

## Informed Consent and Research Authorization for an Adult

The following information is being presented to help you decide whether or not you want to take part in a minimal risk research study, Health-Related Quality of Life Values for Cancer Survivors: Enhancing PROMIS measures for comparative effectiveness research, funded by Moffitt Cancer Center and the National Institutes of Health.

### Purpose

The purpose of this study is to examine the values people place on health. Specifically, the answers provided by you and about 50,000 other participants will help us understand health-related choices of people like you, adults age 18 or older. In the following survey, you will be asked to complete 4 sections. The first section asks you basic demographic questions. The second section asks you about your health. The third section asks you to complete a series of choices between health-related experiences. The fourth section asks you follow-up questions about you and your experience taking this survey.

### Potential Risks

There are no physical risks posed by this study. There may be risk of psychological distress resulting from questions that ask you to evaluate alternative health scenarios. This study does not collect any personal identifying information, except dates and postal code. Your privacy and research records will be kept confidential to the full extent of the law. Authorized research personnel, employees of the Department of Health and Human Services, Liberty IRB, Inc. and its staff, and any other individuals acting on behalf of Moffitt Cancer Center, may inspect the records from this research project.

### Voluntary Participation and Confidentiality

Your participation in this study will take about 15-30 minutes and is entirely voluntary. If you agree to participate, you may withdraw from the study at any time by simply closing your Internet browser. Upon completion, you will be compensated as agreed upon with your panel company. For more information about the study, call Benjamin Craig, Principal Investigator, at 813-745-4673. For information about your rights as a research participant, call Liberty IRB (a committee that has reviewed this research study to help ensure that your rights and welfare as a research participant are protected and that the research study is carried out in an ethical manner) at 386-279-4318.

Please read the following statements. Click "I Understand" if you understand the purpose, potential risks, voluntary participation, and confidentiality of the study. Click "I Do Not Understand" if you do not understand or do not wish to participate in the study. By clicking "I Do Not Understand" you will not be able to continue to the survey.

- I understand  
 I do not understand

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Completed:



To be eligible for this survey, please complete the following questions:

Please select your current state:

Please enter your current 5-digit ZIP code:

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Completed:



What is your sex?

- Male
- Female

What is your age?

What is your birth date?

Month

Day

Year

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Completed:



Are you of Hispanic, Latino, or Spanish origin?

- No, not of Hispanic, Latino, or Spanish origin
- Yes, Mexican, Mexican American, or Chicano
- Yes, Puerto Rican
- Yes, Cuban
- Yes, another Hispanic, Latino, or Spanish origin

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Completed:




What is your race? If necessary, select more than one category.

- |  |                                       |
|--|---------------------------------------|
| <input type="checkbox"/> White                             | <input type="checkbox"/> Asian Indian |
| <input type="checkbox"/> Black or African-American         | <input type="checkbox"/> Chinese      |
| <input type="checkbox"/> American Indian or Alaskan Native | <input type="checkbox"/> Filipino     |
| <input type="checkbox"/> Native Hawaiian                   | <input type="checkbox"/> Japanese     |
| <input type="checkbox"/> Guamanian or Chamorro             | <input type="checkbox"/> Korean       |
| <input type="checkbox"/> Samoan                            | <input type="checkbox"/> Vietnamese   |
| <input type="checkbox"/> Other Pacific Islander            | <input type="checkbox"/> Other Asian  |

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Completed: 

Which of the following best describes your race?

- African American/Black
- Asian/Asian American
- Caucasian/White
- Native American/Inuit/Aleut
- Native Hawaiian/Pacific Islander
- Other

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Completed: 

What is the highest level of school you have completed or the highest degree you have received?

Please select one ... 

What is your best estimate of your total income plus the total income of all family members from all sources, before taxes, in 2015?

Please select one ... 

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Completed:



Which of the following were you doing last week?

- Working for pay at a job or business
- With a job or business, but not at work
- Looking for work
- Working, but not for pay, at a family-owned job or business
- Not working at a job or business and not looking for work
- Retired
- Refuse to answer
- Don't know

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Completed:



Are you now married, widowed, divorced, separated, never married, or living with a partner?

