

*Caregiver Survey*  
(USA version)



Thank you for your interest in this survey about your experience and views on end-of-life care. First, we would like to ask you a few questions.

**A1. In what year were you born? (YYYY)** [Terminate survey if participant is below 21 years old]

**A1.2 What is your gender?**

- 1 Male
- 2 Female
- 3 Other, \_\_\_\_\_

**A2. In the past two years, has a family member or close friend died after a brief or extended period of illness or injury?** [Terminate survey if A2=4]

- Yes, within last 6 months  
1
- Yes, between 6 months and 1 year ago  
2
- Yes, between 1 and 2 years ago  
3
- No  
4

**A3. What was your relationship to the person who died?** If more than one person died, consider the one whose end of life care you were most involved in. For the rest of the survey, we would like you to consider this person when you answer the questions.

The deceased person was my:

- |                             |                     |                             |                              |
|-----------------------------|---------------------|-----------------------------|------------------------------|
| <input type="checkbox"/> 1  | Wife                | <input type="checkbox"/> 8  | Aunt                         |
| <input type="checkbox"/> 2  | Husband             | <input type="checkbox"/> 9  | Uncle                        |
| <input type="checkbox"/> 3  | Partner             | <input type="checkbox"/> 10 | Daughter                     |
| <input type="checkbox"/> 4  | Mother              | <input type="checkbox"/> 11 | Son                          |
| <input type="checkbox"/> 5  | Father              | <input type="checkbox"/> 12 | Grandmother                  |
| <input type="checkbox"/> 6  | Sister              | <input type="checkbox"/> 13 | Grandfather                  |
| <input type="checkbox"/> 7  | Brother             | <input type="checkbox"/> 14 | Close friend                 |
| <input type="checkbox"/> 15 | Colleague/co-worker | <input type="checkbox"/> 16 | Other, please specify: _____ |

Version to use: father

Gender to use: he

his

He

His

him

**A4. How long before his death did you first learn that your father had an illness or injury that could cause his death?** [Terminate survey if A4= 7 or 8]

- 1 Less than 1 month before
- 2 At least 1 month, but less than 2 months
- 3 At least 2 months, but less than 6 months
- 4 At least 6 months, but less than 1 year
- 5 At least 1 year, but less than 2 years
- 6 At least 2 years, but less than 3 years
- 7 More than 3 years before
- 8 Don't know/not sure

**A5. From the time you learned that your father had an illness or injury that could cause his death, how involved were you in...** [Terminate survey if response option selected for A5.1 to A5.3 is 'not at all involved']

**A5.1 Talking with doctors about treatment decisions?**

- |                          |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Not at all involved      | Somewhat involved        | Involved                 | Very involved            |

**A5.2 Helping him get medical care, such as going with him to doctor visits?**

- |                          |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Not at all involved      | Somewhat involved        | Involved                 | Very involved            |

**A6. Which of the following professional services did he receive as a part of his health care or treatment for his illness or injury? A professional is someone who is paid to provide services. (select all that apply)**

- 1 Non-medical support (for example help with housework and planning)
- 2 At-home medical care (for example, help from a visiting nurse to administer treatments)
- 3 In-patient medical care (hospitalizations requiring at least one overnight stay)
- 4 Outpatient medical care (visits to doctors office or specialty clinics)
- 5 Palliative/hospice care (comfort care meant to reduce the impact of symptoms instead of curing the disease)
- 6 Traditional or herbal medicine (for example, treatments not prescribed by medical doctors)
- 7 Other, \_\_\_\_\_

**A7. Which of the following was the main reason for his death?** Please select the reason you believe was most directly related to his death.

