

OCTOBER 2019

## Help Wanted: Californians' Views and Experiences of Serious Illness and End-of-Life Care

# Introduction

Most people will experience serious illness at some point in their lives — as a patient, a caregiver, a family member, or a friend. In 2019, the California Health Care Foundation commissioned a statewide survey to better understand the type of medical care and services Californians would prefer to receive if they had a serious illness or if they were approaching the end of life, and to explore the experiences of those actually dealing with these issues themselves or with loved ones. *Help Wanted: Californians’ Views and Experiences of Serious Illness and End-of-Life Care* reports selected findings from this survey and highlights key differences by race/ethnicity and income level.

**KEY FINDINGS INCLUDE:**

- When palliative care was described to them, 9 in 10 Californians without a serious illness said they would want this type of care if they had a serious illness. Four in 10 of those with a serious illness said they receive this type of help.
- Among respondents with a serious illness, Californians with low incomes reported the highest level of interest in getting supports beyond disease treatment, compared to those with higher incomes.
- Over 9 in 10 respondents of all races/ethnicities and income levels said they would want “as much information as possible” if faced with a serious illness.
- Only 7% of Californians with low incomes who also have a serious illness said they were “very prepared” to deal with their illness if it got worse.
- Survey respondents reported that at the end of life, it would be extremely important to them that their families are not burdened — by treatment costs (70%), by making tough decisions about their care (60%), or by needing to take care of them (59%).
- A majority of respondents said they would prefer to die a natural death (63%) rather than have doctors attempt everything to prolong life (9%). More than 1 in 4 (28%) were not sure.
- More than two-thirds (71%) of respondents said they would want to die at home. However, just over a third of Californians who died in 2017 died at home (36%).

## Help Wanted

Californians’ Views and Experiences of Serious Illness and End-of-Life Care

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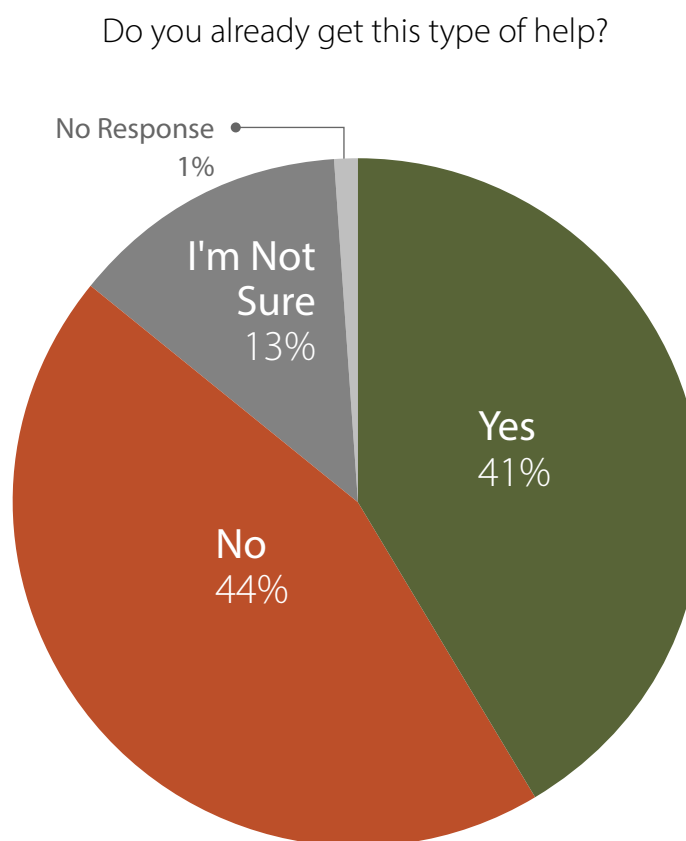
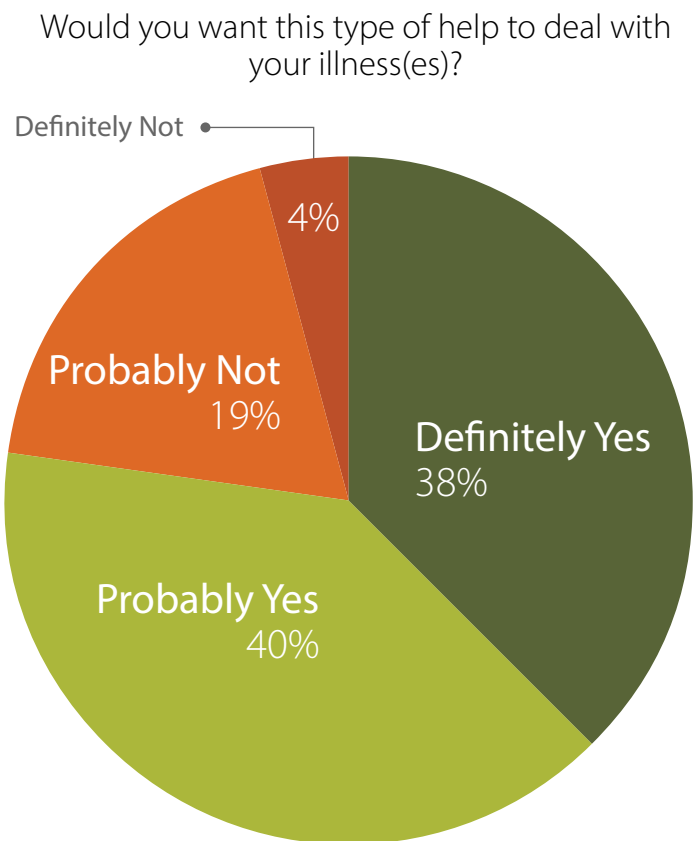
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# Interest in and Receipt of Palliative Care Services

California, 2019

Some people with a serious illness get extra help. This type of help is on top of regular medical care. It could be help with things like dealing with side effects or pain, dealing with stress and other hard feelings, figuring out how to live better with your illness, or finding out what services you might qualify for. Base: respondents with a serious illness (n = 588)



## Help Wanted

Palliative Care Preferences

Three in 4 survey respondents with a serious illness said they would want extra supports for physical and emotional needs that are typically part of palliative care. Four in 10 respondents reported receiving such assistance.

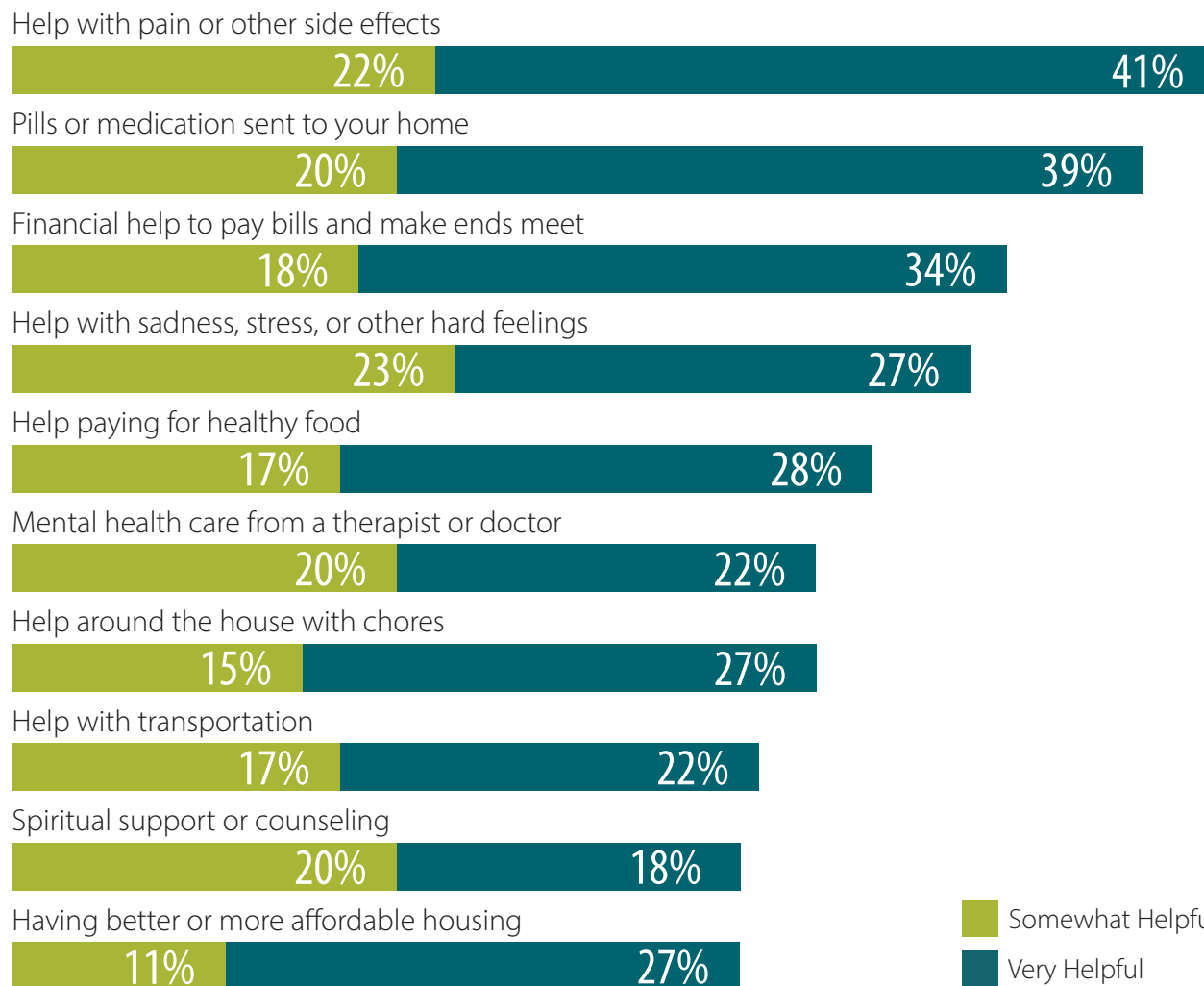
Note: Respondents with a serious illness include those who report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness. Segments may not total 100% due to rounding.

Source: Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

# Helpfulness of Supportive Services

## California, 2019

How helpful would this be for you as you deal with your illness(es)? Base: respondents with a serious illness (n = 588)



Note: Respondents with a serious illness include those who report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness.

Source: Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

### Help Wanted

Palliative Care Preferences

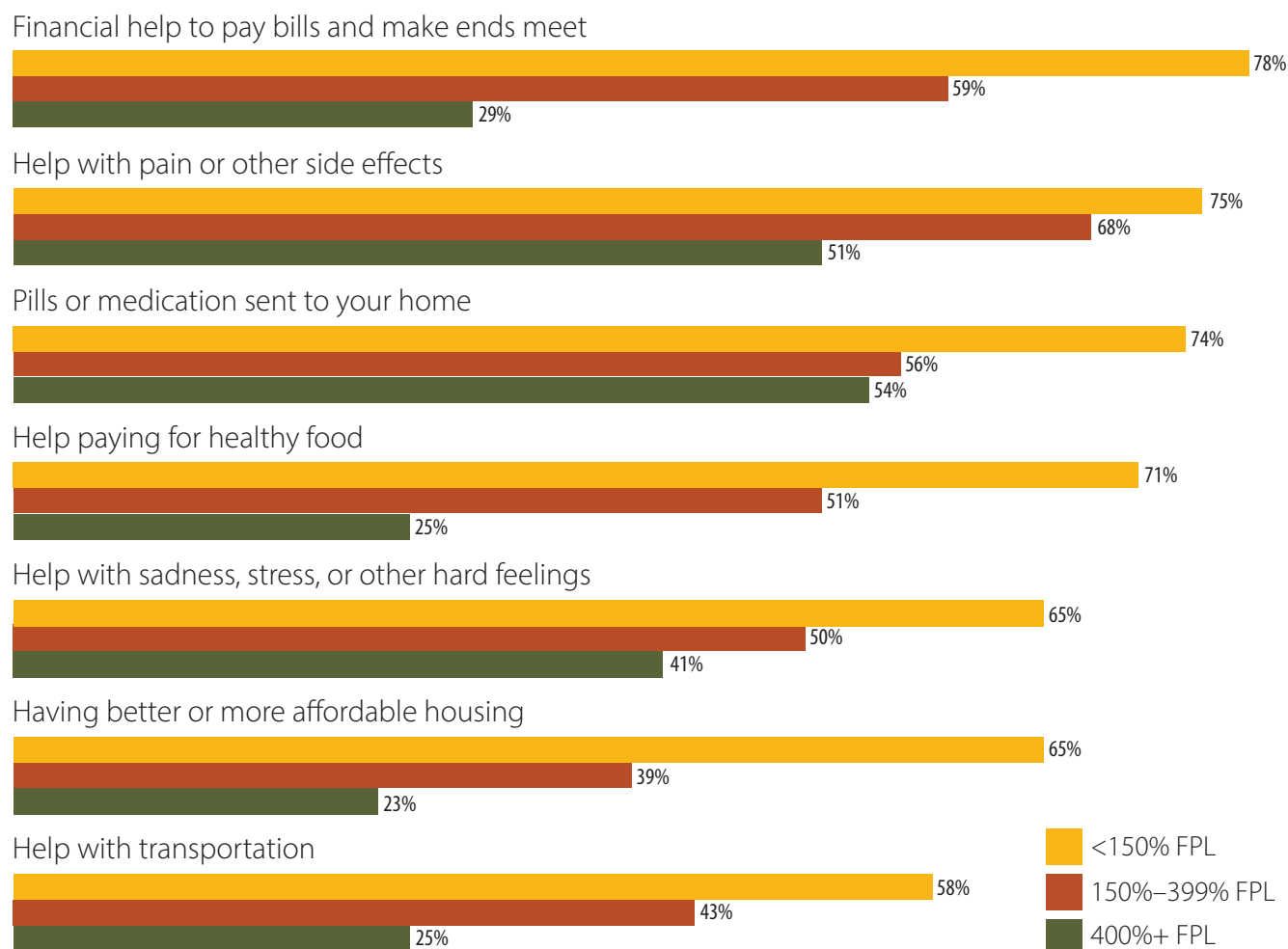
Californians with a serious illness report that various physical, emotional, logistical, and financial supportive services would be helpful. Nearly two-thirds of respondents said that getting help with pain or side effects would be very (41%) or somewhat (22%) helpful. About 6 in 10 said that getting medications sent to their home would be very (39%) or somewhat (20%) helpful.

# Helpfulness of Supportive Services, by Income Level

## California, 2019

PERCENTAGE RESPONDING “VERY HELPFUL” OR “SOMEWHAT HELPFUL”

How helpful would this be for you as you deal with your illness(es)? Base: respondents with a serious illness (n = 588)



Notes: Respondents with a serious illness include those who report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness. In 2019, the federal poverty level (FPL) was \$12,490 for a single person and \$25,750 for a household of four.

