

Views and Experiences of Aging & End-of-Life Care in the US

Conducted September 2022

Conducted by:



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01

Research Study Objectives & Methodology



Research Study Objectives

Overall Objective:

Investigate American views on the US healthcare system, aging, and end-of-life care.

Specific Objectives:

- Understand current perspectives on managed care and its role in the aging process.
- Assess current figures as they compare to [Kaiser Family Foundation's 2017 study](#).
- Gauge trust in the US healthcare system.
- Explore attitudes around aging and the final years of life.
- Gauge preparedness for end-of-life scenarios and care.
- Measure awareness and opinion of hospice care.

Methodology

- An 18-minute online survey distributed to US residents aged 35 and older
- Survey included questions from the [2017 Kaiser Family Foundation Four Country Survey on Aging and End-of-Life Medical Care](#).
- N = 2,009 responses were recorded and analyzed
- Respondents:
 - Census balanced for gender: Female (~50%); Male (~50%)
 - Census balanced for race/ethnicity: White (~60%); Hispanic/Latino (~17%); Black or African American (~16%); Asian (~6%); American Indian/Native American or Alaska Native (~1%)
 - Census balanced for US regions: Northeast (~17%); Midwest (~21%); West (~24%); South (~38%)
- Survey fielded between September 6 and September 16, 2022.

02

Executive Summary & Key Insights



Danil Kirichkov/istockphoto.com/150201



Understanding American attitudes about illness, death, and the healthcare system writ large is of critical importance for developing programs, policies, and services to support the country's aging population. In 2017, the Kaiser Family Foundation and *The Economist* conducted a large-scale, international survey to explore the different facets of how individuals view and experience healthcare in the context of serious illness and the end of life. While a critically important study of its kind at the time, culture and attitudes in the United States have shifted significantly after the global healthcare upheaval of COVID-19.

Views and Experiences with End-of-Life Medical Care in the U.S.

The
Economist

A better way to care for the dying

How the medical profession is starting to move beyond fighting death to easing it

What people want at the end of life

What people most want in their final months

Our survey of what matters most at life's end

In September 2022, NPHI launched a national survey building on the original Kaiser study to get updated insights into how attitudes have and haven't changed. The results in this report offer a detailed portrait of some of the major themes that the US healthcare system must contend with as the population continues to age.

- **Uncertainty:** There is a general lack of clarity around personal plans, care options, and the system's ability to provide care to the aging population.
- **Openness:** Most Americans avoid planning, discussing, and even thinking about their personal wishes related to healthcare later in life, yet they agree that such conversations are important.
- **Trust:** Overall, Americans have little trust in the US healthcare system to provide quality, respectful care at both the individual and systemic level.

The healthcare system—particularly in the serious illness and end-of-life space—is under immense strain. Workforce shortages, high costs, and a growing population of elderly Americans demand a large-scale, strategic transformation of how healthcare supports individuals and families as they age. It is absolutely essential that such a transformation is rooted in the needs and preferences of the population. This report provides valuable insight into the experiences and perceptions of a representative cross-section of Americans.

The majority are concerned with United States' preparedness for the age wave

While overall ratings for the US health system are positive (67%), when it comes to providing care for the aging only 29% say the healthcare system does better than “fair.” Respondents see the aging US population as a problem that our families, institutions, and country are underprepared to deal with.

72%

Don't believe we do a good job caring for the aging.

76%

Believe the aging population is a problem.

14%

Believe the US is prepared to deal with an aging population.

Most Americans have taken few steps to bring their affairs in order

Only a third have their medical wishes written down and less than a fifth have had a conversation with a doctor or healthcare provider about their wishes for end-of-life care. Only 53% of Silent Generation respondents and 38% of Boomers have their wishes written down. Only 25% of Silent Generation respondents and 14% of Boomers have ever had a conversation about end-of-life wishes with a health care provider.



66%

Do not have their wishes for end-of-life medical treatment in a written document.



81%

Have never had a conversation with a healthcare provider about their wishes for end-of-life care.

Americans say they're comfortable talking about death, and would like guidance from doctors

While 74% of respondents say that death is a subject most people avoid, the vast majority also say they are either as comfortable or more comfortable talking about it than their peers. This suggests a disconnect between the perceived stigma around the topic and individual attitudes about it.

89%

Are equally or more comfortable talking about death than average

75%

Say Medicare should cover end-of-life discussions

67%

Are most comfortable discussing their wishes with a doctor

Americans don't trust the healthcare system to prioritize patient well-being over profits

Those born before 1946, report relatively higher trust for the US healthcare system as a whole than younger generations. Respondents without any kind of health insurance report the lowest levels of trust (only 16%) and nearly a third (29%) say they “completely distrust” it. For uninsured respondents who avoid managed care, trust is as strong or stronger a driver of avoidance than logistical reasons like payment or transportation (46%).

31%

Trust the US healthcare system as a whole

18%

Trust the US healthcare system to put people's well-being ahead of profits

Hospice care is well-regarded, especially by those who are most familiar

Almost all (96%) respondents have at least heard the term “hospice care.” Familiarity is a very strong driver of opinion: Those who are most familiar were about six times more likely to give the highest rating than those who don’t know much about it. For those with in-home hospice care experience, care from physicians and nurses and durable medical equipment were rated most important.



77%

Know a little or a lot about hospice



6X

Higher approval of hospice for those with most familiarity

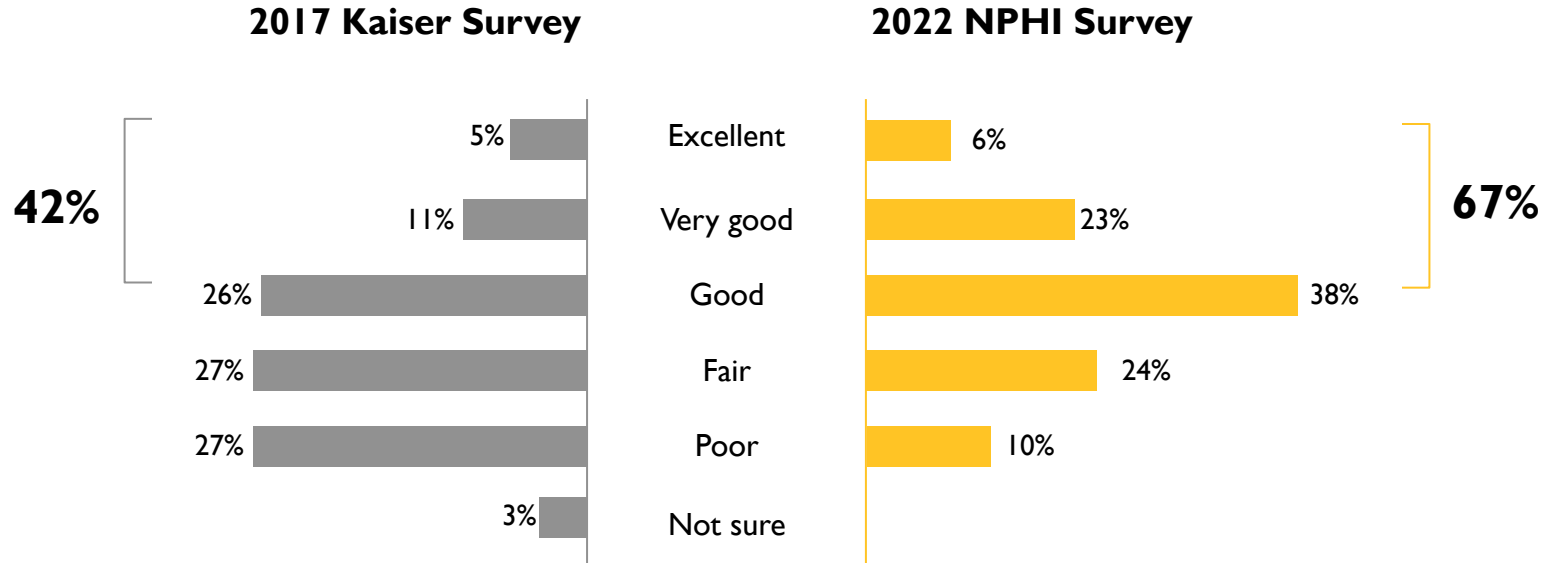
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Detailed Findings: Aging Population and US Preparedness



The US Healthcare System

Respondents gave significantly higher ratings for the US healthcare system than was reported in the 2017 Kaiser survey.



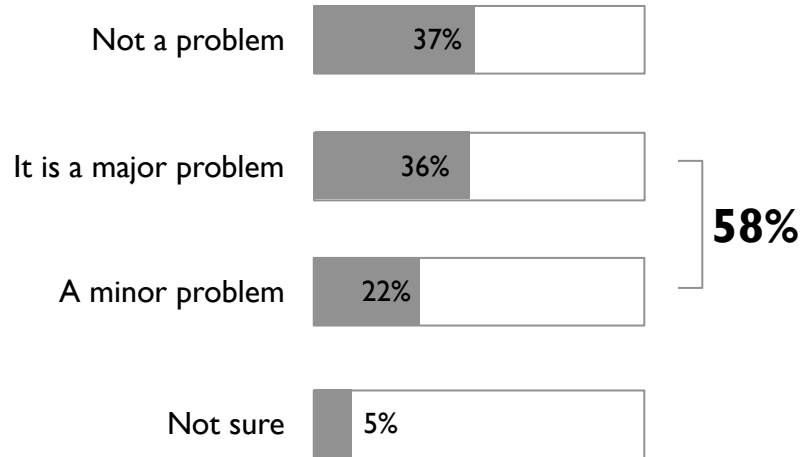
Q6. How would you rate the healthcare system in the US today?

2022 N = 2,009
Kaiser 2017 Survey N = 1,006

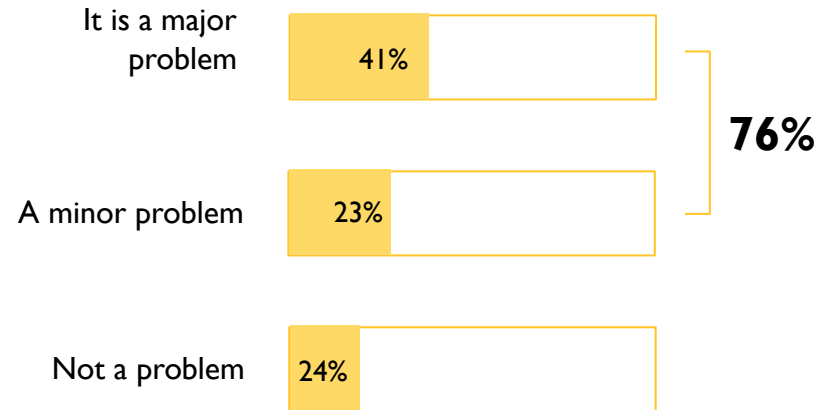
Respondents increasingly see the coming Age Wave in the US as a major problem

76% say the growing number of older people in the US is a problem, up from 58% in the 2017 Kaiser study.

2017 Kaiser Survey



2022 NPHI Survey



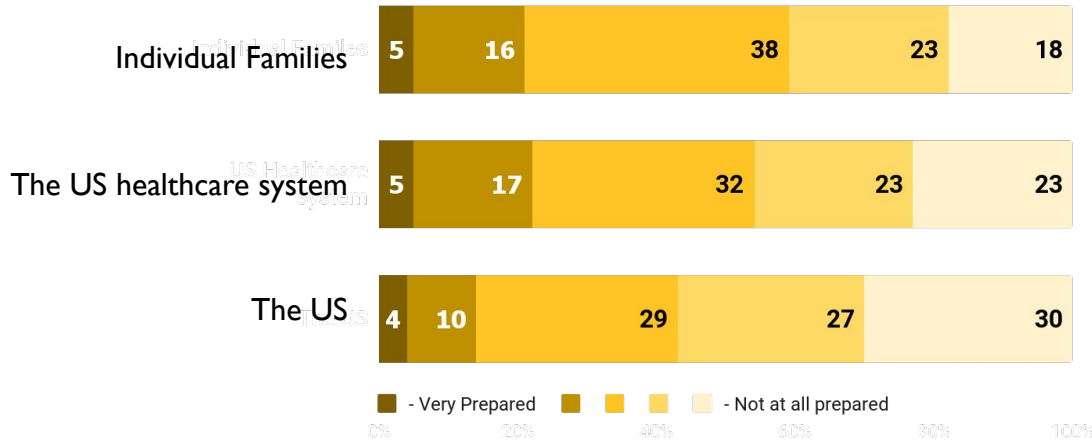
Q7. As you may know, the number of older adults in the US is expected to increase over the next several decades. How much of a problem, if at all, is the growing number of older people in the US?

2022 N = 2,009
Kaiser 2017 Survey N = 1,006

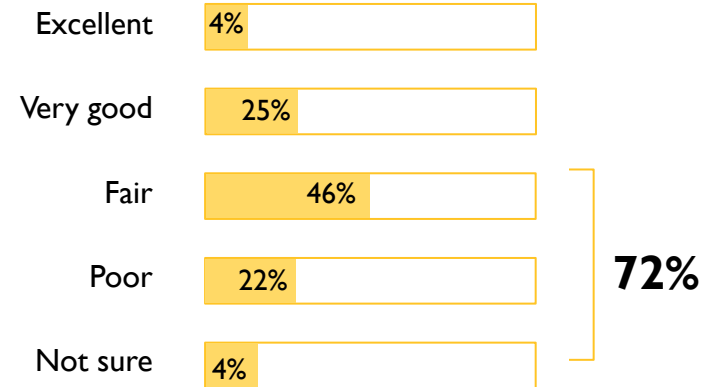
Preparedness for the Age Wave is low

72% of respondents rate the US healthcare system as “fair,” “poor,” or “not sure” when it comes to providing care for the aging.

How prepared are the following to deal with the aging population?



Quality of US health system care for the aging:

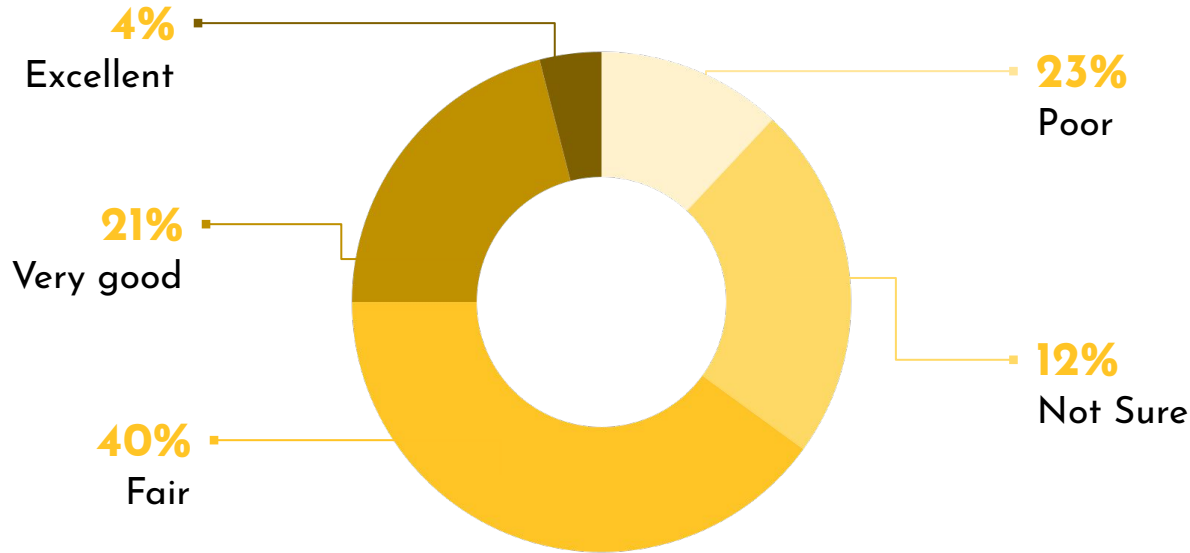


Q8. How prepared do you think the country is to deal with the aging population? (“Don’t knows” not included.)

Q9. How would you rate the US healthcare system when it comes to providing care for the aging?

