



MASSACHUSETTS COALITION FOR  
**SERIOUS ILLNESS CARE**

# Massachusetts Survey on Advance Care Planning and Serious Illness Care

Spring 2018 Survey of Massachusetts Residents

## Research Partners:



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# Methodological Overview

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

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**When?** March 8 – March 25, 2018

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**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.

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**Results?**

Sample	Sample Size	Response Rate AAPOR RR3
Total	1,500	15.2%
Landline	600	18.0%
Cell	900	14.0%

**Design effect = 1.27; Margin of sampling error = +/- 2.9%**

Data Source: SSRS Methodology Report



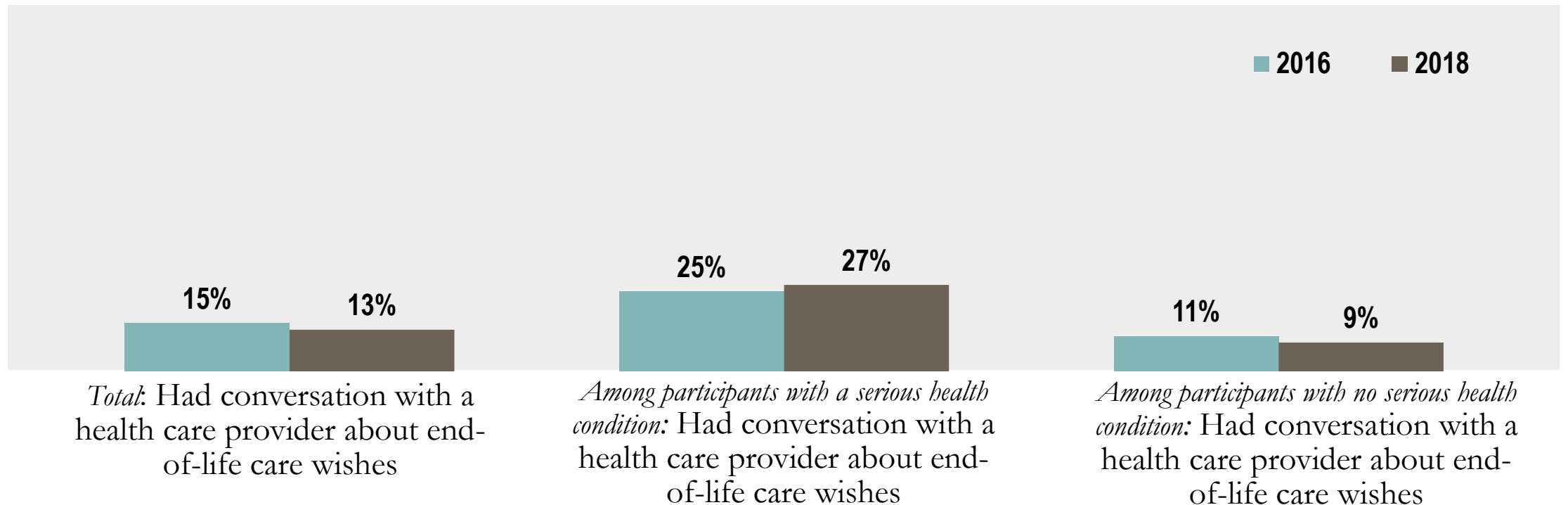
# Analytic Overview and Definitions

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<b>Comparisons over time</b>	Whenever possible, findings were compared between 2016 and 2018.
<b>Comparisons to national data</b>	When questions were similar, comparisons were made to findings from a national study conducted by the Kaiser Family Foundation from May-July 2017. Results from that national study are available at: <a href="http://files.kff.org/attachment/Report-Serious-Illness-in-Late-Life-The-Publics-Views-and-Experiences">http://files.kff.org/attachment/Report-Serious-Illness-in-Late-Life-The-Publics-Views-and-Experiences</a>
<b>Comparisons by participant demographics, health status, and region</b>	Comparisons were made by demographic and health status characteristics of participants as well as region when the minimum sample size for a subgroup of interest was at least 10 individuals.
<b>Serious health condition</b>	At least one hospital stay OR serious illness, medical condition, injury, or disability requiring a lot of medical care in past 12 months
<b>No serious health condition</b>	No hospitalizations AND no serious illness, medical condition, injury or disability requiring a lot of medical care in past 12 months



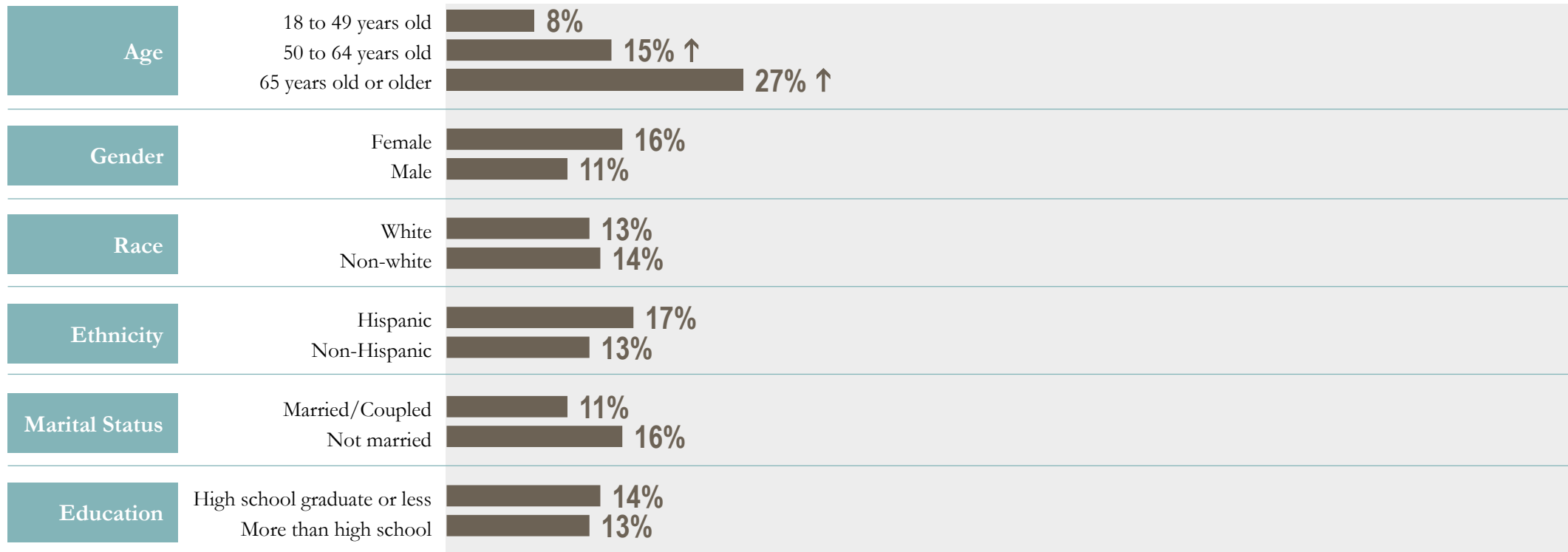
There was no change in the percentage of participants who had a conversation with a health care provider about their end-of-life care wishes.



Q: 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?



## Older participants were significantly more likely to have had a conversation with a health care provider about their end-of-life care wishes.

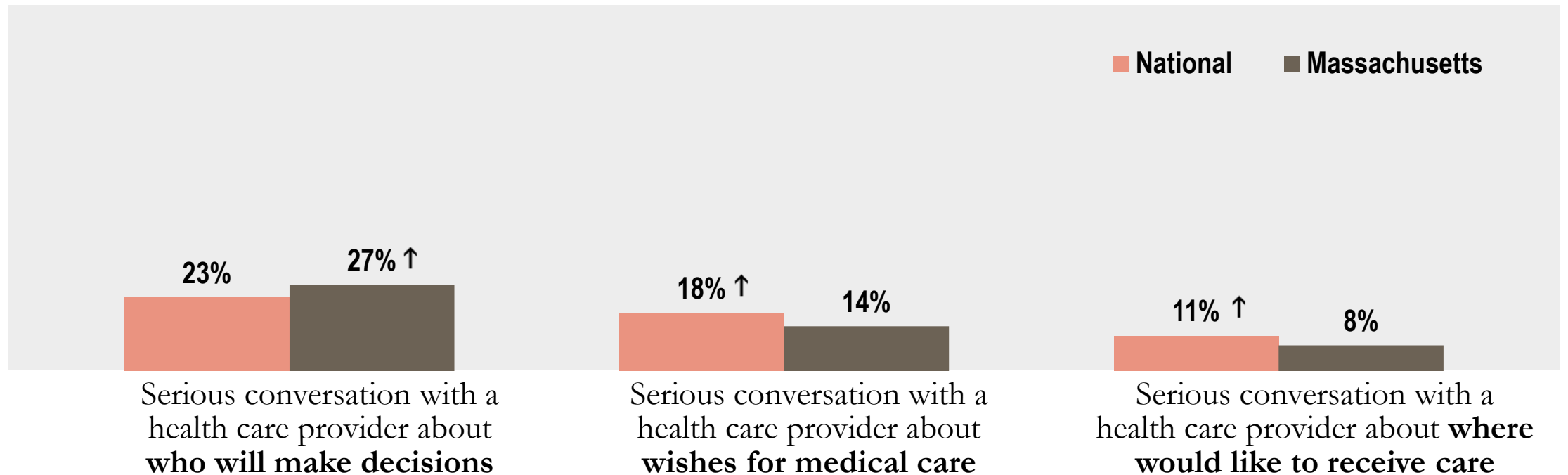


↑ Significantly higher than comparison group at 95% confidence level.

Q: 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?



Compared to national rates, Massachusetts residents were more likely to have talked to a health care provider about who would make medical decisions for them, but less likely to have talked about wishes for care or where to receive care.



Q: Have you ever had a serious conversation with a doctor or other health care provider about who will make decisions about your medical care if you can no longer make them on your own, or not?

