

# **Advance Care Planning Engagement Survey**

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\*Additional analysis concerning the validation of the shorter versions of the survey in English and Spanish are currently underway. Please check on back the [www.prepareforyourcare.org](http://www.prepareforyourcare.org) website in early 2019 for updated results and instructions for how to use these surveys.

## Instructions for Use

The Advance Care Planning (ACP) Engagement Survey has been validated and used in several ACP studies. Several shortened versions of the survey have also been validated including the original 82-item version and a 55-item, 34-item, 15-item, 9-item, and 4-item version.

### References:

- (1) Development and validation of a questionnaire to detect behavior change in multiple advance care planning behaviors. Sudore RL, Stewart AL, Knight SJ, McMahan RD, Feuz M, Miao Y, Barnes DE. PLoS One. 2013 Sep 5;8(9):e72465. doi: 10.1371/journal.pone.0072465. eCollection 2013. PMID: 24039772
- (2) Measuring engagement in advance care planning: a cross-sectional multicentre feasibility study. Howard M, Bonham AJ, Heyland DK, Sudore R, Fassbender K, Robinson CA, McKenzie M, Elston D, You JJ. BMJ Open. 2016 Jun 23;6(6):e010375. doi: 10.1136/bmjopen-2015-010375. PMID:27338877
- (3) Measuring Advance Care Planning: Optimizing the Advance Care Planning Engagement Survey. Sudore RL, Heyland DK, Barnes DE, Howard M, Fassbender K, Robinson CA, Boscardin J, You JJ. J Pain Symptom Manage. 2017 Apr;53(4):669-681.e8. doi: 10.1016/j.jpainsymman.2016.10.367. Epub 2016 Dec 29. PMID: 28042072
- (4) Improving a Full Range of Advance Care Planning Behavior Change and Action Domains: The PREPARE Randomized Trial. Lum, HD, Barnes DE, Katen MT, Shi, Ying, Boscardin, J, Sudore, RL. Journal of pain and symptom management. 2018 Oct; 56(4): 575-581. doi: 10.1016/j.jpainsymman.2018.06.007 PMID: 29940209

## SURVEY SCORING FOR THE FULL 82-ITEM SURVEY VERSION:

The 82-item version of the survey has both Behavior Change Process measures and Action measures. Please see Table 1: of the Survey items on the next page. This table provides the questions, identifies the question as either in the Process or Action domain, and lists sub-domains.

- **The Behavior Change Process items** use a 5-point Likert response option. The Behavior Change Process score is reported as an overall average 5-point Likert score.
  - The Behavior Change Process measure has validated sub-scales of knowledge (“How much do you know...”, contemplation (“How much have you thought about...”), self-efficacy (“How confident are you...”, and readiness (“How ready are you...”. These sub-scales can also be reported separately as average 5-point Likert scales.
- **The Action items** use a dichotomous response option of yes or no. There are 25 items within the sub-domains of medical decisions makers, quality of life and health situations, flexibility for the medical decision makers, and asking medical providers questions. Therefore, the Action score is reported on a 0 to 25-point scale.

Please see the following reference for how these scales have been used in longitudinal randomized trials with repeated measures:

- (5) [Effect of the PREPARE Website vs an Easy-to-Read Advance Directive on Advance Care Planning Documentation and Engagement Among Veterans: A Randomized Clinical Trial.](#)

Sudore RL, Boscardin J, Feuz MA, McMahan RD, Katen MT, Barnes DE.

JAMA Intern Med. 2017 Aug 1;177(8):1102-1109. doi: 10.1001/jamainternmed.2017.1607. PMID: 28520838

**See below for scoring shorter versions of the survey, and additional potential analyses of the Readiness questions.**

## SCORING SHORTER SURVEY VERSIONS (55, 34, 15, 9, AND 4-ITEM VERSIONS):

All shorter versions of the survey use questions from the Behavior Change Process measure. All items use 5-point Likert response options. The Action items, after extensive analysis, were dropped (see reference #3). We suggest you continue to report these shorter versions on an average 5-point Likert scale.

## ADDITIONAL POTENTIAL ANALYSIS OF THE READINESS QUESTIONS:

Each version of the Survey contains Readiness questions. The 4-item version is exclusively made up of Readiness items. The Likert response options for the Readiness questions were adapted from Fried et al. and were expanded for use for all ACP behaviors in the ACP Engagement Survey.

- (6) [Stages of change for the component behaviors of advance care planning](#). Fried TR, Redding CA, Robbins ML, Paiva A, O'Leary JR, Iannone L. J Am Geriatr Soc. 2010 Dec;58(12):2329-36. doi: 10.1111/j.1532-5415.2010.03184. PMID: 21143441

These response options allow the Readiness items to be reported as an average 5-point Likert score, to be dichotomized into a yes or no action item for each ACP behavior, and to categorize participants into behavior change stages for each ACP Behavior.

The Readiness response options:	Behavior Change Stage	Dichotomize yes/no completed the action
I have never thought about it.	Pre-contemplation	No
I have thought about it, but I am not ready to do it.	Pre-contemplation	No
I am thinking about doing it in the next 6 months.	Contemplation	No
I am definitely planning to do it in the next 30 days.	Preparation	No
I have already done it.	Action	Yes
Timing questions (see below)	Maintenance (see below)	

We typically report the percentage of participants who have moved out of pre-contemplation to higher behavior change stages. See the following reference. It is possible to also report the percentage of individuals who moved into any higher stage from baseline, for example, from pre-contemplation to preparation and/or from preparation to action.

- (7) [A novel website to prepare diverse older adults for decision making and advance care planning: a pilot study](#). Sudore RL, Knight SJ, McMahan RD, Feuz M, Farrell D, Miao Y, Barnes DE. J Pain Symptom Manage. 2014 Apr;47(4):674-86. doi: 10.1016/j.jpainsymman.2013.05.023. Epub 2013 Aug 21. PMID: 23972574

### **OPTIONAL:** Timing question to categorize the “Maintenance” behavior stage

It is possible to separate out the Action behavior stage into both an “Action” and “Maintenance” stage by asking about the timing of these ACP actions. If the participant completed the ACP behavior within 6 months they are considered in the “Action” stage, and if they completed the ACP behavior greater than 6 months ago, they are considered in the “Maintenance” stage for that behavior.

Here is one example:

How ready are you to sign official papers naming a person or group of people to make medical decisions for you?

	I have never thought about it.
	I have thought about it, but I am not ready to do it.
	I am thinking about doing it in the next 6 months.
	I am definitely planning to do it in the next 30 days.
X	I have already done it.

**OPTIONAL:** If they answered, “I have already done it,” then ask “When did you do this?”

-Less than 6 months ago (→Action stage)

-More than 6 months ago (→Maintenance stage)

These optional timing questions are marked in blue in the following surveys. The timing questions are not included in the average 5-point Likert scores. They are only asked to be able to further delineate Action into both Action and Maintenance stages.

**Table 1: Original ACP Engagement Survey and Questions Retained in Progressively Shorter Versions After Item Reduction**

Question # <sup>a</sup>	Sub-Scale	Type	Original 82-item Questionnaire	Versions				
				55 items	34 Items	15 items	9 items	4 items
DOMAIN: MEDICAL DECISION MAKER								
1	Knowledge <sup>b</sup>	Process	How well informed are you about who can be a medical decision maker?	X				
2	Knowledge	Process	How well informed are you about what makes someone a good medical decision maker?	X	X			
3	Knowledge	Process	How well informed are you about the types of decisions that a medical decision maker may have to make for you in the future?	X	X			
4	Contemplation <sup>c</sup>	Process	How much have you thought about who your medical decision maker should be?	X	X			
5	Contemplation	Process	How much have you thought about asking someone to be your medical decision maker?	X				
6	Contemplation	Process	How much have you thought about talking with your doctors about who you want your medical decision maker to be?	X				
7	Contemplation	Process	How much have you thought about talking with your other family and friends about who you want your medical decision maker to be?	X				
8	Self- Efficacy <sup>d</sup>	Process	How confident are you that today you could ask someone to be your medical decision maker?	X	X	X	X	
9	Self- Efficacy	Process	How confident are you that today you could talk with your doctor about who you want your medical decision maker to be?	X	X			
10	Self- Efficacy	Process	How confident are you that today you could talk with your other family and friends about who you want your medical decision maker to be?	X	X			
11 <sup>a</sup>	Decision	Action	Have you already decided who you want your medical decision maker to be?					
12 <sup>a</sup>	Readiness <sup>e</sup>	Process	How ready are you to decide who you want your medical decision maker to be?					
13 <sup>a</sup>	Action <sup>f</sup>	Action	Have you already formally asked someone to be your medical decision maker?					
14	Readiness	Process	How ready are you to formally ask someone to be your medical decision maker?	X	X	X	X	
15 <sup>a</sup>	Action	Action	Have you talked with your doctor about who you want your medical decision maker to be?					
16	Readiness	Process	How ready are you to talk with your doctor about who you want your medical decision maker to be?	X	X	X	X	
17 <sup>a</sup>	Action	Action	Have you already talked to your other family and friends about who you want your medical decision maker to be?					

18	Readiness	Process	How ready are you to talk to your other family and friends about who you want your medical decision maker to be?	X	X			
19 <sup>a</sup>	Action	Action	Have you signed official papers naming a person or group of people to make medical decisions for you?					
20	Readiness	Process	How ready are you to sign official papers naming a person or group of people to make medical decisions for you?	X	X	X	X	X
<b>DOMAIN: QUALITY OF LIFE – HEALTH SITUATIONS</b>								
21	Contemplation	Process	How much have you thought about whether or not certain health situations would make your life not worth living?	X				
22	Contemplation	Process	How much have you thought about talking with your medical decision maker about whether or not certain health situations would make your life not worth living?	X				
23	Contemplation	Process	How much have you thought about talking with your doctor about whether or not certain health situations would make your life not worth living?	X				
24	Contemplation	Process	How much have you thought about talking with your other family and friends about whether or not certain health situations would make your life not worth living?	X				
25	Self- Efficacy	Process	How confident are you that today you could talk with your medical decision maker about whether or not certain health situations would make your life not worth living?	X	X			
26	Self- Efficacy	Process	How confident are you that today you could talk with your doctor about whether or not certain health situations would make your life not worth living?	X	X			
27	Self- Efficacy	Process	How confident are you that today you could talk with your other family and friends about whether or not certain health situations would make your life not worth living?	X	X			
28 <sup>a</sup>	Decision	Action	Have you already decided whether or not certain health situations would make your life not worth living?					
29	Readiness	Process	How ready are you to decide whether or not certain health situations would make your life not worth living?	X	X			
30 <sup>a</sup>	Action	Action	Have you talked with your decision maker about whether or not certain health situations would make your life not worth living?					
31	Readiness	Process	How ready are you to talk to your decision maker about whether or not certain health situations would make your life not worth living?	X	X			
32 <sup>a</sup>	Action	Action	Have you talked with your doctor about whether or not certain health situations would make your life not worth living?					
33	Readiness	Process	How ready are you to talk to your doctor about whether or not certain health situations would make your life not worth living?	X	X			

34 <sup>a</sup>	Action	Action	Have you talked with your other family and friends about whether or not certain health situations would make your life not worth living?					
35	Readiness	Process	How ready are you to talk to your other family and friends about whether or not certain health situations would make your life not worth living?	X	X			
36 <sup>a</sup>	Action	Action	Have you signed official papers to put your wishes in writing about whether or not certain health situations would make your life not worth living? These forms are sometimes called an advance directive or living will.					
37	Readiness	Process	How ready are you to sign official papers putting your wishes in writing about whether or not certain health situations would make your life not worth living?	X				
<b>DOMAIN: QUALITY OF LIFE – MEDICAL CARE AT THE END OF LIFE</b>								
38	Contemplation	Process	How much have you thought about the care you would want if you were very sick or near the end of life?	X				
39	Contemplation	Process	How much have you thought about talking with your medical decision maker about the care you would want if you were very sick or near the end of life?	X				
40	Contemplation	Process	How much have you thought about talking with your doctors about the care you would want if you were very sick or near the end of life?	X				
41	Contemplation	Process	How much have you thought about talking with your other family and friends about the care you would want if you were very sick or near the end of life?	X	X			
42	Self- Efficacy	Process	How confident are you that today you could talk with your medical decision maker about the care you would want if you were very sick or near the end of life?	X	X	X	X	
43	Self- Efficacy	Process	How confident are you that today you could talk with your doctor about the care you would want if you were very sick or near the end of life?	X	X	X	X	
44	Self- Efficacy	Process	How confident are you that today you could talk with your other family and friends about the care you would want if you were very sick or near the end of life?	X	X			
45 <sup>a</sup>	Decision	Action	Have you already decided on the medical care you would want if you were very sick or near the end of life?					
46	Readiness	Process	How ready are you to decide on the medical care you would want if you were very sick or near the end of life?	X	X			
47 <sup>a</sup>	Action	Action	Have you talked with your decision maker about what kind of medical care you would want if you were very sick or near the end of life?					
48	Readiness	Process	How ready are you to talk to your decision maker about the kind of medical care you would want if you were very sick or near the end of life?	X	X	X	X	X



49 <sup>a</sup>	Action	Action	Have you ever talked with your doctor about what kind of medical care you want if you were very sick or near the end of life?					
50	Readiness	Process	How ready are you to talk to your doctor about the kind of medical care you would want if you were very sick or near the end of life?	X	X	X	X	X
51 <sup>a</sup>	Action	Action	Have you ever talked with your other family and friends about what kind of medical care you want if you were very sick or near the end of life?					
52	Readiness	Process	How ready are you to talk to your other family and friends about the kind of medical care you would want if you were very sick or near the end of life?	X	X			
53 <sup>a</sup>	Action	Action	Have you signed official papers to put your wishes in writing about the kind of medical care you would want if you were very sick or near the end of life? These forms are sometimes called an advance directive or living will.					
54	Readiness	Process	How ready are you to sign official papers putting your wishes in writing about the kind of medical care you would want if you were very sick or near the end of life?	X	X	X	X	X
<b>DOMAIN: FLEXIBILITY FOR SURROGATE DECISION MAKING</b>								
55	Knowledge	Process	How well informed are you about what it means to give a medical decision maker flexibility to make future decisions?	X				
56	Knowledge	Process	How well informed are you about the different amounts of flexibility a person can give their medical decision maker?	X				
57	Contemplation	Process	How much have you thought about the amount of flexibility you would want to give your medical decision maker?	X				
58	Contemplation	Process	How much have you thought about talking with your medical decision maker about how much flexibility you want to give them?	X	X			
59	Contemplation	Process	How much have you thought about talking with your doctor about how much flexibility you want to give your decision maker?	X				
60	Contemplation	Process	How much have you thought about talking with other friends and family about how much flexibility you want to give your decision maker?	X				
61	Self-Efficacy	Process	How confident are you that today you could talk with your decision maker about how much flexibility you want to give them?	X		X		
62	Self-Efficacy	Process	How confident are you that today you could talk with your doctor about how much flexibility you want to give your medical decision maker?	X	X	X		
63	Self-Efficacy	Process	How confident are you that today you could talk with your other family and friends about how much flexibility you want to give your medical decision maker?	X	X			
64 <sup>a</sup>	Decision	Action	Have you decided how much flexibility you would want to give a medical decision maker if they have to make decisions on your behalf (meaning for you)?					

65 <sup>a</sup>	Readiness	Process	How ready are you to decide how much flexibility you would want to give a medical decision maker if they have to make decisions on your behalf?					
66 <sup>a</sup>	Action	Action	Have you talked with your medical decision maker about how much flexibility you want to give them?					
67	Readiness	Process	How ready are you to talk to your decision maker about how much flexibility you want to give them?	X	X	X		
68 <sup>a</sup>	Action	Action	Have you talked with your doctor about how much flexibility you want to give your medical decision maker?					
69	Readiness	Process	How ready are you to talk to your doctor about how much flexibility you want to give your decision maker?	X	X	X		
70 <sup>a</sup>	Action	Action	Have you already talked to your other family and friends about how much flexibility you want to give your medical decision maker?					
71	Readiness	Process	How ready are you to talk to your other family and friends about how much flexibility you want to give your medical decision maker?	X				
72 <sup>a</sup>	Action	Action	Have you signed official papers to put your wishes in writing about how much flexibility to give your decision maker?					
73	Readiness	Process	How ready are you to sign official papers putting your wishes in writing about how much flexibility to give your decision maker?	X	X			
<b>DOMAIN: ASKING QUESTIONS OF MEDICAL PROVIDERS</b>								
74	Knowledge	Process	How well informed are you about the types of questions you can ask your doctor that will help you make a good medical decision?	X				
75	Contemplation	Process	How much have you thought about questions you will ask your doctor to help make good medical decisions?	X				
76	Self-Efficacy	Process	How confident are you that today you could ask the right questions of your doctor to help make good medical decisions?	X	X	X		
77 <sup>a</sup>	Action	Action	Have you ever asked your doctor about the risks of treatment?					
78 <sup>a</sup>	Action	Action	Have you ever asked your doctor about the benefits of treatments?					
79 <sup>a</sup>	Action	Action	Have you ever asked your doctor about your other options to the treatments the doctors were suggesting?					
80 <sup>a</sup>	Action	Action	Have you ever asked your doctor about what your quality of life would be like after starting a treatment?					
81 <sup>a</sup>	Action	Action	Have you ever asked your doctor to repeat information if you did not understand it the first time?					
82	Readiness	Process	How ready are you to ask your doctor questions to help you make a good medical decision?	X	X	X		

<sup>a</sup> Items reduced prior to factor analysis

<sup>b</sup> Response options for Process-Knowledge items (5-point Likert responses): “Not at all”, “A little”, “Somewhat”, “Fairly”, “Extremely”

<sup>c</sup> Response options for Process-Contemplation items (5-point Likert responses): “Never”, “Once”, “A few times”, “Several times”, “A lot”

<sup>d</sup> Response options for Process-Self-efficacy items (5-point Likert responses): “Not at all”, “A little”, “Somewhat”, “Fairly”, “Extremely”

<sup>e</sup> Response options for Process-Readiness items (5-point Likert responses): “I have never thought about it”, “I have thought about it, but I am not ready to do it”, “I am thinking about doing it in the next 6 months”, “I am definitely planning to do it in the next 30 days”, “I have already done it”

<sup>f</sup> Response options for Action items: “Yes”, “no”, or “I am not sure”. A “no” or “I am not sure” responses are both coded as “no.”

# 82 Item Version

Measuring Advance Care Planning: Optimizing the Advance Care Planning Engagement Survey.  
Sudore RL, Heyland DK, Barnes DE, Howard M, Fassbender K, Robinson CA, Boscardin J, You JJ.  
J Pain Symptom Manage. 2017 Apr;53(4):669-681.e8. doi: 10.1016/j.jpainsymman.2016.10.367. Epub  
2016 Dec 29. PMID: 28042072

## PREPARATION ENGAGEMENT SURVEY

*Introduction*      **We will ask about your experiences and opinions. We may ask about things that you have already done, or have not thought about at all. Just answer as honestly as you can.**

*Over the next few sections we will be asking you about 4 topics:*

- 1. Medical decision makers, or surrogates**
- 2. Deciding what matters most in life**
- 3. Flexibility for a medical decision maker**
- 4. Asking doctors questions**

## 1. Medical Decision Makers

This set of questions ask about medical decision makers. A medical decision maker is a family member or friend who can make decisions for you if you were to become too sick to make your own decisions.

Remember, please give us your honest opinions and there are no right or wrong answers.

### KNOWLEDGE

(1 – DM)

These three questions ask about how well informed you are about medical decision makers. You can use the red answers. *[Read options.]*

How well informed are you about.....	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/ Ref.
1. Who can be a medical decision maker? (PE_S1_K1)		1	2	3	4	5	8 / 9
2. What makes someone a good medical decision maker? (PE_S1_K2)		1	2	3	4	5	8 / 9
3. The types of decisions that a medical decision maker may have to make for you in the future? (PE_S1_K3)		1	2	3	4	5	8 / 9

### THOUGHT ABOUT IT

(1 – DM)

These questions ask about how much you have thought about any of the following. You can use the green answers. *[Read options.]*

How much have you thought about...	Green	Never	Once or twice	A few times	Several times	A lot	Not sure/ Ref.
4. Who your medical decision maker should be? (PE_S1_T1)		1	2	3	4	5	8 / 9
5. Asking someone to be your medical decision maker? (PE_S1_T2)		1	2	3	4	5	8 / 9
6. Talking with your doctors about who you want your medical decision maker to be? (PE_S1_T3)		1	2	3	4	5	8 / 9
7. Talking with your OTHER family and friends about who you want your medical decision maker to be? (PE_S1_T4)		1	2	3	4	5	8 / 9

### SELF-EFFICACY

(1 – DM)

These questions ask about how confident you are to actually talk to someone about who you choose as your decision maker. You can use the red answers. *[Read options.]*

How confident are you that today you could....	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/ Ref.
8. Ask someone to be your medical decision maker? (PE_S1_SE1)		1	2	3	4	5	8 / 9
9. Talk with your doctors about who you want your medical decision maker to be? (PE_S1_SE2)		1	2	3	4	5	8 / 9
10. Talk with your OTHER family and friends about who you want your medical decision maker to be? (PE_S1_SE3)		1	2	3	4	5	8 / 9

**DECISIONS MADE****(1 – DM)**

These questions are about decisions you may have already made. These are things you may have decided in your own mind, even if you haven't talked with anyone about it yet.

11. Have you already decided who you want your medical decision maker to be? (PE_S1_DM)	1 <input type="checkbox"/> Yes    0 <input type="checkbox"/> No	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
11b. If yes, when did you do this? (PE_S1_DECDM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
12. How ready are you to decide who you want your medical decision maker to be? (PE_S1_DM_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

**ACTIONS****(1 – DM)**

*[If no to above, I know you just told me you haven't decided on a DM and I assume no, but ...]*

13. Have you already formally asked someone to be your medical decision maker? (PE_S1_ASKDM)	1 <input type="checkbox"/> Yes    0 <input type="checkbox"/> No	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
13a. If yes, when did you do this? (PE_S1_ASKDM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
14. How ready are you to formally ask someone to be your medical decision maker? (PE_S1_ASKDM_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
15. Have you talked with your DOCTOR about who you want your medical decision maker to be? (PE_S1_TELLDR) 1 <input type="checkbox"/> Yes, we had a very detailed discussion 2 <input type="checkbox"/> Yes, but we just had a general discussion 3 <input type="checkbox"/> No, because I assume my doctor knows who I want 4 <input type="checkbox"/> No, not yet		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
15a. If yes, when did you do this? (PE_S1_TELLDR_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
16. How ready are you to talk with your DOCTOR about who you want your medical decision maker to be? (PE_S1_TELLDR_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it over the next few visits 4 <input type="checkbox"/> I am definitely planning to do it at the next visit 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

Now I am going to ask some questions about talking to other family and friends. “Other family and friends” are people who may be in your life and have opinions about your medical care, but not who you may choose as your medical decision maker.

