

**Supplement Table 1. All responses to the Lyon Advanced Care Planning Survey for adults living with HIV (N=223)**

**Advance Planning and Preparation**

1. Have you ever written down any thoughts about your future health plans?

%	#	
26.91	60	Yes definitely
4.04	9	Very probable
7.17	16	Probably
7.17	16	Probably not
51.57	115	Definitely not
3.14	7	Do not know

2. Advance directives allow people to make their health care choices known before becoming very ill or dying.

a. Have you ever heard about and completed a Health Care Power of Attorney (HCPA), in which you name someone to make decisions about your health care in case you could not?

%	#	
24.22	54	Have heard about and completed
61.88	138	Have heard about
11.66	26	Have not heard about
2.24	5	Do not know

b. Have you ever heard about and completed an Advance Directive, such as Five Wishes?

%	#	
14.80	33	Have heard about and completed
47.09	105	Have heard about but not completed
34.08	76	Have not heard about
4.04	9	Do not know

3. a. Whether you have completed any advance directives/pre-plans or not, have you talked about your wishes for care at end of life with anyone? SELECT ALL THAT APPLY.

%	#	
26.01	58	Spouse/partner
18.39	41	Parents
20.18	45	Siblings (brother/sister)
18.39	41	Friends
5.83	13	Boyfriend/girlfriend
3.14	7	Lawyer
8.52	19	Primary Physician
4.48	10	Clergy (such a minister, rabbi, iman, etc.)
16.14	36	Other (1 Associates, 1 Aunt, 26 Children, 3 Family Members, 1 Godfather, 3 Nieces and/or Nephews, 1 Social Worker)
35.43	79	Have not talked with anyone

3.b. Do you have any children?

%	#	
54.26	121	Yes (proceed to question 3c)
45.74	102	No (proceed to question 4)

3.c. If you have children, have you talked about plans for who will take care of your child/children, if you are not able to? SELECT ALL THAT APPLY.

%	#	
5-83	13	Spouse/partner
7-62	17	Parents
5-83	13	Siblings
1-35	3	Friends
0	0	Boyfriend/Girlfriend
0	0	Lawyer
0	0	Primary Physician
0	0	Clergy
27-35	61	Other, please describe (53 Adult Children, 2 Aunt or Aunt and Cousin, 1 Brother-in-Law, 2 Cousin, 2 Daughter, 2 Family, 1 Godmother and Daughter's Father, 1 Grandkids, 1 Grandparents, 2 N/A, 1 No)

4. If you were ill and knew that you would not get better, who would you want to be involved in decision about your end-of-life care? SELECT ALL THAT APPLY.

%	#	
58-30	130	Myself
78-03	174	My Family
43-95	98	My Doctor
34-08	76	Someone else, please specify (5 Children, 19 Friend, 4 Mother, 4 Sibling, 16 Significant Other, 17 Spouse, 10 Surrogate, 1 Fiancé and Godmother, 1 Imam, 1 Niece, 1 Niece and Friend, 1 Pastor/Spiritual Leaders, 1 Social Worker)

5. When do you think it is the best time to bring up end-of-life decisions?

%	#	
63-86	142	While healthy
7-17	16	When first diagnosed with a life-threatening illness
3-14	7	When first sick from a life-threatening illness
3-59	8	When first hospitalized with a life-threatening illness
0-90	2	If dying
17-49	39	All of the above
0-90	2	Never
1-79	4	Do not know
1-35	3	Other (1 After coming to terms with life threatening illness, 1 sometime after diagnosis)

6. Who are the best people/person on the treatment team to bring it up with you? SELECT ALL THAT APPLY.

%	#	
83-86	187	Physician
19-73	44	Nurse Practitioner
20-63	46	Nurse
39-46	88	Social Worker
21-08	47	Psychologist
25-11	56	Case Manager
20-63	46	Chaplain
17-49	39	Patient Advocate
13-90	31	Other (1 Anyone on the treatment team, 1 Brother, 1 Children, 1 Clinical trial staff, 1 Don't know, 9 Family, 1 Family, partner and friends, 2 Friend, 3 Unknown, 5 Significant other, 1 Most knowledgeable about my specific

health and EOL, 1 Mother, 1 None, 2 Pastor, 1 Psychiatrist,  
3 Surrogate)

7. Do you believe that once you make an important medical decision, for example, to be put on a respirator, a machine that breathes for you, that you would be able to change your mind?

%	#	
39.64	88	Yes definitely
11.71	26	Very probable
12.61	28	Probably
7.21	16	Probably not
13.51	30	Definitely no
15.32	34	Do not know
Frequency Missing = 1		

8. Do you think your doctor or the hospital will respect your wishes, that is, do what you want about medical care?

%	#	
69.96	156	Yes definitely
9.87	22	Very probable
11.66	26	Probably
2.24	5	Probably not
2.69	6	Definitely not
3.59	8	Do not know

9. Do you think your parent/ guardian/ surrogate understands your wishes?

%	#	
71.30	159	Yes definitely
10.31	23	Very probable
8.52	19	Probably
4.04	9	Probably not
1.35	3	Definitely no
4.48	10	Do not know

10. Do you think your parent/guardian/surrogate will respect your wishes, that is, do what you want about your medical care?

