

Topline

Kaiser Family Foundation
Serious Illness in Late Life Survey

November 2017

SURVEY METHODOLOGY

The Kaiser Family Foundation *Serious Illness in Late Life Survey* was conducted by telephone May 4 – July 12, 2017, among a representative, random national sample of 2,040 adults age 18 and over, living in the United States, including Alaska and Hawaii (Note: persons without a telephone could not be included in the random selection process). Computer assisted interviews conducted by landline (n=677) and cell phone (n=1,363, including 798 who had no landline telephone) were carried out in English and Spanish by SSRS. The survey was designed and analyzed by public opinion researchers at the Kaiser Family Foundation, and was funded through a grant from the Gordon and Betty Moore Foundation.

In order to better understand how those with serious illness are faring and what challenges they face in accessing and affording care and support services, the full sample includes additional interviews with people who have experience with serious illness, either personally or with a family member (commonly referred to as an “oversample”).

Individuals were classified as being seriously ill if they met each of the following criteria:

1. they were 65 or older,
2. they said they had functional limitations due to a health or memory problem such as difficulty preparing meals, shopping for groceries, taking medications, getting across a room, eating, dressing, bathing, or using the toilet,
3. they said they have been diagnosed with at least one of the following conditions: diabetes or high blood sugar; asthma, lung disease, emphysema, or COPD; heart disease or had a stroke; cancer, not including skin cancer; Alzheimer’s disease, dementia or memory loss; depression, anxiety or other serious mental health problems; or, chronic kidney disease or kidney failure.

Individuals qualified as a family member of someone with serious illness if their loved one currently met the criteria above or if they did so before they died within the past two years. In order to be included, family members also must have said they knew at least something about their family member’s medical care. The exact wording of the screening questions for each qualifying group can be found starting on page 63.

In total, the survey included 998 interviews with people who met the above definition of having experience with serious illness, including 183 interviews with older adults who are personally seriously ill, 494 with family members of older adults currently living with serious illness, and 321 with family members of older adults who died after a period of serious illness. To ensure there were enough respondents to capture the views and situations of Blacks and Hispanics who have experience with serious illness, the total sample included 278 Blacks with serious illness experience and 282 Hispanics with serious illness experience (in addition to 109 Blacks and 119 Hispanics without serious illness experience). Results for all groups have been adjusted to reflect their actual national distribution (See weighting description below).

The SSRS Omnibus survey (detailed below) estimates that less than 20 percent of adults in the U.S. qualify under this survey’s definition of experience with serious illness. To oversample those with experience with serious illness, particularly those who are Black or Hispanic, the sample plan consisted of three elements:

1. Cell and Landline Phone Random Digit Dialing (RDD) (n=1,444). The dual frame landline and cellular phone sample was generated by Marketing Systems Group (MSG) using RDD procedures. This included 148 respondents reached by cell phone or landline within Census blocks with an estimated larger share of Blacks or Hispanics and 34 respondents reached by landline where directory listings indicated one household member at least has a distinctive Hispanic last name. To randomly select a household member for the landline samples, respondents were selected by asking for the youngest or oldest adult male or female currently at home based on a random rotation. If no one of that gender was available, interviewers asked to speak with the youngest or oldest adult of the opposite gender. For the cell phone sample, interviews were conducted with the adult who answered the phone.
2. Pre-screened Respondents Previously Completing Interviews on the SSRS Omnibus Survey (n=288). Weekly, RDD landline and cellular phone surveys of the general public were used to identify respondents who qualified as having experience with serious illness. Individuals who had previously indicated on the SSRS omnibus survey that they fit the eligibility criteria for this group were re-contacted and re-screened for this survey.
3. Respondents Previously Completing Interviews on the SSRS Omnibus Survey (n=308). Individuals who had previously indicated on the SSRS omnibus survey that they were Black or Hispanic and were 50 or older were re-contacted, as they were generally more likely to be either personally ill themselves or have a family member who is or was before they died. A small sample of Blacks or Hispanics 40-49 years old was also included.

A multi-stage weighting process was applied to ensure an accurate representation of the national adult population. The first stage of weighting involved corrections for sample design, including a correction for the oversampling of telephone exchanges known to have higher incidences of Blacks and Hispanics, the likelihood of non-response for the re-contacted samples, and an adjustment to account for the fact that respondents with both a landline and cell phone have a higher probability of selection. The second weighting stage was conducted separately for those with serious illness experience and those without. There are no known administrative data available for creating demographic weighting parameters for those with experience with serious illness as defined by this survey. Therefore, demographic benchmarks were derived by compiling a sample of all respondents interviewed on the SSRS Omnibus survey between March 22, 2017 and May 28, 2017 (N=14,275) and weighting this sample to match the national adult population based on the 2016 U.S. Census Current Population Survey March Supplement parameters for age, gender, education, race/ethnicity, region, phone status, and population density. This sample was then filtered for respondents qualifying for as having experience with serious illness (N=2,479) and those who do not (11,796) and the weighted demographics of these groups were used as post-stratification weighting parameters for each group in the total sample (including age by gender, education, race/ethnicity, region, population density, marital status, phone

status, and serious illness status (personally seriously ill, living family member, deceased family member, or no recent experience with serious illness). In the final weighting stage, each group (those with experience with serious illness and all others) was weighted to reflect its actual share in the U.S. adult population. All statistical tests of significance account for the effect of weighting.

The margin of sampling error including the design effect for the full sample is plus or minus 3 percentage points. Numbers of respondents and margins of sampling error for key subgroups are shown in the table below. For results based on other subgroups, the margin of sampling error may be higher. Sample sizes and margins of sampling error for other subgroups are available by request. Note that sampling error is only one of many potential sources of error in this or any other public opinion poll. Kaiser Family Foundation public opinion and survey research is a charter member of the [Transparency Initiative](#) of the American Association for Public Opinion Research.

Group	N	Margin of Sampling Error
Total	2040	±3 percentage points
Age		
18-29	261	±7 percentage points
30-49	407	±6 percentage points
50-64	663	±5 percentage points
65 or older	706	±5 percentage points
Race/Ethnicity		
White	1140	±3 percentage points
Black	387	±9 percentage points
Hispanic	401	±9 percentage points
Serious Illness		
Recent experience with serious illness (NET)	998	±4 percentage points
Personally seriously ill and age 65 or older	183	±11 percentage points
Family members of adults 65 or older with serious illness	815	±5 percentage points

The full poll results are representative of the U.S. adult population, including people of all races. The reported results focus on the total sample, reflective of all adult people in the U.S., as well as Whites, Blacks, and Hispanics. While the responses for some smaller groups of the U.S. population, for example, Asian-Americans and people of mixed race, are counted in the “total” poll responses, because adults in this poll were sampled randomly, the number of respondents who identify as Asian or as mixed race was too small to report separately, since the margin of sampling error around any poll result would be so large that the result would be unreliable and potentially misleading.

This questionnaire was administered with the exact questions in the exact order as appears in this document. For the questions about a person’s experience with serious illness, those personally seriously ill or those with living family members with serious illness were asked questions in the present tense. Those family members whose seriously ill loved one is deceased were asked questions in the past tense. In addition, those personally seriously ill were asked directly about their experience, while family members were asked to answer most questions about their loved one’s experience being seriously ill.

Please note: (1) Table percentages may not add to 100 percent due to rounding. (2) Values less than 0.5 percent are indicated by an asterisk (*). (3) “vol.” indicates that a response was volunteered by respondent and not an explicitly offered choice. (4) Data aren’t shown if the number of respondents asked a question (the unweighted N) is less than 100. (5) Don’t know and refused responses were collected separately, but are shown combined.

Screeners Summary Tables

Group Summary Table Based on Total

	Total	White	Black	Hispanic
Experience with serious illness (NET)	16	18	14	10
Self, Personally seriously ill (Group = 1)	2	2	2	1
Living Family Member (Group = 2)	8	9	7	5
Deceased Family Member (Group = 3)	6	7	5	3
No recent experience with serious illness (Group = 0)	84	82	86	90

Seriously Ill Gender Summary Table

Based on total who are personally seriously ill, or who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Male	42	44	32	38
Female	58	56	68	62
<i>N</i>	998	407	278	282

Seriously Ill Age/Age at Death Summary Table

Based on total who are personally seriously ill, or who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
65-74	26	22	32	35
75-84	37	38	37	34
85 or older	36	38	29	31
<i>N</i>	998	407	278	282

Seriously Ill Disease Summary Table

Based on total who are personally seriously ill, or who have a living or deceased family member with serious illness

Percentages will add to more than 100 due to multiple responses.

	Total	White	Black	Hispanic
Yes, Diabetes	35	30	51	47
Yes, Asthma, lung disease, emphysema, or COPD	26	27	21	20
Yes, Heart disease or had a stroke	47	50	42	36
Yes, Cancer, not including skin cancer	24	26	21	20
Yes, Alzheimer's disease, dementia, or memory loss	52	55	46	37
Yes, Depression, anxiety or other serious mental health problems	28	26	23	39
Yes, Chronic kidney disease or kidney failure	14	14	13	13
<i>N</i>	998	407	278	282

Seriously Ill Family Member Relation Summary Table

Based on total who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Parent	56	54	55	63
Spouse	9	10	9	11
Grandparent	21	23	14	16
In-law	7	7	5	4
Brother/Sister/Sibling	3	2	10	5
Aunt/Uncle	5	5	5	3
Other (vol.)	1	*	3	*
Refused	*	*	-	-
<i>N</i>	815	357	209	225

MAIN QUESTIONNAIRE

READ TO ALL: Now, I'm going to ask some GENERAL questions about people with serious health needs or serious illness – that is, people who have serious chronic health conditions and trouble doing everyday tasks independently.

THERE IS NO QUESTION 1

Q2. How would you rate the U.S. health care system when it comes to providing care for older people with serious health needs? Would you say it is excellent, very good, good, fair or poor?

	Total	White	Black	Hispanic
Excellent/Very good/Good (NET)	41	41	36	45
Excellent	4	3	5	8
Very good	11	11	11	12
Good	26	27	20	25
Fair/Poor (NET)	52	52	60	48
Fair	28	27	35	34
Poor	23	25	25	14
Don't know/Refused	7	7	4	7

Q3. Do you think there is (ENOUGH) or (NOT ENOUGH) support available in your community for older people with serious health needs? (rotate items in parentheses)

	Total	White	Black	Hispanic
Enough	43	42	44	48
Not enough	45	45	46	45
Don't know/Refused	12	13	10	7

Q4. How common is it for each of the following to happen to people in their last few years of life? First/Next, (INSERT)? (READ FIRST TWO TIMES AND THEN AS NECESSARY) Would you say this is very common, somewhat common, not too common, or not at all common for people in their last few years of life?) (scramble items b-e)

There is no item a	-----COMMON-----			-----NOT COMMON-----			
	NET	Very common	Somewhat common	NET	Not too common	Not at all common	Don't know/Refused
b. Trouble paying for medical care							
Total	83	53	31	13	9	4	4
White	85	50	35	12	9	3	3
Black	82	59	23	14	10	4	4
Hispanic	83	57	26	14	7	7	3
c. Trouble paying for support services, such as someone to help prepare meals and do household chores							
Total	80	44	36	15	9	5	5
White	82	45	38	12	8	3	6
Black	76	46	31	19	15	4	4
Hispanic	77	43	33	20	8	12	4
d. To move somewhere other than where they want to be living							
Total	74	43	31	21	13	8	5
White	78	42	35	17	11	6	5
Black	71	44	28	24	16	8	5
Hispanic	64	42	22	29	13	16	7
e. Trouble paying for housing							
Total	76	43	33	19	13	6	5
White	76	40	37	19	14	4	5
Black	75	46	29	17	11	6	8
Hispanic	76	49	27	20	9	11	4

- Q5. I'm going to read you two scenarios. Which do you think is more typical of the way people generally die in the U.S.? (READ LIST) (rotate response options 1-2/2-1)

	Total	White	Black	Hispanic
OPTION A: a person dies after many months or years of declining health and increasing use of health care and other support services	74	77	72	68
OPTION B: a person dies suddenly or after a short illness lasting just a few days or weeks	20	18	22	29
Don't know/Refused	6	6	6	3

- Q6. How important do you think it is for people to have written down (INSERT ITEM)? (READ LIST) (scramble items a-b)

	-----IMPORTANT-----			-----NOT IMPORTANT-----			Don't know/Refused
	NET	Very important	Somewhat important	NET	Not too important	Not at all important	
a. Their wishes for medical care in case they become seriously ill, such as the types of treatments they do or don't want to receive							
Total	97	87	10	2	1	1	*
White	98	87	11	2	1	1	*
Black	98	84	13	2	*	2	*
Hispanic	97	91	6	1	*	1	2
b. Who they would like to make decisions about their medical care if they can no longer make them on their own							
Total	98	92	7	2	1	1	*
White	99	93	6	1	1	*	*
Black	98	88	9	2	2	*	-
Hispanic	99	92	7	1	*	1	*

- Q7. When do you think someone should first write something down about who will make decisions about their medical care if they can no longer make them on their own? (READ LIST)

	Total	White	Black	Hispanic
When they turn 18	28	27	35	27
When they get married	17	18	23	11
When they have children	13	14	10	13
When they retire	19	22	13	10
When they are diagnosed with a serious illness	19	15	16	36
Some other time (vol.)	3	2	2	4
Don't know/Refused	1	2	1	*

THERE IS NO QUESTION 8 OR 9

Q10. People have different ideas about what it would mean to have a good quality of life in older age. How important, if at all, are each of the following for you personally when it comes to a good quality of life in older age? (First/Next), (INSERT ITEM). (READ FOR FIRST TWO TIMES AND THEN AS NECESSARY: Would you say this is extremely important to you, very important, somewhat important, or not too important for a good quality of life in older age? (scramble items a-j)

Items a, c, e, g, i- Based on Half Sample A

Items b, d, f, h, j- Based on Half Sample B

	EXTREMELY/VERY -----IMPORTANT-----			SOMEWHAT/NOT TOO -----IMPORTANT-----			Don't know/Refused	N
	NET	Extremely important	Very important	NET	Somewhat important	Not too important		
a. Being able to talk or communicate with others								
Total	94	42	52	6	5	1	-	1,015
White	93	45	48	7	6	*	-	565
Black	94	38	56	6	4	2	-	200
Hispanic	94	33	61	6	5	1	-	199
b. Being able to feed or dress yourself								
Total	91	37	53	9	8	1	*	1,025
White	91	43	48	9	9	*	*	575
Black	89	36	54	11	8	2	-	187
Hispanic	94	23	71	6	2	4	-	202
c. Living WITHOUT severe long-lasting pain								
Total	87	36	52	12	10	2	1	1,015
White	87	38	50	12	11	1	1	565
Black	86	31	55	14	11	3	-	200
Hispanic	91	32	59	9	3	6	*	199
d. Being able to remember things well								
Total	89	35	53	11	9	3	*	1,025
White	89	39	50	11	10	1	-	575
Black	92	42	49	8	4	4	-	187
Hispanic	91	23	68	9	6	2	*	202
e. Being physically active								
Total	84	28	56	16	15	1	*	1,015
White	80	29	52	20	19	1	-	565
Black	89	27	63	11	9	2	-	200
Hispanic	98	31	67	1	1	*	1	199
f. Feeling what you do in life is worthwhile								
Total	83	31	52	16	13	4	*	1,025
White	83	33	50	16	14	3	1	575
Black	77	38	39	23	16	7	-	187
Hispanic	89	19	69	11	8	3	-	202
g. Making sure your wishes for medical care are followed								
Total	91	39	52	9	7	1	*	1,015
White	90	42	49	10	8	1	*	565
Black	96	44	52	4	3	1	-	200
Hispanic	95	32	62	3	3	1	2	199
h. Making sure you're not a burden to your family								
Total	85	38	47	14	11	4	1	1,025
White	86	39	47	13	11	2	1	575
Black	86	37	49	13	9	3	1	187
Hispanic	87	38	48	13	6	7	-	202

