



MASSACHUSETTS COALITION FOR  
**SERIOUS ILLNESS CARE**

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# Massachusetts Survey on Advance Care Planning and End-of-Life Care

Spring 2016 Survey of Massachusetts Residents

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## Research Partners:



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# Methodological Overview

**Who?** Individuals with telephone numbers randomly generated for the State of Massachusetts. Individuals 18 years of age or older were randomly selected within households.

**When?** March 8 – April 3, 2016

**How?** Telephone interviews were conducted by SSRS, Inc. using Computer Assisted Telephone Interviewing (CATI). At least 6 call attempts were made to contact non-responsive numbers. Each non-responsive number was contacted multiple times, varying the times of day, and the days of the week using a programmed differential call rule. Interviews were conducted in English or Spanish.

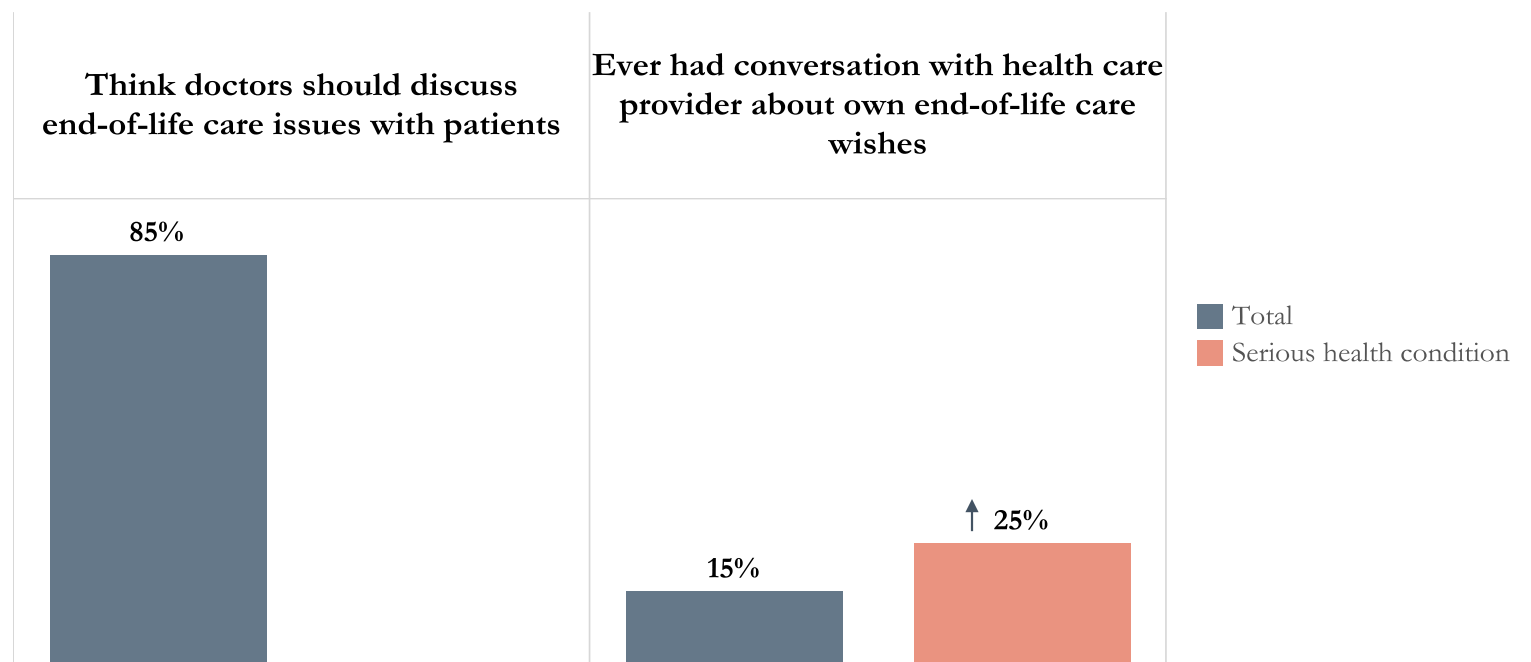
Data were subsequently weighted to produce representative estimates of population parameters. Details on weighting are included in the technical appendix.

## Results?

Sample	Sample Size	Response Rate AAPOR RR3
Total	1,851	25%
Landline	556	20%
Cell	1,295	25%
Design effect = 1.56; Margin of sampling error = +/- 2.28%		



More than 80% of participants believed doctors should discuss end-of-life care issues with patients, but few participated in a discussion - even among those with a serious health condition.



↑ Significantly higher than comparison group at 95% confidence level

Do you think doctors should discuss end-of-life care issues with their patients, or not?

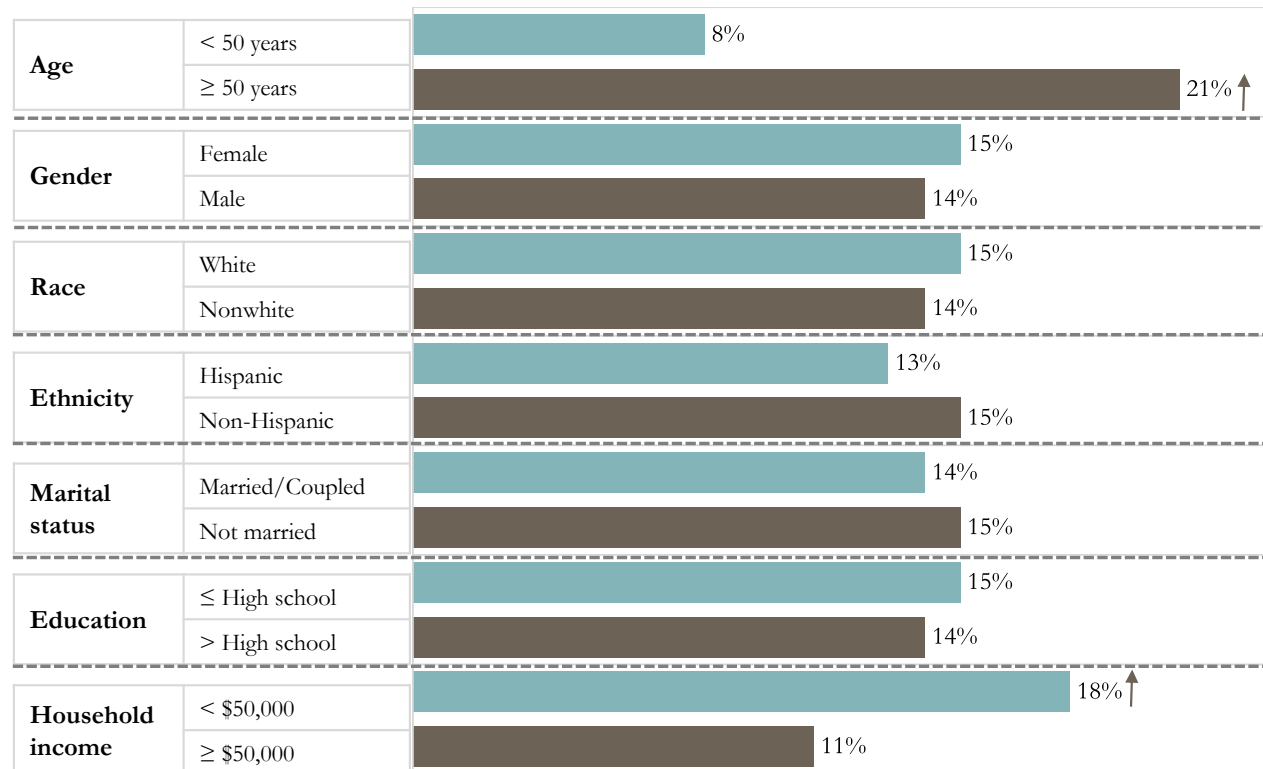
Have you ever had a conversation with a doctor or other health care provider about your wishes for care near the end of your life, or not?