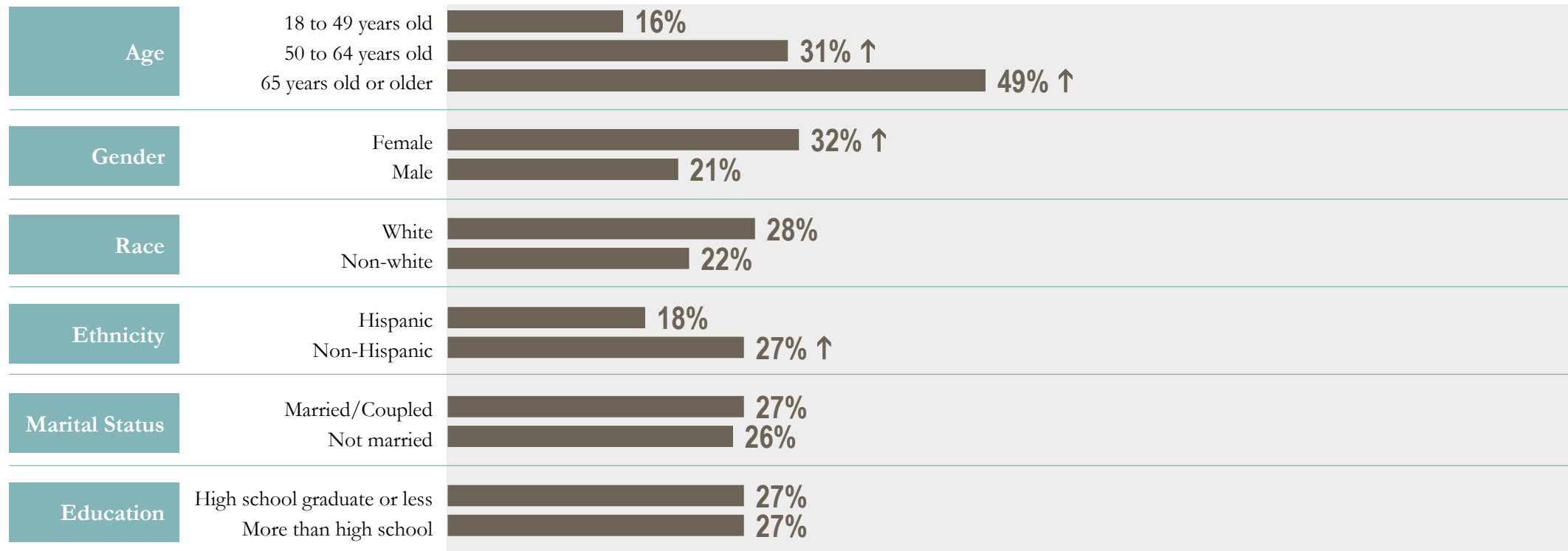
Q: Have you ever had a serious conversation with a doctor or other health care provider about your wishes for your medical care if you become seriously ill, such as the types of treatments you do or don't want to receive, or not?

Q: Have you ever had a serious conversation with a doctor or other health care provider about where you would like to receive care if you become seriously ill, such as at home or in an assisted living facility, or not?





## Older, female, and non-Hispanic participants were significantly more likely to have had a conversation with a health care provider about who would make medical decisions for them.

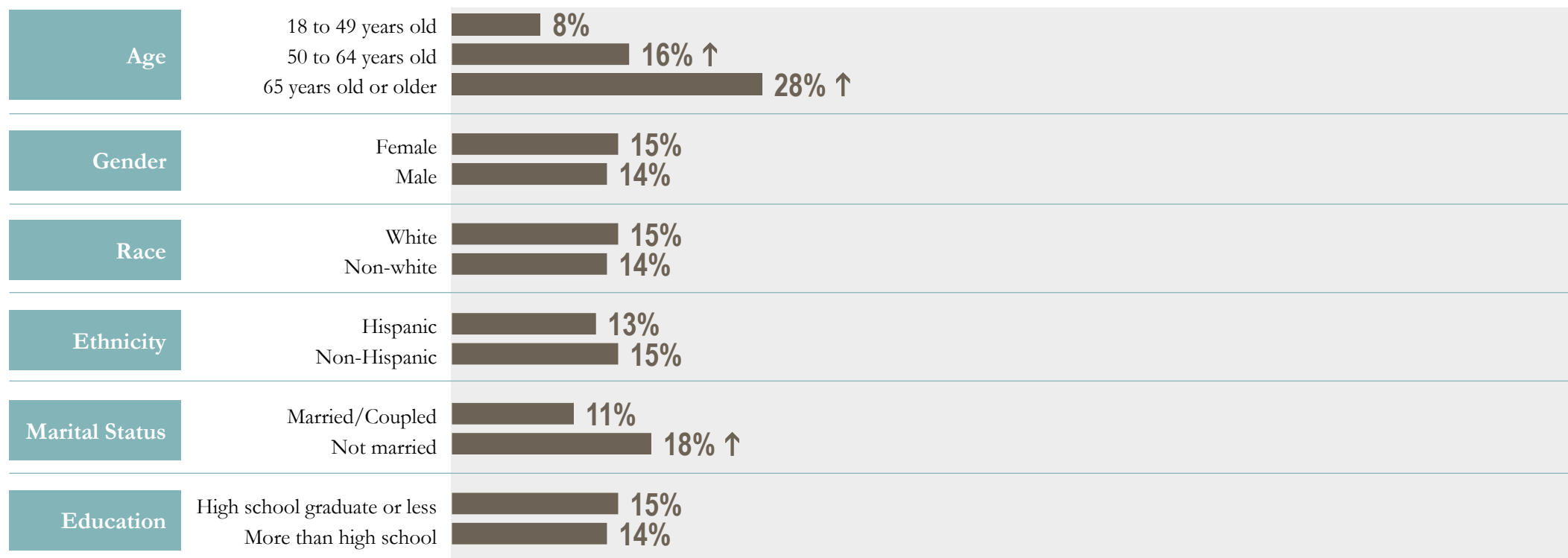


↑ Significantly higher than comparison group at 95% confidence level.

Q: Have you ever had a serious conversation with a doctor or other health care provider about who will make decisions about your medical care if you can no longer make them on your own, or not?



## Older and unmarried participants were significantly more likely to have had a conversation with a health care provider about wishes for medical care if they became seriously ill.

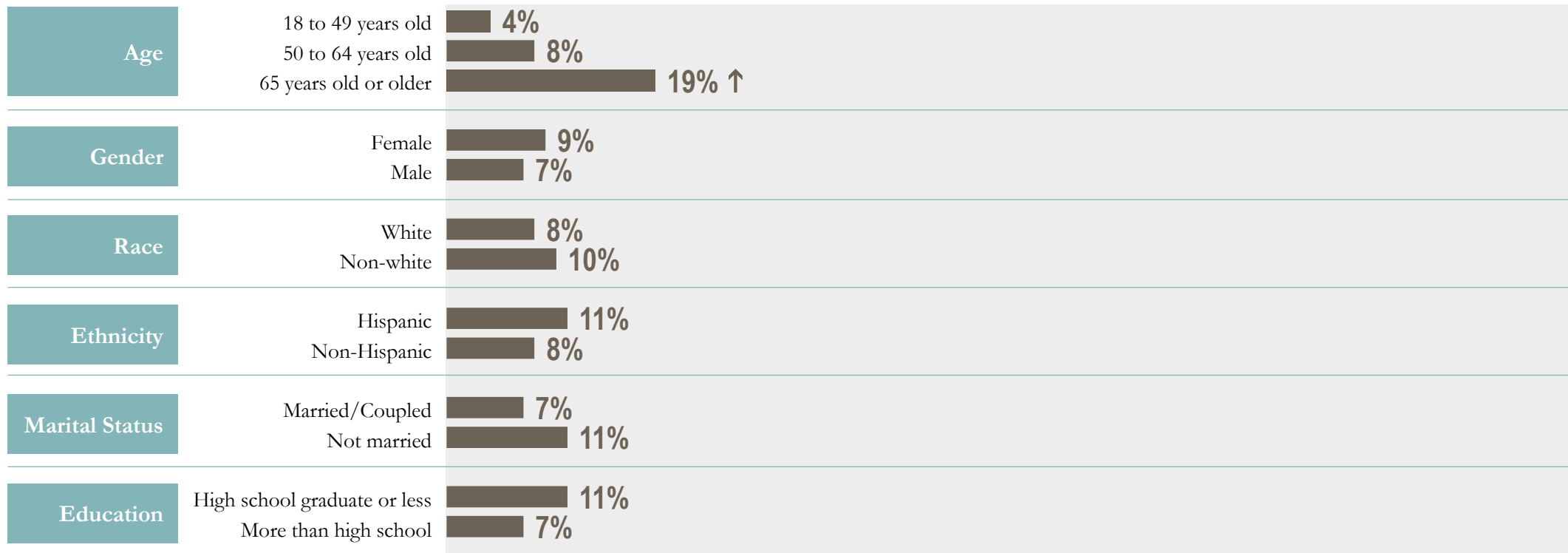


↑ Significantly higher than comparison group at 95% confidence level.

Q: Have you ever had a serious conversation with a doctor or other health care provider about your wishes for your medical care if you become seriously ill, such as the types of treatments you do or don't want to receive, or not?



## Older participants were significantly more likely to have had a conversation with a health care provider about where they would like to receive care if they became seriously ill.



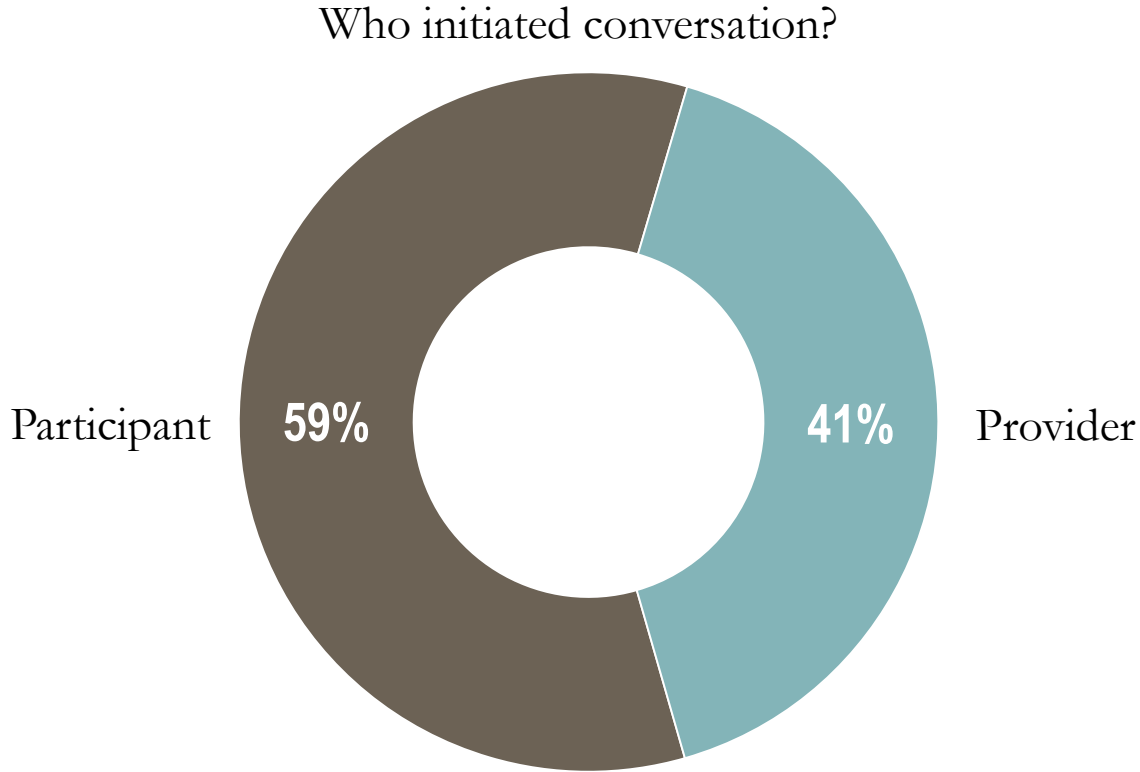
↑ Significantly higher than comparison group at 95% confidence level.

