



CALIFORNIA  
HEALTHCARE  
FOUNDATION

SNAPSHOT

# Final Chapter:

Californians' Attitudes and Experiences with Death and Dying

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February 2012

# Introduction

A large majority of Californians say they would prefer a natural death if they became severely ill, rather than have all possible care provided. They would prefer to die at home instead of a hospital or nursing home. And they want to talk with their doctor about their wishes for care at the end of their lives. However, Californians don't always get what they want, as this research shows. The snapshot combines publicly available data with new research that explores people's experiences around the death of a loved one and their own preferences for end-of-life care.

## HIGHLIGHTS INCLUDE:

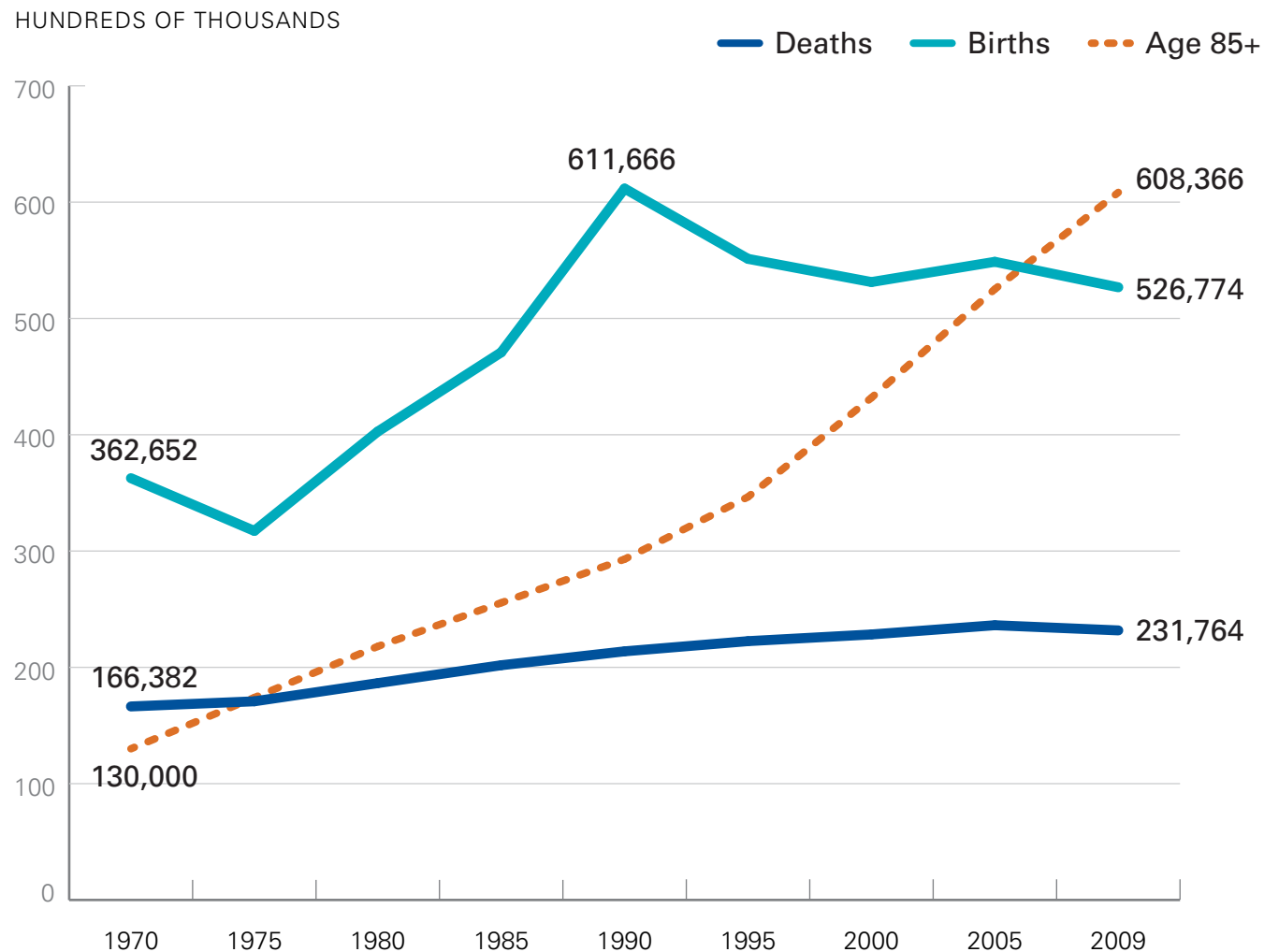
- Californians say the most important factors at the end of their life are making sure their family is not burdened financially by the costs of care (67% say this is extremely important) and being comfortable and without pain (66%).
- Top concerns vary by race/ethnicity. For example, Latinos rate living as long as possible (56%) more highly than do other groups.
- Two-thirds of Californians say they would prefer a natural death if they were severely ill, while only 7% say they would want all possible care to prolong life.
- Sixty percent say that making sure their family is not burdened by tough decisions about their care is "extremely important." However, 56% of Californians have not communicated their end-of-life wishes to the loved one they would want making decisions on their behalf.
- While a large majority of Californians (82%) say it is important to have end-of-life wishes in writing, only 23% say they have done so.
- Almost 80% say they definitely or probably would like to talk with a doctor about end-of-life wishes, but only 7% have had a doctor speak with them about it. Over 80% think it would be a very or somewhat good idea for doctors to be paid for such discussions.
- Seventy percent of Californians say they would prefer to die at home. However, of deaths in California in 2009, 32% occurred at home, 42% in a hospital, and 18% in a nursing home.
- Compared to the nation as a whole, California is trending toward providing more inpatient care and more intensive care in the last six months of life.
- Lack of insurance and language barriers strongly influence Californians' perceptions about whether a recently deceased loved one received excellent or very good care.

## Death and Dying in California

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# Births, Deaths, and Population Age 85+, California, 1970 to 2009, selected years



Sources: State of California, Department of Public Health, Birth, Death, Fetal Deaths, and Infant Deaths by Age, Table 1-2, 2006–2009. California Counts: Population Trends and Profiles, Vol. 2 No. 2, November 2000, Public Policy Institute of California. California Department of Finance, Race/Ethnic Population with Age and Sex Detail, prepared by California Department of Health Services, EPIC Branch, November 30, 2011.

## Death and Dying in California Overview

California's 85+ population is growing quickly and has more than quadrupled over the last 40 years. The elderly also make up a growing share of the state's total population (not shown).

# Leading Causes of Death, United States, 1900, 2002, 2009

## TOP THREE CAUSES OF DEATH

1900	2002	2009
Pneumonia and Influenza	Heart Disease	Heart Disease
Tuberculosis	Cancer	Cancer
Diarrhea and Enteritis	Stroke	Chronic Lower Respiratory Diseases

## Death and Dying in California Overview

The leading causes of US deaths have moved away from infectious illnesses toward chronic conditions over time. Many patients near the end of life may have a longer disease trajectory than in the past and more time to consider their options for care.

Sources: US Department of Health & Human Services, Center for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics Reports, Vol. 59, No. 4, March 16, 2011, Table B. Accessed December 12, 2011, [www.cdc.gov](http://www.cdc.gov).

# Leading Causes of Death, by Race/Ethnicity, California, 2009

TOTAL DEATHS	NO. 1 CAUSE	NO. 2 CAUSE	NO. 3 CAUSE
<b>White/Non-Latino</b> 154,084	Heart Disease 40,996	Cancer 37,095	Chronic Lower Respiratory Diseases 10,201
<b>Latino</b> 38,034	Cancer 8,445	Heart Disease 7,933	Accidents 2,641
<b>Asian/Pacific Islander</b> 18,497	Cancer 5,220	Heart Disease 4,424	Stroke 1,531
<b>African American</b> 17,562	Heart Disease 4,637	Cancer 4,227	Stroke 1,032

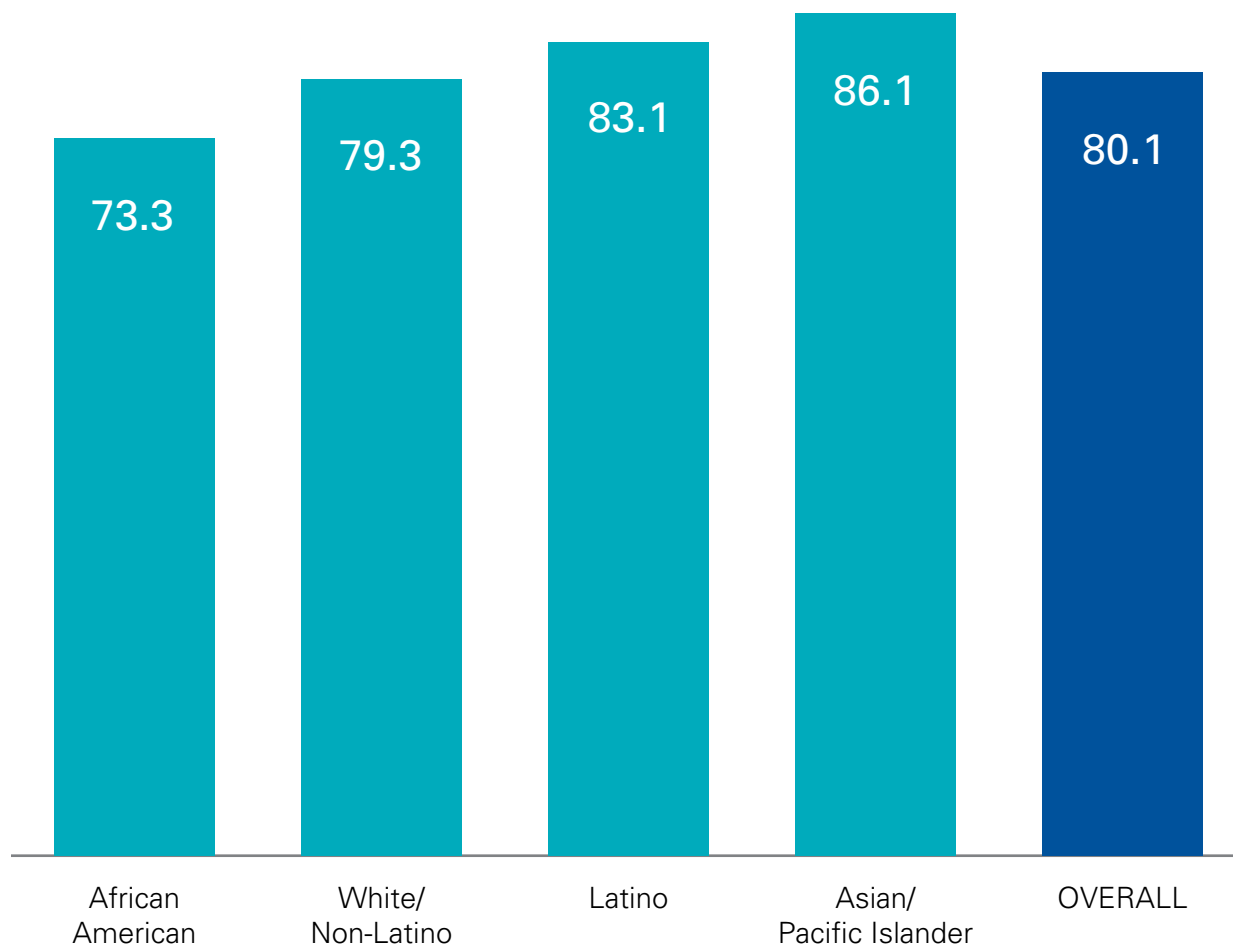
## Death and Dying in California by Race/Ethnicity

Heart disease and cancer were the top two causes of death for Whites, Latinos, Asians, and African Americans in California in 2009.

Sources: California Department of Health Services, Death Statistical Data Tables, Table 5-8, Major Causes of Death by Race/Ethnic Group and Sex, California 2009. Accessed December 14, 2011, [www.cdph.ca.gov](http://www.cdph.ca.gov).

