Online Appendix for:

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<u>Title</u>: Improving Communication about Goals of Care for Hospitalized Patients with Serious Illness: Study Protocol for Two Complementary Randomized Trials

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Jumpstart Guide: A UW Medicine Program

Your patient has a chronic illness and may benefit from a goals of care conversation.

The PHI below is CONFIDENTIAL. Consider speaking with the patient's family if the patient is unable. It is OK to share this guide with other clinicians.

Your patient: John Doe, MRN: H1234567		
Code Status	Full code	10/15/2019
Advance directive	YES	12/15/2018
DPOA health care	YES	10/20/2018
POLST	NO	

- 1. Give yourself 5-10 minutes. The conversation does not have to be long.
- **2.** Introduce the talk as a routine part of care. Some patients are reluctant—don't start with death or CPR.

"I want to know what's important to you so that we provide the best care to fit your goals. Is that OK?"

3. Pick the best topics for your patient. You don't have to do them all.

Topics	Words to try
Understanding	"What have other doctors told you about how serious your illness is and what to expect?
Acceptable states	"What abilities are so important to you that you can't imagine living without them?"
Values	"If you were to get sicker, what would be most important to you?

4. Document a short note A brief summary and a quote (a few of the patient's or their family member's words) are enough. Your colleagues will appreciate it.

Your patient has a chronic illness and may benefit from a goals of care conversation.

The PHI below is CONFIDENTIAL. Consider speaking with the patient's family if the patient is unable. It is OK to share this guide with other clinicians.

Your patient	: John Doe, MRN: H	1234567
Code Status	Full code	10/15/2019
Advance directive	YES	12/15/2018
DPOA health care	YES	10/20/2018
POLST	NO	

- 1. Give yourself 5-10 minutes. The conversation does not have to be long.
- 2. Your patient completed a survey about their goals and preferences. Pick the best topics for your patient based on their responses. You don't have to do them all.
- **3.** Document a short note. A brief summary and a quote (a few of the patient's words) are enough. Your colleagues will appreciate it.

From your patient's survey:

- They did not indicate if they want to talk about goals of care.
- Your patient reported a barrier to talking about their goals: they have a living will and think this means they don't need to talk with their doctor about goals of care.
- They did not indicate how they perceive the current focus of care, and they are unsure of their preferences.
- They did not indicate if they want CPR in current health and did not indicate if they would want CPR if in a state of dependence for ADLs.

Words to try:

"You mentioned in your survey that now may not be the best time to talk about the care you would want if you got sicker. These conversations can be difficult, but could you tell me more about why you don't want to talk about it now?"

"Although it is hard to know which doctors will be there if you get very sick, it is still helpful for us to talk about it. I will document our conversation in your chart to ensure other doctors also know what is important to you in the future."

"Some people prefer care focused on extending life as much as possible; other people prefer care focused on quality of life and comfort. Would it be helpful for me to clarify how I see the focus of your care?"

"You said you currently would want to receive CPR if your heart were to stop beating and you were to die, but NOT if you were to get much sicker and be dependent on others. Is that correct? [If yes] After CPR, what quality of life would you find acceptable?"

Jumpstart Guide: A UW Medicine Program

Your doctor is interested in hearing your thoughts about your medical care and what is important to you. You can show this guide to your doctor to help start a conversation.

We encourage you to bring up two important topics:

- 1. The care you would want if something more serious were to happen *now*.
- 2. The care you would want if something more serious were to happen in the future.

Here is information from your survey. PATIENT NAME, you said:

- You were not sure if you prefer medical care focused on living as long as possible or being as comfortable as possible.
- You did not provide a response regarding what you perceive is the current focus of the medical care you're receiving.
- You did not provide a response about whether, in your current health state, you would want CPR if your heart were to stop beating and you were to die.
- You did not provide a response about whether, if you were to be permanently confined to bed and dependent on others, you would want CPR if your heart were to stop beating and you were to die.