%	#	
77.13	172	Yes definitely
8.97	20	Very probable
9.42	21	Probably
1.35	3	Probably not
0.45	1	Definitely no
2.69	6	Do not know

**Thoughts about Death and Dying**

11. How often has death and dying been talked about in your family?

%	#	
10.31	23	Very often
12.11	27	Often
37.67	84	Occasionally
26.91	60	Rarely
12.11	27	Never
0.90	2	Do not know

12. How comfortable are you talking about death?

%	#	
47.98	107	Very comfortable
28.25	63	Somewhat Comfortable
9.42	21	Neither comfortable or uncomfortable
7.17	16	Not very comfortable
5.83	13	Not at all comfortable
1.35	3	Do not know

13. How likely are you to...

a. Attend funerals or memorial services when a loved one, friend or a classmate dies

%	#	
61.43	137	Very likely
23.32	52	Somewhat likely
2.69	6	Neither likely or unlikely
4.48	10	Not very likely
7.62	17	Not at all likely
0.45	1	Do not know

b. Avoid medical checkups because you are afraid the doctor will find "something serious"

%	#	
3.59	8	Very likely
3.14	7	Somewhat likely
4.04	9	Neither likely or unlikely
4.48	10	Not very likely
81.61	182	Not at all likely
3.14	7	Do not know

c. Speak freely to loved ones about death and dying

%	#	
48.88	109	Very likely
30.49	68	Somewhat likely
3.59	8	Neither likely or unlikely
7.17	16	Not very likely
8.52	19	Not at all likely
1.35	3	Do not know

d. Visit or telephone a friend or relative who has recently lost a loved one in order to see how they are doing

%	#	
66.82	149	Very likely
23.77	53	Somewhat likely
3.14	7	Neither likely or unlikely
0.90	2	Not very likely
4.04	9	Not at all likely
1.35	3	Do not know

e. Preplan your own funeral, for example, choose someone to speak or choose the music you would want

%	#	
48.88	109	Very likely
20.18	45	Somewhat likely
5.83	13	Neither likely or unlikely
5.83	13	Not very likely
14.35	32	Not at all likely

4.93      11      Do not know

14. How afraid if at all, are you of...

a. Dying from a long term illness

%	#	
16.14	36	Very afraid
26.01	58	Somewhat afraid
9.42	21	Neither afraid nor not afraid
6.28	14	Not very afraid
39.01	87	Not at all afraid
3.14	7	Do not know

b. Dying suddenly, such as an accident, or being killed

%	#	
20.18	45	Very afraid
19.28	43	Somewhat afraid
6.28	14	Neither afraid nor not afraid
5.83	13	Not very afraid
46.19	103	Not at all afraid
2.24	5	Do not know

c. Dying alone

%	#	
22.42	50	Very afraid
19.73	44	Somewhat afraid
4.93	11	Neither afraid nor not afraid
4.04	9	Not very afraid
45.29	101	Not at all afraid
3.59	8	Do not know

d. Dying in an institution such as a nursing home or hospital

%	#	
25.56	57	Very afraid
19.28	43	Somewhat afraid
6.28	14	Neither afraid nor not afraid
5.38	12	Not very afraid
39.01	87	Not at all afraid
4.48	10	Do not know

e. Dying painfully

%	#	
43.05	96	Very afraid
26.01	58	Somewhat afraid
3.14	7	Neither afraid nor not afraid
3.14	7	Not very afraid
20.18	45	Not at all afraid
4.48	10	Do not know

15. How strongly do you agree or disagree that...

a. Dying is an important part of life

%	#	
60.09	134	Strongly agree
25.11	56	Agree
4.93	11	Neither agree or disagree
3.59	8	Disagree

2.69	6	Strongly disagree
3.59	8	Do not know

b. If someone could tell me when I would die, I would want to know

%	#	
22.87	51	Strongly agree
12.56	28	Agree
7.62	17	Neither agree or disagree
14.80	33	Disagree
35.43	79	Strongly disagree
6.73	15	Do not know

16. What you think about death and dying, how concerned are you that...

a. The family's money won't last

%	#	
26.01	58	Very concerned
18.83	42	Concerned
8.07	18	Neither concerned nor unconcerned
17.04	38	Not concerned
26.46	59	Not at all concerned
3.59	8	Do not know

b. I will be a burden, or overload, to my family or friends

%	#	
25.56	57	Very concerned
24.22	54	Concerned
5.38	12	Neither concerned nor unconcerned
16.14	36	Not concerned
25.56	57	Not at all concerned
3.14	7	Do not know

17. Which of the following health problems, if any, do you think are worse than death? SELECT ALL THAT APPLY.

%	#	
47.98	107	Living with great pain
34.08	76	Total physical dependency on others, for example, being in a wheelchair
59.64	133	Not being able to communicate my wishes and/or care to family members, for example, being in a coma
22.87	51	None are worse than death

### Dealing with Dying

18. How important would each of the following be to you if you were dealing with your own dying?

a. Family and friends visiting you

%	#	
60.09	134	Very important
21.97	49	Somewhat important
2.24	5	Neither important nor unimportant
6.73	15	Not very important
5.83	13	Not at all important
3.14	7	Do not know

b. Being able to stay in your own home

%	#	
59.19	132	Very important
21.08	47	Somewhat important
4.04	9	Neither important nor unimportant
8.07	18	Not very important
4.04	9	Not at all important
3.59	8	Do not know

c. Honest answers from your doctor

%	#	
95.52	213	Very important
3.14	7	Somewhat important
0.45	1	Neither important nor unimportant
0	0	Not very important
0.90	2	Not at all important
0	0	Do not know

d. Comfort from church services or persons such as a minister, priest, imam, or rabbi

%	#	
52.04	115	Very important
23.98	53	Somewhat important
4.98	11	Neither important nor unimportant
5.43	12	Not very important
10.41	23	Not at all important
3.17	7	Do not know

Frequency Missing = 2

e. Planning your own funeral

%	#	
48.65	108	Very important
29.28	65	Somewhat important
6.76	15	Neither important nor unimportant
6.31	14	Not very important
7.66	17	Not at all important
1.35	3	Do not know

Frequency Missing = 1

f. Being able to complete an advance directive that would let your loved ones know your wishes, if you were unable to speak for yourself

