the windpipe. A tube is usually placed through this opening to provide an airway and to remove secretions from the lungs.
- BiPAP; if yes, when? ________(month)
  - BiPAP is bilevel positive airway pressure. It is a mask placed over the patient’s nose and/or mouth that uses high pressure to push air into the patient’s lungs if they have trouble breathing.
- Artificial nutrition; if yes, when? ________(month)
  - Artificial nutrition can be given through a feeding tube in the stomach or through the nose. Artificial nutrition can also be given through a central venous line, which is called TPN.

**Modified Quality of Dying and Death**

<table>
<thead>
<tr>
<th>We’re about halfway through the survey. For this next set of questions, I would like to ask you about certain aspects of your friend or family member’s death. I will ask you how often a certain thing appeared to happen in the last few days of your friend/family member’s life. Then I will ask you to rank that aspect of the dying experience on a scale from 0 to 10, where 0 means that it was terrible, and 10 means that it was almost perfect.</th>
<th>None of the time</th>
<th>A little bit of the time</th>
<th>Some of the time</th>
<th>A good bit of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
<th>Don’t know</th>
<th>How would you rate this aspect of your friend or family member’s dying experience?</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often did your friend or family member</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>0-10</td>
</tr>
</tbody>
</table>
**Serious Illness Communication Project**  
3/4/2015

<table>
<thead>
<tr>
<th>Question</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>0-10</th>
</tr>
</thead>
<tbody>
<tr>
<td>appear to have his/her pain under control? If your friend or family member did not appear to have any pain, please answer N/A.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How often did your friend or family member appear to have control over what was going on around him/her?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>0-10</td>
</tr>
<tr>
<td>How often was your friend or family member able to feed her/himself?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>0-10</td>
</tr>
<tr>
<td>How often did your friend or family member appear to breathe comfortably?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>0-10</td>
</tr>
<tr>
<td>How often did your friend or family member appear to be at peace with dying?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>0-10</td>
</tr>
<tr>
<td>How often did your friend or family member appear to be depressed or sad?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>0-10</td>
</tr>
<tr>
<td>How often did your friend or family member appear to be unafraid of dying?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>0-10</td>
</tr>
<tr>
<td>How often did your friend or family member laugh and smile?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>0-10</td>
</tr>
<tr>
<td>How often did your friend or family member appear to keep his/her dignity and self-respect?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>0-10</td>
</tr>
<tr>
<td>How often did your friend or family member spend time with his/her family or friends?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>0-10</td>
</tr>
<tr>
<td>How often did your friend or family member spend time alone?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>0-10</td>
</tr>
</tbody>
</table>

If the friend/family member answers the question “How would you rate this aspect of your friend or family member’s dying experience?” with a rating of 5 or below, a follow up question “Can you please tell me more about that?” will be asked. The same question will be asked for any anomalous rating answers (e.g. Most aspects of the dying experience were rated 9 or 10, and one answer was 7).

**For this next set of questions, I will ask you if a certain thing happened during your friend or family member’s last several days. Then I will ask you to rank that aspect of the dying experience on a scale from 0 to 10, where 0 means that it was terrible, and 10 means that it was almost perfect.**

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was your friend or family member touched or hugged by his/her loved ones?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Were all of your friend or family member’s health care costs taken care of?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>How much of a strain were you feeling about health care costs? None, a little, a lot</td>
<td></td>
<td></td>
<td>0-10</td>
</tr>
<tr>
<td>Did your friend or family member say goodbye to loved ones?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Did your friend or family member clear up any bad feelings with others?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Did your friend or family member have one or more visits</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
If the friend/family member answers the question “How would you rate this aspect of your friend or family member’s dying experience?” with a rating of 5 or below, a follow up question “Can you please tell me more about that?” will be asked. The same question will be asked for any anomalous rating answers (e.g. Most aspects of the dying experience were rated 9 or 10, and one answer was 7).

We are about three quarters of the way through the survey – so, nearing the end. For these next questions, please use the same rating scale from 0 to 10, where 0 means that it was terrible, and 10 means that it was almost perfect.

<table>
<thead>
<tr>
<th>Question</th>
<th>Rating Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the moment before your friend or family member’s death, was he/she:</td>
<td>0-10</td>
</tr>
<tr>
<td>Awake and calm, Awake and agitated, Asleep, In a coma or unconsciousness, Don’t know</td>
<td></td>
</tr>
<tr>
<td>How well did your friend or family member’s doctor and medical team inform you about your friend or family member’s condition? Information was more than was needed; Information was just right; OR Information was less than was needed</td>
<td>0-10</td>
</tr>
<tr>
<td>How well did your friend or family member’s doctor and medical team support you in dealing with your friend or family member’s illness?</td>
<td>0-10</td>
</tr>
<tr>
<td>How well did your friend or family member’s doctor/medical team understand what your friend or family member’s wishes were?</td>
<td>0-10</td>
</tr>
<tr>
<td>How well did your friend or family member’s doctor/medical team honor what your friend or family member’s wishes were?</td>
<td>0-10</td>
</tr>
<tr>
<td>Overall, how would you rate the quality of your friend or family member’s dying?</td>
<td>0-10</td>
</tr>
<tr>
<td>Rate the care your friend or family member received from all health care providers (doctors, nurses, social workers and other health care professionals) during the last week of his/her life.</td>
<td>0-10</td>
</tr>
<tr>
<td>Rate the care your friend or family member received from his/her doctor during the last week of his/her life.</td>
<td>0-10</td>
</tr>
<tr>
<td>Please specify which doctor: hospice doctor, medical oncologist, hospital doctor,</td>
<td></td>
</tr>
</tbody>
</table>
If the friend/family member answers any of these questions with a rating of 5 or below, a follow up question “Can you please tell me more about that?” will be asked. The same question will be asked for any anomalous answers (e.g. Most of the questions in this set of questions were rated 9 or 10, and one answer was 7).

Now I’m going to ask you to think about the care that your friend or family member received from his or her oncologist in the last month of life. Please answer the questions below indicating how satisfied you were with the care received. The answer choices are as follows: Very Dissatisfied (VD), Dissatisfied (D), Undecided (U), Satisfied (S), and Very Satisfied (VS).

<table>
<thead>
<tr>
<th>How satisfied were you with...</th>
<th>VD</th>
<th>D</th>
<th>U</th>
<th>S</th>
<th>VS</th>
</tr>
</thead>
<tbody>
<tr>
<td>the information provided about your friend or family member’s prognosis?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>the availability of your friend or family member’s oncologist to you and your family?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>the way you and your family were included in treatment and care decisions?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

We have just a few more questions.

What aspects of your friend or family member’s last month of life do you feel best about?

OPEN-ENDED

What aspects of your friend or family member’s last month of life do you feel worst about?

OPEN-ENDED

Were there any medical treatments or procedures that happened to your friend or family member that you think were inconsistent with his or her previously stated wishes?

YES/NO

If yes: “Please tell me more about that.”

To what extent do you agree with the following statement? “If the doctors and nurses had told me more about my friend or family member’s condition during the last few months of their life, I would have made different decisions about my friend or family member’s care.”

☐ Greatly disagree

☐ Somewhat disagree

☐ Neither agree nor disagree

☐ Somewhat agree

☐ Greatly agree
Can you please tell me more about that?

We would like to get feedback on how burdensome it was to complete this survey. This information will help guide us in future research. Overall, how much of a burden on you was this survey?

- [ ] No burden at all
- [ ] Slight burden
- [ ] Great burden

Is there anything else that you would like to add or to tell us that we haven’t yet touched upon or asked about?

*Thank you so much for taking the time to complete this survey with me today. I know it was time-consuming and difficult, but your efforts and your friend or family member’s efforts for this research study are incredibly valuable and meaningful. We are so grateful for your contributions and for your friend or family member’s contributions.*
Clinician Measures:

Clinician Demographics—Enrollment/consent

1. Full name: ____________________________
2. Date: ___/___/_______
3. Gender (circle one): M F
4. Circle one: MD NP PA
5. Clinic/Disease center: _______________________
6. What percent of your time is spent on clinical duties? _____%
7. Who is the Doctor/NP/PA you share patients with the most? _____________
8. Do you only share patients with this MD/NP/PA in your clinical time (circle one)? Y N
9. If no, who else do you share patients with? ___________________________
10. How many years have you been in practice? _______years
Clinician Confidence—Enrollment, end of training*

*Intervention arm only

Please rate the level of your skill in each of the following areas by circling a number between 1 and 7 where 1 = very unskilled and 7 = very skilled:

<table>
<thead>
<tr>
<th>Date: <em><strong>/</strong></em>/______</th>
<th>Very unskilled</th>
<th>Very skilled</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Discussing end-of-life issues with my patients</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>2. Demonstrating empathy</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>3. Explaining what a health care proxy is</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>4. Talking with patients about who their health care proxy should be</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>5. Estimating prognosis</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>6. Assessing patient understanding of prognosis</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>7. Determining how much information to tell a patient regarding prognosis</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>8. Inquiring about patient fears and worries about disease progression</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>9. Eliciting patient goals</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>10. Assessing patient views on functional impairment</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>11. Assessing patient views on tradeoffs necessary for extending life</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>12. Telling a patient he or she has a poor prognosis</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>13. Telling a patient he or she is dying</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>14. Using therapeutic silence</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>15. Helping patients with reconciliation and good-bye</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>16. Helping families with reconciliation and good-bye</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>17. Responding to a patient’s emotions</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>18. Discussing discontinuing disease-modifying therapy</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>19. Discussing palliative care</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>20. Determining when to refer patients to hospice</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>21. Knowing how to work collaboratively with palliative care specialists</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
<tr>
<td>22. Managing my own stress in caring for the terminally ill</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
</tr>
</tbody>
</table>
Clinician Confidence—End of Study

