

## **INSTRUCTIONS**

Before you begin, you will need:

1. A digital photo of the person for whom you would make “proxy” medical decisions if they were unconscious in the intensive care unit (ICU): your mother, father, husband or wife.
2. To install Flash Player (if your computer does not already have it).
3. A quiet space where you won’t be interrupted for 45 minutes.

## CONSENT

Treatment decisions for critically ill patients are frequently made by loved ones who are under significant emotional stress. The purpose of this research study is to understand the factors that influence family members when making treatment decisions for a relative in the ICU. To participate, you will:

- ❑ Upload a digital photo of a mother, father, husband or wife (the relative you would be responsible to make health care decisions for if they were unconscious in the intensive care unit (ICU)). We will delete the uploaded photo as soon as you complete the survey.
- ❑ Complete a short guided imagery exercise. Half of participants will be asked to do the exercise while looking at the uploaded photo. Half of participants will not see the uploaded photo, but will instead see a photo of a landscape.
- ❑ Watch a video in which a doctor talks to you about a hypothetical medical condition experienced by your relative. Throughout the video you will be asked to respond to the doctor's questions.
- ❑ Complete a questionnaire that will ask you about how you felt during the video and about your background.

In total, participation should take about 45 minutes of your time. There is minimal risk to you. However, if thinking about your relative in the ICU makes you anxious or worried, you may feel uncomfortable. This risk of anxiety is likely (occurs in more than 25 out of 100 people). There is no direct benefit to you. You will receive a \$25 debit card, usable like cash, in the mail upon the completion of study. This is an entirely anonymous questionnaire, and so your responses will not be identifiable in any way. The results of the study will be kept under lock and key. Your participation is voluntary, and you may withdraw from this project at any time. The principal investigator of the study is Dr. Amber Barnato and the research assistant is Jessica Papadopoulos. They can be contacted at (412) 586-9636 or emailed at [barnae@upmc.edu](mailto:barnae@upmc.edu) or [papadopoulosjl@upmc.edu](mailto:papadopoulosjl@upmc.edu).

**CLICK TO AGREE AND PROCEED**

## PHOTO UPLOAD

Please upload a digital photo of the relative for whom you would make “proxy” medical decisions if they were unconscious in the intensive care unit (ICU): your mother, father, husband or wife.

Note: We will delete the uploaded photo as soon as you complete the survey at the end of the study.

### BROWSE and UPLOAD Photo

Please select the relative whose photo you have uploaded:

Mother  
Father  
Husband  
Wife

I am this person's:

Daughter  
Son  
Husband  
Wife

How old is your [relative]?

[ Age ]

Has your [relative] been hospitalized in the last 12 months?

[Yes/No ]

How would you describe your [relative]'s health?

[Excellent, Very Good, Good, Fair, Poor]

## RANDOMIZATION/RELATIONSHIP TABLE PROGRAMMED HERE

Use randomization table to select appropriate video and information from the previous page to customize the video (e.g., the relative's relationship and sex).

Experimental sequence	Relationship/Sex
Permutation 1-32, drawn from randomization table 'rand_assign.xlsx'	Parent – Father/he/his/him
Permutation 1-32, drawn from randomization table 'rand_assign.xlsx'	Parent – Mother/she/hers/her
Permutation 1-32, drawn from randomization table 'rand_assign.xlsx'	Spouse – Husband/he/his/him
Permutation 1-32, drawn from randomization table 'rand_assign.xlsx'	Spouse – Wife/she/hers/her

