Principles for Customizing the Serious Illness Conversation Guide

Introduction
The Serious Illness Conversation Guide was developed through a systematic approach, including expert input, an extensive review of the evidence, and rounds of testing with patients and clinicians. The conversation flows in a way that creates a safe, therapeutic space for clinicians and patients to discuss these issues by:
- Setting up the conversation
- Assessing illness understanding and preferences for information
- Sharing a prognosis based on the patient’s preferences
- Exploring key topics with open-ended questions, including patient goals, fears, strengths, levels of function they find tolerable, acceptable and unacceptable tradeoffs, and what their family knows about their priorities
- Making a recommendation when appropriate based on the patient’s values, goals and the medical situation
- Documenting the conversation

In designing the Conversation Guide, we were conscious that many patients who could benefit from a Serious Illness Conversation do not define themselves as “terminally ill” or “dying” or at the “end of life.” Our language in the Conversation Guide is compassionate, open, and intentionally hypothetical and gentle.

However, we recognize that some of you may find it helpful to customize the Conversation Guide to reflect the specific context in which you are implementing the program. If that is the case, we recommend that you add your institutional logo to the Conversation Guide to make it your own and also read the steps below which provide a more comprehensive review of customization principles.

Steps for customization
1. Understand the Conversation Guide elements and rationale
2. Try the original Serious Illness Conversation Guide yourselves
3. If you decide to customize the Conversation Guide, organize a workgroup
4. Review the principles for customization
5. Test changes
6. Agree on changes and finalize
7. Review licensing

Step 1: Understand the Conversation Guide elements and rationale
The Conversation Guide was developed systematically and tested in multiple settings with different patient populations to determine acceptability of the terminology, wording, and format of the guide. Review the rationale below for the Serious Illness Conversation Guide to understand the reasons behind the questions and the flow.
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<th>Step</th>
<th>Action and Language</th>
<th>Rationale</th>
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| Set-up                           | ● Introduce the idea: “I'm hoping we can talk about where things are with your illness and where they might be going…”  
    Introduce the benefits: “The goal is to make sure that I have the information I need about what matters most to you so I can provide you with the care you desire and support your family if they ever have to make decisions for you.”  
    ● Ask for permission: “is this okay?” | Setting up the conversation builds trust and gives the patient control by gaining the patient’s permission to proceed with the discussion. |
| Illness Understanding and Information Preferences | **What is your understanding now of where you are with your illness?**  
                                          | Understanding the patient’s illness understanding allows the clinician to tailor disclosure to patient readiness and provides information to assess alignment between patient beliefs and reality. |
|                                  | **How much information about what is likely to be ahead would you like from me?**  
                                          | Understanding the patient’s preferences for information allows the clinician to provide desired information, helps the patient retain control, and gives the clinician confidence in proceeding. This question also allows the physician to titrate his/her discussion to meet the patient’s needs. |
| Prognostic communication | Prognostic communication may include one or more of several types of information: 1. Time, expressed as a range to reflect uncertainty: “I wish it were different, but I worry that time may be shorter than we hope. I worry that, in terms of time, we may be talking about months to a year. Of course, we don’t know for sure, and it could be longer or shorter.” 2. Function: “I wish it were different, but I’m worried that this may be as strong as you feel. I’m worried that in the future, you may not be able to manage as well as you are right now, and it is important that we plan for future changes.” 3. Unpredictable prognosis: “Although this treatment may work well, and you could have a lot of time, it’s also possible that something could happen suddenly. It would be helpful to know what is most important to you and what you would want if you became very sick quickly.” | Information about what to expect about their illness is considered “very important” by nearly all patients but is often an unmet need. Clinicians have a responsibility to provide patients with information about prognosis to the degree desired by the patient (and within the limits knowable to the physician) to enable patients to factor this information into their decisions. Obtaining permission from the patient immediately prior to giving the prognosis gives the clinician confidence and allows the clinician to titrate that information in accordance to preferences. Tips after giving prognosis:  ● Allow silence-It is therapeutic to give a patient time to process emotions after hearing difficult news.  ● Respond to emotion by naming it and exploring |  |
| Goals | What are your most important goals if your health situation worsens? | All patients have goals besides just living longer, such as symptom relief, achieving personal goals, or spending time with family. Understanding patient goals helps restore a sense of a positive future for the patient. In addition, |
understanding goals aids the clinician in tailoring advice and recommendations to address patient priorities and contributes to the development of a personalized care plan. It is very important to discuss goals immediately after the prognostic discussion, because it tends to help patients cope with difficult realities surrounding prognosis — having goals is an antidote to the helplessness and hopelessness that patients can feel after receiving a poor prognosis.