<input type="checkbox"/> 1	Arteriosclerosis (disease of the arteries)	<input type="checkbox"/> 13	Natural causes/Old age
<input type="checkbox"/> 2	Cancer	<input type="checkbox"/> 14	Poisoning, injury or accident
<input type="checkbox"/> 3	COVID-19	<input type="checkbox"/> 15	Premature birth or trauma at birth
<input type="checkbox"/> 4	Dementia	<input type="checkbox"/> 16	Respiratory problems (such as Influenza)
<input type="checkbox"/> 5	Genetic/inherited health problems	<input type="checkbox"/> 17	Stroke
<input type="checkbox"/> 6	HIV/AIDS	<input type="checkbox"/> 18	Tuberculosis (or TB)
<input type="checkbox"/> 7	Infection	<input type="checkbox"/> 19	Unknown
<input type="checkbox"/> 8	Heart problems	<input type="checkbox"/> 20	Other, please specify: _____
<input type="checkbox"/> 9	Kidney diseases	<input type="checkbox"/> 21	Did not learn of illness/injury that could cause death in advance
<input type="checkbox"/> 10	Liver diseases		
<input type="checkbox"/> 11	Lung diseases		
<input type="checkbox"/> 12	Malnutrition		

**A8. What was his age at the time of death?            years**

**Timeframe to use:** since learning your xxx had an illness/injury that could cause his death

This survey will help policy makers and doctors understand differences in how people die around the world and what factors people like you think are important at the end of life.

As you answer questions in this survey, please keep in mind that **health care providers** are people who are paid to provide services, such as doctors, nurses, and social workers. **Caregivers** are family and friends who help take care of patient needs.

Later in this survey we will ask you to tell us about your father's experiences with health care providers. But first we would like you to tell us about your own experiences with health care providers as a caregiver.

[\[Choose between pages 7 and 18\]](#)

Consider your own interactions with health care providers near the time of your loved one's death and tell us how much you agree or disagree with each of the statements below. Please check "does not apply" if the statement does not apply in your case.

Additional information will be shown if you place your pointer over the areas below with an exclamation mark (!)

Consider whether health care providers gave <b>you</b> enough information to help with your father's medical needs near the time of her death. Also, consider whether they shared the information with you or you had to ask for the information.						
<b>1. Health care providers gave me clear and timely information on how to care for him near the time of his death.</b>						<input type="checkbox"/> <i>does not apply</i>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Don't know	

Health care providers can help family and friends cope with the stress and sadness associated with losing a loved one. Consider whether you received enough help from health care providers before your father's death.						
<b>2. Health care providers helped me cope emotionally <u>before</u> his death.</b>						<input type="checkbox"/> <i>does not apply</i>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Don't know	



Health care providers can be cold and insensitive or caring and sympathetic when dealing with caregivers. Consider whether the health care providers mostly were kind to you and tried to put themselves in your position.

**3. Health care providers mostly treated me kindly and sympathetically.**  *does not apply*

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Don't know

After a patient's death, health care providers can help family and friends cope with their natural feelings during this difficult time. Consider whether you received enough help after your father's death.

**4. Health care providers offered grief services after his death.**  *does not apply*

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Don't know

Health care provider sometimes offer caregivers information about decisions that need to be made after a person dies, such as how to make funeral arrangements. Consider whether health care professionals gave you clear and timely information to help with the process after your father's death.

**5. Health care providers gave me information on what to do after your father's death.**  *does not apply*

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Don't know

**Now suppose you were responsible for another loved one nearing the end of life.**




We will now ask you a different kind of question than those you just answered. For these questions, we want you to think about different groups of providers for this other loved one.