%	#	
79.82	178	Very important
16.59	37	Somewhat important
0.45	1	Neither important nor unimportant
0.45	1	Not very important
1.35	3	Not at all important
1.35	3	Do not know

g. Fulfilling personal goals/ pleasures

%	#	
62.78	140	Very important
23.32	52	Somewhat important
3.14	7	Neither important nor unimportant
4.48	10	Not very important
4.04	9	Not at all important

2.24	5	Do not know
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h. Reviewing your life history with your family

%	#	
39.01	87	Very important
29.15	65	Somewhat important
7.17	16	Neither important
8.52	19	Not very important
14.80	33	Not at all important
1.35	3	Do not know

i. Having health care professionals visit you at your home

%	#	
47.09	105	Very important
30.49	68	Somewhat important
4.48	10	Neither important nor unimportant
5.38	12	Not very important
11.66	26	Not at all important
0.90	2	Do not know

j. Understanding your treatment choices

%	#	
89.24	199	Very important
9.87	22	Somewhat important
0	0	Neither important nor unimportant
0.45	1	Not very important
0.45	1	Not at all important
0	0	Do not know

19. How important are each of the following to you when you think about dying?

a. Being physically comfortable

%	#	
82.06	183	Very important
14.80	33	Somewhat important
1.79	4	Neither important nor unimportant
0.90	2	Not very important
0	0	Not at all important
0.45	1	Do not know

b. Being free from pain

%	#	
85.65	191	Very important
11.66	26	Somewhat important
0.90	2	Neither important nor unimportant
0.90	2	Not very important
0	0	Not at all important
0.90	2	Do not know

c. Having said everything I want to say to people in my family

%	#	
70.40	157	Very important
21.97	49	Somewhat important
1.79	4	Neither important nor unimportant
1.79	4	Not very important
3.59	8	Not at all important
0.45	1	Do not know



d.	Being at peace spiritually		
	%	#	
	87.44	195	Very important
	8.97	20	Somewhat important
	1.35	3	Neither important nor unimportant
	0.45	1	Not very important
	1.35	3	Not at all important
	0.45	1	Do not know
e.	Not being a burden to loved ones		
	%	#	
	83.41	186	Very important
	13.45	30	Somewhat important
	0.90	2	Neither important nor unimportant
	0.90	2	Not very important
	1.35	3	Not at all important
	0	0	Do not know
f.	Knowing how to say goodbye		
	%	#	
	70.40	157	Very important
	20.63	46	Somewhat important
	1.79	4	Neither important nor unimportant
	2.69	6	Not very important
	2.24	5	Not at all important
	2.24	5	Do not know
g.	Having a sense of your own worth or value		
	%	#	
	76.23	170	Very important
	17.04	38	Somewhat important
	1.35	3	Neither important nor unimportant
	1.35	3	Not very important
	3.14	7	Not at all important
	0.90	2	Do not know
h.	Being off machines that extend life such as life support		
	%	#	
	60.54	135	Very important
	16.14	36	Somewhat important
	4.93	11	Neither important nor unimportant
	3.14	7	Not very important
	6.28	14	Not at all important
	8.97	20	Do not know
i.	Dying a natural death		
	%	#	
	65.47	146	Very important
	19.28	43	Somewhat important
	4.48	10	Neither important nor unimportant
	1.79	4	Not very important
	3.59	8	Not at all important
	5.38	12	Do not know

20. If death were likely to happen in the next few weeks, and you could choose where to die, where would you MOST want to die? CHECK ONE answer only.

%	#	
62.16	138	At home
0.90	2	In an assisted-living facility
17.57	39	In a hospital
0.45	1	In a nursing home
3.15	7	In a residential hospice
15.77	35	Do not know

Frequency Missing = 1

21. Below are some statements related to pain near the end-of-life that have been expressed by people. How strongly do you agree or disagree with each statement?

a. I am afraid my doctor may not believe I am in pain and treat my pain

%	#	
13.57	30	Strongly agree
15.38	34	Agree
7.24	16	Neither agree nor disagree
25.34	56	Disagree
32.13	71	Strongly disagree
6.33	14	Do not know

Frequency Missing = 2

b. I would only take pain medicines when the pain is severe

%	#	
40.09	89	Strongly agree
37.84	84	Agree
2.25	5	Neither agree or disagree
8.56	19	Disagree
8.56	19	Strongly disagree
2.70	6	Do not know

Frequency Missing = 1

c. I am afraid I will become addicted to pain medicines over time

%	#	
14.80	33	Strongly agree
14.80	33	Agree
8.07	18	Neither agree or disagree
26.46	59	Disagree
32.29	72	Strongly disagree
3.59	8	Do not know

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

%	#	
33.63	75	Strongly agree
29.60	66	Agree
7.62	17	Neither agree nor disagree
14.80	33	Disagree
9.42	21	Strongly disagree
4.93	11	Don't know

e. I am afraid I would be given too much pain medicine

%	#	
7.17	16	Strongly agree
10.76	24	Agree
9.42	21	Neither agree or disagree
38.57	86	Disagree
28.70	64	Strongly disagree
5.38	12	Don't know

22. Have you heard of hospice services?

%	#	
87.89	196	Yes
12.11	27	No (if no skip to Q23 & 24)

23. How did you learn about hospice services?

%	#	
67.36	130	I know someone who used hospice services
2.59	5	I have used hospice services myself
1.55	3	I am/was a hospice volunteer
9.33	18	I heard from a health care professional
9.84	19	I read literature/newspaper/TV/radio/other media
8.29	16	I heard from others
1.04	2	No response

Frequency Missing = 3

24. If you were dying, would you want hospice support?

%	#	
53.37	103	Yes
15.54	30	No
30.05	58	Do not know/not sure
1.04	2	No response

Frequency Missing = 3

### **Spiritual Well-Being**

25. Do you consider yourself...? (If not religious/spiritual, skip Q26 and Q27)

%	#	
41.44	92	Very religious/spiritual
48.20	107	Somewhat religious/spiritual
4.95	11	Not very religious/spiritual
4.05	9	Not religious/spiritual
0.45	1	Do not know
0.90	2	No response

