

**Online Appendix A: Summary of results for all conditions, including no default ‘order only’ conditions**

Table A1: Demographics of full sample, including no default ‘order only’ conditions

	Order Only Comfort (n=133)	Order Only Prolong (n=139)	Post Informed Comfort (n=104 <sup>1</sup> )	Post Informed Prolong (n=124)	Pre Informed Comfort (n=125)	Pre Informed Prolong (n=134 <sup>2</sup> )
Male	53%	52%	48%	65%	58%	65%
Mean Age	50.95 (15.76)	49.47 (15.78)	49.71 (14.99)	48.69 (14.68)	49.97 (13.86)	48.89 (14.67)
<b>Race</b>						
Caucasian	92%	88%	86%	79%	93%	95%
Black	2%	1%	2%	2%	0%	1%
Asian	5%	9%	9%	10%	6%	4%
Other Race	2%	2%	3%	9%	1%	1%
<b>Religion</b>						
Non Religious	40%	39%	43%	42%	36%	41%
Catholic	13%	16%	22%	15%	14%	15%
Protestant	25%	17%	14%	20%	18%	23%
Jewish	9%	17%	8%	7%	16%	8%
Other Religion	14%	11%	14%	16%	16%	13%
% CMU	71%	68%	74%	78%	68%	71%
Been in ICU	11%	13%	15%	12%	10%	13%
Experiencing Health Problems	8%	6%	6%	11%	6%	8%