<p>17. Have you already talked to your OTHER FAMILY and FRIENDS about who you want your medical decision maker to be? Remember this would be someone other than your medical decision maker. (PE_S4_DM)</p> <p>1 <input type="checkbox"/> Yes, we had a very detailed discussion</p> <p>2 <input type="checkbox"/> Yes, but we just had a general discussion</p> <p>3 <input type="checkbox"/> No, because I assume my family and friends know who I want</p> <p>4 <input type="checkbox"/> No, not yet</p> <p>5 <input type="checkbox"/> No, because I don't want my family and friends involved in my medical care**</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>17a. If yes, when did you do this? (PE_S4_DM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>18. How ready are you to talk to your OTHER FAMILY and FRIENDS about who you want your medical decision maker to be? (PE_S4_DM_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

<p>19. Have you SIGNED OFFICIAL PAPERS naming a person or group of people to make medical decisions for you? (PE_S1_PAPER)</p>	<p>1 <input type="checkbox"/> Yes    0 <input type="checkbox"/> No</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>19a. If yes, when did you do this? (PE_S1_PAPER_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>20. How ready are you to SIGN OFFICIAL PAPERS naming a person or group of people to make medical decisions for you? (PE_S1_PAPER_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>	



## 2. What Matters Most in Life

Now we want to talk about how some people feel about their quality of life. For instance, how they want to live, and how they do not want to live. Some people think that all health situations or experiences, such as being in a coma or not being able to get out of bed, are worth living through. Other people think that some health situations or experiences would make their life not worth living.

Please give us your honest opinions. There are no right or wrong answers.

### THOUGHT ABOUT IT

(2 – HEALTH SITUATIONS)

The following questions ask about how much you have thought about any of the following issues. You can use the green answers. [Read options.]

How much have you thought about... <i>Green</i>	Never	Once or twice	A few times	Several times	A lot	Not sure/ Ref.
21. Whether or not certain health situations would make your life not worth living? (PE_S2A_T1)	1	2	3	4	5	8 / 9
22. Talking with your DECISION MAKER about whether or not certain health situations would make your life not worth living? (PE_S2A_T2)	1	2	3	4	5	8 / 9
23. Talking with your DOCTORS about whether or not certain health situations would make your life not worth living? (PE_S2A_T3)	1	2	3	4	5	8 / 9
24. Talking with your OTHER family and friends about whether or not certain health situations would make your life not worth living? (PE_S2A_T4)	1	2	3	4	5	8 / 9

### SELF-EFFICACY

(2 – HEALTH SITUATIONS)

The next three questions ask about how confident you are to actually talk to someone about your medical wishes. You can use the red answers. [Read options.]

How confident are you that today you could.... <i>Red</i>	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/ Ref.
25. Talk with your decision maker about whether or not certain health situations would make your life not worth living? (PE_S2A_SE1)	1	2	3	4	5	8 / 9
26. Talk with your doctors about whether or not certain health situations would make your life not worth living? (PE_S2A_SE2)	1	2	3	4	5	8 / 9
27. Talk with your OTHER family and friends about whether or not certain health situations would make your life not worth living? (PE_S2A_SE3)	1	2	3	4	5	8 / 9

**DECISIONS MADE****(2 – HEALTH SITUATIONS)**

The following questions are about decisions you may have already made. These are things you may have decided in your own mind, even if you haven't talked with anyone about it yet. Again, health situations can be such things as being in a coma, or not being able to get out of bed.

28. Have you already decided whether or not certain health situations would make your life not worth living? (PE_S2A_SIT)	1 <input type="checkbox"/> Yes    0 <input type="checkbox"/> No	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
18a. If yes, when did you do this? (PE_S2A_SIT_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
29. How ready are you to decide whether or not certain health situations would make your life not worth living? (PE_S2A_SIT_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

**ACTIONS****(2 – HEALTH SITUATIONS)**

[If no to above, I know you haven't decided about certain health situations, but ...]

30. Have you talked with your DECISION MAKER about whether or not certain health situations would make your life not worth living? (PE_S2A_TELLDLM) 1 <input type="checkbox"/> Yes, we had a very detailed discussion 2 <input type="checkbox"/> Yes, but we just had a general discussion 3 <input type="checkbox"/> No, because I assume my decision maker knows what I want 4 <input type="checkbox"/> No, not yet		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
30a. If yes, when did you do this? (PE_S2A_TELLDLM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
31. How ready are you to talk to your DECISION MAKER about whether or not certain health situations would make your life not worth living? (PE_S2A_TELLDLM_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

32. Have you talked with your DOCTOR about whether or not certain health situations would make your life not worth living? (PE_S2A_TELLDR) 1 <input type="checkbox"/> Yes, we had a very detailed discussion 2 <input type="checkbox"/> Yes, but we just had a general discussion 3 <input type="checkbox"/> No, because I assume my doctor knows what I want 4 <input type="checkbox"/> No, not yet		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
32a. If yes, when did you do this? (PE_S2A_TELLDR_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

<p>33. How ready are you to talk to your DOCTOR about whether or not certain health situations would make your life not worth living? (PE_S2A_TELLDR_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next few visits</p> <p>4 <input type="checkbox"/> I am definitely planning to do it at the next visit</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
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**Now I am going to ask you some questions about talking to other family and friends who would not be your decision maker.**

<p>34. Have you talked with your OTHER FAMILY and FRIENDS about whether or not certain health situations would make your life not worth living? (PE_S4_SIT)</p> <p>1 <input type="checkbox"/> Yes, we had a very detailed discussion</p> <p>2 <input type="checkbox"/> Yes, but we just had a general discussion</p> <p>3 <input type="checkbox"/> No, because I assume my family and friends know what I want</p> <p>4 <input type="checkbox"/> No, not yet</p> <p>5 <input type="checkbox"/> No, because I don't want my family and friends involved in my medical care</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>34a. If yes, when did you do this? (PE_S4_SIT_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

<p>35. How ready are you to talk to your OTHER FAMILY and FRIENDS about whether OR NOT certain health situations would make your life not worth living? (PE_S4_SIT_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
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<p>36. Have you SIGNED OFFICIAL PAPERS to put your wishes in writing about whether or not certain health situations would make your life not worth living? These forms are sometimes called an advance directive or living will. (PE_S2A_PAPER)</p>	<p>1 <input type="checkbox"/> Yes    0 <input type="checkbox"/> No</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>36a. If yes, when did you do this? (PE_S2A_PAPER_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

<p>37. How ready are you to SIGN OFFICIAL PAPERS putting your wishes in writing about whether or not certain health situations would make your life not worth living? (PE_S2A_PAPER_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
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We are switching topics now. The previous questions were about how people would or would not want to live.

The following questions are about specific medical treatments that people may or may never want if they were very sick or at the end of their life. For instance, some people know they would want to be on a breathing machine. Other people know they would never want to be on a breathing machine. Please give us your honest opinions to the following questions about medical treatments. There are no right or wrong answers.

#### THOUGHT ABOUT IT

(2B – CARE AT EOL)

The following questions ask about how much you have thought about any of the following. You can use the green answers. *[Read options.]*

How much have you thought about... <i>Green</i>	Never	Once or twice	A few times	Several times	A lot	Not sure/ Ref.
38. The care you would want if you were very sick or near the end of life? (PE_S2B_T1)	1	2	3	4	5	8 / 9
39. Talking with your decision maker about the care you would want if you were very sick or near the end of life? (PE_S2B_T2)	1	2	3	4	5	8 / 9
40. Talking with your doctors about the care you would want if you were very sick or near the end of life? (PE_S2B_T3)	1	2	3	4	5	8 / 9
41. Talking with your OTHER family and friends about the care you would want if you were very sick or near the end of life? (PE_S2B_T4)	1	2	3	4	5	8 / 9

#### SELF-EFFICACY

(2B – CARE AT EOL)

The next three questions ask about how confident you are to actually talk to someone about your medical wishes. You can use the red answers. *[Read options.]*

How confident are you that today you could.... <i>Red</i>	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/ Ref.
42. Talk with your decision maker about the care you would want if you were very sick or near the end of life? (PE_S2B_SE1)	1	2	3	4	5	8 / 9
43. Talk with your doctors about the care you would want if you were very sick or near the end of life? (PE_S2B_SE2)	1	2	3	4	5	8 / 9
44. Talk with your OTHER family and friends about the care you would want if you were very sick or near the end of life? (PE_S2B_SE3)	1	2	3	4	5	8 / 9

**DECISIONS MADE****(2B – CARE AT EOL)**

The following questions are about decisions you may have already made. These are things you may have decided in your own mind, even if you haven't talked with anyone about it yet.

45. Have you already decided on the medical care you would want if you were very sick or near the end of life? (PE_S2_CARE)	1 <input type="checkbox"/> Yes    0 <input type="checkbox"/> No	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
45a. If yes, when did you do this? (PE_S2_CARE_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
46. How ready are you to decide on the medical care you would want if you were very sick or near the end of life? (PE_S2_CARE_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

**ACTIONS****(2B – CARE AT EOL)**

*[If no to above, I know you haven't decided about the care you'd want, but ...]*

47. Have you ever talked with your DECISION MAKER about what kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_TELLDLM) 1 <input type="checkbox"/> Yes, we had a very detailed discussion 2 <input type="checkbox"/> Yes, but we just had a general discussion 3 <input type="checkbox"/> No, because I assume my decision maker knows what I want 4 <input type="checkbox"/> No, not yet		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
47a. If yes, when did you do this? (PE_S2B_TELLDLM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
48. How ready are you to talk to your DECISION MAKER about the kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_TELLDLM_READY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
49. Have you ever talked with your DOCTOR about what kind of medical care you want if you were very sick or near the end of life? (PE_S2B_TELLDLDR) 1 <input type="checkbox"/> Yes, we had a very detailed discussion 2 <input type="checkbox"/> Yes, but we just had a general discussion 3 <input type="checkbox"/> No, because I assume my doctor knows what I want 4 <input type="checkbox"/> No, not yet		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
49a. If yes, when did you do this? (PE_S2B_TELLDLDR_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

<p>50. How ready are you to talk to your DOCTOR about the kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_TELLDR_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next few visits</p> <p>4 <input type="checkbox"/> I am definitely planning to do it at the next visit</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
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**Now I am going to ask you some questions about talking to other family and friends, so not who you would have as your decision maker.**

<p>51. Have you ever talked with your OTHER FAMILY and FRIENDS about what kind of medical care you want if you were very sick or near the end of life? (PE_S4_CARE)</p> <p>1 <input type="checkbox"/> Yes, we had a very detailed discussion</p> <p>2 <input type="checkbox"/> Yes, but we just had a general discussion</p> <p>3 <input type="checkbox"/> No, because I assume my family and friends know what I want</p> <p>4 <input type="checkbox"/> No, not yet</p> <p>5 <input type="checkbox"/> No, because I don't want my family and friends involved in my medical care</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>51a. If yes, when did you do this? (PE_S4_CARE_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>52. How ready are you to talk to your OTHER FAMILY and FRIENDS about the kind of medical care you would want if you were very sick or near the end of life? (PE_S4_CARE_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

<p>53. Have you SIGNED OFFICIAL PAPERS to put your wishes in writing about the kind of medical care you would want if you were very sick or near the end of life? These forms are sometimes called an advance directive or living will. (PE_S2B_PAPER)</p>	<p>1 <input type="checkbox"/> Yes    0 <input type="checkbox"/> No</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>53a. If yes, when did you do this? (PE_S2B_PAPER_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>54. How ready are you to SIGN OFFICIAL PAPERS putting your wishes about the kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_PAPER_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>		<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

### 3. Flexibility

Now we are going to talk about **flexibility in decision making**. Flexibility means that your decision maker can work with your doctor and change your prior medical decisions, if it is best for you at that time. Patients can decide to give or not give flexibility.

#### KNOWLEDGE

(3 – FLEXIBILITY)

The next two questions ask about flexibility in decision making. You can use the red answers. [Read options.]

How well informed are you about.....	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/ Ref.
55. What it means to give a medical decision maker flexibility to make future decisions? (PE_S3_K1)		1	2	3	4	5	8 / 9
56. The different amounts of flexibility a person can give their medical decision maker? (PE_S3_K2)		1	2	3	4	5	8 / 9

#### THOUGHT ABOUT IT

(3 – FLEXIBILITY)

These questions ask about **how much you have thought** about flexibility. You can use the green answers. [Read options.]

How much have you thought about...	Green	Never	Once or twice	A few times	Several times	A lot	Not sure/ Ref.
57. The amount of flexibility you would want to give your medical decision maker? (PE_S3_T1)		1	2	3	4	5	8 / 9
58. Talking with your medical decision maker about how much flexibility you want to give them? (PE_S3_T2)		1	2	3	4	5	8 / 9
59. Talking with your DOCTOR about how much flexibility you want to give your decision maker? (PE_S3_T3)		1	2	3	4	5	8 / 9
60. Talking with OTHER friends and family about how much flexibility you want to give your decision maker? (PE_S3_T4)		1	2	3	4	5	8 / 9

#### SELF-EFFICACY

(3 – FLEXIBILITY)

These questions ask about **how confident you are** to talk to someone **about flexibility**. You can use the red answers. [Read options.]

How confident are you that today you could....	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/ Ref.
61. Talk with your DECISION MAKER about how much flexibility you want to give them? (PE_S3_SE1)		1	2	3	4	5	8 / 9
62. Talk with your DOCTOR about how much flexibility you want to give your medical decision maker? (PE_S3_SE2)		1	2	3	4	5	8 / 9
63. Talk with your OTHER family and friends about how much flexibility you want to give your medical decision maker? (PE_S3_SE3)		1	2	3	4	5	8 / 9

**DECISIONS MADE****(3 – FLEXIBILITY)**

The following questions are about decisions you may have already made. These are things you may have decided in your own mind, even if you haven't talked with anyone about it yet.

64. Have you decided how much flexibility you would want to give a medical decision maker if they have to make decisions on your behalf (meaning for you)? (PE_S3_FLX)	1 <input type="checkbox"/> Yes    0 <input type="checkbox"/> No	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
64a. If yes, when did you do this? (PE_S3_FLX_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
65. How ready are you to decide how much flexibility you would want to give a medical decision maker if they have to make decisions on your behalf? (PE_S3_FLX_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

**ACTIONS****(3 – FLEXIBILITY)**

[If no to above, I know you haven't decided about flexibility, but ...]

66. Have you talked with your DECISION MAKER about how much flexibility you want to give them? (PE_S3_TELDM) 1 <input type="checkbox"/> Yes, we had a very detailed discussion 2 <input type="checkbox"/> Yes, but we just had a general discussion 3 <input type="checkbox"/> No, because I assume my decision maker knows what I want 4 <input type="checkbox"/> No, not yet		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
66a. If yes, when did you do this? (PE_S3_TELDM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
67. How ready are you to talk to your DECISION MAKER about how much flexibility you want to give them? (PE_S3_TELDM_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
68. Have you talked with your DOCTOR about how much flexibility you want to give your medical decision maker? (PE_S3_TELDR) 1 <input type="checkbox"/> Yes, we had a very detailed discussion 2 <input type="checkbox"/> Yes, but we just had a general discussion 3 <input type="checkbox"/> No, because I assume my doctor knows what I want 4 <input type="checkbox"/> No, not yet		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
68a. If yes, when did you do this? (PE_S3_TELDR_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
69. How ready are you to talk to your DOCTOR about how much flexibility you want to give your decision maker? (PE_S3_TELDR_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next few visits 4 <input type="checkbox"/> I am definitely planning to do it in the next visit 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused



Now I am going to ask you some questions about talking to other family and friends who would not be your decision maker.

<p>70. Have you already talked to your OTHER FAMILY and FRIENDS about how much flexibility you want to give your medical decision maker? (PE_S4_FLX)</p> <p>1 <input type="checkbox"/> Yes, we had a very detailed discussion</p> <p>2 <input type="checkbox"/> Yes, but we just had a general discussion</p> <p>3 <input type="checkbox"/> No, because I assume my family and friends know what I want</p> <p>4 <input type="checkbox"/> No, not yet</p> <p>5 <input type="checkbox"/> No, because I don't want my family and friends involved in my medical care</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>70a. If yes, when did you do this? (PE_S4_FLX_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>71. How ready are you to talk to your OTHER FAMILY and FRIENDS about how much flexibility you want to give your medical decision maker? (PE_S4_FLX_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

<p>72. Have you SIGNED OFFICIAL PAPERS to put your wishes in writing about how much flexibility to give your decision maker? (PE_S3_PAPER)</p>	<p>1 <input type="checkbox"/> Yes    0 <input type="checkbox"/> No</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>73a. If yes, when did you do this? (PE_S3_PAPER_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>73. How ready are you to SIGN OFFICIAL PAPERS to put your wishes in writing about how much flexibility to give your decision maker? (PE_S3_PAPER_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>	

## 4. Asking Your Doctor Questions

Now we are going to talk about asking doctors questions.

### KNOWLEDGE

(5 – ASK DR)

How well informed are you about... <i>Red</i>	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/Ref.
74. The types of questions you can ask your doctor that will help you make a good medical decision? (PE_S5_K1)	1	2	3	4	5	8 / 9

### THOUGHT ABOUT IT

(5 – ASK DR)

How much have you thought about... <i>Green</i>	Never	Once or twice	A few times	Several times	A lot	Not sure/Ref.
75. Questions you will ask your doctor to help make good medical decisions? (PE_S5_T1)	1	2	3	4	5	8 / 9

### SELF-EFFICACY

(5 – ASK DR)

How confident are you that today you could... <i>Red</i>	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/Ref.
76. Ask the right questions of your doctor to help make good medical decisions? (PE_S5_SE1)	1	2	3	4	5	8 / 9

### DECISIONS MADE/ACTIONS

(5 – ASK DR)

Have you ever asked your doctor about...

77. The risks of treatment? (PE_S5_RISKS)	1 <input type="checkbox"/> Yes    0 <input type="checkbox"/> No	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
78. The benefits of treatments? (PE_S5_BENFT)	1 <input type="checkbox"/> Yes    0 <input type="checkbox"/> No	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
79. Your other options to the treatments the doctors were suggesting? (PE_S5_OPTN)	1 <input type="checkbox"/> Yes    0 <input type="checkbox"/> No	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
80. What your quality of life would be like after starting a treatment? (PE_S5_QOL)	1 <input type="checkbox"/> Yes    0 <input type="checkbox"/> No	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
81. To repeat information if you did not understand it the first time? (PE_S5_REPEAT)	1 <input type="checkbox"/> Yes    0 <input type="checkbox"/> No	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
82. How ready are you to ask your doctor questions to help you make a good medical decision? (PE_S5_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

# 55 Item Version

Measuring Advance Care Planning: Optimizing the Advance Care Planning Engagement Survey.  
Sudore RL, Heyland DK, Barnes DE, Howard M, Fassbender K, Robinson CA, Boscardin J, You JJ.  
J Pain Symptom Manage. 2017 Apr;53(4):669-681.e8. doi: 10.1016/j.jpainsymman.2016.10.367. Epub  
2016 Dec 29. PMID: 28042072

## PREPARATION ENGAGEMENT SURVEY

*Introduction*      **We will ask about your experiences and opinions. We may ask about things that you have already done, or have not thought about at all. Just answer as honestly as you can.**

*Over the next few sections we will be asking you about 4 topics:*

- 1. Medical decision makers, or surrogates**
- 2. Deciding what matters most in life**
- 3. Flexibility for a medical decision maker**
- 4. Asking doctors questions**

## 1. Medical Decision Makers

This set of questions ask about medical decision makers. A medical decision maker is a family member or friend who can make decisions for you if you were to become too sick to make your own decisions.

Remember, please give us your honest opinions and there are no right or wrong answers.

### KNOWLEDGE

(1 – DM)

These three questions ask about how well informed you are about medical decision makers. You can use the red answers. *[Read options.]*

How well informed are you about.....	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/ Ref.
1. Who can be a medical decision maker? (PE_S1_K1)		1	2	3	4	5	8 / 9
2. What makes someone a good medical decision maker? (PE_S1_K2)		1	2	3	4	5	8 / 9
3. The types of decisions that a medical decision maker may have to make for you in the future? (PE_S1_K3)		1	2	3	4	5	8 / 9

### THOUGHT ABOUT IT

(1 – DM)

These questions ask about how much you have thought about any of the following. You can use the green answers. *[Read options.]*

How much have you thought about...	Green	Never	Once or twice	A few times	Several times	A lot	Not sure/ Ref.
4. Who your medical decision maker should be? (PE_S1_T1)		1	2	3	4	5	8 / 9
5. Asking someone to be your medical decision maker? (PE_S1_T2)		1	2	3	4	5	8 / 9
6. Talking with your doctors about who you want your medical decision maker to be? (PE_S1_T3)		1	2	3	4	5	8 / 9
7. Talking with your OTHER family and friends about who you want your medical decision maker to be? (PE_S1_T4)		1	2	3	4	5	8 / 9

### SELF-EFFICACY

(1 – DM)

These questions ask about how confident you are to actually talk to someone about who you choose as your decision maker. You can use the red answers. *[Read options.]*

How confident are you that today you could....	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/ Ref.
8. Ask someone to be your medical decision maker? (PE_S1_SE1)		1	2	3	4	5	8 / 9
9. Talk with your doctors about who you want your medical decision maker to be? (PE_S1_SE2)		1	2	3	4	5	8 / 9
10. Talk with your OTHER family and friends about who you want your medical decision maker to be? (PE_S1_SE3)		1	2	3	4	5	8 / 9

**READINESS**
**(1 – DM)**

The following questions are about how ready you are to talk to others about who you want your medical decision maker to be and to put this information in writing.

11. How ready are you to formally ask someone to be your medical decision maker? (PE_S1_ASKDM_RDY)		
1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)		1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA
12. How ready are you to talk with your DOCTOR about who you want your medical decision maker to be? (PE_S1_TELLDR_RDY)		
1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it over the next few visits 4 <input type="checkbox"/> I am definitely planning to do it at the next visit 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)		1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA

Now I am going to ask some questions about talking to other family and friends. "Other family and friends" are people who may be in your life and have opinions about your medical care, but not who you may choose as your medical decision maker.