Frequency Missing = 1

26. How often do you attend religious or spiritual services?

%	#	
19.91	43	Always
22.22	48	Very often
28.24	61	Sometimes
20.83	45	Rarely
8.33	18	Never
0.46	1	Do not know

27. How often does your religion or spirituality help you face your fears or do what you were afraid to do?

%	#	
52.09	112	Everyday
12.09	26	A few times a week
14.42	31	A few times a month
13.02	28	Rarely
5.58	12	Never
2.79	6	Do not know

**About You**

28. How many times in your life have you been seen at an emergency room?

%	#	
2.29	5	0
2.29	5	1
8.26	18	2
8.26	18	3
10.55	23	4
10.09	22	5
5.96	13	6
4.13	9	7
2.29	5	8
0.92	2	9
14.68	32	10
2.29	5	12
2.29	5	15
11.47	25	20
0.46	1	24
2.75	6	30
0.46	1	40
4.13	9	50
0.46	1	60
0.46	1	65
0.46	1	70
4.13	9	100
0.46	1	220
0.46	1	999

Frequency Missing = 5

29. How many times in your life have you ever been hospitalized?

%	#	
5.94	13	0
9.13	20	1
14.61	32	2
11.87	26	3
12.33	27	4
16.89	37	5
5.48	12	6
2.74	6	7
0.91	2	8
0.91	2	9
6.85	15	10
2.28	5	12

1-37	3	15
3-20	7	20
1-83	4	25
1-37	3	30
0-46	1	35
0-91	2	40
0-46	1	50
0-46	1	60

Frequency Missing = 4

29.a. How many nights have you spent in a hospital in the last year?

%	#	
65-47	146	0
3-59	8	1
7-17	16	2
5-38	12	3
4-04	9	4
2-24	5	5
0-45	1	6
1-79	4	7
0-45	1	10
1-35	3	12
1-35	3	14
0-45	1	15
0-45	1	16
0-90	2	20
0-90	2	21
0-45	1	25
1-79	4	30
0-90	2	90
0-45	1	120
0-45	1	180

29.b. How many of those hospitalizations were psychiatric hospitalizations? For example, for behavior problems or depression.

%	#	
86-11	186	0
8-33	18	1
2-31	5	2
0-93	2	3
0-46	1	4
0-46	1	5
0-46	1	6
0-46	1	7
0-46	1	17

29.c. How many nights have you spent psychiatrically hospitalized in the past year?

%	#	
95-71	201	0
0-95	2	1
0-48	1	2
0-48	1	3

0.48	1	7
0.48	1	10
0.95	2	14
0.48	1	30

Variable	N	Mean	Std. Dev.	Min.	Max.
Number of times in the ER in life	218	20.45	71.38	0	999
Number of times hospitalized in life	219	6.46	8.32	0	60
Number of nights in a hospital in the last year	223	4.47	17.34	0	180
Number of psychiatric hospitalizations	216	0.34	1.44	0	17
Number of nights in a psychiatric hospital in the last year	210	0.39	2.61	0	30

**During the Past Four Weeks**

30. How many nights did you stay in a hospital?

%	#	
92.38	206	No nights spent in the hospital
2.69	3	1-2 nights spent in the hospital
2.24	5	3-5 nights
0.45	1	6-10 nights
1.79	4	11-20 nights
0.45	1	>20 nights

Frequency Missing = 3

31. How healthy are you feeling right now?

%	#	
28.25	63	Excellent health
30.04	67	Very good health
22.42	50	Good health
17.04	38	Fair health
2.24	5	Poor health

32. Is your mother alive?

%	#	
48.88	109	No
50.22	112	Yes
0.90	2	Do not know

33. Is your father alive?

%	#	
65.47	146	No
31.39	70	Yes
3.14	7	Do not know

**Supplement Table 2. Responses to Lyon Advance Care Planning Survey responses from adults living with HIV/AIDS by race (N=223).**

**Advance Planning and Preparation**

1. Have you ever written down any thoughts about your future health plans?

<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
50 (26.0)	9 (36)	<b>Yes, definitely</b>
8 (4.2)	1 (4.0)	<b>Yes, probably</b>
12 (6.3)	3 (12.0)	<b>Probably</b>
13 (6.8)	2 (40.0)	<b>Probably not</b>
102 (53.1)	10 (40.0)	<b>Definitely not</b>
7 (3.7)	0 (0.0)	<b>Do not know</b>

2. Advance directives allow people to make their healthcare choices known before becoming very ill or dying.

- a. Have you ever heard about and completed a Health Care Power of Attorney (HCPA), in which you name someone to make decisions about your healthcare in case you could not

<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
41 (21.4)	12 (4.0)	<b>Have heard about and completed</b>
123 (64.1)	11 (44.0)	<b>Have heard about but not completed</b>
24 (12.5)	2 (8.0)	<b>Have not heard about</b>
4 (2.1)	0 (0.0)	<b>Do not know</b>

- b. Have you ever heard about and completed an Advance Directive, such as Five Wishes?

<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
23 (12.0)	9 (36.0)	<b>Have heard about and completed</b>
93 (48.4)	10 (40.0)	<b>Have heard about but not completed</b>
69 (35.9)	5 (20.0)	<b>Have not heard about</b>
7 (3.7)	1 (4.0)	<b>Do not know</b>



3. a. Whether you have completed any advance directives/pre-plans or not, have you talked about your wishes for care at end of life with anyone? SELECT ALL THAT APPLY.