Standard deviations in parentheses

<sup>1</sup> 2 Participants did not complete the demographic survey

<sup>2</sup> 1 Participant did not complete the demographic survey

Table A2: Change in endorsement of comfort items from phase 1 (before being informed of default) to phase 2 (after being informed of default) among the post-informed groups, comparing those defaulted to comfort and prolong choices.

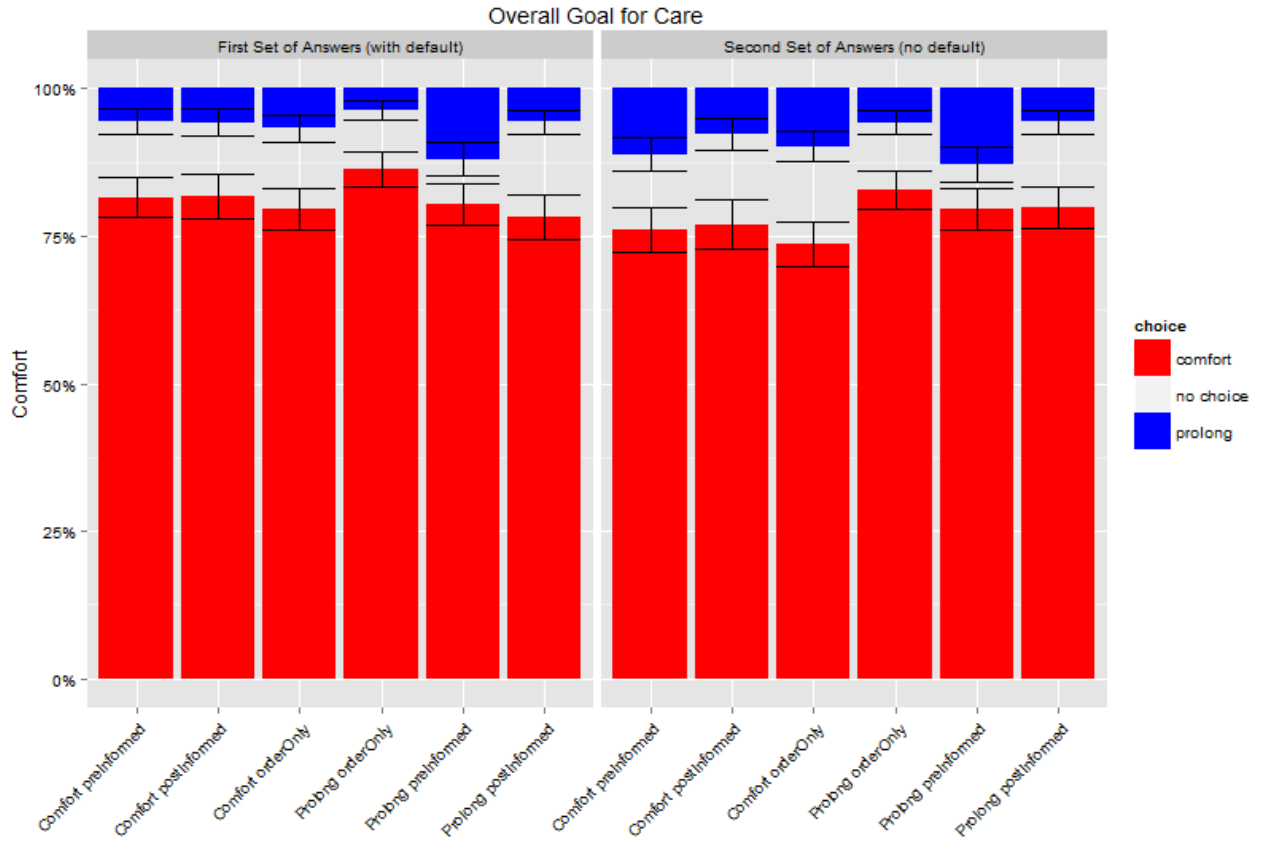
	Post-informed, Comfort Default (n=104)			Post-informed, Prolong Default (n=124)		
	Initial answers	Final answers	% Changed (# Changed)	Initial answers	Final answers	% Changed (# Changed)
Goal is comfort	82%	77%	8.7% (9)	78%	80%	8.1% (10)
total # of comfort choices	2.35	2.37	15.4% (16)	1.51	1.81	20.1% (25)
CPR	41%	40%	4.8% (5)	23%	25%	8.1% (10)
ICU	38%	40%	7.7% (8)	21%	26%	4.8% (6)
Ventilator	55%	56%	6.7% (7)	38%	44%	8.9% (11)
Dialysis	47%	47%	5.8% (6)	27%	38%	10.5% (13)
Feeding Tube	53%	53%	5.8% (6)	41%	49%	9.7% (12)