Please think back to when you first enrolled in this study. Please indicate your skill level in each of the following areas *before* participating in this study. Then, please rate your *current* skill level in each of the following areas. In order to rate your skill level at these two time points, please circle a number between 1 and 7, where 1 = very unskilled and 7 = very skilled:

<table>
<thead>
<tr>
<th>Date: <em><strong>/</strong></em>/______</th>
<th>Very unskilled</th>
<th>Very skilled</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Discussing end-of-life issues with my patients</strong></td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>BEFORE participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>AFTER participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td><strong>2. Demonstrating empathy</strong></td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>BEFORE participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>AFTER participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td><strong>3. Explaining what a health care proxy is</strong></td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>BEFORE participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>AFTER participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td><strong>4. Talking with patients about who their health care proxy should be</strong></td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>BEFORE participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>AFTER participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td><strong>5. Estimating prognosis</strong></td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>BEFORE participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>AFTER participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td><strong>6. Assessing patient understanding of prognosis</strong></td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>BEFORE participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>AFTER participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td><strong>7. Determining how much information to tell a patient regarding prognosis</strong></td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>BEFORE participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>AFTER participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td><strong>8. Inquiring about patient fears and worries about disease progression</strong></td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>BEFORE participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>AFTER participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td><strong>9. Eliciting patient goals</strong></td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>BEFORE participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
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<tr>
<td>AFTER participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td><strong>10. Assessing patient views on functional impairment</strong></td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>BEFORE participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>AFTER participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td><strong>11. Assessing patient views on tradeoffs necessary for extending life</strong></td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>BEFORE participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>AFTER participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td><strong>12. Telling a patient he or she has a poor prognosis</strong></td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>BEFORE participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>AFTER participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td><strong>13. Telling a patient he or she is dying</strong></td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>BEFORE participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>AFTER participating in this study</td>
<td>1 2 3 4 5 6 7</td>
<td>1 2 3 4 5 6 7</td>
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<tr>
<td><strong>14. Using therapeutic silence</strong></td>
<td>BEFORE participating in this study</td>
<td>1</td>
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<td>---------------------------------</td>
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<tr>
<td></td>
<td>AFTER participating in this study</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>15. Helping patients with reconciliation and good-bye</strong></th>
<th>BEFORE participating in this study</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
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<th>7</th>
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<tr>
<td></td>
<td>AFTER participating in this study</td>
<td>1</td>
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<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>16. Helping families with reconciliation and good-bye</strong></th>
<th>BEFORE participating in this study</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>17. Responding to a patient’s emotions</strong></th>
<th>BEFORE participating in this study</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>AFTER participating in this study</td>
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<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>18. Discussing discontinuing disease-modifying therapy</strong></th>
<th>BEFORE participating in this study</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>AFTER participating in this study</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>19. Discussing palliative care</strong></th>
<th>BEFORE participating in this study</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>20. Determining when to refer patients to hospice</strong></th>
<th>BEFORE participating in this study</th>
<th>1</th>
<th>2</th>
<th>3</th>
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<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>21. Knowing how to work collaboratively with palliative care specialists</strong></th>
<th>BEFORE participating in this study</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
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<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>22. Managing my own stress in caring for the terminally ill</strong></th>
<th>BEFORE participating in this study</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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</tbody>
</table>
Serious Illness Communication Project
3/4/2015

Clinician Attitudes -- Enrollment, end of training*, end of study

*Intervention arm only

Please circle the number that best reflects the extent to which you agree or disagree with each of the following statements:

<table>
<thead>
<tr>
<th>Date: <em><strong>/</strong></em>/______</th>
<th>Strongly disagree</th>
<th>Neither agree nor disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Clinicians have a responsibility to help patients prepare for death.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Speaking with a patient about the possibility of her/his death takes away her/his hope.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Clinicians should recommend medical treatments that will help the patient meet his/her life goals.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. Usually, when clinicians discuss patients’ fears about the future, patients become upset.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. Advance care planning is a basic responsibility for clinicians.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. I think that talking about end-of-life issues lowers patients’ quality of life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. Meeting the psychosocial needs of dying patients is my responsibility.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. Working with dying patients is rewarding for me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9. Physicians should not discuss prognosis with patients.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10. Physicians should disclose prognosis only when asked by the patient.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11. Physicians should disclose prognosis without using numbers.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

Imagine a patient who is expected to die of her or his disease:

12. What is the ideal timing for initiating discussion and planning of end-of-life care for this patient?  
_____ months before death
Please complete this side of the page if you DID have a SICG conversation with a study patient.

1. How long did the conversation with this patient take?
   _____minutes

2. How many questions of the Guide did you ask? 1 2 3 4 5 6 7

3. How long do you think this patient has to live?
   □ Days to weeks
   □ Several weeks to a month
   □ Several months to a year
   □ More than a year

4. What did you tell the patient in terms of life expectancy?
   □ I did not give a specific estimate
   □ I gave a specific estimate, which was (select one):
     □ Days to weeks
     □ Several weeks to a month
     □ Several months to a year
     □ More than a year

5. To what extent do you feel you understand the patient’s goals at this time?
   □ Not at all
   □ A little
   □ Somewhat
   □ Very much

6. To what extent did you follow the Guide in your conversation today?
   □ Not at all
   □ A little
   □ Somewhat
   □ Completely

7. We are trying to learn when the Guide format doesn’t fit or work well with the situation. What factors (if any) led you to DEVIATE from the Guide in this discussion, and why? (Select all that apply, and briefly explain):
   □ Time:
   □ Specific Patient situation:
   □ Problems with the Checklist:
   □ Other:

Please complete this side of the page if you DID NOT have a SICG conversation with a study patient.

1. Please choose your reasons for not completing the SICG (select all that apply):
   □ Not appropriate (patient is not sick enough); estimate time when patient will be appropriate:

   □ Not enough time
   □ More appropriate for MD to discuss (NP use only)
   □ Patient is not ready
   □ Patient is anxious
   □ Patient is depressed
   □ Patient is confused
   □ Do not want to take away hope
   □ Patient is ready to talk, but family is not ready
   □ Patient declined to discuss these issues today
   □ Health care proxy is not available today
   □ Other; please specify

Please place the completed form in the bin labeled “SICG study” in your floor’s workroom.
Clinician Acceptability (Intervention arm only)*—After first SICG

Clinician Name:__________________ Date:__/__/__

Please complete this form after your SICG conversation, then return it to the SICG study folder in the workroom on your floor.

Recall the last conversation you had with a patient using the Serious Illness Conversation Guide. Based on this experience, please circle the number below that best reflects the extent to which you agree or disagree with each statement.

<table>
<thead>
<tr>
<th>I think the discussion using the Serious Illness Conversation Guide...</th>
<th>Strongly disagree</th>
<th>Neither agree nor disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. allows for discussion about end-of-life issues in a timely manner.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. format is simple.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. is easy to use.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

Please answer the following questions by circling the number that best reflects your experience:

<table>
<thead>
<tr>
<th>Please answer the following questions by circling the number that best reflects your experience:</th>
<th>Not at all</th>
<th>A medium amount</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. To what extent were you able to evaluate your patient’s understanding of prognosis?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. To what extent did asking about the patient’s information preferences allow you to titrate your delivery of prognostic information to</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. To what extent did you understand your patient’s preferences regarding sharing of information with family member(s)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. To what extent did you gain useful information from asking about the patient’s goals?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. To what extent did you gain useful information from asking about the patient’s fears and worries?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9. To what extent do you understand your patient’s preferences regarding undergoing aggressive treatments?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10. To what extent do you understand the abilities that are most critical to your patient?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11. Overall, how effective was this discussion in understanding your patient’s values and goals about end-of-life care?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

D-49
12. After the study is over, to what extent do you plan to continue to use the Serious Illness Conversation Guide format for discussing these issues with patients?

Different    Similar

13. Is the Serious Illness Conversation Guide similar or different to the structure you usually use to discuss end-of-life issues with patients?

1    2

14. Was the timing of this conversation about end-of-life issues similar or different from your usual practice?

1    2

15. I think the discussion of end-of-life issues made my patient’s emotional state:

- much worse
- slightly worse
- neither worse nor better
- slightly better
- much better

16. How helpful do you find the LMR template “Values and Goals” tab for recording checklist discussions?

- I have not used it.
- Not at all helpful
- A little helpful
- Quite helpful
- Very helpful
- Extremely helpful

17. How easy do you find the LMR template to use?

- Very difficult
- A little difficult
- OK
- A little easy
- Very easy

18. Overall, how much did your discussion of these issues with your patient increase or decrease your satisfaction with your role in your patient’s care?

- greatly decreased
- slightly decreased
- neither increased nor decreased
- slightly increased
- greatly increased
19. If you had a serious, life-threatening illness, would you want your clinician to have a values and goals discussion with you using this Serious Illness Conversation Guide?

☐ Yes
☐ No

Please place the completed form in the folder labeled “SICG study” in the workroom on your floor.

**Clinician Acceptability (Intervention arm only)**—End of the study

Clinician Name:__________________ Date:__/__/__

Recall the last conversation you had with a patient using the Serious Illness Conversation Guide. Based on this experience, please circle the number below that best reflects the extent to which you agree or disagree with each statement.