- Married
- Widowed
- Divorced
- Separated
- Never Married
- Living with a partner
- Refuse to answer
- Don't know

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#### Directions

You will need approximately 20 to 30 minutes  
to complete this survey.

You will be logged out and will not receive payment  
if you close your Internet browser before completing the survey or  
fail to complete the survey within 2 hours.

It is important that you answer every question carefully.  
Each page will advance automatically after each response.  
If you wish, click the back button to change your response.

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Completed:




Please confirm that you understand each of the following:

- I will be asked questions about my health, and understand that this may cause me some stress.
- I will be asked to think about other health problems, including death, and understand that this may cause me some stress.
- I understand that the purpose of this survey is to understand my health preferences to inform the design of better health services.

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Completed: 

In general, would you say your health is:

- Excellent
- Very good
- Good
- Fair
- Poor

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Completed: 

Which best describes your health today?

Mobility

- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

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Completed: 

Which best describes your health today?

Self-Care

- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe problems washing or dressing myself
- I am unable to wash or dress myself

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Completed: 

Which best describes your health today?

Usual activities (e.g., work, study, housework, family or leisure activities)

- I have no problems doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

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Completed: 

Which best describes your health today?

Pain/Discomfort

- I have no pain or discomfort
- I have slight pain or discomfort
- I have moderate pain or discomfort
- I have severe pain or discomfort
- I have extreme pain or discomfort

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Completed: 



Which best describes your health today?

Anxiety/Depression

- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed

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Completed:



We would like to know how good or bad your health is TODAY.

This scale is numbered from 0 to 100.

100 means the **best** health you can imagine.

0 means the **worst** health you can imagine.

Move the slider on the scale to indicate how your health is TODAY.

The worst health  
you can imagine

The best health  
you can imagine

YOUR HEALTH TODAY =

0

0

100



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Completed:



## Section 2: Paired Comparisons

The next questions ask about your health preferences.

Specifically, you will read 2 health descriptions and be asked to choose which you prefer.

Understanding your preferences is critically important for improving health services.

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Completed:



A paired comparison is a choice between two alternative items.  
You choose by clicking on the item you prefer.  
For example, which fruit do you prefer?



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Example #1 of 3

Completed:



The next 2 examples are paired comparisons that describe your health.

Imagine that your health is the same except for the problems described and that there are no differences before or after these problems.

Remember that you must choose the health you prefer from your current perspective.

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Completed: 

Which do you prefer?

Starting today, **12 months** with **good** health

Starting today, **12 months** with **poor** health

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Example #2 of 3

Completed: 

You likely prefer good health over poor health, and choose good health.

The next example is more challenging than this one.

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Completed:



Which do you prefer?

Starting today, **12 months** with **bad** health

Starting today, **12 months** with **poor** health

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Example #3 of 3

Completed:



This "bad versus poor" example is more challenging because the descriptions are more similar.

Sometimes the descriptions may not make sense and your preference may not be clear.

You may or may not have experience with some health problems.

However, we ask that you choose the health description that you prefer from your current perspective.

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Completed: 


The following paired comparisons ask about your preferences on health and lifespan.

Please confirm that you understand each of the following:

- In each of the following descriptions, death refers to a peaceful transition without warning in your sleep of unknown causes outside of your control.
- No one knows when he or she will die; however, each description includes lifespan. Assume that you will not know when you will die.
- Also, assume that you will have no control over the health problems or when you die, regardless of medical attention.

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Completed: 


The following paired comparisons ask about your preferences (what you want), not about your behaviors (what you would do).

Please confirm that you understand each of the following:

- People often do not get to choose what will happen to them, yet they may prefer one outcome over another.
- You may not always get what you want. For example, your preferences describe what you want to eat, your behaviors describe what you do eat.
- You may prefer one outcome over another, yet your actions may differ. This survey is about what you want, not what you would do.

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Completed: 



You will now read a series of 10 paired comparisons that describe your health and length of life.

Understanding your preferences is critically important.

Understanding what you want helps scientists and health care providers improve the design and delivery of health services.