Table A3 – Switching away from default when filling out the form for the first time (with defaults); random effects logistic regressions. Age is centered.

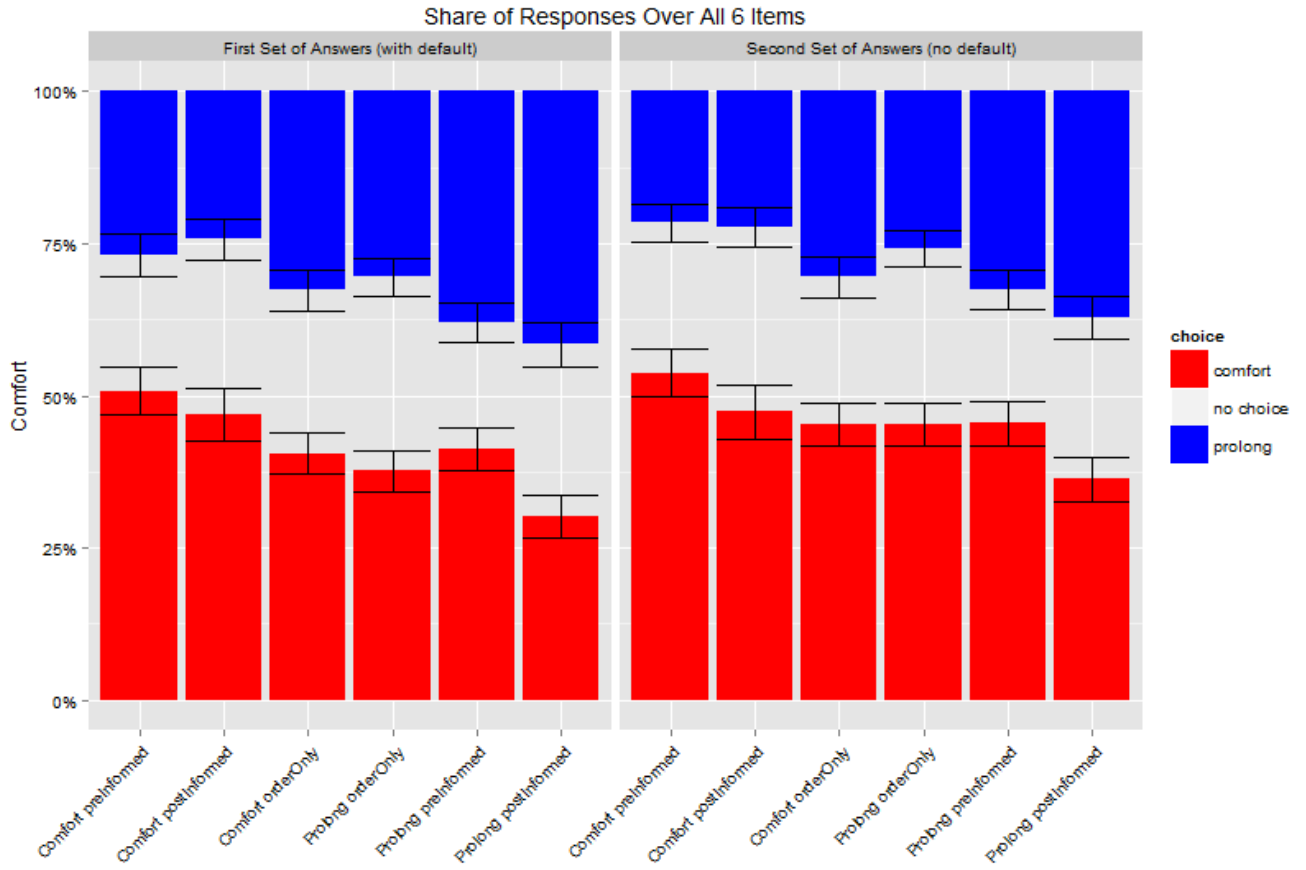
	preInformed		preInformed x Comfort	
preInformed	-0.042 (0.264)	-0.174 (0.373)	0.379 (0.490)	0.148 (0.498)
Comfort			-0.549 (0.526)	-0.508 (0.535)
preInformed x Comfort			-0.849 (0.720)	-0.635 (0.724)
CMU		-0.505 (0.426)		-0.542 (0.422)
Male		0.686 (0.378)		0.626 (0.378)
Age		-0.003 (0.014)		-0.001 (0.014)
Agesq		0.002* (0.001)		0.002* (0.001)
<b>Race</b>				
nonCaucasian		-1.360* (0.604)		-1.329* (0.597)
<b>Religion</b>				
Catholic		-1.210* (0.540)		-1.179* (0.533)
Protestant		0.580 (0.516)		0.470 (0.511)
Jewish		-2.082** (0.660)		-1.945** (0.655)
Other religion		-0.220 (0.560)		-0.239 (0.554)
Constant	0.617 (0.264)	0.743 (0.514)	0.841* (0.352)	1.037 (0.582)
N	2430	2420	2430	2420

\*  $p < 0.05$ , \*\*  $p < 0.01$ , \*\*\*  $p < 0.001$

**Figure A1: Summary of first and second stage responses to overall goal of care question, including no default 'order only' conditions**



**Figure A2: Summary of first and second stage responses to average of 5 specific care question, including no default 'order only' conditions**



## **Online Appendix B: Complete experimental stimuli**

### **Online Consent**

This survey is part of a research study conducted by George Loewenstein at Carnegie Mellon University.

The specific focus of this research is on Advance Directives. The purpose of an Advance Directive is to give individuals the ability to make decisions about their medical treatment in case, for health reasons, they become unable to communicate their wishes.

### **Procedures**

In the main part of the study, we will ask you to complete a shortened version of an Advance Directive. We will also ask you to complete a survey that asks for demographic information and about your prior experience with healthcare decision making and advance directives. The study should take roughly twenty to thirty minutes.