**PLEASE NOTE THE PROVIDER GROUPS WE WILL SHOW YOU ARE NOT THE ONES WHO CARED FOR YOUR FATHER.**

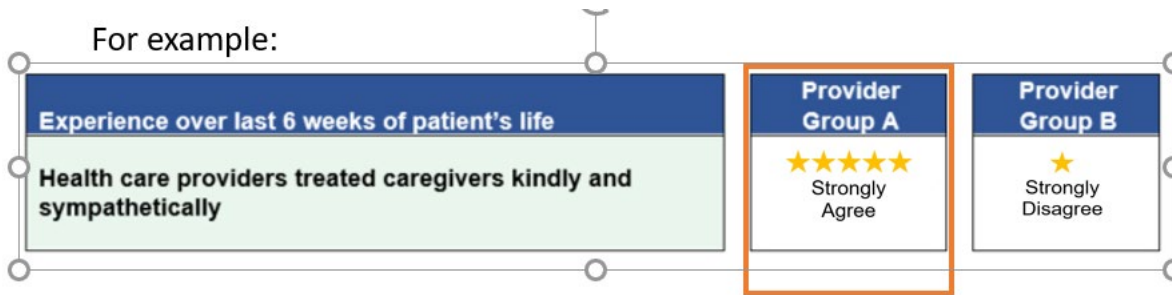
These groups might not even exist in your area. Telling us how you would choose IF these options were available will help us understand what is important to you.

We would like to know which provider group you would choose if all you knew about them were ratings given by other caregivers based on questions like those you answered before.

This box shows how we will use stars to indicate the way caregivers rated their experience with these provider groups.

How strongly caregivers agreed or disagreed with each statement	Star Rating
Most caregivers said they <b>strongly agreed</b>	 <i>(best)</i>
Most caregivers said they <b>neither agreed nor disagreed</b>	
Most caregivers said they <b>strongly disagreed</b>	 <i>(worst)</i>

For example:



Most caregivers **strongly agreed** that providers in Provider Group A treated them kindly and sympathetically. They gave that experience **5 stars**.

For example:



Most caregivers **strongly disagreed** that providers in Provider Group B treated caregivers kindly and sympathetically. They gave that experience **1 star**.

**As you answer the next 4 questions please keep in mind:**

The provider groups we show you could have good ratings for some experiences and bad ratings for others.

Please consider the ratings for all experiences shown and think about **which provider group you would choose** if your loved one had to go to one of these provider groups.

Suppose most caregivers rated Provider Group A and Provider Group B as shown in the table below. Everything else was the same.

Experience over last 6 weeks of patient's life	Provider Group A	Provider Group B
Health care providers gave clear and timely information on how to care for patients	★★★ Neither agree nor disagree	★ Strongly Disagree
Health care providers helped patients to cope emotionally	★★★★★ Strongly Agree	★★★ Neither agreed nor disagree

1. Based on these ratings, which provider group (A or B) gave caregivers better information on how to care for the patients?

- 1 Provider group A
- 2 Provider group B
- 3 Don't know / Not sure

[if Q1 not equal Provider Group A]

Columns in the table below show the ratings for Provider Groups (A and B).

[EXPERIENCE STATEMENT WILL BE RANDOMLY ALLOCATED BASED ON THE EXPERIMENTAL DESIGN AND WILL VARY ACROSS RESPONDENTS. EXAMPLE AS SHOWN BELOW]

Experience over last 6 weeks of patient's life	Provider Group A	Provider Group B
Health care providers gave clear and timely information on how to care for patients	★★★★ Neither agree nor disagree	★ Strongly Disagree
Health care providers helped patients to cope emotionally	★★★★★★ Strongly Agree	★★★ Neither agreed nor disagree

The table shows that:





- Caregivers gave health care professionals in **Group A** 3 stars not agreeing or disagreeing that the information provided was clear and timely.
- Caregivers gave health care professionals in **Group B** 1 star strongly disagreeing that the information provided was clear and timely.

This means that caregivers thought Provider Group A gave better information on how to care for patients near the time of death.



Consider the same Provider Groups.







[EXPERIENCE STATEMENT WILL BE RANDOMLY ALLOCATED BASED ON THE EXPERIMENTAL DESIGN AND WILL VARY ACROSS RESPONDENTS. EXAMPLE AS SHOWN BELOW]

Experience over last 6 weeks of patient's life	Provider Group A	Provider Group B
Health care providers gave clear and timely information on how to care for patients	 Neither agree nor disagree	 Strongly Disagree
Health care providers helped caregivers to cope emotionally	 Strongly Agree	 Neither agreed nor disagree

2. Based on these ratings only, which Provider Group (A or B) would you choose to care for someone like your father?

- 1 Provider Group A
- 2 Provider Group B
- 3 Don't know / Not sure

This choice has 3 options instead of 2.