N = 1,845-1,871

Respondents are divided on how well the US Healthcare system provides end-of-life care — more than 1 in 10 aren't sure



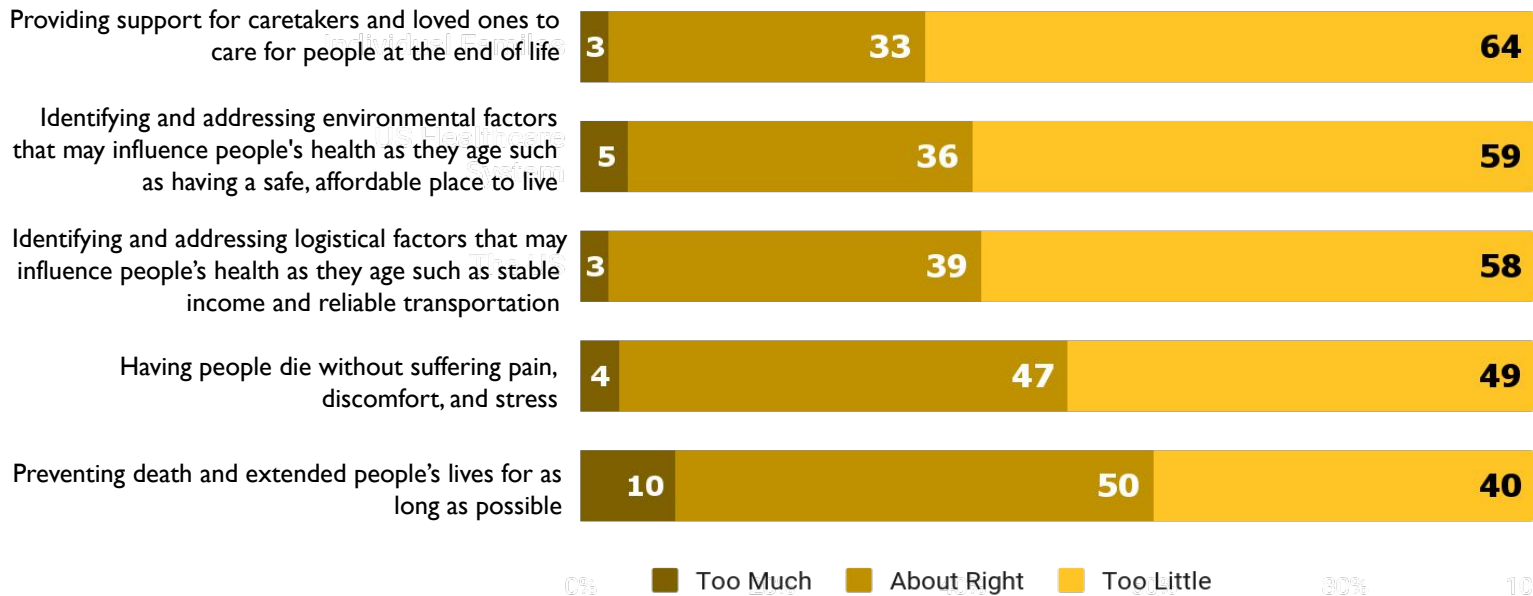
Uninsured respondents are more likely to give a poor rating (36%)

Q10. How would you rate the US healthcare system when it comes to providing end-of-life care? (By end-of-life care, we are referring not only to the health care services that patients receive in the final hours or days of their lives, but also healthcare for people with terminal illnesses that have become advanced, progressive, and incurable.)

N = 2,009

Improving care for the aging: more emphasis on support, comfort, and social determinants of health

Respondents are more likely to think there should be greater emphasis on caretaker support, logistics, and palliative measures, than on prolonging life.



Q11. Do you think the healthcare system in the US places too little, too much, or about the right amount of emphasis on the following?

N = 2,009

US Healthcare System — ratings by age

Younger respondents are more likely to rate the system poorly

	Silent n = 148	Boomer n = 930	Gen X n = 737	Millennial n = 194
Excellent	11%	4%	5%	9%
Very good	38%	27%	18%	15%
Good	32%	41%	37%	31%
Fair	16%	21%	28%	25%
Poor	3%	7%	12%	19%

**Significantly higher/lower, 95% confidence*

Older respondents (Silent Generation and Boomers) are more likely to rate the US healthcare system as “very good” at caring for the aging

	Silent n = 148	Boomer n = 930	Gen X n = 737	Millennial n = 194
Excellent	6%	3%	3%	6%
Very good	39%	31%	19%	16%
Fair	45%	48%	50%	46%
Poor	10%	18%	28%	31%

*Significantly higher/lower, 95% confidence

Q9. How would you rate the US healthcare system when it comes to providing care for the aging? *Not sure responses removed.*

Older respondents are more likely to give higher ratings to the US healthcare system's end-of-life care

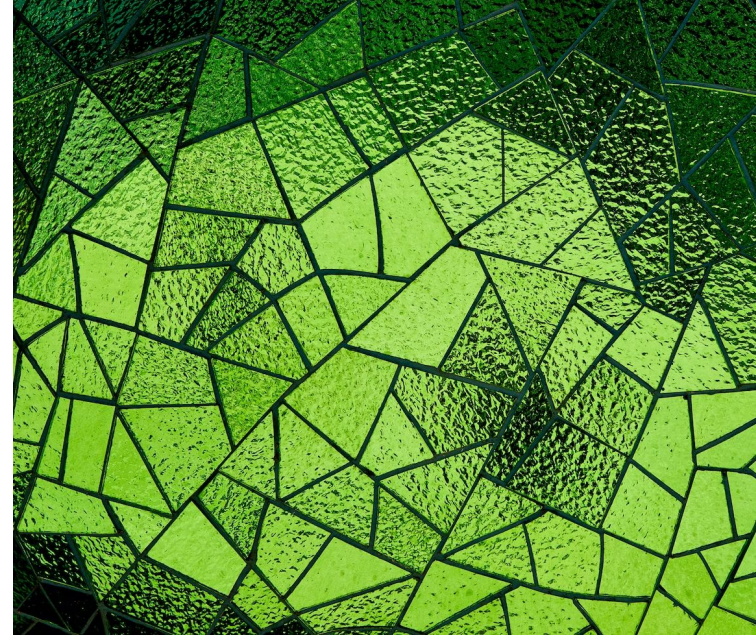
	Silent n = 148	Boomer n = 930	Gen X n = 737	Millennial n = 194
Excellent	5%	5%	5%	6%
Very good	32%	27%	19%	18%
Fair	40%	45%	47%	47%
Poor	23%	24%	29%	28%

*Significantly higher/lower, 95% confidence

Q10. How would you rate the US healthcare system when it comes to providing end-of-life care? (By end-of-life care, we are referring not only to the healthcare services that patients receive in the final hours or days of their lives, but also healthcare for people with terminal illnesses that have become advanced, progressive, and incurable.) *Not sure responses removed.*

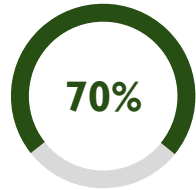
04

Trust in the US Healthcare System

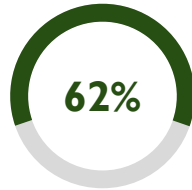


How much do you trust the following?

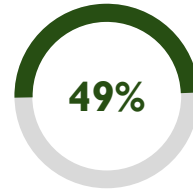
Respondents trust nurses and doctors the most.



Nurses



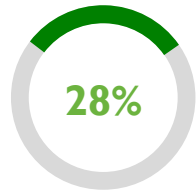
Doctors



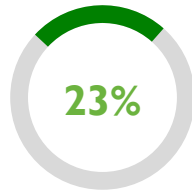
Hospitals



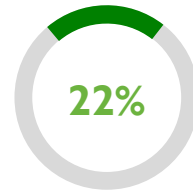
The US Healthcare System



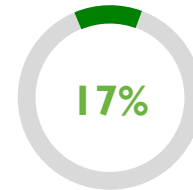
**Reduced fee/
Free clinics**



**Health insurance
companies**



**Pharmaceutical
companies**



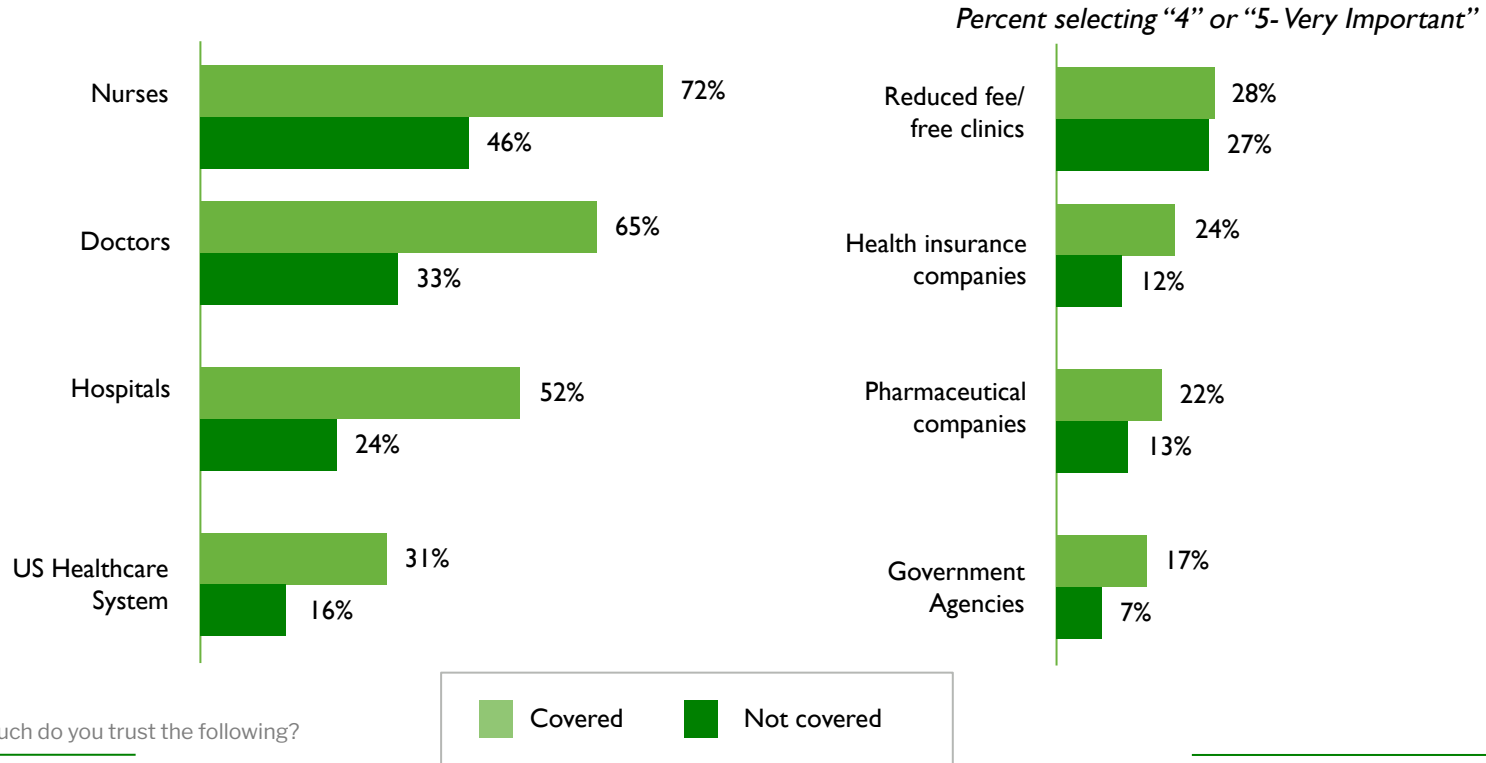
**Government
Agencies**

Q12. How much do you trust the following?

N = 2,009

Comparison: trust among insured vs. uninsured

While all respondents trust nurses and doctors the most, trust is lower overall among respondents without health insurance



Q12. How much do you trust the following?

Trust in nurses, doctors, and hospitals is higher among the oldest respondents

	Silent n = 148	Boomer n = 930	Gen X n = 737	Millennial n = 194
Nurses	85%	76%	63%	59%
Doctors	82%	70%	53%	46%
Hospitals	78%	55%	39%	40%
The US Healthcare System as a whole	49%	35%	22%	26%
Health Insurance companies	37%	27%	17%	18%
Pharmaceutical companies	34%	24%	18%	18%
Reduced fee/Free clinics	29%	27%	27%	32%
Government Agencies	20%	16%	16%	21%

**Significantly higher/lower, 95% confidence*

Q12. How much do you trust the following?

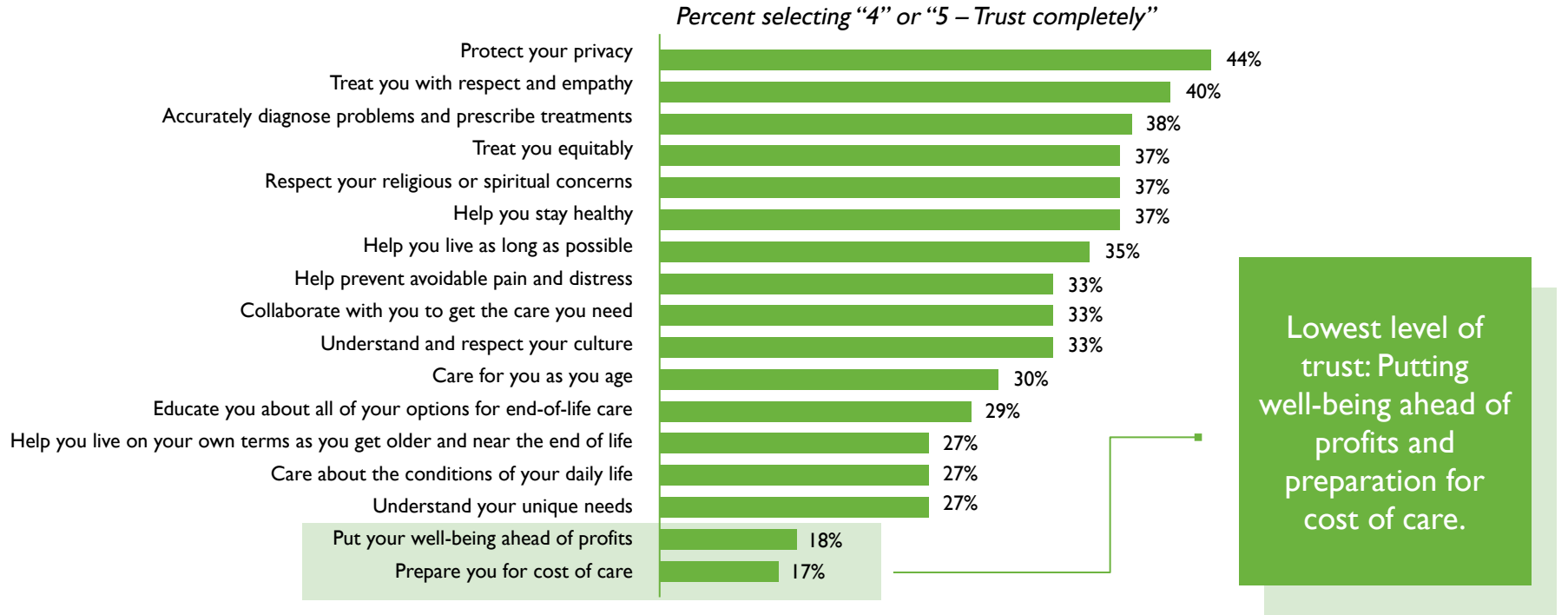
White respondents report higher trust in healthcare

	Black n = 270	Hispanic n = 334	White n = 1,219	Asian/Other n = 186
Nurses	67%	66%	73%	65%
Doctors	58%	57%	66%	55%
Hospitals	46%	46%	53%	41%
Reduced fee/Free clinics	33%	27%	27%	25%
The US Healthcare System as a whole	31%	25%	32%	29%
Health Insurance companies	25%	19%	24%	19%
Pharmaceutical companies	22%	21%	23%	18%
Government Agencies	22%	16%	15%	20%

**Significantly higher/lower, 95% confidence*

Q12. How much do you trust the following?

How much do you trust the US Healthcare System to...?



Q13. How much do you trust the US Healthcare System to...