### **Participant Requirements**

Participation in this study is limited to people over the age of 18.

### **Risks**

The risks and discomfort associated with participation in this study are no greater than those associated with other activities that cause you to think about health and health-related decisions.

### **Benefits**

There may be no personal benefit from your participation in the study but the knowledge received may be of value to science and to policy makers. You will not receive your own Advance Directive when you complete the study, but, if you contact us, we can help to link you to resources that can help you to complete one that would be legally valid

### **Compensation & Costs**

There is no compensation for participation in this study. There will be no cost to you if you participate in this study.

### **Confidentiality**

The data captured for the research does not include any personally identifiable information about you. Your IP address will not be captured. Your data will be stored on a secure server at Carnegie Mellon, and your individual data will not be disclosed to third parties. By participating, you understand and agree that the data and information gathered during this study may be used by Carnegie Mellon and published and/or disclosed by Carnegie Mellon to others outside of Carnegie Mellon.

### **Right to Ask Questions & Contact Information**

If you have any questions about this study, you should feel free to ask them by contacting the Principal Investigator: George Loewenstein, Social Decision Sciences, 5000 Forbes BP 208, Pittsburgh, PA, 15213, 412-268-8787, gl20@andrew.cmu.edu. If you have questions later, desire additional information, or wish to withdraw your participation please contact the Principal Investigator by mail, phone or e-mail in accordance with the contact information listed above.

If you have questions pertaining to your rights as a research participant or to report objections to this study, you should contact the Research Regulatory Compliance Office at Carnegie Mellon University. Email: irb-review@andrew.cmu.edu . Phone: 412-268-1901 or 412-268-5460.

### **Voluntary Participation**

Your participation in this research is voluntary. You may discontinue participation at any time during the research activity.

Q2 I am age 18 or older.

- Yes
- No
- If No Is Selected, Then Skip To End of Survey

Q3 I have read and understand the information above.

- Yes
- No
- If No Is Selected, Then Skip To End of Survey

Q4 I want to participate in this research and continue with the survey.

- Yes
- No
- If No Is Selected, Then Skip To End of Survey

Thank you for choosing to participate in this study about Advance Directives. The purpose of an Advance Directive is to give individuals the ability to make decisions about their medical treatment in case, for health reasons, they become unable to communicate their wishes.

As part of this research, momentarily, we will ask you to complete a brief version of an Advance Directive. Once you complete it, we will ask you additional questions, including some demographic information and some information about your views on health issues.

**[[Displayed only in the preInformed condition:**

**PLEASE READ THE FOLLOWING VERY CAREFULLY; IT IS CRITICAL FOR THE STUDY.**

The specific focus of this research is on ‘defaults’ – decisions that go into effect if people don’t take actions to do something different. Participants in this research project have been divided into two experimental groups.

If you have been assigned to one group, the Advance Directive you complete will have answers to questions checked that will direct health care providers to help relieve pain and suffering even if it means not living as long. If you want something different, you will be asked to check one of the other options and place your initials beside the different option you select.

If you have been assigned to the other group, the Advance Directive you complete will have answers to questions checked that will direct health care providers to prolong your life as much as possible, even if it means you may experience greater pain and suffering. If you want something different, you will be asked to check one of the other options and place your initials beside the different option you select.

Now, please continue on to the Advance Directive and complete it in a fashion that expresses your wishes for treatment if you lack the capacity to understand, make, or communicate desired treatment decisions. ]]

**PLEASE COMPLETE THE FOLLOWING AS IF YOU WERE COMPLETING A REAL ADVANCE DIRECTIVE THAT WOULD BECOME PART OF YOUR MEDICAL RECORD**

The following health care treatment instructions exercise my right to make my own health care decisions. These instructions are intended to provide clear and convincing evidence of my wishes to be followed when I lack the capacity to understand, make, or communicate my treatment decisions. This section of the document will take effect **when and only when I lack the ability to understand, make or communicate a choice regarding a health or personal care decision as verified by my attending physician.**



If I have a condition where I have no reasonable expectation of recovery or chance of regaining a meaningful quality of life, my instructions are as follows:

**[[Displayed only in the comfort condition:**

Q8 Overall Goal of Care

- I want my health care providers and agent to pursue treatments that help relieve my pain and suffering, even if that means that I might not live as long.