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Older participants and those with lower household incomes were significantly more likely to have had a conversation with a health care provider about their end-of-life care wishes.



↑ Significantly higher than comparison group at 95% confidence level

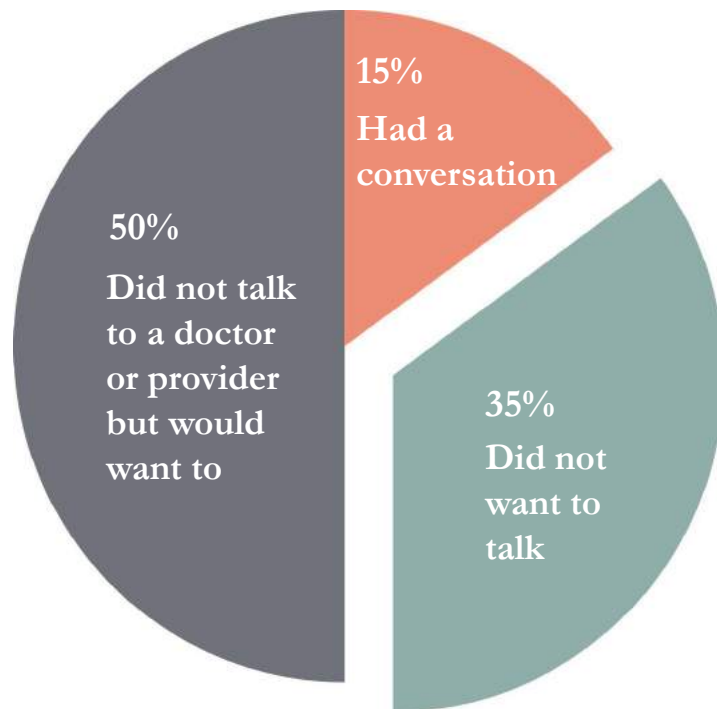


Have you ever had a conversation with a doctor or other health care provider about your wishes for care near the end of your life, or not?

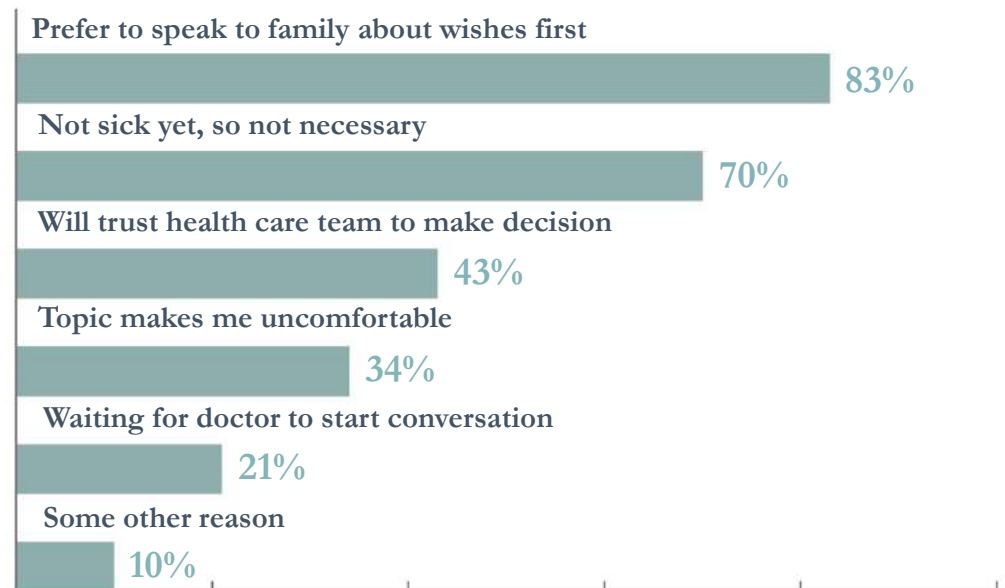
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More than a third of participants did not want to have a conversation about end-of-life care wishes with a doctor or other health care provider.



### Reasons did not want to talk with health care provider:

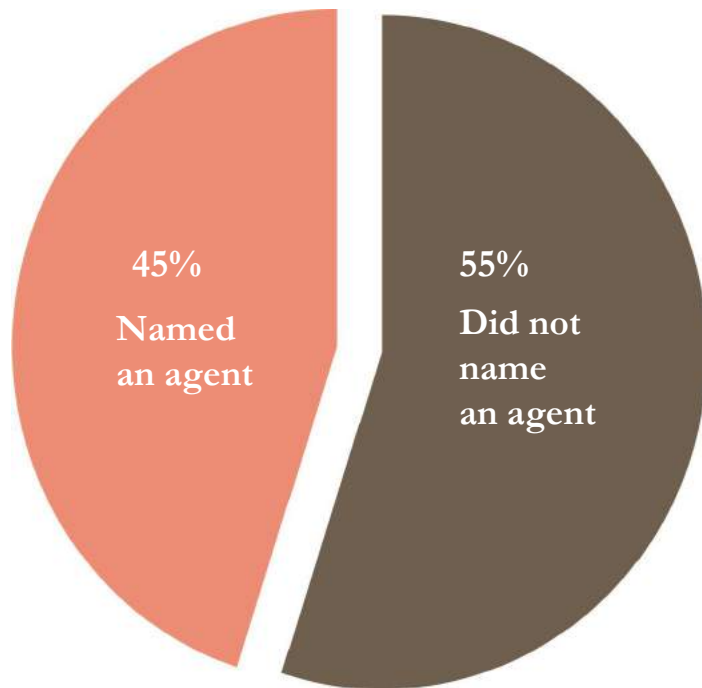


Would you want to talk with a doctor or other health care provider about your wishes for care near the end of your life, or not? Base: Has never had conversation with health care provider.

