



End-of-Life Care Survey of Upstate New Yorkers: Advance Care Planning Values and Actions Summary Report



Executive Summary

Over the last several years, Excellus BlueCross BlueShield has committed to helping its employees and people in the community become more aware of the importance of not only completing advance directives, but also conversing with family, friends and their personal physicians about their individual preferences. Advance directives include the designation of a Health Care Proxy and the completion of a Living Will. While cases like that of Terry Schiavo have helped bring national attention to the issue of advance care planning, most adults in the United States still have not legally expressed their end-of-life care wishes. A nationwide poll conducted by the AARP Bulletin in 2007 found that more than 90% of adults 35 and older are aware of Health Care Proxies and Living Wills, but less than 40% have actually completed these forms.ⁱ Similarly, a nationwide poll conducted by the Pew Research Center in 2005 found that 95% of adults were aware of advance directives, but only 29% of Americans had completed one.ⁱⁱ

To assess consumer attitudes and actions regarding two important advance directives (Health Care Proxies and Living Wills), Excellus BlueCross BlueShield commissioned United Marketing Research to conduct the most comprehensive survey ever done on the topic in upstate New York. Between March 6, 2008, and April 6, 2008, a random sample of 2,000 adults, 18 and older, who reside in 39 upstate New York counties were interviewed by telephone. Respondents were selected using a random digit dialing (RDD) sample. A quota sampling approach also was used to ensure that a statistically significant number of individuals (about 400) would be surveyed within each of five regions (Central New York, Rochester, the Southern Tier, Utica and Western New York). Quotas also were established for respondents 55 and older to help minimize age bias associated with telephone surveys. The margin of error for the overall sample (n = 2,000) is approximately ±2.5%; for each region, the margin of error is ±5%.

Counties Located Within the Five Upstate Regions Surveyed

Rochester	Central NY	Southern Tier	Utica	Western NY
Livingston	Cayuga	Broome	Clinton	Allegany
Monroe	Cortland	Chemung	Delaware	Cattaraugus
Ontario	Jefferson	Chenango	Essex	Chautauqua
Seneca	Lewis	Schuyler	Franklin	Erie
Wayne	Onondaga	Steuben	Fulton	Genesee
Yates	Oswego	Tioga	Hamilton	Niagara
	St. Lawrence		Herkimer	Orleans
	Tompkins		Madison	Wyoming
			Montgomery	
			Oneida	
			Otsego	

Specific issues explored on the survey included:

- Awareness and knowledge of Health Care Proxies and Living Wills
- Completion rates for Health Care Proxies and Living Wills
- Attitudes toward Health Care Proxies and Living Wills
- Reasons for not completing a Health Care Proxy form
- Discussions of Health Care Proxies and Living Wills with family and personal doctor

The survey results provide attitudinal and behavioral assessments for two important advance directives and identify demographic factors that have the most influence on these attitudes and behaviors.

Below is a summary of the findings. The results were weighted by region and age to more accurately reflect the relative size of various segments in the upstate New York population surveyed.

Key Findings

Attitudes and Actions Regarding Health Care Proxies and Living Wills

- Considerable disparity exists between consumer attitudes and behavior as they relate to advance directives. Nearly 9 of 10 adults surveyed (88%) say it is very/fairly important that they have someone who could make medical decisions on their behalf if they had an irreversible terminal condition and were no longer able to make medical decisions on their own. Yet, only 42% indicated they have actually designated a Health Care Proxy who would assume this responsibility.
- Even fewer people reported completing a Living Will (26%), although 80% said it is very/fairly important for them to have such a document.
- Perceived importance of the two advance directives was high even among those who had not completed a Health Care Proxy form or a Living Will. Among those who had not completed a Health Care Proxy form, 81% said it would be very/fairly important for them to have a Health Care Proxy. Of those who had not completed a Living Will, three-quarters (74%) felt that it was very/fairly important for them to have one.
- Overall, about 4 of 5 residents surveyed felt that every adult should have a Health Care Proxy (81%) and a Living Will (78%). Only a small percentage thought that Health Care Proxies and Living Wills were only for old or sick people (11% to 12%).

Regional Variations in Attitudes and Actions

- Significant regional variations were observed in completion rates for Health Care Proxy forms, from a low of 35% in Utica to a high of 47% in Rochester. Attitudes toward Health Care Proxies, on the other hand, showed little variation across regions (85% to 90% saying it was very/fairly important). This was true for Living Wills as well (77% to 83% saying it was very/fairly important). Completion rates for Living Wills varied little across regions (24% to 29%).

Knowledge of Health Care Proxies and Living Wills

- Overall, 3 of 4 upstate New York residents surveyed said that they had heard of the term, Health Care Proxy (75%). Of these, 92% were able to identify the correct definition from a list of choices. Awareness of the term, Health Care Proxy, was somewhat lower in Utica than in other regions (64% vs. 72% to 79% in other regions), which may partly explain the lower completion rate in that region.
- Nine of ten (90%) said they had heard of the term, Living Will. Of these, however, only about three-quarters (74%) were able to identify the correct definition. One of six (17%) mistakenly confused a Living Will with a Last Will and Testament. Knowledge regarding the term, Living Will, did not vary appreciably across regions.