OR

**(If you would like to select either of the two other responses, please place your initials in the box below)**

- I want my health care providers and agent to pursue treatments that help me to live as long as possible, even if that means I might have more pain or suffering.

\_\_\_\_\_

- I do not want to specify one of the above goals. My health care providers and agent may direct the overall goals of my care.

\_\_\_\_\_ ]]

**[[Displayed only in in the prolong condition:**

Q8 Overall Goal of Care

- I want my health care providers and agent to pursue treatments that help me to live as long as possible, even if that means I might have more pain or suffering.

OR

**(If you would like to select either of the two other responses, please place your initials in the box below)**

- I want my health care providers and agent to pursue treatments that help relieve my pain and suffering, even if that means I might not live as long.

\_\_\_\_\_

- I do not want to specify one of the above goals. My health care providers and agent may direct the overall goals of my care.

\_\_\_\_\_ ]]

Q9 In addition, I want my health care providers and agent to focus on the following goals (optional): \_\_\_\_\_

**[[Q11 – Q15 are shown as they are presented in the comfort condition. The ordering and default is adjusted for the prolong condition as in Q8]]**

Now, we would like to ask you about some specific procedures

Q11 Cardiopulmonary resuscitation (CPR) (*manual chest compressions performed to restore blood circulation and breathing*)

- I do not want cardiopulmonary resuscitation (CPR) to be performed if my heart stops beating, even if performing CPR might prolong my life.

OR

**(If you would like to select either of the two other responses, please place your initials in the box below)**

- I request cardiopulmonary resuscitation (CPR) if my heart stops beating, even if performing CPR might increase my pain or suffering.  
\_\_\_\_\_
- I do not wish to specify one of these options. My health care providers and agent may make any decisions about cardiopulmonary resuscitation (CPR) for me.  
\_\_\_\_\_

Q12 Intensive care unit (ICU) admission (*hospital unit that provides specialized equipment, services, and monitoring for critically ill patients, such as higher staffing-to-patient ratios and ventilator support*)

- I do not want to be admitted to the intensive care unit (ICU), even if it might prolong my life.

OR

**(If you would like to select either of the two other responses, please place your initials in the box below)**

- I want to be admitted to the intensive care unit (ICU) to prolong my life, even if it might increase my pain or suffering.  
\_\_\_\_\_
- I do not wish to specify one of these options. My health care providers and agent may make any decisions about admission to the ICU for me.  
\_\_\_\_\_

Q13 Mechanical ventilator use (*a general term to describe machines that assist spontaneous breathing, often using either a mask or a breathing tube*)

- I do not want a mechanical ventilator to be used, even if it might prolong my life.

OR

**(If you would like to select either of the two other responses, please place your initials in the box below)**

- I request the use of a mechanical ventilator to prolong my life, even if it might increase my pain or suffering.  
\_\_\_\_\_
- I do not wish to specify one of these options. My health care providers and agent may make any decisions about the use of a mechanical ventilator for me.  
\_\_\_\_\_

Q14 Dialysis (*kidney filtration by machine*)

- I do not want dialysis to be performed on me, even if it might prolong my life.

OR

**(If you would like to select either of the two other responses, please place your initials in the box below)**

- I request dialysis to prolong my life, even if it might increase my pain or suffering.  
\_\_\_\_\_
- I do not wish to specify one of these options. My health care providers and agent may make any decisions about the use of dialysis for me.  
\_\_\_\_\_

Q15 Feeding tube insertion (*devices used to provide nutrition to patients who cannot swallow, inserted either through the nose and esophagus into the stomach or directly into the stomach through the belly*)

- I do not want to have a feeding tube inserted, even if it might prolong my life.