<b>African Americans</b>	<b>Non-African Americans</b>	
<b>N (%)</b>	<b>N (%)</b>	
44 (22.9)	11 (44.0)	<b>Spouse/partner</b>
34 (17.7)	5 (20.0)	<b>Parents</b>
37 (19.3)	7 (28.8)	<b>Siblings (brother/sister)</b>
30 (15.6)	9 (36.0)	<b>Friends</b>
12 (6.3)	1 (4.0)	<b>Boyfriend/girlfriend</b>
5 (2.6)	2 (8.0)	<b>Lawyer</b>
15 (7.8)	3 (12.0)	<b>Primary Physician</b>
8 (4.2)	1 (4.0)	<b>Clergy (such as minister, rabbi, imam, etc.)</b>
36 (18.8)	5 (20.0)	<b>Other</b>

- b. Do you have any children?

<b>African Americans</b>	<b>Non-African Americans</b>	
<b>N (%)</b>	<b>N (%)</b>	
111 (57.8)	8 (32.0)	<b>Yes (proceed to question 3c)</b>
81 (42.2)	17 (68.0)	<b>No (proceed to question 4)</b>

- c. If you have children, have you talked about plans for who will take care of your child/children, if you are not able to? SELECT ALL THAT APPLY.

<b>African Americans</b>	<b>Non-African Americans</b>	
<b>N (%)</b>	<b>N (%)</b>	
11 (5.7)	1 (4.0)	<b>Spouse/partner</b>
16 (8.3)	0 (0.0)	<b>Parents</b>
13 (6.8)	0 (0.0)	<b>Siblings</b>
3 (1.6)	0 (0.0)	<b>Friends</b>
0 (0.0)	0 (0.0)	<b>Boyfriend/girlfriend</b>
0 (0.0)	0 (0.0)	<b>Lawyer</b>
0 (0.0)	0 (0.0)	<b>Primary Physician</b>
0 (0.0)	0 (0.0)	<b>Clergy</b>
54 (28.1)	7 (28.0)	<b>Other</b>

4. If you were ill and knew that you would not get better, who would you want to be involved in decision about your end-of-life care? SELECT ALL THAT APPLY.

<b>African Americans</b>	<b>Non-African Americans</b>	
<b>N (%)</b>	<b>N (%)</b>	
104 (54.2)	21 (84.0)	<b>Myself</b>
150 (78.1)	18 (72.0)	<b>My Family</b>
78 (40.6)	16 (64.0)	<b>My Doctor</b>
70 (36.5)	9 (36.0)	<b>Someone else</b>

5. When do you think it is the best time to bring up end-of-life decisions?

<b>African Americans</b>	<b>Non-African Americans</b>	
<b>N (%)</b>	<b>N (%)</b>	
119 (62.0)	19 (76.0)	<b>Before getting sick, while healthy</b>
15 (7.8)	0 (0.0)	<b>When first diagnosed with a life-threatening illness</b>
7 (3.7)	0 (0.0)	<b>When first sick from a life-threatening illness</b>
8 (4.2)	0 (0.0)	<b>When first hospitalized with a life-threatening illness</b>
2 (1.0)	0 (0.0)	<b>If dying</b>
34 (17.7)	5 (20.0)	<b>All of the above</b>
1 (0.52)	0 (0.0)	<b>Never</b>
4 (2.1)	0 (0.0)	<b>Do not know</b>
2 (1.0)	1 (4.0)	<b>Other</b>

6. Who are the best people/person on the treatment team to bring it up with you? SELECT ALL THAT APPLY.

<b>African Americans</b>	<b>Non-African Americans</b>	
<b>N (%)</b>	<b>N (%)</b>	
164 (85.4)	19 (76.0)	<b>Physician</b>
35 (18.2)	8 (32.0)	<b>Nurse Practitioner</b>
37 (19.3)	8 (32.0)	<b>Nurse</b>
71 (37.0)	15 (60.0)	<b>Social Worker</b>
36 (18.8)	11 (44.0)	<b>Psychologist</b>
47 (24.5)	9 (36.0)	<b>Case Manager</b>
37 (19.3)	8 (32.0)	<b>Chaplain</b>
29 (15.1)	10 (40.0)	<b>Patient Advocate</b>
25 (13.0)	5 (20.0)	<b>Other</b>

7. Do you believe that once you make an important medical decision, for example, to be put on a respirator, a machine that breathes for you, that you would be able to change your mind?

African Americans N (%)	Non-African Americans N (%)	
79 (41.4)	9 (36.0)	Yes definitely
19 (10.0)	4 (16.0)	Very probable
23 (12.0)	5 (20.0)	Probably
14 (7.3)	2 (8.0)	Probably not
27 (14.1)	2 (8.0)	Definitely no
29 (15.2)	3 (12.0)	Do not know

8. Do you think your doctor or the hospital will respect your wishes, that is, do what you want about medical care?

African Americans N (%)	Non-African Americans N (%)	
136 (70.8)	18 (72.0)	Yes definitely
20 (10.4)	2 (8.0)	Very probable
20(10.4))	4 (16.0)	Probably
4 (2.1)	0 (0.0)	Probably not
6 (3.1)	0 (0.0)	Definitely no
6 (3.1)	1 (4.0)	Do not know

9. Do you think your parent/ guardian/ surrogate understands your wishes?

African Americans N (%)	Non-African Americans N (%)	
139 (72.4)	17 (68.0)	Yes definitely
20 (10.4)	2 (8.0)	Very probable
15 (7.8)	2(8.0)	Probably
8 (4.2)	1 (4.0)	Probably not
3 (1.6)	0 (0.0)	Definitely no
7 (3.7)	3 (12.0)	Do not know

10. Do you think your parent/guardian/surrogate will respect your wishes, that is, do what you want about your medical care?