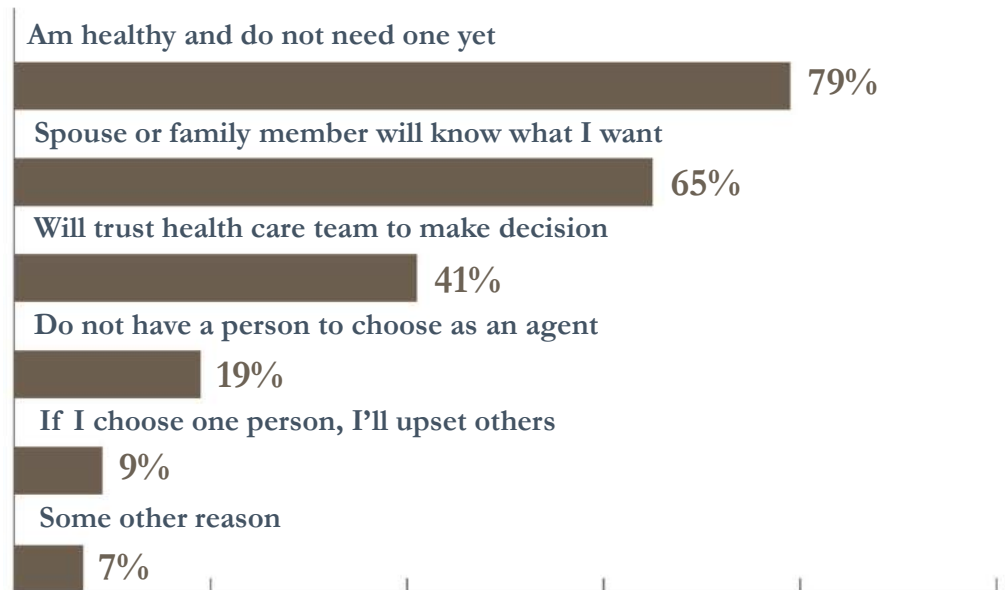
For each of the following statements, please tell me whether or not it is a reason you do not want to talk with a doctor or health care provider about your wishes for care at the end of your life. Base: Does not want to have a conversation with health care provider.



Less than half of participants had completed a health care proxy and named an agent; of those that didn't, most felt it was not needed because they were healthy or their loved one would know what they wanted.



### Reasons did not name agent:

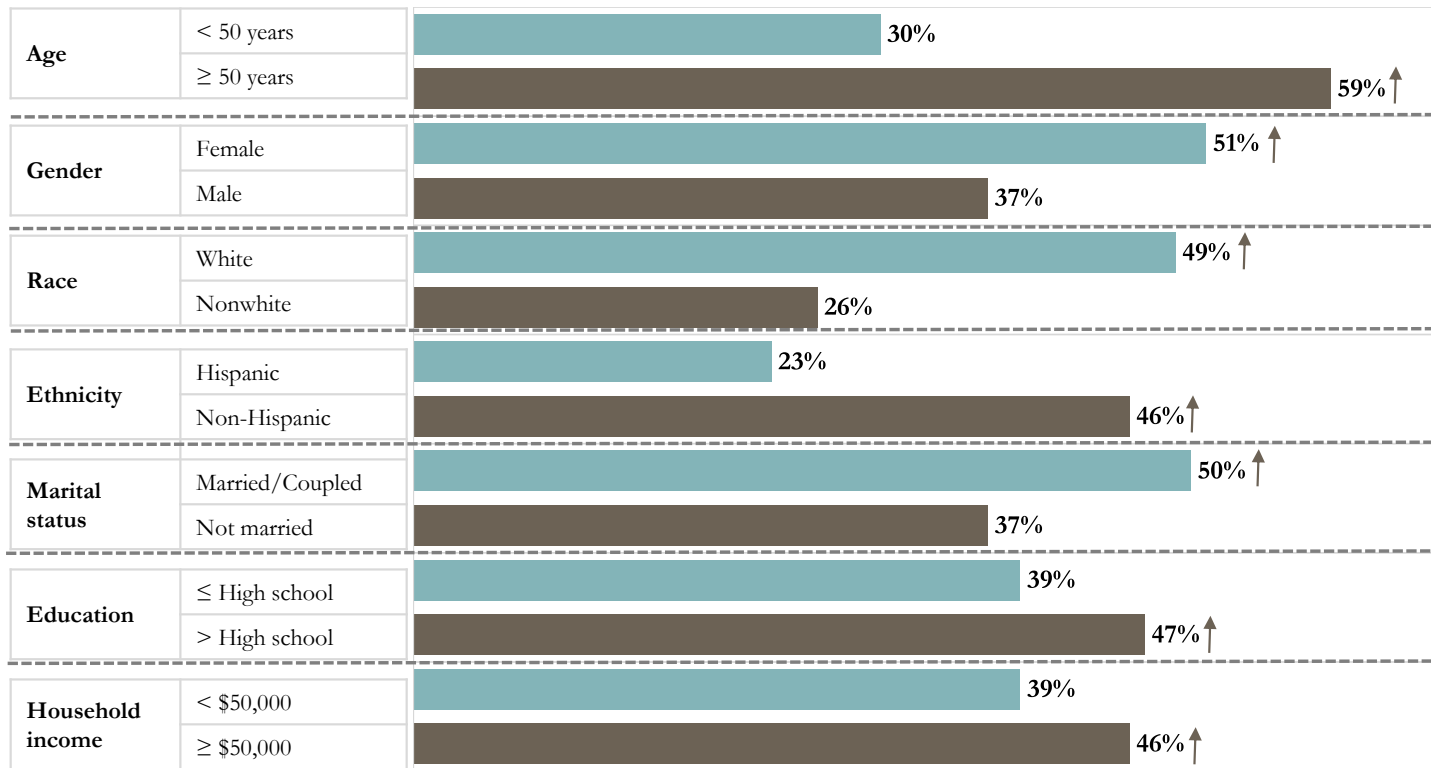


A health care proxy is a legal form where you choose a person, called a health care agent, to make medical decisions for you if you are unable to make them for yourself. This form is completed and signed by you and witnessed by two people. Have you ever completed a form that names someone as your health care agent, or not? For each of the following statements, please tell me whether or not it is a reason why you have never completed a form that names someone as your health care agent.  
Base: Has not named health care agent.





Older, female, white, non-Hispanic, and married participants as well as those with more education and higher incomes were significantly more likely to have named a health care agent.