# Life Expectancy, by Race/Ethnicity, California, 2010

AVERAGE YEARS OF AGE



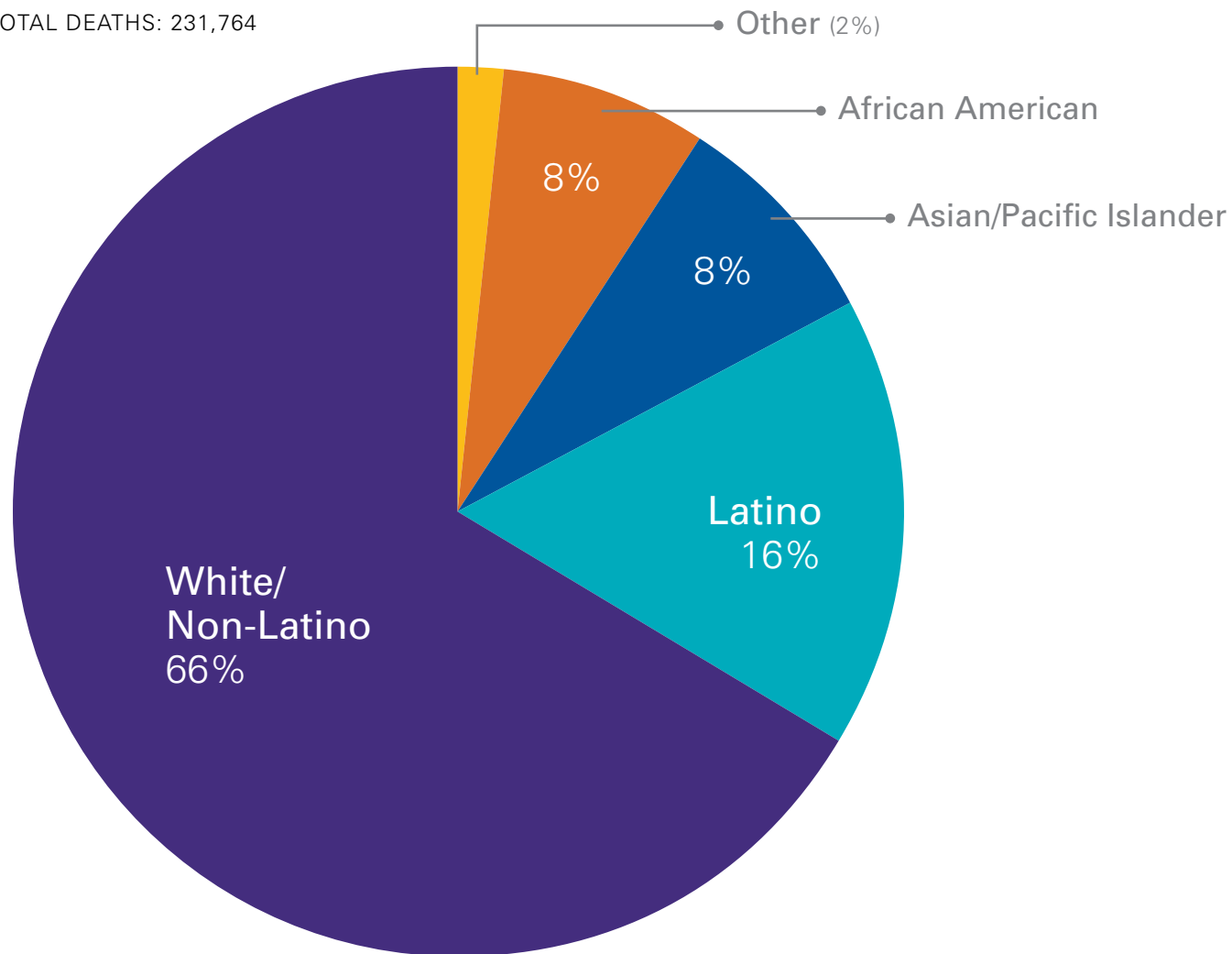
Source: American Human Development Project of the Social Science Research Council, *A Portrait of California: California Human Development Report*, 2011, Health in California Today. Accessed December 14, 2011, [www.measureofamerica.org](http://www.measureofamerica.org).

## Death and Dying in California by Race/Ethnicity

Average life expectancy is a broad measure of the health of a population. In California, Asian/Pacific Islanders have the longest life expectancy, six years over the average for the state. African Americans have a life expectancy that is about seven years shorter than the average.

## Deaths, by Race/Ethnicity, California, 2009

TOTAL DEATHS: 231,764



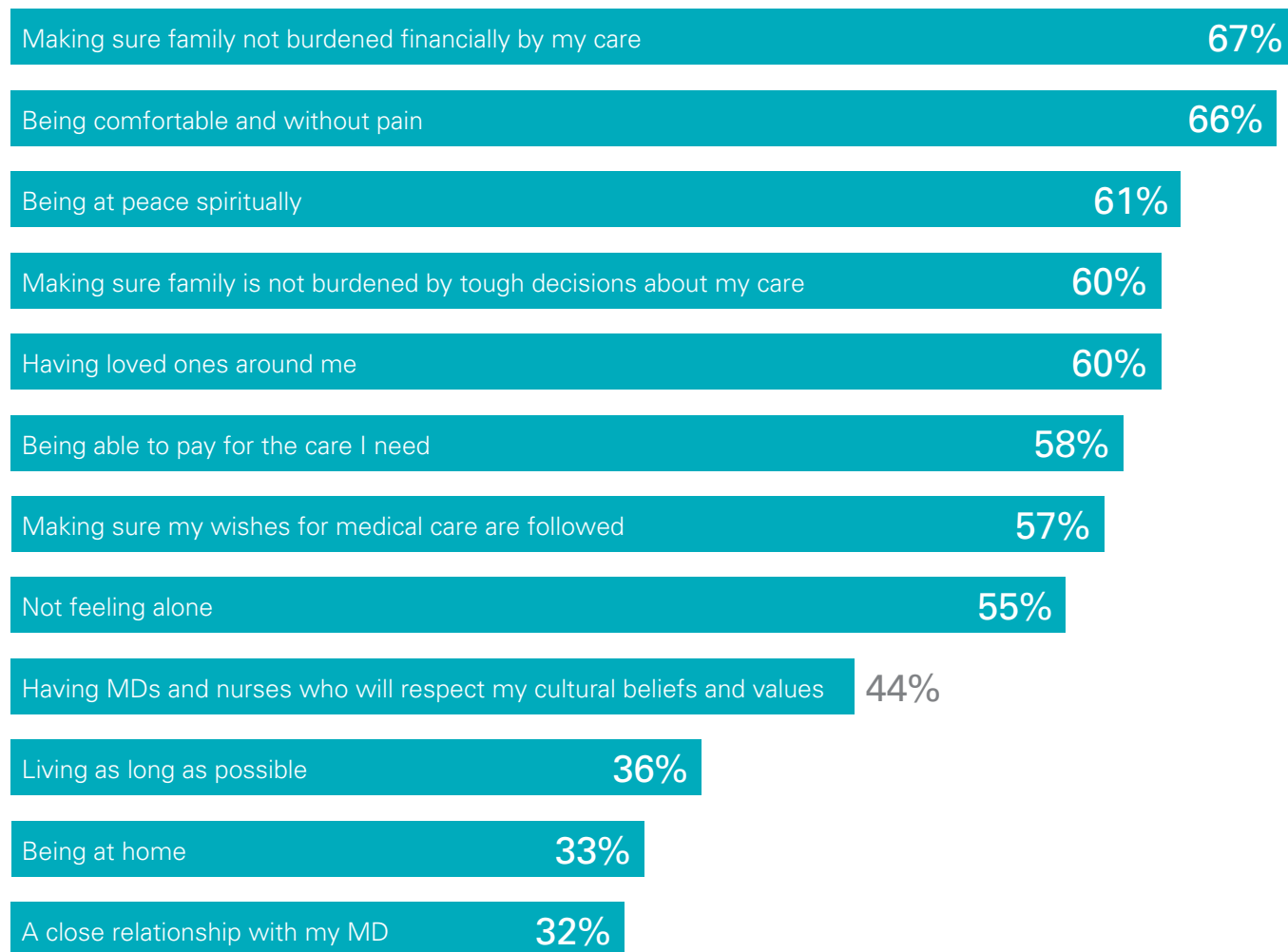
### Death and Dying in California by Race/Ethnicity

Since mortality rates are much higher for older adults, the number of deaths for a racial/ethnic group is determined primarily by the group's age distribution. Because the majority of Californians over 65 are White, this group has the highest number of deaths.

Source: California Department of Public Health, Death Statistical Data Tables, Table 5-18. Deaths by sex and race/ethnic group. California counties and selected city health departments, 2009. Accessed December 14, 2011, [www.cdph.ca.gov](http://www.cdph.ca.gov).

# Most Important Factors at End of Life, California, 2011

RATING FACTOR "EXTREMELY IMPORTANT"

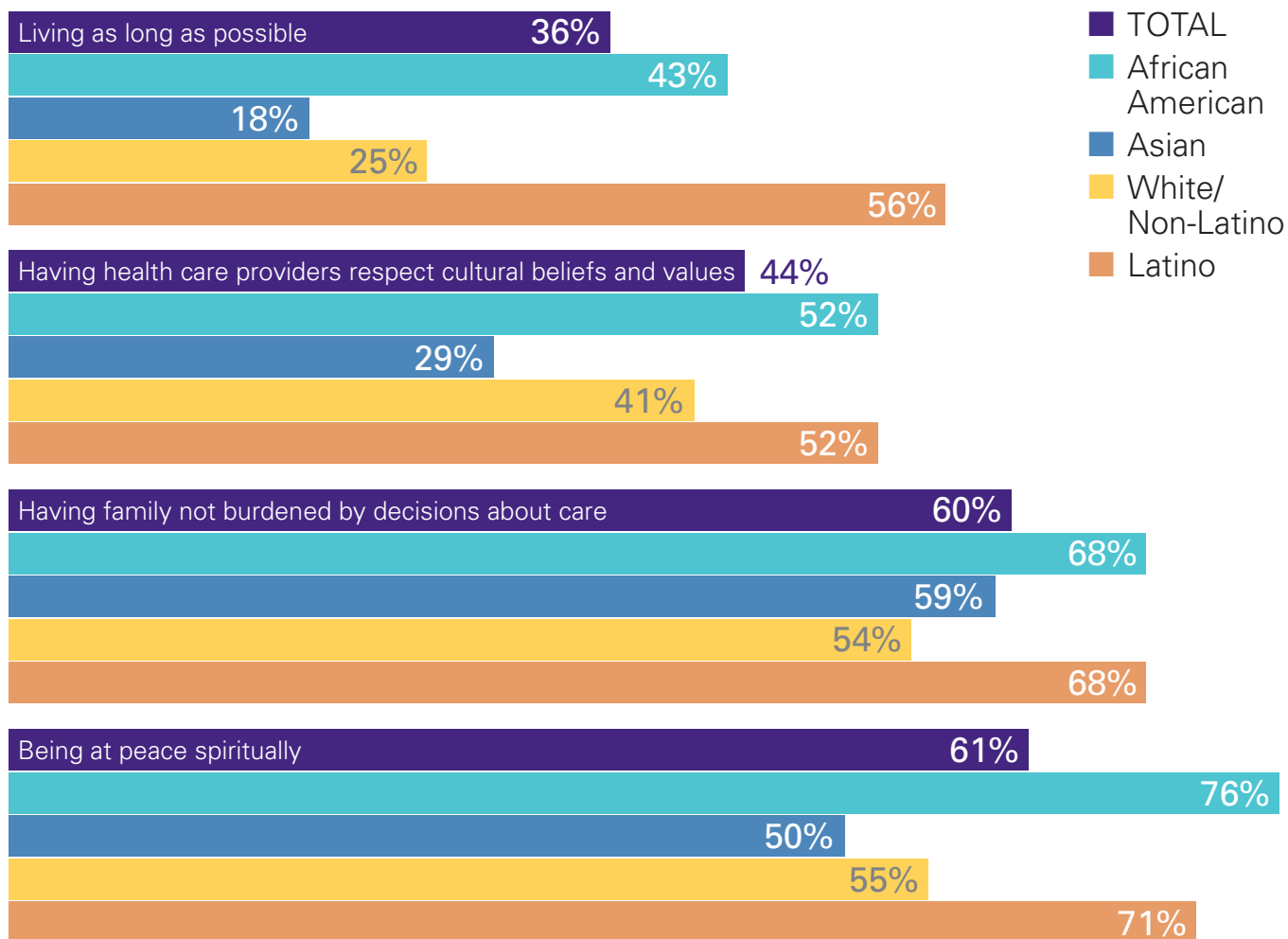


Source: Californians' Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

Californians are most likely to say it is extremely important to them that their care does not burden their family financially.