Experience over last 6 weeks of patient's life	Provider Group A	Provider Group B	Provider Group C
Health care providers gave caregivers clear and timely information on how to care for patients	 Strongly Disagree	 Neither agree nor disagree	 Strongly Agree
Health care providers helped caregivers to cope emotionally	 Strongly Agree	 Neither agree nor disagree	 Strongly Disagree

3. If these were the only options, which Provider Group (A, B, or C) would you choose based on these ratings?

[Example Choice Question –]

[THE ATTRIBUTE LEVELS AND GRAPHICS WILL VARY ACROSS RESPONDENTS. EACH RESPONDENT WILL BE PRESENTED 4 SUCH QUESTIONS. ONE EXAMPLE IS SHOWN BELOW. QUESTIONS WILL BE RANDOMLY ALLOCATED BASED ON THE EXPERIMENTAL DESIGN.]

Experience over last 6 weeks of patient's life	Provider Group A	Provider Group B	Provider Group C
Health care providers provided caregivers clear and timely information on how to care for patients	★	★★★	★★★★★
Health care providers helped caregivers to cope emotionally	★★★★	★★★★★	★
Health care providers treated caregivers kindly and sympathetically	★★★★★	★	★★★★

1. If these were the only options, which Provider Group (A, B, or C) would you choose based on these new ratings?

Now we would like you to tell us about **your father's** experience at the end of life. Please indicate how good you thought the care was from each kind of health care provider.

Provider	Poor	Fair	Good	Very Good	Excellent	Don't know/not sure	Does not apply
Doctors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nurses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Counselors/social worker/psychologists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other support staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**1. The care provided to my father during the last 6 weeks of life mostly was:**

- 1 Very poor
- 2 Poor
- 3 Neither good nor poor
- 4 Good
- 5 Very good
- 6 Don't know/not sure

Please tell us how much you agree or disagree with each statement based on your XXX experience.

Consider his experience with health care providers near the time of his death. Please check “does not apply” if the statement does not apply in your father’s case.

**[EACH RESPONDENT WILL BE PRESENTED ATLEAST 4 QUESTIONS AS SHOWN BELOW. THE AGREEMENT QUESTIONS WILL BE ALLOCATED BASED ON THE EXPERIMENTAL DESIGN.]**

Consider whether health care providers presented information in a way that your father could easily understand. Also, consider whether health care professionals shared the information with your father or he had to ask for this information.					
<b>1. Health care providers delivered clear and timely information so he could make informed decisions.</b> (Please check “does not apply” if dementia or other condition limited his ability to make decisions.)					<input type="checkbox"/> <i>does not apply</i>
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Somewhat disagree	<input type="checkbox"/> Neither agree nor disagree	<input type="checkbox"/> Somewhat agree	<input type="checkbox"/> Strongly agree	<input type="checkbox"/> Don't know

Health care providers can be formal and insensitive or caring and sympathetic when dealing with patients. Consider whether health care providers mostly were kind to your father and tried to put themselves in his position.

**2. Health care providers mostly treated him kindly and sympathetically.**

*does not apply*

Strongly  
disagree

Somewhat disagree

Neither agree nor  
disagree

Somewhat agree

Strongly agree

Don't know

For many people, preparing for death can be a spiritual or cultural experience as well as a physical experience. Some health care providers understand better than others the importance of this aspect of preparing for death. Consider whether health care providers were accepting and gave your father enough help for his spiritual, religious, and cultural needs.

**3. Health care professionals supported his spiritual, religious, and cultural needs.**

*does not apply*

Strongly  
disagree

Somewhat disagree

Neither agree nor  
disagree

Somewhat agree

Strongly agree

Don't know

Some health care providers and care facilities give more access to friends and family than others. Contact can include phone or internet access as well as visits. Consider whether your father felt he had enough contact with friends and family near the time of death.