Here's language you can use to start a conversation with your doctor:

- "Can we talk about medical care focused on being as comfortable as possible compared to medical care focused on living as long as possible? I'm not sure which focus I prefer."
- "Is my current medical care more focused on living as long as possible or being as comfortable as possible? Can we talk about whether that is the right focus for me?"
- "I don't think I would want CPR. Can we talk about that? Should I complete a POLST form or advance directive?"
- "I don't think I would want CPR in the future if I were dependent on others for the rest of my life. Can we talk about that?"

Thank you for using the Jumpstart Guide. We hope this information is helpful.

Jumpstart Guide: A UW Medicine Program

Your family member's doctor here at the hospital is interested in hearing what is most important to PATIENT NAME regarding their medical care. Thank you for being their advocate. You can show this guide to the doctor to help start a conversation.

We encourage you to bring up two important topics with the doctor:

- 1. The care your family member would want if something more serious were to happen *now*.
- 2. The care your family member would want if something more serious were to happen *in the future*.

Here is information from your survey. SURROGATE NAME, you said:

- You were not sure if your family member prefers medical care focused on living as long as possible or being as comfortable as possible.
- You did not provide a response regarding what you perceive is the current focus of the medical care your family member is receiving.
- You did not provide a response about whether, in your family member's current health state, they would want CPR if their heart were to stop beating and they were to die.
- You did not provide a response about whether, if your family member were to be permanently confined to bed and dependent on others, they would want CPR if their heart were to stop beating and they were to die.

Here's language you can use to start a conversation with the doctor:

- "Can we talk about medical care focused on being as comfortable as possible compared to medical care focused on living as long as possible? I'm not sure which focus my family member prefers."
- "Is my family member's current medical care more focused on living as long as possible or being as comfortable as possible? Can we talk about whether that is the right focus for them?"
- "I don't think my family member would want CPR. Can we talk about that? Should we complete a POLST form?"
- "I don't think my family member would want CPR in the future if they were dependent on others for the rest of their life. Can we talk about that?"

Thank you for using the Jumpstart Guide. We hope this information is helpful.

Baseline Survey Part 1 (all study arms)



A Project to Improve Communication About Serious Illness

Thank you for participating in our study to improve communication among doctors, their patients, and patients' families. By improving communication we hope we will help patients receive the care they want.

The questions in this booklet ask you about a number of topics. Some are about discussions you may have had with your doctors, some are about your feelings, and others ask for general information about you so that we might understand more about the people who are participating in this study.

Because many people will be answering these questions, some questions may not apply to you. Please feel free to skip any questions that you do not want to answer or that you feel do not apply to you. Also, some of the questions may seem quite similar. Because we are using questions from different instruments (survey tools), this happens occasionally. We appreciate your patience going through all the questions, even if they seem similar.

All of your answers are confidential.

If you have questions, a member of our research staff would be glad to answer them. We may be reached in our study office: (206) 537-6246.

1

Thank you very much. We appreciate your participation.

 Please fill in today's date:
 _____ / ____ /____

 Month
 Day
 Year

ABOUT YOU

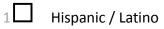
To begin, we would like to ask a few questions about you. These questions help us describe the people who are participating in the study.

- **1.** What is your <u>current</u> marital status? (Mark one box)
 - Single or never married
 - Married or living with partner
 - 2 Divorced or separated
 - 3 Widowed
- **2.** How much education have you completed? (Mark one box)
 - 0 8th grade or less
 - 1 Some high school
 - 2 High school diploma or GED
 - 3 Some college or trade school
 - 4 4-year college degree (for example, BA or BS)
 - 5 Some graduate school
 - 6 Graduate degree (for example, MA, MS, PhD, MD)

3. Which race(s) do you belong to? (Mark ALL that apply)

1	Asian
1	Black or African-American
1	Native American / Alaska Native
1	Native Hawaiian / Samoan / Pacific Islander
1	White
1	Other: please specify