↑ Significantly higher than comparison group at 95% confidence level

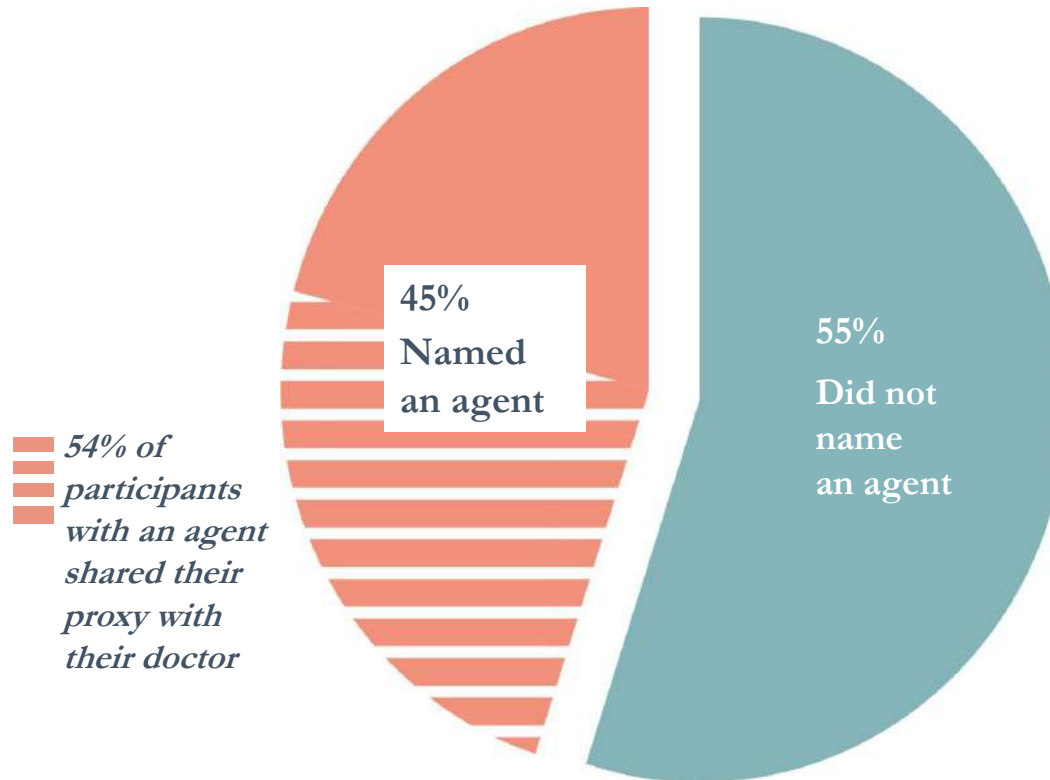


A health care proxy is a legal form where you choose a person, called a health care agent, to make medical decisions for you if you are unable to make them for yourself. This form is completed and signed by you and witnessed by two people. Have you ever completed a form that names someone as our health care agent, or not?

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Among those who had named an agent, just over half had shared a copy of their health care proxy form with their doctor.

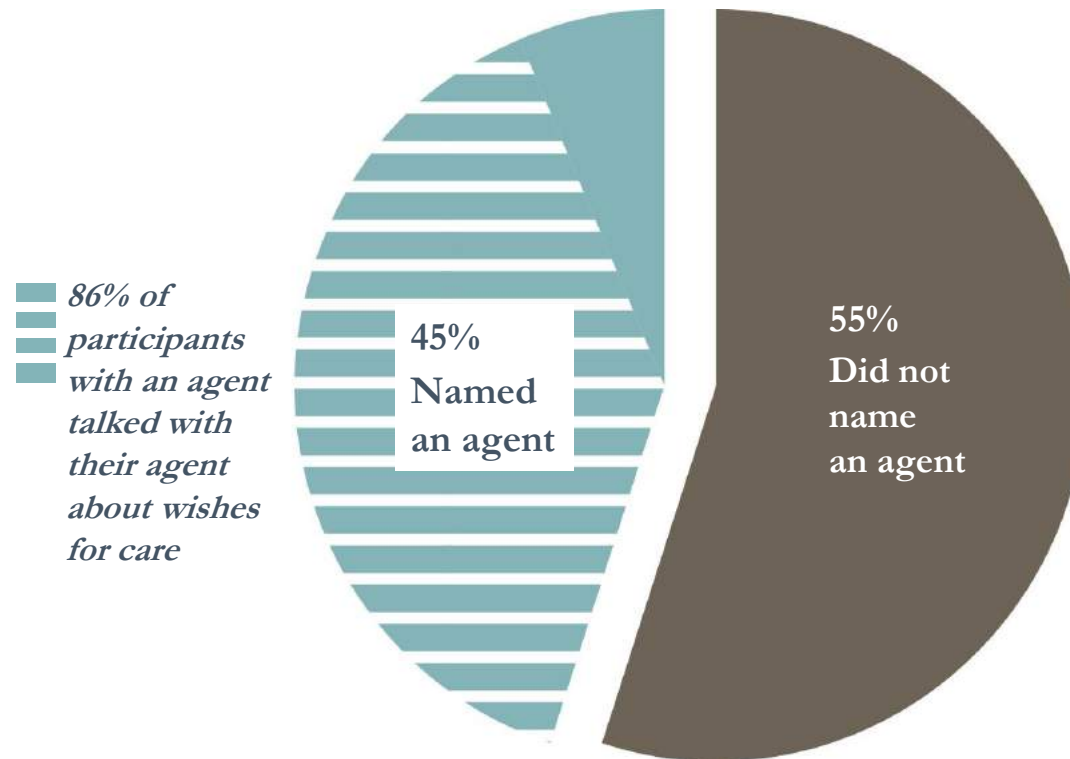


Have you shared a copy of your health care proxy form with your doctor, or not? Base: Named health care agent.

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Among those who had named an agent, nearly 90% had discussed their wishes with their agent.

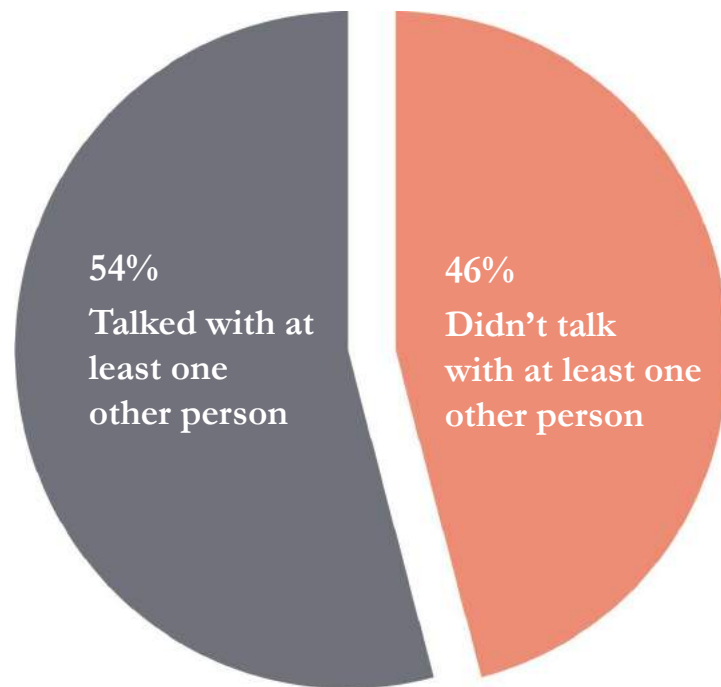


Have you talked to the person that you named as your health care agent about your wishes, or not? Base: Named health care agent.