**4. Health care providers encouraged contact with his friends and family.**

*does not apply*

Strongly disagree

Somewhat disagree

Neither agree nor disagree

Somewhat agree

Strongly agree

Don't know

Some health care providers try harder than others to understand what is important to the patient. Consider whether providers made efforts to get enough information from you or your father to understand what he needed or wanted from his treatments.

**5. Health care providers asked enough questions to understand his needs.**

*does not apply*

Strongly disagree

Somewhat disagree

Neither agree nor disagree

Somewhat agree

Strongly agree

Don't know

Sometimes health care providers can give patients too much treatment to try to extend their lives. Other times they provide too little treatment. Providers also sometimes give patient low-quality treatments that can cause unnecessary suffering. Consider whether your father felt he was given too much treatment, too little treatment or low-quality treatments.

**6. Health care providers provided appropriate levels and quality of life extending treatments.**

*does not apply*

Strongly disagree

Somewhat disagree

Neither agree nor disagree

Somewhat agree

Strongly agree

Don't know

Health care providers use medicines and other methods to help people deal with pain and other discomfort. Some of these can limit patients' ability to stay alert and to talk with people around them. Consider whether your father wanted more or less treatment for his pain and other physical symptoms.

**7. Health care providers controlled his pain and discomfort to his desired levels.**

*does not apply*

Strongly disagree

Somewhat disagree

Neither agree nor disagree

Somewhat agree

Strongly agree

Don't know



Approaching the end of life can be a stressful and emotional experience. Health care providers can help people cope with their natural feelings as they approach the end of life. Consider whether your father received appropriate help from his health care providers.

**8. Health care providers helped him cope emotionally.**

*does not apply*

Strongly disagree

Somewhat disagree

Neither agree nor disagree

Somewhat agree

Strongly agree

Don't know

In addition to quality of care, some health care providers treat patients at hospitals and clinics that are more comfortable and attractive than others. Consider what your father thought about the facilities, equipment and general atmosphere of the places outside the home where **he** received care.

**9. The places where health care providers treated patients were clean, safe, and comfortable.**

*does not apply*

Strongly disagree

Somewhat disagree

Neither agree nor disagree

Somewhat agree

Strongly agree

Don't know

Patients often are seen by many health care providers. Understanding what treatment each provider is doing is important to coordinate health care decisions and avoid unnecessary tests. Consider how well different health care providers shared information about his care without involvement from you or your father.

**10. Care was well coordinated across different healthcare providers.**

*does not apply*

Strongly disagree

Somewhat disagree

Neither agree nor disagree

Somewhat agree

Strongly agree

Don't know

People who approach death can need help with things unrelated to medical concerns. For example, some might need help getting a will or organizing their finances. Others might need help attending a special family event, like a wedding or graduation. Consider whether your father thought that health care providers helped with his non-medical concerns.

**11. Health care providers helped with his non-medical concerns.**

*does not apply*

Strongly  
disagree

Somewhat disagree

Neither agree nor  
disagree

Somewhat agree

Strongly agree

Don't know

Not all options for care at the end of life are covered or covered completely by insurance. Consider whether enough money was available or subsidies provided so that costs did not limit the care your father received.

**12. Costs were not a barrier to his getting appropriate care.**

*does not apply*

Strongly  
disagree

Somewhat disagree

Neither agree nor  
disagree

Somewhat agree

Strongly agree

Don't know

Some people feel strongly about being cared for or dying at home where they can be in a familiar setting with their loved ones. Others prefer to stay at a clinic or a medical facility, where pain and other symptoms can be treated better. Consider whether health care providers did all they could to honor your father's preferences about where he died.

**13. He was able to be cared for and die at his place of choice.**

*does not apply*

Strongly  
disagree

Somewhat disagree

Neither agree nor  
disagree

Somewhat agree

Strongly agree

Don't know

Again suppose you were responsible for another loved one nearing the end of life and were considering which provider group to choose. Last time we showed you ratings from **caregivers**. This time we would like to know which group you would choose if all you knew about them were ratings given by **patients**.