N = 2,009

Uninsured respondents have minimal trust in healthcare



Don't trust the healthcare system to:

- put their well-being ahead of profits
- prepare them for cost of care
- care for them as they age

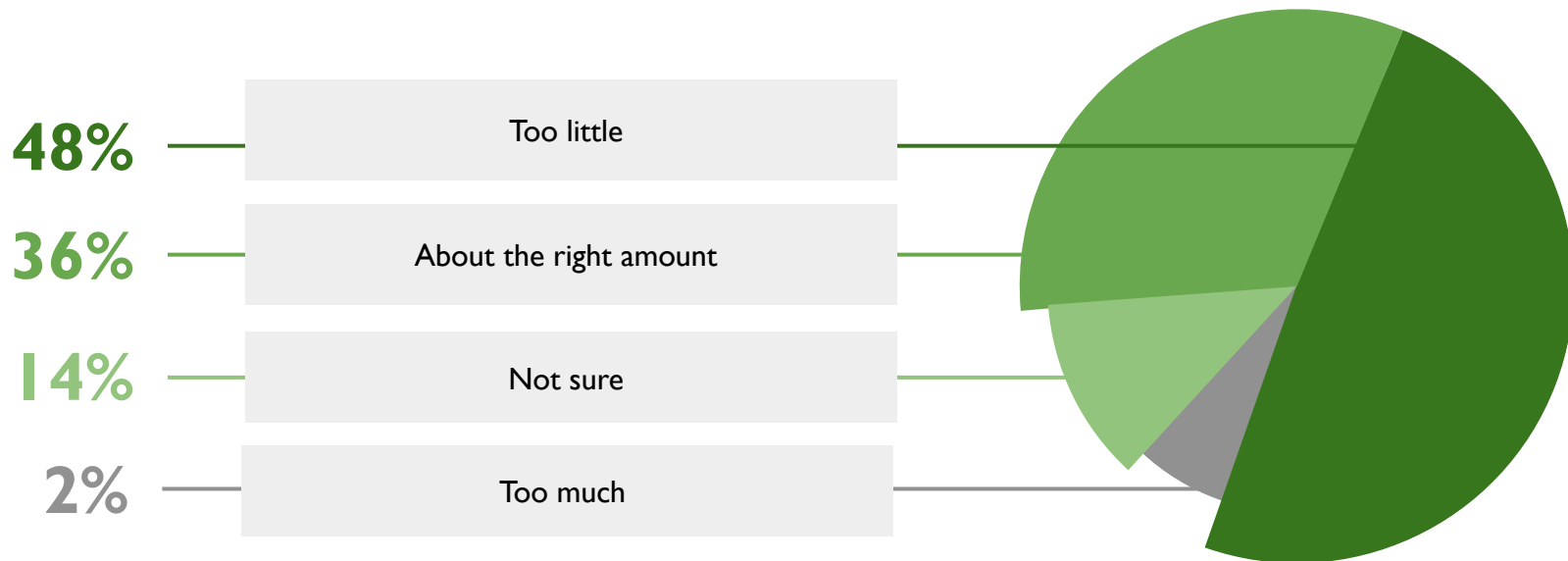


Don't trust the healthcare system to:

- accurately diagnose and treat conditions
- prevent avoidable pain and distress

Control over End-of-Life Decisions

Nearly half of respondents feel people in the US have too little control over decisions about their own medical care at the end of life.



Q14. In general, do you think most people in the US have too much, too little, or about the right amount of control over decisions about their own medical care at the end-of-life?

N = 2,009

Control over End-of-Life Decisions

Older respondents are less likely to say people have too little control, about half of the oldest respondents say the amount of control is about right.

	Silent n = 148	Boomer n = 930	Gen X n = 737	Millennial n = 194
Too much	1%	1%	2%	4%
Too little	33%	48%	50%	52%
About right	49%	39%	32%	29%
Not sure	18%	13%	15%	14%

**Significantly higher/lower, 95% confidence*

Q14. In general, do you think most people in the US have too much, too little, or about the right amount of control over decisions about their own medical care at the end-of-life?

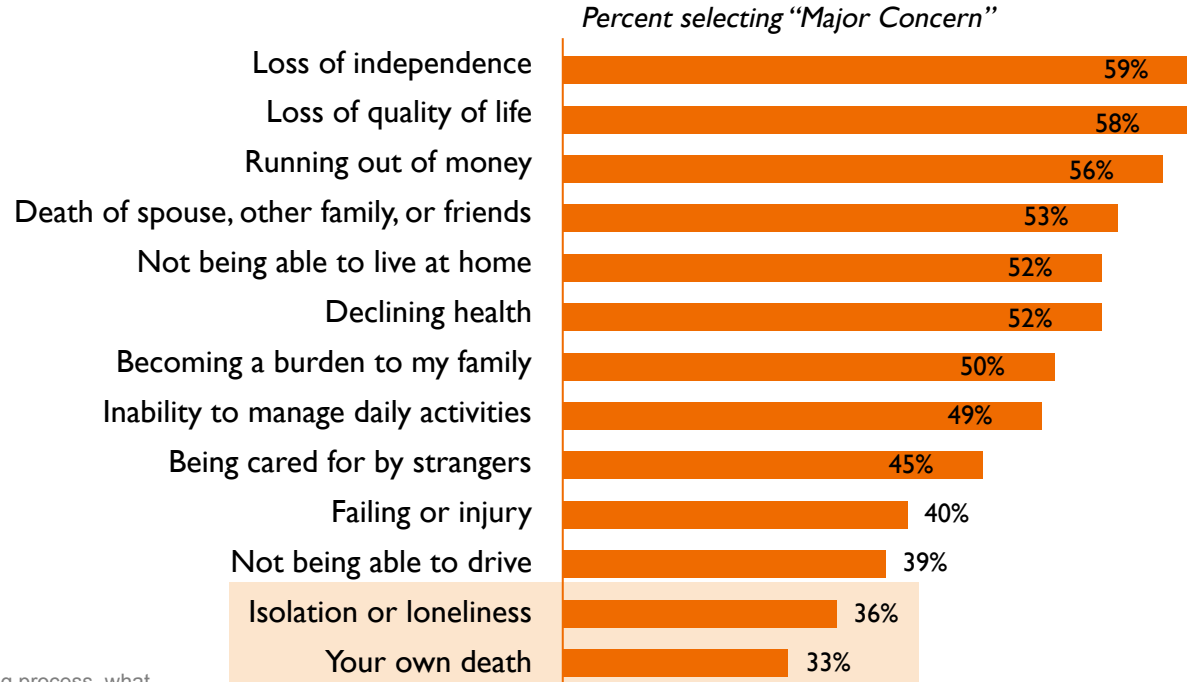
05

Aging & Managed Care



Top Concerns about Aging

Respondents are more concerned about their quality of life as they age than their own death.

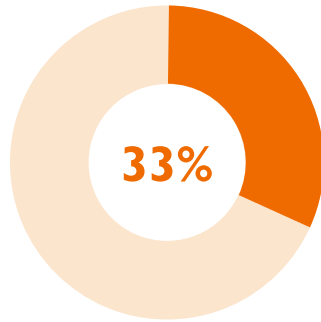


Q17. When you think about your own aging process, what is your level of concern about each of the following?

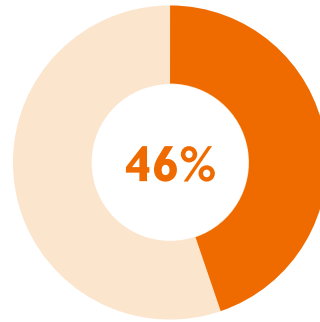
N = 2,009

What is your personal philosophy about healthcare?

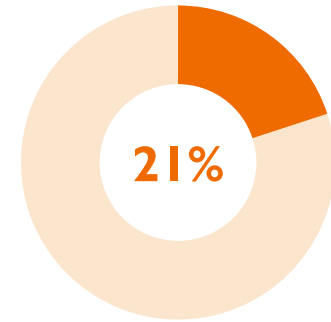
While most respondents follow doctor's recommendations and a third of respondents fully embrace healthcare in their lives, about a fifth actively avoid it.



I will **proactively embrace** it- learning about medical trends and treatments, and discussing them with my practitioner



I will **follow my doctor's recommendations** about preventative care and trust them to tell me if there are changes I need to made



I will **avoid it if possible** and use it only when I need it or I have to

Q15. When you think about your own aging process, which of the following best describes your personal philosophy about the role of healthcare in your life as you age?

N = 2,009

Personal Healthcare Philosophy by Age

The oldest respondents are less likely than other cohorts to either avoid or proactively embrace healthcare.

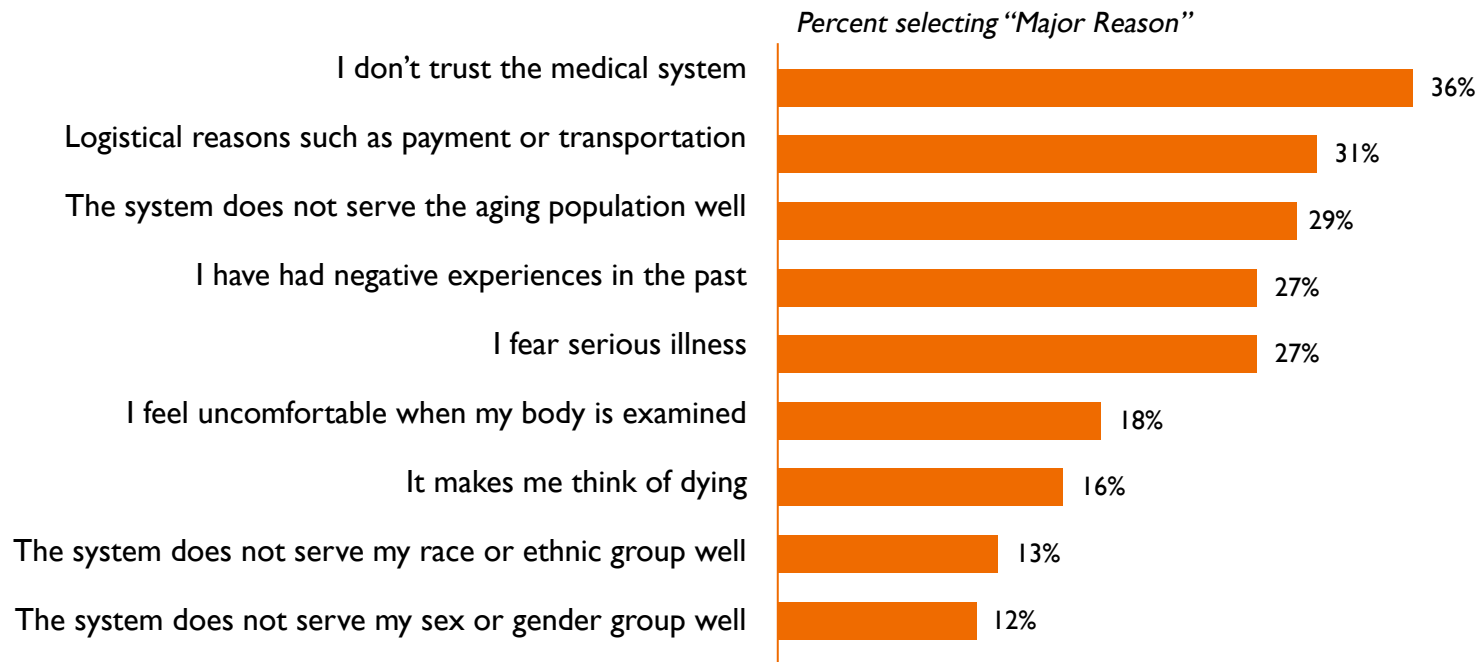
	Silent n = 148	Boomer n = 930	Gen X n = 737	Millennial n = 194
I will avoid it if possible and use it only when I need it or I have to.	10%	18%	25%	29%
I will follow my doctor's recommendations about preventative care and trust them to tell me if there are changes I need to make.	65%	49%	42%	33%
I will proactively embrace it- learning about medical trends and treatments and discussing them with my practitioner.	25%	33%	32%	38%

**Significantly higher/lower, 95% confidence*

Q15. When you think about your own aging process, which of the following best describes your personal philosophy about the role of healthcare in your life as you age?

Reasons for Avoiding Healthcare

Among those who say they avoid it, lack of trust is the top reason, followed by barriers to access such as cost and logistics.



Q16. What are your reasons for avoiding the US healthcare system in your aging process?

N = 423

Reasons to Avoid Healthcare Differ by Race

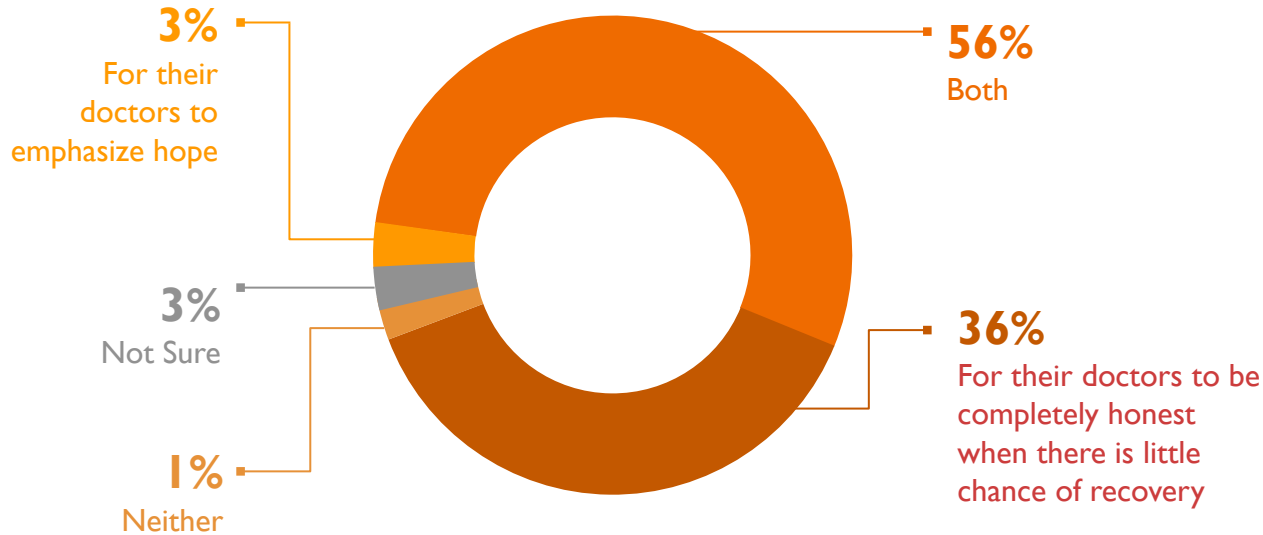
76% of Black respondents say race is a reason they avoid the US healthcare system.

<i>The system does not treat my race or ethnic group well.</i>	Hispanic n = 334	Black n = 270	White n = 1,219	Other n = 186
Major reason	16%	35%	7%	15%
Minor reason	28%	41%	16%	39%
Not at all a reason	55%	24%	77%	46%

**Significantly higher/lower, 95% confidence*

Respondents want doctors to be honest with them

Most want a balance of hope and forthrightness, but honesty is required.



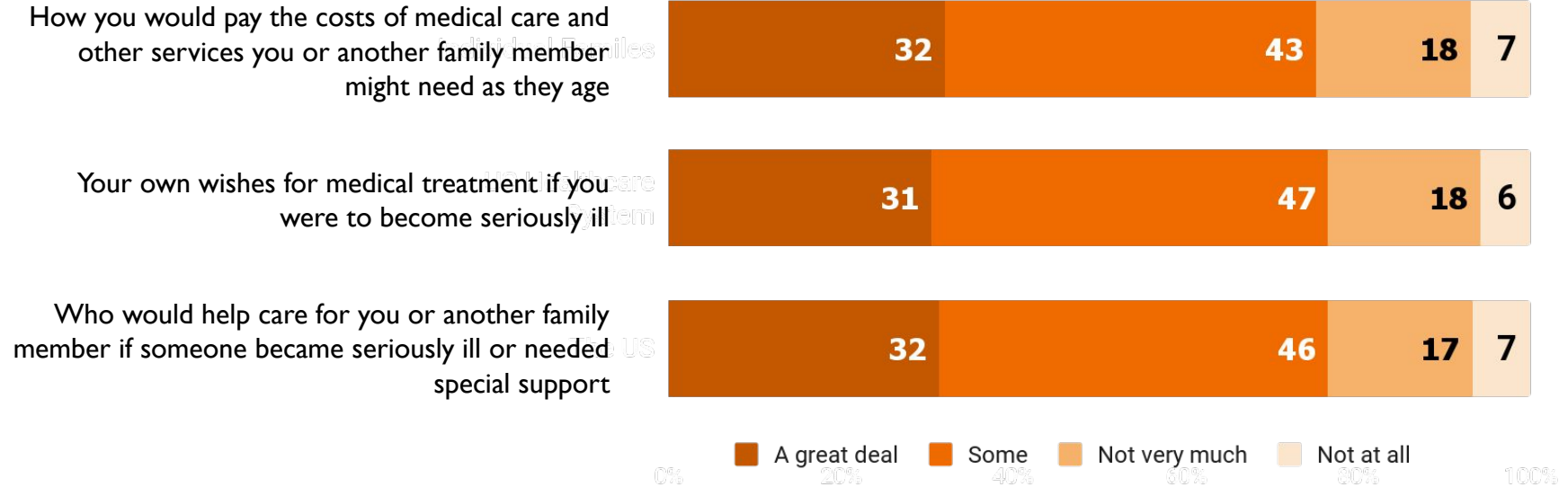
“Maybe patients need both the honest truth and encouraging positivity, because all people ride an emotional rollercoaster, and there will be times to deal with both.”
- Respondent selecting “Both equally”

Q18. When a patient is seriously ill, which of the following do you think is more important?