4. What is your ethnicity? (Mark one box)



- 0 Non-Hispanic / Non-Latino
- 5. In general, would you say your health has been: (*Mark one box*)

0	Excellent
1	Very good
2	Good
3	Fair
4	Poor

		Not at all	Several Days	Most Days	Nearly Every Day
6. Feeling nervo edge	us, anxious or on	0	1	2	3
7. Not being able worrying	e to stop or control	0	1	2	3
8. Feeling down, hopeless	depressed, or	0	1	2	3
9. Little interest doing things	or pleasure in	0	1	2	3

Over the LAST WEEK, how often have you been bothered by the following problems?

10. Without giving exact dollar amounts, how would you describe your household's financial

situation right now? (Mark one box)

- 0 I have difficulty paying the bills no matter what I do
- 1 I have enough money to pay the bills, but only because I have cut back on things
- 2 I have enough money to pay the bills, but little spare money to buy extra or special things
- 3 After paying the bills, I still have enough money for special things that I want

YOUR FEELINGS

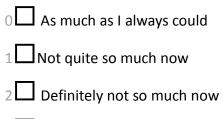
Mark the box of the answer that best describes how you have been feeling during the LAST WEEK. Don't think too long over your replies; your immediate answer is best.

1. I feel tense or 'wound up':

	3 Most of the time
	2 🗖 A lot of the time
	1 From time to time, occasionally
	0 🔲 Not at all
2. I still enjoy t	he things I used to enjoy:
	0 Definitely as much
	1 Not quite so much
	2 Only a little
	3 Hardly at all

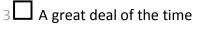
- 3. I get a sort of frightened feeling as if something awful is about to happen:
 - 3 Very definitely and quite badly
 - 2 Yes, but not too badly
 - $1 \square$ A little, but it doesn't worry me
 - 0 Not at all

4. I can laugh and see the funny side of things:



3 🔲 Not at all

5. Worrying thoughts go through my mind:



2 A lot of the time

1 From time to time, but not too often

0 Only occasionally

6. I feel cheerful:



0 Most of the time

- 7. I can sit at ease and feel relaxed:
 - 0 Definitely
 - 1 Usually
 - 2 Not often
 - 3 Not at all

8. I feel as if I am slowed down:

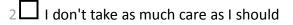


9. I get a sort of frightened feeling like 'butterflies' in the stomach:

0	Not at all
1	Occasionally
2	Quite Often
3	Very Often

10. I have lost interest in my appearance:





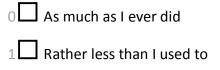
1 I may not take quite as much care

0 I take just as much care as ever

11. I feel restless as if I have to be on the move:

- 3 Very much indeed
- 2 Quite a lot
- 1 Not very much
- 0 Not at all

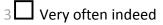
12. I look forward with enjoyment to things:

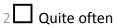


2 Definitely less than I used to

3	Hardly at all
-	i nanany ac an

13. I get sudden feelings of panic:





1 Not very often

0 Not at all

14. I can enjoy a good book or radio or TV program:



1 Sometimes

- 2 Not often
- 3 Very seldom

TALKING ABOUT HEALTH CARE

These questions are about discussions you have had with your doctors concerning the medical care you would want if you were too sick to speak for yourself. These discussions might include whether you would want to receive care such as ICU care, CPR or breathing machines, a nursing home, or hospice care.

1. BEFORE this hospitalization, have you ever discussed with a doctor the kind of medical care you would want if you were too sick to speak for yourself? (*Mark one box*)

1	Yes
0	No
9	I don't know

2. DURING this hospitalization, have you discussed with any of your doctors the kind of medical care you would want if you were too sick to speak for yourself? (*Mark one box*)

1	Yes
0	No
9	I don't know

Thank you for taking time to complete this survey.