# Most Important Factors at End of Life, by Race/Ethnicity, California, 2011

RATING FACTOR "EXTREMELY IMPORTANT"

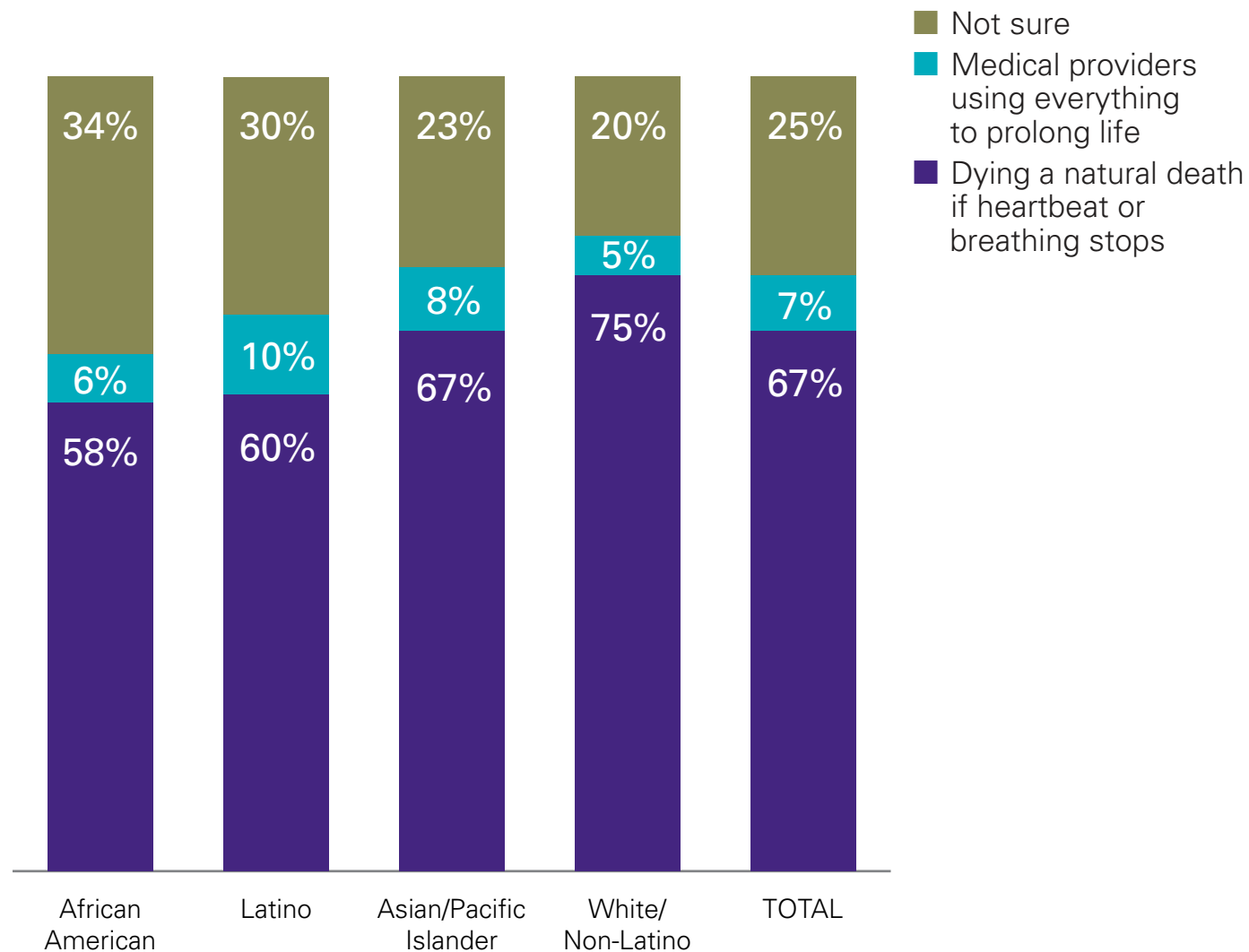


Source: Californians' Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

## Death and Dying in California End-of-Life Concerns

Top concerns vary by race/ethnicity. Latinos rate "living as long as possible" more highly than do other groups. Sixty percent of respondents say it is extremely important that their family not be burdened by decisions regarding their care.

## Preferences Around Prolonging Life, by Race/Ethnicity, California, 2011



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

Source: Californians' Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

### Death and Dying in California

#### End-of-Life Concerns

A large majority of Californians want to die a natural death, rather than receive all possible care to prolong their life.\*

\*Question wording: "If you had an advanced illness, which would you prefer: Doctors and nurses using everything available to attempt to prolong my life (such as a breathing machine or feeding through a tube) — or — Dying a natural death if my heart should stop beating or I should stop breathing".

# Awareness of End-of-Life Terms, California, 2011

PERCENT SAYING THEY HAVE HEARD OF THESE TERMS

Hospice care

73%

Do-not-resuscitate (DNR) order

63%

Advance directive

38%

Palliative care

17%

POLST

13%

## Death and Dying in California

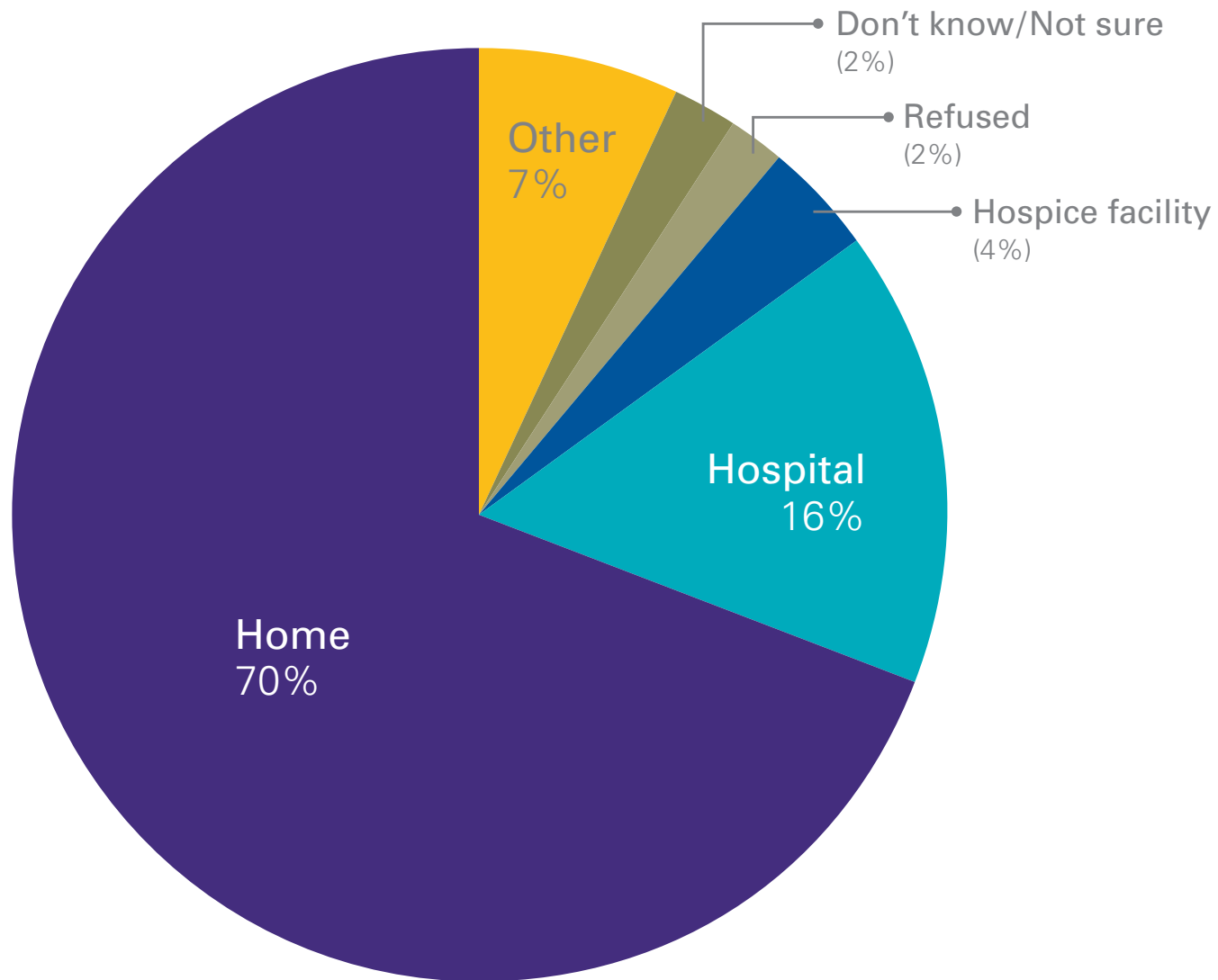
### End-of-Life Concerns

Hospice is familiar to most Californians. Only 13% say they have heard of the POLST (Physician Orders for Life-Sustaining Treatment) form.

Note: POLST is a form that is signed by a patient and his/her doctor, clearly stating what kinds of medical treatment the patient wants toward the end of life. It must be honored by health care providers, even if the patient later loses the ability to indicate his/her wishes.

Source: Californians' Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

## Preferred Location of Death, California, 2011



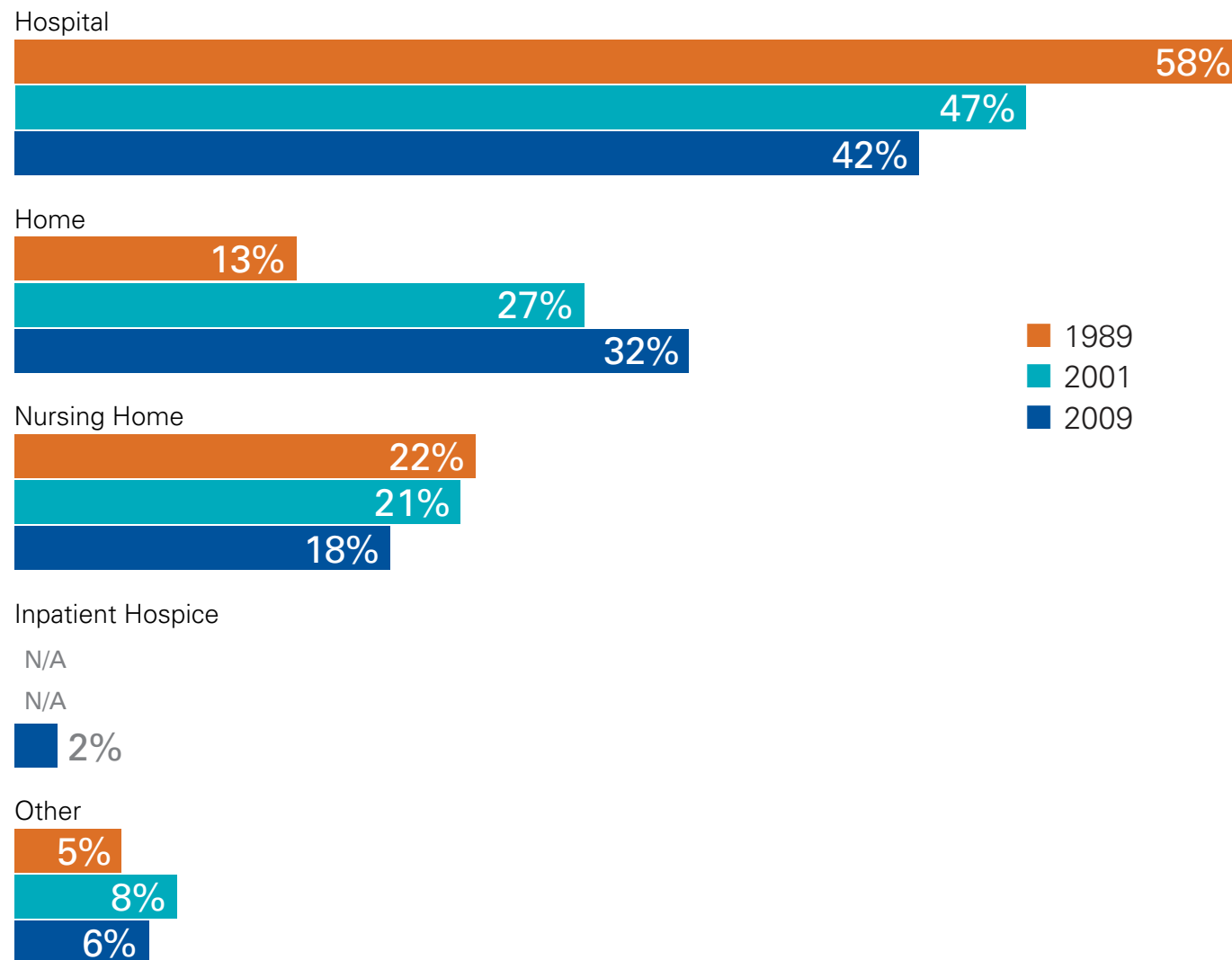
Note: Segments may not add to 100% due to rounding.

Source: Californians' Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

### Death and Dying in California by Location

A large majority of Californians would prefer to die at home rather than in a health care facility.

## Location of Deaths, California, 1989, 2001, 2009

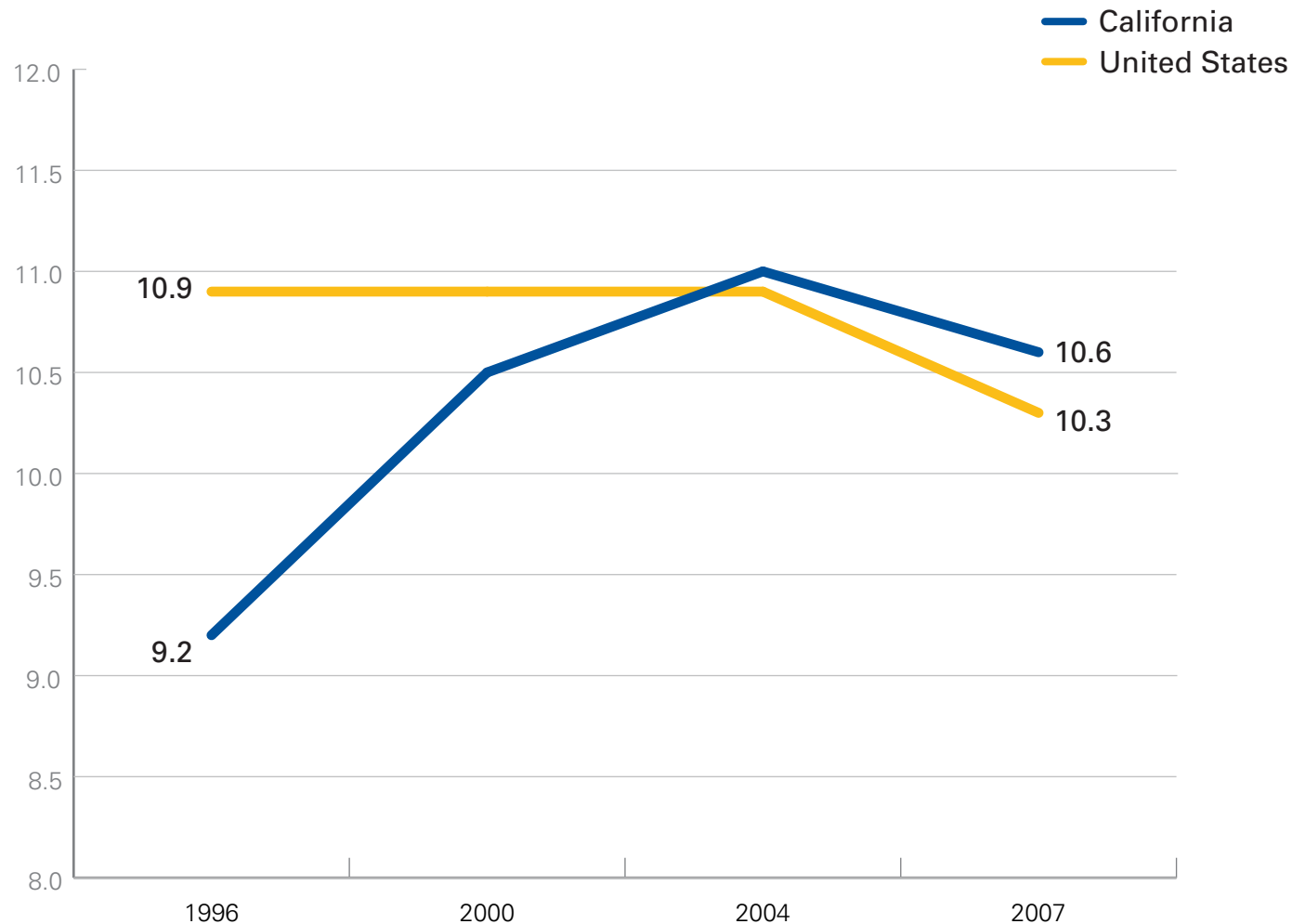


Source: State of California, Department of Public Health, Death Records, 2011.