13. How ready are you to talk with your OTHER FAMILY and FRIENDS about who you want your medical decision maker to be? Remember this would be someone other than your medical decision maker. (PE_S4_DM)		
1 <input type="checkbox"/> Yes, we had a very detailed discussion 2 <input type="checkbox"/> Yes, but we just had a general discussion 3 <input type="checkbox"/> No, because I assume my family and friends know who I want 4 <input type="checkbox"/> No, not yet 5 <input type="checkbox"/> No, because I don't want my family and friends involved in my medical care**		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)		1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA

14. How ready are you to SIGN OFFICIAL PAPERS naming a person or group of people to make medical decisions for you? (PE_S1_PAPER_RDY)		
1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)		1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA

## 2. What Matters Most in Life

Now we want to talk about how some people feel about their quality of life. For instance, how they want to live, and how they do not want to live. Some people think that all health situations or experiences, such as being in a coma or not being able to get out of bed, are worth living through. Other people think that some health situations or experiences would make their life not worth living.

Please give us your honest opinions. There are no right or wrong answers.

### THOUGHT ABOUT IT

(2 – HEALTH SITUATIONS)

The following questions ask about how much you have thought about any of the following issues. You can use the green answers. [Read options.]

How much have you thought about... <i>Green</i>	Never	Once or twice	A few times	Several times	A lot	Not sure/ Ref.
15. Whether or not certain health situations would make your life not worth living? (PE_S2A_T1)	1	2	3	4	5	8 / 9
16. Talking with your DECISION MAKER about whether or not certain health situations would make your life not worth living? (PE_S2A_T2)	1	2	3	4	5	8 / 9
17. Talking with your DOCTORS about whether or not certain health situations would make your life not worth living? (PE_S2A_T3)	1	2	3	4	5	8 / 9
18. Talking with your OTHER family and friends about whether or not certain health situations would make your life not worth living? (PE_S2A_T4)	1	2	3	4	5	8 / 9

### SELF-EFFICACY

(2 – HEALTH SITUATIONS)

The next three questions ask about how confident you are to actually talk to someone about your medical wishes. You can use the red answers. [Read options.]

How confident are you that today you could.... <i>Red</i>	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/ Ref.
19. Talk with your decision maker about whether or not certain health situations would make your life not worth living? (PE_S2A_SE1)	1	2	3	4	5	8 / 9
20. Talk with your doctors about whether or not certain health situations would make your life not worth living? (PE_S2A_SE2)	1	2	3	4	5	8 / 9
21. Talk with your OTHER family and friends about whether or not certain health situations would make your life not worth living? (PE_S2A_SE3)	1	2	3	4	5	8 / 9

**READINESS**
**(2 – HEALTH SITUATIONS)**

The following questions are about how ready you are to decide and talk about health situations. Again, health situations can be such things as being in a coma, or not being able to get out of bed.

22. How ready are you to decide whether or not certain health situations would make your life not worth living? (PE_S2A_SIT_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA 8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

*[If they haven't already done it, say "I know you haven't decided about certain health situations, but ...]*

23. How ready are you to talk to your DECISION MAKER about whether or not certain health situations would make your life not worth living? (PE_S2A_TELLDLM_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA 8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
24. How ready are you to talk to your DOCTOR about whether or not certain health situations would make your life not worth living? (PE_S2A_TELLDLDR_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next few visits 4 <input type="checkbox"/> I am definitely planning to do it at the next visit 5 <input type="checkbox"/> I have already done it	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA 8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

Now I am going to ask you some questions about talking to other family and friends who would not be your decision maker.

25. How ready are you to talk to your OTHER FAMILY and FRIENDS about whether OR NOT certain health situations would make your life not worth living? (PE_S4_SIT_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA 8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused



<p>26. How ready are you to SIGN OFFICIAL PAPERS putting your wishes in writing about whether or not certain health situations would make your life not worth living? (PE_S2A_PAPER_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p>

We are switching topics now. The previous questions were about how people would or would not want to live.

The following questions are about specific medical treatments that people may or may never want if they were very sick or at the end of their life. For instance, some people know they would want to be on a breathing machine. Other people know they would never want to be on a breathing machine. Please give us your honest opinions to the following questions about medical treatments. There are no right or wrong answers.

#### THOUGHT ABOUT IT

(2B – CARE AT EOL)

The following questions ask about how much you have thought about any of the following. You can use the green answers. [Read options.]

How much have you thought about... <i>Green</i>	Never	Once or twice	A few times	Several times	A lot	Not sure/ Ref.
27. The care you would want if you were very sick or near the end of life? (PE_S2B_T1)	1	2	3	4	5	8 / 9
28. Talking with your decision maker about the care you would want if you were very sick or near the end of life? (PE_S2B_T2)	1	2	3	4	5	8 / 9
29. Talking with your doctors about the care you would want if you were very sick or near the end of life? (PE_S2B_T3)	1	2	3	4	5	8 / 9
30. Talking with your OTHER family and friends about the care you would want if you were very sick or near the end of life? (PE_S2B_T4)	1	2	3	4	5	8 / 9

#### SELF-EFFICACY

(2B – CARE AT EOL)

The next three questions ask about how confident you are to actually talk to someone about your medical wishes. You can use the red answers. [Read options.]

How confident are you that today you could.... <i>Red</i>	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/ Ref.
31. Talk with your decision maker about the care you would want if you were very sick or near the end of life? (PE_S2B_SE1)	1	2	3	4	5	8 / 9
32. Talk with your doctors about the care you would want if you were very sick or near the end of life? (PE_S2B_SE2)	1	2	3	4	5	8 / 9
33. Talk with your OTHER family and friends about the care you would want if you were very sick or near the end of life? (PE_S2B_SE3)	1	2	3	4	5	8 / 9

**READINESS**
**(2B – CARE AT EOL)**

The following questions are about how ready you are to decide and talk about the care you would want if you were very sick or near the end of life.

<p>34. How ready are you to decide on the medical care you would want if you were very sick or near the end of life? (PE_S2_CARE_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

*[If they haven't already done it, say "I know you haven't decided about certain health situations, but ...]*

<p>35. How ready are you to talk to your DECISION MAKER about the kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_TELLDN_READY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>36. How ready are you to talk to your DOCTOR about the kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_TELLDR_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next few visits</p> <p>4 <input type="checkbox"/> I am definitely planning to do it at the next visit</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

Now I am going to ask you some questions about talking to other family and friends, so not who you would have as your decision maker.

<p>37. How ready are you to talk to your OTHER FAMILY and FRIENDS about the kind of medical care you would want if you were very sick or near the end of life? (PE_S4_CARE_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

<p>38. How ready are you to SIGN OFFICIAL PAPERS putting your wishes about the kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_PAPER_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p>

### 3. Flexibility

Now we are going to talk about **flexibility in decision making**. Flexibility means that your decision maker can work with your doctor and change your prior medical decisions, if it is best for you at that time. Patients can decide to give or not give flexibility.

#### KNOWLEDGE

(3 – FLEXIBILITY)

The next two questions ask about flexibility in decision making. You can use the red answers. [Read options.]

How well informed are you about.....	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/ Ref.
39. What it means to give a medical decision maker flexibility to make future decisions? (PE_S3_K1)		1	2	3	4	5	8 / 9
40. The different amounts of flexibility a person can give their medical decision maker? (PE_S3_K2)		1	2	3	4	5	8 / 9

#### THOUGHT ABOUT IT

(3 – FLEXIBILITY)

These questions ask about **how much you have thought** about flexibility. You can use the green answers. [Read options.]

How much have you thought about...	Green	Never	Once or twice	A few times	Several times	A lot	Not sure/ Ref.
41. The amount of flexibility you would want to give your medical decision maker? (PE_S3_T1)		1	2	3	4	5	8 / 9
42. Talking with your medical decision maker about how much flexibility you want to give them? (PE_S3_T2)		1	2	3	4	5	8 / 9
43. Talking with your DOCTOR about how much flexibility you want to give your decision maker? (PE_S3_T3)		1	2	3	4	5	8 / 9
44. Talking with OTHER friends and family about how much flexibility you want to give your decision maker? (PE_S3_T4)		1	2	3	4	5	8 / 9

**SELF-EFFICACY****(3 – FLEXIBILITY)**

These questions ask about how confident you are to talk to someone about flexibility. You can use the red answers.  
[Read options.]

How confident are you that today you could....	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/ Ref.
45. Talk with your DECISION MAKER about how much flexibility you want to give them? (PE_S3_SE1)		1	2	3	4	5	8 / 9
46. Talk with your DOCTOR about how much flexibility you want to give your medical decision maker? (PE_S3_SE2)		1	2	3	4	5	8 / 9
47. Talk with your OTHER family and friends about how much flexibility you want to give your medical decision maker? (PE_S3_SE3)		1	2	3	4	5	8 / 9

**READINESS****(3 – FLEXIBILITY)**

The following questions are about how ready you are to talk to others about how much flexibility you want to give your medical decision maker and to put this information in writing.

48. How ready are you to talk to your DECISION MAKER about how much flexibility you want to give them? (PE_S3_TELDM_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
49. How ready are you to talk to your DOCTOR about how much flexibility you want to give your decision maker? (PE_S3_TELDR_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next few visits 4 <input type="checkbox"/> I am definitely planning to do it in the next visit 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

Now I am going to ask you some questions about talking to other family and friends who would not be your decision maker.

50. How ready are you to talk to your OTHER FAMILY and FRIENDS about how much flexibility you want to give your medical decision maker? (PE_S4_FLX_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

<p>51. How ready are you to SIGN OFFICIAL PAPERS to put your wishes in writing about how much flexibility to give your decision maker? (PE_S3_PAPER_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

## 4. Asking Your Doctor Questions

Now we are going to talk about asking doctors questions.

KNOWLEDGE (5 – ASK DR)							
How well informed are you about...	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/ Ref.
52. The types of questions you can ask your doctor that will help you make a good medical decision? (PE_S5_K1)		1	2	3	4	5	8 / 9

THOUGHT ABOUT IT (5 – ASK DR)							
How much have you thought about...	Green	Never	Once or twice	A few times	Several times	A lot	Not sure/ Ref.
53. Questions you will ask your doctor to help make good medical decisions? (PE_S5_T1)		1	2	3	4	5	8 / 9

SELF-EFFICACY (5 – ASK DR)							
How confident are you that today you could...	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/ Ref.
54. Ask the right questions of your doctor to help make good medical decisions? (PE_S5_SE1)		1	2	3	4	5	8 / 9

READINESS (5 – ASK DR)						
<p>55. How ready are you to ask your doctor questions to help you make a good medical decision? (PE_S5_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>					
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>					

## 34 Item Version

Measuring Advance Care Planning: Optimizing the Advance Care Planning Engagement Survey.  
Sudore RL, Heyland DK, Barnes DE, Howard M, Fassbender K, Robinson CA, Boscardin J, You JJ.  
J Pain Symptom Manage. 2017 Apr;53(4):669-681.e8. doi: 10.1016/j.jpainsymman.2016.10.367. Epub  
2016 Dec 29. PMID: 28042072

## PREPARATION ENGAGEMENT SURVEY

*Introduction*      **We will ask about your experiences and opinions. We may ask about things that you have already done, or have not thought about at all. Just answer as honestly as you can.**

*Over the next few sections we will be asking you about 4 topics:*

- 1. Medical decision makers, or surrogates**
- 2. Deciding what matters most in life**
- 3. Flexibility for a medical decision maker**
- 4. Asking doctors questions**

## 1. Medical Decision Makers

This set of questions ask about medical decision makers. A medical decision maker is a family member or friend who can make decisions for you if you were to become too sick to make your own decisions.

Remember, please give us your honest opinions and there are no right or wrong answers.

### KNOWLEDGE

(1 – DM)

These two questions ask about how well informed you are about medical decision makers. You can use the red answers. *[Read options.]*

How well informed are you about.....	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/ Ref.
1. What makes someone a good medical decision maker? (PE_S1_K2)		1	2	3	4	5	8 / 9
2. The types of decisions that a medical decision maker may have to make for you in the future? (PE_S1_K3)		1	2	3	4	5	8 / 9

### THOUGHT ABOUT IT

(1 – DM)

The next question asks about how much you have thought about any of the following. You can use the green answers. *[Read options.]*

How much have you thought about...	Green	Never	Once or twice	A few times	Several times	A lot	Not sure/ Ref.
3. Who your medical decision maker should be? (PE_S1_T1)		1	2	3	4	5	8 / 9

### SELF-EFFICACY

(1 – DM)

These questions ask about how confident you are to actually talk to someone about who you choose as your decision maker. You can use the red answers. *[Read options.]*

How confident are you that today you could....	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/ Ref.
4. Ask someone to be your medical decision maker? (PE_S1_SE1)		1	2	3	4	5	8 / 9
5. Talk with your doctors about who you want your medical decision maker to be? (PE_S1_SE2)		1	2	3	4	5	8 / 9
6. Talk with your OTHER family and friends about who you want your medical decision maker to be? (PE_S1_SE3)		1	2	3	4	5	8 / 9



**READINESS**
**(1 – DM)**

The following questions are about how ready you are to talk to others about who you want your medical decision maker to be and to put this information in writing.

<p>7. How ready are you to formally ask someone to be your medical decision maker?(PE_S1_ASKDM_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>		<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>		<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>8. How ready are you to talk with your DOCTOR about who you want your medical decision maker to be? (PE_S1_TELLDR_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it over the next few visits</p> <p>4 <input type="checkbox"/> I am definitely planning to do it at the next visit</p> <p>5 <input type="checkbox"/> I have already done it</p>		<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>		<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

Now I am going to ask some questions about talking to other family and friends. "Other family and friends" are people who may be in your life and have opinions about your medical care, but not who you may choose as your medical decision maker.

<p>9. How ready are you to talk with your OTHER FAMILY and FRIENDS about who you want your medical decision maker to be? Remember this would be someone other than your medical decision maker. (PE_S4_DM)</p> <p>1 <input type="checkbox"/> Yes, we had a very detailed discussion</p> <p>2 <input type="checkbox"/> Yes, but we just had a general discussion</p> <p>3 <input type="checkbox"/> No, because I assume my family and friends know who I want</p> <p>4 <input type="checkbox"/> No, not yet</p> <p>5 <input type="checkbox"/> No, because I don't want my family and friends involved in my medical care**</p>		<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>		<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

<p>10. How ready are you to SIGN OFFICIAL PAPERS naming a person or group of people to make medical decisions for you? (PE_S1_PAPER_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>		<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>		<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

## 2. What Matters Most in Life

Now we want to talk about how some people feel about their quality of life. For instance, how they want to live, and how they do not want to live. Some people think that all health situations or experiences, such as being in a coma or not being able to get out of bed, are worth living through. Other people think that some health situations or experiences would make their life not worth living.

Please give us your honest opinions. There are no right or wrong answers.

### SELF-EFFICACY

(2 – HEALTH SITUATIONS)

The next three questions ask about how confident you are to actually talk to someone about your medical wishes. You can use the red answers. [Read options.]

How confident are you that today you could.... <i>Red</i>	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/Ref.
11. Talk with your decision maker about whether or not certain health situations would make your life not worth living? (PE_S2A_SE1)	1	2	3	4	5	8 / 9
12. Talk with your doctors about whether or not certain health situations would make your life not worth living? (PE_S2A_SE2)	1	2	3	4	5	8 / 9
13. Talk with your OTHER family and friends about whether or not certain health situations would make your life not worth living? (PE_S2A_SE3)	1	2	3	4	5	8 / 9

### READINESS

(2 – HEALTH SITUATIONS)

The following questions are about how ready you are to decide and talk about health situations. Again, health situations can be such things as being in a coma, or not being able to get out of bed.

14. How ready are you to decide whether or not certain health situations would make your life not worth living? (PE_S2A_SIT_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA 8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

[If they haven't already done it, say "I know you haven't decided about certain health situations, but ..."]

15. How ready are you to talk to your DECISION MAKER about whether or not certain health situations would make your life not worth living? (PE_S2A_TELLD_M_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA 8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

<p>16. How ready are you to talk to your DOCTOR about whether or not certain health situations would make your life not worth living? (PE_S2A_TELLDR_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next few visits</p> <p>4 <input type="checkbox"/> I am definitely planning to do it at the next visit</p> <p>5 <input type="checkbox"/> I have already done it</p>		<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>		<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

**Now I am going to ask you some questions about talking to other family and friends who would not be your decision maker.**

<p>17. How ready are you to talk to your OTHER FAMILY and FRIENDS about whether OR NOT certain health situations would make your life not worth living? (PE_S4_SIT_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>		<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>		<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

We are switching topics now. The previous questions were about how people would or would not want to live.

The following questions are about specific medical treatments that people may or may never want if they were very sick or at the end of their life. For instance, some people know they would want to be on a breathing machine. Other people know they would never want to be on a breathing machine. Please give us your honest opinions to the following questions about medical treatments. There are no right or wrong answers.

## THOUGHT ABOUT IT

(2B – CARE AT EOL)

The following question asks about how much you have thought about your medical wishes. You can use the green answers. [Read options.]

How much have you thought about... <i>Green</i>	Never	Once or twice	A few times	Several times	A lot	Not sure/Ref.
18. Talking with your OTHER family and friends about the care you would want if you were very sick or near the end of life? (PE_S2B_T4)	1	2	3	4	5	8 / 9

## SELF-EFFICACY

(2B – CARE AT EOL)

The next three questions ask about how confident you are to actually talk to someone about your medical wishes. You can use the red answers. [Read options.]

How confident are you that today you could.... <i>Red</i>	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/Ref.
19. Talk with your decision maker about the care you would want if you were very sick or near the end of life? (PE_S2B_SE1)	1	2	3	4	5	8 / 9
20. Talk with your doctors about the care you would want if you were very sick or near the end of life? (PE_S2B_SE2)	1	2	3	4	5	8 / 9
21. Talk with your OTHER family and friends about the care you would want if you were very sick or near the end of life? (PE_S2B_SE3)	1	2	3	4	5	8 / 9

## READINESS

(2B – CARE AT EOL)

The following questions are about how ready you are to decide and talk about the care you would want if you were very sick or near the end of life.

22. How ready are you to decide on the medical care you would want if you were very sick or near the end of life? (PE_S2_CARE_RDY)	1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

**[If they haven't already done it, say "I know you haven't decided about certain health situations, but ..."]**

<p>23. How ready are you to talk to your DECISION MAKER about the kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_TELLDLM_READY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>24. How ready are you to talk to your DOCTOR about the kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_TELLDRL_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next few visits</p> <p>4 <input type="checkbox"/> I am definitely planning to do it at the next visit</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

**Now I am going to ask you some questions about talking to other family and friends, so not who you would have as your decision maker.**

<p>25. How ready are you to talk to your OTHER FAMILY and FRIENDS about the kind of medical care you would want if you were very sick or near the end of life? (PE_S4_CARE_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

<p>26. How ready are you to SIGN OFFICIAL PAPERS putting your wishes about the kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_PAPER_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

### 3. Flexibility

Now we are going to talk about flexibility in decision making. Flexibility means that your decision maker can work with your doctor and change your prior medical decisions, if it is best for you at that time. Patients can decide to give or not give flexibility.

#### THOUGHT ABOUT IT

(3 – FLEXIBILITY)

These questions ask about how much you have thought about flexibility. You can use the green answers. [Read options.]

How much have you thought about... <i>Green</i>	Never	Once or twice	A few times	Several times	A lot	Not sure/Ref.
27. Talking with your medical decision maker about how much flexibility you want to give them? (PE_S3_T2)	1	2	3	4	5	8 / 9

#### SELF-EFFICACY

(3 – FLEXIBILITY)

These questions ask about how confident you are to talk to someone about flexibility. You can use the red answers. [Read options.]

How confident are you that today you could.... <i>Red</i>	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/Ref.
28. Talk with your DOCTOR about how much flexibility you want to give your medical decision maker? (PE_S3_SE2)	1	2	3	4	5	8 / 9
29. Talk with your OTHER family and friends about how much flexibility you want to give your medical decision maker? (PE_S3_SE3)	1	2	3	4	5	8 / 9

#### READINESS

(3 – FLEXIBILITY)

The following questions are about how ready you are to talk to others about how much flexibility you want to give your medical decision maker and to put this information in writing.

30. How ready are you to talk to your DECISION MAKER about how much flexibility you want to give them? (PE_S3_TELLDLM_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)		1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA
31. How ready are you to talk to your DOCTOR about how much flexibility you want to give your decision maker? (PE_S3_TELLDR_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next few visits 4 <input type="checkbox"/> I am definitely planning to do it in the next visit 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)	1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA	8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
--	---	---

<p>32. How ready are you to SIGN OFFICIAL PAPERS to put your wishes in writing about how much flexibility to give your decision maker? (PE_S3_PAPER_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> &gt;6 months ago 99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused</p>

## 4. Asking Your Doctor Questions

Now we are going to talk about asking doctors questions.

SELF-EFFICACY (5 – ASK DR)						
How confident are you that today you could...	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/Ref.
33. Ask the right questions of your doctor to help make good medical decisions? (PE_S5_SE1)	1	2	3	4	5	8 / 9

READINESS (5 – ASK DR)						
<p>34. How ready are you to ask your doctor questions to help you make a good medical decision? (PE_S5_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>					
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> &gt;6 months ago 99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused</p>					

# 15 Item Version

Measuring Advance Care Planning: Optimizing the Advance Care Planning Engagement Survey.  
Sudore RL, Heyland DK, Barnes DE, Howard M, Fassbender K, Robinson CA, Boscardin J, You JJ.  
J Pain Symptom Manage. 2017 Apr;53(4):669-681.e8. doi: 10.1016/j.jpainsymman.2016.10.367. Epub  
2016 Dec 29. PMID: 28042072



## PREPARATION ENGAGEMENT SURVEY

*Introduction*      **We will ask about your experiences and opinions. We may ask about things that you have already done, or have not thought about at all. Just answer as honestly as you can.**

*Over the next few sections we will be asking you about 4 topics:*

- 1. Medical decision makers, or surrogates**
- 2. Deciding what matters most in life**
- 3. Flexibility for a medical decision maker**
- 4. Asking doctors questions**

## 1. Medical Decision Makers

This set of questions ask about medical decision makers. A medical decision maker is a family member or friend who can make decisions for you if you were to become too sick to make your own decisions.

Remember, please give us your honest opinions and there are no right or wrong answers.

### SELF-EFFICACY

(1 – DM)

These questions ask about how confident you are to actually talk to someone about who you choose as your decision maker. You can use the red answers. [Read options.]

How confident are you that today you could....	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/Ref.
1. Ask someone to be your medical decision maker? (PE_S1_SE1)		1	2	3	4	5	8 / 9

### READINESS

(1 – DM)

The following questions are about how ready you are to talk to others about who you want your medical decision maker to be and to put this information in writing.