Q: Have you ever had a serious conversation with a doctor or other health care provider about where you would like to receive care if you become seriously ill, such as at home or in an assisted living facility, or not?



Among participants who had a conversation with a health care provider about their wishes for medical care if they became seriously ill, the majority had initiated the conversation themselves.

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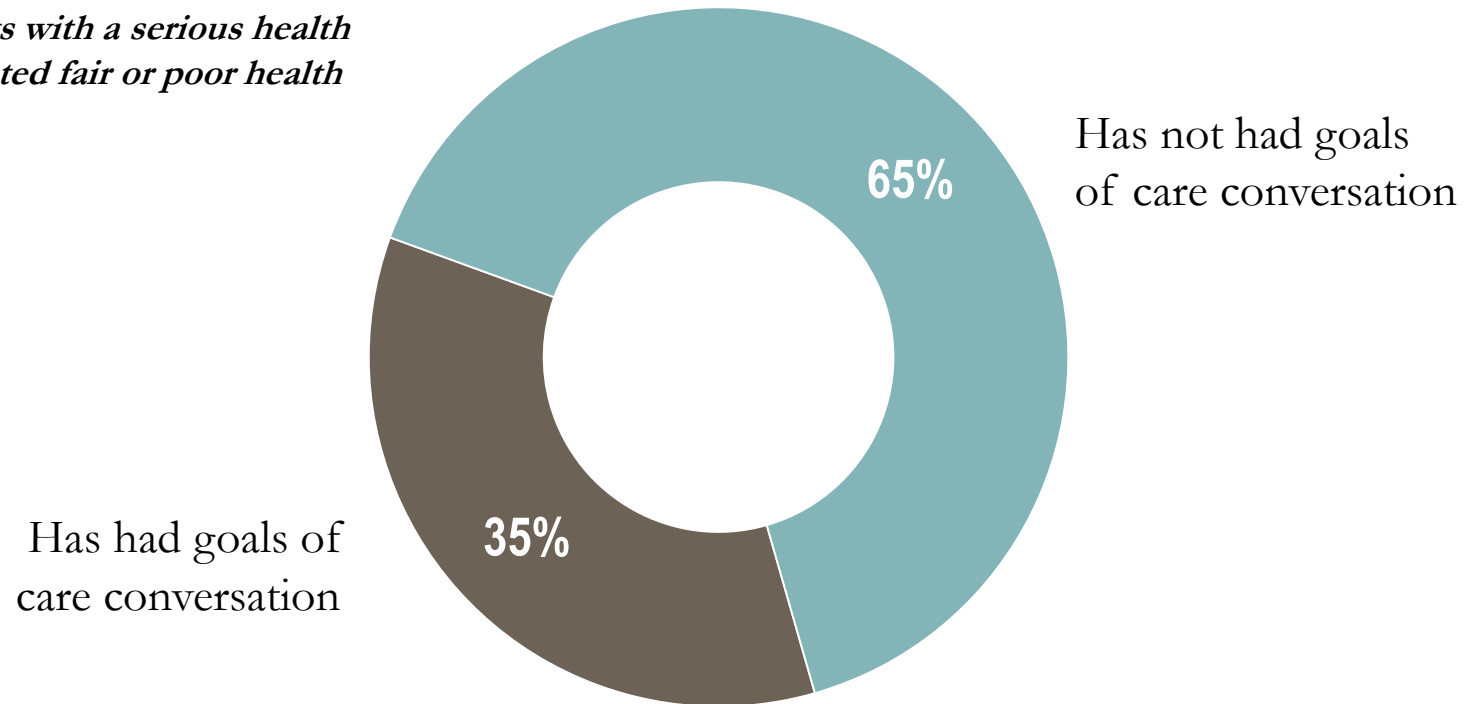


Q: Who initiated this conversation about this?  
Base: Serious conversation with healthcare provider about wishes for medical care if become seriously ill.



# Only 35% of participants with poorer health had ever had a conversation with a health care provider about their goals for care if their health were to get worse.

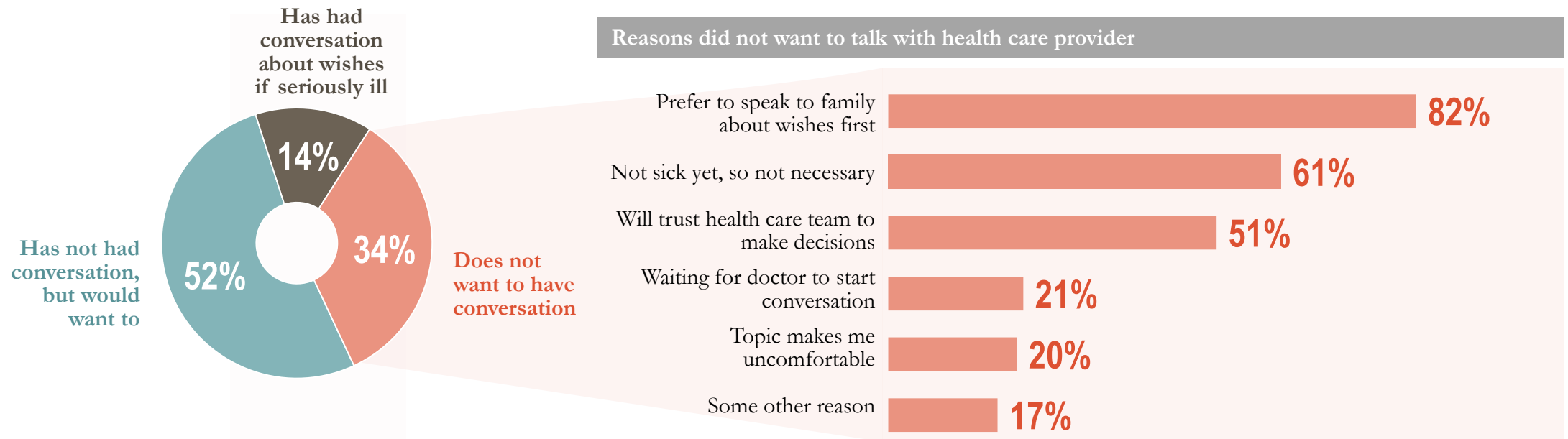
*Among participants with a serious health condition or self-rated fair or poor health*



Q: Have you and your doctor or another health care provider had any conversations about your goals for your care, including what is most important to your quality of life if your health gets worse?  
Base: Had serious health condition in past 12 months or rated health as fair or poor



# More than a third of participants did not want to have a conversation with a health care provider about their wishes for medical care if they were to become seriously ill.



Q: Have you ever had a serious conversation with a doctor or other health care provider about who will make decisions about your medical care if you can no longer make them on your own, or not?

Q: Would you want to talk with doctor or other health care provider about your wishes for your medical care if you become seriously ill, or would you not want to talk to them about this?

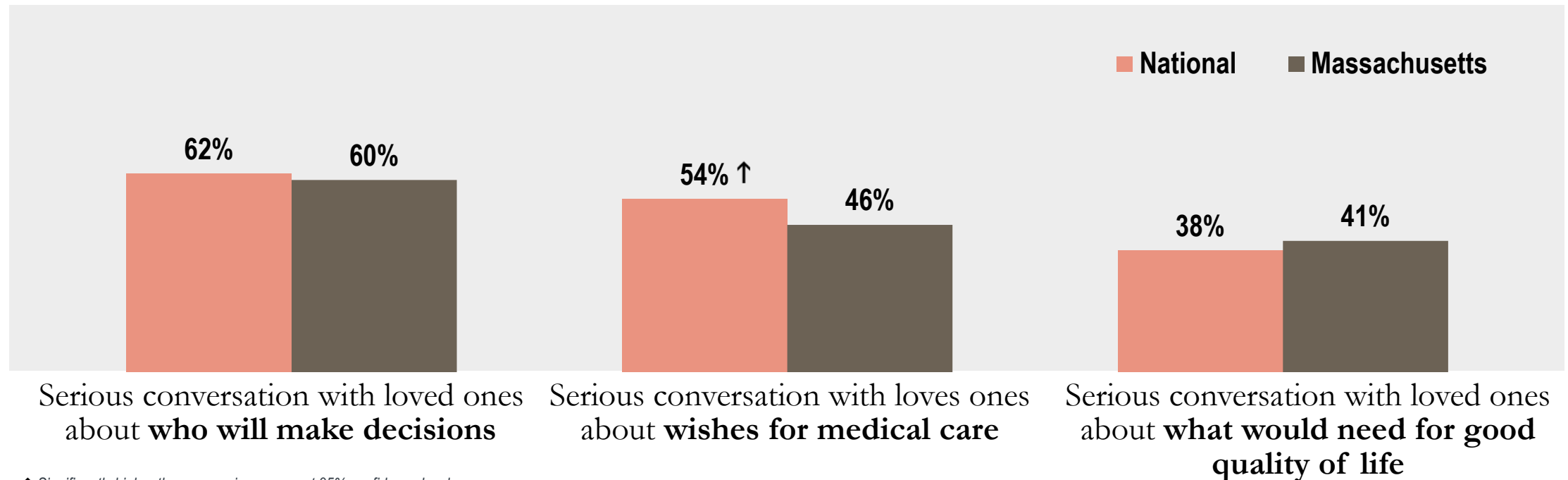
Base: Has not had conversation with health care provider about wishes

Q: 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 medical care if you become seriously ill.