### Death and Dying in California by Location

The number of Californians who died at home has grown 146% since 1989, while deaths in hospitals have declined. In 2009, 42% of deaths occurred in hospitals and about 18% in nursing homes.

## Hospital Days During the Last Six Months of Life, California vs. United States, 1996 to 2007, selected years

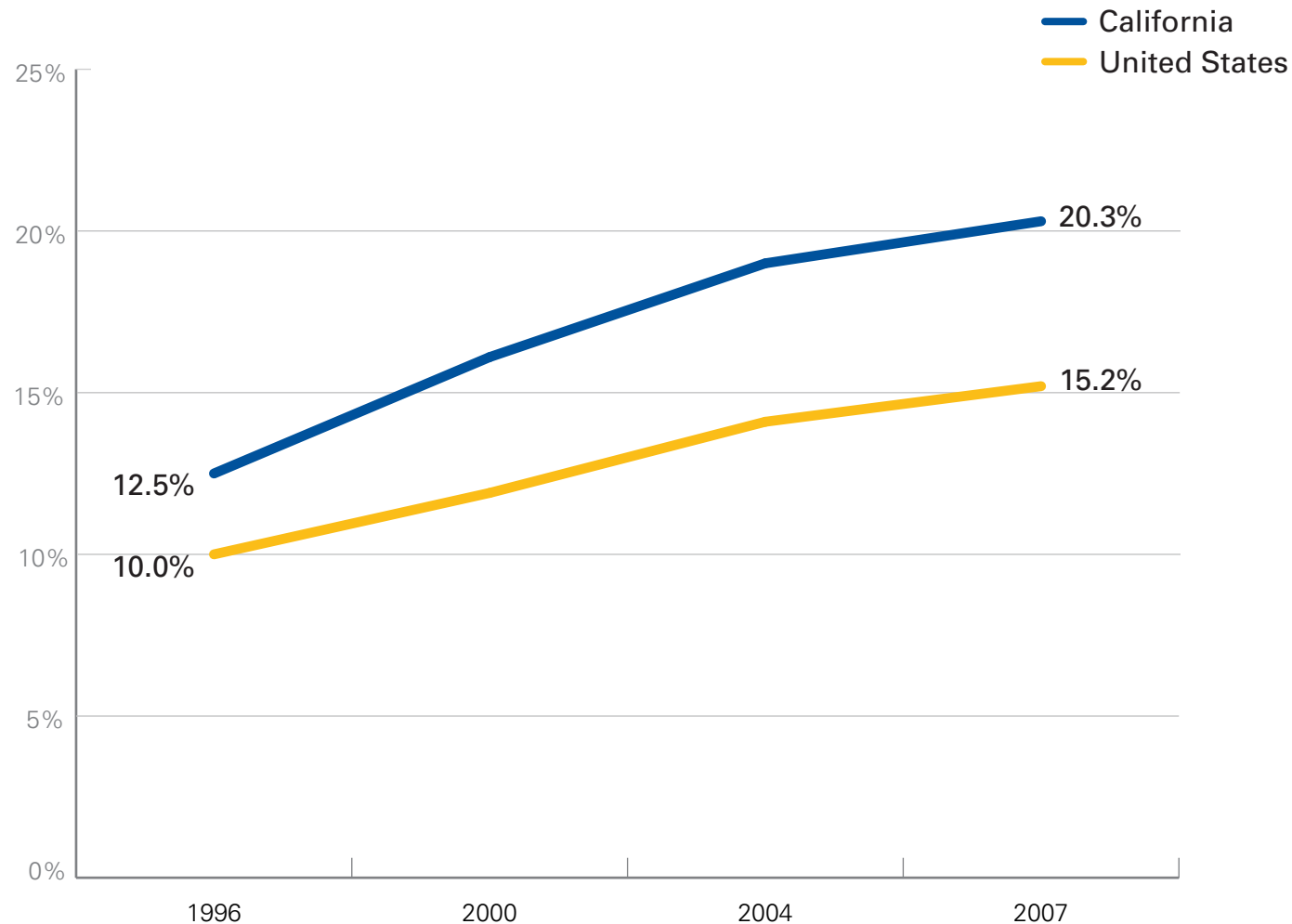


### Death and Dying in California Hospital Care

While the average number of days patients spent in the hospital during the last six months of their lives declined across the nation from 1996 to 2007, the number of days rose in California.

Source: The Dartmouth Institute for Health Policy and Clinical Practice, *The Dartmouth Atlas of Health Care*, Inpatient Days per Decedent During the Last Six Months of Life, by Gender and Level of Care, California. Accessed December 14, 2011, [www.dartmouthatlas.org](http://www.dartmouthatlas.org).

## Patients Spending 7+ Days in ICU/CCU During the Last Six Months of Life, California vs. United States, 1996 to 2007



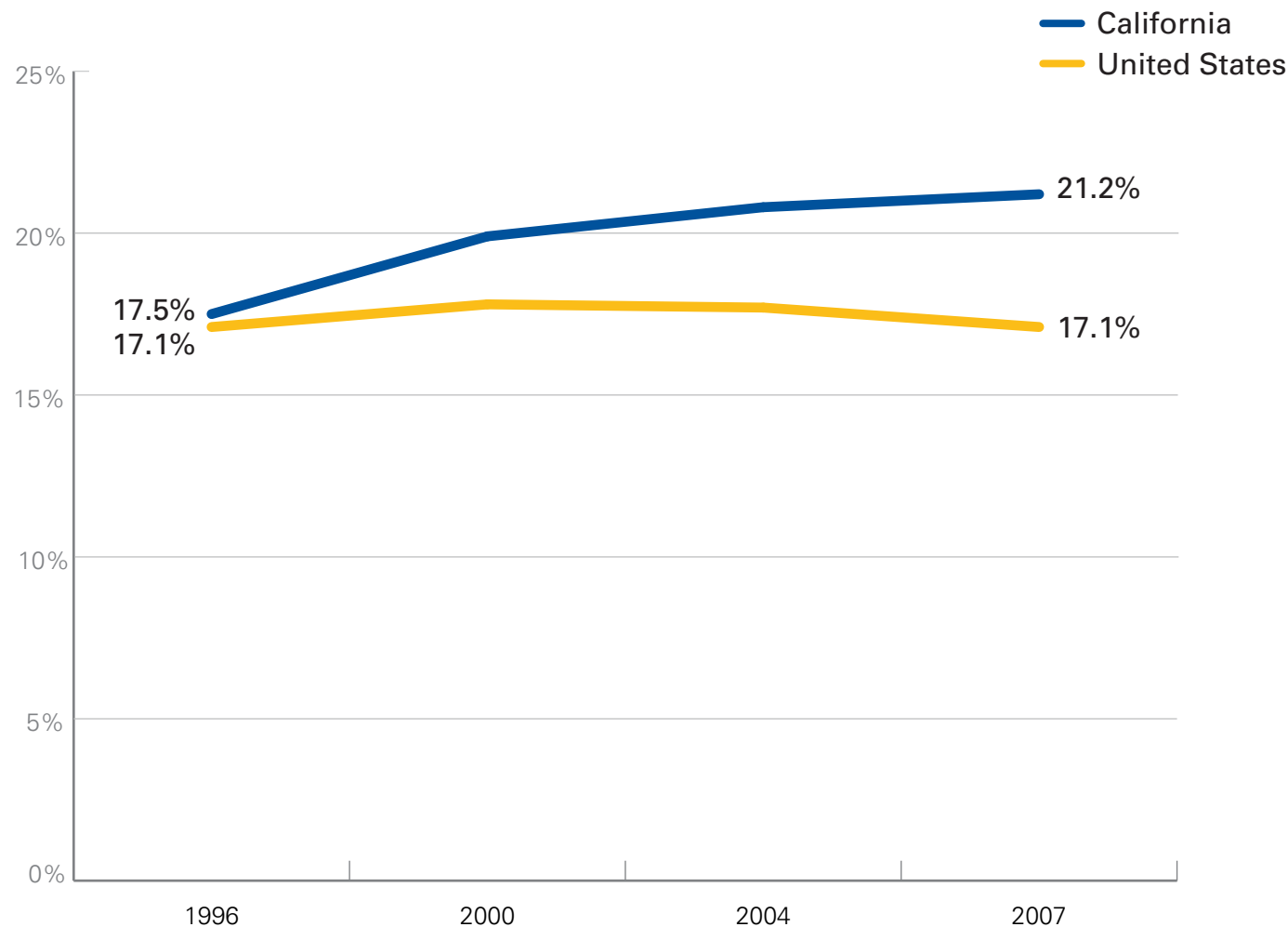
### Death and Dying in California Hospital Care

The percentage of Californians spending seven or more days in intensive care units (both high- and intermediate-intensity beds) almost doubled between 1996 and 2007, and is nearly a third higher than the national average.

This does not reflect Californians' preference for limited intervention.

Source: The Dartmouth Institute for Health Policy and Clinical Practice, *The Dartmouth Atlas of Health Care*, Percent of Decedents Spending 7 or More Days in ICU/CCU During the Last 6 Months of Life, California. Accessed December 12, 2011, [www.dartmouthatlas.org](http://www.dartmouthatlas.org).

## Patients Admitted to ICU/CCU During the Hospitalization in Which Death Occurred, California vs. United States, 1996 to 2007



Source: The Dartmouth Institute for Health Policy and Clinical Practice, The Dartmouth Atlas of Health Care, Percent of Decedents Admitted to ICU/CCU During the Hospitalization in Which Death Occurred, California. Accessed December 12, 2011, [www.dartmouthatlas.org](http://www.dartmouthatlas.org).

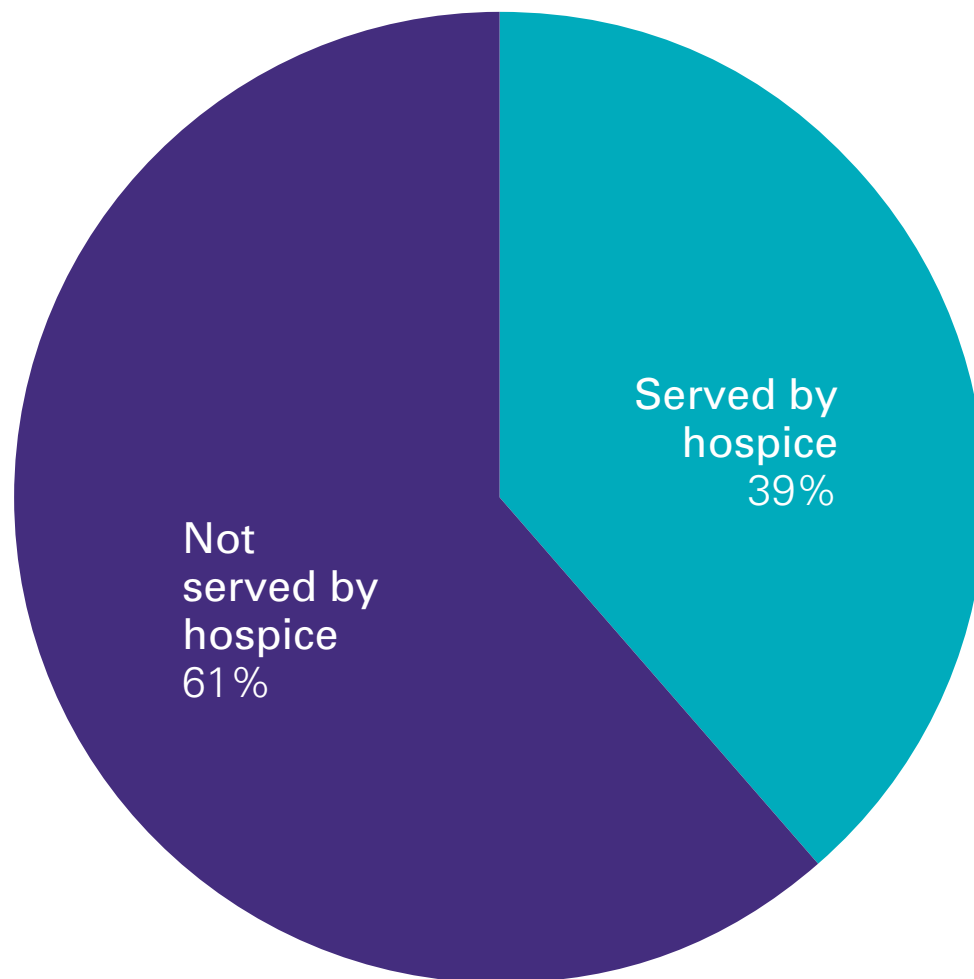
### Death and Dying in California Hospital Care

California was second only to New Jersey in the percentage of patients admitted to ICU/CCU during the hospitalization in which death occurred.\*

This growing trend does not align with Californians' preference to die at home.