2. How ready are you to formally ask someone to be your medical decision maker? (PE_S1_ASKDM_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)		1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA
3. How ready are you to talk with your DOCTOR about who you want your medical decision maker to be? (PE_S1_TELLDR_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it over the next few visits 4 <input type="checkbox"/> I am definitely planning to do it at the next visit 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)		1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA
4. How ready are you to SIGN OFFICIAL PAPERS naming a person or group of people to make medical decisions for you? (PE_S1_PAPER_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)		1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA

## 2. What Matters Most in Life

We are switching topics now. The previous questions were about how people would or would not want to live.

The following questions are about specific medical treatments that people may or may never want if they were very sick or at the end of their life. For instance, some people know they would want to be on a breathing machine. Other people know they would never want to be on a breathing machine. Please give us your honest opinions to the following questions about medical treatments. There are no right or wrong answers.

### SELF-EFFICACY

(2B – CARE AT EOL)

The next two questions ask about how confident you are to actually talk to someone about your medical wishes. You can use the red answers. *[Read options.]*

How confident are you that today you could....	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/Ref.
5. Talk with your decision maker about the care you would want if you were very sick or near the end of life? (PE_S2B_SE1)		1	2	3	4	5	8 / 9
6. Talk with your doctors about the care you would want if you were very sick or near the end of life? (PE_S2B_SE2)		1	2	3	4	5	8 / 9

### READINESS

(2B – CARE AT EOL)

The following questions are about how ready you are to decide and talk about the care you would want if you were very sick or near the end of life.

<p>7. How ready are you to talk to your DECISION MAKER about the kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_TELDM_READY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>8. How ready are you to talk to your DOCTOR about the kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_TELDR_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next few visits</p> <p>4 <input type="checkbox"/> I am definitely planning to do it at the next visit</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

<p>9. How ready are you to SIGN OFFICIAL PAPERS putting your wishes about the kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_PAPER_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

### 3. Flexibility

Now we are going to talk about **flexibility in decision making**. Flexibility means that your decision maker can work with your doctor and change your prior medical decisions, if it is best for you at that time. Patients can decide to give or not give flexibility.

#### SELF-EFFICACY

(3 – FLEXIBILITY)

These questions ask about **how confident you are to talk to someone about flexibility**. You can use the red answers. [Read options.]

How confident are you that today you could.... <i>Red</i>	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/ Ref.
10. Talk with your medical decision maker about how much flexibility you want to give your medical decision maker? (PE_S3_SE2)	1	2	3	4	5	8 / 9
11. Talk with your DOCTOR about how much flexibility you want to give your medical decision maker? (PE_S3_SE2)	1	2	3	4	5	8 / 9

#### READINESS

(3 – FLEXIBILITY)

The following questions are about how ready you are to talk to others about how much flexibility you want to give your medical decision maker and to put this information in writing.

<p>12. How ready are you to talk to your DECISION MAKER about how much flexibility you want to give them? (PE_S3_TELDM_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

13. How ready are you to talk to your DOCTOR about how much flexibility you want to give your decision maker? (PE_S3_TELLDR_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next few visits 4 <input type="checkbox"/> I am definitely planning to do it in the next visit 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)		1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA
		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

## 4. Asking Your Doctor Questions

Now we are going to talk about asking doctors questions.

SELF-EFFICACY						(5 – ASK DR)	
How confident are you that today you could...	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/Ref.
14. Ask the right questions of your doctor to help make good medical decisions? (PE_S5_SE1)		1	2	3	4	5	8 / 9

READINESS		(5 – ASK DR)
15. How ready are you to ask your doctor questions to help you make a good medical decision? (PE_S5_RDY) 1 <input type="checkbox"/> I have never thought about it 2 <input type="checkbox"/> I have thought about it, but I am not ready to do it 3 <input type="checkbox"/> I am thinking about doing it in the next 6 months 4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days 5 <input type="checkbox"/> I have already done it		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)		1 <input type="checkbox"/> Less than 6 mo 2 <input type="checkbox"/> >6 months ago 99 <input type="checkbox"/> NA
		8 <input type="checkbox"/> Not sure 9 <input type="checkbox"/> Refused

# 9 Item Version

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Sudore RL, Heyland DK, Barnes DE, Howard M, Fassbender K, Robinson CA, Boscardin J, You JJ.  
J Pain Symptom Manage. 2017 Apr;53(4):669-681.e8. doi: 10.1016/j.jpainsymman.2016.10.367. Epub  
2016 Dec 29. PMID: 28042072

## PREPARATION ENGAGEMENT SURVEY

### *Introduction*

**We will ask about your experiences and opinions. We may ask about things that you have already done, or have not thought about at all. Just answer as honestly as you can.**

*Over the next few sections we will be asking you about 2 topics:*

- 1. Medical decision makers, or surrogates**
- 2. Deciding what matters most in life**

## 1. Medical Decision Makers

This set of questions ask about medical decision makers. A medical decision maker is a family member or friend who can make decisions for you if you were to become too sick to make your own decisions.

Remember, please give us your honest opinions and there are no right or wrong answers.

### SELF-EFFICACY

(1 – DM)

These questions ask about how confident you are to actually talk to someone about who you choose as your decision maker. You can use the red answers. *[Read options.]*

How confident are you that today you could....	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/Ref.
1. Ask someone to be your medical decision maker? (PE_S1_SE1)		1	2	3	4	5	8 / 9

### READINESS

(1 – DM)

The following questions are about how ready you are to talk to others about who you want your medical decision maker to be and to put this information in writing.

<p>2. How ready are you to formally ask someone to be your medical decision maker? (PE_S1_ASKDM_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>3. How ready are you to talk with your DOCTOR about who you want your medical decision maker to be? (PE_S1_TELLDR_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it over the next few visits</p> <p>4 <input type="checkbox"/> I am definitely planning to do it at the next visit</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>4. How ready are you to SIGN OFFICIAL PAPERS naming a person or group of people to make medical decisions for you? (PE_S1_PAPER_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>



## 2. What Matters Most in Life

We are switching topics now. The previous questions were about how people would or would not want to live.

The following questions are about specific medical treatments that people may or may never want if they were very sick or at the end of their life. For instance, some people know they would want to be on a breathing machine. Other people know they would never want to be on a breathing machine. Please give us your honest opinions to the following questions about medical treatments. There are no right or wrong answers.

### SELF-EFFICACY

(2B – CARE AT EOL)

The next two questions ask about how confident you are to actually talk to someone about your medical wishes. You can use the red answers. *[Read options.]*

How confident are you that today you could....	Red	Not at all	A little	Somewhat	Fairly	Extremely	Not sure/Ref.
5. Talk with your decision maker about the care you would want if you were very sick or near the end of life? (PE_S2B_SE1)		1	2	3	4	5	8 / 9
6. Talk with your doctors about the care you would want if you were very sick or near the end of life? (PE_S2B_SE2)		1	2	3	4	5	8 / 9

### READINESS

(2B – CARE AT EOL)

The following questions are about how ready you are to decide and talk about the care you would want if you were very sick or near the end of life.

<p>7. How ready are you to talk to your DECISION MAKER about the kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_TELDM_READY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>8. How ready are you to talk to your DOCTOR about the kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_TELDR_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next few visits</p> <p>4 <input type="checkbox"/> I am definitely planning to do it at the next visit</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

9. How ready are you to SIGN OFFICIAL PAPERS putting your wishes about the kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_PAPER_RDY)		
1 <input type="checkbox"/> I have never thought about it		8 <input type="checkbox"/> Not sure
2 <input type="checkbox"/> I have thought about it, but I am not ready to do it		9 <input type="checkbox"/> Refused
3 <input type="checkbox"/> I am thinking about doing it in the next 6 months		
4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days		
5 <input type="checkbox"/> I have already done it		
OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)		
1 <input type="checkbox"/> Less than 6 mo		8 <input type="checkbox"/> Not sure
2 <input type="checkbox"/> >6 months ago		9 <input type="checkbox"/> Refused
99 <input type="checkbox"/> NA		

# 4 Item Version

Measuring Advance Care Planning: Optimizing the Advance Care Planning Engagement Survey.  
Sudore RL, Heyland DK, Barnes DE, Howard M, Fassbender K, Robinson CA, Boscardin J, You JJ.  
J Pain Symptom Manage. 2017 Apr;53(4):669-681.e8. doi: 10.1016/j.jpainsymman.2016.10.367. Epub  
2016 Dec 29. PMID: 28042072

## PREPARATION ENGAGEMENT SURVEY

*Introduction*      **We will ask about your experiences and opinions. We may ask about things that you have already done, or have not thought about at all. Just answer as honestly as you can.**

*Over the next few sections we will be asking you about 2 topics:*

- 1. Medical decision makers, or surrogates**
- 2. Deciding what matters most in life**

## 1. Medical Decision Makers

The following question asks about medical decision makers. A medical decision maker is a family member or friend who can make decisions for you if you were to become too sick to make your own decisions.

Remember, please give us your honest opinions and there are no right or wrong answers.

READINESS

(1 – DM)

<p>83. How ready are you to SIGN OFFICIAL PAPERS naming a person or group of people to make medical decisions for you? (PE_S1_PAPER_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>						
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<table border="1"> <tr> <td>1 <input type="checkbox"/> Less than 6 mo</td> <td>8 <input type="checkbox"/> Not sure</td> </tr> <tr> <td>2 <input type="checkbox"/> &gt;6 months ago</td> <td>9 <input type="checkbox"/> Refused</td> </tr> <tr> <td>99 <input type="checkbox"/> NA</td> <td></td> </tr> </table>	1 <input type="checkbox"/> Less than 6 mo	8 <input type="checkbox"/> Not sure	2 <input type="checkbox"/> >6 months ago	9 <input type="checkbox"/> Refused	99 <input type="checkbox"/> NA	
1 <input type="checkbox"/> Less than 6 mo	8 <input type="checkbox"/> Not sure						
2 <input type="checkbox"/> >6 months ago	9 <input type="checkbox"/> Refused						
99 <input type="checkbox"/> NA							

## 2. What Matters Most in Life

The following questions are about specific medical treatments that people may or may never want if they were very sick or at the end of their life. For instance, some people know they would want to be on a breathing machine. Other people know they would never want to be on a breathing machine. Please give us your honest opinions to the following questions about medical treatments. There are no right or wrong answers.

READINESS

(2B – CARE AT EOL)

<p>84. How ready are you to talk to your DECISION MAKER about the kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_TELLDM_READY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>	<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>						
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>	<table border="1"> <tr> <td>1 <input type="checkbox"/> Less than 6 mo</td> <td>8 <input type="checkbox"/> Not sure</td> </tr> <tr> <td>2 <input type="checkbox"/> &gt;6 months ago</td> <td>9 <input type="checkbox"/> Refused</td> </tr> <tr> <td>99 <input type="checkbox"/> NA</td> <td></td> </tr> </table>	1 <input type="checkbox"/> Less than 6 mo	8 <input type="checkbox"/> Not sure	2 <input type="checkbox"/> >6 months ago	9 <input type="checkbox"/> Refused	99 <input type="checkbox"/> NA	
1 <input type="checkbox"/> Less than 6 mo	8 <input type="checkbox"/> Not sure						
2 <input type="checkbox"/> >6 months ago	9 <input type="checkbox"/> Refused						
99 <input type="checkbox"/> NA							

<p>85. How ready are you to talk to your DOCTOR about the kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_TELLDR_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next few visits</p> <p>4 <input type="checkbox"/> I am definitely planning to do it at the next visit</p> <p>5 <input type="checkbox"/> I have already done it</p>		<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>		<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

<p>86. How ready are you to SIGN OFFICIAL PAPERS putting your wishes about the kind of medical care you would want if you were very sick or near the end of life? (PE_S2B_PAPER_RDY)</p> <p>1 <input type="checkbox"/> I have never thought about it</p> <p>2 <input type="checkbox"/> I have thought about it, but I am not ready to do it</p> <p>3 <input type="checkbox"/> I am thinking about doing it in the next 6 months</p> <p>4 <input type="checkbox"/> I am definitely planning to do it in the next 30 days</p> <p>5 <input type="checkbox"/> I have already done it</p>		<p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>
<p>OPTIONAL: If they answered, "I have already done it," then ask "When did you do this?" (PE_S1_DECDM_WHEN)</p>		<p>1 <input type="checkbox"/> Less than 6 mo</p> <p>2 <input type="checkbox"/> &gt;6 months ago</p> <p>99 <input type="checkbox"/> NA</p> <p>8 <input type="checkbox"/> Not sure</p> <p>9 <input type="checkbox"/> Refused</p>

# Encuesta de ochenta y dos preguntas

## Preparación

### *Introduction*

**Tab 6** Esta sección es la más larga. Le preguntaremos sobre sus experiencias y opiniones. Le podemos preguntar acerca de cosas que ya ha hecho o cosas que ni ha pensado en hacer. Responda lo más honestamente que pueda.

En las próximas secciones le preguntaremos acerca de 4 temas:

1. Personas Decisoras o de Substituto
2. Decidir lo que más le importa en la vida
3. Flexibilidad para la persona decisor
4. Hacerle preguntas a su doctor



## 1. Personas Decisoras

Estas preguntas son acerca de las personas decisoras. Una persona decisor es alguien que puede tomar decisiones médicas en su nombre **SÓLO SI** usted está demasiado enfermo para tomar sus propias decisiones.

Recuerde que no hay respuesta correcta o equivocada- por favor denos su honesta opinión.

### KNOWLEDGE

(1 – DM)

Estas 3 preguntas son acerca de qué tan bien informado(a) está usted sobre personas decisoras. [Read options.]

¿Qué tan bien informado(a) esta acerca.....	Red	Para Nada	Un poco	Mas o Menos	Bastante	Extremadam ente	NS/ Ref.
1. de quién puede ser una PERSONA DECISORA? (PE_S1_K1)		1	2	3	4	5	8 / 9
2. de lo que hace que alguien sea una buena PERSONA DECISORA? (PE_S1_K2)		1	2	3	4	5	8 / 9
3. del tipo de decisiones que podrá tomar por usted la PERSONA DECISORA en el futuro? (PE_S1_K3)		1	2	3	4	5	8 / 9

### THOUGHT ABOUT IT

(1 – DM)

Estas preguntas se refieren a qué tanto ha pensado en algo. [Read options.]

¿Qué tanto ha pensado en...	Green	Nunca	Una o Dos Veces	Unas cuantas veces	Bastantes veces	Muchas veces	Not sure/ Ref.
4. quien debería ser su PERSONA DECISORA? (PE_S1_T1)		1	2	3	4	5	8 / 9
5. pedirle a alguien que sea su persona decisor? (PE_S1_T2)		1	2	3	4	5	8 / 9
6. hablar con su doctor sobre quien quiere que sea su persona decisor? (PE_S1_T3)		1	2	3	4	5	8 / 9
7. hablar con sus OTROS familiares y amigos sobre quien desea que fuera su persona decisor? (PE_S1_T4)		1	2	3	4	5	8 / 9

### SELF-EFFICACY

(1 – DM)

Estas preguntas son acerca de qué tan seguro está de que podría hablar sobre a quién ha escogido como su persona decisor.

[Read options.]

Que tan seguro esta de que hoy podria....	Red	Para Nada	Un poco	Mas o Menos	Bastante	Extremadam ente	NS/ Ref.
8. pedirle a alguien que sea su PERSONA DECISORA? (PE_S1_SE1)		1	2	3	4	5	8 / 9
9. hablar con su DOCTOR acerca de quien desea que fuera su persona decisor?(PE_S1_SE2)		1	2	3	4	5	8 / 9
10. hablar con sus OTROS familiares y amigos sobre quién desea que fuera su persona decisor? (PE_S1_SE3)		1	2	3	4	5	8 / 9

## DECISIONS MADE

(1 – DM)

Estas preguntas son acerca de decisiones que quizás ya haya tomado. Pueden ser cosas que posiblemente haya decidido en su mente, aunque no haya hablado con alguien sobre esto todavía.

11. ¿Ya ha decidido quién desea que fuera su PERSONA DECISORA? (PE_S1_DM)	<input type="checkbox"/> Sí <input type="checkbox"/> No	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]
OPTIONAL: If yes, Lo hizo hace <u>MÁS</u> o <u>MENOS</u> de 6 meses? (PE_S1_DECDM_WHEN)	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]
12. ¿Qué tan listo(a) está para decidir quién desea que fuera su PERSONA DECISORA? (PE_S1_DM_RDY)	<input type="checkbox"/> Nunca lo he pensado <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo <input type="checkbox"/> Estoy pensando en hacerlo en los siguientes 6 meses <input type="checkbox"/> Estoy planeando hacerlo en los próximos	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]

## ACTIONS

(1 – DM)

[If no to above, Ya sé que me acaba de decir que no ha decidido quién será su PD y supongo que no, pero..."...]

13. ¿Le ha pedido formalmente a alguien que sea su persona decisora? (PE_S1_ASKDM)	<input type="checkbox"/> Sí <input type="checkbox"/> No	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]
OPTIONAL: If yes, Lo hizo hace <u>MÁS</u> o <u>MENOS</u> de 6 meses? (PE_S1_ASKDM_WHEN)	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]
14. ¿Qué tan listo(a) está para pedirle formalmente a alguien que sea su persona decisora? (PE_S1_DM_RDY)	<input type="checkbox"/> Nunca lo he pensado <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo <input type="checkbox"/> Estoy pensando en hacerlo en los siguientes 6 meses <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días <input type="checkbox"/> Ya lo hice	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

15. ¿Ha hablado con su DOCTOR acerca de quién desea que fuera su persona decisora? (PE_S1_TELLDR)	<input type="checkbox"/> Sí, tuvimos una conversación detallada <input type="checkbox"/> Sí, tuvimos una conversación general <input type="checkbox"/> No, porque asumo que mi doctor sabe lo que quiero <input type="checkbox"/> No, todavía no	
OPTIONAL: If yes, Lo hizo hace <u>MÁS</u> o <u>MENOS</u> de 6 meses? (PE_S1_ASKDM_WHEN)	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]
16. ¿Qué tan listo(a) está para hablar con su DOCTOR acerca de quién desea que fuera su persona decisora?	<input type="checkbox"/> Nunca lo he pensado <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo <input type="checkbox"/> Estoy pensando en hacerlo en las proximas visitas <input type="checkbox"/> Estoy planeando en hacerlo en la proxima visita <input type="checkbox"/> Ya lo hice	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

Ahora le voy a hacer unas preguntas acerca de platicar con sus familiares y amigos, aparte de su persona decisora.

<p>17. ¿Ya ha hablado con sus OTROS familiares y/o amigos acerca de quién quisiera que fuera su persona decisora? Recuerde, serían otras personas que no fueran su persona decisora. (PE_S4_DM)</p>	<p><input type="checkbox"/> Sí, tuvimos una conversación detallada</p> <p><input type="checkbox"/> Sí, tuvimos una conversación general</p> <p><input type="checkbox"/> No, asumo que mis familiares/amigos saben lo que quiero</p> <p><input type="checkbox"/> No, todavía no <span style="float: right;"><input type="checkbox"/> Not Sure</span></p> <p><input type="checkbox"/> No, porque no quiero que mis <span style="float: right;"><input type="checkbox"/> [Ref]</span></p> <p><input type="checkbox"/> familiares y amigos se involucren en mi cuidado médico</p>
<p>OPTIONAL: <i>If yes, Lo hizo hace MÁS o MENOS de 6 meses?</i> (PE_S4_DM_WHEN)</p>	<p><input type="checkbox"/> Less than 6 mo</p> <p><input type="checkbox"/> &gt;6 months ago <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p><input type="checkbox"/> NA <span style="float: right;"><input type="checkbox"/> [Ref]</span></p>
<p>18. ¿Qué tan listo(a) está para hablar con sus OTROS familiares y amigos acerca de quién quisiera que fuera su persona decisora? (PE_S4_DM_RDY)</p>	<p><input type="checkbox"/> Nunca lo he pensado</p> <p><input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p><input type="checkbox"/> Estoy pensando en hacerlo en los siguientes 6 meses</p> <p><input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p><input type="checkbox"/> Ya lo hice <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p style="text-align: right;"><input type="checkbox"/> [Ref]</p>

<p>19. ¿Ha FIRMADO DOCUMENTOS OFICIALES nombrando a una persona o grupo para que tomen decisiones médicas por usted? (PE_S1_PAPER)</p>	<p><input type="checkbox"/> Sí <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p><input type="checkbox"/> No <span style="float: right;"><input type="checkbox"/> [Ref]</span></p>
<p>OPTIONAL: <i>If yes, Lo hizo hace MÁS o MENOS de 6 meses?</i> (PE_S1_PAPER_WHEN)</p>	<p><input type="checkbox"/> Less than 6 mo</p> <p><input type="checkbox"/> &gt;6 months ago <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p><input type="checkbox"/> NA <span style="float: right;"><input type="checkbox"/> [Ref]</span></p>
<p>20. ¿Qué tan listo esta para FIRMAR DOCUMENTOS OFICIALES nombrando a una persona o grupo para tomar decisiones médicas por usted? (PE_S1_PAPER_RDY)</p>	<p><input type="checkbox"/> Nunca lo he pensado</p> <p><input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p><input type="checkbox"/> Estoy pensando en hacerlo en los siguientes 6 meses</p> <p><input type="checkbox"/> Estoy planeando en hacerlo en los próximos 30 días</p> <p><input type="checkbox"/> Ya lo hice <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p style="text-align: right;"><input checked="" type="checkbox"/> [Ref]</p>

## Decidir lo que Más le Importa en la Vida

Ahora queremos hablar de cómo algunas personas se sienten acerca de su calidad de vida. Por ejemplo, cómo quieren vivir, y cómo no quieren vivir. Algunas personas piensan que vale la pena vivir por todas situaciones y experiencias de salud, como estar en un coma o no poder salir de la cama. Otras personas piensan que hay algunas situaciones médicas o experiencias que harían que no valga la pena vivir.

Por favor dénos su opinión honesta. No hay respuesta correcta o equivocada.

### THOUGHT ABOUT IT

### (2 – HEALTH SITUATIONS)

Estas preguntas se refieren a qué tanto ha pensado en algo. [Read options.]