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</table>

Please answer the following questions by circling the number that best reflects your experience:

<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. To what extent were you able to evaluate your patient’s understanding of prognosis?</td>
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<tr>
<td>5. To what extent did asking about the patient’s information preferences allow you to titrate your delivery of prognostic information to</td>
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<tr>
<td>6. To what extent did you understand your patient’s preferences regarding sharing of information with family member(s)?</td>
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<td>7. To what extent did you gain useful information from asking about the patient’s goals?</td>
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<td>8. To what extent did you gain useful information from asking about the patient’s fears and worries?</td>
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<tr>
<td>9. To what extent do you understand your patient’s preferences regarding undergoing aggressive treatments?</td>
</tr>
</tbody>
</table>
10. To what extent do you understand the abilities that are most critical to your patient? 1 2 3 4 5

11. Overall, how effective was this discussion in understanding your patient’s values and goals about end-of-life care? 1 2 3 4 5

12. To what extent did you use the Conversation Guide questions with your patients who were **not** enrolled in the Serious Illness Care Trial? 1 2 3 4 5

13. After the study is over, to what extent do you plan to continue to use the Conversation Guide format for discussing these issues with patients? 1 2 3 4 5

<table>
<thead>
<tr>
<th>Different</th>
<th>Similar</th>
</tr>
</thead>
<tbody>
<tr>
<td>14. Is the Serious Illness Conversation Guide similar or different to the structure you usually use to discuss end-of-life issues with patients?</td>
<td>1 2</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Different</th>
<th>Similar</th>
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<tbody>
<tr>
<td>15. Was the timing of this conversation about end-of-life issues similar or different from your usual practice?</td>
<td>1 2</td>
</tr>
</tbody>
</table>

16. I think the discussion of end-of-life issues made my patient’s emotional state:
   - [ ] much worse
   - [ ] slightly worse
   - [ ] neither worse nor better
   - [ ] slightly better
   - [ ] much better

17. How helpful do you find the LMR template “Values and Goals” tab for recording checklist discussions?
   a. I have not used it.
   b. Not at all helpful
   c. A little helpful
   d. Quite helpful
   e. Very helpful
   f. Extremely helpful

18. How easy do you find the LMR template to use?
   a. Very difficult
   b. A little difficult
   c. OK
   d. A little easy
   e. Very easy

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19. Overall, how much did your discussion of these issues with your patient increase or decrease your satisfaction with your role in your patient’s care?
   □ greatly decreased
   □ slightly decreased
   □ neither increased nor decreased
   □ slightly increased
   □ greatly increased

20. If you had a serious, life-threatening illness, would you want your clinician to have a values and goals discussion with you using this Serious Illness Conversation Guide?
   a. Yes
   b. No

*Please place the completed form in the folder labeled “SICG study” in the workroom on your floor.*
Appendix E: Serious Illness Conversation Guide Materials

Below is the letter that intervention-arm patients will be given by the study coordinator after signing the informed consent form, to prepare them for their conversation with their clinician:

**Talking with your doctor about the future**

*At your next appointment,* your doctor would like to talk with you about your illness, your goals and wishes, and planning for the future. This is an important part of the care we provide for all of our patients.

Our team likes to start talking about this when patients are doing okay. Your illness is serious but stable, so now is a good time to talk about what is ahead, and to do some planning for the future. Patients who think through what is important to them and what their wishes are often feel less anxious, more at peace, and more in control of their situation.

**Before your next appointment**

*Please prepare for your visit by thinking about these things:*  
- What would you like to know about your illness and what is likely to be ahead?  
- What kind of information would help you make decisions about your future?  
- What is most important for you to have a good quality of life?  
- What are you afraid of about your illness?  
- What kinds of medical care do you not want?  
- What do you think it would be like to share these thoughts with your family?  
- If you haven’t already identified a health care proxy, who would be able to fill that role?

**Why is this important?**

Thinking about and sharing your wishes will give you more control over the care you get. It will also help prepare your loved ones to make decisions for you if you can’t make them at some point in the future.

**Talking about the future won’t change your ongoing care**

Talking about the future won’t change the plans we have made so far about your treatment, unless, of course, you want to. We will keep providing the best possible care to control your disease.

**You may find it helpful to bring other people to your next appointment**

You can choose to bring the person who is your health care proxy or other family members to your next visit so they can be a part of the conversation. You can also bring your nurse practitioner, social worker, or chaplain if you like. Please let your doctor’s office know if you would like to bring others to the appointment.

**We understand that your wishes may change over time**

This is the beginning of an ongoing conversation. We know that you may have other questions or concerns in the future. We will keep being here to support you and answer your questions so that you can make informed decisions.

If you have questions before your visit, please contact the study staff at 617-632-6055.
Below is the Conversation Guide intervention-arm clinicians will use to conduct their SICG conversations with intervention-arm patients:

## Serious Illness Conversation Guide

<table>
<thead>
<tr>
<th>CLINICIAN STEPS</th>
<th>CONVERSATION GUIDE</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Set up</td>
<td>Understanding</td>
</tr>
<tr>
<td></td>
<td>What is your understanding now of where you are with your illness?</td>
</tr>
<tr>
<td></td>
<td>Information</td>
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<td></td>
<td>preferences</td>
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<tr>
<td></td>
<td>How much information about what is likely to be ahead with your illness would you like from me?</td>
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<tr>
<td>□ Guide</td>
<td>For example: Some patients like to know about time, others like to know what to expect, others like to know both.</td>
</tr>
<tr>
<td>□ Summarize and confirm</td>
<td></td>
</tr>
<tr>
<td>□ Act</td>
<td>Prognosis</td>
</tr>
<tr>
<td></td>
<td>Share prognosis, tailored to information preferences</td>
</tr>
<tr>
<td></td>
<td>Goals</td>
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<tr>
<td></td>
<td>If your health situation worsens, what are your most important goals?</td>
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<tr>
<td></td>
<td>Fears / Worries</td>
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<tr>
<td></td>
<td>What are your biggest fears and worries about the future with your health?</td>
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<tr>
<td></td>
<td>Function</td>
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<td></td>
<td>What abilities are so critical to your life that you can’t imagine living without them?</td>
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<tr>
<td></td>
<td>Trade-offs</td>
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<tr>
<td></td>
<td>If you become sicker, how much are you willing to go through for the possibility of gaining more time?</td>
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<tr>
<td></td>
<td>Family</td>
</tr>
<tr>
<td></td>
<td>How much does your family know about your priorities and wishes?</td>
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</tbody>
</table>

(Suggest bringing family and/or health care agent to next visit to discuss together)
Below is the Family Communication Guide we will send by mail to intervention-arm patients after their SICG conversation to help them talk about their illness with their family:

Talking about your illness with loved ones and caregivers

This booklet can help you talk with your loved ones about your illness and the future. It is based on what you have already talked about with your doctor.

Talking about your illness with friends and family may not be easy, but it will help them understand what is important to you. It will also help them support you and your decisions.

Before you talk to your loved ones, think about when and where you want to talk. Choose a time and place when you feel relaxed. Be sure you have time to talk for a while. You can use the words in this guide, or use your own words — whatever is easier for you.
Start the conversation

I am doing OK right now, and even though there is no rush, my doctors think we need to begin talking about my future care.

They believe in being prepared and want to know my goals and wishes for medical care.

Since you are important to me, I’d also like you to be part of the conversation.

If at some point I can’t speak for myself, I want you to be able to make decisions for me.

Check in with your loved one

UNDERSTANDING

What is your understanding now of where I am with my illness?

INFORMATION

I know that it may not be easy, but I would like to share information about my illness with you. Is that okay?

How much information about what is likely to be ahead would you like from me?

My doctor and I talked about the outlook for my illness—can I share that with you?
Share what is important to you

GOALS & WISHES
I'd like to share some of my goals that might affect my healthcare decisions. Some things I'm looking forward to are...

EXAMPLES: Meet my new grandchild, celebrate my next birthday, etc.

FEARS & WORRIES
My biggest fears and worries about my future with this illness are...

EXAMPLES: Not being able to make decisions for myself, or having to ask others for help with basic needs.

ABILITIES
I can't imagine not being able to do certain things...

EXAMPLES: Not being able to recognize or interact with people, not being able to care for myself, etc.

TOUGH CHOICES
I know that we may have to choose between treatments that are hard to go through and more time.

EXAMPLES: Being in the hospital, having a feeding tube, living in a nursing home, being on a breathing machine, more chemotherapy, etc.

Here's how I think about those choices...

Plan to talk again

I would like to talk with you about my illness and medical care as my treatment continues. Is that okay?

I know this was probably not an easy conversation. How do you feel now that we have talked?

Are there other people we should talk with?

Remember to talk again with your loved ones / caregivers as your situation or wishes change

E-5
NOTES
You can use this page to write down ideas from your talk, questions for your doctor, or any other thoughts.
Serious Illness Communication Project
3/4/2015

Appendix F: Transcripts of beta-testing conversations

Serious Illness Conversation Guide Beta Testing
Round 3: 08/22/11

MD—Internist

MD: So it’s good to see you out of the hospital.
Pt: Yeah, it’s good to be out of the hospital.
MD: I’m sure. How are things going now that you’re at home?
Pt: Eh, not the greatest.
MD: In terms of?
Pt: I’m just so tired all the time, you know? I can’t, I have no energy.
MD: And is it worse than it was before you went into the hospital?
Pt: Oh yeah, yeah. I’m just so fatigued, I just don’t want to move. It used to be I’d get fatigued when I was doing something. And now, I was talking to my wife, it’s 6 o’clock at night and I haven’t done anything all day but I’m exhausted. Then I get the breathing attacks sometimes, so it’s not been a great road lately.
MD: No, I know you’ve been in and out of the hospital, I think 3 times. So, that’s not easy. It sounds like, compared to a year ago, things are a lot worse.
Pt: I would say yeah, that is true.
MD: Well, today I wanted to talk a little more about your congestive heart failure. First, let you know, of course we’re going to try to do everything to make your heart failure stable, and your symptoms better if we can. But I think we need to prepare for the possibility that things might get worse. Just like they worsened over the past year, it might just be the course of your illness that things are going to continue to get worse. So I thought that we should at least talk about that. Would that be alright with you?
Pt: Yeah, you mean like when I went to the CCU?
MD: Right. Yeah, that’s a pretty scary place.
Pt: I didn’t like the CCU very much.
MD: What was the part about it that you didn’t like the most?
Pt: They don’t tell you anything. Someone’s always running around you all the time. Mary couldn’t visit me when she wanted to, she was waiting outside for 2-3 hours. It was really hard on my wife. They come in, they stick you, they leave. They don’t explain anything.
MD: Well, and there’s a lot of machines, bells and whistles. Well, you know, we definitely want to try to avoid that if we can. But that’s one of the things I would want to talk about, sort of what your goals are for your care as we go forward. So probably where I would start is, what is your understanding of your prognosis at this point? Of where your illness is?
Pt: You guys always talk like that. What is your understanding? I don’t understand it. I’m sick, and I know that I’m not getting better. Even though I got used to doing nothing, right now doing nothing isn’t even comfortable.
MD: That must be very frustrating.
Pt: So, I know I’m getting worse.
MD: Well I think that’s right. I think, as we’ve talked about, with your three hospitalizations and your medication and all those things, I think it is getting worse. We’re probably reaching the limits of the types of treatment we can provide. And so it’s really important for you and for us to talk about what you want as things may get worse. So the way we start to think about that is, if your situation were to get worse, what would your most important goals be?
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Pt: Oh, let me think about that. When you say worse, what do you mean? How worse?