\*The Dartmouth Atlas of Health Care, Percent of Decedents Admitted to ICU/CCU during the hospitalization in which death occurred, by gender. Accessed December 19, 2011, [www.dartmouthatlas.org](http://www.dartmouthatlas.org).

## Deaths Served by Hospice, Medicare Beneficiaries, California, 2010



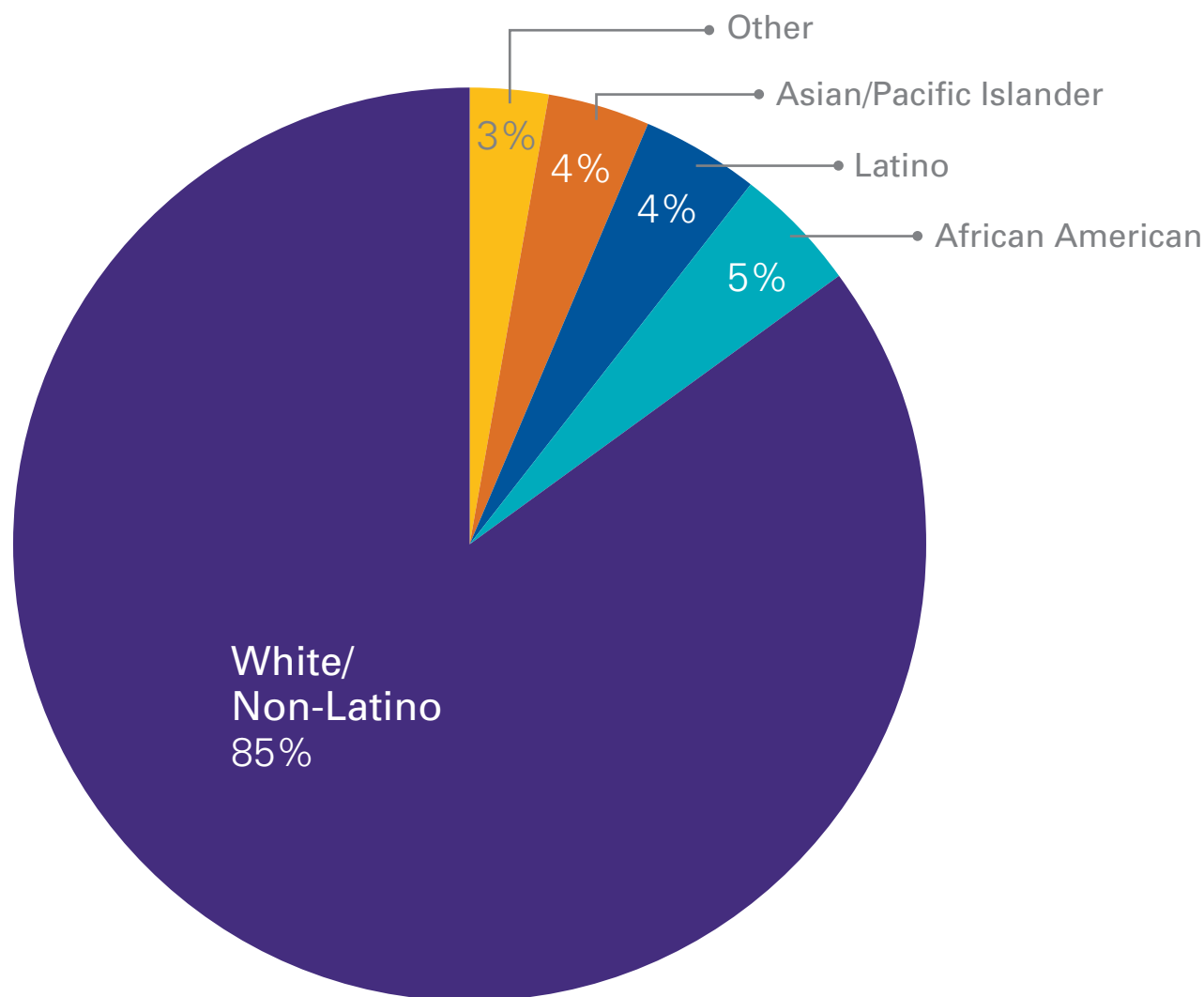
Source: California Hospice and Palliative Care Association, California State Hospice Data Report, 2012.

### Death and Dying in California Hospice Care

Less than 40% of dying Californians were served by hospice in 2010, despite research indicating that hospice patients have better symptom control and a better quality of life.\*

\*Connor, S.R., B. Pyenson, K. Fitch, C. Spence, K. Iwasaki. Comparing Hospice and Non-Hospice Patient Survival Among Patients Who Die Within a Three-Year Window. *Journal of Pain and Symptom Management*, 2007 March; 33(3). The study found the mean survival was 29 days longer for hospice patients than for non-hospice patients.

## Deaths in Hospice Care, by Ethnicity/Race, Medicare Beneficiaries, California, 2010



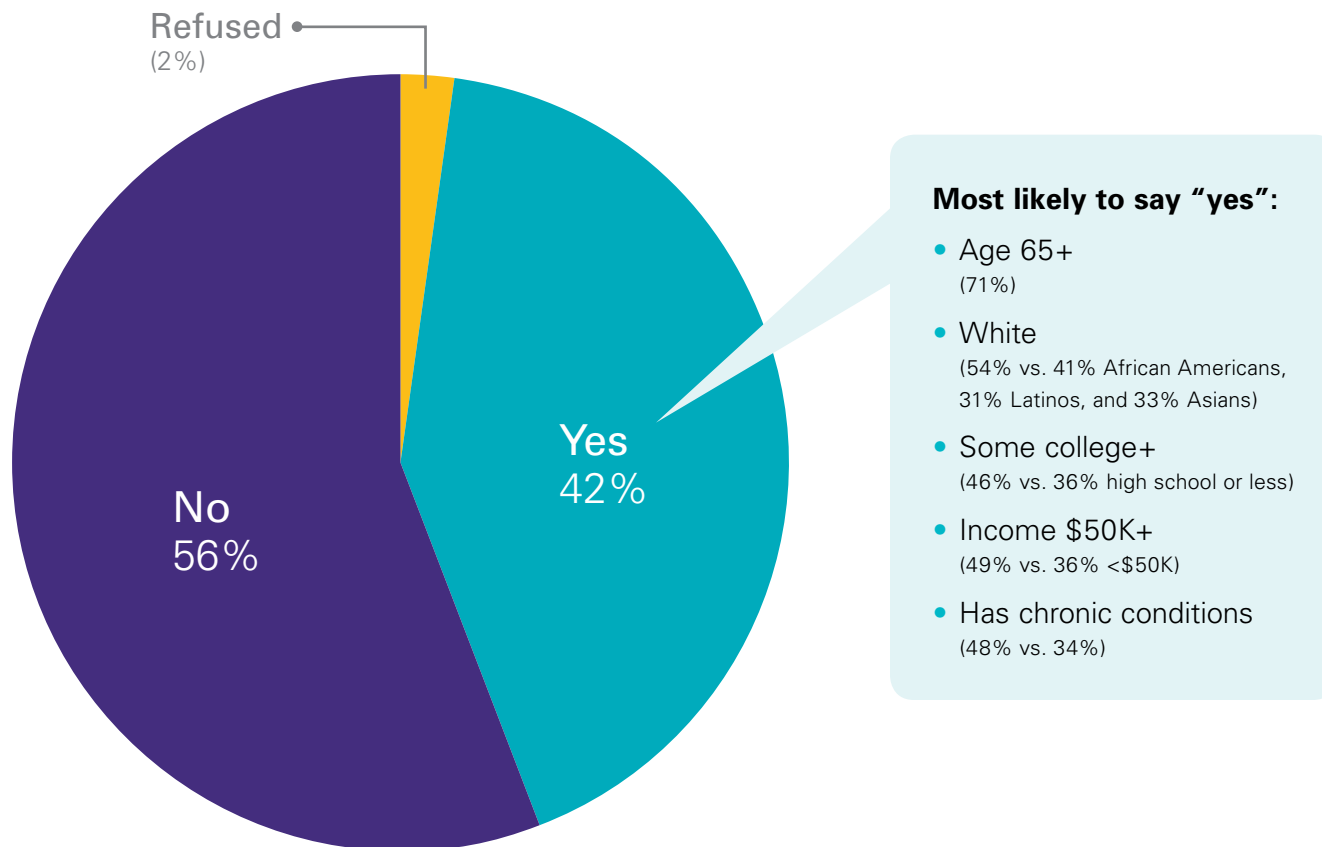
Note: Segments may not add to 100% due to rounding.

Source: California Hospice and Palliative Care Association, California State Hospice Data Report, 2012.

Whites use hospice care more than other racial/ethnic groups in California. They accounted for 85% of hospice deaths in 2010.

# Discussed End-of-Life Wishes with a Loved One, California, 2011

*Have you talked with (the loved one you would want to make decisions on your behalf) about the kind of medical treatment you would want?*



Source: Californians' Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

Fifty-six percent of respondents have not discussed their preferences with the loved one they would want making decisions on their behalf. Among Californians over 65, 71% have had the discussion.

# Barriers to Discussing Wishes with Loved One, California, 2011

*What is the main reason you have not talked (to your loved one) about your wishes for end-of-life medical treatment?*

n = 857

Too many other things to worry about right now

41%

Don't want to think about death or dying

26%

Loved one does not want to talk about death or dying

13%

Too young/long ways off

4%

Haven't thought about it

3%

No one to talk to

3%

White/Non-Latino

15%

Latino

38%

Asian/Pacific Islander

26%

African American

15%

White/Non-Latino

45%

Latino

36%

Asian/Pacific Islander

49%

African American

35%

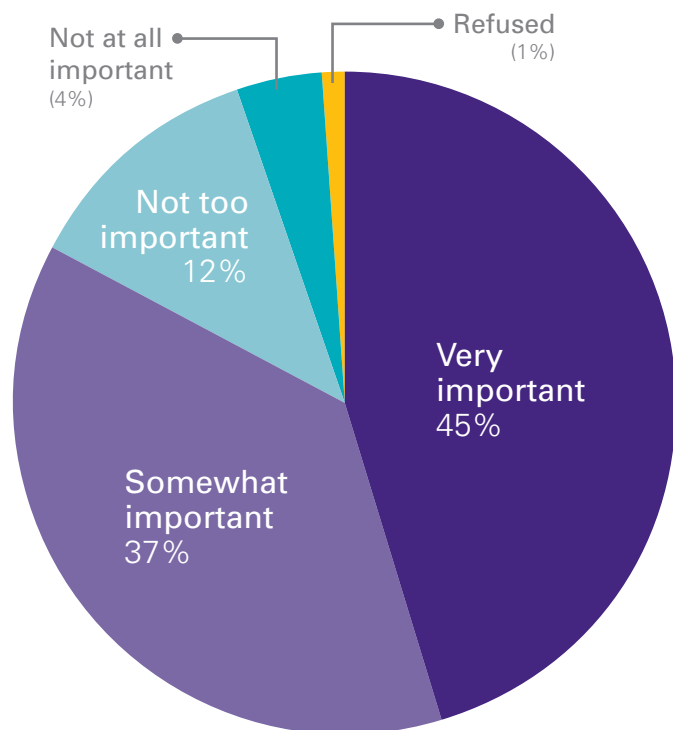
Having too many other things to worry about is a top barrier to discussing end-of-life wishes.

Latinos are more likely than other groups to say they do not want to think about death and dying.

