

Appendix C. Algorithm for Creation of Jumpstart-Tips Form

Algorithm Matrix for Generating Clinician Jumpstart-Tips Forms: Our Recommendations/Study Suggestion

Item 1. **Is your patient ready?**

		b. Want to Discuss/Discuss More?		
		Yes*	No	Don't Know
a. Ever discussed preferences if/when too sick to speak for self?	Yes	Go for it! Ask if there have been any changes since the last time your patient talked to you or to another clinician.	Check what you know; reinforce why it's important to repeat periodically. Try saying: "It is helpful for me if I make sure I am up to date on your views about the care you want."	Ask the patient's permission to talk about preferences; reinforce why these discussions are important. Try saying: "It is helpful for me if I make sure I understand your views about the care you want."
	No*	Go for it! Try saying: "I am interested in knowing your thoughts about that Jumpstart form."	Ask the patient's permission to talk about preferences; reinforce why these discussions are important. Try saying: "It is helpful for me if I make sure I understand your views about the care you want."	Ask the patient's permission to talk about preferences; reinforce why these discussions are important. Try saying: "It is helpful for me if I make sure I understand your views about the care you want."
	Don't remember	Go for it! Try saying: "I am interested in knowing your thoughts about that Jumpstart form."	Ask the patient's permission to talk about preferences; reinforce why these discussions are important. Try saying: "It is helpful for me if I make sure I understand your views about the care you want."	Ask the patient's permission to talk about preferences; reinforce why these discussions are important. Try saying: "It is helpful for me if I make sure I understand your views about the care you want."

Item 2. **What is your patient's perception of current care? [quality of life or extending life]**

		b. Patient Perceives That Current Health Care Is Focused On:		
		EXTENDING LIFE	QUALITY OF LIFE	NOT SURE
a. At this time, if patient had to choose, he/she prefers to focus on:	EXTENDING LIFE	Your patient seems to feel that he/she is getting the care he/she wants at this point. Because the patient is focused on extending life, see the items below about thinking about the future.	Your patient seems to feel that his/her current care does not match his/her goals. It may be worthwhile to check this. Try saying: "Some people prefer care focused on extending life even if it means they might be uncomfortable; other people prefer care focused on quality of life even if it means they may not live as long. If you had to choose, what would you say is more important?"	It would be worthwhile to review what you perceive to be the focus of the patient's care since the patient isn't sure. Because the patient prefers to focus on extending life, see the items below about thinking about the future. Try saying: "Would it be helpful for me to clarify how I see the focus of your care?"
	*QUALITY OF LIFE	Your patient seems to feel that his/her current care does not match his/her goals. It may be worthwhile to check this. Try saying: "Some people prefer care focused on extending life even if it means they might be uncomfortable; other people prefer care focused on quality of life even if it means they may not live as long. If you had to choose, what would you say is more important?" *[If ever = NO and want = YES, add: Assess whether patient is interested in referral to palliative care.]	Your patient seems to feel that he/she is getting the care he/she wants at this point. Because the patient is focused on quality of life, consider whether completion of a POLST form or identifying a surrogate decision maker would be useful. *[If ever = NO and want = YES, add: Assess whether the patient is interested in a referral to palliative care.]	It would be worthwhile to review what you perceive to be the focus of the patient's care since the patient isn't sure. Try saying: "Would it be helpful for me to clarify how I see the focus of your care?" Because the patient prefers to focus on quality of life, consider whether completion of a POLST form or identifying a surrogate decision maker would be useful.
	NOT SURE	Since your patient isn't sure what he/she would choose as his/her focus of care, try saying: "Some people prefer care focused on extending life even if it means they might be uncomfortable; other people prefer care focused on quality of life even if it means they may not live as long. If you had to choose, what would you say is more important?"	Since your patient isn't sure what his/her focus of care is, try saying: "Some people prefer care focused on extending life even if it means they might be uncomfortable; other people prefer care focused on quality of life even if it means they may not live as long. If you had to choose, what would you say is more important?"	Since your patient isn't sure what his/her focus of care is, try saying: "Some people prefer care focused on extending life even if it means they might be uncomfortable; other people prefer care focused on quality of life even if it means they may not live as long. If you had to choose, what would you say is more important?"