<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
149 (77.6)	19 (76.0)	<b>Yes definitely</b>
17 (8.9)	3 (12.0)	<b>Very probable</b>
17 (8.9)	2 (8.0)	<b>Probably</b>
3 (1.6)	0 (0.0)	<b>Probably not</b>
1 (0.5)	0 (0.0)	<b>Definitely no</b>
5 (2.6)	1 (4.0)	<b>Do not know</b>

### **Thoughts about Death and Dying**

11. How often has death and dying been talked about in your family?

<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
21 (10.9)	2 (8.0)	<b>Yes definitely</b>
22 (11.5)	5 (20.0)	<b>Very probable</b>
69 (35.9)	12 (48.0)	<b>Probably</b>
53 (27.6)	5 (20.0)	<b>Probably not</b>
25 (13.0)	1 (4.0)	<b>Definitely no</b>
2 (1.0)	0 (0.0)	<b>Do not know</b>

12. How comfortable are you talking about death?

<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
87 (45.3)	16 (64.0)	<b>Very comfortable</b>
57 (29.7)	6 (24.0)	<b>Somewhat comfortable</b>
21 (10.9)	0 (0.0)	<b>Neither comfortable nor uncomfortable</b>
13 (6.8)	1 (4.0)	<b>Not very comfortable</b>
11 (5.7)	2 (8.0)	<b>Not at all comfortable</b>
3 (1.6)	0 (0.0)	<b>Do not know</b>

13. How likely are you to...

- a. Attend funerals or memorial services when a loved one, friend or a classmate dies

African Americans N (%)	Non-African Americans N (%)	
121 (63.0)	13 (52.0)	Very likely
44 (22.9)	7 (28.0)	Somewhat likely
5 (2.6)	0 (0.0)	Neither likely or unlikely
8 (4.2)	2 (8.0)	Not very likely
14 (7.3)	2 (8.0)	Not at all likely
0 (0.0)	1 (4.0)	Do not know

- b. Avoid medical checkups because you are afraid the doctor will find “something serious”

African Americans N (%)	Non-African Americans N (%)	
8 (4.2)	0 (0.0)	Very likely
6 (3.1)	1 (4.0)	Somewhat likely
7 (3.7)	1 (4.0)	Neither likely or unlikely
10 (5.2)	0 (0.0)	Not very likely
154 (80.2)	23 (92.0)	Not at all likely
7 (3.7)	0 (0.0)	Do not know

- c. Speak freely to loved ones about death and dying

African Americans N (%)	Non-African Americans N (%)	
90 (46.9)	17 (68.0)	Very likely
63 (32.8)	3 (12.0)	Somewhat likely
6 (3.1)	1 (4.0)	Neither likely or unlikely
13 (6.8)	3 (12.0)	Not very likely
17 (8.9)	1 (4.0)	Not at all likely
3 (1.6)	0 (0.0)	Do not know

- d. Visit or telephone a friend or relative who has recently lost a loved one in order to see how they are doing

	<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
e. P	128 (66.7)	17 (68.0)	<b>Very likely</b>
r	45 (23.4)	7 (28.0)	<b>Somewhat likely</b>
e	5 (2.6)	1 (4.0)	<b>Neither likely or unlikely</b>
p	2 (1.0)	0 (0.0)	<b>Not very likely</b>
l	9 (4.7)	0 (0.0)	<b>Not at all likely</b>
a	3 (1.6)	0 (0.0)	<b>Do not know</b>

your own funeral, for example, choose someone to speak or choose the music you would want

	<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
	93 (48.4)	13 (52.0)	<b>Very likely</b>
	42 (21.9)	3 (12.0)	<b>Somewhat likely</b>
	11 (5.7)	2 (8.0)	<b>Neither likely or unlikely</b>
	10 (5.2)	2 (8.0)	<b>Not very likely</b>
	26 (13.5)	5 (20.0)	<b>Not at all likely</b>
	10 (5.2)	0 (0.0)	<b>Do not know</b>

14. How afraid if at all, are you of...

- a. Dying from a long term illness

	<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
	35 (18.2)	1 (4.0)	<b>Very afraid</b>
	48 (25.0)	9 (36.0)	<b>Somewhat afraid</b>
	16 (8.3)	3 (12.0)	<b>Neither afraid nor not afraid</b>
	10 (5.2)	4 (16.0)	<b>Not very afraid</b>
	78 (40.6)	7 (28.0)	<b>Not at all afraid</b>
	5 (2.6)	1 (4.0)	<b>Do not know</b>

b. Dying suddenly, such as an accident, or being killed

African Americans N (%)	Non-African Americans N (%)	
42 (21.9)	3 (12.0)	Very afraid
39 (20.3)	4 (16.0)	Somewhat afraid
11 (5.7)	2 (8.0)	Neither afraid nor not afraid
10 (5.2)	2 (8.0)	Not very afraid
87 (45.3)	14 (56.0)	Not at all afraid
3 (1.6)	0 (0.0)	Do not know

c. Dying alone

African Americans N (%)	Non-African Americans N (%)	
46 (24.0)	3 (12.0)	Very afraid
39 (20.3)	4 (16.0)	Somewhat afraid
6 (3.1)	4 (16.0)	Neither afraid nor not afraid
8 (4.2)	1 (4.0)	Not very afraid
87 (45.3)	12 (48.0)	Not at all afraid
6 (3.1)	1 (4.0)	Do not know

d. Dying in an institution such as a nursing home or hospital

African Americans N (%)	Non-African Americans N (%)	
55 (28.7)	2 (8.0)	Very afraid
33 (17.2)	8 (32.0)	Somewhat afraid
10 (5.2)	4 (16.0)	Neither afraid nor not afraid
9 (4.7)	3 (12.0)	Not very afraid
76 (39.6)	8 (32.0)	Not at all afraid
9 (4.7)	0 (0.0)	Do not know

e. Dying painfully

African Americans N (%)	Non-African Americans N (%)	
84 (43.7)	10 (40.0)	Very afraid
47 (24.5)	9 (36.0)	Somewhat afraid
5 (2.6)	2 (8.0)	Neither afraid nor not afraid
4 (2.1)	2 (8.0)	Not very afraid
43 (22.4)	1 (4.0)	Not at all afraid
9 (4.7)	1 (4.0)	Do not know