N = 2,009

Respondents have given some thought to their own future aging care

Most have given at least some thought to the cost of aging, wishes for medical treatment, and who would care for them when they need it.



Q20. How much have you thought about the following?

N = 2,009

06

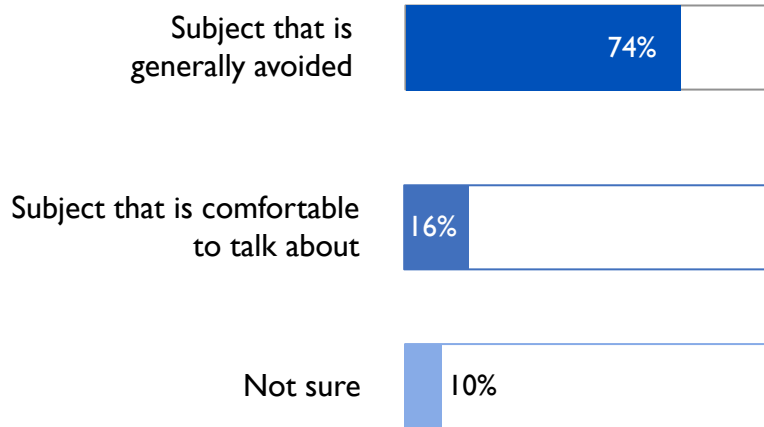
End-of-Life Considerations



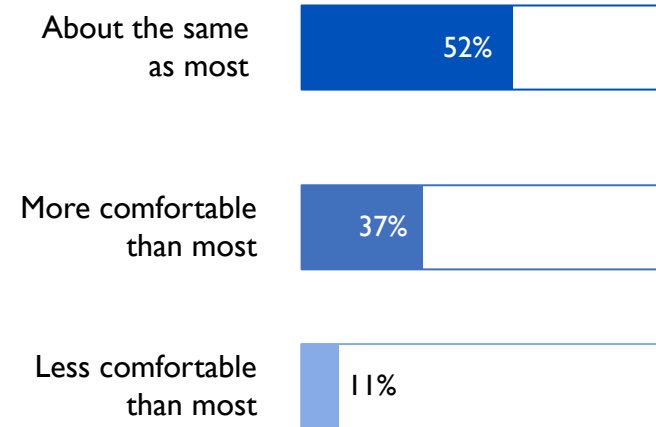
Most respondents feel that death and dying are subjects generally avoided in US society

89% of respondents say they are about as comfortable or more comfortable talking about death than most.

Death and Dying as Subjects in US Society



Comfort Level of Respondent



Q21. In US society, are death and dying subjects that people generally feel comfortable to talk about, or is it a subject that is generally avoided?

Q22. Compared to US society overall, would you say you are more comfortable talking about death than most, less comfortable, or about the same?

N = 2,009

Talking about Death

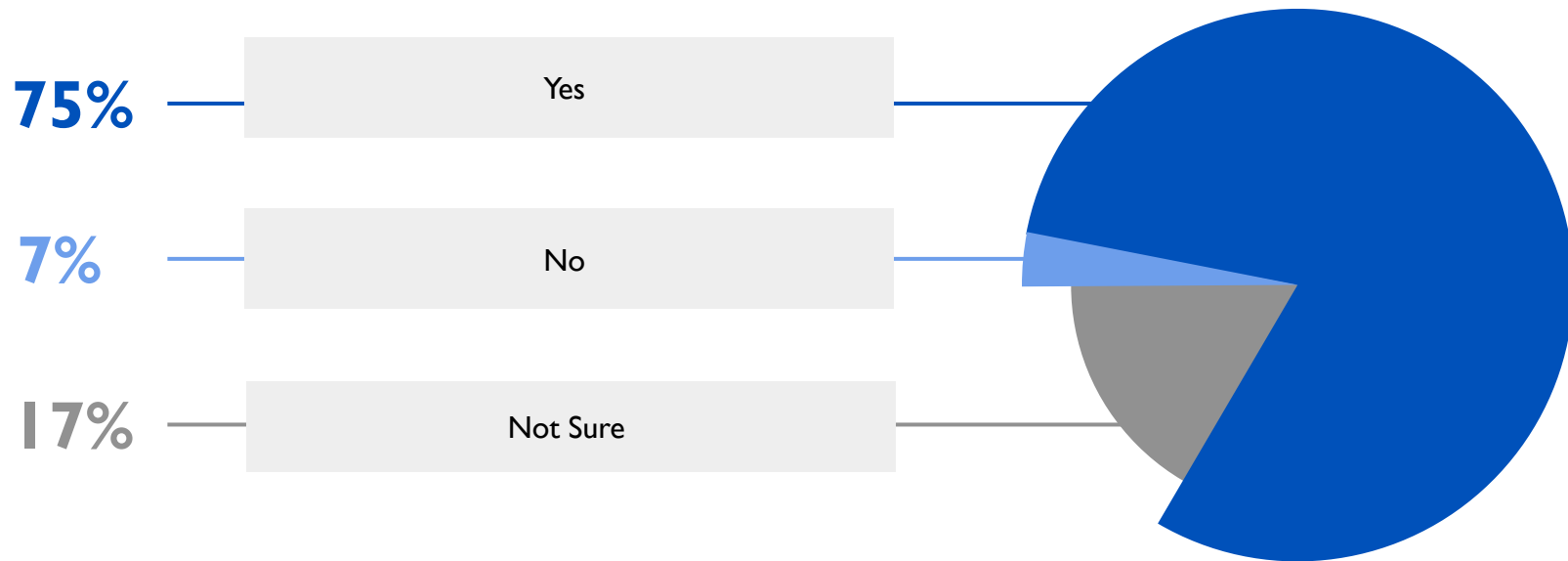
There is minimal difference in comfort talking about death between oldest and youngest generations

	Silent n = 148	Boomer n = 930	Gen X n = 737	Millennial n = 194
More comfortable than most	34%	39%	34%	34%
About the same as most	59%	51%	52%	55%
Less comfortable than most	7%	10%	14%	11%

Q22. Compared to US society overall, would you say you are more comfortable talking about death than most, less comfortable, or about the same?

Respondents want Medicare to cover end-of-life discussions

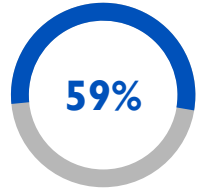
Three-quarters of respondents support coverage for doctor-patient conversations



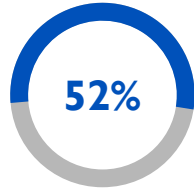
Q19. Do you think Medicare should cover discussions between doctors and patients about end-of-life care options, or not?

N = 2,009

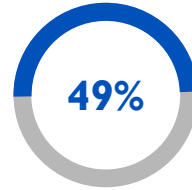
Respondents are most concerned with how their death will affect others



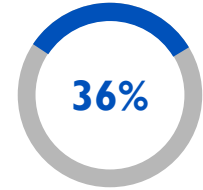
How my loved ones will be affected



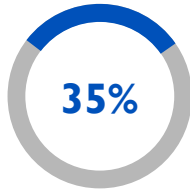
Missing the lives and events of others



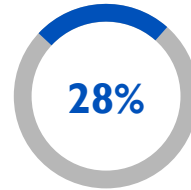
That my death will be painful



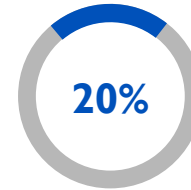
Isolation or loneliness



The loss of time



Whether there is life after death



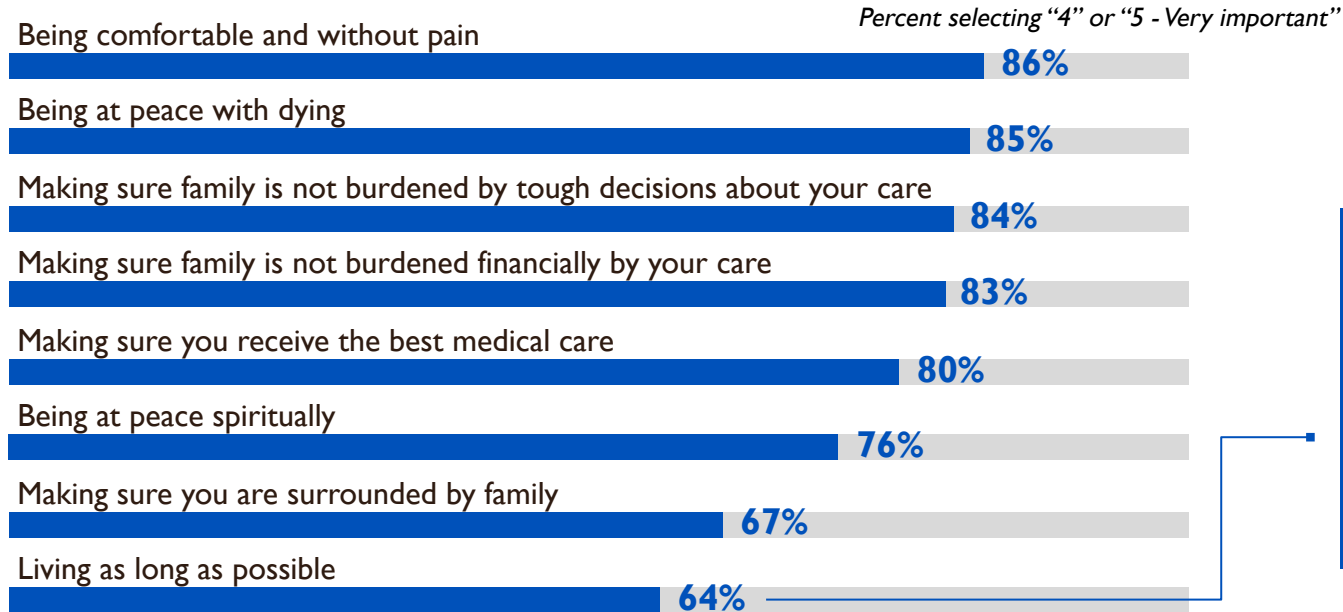
What will happen to my body after I die

Q24: When thinking about your own death, how much of a concern are the following:
BASE Q17. When you think about your own aging process, what is your level of concern about each of the following? "Your own death" major or minor concern

N = 1,449

End-of-Life Circumstances

Respondents value comfort and peace more than living as long as possible.



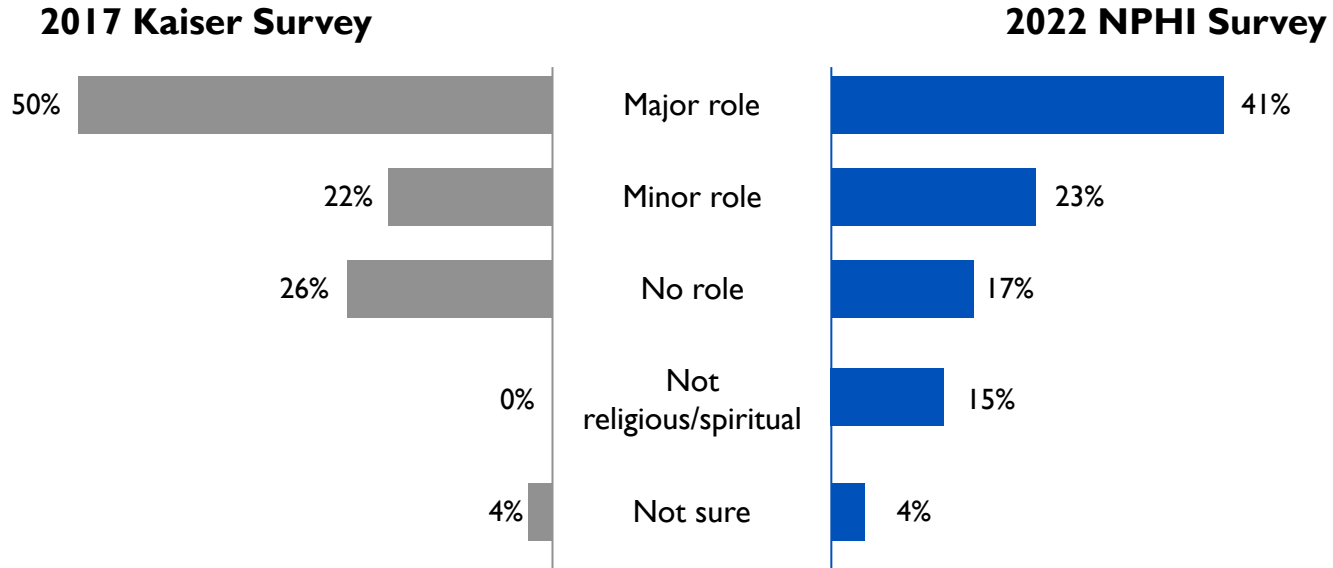
Prolonging life is more important to the most religious respondents (72% vs. 48%)

Q25: Thinking about the circumstances that might surround the end of your own life, how important is each of the following to you?

N = 2,009

Role of Religion in End-of-Life Care

More than half of respondents say that religion impacts their thinking on end-of-life care, but the proportion who say it plays a major role has decreased

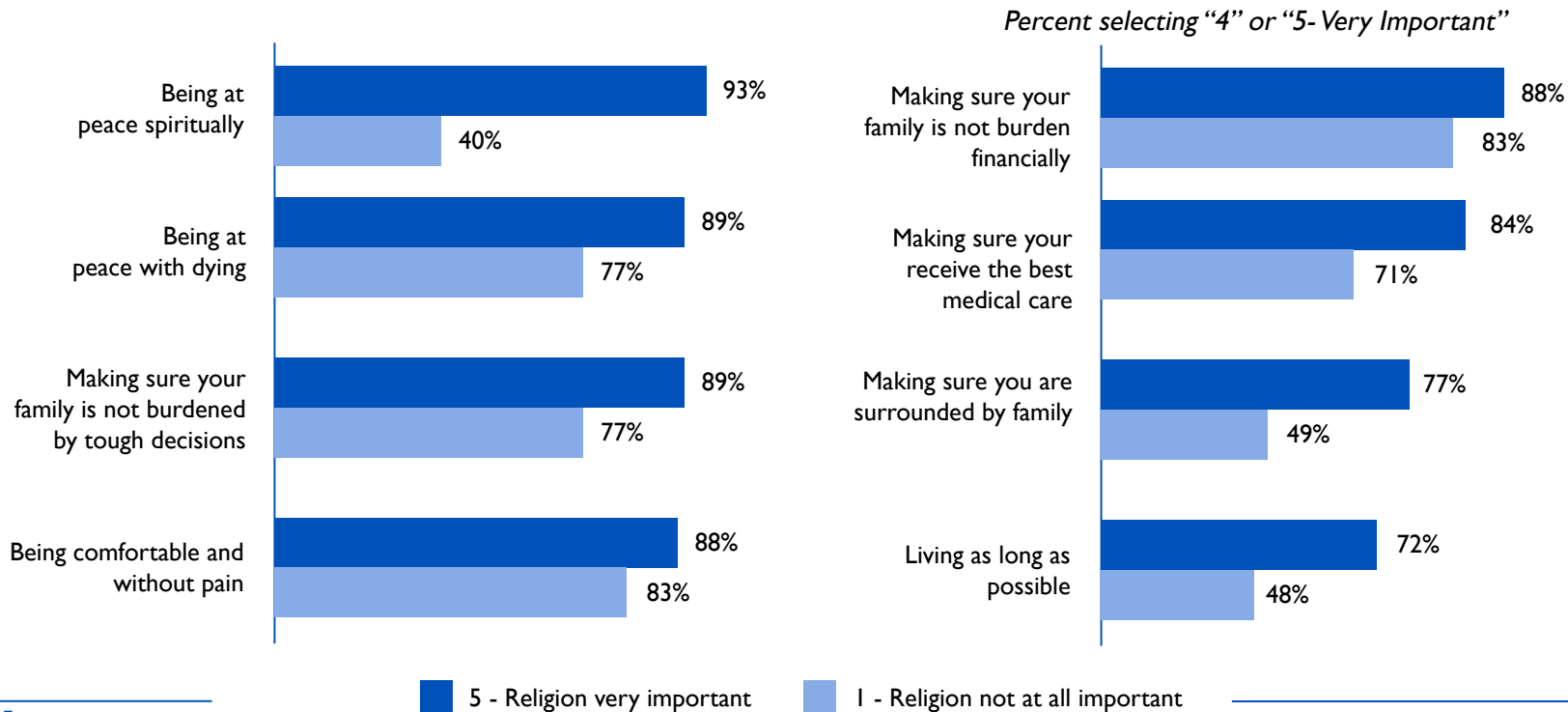


Q26. How big of a role do your religious beliefs play in the way you think about your own wishes for end-of-life care?