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Completed: 

### Which do you prefer?

Starting today, **6 days** with health problems:

- Unable** to walk about
- No** problems washing or dressing self
- Slight** problems doing usual activities
- Moderate** pain or discomfort
- Slightly** anxious or depressed

Then die (**6 days** from today)

Starting today, **6 days** with health problems:

- Severe** problems in walking about
- Severe** problems washing or dressing self
- No** problems doing usual activities
- Slight** pain or discomfort
- Moderately** anxious or depressed

Then die (**6 days** from today)

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Question 1 of 10

Completed:



### Which do you prefer?

Starting today, **30 days** with health problems:

- Unable** to walk about
- Slight** problems washing or dressing self
- No** problems doing usual activities
- Moderate** pain or discomfort
- Slightly** anxious or depressed

Then die (**30 days** from today)

Starting today, **3 days** with health problems:

- Slight** problems in walking about
- No** problems washing or dressing self
- Unable** to do usual activities
- Moderate** pain or discomfort
- Severely** anxious or depressed

Then die (**3 days** from today)

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Question 2 of 10

Completed:



### Which do you prefer?

Starting today, **3 days** with health problems:

- Severe** problems in walking about
- No** problems washing or dressing self
- Slight** problems doing usual activities
- Extreme** pain or discomfort
- Moderately** anxious or depressed

Then die (**3 days** from today)

Starting today, **18 days** with health problems:

- Unable** to walk about
- No** problems washing or dressing self
- No** problems doing usual activities
- No** pain or discomfort
- Severely** anxious or depressed

Then die (**18 days** from today)

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Question 3 of 10

Completed:



### Which do you prefer?

Starting today, **9 days** with health problems:

- No** problems in walking about
- Slight** problems washing or dressing self
- No** problems doing usual activities
- No** pain or discomfort
- Not** anxious or depressed

Then die (**9 days** from today)

Starting today, **15 days** with health problems:

- Slight** problems in walking about
- No** problems washing or dressing self
- No** problems doing usual activities
- Slight** pain or discomfort
- Not** anxious or depressed

Then die (**15 days** from today)

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Question 4 of 10

Completed:





### Which do you prefer?

Starting today, **3 days** with health problems:

- Slight** problems in walking about
- Slight** problems washing or dressing self
- No** problems doing usual activities
- Slight** pain or discomfort
- Slightly** anxious or depressed

Then die (**3 days** from today)

Starting today, **12 days** with health problems:

- No** problems in walking about
- No** problems washing or dressing self
- Slight** problems doing usual activities
- Slight** pain or discomfort
- Not** anxious or depressed

Then die (**12 days** from today)

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Question 5 of 10

Completed:



### Which do you prefer?

Starting today, **21 days** with health problems:

- Unable** to walk about
- No** problems washing or dressing self
- Severe** problems doing usual activities
- Slight** pain or discomfort
- Severely** anxious or depressed

Then die (**21 days** from today)

Starting today, **9 days** with health problems:

- Moderate** problems in walking about
- Unable** to wash or dress self
- Unable** to do usual activities
- Slight** pain or discomfort
- Extremely** anxious or depressed

Then die (**9 days** from today)

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Question 6 of 10

Completed:



### Which do you prefer?

Starting today, **15 days** with health problems:

**Severe** problems in walking about

**Unable** to wash or dress self

**Unable** to do usual activities

**Extreme** pain or discomfort

**Slightly** anxious or depressed

Then die (**15 days** from today)

Starting today, **12 days** with health problems:

**Moderate** problems in walking about

**Slight** problems washing or dressing self

**Severe** problems doing usual activities

**No** pain or discomfort

**Moderately** anxious or depressed

Then die (**12 days** from today)

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Question 7 of 10

Completed:



### Which do you prefer?

Starting today, **6 days** with health problems:

**Severe** problems in walking about

**Severe** problems washing or dressing self

**No** problems doing usual activities

**Severe** pain or discomfort

**Extremely** anxious or depressed

Then die (**6 days** from today)

Starting today, **27 days** with health problems:

**Severe** problems in walking about

**Unable** to wash or dress self

**Severe** problems doing usual activities

**Moderate** pain or discomfort

**Slightly** anxious or depressed

Then die (**27 days** from today)