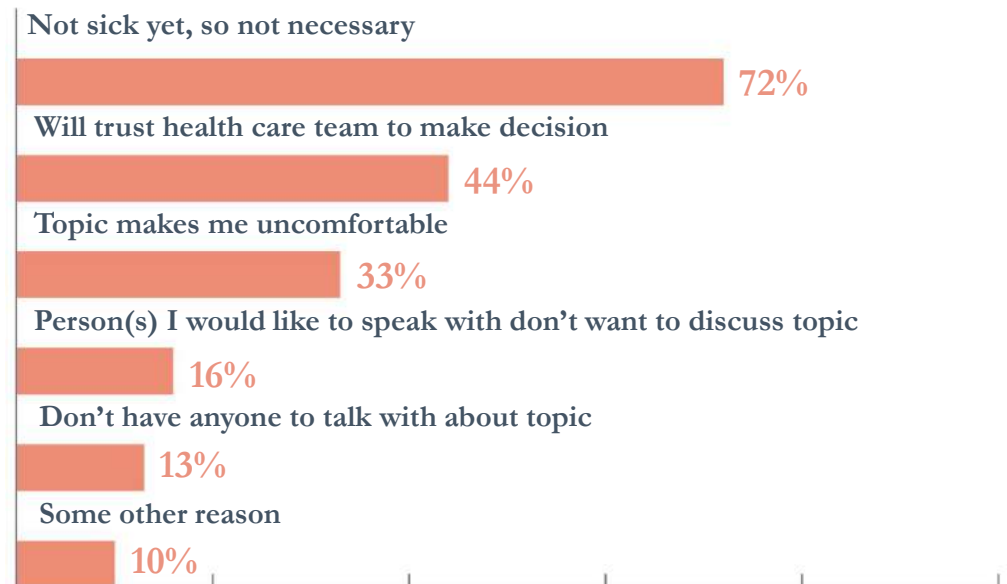
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More than half of participants have had a conversation with someone other than a doctor or health care provider about their end-of-life care wishes.

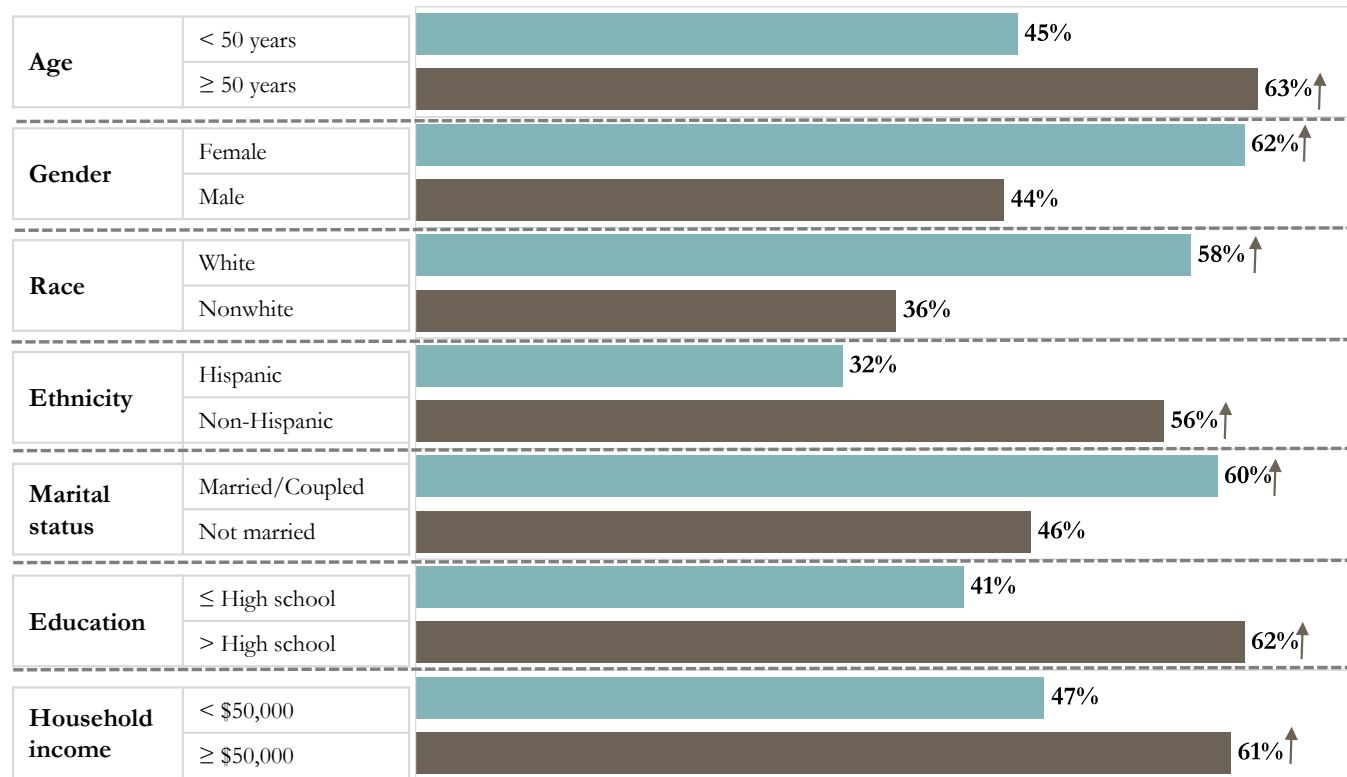


**Reasons have never talked to someone else about wishes for end-of-life care:**



Have you had a conversation with at least one person other than a doctor or other health care provider about your wishes for care near the end of your life, or not?  
For each of the following statements, please tell me whether or not it is a reason why you have never talked to someone about your wishes for care near the end of you life. Base: Has never had conversation with someone other than health care provider.

Older, female, white, non-Hispanic, and married participants as well as those with more education and higher incomes were significantly more likely to have had a conversation with someone other than a health care provider about their end-of-life care wishes.



↑ Significantly higher than comparison group at 95% confidence level

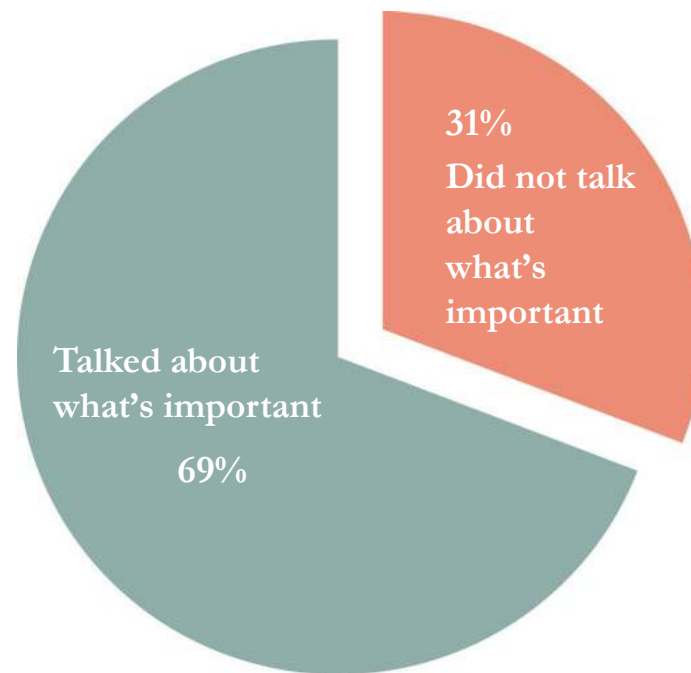


Have you had a conversation with at least one person other than a doctor or other health care provider about your wishes for care near the end of your life, or not?