¿Que tanto ha pensado ... <i>Green</i>	Nunca	Una o Dos Veces	Unas cuantas veces	Bastantes veces	Muchas veces	Not sure/ Ref.
21. <u>si</u> ciertas situaciones de salud podrían hacer que su vida no valga la pena? (PE_S2A_T1)	1	2	3	4	5	8 / 9
22. <u>en</u> hablar con su PERSONA DECISORA acerca de situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_T2)	1	2	3	4	5	8 / 9
23. <u>en</u> hablar con su DOCTOR acerca de situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_T3)	1	2	3	4	5	8 / 9
24. <u>en</u> hablar con sus OTROS familiares y amigos acerca de situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_T4)	1	2	3	4	5	8 / 9

### SELF-EFFICACY

### (2 – HEALTH SITUATIONS)

Las próximas tres preguntas son acerca de qué tan confiando está para hablar sobre sus deseos médicos. [Read options.]

¿Que tan seguro(a) está de que hoy podría.... <i>Red</i>	Para Nada	Un poco	Mas o Menos	Bastante	Extremadamente	NS/ Ref.
25. hablar con su PERSONA DECISORA acerca de situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_SE1)	1	2	3	4	5	8 / 9
26. hablar con su DOCTOR acerca de situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_SE2)	1	2	3	4	5	8 / 9
27. hablar con sus OTROS familiares y amigos acerca de situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_SE3)	1	2	3	4	5	8 / 9

## DECISIONS MADE

## (2 – HEALTH SITUATIONS)

Las siguientes preguntas son sobre decisiones que posiblemente ya haya tomado. Puede ser que las haya decidido en su mente, aunque no haya hablado con alguien sobre esto todavía.

De nuevo, situaciones de salud pueden referirse a estar en un coma o no poder salir de la cama.

28. ¿Ya ha decidido si ciertas situaciones de salud podrían hacer que su vida no valga la pena? (PE_S2A_SIT)	1 <input type="checkbox"/> Sí      0 <input type="checkbox"/> No	<input type="checkbox"/> Not sure <input type="checkbox"/> Refused
OPTIONAL: <i>If yes, Lo hizo hace <u>MÁS</u> o <u>MENOS</u> de 6 meses?</i> (PE_S2A_SIT_WHEN)	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]
29. Qué tan listo(a) está para decidir si ciertas situaciones de salud podrían hacer que su vida no valga la pena? (PE_S2A_SIT_RDY) 1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 5 <input type="checkbox"/> Ya lo hice		<input type="checkbox"/> Not sure <input type="checkbox"/> Refused

## ACTIONS

## (2 – HEALTH SITUATIONS)

*[If no to above, I know you haven't decided about certain health situations, but ...]*

30. ¿Ya ha hablado con su PERSONA DECISORA acerca de ciertas situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_TELLDLM) 1 <input type="checkbox"/> Sí, tuvimos una conversación detallada 2 <input type="checkbox"/> Sí, tuvimos una conversación general 3 <input type="checkbox"/> No, porque asumo que mi persona decisora sabe lo que quiero 4 <input type="checkbox"/> No, todavía no	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]	
OPTIONAL: <i>If yes, Lo hizo hace <u>MÁS</u> o <u>MENOS</u> de 6 meses?</i> (PE_S2A_TELLDLM_WHEN)	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]	
31. ¿Qué tan listo(a) está para hablar con su PERSONA DECISORA acerca de ciertas situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_TELLDLM_RDY) 1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 5 <input type="checkbox"/> Ya lo hice		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]

32. ¿Ya ha hablado con su DOCTOR acerca de ciertas situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_TELLDR)		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
1 <input type="checkbox"/> Sí, tuvimos una conversación detallada 2 <input type="checkbox"/> Sí, tuvimos una conversación general 3 <input type="checkbox"/> No, porque asumo que mi doctor sabe lo que quiero 4 <input type="checkbox"/> No, todavía no		
OPTIONAL: If yes, Lo hizo hace <u>MÁS</u> o <u>MENOS</u> de 6 meses? (PE_S2A_TELLDR_WHEN)		<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]
33. ¿Qué tan listo(a) está para hablar con su DOCTOR acerca de situaciones de salud que podrían hacer que su vida no valga la pena?(PE_S2A_TELLDR_RDY)		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en las próximas visitas 4 <input type="checkbox"/> Estoy planeando hacerlo en la próxima visita 5 <input type="checkbox"/> Ya lo hice		

**Ahora voy a hacer algunas preguntas sobre hablar con otros familiares y amigos aparte de su persona decisora.**

34. ¿Ya ha hablado con sus OTROS familiares y amigos acerca de ciertas situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S4_SIT)		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
1 <input type="checkbox"/> Sí, tuvimos una conversación detallada 2 <input type="checkbox"/> Sí, tuvimos una conversación general 3 <input type="checkbox"/> No, porque asumo que mi doctor sabe lo que quiero 4 <input type="checkbox"/> No, todavía no 5 <input type="checkbox"/> No, porque no quiero que mi familia y amigos se involucren en mi cuidado médico		
OPTIONAL: If yes, Lo hizo hace <u>MÁS</u> o <u>MENOS</u> de 6 meses? (PE_S4_SIT_WHEN)		<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]
35. ¿Qué tan listo(a) está para hablar con sus OTROS familiares y amigos acerca de situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S4_SIT_RDY)		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 5 <input type="checkbox"/> Ya lo hice		

36. ¿Ha FIRMADO DOCUMENTOS OFICIALES para poner sus deseos por escrito acerca de situaciones de salud que podrían hacer que su vida no valga la pena? Estas formas a veces son llamadas formulario de instrucciones anticipadas de atención de salud o testamento vital. (PE_S2A_PAPER)		1 <input type="checkbox"/> Sí      0 <input type="checkbox"/> No <input type="checkbox"/> Not sure <input type="checkbox"/> Refused
OPTIONAL: If yes, Lo hizo hace <u>MÁS</u> o <u>MENOS</u> de 6 meses? (PE_S2A_PAPER_WHEN)		<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]
37. ¿Qué tan listo(a) está para FIRMAR DOCUMENTOS OFICIALES que pongan sus deseos por escrito acerca de situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_PAPER_RDY)		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 5 <input type="checkbox"/> Ya lo hice		

Ahora vamos a cambiar de tema. Las preguntas previas se tratan de cómo la gente quisiera o no quisiera vivir. Las siguientes preguntas son acerca de tratamientos médicos específicos que algunas personas quisieran o no quisieran si estuvieran gravemente enfermos o al final de su vida. Por ejemplo, algunas personas saben que quisieran estar conectados a un respirador. Otras personas saben que nunca quisieran estar conectados a un respirador.

Por favor dénos su honesta opinión en las próximas preguntas acerca de los tratamientos médicos. No hay respuesta correcta o equivocada.

**THOUGHT ABOUT IT** **(2B – CARE AT EOL)**

Estas preguntas se refieren a qué tanto ha pensado en algo. [Read options.]

Qué tanto ha pensado en... <i>Green</i>	Nunca	Una o Dos Veces	Unas cuantas veces	Bastantes veces	Muchas veces	Not sure/ Ref.
38. ¿Qué tanto ha pensado en el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_T1)	1	2	3	4	5	8 / 9
39. ¿Qué tanto ha pensado en hablar con su PERSONA DECISORA acerca del tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_T2)	1	2	3	4	5	8 / 9
40. ¿Qué tanto ha pensado en hablar con su DOCTOR acerca del tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_T3)	1	2	3	4	5	8 / 9
41. ¿Qué tanto ha pensado en hablar con sus OTROS familiares y amigos acerca del tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_T4)	1	2	3	4	5	8 / 9

**SELF-EFFICACY** **(2B – CARE AT EOL)**

Las próximas tres preguntas son acerca de qué tan confiando está para hablar sobre sus deseos médicos. [Read options.]

Qué tan seguro está de que hoy podría... <i>Red</i>	Para Nada	Un poco	Mas o Menos	Bastante	Extremadamente	NS/ Ref.
42. ¿Qué tan seguro(a) está de que hoy podría hablar con su PERSONA DECISORA acerca del tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_SE1)	1	2	3	4	5	8 / 9
43. ¿Qué tan seguro(a) está de que hoy podría hablar con su DOCTOR acerca del tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_SE2)	1	2	3	4	5	8 / 9
44. ¿Qué tan seguro(a) está de que hoy podría hablar con sus OTROS familiares y amigos acerca del tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_SE3)	1	2	3	4	5	8 / 9

## DECISIONS MADE

(2B – CARE AT EOL)

Las siguientes preguntas son sobre decisiones que tal vez ya ha tomado. Estas son cosas que tal vez ya decidió en su mente, incluso si aún no ha hablado con alguien al respecto.

45. ¿Ya ha decidido qué tipo de cuidado médico quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2_CARE)	1 <input type="checkbox"/> Yes    0 <input type="checkbox"/> No	<input type="checkbox"/> Not sure <input type="checkbox"/> Refused
OPTIONAL: If yes, Lo hizo hace <u>MÁS</u> o <u>MENOS</u> de 6 meses? (PE_S2_CARE_WHEN)	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]
46. ¿Qué tan listo(a) está para decidir qué tipo de cuidado médico quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2_CARE_RDY) 1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 5 <input type="checkbox"/> Ya lo hice	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]	

## ACTIONS

(2B – CARE AT EOL)

[If no to above, I know you haven't decided about the care you'd want, but ...]

47. ¿Alguna vez ha hablado con su PERSONA DECISORA sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_TELDM) 1 <input type="checkbox"/> Sí, tuvimos una conversación detallada 2 <input type="checkbox"/> Sí, tuvimos una conversación general 3 <input type="checkbox"/> No, porque asumo que mi persona decisora sabe lo que quiero 4 <input type="checkbox"/> No, todavía no	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
OPTIONAL: If yes, Lo hizo hace <u>MÁS</u> o <u>MENOS</u> de 6 meses? (PE_S2B_TELDM_WHEN)	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]
48. ¿Qué tan listo(a) está para hablar con su PERSONA DECISORA sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_TELDM_READY) 1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 5 <input type="checkbox"/> Ya lo hice	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]



<p>49. ¿Alguna vez ha hablado con su DOCTOR sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_TELLDR)</p> <p>1 <input type="checkbox"/> Sí, tuvimos una conversación detallada</p> <p>2 <input type="checkbox"/> Sí, tuvimos una conversación general</p> <p>3 <input type="checkbox"/> No, porque asumo que mi doctor sabe lo que quiero</p> <p>4 <input type="checkbox"/> No, todavía no</p>	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
<p>OPTIONAL: <i>If yes, Lo hizo hace MÁS o MENOS de 6 meses?</i> (PE_S2B_TELLDR_WHEN)</p>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]
<p>50. ¿Qué tan listo(a) está para hablar con su DOCTOR sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_TELLDR_RDY)</p> <p>1 <input type="checkbox"/> Nunca lo he pensado</p> <p>2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>3 <input type="checkbox"/> Estoy pensando en hacerlo en las próximas visitas</p> <p>4 <input type="checkbox"/> Estoy planeando hacerlo en la próxima visita</p> <p>5 <input type="checkbox"/> Ya lo hice</p>	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]

**Ahora voy a hacer algunas preguntas sobre hablar con otros familiares y amigos aparte de su persona decisora.**

<p>51. ¿Alguna vez ha hablado con sus OTROS familiares y amigos sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S4_CARE)</p> <p>1 <input type="checkbox"/> Sí, tuvimos una conversación detallada</p> <p>2 <input type="checkbox"/> Sí, tuvimos una conversación general</p> <p>3 <input type="checkbox"/> No, porque asumo que mis familiares y amigos saben lo que quiero</p> <p>4 <input type="checkbox"/> No, todavía no</p> <p>5 <input type="checkbox"/> No, porque no quiero que mi familia y amigos se involucren en mi cuidado médico</p>	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
<p>OPTIONAL: <i>If yes, Lo hizo hace MÁS o MENOS de 6 meses?</i> (PE_S4_CARE_WHEN)</p>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]
<p>52. ¿Qué tan listo(a) está para hablar con sus OTROS familiares y amigos sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S4_CARE_RDY)</p> <p>1 <input type="checkbox"/> Nunca lo he pensado</p> <p>2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>5 <input type="checkbox"/> Ya lo hice</p>	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]

<p>53. ¿Ha FIRMADO DOCUMENTOS OFICIALES que pongan sus deseos por escrito sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? Estas formas a veces son llamadas formulario de instrucciones anticipadas de atención de salud o testamento vital. (PE_S2B_PAPER)</p>	<p>1 <input type="checkbox"/> Yes    0 <input type="checkbox"/> No    <input type="checkbox"/> Not sure</p> <p><input type="checkbox"/> Refused</p>
<p>OPTIONAL: <i>If yes, Lo hizo hace MÁS o MENOS de 6 meses?</i> (PE_S2B_PAPER_WHEN)</p>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]
<p>54. ¿Qué tan listo(a) está para FIRMAR DOCUMENTOS OFICIALES que pongan sus deseos por escrito sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_PAPER_RDY)</p> <p>1 <input type="checkbox"/> Nunca lo he pensado</p> <p>2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>5 <input type="checkbox"/> Ya lo hice</p>	<input type="checkbox"/> Not Sure

## Flexibilidad

Ahora hablaremos de la flexibilidad para tomar decisiones médicas.

Flexibilidad significa que su persona decisor(a) puede trabajar con su doctor y cambiar sus decisiones médicas previas, si es lo mejor para usted en ese momento.

**Usted puede decidir dar o no dar flexibilidad.** KNOWLEDGE

**(3 – FLEXIBILITY)**

Las siguientes dos preguntas son acerca de la flexibilidad para tomar decisiones médicas. [Read options.]

Qué tan bien informado está acerca de...	Red	Para Nada	Un poco	Mas o Menos	Bastante	Extremadamente	NS/ Ref.
55. ¿Qué tan bien informado(a) está acerca de lo que significa dar flexibilidad a su persona decisor(a) para tomar decisiones médicas en el futuro? (PE_S3_K1)		1	2	3	4	5	8 / 9
56. 76. ¿Qué tan bien informado(a) está acerca de cuánta flexibilidad un paciente le puede dar a su persona decisor(a)? (PE_S3_K2)		1	2	3	4	5	8 / 9

**THOUGHT ABOUT IT**

**(3 – FLEXIBILITY)**

Estas preguntas son acerca de cuánto ha pensado en la flexibilidad. [Read options.]

Qué tanto ha pensado en...	Green	Nunca	Una o Dos Veces	Unas cuantas veces	Bastantes veces	Muchas veces	Not sure/ Ref.
57. ¿Qué tanto ha pensado en cuánta flexibilidad le quisiera dar a su persona decisor(a)? (PE_S3_T1)		1	2	3	4	5	8 / 9
58. ¿Qué tanto ha pensado en hablar con su PERSONA DECISORA acerca de cuánta flexibilidad le quisiera dar? (PE_S3_T2)		1	2	3	4	5	8 / 9
59. ¿Qué tanto ha pensado en hablar con su DOCTOR acerca de cuánta flexibilidad le quisiera dar a su persona decisor(a)? (PE_S3_T3)		1	2	3	4	5	8 / 9
60. ¿Qué tanto ha pensado en hablar con sus OTROS familiares y amigos acerca de cuánta flexibilidad le quisiera dar a su persona decisor(a)? (PE_S3_T4)		1	2	3	4	5	8 / 9

**SELF-EFFICACY**

**(3 – FLEXIBILITY)**

Estas preguntas son acerca de qué tan seguro(a) está para hablar de flexibilidad. [Read options.]

Qué tan seguro está de que hoy podría...	Red	Para Nada	Un poco	Mas o Menos	Bastante	Extremadamente	NS/ Ref.
61. ¿Qué tan seguro(a) está de que hoy podría hablar con su PERSONA DECISORA acerca de cuánta flexibilidad le quisiera dar? (PE_S3_SE1)		1	2	3	4	5	8 / 9
62. ¿Qué tan seguro(a) está de que hoy podría hablar con su DOCTOR acerca de cuánta flexibilidad le quisiera dar a su persona decisor(a)? (PE_S3_SE2)		1	2	3	4	5	8 / 9
63. ¿Qué tan seguro(a) está de que hoy podría hablar con sus OTROS familiares y amigos acerca de cuánta flexibilidad le quisiera dar a su persona decisor(a)? (PE_S3_SE3)		1	2	3	4	5	8 / 9

## DECISIONS MADE

(3 – FLEXIBILITY)

Las siguientes preguntas son sobre decisiones que tal vez ya ha tomado. Estas son cosas que tal vez ya decidió en su mente, incluso si aún no ha hablado con alguien al respecto.

64. ¿Ha decidido cuánta flexibilidad le quisiera dar a su persona decisora si tuviera que tomar decisiones por usted? (PE_S3_FLX)	1 <input type="checkbox"/> Yes    0 <input type="checkbox"/> No <input type="checkbox"/> Not sure <input type="checkbox"/> Refused
OPTIONAL: If yes, Lo hizo hace <u>MÁS</u> o <u>MENOS</u> de 6 meses? (PE_S3_FLX_WHEN)	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> Not sure <input type="checkbox"/> NA <input type="checkbox"/> [Ref]
65. ¿Qué tan listo(a) está para decidir cuánta flexibilidad le quisiera dar a su persona decisora si él/ella tuviera que tomar decisiones por usted? (PE_S3_FLX_RDY)	<input type="checkbox"/> Not Sure <input type="checkbox"/> Refused
1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 5 <input type="checkbox"/> Ya lo hice	

## ACTIONS

(3 – FLEXIBILITY)

[If no to above, “Ya sé que no ha decidido sobre la flexibilidad, pero...”]

66. ¿Ha hablado con su PERSONA DECISORA acerca de cuánta flexibilidad le quisiera dar? (PE_S3_TELLDLM)	<input type="checkbox"/> Not Sure <input type="checkbox"/> Refused
1 <input type="checkbox"/> Sí, tuvimos una conversación detallada 2 <input type="checkbox"/> Sí, tuvimos una conversación general 3 <input type="checkbox"/> No, porque asumo que mi persona decisora sabe lo que quiero 4 <input type="checkbox"/> No, todavía no	
OPTIONAL: If yes, Lo hizo hace <u>MÁS</u> o <u>MENOS</u> de 6 meses? (PE_S3_TELLDLM_WHEN)	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> Not sure <input type="checkbox"/> NA <input type="checkbox"/> [Ref]
67. ¿Qué tan listo(a) está para hablar con su PERSONA DECISORA acerca de cuánta flexibilidad le quisiera dar? (PE_S3_TELLDLM_RDY)	<input type="checkbox"/> Not Sure <input type="checkbox"/> Refused
1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 5 <input type="checkbox"/> Ya lo hice	
68. ¿Ha hablado con su DOCTOR acerca de cuánta flexibilidad le quisiera dar a su persona decisora? (PE_S3_TELLDLDR)	<input type="checkbox"/> Not Sure <input type="checkbox"/> Refused
1 <input type="checkbox"/> Sí, tuvimos una conversación detallada 2 <input type="checkbox"/> Sí, tuvimos una conversación general 3 <input type="checkbox"/> No, porque asumo que mi doctor sabe lo que quiero 4 <input type="checkbox"/> No, todavía no	
OPTIONAL: If yes, Lo hizo hace <u>MÁS</u> o <u>MENOS</u> de 6 meses? (PE_S3_TELLDLDR_WHEN)	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> Not sure <input type="checkbox"/> NA <input type="checkbox"/> [Ref]
69. ¿Qué tan listo(a) está para hablar con su DOCTOR acerca de cuánta flexibilidad le quiere dar a su persona decisora? (PE_S3_TELLDLDR_RDY)	<input type="checkbox"/> Not Sure
1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en las próximas visitas 4 <input type="checkbox"/> Estoy planeando hacerlo en la próxima visita 5 <input type="checkbox"/> Ya lo hice	

**Ahora voy a hacerle algunas preguntas acerca de hablar con otros familiares y amigos, aparte de su persona decisora.**

<p>70. ¿Ha hablado con sus OTROS familiares y amigos acerca de cuánta flexibilidad le quisiera dar a su persona decisora? (PE_S4_FLX)</p> <p>1 <input type="checkbox"/> Sí, tuvimos una conversación detallada</p> <p>2 <input type="checkbox"/> Sí, tuvimos una conversación general</p> <p>3 <input type="checkbox"/> No, porque asumo que mis familiares y amigos saben lo que quiero</p> <p>4 <input type="checkbox"/> No, todavía no</p> <p>5 <input type="checkbox"/> No, porque no quiero que mi familia y amigos se involucren en mi cuidado médico</p>	<input type="checkbox"/> Not Sure
<p>OPTIONAL: <i>If yes, Lo hizo hace MÁS o MENOS de 6 meses?</i> (PE_S4_FLX_WHEN)</p>	<div> <input type="checkbox"/> Less than 6 mo         <input type="checkbox"/> &gt;6 months ago         <input type="checkbox"/> NA       </div> <div> <input type="checkbox"/> Not sure         <input type="checkbox"/> [Ref]       </div>
<p>71. ¿Qué tan listo(a) está para hablar con sus OTROS familiares y amigos acerca de cuánta flexibilidad le quisiera dar a su persona decisora? (PE_S4_FLX_RDY)</p> <p>1 <input type="checkbox"/> Nunca lo he pensado</p> <p>2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>5 <input type="checkbox"/> Ya lo hice</p>	<input type="checkbox"/> Not Sure

<p>72. ¿Ha FIRMADO DOCUMENTOS OFICIALES para poner sus deseos por escrito acerca de cuánta flexibilidad le quisiera dar a su persona decisora? (PE_S3_PAPER)</p>	<div> 1 <input type="checkbox"/> Yes         0 <input type="checkbox"/> No         <input type="checkbox"/> Not sure       </div>
<p>OPTIONAL: <i>If yes, Lo hizo hace MÁS o MENOS de 6 meses?</i> (PE_S3_PAPER_WHEN)</p>	<div> <input type="checkbox"/> Less than 6 mo         <input type="checkbox"/> &gt;6 months ago         <input type="checkbox"/> NA       </div> <div> <input type="checkbox"/> Not sure         <input type="checkbox"/> [Ref]       </div>
<p>73. ¿Qué tan listo(a) está para firmar DOCUMENTOS OFICIALES que pongan sus deseos por escrito acerca de cuánta flexibilidad le quisiera dar a su persona decisora? (PE_S3_PAPER_RDY)</p> <p>1 <input type="checkbox"/> Nunca lo he pensado</p> <p>2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>5 <input type="checkbox"/> Ya lo hice</p>	<input type="checkbox"/> Not Sure

## Hacerle Preguntas a sus Doctores

Ahora vamos a hablar acerca de hacerle preguntas a su doctor.