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Question 8 of 10

Completed:



### Which do you prefer?

Starting today, **12 days** with health problems:

- Slight** problems in walking about
- No** problems washing or dressing self
- Slight** problems doing usual activities
- Moderate** pain or discomfort
- Extremely** anxious or depressed

Then die (**12 days** from today)

Starting today, **21 days** with health problems:

- No** problems in walking about
- Slight** problems washing or dressing self
- Slight** problems doing usual activities
- Severe** pain or discomfort
- Moderately** anxious or depressed

Then die (**21 days** from today)

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Question 9 of 10

Completed:



### Which do you prefer?

Starting today, **18 days** with health problems:

- Moderate** problems in walking about
- No** problems washing or dressing self
- Severe** problems doing usual activities
- Severe** pain or discomfort
- Severely** anxious or depressed

Then die (**18 days** from today)

Starting today, **21 days** with health problems:

- No** problems in walking about
- No** problems washing or dressing self
- Moderate** problems doing usual activities
- Extreme** pain or discomfort
- Moderately** anxious or depressed

Then die (**21 days** from today)

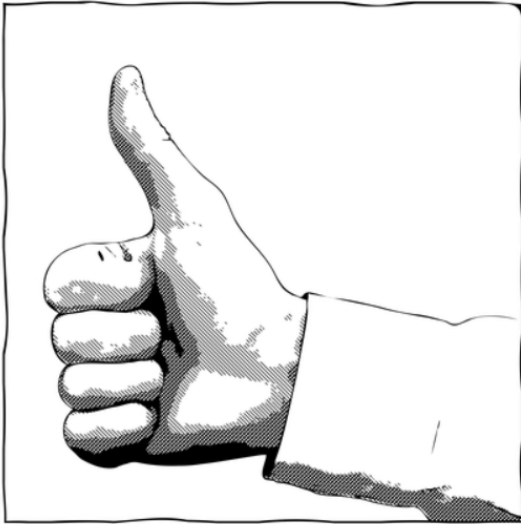
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Question 10 of 10

Completed:






Thank you for your responses to the first series of 10 paired comparisons.

How many of the comparisons included a health description that is impossible from your perspective.

- None of them (0)
- A few of them (1 to 3)
- Some of them (4 to 6)
- Most of them (7 to 9)
- All of them (10)

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Completed: 



You will now read a second series of 10 paired comparisons that describe your health and length of life.

Some of the questions may seem repetitive because we are trying out alternative wording.

Understanding your preferences is critically important for improving health services.

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Completed: 

### Which do you prefer?

Starting today, **30 days** with health problems:

- Slight** problems in walking about
- No** problems washing or dressing self
- Slight** problems doing usual activities
- Slight** pain or discomfort
- Severely** anxious or depressed

Then die (**30 days** from today)

Starting today, **3 days** with no health problems:

- No** problems in walking about
- No** problems washing or dressing self
- No** problems doing usual activities
- No** pain or discomfort
- Not** anxious or depressed

Then die (**3 days** from today)

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Question 1 of 10

Completed:



### Which do you prefer?

Starting today, **30 days** with health problems:

- Moderate** problems in walking about
- Slight** problems washing or dressing self
- Slight** problems doing usual activities
- Severe** pain or discomfort
- Not** anxious or depressed

Then die (**30 days** from today)

Starting today, **15 days** with no health problems:

- No** problems in walking about
- No** problems washing or dressing self
- No** problems doing usual activities
- No** pain or discomfort
- Not** anxious or depressed

Then die (**15 days** from today)

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Question 2 of 10

Completed:



### Which do you prefer?

Starting today, **30 days** with health problems:

- No** problems in walking about
- No** problems washing or dressing self
- Slight** problems doing usual activities
- No** pain or discomfort
- Slightly** anxious or depressed

Then die (**30 days** from today)

Starting today, **21 days** with no health problems:

- No** problems in walking about
- No** problems washing or dressing self
- No** problems doing usual activities
- No** pain or discomfort
- Not** anxious or depressed