		EXTREMELY/VERY			SOMEWHAT/NOT TOO				
		-----IMPORTANT-----			-----IMPORTANT-----				
		NET	Extremely important	Very important	NET	Somewhat important	Not too important	Don't know/Refused	N
i.	Being spiritually fulfilled								
	Total	73	29	44	26	17	9	1	1,015
	White	72	31	41	28	17	11	*	565
	Black	83	44	39	16	12	3	1	200
	Hispanic	81	19	62	17	16	1	2	199
j.	Being financially stable								
	Total	88	36	52	11	9	2	*	1,025
	White	90	39	51	10	9	1	*	575
	Black	93	37	56	7	5	2	-	187
	Hispanic	84	29	55	15	10	5	1	202

Q11. Overall, how confident are you that you will have enough income and assets to last throughout your retirement years, even if you (IF GROUP=2,3,0, INSERT: become seriously ill and) need long-term support either at home or in a nursing home? Are you...? (READ LIST)

	Total	White	Black	Hispanic
Confident (NET)	62	63	68	54
Very confident	24	24	30	21
Somewhat confident	38	39	38	33
Not Confident (NET)	37	35	32	46
Not too confident	21	19	22	27
Not at all confident	16	17	11	19
Don't know/Refused	1	1	*	*

Q12. How worried are you that (IF GROUP=2,3,0, INSERT: if you were to become seriously ill when you're older) you will (INSERT ITEM)? (READ LIST) (scramble items a-e)

	-----WORRIED-----			-----NOT WORRIED-----			
	NET	Very worried	Somewhat worried	NET	Not too worried	Not at all worried	Don't know/Refused
a. Have trouble affording the medical care you need							
Total	65	34	31	35	17	17	*
White	64	30	34	36	18	18	*
Black	62	39	23	38	15	22	*
Hispanic	77	50	26	23	13	10	1
b. Have trouble affording the support services you may need, such as someone to help prepare meals and do household chores							
Total	56	24	32	43	23	20	1
White	55	20	34	45	24	21	*
Black	51	24	27	48	22	26	1
Hispanic	67	43	24	32	19	13	1
c. Not be able to continue living where you want to							
Total	59	26	32	41	21	20	*
White	57	22	34	43	23	20	*
Black	54	25	29	46	19	27	*
Hispanic	72	47	26	28	13	15	*
d. Have trouble affording housing							
Total	50	26	24	49	23	26	*
White	45	20	25	54	25	29	*
Black	54	28	25	46	24	22	-
Hispanic	69	50	19	30	13	17	1
e. Leave debts to your family when you die							
Total	42	24	18	58	23	35	*
White	37	20	17	63	25	38	*
Black	40	22	18	60	22	38	-
Hispanic	63	47	16	37	15	21	1

Q13. What actions have you taken to plan for your own needs as you age? Have you (INSERT ITEM), or not? (INTERVIEWER NOTE for item a: IF RESPONDENT SAYS THEY HAVE LONG TERM CARE INSURANCE, CODE AS YES) (scramble items a-d)

Based on total age 50 or older

	Yes	No	Don't know/Refused	N
a. Set aside money that could be used to pay for ongoing living assistance expenses including nursing home care, a senior community, or care from a home healthcare aide				
Total	43	56	1	1,369
White	46	52	1	763
Black	36	63	1	305
Hispanic	24	76	*	252
b. Looked for information about aging issues and the types of care available to people as they age				
Total	35	65	*	1,369
White	36	63	*	763
Black	35	65	*	305
Hispanic	25	75	-	252
c. Modified your home in any way to make it easier to live in as you grow older				
Total	33	67	*	1,369
White	34	66	*	763
Black	29	71	*	305
Hispanic	39	60	*	252
d. Moved or made plans to move to a community or facility designed for older adults				
Total	10	90	*	1,369
White	10	90	*	763
Black	9	91	*	305
Hispanic	10	90	*	252

READ TO ALL: My next questions are about Medicare, the national health care insurance program mainly for seniors.

Q14. As far as you know, does Medicare pay (INSERT ITEM), or not? [INTERVIEWER NOTE: IF R SAYS 'DON'T KNOW' DO NOT PROBE] (scramble items a-g)

Items a, b, e, f Based on Half Sample A

Items c, d, g Based on Half Sample B

	Yes, Medicare covers	No, Medicare does not cover	Depends (vol.)	Don't know/Refused	N
a. For medical equipment such as wheelchairs and other assistive devices					
Total	65	15	2	18	1,015
White	68	12	2	17	565
Black	63	18	2	17	200
Hispanic	53	22	2	24	199
b. For ongoing support services at home, such as someone to help prepare meals and do household chores					
Total	31	41	1	27	1,015
White	29	43	1	27	565
Black	39	34	6	21	200
Hispanic	28	40	-	32	199
c. For long-term care in a nursing home					
Total	31	37	3	30	1,025
White	30	38	4	29	575
Black	40	34	2	24	187
Hispanic	26	39	1	33	202
d. For transportation to and from medical appointments for those who can no longer drive					
Total	41	34	*	25	1,025
White	36	35	*	29	575
Black	48	35	*	17	187
Hispanic	48	28	*	24	202
e. Doctors to discuss end-of-life care with their patients					
Total	44	25	1	29	1,015
White	44	24	1	31	565
Black	43	32	*	25	200
Hispanic	41	29	3	28	199
f. For care that focuses on the spiritual and emotional aspects of living with a serious illness for those who are expected to live a year or more					
Total	17	49	*	33	1,015
White	13	53	-	33	565
Black	22	44	-	34	200
Hispanic	27	41	-	32	199
g. For care that focuses on giving medical care, pain management, and comfort to those in their final stages of life					
Total	52	20	1	27	1,025
White	53	17	1	29	575
Black	48	32	*	20	187
Hispanic	52	15	3	30	202

READ TO ALL: On another topic...

Q15. Have you ever had a serious conversation with a spouse, parent, child or any other loved one about (INSERT ITEM) or have you not had such a conversation? Next, how about (INSERT ITEM)? (READ FIRST TIME AND THEN AS NECESSARY: Have you ever had a serious conversation with a spouse, parent, child or any other loved one about this or have you not had such a conversation? (scramble items a-f) (IF GROUP=2,3,0: INSERT text in parentheses)

	Yes	No	No one to talk to (vol.)	Don't know/Refused
a. Your wishes for your medical care (if you become seriously ill), such as the types of treatments you do or don't want to receive				
Total	54	46	*	*
White	61	38	*	*
Black	35	65	-	-
Hispanic	41	59	*	*
b. Where you will live if (you become seriously ill and) you're no longer able to live independently				
Total	34	66	*	*
White	36	64	-	*
Black	29	70	-	1
Hispanic	36	63	*	1
c. Who will help take care of you if you need help caring for yourself				
Total	47	52	*	*
White	51	48	*	*
Black	42	57	-	*
Hispanic	41	59	*	1
d. Who will make decisions about your medical care if you can no longer make them on your own				
Total	62	38	*	*
White	67	32	-	*
Black	54	45	-	*
Hispanic	51	49	*	*
e. How you will pay for health care and other support you need (if you become seriously ill)				
Total	36	63	*	1
White	39	60	*	1
Black	31	69	*	*
Hispanic	32	66	1	2
f. What you would need to have a good quality of life (if you become seriously ill)				
Total	38	62	*	1
White	40	59	*	1
Black	34	66	-	*
Hispanic	36	64	*	*

Q15 Summary Table
Based on Total

	Total	White	Black	Hispanic
Yes to any type of serious conversation with a spouse, parent, child or any other loved one	75	79	68	68
No/No one to talk to (vol.)/Don't know/Refused to any type of serious conversation with a spouse, parent, child, or any other loved one	25	21	32	32

Q16. Are these issues something you talked about once or have you discussed these issues on more than one occasion?

Based on total who say they have had a serious conversation with a spouse, parent, child, or any other loved one

	Total	White	Black	Hispanic
Once	23	20	19	38
More than once	72	76	74	55
Don't know/Refused	5	4	6	7
N	1,605	930	309	291

Q15/Q16 Combo Table based on Total

	Total	White	Black	Hispanic
Yes to any type of serious conversation with a spouse, parent, child, or any loved one	75	79	68	68
Once	17	16	13	26
More than once	54	60	50	37
Don't know/Refused	4	4	4	5
No /No one to talk to (vol.)/Don't know/Refused to any type of serious conversation with a spouse, parent, child, or any other loved one	25	21	32	32

Q17. When was the last time you discussed these issues with a loved one? Was it...? (READ LIST)

Based on total who say they have had a serious conversation with a spouse, parent, child or any other loved one

	Total	White	Black	Hispanic
Within the last year	64	64	59	67
1-2 years ago	21	21	27	17
3-5 years ago	8	8	3	11
6-10 years ago	2	2	3	1
More than 10 years ago	3	2	5	3
Don't know/Refused	3	3	4	2
N	1,605	930	309	291

Q15/Q17 Combo Table based on Total

	Total	White	Black	Hispanic
Yes to any type of serious conversation with a spouse, parent, child, or any other loved one	75	79	68	68
Within the last year	48	50	40	45
1-2 years ago	15	16	18	11
3-5 years ago	6	7	2	7
6-10 years ago	1	1	2	1
More than 10 years ago	2	2	3	2
Don't know/Refused	3	3	3	1
No/No one to talk to (vol.)/Don't know/Refused to any type of serious conversation with a spouse, parent, child or any other loved one	25	21	32	32

Q18. Would you want to talk to a spouse, parent, child or any other loved one about your wishes for your medical care (IF GROUP=2,3,0 INSERT: if you become seriously ill), or would you not want to talk to them about this?

Based on total who say they have not had a serious conversation with a spouse, parent, child, or any other loved one about their wishes for medical care

	Total	White	Black	Hispanic
Yes	74	76	86	63
No	25	23	14	37
Don't know/Refused	1	2	*	*
N	849	406	182	206

Q15a/Q18 Combo Table based on Total

	Total	White	Black	Hispanic
Have had a serious conversation with spouse, parent, child, or any other loved one about their wishes for medical care	54	61	35	41
Have not had a serious conversation with spouse, parent, child, or any other loved one about their wishes for medical care	46	38	65	59
Would want to talk with them about this	34	29	56	37
Would not want to talk with them about this	11	9	9	22
Don't know/Refused	1	1	*	*
No one to talk to (vol.)	*	*	-	*
Don't know/Refused	*	*	-	*

Q19. Have you ever had a serious conversation with a doctor or other health care provider (INSERT ITEMS), or not? Next, how (INSERT ITEM), or not? (READ FIRST TIME AND THEN AS NECESSARY: Have you ever had a serious conversation with a doctor or other health care provider about this, or not? (scramble items a-c)

	Yes	No	Don't know/Refused
a. About your wishes for your medical care (IF GROUP=2,3,0 INSERT: if you become seriously ill), such as the types of treatments you do or don't want to receive			
Total	18	82	*
White	18	81	*
Black	17	83	*
Hispanic	17	83	*
b. About who will make decisions about your medical care if you can no longer make them on your own			
Total	23	76	*
White	24	76	*
Black	22	78	-
Hispanic	23	77	-
c. About where you would like to receive care if you become seriously ill, such as at home or in an assisted living facility			
Total	11	88	*
White	9	90	*
Black	16	84	*
Hispanic	14	86	*

Q19 Summary Table
Based on Total

	Total	White	Black	Hispanic
Yes to any type of serious conversation with a doctor or other health care provider	31	30	33	29
No/Don't know/Refused to any type of serious conversation with a doctor or other health care provider	69	70	67	71

Q20. Are these issues something you talked with a health care provider about once or have you discussed these issues with them on more than one occasion?

Based on total who say they have had a serious conversation with a doctor or other health care provider

	Total	White	Black	Hispanic
Once	47	45	48	51
More than once	37	38	45	29
Don't know/Refused	16	17	7	20
N	733	393	164	142

Q19/Q20 Combo Table based on Total

	Total	White	Black	Hispanic
Yes to any type of serious conversation with a doctor or other health care provider	31	30	33	29
Once	14	13	16	15
More than once	11	12	15	9
Don't know/Refused	5	5	2	6
No/Don't know/Refused to any type of serious conversation with a doctor or other health care provider	69	70	67	71

Q21. When was the last time you discussed these issues with a doctor or other health care provider? Was it...? (READ LIST)

Based on total who say they have had a serious conversation with a doctor or other health care provider

	Total	White	Black	Hispanic
Within the last year	41	41	41	48
1-2 years ago	22	21	22	24
3-5 years ago	12	15	8	2
6-10 years ago	5	4	10	4
More than 10 years ago	5	4	9	5
Don't know/Refused	14	15	10	17
N	733	393	164	142

Q19/Q21 Combo Table based on Total

	Total	White	Black	Hispanic
Yes to any type of serious conversation with a doctor or other health care provider	31	30	33	29
Within the last year	13	12	14	14
1-2 years ago	7	6	7	7
3-5 years ago	4	4	3	1
6-10 years ago	2	1	3	1
More than 10 years ago	2	1	3	2
Don't know/Refused	4	5	3	5
No/Don't know/Refused to any type of serious conversation with a doctor or other health care provider	69	70	67	71

Q22. Would you want to talk to a doctor or other health care provider about your wishes for your medical care (if you become seriously ill), or would you not want to talk to them about this? (INSERT "if you become seriously ill" IF GROUP=2,3,0)

Based on total who say they have not had a serious conversation with a doctor or other health care provider about their wishes for medical care, such as the types of treatments they do or don't want to receive

	Total	White	Black	Hispanic
Yes	57	55	63	59
No	42	43	35	40
Don't know/Refused	2	2	2	1
N	1,561	878	285	307

Q19a/Q22 Combo Table based on Total

	Total	White	Black	Hispanic
Have had a serious conversation with a doctor or other health care provider about their wishes for medical care, such as the types of treatments they do or don't want to receive	18	18	17	17
Have not had a serious conversation with a doctor or other health care provider about their wishes for medical care, such as the types of treatments they do or don't want to receive	82	81	83	83
Would want to talk to them about this	47	45	53	49
Would not want to talk to them about this	34	35	29	33
Don't know/Refused	1	2	2	1
Don't know/Refused	*	*	*	*

Q23. Have you ever had a serious conversation with a lawyer or financial planner about your wishes for your medical care (IF GROUP=2,3,0, INSERT: if you become seriously ill), or have you not had such a conversation?

	Total	White	Black	Hispanic
Yes	19	24	11	9
No	81	76	89	91
Don't know/Refused	*	*	-	*

Q24. Would you want to talk to a lawyer or financial planner about this, or not?

Based on total who say they have not talked with a lawyer or financial planner about wishes for medical care

	Total	White	Black	Hispanic
Yes	36	33	42	38
No	63	65	56	62
Don't know/Refused	2	2	2	1
N	1,575	813	320	351

Q23/Q24 Combo Table based on Total

	Total	White	Black	Hispanic
Have talked to a lawyer or financial planner about wishes for medical care	19	24	11	9
Have not talked to a lawyer or financial planner about wishes for medical care	81	76	89	91
Would want to talk to them about this	29	25	38	34
Would not want to talk to them about this	51	49	50	56
Don't know/Refused	1	2	2	1
Don't know/Refused	*	*	-	*

Q25. Have you ever had a serious conversation with a religious or spiritual leader about your wishes for your medical care (IF GROUP=2,3,0, INSERT: if you become seriously ill), or have you not had such a conversation?

	Total	White	Black	Hispanic
Yes	12	12	12	13
No	88	88	88	87
Don't know/Refused	*	*	1	-

Q26. Would you want to talk to a religious or spiritual leader about this, or not?

Based on total who say they have not talked with a religious or spiritual leader about wishes for their medical care

	Total	White	Black	Hispanic
Yes	23	21	26	27
No	75	76	72	72
Don't know/Refused	2	3	2	*
N	1,747	985	323	345

Q25/Q26 Combo Table based on Total

	Total	White	Black	Hispanic
Have talked to a religious or spiritual leader about wishes for medical care	12	12	12	13
Have not talk to a religious or spiritual leader about wishes for medical care	88	88	88	87
Would want to talk to them about this	20	19	22	24
Would not want to talk to them about this	66	67	63	63
Don't know/Refused	2	2	2	*
Don't know/Refused	*	*	1	-

Q27. Do you have a written document that (INSERT ITEM), or not?

	Yes	No	Don't know/Refused
a. Describes your wishes for your medical care (IF GROUP=2,3,0 INSERT: if you become seriously ill), such as the types of treatments you do or don't want to receive (IF NEEDED, "sometimes called a living will, advance treatment directive, a do-not-resuscitate order or DNR, or Physician Orders for Life Sustaining Treatment")			
Total	34	66	1
White	40	59	1
Black	24	76	*
Hispanic	21	79	-
b. Names who you want to make decisions about your medical care if you can no longer make them on your own (IF NEEDED, "sometimes called a health care proxy or surrogate, or durable power of attorney")			
Total	41	58	*
White	47	52	1
Black	36	63	1
Hispanic	30	70	*

Q28. Do you have one document that describes your wishes for medical care and a separate document that names who can make medical decisions for you, or is this information all in the same document?

Based on total who say they have both types of written documents

	Total	White	Black	Hispanic
Separate documents	20	22	10	16
All in the same document	74	72	90	75
Don't know/Refused	6	6	-	9
N	770	512	117	108

Q27/Q28 Combo Table based on Total

	Total	White	Black	Hispanic
Have both types of written documents	31	37	21	21
Information in separate documents	6	8	2	3
Information all in the same document	23	27	19	16
Don't know/Refused	2	2	-	2
Only have one type of written document (NET)	13	12	19	9
Only document describing wishes for medical care	2	2	4	*
Only document naming who you would want to make decisions	10	10	15	9
Do not have either type of written document/Don't know/Refused	56	50	61	70

Q29. Did someone help you with this document or did you write it on your own?

Based on total who say they have only one type of written document or have both types in same document

Q31. Thinking about the document that describes your wishes for your medical care (if you become seriously ill), did someone help you with this document, or did you write it on your own? (INSERT "if you become seriously ill" IF GROUP=2,3,0)

Based on total who have separate documents

Q33. Thinking about the document that names who you want to make decisions about your medical care if you can no longer make them on your own, did someone help you with this document or did you write it on your own?

Based on total who have separate documents

Q30/Q32/Q34. Who helped you with it- was it a doctor, a nurse, a lawyer, a family member, a staff member at a hospital or clinic, or someone else? (ENTER ALL THAT APPLY)

Based on total who say they had someone's help with the document

Q27a/Q28/Q29/Q30/Q31/Q32 Combo Table Based on total who say they have a written document that describes their wishes for medical care

Percentages will add to more than 100 due to multiple responses.

	Total	White	Black	Hispanic
Someone helped with this document	64	69	50	49
Doctor helped	2	3	3	*
Nurse helped	1	1	1	1
Lawyer helped	40	46	21	20
Family member helped	12	12	4	15
Staff member at a hospital or clinic helped	4	4	6	7
Friend helped (vol.)	2	1	4	5
Financial advisor/planner helped (vol.)	1	1	*	-
Someone else helped	4	4	12	1
Don't know/Refused who helped	1	2	-	*
Wrote on own	29	25	42	42
Don't know/Refused if someone helped or wrote on own	1	*	7	*
Don't know/Refused if documents were separate or the same	6	6	-	9
<i>N</i>	<i>829</i>	<i>541</i>	<i>131</i>	<i>120</i>

Q27b/Q28/Q29/Q30/Q33/Q34 Combo Table Based on total who say they have a written document that names who they would want to make decisions about their medical care

Percentages will add to more than 100 due to multiple responses.

	Total	White	Black	Hispanic
Someone helped with this document	59	66	44	41
Doctor helped	2	2	3	*
Nurse helped	1	2	*	1
Lawyer helped	35	42	16	14
Family member helped	12	12	7	17
Staff member at a hospital or clinic helped	4	4	5	5
Friend helped (vol.)	1	1	3	1
Financial advisor/planner helped (vol.)	1	1	*	-
Someone else helped	4	4	9	3
Don't know/Refused who helped	1	1	-	*
Wrote on own	35	28	54	52
Don't know/Refused if someone helped or wrote on own	1	1	2	*
Don't know/Refused if documents were separate or the same	5	5	-	7
N	983	619	173	148

Q27a/Q28/Q29/Q30/Q31/Q32 Combo Table Based on Total

Percentages will add to more than 100 due to multiple responses.

	Total	White	Black	Hispanic
Have a written document that describes wishes for medical care	34	40	24	21
Someone helped with this document	21	28	12	10
Doctor helped	1	1	1	*
Nurse helped	*	1	*	*
Lawyer helped	13	18	5	4
Family member helped	4	5	1	3
Staff member at a hospital or clinic helped	1	2	1	2
Friend helped (vol.)	1	1	1	1
Financial advisor/planner helped (vol.)	*	*	*	-
Someone else helped	1	1	3	*
Don't know/Refused who helped	*	1	-	*
Wrote on own	10	10	10	9
Don't know/Refused if someone helped or wrote on own	*	*	2	*
Don't know/Refused if documents were separate or the same	2	2	-	2
Do not have a written document that describes wishes for medical care/Don't know/Refused	66	60	76	79

Q27b/Q28/Q29/Q30/Q33/Q34 Combo Table Based on Total

Percentages will add to more than 100 due to multiple responses.

	Total	White	Black	Hispanic
Have a written document that names who you want to make decisions about your medical care	41	47	36	30
Someone helped with this document	25	31	16	12
Doctor helped	1	1	1	*
Nurse helped	1	1	*	*
Lawyer helped	15	20	6	4
Family member helped	5	6	3	5
Staff member at a hospital or clinic helped	2	2	2	2
Friend helped (vol.)	1	1	1	*
Financial advisor/planner helped (vol.)	*	*	*	-
Someone else helped	2	2	3	1
Don't know/Refused who helped	*	*	-	*
Wrote on own	14	14	19	16
Don't know/Refused if someone helped or wrote on own	*	*	1	*
Don't know/Refused if documents were separate or the same	2	2	-	2
Do not have a written document that names who you want to make decisions about your medical care/Don't know/Refused	59	53	64	70

Q35. Have you given a copy of this document to (INSERT ITEM), or not? (scramble items a-d)

Items a-c- based on total who say they only have one written document or both are in the same document

Item d- based on those who say they only have a written document naming proxy or both are in the same document

- a. A doctor or other health care provider
- b. A lawyer
- c. A spouse, parent, child, or other loved one
- d. The person you designated to make decisions for you

Q36. Have you given a copy of the document that describes your wishes for your medical care (IF GROUP=2,3,0, INSERT: "if you become seriously ill) to (INSERT ITEM), or not? (scramble items a-d)

Based on total who say they have separate documents

- a. A doctor or other health care provider
- b. A lawyer
- c. A spouse, parent, child, or other loved one
- d. The person you designated to make decisions for you

Q37. Have you given a copy of the document that names who you want to make decisions about your medical care if you can no longer make them on your own to (INSERT ITEM), or not? (scramble items a-d)

Based on total who say they have separate documents

- a. A doctor or other health care provider
- b. A lawyer
- c. A spouse, parent, child, or other loved one
- d. The person you designated to make decisions for you

Q35/Q36 Summary Table Based on total who say they have a written document that describes their wishes for medical care

	Total	White	Black	Hispanic
Given a copy to doctor or other health care provider	30	30	26	32
Given a copy to a lawyer	40	45	21	21
Given a copy to a spouse, parent, child or other loved one	76	78	69	76
Given a copy to the person you designated to make decisions for you	72	75	56	69
<i>N</i>	829	541	131	120

Q35/Q37 Summary Table Based on total who say they have a written document that names who they would want to make decisions about their medical care

	Total	White	Black	Hispanic
Given a copy to doctor or other health care provider	26	26	24	27
Given a copy to a lawyer	36	41	20	15
Given a copy to a spouse, parent, child or other loved one	73	76	67	69
Given a copy to the person you designated to make decisions for you	75	79	60	68
<i>N</i>	983	619	173	148

Q35/Q36 Summary Table Based on Total

	Total	White	Black	Hispanic
Have a written document that describes wishes for medical care	34	40	24	21
Given a copy to doctor or other health care provider	10	12	6	7
Given a copy to a lawyer	13	18	5	4
Given a copy to a spouse, parent, child, or other loved one	25	31	17	16
Given a copy to the person you designated to make decisions for you	24	30	14	15

Q35/Q37 Summary Table Based on Total

	Total	White	Black	Hispanic
Have a written document that names who you want to make decisions about your medical care	41	47	36	30
Given a copy to doctor or other health care provider	11	12	9	8
Given a copy to a lawyer	15	20	7	5
Given a copy to a spouse, parent, child, or other loved one	30	36	24	21
Given a copy to the person you designated to make decisions for you	31	37	22	20

Q38. When did you first create the document that describes your wishes for your medical care (IF GROUP=2,3,0, INSERT: if you become seriously ill)? Was it...? (READ LIST)

Based on total who say they have a written document that describes wishes for medical care

	Total	White	Black	Hispanic
Within the last year	13	11	13	24
1-2 years ago	18	15	35	24
3-5 years ago	28	31	21	21
6-10 years ago	16	17	8	12
More than 10 years ago	23	25	15	19
Don't know/Refused	2	1	7	1
N	829	541	131	120

Q27a/Q38 Combo Table based on Total

	Total	White	Black	Hispanic
Have a written document that describes wishes for medical care	34	40	24	21
Within the last year	4	4	3	5
1-2 years ago	6	6	9	5
3-5 years ago	9	12	5	5
6-10 years ago	5	7	2	2
More than 10 years ago	8	10	4	4
Don't know/Refused	1	*	2	*
Do not have a written document that describes wishes for medical care	66	59	76	79
Don't know/Refused	1	1	*	-

Q39. Have you reviewed the document since you created it, or not?

Based on total who say they have a written document that describes wishes for medical care

	Total	White	Black	Hispanic
Yes	52	52	47	56
No	47	48	46	44
Don't know/Refused	1	*	7	-
N	829	541	131	120

Q27a/Q39 Combo Table based on Total

	Total	White	Black	Hispanic
Have a written document that describes wishes for medical care	34	40	24	21
Have reviewed document since it was created	17	21	11	12
Have not reviewed document since it was created	16	19	11	10
Don't know/Refused	*	*	2	-
Do not have a written document that describes wishes for medical care	66	59	76	79
Don't know/Refused	1	1	*	-

Q40. When was the last time you reviewed the document? Was it...? (READ LIST)

Based on total who say they have a written document that describes wishes for medical care and reviewed it since it was created (sample sizes for Black and Hispanic subgroups insufficient to report)

	Total	White
Within the last year	61	59
1-2 years ago	19	19
3-5 years ago	12	14
6-10 years ago	2	2
More than 10 years ago	4	4
Don't know/Refused	2	2
N	444	297

Q27a/Q39/Q40 Combo Table based on Total

	Total	White	Black	Hispanic
Have a written document that describes wishes for medical care	34	40	24	21
Have reviewed it since it was created	17	21	11	12
Reviewed within the last year	11	12	8	9
Reviewed 1-2 years ago	3	4	3	2
Reviewed 3-5 years ago	2	3	-	2
Reviewed 6-10 years ago	*	*	-	*
Reviewed more than 10 years ago	1	1	*	*
Don't know/Refused	*	1	-	-
Have not reviewed document since it was created	16	19	11	10
Don't know/Refused	*	*	2	-
Do not have a written document that describes wishes for medical care	66	59	76	79
Don't know/Refused	1	1	*	-

Q41. Have you made changes to the document since you first created it, or not?

Based on total who say they have a written document that describes wishes for medical care and have reviewed it since it was created (sample sizes for Black and Hispanic subgroups insufficient to report)

	Total	White
Yes	34	34
No	66	66
Don't know/Refused	-	-
N	444	297

Q27a/Q39/Q41 Combo Table based on Total

	Total	White	Black	Hispanic
Have a written document that describes wishes for medical care	34	40	24	21
Have reviewed document since it was created	17	21	11	12
Have made changes to it since then	6	7	2	5
Have not made changes to it since then	12	14	9	7
Don't know/Refused	-	-	-	-
Have not reviewed document since it was created	16	19	11	10
Don't know/Refused	*	*	2	-
Do not have a written document that describes wishes for medical care	66	59	76	79
Don't know/Refused	1	1	*	-

Q42. Even if you don't have it written down, is there someone you think understands your wishes for your medical care (IF GROUP=2,3,0, INSERT: if you become seriously ill), or not?

Based on total who say they do not have a written document that describes wishes for medical care

	Total	White	Black	Hispanic
Yes	83	89	77	76
No	16	11	22	22
Don't know/Refused	1	*	1	1
N	1,211	599	256	281

- Q43. Do you think that person understands your wishes because (you've talked to them about it) or because (they know you well enough to know what you'd want)? (rotate items in parentheses)

Based on total who do not say they have written document that describes wishes for medical care, but thinks someone understands wishes

	Total	White	Black	Hispanic
You've talked to them about it	38	36	40	47
They know you well enough to know what you'd want	39	41	34	29
Some other reason (vol.)	*	*	-	2
Both (vol.)	23	23	26	21
Don't know/Refused	*	*	-	*
N	1,019	529	219	214

Q27a/Q42/Q43 Combo Table based on Total

	Total	White	Black	Hispanic
Have a written document that describes wishes for medical care	34	40	24	21
Do not have a written document that describes wishes for medical care/Don't know/Refused	66	60	76	79
Thinks someone understands wishes for medical care	55	53	58	60
Because you've talked to them about it	21	19	23	28
Because they know you well enough to know what you'd want	22	22	20	18
Because of both reasons (vol.)	13	12	15	13
Because of some other reason (vol.)	*	*	-	1
Don't know/Refused	*	*	-	*
Doesn't think someone understands wishes for medical care	11	7	17	17
Don't know/Refused	1	*	1	1

- Q44. There are different reasons why people may not have their wishes for medical care written down. For each of the following, please tell me if this is a major reason, minor reason, or not a reason why you have not written down your wishes for your medical care (IF GROUP=2,3,0, INSERT: if you become seriously ill)? First/Next, (INSERT ITEM). [IF NECESSARY: Is this a major reason, minor reason, or not a reason why you have not written down your wishes for your medical care (if you become seriously ill)?] (scramble items a-f)

Based on total who do not say they have a written document that describes wishes for medical care

	-----REASON-----				Don't know/Refused	N
	NET	Major reason	Minor reason	Not a reason		
a. There are too many other things to worry about right now						
Total	63	36	27	36	1	1,211
White	64	35	29	35	2	599
Black	60	33	27	40	1	256
Hispanic	62	43	19	38	*	281
b. You don't want to think about sickness and death						
Total	56	27	29	43	1	1,211
White	53	21	32	46	1	599
Black	64	37	27	35	*	256
Hispanic	66	42	23	34	-	281
c. You're worried you might change your mind about what you want						
Total	42	13	30	57	1	1,211
White	40	10	30	59	*	599
Black	51	20	31	49	*	256
Hispanic	43	14	29	55	2	281
d. You're too young or that's a long ways off						
Total	61	32	29	38	1	1,211
White	64	32	32	36	*	599
Black	50	26	24	50	*	256
Hispanic	61	34	27	37	2	281
e. You haven't thought about it						
Total	58	32	27	41	1	1,211
White	56	29	27	43	1	599
Black	65	34	32	35	*	256
Hispanic	64	39	25	34	2	281
f. You want your doctors to make the decisions for you when needed						
Total	34	11	23	65	1	1,211
White	34	9	25	66	*	599
Black	28	10	17	71	1	256
Hispanic	41	16	25	59	1	281

Q27a/Q44a Combo Table based on Total

	Total	White	Black	Hispanic
Have a written document that describes wishes for medical care	34	40	24	21
Do not have a written document that describes wishes for medical care/Don't know/Refused	66	60	76	79
There are too many other things to worry about right now is a reason (NET)	42	38	45	49
Is a major reason	24	21	25	33
Is a minor reason	18	18	20	15
There are too many other things to worry about is not a reason	24	21	30	29
Don't know/Refused	1	1	*	*

Q27a/Q44b Combo Table based on Total

	Total	White	Black	Hispanic
Have a written document that describes wishes for medical care	34	40	24	21
Do not have a written document that describes wishes for medical care/Don't know/Refused	66	60	76	79
You don't want to think about sickness and death is a reason (NET)	37	32	49	52
Is a major reason	18	13	28	33
Is a minor reason	20	19	21	18
You don't want to think about sickness and death is not a reason	29	28	27	27
Don't know/Refused	*	1	*	-

Q27a/Q44c Combo Table based on Total

	Total	White	Black	Hispanic
Have a written document that describes wishes for medical care	34	40	24	21
Do not have a written document that describes wishes for medical care/Don't know/Refused	66	60	76	79
You're worried you might change your mind about what you want is a reason (NET)	28	24	38	34
Is a major reason	9	6	15	11
Is a minor reason	20	18	23	23
You're worried you might change your mind about what you want is not a reason	38	36	37	43
Don't know/Refused	1	*	*	1

Q27a/Q44d Combo Table based on Total

	Total	White	Black	Hispanic
Have a written document that describes wishes for medical care	34	40	24	21
Do not have a written document that describes wishes for medical care/Don't know/Refused	66	60	76	79
You're too young or that's a long way off is a reason (NET)	41	39	38	48
Is a major reason	21	19	20	26
Is a minor reason	19	20	18	21
You're too young or that's a long way off is not a reason	25	22	38	29
Don't know/Refused	*	*	*	1

Q27a/Q44e Combo Table based on Total

	Total	White	Black	Hispanic
Have a written document that describes wishes for medical care	34	40	24	21
Do not have a written document that describes wishes for medical care/Don't know/Refused	66	60	76	79
You haven't thought about it is a reason (NET)	39	34	49	50
Is a major reason	21	17	25	31
Is a minor reason	18	16	24	20
You haven't thought about it is not a reason	27	26	26	27
Don't know/Refused	1	1	*	1

Q27a/Q44f Combo Table based on Total

	Total	White	Black	Hispanic
Have a written document that describes wishes for medical care	34	40	24	21
Do not have a written document that describes wishes for medical care/Don't know/Refused	66	60	76	79
You want your doctors to make the decisions for you when needed is a reason (NET)	22	21	21	32
Is a major reason	7	5	8	13
Is a minor reason	15	15	13	19
You want your doctors to make the decisions for you when needed is not a reason	43	40	54	46
Don't know/Refused	1	*	1	1

Q45. Do you have a will that describes how you would like your money and belongings to be handled after your death, or not?

	Total	White	Black	Hispanic
Yes	40	47	33	23
No	60	52	67	77
Don't know/Refused	*	*	-	*

Q46a. In general, would you say your health is...? (READ LIST)

Based on total with living or deceased family member with serious illness

	Total	White	Black	Hispanic
Excellent/Very good/Good (NET)	82	86	70	70
Excellent	21	22	7	14
Very good	30	32	25	25
Good	32	32	37	32
Only fair/Poor (NET)	18	14	30	30
Only fair	15	13	25	25
Poor	2	2	5	5
Don't know/Refused	*	-	-	*
N	815	357	209	225

READ TO ALL: Moving on to a different topic...

READ IF GROUP=2: The next series of questions ask about your (INSERT TEXT FROM FAMILY VAR) who has a serious chronic health condition and trouble doing everyday tasks independently.

READ IF GROUP=3: The next series of questions ask about your deceased (INSERT TEXT FROM FAMILY VAR) who had a serious chronic health condition and trouble doing everyday tasks independently.

NOTE: Those with serious illness were asked about themselves, personally, while those with a family member with a serious illness, living or deceased, were asked to answer most questions thinking about their family member. Those with serious illness and those with a living family member with serious illness were asked the questions in the present tense, whereas those with a deceased family member were asked the questions in the past tense. The different language used is shown in brackets.

Q46. In general, would you say {your/their} health is...? (READ LIST)

Based on total who are personally seriously ill, who have a living family member with serious illness, or those without recent experience with serious illness

	Total	White	Black	Hispanic
Excellent/Very good/Good (NET)	77	79	80	67
Excellent	22	22	21	22
Very good	30	32	24	26
Good	25	24	35	19
Only fair/Poor (NET)	23	21	20	33
Only fair	15	14	12	25
Poor	7	7	9	8
Don't know/Refused	*	*	*	*
N	1,719	993	310	314

READ : Next I'm going to read you some problems that older people sometimes face.

Q47. First/Next, is (INSERT ITEM) a problem for you, or not? (IF PROBLEM: is this a major or minor problem for you?) (scramble items a-e)

Based on total who are personally seriously ill (sample sizes for White, Black, and Hispanic subgroups insufficient to report)

	NET	-----YES A PROBLEM-----			Don't know/Refused	N
		Yes, a major problem	Yes, a minor problem	No, not a problem		
a. Being forgetful						
Total	52	12	40	48	-	183
b. Feeling like you are a burden on others						
Total	44	17	26	56	*	183
c. Not feeling needed by other people						
Total	30	8	22	69	*	183
d. Often feeling sad or depressed						
Total	44	12	32	56	-	183
e. Loneliness						
Total	46	14	32	54	-	183

Q48. First/Next, {is/was} (INSERT ITEM) a problem for your (INSERT FAMILY MEMBER) {now/before they died}, or not? [IF PROBLEM: {Is/was} this a major or minor problem for them?] (scramble items a-e)

Based on total with living or deceased family member with serious illness

		-----YES A PROBLEM-----				
		NET	Yes, a major problem	Yes, a minor problem	No, not a problem	Don't know/Refused
						N
a.	Being forgetful					
	Total	73	50	23	27	*
	White	74	53	21	26	*
	Black	69	40	29	30	1
	Hispanic	67	41	26	33	-
b.	Feeling like they are a burden on others					
	Total	51	25	26	46	3
	White	53	26	27	44	3
	Black	43	19	24	55	2
	Hispanic	47	26	21	52	1
c.	Not feeling needed by other people					
	Total	38	21	17	59	3
	White	39	21	18	58	3
	Black	31	16	15	68	1
	Hispanic	43	30	12	53	5
d.	Often feeling sad or depressed					
	Total	57	32	25	40	3
	White	59	33	27	37	3
	Black	40	23	17	59	1
	Hispanic	57	33	25	43	*
e.	Loneliness					
	Total	48	24	23	51	2
	White	50	24	26	48	2
	Black	35	18	17	64	*
	Hispanic	44	29	15	55	1

READ IF GROUP=1,2,3: Now moving on to my next set of questions...

Q49. {In the past year/In the year before they died}, {have you had/have they had/did they have} a problem (INSERT ITEM), or not? What about (INSERT)? (IF NECESSARY: {In the past year/In the year before they died}, {have you had/have they had/did they have} a problem (INSERT ITEM), or not?) (scramble items a-j)

Based on total who are personally seriously ill, or who have a living or deceased family member with serious illness

	Yes	No	Don't know/Refused	N
a. Paying for medical tests or treatments				
Total	17	80	3	998
White	15	81	4	407
Black	21	78	1	278
Hispanic	23	76	1	282
b. Paying for medications				
Total	20	79	1	998
White	18	81	1	407
Black	19	80	1	278
Hispanic	28	72	1	282
c. Paying for support services, such as someone to help {you/them} prepare meals and do household chores				
Total	20	79	1	998
White	19	81	*	407
Black	18	80	2	278
Hispanic	24	75	1	282
d. Finding someone to provide support services, such as someone to help {you/them} prepare meals and do household chores				
Total	20	78	2	998
White	20	78	2	407
Black	21	78	1	278
Hispanic	22	78	*	282
e. Paying for housing				
Total	12	87	1	998
White	11	88	2	407
Black	12	88	*	278
Hispanic	16	83	1	282
f. Getting transportation to appointments or running errands				
Total	24	75	1	998
White	23	76	1	407
Black	22	78	-	278
Hispanic	28	72	-	282
g. Preparing meals				
Total	39	60	1	998
White	40	58	2	407
Black	42	58	-	278
Hispanic	37	63	*	282
h. Understanding instructions for {your/their} medications and medical care				
Total	48	50	2	998
White	49	49	2	407
Black	45	53	1	278
Hispanic	36	64	1	282
i. Being able to get to medical appointments because of {your/their} health				
Total	30	70	*	998
White	28	72	-	407
Black	26	73	1	278
Hispanic	27	73	*	282

- Q50. {In the past year/in the year before they died}, {have you gone/have they gone/did they go} to the emergency room, or not? [IF YES: How many times {In the past year/in the year before they died} {have you gone/have they gone/did they go} to the emergency room? Once, two or three times, four or five times, or more than five times {in the past year/in the year before they died}??]

Based on total who are personally seriously ill, or who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
No, never went to ER in past year/year before they died	35	35	34	40
Yes (NET)	64	63	63	59
Yes, once	16	14	19	20
Yes, 2-3 times	30	32	27	27
Yes, 4-5 times	8	7	8	5
Yes, more than 5 times	10	9	9	8
Don't know/Refused	2	2	3	1
N	998	407	278	282

- Q51. {In the past year/in the year before they died}, {have you stayed/have they stayed/did they stay} overnight in a hospital, or not? [IF YES: How many times {In the past year/in the year before they died} {have you stayed/have they stayed/did they stay} in the hospital overnight? Once, two or three times, four or five times, or more than five times {in the past year/in the year before they died}??]

Based on total who are personally ill, or who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
No, never stayed overnight in hospital in past year/year before they died	41	41	39	46
Yes (NET)	58	58	60	53
Yes, once	18	18	20	24
Yes, 2-3 times	24	24	27	19
Yes, 4-5 times	7	9	7	4
Yes, more than 5 times	8	7	7	7
Don't know/Refused	1	1	1	*
N	998	407	278	282

THERE IS NO QUESTION 52

		-----ALWAYS/OFTEN-----			-----SOMETIMES/RARELY/NEVER-----			Don't/Didn't need this		Don't	N
		NET	Always	Often	NET	Sometimes	Rarely	Never (vol.)	(vol.)	know/Refused	
g.	To understand {your/their} health condition and treatment										
	Total	73	50	23	24	14	8	1	2	2	998
	White	72	48	24	23	15	7	1	2	3	407
	Black	73	54	19	26	12	12	2	*	*	278
	Hispanic	74	54	20	24	14	8	1	1	1	282
h.	To express {your/their} wishes for {your/their} medical care										
	Total	71	50	21	23	13	7	2	2	5	998
	White	71	49	22	22	14	6	2	2	6	407
	Black	68	54	14	28	15	12	1	2	1	278
	Hispanic	71	54	17	25	13	10	3	*	3	282

Q54. As a family member {of someone with a serious illness/of someone who died after a serious illness}, how often, {do/did} YOU get the help you {need/needed} (INSERT ITEM)? What about (INSERT ITEM)? [As needed: How often, {do/did} YOU get the help you need/needed (INSERT)? [IF NECESSARY: Always, often, sometimes, or rarely?]] (READ LIST) (scramble items a-d)

Based on total who have a living or deceased family member with serious illness

		-----ALWAYS/OFTEN-----			-----SOMETIMES/RARELY/NEVER-----			Don't/Didn't need this		Don't	N
		NET	Always	Often	NET	Sometimes	Rarely	Never (vol.)	(vol.)	know/Refused	
a.	To manage feelings of anxiety or sadness										
	Total	46	31	15	45	19	19	7	8	1	815
	White	44	29	15	47	20	19	7	9	1	357
	Black	54	42	13	41	16	19	6	5	-	209
	Hispanic	54	39	15	42	15	20	8	4	-	225
b.	In spiritual support or counseling										
	Total	53	35	17	40	14	20	6	7	1	815
	White	52	34	18	39	15	19	6	8	1	357
	Black	65	51	14	33	10	17	6	2	-	209
	Hispanic	52	39	13	44	15	21	8	3	*	225
c.	To understand your loved one's health condition and treatment										
	Total	71	50	21	28	15	11	2	1	*	815
	White	71	48	23	27	15	11	1	1	*	357
	Black	78	61	17	21	8	12	2	1	-	209
	Hispanic	65	50	15	35	19	12	3	*	-	225
d.	Coordinating their care across different doctors or clinics										
	Total	54	38	15	35	16	15	4	11	*	815
	White	52	35	16	35	17	14	3	14	*	357
	Black	61	51	10	34	17	15	3	5	*	209
	Hispanic	61	41	20	36	15	15	5	3	1	225

- Q55. How often, if at all, {do you/do they/did they} have someone present to help {you/them} with everyday activities, such as bathing, dressing, shopping or remembering medications? (READ LIST)

Based on total who are personally seriously ill, or who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Always/Several hours per day (NET)	74	74	69	78
Always	61	61	60	68
Several hours per day	13	13	9	10
Once a day/A few times a week (NET)	12	12	14	10
Once a day	3	3	5	3
A few times a week	9	10	9	8
Less often than that	9	8	13	7
Never/Don't have any help (vol.)	4	5	3	3
Don't know/Refused	1	1	1	1
<i>N</i>	<i>998</i>	<i>407</i>	<i>278</i>	<i>282</i>

- Q56. Do you think {you/they} ({are/were} getting help often enough) or do you think {you/they} ({need/needed} help more often)? (rotate items in parentheses)

Based on total who are personally seriously ill, or who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Getting help often enough	53	53	50	55
Need help more often	44	44	48	42
Don't know/Refused	3	2	1	2
<i>N</i>	<i>998</i>	<i>407</i>	<i>278</i>	<i>282</i>

- Q57. {Do/did} you personally help your family member with everyday activities, such as bathing, dressing, shopping or remembering medications, or not?

Based on total who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Yes	57	56	63	60
No	42	44	37	40
Don't know/Refused	*	*	-	*
<i>N</i>	<i>815</i>	<i>357</i>	<i>209</i>	<i>225</i>

- Q58. {Do/Did} you help your family member with any medical-nursing tasks? This might include giving medicines like pills or injections, tube feedings, wound care, monitoring blood pressure or blood sugar, helping with incontinence, or operating equipment like hospital beds or oxygen tanks. [INTERVIEWER NOTE: IF RESPONDENT INTERRUPTS WITH YES, CODE AS YES, OTHERWISE, READ FULL QUESTION] [PROMPT YES OR NO IF NEEDED]

Based on total who have a living or deceased family member with serious illness who say they personally help/helped with everyday activities

	Total	White	Black	Hispanic
Yes	74	71	80	73
No	26	29	20	27
Don't know/Refused	-	-	-	-
<i>N</i>	<i>491</i>	<i>207</i>	<i>132</i>	<i>136</i>

Q57/Q58 Combo Table Based on total who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Personally help/helped with everyday activities	57	56	63	60
Yes, help/helped with medical-nursing tasks	42	40	50	44
No, do/did not help with medical-nursing tasks	15	16	13	16
Don't know/Refused	-	-	-	-
Does/did not personally help with everyday activities	42	44	37	40
Don't know/Refused	*	*	-	*
<i>N</i>	815	357	209	225

- Q59. {Do you/do they/did they} receive help with everyday activities, such as bathing, dressing, shopping or remembering medications from (INSERT ITEM), or not? How about from (INSERT ITEM)? [IF NECESSARY: {Do you/do they/did they} receive help with everyday activities from (INSERT ITEM), or not?] (scramble items a-c)

Based on total who are personally seriously ill, or who have a living or deceased family member with serious illness

	Yes	No	Don't know/Refused	<i>N</i>
a. Family members (IF GROUP=2,3 AND Q57=1 INSERT: other than yourself)				
Total	71	28	1	998
White	70	29	1	407
Black	76	23	1	278
Hispanic	65	35	-	282
b. Friends				
Total	25	74	1	998
White	25	74	2	407
Black	34	64	1	278
Hispanic	24	76	-	282
c. Paid nurses or health care aides				
Total	55	44	1	998
White	57	42	1	407
Black	45	52	3	278
Hispanic	47	53	-	282

- Q60. How easy or difficult {is/was} it for {you/them} to get the help {you need/they need/they needed} with everyday activities? (READ LIST)

Based on total who are personally seriously ill, or who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Easy (NET)	71	72	77	61
Very easy	42	42	45	40
Somewhat easy	29	29	32	22
Difficult (NET)	27	26	21	36
Somewhat difficult	19	18	14	20
Very difficult	8	7	6	16
Don't know/Refused	2	2	3	2
<i>N</i>	998	407	278	282

Q61. {In the past year/In the year before they died}, was there a time {you/they} did NOT get the help {you/they} needed with everyday activities because of the cost, or not?

Based on total who are personally seriously ill, or who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Yes	18	14	19	24
No	80	83	77	74
Don't know/Refused	2	2	5	2
N	998	407	278	282

THERE IS NO QUESTION 62

Q63. How well trained do you think family members (other than yourself) {are/were} to provide care to {you/your loved one}? (READ LIST)

Based on total who are personally seriously ill, or who have a living or deceased family member with serious illness who say they receive/received help with everyday activities from other family members

	Total	White	Black	Hispanic
Well trained (NET)	74	72	83	75
Very well trained	37	34	46	41
Somewhat well trained	37	38	36	34
Not well trained (NET)	25	27	17	22
Not too well trained	16	18	8	15
Not at all well trained	9	9	8	7
Don't know/Refused	1	1	1	2
N	681	271	195	190

Q59a/Q63 Combo Table based on total who are personally seriously ill, or who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Receive/received help with everyday activities from other family members	71	70	76	65
Well trained (NET)	53	50	63	49
Very well trained	26	24	35	27
Somewhat well trained	26	26	28	22
Not well trained (NET)	18	19	13	15
Not too well trained	12	13	6	10
Not at all well trained	6	6	6	5
Don't know/Refused	1	1	1	2
Do/did not receive help with everyday activities from other family members	28	29	23	35
Don't know/Refused	1	1	1	-
N	998	407	278	282

THERE IS NO QUESTION 64

Q65. How well trained do you think {your/their} friends {are/were} to provide care to {you/your loved one}? (READ LIST)

Based on total who are personally seriously ill, or who have a living or deceased family member with serious illness who say they receive/received help (sample sizes for Black and Hispanic subgroups insufficient to report)

	Total	White
Well trained (NET)	66	63
Very well trained	21	20
Somewhat well trained	45	43
Not well trained (NET)	27	30
Not too well trained	10	11
Not at all well trained	17	19
Don't know/Refused	7	8
N	253	102

Q59b/Q65 Combo Table based on total who are personally seriously ill, or who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Receive/received help with everyday activities from friends	25	25	34	24
Well trained (NET)	17	15	26	18
Very well trained	5	5	9	5
Somewhat well trained	11	10	18	12
Not well trained (NET)	7	7	6	6
Not too well trained	3	3	2	3
Not at all well trained	4	5	4	3
Don't know/Refused	2	2	2	1
Do/did not receive help with everyday activities from friends	74	74	64	76
Don't know/Refused	1	2	1	-
N	998	407	278	282

Q66. How would you rate the quality of care provided by paid nurses or health care aides? (READ LIST)

Based on total who are personally seriously ill, or who have a living or deceased family member with serious illness who say they receive/received help with everyday activities from paid nurses or health care aides

	Total	White	Black	Hispanic
Excellent/Very good/Good (NET)	88	89	84	88
Excellent	30	30	27	43
Very good	33	32	32	32
Good	25	28	26	13
Fair/Poor (NET)	12	10	16	10
Fair	10	9	7	7
Poor	2	2	8	2
Don't know/ Refused	*	*	-	3
N	507	233	125	133

Q59c/Q66 Combo Table based on total who are personally seriously ill, or who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Receive/received help with everyday activities from paid nurses/health care aids	55	57	45	47
Excellent/Very good/Good (NET)	48	51	38	41
Quality of care is excellent	17	17	12	20
Quality of care is very good	18	18	14	15
Quality of care is good	14	16	11	6
Fair/Poor (NET)	7	6	7	5
Quality of care is fair	5	5	3	3
Quality of care is poor	1	1	4	1
Don't know/Refused	*	*	-	1
Do/did not receive help with everyday activities from paid nurses/health care aids	44	42	52	53
Don't know/Refused	1	1	3	-
N	998	407	278	282

Q67. How well trained do you think paid nurses or health care aides {are/were} to provide care to {you/your loved one}? (READ LIST)

Based on total who are personally seriously ill, or who have a living or deceased family member with serious illness who say they receive/received help with everyday activities from paid nurses or health care aids

	Total	White	Black	Hispanic
Well trained (NET)	89	88	92	92
Very well trained	53	51	65	69
Somewhat well trained	36	37	28	24
Not well trained (NET)	10	11	8	5
Not too well trained	8	9	6	4
Not at all well trained	2	1	1	1
Don't know/Refused	1	1	-	2
N	507	233	125	133

Q59c/Q67 Combo Table based on total who are personally seriously ill, or who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Receive/received help with everyday activities from paid nurses/health care aids	55	57	45	47
Well trained (NET)	49	51	41	44
Very well trained	29	29	29	32
Somewhat well trained	20	21	12	11
Not well trained (NET)	5	6	3	2
Not too well trained	4	5	3	2
Not at all well trained	1	1	1	1
Don't know/Refused	*	*	-	1
Do/did not receive help with everyday activities from paid nurses/health care aids	44	42	52	53
Don't know/Refused	1	1	3	-
N	998	407	278	282

READ IF Q57=1: The next few questions are about the care that you personally {provide/provided}...

Q68. Did you receive any training from a nurse or other health professional on (INSERT ITEM), or not? (scramble items a-c; always show item d last)

Based on total who have a living or deceased family member with serious illness who say they personally help/helped with everyday activities

	Yes	No	Not applicable (vol.)	Don't know/Refused	N
a. How to administer medications					
Total	46	53	1	*	491
White	46	53	1	*	207
Black	43	57	*	-	132
Hispanic	56	43	1	-	136
b. How to recognize signs of pain or distress					
Total	47	52	1	1	491
White	45	53	1	1	207
Black	46	54	*	-	132
Hispanic	49	50	2	-	136
c. How to help your loved one move safely					
Total	52	47	1	*	491
White	49	49	1	*	207
Black	50	49	1	-	132
Hispanic	52	48	-	-	136
d. Any other skills you (need/needed) to provide care for your loved one					
Total	39	59	1	*	491
White	37	61	2	*	207
Black	38	62	*	-	132
Hispanic	43	57	*	-	136

Q57/Q68a. Combo Table based on total who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Personally help/helped with everyday activities	57	56	63	60
Received training on how to administer medications	27	26	27	33
Did not receive training on how to administer medications	30	30	36	26
Not applicable (vol.)	*	*	*	1
Don't know/Refused	*	*	-	-
Does/did not personally help with everyday activities	42	44	37	40
Don't know/Refused	*	*	-	*
N	815	357	209	225

Q57/Q68b. Combo Table based on total who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Personally help/helped with everyday activities	57	56	63	60
Received training on how to recognize signs of pain or distress	27	25	29	29
Did not receive training on how to recognize signs of pain or distress	30	30	34	30
Not applicable (vol.)	1	1	*	1
Don't know/Refused	*	*	-	-
Does/did not personally help with everyday activities	42	44	37	40
Don't know/Refused	*	*	-	*
N	815	357	209	225

Q57/Q68c. Combo Table based on total who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Personally help/helped with everyday activities	57	56	63	60
Received training on how to help loved one move safely	30	28	32	31
Did not receive training on how to help loved one move safely	27	27	31	29
Not applicable (vol.)	1	1	*	-
Don't know/Refused	*	*	-	-
Does/did not personally help with everyday activities	42	44	37	40
Don't know/Refused	*	*	-	*
<i>N</i>	815	357	209	225

Q57/Q68d. Combo Table based on total who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Personally help/helped with everyday activities	57	56	63	60
Received training on any other skills needed to provide care for loved one	23	21	24	26
Did not receive training on any other skills needed to provide care for loved one	34	34	39	34
Not applicable (vol.)	1	1	*	*
Don't know/Refused	*	*	-	-
Does/did not help with everyday activities	42	44	37	40
Don't know/Refused	*	*	-	*
<i>N</i>	815	357	209	225

Q69. How well trained do you think you personally {are/were} to provide care to your loved one? (READ LIST)

Based on total who have a living or deceased family member with serious illness who say they personally help/helped with everyday activities

	Total	White	Black	Hispanic
Well trained (NET)	82	81	82	84
Very well trained	34	32	50	43
Somewhat well trained	48	50	32	42
Not well trained (NET)	18	18	17	16
Not too well trained	14	14	13	12
Not at all well trained	4	5	4	3
Don't know/Refused	*	*	1	-
<i>N</i>	491	207	132	136

Q57/Q69 Combo Table based on total who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Personally help/helped with everyday activities	57	56	63	60
Well trained (NET)	47	46	52	50
Very well trained	20	18	32	26
Somewhat well trained	27	28	20	25
Not well trained (NET)	10	10	11	9
Not too well trained	8	8	8	7
Not at all well trained	3	3	3	2
Don't know/Refused	*	*	1	-
Does/did not personally help with everyday activities	42	44	37	40
Don't know/Refused	*	*	-	*
<i>N</i>	815	357	209	225

Q70. {Is/Was} there someone that {can/could} give you a break from caring for your loved one when you {need/needed} it, or not?

Based on total who have a living or deceased family member with serious illness who say they personally help/helped with everyday activities

	Total	White	Black	Hispanic
Yes	79	80	76	75
No	21	20	21	25
Don't know/Refused	*	*	2	-
N	491	207	132	136

Q57/Q70 Combo Table based on total who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Personally help/helped with everyday activities	57	56	63	60
Yes there is/was someone who can give you a break	45	45	48	45
No, there isn't/wasn't someone who can give you a break	12	11	13	15
Don't know/Refused	*	*	1	-
Does/did not personally help with everyday activities	42	44	37	40
Don't know/Refused	*	*	-	*
N	815	357	209	225

Q71. {Do/did} you personally help your family member (INSERT AND RANDOMIZE), or not? (scramble items a-c)

Based on total who have a living or deceased family member with serious illness

	Yes	No	Don't know/Refused	N
a. Manage their finances				
Total	43	57	*	815
White	41	59	-	357
Black	46	54	-	209
Hispanic	41	58	*	225
b. Coordinate care across different doctors or clinics				
Total	55	44	1	815
White	54	46	1	357
Black	55	45	*	209
Hispanic	59	41	*	225
c. With transportation, either by driving them, or by helping them get transportation				
Total	67	33	*	815
White	65	35	-	357
Black	69	31	-	209
Hispanic	69	31	*	225

Q72. Thinking now of all the kinds of help you {provide/provided} for your family member, about how much time in an average week {do/did} you spend helping them? {Are/Were} you helping them ...? (READ LIST)

Based on total who have a living or deceased family member with serious illness who say they personally help/helped with daily activities, managing finances, assistance coordinating care across different doctors/clinics, or help with transportation

	Total	White	Black	Hispanic
All the time	27	23	37	34
Several hours a day	24	22	26	24
About an hour a day	12	14	5	5
A few hours a week	24	26	20	27
Less than that	13	14	11	9
Don't know/Refused	1	1	2	*
<i>N</i>	<i>676</i>	<i>295</i>	<i>175</i>	<i>183</i>

Q57/Q71/Q72 Combo Table based on total who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Personally help/helped with daily activities, managing finances, or assistance coordinating care across different doctors/clinics, or help with transportation	81	79	83	81
All the time	21	18	31	28
Several hours a day	19	18	22	19
About an hour a day	10	11	4	4
A few hours a week	19	20	17	22
Less than that	10	11	9	8
Don't know/Refused	1	1	1	*
Does/did not personally help with daily activities, managing finances, or assistance coordinating care across different doctors/clinics, or help with transportation	19	21	17	19
Don't know/Refused	*	*	-	*
<i>N</i>	<i>815</i>	<i>357</i>	<i>209</i>	<i>225</i>

THERE IS NO QUESTION 73

Q74. How confident are you that your loved one will have enough income and assets to last for the rest of their life – would you say you're...? (READ LIST)

Based on total who have a living family member with serious illness

	Total	White	Black	Hispanic
Confident (NET)	71	71	70	73
Very confident	43	42	40	43
Somewhat confident	28	28	30	30
Not confident (NET)	28	29	27	25
Not too confident	12	13	11	14
Not at all confident	16	16	16	11
Don't know/Refused	2	1	2	2
<i>N</i>	<i>494</i>	<i>210</i>	<i>132</i>	<i>138</i>

READ IF GROUP=2,3: Now I'm going to ask about some things you may or may not have talked with your loved one about...

Q75. {Have/Had/Did} you ever {had/have} a serious conversation with your loved one about (INSERT ITEM) or {have/had/did} you not {had/have} such a conversation? How about (INSERT ITEM)? (READ FIRST TIME THEN AS NECESSARY: {Have/had} you ever had a serious conversation with your loved one about this or {have/had} you not had such a conversation? (scramble items a-f)

Based on total who have a living or deceased family member with serious illness

	Yes	No	Don't know/Refused	N
a. THEIR wishes for their medical care, such as the types of treatments they {do or don't/did or didn't} want to receive				
Total	60	40	*	815
White	62	38	-	357
Black	52	48	1	209
Hispanic	49	50	*	225
b. Where THEY {will/would} live if they {are/were} no longer able to live independently				
Total	54	46	*	815
White	54	46	*	357
Black	51	49	-	209
Hispanic	52	47	1	225
c. Who {will/would} help take care of them if they are no longer able to care for themselves				
Total	60	40	*	815
White	60	39	*	357
Black	55	45	-	209
Hispanic	55	45	*	225
d. Who {will/would} make decisions about their medical care if they can no longer make them on their own				
Total	60	39	*	815
White	60	40	*	357
Black	59	40	1	209
Hispanic	55	45	*	225
e. How they {will/would} pay for help with daily tasks or care that {is/was} not covered by health insurance				
Total	41	59	1	815
White	42	58	*	357
Black	32	66	2	209
Hispanic	41	55	4	225
f. What they {need/needed} to have a good quality of life				
Total	54	46	1	815
White	54	45	1	357
Black	45	55	1	209
Hispanic	54	46	*	225

Q75. Summary Table based on total who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Yes to any type of serious conversation with your loved one	77	78	75	71
No/Don't know/Refused to any type of serious conversation with your loved one	23	22	25	29

Q76. Generally, who raised these issues? Was it you or your loved one?

Based on total who have a living or deceased family member with serious illness who say they have had a serious conversation with a loved one

	Total	White	Black	Hispanic
Me	45	45	41	33
Loved one	25	24	31	35
Someone else (vol.)	6	6	6	8
Both of us (vol.)	22	23	19	22
Don't know/ Refused	2	2	3	3
<i>N</i>	<i>641</i>	<i>288</i>	<i>161</i>	<i>172</i>

Q75/Q76 Combo Table based on total who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Had a serious conversation with loved one	77	78	75	71
Respondent raised the issue	34	35	30	23
Loved one raised the issue	19	19	23	25
Someone else raised the issue (vol.)	5	4	5	5
Both raised the issue (vol.)	17	18	15	16
Don't know/Refused	1	1	2	2
Did not have conversation with loved one/Don't know/Refused	23	22	25	29
<i>N</i>	<i>815</i>	<i>357</i>	<i>209</i>	<i>225</i>

Q77. {Does/Did} your loved one have a written document that (INSERT ITEM), or not? (IF NEEDED, "sometimes called a living will, advance treatment directive, a do-not-resuscitate order or DNR, or Physician Orders for Life Sustaining Treatment") (IF NEEDED, "sometimes called a health care proxy or surrogate, or durable power of attorney") (scramble items a-b)

Based on total who have a living or deceased family member with serious illness

	Yes	No	Don't know/Refused	<i>N</i>
a. {Describes/described} their wishes for their medical care, such as the types of treatments they {do or don't/did or didn't} want to receive				
Total	60	35	5	<i>815</i>
White	65	30	5	<i>357</i>
Black	38	54	8	<i>209</i>
Hispanic	41	53	6	<i>225</i>
b. {Names/named} who they want to make decisions about their medical care if they {can/could} no longer make them on their own				
Total	70	26	4	<i>815</i>
White	76	21	4	<i>357</i>
Black	48	44	8	<i>209</i>
Hispanic	49	46	6	<i>225</i>

Q78. Are you the person they designated to make decisions about their medical care, or {is it/was that} someone else?

Based on total who have a living or deceased family member with serious illness who say they have/had a document that names/named who they want to make decisions about their medical care

	Total	White	Black	Hispanic
You are the person designated	47	46	50	52
Someone else	53	53	50	48
Don't know/Refused	*	1	-	-
N	527	280	110	120

Q77b/Q78 Combo Table based on total who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Has/had written document that names/named who they want to make decisions about their medical care if they can/could no longer make them on their own	70	76	48	49
Respondent is designated person	33	35	24	25
Someone else is designated person	37	40	24	23
Don't know/Refused	*	*	-	-
Does not/did not have document that names/named who they want to make decisions about their medical care if they can/could no longer make them on their own	26	21	44	46
Don't know/Refused	4	4	8	6
N	815	357	209	225

Q79. {Do/did} you know where to find the document that {describes/described} their wishes for their medical care if you were to need it, or not?

Based on total who have a living or deceased family member with serious illness who say they have/had a written document that describes/described their wishes for their medical care (sample sizes for Black and Hispanic subgroups insufficient to report)

	Total	White
Yes	80	79
No	19	21
Don't know/Refused	1	1
N	443	242

Q77a/Q79 Combo Table based on total who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Has/had written document that describes/described their wishes for their medical care	60	65	38	41
Respondent knows where to find document	48	51	33	33
Respondent does not know where to find document	11	13	6	7
Don't know/Refused	*	1	-	1
Does/did not have a written document that describes/described their wishes for their medical care	35	30	54	53
Don't know/Refused	5	5	8	6
N	815	357	209	225

THERE IS NO QUESTION 80

Q81. {Have you referred to/did you refer to} this document in making decisions about their medical care, or not?

Based on total who have a living or deceased family member with serious illness who say they have/had a written document that describes/described their wishes for their medical care (sample sizes for Black and Hispanic subgroups insufficient to report)

	Total	White
Yes	37	35
No	59	61
Not applicable/Don't make decisions about their care (vol.)	4	4
Don't know/Refused	-	-
<i>N</i>	<i>443</i>	<i>242</i>

Q77a/Q81 Combo Table based on total who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Has/had written document that describes/described their wishes for their medical care	60	65	38	41
Respondent has/had referred to document in making decisions about loved one's medical care	22	23	20	20
Respondent has/had not referred to document in making decisions about loved one's medical care	36	40	16	20
Not applicable/Don't make decisions about their care (vol.)	2	3	2	*
Don't know/Refused	-	-	-	-
Does/did not have a written document that describes/described their wishes for their medical care	35	30	54	53
Don't know/Refused	5	5	8	6
<i>N</i>	<i>815</i>	<i>357</i>	<i>209</i>	<i>225</i>

Q82. How helpful, if at all, {is/was} this document in helping you make decisions about their medical care? (READ LIST)

Based on total who have a living or deceased family member with serious illness who say they have/had a written document that describes/described their wishes for their medical care and they have referred to the document (sample sizes for White, Black, and Hispanic subgroups insufficient to report)

	Total
Helpful (NET)	94
Very helpful	73
Somewhat helpful	22
Not helpful (NET)	6
Not too helpful	3
Not at all helpful	3
Don't know/Refused	-
<i>N</i>	<i>197</i>

Q77a/Q81/Q82 Combo Table based on total who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Has/had written document that describes/described their wishes for their medical care	60	65	38	41
Respondent has/had referred to document in making decisions about loved one's medical care	22	23	20	20
Helpful (NET)	21	21	19	18
Very helpful	16	16	16	16
Somewhat helpful	5	5	3	2
Not helpful (NET)	1	1	1	1
Not too helpful	1	1	1	1
Not at all helpful	1	1	*	*
Don't know/Refused	-	-	-	-
Respondent has/had not referred to document in making decisions about loved one's medical care	36	40	16	20
Not applicable/don't make decisions about their care (vol.)	2	3	2	*
Don't know/Refused	-	-	-	-
Does/did not have a written document that describes/described their wishes for their medical care	35	30	54	53
Don't know/Refused	5	5	8	6
N	815	357	209	225

Q83. To the best of your knowledge, {have/had} they made changes to the document since they first created it, or not?

Based on total who have a living or deceased family member with serious illness who say they have/had a written document that describes/described their wishes for their medical care (sample sizes for Black and Hispanic subgroups insufficient to report)

	Total	White
Yes	20	22
No	72	70
Don't know/Refused	7	8
N	443	242

Q77a/Q83 Combo Table based on total who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Has/had a written document that describes/described their wishes for their medical care	60	65	38	41
They have made changes since it was first created	12	14	6	9
They have not made changes since it was first created	43	46	30	29
Don't know/Refused	4	5	2	3
Does/did not have a written document that describes/described their wishes for their medical care	35	30	54	53
Don't know/Refused	5	5	8	6
N	815	357	209	225

- Q84. How well do you feel you know your loved one's wishes for medical care, such as the types of treatments they do or don't want to receive? Do you feel like (you know exactly what they want), you have a pretty good idea, or (you don't really know what their wishes are)? (rotate items in parentheses)

Based on total who have a living family member with serious illness

	Total	White	Black	Hispanic
Exactly	42	45	34	39
Pretty good idea	44	44	47	34
Don't really know	13	11	19	26
Don't know/Refused	*	*	-	1
<i>N</i>	494	210	132	138

- Q85. How well did you feel you knew their wishes for medical care, such as the types of treatments they did or did not want to receive? Did you feel like (you knew exactly what they wanted), you had a pretty good idea, or (you didn't really know what their wishes were)? (rotate items in parentheses)

Based on total who have a deceased family member with serious illness (sample sizes for Black and Hispanic subgroups insufficient to report)

	Total	White
Exactly	39	39
Pretty good idea	46	47
Don't really know	14	13
Don't know/Refused	1	*
<i>N</i>	321	147

- Q86. {Is/Was} there another family member that {knows/knew} their wishes better than you {do/did}, or not?

Based on total who have a living or deceased family member with serious illness who say they didn't really know family member's wishes (sample sizes for White, Black, and Hispanic subgroups insufficient to report)

	Total
Yes	83
No	16
Don't know/Refused	2
<i>N</i>	116

Q84/Q85/Q86 Combo Table based on total who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Respondent knows/knew exactly family member's wishes	41	42	34	39
Respondent has/had a pretty good idea of family member's wishes	45	45	47	34
Respondent doesn't/didn't really know family member's wishes	14	12	18	25
Another family member knows/knew them better	11	11	14	14
Another family member does/did not know them better	2	1	4	11
Don't know/Refused	*	*	1	*
Don't know/Refused	1	*	1	1
<i>N</i>	815	357	209	225

- Q87. Thinking about the type of medical care {you want/you think your family member wants/ you think your family member wanted} to receive, how closely {are your/do you think their} wishes about medical care {being/are being/were} followed? (READ LIST)

Based on total who are personally seriously ill, or who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Closely (NET)	93	94	90	86
Very closely	63	64	63	59
Somewhat closely	30	30	27	27
Not closely (NET)	5	4	8	12
Not too closely	3	2	7	9
Not at all closely	2	2	1	3
Don't know/Refused	2	2	2	2
N	998	407	278	282

- Q88. How often would you say there {are/were} disagreements among family members about what sort of medical care your loved one should or should not receive? (READ LIST)

Based on total who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Often/Sometimes (NET)	31	29	27	43
Often	9	8	9	21
Sometimes	22	21	19	22
Rarely/Never (NET)	68	71	70	54
Rarely	26	28	26	14
Never	42	42	44	39
Don't know/Refused	1	*	3	3
N	815	357	209	225

- Q89. Now I'd like to ask you a question about hospice care. Hospice care focuses on giving medical care, pain management, and comfort to those in their final stages of life and can be provided either at the patient's home or in a facility. {Have you had/Has your loved one had/Did your loved one have} experience with hospice care in {the past year/the year before they died}?

Based on total who are personally seriously ill, or who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Yes	31	32	30	24
No	67	67	68	74
Don't know/Refused	2	1	3	1
N	998	407	278	282

- Q90. {Is/Was} this hospice care at home, in a hospice facility, in a hospital, in a nursing home, or somewhere else? (IF MORE THAN ONE RESPONSE: Where did the most recent experience with hospice care take place?)

Based on total who are personally seriously ill, or who have a living or deceased family member with serious illness who say they have/had experienced hospice care (sample sizes for Black and Hispanic subgroups insufficient to report)

	Total	White
At home	52	52
In a hospice facility	11	12
In a hospital	9	8
In a nursing home	25	26
Somewhere else	3	2
Don't know/Refused	*	-
N	277	121

Q89/Q90 Combo Table based on total who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Have/had experienced hospice care	31	32	30	24
At home	16	17	17	14
In a hospice facility	4	4	5	3
In a hospital	3	3	3	3
In a nursing home	8	8	4	4
Somewhere else	1	1	1	1
Don't know/Refused	*	-	*	*
Have/had not experienced hospice care	67	67	68	74
Don't know/Refused	2	1	3	1
N	998	407	278	282

- Q91. Where do {you/they} currently live ...? [INTERVIEWER NOTE if respondent says Retirement community, code as own home or apartment]
 (IF NEEDED: Nursing home: a facility that provides residents with a room, meals, personal care, nursing care, and medical services.
 Assisted living community: provides services to people who are not able to live independently, but does not require the level of care provided by a nursing home or other medical facility) (READ LIST) (ONLY DISPLAY CODE 2 IF GROUP=2)

Based on total who are personally seriously ill, or who have a living family member with serious illness

	Total	White	Black	Hispanic
In {your/their} own home or apartment	59	56	63	68
In your household	8	8	10	11
With {a/another} family member	9	8	14	16
In an assisted living facility where {you/they} receive some help	12	14	6	2
In a nursing home	9	10	5	2
Hospital (vol.)	*	*	*	-
Somewhere else (vol.)	3	3	2	*
Don't know/Refused	*	-	-	*
N	677	260	201	195

- Q92. Do {you/they} currently live alone, or not?

Based on total who are personally seriously ill, or who have a living family member with serious illness who says they still live in own home or apartment

	Total	White	Black	Hispanic
Yes	36	39	34	32
No	64	61	64	68
Don't know/Refused	*	-	2	-
N	426	150	130	132

Q93. Do {you/they} currently live with {your/their} spouse, an adult child, or someone else?

Based on total who are personally seriously ill, or who have a living family member with serious illness who says they still live in own home or apartment, but does not currently live alone (sample sizes for White, Black, and Hispanic subgroups insufficient to report)

	Total
Spouse	55
Adult child	38
Adult grandchild (vol.)	2
Niece/Nephew (vol.)	*
Sister/Brother (vol.)	*
Someone else	4
Don't know/Refused	1
<i>N</i>	263

Q91/Q92/Q93 Combo Table based on total who are personally seriously ill, or who have a living family member with serious illness

	Total	White	Black	Hispanic
Currently live in own home/apartment	59	56	63	68
Does not live alone	37	34	40	47
Lives with spouse	20	20	17	21
Lives with adult child	14	12	20	20
Lives with adult grandchild (vol.)	1	*	1	2
Lives with niece/nephew (vol.)	*	-	*	1
Lives with sister/brother (vol.)	*	-	1	*
Lives with someone else	2	1	1	1
Don't know/Refused	*	*	*	1
Lives alone	21	22	21	22
Don't know/Refused	*	-	1	-
In your household	8	8	10	11
With (a/another) family member	9	8	14	16
In an assisted living facility where {you/they} receive some help	12	14	6	2
In a nursing home	9	10	5	2
Hospital (vol.)	*	*	*	-
Somewhere else (vol.)	3	3	2	*
Don't know/Refused	*	-	-	*
<i>N</i>	677	260	201	195

Q94. Is this where {you/you think they} would like to be living or would {you/they} rather be living somewhere else?

Based on total who are personally seriously ill, or who have a living family member with serious illness

	Total	White	Black	Hispanic
Where they would like	74	72	79	85
Rather be living somewhere else	24	26	16	14
Don't know/Refused	2	2	4	1
<i>N</i>	677	260	201	195

Q95. Where would {you/they} rather be? (DO NOT READ)

Based on total who are personally seriously ill, or who have a living family member with serious illness who says they would rather be living somewhere else (sample sizes for White, Black, and Hispanic subgroups insufficient to report)

	Total
In own home or apartment (vol.)	74
In your household (vol.)	4
With another family member (vol.)	10
In an assisted living facility where {they receive /she/he receives} some help (vol.)	1
In a nursing home (vol.)	*
Somewhere else (vol.)	9
Don't know/Refused	2
<i>N</i>	130

Q94/Q95 Combo Table based on total self or living family member group

	Total	White	Black	Hispanic
Living where they would like	74	72	79	85
Would rather be living somewhere else	24	26	16	14
In own home/apartment (vol.)	18	20	10	7
In your household (vol.)	1	1	-	1
With another family member (vol.)	2	2	*	4
In an assisted living facility where they receive some help (vol.)	*	-	1	1
In a nursing home (vol.)	*	-	-	1
Somewhere else (vol.)	2	2	3	1
Don't know/Refused	*	*	1	-
Don't know/Refused	2	2	4	1
<i>N</i>	677	260	201	195

Q96. How easy or difficult has it been for {you/them} to be able to stay in {your/their} own home or apartment? (GET ANSWER THEN ASK: Is that very {easy/difficult} or somewhat {easy/difficult}?)

Based on total who are personally seriously ill, or who have a living family member with serious illness who says they currently live in own home/apartment

	Total	White	Black	Hispanic
Easy (NET)	74	70	78	81
Very easy	50	44	49	63
Somewhat easy	24	26	29	18
Difficult (NET)	26	29	21	19
Somewhat difficult	21	24	15	13
Very difficult	5	5	6	6
Don't know/Refused	1	1	1	-
<i>N</i>	426	150	130	132

Q91/Q96 Combo Table based on total who are personally seriously ill, or who have a living family member with serious illness

	Total	White	Black	Hispanic
Currently live in own home/apartment	59	56	63	68
Easy (NET)	43	39	49	56
Has been very easy to be able to stay	29	25	31	43
Has been somewhat easy to be able to stay	14	15	18	12
Difficult (NET)	15	16	13	13
Has been somewhat difficult to be able to stay	12	14	10	9
Has been very difficult to be able to stay	3	3	4	4
Don't know/Refused	*	*	1	-
Does not currently live in home own/apartment	41	44	37	31
Don't know/Refused	*	-	-	*
N	677	260	201	195

Q97. Do you think {you/they} will be able to stay there for the rest of {your/their} life, or not?

Based on total who are personally seriously ill, or who have a living family member with serious illness who says they currently live in own home/apartment

	Total	White	Black	Hispanic
Yes	66	63	71	70
No	22	25	21	17
Don't know/Refused	12	12	8	13
N	426	150	130	132

Q91/Q97 Combo Table based on total self or living family member group

	Total	White	Black	Hispanic
Currently live in own home/apartment	59	56	63	68
Yes, think will be able to stay there for rest of life	39	35	44	48
No, do not think will be able to stay there for rest of life	13	14	14	12
Don't know/Refused	7	6	5	9
Does not currently live in home own/apartment	41	44	37	31
Don't know/Refused	*	-	-	*
N	677	260	201	195

Q98. Where did your loved one die? Did they die...? [INTERVIEWER NOTE if respondent says Retirement community, code as own home or apartment] (IF NEEDED: Nursing home: a facility that provides residents with a room, meals, personal care, nursing care, and medical services. Assisted living community: provides services to people who are not able to live independently, but does not require the level of care provided by a nursing home or other medical facility) (READ LIST)

Based on total who have a deceased family member with serious illness (sample sizes for Black and Hispanic subgroups insufficient to report)

	Total	White
In their own home or apartment	34	34
In your household	4	4
With another family member	4	3
In an assisted living facility where they received some help	14	17
In a nursing home	15	15
At a hospice care center	6	6
In a hospital	20	20
Somewhere else	1	1
Don't know/Refused	1	1
N	321	147

Q99. Do you think this is where your loved one wanted to die, or do you think they would have preferred to die somewhere else?

Based on total who have a deceased family member with serious illness (sample sizes for Black and Hispanic subgroups insufficient to report)

	Total	White
Where they wanted	49	49
Preferred to die somewhere else	37	36
Don't know/Refused	14	15
N	321	147

Q100. Where do you think they would have rather died? (DO NOT READ)

Based on total who have a deceased family member with serious illness who thinks loved one would have preferred to die somewhere else (sample sizes for White, Black, and Hispanic subgroups insufficient to report)

	Total
In own home or apartment (vol.)	89
In your household (vol.)	1
In an assisted living facility where they receive some help (vol.)	1
Hospital (vol.)	*
Somewhere else (vol.)	5
Don't know/Refused	4
N	116

Q99/Q100 Combo Table based on total deceased family member group (sample sizes for Black and Hispanic subgroups insufficient to report)

	Total	White
Thinks loved one was where they wanted to die	49	49
Thinks loved one would have preferred to die somewhere else	37	36
In own home/apartment (vol.)	33	32
In your household (vol.)	*	*
In an assisted living facility where they receive some help (vol.)	*	*
Hospital (vol.)	*	-
Somewhere else (vol.)	2	2
Don't know/Refused	2	1
Don't know/Refused	14	15
N	321	147

- Q101. Where did your loved one live the last few months of their life? Did they live...? (READ LIST) (IF NECESSARY: Hospice care focuses on giving medical care, pain management, and comfort to those in their final stages of life and can be provided either at the patient's home or in a facility. IF NEEDED: If loved one lived somewhere a month or less before they died, answer about previous living arrangement.) [INTERVIEWER NOTE if respondent says Retirement community, code as own home or apartment] (IF NEEDED: Nursing home: a facility that provides residents with a room, meals, personal care, nursing care, and medical services. Assisted living community: provides services to people who are not able to live independently, but does not require the level of care provided by a nursing home or other medical facility)

Based on total who have a deceased family member with serious illness (sample sizes for Black and Hispanic subgroups insufficient to report)

	Total	White
In their own home or apartment	48	48
In your household	5	5
With another family member	7	5
In an assisted living facility where they receive some help	16	19
In a nursing home	19	16
At a hospice care center	2	3
Hospital (vol.)	3	4
Somewhere else	-	-
Don't know/Refused	-	-
<i>N</i>	321	147

- Q102. Do you think this is where your loved one wanted to live their last few months of life, or do you think they would have preferred to live somewhere else?

Based on total who have a deceased family member with serious illness (sample sizes for Black and Hispanic subgroups insufficient to report)

	Total	White
Where they wanted	61	61
Preferred to live somewhere else	35	34
Don't know/Refused	4	5
<i>N</i>	321	147

- Q103. How easy or difficult was it for them to be able to stay in their own home or apartment? (GET ANSWER THEN ASK: Is that very [easy/difficult] or somewhat [easy/difficult]?)

Based on total who have a deceased family member with serious illness whose loved one died or lived last few months of life at home (sample sizes for White, Black, and Hispanic subgroups insufficient to report)

	Total
Easy (NET)	65
Very easy	38
Somewhat easy	27
Difficult (NET)	34
Somewhat difficult	18
Very difficult	16
Don't know/Refused	1
<i>N</i>	174

Q98/Q101/Q103 Combo Table based on total who have a deceased family member with serious illness

	Total	White
Loved one died at home or lived last few months of life at home	52	52
Easy (NET)	34	33
Very easy for them to be able to stay at home	20	18
Somewhat easy for them to be able to stay at home	14	15
Difficult (NET)	18	20
Somewhat difficult for them to be able to stay at home	9	11
Very difficult for them to be able to stay at home	8	9
Don't know/Refused	1	-
Loved one did not die or live last few months of live at home/Don't know/Refused	48	48
N	321	147

Q104. Did your loved one live alone at any time during the last few months of their life, or not?

Based on total who have a deceased family member with serious illness whose loved one lived last few months of life at home (sample sizes for White, Black, and Hispanic subgroups insufficient to report)

	Total
Yes	22
No	78
Don't know/Refused	-
N	160

Q101/Q104 Combo Table based on total who have a deceased family member with serious illness (sample sizes for Black and Hispanic subgroups insufficient to report)

	Total	White
Lived at home during last few months of life	48	48
Lived alone	11	10
Did not live alone	38	38
Don't know/Refused	-	-
Did not live at home during last few months of life	52	52
Don't know/Refused	-	-
N	321	147

Q105. Did they live with their spouse, an adult child, or someone else?

Based on total who have a deceased family member with serious illness whose loved one lived last few months of life at home and did not live alone (sample sizes for White, Black, and Hispanic subgroups insufficient to report)

	Total
Spouse	59
Adult child	27
Adult grandchild (vol.)	2
Niece/Nephew (vol.)	*
Sister/Brother (vol.)	2
Someone else	10
Don't know/Refused	*
N	129

Q101/Q104/Q105 Combo Table based on total who have a deceased family member with serious illness (*sample sizes for Black and Hispanic subgroups insufficient to report*)

	Total	White
Lived at home during last few months of life	48	48
Did not live alone	38	38
Lived with spouse	22	24
Lived with adult child	10	8
Lived with adult grandchild (vol.)	1	1
Lived with niece/nephew (vol.)	*	-
Lived with sister/brother (vol.)	1	*
Lived somewhere else	4	5
Don't know/Refused	*	-
Lived alone	11	10
Don't know/Refused	-	-
Did not live at home during last few months of life	52	52
Don't know/Refused	-	-
<i>N</i>	321	147

B32A. Thinking about the health insurance {you/your loved one} {have/has/had}, in addition to Medicare, {do you/do they/did they} also have coverage through Medicaid, the government health insurance and long-term care program for certain low-income adults, or {do you/do they/did they} only have coverage through Medicare?

Based on total who are personally seriously ill, or who have a living or deceased family member with serious illness

	Total	White	Black	Hispanic
Yes, also MediCAID	35	32	40	43
Only MediCARE coverage	50	51	46	41
Don't know/Refused	16	17	14	16
<i>N</i>	998	407	278	282

READ TO ALL: Now, generally speaking...

Q106. While you were growing up, how often were death and dying talked about in your family?

	Total	White	Black	Hispanic
Never/Rarely (NET)	49	47	43	61
Never	19	16	21	26
Rarely	30	31	22	35
Occasionally/Fairly Often (NET)	51	53	56	39
Occasionally	33	36	34	23
Fairly often	18	17	22	16
Don't know/Refused	*	*	*	*

Q107. Have you ever had a serious conversation with a parent or other family member about THEIR wishes for medical care if they were to become seriously ill, or not?

Based on total who have a living or deceased family member with serious illness who did not say they have had a serious conversation with a loved one about their wishes for medical care, or those who are personally seriously ill or who do not have recent experience with serious illness

	Total	White	Black	Hispanic
Yes	52	57	39	48
No	47	43	61	52
Don't know/Refused	*	*	*	*
<i>N</i>	1555	905	276	276

THEIRCONVO Q75a/Q107 Summary Table based on total: Conversation about a loved ones wishes for medical care

	Total	White	Black	Hispanic
Has ever had a serious conversation with a parent or other family member about their wishes for medical care if they were to become seriously ill	56	61	43	50
Has not ever had a serious conversation with a parent or other family member about their wishes for medical care if they were to become seriously ill/Don't know/Refused	44	39	57	50

Q108. Have you ever had a family member or close friend die after a period of serious illness that lasted more than a month, or not?

Based on total who are personally seriously ill, or who have a living family member with serious illness, or those who do not have recent experience with serious illness

	Total	White	Black	Hispanic
Yes	66	72	62	55
No	33	27	37	44
Don't know/Refused	1	1	1	1
N	1,719	993	310	314

DECLINE GROUP/Q108 Summary Table Based on Total: Experience with death after a period of serious illness

	Total	White	Black	Hispanic
Has ever had a family member/close friend die after a period of serious illness lasting more than a month	68	74	64	57
Has not ever had a family member/close friend die after a period of serious illness lasting more than a month	32	26	36	43
Don't know/Refused	-	-	-	-

READ TO ALL: Now I have a few questions we will use to describe the people who took part in our survey...

RSEX. Are you male or female?

	Total	White	Black	Hispanic
Male	48	49	51	46
Female	52	51	49	54
Other (vol.)	-	-	-	-
Don't know/Refused	*	*	-	-

D4. Are you, yourself, now covered by any form of health insurance or health plan or do you not have health insurance at this time? (READ IF NECESSARY: A health plan would include any private insurance plan through your employer or a plan that you purchased yourself, as well as a government program like Medicare or [Medicaid/ INSERT STATE-SPECIFIC MEDICAID NAME])?

	Total	White	Black	Hispanic
Covered by health insurance	88	92	81	73
Not covered by health insurance	11	7	17	26
Don't know/Refused	1	*	2	1

D4a. Which of the following is your MAIN source of health insurance coverage? Is it a plan through your employer, a plan through your spouse's employer, a plan you purchased yourself either from an insurance company or a state or federal marketplace, are you covered by Medicare or (Medicaid/[INSERT STATE-SPECIFIC MEDICAID NAME]), or do you get your health insurance from somewhere else? [INTERVIEWER NOTE: IF R SAYS THEY GOT INSURANCE THROUGH HEALTHCARE.GOV, OBAMACARE, OR A STATE HEALTH INSURANCE MARKETPLACE/EXCHANGE, CODE AS 3].

Based on total insured

	Total	White	Black	Hispanic
Plan through your employer	33	33	39	32
Plan through your spouse's employer	14	16	11	11
Plan you purchased yourself	9	9	5	10
Medicare	21	24	18	14
Medicaid/[STATE-SPECIFIC MEDICAID NAME]	11	8	16	18
Somewhere else	2	2	3	2
Plan through your parents/mother/father (vol.)	6	5	7	10
Military/Veterans	2	3	1	1
Don't know/Refused	1	1	1	3
N	1,823	1,074	337	311

D4/D4a Combo Table based on Total

	Total	White	Black	Hispanic
Covered by health insurance	88	92	81	73
Plan through your employer	29	31	32	23
Plan through your spouse's employer	13	14	9	8
Plan you purchased yourself	8	8	4	7
Medicare	18	22	15	10
Medicaid	10	8	13	13
Somewhere else	2	2	2	1
Plan through your parents/mother/father (vol.)	5	4	6	7
Don't know/Refused	1	1	1	2
Not covered by health insurance	11	7	17	26
Don't know/Refused	1	*	2	1

Q108b. Do you have a private long-term care insurance policy, that is, insurance that pays for nursing home and home care services over a long period of time, or not?

	Total	White	Black	Hispanic
Yes	16	15	22	12
No	79	78	74	87
Don't know/Refused	5	7	3	1

D2b. Are you currently married, living with a partner, widowed, divorced, separated, or have you never been married?

	Total	White	Black	Hispanic
Married	52	57	40	43
Living with a partner	6	5	4	13
Widowed	7	8	6	4
Divorced	8	9	8	6
Separated	3	1	3	8
Never been married	24	19	39	25
Don't know/Refused	1	*	1	*

Q109. How many children, under age 19, are living in your household?

	Total	White	Black	Hispanic
None/No children under 19 in household (vol.)	63	68	64	42
1	14	12	16	19
2	14	11	11	23
3	6	5	6	11
4+	3	2	4	5
Don't know/Refused	1	*	-	1

D3. What best describes your employment situation today? (READ IN ORDER)

	Total	White	Black	Hispanic
Employed (NET)	56	53	55	61
Employed full-time	45	44	48	46
Employed part-time	10	9	7	14
Unemployed and currently seeking employment	4	3	7	6
Unemployed and not seeking employment	3	2	2	4
A student	4	4	3	5
Retired	20	25	18	7
On disability and can't work	7	7	11	3
A homemaker or stay at home parent	6	5	5	13
Don't know/Refused	*	*	*	*

Q110. Next, aside from Social Security contributions, are you currently saving for retirement, such as putting money into a 401K, IRA, Individual Retirement Account, or another retirement savings account, or not? (IF RESPONDENT SAYS 'NOT SAVING AT ALL/NOT SAVING FOR ANYTHING,' MARK 2 'NO')

Based on total who are not retired

	Total	White	Black	Hispanic
Yes, saving for retirement	53	60	49	32
No, not saving for retirement	47	39	51	68
Don't know/Refused	1	1	*	*
<i>N</i>	<i>1,408</i>	<i>750</i>	<i>255</i>	<i>310</i>

D3/Q110 Combo Table based on Total

	Total	White	Black	Hispanic
Not retired	80	75	82	93
Yes, saving for retirement	42	45	40	29
No, not saving for retirement	37	29	42	63
Don't know/Refused	1	1	*	*
Retired	20	25	18	7

D8. In politics today, do you consider yourself a (Republican), (Democrat), an Independent, or what? (rotate items in parentheses)

	Total	White	Black	Hispanic
Republican	24	32	5	10
Democrat	29	25	52	31
Independent	29	28	26	33
Or what/Other/None/No preference	11	9	12	12
Don't know/Refused	7	6	5	14

D21. Aside from weddings and funerals, how often if ever do you attend religious services? (READ LIST)

	Total	White	Black	Hispanic
Once a week or more (NET)	35	34	46	38
At least once a week	26	24	39	29
Almost every week	9	10	7	9
Less often (NET)	64	65	54	62
About once a month	12	11	13	14
Less often than that	28	30	22	22
Never	25	24	18	26
Don't know/Refused	1	1	*	*

Religion Combo Table based on Total

	Total	White	Black	Hispanic
Evangelical Protestant	24	25	39	11
Mainline Protestant	28	32	31	12
Catholic	22	18	7	58
Other Christian	2	2	1	2
Atheist/Agnostic/None	17	18	11	15
Other	8	5	11	3

Race Religion Combo Table based on Total

	Total	White	Black	Hispanic
White Evangelical Protestant	16	25	-	-
White Mainline Protestant	20	32	-	-
Black Protestant	1	-	5	-
White Catholic	11	18	-	-
Hispanic Catholic	9	-	-	58
Other	43	25	95	42

D11. What is the highest level of school you have completed or the highest degree you have received? (DO NOT READ) [INTERVIEWER NOTE: Enter code 3-HS grad if R completed training that did NOT count toward a degree]

	Total	White	Black	Hispanic
HS grad or less (NET)	41	36	44	67
Less than high school (Grades 1-8 or no formal schooling)	5	2	7	19
High school incomplete (Grades 9-11 or Grade 12 with no diploma)	7	7	6	7
High school graduate (Grade 12 with diploma or GED certificate)	29	27	31	41
Some college (NET)	28	28	32	21
Some college, no degree (includes some community college)	18	18	20	12
Two year associate degree from a college or university	10	10	12	9
College grad (NET)	30	36	23	13
Four year college or university degree/Bachelor's degree (e.g., BS, BA, AB)	17	20	10	8
Some postgraduate or professional school, no postgraduate degree	2	2	*	1
Post-graduate or professional degree, including master's, doctorate, medical, or law degree (e.g., MA, MS, PhD, MD, JD)	12	14	12	4
Don't know/Refused	1	*	2	-

D12. Are you, yourself, of Hispanic or Latino background, such as Mexican, Puerto Rican, Cuban, or some other Spanish background?

D13. What is your race? Are you white, black, Asian or some other race? (IF RESPONDENT SAYS HISPANIC ASK: Do you consider yourself a white Hispanic or a black Hispanic? CODE AS WHITE (1) OR BLACK (2). IF RESPONDENTS REFUSED TO PICK WHITE OR BLACK HISPANIC, RECORD HISPANIC AS "OTHER," CODE 4)

Race Summary Table based on Total

	Total
White non-Hispanic	64
Black non-Hispanic	12
Hispanic	15
Asian	3
Other/mixed race	4
Don't know/Refused	1

D12a. Were you born in the United States, on the island of Puerto Rico, or in another country?

Based on total Hispanics

	Total
U.S.	45
Puerto Rico	3
Another country	51
Don't know/Refused	*
<i>N</i>	<i>401</i>

- D14. Last year – that is, in 2016 – what was your total family income from all sources, before taxes? Just stop me when I get to the right category. (READ)

	Total	White	Black	Hispanic
Less than \$40k (NET)	37	31	44	50
Less than \$20,000	17	14	20	24
\$20,000 to less than \$30,000	11	9	15	19
\$30,000 to less than \$40,000	9	8	10	8
\$40k to less than \$90k (NET)	26	29	20	24
\$40,000 to less than \$50,000	7	8	8	6
\$50,000 to less than \$75,000	12	13	8	13
\$75,000 to less than \$90,000	7	8	4	5
\$90k or more (NET)	24	28	21	9
\$90,000 to less than \$100,000	4	6	3	1
\$100,000 or more	19	22	18	8
Refused	13	12	14	17

- L1. Now thinking about your telephone use... Do you have a working cell phone?

Based on total landline respondents

	Total
Yes, have cell phone	75
No, do not	24
Don't know/Refused	1
N	677

- L1a. Does anyone else in your household have a working cell phone?

Based on total landline respondents who do not personally have a landline

	Total
Yes, someone in household has cell phone	36
No	60
Don't know/Refused	4
N	131

- C1. Now thinking about your telephone use...Is there at least one telephone INSIDE your home that is currently working and is not a cell phone?

Based on total cell phone respondents

	Total
Yes, has a home telephone	32
No, no home telephone	67
Don't know/Refused	1
N	1,363

L1/C1 Combo Table based on Total

	Total
Cell phone only	52
Both LL and Cell	42
Landline only	6
Don't know/Refused	1

HH1. How many adults, age 18 and over, currently live in your household INCLUDING YOURSELF?

Based on total cell phone respondents

	Total	White	Black	Hispanic
1	21	22	29	13
2	51	55	41	43
3	16	14	21	24
4+	10	8	7	20
Don't know/Refused	1	1	1	1
N	1,363	757	231	295

SCREENER QUESTIONS

HH1. So that I can select one person in your household, could you please tell me: How many adults 18 or older live in your household? Please include yourself and all the adults who live with you. [INTERVIEWER: PLEASE CONFIRM PERSON ON THE LINE IS AN ADULT]

S12a. Are you, yourself, of Hispanic or Latino background, such as Mexican, Puerto Rican, Cuban, or some other Spanish background?

S12b. What is your race? Are you white, black, Asian or some other race? (IF RESPONDENT SAYS HISPANIC ASK: Do you consider yourself a white Hispanic or a black Hispanic? CODE AS WHITE (1) OR BLACK (2). IF RESPONDENTS REFUSED TO PICK WHITE OR BLACK HISPANIC, RECORD HISPANIC AS "OTHER," CODE 4)

D5. So I ask you the right questions, can you please tell me your age?

D6. Could you please tell me if you are between the ages of...? (READ LIST)

S01. Have you ever been diagnosed with (INSERT ITEM)? (INTERVIEWER, IF NECESSARY: IF RESPONDENT ASKS IF SHOULD INCLUDE BORDERLINE CONDITIONS, SAY YES.) (scramble items a-g; always ask item h last)

- a. Diabetes
- b. Asthma, lung disease, emphysema, or COPD
- c. Heart disease or had a stroke
- d. Cancer, not including skin cancer
- e. Alzheimer's disease, dementia or memory loss
- f. Depression, anxiety or other serious mental health problems
- g. Chronic kidney disease or kidney failure

S02. Because of a health or memory problem, do you have difficulty independently preparing meals, shopping for groceries, making telephone calls, or taking medication? (INTERVIEWER: IF RESPONDENT SAYS THEY HAVE DIFFICULTY, BUT THEY STILL DO THOSE THINGS ON THEIR OWN, CODE AS YES)

S03. Because of a health or memory problem, do you have difficulty independently getting across a room, dressing, bathing, eating, getting in or out of bed, or using the toilet? (INTERVIEWER: IF RESPONDENT SAYS THEY HAVE DIFFICULTY, BUT THEY STILL DO THOSE THINGS ON THEIR OWN, CODE AS YES)

LIVING FAMILY MEMBER

S04. Do you have a parent, spouse or other close family member who, because of a health or memory problem, has difficulty independently completing everyday activities such as preparing meals, shopping for groceries, taking medications, getting across a room, eating, dressing, bathing, or using the toilet? (INTERVIEWER: IF RESPONDENT SAYS THEY HAVE DIFFICULTY, BUT THEY STILL DO THOSE THINGS ON THEIR OWN, CODE AS YES)

S05. (Thinking of the oldest of these family members,) Is that person 65 or older? (INSERT "Thinking of the oldest of these family members," IF S04=2)

S05a. How old is that person?

S05b. Is that person male or female?

S06. Who is that person? Is it a parent, a spouse, or another close family member? (IF ANOTHER CLOSE FAMILY MEMBER, PLEASE PROBE WITH: Which close family member would that be?)

S07. Has that person ever been diagnosed with (INSERT ITEM)? (INTERVIEWER, IF NECESSARY: IF RESPONDENT ASKS IF SHOULD INCLUDE BORDERLINE CONDITIONS, SAY YES.) (scramble items a-g; always ask item h last)

- a. Diabetes
- b. Asthma, lung disease, emphysema, or COPD
- c. Heart disease or had a stroke
- d. Cancer, not including skin cancer
- e. Alzheimer's disease, dementia or memory loss
- f. Depression, anxiety or other serious mental health problems
- g. Chronic kidney disease or kidney failure

S07aa. Thinking about this family member, how much do you know about this person's medical care?

DECEASED FAMILY MEMBER

S08. Have you experienced the death of a parent, spouse, or other close family member in the past two years, or not?

S09. (Thinking of this family member who died most recently,) Was that person 65 or older when they died? (INSERT "Thinking of this family member who died most recently," IF S08=2)

S09a. How old was that person when they died?

S09b. Was that person male or female?

S10. Who was that person? Was it a parent, a spouse, or another close family member? (IF ANOTHER CLOSE FAMILY MEMBER, PLEASE PROBE WITH: Which close family member would that be?)

S11. Before they died, did they have difficulty, because of a health or memory problem, completing everyday activities independently such as preparing meals, shopping for groceries, taking medications, getting across a room, eating, dressing, bathing, or using the toilet?

S12. Did they have trouble taking care of themselves for more than a month before they died, or was it less time than that?

S13. Before they died, was that person ever diagnosed with (INSERT ITEM)? (INTERVIEWER, IF NECESSARY: IF RESPONDENT ASKS IF SHOULD INCLUDE BORDERLINE CONDITIONS, SAY YES.) (scramble items a-g; always ask item h last)

- a. Diabetes
- b. Asthma, lung disease, emphysema, or COPD
- c. Heart disease or had a stroke
- d. Cancer, not including skin cancer
- e. Alzheimer's disease, dementia or memory loss
- f. Depression, anxiety or other serious mental health problems
- g. Chronic kidney disease or kidney failure

S13aa. Thinking about this family member, how much did you know about this person's medical care?



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This publication (#9098-T) is available on the
Kaiser Family Foundation website at www.kff.org.

Filling the need for trusted information on national health issues,
the Kaiser Family Foundation is a nonprofit organization based in Menlo Park, California.