15. How strongly do you agree or disagree that...

a. Dying is an important part of life

African Americans N (%)	Non-African Americans N (%)	
113 (21.9)	17 (68.0)	Strongly agree
52 (20.3)	3 (12.0)	Agree
7 (5.7)	3 (12.0)	Neither agree or disagree
8 (5.2)	0 (0.0)	Disagree
5 (45.3)	1 (4.0)	Strongly disagree
7 (1.6)	1 (4.0)	Do not know

b. If someone could tell me when I would die, I would want to know

African Americans N (%)	Non-African Americans N (%)	
47 (21.9)	3 (12.0)	Strongly agree
26 (20.3)	2 (8.0)	Agree
10 (5.7)	5 (20.0)	Neither agree or disagree
26 (5.2)	7 (28.0)	Disagree
68 (45.3)	8 (32.0)	Strongly disagree
15 (1.6)	0 (0.0)	Do not know



16. What you think about death and dying, how concerned are you that...

a. The family's money won't last

African Americans N (%)	Non-African Americans N (%)	
54 (28.1)	3 (12.0)	Very concerned
35 (18.2)	5 (20.0)	Concerned
14 (7.3)	3 (12.0)	Neither concerned nor unconcerned
34 (17.7)	4 (16.0)	Not concerned
47 (24.5)	10 (40.0)	Not at all concerned
8 (4.2)	0 (0.0)	Do not know

b. I will be a burden, or overload, to my family or friends

African Americans N (%)	Non-African Americans N (%)	
54 (28.1)	3 (12.0)	Very concerned
46 (24.0)	6 (24.0)	Concerned
7 (3.7)	5 (20.0)	Neither concerned nor unconcerned
31 (16.2)	4 (16.0)	Not concerned
47 (24.5)	7 (28.0)	Not at all concerned
7 (3.7)	0 (0.0)	Do not know

17. Which of the following health problems, if any, do you think are worse than death?  
SELECT ALL THAT APPLY.

African Americans N (%)	Non-African Americans N (%)	
86 (44.8)	17 (68.0)	Living with great pain
62 (32.3)	11 (44.0)	Total physical dependency on others, for example, being in a wheelchair
109 (56.8)	20 (80.0)	Not being able to communicate my wishes and/or care to family members, for example, being in a coma
48 (25.0)	2 (8.0)	None are worse than death

**Dealing with Dying**

18. How important would each of the following be to you if you were dealing with your own dying?

a. Family and friends visiting you

African Americans N (%)	Non-African Americans N (%)	
116 (60.4)	14 (56.0)	Very important
44 (22.9)	3 (12.0)	Somewhat important
4 (2.1)	1 (4.0)	Neither important nor unimportant
10 (5.2)	5 (20.0)	Not very important
11 (5.7)	2 (8.0)	Not at all important
7 (3.7)	0 (0.0)	Do not know

b. Being able to stay in your own home

African Americans N (%)	Non-African Americans N (%)	
116 (60.4)	13 (52.0)	Very important
38 (19.8)	7 (28.0)	Somewhat important
7 (3.7)	2 (8.0)	Neither important nor unimportant
16 (8.3)	2 (8.0)	Not very important
8 (4.2)	1 (4.0)	Not at all important
7 (3.7)	0 (0.0)	Do not know

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answers from your doctor

African Americans N (%)	Non-African Americans N (%)	
183 (95.3)	25 (100.0)	Very important
6 (3.1)	0 (0.0)	Somewhat important
1 (0.52)	0 (0.0)	Neither important nor unimportant
0 (0.0)	0 (0.0)	Not very important
2 (1.0)	0 (0.0)	Not at all important
0 (0.0)	0 (0.0)	Do not know

d. Comfort from church services or persons such as a minister, priest, imam, or rabbi

African Americans N (%)	Non-African Americans N (%)	
107 (56.3)	7 (28.0)	Very important
49 (25.8)	2 (8.0)	Somewhat important
7 (3.7)	4 (16.0)	Neither important nor unimportant
9 (4.7)	2 (8.0)	Not very important
13 (6.8)	9 (36.0)	Not at all important
5 (2.6)	1 (4.0)	Do not know

e. Planning your own funeral

African Americans N (%)	Non-African Americans N (%)	
96 (50.3)	10 (40.0)	Very important
58 (30.4)	7 (28.0)	Somewhat important
10 (5.2)	4 (16.0)	Neither important nor unimportant
11 (5.8)	2 (8.0)	Not very important
13 (6.8)	2 (8.0)	Not at all important
3 (1.6)	0 (0.0)	Do not know

f. Being able to complete an advance directive that would let your loved ones know your wishes, if you were unable to speak for yourself

African Americans N (%)	Non-African Americans N (%)	
154 (80.2)	22 (88.0)	Very important
32 (16.7)	2 (8.0)	Somewhat important
0 (0.0)	0 (0.0)	Neither important nor unimportant
1 (0.52)	0 (20.0)	Not very important
2 (1.0)	1 (4.0)	Not at all important
3 (1.6)	0 (0.0)	Do not know

g. Fulfilling personal goals/ pleasures

<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>
123 (64.1)	15 (60.0)
47 (24.5)	3 (12.0)
3 (1.6)	3 (12.0)
9 (4.7)	0 (0.0)
7 (3.7)	2 (8.0)
3 (1.6)	2 (8.0)

**Very important**  
**Somewhat important**  
**Neither important nor unimportant**  
**Not very important**  
**Not at all important**  
**Do not know**

h. Reviewing your life history with your family

<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>
79 (41.2)	6 (24.0)
56 (29.2)	8 (32.0)
10 (5.2)	5 (20.0)
17 (8.9)	1 (4.0)
28 (14.6)	4 (16.0)
2 (1.0)	1 (4.0)