N = 2,009

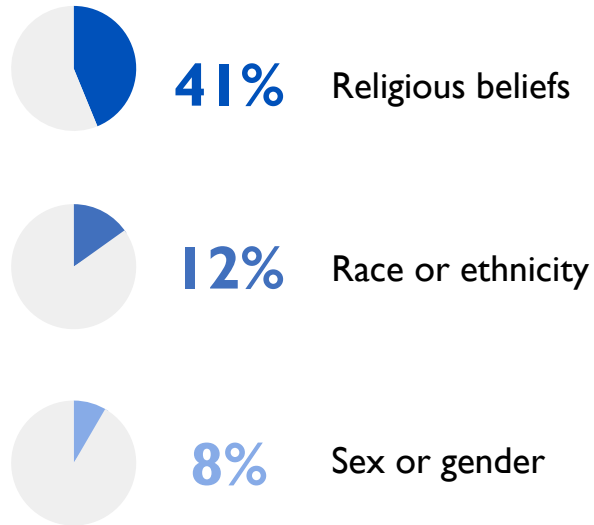
Religion and End-of-Life Circumstances

Respondents who say that religion is very important in their lives tend to place greater importance on end-of-life circumstances in general



Religion plays a greater role in attitudes about end-of-life than other facets of identity

Plays a “major role”:



Open-ended remarks reveal past experiences drive many concerns related to race or gender:

“I have some concerns about receiving less pain management and less consideration because I am female. I have been denied any pain management while giving birth despite being given drugs that made labor pains especially bad. This concerns me, as I feel like I have been failed by the system and had my pain ignored in the past.”

– Respondent selecting “Major role” for sex and gender identity in wishes for end-of-life care

Q26-28: How big of a role does ...play in the way you think about your own wishes for end-of-life care?

N = 2,009

Black, Hispanic, and other non-white respondents were more likely to say their race and ethnicity play a role in their wishes for end-of-life care

	Hispanic n = 334	Black n = 270	White n = 1,219	Other n = 186
Major Role	15%	26%	7%	18%
Minor Role	27%	26%	13%	25%
No role	51%	38%	75%	49%
Not sure	7%	10%	6%	8%

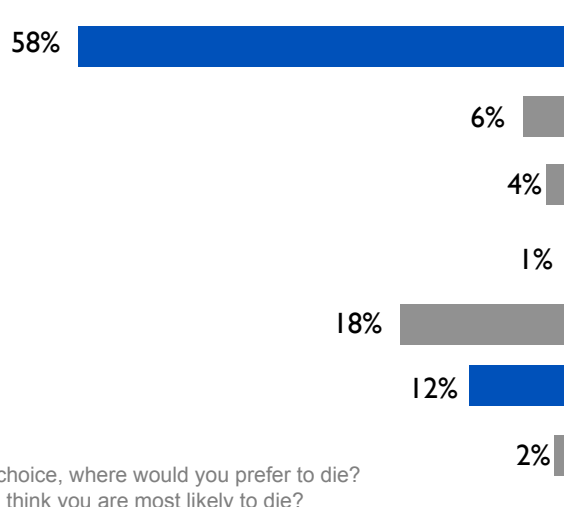
**Significantly higher/lower, 95% confidence*

Q26. How big of a role do your religious beliefs play in the way you think about your own wishes for end-of-life care?

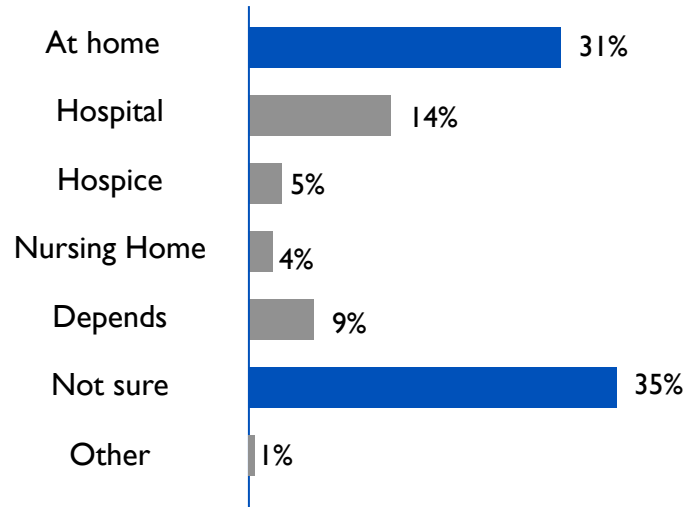
Where would you prefer to die? Where do you think you are most likely to die?

Dying at home is preferred if given a choice, one-third expect to die at home, and more than one-third aren't sure. (Home-based hospice not included in responses.)

Where would you prefer to die?



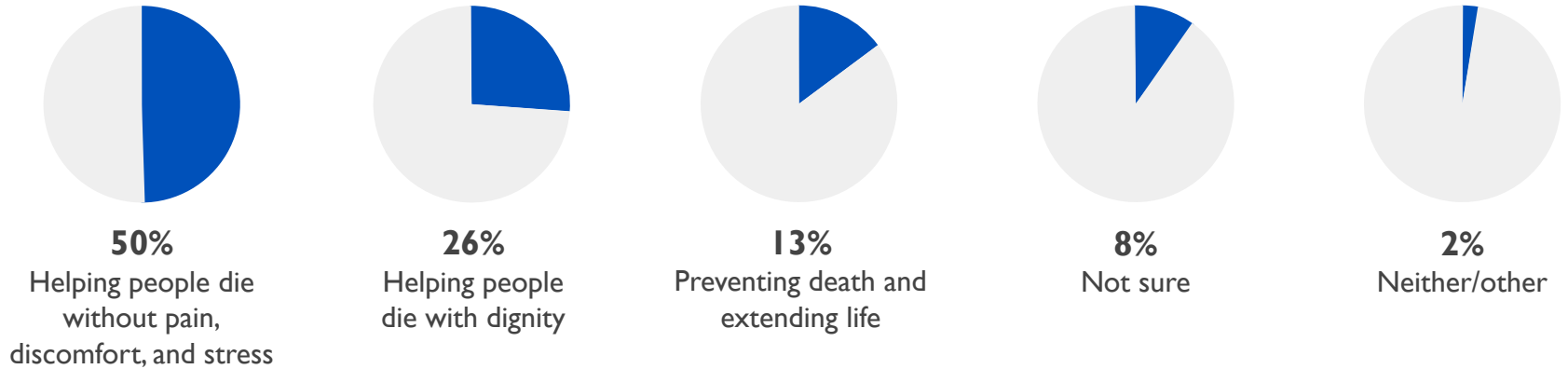
Where do you think you're most likely to die?



Q29: If you have a choice, where would you prefer to die?
Q30: Where do you think you are most likely to die?

N = 2,009

Dignity and comfort are rated as more important healthcare priorities than extending life as long as possible



Q31: Which of the following do you think should be more important when it comes to healthcare at the end of people's lives?

N = 2,009

Assisted Dying: Dignity and Choice

When asked for general thoughts and concerns about death and dying, 47 comments advocated for medically-assisted death. Six arguments were made against assisted dying, mainly invoking religious considerations.



“Assisted death should be considered in end-of-life decisions.”

“I think it is important for those with terminal illnesses be able to die with dignity before their quality of life drops drastically.”

“Oh boy, I’m not concerned about death but I’m very concerned about dying. I wish there was a better understanding of dying on your own terms, with dignity.”

“People should have the right to decide whether they want to live or die.”

“When it is my time to die I want to be helped to move on and not suffer more than necessary.”

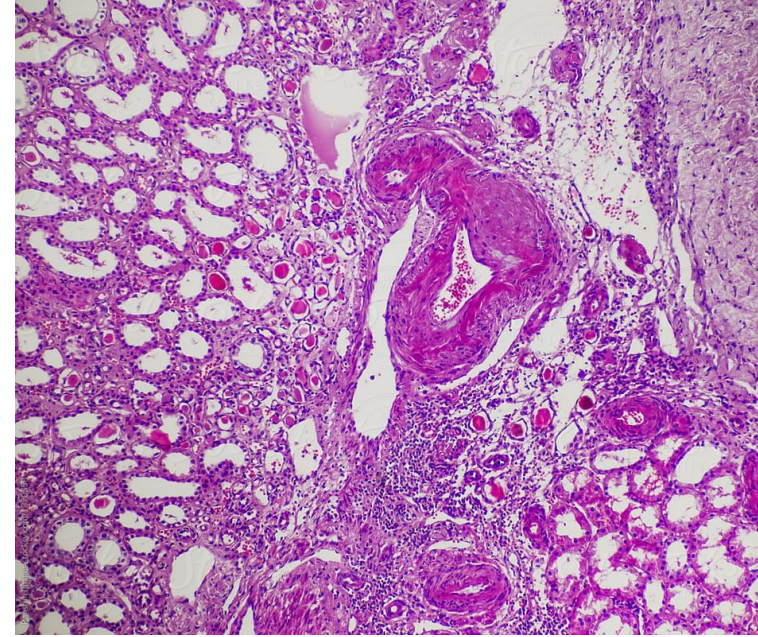
“The thought of not having assisted suicide available to everyone is incomprehensible. I want to go when I am no longer enjoying living and it’s really nobody’s business but mine.”

“God alone has the right to end life.”

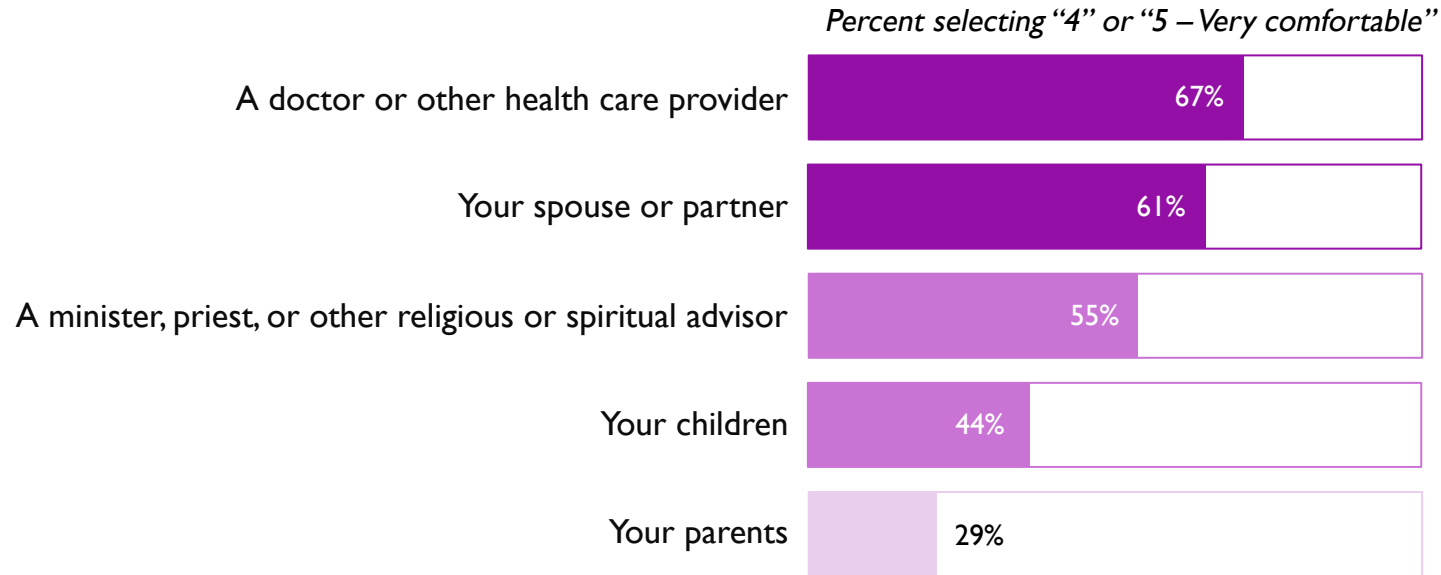
Q32. Do you have any other thoughts or concerns about death and dying you would like to share?

07

End-of-Life Planning



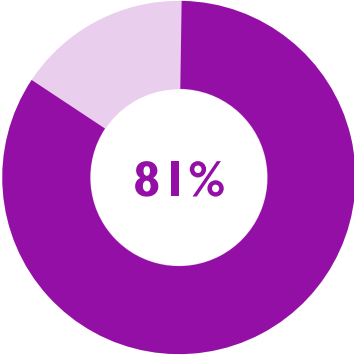
Respondents are most comfortable talking with a medical professional about their end-of-life medical wishes



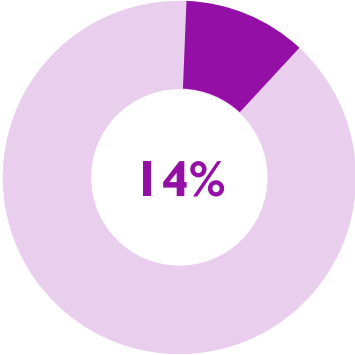
Q33: How comfortable would you be talking about your own end-of-life medical wishes with the following?

N = 2,009

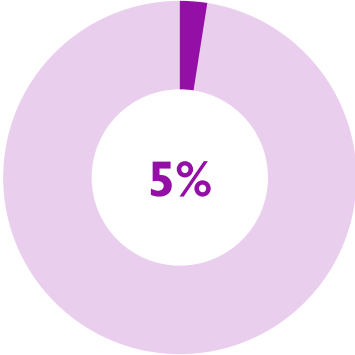
Most have never discussed their end-of-life care wishes with a healthcare provider



No



Yes

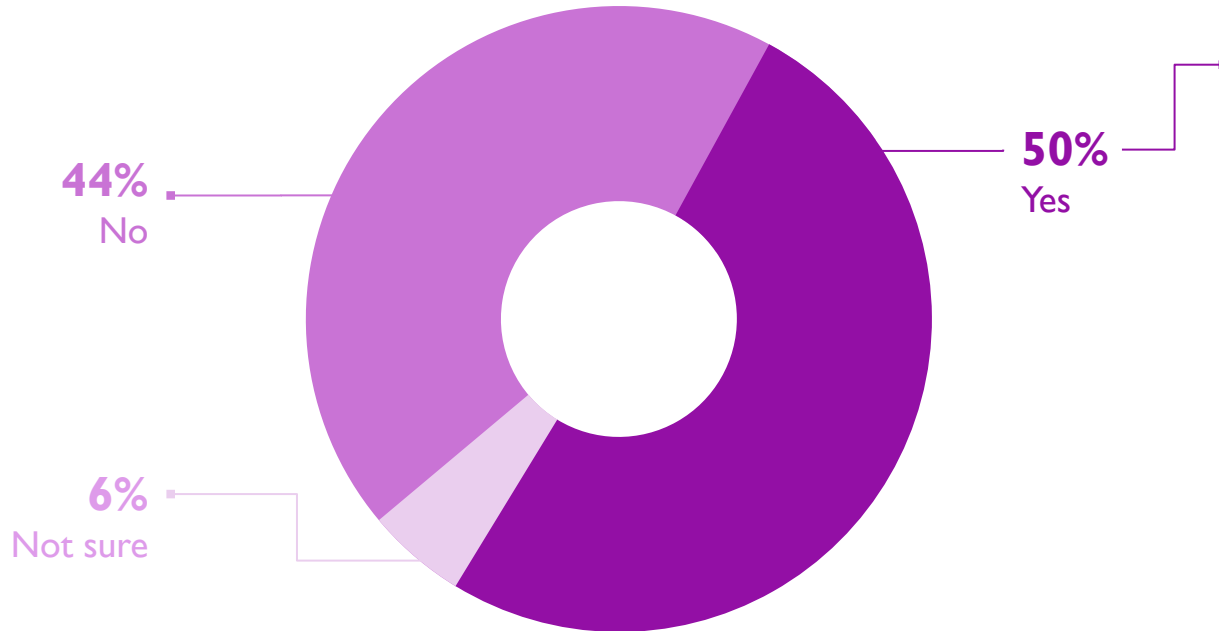


Not sure

Q36: Have you ever had a conversation with a doctor or other health care provider about your wishes for your care at the end of your life, or not?