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Among those who had talked to **anyone** about their end-of-life-care wishes, the majority had discussed what was important to them if they were facing an illness or condition that made it hard to function in day-to-day activities.

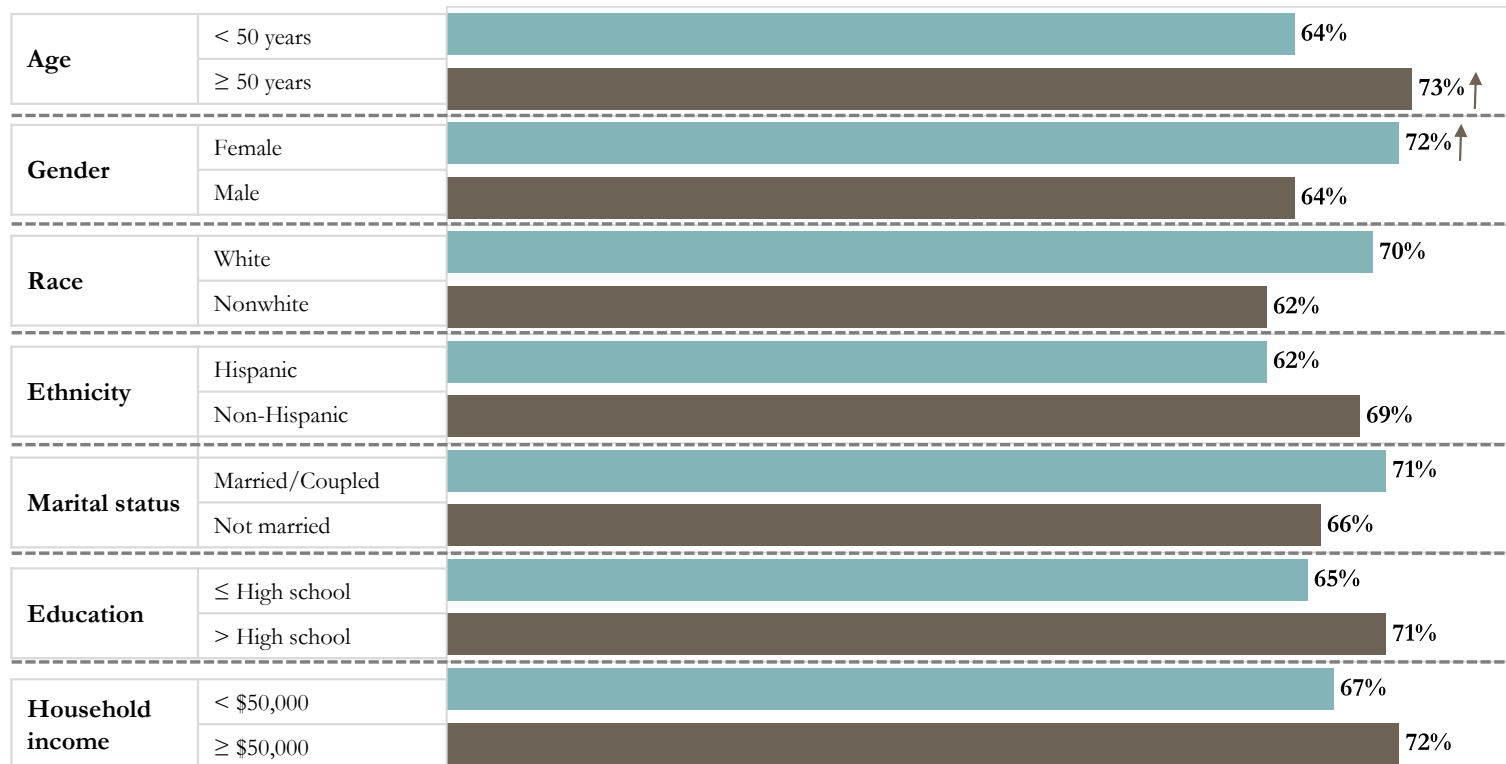


People have many different types of conversations about what is important if they were facing an illness or condition that made it hard for them to function in their day-to-day activities. These conversations can include such topics as their goals for care, which abilities are so critical to their life that they can't imagine living without them, or whether or not they want certain types of life-prolonging care. Have you had a conversation with anyone about what is important to you if you were facing an illness or condition that made it hard for you to function in your day-to-day activities? Base: Had end-of-life conversation with doctor, health care agent or someone else.

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Participants who were older and female were significantly more likely to have had a conversation with at least one person about what is important to them if they were facing an illness or condition making it hard to function in day-to-day activities.



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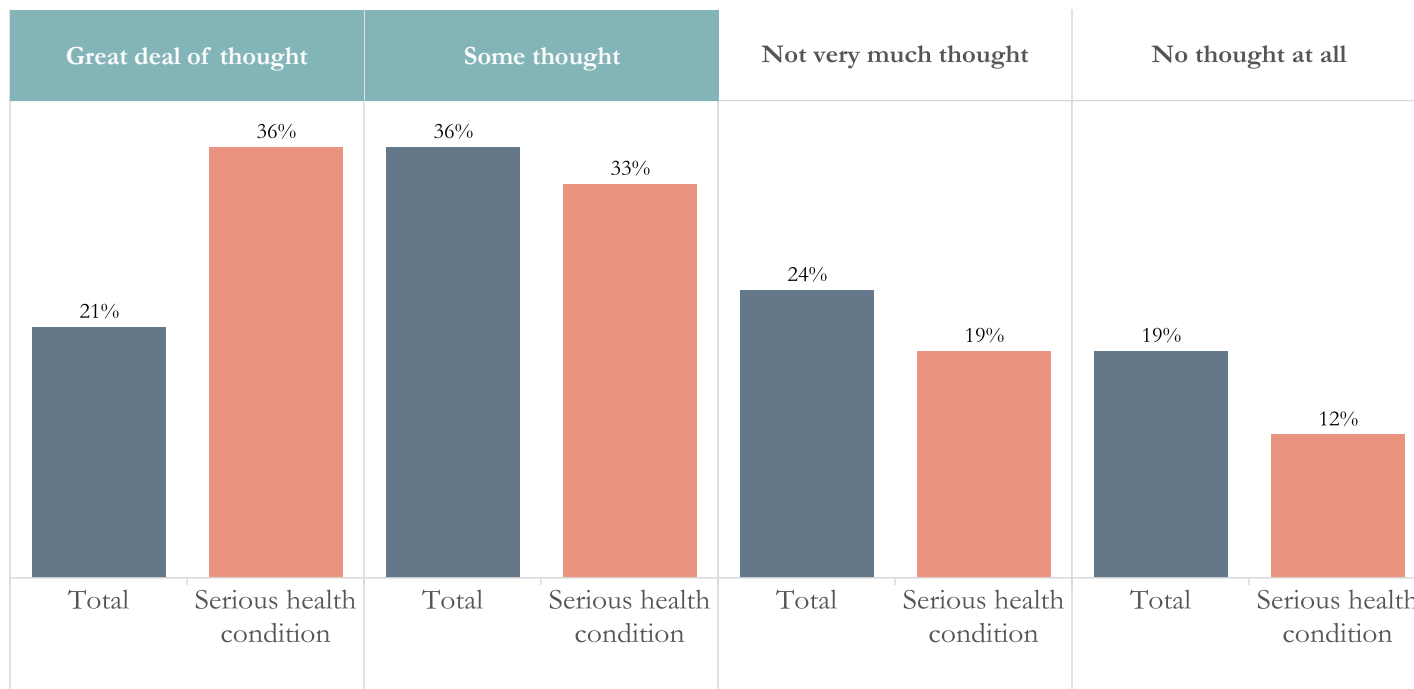


Have you had a conversation with anyone about what is important to you if you were facing an illness or condition that made it hard for you to function in your day-to-day activities?