If you have any comments, please feel free to add them to the space below, or call

(206) 537-6246 to talk with our study team. Thank you again for your help.

Additional comments (optional):



STOP HERE.

The research coordinator will let you know if you need to complete any remaining items in the questionnaire.

Baseline Survey Part 2 (Bi-directional Jumpstart arm)

CHOOSING CARE

We are interested in the kind of care you prefer and the kind of care you are now receiving.

1. If you had to make a choice at this time, would you prefer a plan of medical care that focuses on extending life, even if it means having more pain and discomfort, or would you want a plan of medical care that focuses on relieving your pain and discomfort as much as possible, even if that means not living as long? (Mark one box)



Extending life, even if it means having more pain and discomfort



Relieving pain and discomfort as much as possible, even if that means not living as long



- I'm not sure which I would choose
- 2. Using those same categories, which of the following best describes the focus of the medical **care you are currently receiving?** (Mark one box)



- Extending life, even if it means having more pain and discomfort
- Relieving pain and discomfort as much as possible, even if that means not living as long



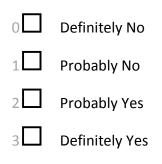
- I don't know, not sure
- 3. Do you think that your current medical care is in line with your goals? (Mark one box)
 - 0 Not at all
 - Mostly not
 - Somewhat
 - Mostly
 - Completely
- 4. Have you ever thought about what kinds of life-sustaining treatments you would want, or **not want, if you got a lot sicker?** (Mark one box)



These next questions are about your preferences about CPR, a procedure that is administered if a person's heart stops. CPR, or cardiopulmonary resuscitation, consists of electric shocks to the heart, pumping on the chest, and help with breathing. It is important to realize that, for most people, CPR doesn't work and they do not survive the attempt of CPR.

5. In your current health, would you want CPR if your heart were to stop beating? (Mark one

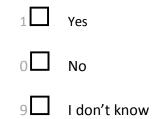
box)



6. If you were permanently confined to bed and <u>dependent on others</u> for all your care, would you want CPR if your heart were to stop? (*Mark one box*)

0	Definitely No
1	Probably No
2	Probably Yes
3	Definitely Yes

7. Would you like to have a discussion with any of your hospital doctors about the medical care you would want if you became too sick to speak for yourself? (This discussion might include whether you would want to receive care such as ICU care, CPR or breathing machines, a nursing home, or hospice care.)



TALKING ABOUT CARE: WHAT MAKES TALKING HARDER?

Which, if any, of the following reasons might make it hard for you to talk with any of your doctors about care you would choose if you were too sick to speak for yourself?

	Barriers	Yes, this applies to me (True)	No, this does not apply to me (False)
1.	I don't know what kind of care I would want if I were too sick to speak for myself.	1	0
2.	I'm not ready to talk about the care I would want if I were too sick to speak for myself.	1	0
3.	I don't like to talk about getting very sick.	1	0
4.	My doctor never seems to have the time to talk about issues like end-of- life care.	1	0
5.	I would rather concentrate on staying alive than talk about death.	1	0
6.	I feel that talking about death can bring death closer.	1	0
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.	1	0
8.	I'm not sure which doctor would be taking care of me if I were too sick to speak for myself.	1	0
9.	My ideas about the kind of medical care I want change at different times.	1	0
10	. I have <u>not</u> felt sick enough to talk with my doctor about end-of- life care.	1	0
11	. If any of these reasons apply to you, which ONE is the <u>main</u> <u>reason</u> that it is hard to talk with your doctor about care you might choose if you were too sick to speak for yourself? <i>Please</i> <i>fill in the number of that item in this box.</i>		

TALKING ABOUT CARE: WHAT MAKES TALKING EASIER?

People also have reasons for wanting to talk about care they might choose if they were to become too sick to speak for themselves. Which, if any, of the following reasons might make you *want* to discuss care choices with any of your doctors?