Source: Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

### Help Wanted

Palliative Care Preferences

Across all supportive services included in the survey, a higher proportion of low-income respondents with serious illness reported the helpfulness of these services compared to respondents with higher incomes. Three of four low-income respondents with a serious illness said that receiving financial assistance with bills, getting help with pain, and having pills sent home would be very or somewhat helpful.\*

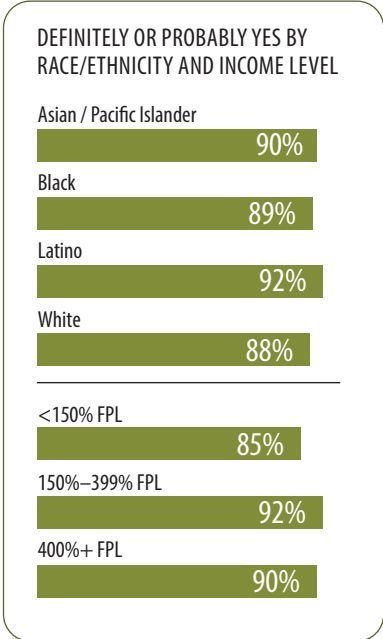
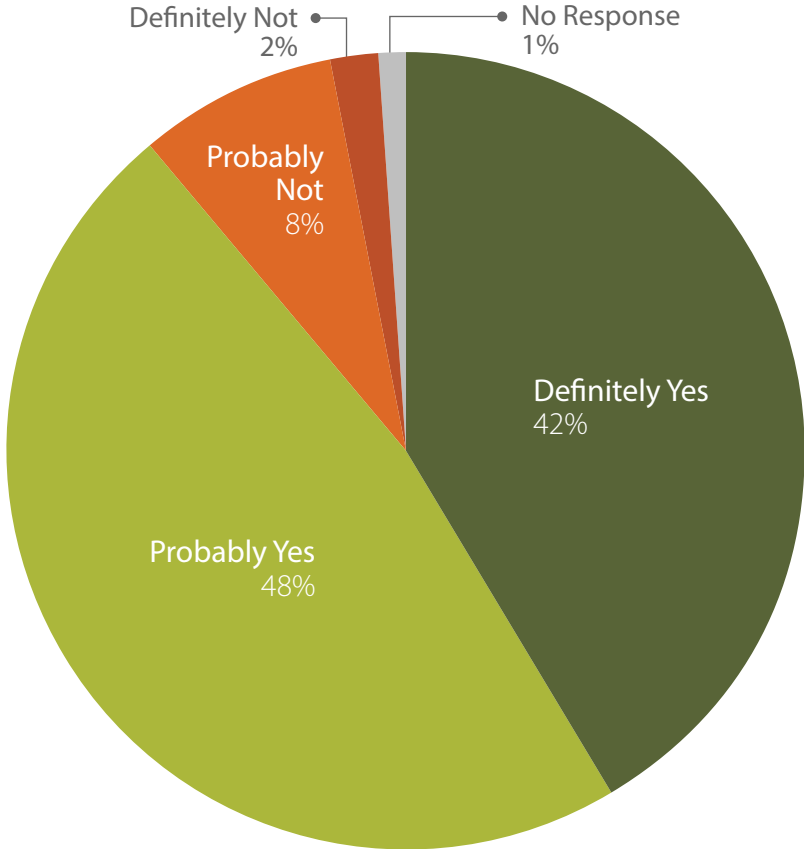
\* For more details see fact sheet *Extra Support Most Helpful to Low-Income Californians with Serious Illness* available at [www.chcf.org/helpwanted](http://www.chcf.org/helpwanted).

# Interest in Palliative Care Services

## California, 2019

DO YOU THINK YOU WOULD WANT THIS TYPE OF HELP IF YOU HAD A SERIOUS ILLNESS, LIKE CANCER?

Some people with a serious illness get extra help. This type of help is on top of regular medical care. It could be help with things like dealing with side effects or pain, dealing with stress and other hard feelings, figuring out how to live better with your illness, or finding out what services you might qualify for. Do you think you would want this type of help if you had a serious illness, like cancer? Base: respondents without a serious illness (n = 2,000)



### Help Wanted

Palliative Care Preferences

Nine in 10 survey respondents without a serious illness said they would want assistance beyond regular medical care — the kinds of supports provided by palliative care — if they had a serious illness. This broad interest was consistently reported across race/ethnicity and income.

Notes: Respondents without a serious illness are those who do not report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness. In 2019, the federal poverty level (FPL) was \$12,490 for a single person and \$25,750 for a household of four. Segments may not total 100% due to rounding.

Source: Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

# Interest in Aspects of Palliative Care California, 2019

## PERCENTAGE RESPONDING YES

*If you had a serious illness, would you want any of your doctors or health care providers to . . . Base: respondents without a serious illness (n = 2,000)*

Talk about both the good and bad things that could happen with your treatment(s)?

93%

Talk about what to expect if your illness gets worse?

93%

Do everything they can to help with pain or side effects?

92%

Talk about how to make your life better as you live with your illness?

90%

Talk about any fear, stress, or sadness you may be feeling?

89%

Ask what is most important for you as you live your life with your illness?

88%

Note: Respondents without a serious illness are those who do not report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness.

Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

## Help Wanted

Palliative Care Preferences

The vast majority of respondents without a serious illness expressed interest in receiving the kinds of services that are typically provided as part of palliative care. Nine in 10 would want to discuss what to expect if their illness got worse, good and bad impacts of treatment, and how to live better with their illness. This high level of interest contrasts with experiences reported by respondents with serious illness (see page 8).

# Experiences with Aspects of Palliative Care California, 2019

## PERCENTAGE RESPONDING YES

Have any of your health care providers . . . Base: respondents with a serious illness (n = 588)

Talked about both the good and bad things that could happen with your treatment(s)?

65%

Talked about how to make your life better as you live with your illness?

58%

Talked about what to expect if your illness gets worse?

49%

Done everything they can to help with pain or side effects?

45%

Asked what is most important for you as you live your life with your illness?

36%

Talked about any fear, stress, or sadness you may be feeling?

35%

Note: Respondents with a serious illness include those who report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness.

Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

## Help Wanted

Palliative Care Preferences

Nearly two-thirds of California respondents with a serious illness reported that providers have talked about both the good and bad things that could happen with treatment. Other important discussions about aspects of living with serious illness were reported less frequently.

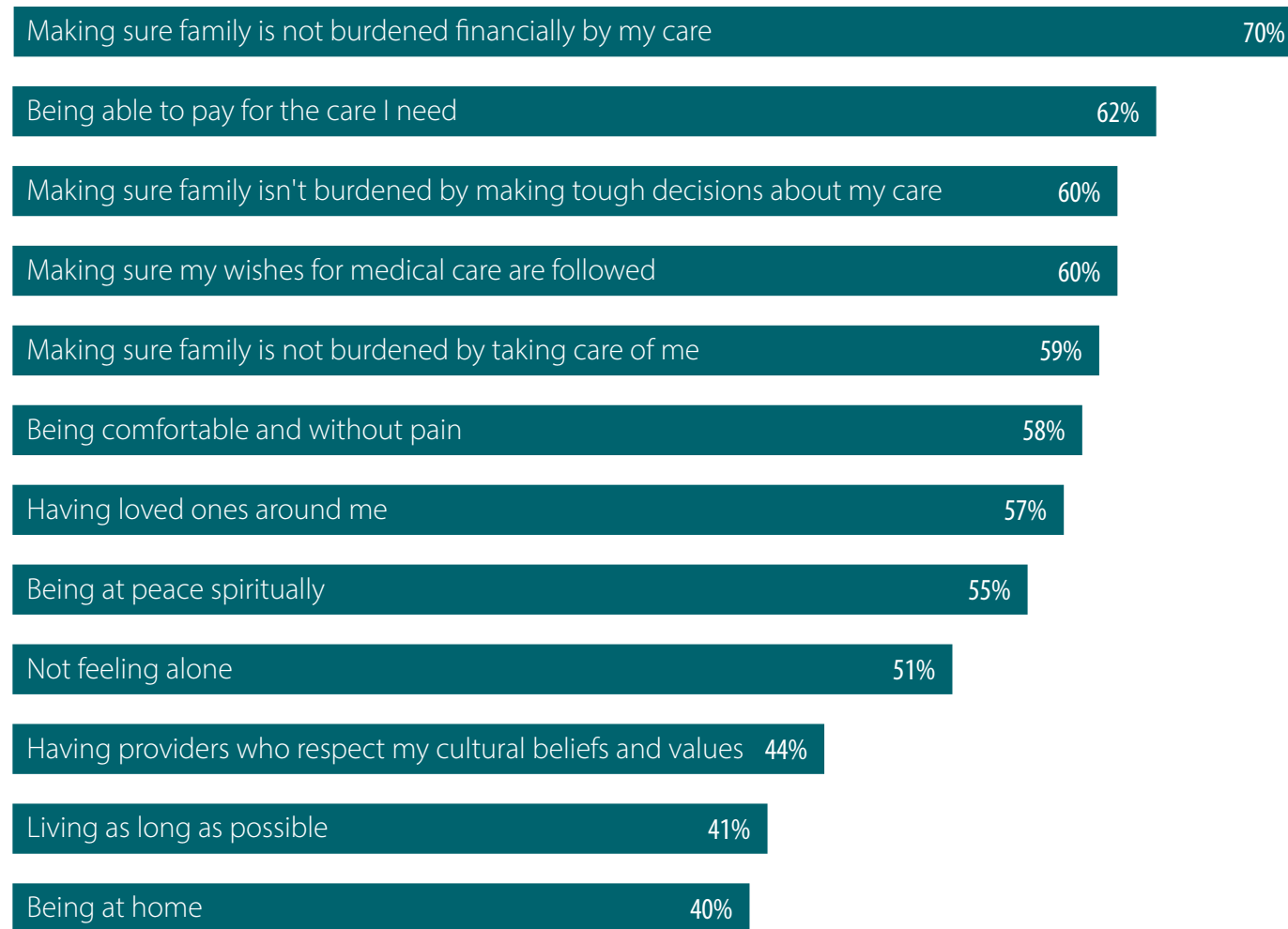


# Most Important Factors at End of Life

## California, 2019

PERCENTAGE RESPONDING “EXTREMELY IMPORTANT”

How important is each of the following to you at the end of your life? Base: all respondents (n = 2,588)



Notes: Question is based on a 1-to-7 scale, from 1 being “not at all important” to 7 being “extremely important.” Data reflect the percentage of respondents who rated each response a 7. Additional responses included: “A close relationship with my doctor” (32%), “Seeing friends or family I have not seen in a long time” (25%), and “Going back to my hometown or country where I’m from” (15%).

Source: *Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

### Help Wanted

End-of-Life Preferences

Californians are most likely to say a top preference at the end of life is that their family members are not burdened by health care costs and decisions. Survey respondents also noted that being able to pay for the care they need and making sure their wishes are followed were extremely important.

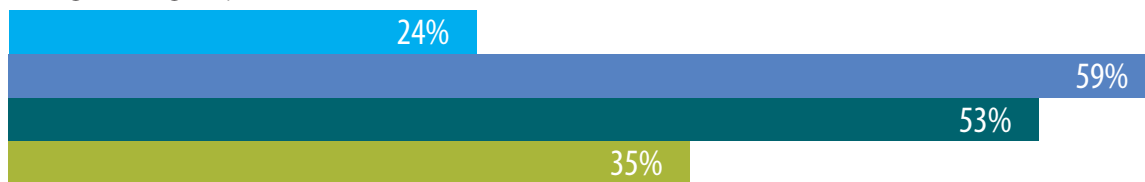
# Variation in End-of-Life Preferences, by Race/Ethnicity

## California, 2019

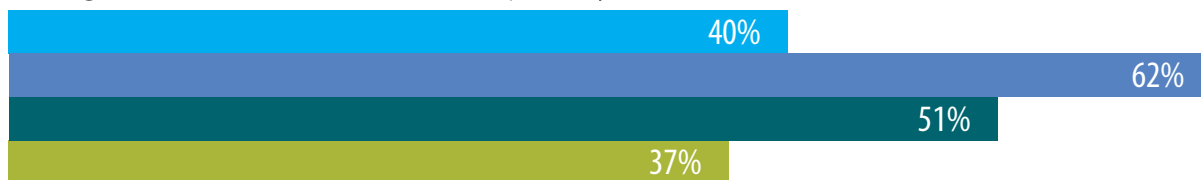
PERCENTAGE RESPONDING “EXTREMELY IMPORTANT”

How important is each of the following to you at the end of your life? Base: all respondents (n = 2,588)

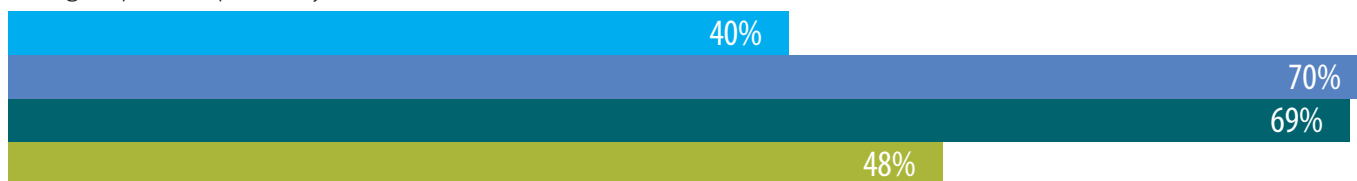
Living as long as possible



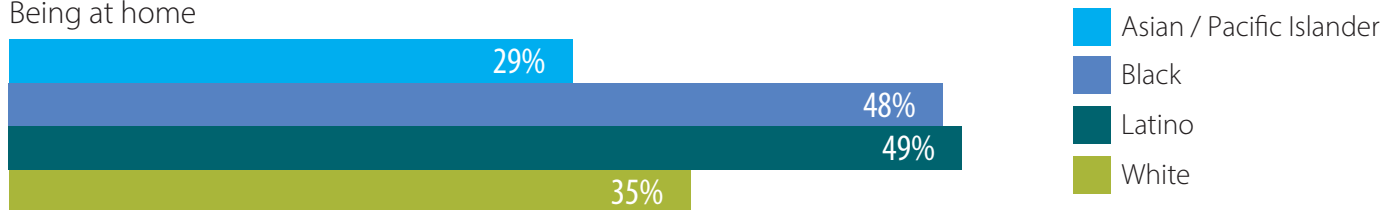
Having doctors and nurses who will respect my cultural beliefs and values



Being at peace spiritually



Being at home



Notes: Question is based on a 1-to-7 scale, from 1 being “not at all important” to 7 being “extremely important.” Data reflect the percentage of respondents who rated each a 7.

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

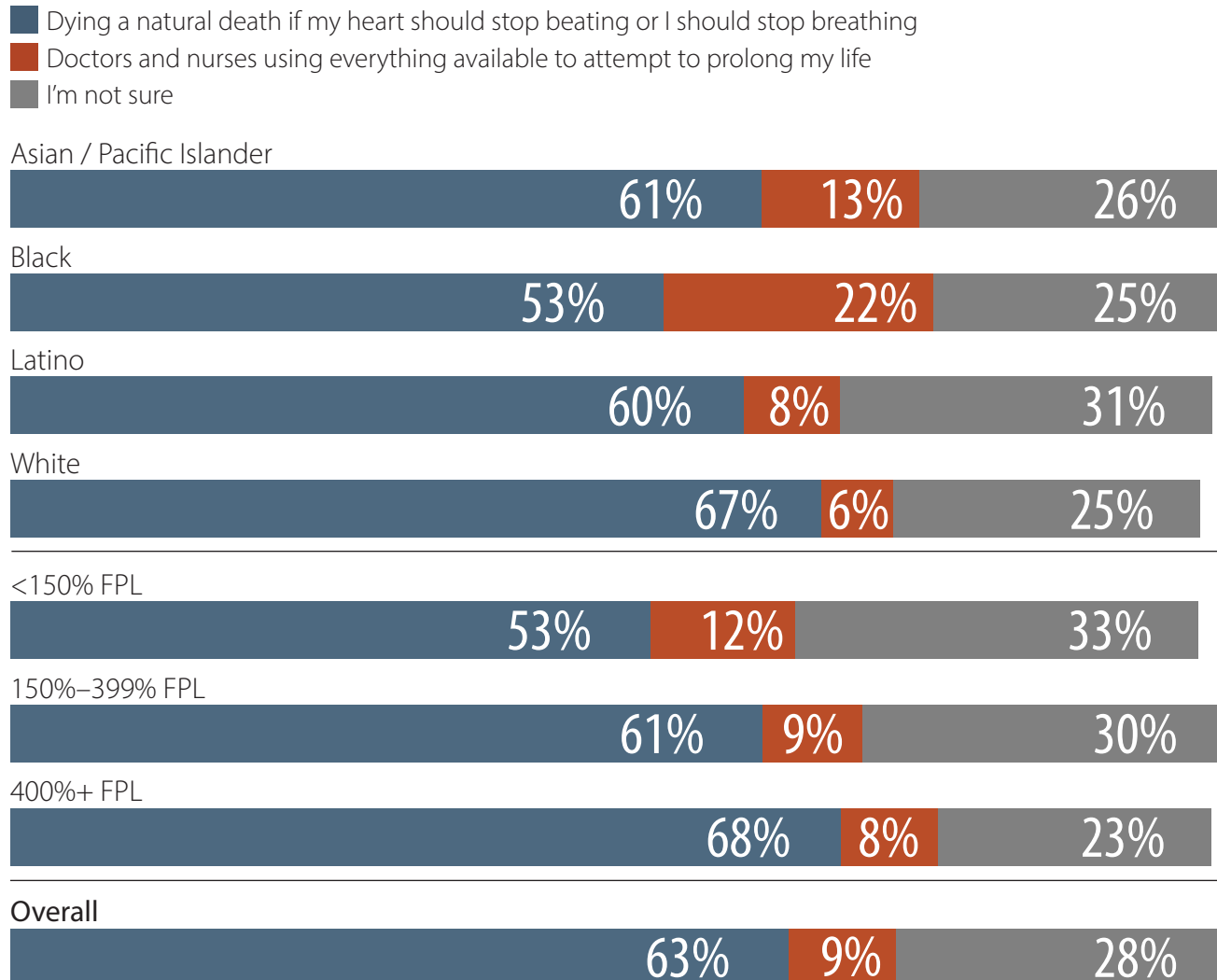
### Help Wanted

End-of-Life Preferences

While there was general agreement on the most important factors at the end of life across racial and ethnic groups, some factors were more important to some groups. Latino and Black Californians were particularly likely to prioritize spiritual peace and culturally respectful providers, as well as living as long as possible and being at home.