N = 2,009

50% of respondents have had a serious conversation with a loved one about their wishes for end-of-life medical care



This number has decreased compared to **56%** of US respondents in the Kaiser Study who reported having had a serious conversation about their end-of-life wishes with a loved one.

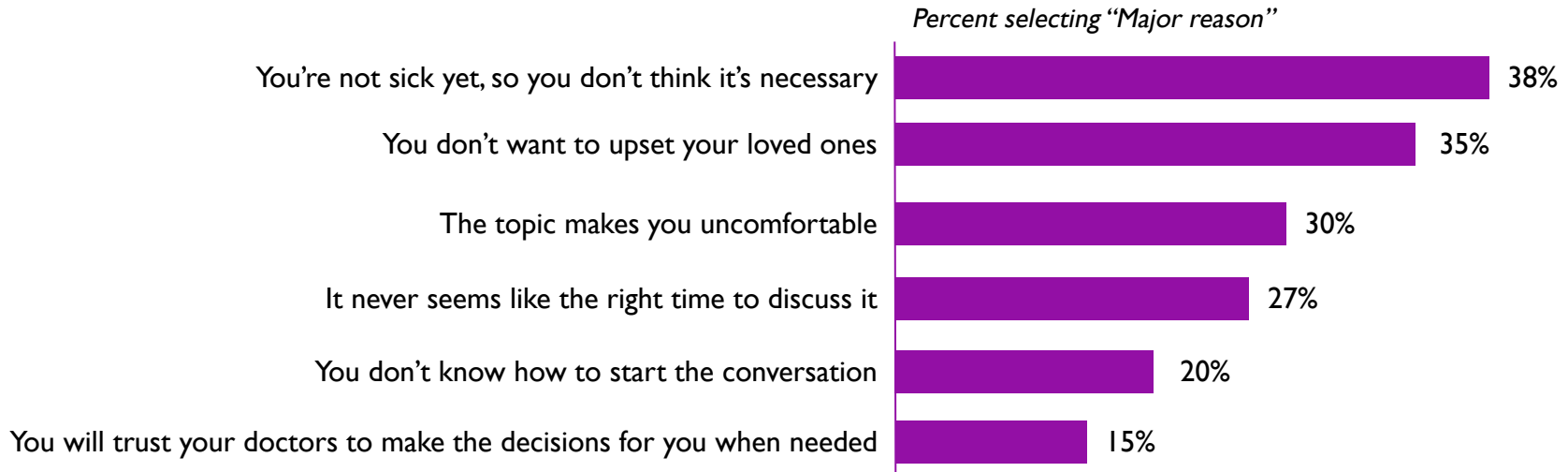
*significant difference at a 95% confidence level

Q34: Have you ever had a serious conversation with a spouse, parent, child, or any other loved one about your wishes for end-of-life medical care, such as what you do or don't want when you're dying?

N = 2,009

For those who haven't yet had a serious conversation, many see it as unnecessary if they aren't already sick

Avoiding upsetting loved ones and avoiding discomfort are also top reasons.

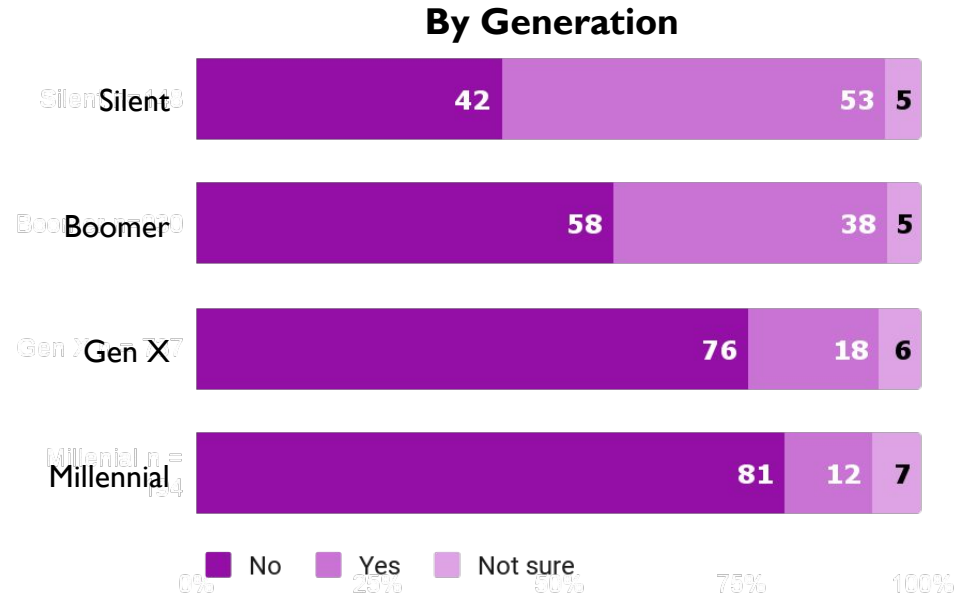
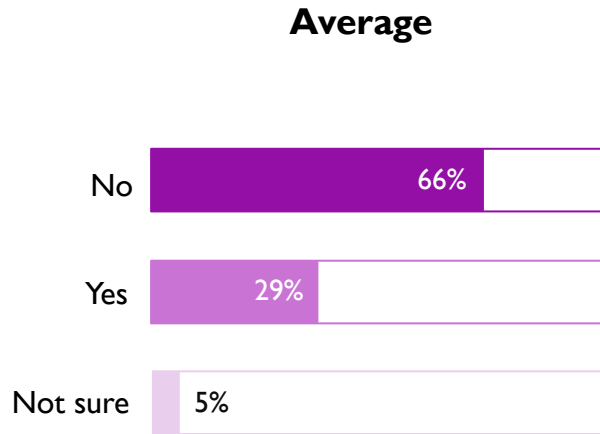


Q35: Which of the following are reasons, or not reasons, why you haven't had a conversation with your loved ones?

N = 882

Documentation for end-of-life wishes is low

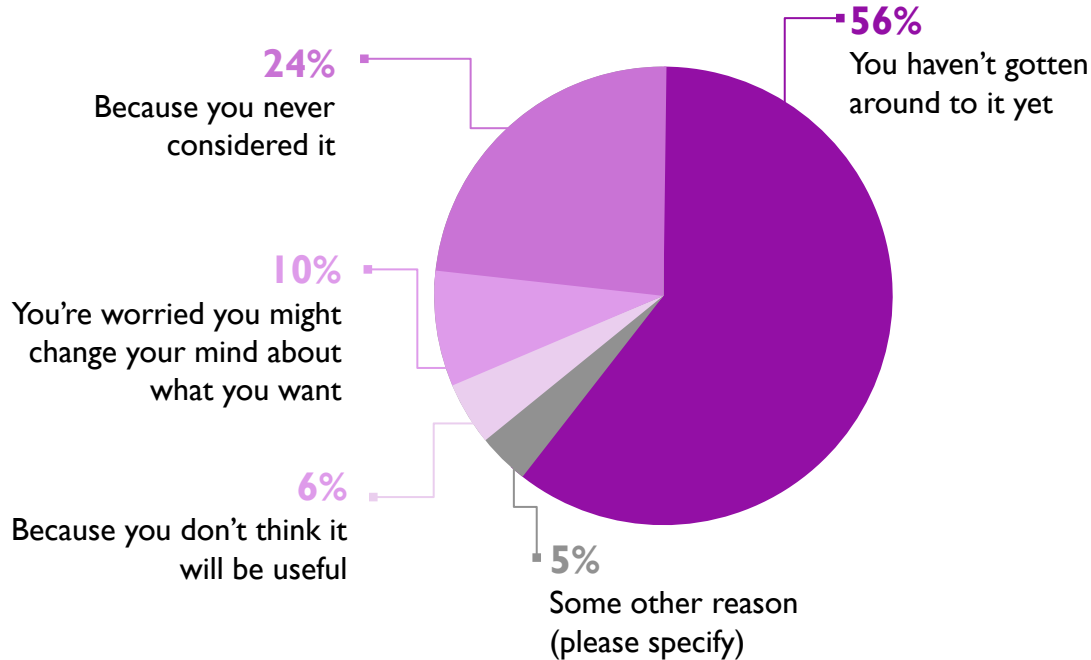
Even among the oldest respondents, only about half have their wishes in a written document.



Q38: Do you have your end-of-life wishes for medical treatment in a written document?

N = 2,009

Respondents who haven't written down their treatment wishes are most likely to cite procrastination as the reason

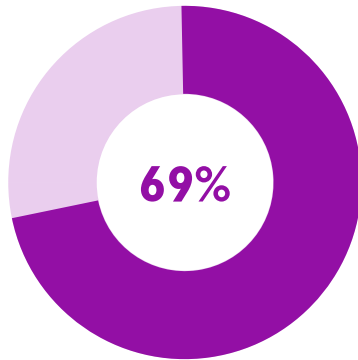


“My husband and I recently had our wills made and medical directive, living will, was part of that. He filled his out with his wishes, but I couldn't do it. There are just too many variables. I would want my family to talk to multiple doctors and each other before deciding on what to do for me if I was incapacitated and couldn't talk for myself and my condition was dire. I don't like these written living wills because I feel there are a lot of things that can happen that they don't address.”

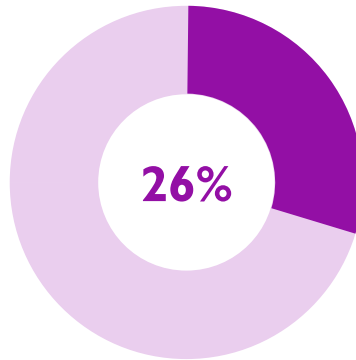
Q39: What's the main reason you don't have your end-of-life wishes in a written document?

N = 1,317

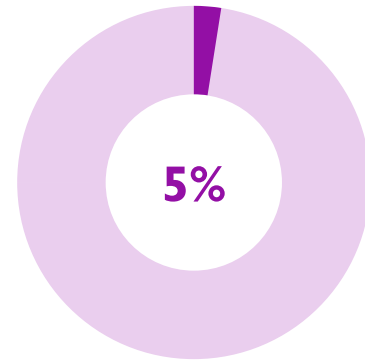
Most have never discussed a family member's end-of-life care wishes with a healthcare provider



No



Yes



Not sure

Q37: Have you ever participated in a discussion with a doctor or other healthcare provider about another family member's wishes for their care at the end of their life?

N = 2,009

Planning for Death and Dying

Discomfort or powerlessness leading to avoidance was described in 76 comments.

34 of the 76 respondents talk about the empowerment of having plans in place.



Planning relieves unnecessary stress.

“I don’t think that anyone wants to think about this subject but it needs to be discussed and have some type of arrangements in place ahead of time so its not put on family members.”

“Making decisions ahead of time relieves pain and stress.”

“Death and taxes are the only two certainties in life. We should discuss them. We should be open to them. We should support a death plan in a manner similar to the way we support Birth Plans.”

Why think about it?

It’s too scary and there’s nothing I can do about it.

“I don’t really like this topic, but I don’t think I have any concerns or thoughts, what needs to happen will happen anyways.”

“I am only 82 and haven’t really given it much thought.”

“Death scares me. I don’t like to think about it and about never being able to see my loved ones again.”

“It’s definitely a tough subject to think about.”

Q32. Do you have any other thoughts or concerns about death and dying you would like to share?

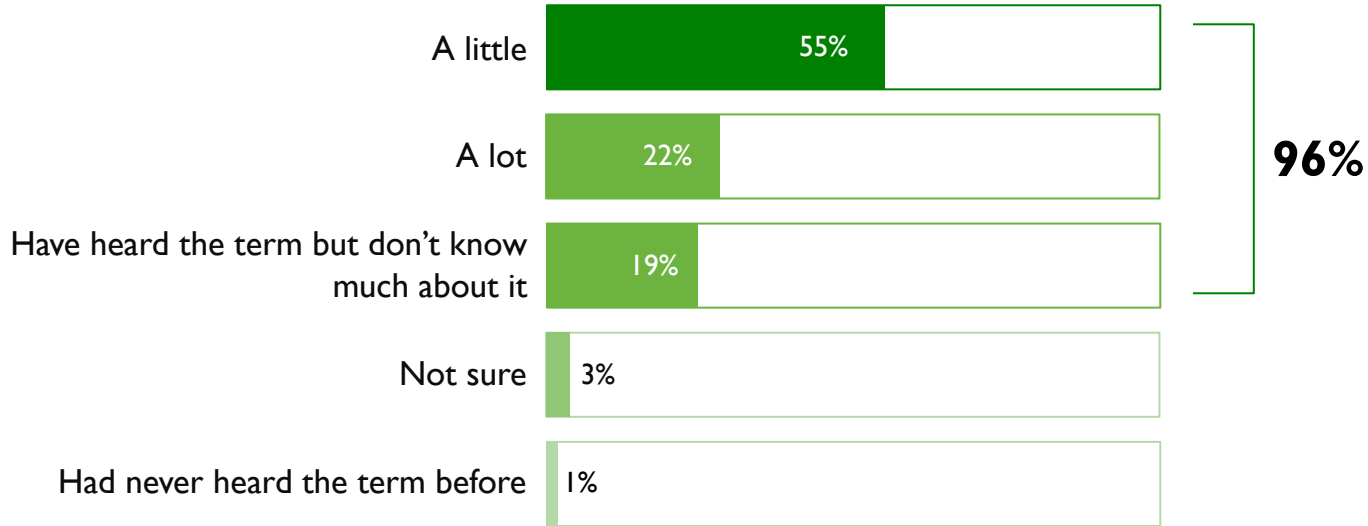
08

Hospice Awareness & Experience



Familiarity with Hospice Care

Nearly all respondents (96%) have at least heard of hospice care.

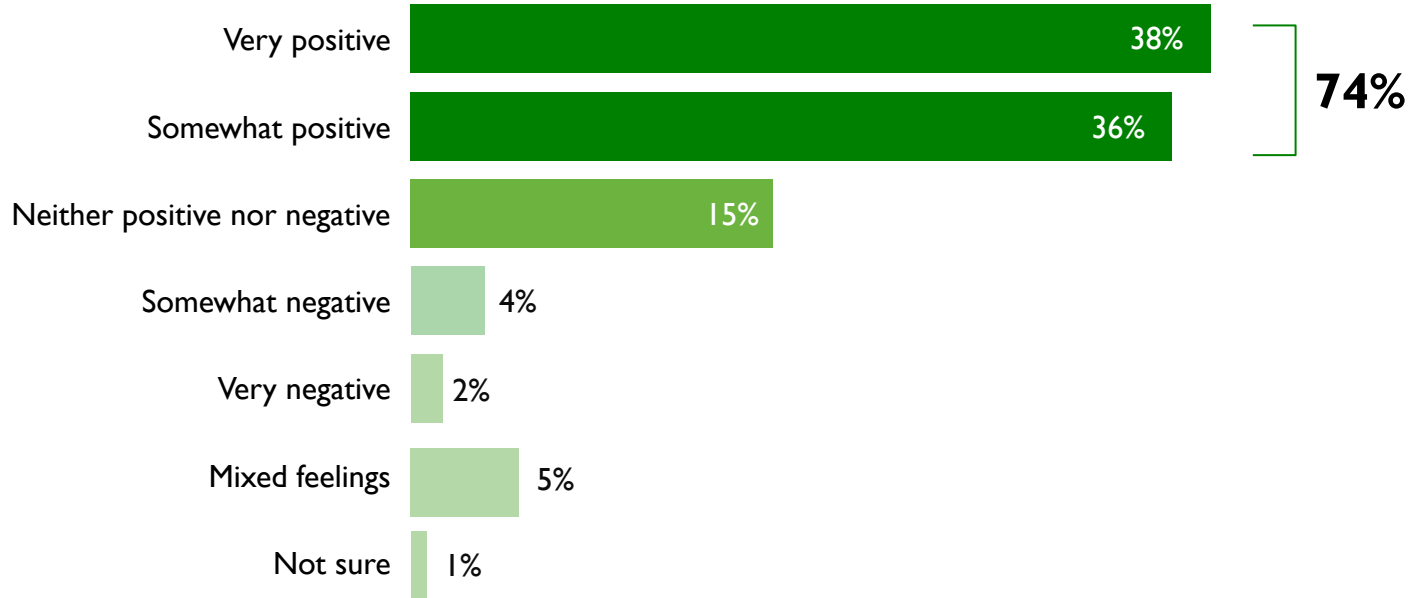


Q40: How much would you say you know about hospice care?