Base: Does not want to talk to health care provider about wishes



Massachusetts was consistent with national rates for talking with loved ones about who would make medical decisions, and what they would need for a good quality of life in the face of serious illness. Participants were less likely to have talked to loved ones about their wishes for medical care.



↑ Significantly higher than comparison group at 95% confidence level.

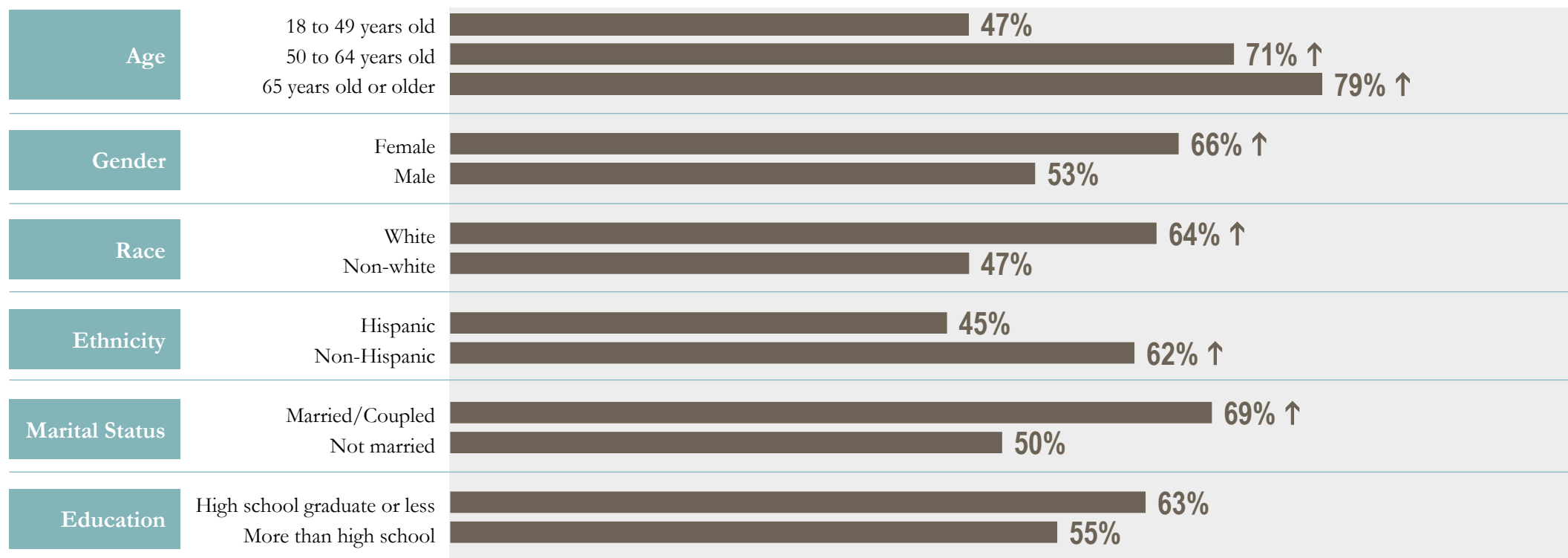
Q: Have you ever had a serious conversation with a spouse, parent, child, or any other loved one about who will make decisions about your medical care if you can no longer make them on your own, or have you not had such a conversation?

Q: Have you ever had a serious conversation with a spouse, parent, child, or any other loved one about your wishes for your medical care if you become seriously ill such as the types of treatments you do or don't want to receive, or have you not had such a conversation? *National*

Q: Have you ever had a serious conversation with a spouse, parent, child, or any other loved one about what you would need to have a good quality of life if you become seriously ill, or have you not had such a conversation? *National*



## Older, female, White, non-Hispanic, and married participants were significantly more likely to have had a conversation with loved ones about who would make decisions if they were no longer able to make them on their own.



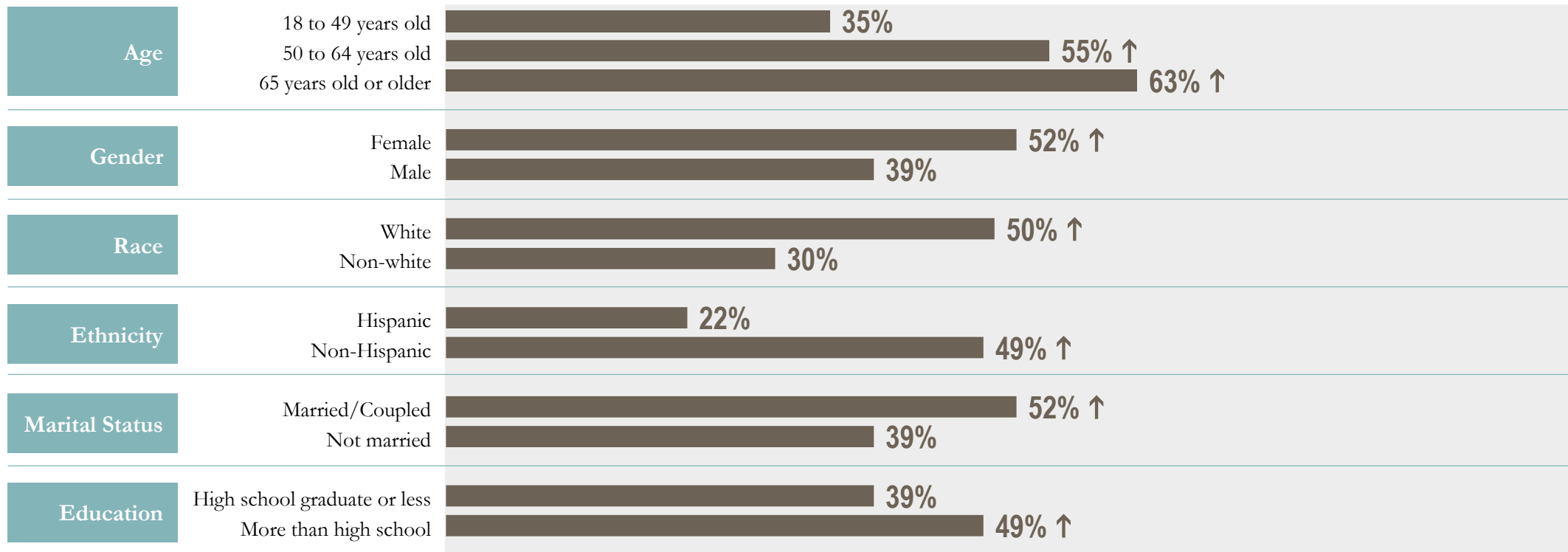
↑ Significantly higher than comparison group at 95% confidence level.

Q: Have you ever had a serious conversation with a spouse, parent, child, or any other loved one about who will make decisions about your medical care if you can no longer make them on your own, or have you not had such a conversation?





**Older, female, white, non-Hispanic, and married participants as well as those with more education were significantly more likely to have had a conversation with loved ones about wishes for medical care if they became seriously ill.**

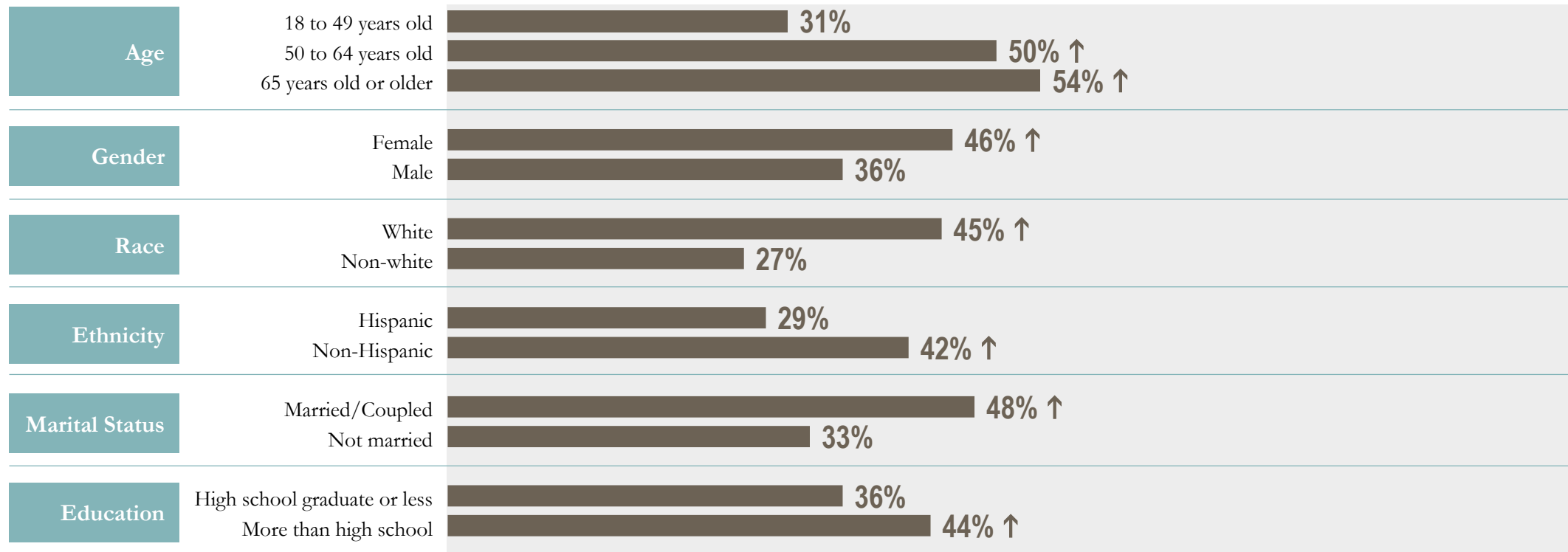


↑ Significantly higher than comparison group at 95% confidence level.

Q: Have you ever had a serious conversation with a spouse, parent, child, or any other loved one about your wishes for your medical care if you become seriously ill such as the types of treatments you do or don't want to receive, or have you not had such a conversation?