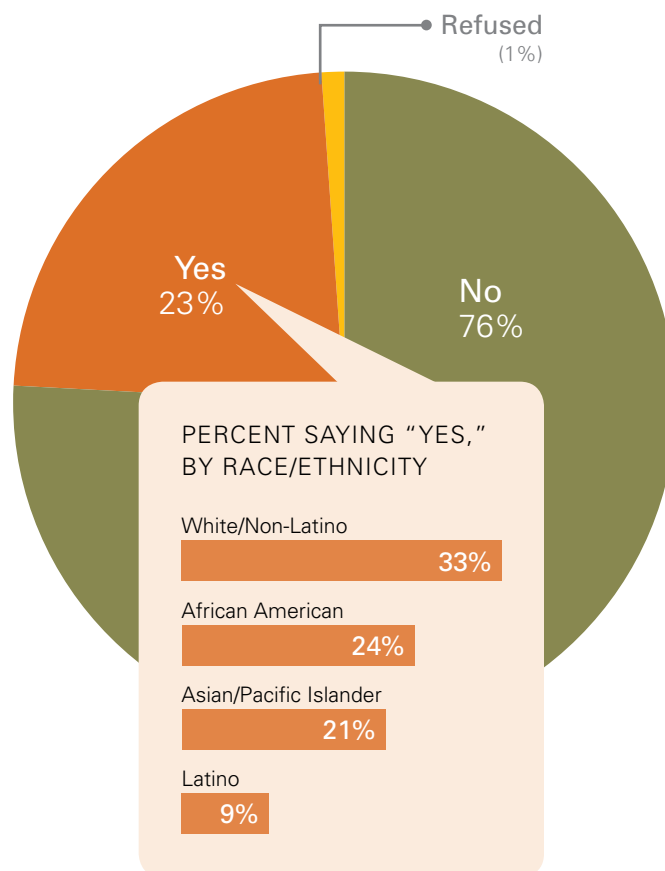
Source: Californians' Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

# Put End-of-Life Wishes in Writing, California, 2011

*How important do you feel it is to have your wishes in writing?*



*Do you have any of your wishes regarding the medical treatment you would want in a written document?*



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

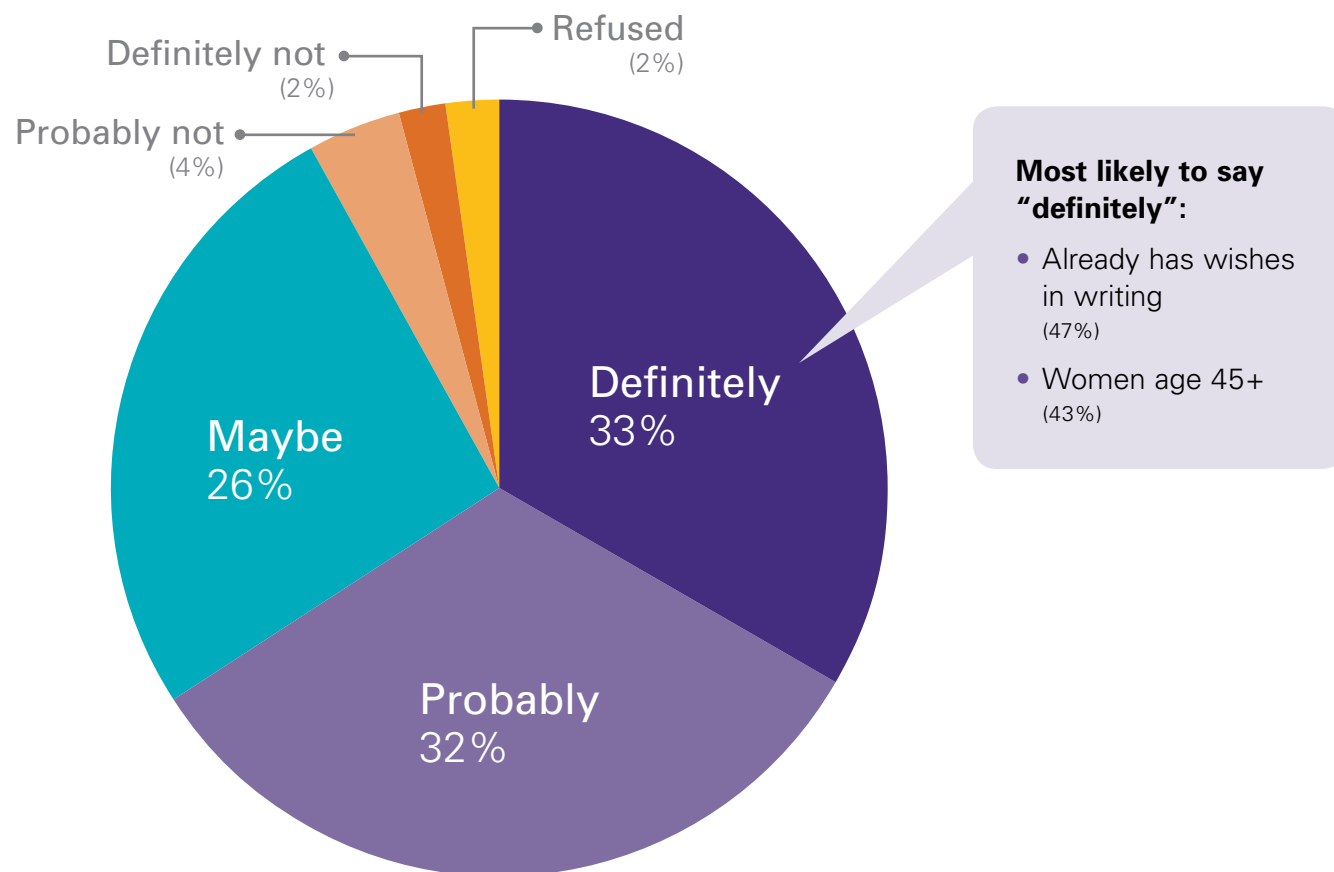
Source: Californians' Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

While a large majority of Californians feel it is important to put their wishes in writing, only 23% say they have done so.

White, non-Latino Californians are three times as likely as Latinos to have their end-of-life wishes in a written document.

# Attitudes Toward POLST for Self, California, 2011

*If you were seriously ill, do you think you would want to fill out a POLST [Physician Orders for Life-Sustaining Treatment] form with your doctor?*



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

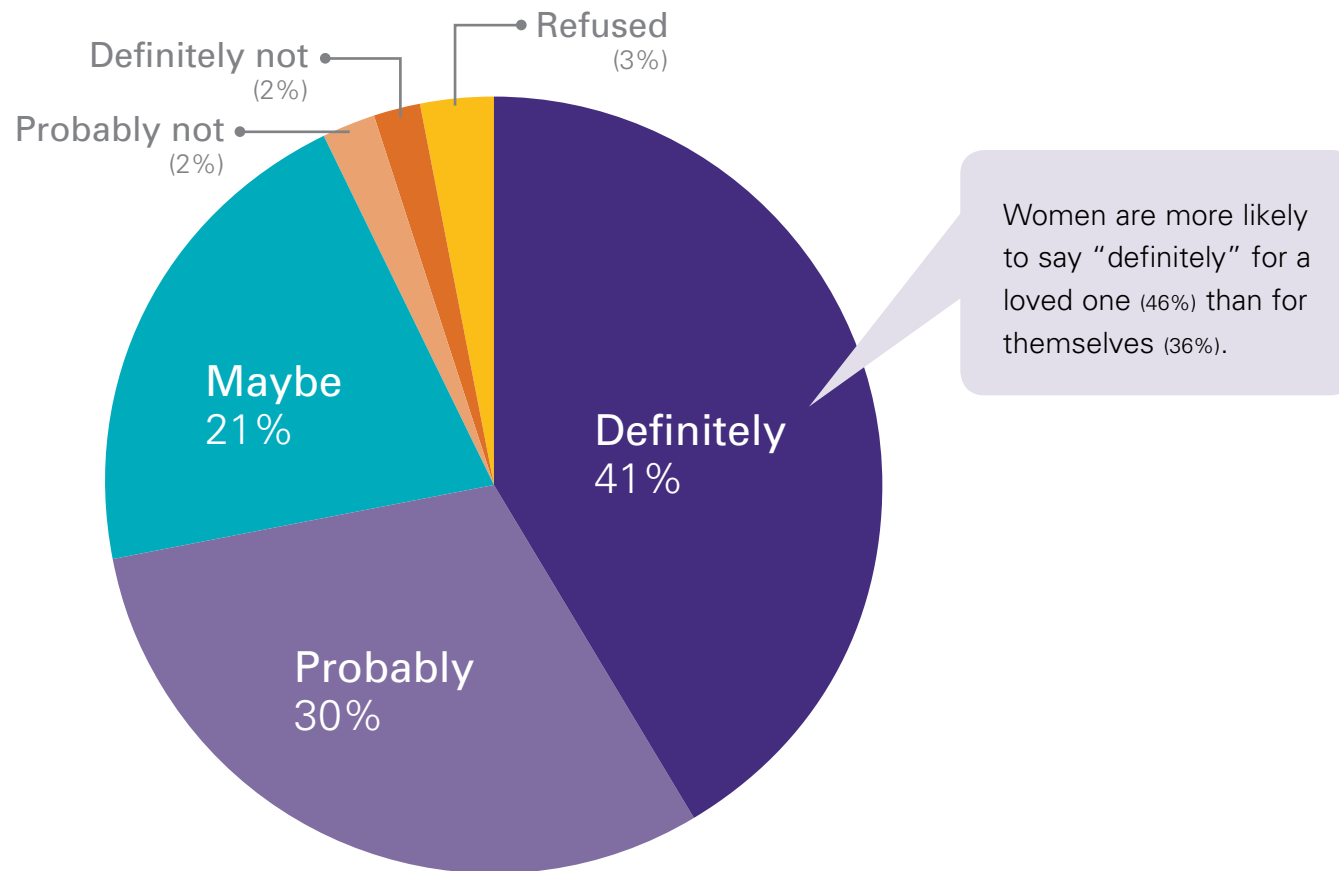
Source: Californians' Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

After hearing a description of POLST,\* almost two-thirds of Californians say they would definitely or probably want to fill out a POLST form if they were seriously ill.

\*POLST is a form for seriously ill patients that is signed by a patient and his or her doctor. The form, printed on bright pink paper, clearly says what kinds of medical treatment the patient wants toward the end of his or her life and must be honored by health care providers. POLST works even if the patient later loses the ability to say what he or she wants.

# Attitudes Toward POLST for Loved One, California, 2011

*If a loved one were seriously ill, would you want them to fill out a POLST form so you would be clear about what he or she wanted?*



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

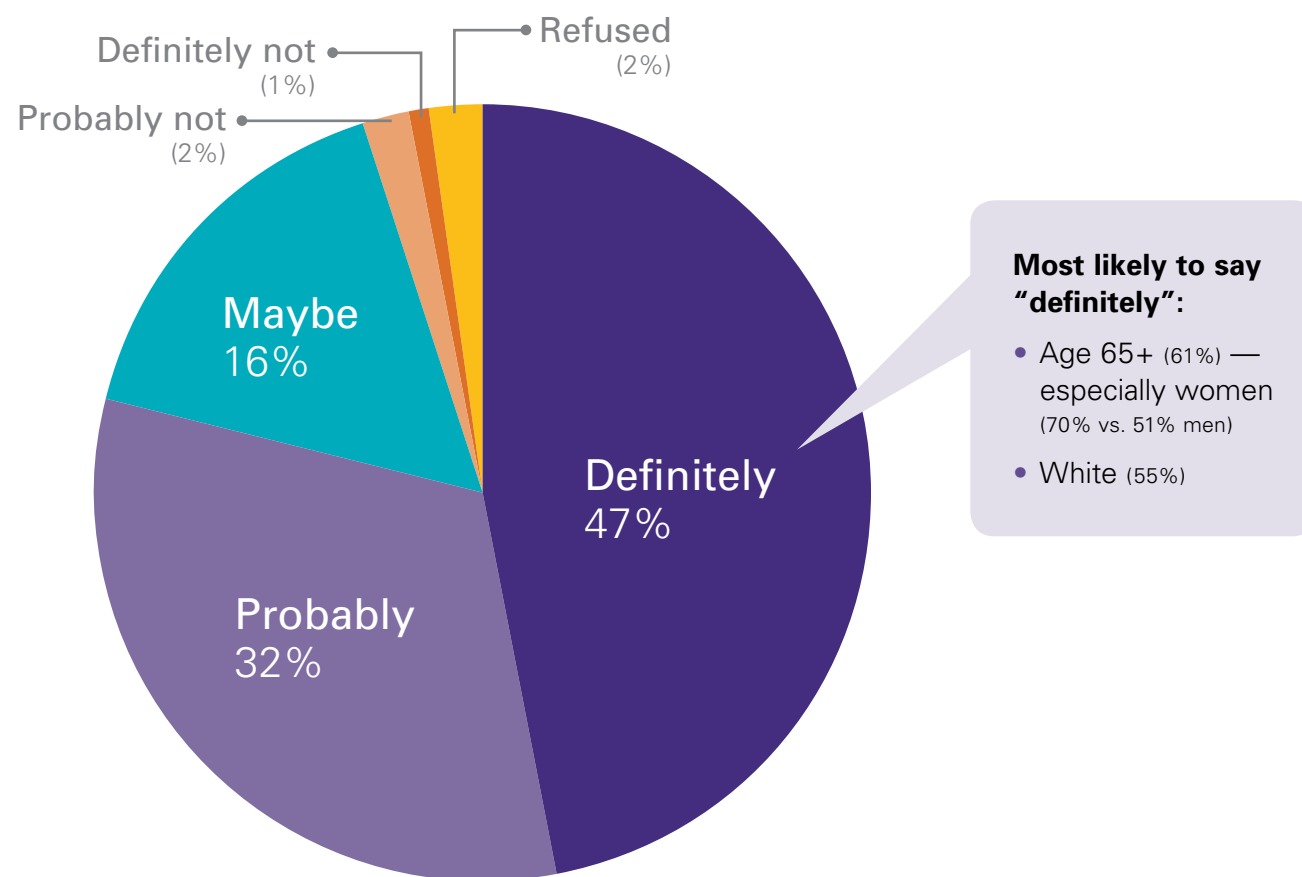
Source: Californians' Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

Seventy-one percent of Californians say they would definitely or probably want their loved one to fill out a POLST\* form if they were seriously ill.