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More than half of participants had given at least some thought to their wishes for medical treatment if they were facing an illness or condition that made it hard to function in day-to-day activities.



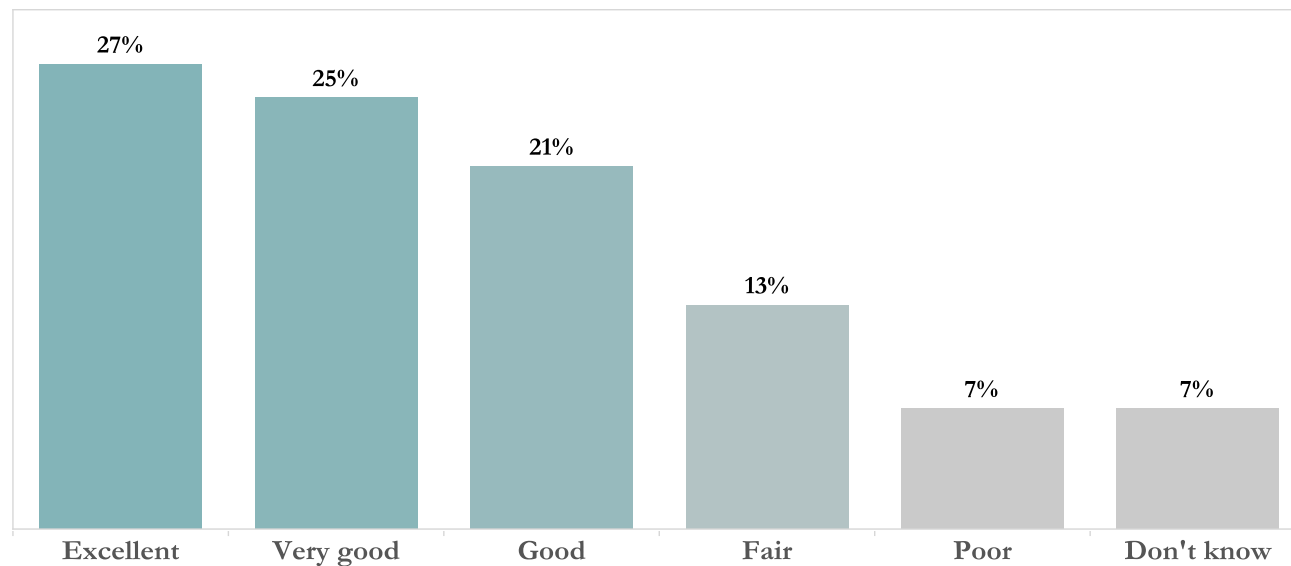
Before today, how much had you thought about your own wishes for medical treatment if you were facing an illness or condition that made it hard for you to function in your day-to-day activities?

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Among participants who had a loved one die in the last 12 months in Massachusetts, half rated the care that their loved one received at the end of life as excellent or very good, but 1 in 5 rated the care as only fair or poor.



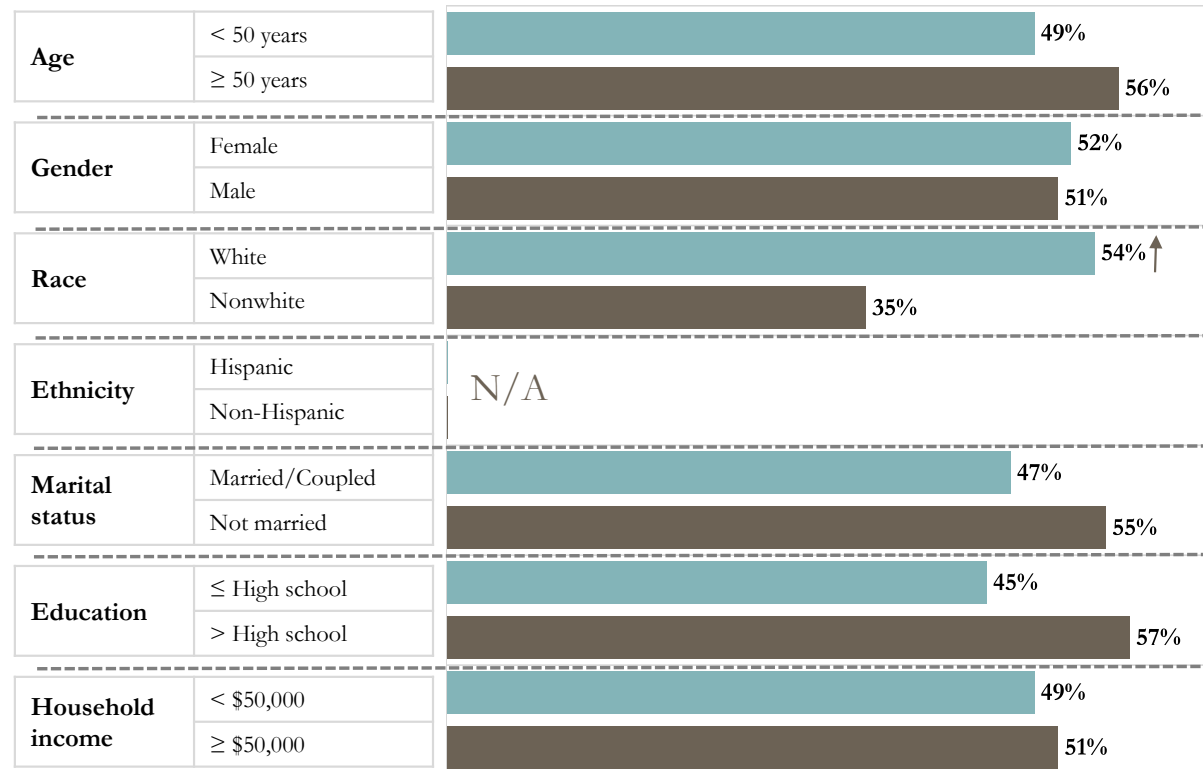
In the last 12 months, did you have a loved one die? Did this person die in Massachusetts?  
Overall, how would you rate the care your loved one received at the end of their life? Base: Death of a loved one in Massachusetts.



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Among participants who had a loved one die in the last 12 months in Massachusetts, white participants were significantly more likely to rate the care received by their loved one as excellent or very good.