OR

**(If you would like to select either of the two other responses, please place your initials in the box below)**

- I request feeding tube insertion to prolong my life, even if it might increase my pain or suffering.  
\_\_\_\_\_
- I do not wish to specify one of these options. My health care providers and agent may make any decisions about insertion of a feeding tube for me.  
\_\_\_\_\_

**[[Displayed only in the preInformed condition:**

In past surveys, some of our respondents have wanted to revise their answers after seeing the full set of questions. Starting on the next page, we are going to present the same Advance Directive and ask you to complete the individual items a second time. This will allow you to either confirm or change your responses now that you know all of the treatments that are included. Please do not leave any of the items blank.

Just as you did before, please complete these items so that they express your wishes for treatment in situations where you would lack the capacity to understand, make, or communicate your treatment decisions directly. ]]

**[[Displayed only in the postInformed condition:**

**PLEASE READ THE FOLLOWING VERY CAREFULLY; IT IS CRITICAL FOR THE STUDY.**

The specific focus of this research is on 'defaults' – decisions that go into effect if people don't take actions to do something different. Participants in this research project have been divided into two experimental groups.

If you have been assigned to one group, the Advance Directive you complete will have answers to questions checked that will direct health care providers to help relieve pain and suffering even if it means not living as long. If you want something different, you will be asked to check one of the other options and place your initials beside the different option you select.

If you have been assigned to the other group, the Advance Directive you complete will have answers to questions checked that will direct health care providers to prolong your life as much as possible, even if it means you may experience greater pain and suffering. If you want something different, you will be asked to check one of the other options and place your initials beside the different option you select.

Now, please continue on to the Advance Directive and complete it in a fashion that expresses your wishes for treatment if you lack the capacity to understand, make, or communicate desired treatment decisions. ]]

**If I have a condition where I have no reasonable expectation of recovery or chance of regaining a meaningful quality of life, my instructions are as follows:**

**[[Displayed only in the comfort condition:**

Q18 Overall Goal of Care

- I want my health care providers and agent to pursue treatments that help relieve my pain and suffering, even if that means that I might not live as long.
- I want my health care providers and agent to pursue treatments that help me to live as long as possible, even if that means I might have more pain or suffering.
- I do not want to specify one of the above goals. My health care providers and agent may direct the overall goals of my care.]]

**[[Displayed only in the prolong condition:**

Q18 Overall Goal of Care

- I want my health care providers and agent to pursue treatments that help me to live as long as possible, even if that means I might have more pain or suffering.
- I want my health care providers and agent to pursue treatments that help relieve my pain and suffering, even if that means I might not live as long.
- I do not want to specify one of the above goals. My health care providers and agent may direct the overall goals of my care. ]]

Q19 In addition, I want my health care providers and agent to focus on the following goals (optional): \_\_\_\_\_

**[[Q21 – Q25 are shown as they are presented in the comfort condition. The ordering and is adjusted for the prolong condition as in Q18]]**

Now we would like to ask you about the specific procedures

Q21 Cardiopulmonary resuscitation (CPR) (*manual chest compressions performed to restore blood circulation and breathing*)

- I do not want cardiopulmonary resuscitation (CPR) to be performed if my heart stops beating, even if performing CPR might prolong my life.
- I request cardiopulmonary resuscitation (CPR) if my heart stops beating, even if performing CPR might increase my pain or suffering.
- I do not wish to specify one of these options. My health care providers and agent may make any decisions about cardiopulmonary resuscitation (CPR) for me.

Q22 Intensive care unit (ICU) admission (*hospital unit that provides specialized equipment, services, and monitoring for critically ill patients, such as higher staffing-to-patient ratios and ventilator support*)

- I do not want to be admitted to the intensive care unit (ICU), even if it might prolong my life.
- I want to be admitted to the intensive care unit (ICU) to prolong my life, even if it might increase my pain or suffering.
- I do not wish to specify one of these options. My health care providers and agent may make any decisions about admission to the ICU for me.

Q23 Mechanical ventilator use (*a general term to describe machines that assist spontaneous breathing, often using either a mask or a breathing tube*)

- I do not want a mechanical ventilator to be used, even if it might prolong my life.
- I request the use of a mechanical ventilator to prolong my life, even if it might increase my pain or suffering.
- I do not wish to specify one of these options. My health care providers and agent may make any decisions about the use of a mechanical ventilator for me.