MD: Well, say your breathing starts to worsen, say you need to go back into the hospital; those are just some examples.

Pt: I would want to not be in the hospital for a long time.

MD: Ok, that’s important to know.

Pt: I’d rather be home.

MD: Ok. And what about certain kinds of treatments or anything like that, have you thought about any of those in any detail? I know you talked about how you hated being in the Intensive Care Unit. So when you say the hospital, are you thinking more of the ICU?

Pt: I wouldn’t want to be in the CCU for a long period of time. If it was really short, maybe. I just know that I’d rather be home.

MD: And what’s your biggest fear and worry about the future?

Pt: That’s a hard one. There’s a couple of them.

MD: I’m sure.

Pt: I used to worry about the breathing attacks, like I was never going to catch my breath again. That used to be my big worry. I’d be short of breath, I’d see the look on my wife’s face and I’d see how scared she was. And now that’s kind of switched a little bit. I lay in bed all day and I say to myself, What if I’m never going to get enough energy to do anything? Now I’m just going to be here, and that’s it. What about that now?

MD: What are some of the things you want to be able to do?

Pt: Look, doc, I know I’m not going to run the marathon, I know that I’m not going to be outside jumping around. But I’d just like to go outside, make it down the hall or downstairs to watch some TV without…I’m so fatigued I’m ready to crash and fall asleep.

MD: Right. Besides the worry about fatigue and that sort of thing, anything else that’s a big fear and worry that you have?

Pt: I worry about it just happening when my wife’s there alone with me. I think that would really hurt her.

MD: Do you think she has supports around her for that kind of circumstance?

Pt: Probably not enough, you know.

MD: Is she your health care proxy, who makes decisions?

Pt: Yeah. I don’t know how smart that was, it’s a lot of pressure on her.

MD: Does she know what your wishes are for your health, and your goals?

Pt: We haven’t really talked about a lot of it. She knows I didn’t like the CCU. Seems like when we just have some time together that’s good and I’m not exhausted, we just try to forget about it.

MD: Well, it would probably be good to at least start having those conversations, to make it maybe a little easier on her if she has to make those decisions. That’s something for you to think about. As you start having those conversations with her, even for you to think about, are there specific health states that you would find unacceptable, that you would never want to be in?

Pt: [brief silence] Maybe we should be talking about this with her because she’s the proxy. I mean, is that ok?

MD: Well, we can always have these conversations with her, if you wanted to bring her to an appointment. Or if you wanted to have the conversation at home, it’s something that you should think a little bit about in advance in order to talk to her about what you would want if she had to make decisions for you.

Pt: I don’t want to be in the hospital for a long time, you know? That’s the big thing.

MD: Right. Are there other states that might be unacceptable, like not being able to eat by yourself, needing a feeding tube, for example, or having to live in a nursing home, those kinds of things?
Pt: I don’t want to be in a nursing home. I wouldn’t want to have that feeding tube in. I’m OK sitting there, if I can read, I’m OK with that. If I can have some time without being so exhausted and without the breathing attacks. But yeah, I don’t want a feeding tube.

MD: Ok. And then as go forward, how much information about your condition would you want me to be telling you so you can be thinking about decisions about treatment?

Pt: Well, you’re supposed to tell me everything, right?

MD: That’s what I would think. Some patients may say, “Don’t tell me certain things.”

Pt: What wouldn’t?

MD: Well, a lot of people don’t want to know what we think about prognosis, it’s often a guess anyway. I think it’s the best thing for us to talk openly about…

Pt: What do you guys mean when you say prognosis? I’m not a doctor, I don’t get that stuff sometimes.

MD: Yeah. Well, prognosis is the expected amount of time we think someone might live. It’s of course a guess. There’s people who don’t live as long as we expect, and there’s people who live way longer than we expect. So prognosis is just a guess. But sometimes it helps people to start planning if they know based on how sick they are today, our best guess is a certain amount of time, knowing that we could be wrong, but that’s our best guess at this point.

Pt: You got kids?

MD: Mmm-hmmm.

Pt: I got a granddaughter, she’s really cool. What I think is cool anyway, I don’t know what cool is.

MD: I’m sure she is.

Pt: She graduates from college in the Spring, she’s got 2 semesters left. I would like to be there. So, um…

MD: That’s a really important goal.

Pt: Am I [sighs] Do I have a shot at being there?

MD: We will do our best to get you there. We can’t make any promises, but we can certainly do our best. And knowing that that’s something that you really want to achieve, we can try to make sure that whatever care we’re giving you is sort of geared with that in mind. So there might be more or less aggressive things that we do based on the fact that we know that’s a really important goal for you.

Pt: So is that?

MD: So yes, I think there’s a shot, and I think we can try to adjust what we do to try to get you there. No guarantees, but we’ll do our best. [pause] So I think that it’s really important for you and your wife to start talking about these things. It’s important for her to know that’s an important goal for you. I definitely heard you in terms of not wanting to be in the hospital, and especially in the ICU, and not wanting feeding tubes and those kinds of things. So you and I can try to work together to make sure we’re giving you care that is the kind of care that you ant and helps you get to your goals.

Pt: OK.

MD: Ok? Any questions for me?

Pt: Um, well you asked me that question about prognosis and what do I want to know. So um, you said you’d work really hard at getting me where I want to go. What are the chances?

MD: Well, I think I probably can’t give you a percentage or anything like that. But I can say that, given how sick you are with your illness, usually people might make it about a year. Um, and that’s again an average, people can be on either side. But the graduation is before a year and, like I said, I think that’s something we can try hard to get you to and accomplish.

Pt: [silence] Wow, sounds like…a year.
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**MD:** I know, it’s hard.  
**Pt:** Well, I asked, it’s OK.  
**MD:** Ok. And we’ll meet frequently.  
[END]

**Feedback:**  
**RB:** How was it?  
**MD:** I hate having to look at the thing while I’m asking questions.  
**RB:** That’s a common complaint.  
**MD:** I mean, the more you get used to it, the less you have to look at the prompt. If I’m asking about diabetes, I don’t have to look at the thing. I thought it went ok, we’ll see what you think. I kind of alternated the order a little bit, just based on what he said, the conversation. I thought, prognosis is always challenging, but I thought it went ok. The goals and hopes, I thought was ok as well. We kind of came back to it a little bit later. The fears and worries were ok. I thought the tradeoffs, I know we aren’t supposed to necessarily be checking off, “Do you want to be DNR, do you want to be shocked?” I felt like it was easy to get into that slippery slope with that one. And then kind of the same with the function, because once you say feeding tube, you get into intubation and all that stuff. So I felt like there was a slippery slope there. I think patients, understandably, ask “What are you talking about?”  
**RB:** Mostly people have had to give examples for that.  
**MD:** Then you list one thing and people focus on that, but there might be other things that you really need to talk about too. Then you do feel like you’re going into a laundry list. The proxy/family thing I thought was ok. And then that last question was really hard, about how much information. Your response was what I was saying before you came in the room. Of course, why shouldn’t I tell you everything?  
**Pt:** That’s what everyone thinks their answer is. That’s what all the patients think, but then when we define it, a lot of people are like “Whoa.” So the trick to that is defining it.  
**MD:** Well, I think maybe it needs to be more specific, even. Because I clarified and said prognosis information, which I wasn’t sure if that’s really what you were getting at.  
**RB:** We’ve had people interpret it as a bunch of different things. Because some people interpret it as what lies ahead, maybe you’ll get more tired or more short of breath.  
**MD:** Yeah, so it’s a little too vague there in terms of what the intent is, I think. So that was sort of the feedback on the questions. But even using it, I felt like the eye contact was OK and I was able to do most of it.  
**John:** I didn’t notice any going back and forth, I didn’t lose eye contact, I didn’t feel like you were ignoring me or anything like that. I felt like you were right there with me, very empathetic. You answered all my questions, everything was very clear. I think there’s some opportunity for a little more communication with the granddaughter, you can lighten things up a little bit. It’s a tool for you, you can grab it. But overall I thought it was very good. When doctors say prognosis, I always throw at them “What are you talking about, prognosis?” So I thought you explained that very well. When you did explain it, that’s where we got to my hopes and goals, it kind of just flowed right in there.  
**RB:** I thought it was great. I think it’s hard, this is hard. We’ve had people doing it that do this every day, so these just roll off their tongues. So it’s interesting to see someone who doesn’t do it all the time.  
**MD:** I did primary care, I don’t do it anymore. It’s interesting to see for a PCP, if I’ve known this patient for 5 or 6 years, it’s almost emotional. It makes it hard.
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**John:** There are actually statistics that go with that. The length of time that the patient has been in the PCP’s care is directly coefficient to getting incorrect information about prognosis. The longer you know the patient, the less they’ll tell you.