↑ Significantly higher than comparison group at 95% confidence level

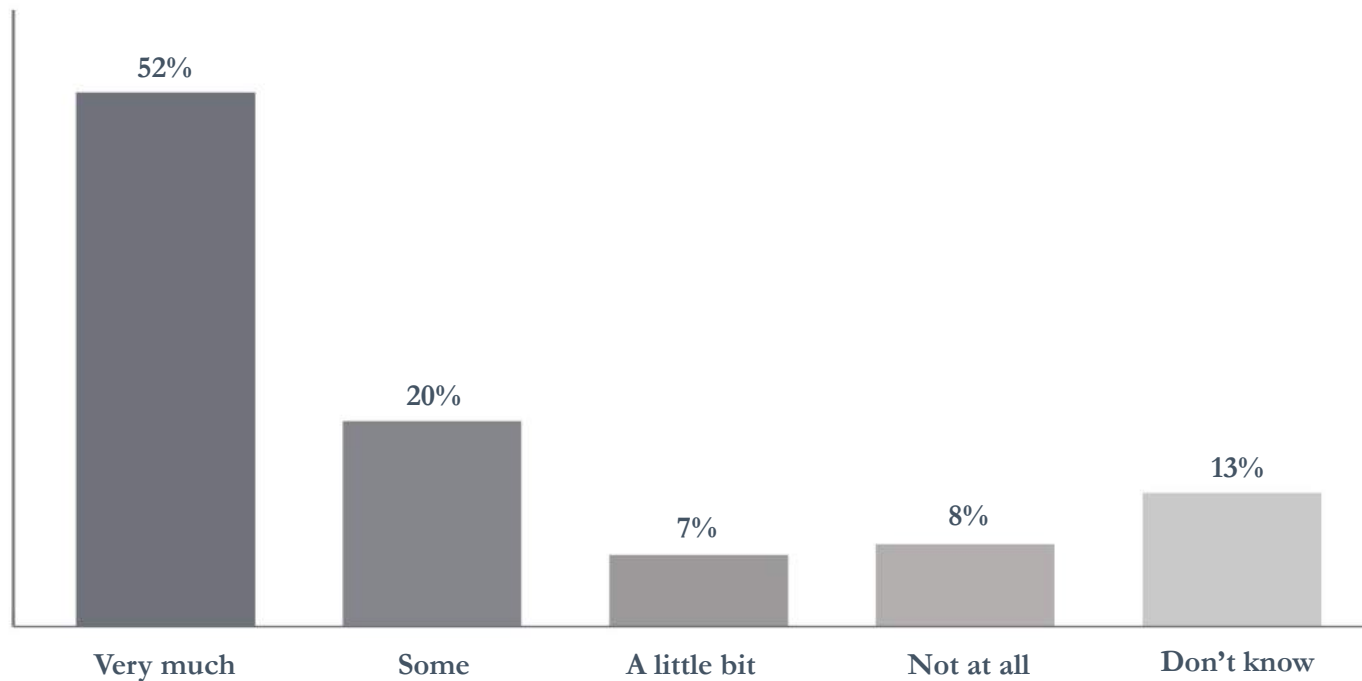


Overall, how would you rate the care your loved one received at the end of their life? Base: Death of a loved one in Massachusetts.

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Among participants who had a loved one die in the last 12 months in Massachusetts, about half stated that their loved one's wishes were very much followed and honored by health care providers.



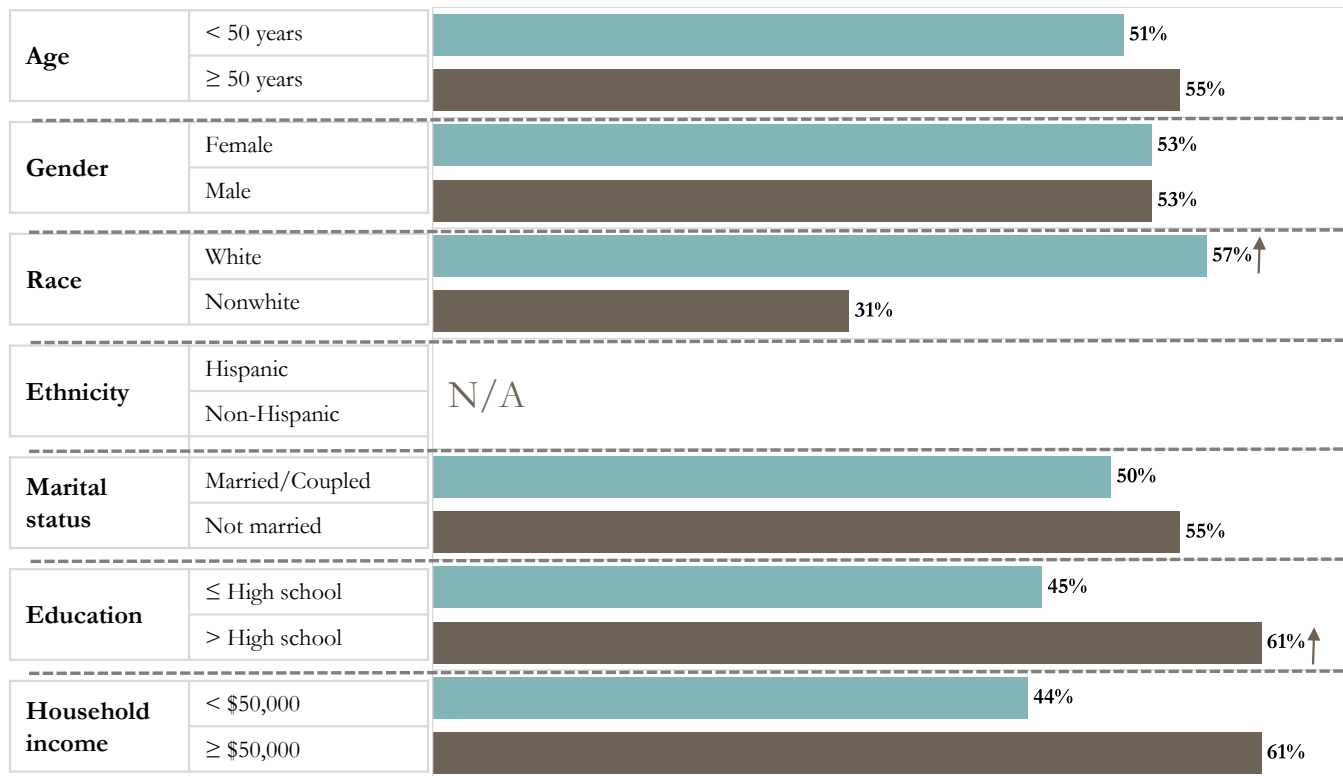
In the last 12 months, did you have a loved one die? Did this person die in Massachusetts?  
To what extent would you say that your loved one's wishes were followed and honored by health care providers at the end of their life? Base: Death of a loved one in Massachusetts.



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Among participants who had a loved one die in the last 12 months in Massachusetts, white participants and those with more education were significantly more likely to state that their loved one's wishes were very much followed and honored by health care providers.



↑ Significantly higher than comparison group at 95% confidence level

To what extent would you say that your loved one's wishes were followed and honored by health care providers at the end of their life? Base: Death of a loved one in Massachusetts.