**Older, female, white, non-Hispanic, and married participants as well as those with more education were significantly more likely to have had a conversation with loved ones about what they would need for a good quality of life.**

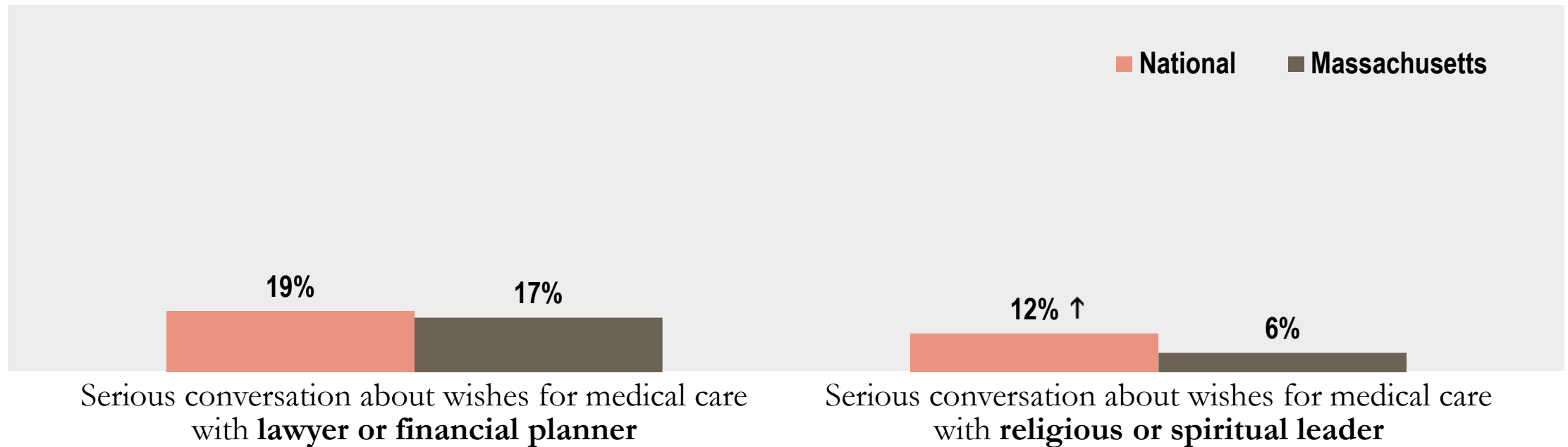


↑ Significantly higher than comparison group at 95% confidence level.

Q: Have you ever had a serious conversation with a spouse, parent, child, or any other loved one about what you would need to have a good quality of life if you become seriously ill, or have you not had such a conversation?



Consistent with national rates, less than 20% of participants talked about their wishes for care with a lawyer or financial planner. Less than 10% talked with religious or spiritual leaders, which was significantly lower than national rates.



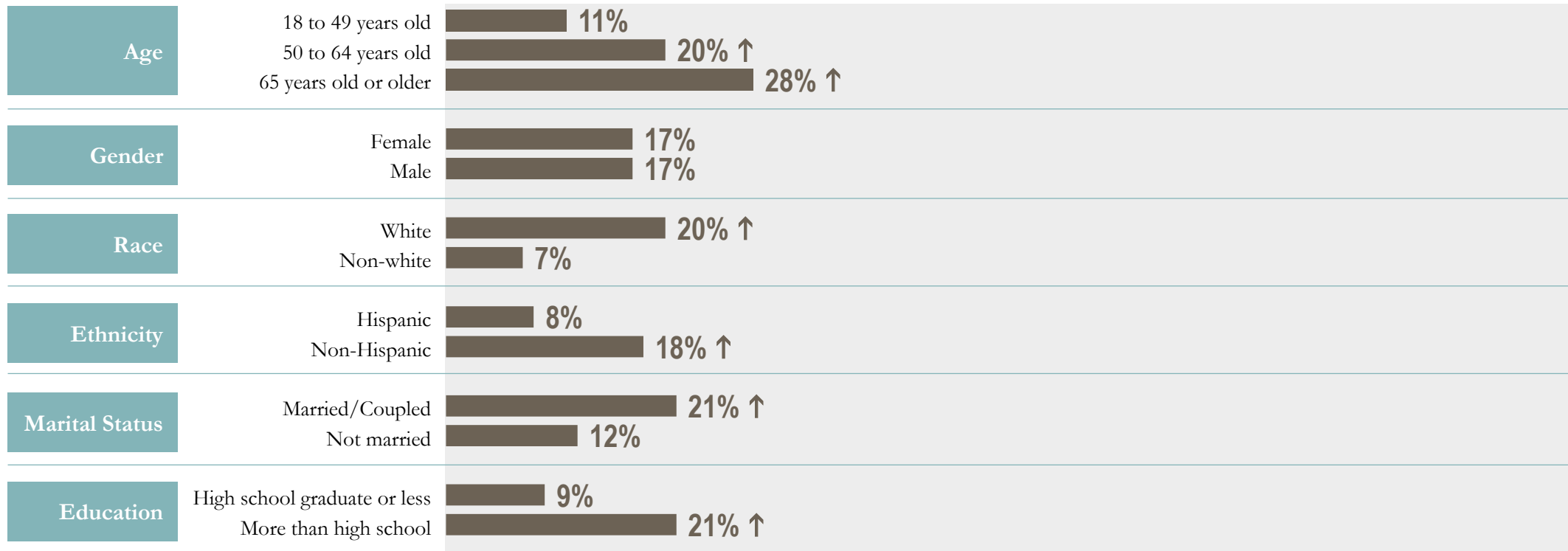
↑ Significantly higher than comparison group at 95% confidence level.

Q: Have you ever had a serious conversation with a lawyer or financial planner about your wishes for your medical care if you become seriously ill, or have you not had such a conversation?

Q: Have you ever had a serious conversation with a religious or spiritual leader about your wishes for your medical care if you become seriously ill, or have you not had such a conversation?



**Older, white, non-Hispanic, and married participants as well as those with more education were significantly more likely to have had a conversation with a lawyer or financial planner about wishes for medical care if they became seriously ill.**

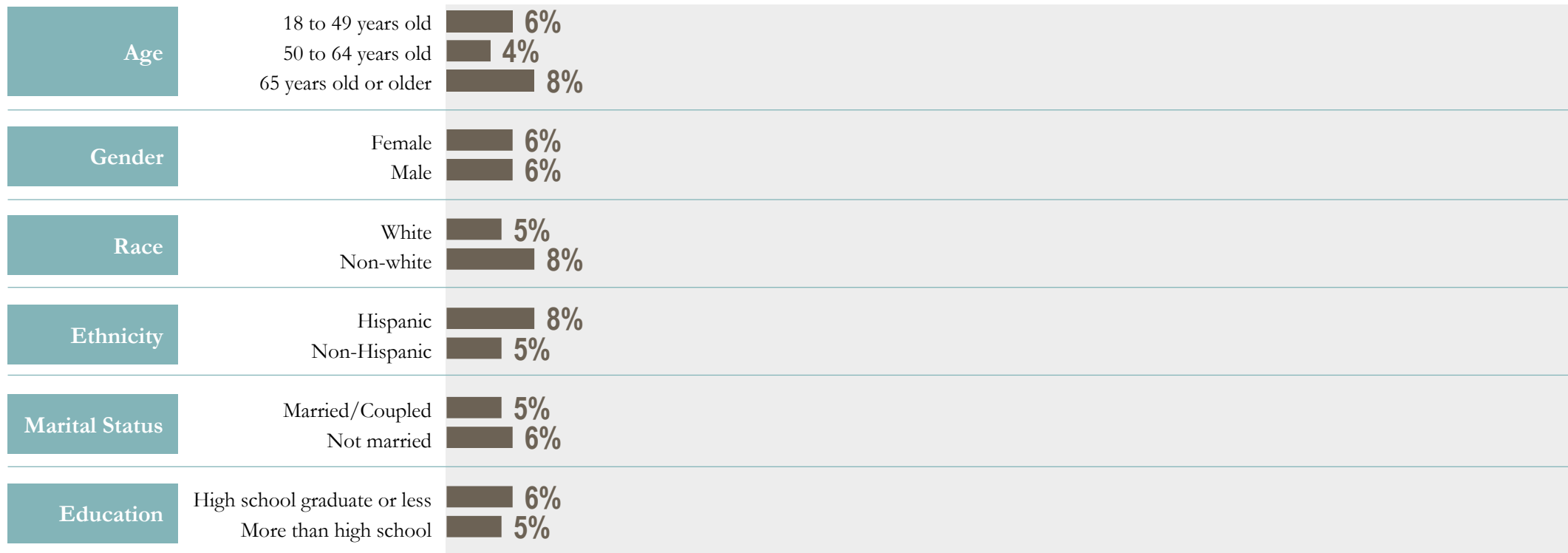


↑ Significantly higher than comparison group at 95% confidence level.

Q: Have you ever had a serious conversation with a lawyer or financial planner about your wishes for your medical care if you become seriously ill, or have you not had such a conversation?



## No participant characteristics were significantly associated with having had a conversation with a religious or spiritual leader about wishes for medical care if they became seriously ill.

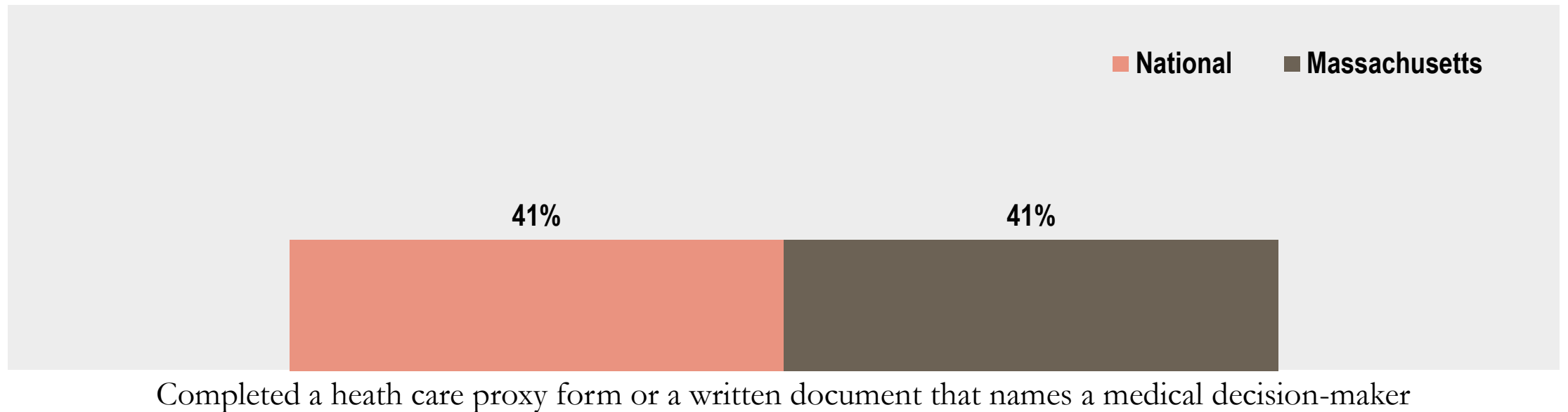


Q: Have you ever had a serious conversation with a religious or spiritual leader about your wishes for your medical care if you become seriously ill, or have you not had such a conversation?