# Preferences Around Prolonging Life, by Race/Ethnicity and Income Level, California, 2019

If you had an advanced illness, which would you prefer? Base: all respondents (n = 2,588)



Notes: In 2019, the federal poverty level (FPL) was \$12,490 for a single person and \$25,750 for a household of four. Nonresponders not shown. Segments may not total 100% due to nonresponse or rounding.

Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

## Help Wanted

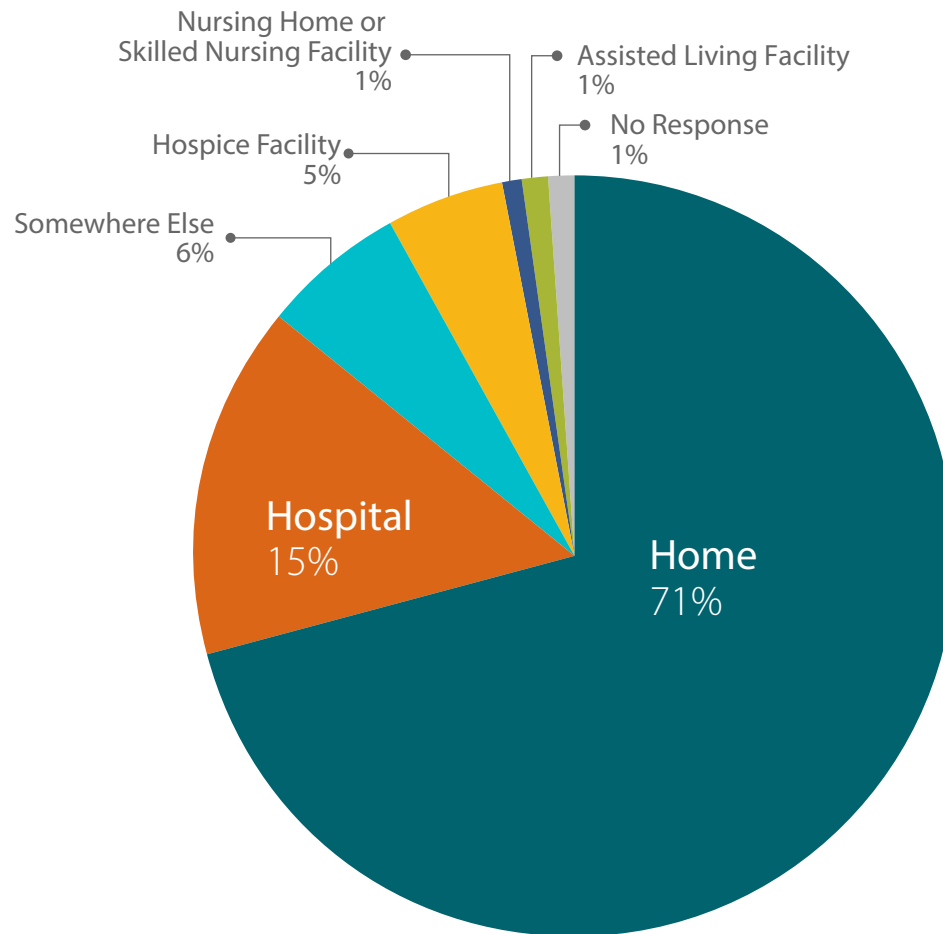
### End-of-Life Preferences

More than 6 in 10 Californians surveyed prefer dying a natural death, compared to about 1 in 10 who would want to receive all possible care to prolong life. Black respondents (22%) were more likely to prefer prolonging life than other racial/ethnic groups. Across all racial/ethnic groups, at least 1 in 4 were not sure.

# Preferred Location of Death

## California, 2019

If given a choice at the end of your life, where would you want to be when you die? Base: all respondents (n = 2,588)



Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

### Help Wanted

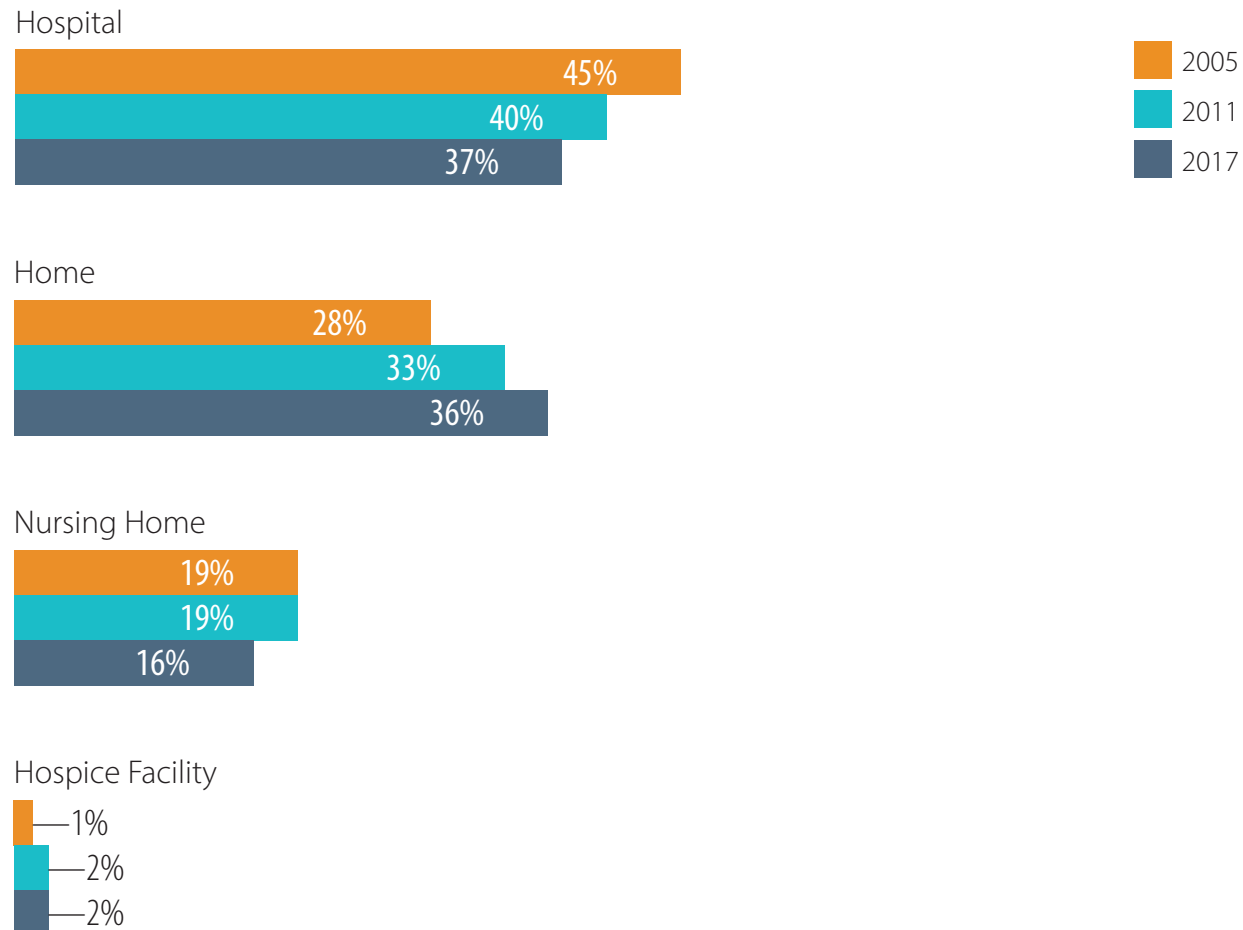
End-of-Life Preferences

A large majority of Californians would prefer to die at home rather than in a health care facility. The proportion wanting to die at home is consistent with CHCF's 2011 survey findings (70%).\*

\* Lake Research Partners and Coalition for Compassionate Care of California, *Final Chapter: Californians' Attitudes and Experiences with Death and Dying*, February 2012, [www.chcf.org](http://www.chcf.org).

# Location of Death

California, 2005, 2011, and 2017



Notes: *Hospital* includes inpatient, outpatient, emergency room, or dead on arrival at hospital. *Other* and *place of death unknown* are not shown.

Source: Multiple Cause of Death files (1999–2017), CDC WONDER Online Database, Centers for Disease Control and Prevention, accessed September 4, 2019, <http://wonder.cdc.gov>.

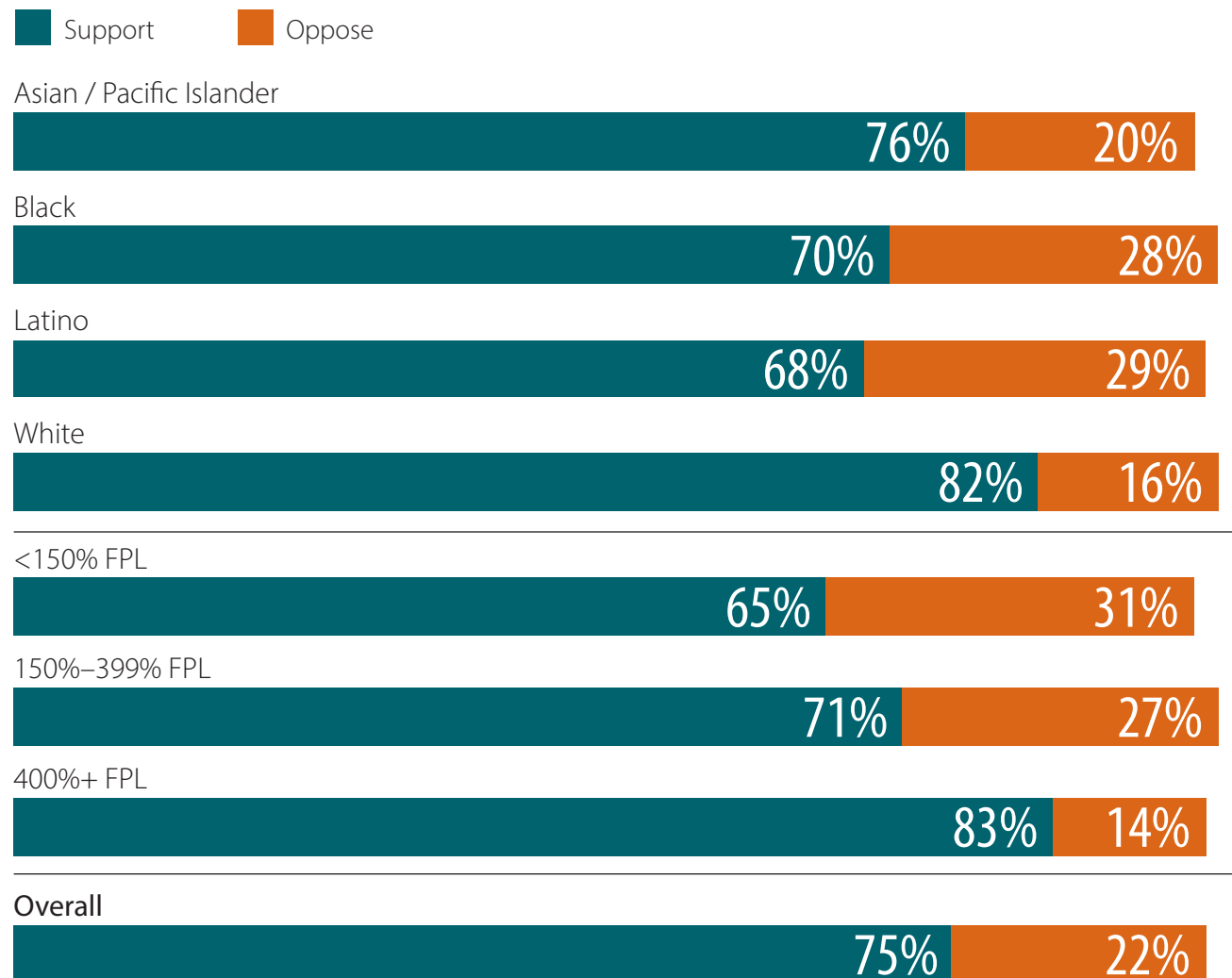
## Help Wanted

End-of-Life Preferences

Despite the survey finding that 71% of Californians would prefer to die at home, only 36% of Californians who died in 2017 did so at home. The proportion of Californians dying at home has increased since 2005, while the proportion who died in the hospital decreased from 45% in 2005 to 37% in 2017.

# Views of the End of Life Option Act, by Race/Ethnicity and Income Level, California, 2019

In June 2016, the End of Life Option Act became law in California. This state law gives some terminally ill adults the option to take life-ending medication prescribed by a doctor. Do you support or oppose people having this option? Base: all respondents (n = 2,588)



Notes: In 2019, the federal poverty level (FPL) was \$12,490 for a single person and \$25,750 for a household of four. Nonresponders not shown. Segments may not total 100% due to nonresponse or rounding.

Source: Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

## Help Wanted

End-of-Life Preferences

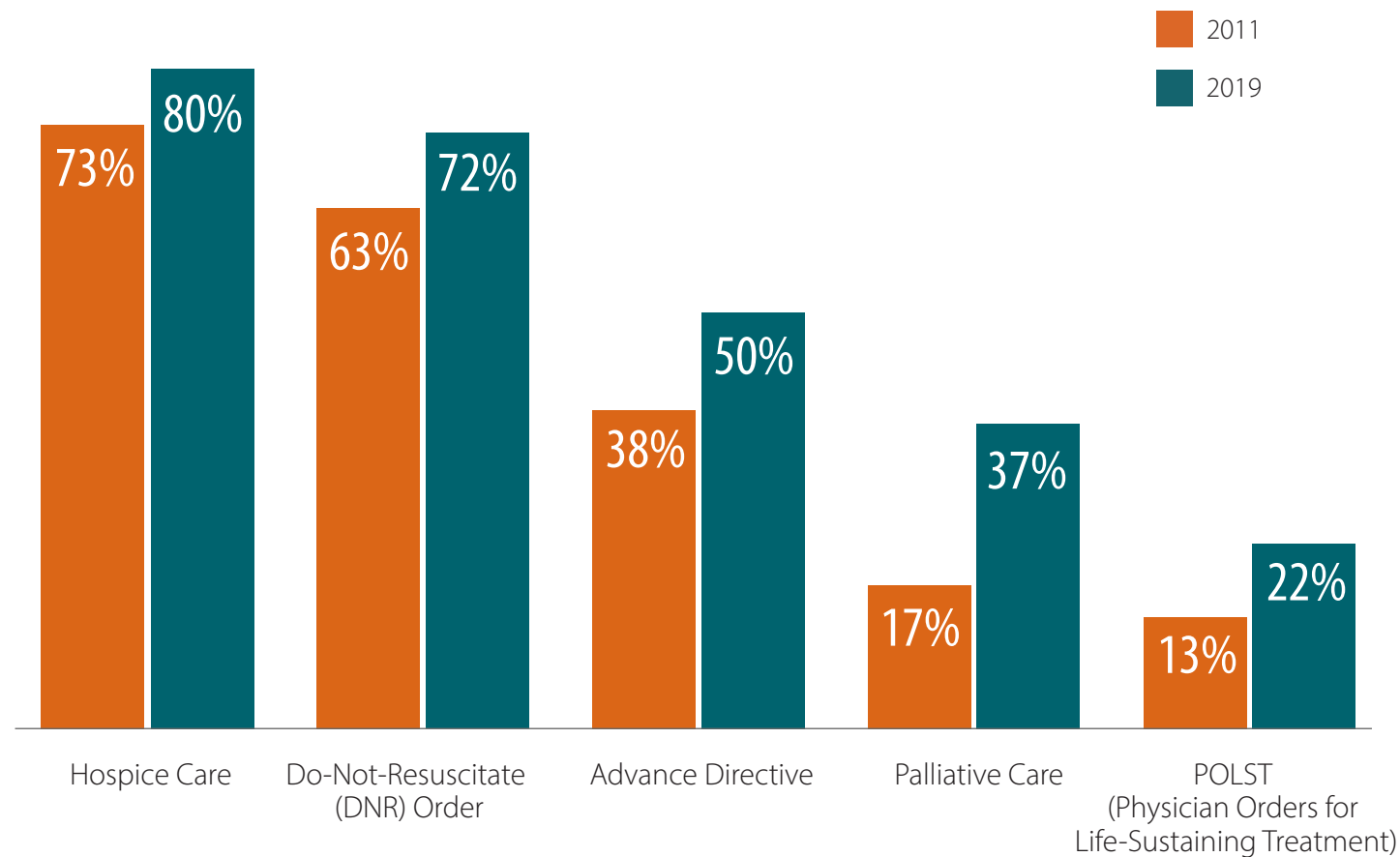
Three in four Californians surveyed support the End of Life Option Act, the California state law that gives some terminally ill adults the option to take life-ending medication prescribed by a physician. Support of this act varied by race/ethnicity and income, with the highest levels of support among white respondents and those respondents at or above 400% of the federal poverty level (FPL).