Remember: **These groups are NOT those who cared for your loved one before.**

**As you answer the next 4 questions please keep in mind:**

- Assume your loved one does not have dementia or another conditions that limits their ability to make decisions.
- The provider groups we show you may have good ratings for some experiences and bad ratings for others.
- Please consider the ratings for all experiences shown and think about **which group you would choose** if your loved one needed care from these providers.

**[Example Choice Question –]**

[THE ATTRIBUTE LEVELS AND GRAPHICS WILL VARY ACROSS RESPONDENTS. EACH RESPONDENT WILL BE PRESENTED 4 SUCH QUESTIONS. ONE EXAMPLE IS SHOWN BELOW. QUESTIONS WILL BE RANDOMLY ALLOCATED BASED ON THE EXPERIMENTAL DESIGN.]

Experience over last 6 weeks of life	Provider Group A	Provider Group B	Provider Group C
Health care providers gave patients clear and timely information so patient could make informed decisions.	★	★★★	★
Health care providers treated patients kindly and sympathetically.	★★★	★★★★★	★
Health care providers supported patients' spiritual, religious, and/or cultural needs.	★	★★★	★★★★★
Health care providers allowed patients to contact their friends and family.	★★★★★	★	★★★

1. If these were the only options, which Provider Group (A, B, or C) would you choose based on these ratings?





**ADDITIONAL DEMOGRAPHIC INFORMATION [PATIENT]**

**Please tell us more about your loved one.**

**1. Which religion did he follow?**

- |                            |              |                            |   |
|----------------------------|--------------|----------------------------|---|
| <input type="checkbox"/> 1 | Christianity | <input type="checkbox"/> 5 | Judaism   |
| <input type="checkbox"/> 2 | Islam        | <input type="checkbox"/> 6 | Other, please specify: _____                                      |
| <input type="checkbox"/> 3 | Hinduism     | <input type="checkbox"/> 7 | Did not follow any specific religion, but was a spiritual person. |
| <input type="checkbox"/> 4 | Buddhism     | <input type="checkbox"/> 8 | Atheist/ Agnostic   |

**2. What was his primary spoken language?**

- |                            |          |                            |                              |
|----------------------------|----------|----------------------------|------------------------------|
| <input type="checkbox"/> 1 | English  | <input type="checkbox"/> 6 | French                       |
| <input type="checkbox"/> 2 | Spanish  | <input type="checkbox"/> 7 | Other, please specify: _____ |
| <input type="checkbox"/> 3 | Mandarin |                            |                              |
| <input type="checkbox"/> 4 | Russian  |                            |                              |
| <input type="checkbox"/> 5 | Tagalog  |                            |                              |

- 3 **Did his condition or treatments make it difficult for him to communicate during the last 6 weeks of life?**
- 1 Yes
- 2 No
- 4 **Did he have trouble getting what he needed during the last 6 weeks of life because he did not speak the same language as his doctors or nurses?**
- 1 Yes
- 2 No
- 5 **Did he need an interpreter, signer, or family member to help him communicate with health care provider during the last 6 weeks of life?**
- 1 Yes
- 2 No
- 3 Don't know/not sure
- 6 **Did his condition or treatments seriously limit his memory or reasoning, requiring a family member to make health care decisions for him toward end of life?**
- 1 Yes
- 2 No

7. **[If 3=yes, 4=yes or 6=yes] How sure was the family member that he or she understood what care he wanted?**

- 1 Very sure
- 2 Somewhat sure
- 3 Neither sure nor unsure
- 4 Somewhat unsure
- 5 Very unsure
- 6 Don't know

8. **What was his marital status at the time of death?**

- 1 Single / never married
- 2 Married / living as a couple / civil partnership
- 3 Divorced or separated
- 4 Widowed / surviving partner
- 5 Other, please specify: \_\_\_\_\_
- 6 Don't know/not sure

9. **What kind of health insurance did he have? [check all that apply]**

- 1 Public insurance provided by the government (Medicare or Medicaid)
- 2 Through an employer or union
- 3 Through a state or federal insurance exchange
- 4 Veteran's affairs
- 5 None
- 6 Other, \_\_\_\_\_
- 7 Don't Know
- 8 He did not have health insurance