## Consistent with national rates, about 4 in 10 participants had completed a health care proxy form.

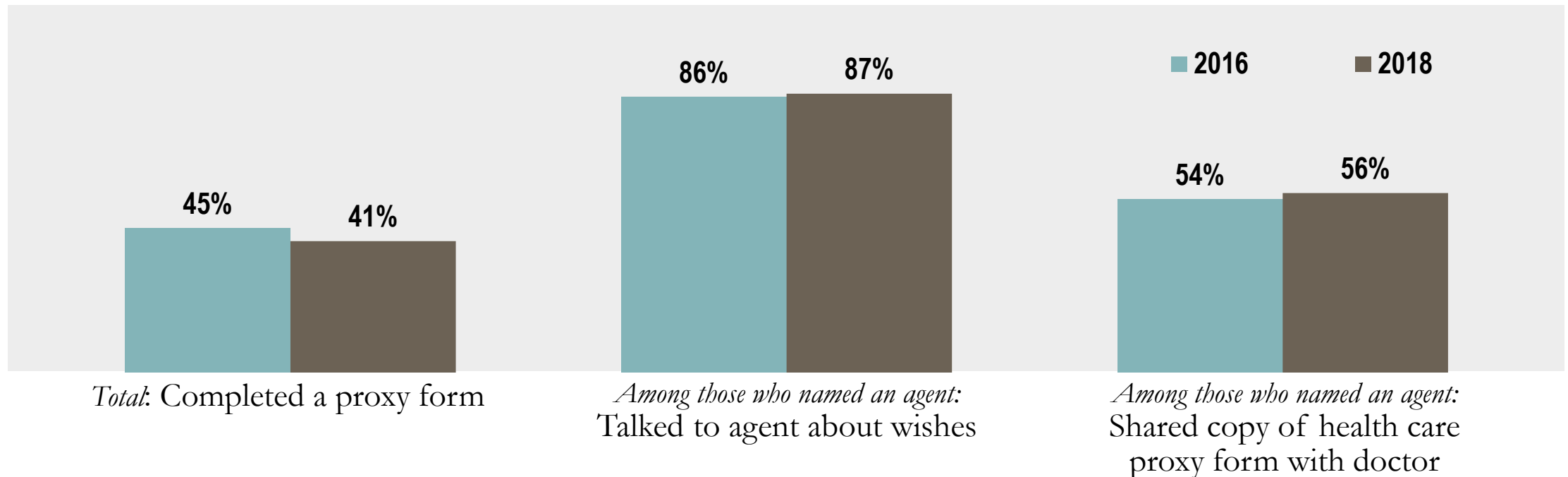
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Q: *Massachusetts:* A health care proxy is a legal form where you choose a person, called a health care agent, to make medical decisions for you if you are unable to make them for yourself. This form is completed and signed by you and witnessed by two people. Have you ever completed a form that names someone as your health care agent, or not?  
*National:* Do you have a written document that names who you want to make decisions about your medical care if you can no longer make them on your own?



There was no change in the percentage of participants completing a proxy form. Among those who had, there was no change in the number who talked to their agent or who shared their form with their doctor.



Q: 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.

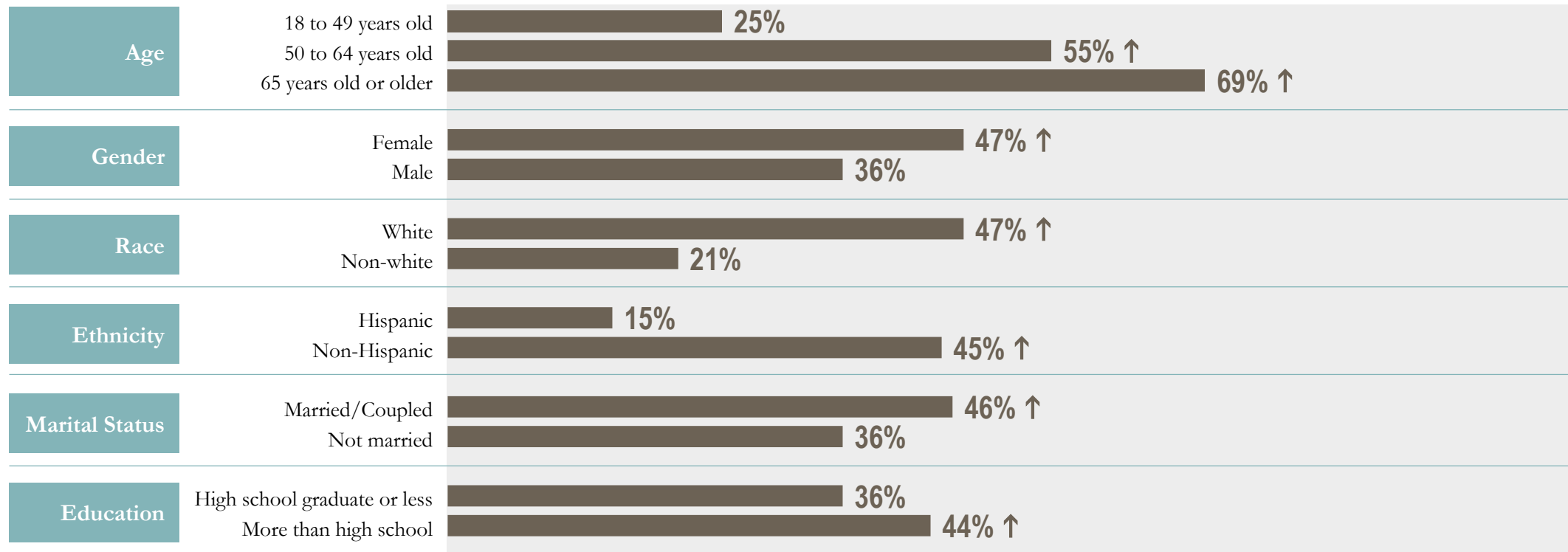
This form is completed and signed by you and witnessed by two people. Have you ever completed a form that names someone as our health care agent, or not?

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

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



## Older, female, white, non-Hispanic, and married participants as well as those with more education were significantly more likely to have completed a health care proxy form.



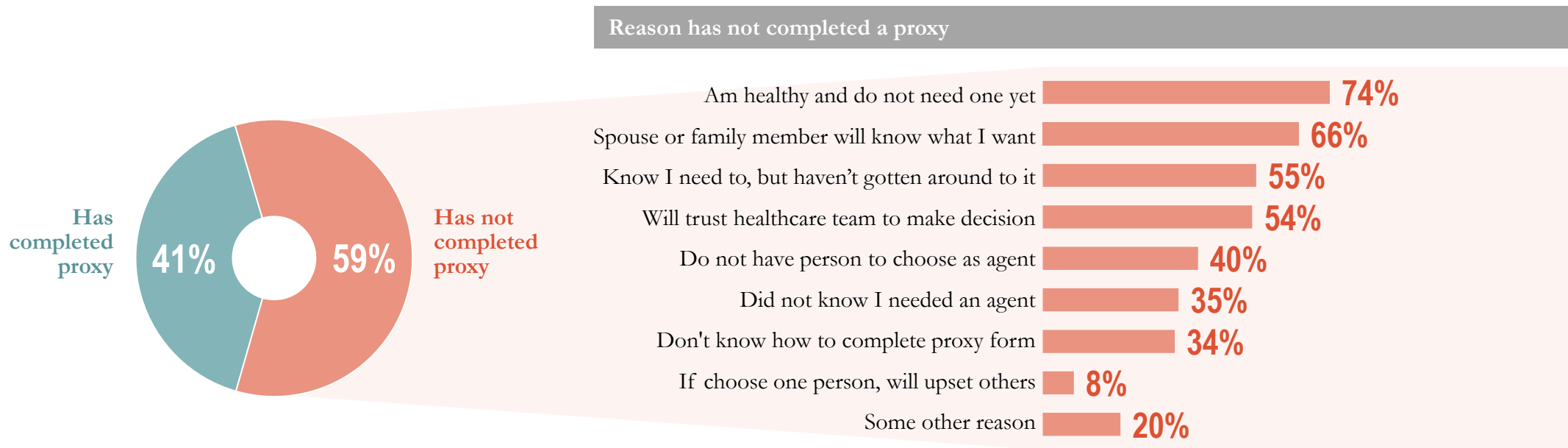
↑ Significantly higher than comparison group at 95% confidence level.

Q: 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?





Of the participants who had not completed a proxy form, most felt it was not needed because they were healthy or their loved one would know what they wanted.



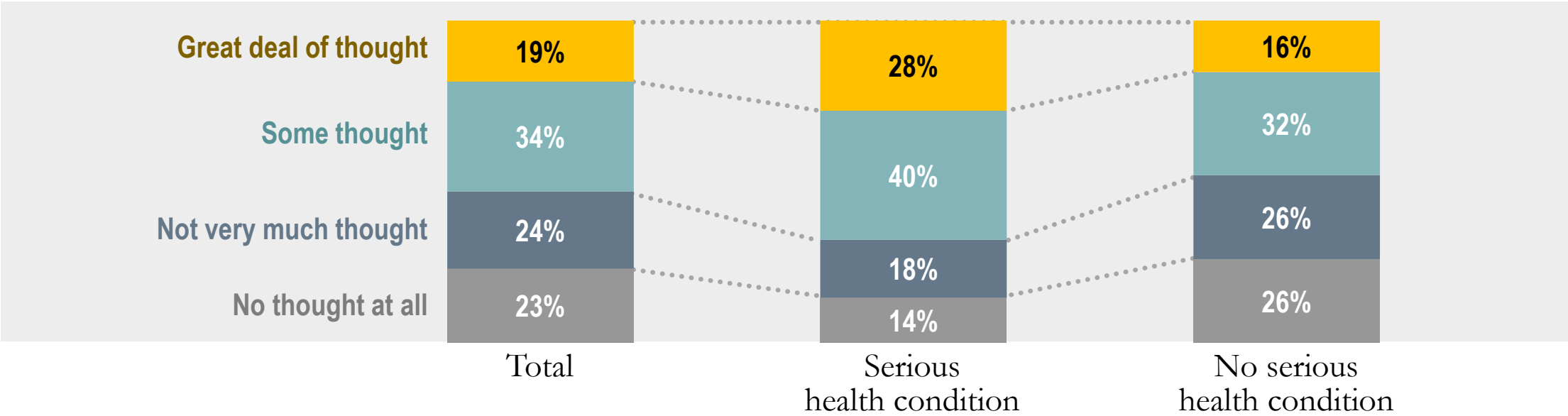
Q: A health care proxy is a legal form where you choose a person, called a health care agent, to make medical decisions for you if you are unable to make them for yourself.

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?

Q: 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*



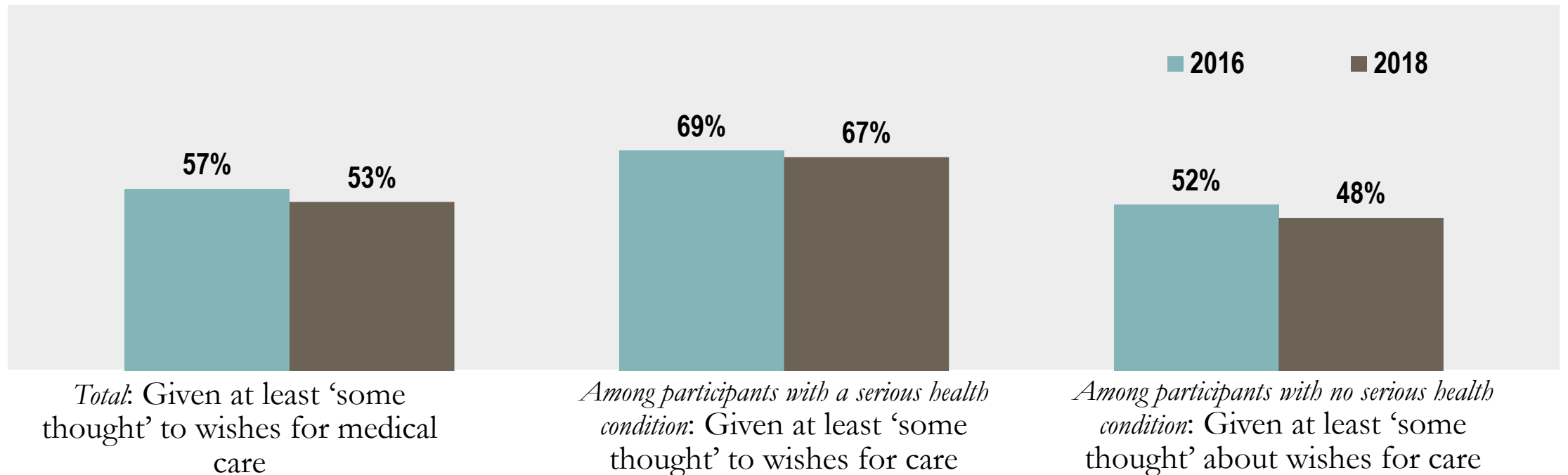
Just over half of participants had given at least some thought to their wishes for medical treatment if they were facing an illness or condition that made it hard to function in day-to-day activities.



Q: 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?



There was no change in the percentage of participants who had given at least some thought to their wishes for medical care in the face of serious illness.

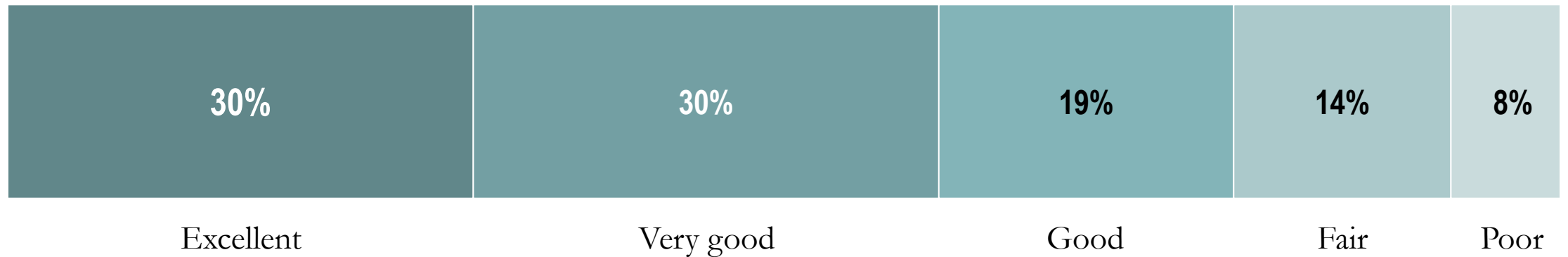


Q: Before today, how much had you thought about your own wishes for medical treatment if you were facing an illness or condition that made it hard for you to function in your day-to-day activities?



Overall, 19% of participants reported the death of a loved one in Massachusetts in the past 12 months. Among participants who had a loved one die in the past 12 months, 60% rated the care that their loved one received at the end of life as excellent or very good.

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Q: Overall, how would you rate the care your loved one received at the end of their life? *Base: Death of a loved one and death not sudden*



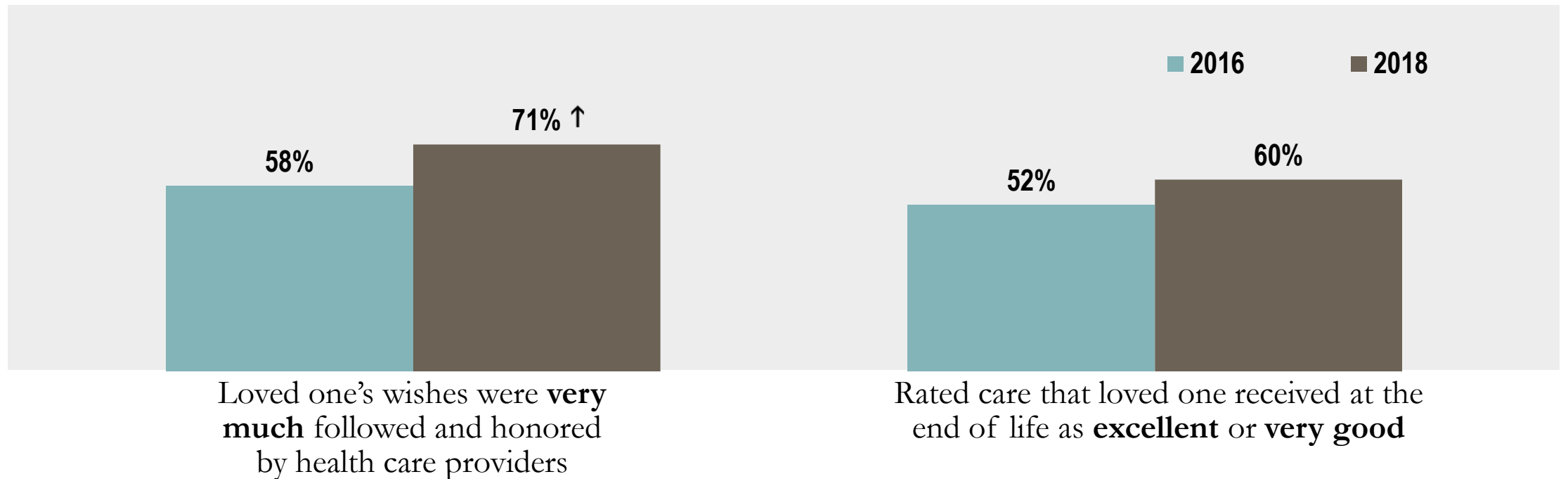
Among all participants who had a loved one die in the past 12 months, 70% reported that their loved one's wishes were very much followed and honored by health care providers at the end of life.



Q: 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 and death not sudden



There was a significant increase in the percentage of participants who said their loved one's wishes were honored at the end of life. Participants' assessment of care quality also improved, but not significantly.



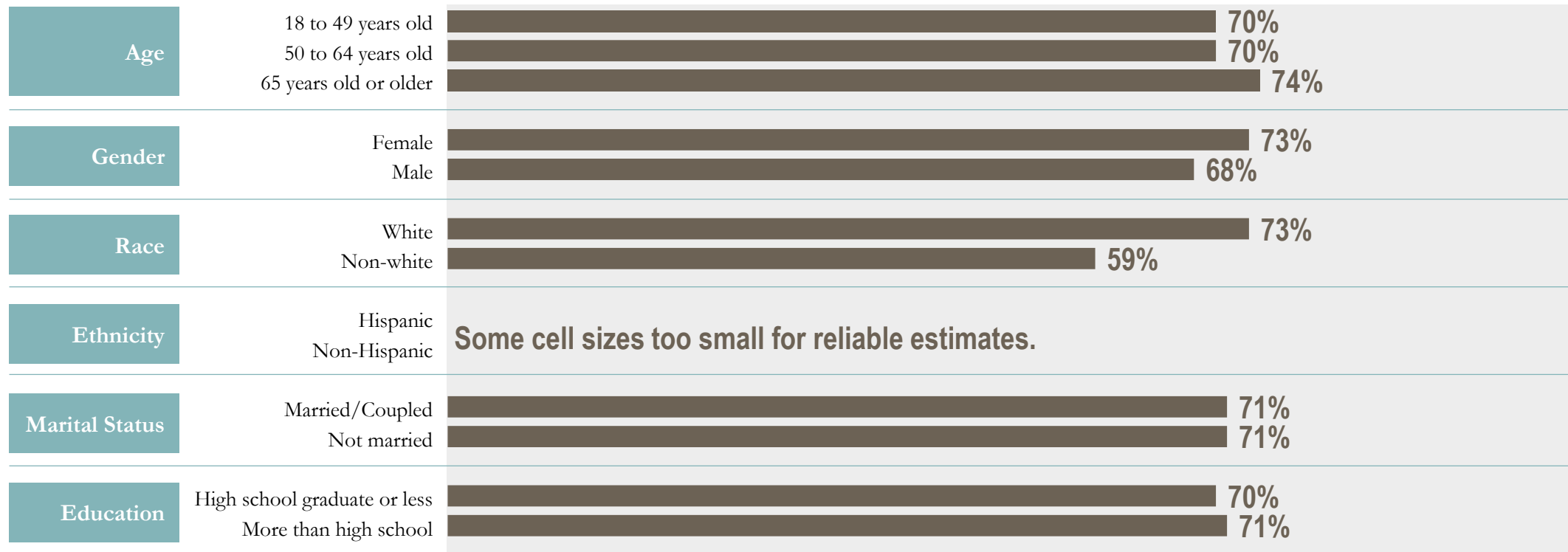
↑ Significantly higher than comparison group at 95% confidence level.