# Awareness of Serious Illness and End-of-Life Terms

## California, 2011 and 2019

PERCENTAGE RESPONDING YES

Have you ever heard of any of the following terms? Base: all respondents (n = 2,588)



### Help Wanted

Preparedness

In 2019, a higher percentage of Californians surveyed indicated they were familiar with terms related to serious illness and end-of-life care than in 2011.\* While four in five survey respondents had heard of hospice care in 2019, less than two in five respondents had heard of palliative care, and about one in five had heard of POLST (Physician Orders for Life-Sustaining Treatment).

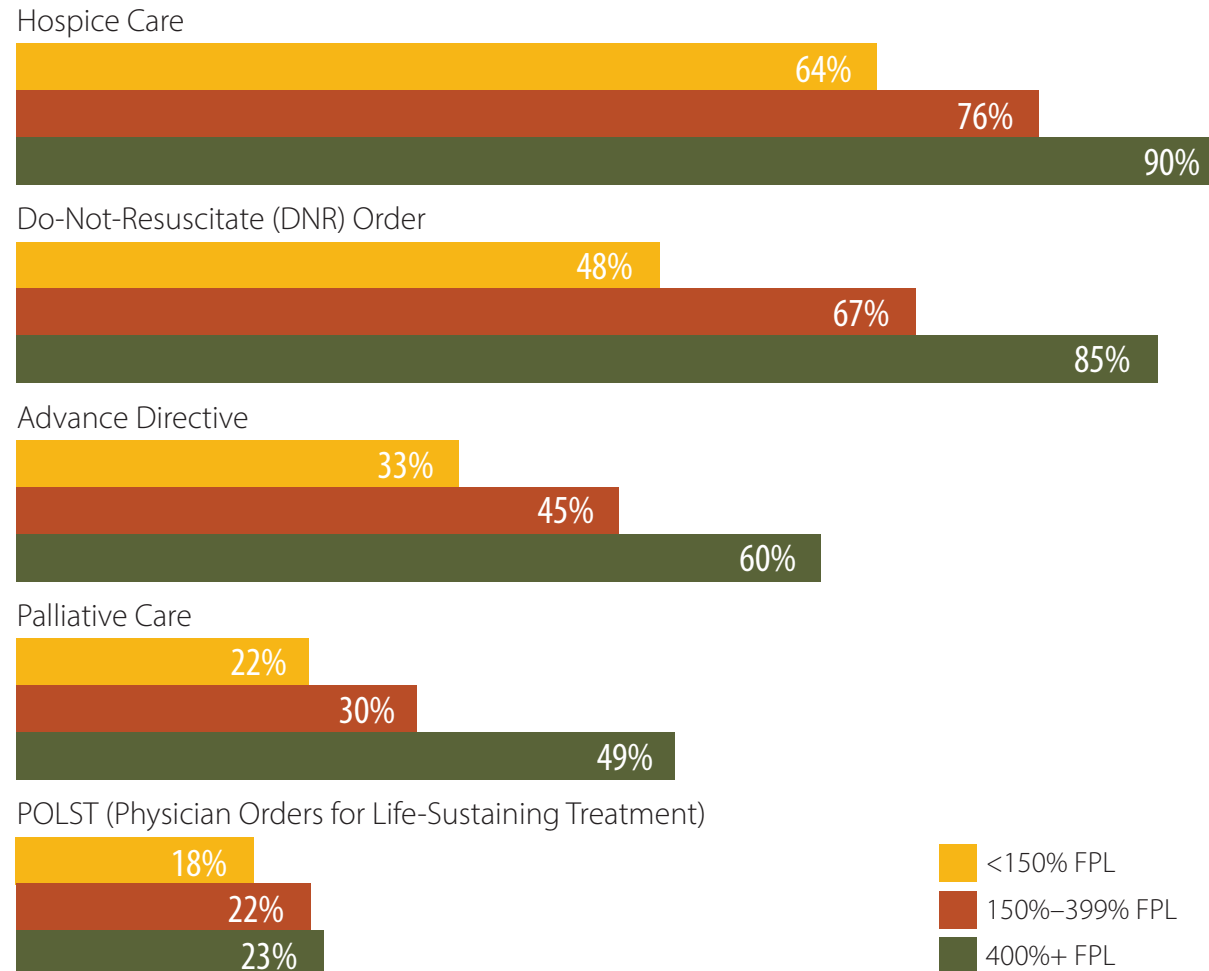
\* Lake Research Partners and Coalition for Compassionate Care of California, Final Chapter: Californians' Attitudes and Experiences with Death and Dying, February 2012, [www.chcf.org](http://www.chcf.org).

Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

# Awareness of Serious Illness and End-of-Life Terms, by Income Level, California, 2019

PERCENTAGE RESPONDING YES

Have you ever heard of any of the following terms? Base: all respondents (n = 2,588)



Note: In 2019, the federal poverty level (FPL) was \$12,490 for a single person and \$25,750 for a household of four.

Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

## Help Wanted

Preparedness

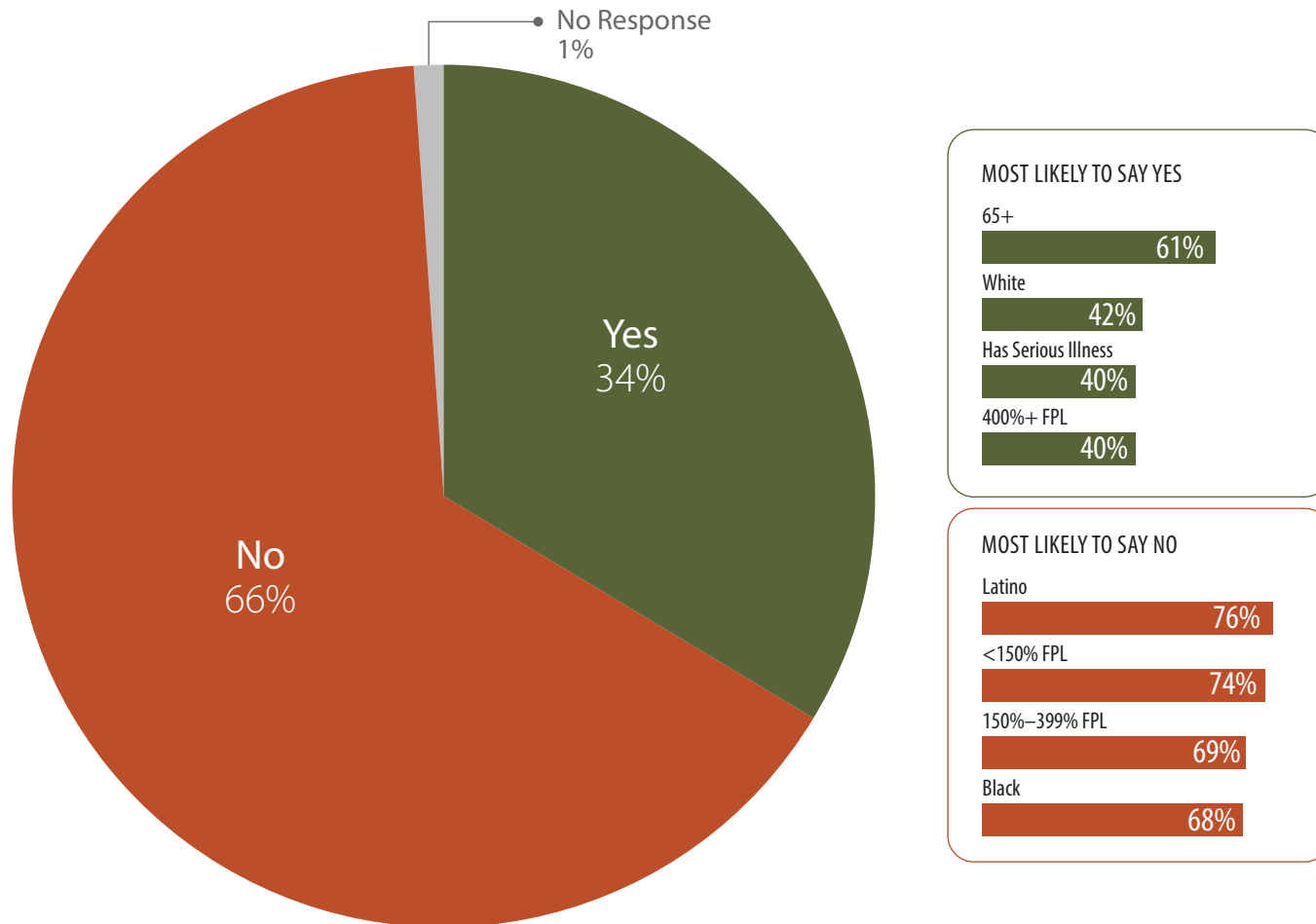
Familiarity with terms related to serious illness and end-of-life care varied across income levels. Survey respondents under 150% of the federal poverty level (FPL) were least familiar with each term, while respondents at or above 400% FPL were most familiar with each term. Across income groups, the highest level of familiarity was with hospice care and the lowest was with POLST (Physician Orders for Life-Sustaining Treatment).



# End-of-Life Wishes in Writing, by Demographic Groups

## California, 2019

Do you have any of your wishes regarding the medical treatment you would want in a written document? Base: all respondents (n = 2,588)



Note: In 2019, the federal poverty level (FPL) was \$12,490 for a single person and \$25,750 for a household of four. Respondents with a serious illness include those who report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness. Segments may not total 100% due to rounding.

Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

### Help Wanted

Preparedness

Two-thirds of Californians surveyed do not have their end-of-life wishes in writing. Older adults are most likely to say they have written documentation of their wishes. Latino respondents and those under 150% of the federal poverty level (FPL) were most likely to say they do not have wishes in writing. The proportion of survey respondents who reported having their wishes in writing (34%) was higher than in CHCF's 2011 survey (23%).\*

\* Lake Research Partners and Coalition for Compassionate Care of California, *Final Chapter: Californians' Attitudes and Experiences with Death and Dying*, February 2012, [www.chcf.org](http://www.chcf.org).

# Barriers to Documenting End-of-Life Wishes

## California, 2019

PERCENTAGE RESPONDING YES

*Are any of these a reason you do not have your wishes in writing? Base: respondents who do not have their wishes in writing (n = 1,633)*

I trust my family to make decisions for me

47%

I'm too busy right now with other things

42%

I don't want to think about death or dying

41%

I don't know how to put wishes in a legal document

34%

A legal document is too permanent

16%

Doctors might not give me care that could help

15%

I don't know why I would need this

14%

### Help Wanted

Preparedness

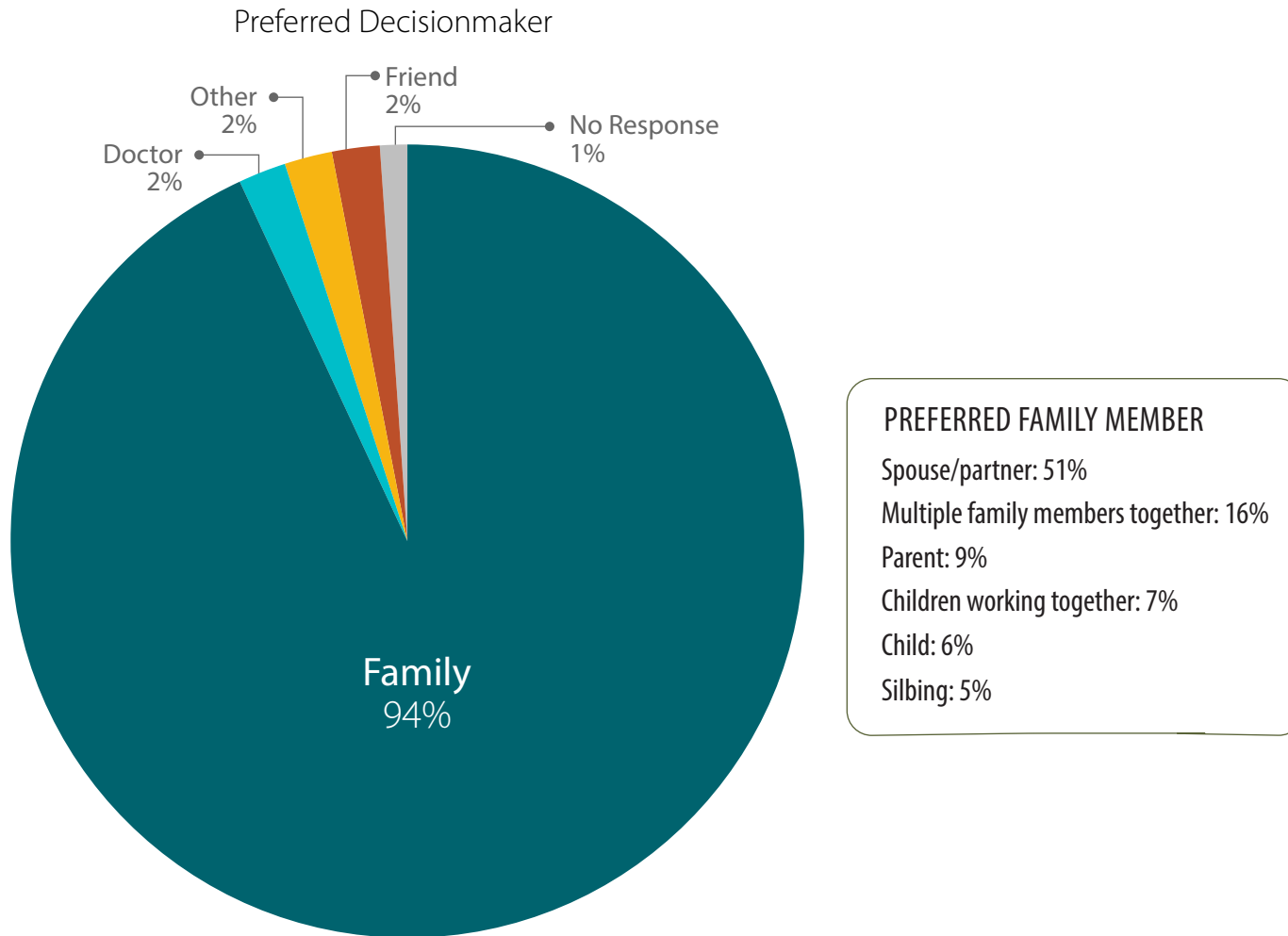
Among survey respondents who had not put their end-of-life wishes in writing, the main reasons for not doing so included having trust in family members to make decisions, feeling too busy, and not wanting to think about death or dying.

Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

# Preferred Decisionmaker

## California, 2019

Let's say you were not able to make decisions about your care near the end of your life. Who would you want to make decisions about your care? Base: all respondents (n = 2,588)



Notes: The full question asked was, "Let's say you were not able to make decisions about your care near the end of your life. Your doctor says there are different options. Someone has to decide for you. Who would you want to make decisions about your care?" Segments may not total 100% due to rounding.

Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

### Help Wanted

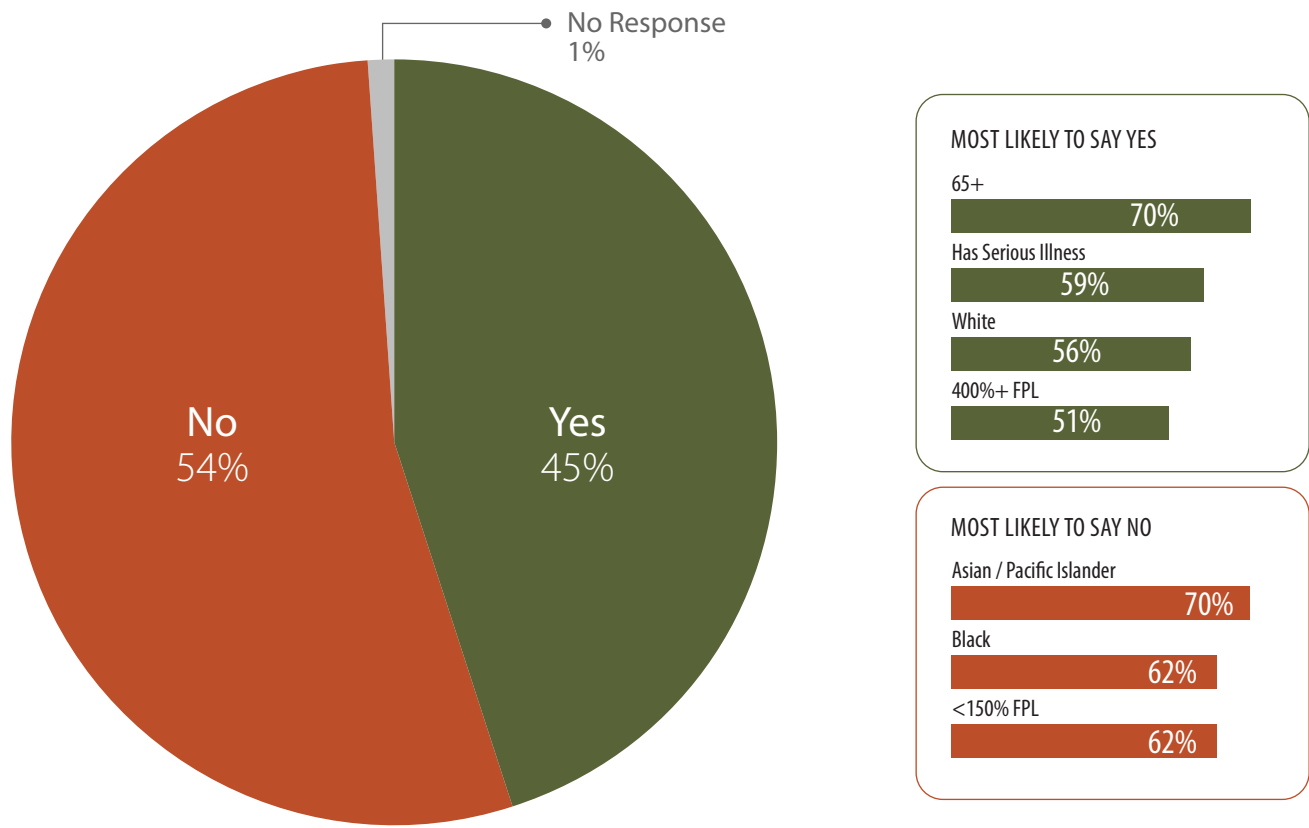
Preparedness

Nearly all Californians surveyed would want family members to make decisions about their care near the end of life, if they were unable to make decisions for themselves. Half reported wanting their spouse or partner to make those decisions.

# Discussed End-of-Life Wishes, by Demographic Groups

## California, 2019

Have you talked with this person (preferred decisionmaker) about the kind of medical care you would want near the end of your life? Base: all respondents (n = 2,588)



Notes: Respondents with a serious illness include those who report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness. In 2019, the federal poverty level (FPL) was \$12,490 for a single person and \$25,750 for a household of four.

Source: Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

### Help Wanted

Preparedness

Slightly less than half of survey respondents have talked with their preferred decisionmaker about the kind of medical care they would want near the end of life. Respondents age 65 and older and those with a serious illness were most likely to have discussed their wishes with their preferred decisionmaker. Asian / Pacific Islander, Black, and low-income respondents were least likely to have had these discussions.

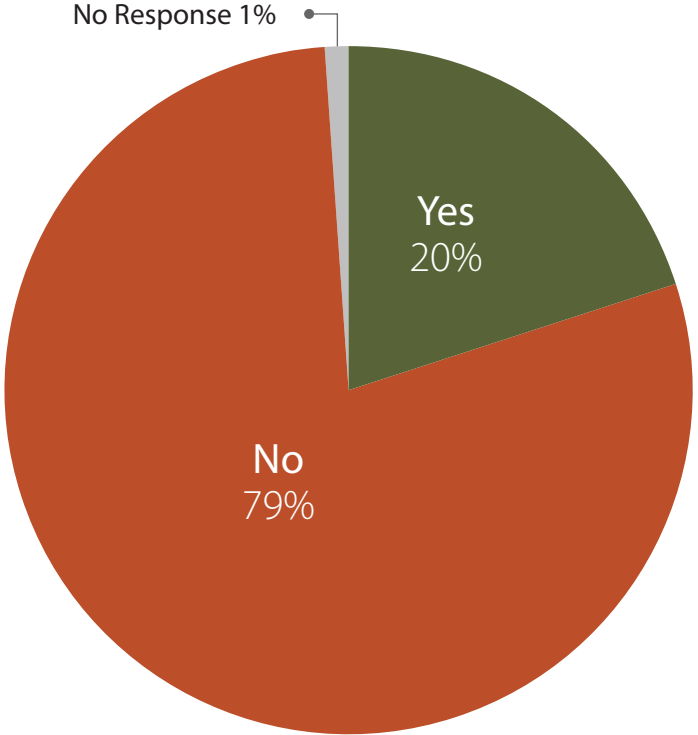
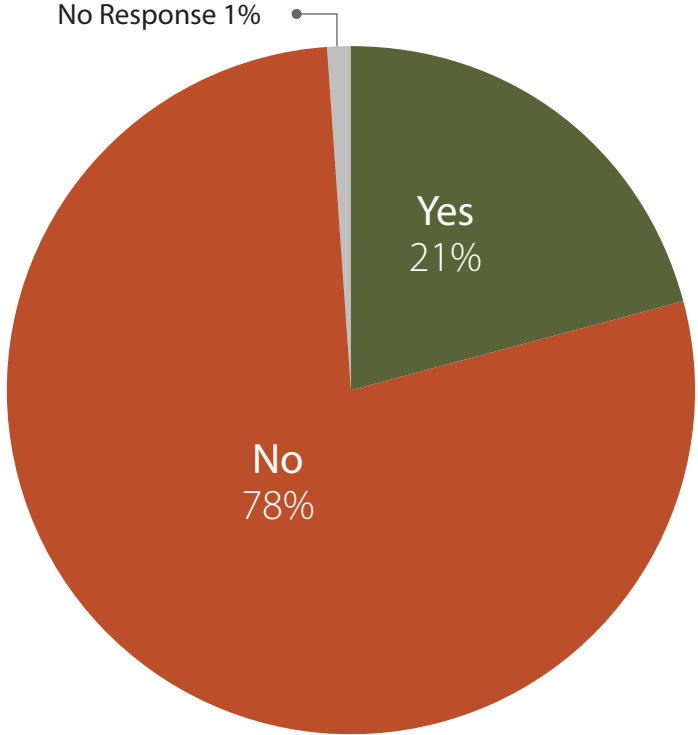
# Doctor Has Asked About End-of-Life Wishes

## California, 2019

Have you ever had a doctor ask you about your wishes for medical treatment at the end of your life?

Among Those with a Serious Illness  
Base: respondents with a serious illness (n = 588)

Among Those Age 65 and Older  
Base: respondents age 65+ (n = 553)



### Help Wanted Preparedness

One in five survey respondents with a serious illness and one in five respondents age 65 or older reported that their doctor has asked about their end-of-life wishes. Among all respondents, about 1 in 10 (9%) said that their doctor had asked about end-of-life wishes (not shown).

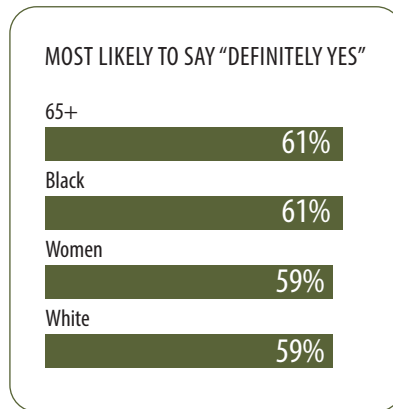
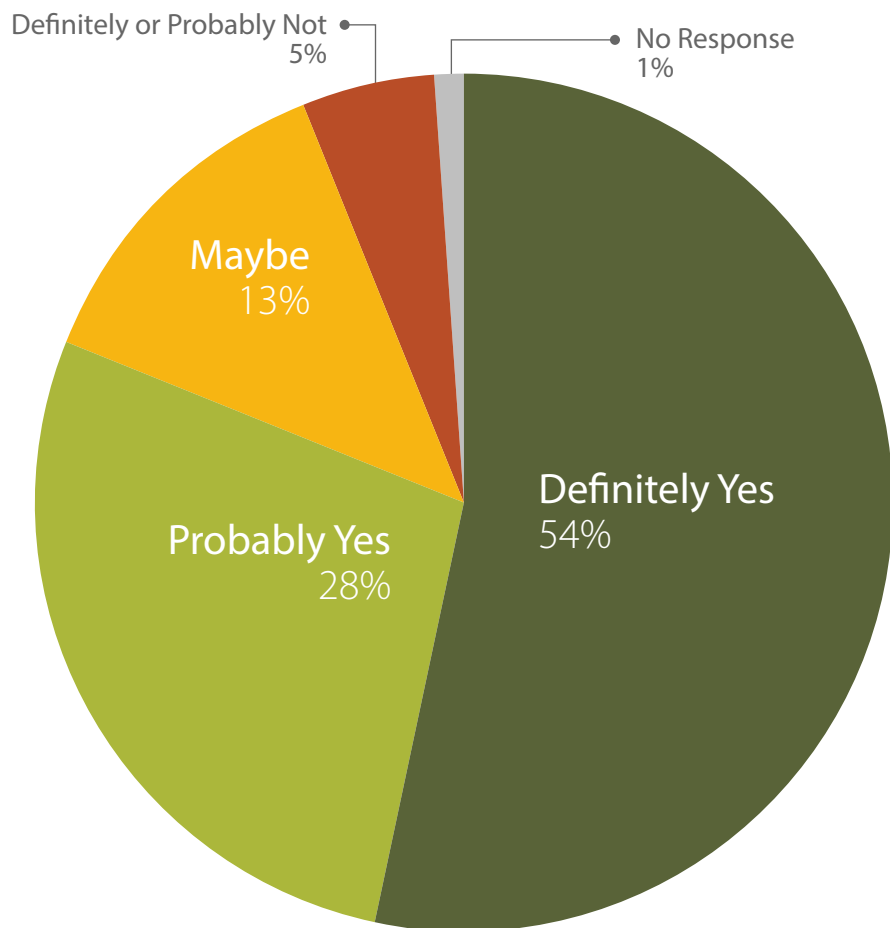
Notes: Respondents with a serious illness include those who report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness.

Source: Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

# Would Like to Talk to Doctor About End-of-Life Wishes

## California, 2019

If you were seriously ill, would you like to talk with your doctor about your wishes for medical treatment towards the end of your life? Base: all respondents (n = 2,588)



### Help Wanted

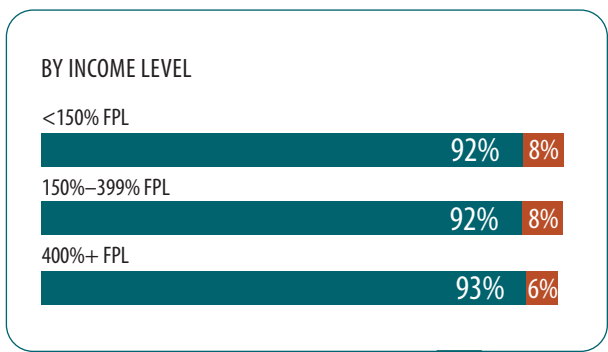
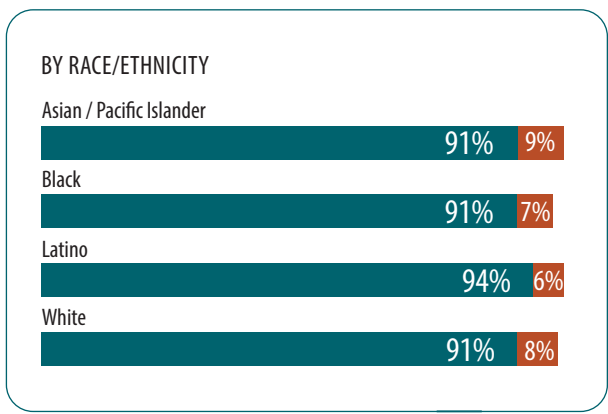
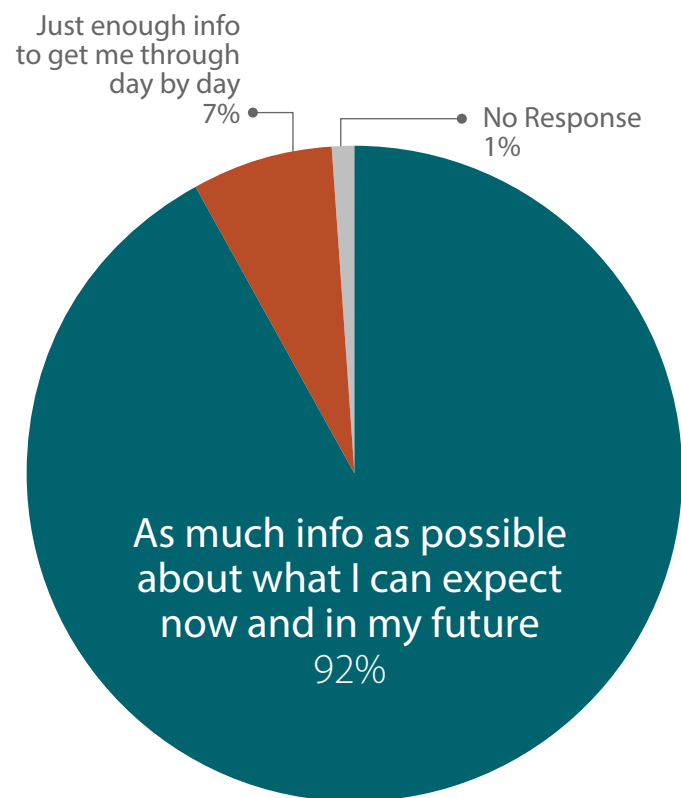
Preparedness

About four in five Californians surveyed said they would definitely (54%) or probably (28%) want to talk with their doctor about their wishes for medical treatment toward the end of life. Older adults, Black respondents, women, and white respondents were most likely to say they would definitely want to talk with their doctor about their wishes.

Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019. Segments may not total 100% due to rounding.

# Information Preferences Around Serious Illness, by Race/Ethnicity and Income Level, California, 2019

If you had a serious illness, how much information would you want from your health care provider? Base: respondents without a serious illness (n = 2,000)



## Help Wanted

Preparedness

About 9 in 10 Californians without a serious illness reported that they would like as much information as possible from their health care provider if they had a serious illness. Results were consistent across income levels and racial/ethnic groups.