KNOWLEDGE		(5 –ASK DR)					
Qué tan bien informado está acerca de...	Red	Para Nada	Un poco	Mas o Menos	Bastante	Extremadam ente	NS/ Ref.
74. ¿Qué tan informado(a) está acerca de qué tipos de preguntas le podría hacer a su DOCTOR que le ayuden a tomar una buena decisión médica? (PE_S5_K1)		1	2	3	4	5	8 / 9

THOUGHT ABOUT IT		(5 –ASK DR)				
Qué tanto ha pensado en... <i>Green</i>	Nunca	Una o Dos Veces	Unas cuantas veces	Bastantes veces	Muchas veces	Not sure/ Ref.
75. ¿Qué tanto ha pensado en qué preguntas le haría a su DOCTOR para ayudarle a tomar una buena decisión médica? (PE_S5_T1)	1	2	3	4	5	8 / 9

SELF-EFFICACY		(5 –ASK DR)					
Qué tan seguro está de que hoy podría...	Red	Para Nada	Un poco	Mas o Menos	Bastante	Extremadam ente	NS/ Ref.
76. ¿Qué tan seguro está de que hoy podría hacerle a su DOCTOR las preguntas correctas para ayudarle a tomar una buena decisión médica? (PE_S5_SE1)		1	2	3	4	5	8 / 9

DECISIONS MADE/ACTIONS		(5 – ASK DR)		
Responda a estas preguntas con Sí o No				
77. ¿Alguna vez le ha preguntado a su DOCTOR sobre los riesgos del tratamiento? (PE_S5_RISKS)	1 <input type="checkbox"/> Yes	0 <input type="checkbox"/> No	<input type="checkbox"/> Not Sure	
78. ¿Alguna vez le ha preguntado a su DOCTOR sobre los beneficios del tratamiento? (PE_S5_BENFT)	1 <input type="checkbox"/> Yes	0 <input type="checkbox"/> No	<input type="checkbox"/> Not Sure	
79. ¿Alguna vez le ha preguntado a su DOCTOR si tenía otras opciones de tratamiento diferentes a las que le estaban sugiriendo los doctores? (PE_S5_OPTN)	1 <input type="checkbox"/> Yes	0 <input type="checkbox"/> No	<input type="checkbox"/> Not Sure	
80. ¿Alguna vez le ha preguntado a su DOCTOR cómo sería su calidad de vida después de comenzar un tratamiento? (PE_S5_QOL)	1 <input type="checkbox"/> Yes	0 <input type="checkbox"/> No	<input type="checkbox"/> Not Sure	
81. ¿Alguna vez le ha pedido a su DOCTOR que le repita alguna información si no le entendió la primera vez? (PE_S5_REPEAT)	1 <input type="checkbox"/> Yes	0 <input type="checkbox"/> No	<input type="checkbox"/> Not Sure <input type="checkbox"/> Refused	
82. ¿Qué tan listo(a) está para hacerle preguntas a su DOCTOR que le ayuden a tomar una buena decisión médica? (PE_S5_RDY) 1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 5 <input type="checkbox"/> Ya lo hice			<input type="checkbox"/> Not Sure  <input type="checkbox"/> Refused	

# **Encuesta de cincuenta y cinco preguntas**

## Preparación

### *Introduction*

**Tab 6 Esta sección es la más larga. Le preguntaremos sobre sus experiencias y opiniones. Le podemos preguntar acerca de cosas que ya ha hecho o cosas que ni ha pensado en hacer. Responda lo más honestamente que pueda.**

En las próximas secciones le preguntaremos acerca de 4 temas:

1. Personas Decisoras o de Substituto
2. Decidir lo que más le importa en la vida
3. Flexibilidad para la persona decisor
4. Hacerle preguntas a su doctor

## 1. Personas Decisoras

Estas preguntas son acerca de las personas decisoras. Una persona decisor es alguien que puede tomar decisiones médicas en su nombre SÓLO SI usted está demasiado enfermo para tomar sus propias decisiones.

Recuerde que no hay respuesta correcta o equivocada- por favor denos su honesta opinión.

### KNOWLEDGE

(1 – DM)

Estas 3 preguntas son acerca de qué tan bien informado está sobre las personas decisoras. [Read options.]

¿Que tan bien informado(a) esta acerca.....	Red	Para Nada	Un poco	Mas o Menos	Bastante	Extremadamente	NS/ Ref.
1. de quién puede ser una PERSONA DECISORA? (PE_S1_K1)		1	2	3	4	5	8 / 9
2. de lo que hace que alguien sea una buena PERSONA DECISORA? (PE_S1_K2)		1	2	3	4	5	8 / 9
3. del tipo de decisiones que podrá tomar por usted la PERSONA DECISORA en el futuro? (PE_S1_K3)		1	2	3	4	5	8 / 9

### THOUGHT ABOUT IT

(1 – DM)

Estas preguntas son acerca de qué tanto ha pensado en algo. [Read options.]

¿Que tanto ha pensado en...	Green	Nunca	Una o Dos Veces	Unas cuantas veces	Bastantes veces	Muchas veces	Not sure/ Ref.
4. quien deberia ser su PERSONA DECISORA? (PE_S1_T1)		1	2	3	4	5	8 / 9
5. pedirle a alguien que sea su persona decisor? (PE_S1_T2)		1	2	3	4	5	8 / 9
6. hablar con su doctor sobre quien quiere que sea su persona decisor? (PE_S1_T3)		1	2	3	4	5	8 / 9
7. hablar con sus OTROS familiares y amigos sobre quien desea que fuera su persona decisor? (PE_S1_T4)		1	2	3	4	5	8 / 9

### SELF-EFFICACY

(1 – DM)

Estas preguntas son acerca de que tñ seguro se siente para hablar sobre a quién ha elegido como su persona decisor. [Read options.]

Que tan seguro esta de que hoy podria....	Red	Para Nada	Un poco	Mas o Menos	Bastante	Extremadamente	NS/ Ref.
8. pedirle a alguien que sea su PERSONA DECISORA? (PE_S1_SE1)		1	2	3	4	5	8 / 9
9. hablar con su DOCTOR acerca de quien desea que fuera su persona decisor?(PE_S1_SE2)		1	2	3	4	5	8 / 9
10. hablar con sus OTROS familiares y amigos sobre quién desea que fuera su persona decisor? (PE_S1_SE3)		1	2	3	4	5	8 / 9



Las siguientes preguntas son acerca de qué tan listo está para hablar con otras personas sobre quién desea que sea su persona decisora y para poner esta información por escrito.

<p>11. ¿Qué tan listo(a) está para pedirle formalmente a alguien que sea su persona decisora? (PE_S1_DM_RDY)</p>	<p><input type="checkbox"/> <u>Nunca</u> lo he pensado</p> <p><input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p><input type="checkbox"/> <u>Estoy pensando</u> en hacerlo en los siguientes 6 meses</p> <p><input type="checkbox"/> <u>Estoy planeando</u> hacerlo en los próximos 30 días</p> <p><input type="checkbox"/> Ya lo <u>hice</u> <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p style="text-align: right;"><input type="checkbox"/> [Ref]</p>	
<p>OPTIONAL: If they answered, “Ya lo hice,” then ask “Cuando lo hizo?” (PE_S1_DECDM_WHEN)</p>	<p><input type="checkbox"/> Less than 6 mo</p> <p><input type="checkbox"/> &gt;6 months ago <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p><input type="checkbox"/> NA <span style="float: right;"><input type="checkbox"/> [Ref]</span></p>	
<p>12. ¿Qué tan listo(a) está para hablar con su DOCTOR acerca de quién desea que fuera su persona decisora?</p> <p>OPTIONAL: If they answered, “Ya lo hice,” then ask “Cuando lo hizo?” (PE_S1_DECDM_WHEN)</p>	<p><input type="checkbox"/> <u>Nunca</u> lo he pensado</p> <p><input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p><input type="checkbox"/> <u>Estoy pensando</u> en hacerlo en los siguientes 6 meses</p> <p><input type="checkbox"/> <u>Estoy planeando</u> hacerlo en los</p> <p><input type="checkbox"/> Less than 6 mo</p> <p><input type="checkbox"/> &gt;6 months ago</p> <p><input type="checkbox"/> NA</p>	<p><input type="checkbox"/> Not Sure</p> <p><input type="checkbox"/> [Ref]</p> <p><input type="checkbox"/> Not Sure</p> <p><input type="checkbox"/> [Ref]</p>

Ahora voy a hacerle algunas preguntas acerca de hablar con otros familiares y amigos. “Otros familiares y amigos” son personas que pueden ser parte de su vida y tener opiniones acerca de su cuidado médico, pero ellos so serían a quienes usted elegiría como persona decisora.

<p>13. ¿Qué tan listo(a) está para hablar con sus OTROS familiares y amigos acerca de quién quisiera que fuera su persona decisora? (PE_S4_DM_RDY)</p> <p>OPTIONAL: If they answered, “Ya lo hice,” then ask “Cuando lo hizo?” (PE_S1_DECDM_WHEN)</p>	<p><input type="checkbox"/> <u>Nunca</u> lo he pensado</p> <p><input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p><input type="checkbox"/> <u>Estoy pensando</u> en hacerlo en los siguientes 6 meses</p> <p><input type="checkbox"/> <u>Estoy planeando</u> hacerlo en los próximos 30 días</p> <p><input type="checkbox"/> Ya lo <u>hice</u> <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p style="text-align: right;"><input type="checkbox"/> [Ref]</p> <p><input type="checkbox"/> Less than 6 mo</p> <p><input type="checkbox"/> &gt;6 months ago <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p><input type="checkbox"/> NA <span style="float: right;"><input type="checkbox"/> [Ref]</span></p>	
<p>14. ¿Qué tan listo esta para FIRMAR DOCUMENTOS OFICIALES nombrando a una persona o grupo para tomar decisiones médicas por usted? (PE_S1_PAPER_RDY)</p> <p>OPTIONAL: If they answered, “Ya lo hice,” then ask “Cuando lo hizo?” (PE_S1_DECDM_WHEN)</p>	<p><input type="checkbox"/> <u>Nunca</u> lo he pensado</p> <p><input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo <u>Estoy</u></p> <p><input type="checkbox"/> <u>pensando</u> en hacerlo en los siguientes 6 meses</p> <p><input type="checkbox"/> <u>Estoy planeando</u> en hacerlo en los próximos 30 días</p> <p><input type="checkbox"/> Ya lo <u>hice</u> <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p style="text-align: right;"><input type="checkbox"/> [Ref]</p> <p><input type="checkbox"/> Less than 6 mo</p> <p><input type="checkbox"/> &gt;6 months ago <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p><input type="checkbox"/> NA <span style="float: right;"><input type="checkbox"/> [Ref]</span></p>	

## Decidir lo que Más le Importa en la Vida

Ahora queremos hablar de cómo algunas personas se sienten acerca de su calidad de vida. Por ejemplo, cómo quieren vivir, y cómo no quieren vivir. Algunas personas piensan que vale la pena vivir por todas situaciones y experiencias de salud, como estar en un coma o no poder salir de la cama. Otras personas piensan que hay algunas situaciones médicas o experiencias que harían que no valga la pena vivir.

Por favor dénos su opinión honesta. No hay respuesta correcta o equivocada.

### THOUGHT ABOUT IT

### (2 – HEALTH SITUATIONS)

Estas preguntas son acerca de qué tanto ha pensado en algo. [Read options.]

¿Que tanto ha pensado ... <i>Green</i>	Nunca	Una o Dos Veces	Unas cuantas veces	Bastantes veces	Muchas veces	Not sure/ Ref.
15. <u>si</u> ciertas situaciones de salud podrían hacer que su vida no valga la pena? (PE_S2A_T1)	1	2	3	4	5	8 / 9
16. <u>en</u> hablar con su PERSONA DECISORA acerca de situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_T2)	1	2	3	4	5	8 / 9
17. <u>en</u> hablar con su DOCTOR acerca de situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_T3)	1	2	3	4	5	8 / 9
18. <u>en</u> hablar con sus OTROS familiares y amigos acerca de situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_T4)	1	2	3	4	5	8 / 9

### SELF-EFFICACY

### (2 – HEALTH SITUATIONS)

Las siguientes 3 preguntas son acerca de qué tan seguro se siente para hablar sobre sus deseos médicos . [Read options.]

¿Que tan seguro(a) esta de que hoy podria.... <i>Red</i>	Para Nada	Un poco	Mas o Menos	Bastante	Extremadamente	NS/ Ref.
19. hablar con su PERSONA DECISORA acerca de situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_SE1)	1	2	3	4	5	8 / 9
20. hablar con su DOCTOR acerca de situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_SE2)	1	2	3	4	5	8 / 9
21. hablar con sus OTROS familiares y amigos acerca de situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_SE3)	1	2	3	4	5	8 / 9

Las siguientes preguntas son acerca de qué tan listo se siente para decidir y hablar sobre situaciones de salud. De nuevo, situaciones de salud pueden referirse a estar en un coma o no poder salir de la cama.

22. Qué tan listo(a) está para decidir si ciertas situaciones de salud podrían hacer que su vida no valga la pena? <small>(PE_S2A_SIT_RDY)</small> 1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 5 <input type="checkbox"/> Ya lo hice	<input type="checkbox"/> Not sure <input type="checkbox"/> Refused
OPTIONAL: If they answered, "Ya lo hice," then ask "Cuándo lo hizo?" <small>(PE_S1_DECDM_WHEN)</small>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

*[If they haven't already done it, say "sé que no ha decidido sobre ciertas situaciones de salud, pero..."]*

23. ¿Qué tan listo(a) está para hablar con su PERSONA DECISORA acerca de ciertas situaciones de salud que podrían hacer que su vida no valga la pena? <small>(PE_S2A_TELLDM_RDY)</small> 1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 5 <input type="checkbox"/> Ya lo hice	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
OPTIONAL: If they answered, "Ya lo hice," then ask "Cuándo lo hizo?" <small>(PE_S1_DECDM_WHEN)</small>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]
24. ¿Qué tan listo(a) está para hablar con su DOCTOR acerca de situaciones de salud que podrían hacer que su vida no valga la pena? <small>(PE_S2A_TELLDR_RDY)</small> 1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en las próximas visitas 4 <input type="checkbox"/> Estoy planeando hacerlo en la próxima visita 5 <input type="checkbox"/> Ya lo hice	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
OPTIONAL: If they answered, "Ya lo hice," then ask "Cuándo lo hizo?" <small>(PE_S1_DECDM_WHEN)</small>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

Ahora voy a hacerle algunas preguntas acerca de hablar con otros familiares y amigos quienes no serían su persona decisora.

25. ¿Qué tan listo(a) está para hablar con sus OTROS familiares y amigos acerca de situaciones de salud que podrían hacer que su vida no valga la pena? <small>(PE_S4_SIT_RDY)</small> 1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 5 <input type="checkbox"/> Ya lo hice	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
OPTIONAL: If they answered, "Ya lo hice," then ask "Cuándo lo hizo?" <small>(PE_S1_DECDM_WHEN)</small>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

26. ¿Qué tan listo(a) está para FIRMAR DOCUMENTOS OFICIALES que pongan sus deseos por escrito acerca de situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_PAPER_RDY)	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 6 <input type="checkbox"/> Ya lo hice	
OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

Ahora vamos a cambiar de tema. Las preguntas previas se tratan de cómo la gente quisiera o no quisiera vivir. Las siguientes preguntas son acerca de tratamientos médicos específicos que algunas personas quisieran o no quisieran si estuvieran gravemente enfermos o al final de su vida. Por ejemplo, algunas personas saben que quisieran estar conectados a un respirador. Otras personas saben que nunca quisieran estar conectados a un respirador.

Por favor dénos su honesta opinión en las próximas preguntas acerca de los tratamientos médicos. No hay respuesta correcta o equivocada.

THOUGHT ABOUT IT		(2B – CARE AT EOL)				
Estas preguntas son acerca de <u>qué tanto ha pensado en algo</u> . [Read options.]						
Que tanto ha pensado acerca de... <span style="float: right;"><i>Green</i></span>	Nunca	Una o Dos Veces	Unas cuantas veces	Bastantes veces	Muchas veces	Not sure/ Ref.
27. ¿Qué tanto ha pensado en el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_T1)	1	2	3	4	5	8 / 9
28. ¿Qué tanto ha pensado en hablar con su PERSONA DECISORA acerca del tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_T2)	1	2	3	4	5	8 / 9
29. ¿Qué tanto ha pensado en hablar con su DOCTOR acerca del tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_T3)	1	2	3	4	5	8 / 9
30. ¿Qué tanto ha pensado en hablar con sus OTROS familiares y amigos acerca del tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_T4)	1	2	3	4	5	8 / 9

SELF-EFFICACY		(2B – CARE AT EOL)				
The next three questions ask about <u>how confident you are</u> to actually talk about <u>your medical wishes</u> . [Read options.]						
Qué tan seguro está de que hoy podría... <span style="float: right;"><i>Red</i></span>	Para Nada	Un poco	Mas o Menos	Bastante	Extremadam ente	NS/ Ref.
31. ¿Qué tan seguro(a) está de que hoy podría hablar con su PERSONA DECISORA acerca del tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_SE1)	1	2	3	4	5	8 / 9

32. ¿Qué tan seguro(a) está de que hoy podría hablar con su DOCTOR acerca del tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_SE2)	1	2	3	4	5	8 / 9
33. ¿Qué tan seguro(a) está de que hoy podría hablar con sus OTROS familiares y amigos acerca del tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_SE3)	1	2	3	4	5	8 / 9

## DISPOSICIÓN

(2B – CARE AT EOL)

Las siguientes preguntas son acerca de qué tan listo está para decidir y hablar sobre el tipo de cuidados que quisiera si estuviera muy enfermo o al final de su vida.

34. ¿Qué tan listo(a) está para decidir qué tipo de cuidado médico quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2_CARE_RDY)		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 5 <input type="checkbox"/> Ya lo hice		
OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)		<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA
		<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

*[If they haven't already done it, say "sé que no ha decidido sobre ciertas situaciones de salud, pero..."]*

35. ¿Qué tan listo(a) está para hablar con su PERSONA DECISORA sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_TELLDM_READY)		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 5 <input type="checkbox"/> Ya lo hice		
OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)		<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA
		<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

36. ¿Qué tan listo(a) está para hablar con su DOCTOR sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_TELLDR_RDY)		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 5 <input type="checkbox"/> Ya lo hice		
OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)		<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA
		<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

Ahora voy a hacerle algunas preguntas acerca de hablar con otros familiares o amigos, o sea no quien usted elegiría como persona decisora.

<p>37. ¿Qué tan listo(a) está para hablar con sus OTROS familiares y amigos sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S4_CARE_RDY)</p> <p>1 <input type="checkbox"/> Nunca lo he pensado</p> <p>2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>5 <input type="checkbox"/> Ya lo hice</p>		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?"</p> <p>(PE_S1_DECDM_WHEN)</p>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

<p>2. ¿Qué tan listo(a) está para FIRMAR DOCUMENTOS OFICIALES que pongan sus deseos por escrito sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida?</p> <p>(PE_S2B_PAPER_RDY)</p> <p>1 <input type="checkbox"/> Nunca lo he pensado</p> <p>2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>5 <input type="checkbox"/> Ya lo hice</p>		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?"</p> <p>(PE_S1_DECDM_WHEN)</p>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

## Flexibility

Ahora hablaremos de la flexibilidad para tomar decisiones médicas.

Flexibilidad significa que su persona decisora puede trabajar con su doctor y cambiar sus decisiones médicas previas, si es lo mejor para usted en ese momento.

**Usted puede decidir dar o no dar flexibilidad.** KNOWLEDGE

**(3 – FLEXIBILITY)**

Las siguientes dos preguntas son acerca de la flexibilidad para tomar decisiones médicas. [Read options.]

Qué tan bien informado está acerca de...	<i>Red</i>	Para Nada	Un poco	Mas o Menos	Bastante	Extremadamente	NS/ Ref.
39. ¿Qué tan bien informado(a) está acerca de lo que significa dar flexibilidad a su persona decisora para tomar decisiones médicas en el futuro? (PE_S3_K1)		1	2	3	4	5	8 / 9
40. ¿Qué tan bien informado(a) está acerca de cuánta flexibilidad un paciente le puede dar a su persona decisora? (PE_S3_K2)		1	2	3	4	5	8 / 9

**THOUGHT ABOUT IT**

**(3 – FLEXIBILITY)**

Estas preguntas son acerca de cuánto ha pensado de la flexibilidad. [Read options.]

Que tanto ha pensado acerca de...	<i>Green</i>	Nunca	Una o Dos Veces	Unas cuantas veces	Bastantes veces	Muchas veces	Not sure/ Ref.
41. ¿Qué tanto ha pensado en cuánta flexibilidad le quisiera dar a su persona decisora? (PE_S3_T1)		1	2	3	4	5	8 / 9
42. ¿Qué tanto ha pensado en hablar con su PERSONA DECISORA acerca de cuánta flexibilidad le quisiera dar? (PE_S3_T2)		1	2	3	4	5	8 / 9
43. ¿Qué tanto ha pensado en hablar con su DOCTOR acerca de cuánta flexibilidad le quisiera dar a su persona decisora? (PE_S3_T3)		1	2	3	4	5	8 / 9
44. ¿Qué tanto ha pensado en hablar con sus OTROS familiares y amigos acerca de cuánta flexibilidad le quisiera dar a su persona decisora? (PE_S3_T4)		1	2	3	4	5	8 / 9

**SELF-EFFICACY**

**(3 – FLEXIBILITY)**

Estas preguntas son acerca de qué tan seguro(a) esta para hablar de flexibilidad. [Read options.]

Qué tan seguro está de que hoy podría...	<i>Red</i>	Para Nada	Un poco	Mas o Menos	Bastante	Extremadamente	NS/ Ref.
45. ¿Qué tan seguro(a) está de que hoy podría hablar con su PERSONA DECISORA acerca de cuánta flexibilidad le quisiera dar? (PE_S3_SE1)		1	2	3	4	5	8 / 9
46. ¿Qué tan seguro(a) está de que hoy podría hablar con su DOCTOR acerca de cuánta flexibilidad le quisiera dar a su persona decisora? (PE_S3_SE2)		1	2	3	4	5	8 / 9
47. ¿Qué tan seguro(a) está de que hoy podría hablar con sus OTROS familiares y amigos acerca de cuánta flexibilidad le quisiera dar a su persona decisora? (PE_S3_SE3)		1	2	3	4	5	8 / 9

Las siguientes preguntas son acerca de qué tan listo está para hablar con otros sobre cuánta flexibilidad usted quisiera dar a su persona decisora y para poner esta información por escrito.