Item 3. **What makes it harder for your patient to talk about this? [barriers]**

1. I don't know what kind of care I would want if I were to get very sick.	Explain that the patient doesn't need to know what he/she wants. Try saying: "Even if you aren't sure what kind of care you want in the future, it is very helpful to me if we talk about the things that are most important to you about your quality of life and health care."
2. I'm not ready to talk about the care I would want if I were to get very sick.	Acknowledge patient's uncertainty and worry (emotion). Try saying: "Some people find it hard to talk about their future health care. Would you consider giving it a try for a few minutes? At any time, you can just say, 'Okay, that's enough for today.'"
3. I don't like to talk about getting very sick.	
4. My doctor never seems to have the time to talk about issues like end-of-life care.	Explore patient's beliefs and acknowledge discomfort. Try saying: "Sometimes people worry that doctors don't have enough time or wouldn't agree with your thoughts. I want you to know that I consider this topic really important."
5. I would rather concentrate on staying alive than talk about death.	Acknowledge patient's worry (emotion). Try saying: "Some people find it hard to talk about their future health care. Would you consider giving it a try for a few minutes? At any time, you can just say, 'Okay, that's enough for today.'"
6. I feel that talking about death can bring death closer.	
7. I have a living will, and that means I don't need to talk with my doctor about the care I would want if I were too sick to speak for myself.	Explore patient's beliefs, acknowledge discomfort, explain why it's good to verify. Try saying: "If I have worked with a patient, I usually have some idea of how he or she feels about these decisions, but I appreciate checking with you to make sure I have it right."
8. My ideas about the kind of medical care I want change at different times.	Explain that talking now starts a process of learning for you and your patient. Try saying: "This is a big topic. Some people need time before they know what decisions would be best. Others worry that they might change their mind in the future. Either way, it still helps me to know something about what you think, even if it's not final."
9. I have not felt sick enough to talk with my doctor about end-of-life care.	Encourage patient to be thinking and talking with you about this topic. Try saying: "If I am taking care of a patient, I usually have some idea of how he or she feels about these decisions. But I appreciate checking with you to make sure I have it right."
10. I'm not sure which doctor would be taking care of me if I were to get very sick.	Explain that the patient doesn't need to know which clinician will be caring for him/her at the end of life. Try saying: "Although you may see a lot of doctors and it's hard to know which of us will be there if you get very sick, it's still important to talk with me about these issues. I will document your choices so other doctors have access to this information."

** If no single, most important barrier is endorsed, we will feedback one barrier, chosen at random, of those that were endorsed.

** If no barriers are endorsed, facilitators will be included.

** If no barriers or facilitators are endorsed, use. Explain that talking now starts a process of learning for you and your patient. Try saying: "If I am taking care of a patient, I usually have some idea of how he or she feels about these decisions, but I appreciate checking with you to make sure I have it right."

Item 3 (alternate). **What makes it easier for your patient to talk about this? [facilitators]**

1. I have been very sick so it is easier to talk about this.	Reinforce the helpful effect of previous experiences on patient's decision making. Try saying: "You mentioned on the survey that you have some personal experience with this. Could you tell me how your experience influences your thinking?"
2. I have had family or friends who have died so it is easier to talk about this.	
3. I worry about the quality of my life in the future.	Acknowledge that concerns about quality of life make advance care planning important. Try saying: "You mentioned on the survey that you worry about your quality of life in the future. It would be helpful for me if I understood what you consider to be important for your quality of life."
4. I worry that I could be a burden on my friends and family if I were to become very sick.	Reinforce the idea that advance care planning can reduce the burden on family/friends. Try saying: "It can reduce the burden on your family and friends if you talk with me and with them about the kind of care you would want if you got very sick."

** If no single, most important facilitator endorsed, we will feedback one facilitator, chosen at random, of those that were endorsed.

** If no barriers or facilitators are endorsed, use. Explain that talking now starts a process of learning for you and your patient. Try saying: "If I am taking care of a patient, I usually have some idea of how he or she feels about these decisions, but I appreciate checking with you to make sure I have it right."