**MD:** So I can just imagine that would be hard. But on the other hand you know the person well. So diving into that granddaughter stuff, the rapport is there.

**RB:** And this is artificial because you don’t’ really know him.

**MD:** But in general, it was really helpful. I’m sure if I saw someone in clinic and I had to have this kind of conversation, I wouldn’t have this kind of structure normally. I’m not even sure I would have even had the conversation in my practice, I would let the cardiologist talk to them about it. I think something like this could be very helpful, just to remind you what you should talk to them about. And focusing on the goals rather than the procedures, that’s why I worry about those 2 questions. It’s really easy to start getting into this list.

**RB:** They actually have a very structured conversation that happens in LaCrosse and they actually follow a very similar protocol. However, for those 2 questions, they actually do very specific patient scenarios and they have people rank them. It actually takes a lot longer time, they go through each thing separately. I think they get really good information out of it, but it’s extremely time consuming, so that’s the problem. It’s interesting, because we just had Tia do it, and she said she didn’t ask the questions these ways. And she’s a geriatric physician, so a lot of her patients are appropriate for this. She said she was going to use these now.

**MD:** You could also start this conversation today, and then next time, let’s talk a little more about those things that you didn’t want.

**RB:** Exactly. In some ways, these are longer and more into the conversation and into the illness that you need to know those. [pause] So do you use any of these questions, generally?

**MD:** I being the bad doctor that I am, probably don’t.

**RB:** Yeah. Well Tia said she uses prognosis and goals, and some of the family, but not any of the others.

**MD:** I might do family. Prognosis is challenging because a lot of us get scared of that. It was good that I had this, and I saw that he had about a year. But there are a lot of times when you just don’t know and I think that’s what people are going to be nervous about.

**RB:** And in terms of, if you had to pick just 3 that you’d keep, which ones? It sounds like you weren’t crazy about the tradeoffs and function.

**MD:** Yeah, and I didn’t even ask that in the right way, now that I look at it. That was me trying not to read off the paper. I was asking more about function.

**RB:** Yeah, you asked about specific treatments. I think people answer it a little bit better when you use those actual words.

**MD:** I think that would actually be good if I had done it the right way.

**RB:** I think you said “certain kinds of treatment.” And what we’re trying to get at is tradeoffs with time, and so it’s not actually about the actual treatment. It’s more about trying to get a general sense of how they feel about time.

**MD:** I think you probably don’t need both of these. If you’re narrowing these down, I think you have to do prognosis. It’s not really prognosis, it’s your understanding, but you have to start there. I like the goals and hopes, and the fears and worries. Function, as you know I didn’t like that. And I think it’s important to know who that is, the proxy. I think this unacceptable will come in here, to the tradeoffs one, because someone might say “For no amount of time will I do…”

**RB:** What did you think of the wordings of the questions?

**MD:** I didn’t like ‘health states.’

**RB:** What do you think about ‘health conditions’ there, or just ‘conditions’?
MD: Well, condition’s better than state, but I still worry about it being jargony. I don’t know what the right word is. Functional status is not OK. If you got really colloquial, you could say something like 'specific ways of living.' Something that’s not medical language at all.

RB: Yeah, that’s how we’ve been trying to do most of the other ones, but for that one we haven’t figured it out yet.

MD: I think the wording on the last one is problematic.

RB: You moved things around. Do you think they’re in the right order, or do you think there are some that would fit in different places?

MD: Well, the reason I moved family up to after fears and worries, is because I thought that those are important to tell someone about. But tradeoffs are important too probably. I’d leave it, I think it just depends on the conversation. You could even think about putting it above goals and hopes. If we’re talking about this, who’s important to make sure they know this as well? I’m sure the format will be different, but I sometimes couldn’t see the question even though you’ve italicized it. You might want to bold-face the whole question, so you can see it better. Or you could do 2 columns or something, because I lost the question.

RB: Did you feel comfortable asking the questions?

MD: Yeah. Except for the prognosis stuff, but it was still ok. But when he asked me, I thought that it went ok, but not great. I felt pretty comfortable, but I’m also more used to thinking about this because I went to a day-long retreat about it!

RB: We sort of envision that we might split it into 3 parts, depending on the order of the questions.

MD: Split it into different visits if you don’t have time? I think you want to talk about the proxy thing pretty early, it just seems like they might want to bring that person with them.

RB: Yeah, we’re trying to have it so that the proxy is actually present for one of the conversations. We haven’t decided whether we want it to be a requirement or not, because we’re afraid that we’ll lose too many people.

MD: Exactly. But I also think there’s value in this patient thinking through it before having the proxy there. The first visit, I don’t think I would bring them.

MS: But if they talk about the HCP during the first visit, and talk about what the HCP knows, then the doctor can offer to have them come to the next visit and facilitate the conversation.

MD: Right.

RB: Yeah, we were thinking about making a prompt here, if the patient hasn’t talked with their family, to offer to help. And maybe we should move the prompts over to the other side. We keep moving things back to where they were before, maybe that means we’re getting closer.

MD: But definitely, the examples being somehow separate would help.

MS: And if it looks nicer, then where the questions are might not be as important.

RB: And it’ll be easier to read, right.

MD: And you can skip around easier too.

RB: And finally, did you feel that the information you got was useful?

MD: I did. I thought it was useful. I just thought the questions were good for getting the conversation going.
MD—Surgeon, Critical Care and Trauma

**MD:** Thanks for coming in today. So how have you been doing?

**Pt:** You know, fair to middling.

**MD:** Tell me more, what does that mean?

**Pt:** Oh, I get a little tired, fatigued, winded. It’s hard to rest.

**MD:** Mmm-hmm, tell me.

**Pt:** It used to be, before I went to the CCU I could lay down, not do much. I’d still get some breathing attacks occasionally. But now I get so fatigued, I don’t even get much rest.

**MD:** Are there particular things that make you more tired than others?

**Pt:** It just seems I get tired all the time, like I’m always fatigued, no matter what I do. And like I said before, I used to go down or up the stairs; if I did a little too much I’d just stop and breathe. But now it’s even if I’m laying down, I just have no energy at all.

**MD:** How’s your breathing?

**Pt:** I get short of breath, I get the attacks. And those are pretty scary.

**MD:** Yeah, I bet they are.

**Pt:** My wife doesn’t really know what to do. We’ve always got our finger on the button, ready to call 911. We’re just waiting for me to catch my breath. That’s disturbing, that’s hard.

**MD:** That sounds very scary.

**Pt:** Yeah. I think she gets really scared.

**MD:** Well, you know, you were in the CCU recently and I saw you after that. But there were some things that I wanted to talk about with you about how you feel about what’s going on with your illness, where you see things going. And I thought that would be better handled in a separate conversation. I’m just wondering, can you tell me how you perceive things going with your illness? Where you’ve been, where you are now, and where you think this might be going.

**Pt:** Yeah, alright. Well, you know when they gave me the pacemaker, it helped a little bit and seemed like things were going pretty good. But now it seems like things are going downhill, honestly. To be laying in bed and to be fatigued from doing nothing, nothing at all.

**MD:** And do you think that it’s getting worse, your illness?

**Pt:** Yeah, that’s kind of what I’m saying, I feel like it’s getting worse.

**MD:** And do you have any idea about how this may continue?

**Pt:** I was kind of hoping you’d tell me that [laughs]. All I can do is guess, I don’t know.

**MD:** Well my crystal ball doesn’t work that well all the time. But your disease right now is stable. After the CCU we’ve managed to get you on some medications that seem to be holding. But I’m also concerned that you’re not getting better, that you’re getting worse, and your illness is pretty serious. And we’re committed to doing everything we can for you to help you and your family get through this, and to meet all of your needs. And your illness is serious enough that it’s not just your medical needs; it’s also your emotional needs and planning for the future. Which can be hard to talk about, but I’m hoping that we can do that here today. Is that OK with you?

**Pt:** Yeah, that’s OK.

**MD:** Most of the time, in situations like this, we always hope for the best; but my job is to worry for you and to plan for things that may not go as we would like. You mentioned to me that your wife is scared and concerned, and she’s not sure what to do. So I’m hoping that you and I can talk about what your goals and values are for taking care of you the best way that we can. And
that’ll help us, me and your wife, to care for you in the even that you won’t be able to talk for yourself.

Pt: That I won’t be able to talk for myself?

MD: Sometimes, like when you were in the CCU, you were so sick and having difficulty breathing that, even though you were awake, you probably weren’t able to communicate.

Pt: I could hardly talk at all, yeah.

MD: So we want to make sure you stay in control of what’s going on and that you’re telling us in anticipation of what you would want.

Pt: You think I could be back in that same situation again?

MD: I think it’s likely that you could be, yeah.

Pt: Likely?

MD: Yeah, I think so. We do our work looking at large groups of patients who have conditions similar to yours; and every single individual is different. But we’ve done a lot for you and the treatments that we’re giving you aren’t necessarily making you better. I think that’s what you’re telling me, that you’re still having some shortness of breath and even when you’re resting. So my job is to worry that there may be, there will likely be another episode where you take a step backwards before you take a step forward.

Pt: And go back to the CCU?

MD: Potentially, but let’s talk about that. That sounds like it’s something that really bothers you.

Pt: Yeah, that really wasn’t a good experience for me. Being in the CCU, it was very difficult.

MD: What was difficult about it?

Pt: Everything. Mary can’t come and visit when she wants to, they keep her waiting out there in the waiting room. People running around the room, you never get any rest. They’re always sticking you with something, machines are always beeping. Nobody really explains, they don’t take the time to explain. They’re running in and out of the room and you don’t know what’s going on. I didn’t like that.