<p>48. ¿Qué tan listo(a) está para hablar con su PERSONA DECISORA acerca de cuánta flexibilidad le quisiera dar? (PE_S3_TELDM_RDY)</p> <p>a. <input type="checkbox"/> Nunca lo he pensado</p> <p>b. <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>c. <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>d. <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>e. <input type="checkbox"/> Ya lo hice</p>		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)</p>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]
<p>49. ¿Qué tan listo(a) está para hablar con su DOCTOR acerca de cuánta flexibilidad le quiere dar a su persona decisora? (PE_S3_TELDR_RDY)</p> <p>a. <input type="checkbox"/> Nunca lo he pensado</p> <p>b. <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>c. <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>d. <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>e. <input type="checkbox"/> Ya lo hice</p>		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)</p>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

Ahora voy a hacerle algunas preguntas acerca de hablar con otros familiares y amigos que no serían su persona decisora.

<p>50. ¿Ha hablado con sus OTROS familiares y amigos acerca de cuánta flexibilidad le quisiera dar a su persona decisora? (PE_S4_FLX)</p> <p>a. <input type="checkbox"/> Nunca lo he pensado</p> <p>b. <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>c. <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>d. <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>e. <input type="checkbox"/> Ya lo hice</p>		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)</p>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

<p>51. ¿Qué tan listo(a) está para firmar DOCUMENTOS OFICIALES que pongan sus deseos por escrito acerca de cuánta flexibilidad le quisiera dar a su persona decisora? (PE_S3_PAPER_RDY)</p> <p>a. <input type="checkbox"/> Nunca lo he pensado</p> <p>b. <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>c. <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>d. <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>e. <input type="checkbox"/> Ya lo hice</p>		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)</p>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]



## Hacerle Preguntas a sus Doctores

Ahora vamos a hablar acerca de hacerle preguntas a su doctor.

KNOWLEDGE (5 –ASK DR)						
Qué tan bien informado está acerca de... <i>Red</i>	Para Nada	Un poco	Mas o Menos	Bastante	Extremadam ente	NS/ Ref.
52. ¿Qué tan informado(a) está acerca de qué tipos de preguntas le podría hacer a su DOCTOR que le ayuden a tomar una buena decisión médica? (PE_S5_K1)	1	2	3	4	5	8 / 9

THOUGHT ABOUT IT (5 –ASK DR)						
Que tanto ha pensado acerca de... <i>Green</i>	Nunca	Una o Dos Veces	Unas cuantas veces	Bastantes veces	Muchas veces	Not sure/ Ref.
53. ¿Qué tanto ha pensado en qué preguntas le haría a su DOCTOR para ayudarle a tomar una buena decisión médica? (PE_S5_T1)	1	2	3	4	5	8 / 9

SELF-EFFICACY (5 –ASK DR)						
Qué tan seguro está de que hoy podría... <i>Red</i>	Para Nada	Un poco	Mas o Menos	Bastante	Extremadam ente	NS/ Ref.
54. ¿Qué tan seguro está de que hoy podría hacerle a su DOCTOR las preguntas correctas para ayudarle a tomar una buena decisión médica? (PE_S5_SE1)	1	2	3	4	5	8 / 9

### DECISIONS MADE/ACTIONS (5 – ASK DR)

Responda a estas preguntas con Sí o No

<p>55. ¿Qué tan listo(a) está para hacerle preguntas a su doctor que le ayuden a tomar una buena decisión médica? (PE_S3_PAPER_RDY)</p> <p>a. <input type="checkbox"/> Nunca lo he pensado</p> <p>b. <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>c. <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>d. <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>e. <input type="checkbox"/> Ya lo hice</p>		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)</p>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

# Encuesta de treinta y cuatro pregunta

## Preparación

### *Introduction*

**Tab 6** Esta sección es la más larga. Le preguntaremos sobre sus experiencias y opiniones. Le podemos preguntar acerca de cosas que ya ha hecho o cosas que ni ha pensado en hacer. Responda lo más honestamente que pueda.

En las próximas secciones le preguntaremos acerca de 4 temas:

1. Personas Decisoras o de Substituto
2. Decidir lo que más le importa en la vida
3. Flexibilidad para la persona decisor
4. Hacerle preguntas a su doctor

## 1. Personas Decisoras

Estas preguntas son acerca de las personas decisoras. Una persona decisor es alguien que puede tomar decisiones médicas en su nombre SÓLO SI usted está demasiado enfermo para tomar sus propias decisiones.

Recuerde que no hay respuesta correcta o equivocada- por favor denos su honesta opinión.

### KNOWLEDGE

(1 – DM)

Estas 3 preguntas son acerca de qué tan bien informado está sobre las personas decisoras. [Read options.]

¿Que tan bien informado(a) esta acerca.....	Red	Para Nada	Un poco	Mas o Menos	Bastante	Extremadam ente	NS/ Ref.
1. de lo que hace que alguien sea una buena PERSONA DECISORA? (PE_S1_K2)		1	2	3	4	5	8 / 9
2. del tipo de decisiones que podrá tomar por usted la PERSONA DECISORA en el futuro? (PE_S1_K3)		1	2	3	4	5	8 / 9

### THOUGHT ABOUT IT

(1 – DM)

Estas preguntas son acerca de qué tanto ha pensado en algo. [Read options.]

¿Que tanto ha pensado en...	Green	Nunca	Una o Dos Veces	Unas cuantas veces	Bastantes veces	Muchas veces	Not sure/ Ref.
3. quien deberia ser su PERSONA DECISORA? (PE_S1_T1)		1	2	3	4	5	8 / 9

### SELF-EFFICACY

(1 – DM)

Estas preguntas son acerca de que tñ seguro se siente para hablar sobre a quién ha elegido como su persona decisor. [Read options.]

Que tan seguro esta de que hoy podria....	Red	Para Nada	Un poco	Mas o Menos	Bastante	Extremadam ente	NS/ Ref.
4. pedirle a alguien que sea su PERSONA DECISORA? (PE_S1_SE1)		1	2	3	4	5	8 / 9
5. hablar con su DOCTOR acerca de quien desea que fuera su persona decisor?(PE_S1_SE2)		1	2	3	4	5	8 / 9
6. hablar con sus OTROS familiares y amigos sobre quién desea que fuera su persona decisor? (PE_S1_SE3)		1	2	3	4	5	8 / 9

Las siguientes preguntas son acerca de qué tan listo está para hablar con otras personas sobre quién desea que sea su persona decisor y para poner esta información por escrito.

<p>7. ¿Qué tan listo(a) está para pedirle formalmente a alguien que sea su persona decisor(a)? (PE_S1_DM_RDY)</p>	<p><input type="checkbox"/> <u>Nunca</u> lo he pensado</p> <p><input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p><input type="checkbox"/> <u>Estoy pensando</u> en hacerlo en los siguientes 6 meses</p> <p><input type="checkbox"/> <u>Estoy planeando</u> hacerlo en los próximos 30 días</p> <p><input type="checkbox"/> Ya lo <u>hice</u> <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p style="text-align: right;"><input type="checkbox"/> [Ref]</p>	
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)</p>	<p><input type="checkbox"/> Less than 6 mo</p> <p><input type="checkbox"/> &gt;6 months ago <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p><input type="checkbox"/> NA <span style="float: right;"><input type="checkbox"/> [Ref]</span></p>	
<p>8. ¿Qué tan listo(a) está para hablar con su DOCTOR acerca de quién desea que fuera su persona decisor(a)?</p> <p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)</p>	<p><input type="checkbox"/> <u>Nunca</u> lo he pensado</p> <p><input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p><input type="checkbox"/> <u>Estoy pensando</u> en hacerlo en los siguientes 6 meses</p> <p><input type="checkbox"/> <u>Estoy planeando</u> hacerlo en los</p> <p><input type="checkbox"/> Less than 6 mo</p> <p><input type="checkbox"/> &gt;6 months ago</p> <p><input type="checkbox"/> NA</p>	<p><input type="checkbox"/> Not Sure</p> <p><input type="checkbox"/> [Ref]</p> <p><input type="checkbox"/> Not Sure</p> <p><input type="checkbox"/> [Ref]</p>

Ahora voy a hacerle algunas preguntas acerca de hablar con otros familiares y amigos. "Otros familiares y amigos" son personas que pueden ser parte de su vida y tener opiniones acerca de su cuidado médico, pero ellos so serían a quienes usted elegiría como persona decisor(a).

<p>9. ¿Qué tan listo(a) está para hablar con sus OTROS familiares y amigos acerca de quién quisiera que fuera su persona decisor(a)? (PE_S4_DM_RDY)</p> <p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)</p>	<p><input type="checkbox"/> <u>Nunca</u> lo he pensado</p> <p><input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p><input type="checkbox"/> <u>Estoy pensando</u> en hacerlo en los siguientes 6 meses</p> <p><input type="checkbox"/> <u>Estoy planeando</u> hacerlo en los próximos 30 días</p> <p><input type="checkbox"/> Ya lo <u>hice</u> <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p style="text-align: right;"><input type="checkbox"/> [Ref]</p> <p><input type="checkbox"/> Less than 6 mo</p> <p><input type="checkbox"/> &gt;6 months ago <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p><input type="checkbox"/> NA <span style="float: right;"><input type="checkbox"/> [Ref]</span></p>	
<p>10. ¿Qué tan listo esta para FIRMAR DOCUMENTOS OFICIALES nombrando a una persona o grupo para tomar decisiones médicas por usted? (PE_S1_PAPER_RDY)</p> <p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)</p>	<p><input type="checkbox"/> <u>Nunca</u> lo he pensado</p> <p><input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo <u>Estoy</u></p> <p><input type="checkbox"/> <u>pensando</u> en hacerlo en los siguientes 6 meses</p> <p><input type="checkbox"/> <u>Estoy planeando</u> en hacerlo en los próximos 30 días</p> <p><input type="checkbox"/> Ya lo <u>hice</u> <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p style="text-align: right;"><input type="checkbox"/> [Ref]</p> <p><input type="checkbox"/> Less than 6 mo</p> <p><input type="checkbox"/> &gt;6 months ago <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p><input type="checkbox"/> NA <span style="float: right;"><input type="checkbox"/> [Ref]</span></p>	

## Decidir lo que Más le Importa en la Vida

Ahora queremos hablar de cómo algunas personas se sienten acerca de su calidad de vida. Por ejemplo, cómo quieren vivir, y cómo no quieren vivir. Algunas personas piensan que vale la pena vivir por todas situaciones y experiencias de salud, como estar en un coma o no poder salir de la cama. Otras personas piensan que hay algunas situaciones médicas o experiencias que harían que no valga la pena vivir.

Por favor dénos su opinión honesta. No hay respuesta correcta o equivocada.

### THOUGHT ABOUT IT

### (2 – HEALTH SITUATIONS)

Las siguientes 3 preguntas son acerca de qué tan seguro se siente para hablar sobre sus deseos médicos . [Read options.

¿Que tan seguro(a) esta de que hoy podria....	Red	Para Nada	Un poco	Mas o Menos	Bastante	Extremadam ente	NS/ Ref.
11. hablar con su PERSONA DECISORA acerca de situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_SE1)		1	2	3	4	5	8 / 9
12. hablar con su DOCTOR acerca de situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_SE2)		1	2	3	4	5	8 / 9
13. hablar con sus OTROS familiares y amigos acerca de situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_SE3)		1	2	3	4	5	8 / 9

### DISPOSICIÓN

### (2 – HEALTH SITUATIONS)

Las siguientes preguntas son acerca de qué tan listo se siente para decidir y hablar sobre situaciones de salud. De nuevo, situaciones de salud pueden referirse a estar en un coma o no poder salir de la cama.

14. Qué tan listo(a) está para decidir si ciertas situaciones de salud podrían hacer que su vida no valga la pena? (PE_S2A_SIT_RDY) 6 <input type="checkbox"/> Nunca lo he pensado 7 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 8 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 9 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 10 <input type="checkbox"/> Ya lo hice	<input type="checkbox"/> Not sure <input type="checkbox"/> Refused
OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

[If they haven't already done it, say "sé que no ha decidido sobre ciertas situaciones de salud, pero..."]

15. ¿Qué tan listo(a) está para hablar con su PERSONA DECISORA acerca de ciertas situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_TELLDM_RDY) 6 <input type="checkbox"/> Nunca lo he pensado 7 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 8 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 9 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 6 <input type="checkbox"/> Ya lo hice	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

16. ¿Qué tan listo(a) está para hablar con su DOCTOR acerca de situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S2A_TELLDR_RDY) 6 <input type="checkbox"/> Nunca lo he pensado 7 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 8 <input type="checkbox"/> Estoy pensando en hacerlo en las próximas visitas 9 <input type="checkbox"/> Estoy planeando hacerlo en la próxima visita 10 <input type="checkbox"/> Ya lo hice	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

**Ahora voy a hacerle algunas preguntas acerca de hablar con otros familiares y amigos quienes no serían su persona decisora.**

17. ¿Qué tan listo(a) está para hablar con sus OTROS familiares y amigos acerca de situaciones de salud que podrían hacer que su vida no valga la pena? (PE_S4_SIT_RDY) 5 <input type="checkbox"/> Nunca lo he pensado 6 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 7 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 8 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 1 <input type="checkbox"/> Ya lo hice	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

**Ahora vamos a cambiar de tema. Las preguntas previas se tratan de cómo la gente quisiera o no quisiera vivir. Las siguientes preguntas son acerca de tratamientos médicos específicos que algunas personas quisieran o no quisieran si estuvieran gravemente enfermos o al final de su vida. Por ejemplo, algunas personas saben que quisieran estar conectados a un respirador. Otras personas saben que nunca quisieran estar conectados a un respirador.**

**Por favor dénos su honesta opinión en las próximas preguntas acerca de los tratamientos médicos. No hay respuesta correcta o equivocada.**

**THOUGHT ABOUT IT**
**(2B – CARE AT EOL)**

Estas preguntas son acerca de qué tanto ha pensado en algo. [Read options.]

Que tanto ha pensado acerca de... <span style="float: right;"><i>Green</i></span>	Nunca	Una o Dos Veces	Unas cuantas veces	Bastantes veces	Muchas veces	Not sure/ Ref.
18. ¿Qué tanto ha pensado en hablar con sus OTROS familiares y amigos acerca del tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_T4)	1	2	3	4	5	8 / 9

**SELF-EFFICACY**
**(2B – CARE AT EOL)**

**The next three questions ask about how confident you are to actually talk about your medical wishes. [Read options.]**

Qué tan seguro está de que hoy podría... <span style="float: right;"><i>Red</i></span>	Para Nada	Un poco	Mas o Menos	Bastante	Extremadamamente	NS/ Ref.
19. ¿Qué tan seguro(a) está de que hoy podría hablar con su PERSONA DECISORA acerca del tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_SE1)	1	2	3	4	5	8 / 9

20. ¿Qué tan seguro(a) está de que hoy podría hablar con su DOCTOR acerca del tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_SE2)	1	2	3	4	5	8 / 9
21. ¿Qué tan seguro(a) está de que hoy podría hablar con sus OTROS familiares y amigos acerca del tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_SE3)	1	2	3	4	5	8 / 9

## DISPOSICIÓN

(2B – CARE AT EOL)

Las siguientes preguntas son acerca de qué tan listo está para decidir y hablar sobre el tipo de cuidados que quisiera si estuviera muy enfermo o al final de su vida.

22. ¿Qué tan listo(a) está para decidir qué tipo de cuidado médico quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2_CARE_RDY)		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 5 <input type="checkbox"/> Ya lo hice		
OPTIONAL: If they answered, "Ya lo hice," then ask "Cuándo lo hizo?" (PE_S1_DECDM_WHEN)		<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

*[If they haven't already done it, say "sé que no ha decidido sobre ciertas situaciones de salud, pero..."]*

23. ¿Qué tan listo(a) está para hablar con su PERSONA DECISORA sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_TELLDLM_READY)		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 5 <input type="checkbox"/> Ya lo hice		
OPTIONAL: If they answered, "Ya lo hice," then ask "Cuándo lo hizo?" (PE_S1_DECDM_WHEN)		<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

24. ¿Qué tan listo(a) está para hablar con su DOCTOR sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_TELLDR_RDY)		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
1 <input type="checkbox"/> Nunca lo he pensado 2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo 3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses 4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días 5 <input type="checkbox"/> Ya lo hice		
OPTIONAL: If they answered, "Ya lo hice," then ask "Cuándo lo hizo?" (PE_S1_DECDM_WHEN)		<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]



Ahora voy a hacerle algunas preguntas acerca de hablar con otros familiares o amigos, o sea no quien usted elegiría como persona decisora.

<p>25. ¿Qué tan listo(a) está para hablar con sus OTROS familiares y amigos sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S4_CARE_RDY)</p> <p>1 <input type="checkbox"/> Nunca lo he pensado</p> <p>2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>5 <input type="checkbox"/> Ya lo hice</p>	<p><input type="checkbox"/> Not Sure</p> <p><input type="checkbox"/> [Ref]</p>
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?"</p> <p>(PE_S1_DECDM_WHEN)</p>	<p><input type="checkbox"/> Less than 6 mo</p> <p><input type="checkbox"/> &gt;6 months ago</p> <p><input type="checkbox"/> NA</p> <p><input type="checkbox"/> Not sure</p> <p><input type="checkbox"/> [Ref]</p>

<p>26. ¿Qué tan listo(a) está para FIRMAR DOCUMENTOS OFICIALES que pongan sus deseos por escrito sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida?</p> <p>(PE_S2B_PAPER_RDY)</p> <p>1 <input type="checkbox"/> Nunca lo he pensado</p> <p>2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>5 <input type="checkbox"/> Ya lo hice</p>	<p><input type="checkbox"/> Not Sure</p> <p><input type="checkbox"/> [Ref]</p>
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?"</p> <p>(PE_S1_DECDM_WHEN)</p>	<p><input type="checkbox"/> Less than 6 mo</p> <p><input type="checkbox"/> &gt;6 months ago</p> <p><input type="checkbox"/> NA</p> <p><input type="checkbox"/> Not sure</p> <p><input type="checkbox"/> [Ref]</p>

## Flexibility

Ahora hablaremos de la flexibilidad para tomar decisiones médicas.

Flexibilidad significa que su persona decisora puede trabajar con su doctor y cambiar sus decisiones médicas previas, si es lo mejor para usted en ese momento.

### THOUGHT ABOUT IT

(3 – FLEXIBILITY)

Estas preguntas son acerca de cuánto ha pensado acerca de la flexibilidad. [Read options.]

Que tanto ha pensado acerca de...	Green	Nunca	Una o Dos Veces	Unas cuantas veces	Bastantes veces	Muchas veces	Not sure/ Ref.
27. Qué tanto ha pensado en hablar con su PERSONA DECISORA acerca de cuánta flexibilidad le quisiera dar? (PE_S3_T2)		1	2	3	4	5	8 / 9

### SELF-EFFICACY

(3 – FLEXIBILITY)

Estas preguntas son acerca de qué tan seguro(a) esta para hablar de flexibilidad. [Read options.]

Qué tan seguro está de que hoy podría...	Red	Para Nada	Un poco	Mas o Menos	Bastante	Extremadamente	NS/ Ref.
28. ¿Qué tan seguro(a) está de que hoy podría hablar con su DOCTOR acerca de cuánta flexibilidad le quisiera dar a su persona decisora? (PE_S3_SE2)		1	2	3	4	5	8 / 9
29. ¿Qué tan seguro(a) está de que hoy podría hablar con sus OTROS familiares y amigos acerca de cuánta flexibilidad le quisiera dar a su persona decisora? (PE_S3_SE3)		1	2	3	4	5	8 / 9

### DISPOSICIÓN

(3 – FLEXIBILITY)

Las siguientes preguntas son acerca de qué tan listo está para hablar con otros sobre cuánta flexibilidad usted quisiera dar a su persona decisora y para poner esta información por escrito.

<p>30. ¿Qué tan listo(a) está para hablar con su PERSONA DECISORA acerca de cuánta flexibilidad le quisiera dar? (PE_S3_TELLDL_RDY)</p> <p>a. <input type="checkbox"/> Nunca lo he pensado</p> <p>b. <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>c. <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>d. <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>e. <input type="checkbox"/> Ya lo hice</p>	<p><input type="checkbox"/> Not Sure</p> <p><input type="checkbox"/> [Ref]</p>
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuándo lo hizo?" (PE_S1_DECDL_WHEN)</p>	<p><input type="checkbox"/> Less than 6 mo</p> <p><input type="checkbox"/> &gt;6 months ago</p> <p><input type="checkbox"/> NA</p> <p><input type="checkbox"/> Not sure</p> <p><input type="checkbox"/> [Ref]</p>
<p>31. ¿Qué tan listo(a) está para hablar con su DOCTOR acerca de cuánta flexibilidad le quiere dar a su persona decisora? (PE_S3_TELLDR_RDY)</p> <p>a. <input type="checkbox"/> Nunca lo he pensado</p> <p>b. <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>c. <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>d. <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>e. <input type="checkbox"/> Ya lo hice</p>	<p><input type="checkbox"/> Not Sure</p> <p><input type="checkbox"/> [Ref]</p>
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuándo lo hizo?" (PE_S1_DECDL_WHEN)</p>	<p><input type="checkbox"/> Less than 6 mo</p> <p><input type="checkbox"/> &gt;6 months ago</p> <p><input type="checkbox"/> NA</p> <p><input type="checkbox"/> Not sure</p> <p><input type="checkbox"/> [Ref]</p>

<p>32. ¿Qué tan listo(a) está para firmar DOCUMENTOS OFICIALES que pongan sus deseos por escrito acerca de cuánta flexibilidad le quisiera dar a su persona decisora? (PE_S3_PAPER_RDY)</p> <p>a. <input type="checkbox"/> Nunca lo he pensado</p> <p>b. <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>c. <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>d. <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>e. <input type="checkbox"/> Ya lo hice</p>	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?"</p> <p>(PE_S1_DECDM_WHEN)</p>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA
<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]	

## Hacerle Preguntas a sus Doctores

**Ahora vamos a hablar acerca de hacerle preguntas a su doctor.**

SELF-EFFICACY		(5 – ASK DR)					
Qué tan seguro está de que hoy podría...	Red	Para Nada	Un poco	Mas o Menos	Bastante	Extremadam ente	NS/ Ref.
33. ¿Qué tan seguro está de que hoy podría hacerle a su DOCTOR las preguntas correctas para ayudarle a tomar una buena decisión médica? (PE_S5_SE1)		1	2	3	4	5	8 / 9

## READINESS (5 – ASK DR)

<p>34. ¿Qué tan listo(a) está para hacerle preguntas a su doctor que le ayuden a tomar una buena decisión médica? (PE_S3_PAPER_RDY)</p> <p>a. <input type="checkbox"/> Nunca lo he pensado</p> <p>b. <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>c. <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>d. <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>e. <input type="checkbox"/> Ya lo hice</p>	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?"</p> <p>(PE_S1_DECDM_WHEN)</p>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA
<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]	

# Encuesta de quince pregunta

## Preparación

### *Introduction*

**Tab 6** Esta sección es la más larga. Le preguntaremos sobre sus experiencias y opiniones. Le podemos preguntar acerca de cosas que ya ha hecho o cosas que ni ha pensado en hacer. Responda lo más honestamente que pueda.