Sequence	Emotional State	MD Emotion handling	Default is CPR or no CPR	Frame: Patient's or surrogate's decision	Frame: "DNR" or "AND"
1	hot	EH(+)	CPR	surrogate's	DNR
2	hot	EH(+)	CPR	surrogate's	AND
3	hot	EH(+)	CPR	patient's	DNR
4	hot	EH(+)	CPR	patient's	AND
5	hot	EH(+)	No CPR	surrogate's	DNR
6	hot	EH(+)	No CPR	surrogate's	AND
7	hot	EH(+)	No CPR	patient's	DNR
8	hot	EH(+)	No CPR	patient's	AND
9	hot	EH(-)	CPR	surrogate's	DNR
10	hot	EH(-)	CPR	surrogate's	AND
11	hot	EH(-)	CPR	patient's	DNR
12	hot	EH(-)	CPR	patient's	AND
13	hot	EH(-)	No CPR	surrogate's	DNR
14	hot	EH(-)	No CPR	surrogate's	AND
15	hot	EH(-)	No CPR	patient's	DNR
16	hot	EH(-)	No CPR	patient's	AND
17	cold	EH(+)	CPR	surrogate's	DNR
18	cold	EH(+)	CPR	surrogate's	AND
19	cold	EH(+)	CPR	patient's	DNR
20	cold	EH(+)	CPR	patient's	AND
21	cold	EH(+)	No CPR	surrogate's	DNR
22	cold	EH(+)	No CPR	surrogate's	AND
23	cold	EH(+)	No CPR	patient's	DNR
24	cold	EH(+)	No CPR	patient's	AND
25	cold	EH(-)	CPR	surrogate's	DNR
26	cold	EH(-)	CPR	surrogate's	AND
27	cold	EH(-)	CPR	patient's	DNR
28	cold	EH(-)	CPR	patient's	AND
29	cold	EH(-)	No CPR	surrogate's	DNR
30	cold	EH(-)	No CPR	surrogate's	AND
31	cold	EH(-)	No CPR	patient's	DNR
32	cold	EH(-)	No CPR	patient's	AND

## EMOTIONAL INDUCTION

For those randomized to the “hot” state:

At the top left of the screen, you will see the photograph of your [relative]. Before we begin the video, we'd like you to call to mind something that your [relative] did that you feel grateful for. Please look at the photograph and imagine the situation when the thing you feel grateful for occurred. After you have thought about it for 30 seconds, click on the box below.

A blue rectangular button with rounded corners and a slight gradient, containing the word "Continue" in white text.

How difficult was it for you to imagine the situation?

[very difficult, somewhat difficult, neither difficult nor easy, somewhat easy, very easy]

How grateful did you feel when you were thinking of the situation?

[not at all grateful, somewhat grateful, quite grateful, extremely grateful]

Now, we'd like you to call to mind a situation in which you had an interaction with your [relative] that was especially meaningful for you. Please look at the photograph again and imagine the meaningful interaction. After you have imagined it for about 30 second, please click on the box below.

A blue rectangular button with rounded corners and a slight gradient, containing the word "Continue" in white text.

How difficult was it for you to imagine the interaction?

[very difficult, somewhat difficult, neither difficult nor easy, somewhat easy, very easy]

How meaningful was the interaction that you imagined?

[not at all meaningful, somewhat meaningful, quite meaningful, extremely meaningful]

For those randomized to the “cold” state:

At the top left of the screen, you will see a photograph of a park. Before we begin the video, we'd like you to call to mind a time that you walked in a park. Please look at the photograph, then imagine the trees and plants you would see while walking in the park. After you have thought about it for 30 seconds, click on the box below.

**Continue**

How difficult was it for you to imagine the trees and plants?

[very difficult, somewhat difficult, neither difficult nor easy, somewhat easy, very easy]

Now call to mind a time you walked in a park and imagine the path you took. Please look at the photograph, then imagine the path you took on the walk. After you have thought about it for 30 seconds, click on the box below.

**Continue**

How difficult was it for you to imagine the path you took on the walk?

[very difficult, somewhat difficult, neither difficult nor easy, somewhat easy, very easy]

## MEETING WITH ICU DOCTOR

Video: TICU scene: doctor at nurses station writing in a chart. Checks beeper, then walks to a conference room, opens door, and enters.