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<thead>
<tr>
<th><strong>Fears</strong></th>
<th><strong>What are your biggest fears and worries about the future with your health?</strong></th>
<th>Expressing fears, even if they cannot be “fixed” is therapeutic and allows the patient to feel understood, supported, and less alone. When appropriate, the clinician can provide appropriate reassurance and focus therapies to address patient concerns.</th>
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<tbody>
<tr>
<td><strong>Sources of Strength</strong></td>
<td><strong>What gives you strength as you think about the future with your illness?</strong></td>
<td>People bring with them to serious illness personal, cultural and familial assets that help them negotiate their illness and maintain hope in difficult times. These assets should be understood and nurtured by treating clinicians, and the only way to know about them is to ask. A question about strengths helps bring these assets to light and deepens the relationship between a clinician and a patient. Asking about them also creates a positive counterpoint to the difficult issues that often arise in these discussions.</td>
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<td><strong>Function</strong></td>
<td><strong>What abilities are so critical to your life that you can't imagine living without them?</strong></td>
<td>Patients view impairments in function differently. For some, maintenance of cognitive function is essential; other patients may feel</td>
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that not being able to provide self-care is an intolerable deficit that would cause them to make different treatment choices. An opportunity to express views of critical abilities helps guide complex decisions. Focusing on function and tradeoffs also communicates to the patient that there may be some difficult choices ahead.

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<th>Tradeoffs</th>
<th>If you become sicker, how much are you willing to go through for the possibility of gaining more time?</th>
<th>Patients may view time in the hospital, invasive procedures, or treatments differently, particularly when weighing those against the value of time at home and other priorities. Allowing patients to reflect on the tradeoffs that might be necessary to achieve different outcomes promotes informed decision-making.</th>
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<td>Family</td>
<td>How much does your family know about your priorities and wishes?</td>
<td>Patients vary in how involved they want family members to be and how much they want their own values, as opposed to those of family members, to determine care. By exploring these issues with the patient, the clinician can help the patient develop a plan for engaging family members in these critical discussions.</td>
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| Make a recommendation      | “Given your goals and priorities, and what we know about your illness at this stage, I recommend...” | The best decisions are made when the patient’s goals and priorities are synthesized with the medical realities and the treatment options. The steps of a good recommendation include:  
● Summarize the patient’s goals and values relevant to future decisions  
● Make a recommendation that integrates both the patient’s goals and the medical situation  
● Affirm commitment to ongoing care |
Step 2: Try the original Serious Illness Conversation Guide yourselves
We encourage clinical champions to start planning their modifications to the Conversation Guide first by using the existing guide and wording with several patients. It might surprise you how comfortable your patients are with the original questions and phrasing. After you are comfortable using the Conversation Guide, consider customizing it to make it your own.

Step 3: Organize a workgroup to customize the Serious Illness Conversation Guide, including end-users
If you decide to customize the Conversation Guide, we recommend that the customization workgroup include clinical members of your implementation team and at least one end-user clinician. An end-user clinician is an individual who will be using the Conversation Guide in his/her practice (i.e. oncologist, primary care nurse, etc.). This will give you a better sense of the context in which the Guide will be used to frame your changes.

Step 4: Review the principles for customization
If you choose not to customize the guide content, consider adding your organization’s logo to the Conversation Guide.

If you choose to customize:
   a. Respect the spirit of the Conversation Guide - open-ended, patient-centered, compassionate
   b. Use language that is comfortable to say
   c. Keep the design simple and easy to read
   d. Keep it as short and concise as possible to meet your goals
   e. Follow appropriate licensing (see step 7)

Step 5: Test changes
Pilot testing of the customized guide can occur in multiple ways:
   - Read it out loud to a colleague before using it with patients to make sure that the questions are easy to say aloud
   - Test any changes with a few patients or family members before you finalize the Conversation Guide
   - Tip: If you change the Conversation Guide, ensure that the Serious Illness Conversation EHR template reflects the modified guide exactly.

Step 6: Agree on changes
The workgroup will agree on the modifications to the Serious Illness Conversation Guide and finalize it to be used for training and implementation.

Step 7: Understand licensing
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If you choose to modify the Conversation Guide, please consider sending your modified guide to our team at seriousillnesscare@ariadnelabs.org.