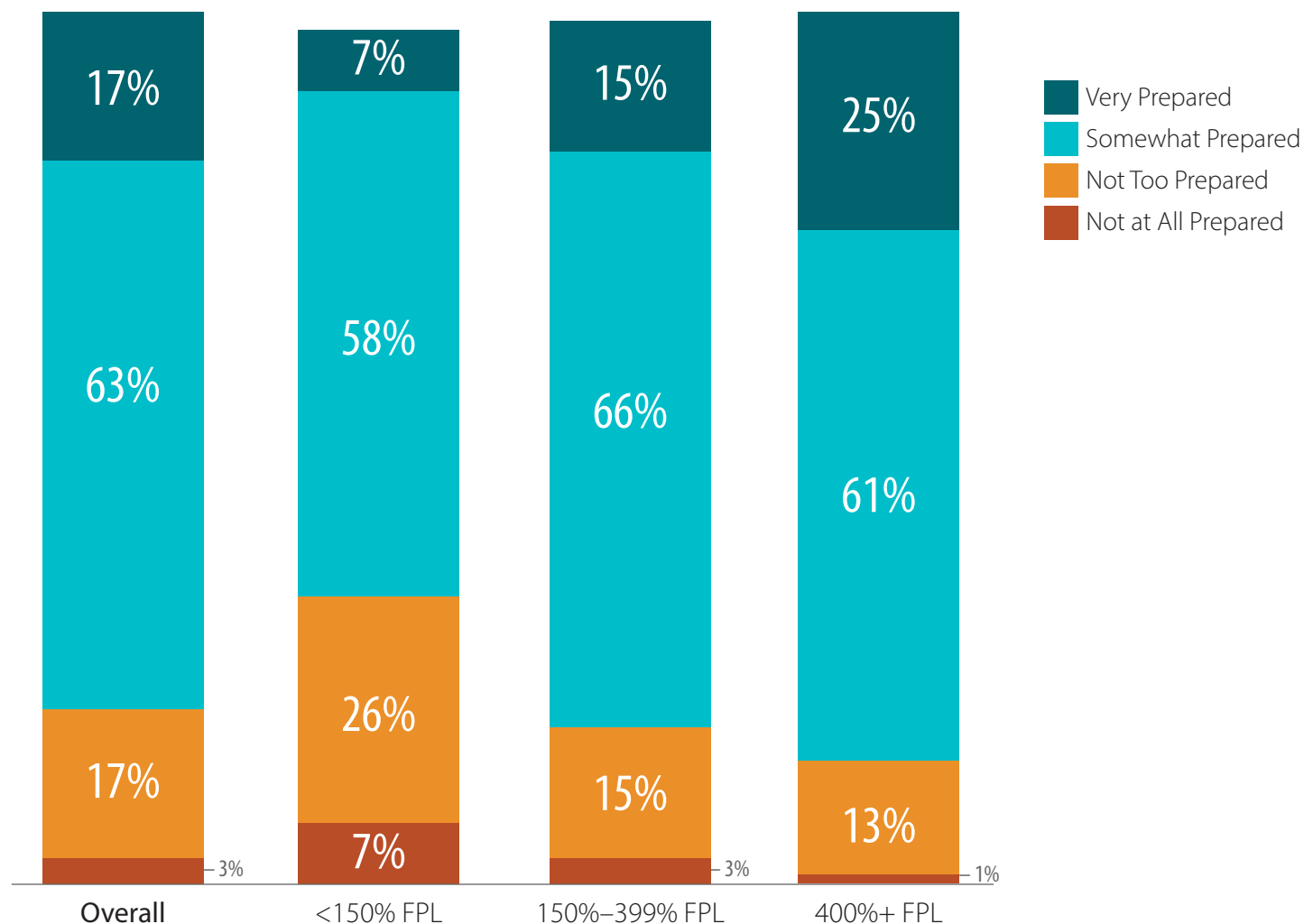
Notes: Respondents without a serious illness are those who do not report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness. In 2019, the federal poverty level (FPL) was \$12,490 for a single person and \$25,750 for a household of four.

Source: Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

# Feeling Prepared If Illness Gets Worse, by Income Level

## California, 2019

How prepared do you feel to deal with your illness(es) if it gets worse in the future? By prepared, we mean you know what is going on, you can plan for what is coming, and you feel ready. Base: respondents with a serious illness (n = 588)



Notes: Respondents with a serious illness include those who report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness. In 2019, the federal poverty level (FPL) was \$12,490 for a single person and \$25,750 for a household of four. Nonresponders not shown. Segments may not total 100% due to nonresponse or rounding.

Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

### Help Wanted

#### Preparedness

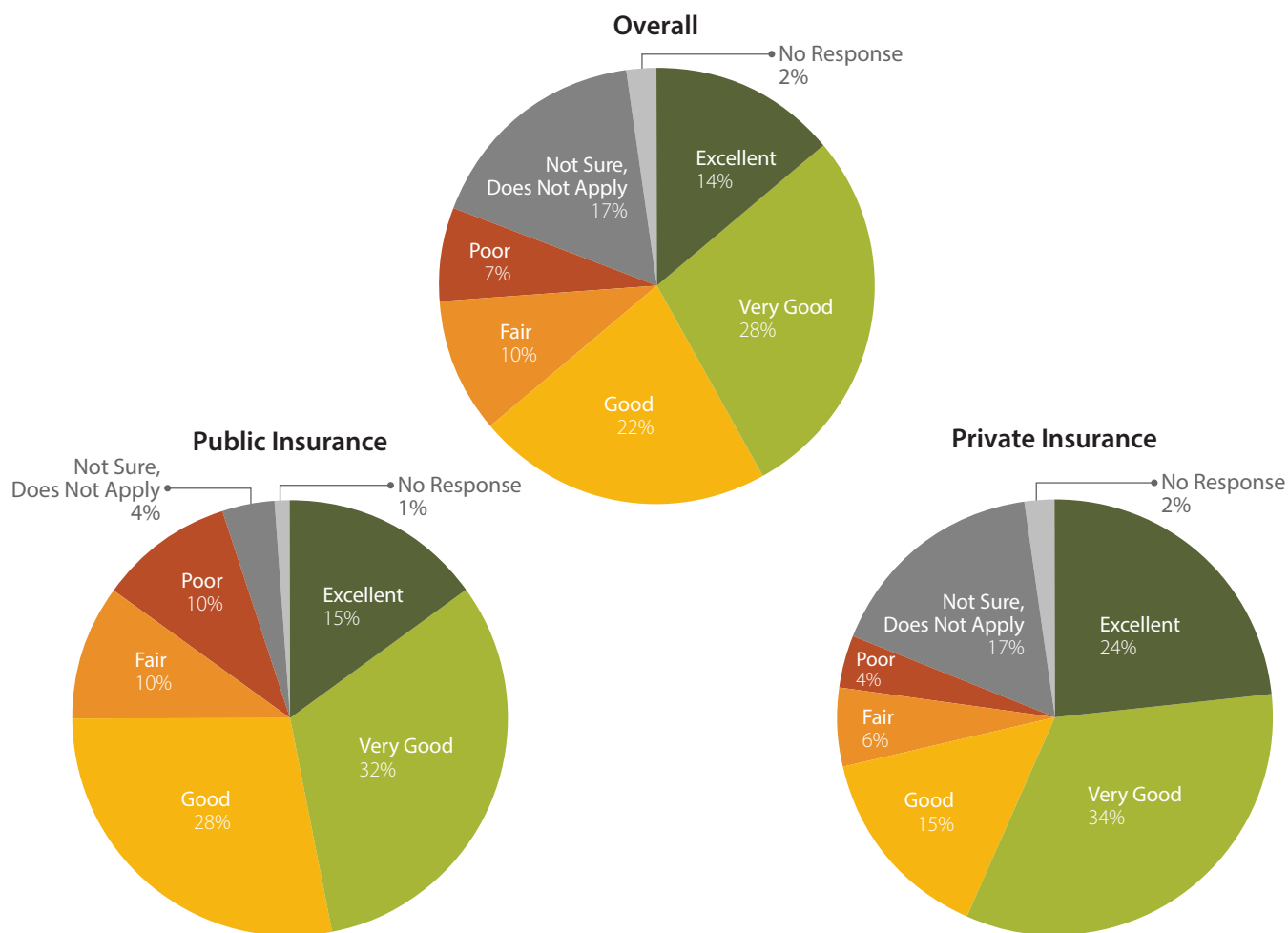
One in 6 survey respondents with a serious illness felt very prepared to deal with their illness(es) if it worsens.

Adults with the lowest incomes are the least likely to feel prepared, with 1 in 14 reporting that they felt very prepared.



# Overall Rating of End-of-Life Care of Loved One, by Insurance Type, California, 2019

Overall, how would you rate the care your loved one received at the end of life — that is, in the last few months of their life?  
 Base: respondents who lost a close loved one within the past two years (n = 1,276)



Notes: *Public insurance* includes respondents who said their loved one's source of coverage was either Medicare only, Medi-Cal only, Medicare and Medi-Cal, or VA benefits / Tri-Care. *Private insurance* includes respondents who said their loved one's source of coverage was through an employer or a private plan they purchased on their own. Segments may not total 100% due to rounding.

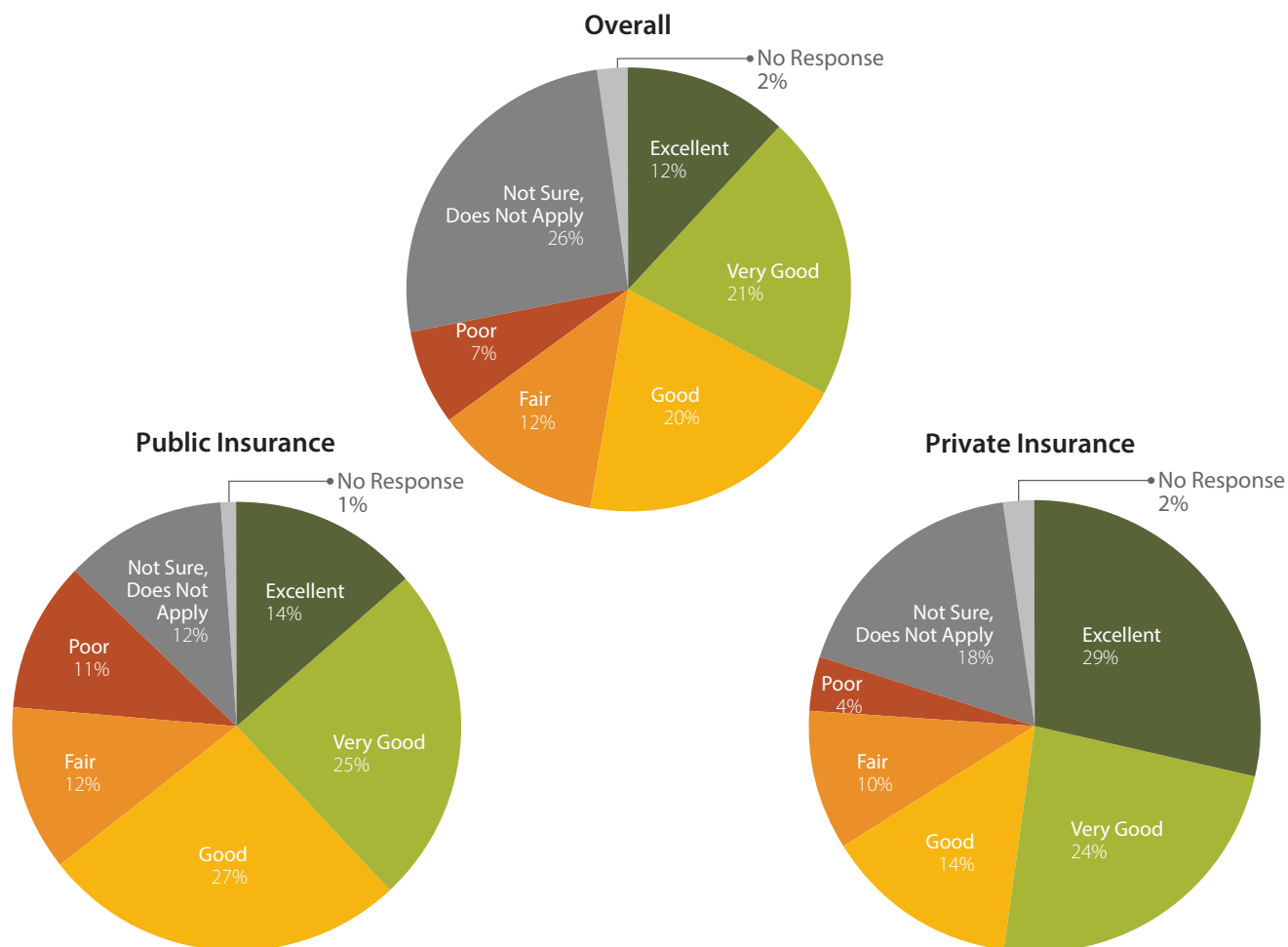
Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

## Help Wanted End-of-Life Care

Among survey respondents who lost a loved one in the past two years, 4 in 10 rated the care their loved one received as either excellent (14%) or very good (28%). One in 14 (7%) rated their loved one's care as poor. Respondents whose loved one had private insurance were more likely than those with public insurance to rate care as excellent (24% vs. 15%).

# Provider Communication at End of Life, by Insurance Type California, 2019

Overall, how would you rate the doctors in terms of how well they communicated with your loved one and family members about treatment options? Base: respondents who lost a close loved one within the past two years (n = 1,276)



Notes: *Public insurance* includes respondents who said their loved one's source of coverage was either Medicare only, Medi-Cal only, Medicare and Medi-Cal, or VA benefits / Tri-Care. *Private insurance* includes respondents who said their loved one's source of coverage was through an employer or a private plan they purchased on their own. Segments may not total 100% due to rounding.

Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

## Help Wanted End-of-Life Care

Among survey respondents who lost a loved one in the past two years, 1 in 3 reported that doctors' communication about treatment options was either excellent (12%) or very good (21%). One in 14 (7%) rated the doctors' communication as poor. Respondents whose loved one had private insurance were twice as likely as those with public coverage to rate communication as excellent (29% vs. 14%).

# Loved One's Experience with Aspects of Palliative Care

## California, 2019

*As far as you know, did your loved one's doctors or health care providers . . . Base: respondents who helped make health care decisions for a loved one who died from a serious or chronic health problem in the past two years (n = 238)*

Do everything they could to help with your loved one's pain or side effects from their illness or treatment?

74%

Talk with you or your loved one about how to make your loved one's life better as they lived with their illness?

74%

Talk with you or your loved one about what to expect if their illness got worse?

73%

Talk with you or your loved one about both the good and bad things that could happen with their treatment?

72%

Ask what was most important for your loved one as they lived their life with their illness?

64%

Talk with you or your loved one about any fear, stress, or sadness you or they were feeling?