Then die (**21 days** from today)

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Question 3 of 10

Completed:



### Which do you prefer?

Starting today, **30 days** with health problems:

- Slight** problems in walking about
- Moderate** problems washing or dressing self
- Severe** problems doing usual activities
- Severe** pain or discomfort
- Slightly** anxious or depressed

Then die (**30 days** from today)

Starting today, **12 days** with no health problems:

- No** problems in walking about
- No** problems washing or dressing self
- No** problems doing usual activities
- No** pain or discomfort
- Not** anxious or depressed

Then die (**12 days** from today)

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Question 4 of 10

Completed:



### Which do you prefer?

Starting today, **30 days** with health problems:

- Slight** problems in walking about
- No** problems washing or dressing self
- Slight** problems doing usual activities
- Moderate** pain or discomfort
- Extremely** anxious or depressed

Then die (**30 days** from today)

Starting today, **6 days** with no health problems:

- No** problems in walking about
- No** problems washing or dressing self
- No** problems doing usual activities
- No** pain or discomfort
- Not** anxious or depressed

Then die (**6 days** from today)

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Question 5 of 10

Completed:



### Which do you prefer?

Starting today, **30 days** with health problems:

- Moderate** problems in walking about
- Moderate** problems washing or dressing self
- Slight** problems doing usual activities
- Slight** pain or discomfort
- Extremely** anxious or depressed

Then die (**30 days** from today)

Starting today, **9 days** with no health problems:

- No** problems in walking about
- No** problems washing or dressing self
- No** problems doing usual activities
- No** pain or discomfort
- Not** anxious or depressed

Then die (**9 days** from today)

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Question 6 of 10

Completed:



### Which do you prefer?

Starting today, **30 days** with health problems:

- Moderate** problems in walking about
- Slight** problems washing or dressing self
- Severe** problems doing usual activities
- Severe** pain or discomfort
- Slightly** anxious or depressed

Then die (**30 days** from today)

Starting today, **9 days** with no health problems:

- No** problems in walking about
- No** problems washing or dressing self
- No** problems doing usual activities
- No** pain or discomfort
- Not** anxious or depressed

Then die (**9 days** from today)

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Question 7 of 10

Completed:



### Which do you prefer?

Starting today, **30 days** with health problems:

- Slight** problems in walking about
- No** problems washing or dressing self
- No** problems doing usual activities
- No** pain or discomfort
- Severely** anxious or depressed

Then die (**30 days** from today)

Starting today, **15 days** with no health problems:

- No** problems in walking about
- No** problems washing or dressing self
- No** problems doing usual activities
- No** pain or discomfort
- Not** anxious or depressed

Then die (**15 days** from today)

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Question 8 of 10

Completed:





### Which do you prefer?

Starting today, **30 days** with health problems:

- Moderate** problems in walking about
- No** problems washing or dressing self
- Moderate** problems doing usual activities
- Moderate** pain or discomfort
- Not** anxious or depressed

Then die (**30 days** from today)

Starting today, **27 days** with no health problems:

- No** problems in walking about
- No** problems washing or dressing self
- No** problems doing usual activities
- No** pain or discomfort
- Not** anxious or depressed

Then die (**27 days** from today)

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Question 9 of 10

Completed:



### Which do you prefer?

Starting today, **30 days** with health problems:

- No** problems in walking about
- Slight** problems washing or dressing self
- Slight** problems doing usual activities
- Slight** pain or discomfort
- Not** anxious or depressed

Then die (**30 days** from today)

Starting today, **18 days** with no health problems:

- No** problems in walking about
- No** problems washing or dressing self
- No** problems doing usual activities
- No** pain or discomfort
- Not** anxious or depressed

Then die (**18 days** from today)

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Question 10 of 10

Completed:





Thank you for your responses to the second series of 10 paired comparisons.

How many of the comparisons included a health description that is impossible from your perspective.

- None of them (0)
- A few of them (1 to 3)
- Some of them (4 to 6)
- Most of them (7 to 9)
- All of them (10)

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Completed:

You will now read the final series of paired comparisons.

These questions describe your health and length of life at their extremes.