Facilitators	Yes, this applies to me (True)	No, this does not apply to me (False)
1. I have been very sick in the past, so it is easier to talk about.	1	0
2. I have had family or friends who have died, so it is easier to talk about.	1	0
3. I worry about the quality of my life in the future.	1	0
4. I worry I could be a burden on my friends and family if I were to become too sick to speak for myself.	1	0
5. If any of these reasons apply to you, which ONE is the <u>main</u> <u>reason</u> that it is easier to talk with your doctor about care you might choose? <i>Please fill in the number of that item in this box.</i>		

Thank you for taking time to complete this survey.

If you have any comments, please feel free to add them to the space below, or call

(206) 537-6246 to talk with our study team. Thank you again for your help.

Additional comments (optional): _____

Timepoint 2 Survey for All Arms



A Project to Improve Communication About Serious Illness

Thank you for your continuing participation in our study to improve communication among doctors, their patients, and patients' families. As you may recall, we hope that by improving communication we will help patients receive the care they want.

Like the questionnaire that you completed a few days ago, this survey has questions about your experiences in the hospital, your preferences for care and your overall health. Some of these are ones that you may have answered before.

Because many people will be answering these questions, some questions may not apply to you. Please feel free to skip any questions that you do not want to answer or that you feel do not apply to you. All your answers are confidential.

If you have questions or need assistance to complete this survey, a member of our research staff would be glad to help you. We may be reached at our study office: (206) 537-6246.

1

Thank you very much. We appreciate your participation.

Please fill in today's date:	/		/
	Month	Day	Year

TALKING ABOUT HEALTH CARE

These questions are about discussions you have had with your doct	ors concerning the medical care		
you would want if you were too sick to speak for yourself. These discussions might include whether			
you would want to receive care such as ICU care, CPR or breathing r	nachines, a nursing home, or		
hospice care. YOU ENROLLED IN OUR STUDY ON (while you were in the hospital),			
and we are particularly interested in discussions you have had SINCE THAT TIME.			

1. SINCE JOINING OUR STUDY, have you discussed with any of your doctors the kind of medical care you would want if you were too sick to speak for yourself? (*Mark one box*)

1	Yes
0	No \rightarrow Go to question 2
9	I don't know \rightarrow Go to question 2
\rightarrow 1b. To what extent did th	ese discussions with the doctor meet your needs for information
about your medical c	are? (Mark one box)
0	None of my needs were met
1	A few of my needs were met
2	Many of my needs were met
3	Most of my needs were met
4	All of my needs were met
2. Would you like to have a d	iscussion or additional discussions of this type with one of your
doctors? (Mark one box)	
1	Voc

1	Yes
0	No
9	I don't know

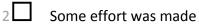
2

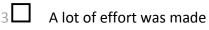
Whether or not you have had discussions of this type with your doctors, how much effort was made by your doctors and other members of your healthcare team to:

3. Help you understand your health issues? (Mark one box)



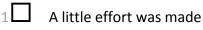
- No effort was made
- A little effort was made





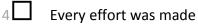
- 4 Every effort was made
- 4. Listen to the things that matter most to you about your health issues? (Mark one box)







3 A lot of effort was made

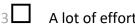


5. Include what matters most to you in choosing what to do next? (Mark one box)



- No effort was made
- 1 A little effort was made





A lot of effort was made

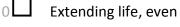


Every effort was made

CHOOSING CARE

We are interested in the kind of care you prefer and the kind of care you are now receiving.