Voice over during video: As I think you know, your [relation] has been admitted to the intensive care unit (ICU) of our hospital. [S/he] had a fever, cough, and difficulty breathing. In the last few hours she was placed on a breathing machine. The doctors have hopefully explained to you that the cause of the difficulty breathing is pneumonia. The intensive care doctor responsible for your [relation's] care is coming in to meet with you now.



Start

Doctor: Hello, I'm Dr. Smith. I'm one of the ICU doctors here, and I'm taking care of your [mother/father/wife/husband].

I'd like to bring you up to speed on what's going on. But before I do, why don't you tell me what you've been told so far.

Continue

Emotion handling absent

Doctor: Right, right. Your [relation] has been admitted to the ICU for pneumonia and [s/he] is on a breathing machine.

Emotion handling present

Doctor: Right, right. Your [relation] has been admitted to the ICU for pneumonia and [s/he] is on a breathing machine. **This must feel really overwhelming to have everything happen so suddenly.**

Doctor: **Would it be ok if I tell you what I know?**

Continue

Doctor: Let me try to summarize what I know. [She/he] came into the hospital feeling very short of breath, and [she/he] wasn't getting enough oxygen. [Her/his] oxygen levels were so low, that we had to put a tube down [her/his] throat and put [her/him] on a breathing machine. Still, even on the breathing machine, [her/his] oxygen levels are not as high as we'd like.

Why is this happening?

Emotion handling absent

Emotion handling present

Doctor: **{Nods as if hearing question} You must be really worried. It's natural to feel this way.**

Doctor: The x-rays show a possible pneumonia, and we are treating it with antibiotics. But it's not just a simple pneumonia. Usually when we put someone with pneumonia on a breathing machine their oxygen levels come right up. Here, the fact that [her/his] oxygen levels is still so low and [her/his] blood pressure is also low, tells us that [she/he] probably also has sepsis and acute lung injury.

What's sepsis and acute lung injury?



Doctor: That's a good question. Let me explain. Most of the time when we get an infection the body is able to contain it—think of an ear infection. But sometimes the infection becomes so severe that it spreads throughout the body, causing inflammation and low pressure. We call that condition sepsis. When the inflammation causes damage to the lung, we call that condition acute lung injury

Emotion handling absent

Doctor:

Emotion handling present

Doctor: I've given you a lot of information. How are you feeling?

## Will [s/he] recover?

Doctor: At this point it's hard to say. We can treat the infection with antibiotics, but our treatments can take a couple of days or more before we know if they'll work. And the statistics are not too good. Around 40% of people who are just like [her/him] will die from this.

Emotion handling absent

Doctor: [S/he] is really sick.

Emotion handling present

Doctor: I wish I could tell you something different, but [s/he] is really sick.

## What is the plan?

Doctor: Well, we're going to keep [her/him] in the ICU, we'll support her on the breathing machine, and use IV fluids to keep [her/his] blood pressure up. We're going to keep an extremely close eye on [her/him], and wait to see if her body heals.

Emotion handling absent

Emotion handling present

Doctor: This is all very scary, I know. I want you to know that we are here for you, and we'll let you know if anything changes.

Continue

Doctor: Before we finish our meeting, there is one more thing that we need to discuss. When someone is this sick in the ICU their heart could stop beating. If your [relation]'s heart were to stop beating, we need to know whether to give CPR and electric shocks to try to restart [his/her] heart. When we give CPR and electric shocks, the likelihood of survival is really low. Fewer than 10% of people like [him/her] who get CPR in the hospital survive – 90% die despite CPR.

Continue

<u>Default – CPR</u> Doctor: People have different thoughts on this, but in my experience, most people want CPR.	<u>Default – no CPR</u> Doctor: People have different thoughts on this, but in my experience, most people <b>don't want</b> CPR.
<u>Frame – Surrogate's decision</u> Doctor: Do you want us to do CPR on your [relation]?	<u>Frame – Patient's decision</u> Doctor: <b>If your [relation] were sitting right here with us, what would [s/he] tell you [s/he] wanted? Would [s/he] want us to do CPR?</b>
<u>Frame – DNR</u> Doctor: Or [would s/he / do you] want a do-not-resuscitate order?	<u>Frame – AND</u> Doctor: Or [would s/he /do you] want us to <b>allow a natural death?</b>

For those randomized to DNR

Perform CPR

Do Not Resuscitate

For those randomized to AND:

Perform CPR

Allow Natural Death

Doctor: Okay, we will do that. We'll meet again in a few days, or sooner if we need to.