**10 How would you describe his household income?**

- 1 Low income
- 2 Lower- middle income
- 3 Middle income
- 4 Upper-middle income
- 5 High income

**11. What was the highest level of education he completed?**

- |   |   |
|---|---|
| <input type="checkbox"/> 1 Less than high school                            | <input type="checkbox"/> 6 Associate's degree or 2-year college degree                      |
| <input type="checkbox"/> 2 Some high school                                 | <input type="checkbox"/> 7 4-year college degree (such as BA, BS)                           |
| <input type="checkbox"/> 3 High school graduate or equivalent (such as GED) | <input type="checkbox"/> 8 Some graduate school but no degree                               |
| <input type="checkbox"/> 4 Some college but no degree                       | <input type="checkbox"/> 9 Graduate or professional degree (such as MBA, MS, MA, MD or PhD) |
| <input type="checkbox"/> 5 Technical school                                 | <input type="checkbox"/> 10 Don't know/not sure   |

## DEMOGRAPHIC INFORMATION [CAREGIVER]

### More information about you

**12. What is your religion?**

- |                            |              |                            |  |
|----------------------------|--------------|----------------------------|--|
| <input type="checkbox"/> 1 | Christianity | <input type="checkbox"/> 5 | Judaism  |
| <input type="checkbox"/> 2 | Islam        | <input type="checkbox"/> 6 | Other, please specify:   |
| <input type="checkbox"/> 3 | Hinduism     | <input type="checkbox"/> 7 | Do not follow any specific religion,<br>but a spiritual person |
| <input type="checkbox"/> 4 | Buddhism     | <input type="checkbox"/> 8 | Atheist/ Agnostic  |

**13. What is your current marital status?**

- |                            |   |                            |                              |
|----------------------------|---|----------------------------|------------------------------|
| <input type="checkbox"/> 1 | Single / never married                              | <input type="checkbox"/> 4 | Widowed / surviving partner  |
| <input type="checkbox"/> 2 | Married / living as a couple / civil<br>partnership | <input type="checkbox"/> 5 | Other, please specify: _____ |
| <input type="checkbox"/> 3 | Divorced or separated                               |                            |                              |

**14. What is your current employment status?**

- |                            |                                 |                            |                            |
|----------------------------|---------------------------------|----------------------------|----------------------------|
| <input type="checkbox"/> 1 | Working full-time               | <input type="checkbox"/> 4 | Retired and/or not working |
| <input type="checkbox"/> 2 | Working part-time               | <input type="checkbox"/> 5 | Homemaker                  |
| <input type="checkbox"/> 3 | Unemployed but looking for work |                            |                            |

**15. What is the highest level of education you have completed?**

- |                            |   |                            |  |
|----------------------------|---|----------------------------|--|
| <input type="checkbox"/> 1 | Less than high school                   | <input type="checkbox"/> 6 | Associate's degree or 2-year college degree                    |
| <input type="checkbox"/> 2 | Some high school                        | <input type="checkbox"/> 7 | 4-year college degree (such as BS)                             |
| <input type="checkbox"/> 3 | High school or equivalent (such as GED) | <input type="checkbox"/> 8 | Some graduate school but no degree                             |
| <input type="checkbox"/> 4 | Some college but no degree              | <input type="checkbox"/> 9 | Graduate or professional degree (such as MBA, MS, MA, MD, PhD) |
| <input type="checkbox"/> 5 | Technical school                        |                            |  |

**16. Please tell us how much you agree with each of the following statements.**

	<b>Strongly agree</b>	<b>Agree</b>	<b>Neither agree nor disagree</b>	<b>Disagree</b>	<b>Strongly disagree</b>
I prefer to leave all health care decisions to the doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am able to help doctors understand what is important to me about my health care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My health depends mostly on luck.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can do things to improve my health other than what doctors tell me to do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I want as much information as possible to make decisions about my health care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Thank you for completing this survey.**