53%

### Help Wanted

End-of-Life Care

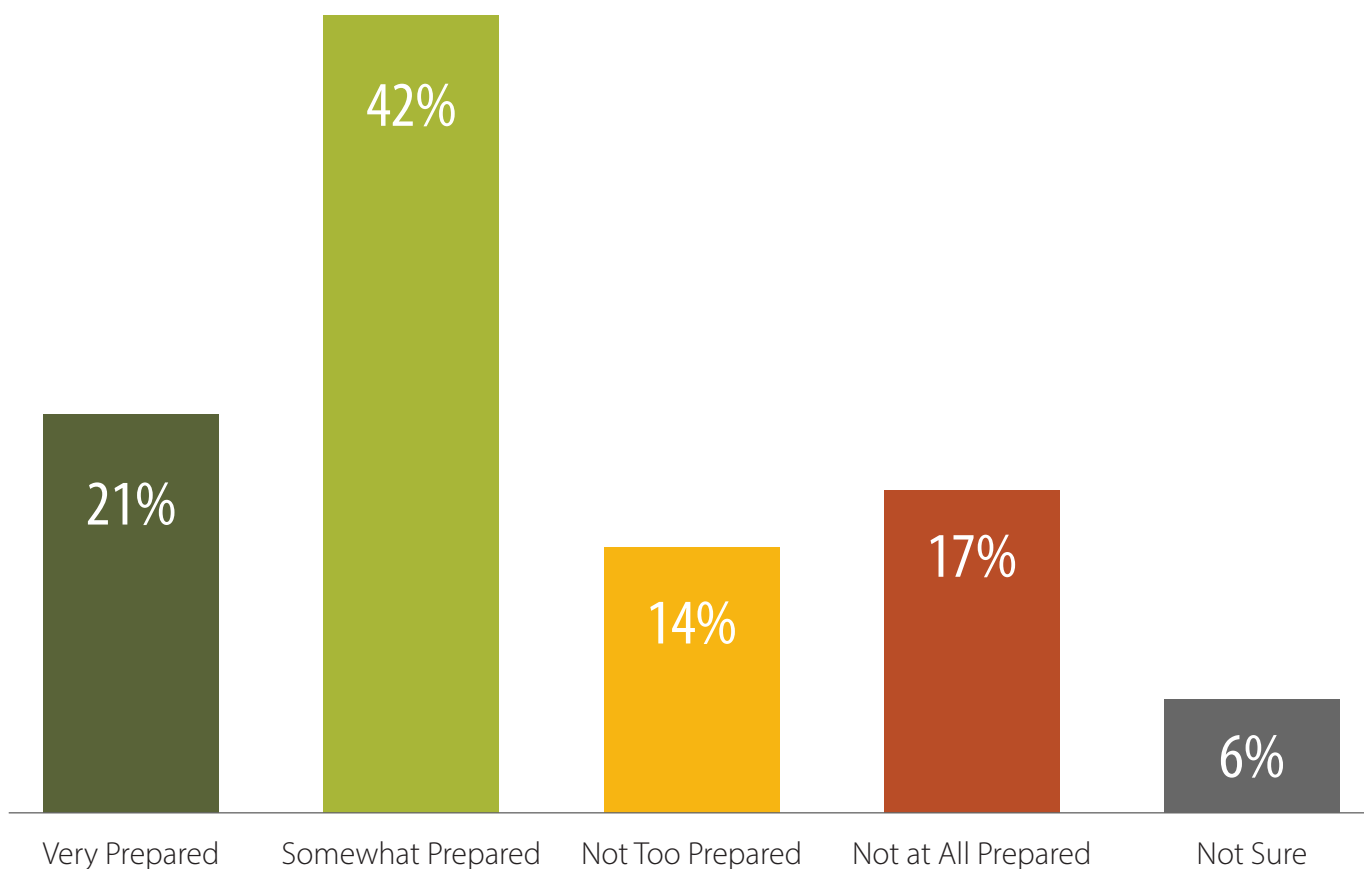
More than 7 in 10 survey respondents reported that providers did everything they could to help with their loved one's pain and side effects and discussed important aspects of their illness. Slightly more than half reported that providers discussed difficult emotions with their loved ones.

Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

# Loved One Feeling Prepared as Illness Got Worse

## California, 2019

How prepared was your loved one to deal with their illness as it got worse? Base: respondents who helped make health care decisions for a loved one who died from a serious or chronic health problem in the past two years (n = 238)



Note: This question defined *prepared* as “your loved one knew what was going on, they could plan for what was coming, and they felt ready.”

Source: *Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

### Help Wanted

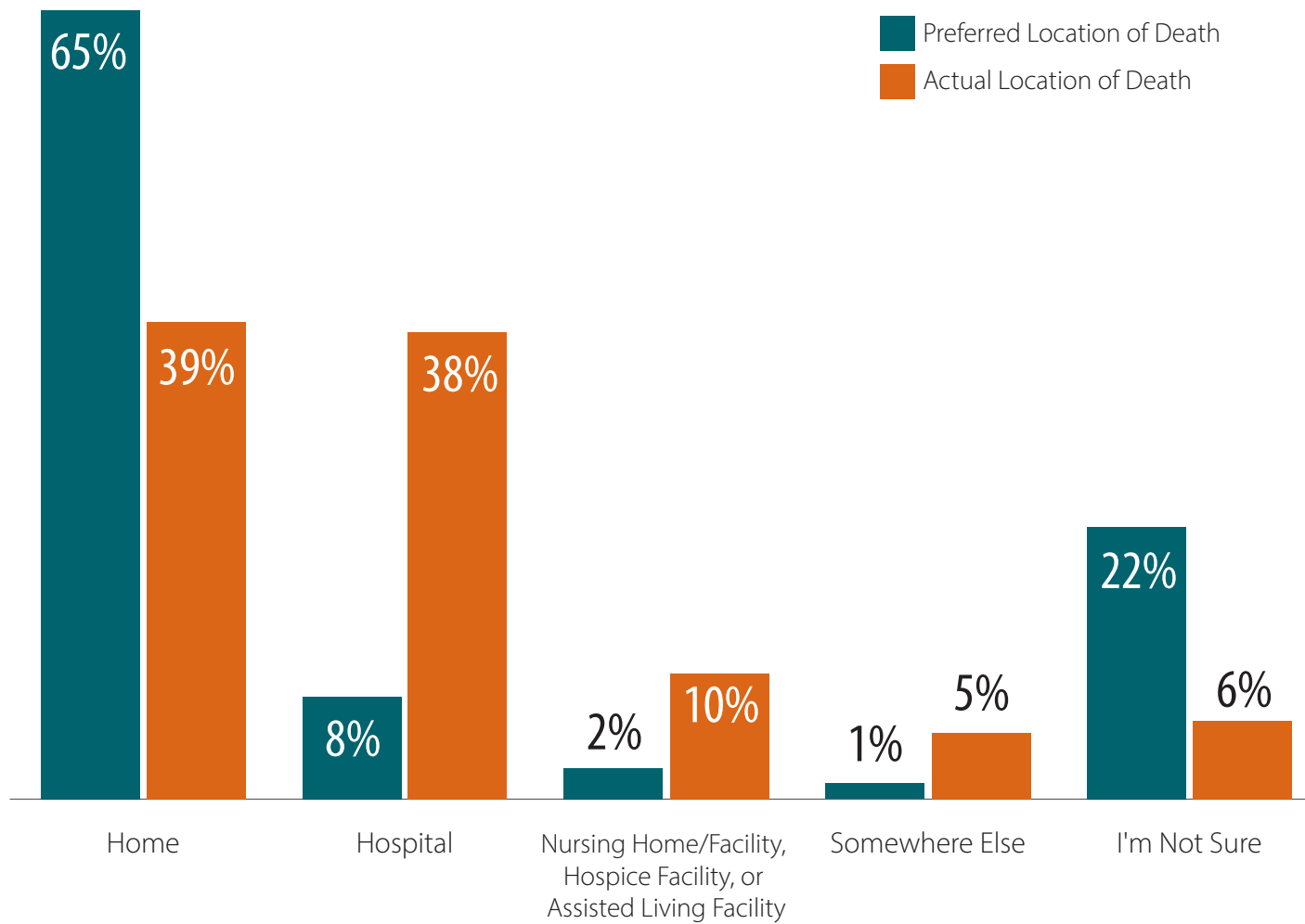
End-of-Life Care

Three in 10 survey respondents reported that their loved one was unprepared to deal with their illness as it got worse. Two in 10 thought their loved one was very prepared.

# Preferred Versus Actual Location of Death

## California, 2019

As far as you know, where do you think your loved one would have wanted to die if given the choice? Where did your loved one die? Base: respondents who lost a close loved one within the past two years (n = 1,276)



Notes: Nonresponders not shown. Segments may not total 100% due to nonresponse or rounding.

Source: Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

### Help Wanted

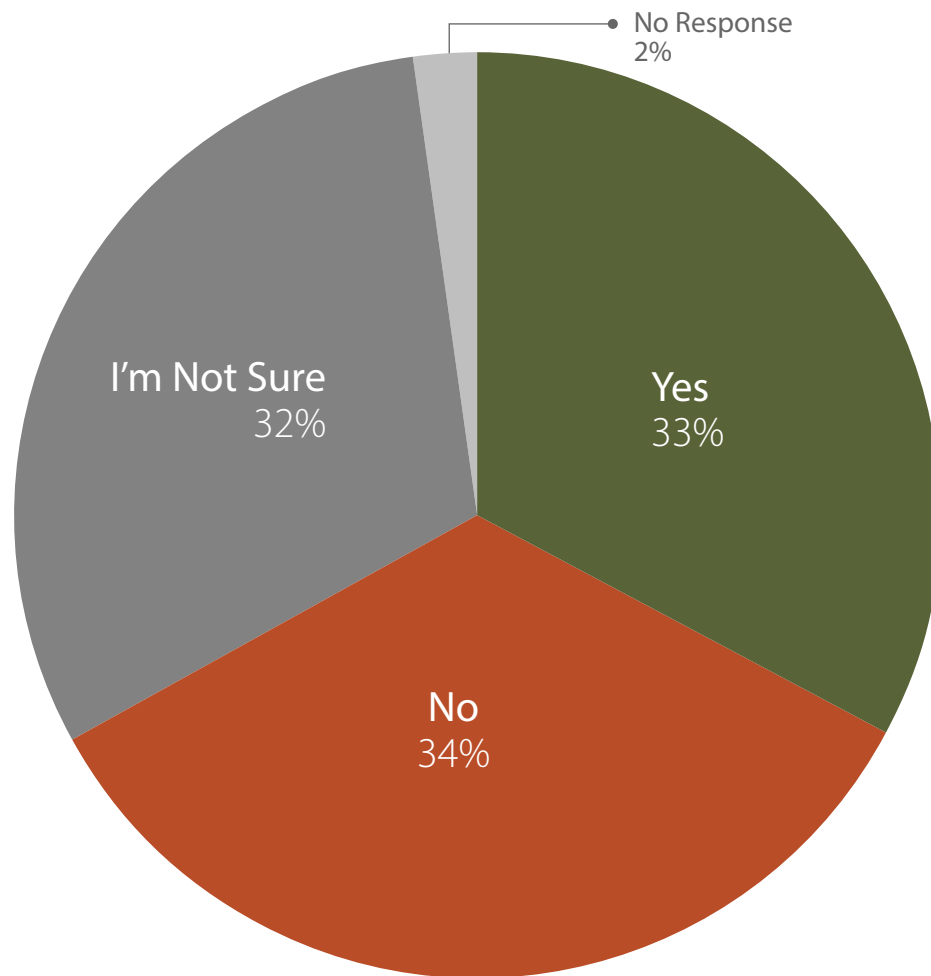
End-of-Life Care

Many survey respondents reported that their loved ones did not pass away in their preferred location. Nearly 2 in 3 respondents reported that their loved ones would have preferred to die at home, while only 4 in 10 were able to do so. In contrast, nearly 4 in 10 died in the hospital, which was the preferred location for less than 1 in 10 loved ones.

# Loved One's Experience at End of Life

## California, 2019

Think about the very end of your loved one's life. Do you think the end went the way your loved one wanted it to go? Base: respondents who had a loved one die from a serious or chronic health problem in the past two years (n = 889)



Note: Segments may not total 100% due to rounding.

Source: Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

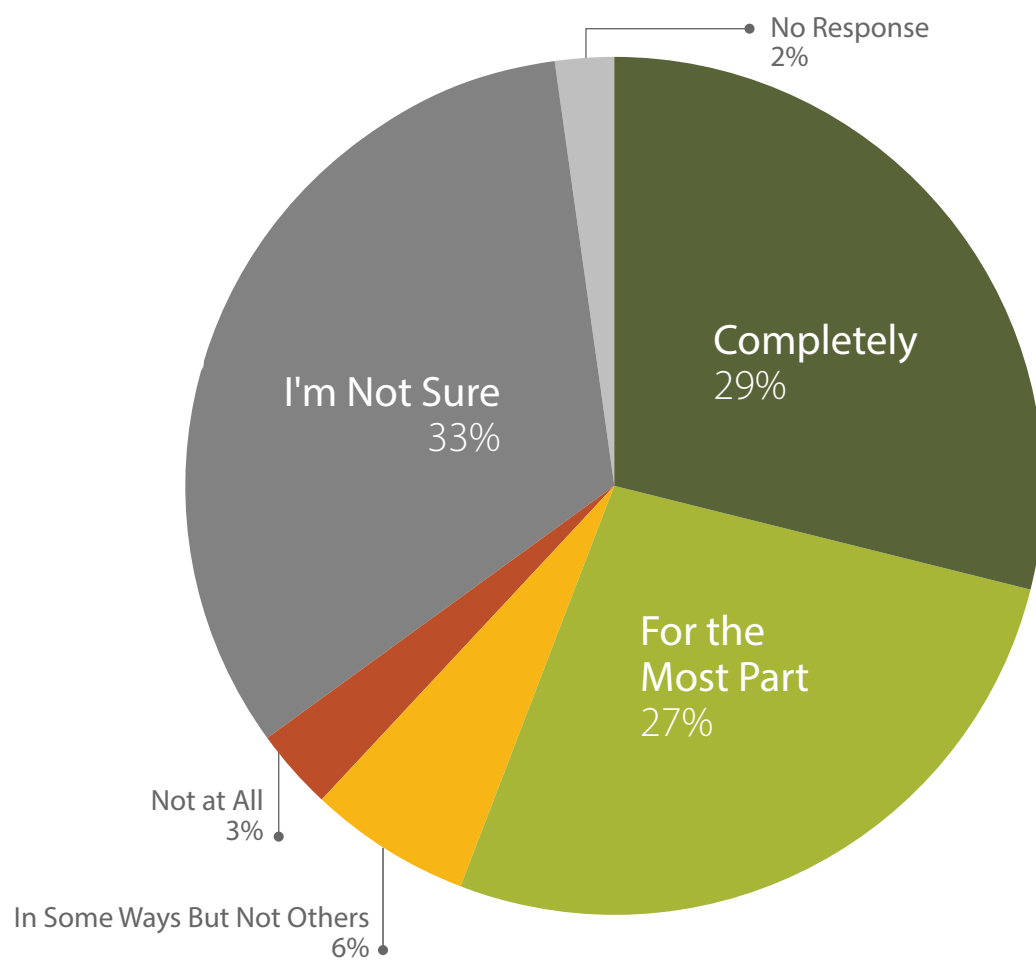
### Help Wanted

End-of-Life Care

Among respondents with a loved one who died from a serious illness in the past two years, about one in three reported that the end of that person's life did not go the way their loved one wanted. About the same proportion thought it did go the way their loved one wanted.