<u>Emotion handling absent</u> Doctor: Just ask the nurse to page me if you want to talk to me.	<u>Emotion handling present</u> <b>We will do all we can do to help you.</b> Just ask the nurse to page me if you want to talk to me.
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## POST-MEETING SURVEY

{Profile of Mood States, short form}

Below is a list of words that describe feelings that people have. Please read each word carefully. Then check the box under what best describes how you feel having just made this decision for your relative in the ICU.

[Response options (code): Not at all (0); A little (1); Moderately (2); Quite a bit (3); Extremely (4)]

- 1.) Tense
- 2.) Angry
- 3.) Confused
- 4.) Shaky
- 5.) Sad
- 6.) Grouchy
- 7.) Unworthy
- 8.) Uneasy
- 9.) Annoyed
- 10.) Discouraged
- 11.) Nervous
- 12.) Lonely
- 13.) Muddled
- 14.) Anxious
- 15.) Gloomy
- 16.) Bewildered
- 17.) Furious
- 18.) Efficient
- 19.) Bad-tempered
- 20.) Forgetful

{See POMS Manual for Scoring}

{Decisional Conflict Scale}

You chose [CHOSEN OPTION] over [NOT-CHOSEN OPTION]  
Considering the option you chose, please answer the following questions:

[Response choices (codes) are: Strongly agree (0); Agree (1); Neither agree nor disagree (2); Disagree (3); Strongly Disagree (4)]

- 21.) I know which options are available.
- 22.) I know the benefits of each option.
- 23.) I know the risks and side effects of each option.
- 24.) I am clear about which benefits matter most my relative
- 25.) I am clear about which risks and side effects matter most to my relative

- 26.) I am clear about which is most important to my relative (the benefits or the risks and side effects)
- 27.) I have enough support from others to make a choice.
- 28.) I am choosing without pressure from others.
- 29.) I have enough advice to make a choice.
- 30.) I am clear about the best choice for my relative.
- 31.) I feel sure about what to choose.
- 32.) This decision was easy for me to make.
- 33.) I feel I have made an informed choice.
- 34.) My decision shows what is important to my relative
- 35.) I expect to stick with the decision.
- 36.) I am satisfied with the decision.

{See DCS Users Guide for scoring}

{Comprehension}

- 37.) Click all of the treatments that your [insert relationship] is currently receiving in the ICU (select ALL that apply).

Antibiotics

Mechanical ventilation (breathing machine)

Pressors (medicine to increase the blood pressure)

Dialysis (kidney machine)

I don't know.

- 38.) What is causing your [insert relationship] to be so sick? (Select the single best answer)

An infection of the lungs (pneumonia).

An infection of the lungs (pneumonia) that caused a heart attack and shock.

An infection of the lungs (pneumonia), that has caused sepsis and lung injury.

An infection of the lungs (pneumonia), that has caused respiratory failure and kidney failure.

I don't know.

- 39.) What is the likelihood that a person with this illness will die?

5%

10%

20%

40%

60%

I don't know.

- 40.) What is the likelihood that your [insert relationship] will die?

5%

10%

20%

40%

60%

I don't know.

41.) For a person with this illness, how likely is it for them to survive if they need CPR to restart their heart?

5%

10%

20%

40%

60%

I don't know

42.) How likely is your [insert relationship] to survive if [he/she] needs CPR to restart [his/her] heart?