Reasons for Not Completing a Health Care Proxy

- Only 18% of those surveyed said they saw no need to complete a Health Care Proxy form, a finding that did not vary much across regions (15% to 21%).
- The most common reasons given for not completing a Health Care Proxy form included:
 - Don't need it/Don't think it's important (mentioned by 27% of those who did not complete the form)
 - Don't know enough about it (21%)
 - Too young to be concerned about it (12%)
 - Not having the time/Haven't gotten around to it (11%)
 - Not knowing where to get the forms (5%)
 - Don't know who to designate as my Health Care Proxy (5%)
 - Uncomfortable thinking about such things (5%)

Influence of Demographic Factors on Actions, Attitudes, and Knowledge Regarding Advance Directives

- **Age** is, by far, the most important demographic factor influencing completion rates for both Health Care Proxies and Living Wills. For Health Care Proxies, completion rates ranged from 11% for young adults (ages 18 to 24) to 67% for seniors (age 65+). For Living Wills, completion rates ranged from 6% for young adults to 51% for seniors. Completion rates for the two advance directives improved only slightly between the ages of 35 and 64 (44% to 52% for Health Care Proxies, 24% to 29% for Living Wills). After age 65, completion rates were significantly higher (up to 67% for Health Care Proxies and 51% for Living Wills).
- The influence of age on attitudes toward Health Care Proxies and Living Wills was considerably less dramatic. Younger adults, ages 18 to 34, were somewhat less likely to perceive Health Care Proxies and Living Wills as important to them. After age 35, attitudes plateaued at a fairly high level, with about 90% saying Health Care Proxies are very/fairly important and more than 80% saying Living Wills are important.

Other demographic factors that appear to influence completion rates include:

- **Gender:** Women were significantly more likely than men to report completing Health Care Proxies (46% vs. 36%) and Living Wills (28% vs. 23%).
- **Education:** Those with advanced college degrees were more likely to report completing a Health Care Proxy form (49% vs. 38% of those without any college education). The effect of education, however, was not seen after the age of 55.
- Attitudes toward Health Care Proxies also appear to be affected by gender and education, with women and adults with advanced college degrees more likely to feel that Health Care Proxies are important to them (91% of women vs. 83% of men; 93% of those with advanced degrees vs. 85% of those without a college education). Women were also more likely than men to judge Living Wills as being important to them (83% vs. 73% of men).
- Factors influencing awareness and knowledge of Health Care Proxies included age, gender, and education. Awareness was highest for women (81% vs. 63% of men), adults between the ages of 35 and 64 (81% to 83%), and those with advanced college degrees (90%). College graduates and adults between the ages of 45 and 64 appeared to be most knowledgeable about Living Wills.

Discussions With Doctors/Family Members

- Just over a third of respondents said that their doctor had talked to them about Health Care Proxies and Living Wills (35%). The figure was significantly higher in Rochester (47%) than in other regions (CNY, 35%; the Southern Tier, 34%; WNY, 33%; and Utica, 27%.) Those findings may help explain significant completion rate differences among regions. Women also were much more likely than men to report that their doctor had spoken to them about advance directives (41% vs. 26% of men).
- Two-thirds said that they have had a conversation with a family member or close friend about Health Care Proxies and Living Wills (67%), a figure that did not vary much across regions (62% to 71%). Again, women were more likely to report having such a conversation (73% vs. 55% of men).
- Among those who have completed a Health Care Proxy form, 94% said they have shared their wishes with their family and the person they designated as their Health Care Proxy. Similarly, among those who have completed a Living Will, 92% said they have shared their wishes with their family and close friends.

Other Findings

- About 3 of every 4 respondents (77%) thought that a legal form would be required in order to designate a particular person who could make medical decisions for them in the event they are no longer able to communicate. The result showed relatively little variation across key demographics, e.g., age, gender, region, education, health status.
- Of adults surveyed, 92% said they would want someone in particular to make medical care decisions for them in the event they were unable to communicate and make decisions about their own medical care. Of these, about half would want their spouse to make the medical decisions (52%), 19% mentioned a son or daughter, 14% a parent, and 8% said another close relative. Few would choose a close friend (1%), their doctor (less than 1%) or their attorney (less than 1%).

Conclusions

- A significant disparity exists between attitudes and actions as they relate to two key advance directives (Health Care Proxies and Living Wills). While most adults in upstate New York feel that Health Care Proxies (88%) and Living Wills (80%) are important for them to have, only 42% have designated a Health Care Proxy and just 26% have completed a Living Will.

- Significant regional variations exist in completion rates for Health Care Proxies. The highest rate is in Rochester (47%) and lowest in Utica (35%). Evidence suggests that the difference could be driven, in part, by physician communication with patients as the highest rate of discussion with doctors occurred in Rochester (47% vs. Utica, 27%). Studies in the medical literature have demonstrated that physician counseling markedly increases the completion rate of advance directives.^{iii iv v vi vii viii ix}
- Age is the most important factor affecting completion rates for Health Care Proxies and Living Wills. As people grow older, they are much more likely to engage in advance care planning, especially after they reach age 65. Other demographic factors that influence the decision to act include gender and level of education.
- Age, gender, and level of education also affect awareness of and attitudes toward advance directives. In general, women and adults age 35 and older are more likely to perceive Health Care Proxies and Living Wills to be important.

Key Resource

For more information about advance care planning, go to compassionandsupport.org.

References

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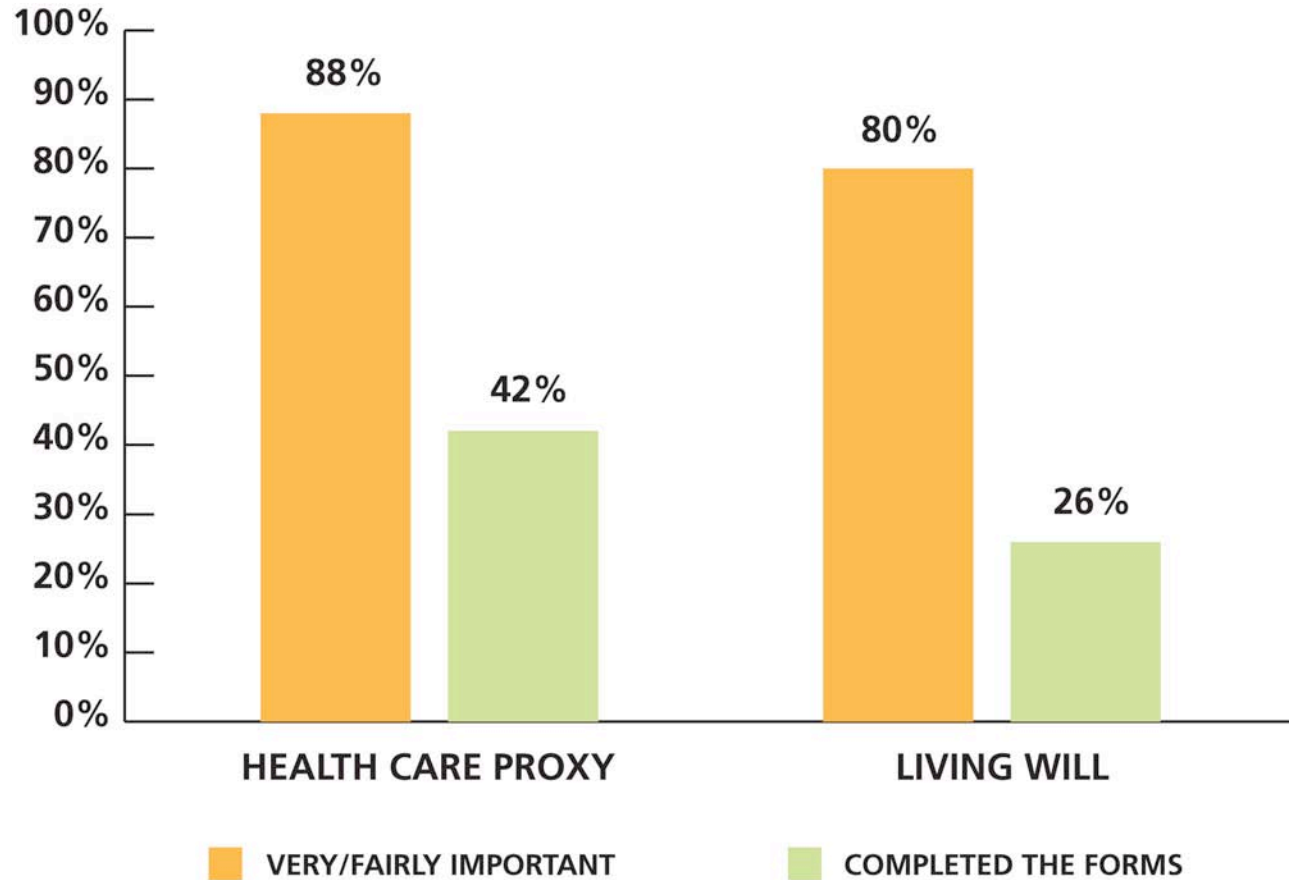
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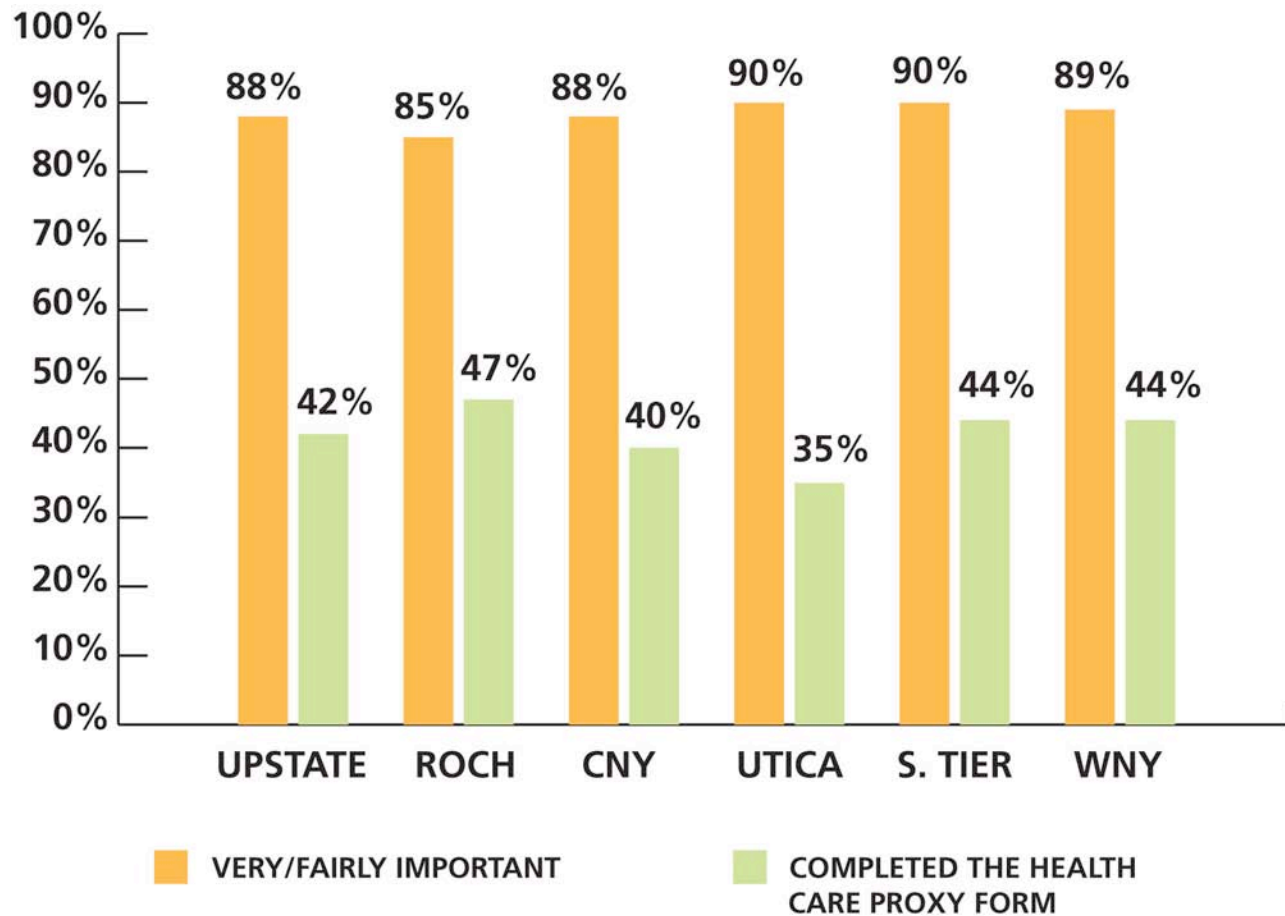


Disparity between consumer attitudes and actions regarding advance directives



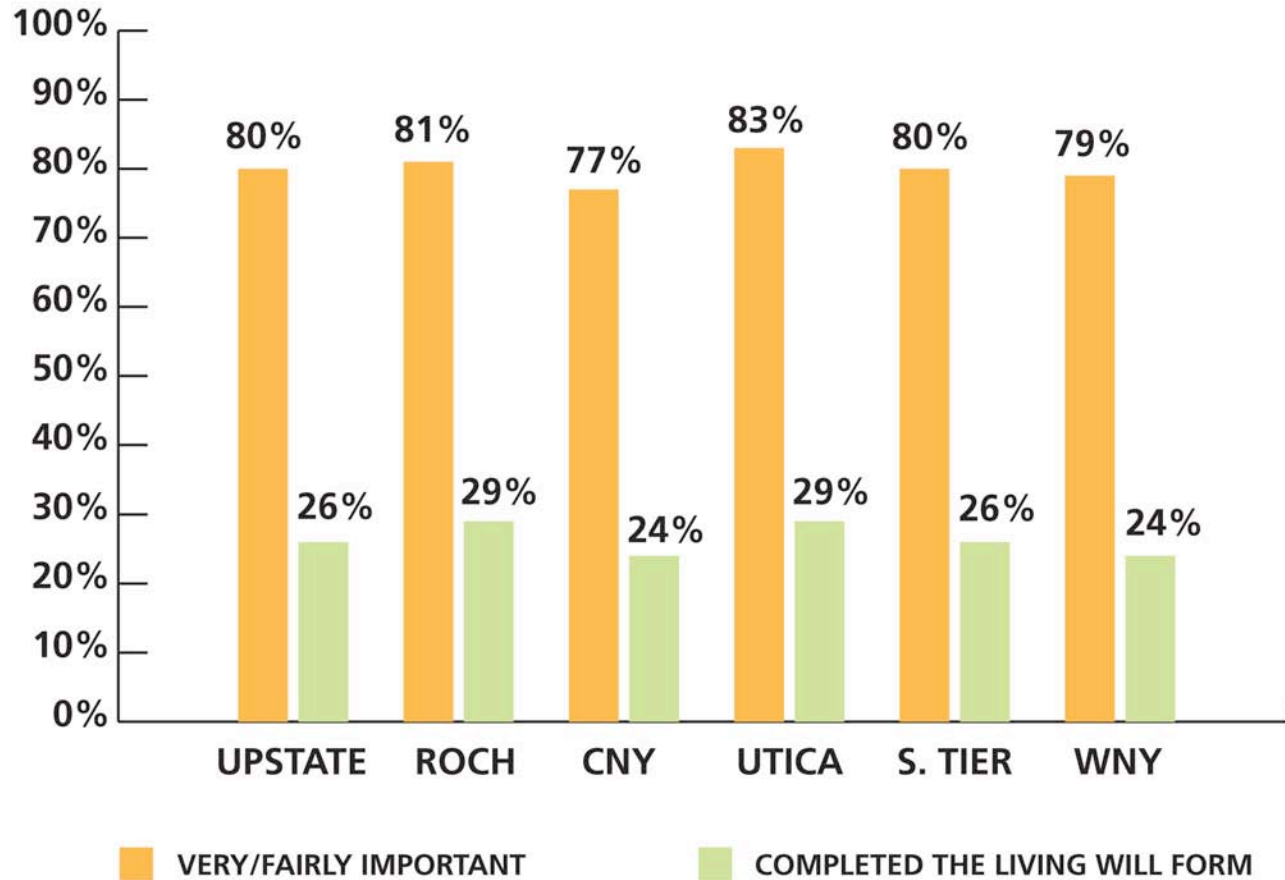


Disparity between attitudes and actions regarding Health Care Proxies



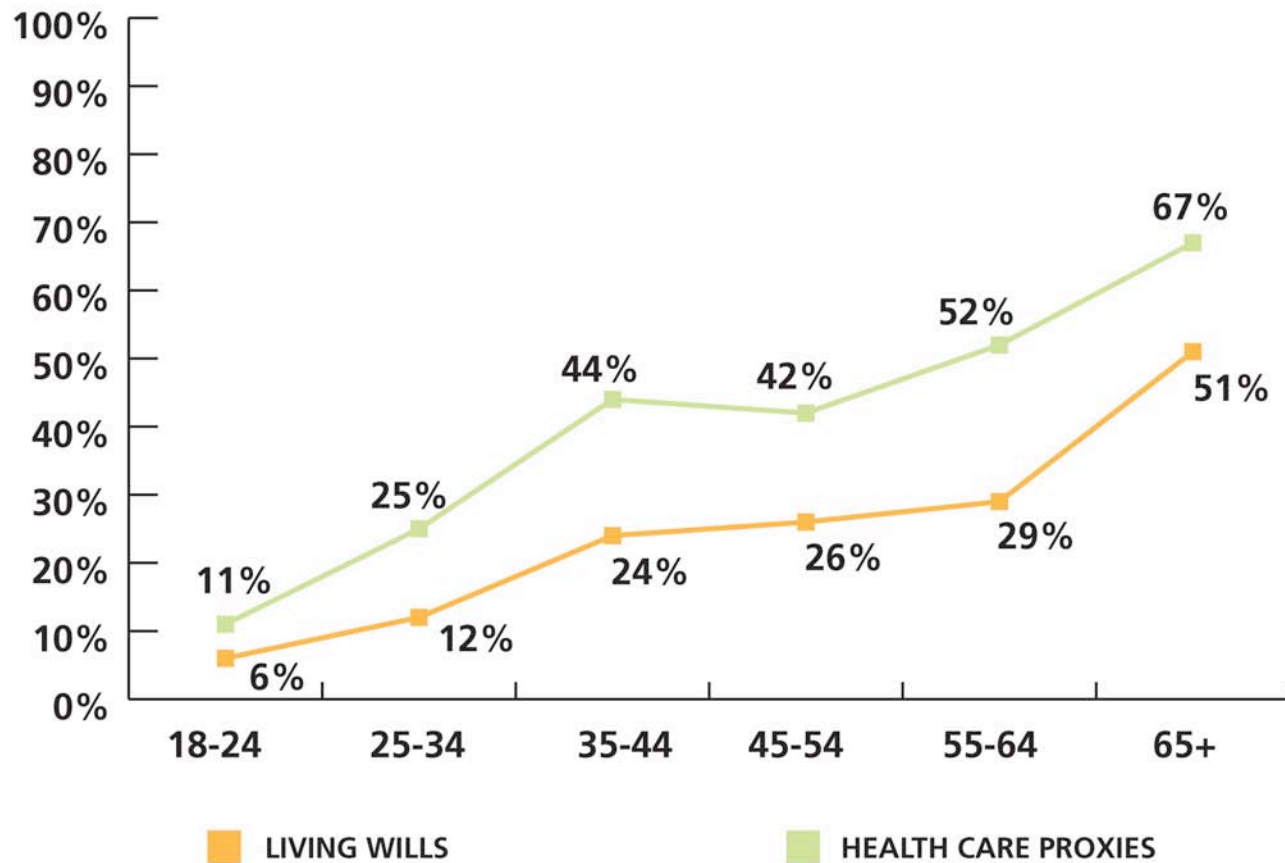


Disparity between attitudes and actions regarding Living Wills



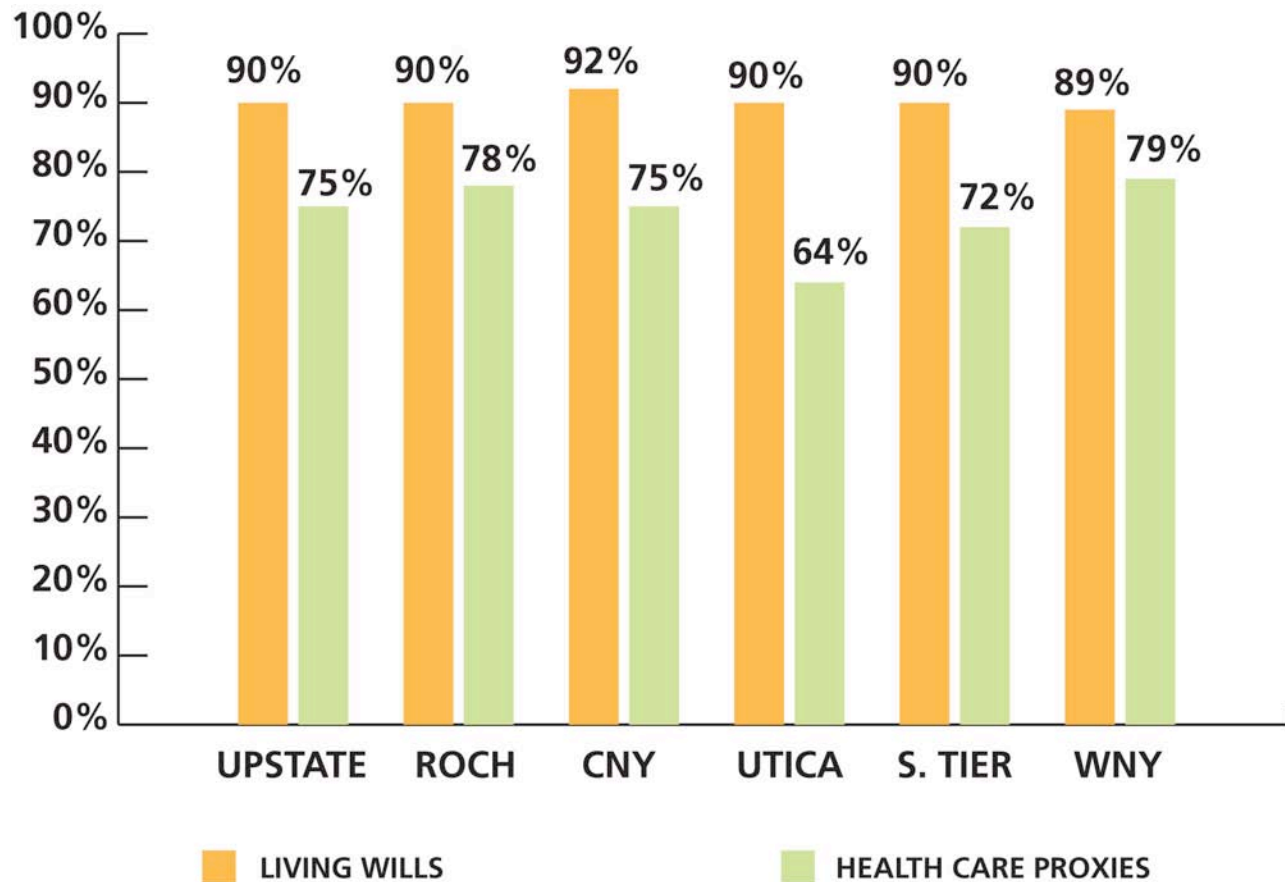


Influence of age on completion rates



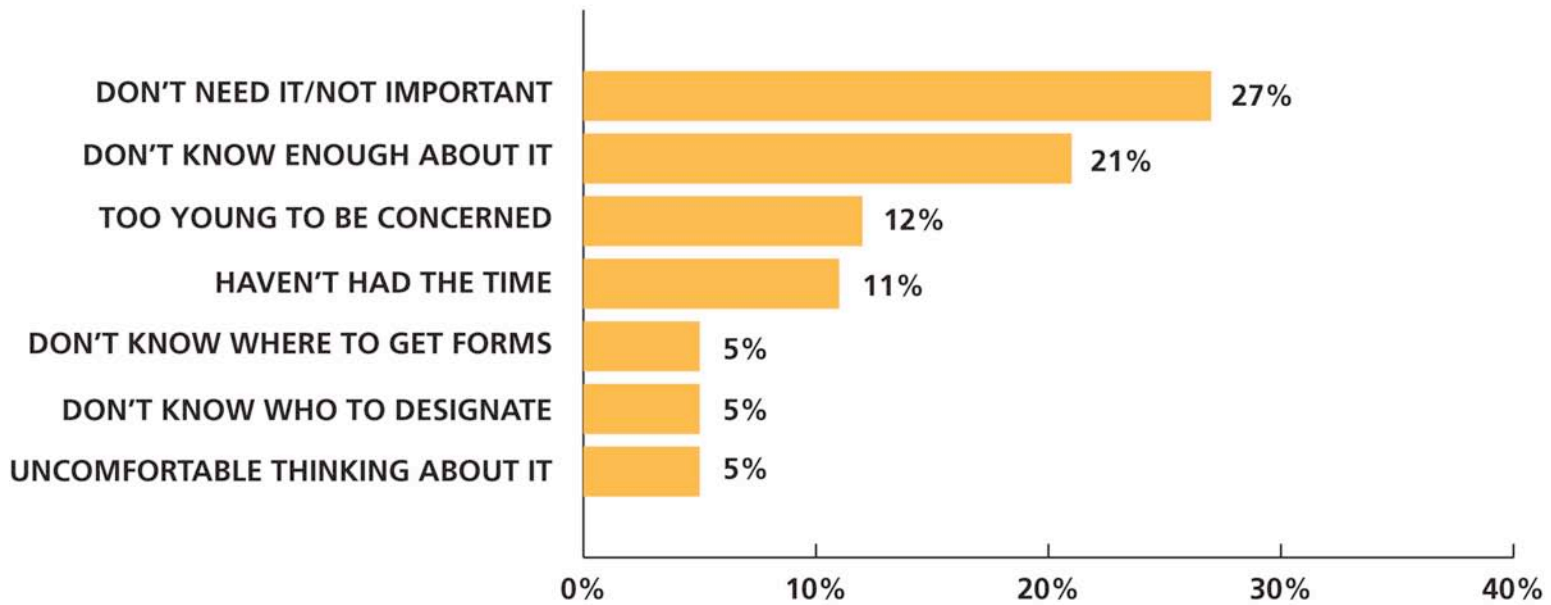


Awareness of advance directives



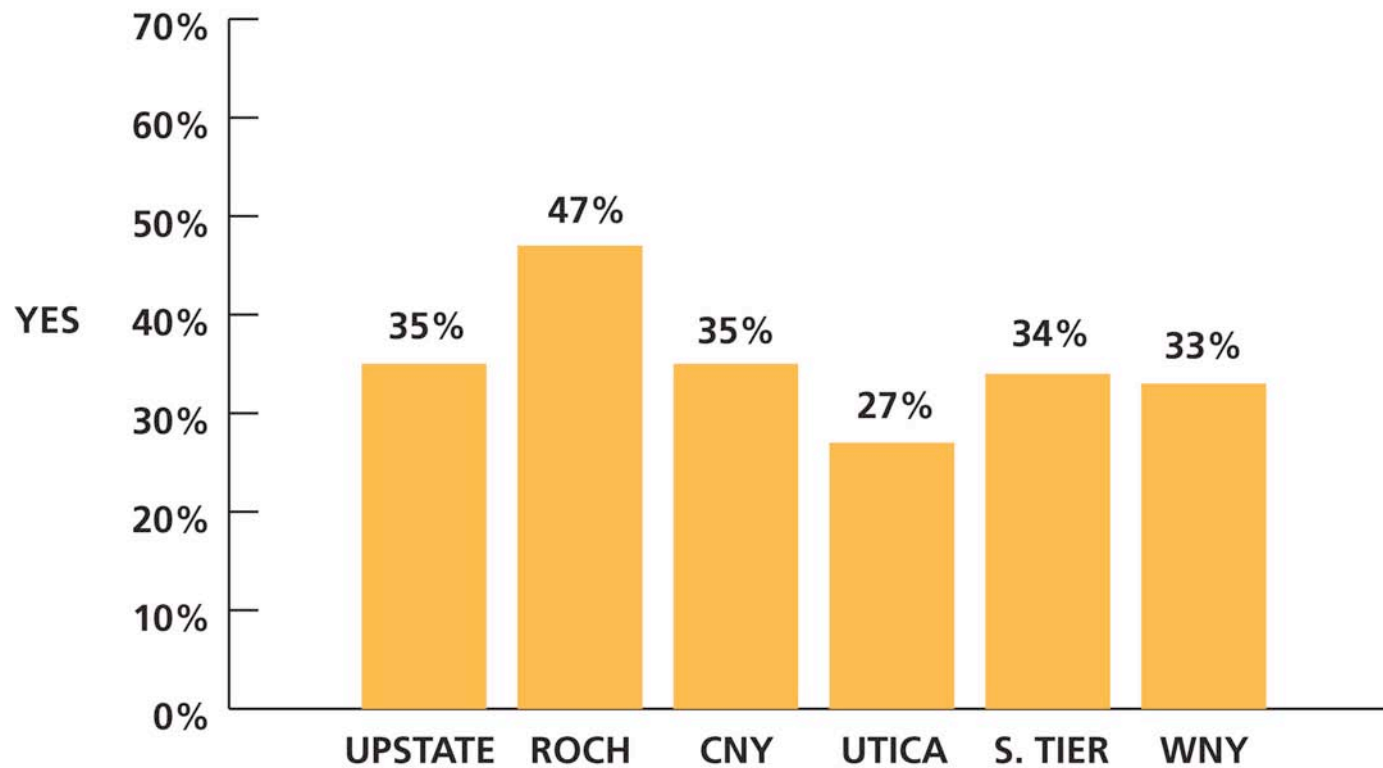


Reasons for not completing Health Care Proxy



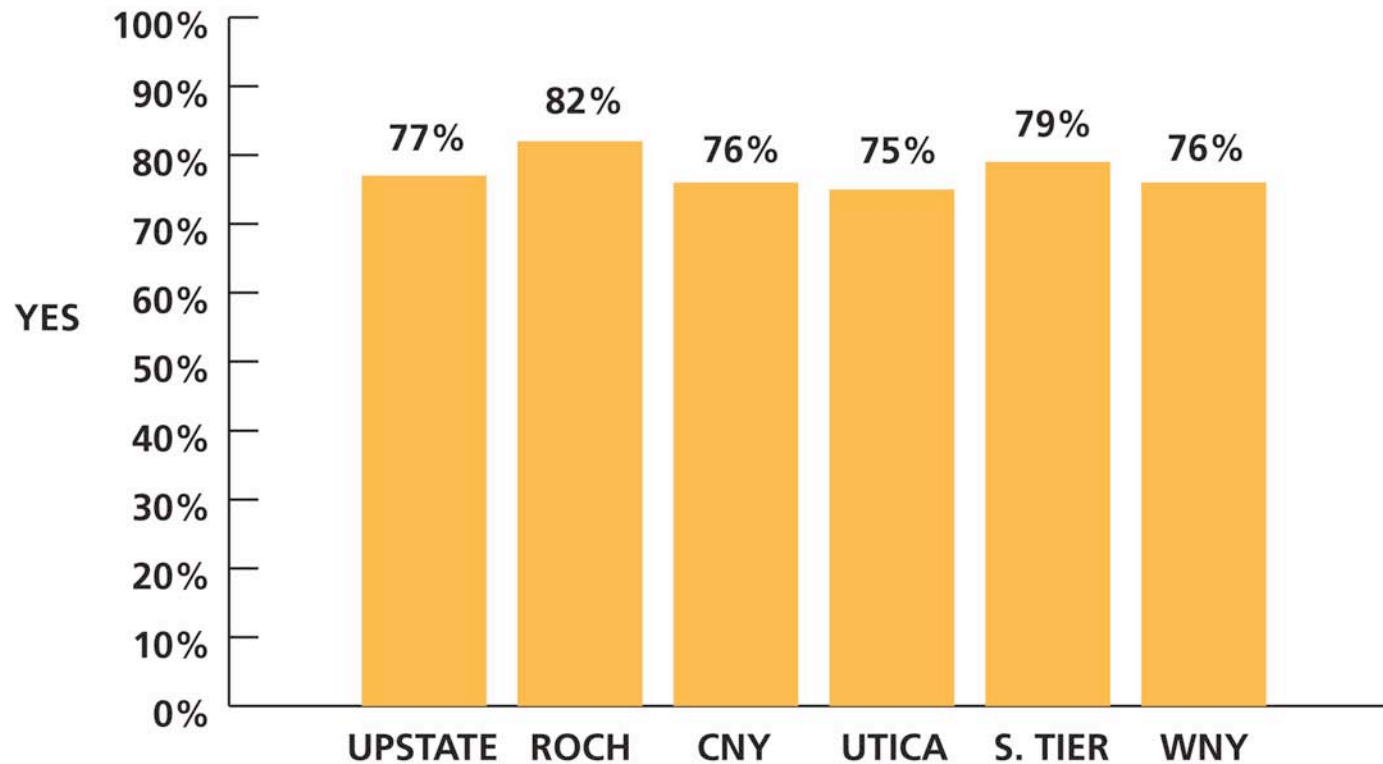


Has your doctor ever talked to you about Health Care Proxies and Living Wills?



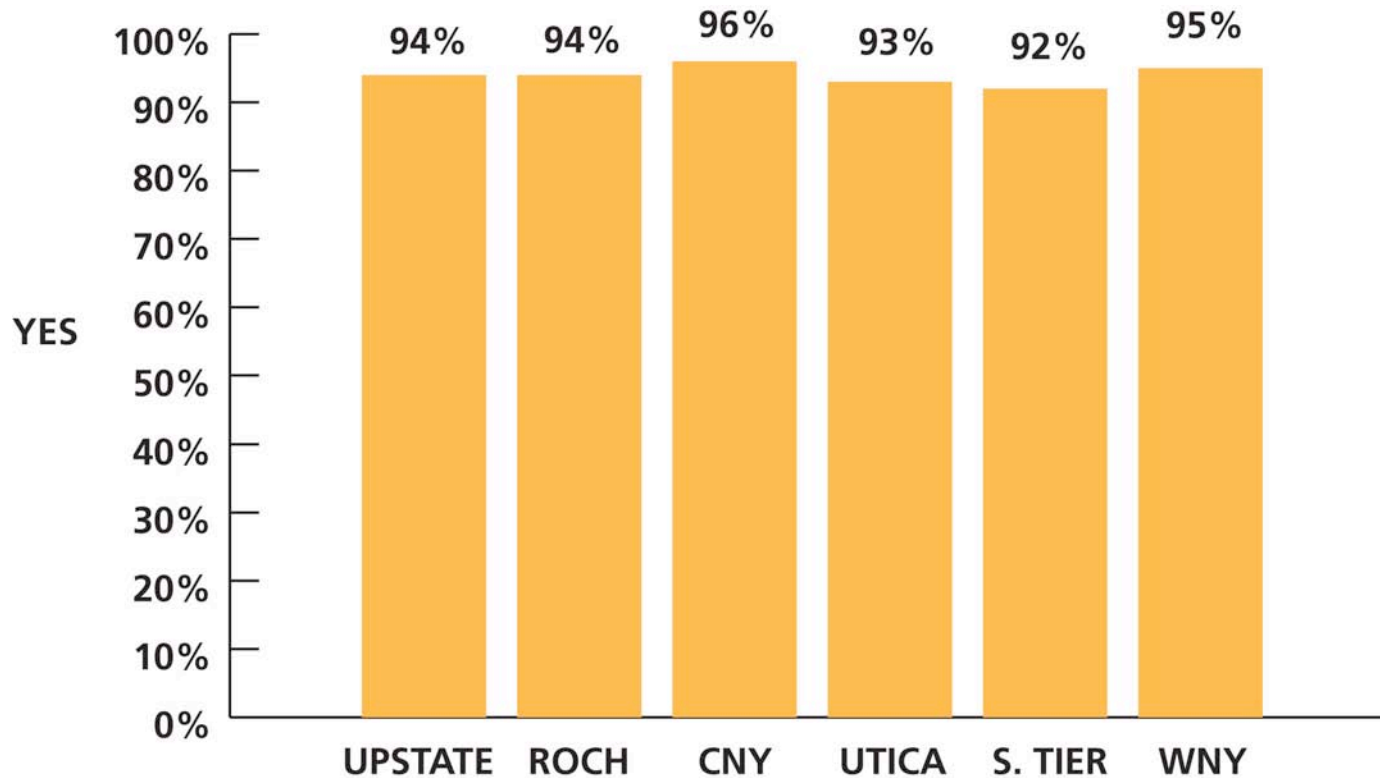


Do you think you need a legal form to specify someone to make medical care decisions for you?



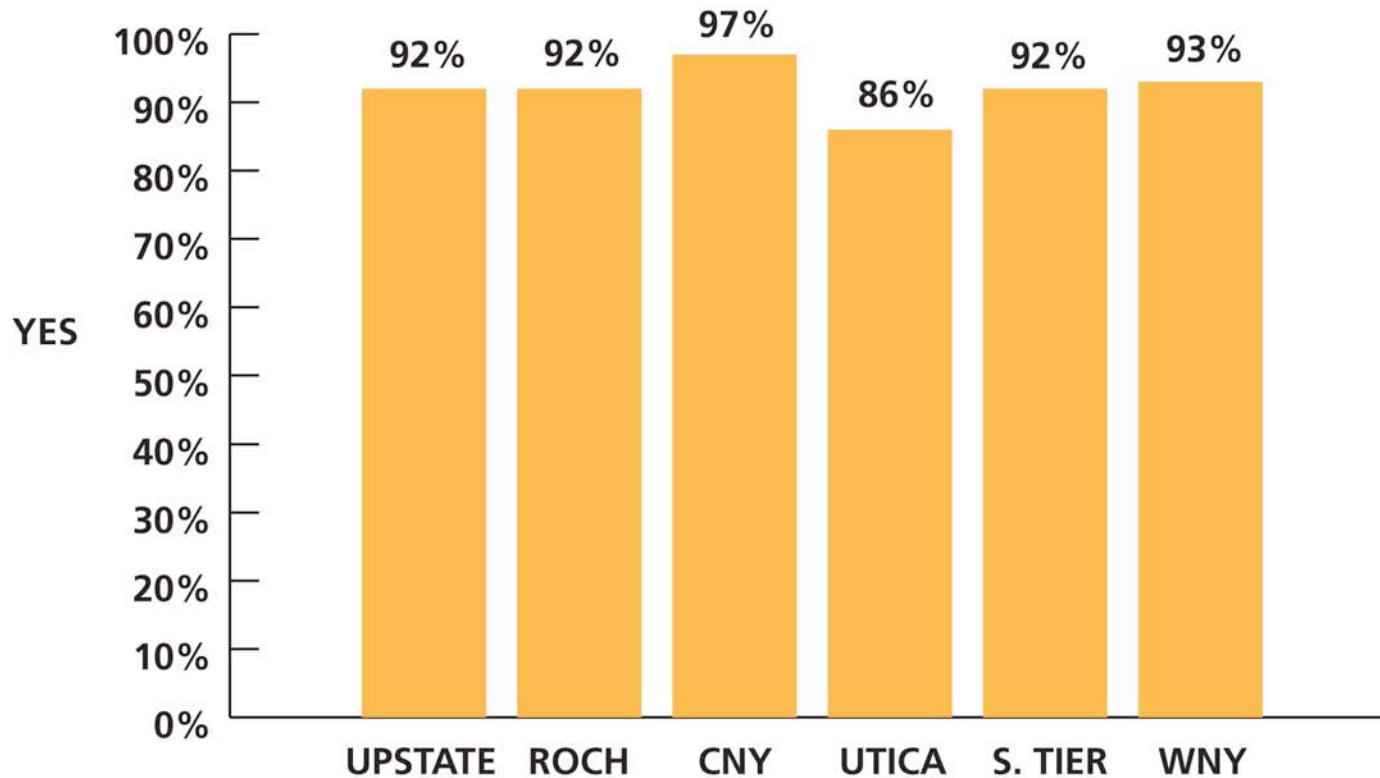


Have you shared your wishes with your family and the person you designated as your Health Care Proxy?





Have you shared your wishes as described in your Living Will with your family and close friends?





Click on the Advance Care Planning link at compassionandsupport.org to learn more.