# Loved One's End-of-Life Wishes Followed California, 2019

To what extent do you feel your loved one's end-of-life wishes were followed and honored by the doctors, nurses, and other health care providers who cared for them? Base: respondents who lost a close loved one within past two years (n = 1,276)



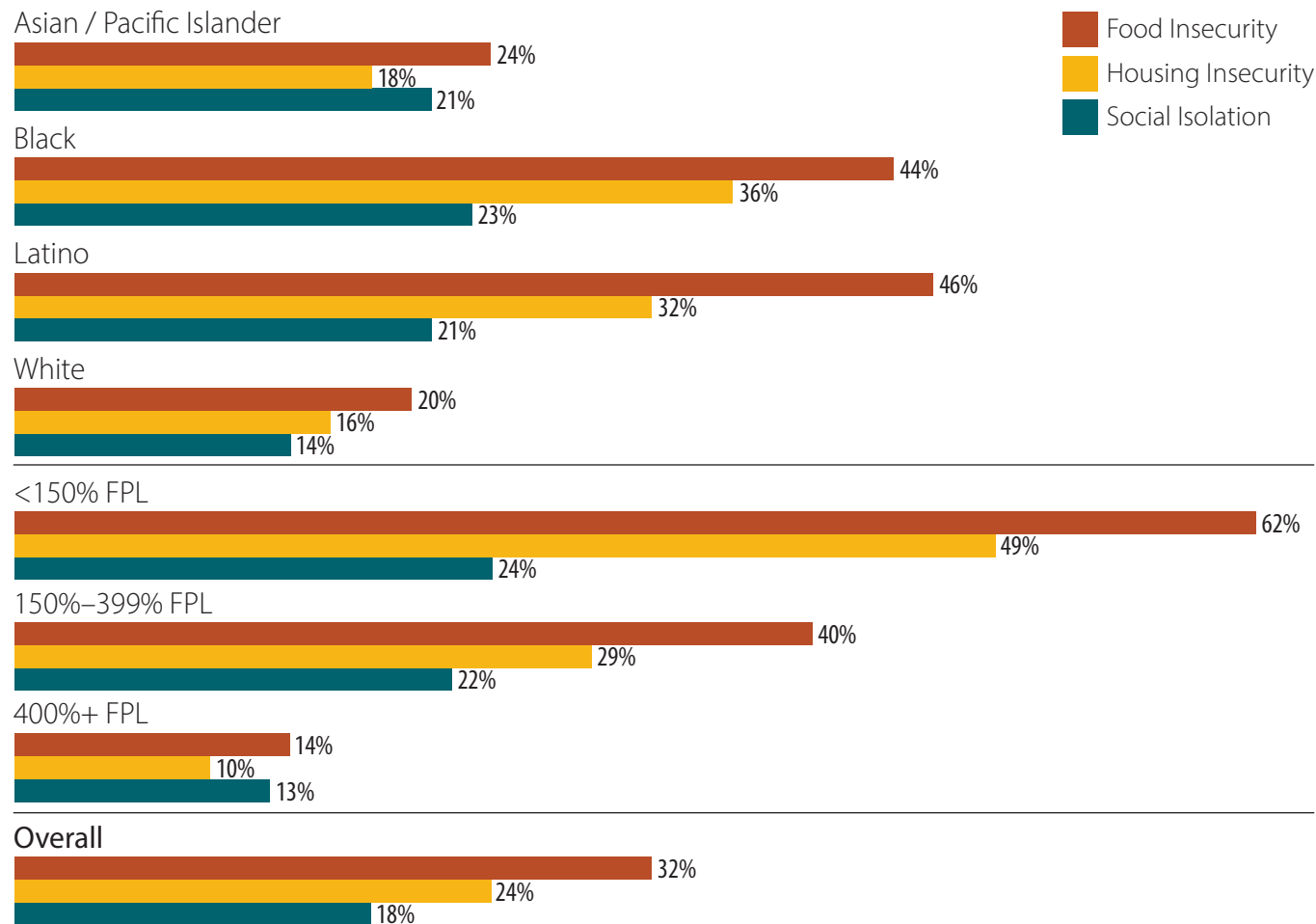
Source: Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

## Help Wanted

End-of-Life Care

A majority of survey respondents reported that their loved one's end-of-life wishes were either completely followed and honored (29%) by the health care providers who cared for them, or followed and honored for the most part (27%). One-third of respondents were not sure.

# Factors That May Impact Health and Access to Care, by Race/Ethnicity and Income Level, California, 2019



## Help Wanted Influencing Factors

Social isolation, housing insecurity, and food insecurity can all negatively impact a person's health and ability to access care when needed. Survey respondents of color and those with the lowest incomes were disproportionately likely to report a lack of social networks and an insecurity with basic needs.

Notes: *Social isolation* includes respondents who disagree with the statement "When I feel lonely there are several people I can talk to." *Housing insecurity* includes respondents who say it is hard to pay their rent or mortgage every month. *Food insecurity* includes respondents who say they often or sometimes "don't have enough to eat" or "have enough to eat but not always the kinds of food we want." In 2019, the federal poverty level (FPL) was \$12,490 for a single person and \$25,750 for a household of four.

Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

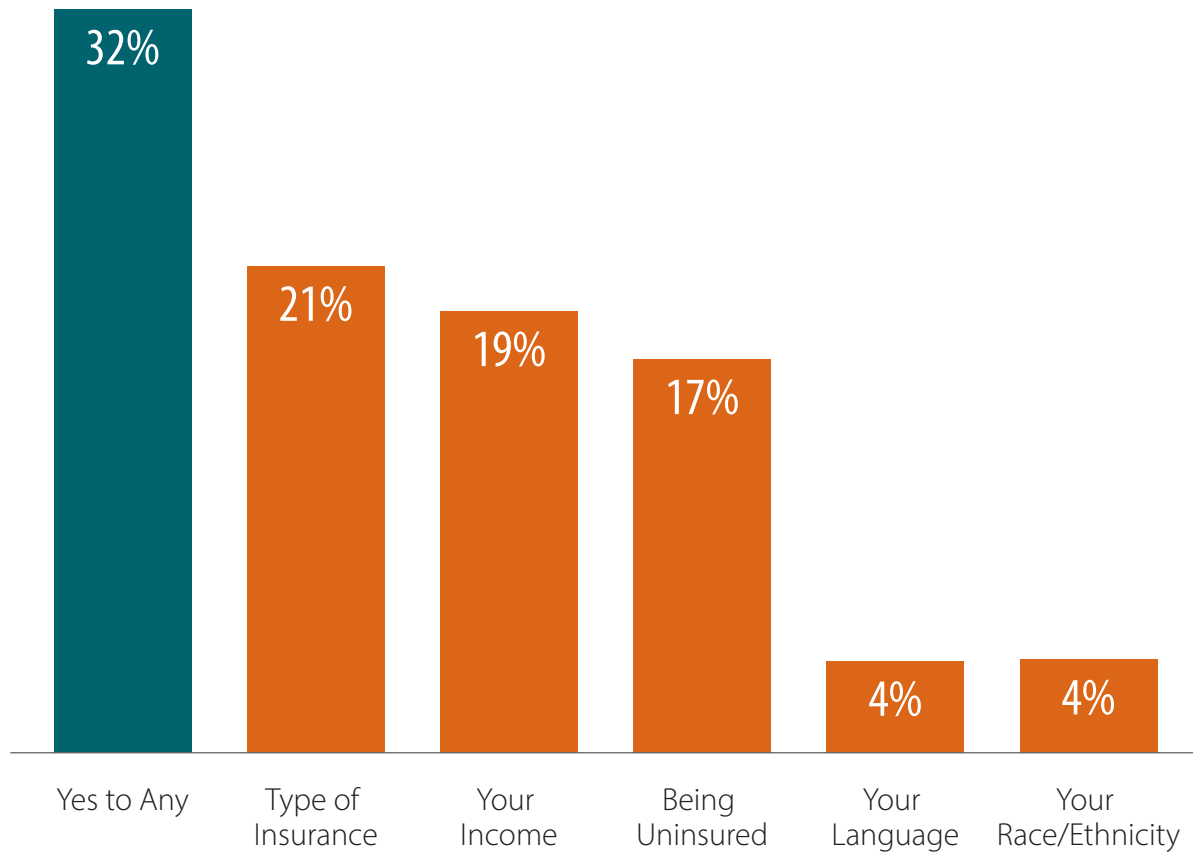


# Barriers to Accessing Health Care

## California, 2019

PERCENTAGE RESPONDING YES

Have you ever felt like you could not get health care services you needed because of . . . Base: all respondents (n = 2,588)



Source: Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

### Help Wanted

Influencing Factors

One in three survey respondents said they have faced barriers to getting the health care services they need.

The most common barriers cited were insurance status or type and income.

# Barriers to Accessing Health Care, by Race/Ethnicity and Income Level, California, 2019

PERCENTAGE RESPONDING YES TO ANY

*Have you ever felt like you could not get health care services you needed because of your race/ethnicity, your language, being uninsured, your income, or your type of insurance? Base: all respondents (n = 2,588)*

Asian / Pacific Islander

24%

Black

43%

Latino

40%

White

26%

<150% FPL

44%

150%–399% FPL

40%

400%+ FPL

20%

Overall

32%

## Help Wanted

Influencing Factors

About 4 in 10 Black, Latino, and low-income respondents said they reported feeling like they could not get needed health care services because of their race/ethnicity, language, insurance status or type, and/or income level. Black respondents were much more likely to cite race/ethnicity as a barrier (14%) than Latino (6%), Asian / Pacific Islander (2%), and white (2%) respondents (not shown).

Note: In 2019, the federal poverty level (FPL) was \$12,490 for a single person and \$25,750 for a household of four.

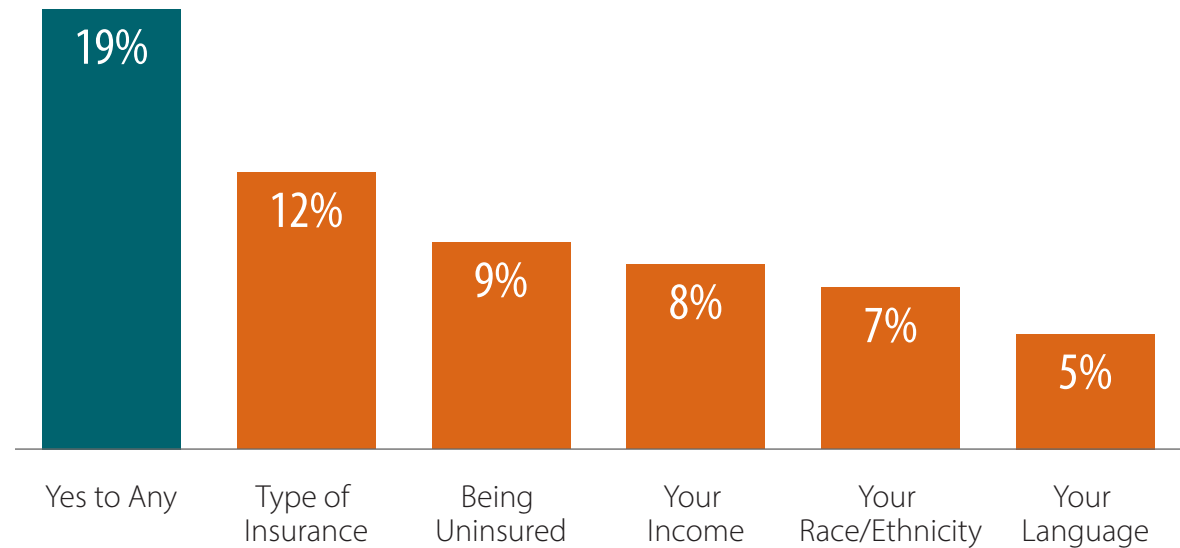
Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

# Felt Judgment or Discrimination from Provider

## California, 2019

PERCENTAGE RESPONDING YES

*Have you ever felt judged or treated differently by a health care provider because of . . . Base: all respondents (n = 2,588)*



Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

**Help Wanted**  
Influencing Factors

One in five survey respondents said they felt judged or treated differently by a health care provider. The most common reasons for feeling judged or treated differently were the respondent's type of insurance or being uninsured.

# Felt Judgment or Discrimination from Provider, by Race/Ethnicity and Income Level, California, 2019

PERCENTAGE RESPONDING YES TO ANY

*Have you ever felt judged or treated differently by a health care provider because of your race/ethnicity, your language, being uninsured, your income or your type of insurance? Base: all respondents (n = 2,588)*

Asian / Pacific Islander



Black



Latino



White



<150% FPL



150%–399% FPL



400%+ FPL



Overall



Note: In 2019, the federal poverty level (FPL) was \$12,490 for a single person and \$25,750 for a household of four.

Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

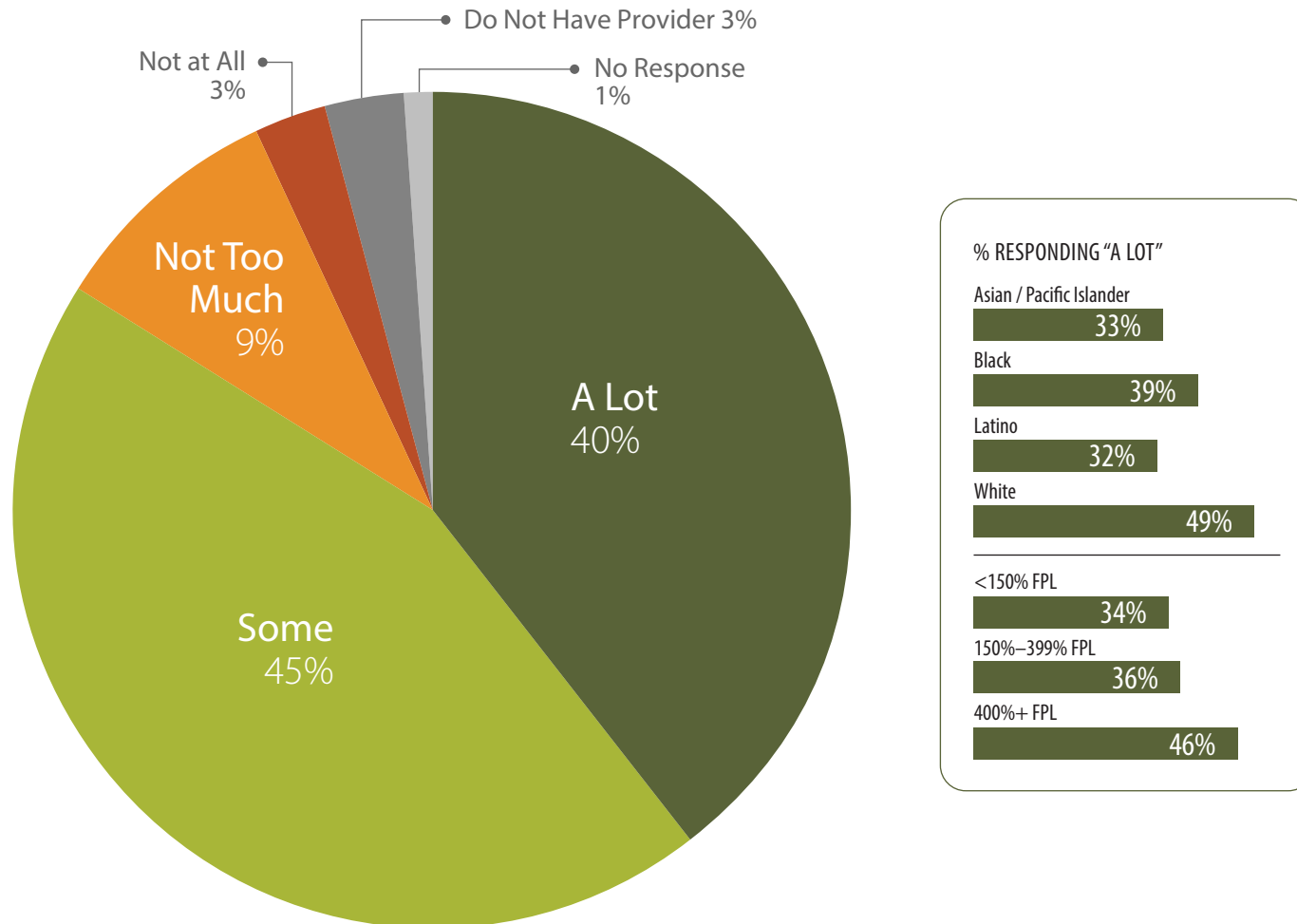
## Help Wanted

Influencing Factors

Roughly one in three Black survey respondents and those living below 150% of the federal poverty level (FPL) reported feeling judged or treated differently because of their insurance status or type, income, language, and/or race/ethnicity.

# Trust in Health Care Providers, by Race/Ethnicity and Income Level, California, 2019

In general, how much do you trust your health care providers to act in your best interest? Base: all respondents (n = 2,588)



## Help Wanted Influencing Factors

Overall, 40% of survey respondents expressed a lot of trust in their health care providers to act in their best interest; white and high-income respondents were most likely to report a lot of trust in their providers. Only 12% of respondents had not much or no trust in their providers to act in their best interests.

Note: In 2019, the federal poverty level (FPL) was \$12,490 for a single person and \$25,750 for a household of four. Segments may not total 100% due to rounding.

Source: Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

# Methodology

The survey was conducted June 6 through July 2, 2019, among a representative sample of 2,588 Californians age 18 and older, including 1,276 respondents who have lost a loved one in the past two years. The margin of error is +/- 3.1 percentage points for the total results.

The survey was administered using Ipsos's KnowledgePanel, which is the first online research panel that is representative of the US population. Panel members are randomly recruited through address-based sampling methods, and households are provided with hardware and access to the Internet if needed.

For additional information on methodology and demographics of respondents, visit [www.chcf.org/helpwanted](http://www.chcf.org/helpwanted).

## Help Wanted

Californians' Views and Experiences of Serious Illness and End-of-Life Care

### AUTHORS

**PerryUndem Research/Communication** is a nonpartisan public opinion research firm based in Washington, DC. PerryUndem studies opinion on a number of public policy issues, including health care and topics related to equity. Learn more at [www.perryundem.com](http://www.perryundem.com).

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