5%

10%

20%

40%

60%

I don't know

{Trust in Physician Scale}

[Response choices (coding) are: Strongly Agree (5), Agree (4), Neutral (3), Disagree (2), Strongly Disagree (1)]

43.) Dr. Smith cares more about what is convenient for him than about my [insert relationship]'s needs\*.

44.) Dr. Smith is extremely thorough and careful.

45.) I completely trust Dr. Smith's decisions about which medical treatments are best for my [insert relationship].

46.) Dr. Smith is totally honest in telling me about all of the different treatment options available for my [insert relationship]'s condition.

47.) All in all, I have complete trust in Dr. Smith.

{Responses are summed (range 5–25) with higher scores indicating more trust. \*Negatively worded item is reverse coded. Scale characteristics as reported by Dugan and Hall in a national sample of English-speaking adults. (1) Cronbach's alpha of 0.86. The mean of the scale was 20.43, with a standard deviation of 3.13. The skewness was -1.05, and the reported kurtosis was 2.52.}

{Patient trust in the medical profession}

[Response choices (coding) are: Strongly Agree (5), Agree (4), Neutral (3), Disagree (2), Strongly Disagree (1)]

48.) Sometimes doctors care more about what is convenient for them than about their patients' medical needs.

49.) Doctors are extremely thorough and careful.

50.) I completely trust doctors' decisions about which medical treatments are best.

51.) A doctor would never mislead me about anything.

52.) All in all, I trust doctors completely.

{Responses are summed (range 5–25) with higher scores indicating more trust. \*Negatively worded item is reverse coded. Scale characteristics as reported by Dugan and Hall in a national sample of English-speaking adults. (1) Cronbach's alpha of 0.77. The mean of the 5-item scale was 14.97, with a standard deviation of 3.38. The skewness was -1.149, and the reported kurtosis was -0.330.}

Please answer the following questions about yourself:

{Experience with the ICU}

53.) Have you ever had a relative in the Intensive Care Unit (ICU)?

Yes [If yes, ask:] Which relative(s) [free text]

No

54.) Have you ever had a relative die in an ICU?

Yes [If yes, ask:] Which relative(s) [free text]

No

{Beliefs about LST}

55.) It is always morally wrong to withhold (not start) life-support (such as a breathing machine). [Agree/Disagree]

56.) It is always morally wrong to withdraw (stop) life-support (such as a breathing machine). [Agree/Disagree]

{Demographics}

57.) Your age?

58.) Are you:

Male

Female

59.) What is your ethnicity?

Hispanic or Latino

Non-Hispanic or Latino

Prefer not to answer

60.) What is your race?

American Indian or Alaska Native

Asian

Black or African American

Native Hawaiian or other Pacific Islander

White

Prefer not to answer

61.) What is the highest level of education you have completed?

Some High School

High School/GED

Some college

2-year college degree (Associate)

4-year college degree (BA/BS)

Master Degree

Doctoral Degree

Professional Degree (MD/JD)

{Religiosity items}

62.) What is your present religion, if any?

Protestant

Roman Catholic

Mormon

Orthodox such as Greek or Russian Orthodox

Non-denominational Christian

Jewish

Muslim

Buddhist

Hindu

Atheist

Agnostic

Something else

Nothing in particular

No answer

63.) Do you believe in god or a universal spirit?

Yes  
No  
Other  
Don't know/refuse

64.) If you believe in God or a universal spirit, how certain are you of this belief?

Absolutely certain  
Fairly certain  
Not too certain  
Not at all certain  
Don't know/Refuse

In this survey, we've asked you to make decisions on behalf of your [relation]. We are interested in knowing what your [relation] would choose for themselves in this hypothetical scenario.

65.) How confident are you that the CPR decision you made for your [relation] is the same as what [he/she] would have chosen for [him/herself]?  
[Very Confident; Confident; Somewhat Confident; Not Confident]

66.) Are you willing to send your [relation] an e-mail with a link to a question about the CPR decision that they would have made for themselves in this situation? (See question below)  
[Yes, I'm willing; I can't, they don't have an e-mail address; No, I'm not willing]

This is the question we will ask your [relation] to answer:

Imagine that you have been admitted to the ICU with a life-threatening illness. You have pneumonia and the infection has spread into your blood and the rest of your body (sepsis) causing severe damage to your lungs (acute lung injury). You are on a breathing machine and are receiving antibiotics to treat the infection and intravenous (by vein) fluids to treat low blood pressure.