En las próximas secciones le preguntaremos acerca de 4 temas:

1. Personas Decisoras o de Substituto
2. Decidir lo que más le importa en la vida
3. Flexibilidad para la persona decisor
4. Hacerle preguntas a su doctor

## 1. Personas Decisoras

Estas preguntas son acerca de las personas decisoras. Una persona decisor es alguien que puede tomar decisiones médicas en su nombre SÓLO SI usted está demasiado enfermo para tomar sus propias decisiones.

Recuerde que no hay respuesta correcta o equivocada- por favor denos su honesta opinión.

### SELF-EFFICACY

(1 – DM)

Estas preguntas son acerca de que tan seguro se siente para hablar sobre a quién ha elegido como su persona decisor. [Read options.]

Que tan seguro esta de que hoy podria....	Red	Para Nada	Un poco	Mas o Menos	Bastante	Extremadam ente	NS/ Ref.
1. pedirle a alguien que sea su PERSONA DECISORA? (PE_S1_SE1)		1	2	3	4	5	8 / 9

### DISPOCISIÓN

(1 – DM)

Las siguientes preguntas son acerca de qué tan listo está para hablar con otras personas sobre quién desea que sea su persona decisor y para poner esta información por escrito.

<p>2. ¿Qué tan listo(a) está para pedirle formalmente a alguien que sea su persona decisor? (PE_S1_DM_RDY)</p>	<p><input type="checkbox"/> <u>Nunca</u> lo he pensado</p> <p><input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p><input type="checkbox"/> <u>Estoy pensando</u> en hacerlo en los siguientes 6 meses</p> <p><input type="checkbox"/> <u>Estoy planeando</u> hacerlo en los próximos 30 días</p> <p><input type="checkbox"/> Ya lo <u>hice</u> <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p style="text-align: right;"><input type="checkbox"/> [Ref]</p>
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)</p>	<p><input type="checkbox"/> Less than 6 mo</p> <p><input type="checkbox"/> &gt;6 months ago <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p><input type="checkbox"/> NA <span style="float: right;"><input type="checkbox"/> [Ref]</span></p>
<p>3. ¿Qué tan listo(a) está para hablar con su DOCTOR acerca de quién desea que fuera su persona decisor?</p>	<p><input type="checkbox"/> <u>Nunca</u> lo he pensado</p> <p><input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p><input type="checkbox"/> <u>Estoy pensando</u> en hacerlo en los siguientes 6 meses</p> <p><input type="checkbox"/> <u>Estoy planeando</u> hacerlo en los siguientes 6 meses</p> <p><input type="checkbox"/> Less than 6 mo</p> <p><input type="checkbox"/> &gt;6 months ago</p> <p><input type="checkbox"/> NA</p> <p style="text-align: right;"><input type="checkbox"/> Not Sure</p> <p style="text-align: right;"><input type="checkbox"/> [Ref]</p>
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)</p>	<p><input type="checkbox"/> Not Sure</p> <p style="text-align: right;"><input type="checkbox"/> [Ref]</p>
<p>4. ¿Qué tan listo esta para FIRMAR DOCUMENTOS OFICIALES nombrando a una persona o grupo para tomar decisiones médicas por usted? (PE_S1_PAPER_RDY)</p>	<p><input type="checkbox"/> <u>Nunca</u> lo he pensado</p> <p><input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo <u>Estoy</u></p> <p><input type="checkbox"/> <u>pensando</u> en hacerlo en los siguientes 6 meses</p> <p><input type="checkbox"/> <u>Estoy planeando</u> en hacerlo en los próximos 30 días</p> <p><input type="checkbox"/> Ya lo <u>hice</u> <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p style="text-align: right;"><input type="checkbox"/> [Ref]</p>
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)</p>	<p><input type="checkbox"/> Less than 6 mo</p> <p><input type="checkbox"/> &gt;6 months ago <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p><input type="checkbox"/> NA <span style="float: right;"><input type="checkbox"/> [Ref]</span></p>

## Decidir lo que Más le Importa en la Vida

Ahora queremos hablar de cómo algunas personas se sienten acerca de su calidad de vida. Por ejemplo, cómo quieren vivir, y cómo no quieren vivir.

Ahora vamos a cambiar de tema. Las preguntas previas se tratan de cómo la gente quisiera o no quisiera vivir. Las siguientes preguntas son acerca de tratamientos médicos específicos que algunas personas quisieran o no quisieran si estuvieran gravemente enfermos o al final de su vida. Por ejemplo, algunas personas saben que quisieran estar conectados a un respirador. Otras personas saben que nunca quisieran estar conectados a un respirador.

Por favor dénos su honesta opinión en las próximas preguntas acerca de los tratamientos médicos. No hay respuesta correcta o equivocada.

### SELF-EFFICACY

(2B – CARE AT EOL)

The next three questions ask about how confident you are to actually talk about your medical wishes. [Read options.]

Qué tan seguro está de que hoy podría...	Red	Para Nada	Un poco	Mas o Menos	Bastante	Extremadam ente	NS/ Ref.
5. ¿Qué tan seguro(a) está de que hoy podría hablar con su PERSONA DECISORA acerca del tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_SE1)		1	2	3	4	5	8 / 9
6. ¿Qué tan seguro(a) está de que hoy podría hablar con su DOCTOR acerca del tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_SE2)		1	2	3	4	5	8 / 9

### DISPOSICIÓN

(2B – CARE AT EOL)

Las siguientes preguntas son acerca de qué tan listo está para decidir y hablar sobre el tipo de cuidados que quisiera si estuviera muy enfermo o al final de su vida.

<p>7. ¿Qué tan listo(a) está para hablar con su PERSONA DECISORA sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_TELDM_READY)</p> <p>1 <input type="checkbox"/> Nunca lo he pensado</p> <p>2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>5 <input type="checkbox"/> Ya lo hice</p>	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)</p>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

<p>8. ¿Qué tan listo(a) está para hablar con su DOCTOR sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_TELLDR_RDY)</p> <p>1 <input type="checkbox"/> Nunca lo he pensado</p> <p>2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>5 <input type="checkbox"/> Ya lo hice</p>	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)</p>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

<div>3. ¿Qué tan listo(a) está para FIRMAR DOCUMENTOS OFICIALES que pongan sus deseos por escrito sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_PAPER_RDY)</div> <div>6 <input type="checkbox"/> Nunca lo he pensado</div> <div>7 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</div> <div>8 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</div> <div>9 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</div> <div>10 <input type="checkbox"/> Ya lo hice</div>		<div><input type="checkbox"/> Not Sure</div> <div><input type="checkbox"/> [Ref]</div>
<div>OPTIONAL: If they answered, “Ya lo hice,” then ask “Cuando lo hizo?” (PE_S1_DECDM_WHEN)</div>	<div><input type="checkbox"/> Less than 6 mo</div> <div><input type="checkbox"/> &gt;6 months ago</div> <div><input type="checkbox"/> NA</div>	<div><input type="checkbox"/> Not sure</div> <div><input type="checkbox"/> [Ref]</div>



## Flexibility

Ahora hablaremos de la flexibilidad para tomar decisiones médicas.

Flexibilidad significa que su persona decisor(a) puede trabajar con su doctor y cambiar sus decisiones médicas previas, si es lo mejor para usted en ese momento.

### SELF-EFFICACY

(3 – FLEXIBILITY)

Estas preguntas son acerca de qué tan seguro(a) está para hablar de flexibilidad. *[Read options.]*

Qué tan seguro está de que hoy podría...	Red	Para Nada	Un poco	Mas o Menos	Bastante	Extremadam ente	NS/ Ref.
10. ¿Qué tan seguro(a) está de que hoy podría hablar con su persona decisor(a) acerca de cuánta flexibilidad le quisiera dar? (PE_S3_SE2)		1	2	3	4	5	8 / 9
11. ¿Qué tan seguro(a) está de que hoy podría hablar con su DOCTOR acerca de cuánta flexibilidad le quisiera dar a su persona decisor(a)? (PE_S3_SE3)		1	2	3	4	5	8 / 9

### DISPOSICIÓN

(3 – FLEXIBILITY)

Las siguientes preguntas son acerca de qué tan listo está para hablar con otros sobre cuánta flexibilidad usted quisiera dar a su persona decisor(a) y para poner esta información por escrito.

<p>12. ¿Qué tan listo(a) está para hablar con su PERSONA DECISORA acerca de cuánta flexibilidad le quisiera dar? (PE_S3_TELDM_RDY)</p> <p>a. <input type="checkbox"/> Nunca lo he pensado</p> <p>b. <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>c. <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>d. <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>e. <input type="checkbox"/> Ya lo hice</p>	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)</p>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]
<p>13. ¿Qué tan listo(a) está para hablar con su DOCTOR acerca de cuánta flexibilidad le quiere dar a su persona decisor(a)? (PE_S3_TELDR_RDY)</p> <p>a. <input type="checkbox"/> Nunca lo he pensado</p> <p>b. <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>c. <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>d. <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>e. <input type="checkbox"/> Ya lo hice</p>	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)</p>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA <input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

## Hacerle Preguntas a sus Doctores

Ahora vamos a hablar acerca de hacerle preguntas a su doctor.

### SELF-EFFICACY

(5 –ASK DR)

Qué tan seguro está de que hoy podría...	Red	Para Nada	Un poco	Mas o Menos	Bastante	Extremadamente	NS/ Ref.
14. ¿Qué tan seguro está de que hoy podría hacerle a su DOCTOR las preguntas correctas para ayudarlo a tomar una buena decisión médica? (PE_S5_SE1)		1	2	3	4	5	8 / 9

### READINESS

(5 – ASK DR)

<p>15. ¿Qué tan listo(a) está para hacerle preguntas a su doctor que le ayuden a tomar una buena decisión médica? (PE_S3_PAPER_RDY)</p> <p>a. <input type="checkbox"/> Nunca lo he pensado</p> <p>b. <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>c. <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>d. <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>e. <input type="checkbox"/> Ya lo hice</p>		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?"</p> <p>(PE_S1_DECDM_WHEN)</p>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

# Encuesta de nueve pregunta

## Preparación

### *Introduction*

**Tab 6** Esta sección es la más larga. Le preguntaremos sobre sus experiencias y opiniones. Le podemos preguntar acerca de cosas que ya ha hecho o cosas que ni ha pensado en hacer. Responda lo más honestamente que pueda.

En las próximas secciones le preguntaremos acerca de 2 temas:

1. Personas Decisoras o de Substituto
2. Decidir lo que más le importa en la vida

## 1. Personas Decisoras

Estas preguntas son acerca de las personas decisoras. Una persona decisor es alguien que puede tomar decisiones médicas en su nombre SÓLO SI usted está demasiado enfermo para tomar sus propias decisiones.

Recuerde que no hay respuesta correcta o equivocada- por favor denos su honesta opinión.

### SELF-EFFICACY

(1 – DM)

Estas preguntas son acerca de que tan seguro se siente para hablar sobre a quién ha elegido como su persona decisor. [Read options.]

Que tan seguro esta de que hoy podria....	Red	Para Nada	Un poco	Mas o Menos	Bastante	Extremadam ente	NS/ Ref.
1. pedirle a alguien que sea su PERSONA DECISORA? (PE_S1_SE1)		1	2	3	4	5	8 / 9

### DISPOCISIÓN

(1 – DM)

Las siguientes preguntas son acerca de qué tan listo está para hablar con otras personas sobre quién desea que sea su persona decisor y para poner esta información por escrito.

2. ¿Qué tan listo(a) está para pedirle formalmente a alguien que sea su persona decisor? (PE_S1_DM_RDY)	<input type="checkbox"/> <u>Nunca</u> lo he pensado <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo <input type="checkbox"/> <u>Estoy pensando</u> en hacerlo en los siguientes 6 meses <input type="checkbox"/> <u>Estoy planeando</u> hacerlo en los próximos 30 días <input type="checkbox"/> Ya lo <u>hice</u>	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]
OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]
3. ¿Qué tan listo(a) está para hablar con su DOCTOR acerca de quién desea que fuera su persona decisor?	<input type="checkbox"/> <u>Nunca</u> lo he pensado <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo <input type="checkbox"/> <u>Estoy pensando</u> en hacerlo en los siguientes 6 meses <input type="checkbox"/> <u>Estoy planeando</u> hacerlo en los	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA	<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]

4. ¿Qué tan listo esta para FIRMAR DOCUMENTOS OFICIALES nombrando a una persona o grupo para tomar decisiones médicas por usted? (PE_S1_PAPER_RDY)	<input type="checkbox"/> <u>Nunca</u> lo he pensado <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo <u>Estoy</u> <input type="checkbox"/> <u>pensando</u> en hacerlo en los siguientes 6 meses <input type="checkbox"/> <u>Estoy planeando</u> en hacerlo en los próximos 30 días <input type="checkbox"/> Ya lo <u>hice</u>	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]
OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

## Decidir lo que Más le Importa en la Vida

Ahora queremos hablar de cómo algunas personas se sienten acerca de su calidad de vida. Por ejemplo, cómo quieren vivir, y cómo no quieren vivir.

Ahora vamos a cambiar de tema. Las preguntas previas se tratan de cómo la gente quisiera o no quisiera vivir. Las siguientes preguntas son acerca de tratamientos médicos específicos que algunas personas quisieran o no quisieran si estuvieran gravemente enfermos o al final de su vida. Por ejemplo, algunas personas saben que quisieran estar conectados a un respirador. Otras personas saben que nunca quisieran estar conectados a un respirador.

Por favor dénos su honesta opinión en las próximas preguntas acerca de los tratamientos médicos. No hay respuesta correcta o equivocada.

### SELF-EFFICACY

(2B – CARE AT EOL)

The next three questions ask about how confident you are to actually talk about your medical wishes. [Read options.]

Qué tan seguro está de que hoy podría...	Red	Para Nada	Un poco	Mas o Menos	Bastante	Extremadam ente	NS/ Ref.
5. ¿Qué tan seguro(a) está de que hoy podría hablar con su PERSONA DECISORA acerca del tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_SE1)		1	2	3	4	5	8 / 9
6. ¿Qué tan seguro(a) está de que hoy podría hablar con su DOCTOR acerca del tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_SE2)		1	2	3	4	5	8 / 9

### DISPOSICIÓN

(2B – CARE AT EOL)

Las siguientes preguntas son acerca de qué tan listo está para decidir y hablar sobre el tipo de cuidados que quisiera si estuviera muy enfermo o al final de su vida.

<p>7. ¿Qué tan listo(a) está para hablar con su PERSONA DECISORA sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_TELLDLM_READY)</p> <p>9 <input type="checkbox"/> Nunca lo he pensado</p> <p>10 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>11 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>12 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>13 <input type="checkbox"/> Ya lo hice</p>		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)</p>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

<p>8. ¿Qué tan listo(a) está para hablar con su DOCTOR sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_TELLDLR_RDY)</p> <p>1 <input type="checkbox"/> Nunca lo he pensado</p> <p>2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>5 <input type="checkbox"/> Ya lo hice</p>		<input type="checkbox"/> Not Sure <input type="checkbox"/> [Ref]
<p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?" (PE_S1_DECDM_WHEN)</p>	<input type="checkbox"/> Less than 6 mo <input type="checkbox"/> >6 months ago <input type="checkbox"/> NA	<input type="checkbox"/> Not sure <input type="checkbox"/> [Ref]

<p>9. ¿Qué tan listo(a) está para FIRMAR DOCUMENTOS OFICIALES que pongan sus deseos por escrito sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida?</p> <p>(PE_S2B_PAPER_RDY)</p> <p>1 <input type="checkbox"/> Nunca lo he pensado</p> <p>2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo</p> <p>3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses</p> <p>4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días</p> <p>5 <input type="checkbox"/> Ya lo hice</p>		<p><input type="checkbox"/> Not Sure</p> <p><input type="checkbox"/> [Ref]</p>
<p>OPTIONAL: If they answered, “Ya lo hice,” then ask “Cuando lo hizo?”</p> <p>(PE_S1_DECDM_WHEN)</p>		<p><input type="checkbox"/> Less than 6 mo</p> <p><input type="checkbox"/> &gt;6 months ago</p> <p><input type="checkbox"/> NA</p> <p><input type="checkbox"/> Not sure</p> <p><input type="checkbox"/> [Ref]</p>

# Encuesta de cuatro pregunta



## Preparación

### *Introduction*

**Tab 6** Esta sección es la más larga. Le preguntaremos sobre sus experiencias y opiniones. Le podemos preguntar acerca de cosas que ya ha hecho o cosas que ni ha pensado en hacer. Responda lo más honestamente que pueda.

En las próximas secciones le preguntaremos acerca de 2 temas:

1. Personas Decisoras o de Substituto
2. Decidir lo que más le importa en la vida

## 1. Personas Decisoras

Estas preguntas son acerca de las personas decisoras. Una persona decisor es alguien que puede tomar decisiones médicas en su nombre SÓLO SI usted está demasiado enfermo para tomar sus propias decisiones.

Recuerde que no hay respuesta correcta o equivocada- por favor denos su honesta opinión.

### DISPOSICIÓN

(1 – DM)

Las siguientes preguntas son acerca de qué tan listo está para hablar con otras personas sobre quién desea que sea su persona decisor y para poner esta información por escrito.

<p>1. ¿Qué tan listo esta para FIRMAR DOCUMENTOS OFICIALES nombrando a una persona o grupo para tomar decisiones médicas por usted? (PE_S1_PAPER_RDY)</p>	<p><input type="checkbox"/> <u>Nunca</u> lo he pensado</p> <p><input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo <u>Estoy</u></p> <p><input type="checkbox"/> <u>pensando</u> en hacerlo en los siguientes 6 meses</p> <p><input type="checkbox"/> <u>Estoy planeando</u> en hacerlo en los próximos 30 días</p> <p><input type="checkbox"/> Ya lo <u>hice</u> <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p style="text-align: right;"><input type="checkbox"/> [Ref]</p>
<p>OPTIONAL: If they answered, “Ya lo hice,” then ask “Cuando lo hizo?” (PE_S1_DECDM_WHEN)</p>	<p><input type="checkbox"/> Less than 6 mo</p> <p><input type="checkbox"/> &gt;6 months ago <span style="float: right;"><input type="checkbox"/> Not sure</span></p> <p><input type="checkbox"/> NA <span style="float: right;"><input type="checkbox"/> [Ref]</span></p>

## Decidir lo que Más le Importa en la Vida

Ahora queremos hablar de cómo algunas personas se sienten acerca de su calidad de vida. Por ejemplo, cómo quieren vivir, y cómo no quieren vivir.

Ahora vamos a cambiar de tema. Las preguntas previas se tratan de cómo la gente quisiera o no quisiera vivir. Las siguientes preguntas son acerca de tratamientos médicos específicos que algunas personas quisieran o no quisieran si estuvieran gravemente enfermos o al final de su vida. Por ejemplo, algunas personas saben que quisieran estar conectados a un respirador. Otras personas saben que nunca quisieran estar conectados a un respirador.

Por favor dénos su honesta opinión en las próximas preguntas acerca de los tratamientos médicos. No hay respuesta correcta o equivocada.

### DISPOSICIÓN

(2B – CARE AT EOL)

Las siguientes preguntas son acerca de qué tan listo está para decidir y hablar sobre el tipo de cuidados que quisiera si estuviera muy enfermo o al final de su vida.

<p>2. ¿Qué tan listo(a) está para hablar con su PERSONA DECISORA sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_TELLDM_READY)</p> <p>1 <input type="checkbox"/> Nunca lo he pensado  2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo  3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses  4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días  5 <input type="checkbox"/> Ya lo hice</p> <p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?"  (PE_S1_DECDM_WHEN)</p>	<div style="border: 1px solid black; padding: 5px;"> <input type="checkbox"/> Not Sure  <input type="checkbox"/> [Ref] </div> <div style="border: 1px solid black; padding: 5px;"> <input type="checkbox"/> Less than 6 mo  <input type="checkbox"/> &gt;6 months ago  <input type="checkbox"/> NA </div> <div style="border: 1px solid black; padding: 5px;"> <input type="checkbox"/> Not sure  <input type="checkbox"/> [Ref] </div>
<p>3. ¿Qué tan listo(a) está para hablar con su DOCTOR sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida? (PE_S2B_TELLDR_RDY)</p> <p>1 <input type="checkbox"/> Nunca lo he pensado  2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo  3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses  4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días  5 <input type="checkbox"/> Ya lo hice</p> <p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?"  (PE_S1_DECDM_WHEN)</p>	<div style="border: 1px solid black; padding: 5px;"> <input type="checkbox"/> Not Sure  <input type="checkbox"/> [Ref] </div> <div style="border: 1px solid black; padding: 5px;"> <input type="checkbox"/> Less than 6 mo  <input type="checkbox"/> &gt;6 months ago  <input type="checkbox"/> NA </div> <div style="border: 1px solid black; padding: 5px;"> <input type="checkbox"/> Not sure  <input type="checkbox"/> [Ref] </div>
<p>4. ¿Qué tan listo(a) está para FIRMAR DOCUMENTOS OFICIALES que pongan sus deseos por escrito sobre el tipo de cuidado médico que quisiera si se encontrara gravemente enfermo o al final de su vida?  (PE_S2B_PAPER_RDY)</p> <p>1 <input type="checkbox"/> Nunca lo he pensado  2 <input type="checkbox"/> Lo he pensado, pero no estoy listo(a) para hacerlo  3 <input type="checkbox"/> Estoy pensando en hacerlo en los próximos 6 meses  4 <input type="checkbox"/> Estoy planeando hacerlo en los próximos 30 días  5 <input type="checkbox"/> Ya lo hice</p> <p>OPTIONAL: If they answered, "Ya lo hice," then ask "Cuando lo hizo?"  (PE_S1_DECDM_WHEN)</p>	<div style="border: 1px solid black; padding: 5px;"> <input type="checkbox"/> Not Sure  <input type="checkbox"/> [Ref] </div> <div style="border: 1px solid black; padding: 5px;"> <input type="checkbox"/> Less than 6 mo  <input type="checkbox"/> &gt;6 months ago  <input type="checkbox"/> NA </div> <div style="border: 1px solid black; padding: 5px;"> <input type="checkbox"/> Not sure  <input type="checkbox"/> [Ref] </div>