Some of the questions may seem repetitive because we are trying out alternative wording.

Understanding your preferences is critically important for improving health services.

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Completed:



Each of the following questions concern your lifespan.

How many more years do you expect to live?

Please select one ... ▾

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Completed:

Today or in the future, you may suffer slightly from pain, discomfort, anxiety and depression.

Which do you prefer?

- Immediate death
- Suffer slightly for the next 24 hours then live the rest of my life with no health problems

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Completed:

Today or in the future, you may have slight problems walking, doing your usual activities, and washing or dressing yourself.

Which do you prefer?

- Immediate death
- Disabled slightly for the next 24 hours then live the rest of my life with no health problems

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Completed:



Note: If Immediate death is selected for either of the above two questions one more additional question (below) is asked. If not, then the question below is skipped. Also, if the respondent notes that they would prefer immediate death for the below question, then the following two questions regarding shortening one's lifespan by 24 hours to avoid health problems is skipped due to redundancy.

Today or in the future, you may suffer slightly and be disabled slightly.

Which do you prefer?

- Immediate death
- Suffer slightly and be disabled slightly for the next 24 hours then live the rest of my life with no health problems

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Completed:




Today or in the future, you may suffer extremely from pain, discomfort, anxiety and depression.

Which do you prefer?

- Shorten my lifespan by 1 day
- Suffer extremely for the rest of my life

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Completed: 


Today or in the future, you may be unable to walk, to do your usual activities, and to wash or dress yourself.

Which do you prefer?

- Shorten my lifespan by 1 day
- Disabled completely for the rest of my life

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Completed: 

Note: If the respondent answers that they would prefer to suffer or be disabled for the rest of their life rather than shortening lifespan by 1 day, another follow-up question (below) is asked.


Today or in the future, you may suffer extremely and be disabled completely.

Which do you prefer?

- Shorten my lifespan by 1 day
- Suffer extremely and be disabled completely for the rest of my life

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Completed: 

Today or in the future, you may suffer from extreme pain, discomfort, anxiety and depression.

Which do you prefer?

- Immediate death
- Suffer extremely for the rest of my life

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Completed:



Today or in the future, you may be unable to walk, to do your usual activities, and/or to wash or dress yourself.

Which do you prefer?

- Immediate death
- Disabled completely for the rest of my life

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Completed:



Note: If the respondent states that they prefer being disabled or suffer extremely for the rest of their life, then an additional follow-up question (below) is asked.

Today or in the future, you may suffer extremely and be disabled completely.

Which do you prefer?

- Immediate death
- Suffer extremely and be disabled completely for the rest of my life

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Completed:



Congratulations!

You are almost done.

How would you describe this survey?

	Not True	Sometimes True	Often True
Challenging, tricky, tough, difficult	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Enjoyable, amusing, entertaining, fun	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Depressing, sad, scary, distressing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unclear, vague, nebulous	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ridiculous, implausible, unrealistic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Morbid, morose, dismal, bleak, grim, somber	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Weird, unusual, bizarre, odd, strange	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Interesting, thought provoking, eye-opening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Completed:



Please enter any comments and/or suggestions you have regarding this survey.

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Completed:



To better understand your health preferences, the following questions ask about your views on euthanasia and assisted suicide.

In each case, it is important to understand that the patient was competent and well-informed when she or he explicitly asked the doctor to perform these actions.

Please state your level of agreement with the following statements:

	Fully disagree	Disagree to some extent	Neither agree nor disagree	Agree to some extent	Fully agree
The doctor should be allowed to terminate life prolonging treatment such as i.v. nutrition or respirator treatment, so that the lifespan of the patient is likely to be shorter (passive euthanasia).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The doctor should be allowed to perform an act, such as giving an injection, which aims at painlessly shortening the patient's life (active euthanasia).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The doctor should be able to help the patient, so that he or she may end his/her life in a painless way (assisted suicide).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Please enter any comments and/or suggestions you have regarding your perspective on euthanasia and/or assisted suicide.

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Completed:



Thank you for your participation!

You have completed the entire survey.

Please click the submit button.

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SUBMIT



Completed:



Thank you for your time!

OK