Item 4. **In the future: I [want/don't want] CPR**

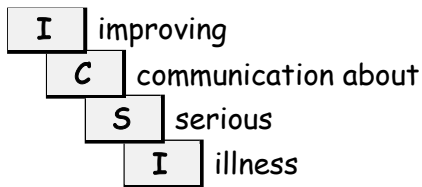
		b. In State of Dependence on Others for ADLs (Confined to Bed)	
		DEFINITELY or PROBABLY WANTS CPR	DEFINITELY or PROBABLY DOES <u>NOT</u> WANT CPR
a. In current state of health	DEFINITELY or PROBABLY WANTS CPR	Confirm patient's desire to receive CPR. Try saying: "You have indicated that you would want to receive CPR if your heart were to stop beating. Is that correct? Are there any other treatments or situations that we should talk about?"	Confirm patient's desire to receive CPR. Try saying: "You have indicated that you would want to receive CPR if your heart were to stop beating in your current state of health, but not if you were to get much sicker and be dependent on others. Is that correct?"
	DEFINITELY or PROBABLY DOES <u>NOT</u> WANT CPR	These responses seem inconsistent. Assess patient's wishes about CPR. Try saying: "You have indicated that you would not want to receive CPR if your heart were to stop beating in your current state of health, but you would want it if you were much sicker and dependent on others. Is that correct? Can you tell me more about that?"	Confirm patient's desire not to receive CPR. Try saying: "You have indicated that you would not want to receive CPR if your heart were to stop beating. Is that correct?" If yes, consider completing a POLST form or a referral to palliative care.

** If there is no information for this section (eg, patient skipped this page), use: "[skipped this page of survey]" or "[skipped this item]" and recommend the following:

Because your patient did not provide any answers to this item/these items, our recommendation is to address this topic in light of the patient's answer about his/her preferences for focusing on extending life or quality of life.

Item 5. **Wrap-up**

Please don't forget to document any discussions you have with the patient in the medical record.



Algorithm for Clinician Version, Jumpstart-Tips Form: Your Patient's Perceptions of Communication and Care

Here's a summary of what your patient, [patient name], endorsed on our questionnaire about goals of care. Your appointment with this patient is coming up on [appointment date]. We're providing this information to help facilitate a discussion about his/her goals of care, both currently and in the event he/she is unable to speak for himself/herself in the future. Feel free to use or adapt these suggestions to your style and your patient.

Is your patient ready to discuss goals of care or end of life wishes/preferences?

- Ever discussed preferences if/when too sick to speak for self?.....YES
- Ever discussed preferences if/when too sick to speak for self?.....NO
- Ever discussed preferences if/when too sick to speak for self?.....DON'T KNOW
- Ever discussed preferences if/when too sick to speak for self?.....[other comment]
- Want to discuss/discuss more?YES
- Want to discuss/discuss more?NO
- Want to discuss/discuss more?DON'T KNOW
- Want to discuss/discuss more?[other comment]

STUDY SUGGESTION: [matrix]

What is your patient's perception of current care? [quality of life (relieving pain/discomfort) versus extending life]

- Prefers to focus on.....EXTENDING LIFE
- Prefers to focus on.....QUALITY OF LIFE
- Prefers to focus on.....NOT SURE
- Perception that care now is focusing onEXTENDING LIFE
- Perception that care now is focusing onQUALITY OF LIFE
- Perception that care now is focusing onNOT SURE

STUDY SUGGESTION: [matrix]

What makes it harder for your patient to talk about this? [barriers]

- "I don't know what kind of care I would want if I were to get very sick."
- "I'm not ready to talk about the care I would want if I were to get very sick."
- "I don't like to talk about getting very sick."
- "My doctor never seems to have the time to talk about issues like end-of-life care."
- "I would rather concentrate on staying alive than talk about death."
- "I feel that talking about death can bring death closer."
- "I have a living will, and that means I don't need to talk with my doctor about the care I would want if I were too sick to speak for myself."
- "My ideas about the kind of medical care I want change at different times."
- "I have not felt sick enough to talk with my doctor about end-of-life care."
- "I'm not sure which doctor would be taking care of me if I were to get very sick."

What makes it easier for your patient to talk about this? [facilitators]

- "I have been very sick, so it is easier to talk about."