\*POLST is a form for seriously ill patients that is signed by a patient and his or her doctor. The form, printed on bright pink paper, clearly says what kinds of medical treatment the patient wants toward the end of his or her life and must be honored by health care providers. POLST works even if the patient later loses the ability to say what he or she wants.

# Would Like to Talk to Doctor About End-of-Life Wishes, California, 2011

*If you were seriously ill, would you like to talk with your doctor about your wishes for medical treatment toward the end of your life?*



Source: Californians' Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

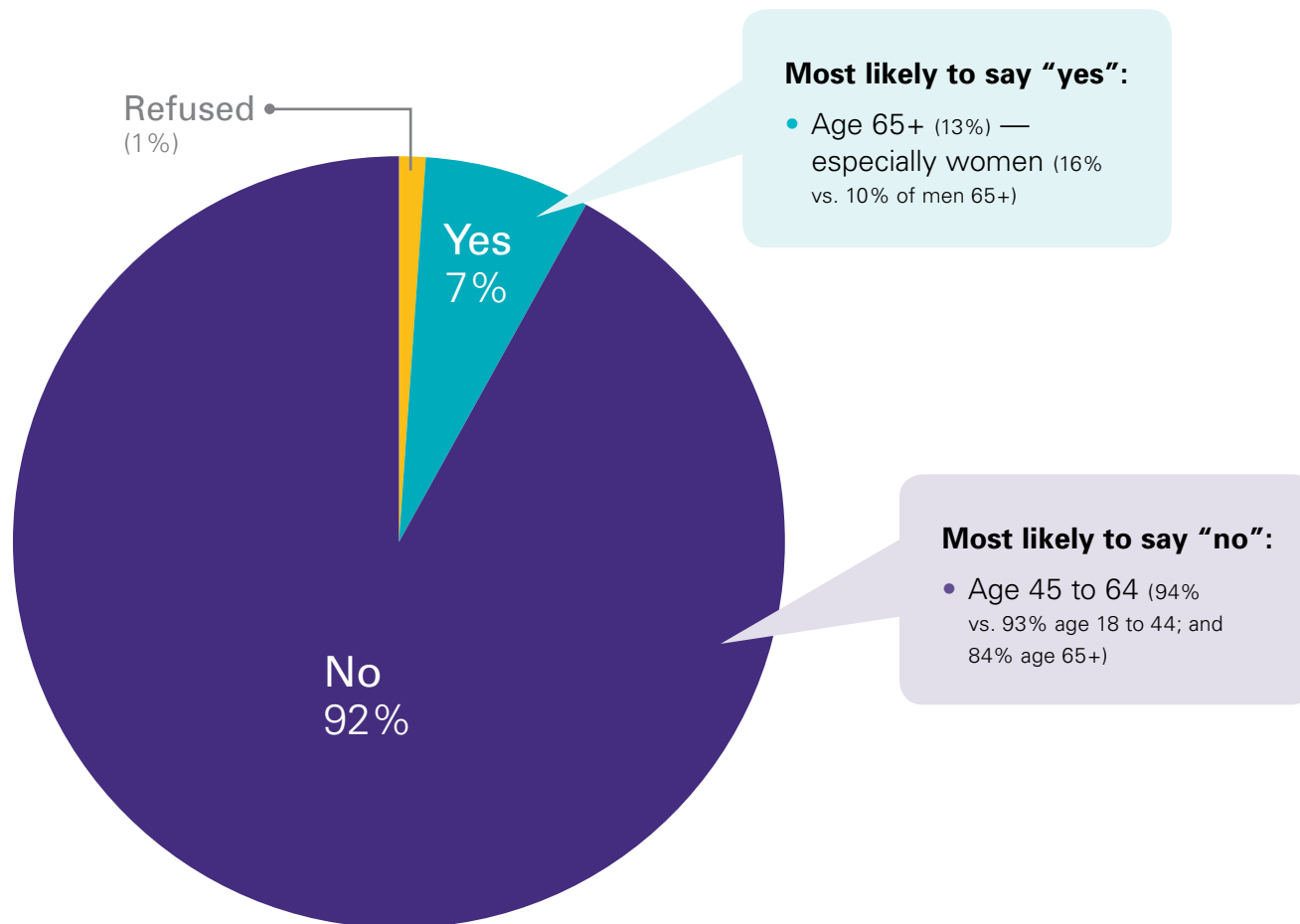
Most Californians (79%) would want to discuss their wishes for medical treatment with their doctor if they were seriously ill.

Other research has suggested such conversations are not associated with patients feeling "depressed," "sad," "terrified," or "worried."\*

\*Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment. Wright, Zhang, Ray, Mack, Trice, Balboni, Mitchell, Jackson, Block, Maciejewski, Prigerson. *JAMA*, October 8, 2008, Vol. 300, No. 14.

# Doctor Talking with Patient About End-of-Life Wishes, California, 2011

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



Source: Californians' Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

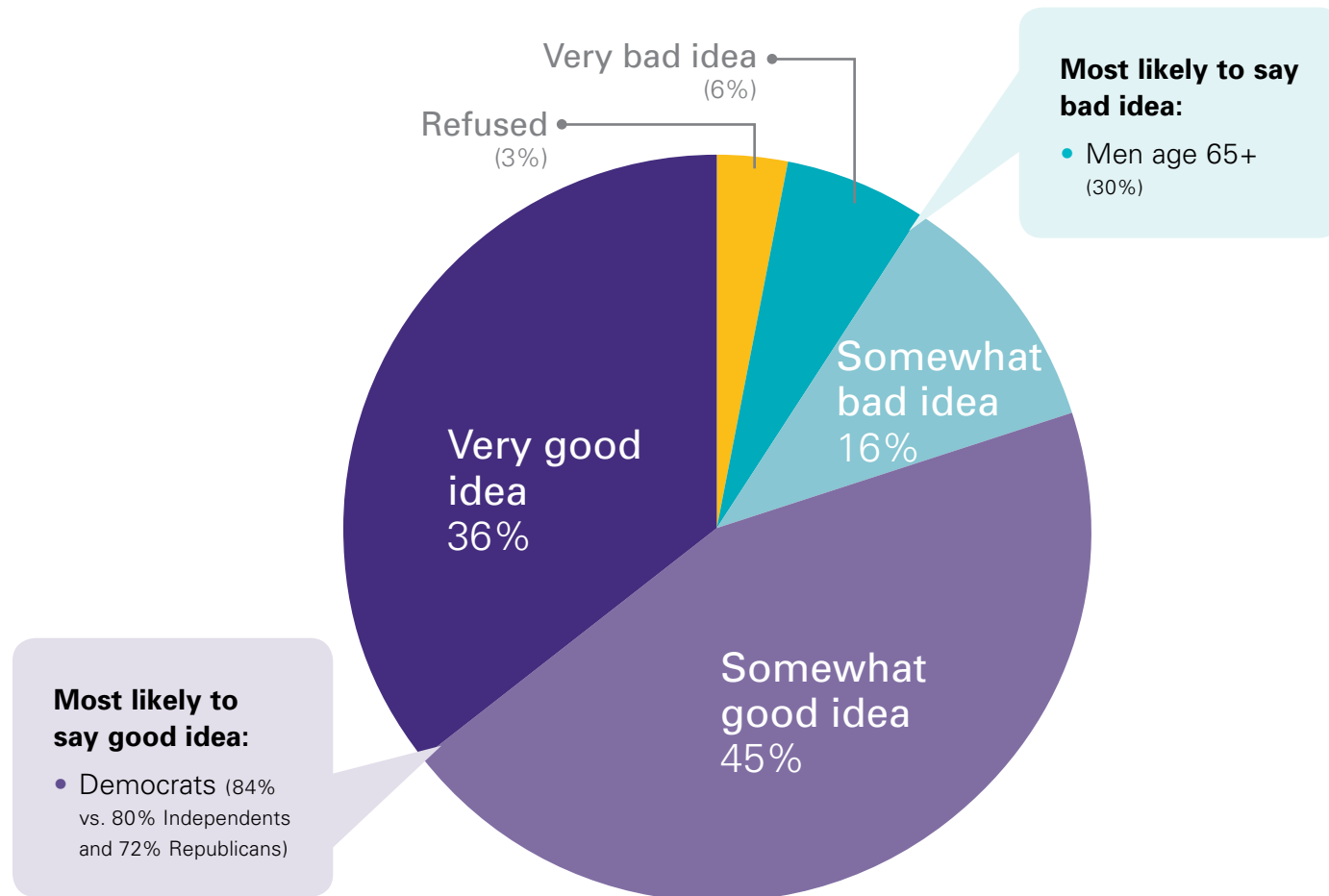
Only 7% say their doctor has talked with them about their wishes.

Research indicates that patients who had such discussions were more likely to have a DNR and to prefer comfort-focused care over life-extending therapies.\*

\*Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment. Wright, Zhang, Ray, Mack, Trice, Balboni, Mitchell, Jackson, Block, Maciejewski, Prigerson. *JAMA*, October 8, 2008, Vol. 300, No. 14.

# Physician Reimbursement for End-of-Life Discussion, California, 2011

*One idea is to have insurance plans cover a doctor's time to talk with patients about treatment options towards the end of life. Do you think this is a good idea or a bad idea?*



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

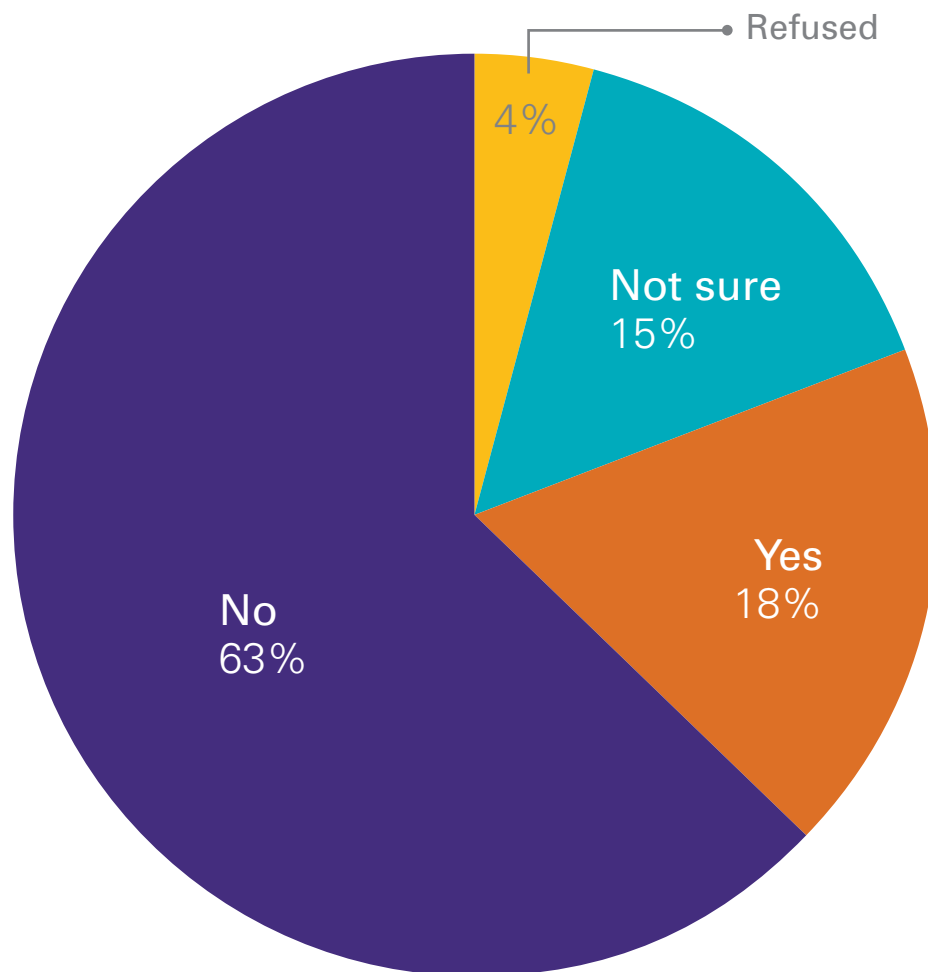
Source: Californians' Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

More than four out of five Californians say reimbursing physicians for talking about end-of-life treatment options is a good idea.