MD: So if your health were to worsen, what are the goals that are most important to you?

Pt: You got kids?

MD: Yeah, I do.

Pt: I got a granddaughter, she’s 21. She’s graduating college in the spring, she’s got 2 semesters left. I want to be able to see her graduate, that’s really important to me.

MD: So that’s an important objective, an important time goal for us to get to. Ok. If in order to get that goal, you needed to go back to the CCU or potentially being on a breathing machine, is that something you would want? It sounds like that time in the CCU was really hard for you.

Pt: Breathing machine, wow, I’ve never thought about that

MD: I don’t think you have to think about that specifically. It’s just helpful for us to get some sense of what are the things that are most important to you, so we can help make decisions for you.

Pt: I mean, I guess if it was a really short stay in the CCU; I’d much prefer being in a regular hospital bed. But I’d like to stay home as much as possible, be out of the hospital.

MD: Ok. So staying home [hand gesturing 3 levels] is first priority; second thing is ok to go to the hospital; third thing is if you have to go back to the CCU, for a short period of time. But you’re not particularly happy about it, are you?

Pt: No, no. I think if I brought my wife in, she’d say the same thing. The CCU was tough for both of us.

MD: I’m sorry to hear that. What are your biggest fears and worries about the future with your illness?
Pt: I guess not being able to catch my breath, having those breathing attacks. We just don’t know what to do, we just wait. You call 911 and they show up and you’re ok, and you feel foolish. If you don’t call 911, you don’t know. You feel like you’re drowning. Those attacks are really bad, on top of the fatigue that comes with it.

MD: Right. And have you ever felt that the rescue medications that we’ve given you are helpful? Or do we need to work more on that?

Pt: I think it’d be helpful if we checked, went over them. Everything doesn’t work. Maybe I’m asking too much, maybe there just isn’t; but if they could work better that would be great.

MD: I think we should talk about that a little bit more, about what to do because it’s really scary to you. My concern is that if you’re having those episodes, it’s probably decreasing your quality of life.

Pt: Yeah. Most of the time we just wait, we don’t call, we wait for it to pass. It’s the times that you don’t know, that’s the hard part. I see the look on my wife’s face, and…I’m still very much in love with her, I don’t like to see her like that.

MD: Well, I think also it might be helpful if maybe I could talk to your wife sometime as well, to try to help her understand what’s going on a little bit better.

Pt: Yeah, well she’s my proxy. But maybe I’m putting too much pressure on her by making her my proxy, it’s too hard. I don’t know.

MD: Is there anybody else you think?

Pt: I was thinking about my son, but I’m not really sure. Maybe we should have that conversation with my wife first.

MD: I think that’s a really important outcome of this conversation, I’d like to learn how we can make this easier for you and your wife. Are there specific conditions or things that you would find unacceptable? You know, we talked about your concerns about going back to the CCU.

Pt: Like I said, I think the CCU would be ok if it’s short. I really would prefer not to go back, I’d rather be home. You mentioned breathing machines, I would not want that. Again I probably should talk that over with my wife.

MD: And if you needed a feeding tube or anything, are there other things that you’ve thought of that would be unacceptable?

Pt: Yeah, you know, I’m a librarian, books are my thing. If I can just sit and read; I know I’m not going to run the marathon. I would be pretty content if I wasn’t so fatigued and had those attacks. I don’t think I could deal with a feeding tube.

MD: Being able to read and understand language is really important to you.

Pt: Yeah.

MD: Ok. How much have you discussed these things with your wife? How much do you think she knows about your wishes?

Pt: We’re probably like the biggest deniers in the world. When we’re not in panic mode, we just try to think about something else. When I’m not having attacks, we just try to be happy. So we’re not really; maybe that’s my fault, maybe I should bring it up. But I don’t want to, I just want us to have a good time. So we haven’t really talked a lot about it.

MD: Sometimes talking about it can help reduce the anxiety. And as I said I would be happy to help with that conversation, because I know it can be hard to have it just the two of you.

Pt: Yeah, that might be something that would be ok.

MD: Maybe the next time we can make an appointment for her to come too. So I just want to kind of recap what we just talked about. Are there other things that you need to know? Concerns about your illness moving forward. Things that we can do to help make sure that you have the best quality of life going ahead.

Pt: Well, if I had a question for you, maybe you could answer that for me?
MD: Sure, I can try.
Pt: The way things are, do I have a decent shot at seeing my granddaughter graduate?
MD: You have a shot. I’ll say that I’m concerned that you may not make it there.
Pt: [heavy sigh]
MD: I know that’s really hard to hear, but I’m concerned that’s a real possibility. But we’re going to do everything we can to get you there. We’re going to do everything we can together, with all of the tools we have here and with your family to help you cross that line at least. But at this stage in your illness, things can be unpredictable. And I think you know that because of the things you’ve been experiencing at home. I think what’s important moving forward is helping you get there, but also making sure that time is really a good time for you, the best we can make it.
Pt: Yeah. Alright.
MD: I think we’re at a point where things are stable, you were just in the CCU. How long it’s going to be, we don’t know for sure. We’re going to do everything we can to optimize, to make sure you’re on the best medical regimen we can find for you. And I think shortly we’re going to try to meet again to talk about those episodes where you need rescuing. And also talk with your wife. But what I’m hearing is that milestone of your granddaughter’s graduation is really important to you.
Pt: Yeah, it is.
MD: And we’re going to do everything we can to get you there. And if need be, for a short period of time, you would be admitted to the CCU, but only for a short period of time. But you wouldn’t want a breathing machine or anything like that. And in the meantime, while you’re home, we’re going to continue to do everything we can to keep you out of the hospital. Ok? So next time we’ll bring your wife. Very nice to see you.

Feedback:
MD: I’m a trauma surgeon, so often times we’re not having these conversations with the patients themselves. It’s intense.
RB: So tell is how it was for you.
MD: You know, it was helpful having this framework. I wish I’d committed it to memory a little bit better.
RB: That’s a common comment.
MD: I feel like I got to everything. The decision-making one was a little bit hard for me, because I don’t really know what the prognosis is. So it goes back to doing this when there’s the uncertainty. So I did the best I could with that. So I kind of came back to it at the end. It was helpful having this to look to, I hope it wasn’t too intrusive for you. It was definitely intense. I think having the framework was actually very helpful.
John: I thought you had a very nice pace. You didn’t rush me, you didn’t have your own agenda. Being that you had a list to go through, I thought that the pace was really nice. It didn’t feel artificial or anything like that. When a doctor walks into a room, they always have an agenda about what they’re going to do, and that agenda always changes immediately based on the communication. You stuck to what you needed to stick to, but it felt very natural. You were very empathetic, so that helps a great deal. In the beginning you gave me a couple of warning shots, so that was nice; you said “we’ll prepare for this, but just in case.” Your language that you were concerned was also a warning shot for me, that tells me something heavy is coming. You always checked in with me about what I wanted, which was really nice. A couple of missed opportunities, tools you can use: when I asked you about time and if I’d make it to my granddaughter’s graduation, you want to always make sure that you clarify that. Make sure you
know what I’m asking about, because I could be asking about anything. You want to double-check with me. And there was an opportunity for silence after you answered me. As a patient, after you told me I had a shot, I didn’t hear much after that. So there’s a little opportunity for silence there. There’s also opportunities for bonding with the granddaughter. A simple thing like, tell me about your granddaughter, will get you miles down the road. In general, I thought you did a wonderful job; really nice tone, very caring, nice pace, it felt very natural.

MD: How long did that take?

RB: It was about 15 minutes. That’s what we’ve been averaging. And I thought you got through a lot in those 15 minutes. I thought you did a great job. It was really clear to me that you do this with families a lot, and I thought it was really great. You had a lot of empathic statements, like “it sounds really scary.” The other thing you did well was framing it, checking in if it was OK to talk about this today. The only other thing, I thought you could have used other words when you said “you have a shot.” I like to say “I wish” statements, like “I wish that it could be, but I’m worried that it may not.” That’s realigning, and then you’re on his side. You could have used that statement there well. I love using that because it automatically says that it’s not definitely going to happen, but it puts you on their side. You’re also the only person that has said “I’m concerned that you may not make it to the graduation.” I thought that was really brave. We sort of made it intentionally ambiguous. There’s definitely a chance he’ll make it. But I thought that was really brave and you did a nice job around that. I thought that part at the end was a little bit softer than the middle part, and very nice. Overall, I thought it was great.

John: And you covered a great deal of ground. If you think about where you got me with the breathing tube and the feeding tube, that’s huge.

MD: Actually, one question that I have is, I was hesitant to get into breathing tube, feeding tube; because it’s such a tough topic. I’m not sure how specific to be.

RB: What we’re trying to do with this tool is open the conversation and leave that open for the next visit. We’re not trying to make those decisions in this visit, unless it’s appropriate from a clinical standpoint.

John: So I have a question. You were hesitant to bring that up, but what convinced you to delve into it?

MD: That I thought it was unfair to you not to, the ambiguity was unfair.

John: Is it also because you felt that the conversation was comfortable to do that with this patient.

MD: Yeah, I think so.

John: Because that shows that you’re in tune with the patient. You’re adjusting to what’s going back and forth.

MD: I didn’t feel time-pressured, but I was cognizant of the time. But I was very much interested in what was so bad about your CCU stay. You talked a lot about your wife, but I didn’t really get into what was so hard about it for you. I’m also an intensivist, so I’m thinking you probably had patients around you that were trached, and thinking “Don’t let that happen to me.” I thought that you knew about it, that I wasn’t bringing anything up that you hadn’t thought about already.