Q24 Dialysis (*kidney filtration by machine*)

- I do not want dialysis to be performed on me, even if it might prolong my life.
- I request dialysis to prolong my life, even if it might increase my pain or suffering.
- I do not wish to specify one of these options. My health care providers and agent may make any decisions about the use of dialysis for me.

Q25 Feeding tube insertion (*devices used to provide nutrition to patients who cannot swallow, inserted either through the nose and esophagus into the stomach or directly into the stomach through the belly*)

- I do not want to have a feeding tube inserted, even if it might prolong my life.
- I request feeding tube insertion to prolong my life, even if it might increase my pain or suffering.
- I do not wish to specify one of these options. My health care providers and agent may make any decisions about insertion of a feeding tube for me.

Q26 What is your agent's duty?

- My agent must follow these instructions.
- These instructions are only guidelines. My agent shall have final say, and may override any of my instructions unless I specifically indicate exceptions.

Q27 Gender

- Male
- Female

Q28 Age \_\_\_\_\_

Q29 Race

- American Indian/Alaska Native
- Asian
- Native Hawaiian or Other Pacific Islander
- Black or African American
- White
- Other \_\_\_\_\_

Q30 Ethnicity

- Hispanic
- Non-Hispanic

Q31 What is your religious affiliation?

- None
- Roman Catholic
- Protestant
- Jewish
- Muslim
- Buddhist
- Hindu
- Other \_\_\_\_\_

Q32 How important is religion in your life?

- Very important
- Somewhat important
- Not important at all

Q33 Have you ever experienced the death of a loved one, either a relative or close friend?

- Yes
- No
- If No Is Selected, Then Skip To Q37

Q34 Of these, how many of them died while in the **intensive care unit (ICU)**?

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Q35 How familiar are you with the care they received while in the ICU

- Very familiar
- Somewhat familiar
- Not familiar at all
- Not applicable

Q36 In general, how would you describe the care delivered in the ICU?

- Very caring
- Somewhat caring
- Not very caring
- Not applicable

Q37 Have you ever been a patient in a hospital intensive care unit (ICU)?

- Yes
- No

Q38 Are you currently experiencing any potentially serious health problems?

- Yes
- No

Q39 If yes, describe \_\_\_\_\_

Q40 On a scale of 0 to 100, where 0 is the worst health condition you can imagine and 100 is the best that you can imagine, what number would you assign to your current health? (please answer with a numeric value [0,100])

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Q41 Have you documented your own preferences for end-of-life care in any way? Please indicate if you have any of the following (check all that apply).

- An advance directive or living will
- A durable power of attorney
- An organ donor registration card
- Other \_\_\_\_\_
- I have not documented my end-of-life preferences

Q42 Have you made decisions for another person during a critical illness?

- Yes
- No



Answer If Q42 Yes Is Selected

Q43 If yes, please describe \_\_\_\_\_

Answer If Q42 Yes Is Selected

Q44 Did your loved one survive that experience?

- Yes
- No

Answer If Q44 Yes Is Selected

Q45 If yes, please describe \_\_\_\_\_

Answer If Q44 Yes Is Selected

Q46 What is your relationship to that person?

- Spouse/ or significant other
- I am their child
- I am their parent
- Other \_\_\_\_\_

Answer If Q44 No Is Selected

Q47 What was your relationship to that person?

- Spouse/ or significant other
- I was their child
- I was their parent
- Other \_\_\_\_\_

Q49 Today in the United States, the average person lives almost 78 years, but a particular person's life span will be affected by many different things, such current health, lifestyle, family history, and environment. In your opinion, considering your own set of circumstances, to what age do you think you will live? \_\_\_\_\_

Q50 If you would like to receive a summary of the results of this study when it is completed, please enter your email in the space provided. If you would prefer that your email cannot be connected with your responses, you can also email us at the address from which you received the request to participate. \_\_\_\_\_