- “I have had family or friends who have died, so it is easier to talk about.”
- “I worry about the quality of my life in the future.”
- “I worry that I could be a burden on my friends and family if I were to become very sick.”

What makes it harder or easier for your patient to talk about this? [barriers/facilitators]

- (Your patient did not endorse any of the barriers or facilitators that were presented.)

STUDY SUGGESTION: [matrix]

In the future: [CPR]

In current state of health.....DEFINITELY DOES NOT WANT CPR
 In current state of health.....PROBABLY DOES NOT WANT CPR
 In current state of health.....PROBABLY WANTS CPR
 In current state of health.....DEFINITELY WANTS CPR

In state of dependent on others for ADLsDEFINITELY DOES NOT WANT CPR
 In state of dependent on others for ADLsPROBABLY DOES NOT WANT CPR
 In state of dependent on others for ADLsPROBABLY WANTS CPR
 In state of dependent on others for ADLsDEFINITELY WANTS CPR

STUDY SUGGESTION: [matrix]

Wrap-up and thank you

Thank you for your participation and please remember to document any discussions you have with the patient in the medical record.

I improving
C communication about
S serious
I illness

Algorithm for Patient Jumpstart-Tips Form:

“Getting a jumpstart on your appointment with your doctor.”

Thank you for being in our study. You filled out a questionnaire for us a little while ago. This is a friendly reminder that you will have an appointment with your doctor soon. We want to help you make the most of your appointment

Talking to your doctor about your medical care: It’s easier than you think.

Your doctor is interested in hearing your thoughts and worries about your medical care. The doctor and nurse will be grateful that you are willing to talk. You don’t have to go into lots of detail. Just get the conversation started.

Here are 2 important questions: [Take this sheet of paper in to your appointment!]

1. Could we talk about what I want if something serious were to happen *now* in my current state of health?
2. I am hoping for the best, but I also want to plan for something serious happening *in the future*. Could we talk about that?

If you feel a little nervous . . .

It’s okay! Many people think that the doctor might not have time or might know best—but remember that you are the expert on what is important in your life. So just give these questions a try!

Here is some information from your questionnaire. These are just reminders for you. You can change your mind at any time.

We asked:	<i>Have you talked to your doctor about medical care you would want if you got too sick to speak for yourself?</i>
	You answered: <u>Yes \ No \ I don’t know</u>
We asked:	<i>Would you like to talk about what is important in your medical care if you got too sick to speak for yourself?</i>
	You answered: <u>Yes \ No \ I don’t know</u>
We asked:	<i>Do you prefer that your medical care be more focused on extending life or on quality of life?</i>
	You answered: <u>My priority is on EXTENDING LIFE.</u>
	You answered: <u>My priority is on QUALITY OF LIFE (relieving pain and discomfort).</u>
	You answered: <u>I am NOT SURE</u>
We asked:	<i>Is your current medical care more focused on extending life or on quality of life?</i>
	You answered: <u>Seems focused on EXTENDING LIFE</u>
	You answered: <u>Seems focused on QUALITY OF LIFE (relieving pain and discomfort)</u>
	You answered: <u>I am NOT SURE.</u>
We asked:	<i>Have you thought about whether you would want CPR?</i>
	You answered: If my health were like it is today, I would <u>DEFINITELY NOT WANT CPR.</u>
	You answered: If my health were like it is today, I would <u>PROBABLY NOT WANT CPR.</u>
	You answered: If my health were like it is today, I would <u>PROBABLY WANT CPR.</u>
	You answered: If my health were like it is today, I would <u>DEFINITELY WANT CPR.</u>
	You answered: If I were confined to bed and dependent on others, I’d <u>DEFINITELY NOT WANT CPR.</u>
	You answered: If I were confined to bed and dependent on others, I’d <u>PROBABLY NOT WANT CPR.</u>
	You answered: If I were confined to bed and dependent on others, I’d <u>PROBABLY WANT CPR.</u>
	You answered: If I were confined to bed and dependent on others, I’d <u>DEFINITELY WANT CPR.</u>

We hope this information is useful. Feel free to take this to your appointment—pull it out when you are talking to your doctor or nurse.