MS: I think something you did really well is, you asked about the feeding tube and breathing tube, but you didn’t focus on those. You did keep it at the big picture. At one point you said “So if I’m hearing you correctly, staying home is your first priority.” You kind of ranked it. You kept it bigger, but then bringing in the details that he brought up. I thought that was fine. I think there’s room for that a little bit in here, and it’s not entirely clear that you can or cannot bring it up. If it comes up, I think that’s fine.

John: It was very nice for me as a patient that you ranked that. It was very clear.
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MS: Right, it showed that you had heard him.
MD: Yeah, this is very helpful.
RB: I'm torn because I think it was good that you got the information that he probably wouldn't want to be intubated. That was good information. Would you enter DNI order after that conversation? Maybe, I don't know. You'd probably want to clarify it more, or you could at least put it in text. The short time in the CCU is helpful. If he came to the ER short of breath, they would do everything; then they'd send him to the CCU and you would have that information there.
MD: One of my concerns about that line of communication has been having an outpatient provider having that information, and not having it available in an inpatient setting. I think now that I've actually had the conversation, yes it'd be a lot easier to get that transmitted.
MS: Well in this conversation, you made it very clear that it's important to bring the wife in and have a conversation with her. And it sounded like you would have gotten to all those specific things at the conversation with the wife. And then you would have been able to actually write them down and fill out orders. I think it would have been the next thing.
John: And you reinforced it towards the end, too, you said next time bring your wife.
RB: So did you feel comfortable asking the questions?
MD: I didn't feel less comfortable than I do normally.
RB: So you've been doing this for a while now. Do you use most of those questions? Which ones are new?
MD: No. Let's see, decision-making I don't use; but to be fair, that's because I don't deal with chronic conditions very often. Goals I use, fears/worries I don't typically address them so directly. Tradeoffs, I don't typically address them so directly. Function, yes. I'm mostly talking with families, so that's not such an issue. That being said, I do ask the family how much they know, and how much they knew before all this happened. I try to draw out as much information as I can from them about that. But yeah, there's a lot of stuff here that I don't address directly. I would guess that most of my colleagues don't either. That's probably because anxiety and concerns about time pressures and what to do if someone says their biggest fear is that they're going to die. The lack of skill, I think, is the hardest part.
RB: One of the things that I think would be good for your next phase of learning: if someone's not going to make it to a milestone, it's good to bring up legacy work. You should try to go with Phil and Amanda to see him do one of those. It has to be a pretty self-aware patient, and I wouldn't bring it up unless they're really understanding and accepting that they're not going to make it. But even for people who are really anxious, it can be a nice closure.
MS: So as far as the question themselves, what do you think of the wording? Is there anything you would change? Anything that's not clear?
MD: I guess the prognostic understanding, I kind of rephrased it because I was concerned that he wouldn't understand. I'm trying to get a sense of the trajectory, which is not a great word to use with patients. But I knew what this meant, so I can improvise. The decision-making, again, that's just hard.
RB: How did you interpret that question?
MD: I look at this as medical and prognostic information. I actually see that as prognosis rather than decision-making.
RB: Do you have another term that we could use besides decision-making? Because I think that's the wrong title for that.
MD: I guess one question I have is, what is the importance of that to the Checklist?
RB: That one came out of the meeting, and I attribute it to Terry O’Malley. He says that in Advance Care Planning, the most important thing is to establish a framework about how you're
going to make decisions and who’s going to do that. So that was originally the questions: how are you going to make the decisions, who’s going to make them, and how much information do you want? Once he establishes that, he feels like everything flows from there. But the question has changed so many times that, right now, the title doesn’t fit the question. I actually think it’s a really good question.

[Rachel arrives]

RB: We’re actually talking about the decision-making question. Right now I think the title doesn’t match the question very well. It’s been a problematic question for people. So the way that the question is working now, people are interpreting it mean prognostic information. I think that’s useful, but if we’re doing that, we need to change the title.

SB: I agree. So we’re back to information preferences.

RB: I think the original intent of decision-making was the idea of how you make decisions and who’s involved. I think we need to think about that one more.

SB: Yeah. I agree.

RB: So let’s go to goals.

MD: I thought that was clear. And I like the italicized part, that was helpful.

RB: And did you find that it was OK to read? This was the first time we’ve had it shaded out.

MD: Yeah, I thought that was good. Fears and worries is good. Tradeoffs, this is a tough one. He gave us a milestone, which was helpful. We could establish, if this then that. I fear that somebody who wants to be more liberal with that is going to struggle even more. Somebody who doesn’t want to say this is a big picture conversation.

RB: He’s been acting as wanting to know everything.

MD: I think it’s a good question, but following it up with examples of certain conditions you would find unacceptable.

MS: So combine the 2?

MD: Almost. I just worry about getting into this laundry list of procedures.

RB: Right. We just want to get a general sense.

MS: I think you got to the tradeoffs without asking the question specifically, but in other questions you had asked. You got to it when he talked about not wanting to go back to the CCU, so then you asked about other things he wasn’t willing to go through.

MD: I’m thinking of patients who say that they don’t know what they’re going to go through to gain more time. Then how do you avoid the laundry list.

SB: I don’t know. Do you think getting through the laundry list is so bad? I think it gives people something to think about. It’s important to stop and listen to people. If they say they really don’t know, you can just give some examples. I think it’s fine to list them as examples to cue people.

RB: And pause between them. We may want to cue the pauses.

MD: Well, you could cue the pauses or even say that you do not have to have a resolution to these questions at the end of this conversation.

RB: That’s actually a really good point, I think that’s a big stress for people.

SB: I wonder whether that’s part of the introduction. You could say, “We’re raising a bunch of questions, but we don’t necessarily need to answer them all today.”

RB: I think that’s a really great point, because doctors are so definitive. How about the family one?

MD: Yeah, I think that’s fine.
Appendix G: Semi-structured interview guide for beta-testing

This guide was used during beta-testing of the SICG. We asked these questions to the test clinician after they had completed the mock interview with the standardized patient/actor. This helped us edit and perfect the Serious Illness Conversation Guide.

The Serious Illness Conversation Guide is currently in the development stage, and we are seeking input from clinicians in order to make it as effective and user-friendly as possible. Your detailed feedback is greatly appreciated and completely confidential.

**Content:**
What did you think, in general, of the content of the questions?

What questions did you feel were most/least useful?

How did the order work?

Are there ways you would have preferred to ask about prognosis?

Are there ways you would have preferred to ask about decision-making preferences?

Are there ways you would have preferred to ask about fears and worries?

Are there ways you would have preferred to ask about goals?

Are there ways you would have preferred to ask about tradeoffs?

Are there ways you would have preferred to ask about function?

Are there ways you would have preferred to ask about family?

What would you change about the checklist as a whole?

If you could use any questions from the list as well as your own, what would your key questions be?

**Conversation:**
Did the conversation flow? □ YES □ NO How?

Did you feel comfortable asking the questions? □ YES □ NO Why or why not?

Would you use the checklist in a conversation with a patient? □ YES □ NO Why or why not?

How comfortable do you think you would be revisiting this in 3 months?

Did you feel that the information you obtained was useful? different from your usual conversations?
### Serious Illness Communication Project Training Program

**Goals:**
By the end of the program, learners will be able to demonstrate:

<table>
<thead>
<tr>
<th>Goal</th>
<th>Outcome</th>
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<tr>
<td><strong>1. Communication Skills</strong></td>
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| Use of silence, facilitating patient talk | • Allows silence before responding when patient is taking in information or expressing emotion  
• Patient speaks >50% of time |
| Acknowledging and responding to patient/family emotion | • Acknowledges difficult emotions during discussion  
• Responds to emotion with empathic comment or further exploration  
• Avoids using information or premature reassurance to respond to emotion |
| Eliciting patient concerns | • Encourages patient to express fears, worries, other concerns |
| Assessing patient receptivity | • Accurately assesses patient’s receptivity to receiving new information and considering other options for treatment |
| Recognizing appropriate time for exploration and for making a recommendation | • Recognizes appropriate time for exploring other options based on the fact that disease has progressed or prognosis has gotten worse  
• Makes a recommendation based on an accurate assessment of patient receptivity |
| Identifying key challenging scenarios in using the checklist, and strategies for addressing them. | • Describes three concrete strategies for dealing with crying, anger, denial, and avoidance |
| **2. Mastery of SICG** | |
| Effective use of checklist | • Clinician completes all elements of checklist |
| Documentation of discussion in ACP module | • Documents critical information for colleagues in ACP module |

**Training Program:** 150 minutes, 6 participants, 2 facilitators, breakout groups of 3

**Preparation (pre-training session):**
- “Letting Go” by Atul Gawande
- Review checklist

**Introduction (5 minutes):**
- A Tale of Two Stories: Positive and negative outcomes at EOL
- Goals, philosophy, ground rules, overview of session

**Didactic Session (40 minutes):**
- Why a Serious Illness Conversation Guide?
  - Demonstrate that clinician is open to discussing these issues
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- Stimulate patient reflection about values and goals
- Stimulate discussion of values and goals with family, proxy, and clinicians
- Allow time for processing of information and feelings
- Goal of initial checklist is NOT to make decisions about EOL treatments

- Challenges in discussing advance care planning/values and goals—*distribute Reference Guide for Clinicians (see attached)*
  - Time
  - Maintaining hope
  - Uncertainty re: prognosis—give range, not numbers
  - Variability in patient preferences, wishes about discussion
  - Psychological readiness of patient

**Demonstration of Checklist (15 minutes):**
- Introduction of observation form
- Discussion: “I hate role play”
- Demonstration of checklist-guided discussion with faculty and standardized patient
  (“Does this mean I am dying?”)
- Debriefing and deconstruction of checklist discussion using observation form

**Skills practice I – a straightforward scenario (30 minutes)**
- One interviewer, one observer, one faculty, one standardized patient
  - Structured assessment form completed by observer
  - 15 minute checklist discussion
  - 15 minute debriefing using structured assessment form