1. If you had to make a choice at this time, would you prefer a plan of medical care that focuses on extending life, even if it means having more pain and discomfort, or would you want a plan of medical care that focuses on relieving your pain and discomfort as much as possible, even if that means not living as long? (Mark one box)



Extending life, even if it means having more pain and discomfort



Relieving pain and discomfort as much as possible, even if that means not living as long



- I'm not sure which I would choose
- 2. Using those same categories, which of the following best describes the focus of the medical **care you are currently receiving?** (Mark one box)



- Extending life, even if it means having more pain and discomfort
- Relieving pain and discomfort as much as possible, even if that means not living as long



- I don't know, not sure
- 3. Do you think that your current medical care is in line with your goals? (Mark one box)
 - 0 Not at all
 - Mostly not
 - Somewhat
 - Mostly
 - Completely
- 4. Have you ever thought about what kinds of life-sustaining treatments you would want, or **not want, if you got a lot sicker?** (Mark one box)



These questions are about CPR, or cardiopulmonary resuscitation, a procedure that is administered if a person's heart stops. CPR consists of electric shocks to the heart, pumping on the chest, and help with breathing. It is important to realize that, for most people, CPR doesn't work.

5. In your current health, would you want CPR if your heart were to stop beating? (Mark one

box)

- Definitely No
 Probably No
 Probably Yes
 Definitely Yes
- 6. If you were permanently confined to bed and <u>dependent on others</u> for all your care, would you want CPR if your heart were to stop? (*Mark one box*)

0	Definitely No
1	Probably No
2	Probably Yes
3	Definitely Yes

HOW WELL DID THE DOCTOR TALK TO YOU?

We know that many people think very highly of their doctors. To help us improve communication between doctors and patients, please be critical. If you cannot rate your doctor on a question because he or she has not done it, please select, "My doctor has not done this." You may also indicate, "I do not know."

Thinking of ONE of your doctors caring for you SINCE you enrolled in our study on _____,

how good was he or she at: (mark one box for each item)

		The wor coul ima	ld								The st I co imag	buld	My doctor has not done this	l do not know
		0	1	2	3	4	5	6	7	8	9	10	888	999
1.	Talking with you about your													
	feelings concerning the													
	possibility that you might get													
	sicker?													
2.	Talking with you about the													
	details concerning the													
	possibility that you might get													
	sicker?													
3.	Involving you in the decisions													
	about the treatments that you													
	want if you get too sick to				ш	ш								
	speak for yourself?													
4.	Asking about the things in life													
	that are important to you?											<u> </u>		

5. How much do you agree or disagree with the following statement:

"The discussions I had with my doctor covered all of the important topics that needed to be discussed." (*Mark one box*)

1	Strongly disagree
2	Disagree
3	Neither agree nor disagree
4	Agree
5	Strongly agree
888	Does not apply to me; no discussion with the doctor occurred

6. How satisfied are you with the quality of the conversations your doctor had with you?

(Mark one box)

1	Extremely dissatisfied
2	Dissatisfied
3	Neither satisfied nor dissatisfied
4	Satisfied
5	Extremely satisfied
888	Does not apply to me; no discussion with the doctor occurred

7. How would you rate the overall helpfulness of your discussions with your doctor? (*Mark one box*)

1	Poor (several needed topics were not covered or were covered poorly)
2	Fair
3	Good
4	Very good
5	Outstanding (couldn't have been better)
888	Does not apply to me; no discussion with the doctor occurred

8. What overall rating would you give the discussions you had with your doctor? (Mark one

box)

- 1 Poor (several needed topics were not covered or were covered poorly)
- 2 Fair
- 3 Good
- 4 Very good
- 5 Outstanding (couldn't have been better)
- 888 Does not apply to me; no discussion with the doctor(s) occurred

YOUR HEALTH NOW

1. In general, would you say your health is: (Mark one box)

0	Excellent					
1	Very good					
2	Good					
3	Fair					
4	Poor					

2. How much of a burden on you was it to complete this questionnaire, on a scale where 0 means "no burden at all" and 10 means "a very great burden"? (*Mark one box*)

No burde at all	n								great	A very burden
0	1	2	3	4	5	6	7	8	9	10

Thank you for taking time to complete this survey. If you have any comments, please feel free to add them to the space below, or call (206) 537-6246 to talk with our study team. Thank you again for your help.

Additional comments (optional): _____