N = 2,009

Opinions of Hospice Care are Positive

For those who know at least a little bit about hospice care, 74% have a positive opinion.

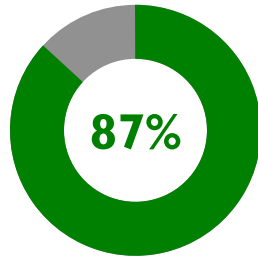


Q41: What is your opinion on hospice care?

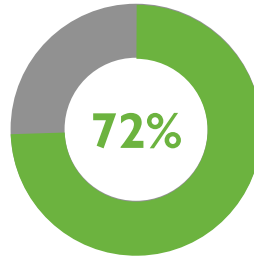
N = 1,541

Opinion of Hospice Care by Race/Ethnicity

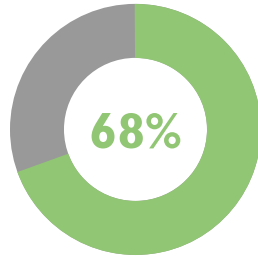
White respondents have a higher opinion of hospice care than other groups.



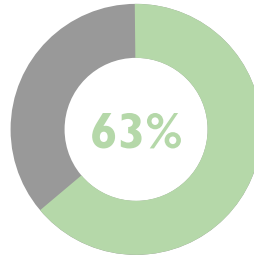
White



Hispanic



Black



Other

Regard for hospice care is also higher among Silent Generation (89%) and Boomers (85%).

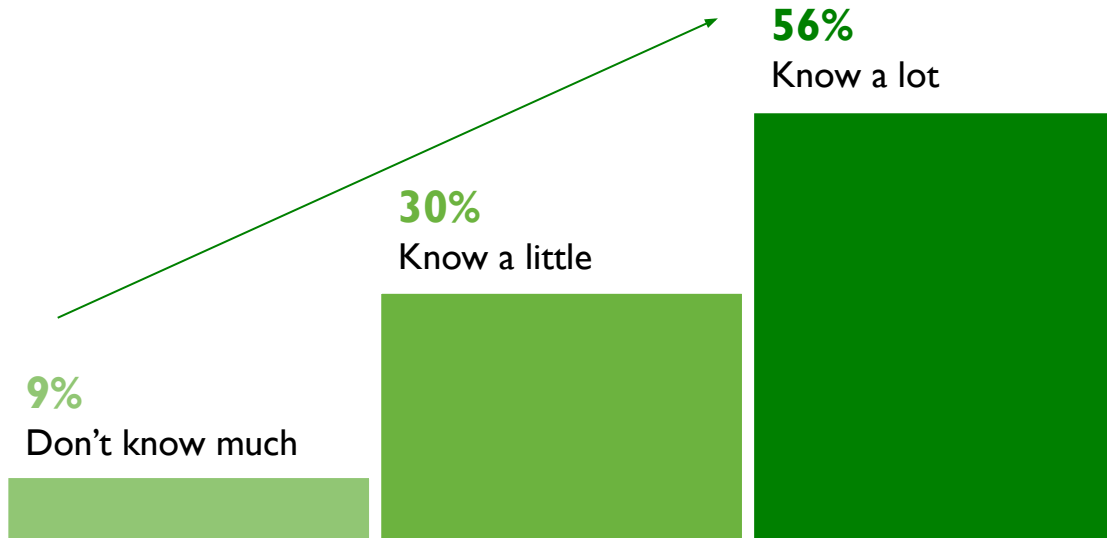
Q41: What is your opinion on hospice care?

N = 1,541

Familiarity Lifts Opinion

Respondents who say they know a lot about hospice care are much more likely to have a very positive opinion than those who know a little or not much.

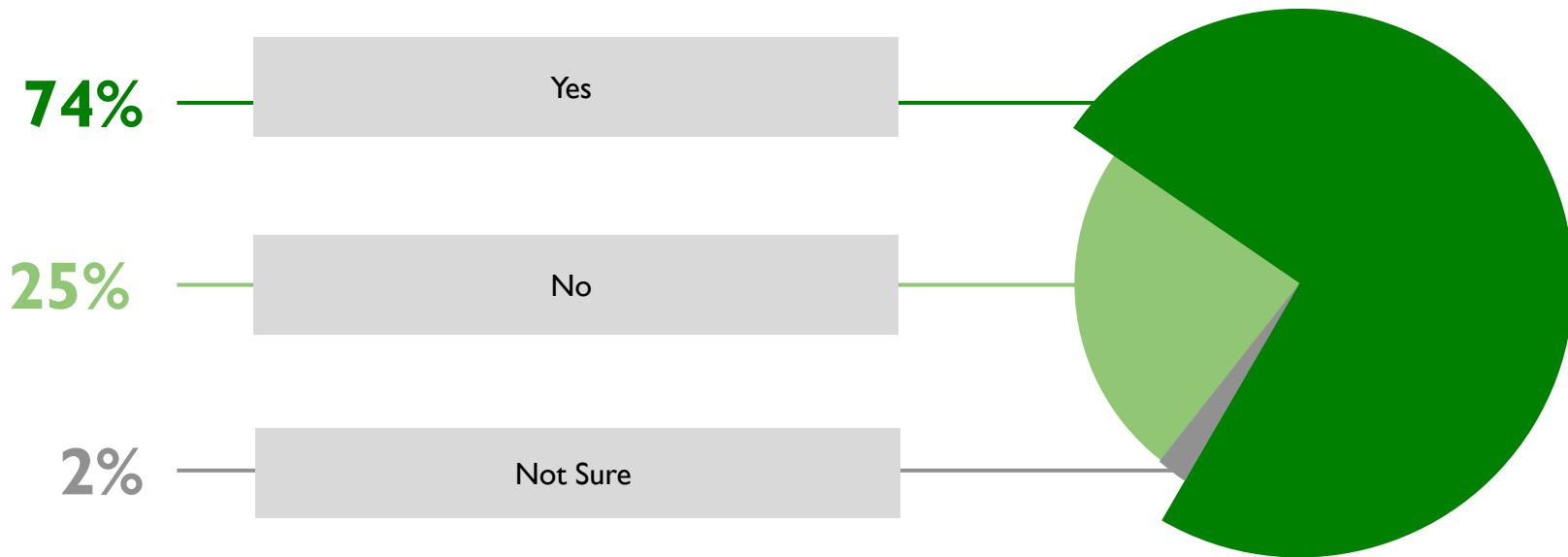
Percent selecting “5 – very positive” opinion on hospice care



Q40: How much would you say you know about hospice care?

Most familiarity comes from direct experience

Among respondents who are familiar (at least heard the term) with hospice care, a quarter have experience with hospice care, either for themselves or a loved one, in the last five years.

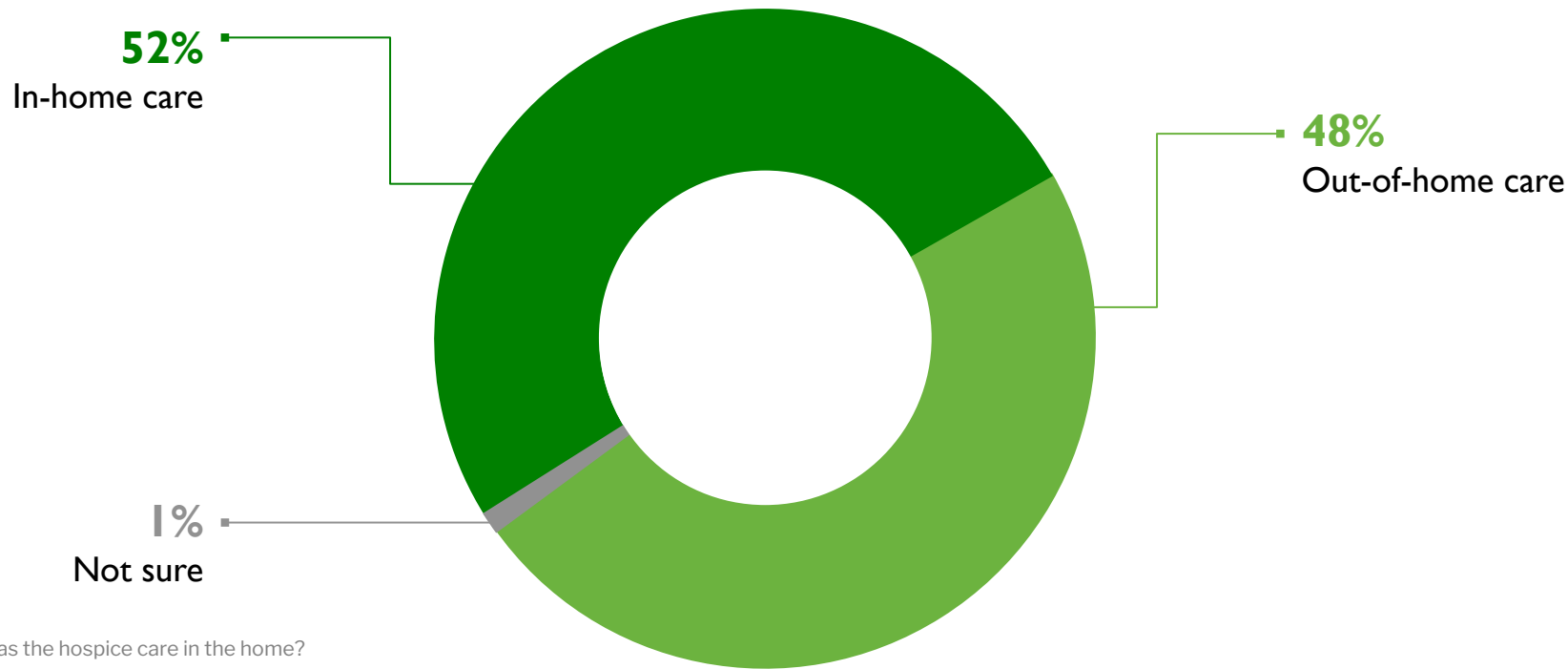


Q42: Have you or someone in your household had any experience with hospice care in the past 5 years?

N = 1,925

In-home Hospice Experience

Recent hospice care experience is about evenly divided between in- and out-of-home (“home” as defined by respondent).

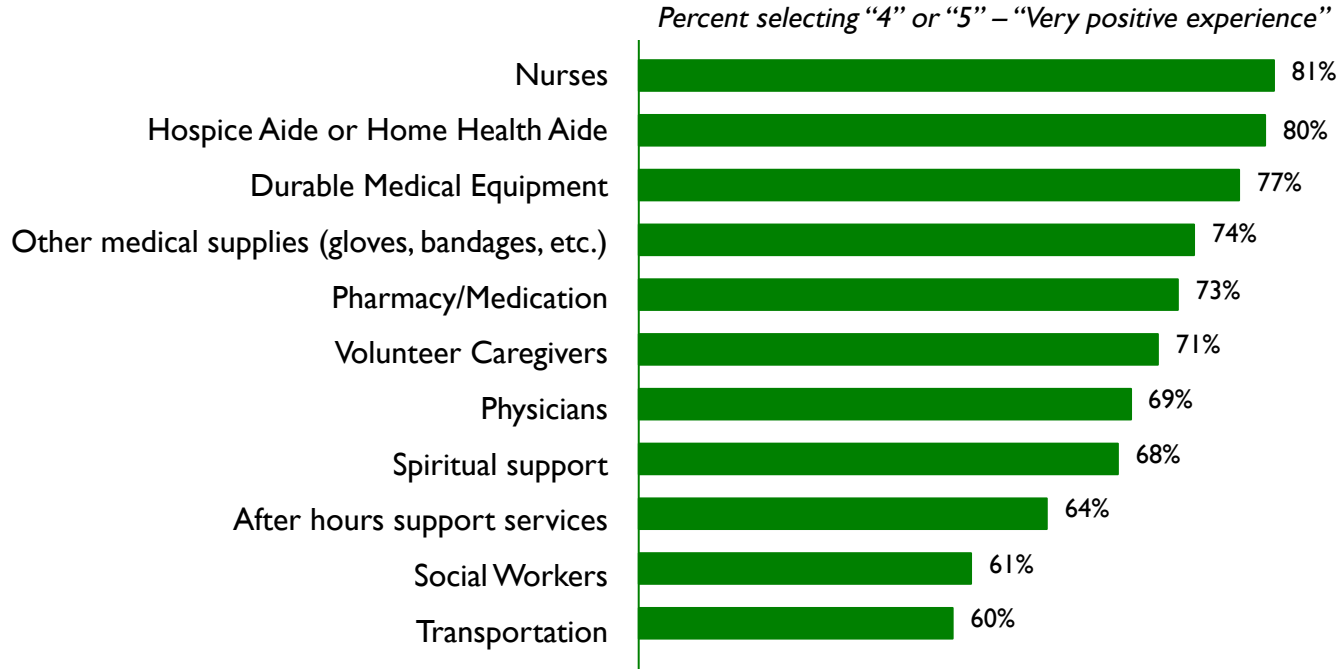


Q43: Was the hospice care in the home?

N = 476

Experience with Aspects of In-home Hospice

Nurses and aides get top ratings, followed by durable equipment and supplies.

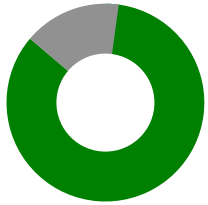


Q45: Please rate your experience with the following aspects of in-home hospice:

N = 179-238

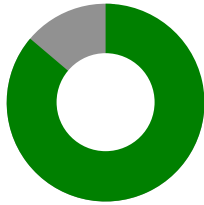
Important Aspects of Hospice Care

Care from doctors and nurses rated as most important.



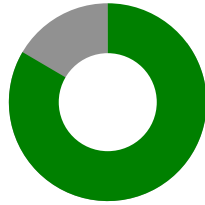
84%

Patient care from physicians



84%

Patient care from nurses



80%

Durable Medical Equipment in the home



61%

Religious and spiritual counseling for patients



59%

Religious and spiritual counseling for families



49%

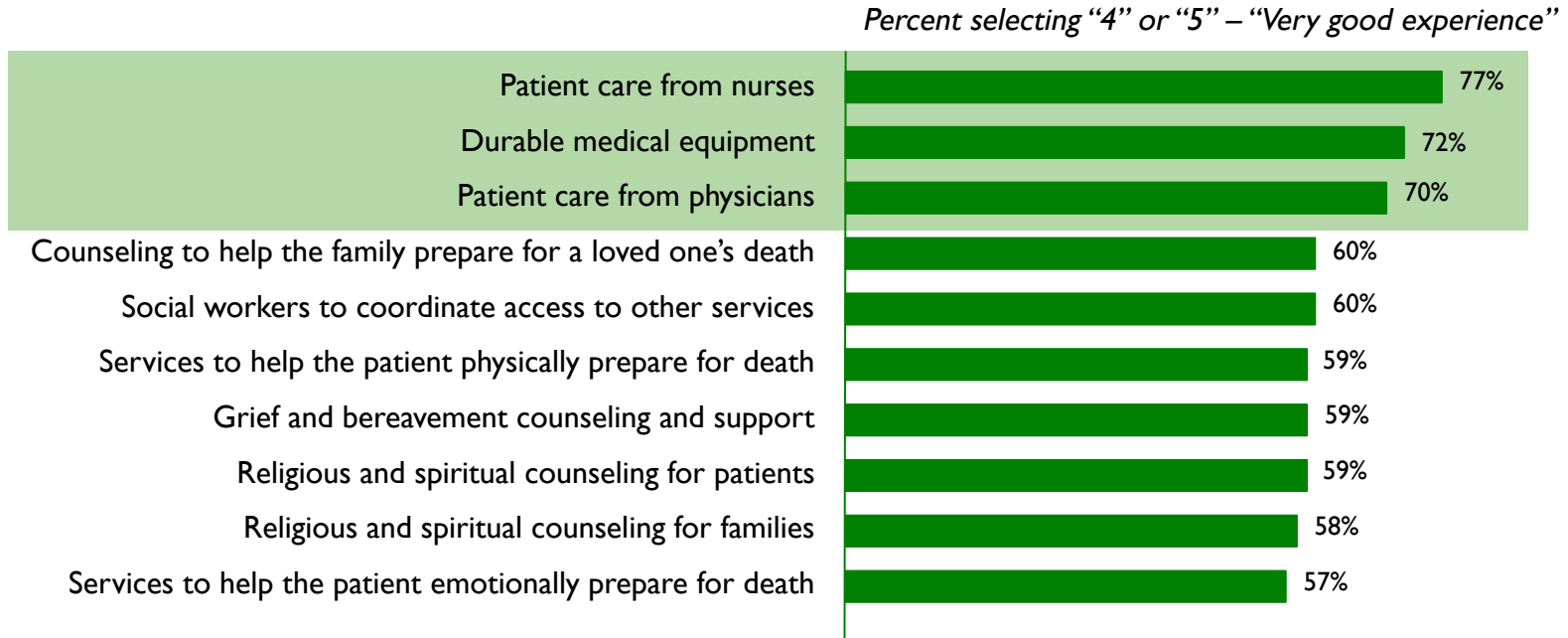
Help reaching “bucket list” goals before illness is too advanced

Q49: Below are a list of services commonly included in hospice care. Please rate how important you feel it is for the item to be included in hospice care.

N = 1,917-1,924

Experience with Aspects of Hospice Care

The top three services are also the top three rated most important.



Q50: Looking again at the same list of services that may be included in hospice care, please rate your experience (if any) with this service.

N = 278-435

Gap Analysis Between Importance and Performance

Respondents feel hospice care falls short in care from doctors, preparing patients for death, respite for caregivers, and counseling for families.

ATTRIBUTE	AVERAGE IMPORTANCE RATING	AVERAGE PERFORMANCE RATING	GAP SCORE	
Patient care from nurses	4.52	4.14	92%	<i>90-100% Perfect alignment</i>
Durable Medical Equipment in the home	4.43	4.03	91%	
Patient care from physicians	4.4	3.9	89%	<i>90% or below Below expectations</i>
Respite care for caregivers	4.3	3.68	86%	
Services to help the patient physically prepare for death	4.29	3.68	86%	<i>Above 100% Above expectations</i>
Counseling to help the patient with fears about their own death	4.29	3.64	85%	
Services to help the patient emotionally prepare for death	4.29	3.64	85%	
Counseling to help the family prepare for a loved one's death	4.21	3.66	87%	

Gap Analysis Between Importance and Performance

There is room to improve on services, including social workers, grief and bereavement counseling, death awareness and education, and help with activities like funeral planning and housework.

ATTRIBUTE	AVERAGE IMPORTANCE RATING	AVERAGE PERFORMANCE RATING	GAP SCORE
Social workers to coordinate access to other services or resources	4.17	3.69	88%
Grief and bereavement counseling and support	4.16	3.69	89%
Death awareness education and training	3.98	3.56	89%
Assistance with planning a funeral	3.93	3.46	88%
Religious and spiritual counseling for patients	3.91	3.73	95%
Religious and spiritual counseling for families	3.9	3.71	95%
Housework and shopping	3.85	3.46	90%
Help reaching “bucket list” goals before illness is too advanced	3.53	3.34	95%

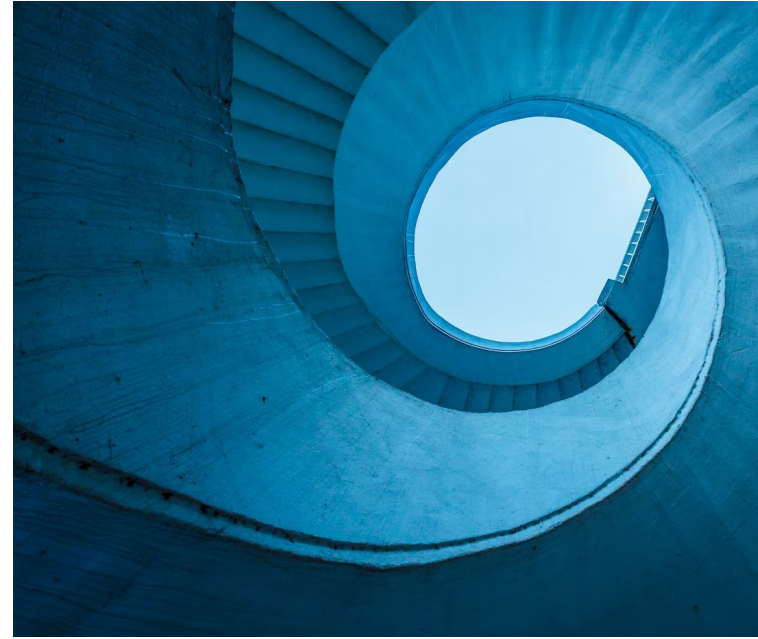
*90-100%
Perfect
alignment*

*90% or below
Below
expectations*

*Above 100%
Above
expectations*

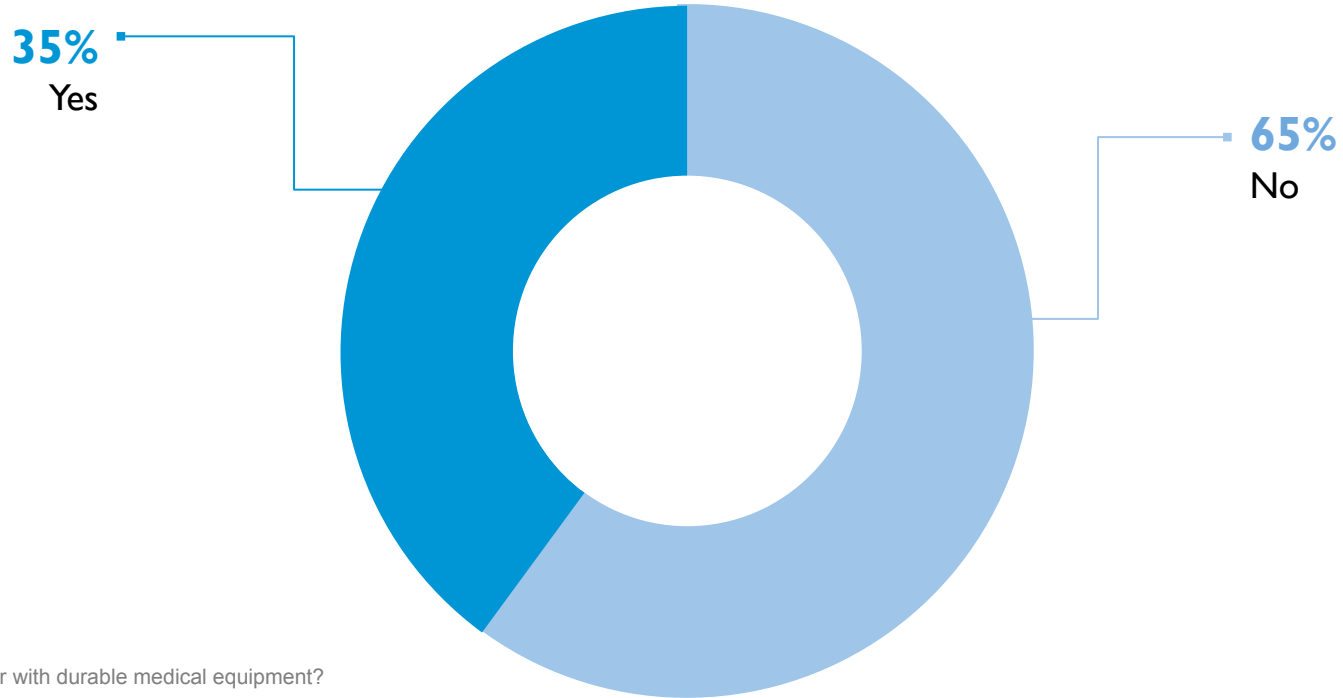
09

Durable Medical Equipment



Durable Medical Equipment

About a third of all respondents are familiar with durable medical equipment.

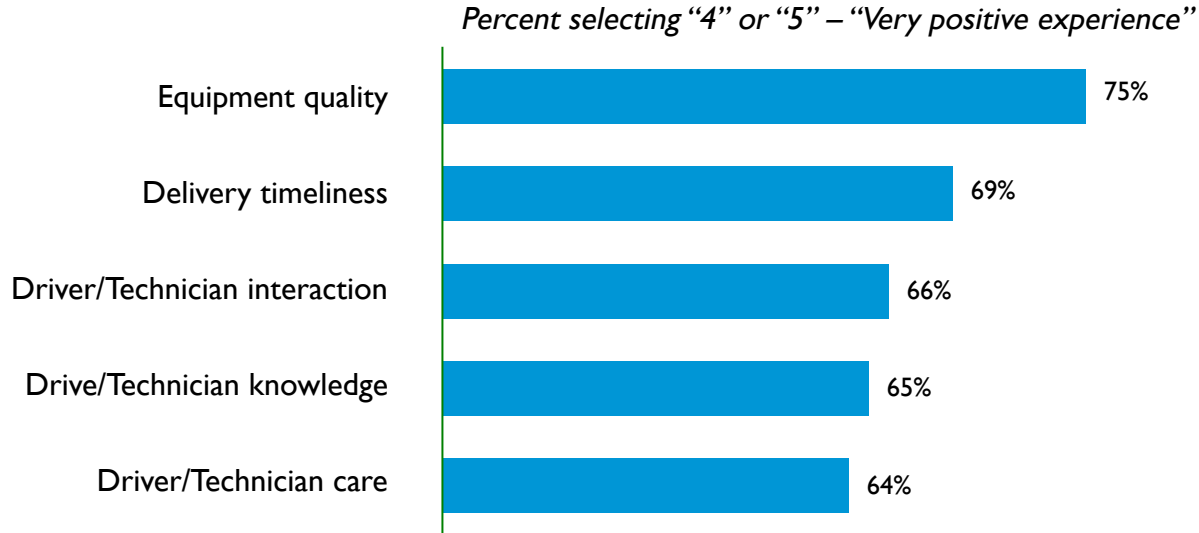


Q44: Are you familiar with durable medical equipment?

N = 2,009

Durable Medical Equipment

Equipment quality gets top marks.



Q47: Please rate your experience with the following aspects of durable medical equipment (such as hospital beds, oxygen tanks and concentrators, wheelchairs, etc.)

Base: Q44. Are you familiar with Durable Medical Equipment is Yes

N = 482-569

Durable Medical Equipment: Why do you give this rating?

Rating “1 - Very negative experience” or “2 - Negative experience”



- *“Wasn’t offered anything until too late for my mom who myself and husband had to take care of with very little help from anybody.”*
- *“Very expensive. If you don't have money it's going to be a problem.”*
- *“Negative experience with durable medical equipment coordination during Hospice service.”*
- *“Medical equipment was supposed to be delivered but all the pieces weren't in package, and they never delivered the rest of it so my mom starved and became dehydrated til death.”*

Q46: Why do you give this rating for durable medical equipment?

Durable Medical Equipment: Why do you give this rating?

Rating “5 - Very positive experience”

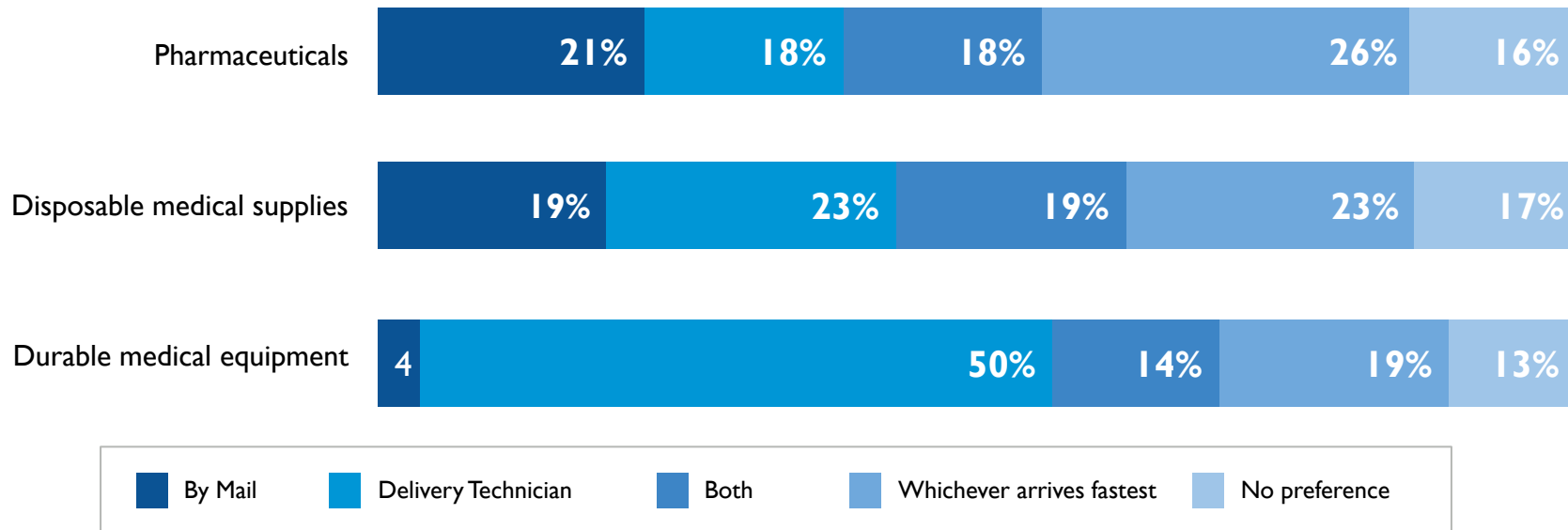


- *“Because when my brother died the had all the equipment we needed before he got home from the hospital.”*
- *“My dad was dying from cancer, we had hospice , they brought in everything he needed, hospital bed, all that and it was in great shape.”*
- *“Easy to obtain and helpful.”*
- *“It was delivered and picked up on time and it functioned well.”*
- *“Easy to use. The team that delivered walked us through how to use and a number to call with any questions day or night.”*
- *“Whatever equipment was needed was attainable & delivered to the house.”*
- *“It was easy to order and receive all of the durable medical equipment needed at home in a timely fashion.”*
- *“An adjustable hospital bed was provided and was a great comfort.”*
- *“Hospice delivered all of the medical equipment we needed so my grandmother would be comfortable at home.”*

Q46: Why do you give this rating for durable medical equipment?

Receiving Medical Equipment and Supplies

Respondents prefer to receive durable medical equipment from a delivery technician.



Q48. How would you prefer to receive the following items?
Base: Q44. Are you familiar with Durable Medical Equipment is Yes

N = 703

10

Respondent Profiles



Demographic Information

DEMOGRAPHIC	GROUP	COUNT	SAMPLE PROPORTION
GENDER	Male	996	50%
	Female	1,008	50%
AGE	Silent	148	7%
	Boomer	930	46%
	Gen X	737	37%
	Millennial	194	10%
RELIGION OR FAITH PRACTICED	Christianity	1,285	64%
	Judaism	65	3%
	Hinduism or Buddhism	34	2%
	Spirituality	105	5%
	Something Else	88	4%
	Not Spiritual or Religious	416	21%

Note: What religious practice or faith do you practice? Select all that apply, percentages may not sum to 100 percent.

Demographic Information

DEMOGRAPHIC	GROUP	COUNT	SAMPLE PROPORTION
ETHNICITY	Latino/Hispanic	334	17%
	Not Latino/Hispanic	1,675	83%
FIRST LANGUAGE	English	1,833	91%
	Another Language	176	9%
RACE	Non-Hispanic White	1,219	60%
	Black or African-American	270	16%
	American Indian or Alaska Native	16	1%
	Asian, Native Hawaiian or Pacific Islander	116	7%
	Another Race	54	3%

Note: Nearly all questions included a “prefer not to answer” option. The proportion selecting “prefer not to answer” is not presented above, so percentages may not sum to 100 percent.

Demographic Information

DEMOGRAPHIC	GROUP	COUNT	SAMPLE PROPORTION
HIGHEST LEVEL OF EDUCATION	HS Diploma, GED or Below	430	21%
	Some college	412	21%
	Associates	281	14%
	Bachelor's Degree	582	29%
	Master's or Professional Degree	265	13%
	Doctorate or Ph.D.	33	2%
HOUSEHOLD INCOME	Under \$49,000	872	44%
	\$50,000 - \$99,000	666	33%
	\$100,000 or more	770	19%

Note: Nearly all questions included a “prefer not to answer” option. The proportion selecting “prefer not to answer” is not presented above, so percentages may not sum to 100 percent.

Demographic Information

DEMOGRAPHIC	GROUP	COUNT	SAMPLE PROPORTION
HEALTH INSURANCE	Plan through employer	518	26%
	Plan through spouse's employer	164	8%
	Plan you purchased yourself	151	8%
	Medicare	748	37%
	Medicaid/State specific program	218	11%
	Somewhere else	4	0%
	Plan through parents	2	0%
	Through the military/VA	63	3%
	Not sure	15	1%
	Not covered	126	6%

Note: Nearly all questions included a “prefer not to answer” option. The proportion selecting “prefer not to answer” is not presented above, so percentages may not sum to 100 percent.

Thank you!



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