**Skills practice II– Patient cries, is angry, or is in denial (30 minutes)**
- One interviewer, one observer, one faculty, one standardized patient
  - Structured assessment form completed by observer
  - 15 minute checklist discussion
  - 15 minute debriefing using structured assessment form

**Wrap-up (45 minutes)**
- Brief wrap-up of key learning points
- Use of structured documentation in LMR
- Review of next steps: Description of triggering SICG and coaching program
- Feedback and Q&A

**Coaching Intervention:**
- Regular coaching sessions scheduled throughout intervention at monthly intervals
- 4-6 participants per session
- “In the moment” individual coaching: Email mailbox to request coaching/debriefing within 24-48 hours for urgent or distressing cases
- Logistics:
  - Before coaching session, participants identify learning goal based on their experiences using the Checklist
  - Participants present challenges in their discussions, focusing on their last case or other challenging scenarios
Coach identifies common themes and learning goals
Group discussion of approaches to challenges presented, including use of mini-role play or full skill practice
Summary of take-away points
Evaluation of coaching session
**SICG Conversation Evaluation form:**

<table>
<thead>
<tr>
<th>Subject Code:</th>
<th>CD #:</th>
<th>Track #:</th>
<th><strong>Communication Skill</strong></th>
<th>Rating</th>
<th>Points</th>
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<tbody>
<tr>
<td><strong>General Patient-Centered Interviewing Skills</strong></td>
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<tr>
<td>1. Addresses goals of discussion (i.e. control for patient, peace for family)</td>
<td>1=Yes/0=No</td>
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<tr>
<td>2. Seeks permission to engage in discussion</td>
<td>1=Yes/0=No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Uses statements to ensure understanding of patient’s statements (“It sounds like…”)</td>
<td>1=Yes/0=No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Allows silence before responding</td>
<td>1=Yes/0=No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Patient speaks &gt;50% of time</td>
<td>1=Yes/0=No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Makes explicit statement of partnership building/non-abandonment/ongoing involvement in patient’s care</td>
<td>1=Yes/0=No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Addresses ongoing process for shared decision-making</td>
<td>1=Yes/0=No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Achieves an appropriate balance between encouraging patient to address difficult issue, and allowing patient to opt out of discussion (is gentle in pushing patient)</td>
<td>1=Yes/0=No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Subtotal** /8

| **Discussing Goals of Care/Checklist Items** |       |         |                          |        |        |
| 9. Asks patient about prior experiences with EOL decision making or about assignment of Healthcare Proxy | 1=Yes/0=No |        |                          |        |        |
| 10. Explores patient’s understanding of his/her current condition/prognosis | 1=Yes/0=No |        |                          |        |        |
| 11. Explicitly asks patient about the amount/type of information they would like to be provided | 1=Yes/0=No |        |                          |        |        |
| 12. Explores the patient’s values and important goals | 1=Yes/0=No |        |                          |        |        |
| 13. Explicitly asks about patient’s fears, worries, or concerns about the future | 1=Yes/0=No |        |                          |        |        |
| 14. Uses direct and clear language in describing prognosis | 1=Yes/0=No |        |                          |        |        |
| 15. Explores importance of functional status (i.e. abilities that are important to the patient’s life) | 1=Yes/0=No |        |                          |        |        |
| 16. Discusses probable clinical scenarios/tradeoffs that the patient might face | 1=Yes/0=No |        |                          |        |        |
| 17. Explores patient’s preferences for proxy and family involvement | 1=Yes/0=No |        |                          |        |        |
| 18. Proposes an explicit recommendation about course of treatment that balances patient’s goals, values, and concerns with realistic medical treatment options | 1=Yes/0=No |        |                          |        |        |
| 19. Offers help to patient in talking through goals and wishes with family | 1=Yes/0=No |        |                          |        |        |
| 20. Provides a closing statement summarizing the conversation | 1=Yes/0=No |        |                          |        |        |

**Subtotal** /12
<table>
<thead>
<tr>
<th>Responding to Emotion</th>
<th>1=Yes/0=No</th>
</tr>
</thead>
<tbody>
<tr>
<td>21. Validates or expresses understanding of the patient’s emotional reaction</td>
<td>1=Yes/0=No</td>
</tr>
<tr>
<td>22. Explores patient’s emotional reaction(s) in greater detail (i.e. “tell me more…”)</td>
<td>0=None/1=once/2=2+times</td>
</tr>
<tr>
<td>23. Responds to emotion with empathic comment or further exploration</td>
<td>1=Yes/0=No</td>
</tr>
<tr>
<td>24. Immediately provides information in response to expression of emotion</td>
<td>1=Yes/0=No</td>
</tr>
<tr>
<td>25. Immediately provides reassurance in response to expression of emotion</td>
<td>-1=provides information</td>
</tr>
<tr>
<td></td>
<td>Subtotal /5</td>
</tr>
<tr>
<td></td>
<td>TOTAL /25</td>
</tr>
</tbody>
</table>
## Serious Illness Conversation Guide Training Program Evaluation

Clinician type (circle one): MD NP  PA

### How much did each of the following elements of the program contribute to your learning today?

<table>
<thead>
<tr>
<th>Element</th>
<th>Not at all</th>
<th>Somewhat</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reading materials (Atul Gawande’s “Letting Go”)</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Introduction/reflection</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discussion of evidence base for end-of-life communication</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discussion of values and goals communication challenges</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Review of checklist and orientation materials</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Demonstration of checklist-guided discussion (Dr. Block and actor)</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Debriefing of checklist-guided discussion</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>First (“easy”) role play</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feedback received on ”easy” role play</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Second (“hard”) role play</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feedback received on ”hard” role play</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wrap up discussion/group debrief</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reference Guide for Clinicians</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### To what extent do you feel able/comfortable in implementing the following practices in your next discussion with a patient about end-of-life issues?

<table>
<thead>
<tr>
<th>Practice</th>
<th>Not at all</th>
<th>Somewhat</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Using silence to allow patient to take in information or express emotion</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acknowledging difficult emotions during conversation</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Responding to patient/family emotion</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eliciting patient concerns</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speaking less than 50% of time in this discussion</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowing what to do in challenging situations</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall, how effective was this session in enhancing your confidence in talking with patients in the format described?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall, how effective did you find this program to be in improving your skills in conducting a discussion about end-of-life care?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

What is the most important thing you learned in this workshop?

What could we do to improve this workshop for other clinicians like you?
Appendix I: ACP module to document conversations
Below is the content included in the ACP module, which intervention-arm clinicians will use to document discussions during the study. Each question is on its own screen, with the possibility of saving one screen at a time, and saving incomplete forms and to return later. The module also keeps track of the history of documentation, with the latest entry showing up first on the home screen of the “Values and Goals” tab.

Prognostic understanding: What is your understanding now of where you are with your illness?
Free text:

☐ No understanding of prognosis
☐ Overestimates survival
☐ Appropriate understanding of prognosis as communicated by me today
☐ Underestimates survival
☐ Not discussed

Information preferences: How much information about what is likely to be ahead with your illness would you like from me?
Free text:

☐ Patient wants to be fully informed
☐ Patient wants to be informed of big picture, but not details
☐ Patient wants some information, but “no bad news”
☐ Patient doesn’t want any information him/herself

Prognostic communication: Please select the terms you (MD) used to describe prognosis to the patient:
☐ More than a year
☐ Several months to a year
☐ Several weeks to months
☐ Days to weeks
☐ Did not discuss and why
Free text:

Goals: If your health situation worsens, what are your most important goals?
Free text:
Serious Illness Communication Project
3/4/2015

☐ Live as long as possible, no matter what
☐ Be at home
☐ Be physically comfortable
☐ Be mentally aware
☐ Not be a burden
☐ Be independent
☐ Have my medical decisions respected
☐ Provide support for family
☐ Be spiritually and emotionally at peace
☐ Achieve particular life goal, please specify:________________________

Fears/worries: What are your biggest fears and worries about the future with your health?
Free text:

☐ Pain
☐ Other symptoms
☐ Emotional distress
☐ Spiritual distress
☐ Concerns about meaning of my life
☐ Burdening family
☐ Ability to care for others (e.g., children, ill spouse)
☐ Other family concerns
☐ Loss of control
☐ Getting treatments I don’t want
☐ Loss of dignity
☐ Preparing for death
☐ Finances
☐ Other ____________

Unacceptable levels of Function: What abilities are so critical to your life that you can’t imagine living without them?
Free text:

☐ Being unconscious
☐ Being unable to talk
☐ Being in pain or very uncomfortable
☐ Not being myself
☐ Not being able to care for myself, including toileting and feeding
☐ Being unable to interact with others
Tradeoffs: If you become sicker, how much are you willing to go through for the possibility of gaining more time?
Free text:

I don’t want to:
- Be on a ventilator
- Live in a nursing home
- Be uncomfortable
- Be in the hospital
- Be in the ICU
- Undergo aggressive tests and/or procedures
- Have a feeding tube

Family: How much does your family know about your priorities and wishes?
Free text:

- Extensive discussion with family about goals and wishes
- Some discussion, but incomplete
- No discussion, but plans to address these issues
- No discussion; wants help talking with family
- Wants clinician to talk with family
- Does not want family informed

The screen shot below shows the Values and Goals Summary tab in LMR, with each question from the Serious Illness Conversation Guide listed on the left-hand menu:
The screen shot below shows detail of the Prognostic Understanding question in the LMR ACP module; clinicians will be able to select from multiple options and to enter free text:

This discussion occurred at a particular moment in time in this disease context. These are not medical orders; the patient preferences listed here should be reviewed regularly and revised before medical decisions are made.
The screen shot below shows detail of the Information Preferences question in the LMR ACP module; clinicians will be able to select from multiple options and to enter free text: