Thoughts of Nebraskans about living at the end of life and implications for those working to improve care and conditions for chronically and terminally ill Nebraskans

nehospice.org
About the Nebraska Hospice and Palliative Care Association

The Nebraska Hospice and Palliative Care Association (NHPCA) is a collaborative effort of more than 60 organizations with an interest in quality care for terminally and chronically ill Nebraskans. Established as a 501(c)3 community betterment non-profit in 1983, NHPCA represents Nebraska’s hospices and more than a dozen other health care organizations, businesses, and individuals.

NHPCA pursues initiatives in five broad areas: professional education, community engagement, advocacy, research, and quality improvement. For more information about NHPCA initiatives and how you can get involved, visit nehospice.org.

Vision: No Nebraskan lives in pain or dies badly. Nebraskans with chronic or end-of-life conditions, regardless of age, live their last months to the fullest, with their wishes expressed and respected, their pain and suffering alleviated, their fears and questions heard and addressed, their relational, spiritual, cultural, and financial needs met, and their loved ones around them and supported up to and following their death.

Acknowledgements

The 2017 Nebraska End-of-Life Survey was funded by Blue Cross Blue Shield Fund for Quality and Efficient Health Care Donor Advised Fund of the Nebraska Community Foundation and conducted by the University of Nebraska-Lincoln, Bureau of Sociological Research. NHPCA thanks these organizations for their contributions to this pioneering research.

Background

The Nebraska End-of-Life Survey has been conducted four times—in 2003, 2006, 2011 and 2017. Results of all surveys are available at www.nehospice.org.

When the survey was conducted for the first time in 2003, it was a collaborative effort of NHPCA, the Nebraska Coalition for Compassionate Care, and the Robert Wood Johnson Foundation. The purpose of the survey was to find out Nebraskans’ views on end-of-life issues, identify baseline measures for efforts to improve end-of-life care and conditions in Nebraska, and help those involved in such efforts to focus their activities and set appropriate priorities. The survey was the first of its kind in the nation.

The End-of-Life Survey draws on the work of the Life’s End Institute: Missoula Demonstration Project and of AARP-North Carolina and the Carolinas Center for Hospice and End of Life Care, who generously provided their 2003 survey and report of North Carolina AARP members as a model.

Kaye Norris, PhD, was the principal researcher for the 2003 and 2006 surveys. Charles Asp, PhD, provided statistical analysis support for the 2003 and 2006 surveys. The University of Nebraska-Lincoln, Bureau of Sociological Research was the principal researcher for the 2011 and 2017 surveys. NHPCA Vice President of Hospice and Palliative Care Jennifer Eurek has chaired the project since 2003.
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FINDINGS

Section 1: Hospice Services
As seen in Figure 1, when respondents were asked if they had heard of hospice services nearly all (94.8%) reported they knew of hospice services. Of those who knew of hospice services, 47.5% have heard a lot about hospice services and 47.3% had heard a little about hospice services. A small amount of respondents (5.2%) had not heard of hospice services.

![Figure 1. Have you heard of hospice services? (n=1118)](image)

Of the respondents who had heard about hospice, most (67.5%) learned about it because someone they knew used hospice. Others knew about hospice from hearing about it from others (37.1%), followed by through reading about it (20.0%), from a health care professional (19.5%), other sources (9.5%), through using hospice themselves (3.6%), on a website or social media (1.1%), and as a hospice volunteer (1.0%) (Figure 2).

Some respondents knew about hospice through a website or social media. For these respondents, the most common location to learn about hospice was through their own research, a general website, or specific social media (i.e. Facebook). Of the respondents who knew about hospice from other sources, most knew of hospice through their careers and training in the fields of healthcare and social services.

![Figure 2: How did you learn about hospice services? (n=1128)](image)
Nearly two-thirds (62.7%) of respondents reported that they would like hospice if they were dying. Some respondents are not yet sure if they would like to use hospice (32.2%) and a small number (5.1%) do not want hospice at the end of their life (Figure 3).

![Figure 3: Desire for hospice support near death (n=1114)](image)

Of those respondents who do want to use hospice care, the majority (59.0%) would prefer for the care to happen in their own home, followed by in a hospice residence (24.7%), a residential facility like assisted living (21.1%), a hospital (16.9%), a nursing home (14.5%), or other location (1.9%) (Figure 4). Some respondents answered they would want hospice care at a location other than those listed in Figure 4. Many indicated that their location would depend on their current health condition and situation, others would like to be in a family member’s home, and some are unsure as to which location they would like to have hospice care.

![Figure 4: Location of desired hospice care (n=1128)](image)
Respondents identified to the best of their knowledge if Medicare pays for hospice services. Over half (62.1%) of respondents were unsure if Medicare would pay for hospice, while some (32.1%) thought Medicare would pay for hospice, and only a small amount (5.8%) stated that Medicare would not pay for hospice (Figure 5).

![Figure 5: Does Medicare pay for hospice services? (n=1111)](image)

When thinking about which chronic illnesses hospice services would be helpful for, respondents overwhelmingly identified cancer (91.3%) followed by stroke (77.8%), Alzheimer’s disease (75.1%), lung disease (65.2%), heart disease (63.4%), and other conditions (11.5%) (Figure 6). Of people who specified other conditions that hospice would be helpful with, the most common were any end of life condition and terminal illnesses.

![Figure 6: Which chronic illnesses are hospice services helpful? (n=1128)](image)
A combined 36.8% of respondents were very interested or somewhat interested in hearing more about hospice care. Some respondents (15.3%) were unsure if they would like to have more information about hospice. About half of respondents (47.8%) were not interested in hearing more about hospice care (Figure 7).

Figure 7: Interest in hearing more about hospice care (n=1114)
Section 2: Palliative Care

When asked if they knew about palliative care, over half of respondents (62.6%) had never heard of palliative care. About one-fourth (23.6%) of respondents have heard a little about palliative care followed by a smaller amount of respondents (13.8%) who have heard a lot about palliative care (Figure 8).

Respondents who had heard of palliative care knew of it in a myriad of different manners. The largest group (14.4%) were aware of palliative care because they knew someone who used these services followed by hearing from others (13.2%), from a healthcare professional (11.7%), through reading about it (10.1%), another source (6.6%), a website or social media (1.5%), using palliative care themselves (0.8%), and being a hospice volunteer (0.8%) (Figure 9). Of those who learned about palliative care on a website or social media, most found their information through a general Google search or medical website. Respondents who knew about palliative care from other sources largely learned their information through professional lives within the medical field working in general medicine and with geriatric groups.
When asked if they wanted palliative care, most respondents (68.5%) are not yet sure if they would like to use palliative care. Over one-fourth (27.1%) reported that they would like to have palliative care and a small percent (4.5%) would not want palliative care if they were seriously ill (Figure 10).

Of those respondents who do want to use palliative care, some (27.0%) would prefer for the care to happen in their own home, followed by a hospital (13.5%), a residential facility like assisted living (13.4%), a nursing home (10.1%), or other location (1.1%) (Figure 11). Some respondents answered they would want palliative care at a location other than those listed in Figure 11. The overwhelming majority indicated that their desired location would depend on their current health condition and current residence.
Respondents identified to the best of their knowledge if Medicare pays for palliative care. The majority (85.1%) of respondents were unsure if Medicare would pay for palliative care while some (11.8%) thought Medicare would pay for palliative care, and only a small amount (3.1%) stated that Medicare would not pay for palliative care (Figure 12).

**Figure 12: Does Medicare pay for palliative care? (n=1048)**

Respondents were asked to identify which chronic illnesses palliative care would be helpful for and over half of respondents identified cancer (53.9%) followed by stroke (45.4%), lung disease (45.0%), heart disease (44.2%), Alzheimer's disease (43.9%), and other conditions (14.6%) (Figure 13). Of people who specified other conditions that palliative care would be helpful with the most common were terminal illnesses as well as end stages of diseases.

**Figure 13: For which chronic illnesses are palliative care helpful? (n=1128)**
A combined 40.3% of respondents were very interested or somewhat interested in hearing more about palliative care. Some respondents (18.2%) were unsure if they would like to have more information about palliative care. Many (41.5%) were not interested in hearing more about palliative care (Figure 14).

Figure 14: Interested in hearing more about palliative care (n=1043)
Section 3: Support near the End of Life

When thinking about what their support expectations were near the end of life, respondents identified which types of support they think they will need. The overwhelming majority (92.3%) indicated that they will need someone to know what they want when they die, followed by needing someone to listen when they talk (89.5%), knowing about their illness (83.9%), helping with chores (83.8%), providing transportation (81.1%), giving encouragement (78.1%), engaging in fun activities (71.5%), understanding what they are going through (67.5%), and caring for other family members (59.2%). For each of the support expectations given, over half of respondents indicated that they expected to need support (Figure 15).

Figure 15: Support expectations from others needed at the end of life

As seen in Table 1, respondents identified who would provide the specific support needed by selecting all that apply among spouse/partner, children, other family, friends/neighbors, health providers, work associates, community organizations, church/place of worship, or other. When they are in need of someone to listen to them and their needs respondents expect their spouse/partner (76%) to be this support followed by their children (74%) and health providers (62%). Respondents also noted that their personal caregivers would listen to them. The majority of respondents (67%) plan for their spouse/partner and children (66%) to provide transportation. Several respondents identified they would use taxi services such as Uber or Lyft for transportation. Thinking of help with chores, most people (68%) selected that they plan to rely
on their spouse/partner to help with chores as well as their children (67%). Many respondents intend to hire professional cleaning services to complete chores. When planning to do fun things, most people plan on doing these activities with friends and family either with their spouse/partner (63%), children (62%), friends/neighbors (52%), and other family members (50%). Several people indicated that they plan to do fun activities with their grandchildren and social groups. Knowing desires after they have died rests firmly with spouses (79%) and children (77%). Near the end of their life, respondents expect that their children (46%), spouse/partner (45%), and other family members (40%) will provide remaining care for family members. Some people wrote in that they have taken legal steps such as a will, power of attorney, or trust to help ensure the care of their family members.

When looking for encouragement, respondents plan to turn largely to their spouse/partner (67%) and children (62%) for support. Additionally, many noted that they intend to go to professionals within the health and social services fields such as their home health care or counselors for encouragement. For understanding of what they are going through, respondents predict that they will go to their spouse/partner (50%), children (43%), and health providers (40%). Some respondents wrote in that they plan to engage in support groups, meet with counselors, and hospice workers. Respondents identify that their spouse/partner (64%), children (59%), and health providers (59%) will have knowledge about their illness. Furthermore, multiple respondents plan to turn to religious leaders and health professionals for understanding about their specific illnesses.

<table>
<thead>
<tr>
<th>Providers of support</th>
<th>Support needed</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Listen</td>
<td>Transport</td>
<td>Chores</td>
<td>Fun things</td>
<td>Know desires</td>
<td>Care for family</td>
<td>Encourage</td>
<td>Understand</td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>76%</td>
<td>67%</td>
<td>68%</td>
<td>63%</td>
<td>79%</td>
<td>45%</td>
<td>67%</td>
<td>50%</td>
</tr>
<tr>
<td>Children</td>
<td>74%</td>
<td>66%</td>
<td>67%</td>
<td>62%</td>
<td>77%</td>
<td>46%</td>
<td>62%</td>
<td>43%</td>
</tr>
<tr>
<td>Other family</td>
<td>57%</td>
<td>51%</td>
<td>47%</td>
<td>50%</td>
<td>42%</td>
<td>40%</td>
<td>52%</td>
<td>35%</td>
</tr>
<tr>
<td>Friends/neighbors</td>
<td>49%</td>
<td>44%</td>
<td>38%</td>
<td>52%</td>
<td>19%</td>
<td>21%</td>
<td>52%</td>
<td>31%</td>
</tr>
<tr>
<td>Health providers</td>
<td>62%</td>
<td>25%</td>
<td>20%</td>
<td>9%</td>
<td>23%</td>
<td>12%</td>
<td>30%</td>
<td>40%</td>
</tr>
<tr>
<td>Work associates</td>
<td>13%</td>
<td>7%</td>
<td>7%</td>
<td>11%</td>
<td>2%</td>
<td>3%</td>
<td>13%</td>
<td>9%</td>
</tr>
<tr>
<td>Community organization</td>
<td>15%</td>
<td>23%</td>
<td>21%</td>
<td>16%</td>
<td>2%</td>
<td>10%</td>
<td>15%</td>
<td>13%</td>
</tr>
<tr>
<td>Church/place of worship</td>
<td>52%</td>
<td>23%</td>
<td>21%</td>
<td>24%</td>
<td>19%</td>
<td>14%</td>
<td>38%</td>
<td>24%</td>
</tr>
<tr>
<td>Other</td>
<td>3%</td>
<td>3%</td>
<td>6%</td>
<td>2%</td>
<td>4%</td>
<td>2%</td>
<td>1%</td>
<td>1%</td>
</tr>
</tbody>
</table>
Section 4: Advance Directives

Health Care Power of Attorney (HCPA) have been completed by 29.1% of respondents while more than half (59.6%) of respondents have heard about one but do not have it completed and few (11.3%) have not heard about a HCPA. Similarly, living wills have been completed by 29.9%, known by the majority (65.4%), and unknown by a small (4.7%) number of respondents. Over one-third (39.2%) of respondents have completed a last will and testament while over half (56.7%) have heard of one but not completed it, leaving a small percent (4.1%) without any knowledge. Funeral or burial pre-plans are less common to be completed (10.7%) even though the majority of respondents (84.5%) identified knowing about these plans. Over half (55.1%) of respondents have signed up to be an organ or tissue donor, less than half (41.1%) know about the program but are not signed up, and few (3.8%) have not heard about the program (Figure 16).

Figure 16: Advance care directives knowledge and action

<table>
<thead>
<tr>
<th>Description</th>
<th>Have heard about and completed</th>
<th>Have heard about but not completed</th>
<th>Have not heard about</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Health Care Power of Attorney (HCPA)</td>
<td>29.1%</td>
<td>59.6%</td>
<td>11.3%</td>
</tr>
<tr>
<td>A living will in which you state the kind of health care you want or don't</td>
<td>29.9%</td>
<td>65.4%</td>
<td>4.7%</td>
</tr>
<tr>
<td>A last will and testament that controls how your assets are to be distributed</td>
<td>39.2%</td>
<td>56.7%</td>
<td>4.1%</td>
</tr>
<tr>
<td>Funeral or burial pre-plans in which you plan or purchase in advance any</td>
<td>10.7%</td>
<td>84.5%</td>
<td>4.9%</td>
</tr>
<tr>
<td>goods or services for yourself</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Signing up to have your organs and/or tissue donated after you die for use</td>
<td>55.1%</td>
<td>41.1%</td>
<td>3.8%</td>
</tr>
<tr>
<td>by others in need of transplants</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
More than two-thirds (70.2%) of respondents have not completed an advanced directive (Figure 17).

Figure 17: Has the respondent completed an advanced directive? (n=1091)

Of those who had completed an advanced directive, the most common manner (22.3%) was to complete it through a lawyer’s office followed by other means (4.1%), a hospital (3.0%), physician’s office (1.4%), presentation about advanced directives (1.1%), and a website (0.5%). Respondents who completed their advanced directive on a website often did not remember the website information or completed it on legalzoom.com. If respondents selected other, they had the option to specify where they completed their advanced directive. The overwhelming majority completed it at the department of motor vehicles (Figure 18).

Figure 18: Advanced directive completion location (n=1128)
Most respondents (62.6%) have talked with their spouse/partner as well as family (46.6%) about their wishes for their care at the end of their life. Less than a quarter of respondents identified talking with friends (13.5%), a lawyer (11.0%), primary care physician (3.5%), clergy (2.0%), others (0.8%), or not talking with anyone (21.1%) about their desires for their end of life care. Of the respondents who selected other, the majority denied talking with select family members (Figure 19).

**Figure 19: Whom have you talked with about your wishes for end of life care? (n=1128)**

![Bar chart showing the distribution of respondents who talked with different people about their wishes for end of life care.](chart19)

Respondents were asked whom would they like to talk with about their wishes for end of life care. Over three-quarters of respondents indicated that they would like to talk with a spouse/partner (76.7%) and family (63.5%). One-third (33.8%) desire talking to their physician followed by clergy (20.1%), a lawyer (20.0%), friends (16.7%), no one (5.4%), or other people not listed (1.5%). Respondents also noted a desire to talk with a specific family member or a funeral director/mortician (Figure 20).

**Figure 20: Whom would you like to talk with about your wishes for end of life care? (n=1128)**

![Bar chart showing the distribution of respondents who would like to talk with different people about their wishes for end of life care.](chart20)
Respondents identified that primary physicians are the most trusted (77.2%) providers of information on end-of-life issues followed by lawyers (41.6%), local hospices (40.5%), local hospitals (32.7%), clergy (31.8%), American Cancer Society (7.6%), AARP (7.5%), other sources (4.3%), and lastly websites/social media (0.9%). Other sources of information indicated by respondents were family members and reputable websites (Figure 21).

Figure 21: Trusted providers of end-of-life issues (n=1128)
Section 5: Thinking about Pain

Most respondents (72.1%) are not concerned about their future doctor’s perception and treatment of their pain levels, while a smaller percent (8.0%) is unsure. Using pain medication only when pain is severe is the indicated plan for most (79.8%) respondents. One-third of respondents (36.6%) are concerned about addiction to pain medication and nearly three-fourths (71.7%) plan to take the lowest amount of medicine but the majority (66.6%) are not concerned about being given too much pain medicine by their physician (Figure 22).

*Figure 22: Statements related to thinking about pain, medicine, and physicians*

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am afraid my doctor may not believe I am in pain or may not treat my pain (n=1099)</td>
<td>3.7%</td>
<td>16.3%</td>
<td>25.2%</td>
<td>46.9%</td>
<td>8.0%</td>
</tr>
<tr>
<td>I would only take pain medicines when the pain is severe (n=1097)</td>
<td>41.7%</td>
<td>38.1%</td>
<td>9.7%</td>
<td>7.9%</td>
<td>2.6%</td>
</tr>
<tr>
<td>I am afraid I will become addicted to the pain medicines over time (n=1095)</td>
<td>11.4%</td>
<td>25.2%</td>
<td>19.9%</td>
<td>37.1%</td>
<td>6.3%</td>
</tr>
<tr>
<td>I would take the lowest amount of medicine possible to save larger doses for later when the pain is worse (n=1101)</td>
<td>40.1%</td>
<td>31.6%</td>
<td>11.5%</td>
<td>10.2%</td>
<td>6.6%</td>
</tr>
<tr>
<td>I am afraid I would be given too much pain medicine (n=1099)</td>
<td>7.1%</td>
<td>18.4%</td>
<td>29.6%</td>
<td>37.0%</td>
<td>7.9%</td>
</tr>
</tbody>
</table>
Section 6: Thoughts on Death

When talking about death, the largest group of respondents identified that they were very comfortable talking about death (42.8%), followed by somewhat comfortable (38.5%), not very comfortable (12.8%), not at all comfortable (3.4%), and not sure (2.5%). The overwhelming majority (88.3%) would be very comfortable or somewhat comfortable writing their will if they thought that their death would occur soon. Similarly, most (80.0%) were comfortable thinking about life after death (Figure 23).

Figure 23: Comfortability with death

- Talking about death (n=1106):
  - Very comfortable: 42.8%
  - Somewhat comfortable: 38.5%
  - Not very comfortable: 12.8%
  - Not at all comfortable: 3.4%
  - Not sure: 2.5%

- Writing my will if I thought my death would occur soon (n=1083):
  - Very comfortable: 60.2%
  - Somewhat comfortable: 28.1%
  - Not very comfortable: 6.7%
  - Not at all comfortable: 2.0%

- Thinking about life after death (n=1096):
  - Very comfortable: 48.9%
  - Somewhat comfortable: 31.1%
  - Not very comfortable: 10.3%
  - Not at all comfortable: 4.3%
Respondents are very or somewhat (88.3%) likely to attend funerals, visitations, or memorial services, read information related to death and dying (67.3%), watch television programs or movies that have death and dying (69.3%), speak to loved ones about death freely (76.3%), as well as visit or call someone who recently had a loved one pass away (86.2%). Additionally, they are very likely or somewhat likely to pre-plan their own funeral service (69.0%) and pre-plan the funeral service of someone in their care (75.5%). However, they are unlikely (82.5%) to avoid going to a medical checkup out of fear that a physician may find something seriously wrong (Figure 24).

**Figure 24: Likelihood of engaging or avoiding social events involving death and/or dying**
Many respondents have a fear associated with dying. Over half (59.7%) are either very afraid or somewhat afraid of dying from a long-term illness. Over one-third (41.6%) are afraid of dying suddenly. Nearly half (46.6%) are afraid they will die alone. Similarly, half (50.5%) are either very afraid or somewhat afraid of dying in a facility such as a nursing home or hospital. However, nearly three-fourths of respondents (70.4%) are either very afraid or somewhat afraid of dying painfully (Figure 25).

Figure 25: Fear related to dying

- Dying from a long-term illness (n=1081):
  - Very afraid: 12.9%
  - Somewhat afraid: 46.8%
  - Not very afraid: 24.5%
  - Not at all afraid: 11.7%
  - Not sure: 4.4%

- Dying suddenly (n=1073):
  - Very afraid: 11.2%
  - Somewhat afraid: 30.4%
  - Not very afraid: 29.3%
  - Not at all afraid: 26.0%
  - Not sure: 3.2%

- Dying alone (n=1053):
  - Very afraid: 16.8%
  - Somewhat afraid: 29.8%
  - Not very afraid: 29.4%
  - Not at all afraid: 20.6%
  - Not sure: 3.4%

- Dying in a facility such as a nursing home or hospital (n=1071):
  - Very afraid: 16.8%
  - Somewhat afraid: 33.7%
  - Not very afraid: 29.6%
  - Not at all afraid: 14.8%
  - Not sure: 5.0%

- Dying painfully (n=1075):
  - Very afraid: 29.3%
  - Somewhat afraid: 41.1%
  - Not very afraid: 17.9%
  - Not at all afraid: 7.3%
  - Not sure: 4.4%
Overall, respondents have a positive perspective on old age and dying shown through the large percent (86.6%) that think there is a special value in getting older, agreeing that dying is an important part of life (84.2%), and agreeing caring for people who are dying is a rewarding experience (62.9%). Only about one-third (35.5%) want medical interventions to keep them alive for as long as possible. However, most (81.1%) would want to know if they had six months or less to live (Figure 26).

Figure 26: Perceptions about old age and dying

Concerns about financial longevity and burden on family can be a source of unease for people when thinking of aging and dying. Most respondents (61.9%) identified that they are concerned that their money or their spouses money will not last compared to over half (58.2%) who are concerned that their family’s money will not last. Along these lines, over two-thirds (68.0%) express concern that they will be a burden on their friends or family (Figure 27).

Figure 27: Concerns about finances and burden on family in old age
Respondents answered a myriad of factors in relation to social, economic, and health factors when dealing with their own deaths. Social factors that respondents identified as very important were visits from friends and family (65.0%), fulfilling personal goals (50.9%), and giving to others (49.0%). Economic factors that respondents identified as very important were being able to complete a will (70.8%), getting finances in order (66.9%), and being able to stay in their home (58.4%). Health factors that respondents identified as very important were honest answers from doctors (91.3%), understanding treatment options (76.5%), and knowing what medicine was available to you (67.0%) (Figure 28).

**Figure 28: Importance of social, economic, and health factors when dealing with own dying**

<table>
<thead>
<tr>
<th>Factor</th>
<th>Very important</th>
<th>Somewhat important</th>
<th>Not very important</th>
<th>Not at all important</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family/friends visiting you (n=1086)</td>
<td>65.0%</td>
<td>27.4%</td>
<td>1.3%</td>
<td>0.8%</td>
<td>3.5%</td>
</tr>
<tr>
<td>Being able to stay in your home (n=1082)</td>
<td>58.4%</td>
<td>33.3%</td>
<td>6.6%</td>
<td>0.2%</td>
<td>0.6%</td>
</tr>
<tr>
<td>Honest answers from your doctor (n=1080)</td>
<td>91.3%</td>
<td>6.6%</td>
<td>0.3%</td>
<td>0.3%</td>
<td>0.6%</td>
</tr>
<tr>
<td>Comfort from religious/spiritual services or persons (n=1084)</td>
<td>47.6%</td>
<td>29.1%</td>
<td>12.9%</td>
<td>7.5%</td>
<td>2.9%</td>
</tr>
<tr>
<td>Knowing medicine was available to you (n=1081)</td>
<td>67.0%</td>
<td>27.3%</td>
<td>0.6%</td>
<td>2.4%</td>
<td>0.6%</td>
</tr>
<tr>
<td>Planning your own funeral or memorial service (n=1079)</td>
<td>33.5%</td>
<td>42.1%</td>
<td>16.7%</td>
<td>4.5%</td>
<td>3.1%</td>
</tr>
<tr>
<td>Being able to complete your will (n=1065)</td>
<td>70.8%</td>
<td>23.6%</td>
<td>1.0%</td>
<td>2.8%</td>
<td>1.8%</td>
</tr>
<tr>
<td>Fulfilling personal goals/pleasures (n=1079)</td>
<td>50.9%</td>
<td>33.5%</td>
<td>11.2%</td>
<td>2.2%</td>
<td>2.3%</td>
</tr>
<tr>
<td>Reviewing your life history with your family (n=1074)</td>
<td>31.9%</td>
<td>40.6%</td>
<td>20.8%</td>
<td>4.1%</td>
<td>2.7%</td>
</tr>
<tr>
<td>Having health care professionals visit you at your home (n=1083)</td>
<td>30.7%</td>
<td>44.2%</td>
<td>18.3%</td>
<td>2.0%</td>
<td>4.8%</td>
</tr>
<tr>
<td>Getting your finances in order (n=1077)</td>
<td>66.9%</td>
<td>25.5%</td>
<td>4.3%</td>
<td>1.3%</td>
<td>2.1%</td>
</tr>
<tr>
<td>Understanding your treatment options (n=648)</td>
<td>76.5%</td>
<td>21.0%</td>
<td>0.4%</td>
<td>0.3%</td>
<td>1.2%</td>
</tr>
<tr>
<td>Giving to others in time, gifts, or wisdom (n=1081)</td>
<td>49.0%</td>
<td>35.3%</td>
<td>8.7%</td>
<td>3.1%</td>
<td>3.8%</td>
</tr>
</tbody>
</table>
In a comparison of death and severe health conditions, respondents identified health conditions that they felt would be worse than dying. Over three-fourths (76.9%) of respondents felt that total physical dependency on another would be worse than death followed by not being able to communicate their wishes and/or needs (64.0%), and living with great pain (58.0%). Only 6.0% of respondents identified that none of these health problems would be worse than death (Figure 29).

![Figure 29: Health problems identified as worse than death (n=1128)](chart)

When asked their preference on a manner in which to die, most respondents (75.3%) identified that they would like to die in their sleep. Less than half of respondents choose sudden death (34.4%), other (3.3%), or long-term illness (2.4%) (Figure 30). Of those who stated they would prefer to die in another manner the most were physician-assisted suicide or in peace.

![Figure 30: Respondents desired manner to die (n=1128)](chart)
Overall, respondents selected that they would prefer to die in their homes (75.1%) followed by in a residential hospice (20.0%), and in a hospital (15.8%). Other common locations people chose were at a beautiful outdoor location, camping, and a location that minimizes burden on their family members (Figure 31).

**Figure 31: Desired location to die with a terminal illness (n=1128)**

- Home: 75.1%
- In an assisted living facility: 8.6%
- In a hospital: 15.8%
- In a nursing home: 3.2%
- In a residential hospice: 20.0%
- Other: 4.7%
- I have no preference: 7.3%
Section 7: Religion and Spirituality

Respondents largely (91.2%) identified as being religious or spiritual with one-third (31.7%) being very religious/spiritual and nearly half (45.7%) classifying as somewhat religious/spiritual (Figure 32). To that end, most (92.0%) who identified as religious attend religious or spiritual services with nearly half (45.7%) attending regularly (Figure 33). Overall, nearly all (90.7%) of those who are religious/spiritual have found some strength from their beliefs, with about half (40.1%) finding strength daily (Figure 34). When thinking about end of life desires for religious/spiritual support, more than half (58.1%) of respondents would like support at least weekly with a small percent (5.9%) not wanting religious/spiritual support (Figure 35).

Figure 32: Respondent level of religiosity/spirituality (n=1083)

Figure 33: Respondent attendance at religious/spiritual services (n=999)
Figure 34: Frequency of finding strength in religion or spirituality (n=988)

- One or more times a day: 40.1%
- A few times a week: 23.4%
- A few times a month: 14.1%
- Once a month or less: 13.1%
- Never: 6.1%
- Not religious/spiritual: 3.2%

Figure 35: Desired frequency of religious/spiritual support at the end of life (n=978)

- One or more times a day: 24.3%
- A few times a week: 33.8%
- A few times a month: 20.3%
- Once a month or less: 13.2%
- Never: 5.9%
- Not religious/spiritual: 2.6%
In August of 2003, NHPCA conducted the first randomly sampled statewide end-of-life survey in the United States. This survey was then repeated by NHPCA in August of 2006 and August of 2010. 300 respondents completed the survey in 2003, 315 in 2006, and 862 in 2010. Chi-square tests were conducted in order to access if the changes over time were statistically significant. Differences are reported for responses that were significant (indicated by * if $p < 0.05$, ** if $p < 0.01$, *** if $p < 0.001$).

Section 1: Hospice Services

As with past years, the most common response to how 2017 participants learned about hospice services was from knowing someone who had used hospice (Figure 52). This percentage increased greatly from 2003 (37.0%) to 2006 (56.2%), then increased again to 69.1% in 2010, and stayed consistent in 2017 (68.4%). I have used hospice services myself and I heard from a health care professional have not shown significant differences over the years.

**Figure 52. Ways that you learned about hospice services**

<table>
<thead>
<tr>
<th>Response</th>
<th>2003</th>
<th>2006</th>
<th>2010</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>I know someone who used hospice***</td>
<td>37.0%</td>
<td>56.2%</td>
<td>69.1%</td>
<td>68.4%</td>
</tr>
<tr>
<td>I have used hospice services myself</td>
<td>4.3%</td>
<td>5.7%</td>
<td>5.6%</td>
<td>5.1%</td>
</tr>
<tr>
<td>I am/was a hospice volunteer*</td>
<td>1.7%</td>
<td>3.8%</td>
<td>2.3%</td>
<td>1.2%</td>
</tr>
<tr>
<td>I heard from a health care professional</td>
<td>17.3%</td>
<td>22.5%</td>
<td>20.5%</td>
<td>21.0%</td>
</tr>
<tr>
<td>I heard from others***</td>
<td>18.7%</td>
<td>35.2%</td>
<td>38.1%</td>
<td>37.4%</td>
</tr>
<tr>
<td>I read literature/newspaper/TV/radio/other media**</td>
<td>18.0%</td>
<td>25.7%</td>
<td>26.5%</td>
<td>20.7%</td>
</tr>
</tbody>
</table>
When respondents were asked if they would want hospice support if needed (Figure 53), the percentage of 2017 respondents who indicated "yes" (66.4%) was higher than 2010 (57.6%), but much lower than it was in 2003 (82.9%).

**Figure 53. Would you want hospice support***

As seen in Figure 54, of those who would want to receive hospice services, the percentage continues to increase of those who would want to receive hospice services in their own home (62.1% in 2017), in a hospice residence (25.5% in 2017), and in a residential facility such as an assisted living facility (22.5% in 2017). Respondents in 2017 are also more likely to want to receive hospice services in a nursing home and in a hospital than in 2010. All locations were lowest in 2003, and then have continued to increase or remain consistent after 2010.

**Figure 54. Where you would want to receive hospice services***
Responses to which chronic illnesses hospice support would be helpful have all seen significant increases since the question was first asked in 2006 (Figure 55). For example, while 65.7% of 2006 respondents chose stroke, over three-quarters (77.3%) of 2017 respondents did.

Figure 55. For which chronic illnesses would hospice support be helpful

Although participants in 2017 were less likely to respond “not at all interested” in hearing more about hospice services (18.0%) than 2010 respondents (26.2%), they were the least likely to respond “very interested” (11.0%) (Figure 56).

Figure 56. Interest in hearing more about hospice services***
Section 2: Palliative Care

Questions on palliative care were added to the survey in 2010. Although over half (61.1%) of 2017 respondents have never heard of palliative care, a combined 38.9% have heard either a little or a lot about palliative care, which is a significant increase from the 27.8% of 2010 respondents who had heard a little or a lot about palliative care (Figure 57).

Figure 57. Have you heard of palliative care***

<table>
<thead>
<tr>
<th></th>
<th>2010</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>No, I have never heard of palliative care</td>
<td>72.2%</td>
<td>61.1%</td>
</tr>
<tr>
<td>Yes, I have heard a little about palliative care</td>
<td>16.0%</td>
<td>24.6%</td>
</tr>
<tr>
<td>Yes, I have heard a lot about palliative care</td>
<td>11.8%</td>
<td>14.3%</td>
</tr>
</tbody>
</table>

There were also significant increases in how respondents had heard about palliative care (Figure 58). There was a significant increase in those who know someone who used palliative care (10.8% in 2010, 15.3% in 2017) and in those who have heard about palliative care from others (7.7% in 2010, 12.9% in 2017).

Figure 58. Ways that you learned about palliative care

<table>
<thead>
<tr>
<th></th>
<th>2010</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>I know someone who used palliative care**</td>
<td>10.8%</td>
<td>15.3%</td>
</tr>
<tr>
<td>I have used palliative care myself</td>
<td>1.0%</td>
<td>1.0%</td>
</tr>
<tr>
<td>I am/was a hospice volunteer</td>
<td>1.4%</td>
<td>1.0%</td>
</tr>
<tr>
<td>I heard from a health care professional</td>
<td>10.4%</td>
<td>12.8%</td>
</tr>
<tr>
<td>I heard from others***</td>
<td>7.7%</td>
<td>12.9%</td>
</tr>
<tr>
<td>I read literature/newspaper/TV/radio/other media</td>
<td>10.1%</td>
<td>10.5%</td>
</tr>
</tbody>
</table>
Those who responded they would like to receive palliative care if needed also significantly increased in 2017 (Figure 59). Although many were still unsure (67.9% in 2017), over one-quarter of 2017 respondents (28.2%) would like to receive this care, compared to 19.5% in 2010.

**Figure 59. Would you like to receive palliative care***

<table>
<thead>
<tr>
<th></th>
<th>2010</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>5.1%</td>
<td>3.9%</td>
</tr>
<tr>
<td>Don't know/Not sure</td>
<td>75.3%</td>
<td>67.9%</td>
</tr>
<tr>
<td>Yes</td>
<td>19.5%</td>
<td>28.2%</td>
</tr>
</tbody>
</table>

There were also significant differences in where respondents would like to receive palliative care (Figure 60).

**Figure 60. Where would you want to receive palliative care**

- In a hospital: 2010 - 11.5%, 2017 - 14.4%
- In a nursing home**: 2010 - 7.0%, 2017 - 10.4%
- In my own home**: 2010 - 22.2%, 2017 - 28.0%
- In a residential facility such as an assisted living facility**: 2010 - 10.1%, 2017 - 14.5%
More knowledge about palliative care led to significant increases in the percentage of respondents who chose which chronic illnesses palliative care would be beneficial for (Figure 61).

Figure 61. For which chronic illnesses would palliative care be helpful

There were also significant changes in the level of interest in hearing more about palliative care (Figure 62). Although the percentage of those who are not at all interested decreased in 2017 (20.4%), the percentage of those who are very interested also decreased in 2017 (13.6%).

Figure 62. Level of interest in hearing more about palliative care**
Section 3: Support near the End of Life

Participants were asked about the types of support they expect to need near the end of their life and whom they expect to provide each type of support. As seen in Figure 63, all nine categories of support have presented a similar pattern from 2003 to 2017. Following a declining trend, most of the categories underwent a drastic drop in 2010. However, all nine categories rose in 2017, with the need for someone to understand what the participant has been going through having the largest increase (57.7% in 2010 and 71.4% in 2017). Expecting to need someone to help care for family members has shown the most significant decrease over the years, going from 85.7% in 2003 to 52.5% in 2017.

Figure 63. Support needed near end of life

- Someone to listen when I talk
- Someone to provide transportation
- Someone to help with chores
- Someone to do fun things with me
- Someone to know what I want when I die
- Someone to help care for other family members
- Someone to encourage me when I’m down
- Someone to understand what I’m going through
- Someone to know about my illness
When asked who they expected to need support from when it comes to having someone listen when they talk (Figure 64), there were some significant differences throughout the years. Although still lower than most categories, community organizations (13.7%) and work associates (12.1%) both increased in 2017 to the highest they have been throughout the years. Health providers also had a significant increase. The percentage of respondents who expect to need health providers to listen when they talk jumped from 40.0% in 2010 to 61.8% in 2017.

Figure 64. I expect to need someone to listen when I talk
As seen in Figure 65, 2017 respondents had different expectations of whom they expect to provide transportation. Compared to past years, other family (46.8%), friends/neighbors (41.5%), health providers (24.3%), community organizations (22.2%), and work associates (5.9%) were all highest in 2017.

Figure 65. I expect to need someone to provide transportation
There were also significant increases in who respondents expect to assist with chores (Figure 6). Children, other family, and friends/neighbors did not see significant changes, but all other categories did. Work associates has been gradually increasing over the years, and jumped to 5.6% in 2017, compared to only 1.7% in 2003.

*Figure 66. I expect to need someone to help with chores*
Whom respondents expect to need to do fun things with saw significant changes in all categories (Figure 67). While most categories took a dramatic drop in 2010, they increased in 2017. For example, friends/neighbors decreased from 54.7% in 2003 to 38.9% in 2010, but increased back up to 48.8% in 2017.

Figure 67. I expect to need someone to do fun things with me
There were many significant changes in whom respondents expect to know what they want when they die (Figure 68). Spouse/partner decreased from 2003 (72.3%) to 2006 (54.0%) but has increased since (69.7% in 2017). The same is true with children. While the percentage dropped from 73.7% in 2003 to 62.8% in 2010, it has since increased back to three-fourths (74.6%) of 2017 respondents.

Figure 68. I expect to need someone to know what I want when I die
Whom respondents expect to help care for other family members have seen significant changes (Figure 69). All categories have seen decreases over the years. Most categories saw consistent decreases from 2003 to 2010, then increased in 2017, but are still lower than they were in 2003. Over half (52.7%) of 2003 respondents expected this help from their spouse/partner, while only 31.1% of 2010 respondents saw this same need. While this increased to over one-third (36.2%) in 2017, it is still much lower than it was in 2003.

*Figure 69. I expect to need someone to help care for other family members*
Similarly, whom respondents expect to need to encourage them when they are down, also saw decreases from 2003 to 2010 in most categories, with an increase in 2017 (Figure 70). While 70.2% of 2006 respondents thought children should provide this support, only half (51.5%) of 2010 respondents said the same. This increased to 59.7% in 2017, but is still lower than it was in earlier years.

*Figure 70. I expect to need someone to encourage me when I’m down*

<table>
<thead>
<tr>
<th>Category</th>
<th>2003</th>
<th>2006</th>
<th>2010</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse/partner***</td>
<td>65.3%</td>
<td>56.5%</td>
<td>51.7%</td>
<td>58.9%</td>
</tr>
<tr>
<td>Children***</td>
<td>69.0%</td>
<td>70.2%</td>
<td>51.5%</td>
<td>59.7%</td>
</tr>
<tr>
<td>Other family***</td>
<td>58.0%</td>
<td>52.4%</td>
<td>42.0%</td>
<td>49.6%</td>
</tr>
<tr>
<td>Friends/neighbors***</td>
<td>55.0%</td>
<td>48.9%</td>
<td>40.7%</td>
<td>50.2%</td>
</tr>
<tr>
<td>Health providers***</td>
<td>30.7%</td>
<td>29.8%</td>
<td>21.1%</td>
<td>29.3%</td>
</tr>
<tr>
<td>Work associates</td>
<td>10.3%</td>
<td>9.5%</td>
<td>7.3%</td>
<td>10.2%</td>
</tr>
<tr>
<td>Community organizations**</td>
<td>8.0%</td>
<td>6.3%</td>
<td>8.8%</td>
<td>12.7%</td>
</tr>
</tbody>
</table>
Again, whom participants expect to need to understand what they are going through experienced a similar pattern of decreases from 2003 to 2010, then an increase in 2017 (Figure 71). However, health providers (39.7%) and community organizations (12.0%) peaked in 2017, while all other categories with significant changes were highest in 2003.

**Figure 71. I expect to need someone to understand what I’m going through**
While most categories showed significant changes in whom respondents expect to need to know about their illness, health providers saw the largest increase (Figure 72). While it stayed consistently under half from 2003 to 2010 (46.7% in 2003, 43.5% in 2006, 46.3% in 2010), it jumped to 57.2% in 2017.

*Figure 72. I expect to need someone to know about my illness*
Section 4: Advance Directives

As with past years, almost all 2017 respondents have heard about completing a last will and testament, but the percentage of respondents who have actually completed it has been decreasing since 2006 (Figure 73). While over half (55.9%) of 2006 respondents reported having completed this, 47.4% of 2017 said the same.

**Figure 73. Last will and testament***

While not many have completed funeral or burial pre-plans, again most have heard about them (Figure 74). However, aside from the peak in 2006 (21.2%), there was an increase in how many 2017 respondents have completed this task (16.1%).

**Figure 74. Funeral or burial pre-plans***
As seen in Figure 75, 2017 participants were markedly more likely than those in previous years to have signed up to donate organs and/or tissue after death, as demonstrated by a sharp rise after 2006 (38.9% in 2006, 53.0% in 2017).

*Figure 75. Signing up to have your organs and/or tissue donated after you die***
Participants’ likeliness to have talked about their wishes for care at end of life with friends (22.0% in 2003, 12.9% in 2017) has been decreasing over the years (Figure 76).

*Figure 76. With whom have you talked about your wishes for care at the end of your life*
As seen in Figure 77, there has been a continuing decrease in participants wanting a clergy to initiate a conversation on end-of-life issues (32.0% in 2003, 22.3% in 2017). The same was true with wanting friends (26.3% in 2003, 14.2% in 2017) to initiate this type of conversation. However, since 2006, a growing number of participants responded that they would want their family (61.9% in 2006, 66.1% in 2017) or spouse/partner (53.3% in 2006, 65.6% in 2017) to open up this conversation. In addition, notable rises in percentages for both primary physician (34.9%) and lawyer (19.1%) were present among 2017 participants after a downward trend from 2003 to 2010.

Figure 77. Who would you want to initiate a conversation with you regarding end-of-life issues
The number of participants who have indicated trust in clergy to provide information on end-of-life issues has continued to decrease over the years (49.7% in 2003, 32.5% in 2017) (Figure 78). However, primary physicians (76.9% in 2017), lawyers (37.8% in 2017), and local hospice (38.3% in 2017) were all ranked as more trustworthy for providing information than in any previous year.

Figure 78. Whom would you trust to provide information on end-of-life issues

<table>
<thead>
<tr>
<th>Category</th>
<th>2003</th>
<th>2006</th>
<th>2010</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary physician**</td>
<td>71.0%</td>
<td>67.3%</td>
<td>70.8%</td>
<td>76.9%</td>
</tr>
<tr>
<td>Local hospital</td>
<td>27.7%</td>
<td>22.5%</td>
<td>26.2%</td>
<td>29.5%</td>
</tr>
<tr>
<td>Local hospice**</td>
<td>33.0%</td>
<td>28.6%</td>
<td>34.0%</td>
<td>38.3%</td>
</tr>
<tr>
<td>Lawyer***</td>
<td>32.0%</td>
<td>26.0%</td>
<td>30.9%</td>
<td>37.8%</td>
</tr>
<tr>
<td>Clergy***</td>
<td>49.7%</td>
<td>48.6%</td>
<td>40.5%</td>
<td>32.5%</td>
</tr>
<tr>
<td>American Cancer Society**</td>
<td>14.0%</td>
<td>6.7%</td>
<td>9.9%</td>
<td>7.4%</td>
</tr>
<tr>
<td>AARP</td>
<td>10.0%</td>
<td>6.7%</td>
<td>7.3%</td>
<td>7.1%</td>
</tr>
<tr>
<td>No one</td>
<td>5.3%</td>
<td>7.0%</td>
<td>6.3%</td>
<td>5.1%</td>
</tr>
</tbody>
</table>

** Indicates significant difference from previous year.
*** Indicates significant difference from previous year.
Section 5: Thinking about Pain

The percentage of those who strongly disagree that they are afraid their doctor may not believe in or treat their pain has shown a significant increase, doubling in 2017 (52.6%) from what it was in 2003 (26.1%) (Figure 79). Those who strongly agree has also decreased significantly in 2017 (4.8%).

*Figure 79. I am afraid my doctor may not believe I am in pain or may not treat my pain***

The percentage of respondents who reported they strongly agree that they would only take pain medications when the pain is severe has significantly increased since past years (Figure 80). While around one-third of respondents consistently stated this in 2003 (34.1%), 2006 (34.1%), and 2010 (34.6%), this jumped to closer to half (42.0%) in 2017.

*Figure 80. I would only take pain medications when the pain is severe**
Respondents in 2017 were more likely to report that they would take the lowest amount of medicine possible to save larger doses for later when the pain is worse (Figure 81). Combined, three-fourths (75.9%) of 2017 respondents reported they either somewhat or strongly agree that they would do this, which is similar to past years, but there were more that strongly agreed (40.8%) than in any other year.

*Figure 81. I would take the lowest amount of medicine possible to save larger doses for later when the pain is worse*

![Chart showing responses to taking lowest medicine](chart)

When asked if they are afraid they would be given too much pain medication (Figure 82), 2017 respondents were less likely to agree (27.8% combined somewhat agree and strongly agree) than in previous years like 2006 (38.1% combined). Respondents in 2017 were most likely to strongly disagree (41.8%), which was the highest of all years.

**Figure 82. Afraid of being given too much pain medicine**

![Chart showing responses to being afraid of too much pain medication](chart)
Section 6: Thoughts on Death

As seen in Figure 83, 2017 participants reported feeling less comfortable talking about death than previous year respondents. Although nearly half (44.0%) of 2017 respondents reported that they are very comfortable talking about death, there were more respondents that reported being not very or not at all comfortable (15.8% combined) than in years like 2006 (7.2% combined).

Figure 83. Level of comfort in talking about death***

The same was true in 2017 respondents comfort level in thinking about life after death (Figure 84). While over half (54.4%) of 2017 respondents reported they are very comfortable, the percentage of those who are not very or not at all comfortable was again higher than in past years (14.2% combined). The percentage of those who are somewhat comfortable has been steadily declining over the years, while the percentage of those who are not very comfortable has been steadily increasing.

Figure 84. Level of comfort in thinking about life after death*

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*Figure 84: Adjusted data for comparison purposes.*

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Each year, over half of respondents have reported they are very likely to attend funerals, visitations, or memorial services, with the peak being 2017 respondents (59.9%) (Figure 85). The percentage of respondents who reported they are not at all likely has remained low, but has gradually increased each year.

*Figure 85. Likeliness of attending funerals, visitations, or memorial services*

As seen in Figure 86, 2017 respondents were the least likely to read books, newspaper articles and/or other information that deal with the subject of death and dying (28.6% combined not very and not at all likely). However, those who reported being very likely to read these materials has not fluctuated much over the years (37.1% in 2003, 36.5% in 2006, 34.5% in 2010, and 35.4% in 2017).

*Figure 86. Likeliness to read books, newspaper articles and/or other information that deal with the subject of death and dying*
While the percentage (58.2%) of 2017 respondents who reported they are not at all likely to avoid medical checkups in fear of their doctor finding something wrong was lower than in 2010 (62.7%), it has increased from 2003 (49.7%) and 2006 (46.4%) (Figure 87). The percentage of those who responded “very likely” has remained low for 2010 (3.9%) and 2017 (4.3%), especially compared to 2003 (9.2%) and 2006 (9.5%).

*Figure 87. Likelihood to avoid medical checkups because of fear that the doctor will find something serious***

Over half (50.4%) of 2017 respondents reported being very likely to visit or telephone a friend or relative who has recently lost a loved one, which was an increase after the drop in 2010 (46.0%) (Figure 88).

*Figure 88. Likelihood to visit or telephone a friend or relative who has recently lost a loved one*
There were less 2017 respondents who reported being very afraid of dying from a long-term illness than any other year (13.9%) (Figure 89). However, while the percentage of respondents who reported they are not at all afraid was steadily increasing over the years, it took a slight decrease in 2017 (11.5%) from 2010 (12.7%).

Figure 89. Fear of dying from a long-term illness*

![Bar chart showing fear levels for long-term illness from 2003 to 2017.]

The trend for participants to respond they are not very afraid of dying suddenly continues to decrease over the years (42.9% in 2003, 39.6% in 2006, 32.5% in 2010, and 32.0% in 2017) (Figure 90). Likewise, a growing number of participants indicated they were somewhat afraid of dying suddenly (23.2% in 2003, 23.9% in 2006, 24.1% in 2010, and 29.8% in 2017) or very afraid of dying suddenly (7.2% in 2006, 9.1% in 2010, and 10.3% in 2017). There was also a decrease in the percentage of 2017 respondents who are not at all afraid (34.3% in 2010, 27.9% in 2017) after the previous upward trend from 2003 to 2010.

Figure 90. Fear of dying suddenly***

![Bar chart showing fear levels for dying suddenly from 2003 to 2017.]

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There has been a steady decline in the percentage of respondents who reported they strongly agree that dying is an important part of life, since a spike in 2006 (Figure 9.1). While three-fourths (65.9%) of 2006 respondents strongly agreed with this statement, this dropped to just above half (53.0%) of 2017 respondents. The percentage of those who strongly disagree with this statement has also steadily increased since 2006 (1.0% in 2006, 3.8% in 2017).

**Figure 9.1. Dying is an important part of life***

Although over half (59.5%) of 2017 participants strongly agree that they would want to know if they likely had six months or less to live, this has stayed consistently lower than it was in 2003 (67.8%) and 2006 (69.4%), after dropping in 2010 (59.1%) (Figure 9.2).

**Figure 9.2. If someone could tell me that I likely have six months or less to live, I would want to know**

---

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The percentage of those who strongly disagree that they would want medical interventions to keep them alive as long as possible has been declining since the question was first asked in 2006 (Figure 93). While half (50.5%) of 2006 respondents strongly disagreed with this, it has dropped down to one-third (32.6%) of 2017 respondents saying the same. Likewise, the percentage of those who strongly agree has been steadily increasing (5.3% in 2006, 6.6% in 2010, and 8.9% in 2017).

Figure 93. If I knew I was dying, I would want medical interventions to keep me alive as long as possible***

Fluctuations in the level of concern of being a burden to family or friends were found over the years (Figure 94). Participants in 2017 were less likely than 2010 participants to say they were not at all concerned (10.5% in 2010, 9.2% in 2017) or very concerned (38.0% in 2010, 32.6% in 2017). The most common response for 2017 respondents was somewhat concerned (40.1%), which was also the case in 2003 (36.2%) and 2006 (39.4%).

Figure 94. Concern that I will be a burden to my family or friends*
The percentage of those who reported that having friends/family visit them is somewhat important increased significantly in 2017 from past years (Figure 95). Due to this, the percentage of those who classified this as very important dropped to two-thirds (65.5%) in 2017, after consistently staying above three-quarters in 2003 (77.6%), 2006 (79.7%), and 2010 (75.5%).

Figure 95. Importance of family/friends visiting you***

Being able to stay in their own home has always been something that the majority of respondents classify as very important (Figure 96). Although this was on a steady decline from 2003 (66.7%) to 2010 (56.0%), it increased in 2017 (61.9%).

Figure 96. Importance of being able to stay in your own home**
Respondents in 2017 found it less important to gain comfort from religious services or persons than past year respondents (Figure 97). Although over half (54.0%) of 2017 respondents find it very important, this is lower than past years, and there were more who classified it as not very important or not at all important than past years (18.6% combined).

**Figure 97. Importance of comfort from religious/spiritual services or persons***

After declining from 2003 to 2010, the percentage of 2017 participants who find it very important to have health care professionals visit them at their home has increased (36.9%), but is still much lower than it was in 2003 (46.5%) (Figure 98). The percentage of those who find it not very important has been gradually increasing over the years (11.1% in 2003, 14.9% in 2006, 17.6% in 2010, and 17.7% in 2017).

**Figure 98. Importance of having health care professionals visit you at your home***
Although there have been some significant changes in the importance of understanding treatment options, the majority of respondents have classified this as very important every year (Figure 99). Slightly less 2017 respondents (82.7%) classified this as very important than 2010 respondents (83.9%), which are both a decline from 2003 (88.9%).

Figure 99. Importance of understanding your treatment options*

Although half (49.6%) of 2017 respondents find it very important to give to others in time, gifts, or wisdom, the percentage of those who find it not very important or not at all important has increased (12.8%) (Figure 100). Respondents in 2017 were more likely to classify this as somewhat important that they were in past years.

Figure 100. Importance of giving to others in time, gifts, or wisdom***
Compared to previous years, 2017 participants were significantly less likely to consider not being able to communicate wishes/needs to family or friends (65.2%) worse than death (Figure 101). They were also less likely to see the total physical dependency on others worse than death (84.3% in 2003, 77.1% in 2017). Living with great pain did not see any statistically significant differences over the years.

**Figure 101. Health problems worse than death**
When respondents were asked where they would most want to die if they were terminally ill and had the choice, only home and having no preference showed significant changes between 2010 and 2017 (Figure 102). This question was not asked until the 2010 administration. In both years, home was the most commonly chosen category, but this increased from about two-thirds (66.8%) in 2010, to closer to three-fourths (71.6%) in 2017. Respondents in 2017 were also more likely to have a preference than 2010 respondents. While 15.8% of 2010 respondents reported that they have no preference, this was nearly cut in half by 2017 respondents (8.6%).

Figure 102. If you were terminally ill and could choose where to die, where would you most want to die

<table>
<thead>
<tr>
<th>Location</th>
<th>2010</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home*</td>
<td>66.8%</td>
<td>71.6%</td>
</tr>
<tr>
<td>In an assisted living facility</td>
<td>6.5%</td>
<td>8.4%</td>
</tr>
<tr>
<td>In a hospital</td>
<td>14.8%</td>
<td>17.8%</td>
</tr>
<tr>
<td>In a nursing home</td>
<td>2.3%</td>
<td>3.7%</td>
</tr>
<tr>
<td>In a residential hospice</td>
<td>21.0%</td>
<td>21.2%</td>
</tr>
<tr>
<td>I have no preference***</td>
<td>15.8%</td>
<td>8.6%</td>
</tr>
</tbody>
</table>
METHODOLOGY

Introduction
This report presents a detailed account of the design and fielding of the Nebraska End-of-Life Survey, commissioned by the Nebraska Hospice and Palliative Care Association (NHPCA) and conducted by the Bureau of Sociological Research (BOSR). Users of the Nebraska End-of-Life Survey data will find it an important reference source for answers to questions about methodology.

Questionnaire Design
The Nebraska End-of-Life Survey is administered as a mail survey. The questionnaire is based on the survey used in the previous studies, which were designed by NHPCA in consultation with BOSR and formatted by BOSR. All materials were in English.

Sampling Design
The sampling design of the Nebraska End-of-Life survey used a postal delivery sequence based sample of household addresses (ABS). The sample includes addresses for individuals and households who have an address according to the US Postal Service. To maintain a probability sample, the adult (age 19 or older) in the household with the next birthday after January 1, 2017 was asked to complete the survey.

The sample for the Nebraska End-of-Life survey was purchased from Survey Sampling International, LLC (SSI). A total of 3,000 addresses were provided to BOSR by SSI on January 20, 2017. These addresses were drawn throughout Nebraska with equal probability of selection.

Data Collection Process
Data were collected between February 2, 2017 and May 16, 2017. The initial survey packet was sent to all sampled addresses on February 2, 2017. Each survey packet contained a cover letter (Appendix A), survey booklet (Appendix B), cash incentive of $1, and large postage-paid business reply envelope. Reminder postcards were sent to each household on February 8, 2017 (Appendix C). Non-responders were mailed replacement packets (contents discussed above omitting the $1 incentive) on February 22, 2017. Completed surveys were collected by BOSR through May 16, 2017.

Response Rate
A total of 1,128 adults returned the survey. The overall response rate for this survey, calculated using AAPOR’s standard definition for response rate 2 is 39.1%. It should be noted, however, that due to the mode of data collection (mail), it is uncertain if surveys reached the entire sample. Of the 3,000 addresses sampled, 3.8% (n=113) were deemed ineligible due to housing vacancies, business addresses, or no eligible respondent living in the household. Refusals (e.g., blank survey returned; letter, phone call, or email stating refusal to participate) were obtained from 3.9% (n=117) of the sample.

Data Processing
Data entry was completed by professional data-entry staff. Many of the data-entry workers had previous experience in data entry on other mail survey projects. The data-entry staff was supervised by permanent BOSR project staff.

Data entry was completed in two steps. First, one data-entry worker would enter responses from a single survey. Second, another data-entry worker would re-key the survey and be alerted to any discrepancies with the first entry. Supervisory staff members were available to answer
questions about discrepancies or illegible responses. The data-entry staff is paid by the hour, not by the number of surveys entered. This method of payment is used so that we can ensure the high quality of the data collected by our staff.

Data Cleaning
The data are recorded and stored on a secure server located within the Sociology Department at UNL. The Statistical Package for the Social Sciences (SPSS) software package was used to process and document the dataset.

The first step in data cleaning was to generate variable and value labels. The second step was to run frequency distributions on each of the variables in the survey and check for out-of-range values on all survey items for possible data-entry errors.

Data Weights
Data were weighted for the overall dataset meant to be representative of the overall area sampled.

The data were weighted in two ways to account for the within household probability of selection and population characteristics. First, the number of adults living in the household was adjusted for within-household selection probability. Next, poststratification weights were applied based on age and gender in order for the data to more closely resemble the population. The final weight in the dataset is called Pwate.

Throughout this report 2017 data is presented in weighted form, so it is more representative of the population. For consistency with previous years’ data, unweighted responses are used when comparing changes over time.

Design Effects
The design effect due to weighting adjustments is 1.60, which represents the loss in statistical efficiency that results from unequal weights\(^1\).

Appropriate adjustments need to be incorporated into statistical tests when using the Nebraska End-of-Life Survey data. See Estimate of Sampling Error in Appendix D.

Questions
Any questions regarding this report or the data collected can be directed to the Bureau of Sociological Research at the University of Nebraska-Lincoln by calling (402) 472-3672 or by sending an email to bosr@unl.edu.

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\(^1\) The formula used is: 

$$1 + cv^2(w) = \frac{n(\sum w_i^2)}{(\sum w_i)^2}$$
SURVEY RESPONDENT DEMOGRAPHIC INFORMATION

Self-rated health was high overall for respondents. Most stated that they have excellent (17.5%) or very good (44.0%) health while a small percent (1.2%) identified having poor overall health (Figure 36).

![Figure 36: Overall self-rated health (n=1091)](image)

Nearly one-fourth (22.4%) of respondents were caregivers (Figure 37).

![Figure 37: Is the respondent a caregiver? (n=1076)](image)
Some (10.4%) respondents had serious chronic illnesses while slightly more (12.5%) were in households where someone had a serious chronic illness (Figure 38).

**Figure 38: Respondent and household chronic illness**

<table>
<thead>
<tr>
<th>Do you have any serious chronic illnesses (n=1066)</th>
<th>10.4%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does a member of your household have any serious chronic illnesses (n=1095)</td>
<td>12.5%</td>
</tr>
</tbody>
</table>

For respondents, the most common chronic serious illnesses were other conditions (4.7%), followed by heart disease (3.9%), and cancer (2.2%) (Figure 39). Other common conditions for respondent’s serious illnesses were arthritis, chronic pain, and diabetes.

**Figure 39: Respondent serious chronic illness (n=1128)**

- Cancer: 2.2%
- Heart disease: 3.9%
- Alzheimer’s disease: 0.4%
- Lung disease: 1.4%
- In a residential hospice: 1.1%
- Other: 4.7%
At the household level, the most common chronic serious illnesses were heart disease (6.1%), cancer (5.0%), other conditions (3.6%), Alzheimer’s disease (3.2%), and lung disease (3.2%) (Figure 40). Other common conditions for household member’s serious illnesses were Parkinson’s disease and diabetes.

**Figure 40: Household member serious chronic illness (n=1128)**

![Bar chart showing the distribution of chronic serious illnesses among household members.]

- Cancer: 5.0%
- Heart disease: 6.1%
- Alzheimer’s disease: 3.2%
- Lung disease: 3.2%
- In a residential hospice: 2.5%
- Other: 3.6%

Two-thirds (64.2%) of respondents were female (Figure 41).

**Figure 41: Respondent sex (n=1115)²**

![Pie chart showing gender distribution among respondents.]

- Male: 35.8%
- Female: 64.2%

² Since poststratification weights were applied based on age and gender, these two variables are presented in unweighted form here.
Age of respondents ranged from 19 to 75 and older with the largest percent of respondents (23.8%) being 55-64 years old (Figure 42).

![Figure 42: Respondent age (n=1101)³](image)

The majority of respondents (68.2%) are married with a smaller number (15.2%) of people who are single, followed by divorced (8.6%), widowed (3.8%), living together as married (3.3%), and separated (0.9%) (Figure 43).

![Figure 43: Respondent marital status (n=1111)](image)

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³ Since poststratification weights were applied based on age and gender, these two variables are presented in unweighted form here.
Educational attainment of respondents ranges from a small percent (1.8%) not completing high school, 14.5% completing high school, and the remaining majority (83.7%) attending and/or graduating from college (Figure 44).

**Figure 44: Respondent highest level of education (n=1108)**

Nearly two-thirds of respondents (62.5%) work full-time, followed by people who have retired (17.5%), are working part-time (12.9%), and the remainder are unemployed (1.8%), in school (4.4%), homemakers (6.5%), are people with disabilities and unable to work (3.2%), or other (1.8%) (Figure 45). Other employment statuses include being self-employed and helping family members through unpaid labor.

**Figure 45: Respondent work status (n=1128)**
A small percent (3.9%) of respondents identify as Hispanic or Latino (Figure 46).

![Figure 46: Respondent ethnicity (n=1070)](image)

Most respondents (93.3%) were white with the largest racial minority (3.5%) being Asian (Figure 47).

![Figure 47: Respondent race (n=1128)](image)
Household size varied as 12.0% were one person, over one-third (35.4%) were two people, 38.9% were three or four people, and 13.8% were households of five or more people (Figure 48).

**Figure 48: Household size (n=1101)**

Household income ranged from less than $10,000 per year to $75,000 or more per year. The largest (45.9%) income bracket was $75,000 with a small percent (3.8%) having a household income less than $10,000 per year (Figure 49).

**Figure 49: Household income (n=1024)**
Slightly more than half (55.9%) of respondents had an affiliation with an organized faith community (Figure 50).

Figure 50: Organized faith community affiliation (n=1089)

10.4% of respondents were veterans (Figure 51).

Figure 51: Is the respondent a veteran? (n=1114)
APPENDIX A: COVER LETTERS

First cover letter

UNIVERSITY OF NEBRASKA
Lincoln

BUREAU OF SOCIOLOGICAL RESEARCH
Department of Sociology
907 Oldfather Hall
P.O. Box 840313
Lincoln, NE 68588-0313
(402) 472-3812
FAX (402) 472-4500
1-800-480-4549
Email: bosr@unl.edu

Date

Nebraska Resident:
<Address>
<City>, <State> <Zipcode>

Dear Nebraska Resident,

We need your help with an important study. Your household has been randomly selected to participate in the fourth Nebraska End-of-Life Survey. Results of this survey will help those working to improve end-of-life care and conditions across Nebraska, like the Nebraska Hospice and Palliative Care Association and its partner organizations. This important study asks questions about end-of-life issues such as the kind of care you want, your wishes, and the choices you’ll make concerning the end of your life.

We rely on the kindness of people like you to make the survey work. Please have the adult age 19 or older in your household who has the next birthday after January 1, 2017, do the survey. This will help us make sure we hear from all different types of Nebraskans.

Some of this survey’s questions may seem unusual, or make you feel uncomfortable. End-of-life issues aren’t discussed often, but they are important. Participation in this study is voluntary, and you have the right to not answer any question you wish by simply leaving the item blank. However, you can help us very much by taking a few minutes to share your opinions and/or experiences.

Enclosed you will find $1 as a small token of appreciation. Once you have completed the survey, please use the postage-paid, addressed return envelope enclosed in the survey packet to return your survey to the Bureau of Sociological Research (BOSR). If you prefer not to respond, please return the blank questionnaire in the enclosed envelope. Your answers are completely confidential. Data will be released to the researchers only as summaries and no individual’s answers will be identified.

Please contact us by telephone at 1-800-480-4549 or by e-mail at bosr@unl.edu with any questions you may have about this survey.

Thank you very much for helping with this important study.

Lindsey Witt-Swanson
Assistant Director
Bureau of Sociological Research
University of Nebraska-Lincoln
Date

Nebraska Resident
<Address>
<City>, <State> <Zipcode>

Dear Nebraska Resident,

A few weeks ago we sent a letter asking a member of your household to complete the Nebraska End-of-Life Survey. We are writing again because we have not yet received your household’s response. We believe this survey will help those working to improve end-of-life care and conditions across Nebraska, like the Nebraska Hospice and Palliative Care Association and its partner organizations. This important study asks questions about end-of-life issues such as the kind of care you want, your wishes, and the choices you’ll make concerning the end of your life.

We are writing again because your survey is important to us. It is only by hearing from nearly everyone in the sample that we can be sure the results truly represent the people of Nebraska. We hope the adult age 19 or older in your household who has the next birthday after January 1, 2017, will complete the questionnaire soon.

Some of this survey’s questions may seem unusual, or make you feel uncomfortable. End-of-life issues aren’t discussed often, but they are important. Participation in this study is voluntary, and you have the right to not answer any question you wish by simply leaving the item blank. However, you can help us very much by taking a few minutes to share your opinions and/or experiences.

This survey is completely voluntary. All results will be reported in aggregate form so that no individual can be identified. Once you have completed the survey, please use the postage-paid, addressed return envelope enclosed in the survey packet to return your survey to the Bureau of Sociological Research (BOSR). If you prefer not to respond, please return the blank questionnaire in the enclosed envelope.

If you have any questions about this survey please contact the Bureau of Sociological Research by telephone at 1-800-480-4549 or by e-mail at bosr@unl.edu.

Thank you very much for helping with this important study.

Lindsey Witt-Swanson
Assistant Director
Bureau of Sociological Research
University of Nebraska-Lincoln
Nebraska End-of-Life Survey

This survey is about end-of-life issues such as the kind of care you want, your wishes, and the choices you'll make regarding end of life care. Some topics may be sensitive, but your participation in this study is appreciated. Your responses are critical in helping support Nebraskans dealing with these issues. The survey should take approximately 20 minutes to complete.

Hospice Services

1. Have you heard of hospice services?
   - No, I have never heard of hospice services — Go to Question 2
   - Yes, I have heard a little about hospice services
   - Yes, I have heard a lot about hospice services

1a. How did you learn about hospice services?  
   (Mark all that apply)
   - I know someone who used hospice
   - I have used hospice services myself
   - I am/was a hospice volunteer
   - I heard from a health care professional
   - I heard from others
   - I read literature/newspaper/TV/radio/other media
   - On a website or social media — please specify: ________
   - Other — please specify: ________

2. If you were dying, would you want hospice support?
   - No — Go to Question 3
   - Don't know/Not sure — Go to Question 3
   - Yes

2a. Where would you want to receive hospice support?  
   (Mark all that apply)
   - In a hospice residence
   - In a hospital
   - In a nursing home
   - In my own home
   - In a residential facility such as an assisted living facility
   - Other — please specify: ________

3. To the best of your knowledge, does Medicare pay for hospice services?
   - Yes
   - No
   - Not sure

4. For which of the following chronic illnesses do you think hospice services would be helpful?  
   (Mark all that apply)
   - Cancer
   - Heart disease
   - Alzheimer's disease
   - Lung disease
   - Stroke
   - Other — please specify: ________

5. How interested would you be to hear more about hospice services?
   - Very interested
   - Somewhat interested
   - Not very interested
   - Not at all interested
   - Not sure

Palliative Care

6. Have you heard of palliative care?
   - No, I have never heard of palliative care — Go to Question 7
   - Yes, I have heard a little about palliative care
   - Yes, I have heard a lot about palliative care

6a. How did you learn about palliative care?  
   (Mark all that apply)
   - I know someone who used palliative care
   - I have used palliative care myself
   - I am/was a hospice volunteer
   - I heard from a health care professional
   - I heard from others
   - I read literature/newspaper/TV/radio/other media
   - On a website or social media — please specify: ________
   - Other — please specify: ________
7. If you were seriously ill, would you want palliative care?
   ○ No → Go to Question 8
   ○ Don't know/Not sure → Go to Question 8
   ○ Yes

7a. Where would you want to receive palliative care?
   (Mark all that apply)
   ■ In a hospital
   ■ In a nursing home
   ■ In my own home
   ■ In a residential facility such as an assisted living facility
   ■ Other -- please specify: __________

8. To the best of your knowledge, does Medicare pay for palliative care?
   ○ Yes
   ○ No
   ○ Not sure

9. For which of the following chronic illnesses do you think palliative care would be helpful?
   (Mark all that apply)
   ■ Cancer
   ■ Heart disease
   ■ Alzheimer's disease
   ■ Lung disease
   ■ Stroke
   ■ Other -- please specify: __________

10. How interested would you be to hear more about palliative care?
    ○ Very interested
    ○ Somewhat interested
    ○ Not very interested
    ○ Not at all interested
    ○ Not sure

11. I expect to need someone to listen when I talk.
    ○ No → Go to Question 12
    ○ Yes

11a. Who should provide this type of support?
    (Mark all that apply)
    ■ Spouse/partner
    ■ Children
    ■ Other family
    ■ Friends/neighbors
    ■ Health providers
    ■ Work associates
    ■ Community organizations
    ■ Church/Place of worship
    ■ Other -- please specify: __________

12. I expect to need someone to provide transportation.
    ○ No → Go to Question 13
    ○ Yes

12a. Who should provide this type of support?
    (Mark all that apply)
    ■ Spouse/partner
    ■ Children
    ■ Other family
    ■ Friends/neighbors
    ■ Health providers
    ■ Work associates
    ■ Community organizations
    ■ Church/Place of worship
    ■ Other -- please specify: __________

13. I expect to need someone to help with chores.
    ○ No → Go to Question 14
    ○ Yes

13a. Who should provide this type of support?
    (Mark all that apply)
    ■ Spouse/partner
    ■ Children
    ■ Other family
    ■ Friends/neighbors
    ■ Health providers
    ■ Work associates
    ■ Community organizations
    ■ Church/Place of worship
    ■ Other -- please specify: __________
14. I expect to need someone to do fun things with me.
   ○ No ➔ Go to Question 15
   ○ Yes

14a. Who should provide this type of support?
     (Mark all that apply)
     - Spouse/partner
     - Children
     - Other family
     - Friends/neighbors
     - Health providers
     - Work associates
     - Community organizations
     - Church/Place of worship
     - Other -- please specify:

15. I expect to need someone to know what I want when I die.
   ○ No ➔ Go to Question 16
   ○ Yes

15a. Who should provide this type of support?
     (Mark all that apply)
     - Spouse/partner
     - Children
     - Other family
     - Friends/neighbors
     - Health providers
     - Work associates
     - Community organizations
     - Church/Place of worship
     - Other -- please specify:

16. I expect to need someone to help care for other family members.
   ○ No ➔ Go to Question 17
   ○ Yes

16a. Who should provide this type of support?
     (Mark all that apply)
     - Spouse/partner
     - Children
     - Other family
     - Friends/neighbors
     - Health providers
     - Work associates
     - Community organizations
     - Church/Place of worship
     - Other -- please specify:

17. I expect to need someone to encourage me when I’m down.
   ○ No ➔ Go to Question 18
   ○ Yes

17a. Who should provide this type of support?
     (Mark all that apply)
     - Spouse/partner
     - Children
     - Other family
     - Friends/neighbors
     - Health providers
     - Work associates
     - Community organizations
     - Church/Place of worship
     - Other -- please specify:

18. I expect to need someone to understand what I’m going through.
   ○ No ➔ Go to Question 19
   ○ Yes

18a. Who should provide this type of support?
     (Mark all that apply)
     - Spouse/partner
     - Children
     - Other family
     - Friends/neighbors
     - Health providers
     - Work associates
     - Community organizations
     - Church/Place of worship
     - Other -- please specify:

19. I expect to need someone to know about my illness.
   ○ No ➔ Go to Question 20
   ○ Yes

19a. Who should provide this type of support?
     (Mark all that apply)
     - Spouse/partner
     - Children
     - Other family
     - Friends/neighbors
     - Health providers
     - Work associates
     - Community organizations
     - Church/Place of worship
     - Other -- please specify:
**Advance Directives**

Advance directives allow people to make their health care choices known in advance of an incapacitating illness or death.

20. Which of the following advance directives and other pre-plans have you heard about and completed?

<table>
<thead>
<tr>
<th>Have heard about and completed</th>
<th>Have heard about but not completed</th>
<th>Have not heard about</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. A Health Care Power of Attorney (HCPA) in which you name someone to make decisions about your health care in the event you become incapacitated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. A living will in which you state the kind of health care you want or don’t want under certain circumstances</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. A last will and testament that controls how your assets are to be distributed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. Funeral or burial pre-plans in which you plan or purchase in advance any goods or services for yourself</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e. Signing up to have your organs and/or tissue donated after you die for use by others in need of transplants</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

21. Have you completed an advance directive?

- [ ] Yes
- [ ] No → Go to Question 22

21a. Where did you get the advance directive form? *(Mark all that apply)*

- [ ] Lawyer’s office
- [ ] Physician’s office
- [ ] Hospital
- [ ] Presentation about advance directives
- [ ] Website -- please specify: ____________________________
- [ ] Other -- please specify: ____________________________

22. With whom have you talked about your wishes for care at the end of your life? *(Mark all that apply)*

- [ ] Spouse/partner
- [ ] Family
- [ ] Friends
- [ ] Lawyer
- [ ] Primary physician
- [ ] Clergy (such as a minister, rabbi, etc.)
- [ ] Other -- please specify: ____________________________
- [ ] No one

23. Who would you want to initiate a conversation with you regarding end-of-life issues? *(Mark all that apply)*

- [ ] Spouse/partner
- [ ] Family
- [ ] Friends
- [ ] Lawyer
- [ ] Primary physician
- [ ] Clergy (such as a minister, rabbi, etc.)
- [ ] Other -- please specify: ____________________________
- [ ] No one

24. Who would you trust to provide information on end-of-life issues? *(Mark all that apply)*

- [ ] Primary physician
- [ ] Local hospital
- [ ] Local hospice
- [ ] Lawyer
- [ ] Clergy (such as a minister, rabbi, etc.)
- [ ] American Cancer Society
- [ ] AARP
- [ ] Website/Social media -- please specify: ____________________________
- [ ] Other -- please specify: ____________________________
- [ ] No one
### Thinking About Pain

25. How strongly do you agree or disagree with each statement:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I am afraid my doctor may not believe I am in pain or may not treat my pain.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>b. I would only take pain medicines when the pain is severe.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>c. I am afraid I will become addicted to the pain medicines over time.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>d. I would take the lowest amount of medicine possible to save larger doses for later when the pain is worse.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>e. I am afraid I would be given too much pain medicine.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

### Thoughts on Death

26. How comfortable are you with:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Very comfortable</th>
<th>Somewhat comfortable</th>
<th>Not very comfortable</th>
<th>Not at all comfortable</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Talking about death</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>b. Writing my will if I thought my death would occur soon</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>c. Thinking about life after death</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

27. How likely are you to:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Very likely</th>
<th>Somewhat likely</th>
<th>Not very likely</th>
<th>Not at all likely</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Attend funerals, visitations, or memorial services</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>b. Read books, newspaper articles and/or other information that deal with the subject of death and dying</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>c. Watch television programs or movies that deal with the subject of death and dying</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>d. Avoid medical checkups because I am afraid the doctor will find “something serious”</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>e. Speak freely to loved ones about death and dying</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>f. Visit or telephone a friend or relative who has recently lost a loved one in order to see how they are doing</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>g. Preplan my own funeral or memorial service</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>h. Preplan the funeral or memorial service of someone you’re caring for</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
28. How afraid, if at all, are you of:

<table>
<thead>
<tr>
<th>Option</th>
<th>Very afraid</th>
<th>Somewhat afraid</th>
<th>Not very afraid</th>
<th>Not at all afraid</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Dying from a long-term illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Dying suddenly</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. Dying alone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. Dying in a facility such as a nursing home or hospital</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e. Dying painfully</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

29. How strongly do you agree or disagree that:

<table>
<thead>
<tr>
<th>Option</th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. There is a special value in getting old</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Dying is an important part of life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. If someone could tell me that I likely have six months or less to live, I would want to know</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. Caring for people who are dying is a rewarding experience</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e. If I knew I was dying, I would want medical interventions to keep me alive as long as possible</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

30. When you think about death and dying, how concerned are you that:

<table>
<thead>
<tr>
<th>Option</th>
<th>Very concerned</th>
<th>Somewhat concerned</th>
<th>Not very concerned</th>
<th>Not at all concerned</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. My (or my spouse/partner’s) money won’t last</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. My family’s money won’t last</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. I will be a burden to my family or friends</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

31. How important would each of the following be to you when dealing with your own dying?

<table>
<thead>
<tr>
<th>Option</th>
<th>Very important</th>
<th>Somewhat important</th>
<th>Not very important</th>
<th>Not at all important</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Family/friends visiting you</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Being able to stay in your home</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. Honest answers from your doctor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. Comfort from religious/spiritual services or persons</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e. Knowing medicine was available to you</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f. Planning your own funeral or memorial service</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g. Being able to complete your will</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h. Fulfilling personal goals/plasures</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i. Reviewing your life history with your family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>j. Having health care professionals visit you at your home</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>k. Getting your finances in order</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>l. Understanding your treatment options</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>m. Giving to others in time, gifts, or wisdom</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
32. Which of the following health problems, if any, do you think are worse than death? (Mark all that apply)
   - Living with great pain
   - Total physical dependency on others, such as being in a coma
   - Not being able to communicate my wishes and/or needs to family and friends
   - None of these are worse than death

33. If you could choose one way to die, what would your choice be? (Mark all that apply)
   - Sudden death
   - Long-term illness
   - Death while sleeping
   - Other -- please specify: 
   - I have no preference

34. If you were terminally ill and could choose where to die, where would you most want to die? (Mark all that apply)
   - Home
   - In an assisted living facility
   - In a hospital
   - In a nursing home
   - In a residential hospice (hospice services provided by a hospice-owned facility)
   - Other -- please specify:
   - I have no preference

35. Do you consider yourself:
   - Very religious/spiritual
   - Somewhat religious/spiritual
   - Not very religious/spiritual
   - Not at all religious/spiritual
   - Go to Question 39

36. How often do you attend religious or spiritual services?
   - Regularly
   - Occasionally
   - Rarely
   - Never
   - Not religious/spiritual

37. How often do you find strength in your religion or spirituality?
   - One or more times a day
   - A few times a week
   - A few times a month
   - Once a month or less
   - Never
   - Not religious/spiritual

38. How often would you want religious/spiritual support at the end of life?
   - One or more times a day
   - A few times a week
   - A few times a month
   - Once a month or less
   - Never
   - Not religious/spiritual

About You
The following questions are for classification purposes only and will be kept entirely confidential.

39. In general, how would you rate your own health right now?
   - Excellent health
   - Very good health
   - Good health
   - Fair health
   - Poor health

40. Are you a caregiver?
   - Yes
   - No

41. Do you have any serious chronic illnesses?
   - No ➔ Go to Question 42
   - Yes

41a. Which of the following describe your serious chronic illness(es)? (Mark all that apply)
   - Cancer
   - Heart disease
   - Alzheimer’s disease
   - Lung disease
   - Stroke
   - Other -- please specify: 
42. Does a member of your household have any serious chronic illnesses?  
   ○ No → Go to Question 43  
   ○ Yes  

42a. Which of the following describe the serious chronic illness(es)?  
   (Mark all that apply)  
   □ Cancer  
   □ Heart disease  
   □ Alzheimer's disease  
   □ Lung disease  
   □ Stroke  
   □ Other → please specify: [ ]  

43. Are you:  
   ○ Male  
   ○ Female  

44. What was your age at your last birthday?  
   [ ] years old  

45. What is your current marital status?  
   ○ Single, never married  
   ○ Married  
   ○ Living together as married  
   ○ Separated  
   ○ Divorced  
   ○ Widowed  

46. What is the highest level of education that you completed?  
   ○ Less than high school  
   ○ High school graduate or equivalent  
   ○ Some college or technical training  
   ○ College graduate (4 years)  
   ○ Post-graduate or professional degree  

47. Which of the following describe your current employment status?  
   (Mark all that apply)  
   □ Working full-time  
   □ Working part-time  
   □ Unemployed  
   □ Retired  
   □ In school  
   □ Homemaker  
   □ Disabled  
   □ Other → please specify: [ ]  

48. What is your ethnicity?  
   ○ Hispanic or Latino  
   ○ Not Hispanic or Latino  

49. What is your race?  
   (Mark all that apply)  
   □ White  
   □ Black or African American  
   □ Asian  
   □ American Indian or Alaska Native  
   □ Native Hawaiian or Pacific Islander  
   □ Some other race  

50. How many people, including yourself, live in your household?  
   [ ]  

51. What was your annual household income before taxes in 2016?  
   ○ Less than $10,000  
   ○ $10,000 to $15,999  
   ○ $20,000 to $29,999  
   ○ $30,000 to $39,999  
   ○ $40,000 to $49,999  
   ○ $50,000 to $59,999  
   ○ $60,000 to $74,999  
   ○ $75,000 or more  

52. Are you affiliated with an organized faith community?  
   ○ No  
   ○ Yes → please specify denomination: [ ]  

53. What is your 5-digit zip code?  
   [ ] [ ] [ ] [ ] [ ]  

54. Are you a veteran?  
   ○ Yes  
   ○ No  

Thank you! That completes our questions. We greatly appreciate the time you have taken to complete this survey. For your convenience, please use the postage-paid return envelope included in your survey packet to return your questionnaire to the Bureau of Sociological Research. Questions or requests from this survey can be directed to:  
Bureau of Sociological Research,  
University of Nebraska - Lincoln  
Phone: 800-480-4549 (toll free)  
Email: bssr@unl.edu
APPENDIX C: REMINDER POSTCARD

Back:

Last week we sent your household a survey on behalf of the Nebraska Hospice and Palliative Care Association. Results of this survey will help those working to improve end-of-life care and conditions across Nebraska.

If you have already completed and returned your survey to us, please accept our sincere thanks. If not, we hope this postcard will serve as a reminder to have the adult age 19 or older in your household who will have the next birthday after January 1, 2017, complete the survey today. While participation is voluntary, you can help us very much by taking a few minutes to fill out the survey.

If you did not receive a questionnaire or if it was misplaced, please call 1-800-480-4549, and we will send you another survey. If for some reason you prefer not to respond, please return the blank questionnaire in the postage-paid return envelope enclosed in your survey packet.

Again, we appreciate your participation and look forward to receiving your survey.

Sincerely,
Lindsey Witt-Swanson, Assistant Director
Bureau of Sociological Research
University of Nebraska-Lincoln

Front:

UNIVERSITY OF NEBRASKA
Lincoln

907 Oldfather Hall
P.O. Box 880325
Lincoln, NE 68588-0325

RETURN SERVICE REQUESTED
APPENDIX D: ESTIMATE OF SAMPLING ERROR

Table 1 displays the Nebraska End-of-Life Survey data by the variables used in weighting. One can compare the results weighted and unweighted from the Nebraska End-of-Life Survey compared to the Census information in order to see the effects of weighting.

Table 1. Representativeness of the Nebraska End-of-Life Survey Sample by Weighting Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>Based on 2010 Census</th>
<th>NE End-of-Life, Unweighted</th>
<th>NE End-of-Life,Weighted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>49.1%</td>
<td>35.8%</td>
<td>49.0%</td>
</tr>
<tr>
<td>Female</td>
<td>50.9%</td>
<td>64.2%</td>
<td>51.0%</td>
</tr>
<tr>
<td>19-34</td>
<td>29.9%</td>
<td>16.3%</td>
<td>30.2%</td>
</tr>
<tr>
<td>35-49</td>
<td>26.1%</td>
<td>18.5%</td>
<td>25.7%</td>
</tr>
<tr>
<td>50-64</td>
<td>25.6%</td>
<td>33.7%</td>
<td>25.8%</td>
</tr>
<tr>
<td>65+</td>
<td>18.4%</td>
<td>31.5%</td>
<td>18.3%</td>
</tr>
</tbody>
</table>

Table 2 presents margins of sampling error for some of the most likely sample sizes not taking the design effect from the weighting into account. Exact margins of error for alternative specifications of sample size and reported percentages can be easily computed by using the following formula for the 95% confidence level:

Margin of error = 1.96 * square root (p(1-p)/n)

where:
- p = the expected proportion selecting the answer
- n = number of responses

Table 2. Approximate Margins of Error of Percentages by Selected Sample Size NOT Accounting for Design Effect

<table>
<thead>
<tr>
<th>Reported Percentage</th>
<th>Full Sample*</th>
<th>75% Sample</th>
<th>50% Sample</th>
<th>33.3% Sample</th>
<th>25% Sample</th>
<th>10% Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=1128</td>
<td>n=846</td>
<td>n=564</td>
<td>n=376</td>
<td>n=282</td>
<td>n=112</td>
</tr>
<tr>
<td>50</td>
<td>2.92%</td>
<td>3.37%</td>
<td>4.13%</td>
<td>5.05%</td>
<td>5.84%</td>
<td>9.26%</td>
</tr>
<tr>
<td>40 or 60</td>
<td>2.86%</td>
<td>3.30%</td>
<td>4.04%</td>
<td>4.95%</td>
<td>5.72%</td>
<td>9.07%</td>
</tr>
<tr>
<td>30 or 70</td>
<td>2.67%</td>
<td>3.09%</td>
<td>3.78%</td>
<td>4.63%</td>
<td>5.35%</td>
<td>8.49%</td>
</tr>
<tr>
<td>20 or 80</td>
<td>2.33%</td>
<td>2.70%</td>
<td>3.30%</td>
<td>4.04%</td>
<td>4.67%</td>
<td>7.41%</td>
</tr>
<tr>
<td>10 or 90</td>
<td>1.75%</td>
<td>2.02%</td>
<td>2.48%</td>
<td>3.03%</td>
<td>3.50%</td>
<td>5.56%</td>
</tr>
<tr>
<td>5 or 95</td>
<td>1.27%</td>
<td>1.47%</td>
<td>1.80%</td>
<td>2.20%</td>
<td>2.54%</td>
<td>4.04%</td>
</tr>
</tbody>
</table>

* 95% confidence interval states that in 95 out of 100 samples drawn using the same sample size and design, the interval will contain the population value

When accounting for design effects due to weighting, the adjusted sampling error will be increased as shown when comparing Table 2 to Table 3 where the sampling design effect is incorporated:

Margin of error = square root (deff) * 1.96 * square root (p(1-p)/n)

where:
- deff = design effects
- p = the expected proportion selecting the answer
- n = number of responses
Table 3. Approximate Margins of Error of Percentages by Selected Sample Size 
Accounting for the Design Effect of Weighting

<table>
<thead>
<tr>
<th>Reported Percentage</th>
<th>Full Sample*</th>
<th>75% Sample</th>
<th>50% Sample</th>
<th>33.3% Sample</th>
<th>25% Sample</th>
<th>10% Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>50</td>
<td>3.69%</td>
<td>4.26%</td>
<td>5.22%</td>
<td>6.39%</td>
<td>7.38%</td>
<td>11.71%</td>
</tr>
<tr>
<td>40 or 60</td>
<td>3.62%</td>
<td>4.18%</td>
<td>5.11%</td>
<td>6.26%</td>
<td>7.23%</td>
<td>11.48%</td>
</tr>
<tr>
<td>30 or 70</td>
<td>3.38%</td>
<td>3.91%</td>
<td>4.78%</td>
<td>5.86%</td>
<td>6.77%</td>
<td>10.74%</td>
</tr>
<tr>
<td>20 or 80</td>
<td>2.95%</td>
<td>3.41%</td>
<td>4.18%</td>
<td>5.11%</td>
<td>5.91%</td>
<td>9.37%</td>
</tr>
<tr>
<td>10 or 90</td>
<td>2.21%</td>
<td>2.56%</td>
<td>3.13%</td>
<td>3.84%</td>
<td>4.43%</td>
<td>7.03%</td>
</tr>
<tr>
<td>5 or 95</td>
<td>1.61%</td>
<td>1.86%</td>
<td>2.28%</td>
<td>2.79%</td>
<td>3.22%</td>
<td>5.11%</td>
</tr>
</tbody>
</table>

* 95% confidence interval states that in 95 out of 100 samples drawn using the same sample size and design, the interval will contain the population value.
APPENDIX E: AAPOR TRANSPARENCY INITIATIVE IMMEDIATE DISCLOSURE ITEMS

1. Who sponsored the research study: Introduction
2. Who conducted the research study: Introduction
3. If who conducted the study is different from the sponsor, the original sources of funding will also be disclosed: Introduction
4. The exact wording and presentation of questions and response options whose results are reported. This includes preceding interviewer or respondent instructions and any preceding questions that might reasonably be expected to influence responses to the reported results: Appendix B
5. A definition of the population under study and its geographic location: Sampling Design
6. Dates of data collection: Data Collection Process
7. A description of the sampling frame(s) and its coverage of the target population, including mention of any segment of the target population that is not covered by the design. This many include, for example, exclusion of Alaska and Hawaii in U.S. surveys; exclusion of specific provinces or rural areas in international surveys; and exclusion of non-panel members in panel surveys. If possible the estimated size of non-covered segments will be provided. If a size estimate cannot be provided, this will be explained. If no frame or list was utilized, this will be indicated: Sampling Design
8. The name of the sample supplier, if the sampling frame and/or the sample itself was provided by a third party: Sampling Design
9. The methods used to recruit the panel or participants, if the sample was drawn from a pre-recruited panel or pool of respondents: Not applicable to project
10. A description of the sample design, giving a clear indication of the method by which the respondents were selected, recruited, intercepted or otherwise contacted or encountered, along with any eligibility requirements and/or oversampling. If quotas were used, the variables defining the quotas will be reported. If a within-household selection procedure was used, this will be described. The description of the sampling frame and sample design will include sufficient detail to determine whether the respondents were selected using probability or non-probability methods: Sampling Design
11. Method(s) and mode(s) used to administer the survey (e.g., CATI, CAPI, ACASI, IVR, mail survey, web survey) and the language(s) offered: Questionnaire Design
12. Sample sizes (by sampling frame if more than on was used) and a discussion of the precision of the findings. For probability samples, the estimates of sampling error will be reported, and the discussion will state whether or not the reported margins of sampling error or statistical analyses have been adjusted for the design effect due to weighting, clustering, or other factors. Disclosure requirements for non-probability samples are different because the precision of estimates from such samples is a model-based measure (rather than the average deviation from the population value over all possible samples). Reports of non-probability samples will only provide measures of precision if they are accompanied by a detailed description of how the underlying model was specified, its assumptions validated and the measure(s) calculated. To avoid confusion, it is best to avoid using the term “margin of error” or “margin of sampling error” in conjunction with non-probability samples: Appendix D
13. A description of how the weights were calculated, including the variables used and the sources of weighting parameters, if weighted estimates are reported: Data Weights

14. If the results reported are based on multiple samples or multiple modes, the preceding items will be disclosed for each: Not applicable to project

15. Contact for obtaining more information about the study: Questions