# End-of-Life Experiences with a Loved One: Use of Social Media, California, 2011

*Did you or others share information about your loved one's health through a website like CaringBridge, Facebook, or some other site?*

n = 393

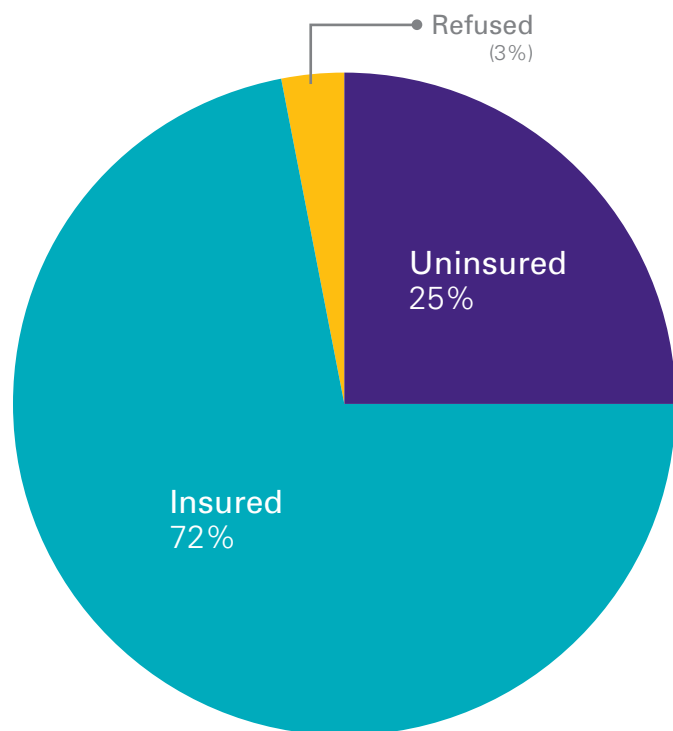


Nearly one in five respondents who recently lost a loved one say information was shared about their loved one's health on a website. Of those, 89% used Facebook.

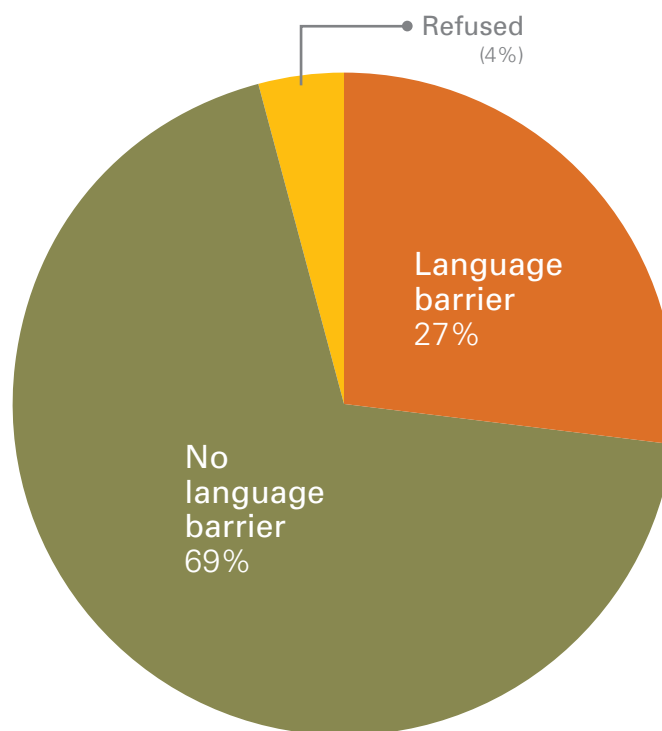
Source: Californians' Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

# Death of a Loved One, by Health Insurance Status and Language Barrier, California, 2011

*At the end of your loved one's life,  
what was their health insurance status?*



*To what extent, if at all, was language a barrier to  
your loved one getting the best possible care?*



n = 393

Among Californians who have lost a loved in the past 12 months:

- One-fourth say their loved one was uninsured at the end of his or her life.
- Twenty-seven percent say their loved one faced a language barrier to getting the best possible care.

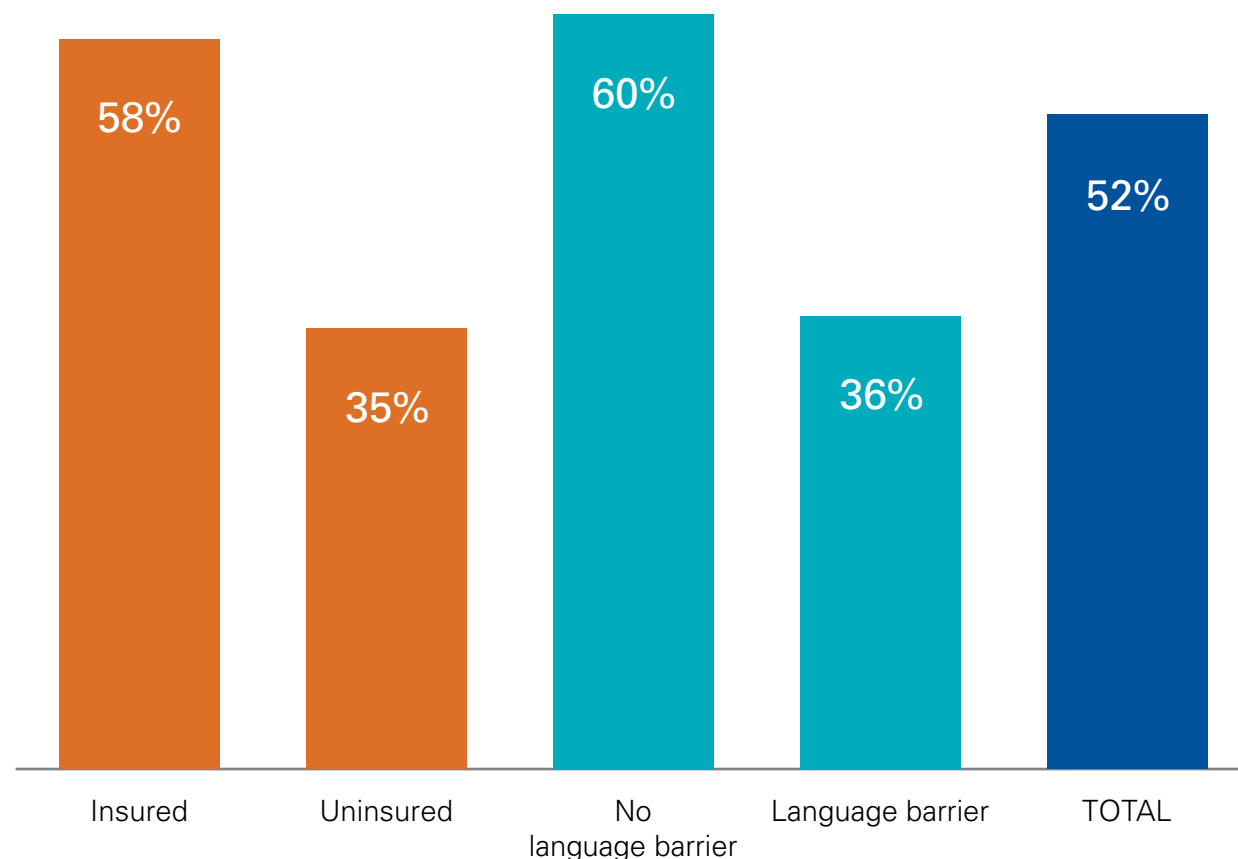
Source: Californians' Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

# Overall Rating of End-of-Life Care of Loved One, by Insurance Status and Language Barrier, California, 2011

*Overall, how would you rate the care your loved one received at the end of their life?*

PERCENT SAYING “EXCELLENT” OR “VERY GOOD”

n = 393



Note: Because sample sizes for uninsured (n=70) and facing a language barrier (n=71) are smaller than ideal, statistical tests of the differences across groups were conducted using Chi-Square tests. The difference between insured and uninsured is statistically significant at 99% level of confidence. Likewise, the difference between language barrier and no language barrier is statistically significant at 99% level of confidence.

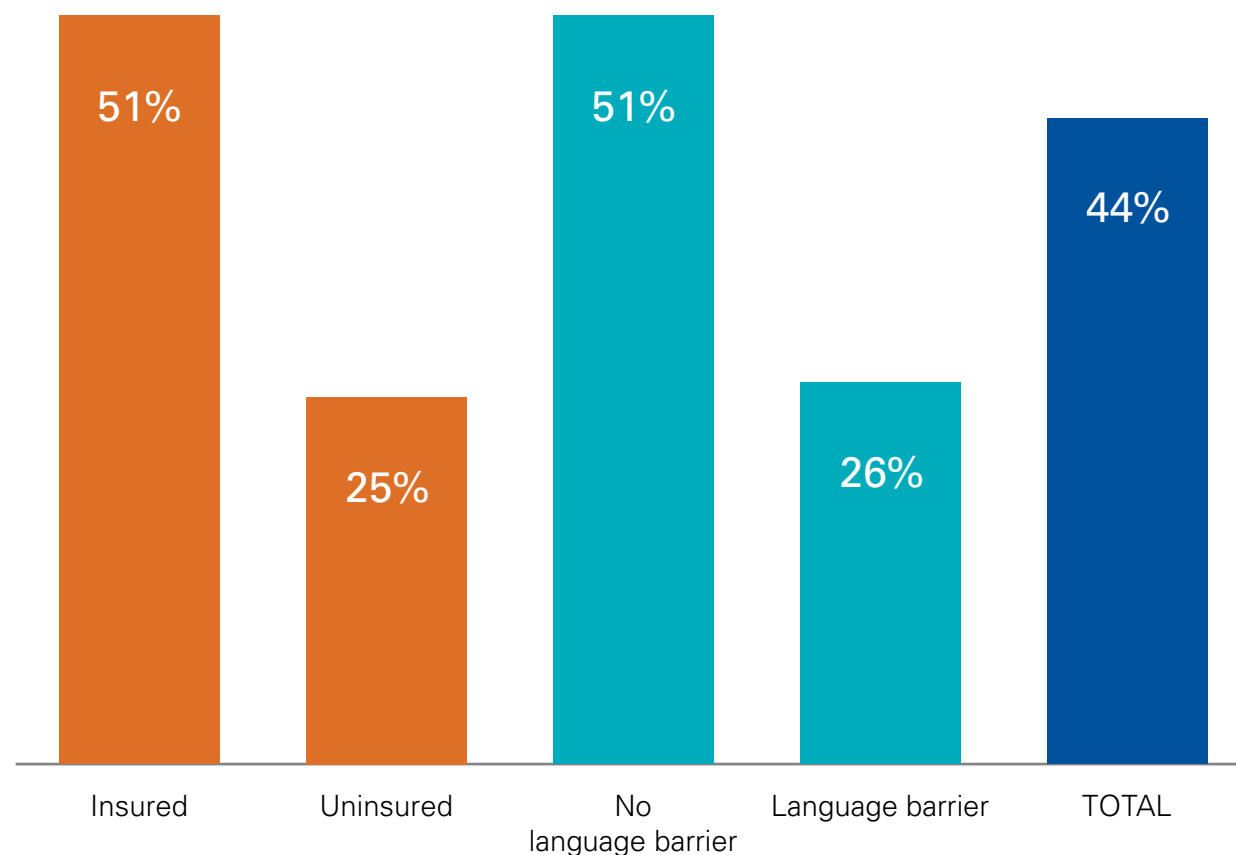
Source: Californians’ Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

Individuals whose loved one was uninsured or faced a language barrier were much less likely than others to say their loved one received excellent or very good care.

# Loved One's Wishes Completely Followed, by Insurance Status and Language Barrier, California, 2011

PERCENT WHO SAID WISHES WERE COMPLETELY FOLLOWED AND HONORED

n = 393



Note: Because sample sizes for uninsured (n=70) and facing a language barrier (n=71) are smaller than ideal, statistical tests of the differences across groups were conducted using Chi-Square tests. The difference between insured and uninsured is statistically significant at 99% level of confidence. Likewise, the difference between language barrier and no language barrier is statistically significant at 99% level of confidence.

Source: Californians' Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

Insurance status and the presence of a language barrier influenced whether respondents felt their loved one's wishes were completely followed and honored by health care providers.

## Authors

**Lake Research Partners** provides public opinion and research-based strategy for campaigns, issue advocacy groups, foundations, unions, and nonprofit organizations.

[www.lakeresearch.com](http://www.lakeresearch.com)

**The Coalition for Compassionate Care of California** is a partnership of nearly 200 regional and statewide organizations dedicated to the advancement of palliative medicine and end-of-life care in California.

[www.coalitionccc.org](http://www.coalitionccc.org)

## Methodology

The survey was conducted October 26 through November 3, 2011 among a representative sample of 1,669 Californians 18 and older, including 393 respondents who have lost a loved one in the past 12 months, using Knowledge Networks. The margin of error is 2.4 percentage points for the total results.

### Survey Respondents Demographics

GENDER		AGE GROUP	
Men . . . . .	49%	18 to 24 . . . . .	11%
Women . . . . .	51%	25 to 29 . . . . .	12%
		30 to 34 . . . . .	9%
		35 to 39 . . . . .	10%
		40 to 44 . . . . .	9%
		45 to 49 . . . . .	9%
		50 to 54 . . . . .	9%
		55 to 59 . . . . .	9%
		60 to 64 . . . . .	7%
		65 to 69 . . . . .	7%
		70 to 74 . . . . .	4%
		75+ . . . . .	2%
		(Not ascertained) . . . . .	2%
RACE/ETHNICITY			
White/Non-Latino . . . . .	47%		
Latino . . . . .	33%		
Asian/Pacific Islander . . . . .	12%		
African American . . . . .	6%		
Other . . . . .	1%		
2+ races . . . . .	1%		

### FOR MORE INFORMATION



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