Q: 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

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



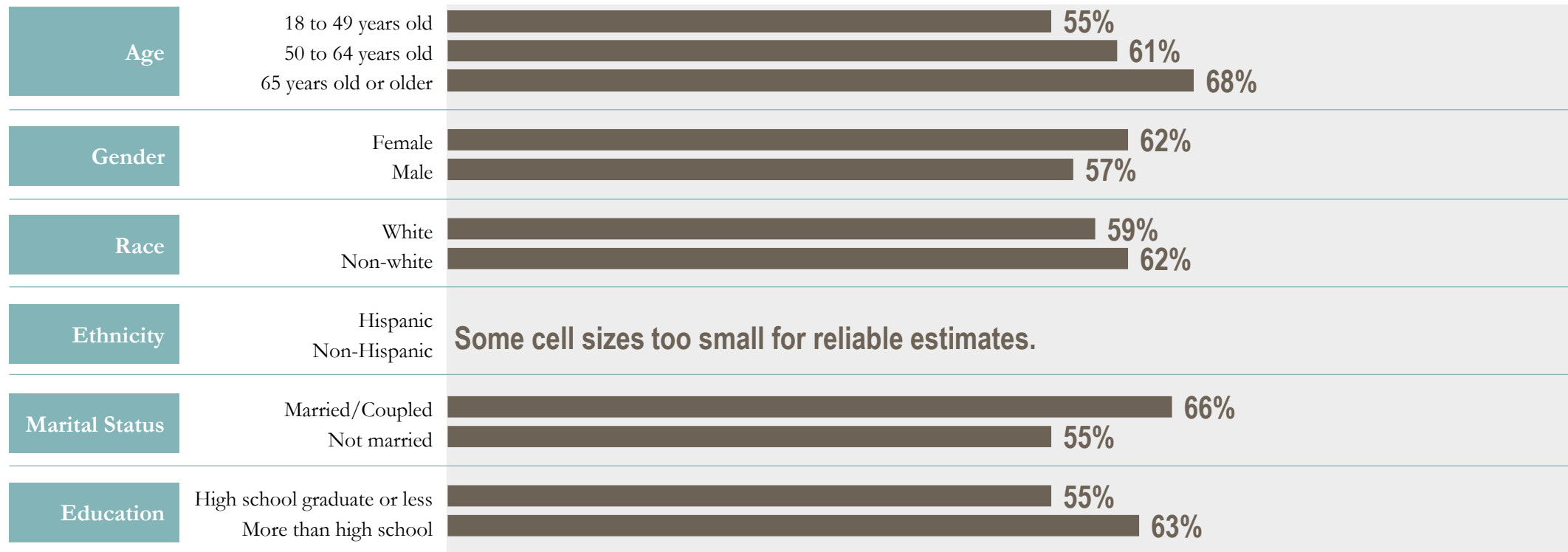
## Reports that a loved one's wishes were very much honored by health care providers at the end of life did not differ significantly by any participant characteristics.



Q: 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 past year and involved in loved one's care



## Ratings of excellent or very good care received by a loved one at the end of life did not differ significantly by any participant characteristics.



Q: Overall, how would you rate the care your loved one received at the end of their life? Base: Death of a loved one in past year and involved in loved one's care





## About half of participants said that their loved ones had talked very much about their wishes for care with both providers and family .



Q: To what extent did a healthcare team talk to your loved one about his or her wishes for care near the end of life? Base: Death of a loved one in past year and involved in loved one's care

Q: To what extent did you or family members or friends talk to your loved one about his or her wishes for care near the end of life? Base: Death of a loved one in past year and involved in loved one's care

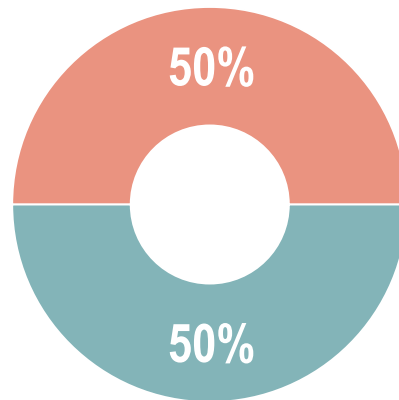
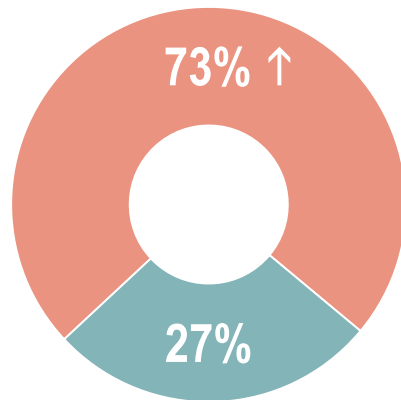


# Those who reported more conversations about their loved one's wishes were more likely to say that their loved one's care was very good or excellent.

**Extent to which healthcare team talked to loved one about wishes**

Very much

Not at all,  
a little, somewhat



Care rating:

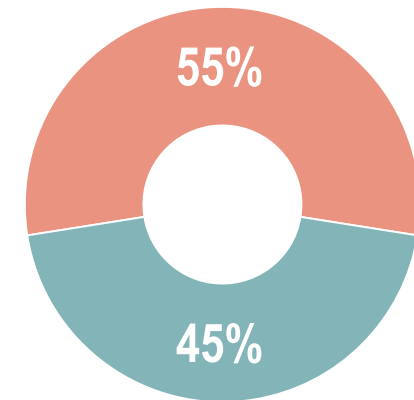
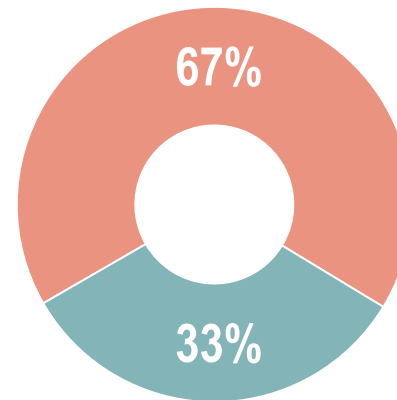
Excellent/  
Very Good

Good/  
Fair/Poor

**Extent to which respondent, family member, or friend talked to loved one about wishes**

Very much

Not at all,  
a little, somewhat



↑ Significantly higher than comparison group at 95% confidence level.

Q: Overall, how would you rate the care your loved one received at the end of their life? Base: Death of a loved one in past years (n=283)

Q: To what extent did a healthcare team talk to your loved one about his or her wishes for care near the end of life? Base: Death of a loved one in year and involved in loved one's care

Q: To what extent did you or family members or friends talk to your loved one about his or her wishes for care near the end of life? Base: Death of a loved one in past year and involved in loved one's care

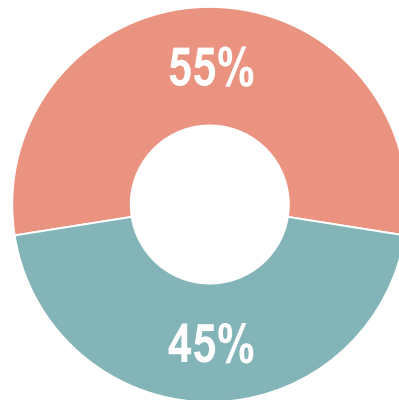
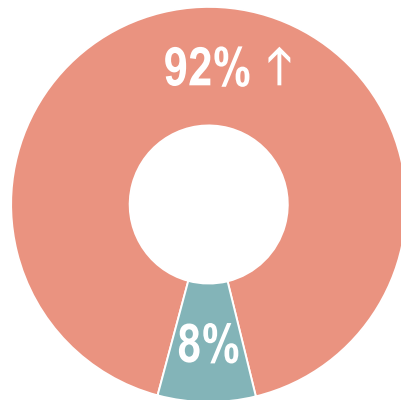


# Those who reported more conversations about their loved one's wishes were more likely to report that their loved one's wishes were very much honored.

**Extent to which healthcare team talked to loved one about wishes**

Very much

Not at all,  
a little, somewhat



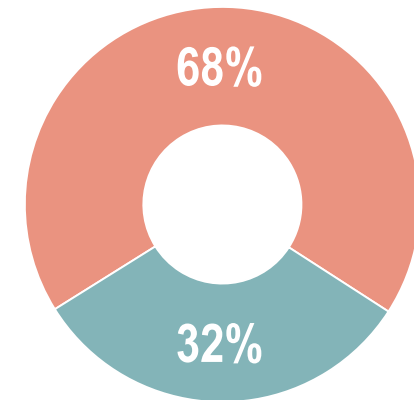
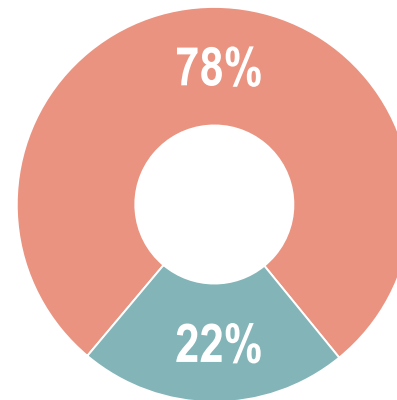
Care rating:

- Wishes very much honored
- Wishes not at all, a little bit, somewhat honored

**Extent to which respondent, family member, or friend talked to loved one about wishes**

Very much

Not at all,  
a little, somewhat



↑ Significantly higher than comparison group at 95% confidence level.

Q: 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 past year

Q: To what extent did a healthcare team talk to your loved one about his or her wishes for care near the end of life? Base: Death of a loved one in past year and involved in loved one's care

Q: To what extent did you or family members or friends talk to your loved one about his or her wishes for care near the end of life? Base: Death of a loved one in past year and involved in loved one's care





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