With this illness, 40% (40 out of 100 people) will die; 60% (60 out of 100 people) will survive.

When someone is this sick in the ICU their heart could stop beating. The doctors and nurses can perform CPR and give electric shocks to try to restart the heart.

With CPR and electric shocks, 90% (90 out of 100 people) will die, 10% (10 out of 100 people) will survive.

If your heart were to stop beating while you are in the ICU on life support, what do you want?

**CPR and electric shocks**

**No CPR or electric shocks**





{If yes, create a mechanism in the survey to generate an e-mail address with a link back to a survey linked to the answers on this survey.}

To: [insert your [relation]'s e-mail address]  
From: [insert your e-mail address]  
Subject: Can you answer this survey question?

{Free text box for message should be pre-populated, but allow for editing}  
I just completed a survey asking me about medical decisions that I would make for you if you were sick in the ICU. The researchers want to compare what I answered to what you would answer for yourself. Click on the link, below, to answer the question. Thanks.

## THANK YOU!

Thank you for your participation.

{For CMU subjects} The survey you just completed is in its pilot phase. We are interested in your feedback as we improve the survey. If you are willing to be interviewed about your experience completing the survey, please provide a contact phone number here [insert phone number]

{For community subjects} We will use the University of Pittsburgh WePay system to compensate you \$25 for your time. This system loads a debit card with money electronically. You can use the card to make purchases or to withdraw cash from an ATM. Click [here](#) for a copy of the University of Pittsburgh WePay brochure.

Please complete the information below to receive your WePay card in the mail. The IRS requires us to collect your social security number (SSN) for tax purposes. If you do not want to provide your SSN, we will automatically deduct 28% (\$7) from the \$25 to withhold taxes, and your WePay card will be loaded with \$18 instead. Your information is kept on a secure University of Pittsburgh server and is not linked to your survey responses in any way.

{Jess – can you mock up the information we need to collect for WePay}

**CONSENT [for relation]**

Your [relation] participated in a study by researchers at the University of Pittsburgh and Carnegie Mellon University. The purpose of the research study is to understand the factors that influence family members when making treatment decisions for a relative in the ICU. Your [relation] provided you a link to this survey to answer 1 question. Answering the question will take 2 minutes of your time. There are no direct risks or benefits to you. Your answer will be linked to the answers your [relation] provided, but both answers are anonymous – they cannot be linked back to you in any way. Your e-mail address will not be saved. Your participation is voluntary.

The principal investigator of the study is Dr. Amber Barnato and the research assistant is Jessica Papadopoulos. They can be contacted at (412) 586-9636 or emailed at [barnae@upmc.edu](mailto:barnae@upmc.edu) or [papadopoulosjl@upmc.edu](mailto:papadopoulosjl@upmc.edu).

**CLICK TO AGREE AND PROCEED**

Imagine that you have been admitted to the ICU with a life-threatening illness. You have pneumonia and the infection has spread into your blood and the rest of your body (sepsis) causing severe damage to your lungs (acute lung injury). You are on a breathing machine and are receiving antibiotics to treat the infection and intravenous (by vein) fluids to treat low blood pressure.

With this illness, 40% (40 out of 100 people) will die; 60% (60 out of 100 people) will survive.

When someone is this sick in the ICU their heart could stop beating. The doctors and nurses can perform CPR and give electric shocks to try to restart the heart.

With CPR and electric shocks, 90% (90 out of 100 people) will die, 10% (10 out of 100 people) will survive.

If your heart were to stop beating while you are in the ICU on life support, what do you want?

CPR and electric shocks

No CPR or electric shocks