**Very important**  
**Somewhat important**  
**Neither important nor unimportant**  
**Not very important**  
**Not at all important**  
**Do not know**

i. Having healthcare professionals visit you at your home

<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>
95 (49.5)	9 (36.0)
58 (30.2)	9 (36.0)
6 (3.1)	2 (8.0)
9 (4.7)	2 (8.0)
22 (11.5)	3 (12.0)
2 (1.0)	0 (0.0)

**Very important**  
**Somewhat important**  
**Neither important nor unimportant**  
**Not very important**  
**Not at all important**  
**Do not know**

j. Understanding your treatment choices

African Americans N (%)	Non-African Americans N (%)	
168 (87.5)	25 (100.0)	Very important
22 (11.5)	0 (0.0)	Somewhat important
0 (0.0)	0 (0.0)	Neither important nor unimportant
1 (0.52)	0 (0.0)	Not very important
1 (0.52)	0 (0.0)	Not at all important
0 (0.0)	0 (0.0)	Do not know

19. How important are each of the following to you when you think about dying?

a. Being physically comfortable

African Americans N (%)	Non-African Americans N (%)	
154 (80.2)	22 (88.0)	Very important
32 (16.7)	2 (8.0)	Somewhat important
0 (0.0)	0 (0.0)	Neither important nor unimportant
1 (0.52)	0 (20.0)	Not very important
2 (1.0)	1 (4.0)	Not at all important
3 (1.6)	0 (0.0)	Do not know

b. Being free from pain

African Americans N (%)	Non-African Americans N (%)	
165 (85.9)	21 (84.0)	Very important
22 (11.5)	3 (12.0)	Somewhat important
2 (1.0)	0 (0.0)	Neither important nor unimportant
1 (0.52)	1 (4.0)	Not very important
0 (0.0)	0 (0.0)	Not at all important
2 (1.0)	0 (0.0)	Do not know

c. Having said everything I want to say to people in my family

African Americans N (%)	Non-African Americans N (%)
138 (71.9)	15 (60.0)
39 (20.3)	8 (32.0)
3 (1.6)	1 (4.0)
4 (2.1)	0 (0.0)
7 (3.7)	1 (4.0)
1 (0.52)	0 (0.0)

Very important  
Somewhat important  
Neither important nor unimportant  
Not very important  
Not at all important  
Do not know

d. Being at peace spiritually

African Americans N (%)	Non-African Americans N (%)
172 (89.6)	19 (76.0)
15 (7.8)	3 (12.0)
2 (1.0)	1 (4.0)
1 (0.52)	0 (0.0)
1 (0.52)	2 (8.0)
1 (0.52)	0 (0.0)

Very important  
Somewhat important  
Neither important nor unimportant  
Not very important  
Not at all important  
Do not know

e. Not being a burden to loved ones

African Americans N (%)	Non-African Americans N (%)
162 (84.4)	20 (80.0)
25 (13.0)	4 (16.0)
1 (0.52)	1 (4.0)
1 (0.52)	0 (0.0)
3 (1.6)	0 (0.0)
0 (0.0)	0 (0.0)

Very important  
Somewhat important  
Neither important nor unimportant  
Not very important  
Not at all important  
Do not know

f. Knowing how to say goodbye

African Americans N (%)	Non-African Americans N (%)
137 (71.4)	17 (68.0)
37 (19.3)	6 (24.0)
3 (1.6)	1 (4.0)
5 (2.6)	1 (4.0)
5 (2.6)	0 (0.0)
5 (2.6)	0 (0.0)

Very important  
Somewhat important  
Neither important nor unimportant  
Not very important  
Not at all important  
Do not know

g. Having a sense of your own worth or value

<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
147 (76.6)	19 (76.0)	<b>Very important</b>
31 (16.2)	6 (24.0)	<b>Somewhat important</b>
3 (1.6)	0 (0.0)	<b>Neither important nor unimportant</b>
2 (1.0)	0 (0.0)	<b>Not very important</b>
7 (3.7)	0 (0.0)	<b>Not at all important</b>
2 (1.0)	0 (0.0)	<b>Do not know</b>

h. Being off machines that extend life such as life support

<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
114 (59.4)	17 (68.0)	<b>Very important</b>
34 (17.7)	2 (8.0)	<b>Somewhat important</b>
8 (4.2)	2 (8.0)	<b>Neither important nor unimportant</b>
5 (2.6)	1 (4.0)	<b>Not very important</b>
13 (6.8)	1 (4.0)	<b>Not at all important</b>
18 (9.4)	2 (8.0)	<b>Do not know</b>

i. Dying a natural death

<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
127 (66.2)	16 (64.0)	<b>Very important</b>
36 (18.8)	7 (28.0)	<b>Somewhat important</b>
8 (4.2)	1 (4.0)	<b>Neither important nor unimportant</b>
4 (2.1)	0 (0.0)	<b>Not very important</b>
7 (3.7)	1 (4.0)	<b>Not at all important</b>
10 (5.2)	0 (0.0)	<b>Do not know</b>

20. If death were likely to happen in the next few weeks, and you could choose where to die, where would you MOST want to die? CHECK ONE answer only. \*Missing=1

<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
116 (60.7)	19 (76.0)	<b>At home</b>
1 (0.52)	1 (4.0)	<b>In an assisted-living facility</b>
37 (19.4)	1 (4.0)	<b>In a hospital</b>
1 (0.52)	0 (0.0)	<b>In a nursing home</b>
4 (2.1)	2 (8.0)	<b>In a residential hospice</b>
32 (16.8)	2 (8.0)	<b>Do not know</b>

21. Below are some statements related to pain near the end-of-life that have been expressed by people. How strongly do you agree or disagree with each statement? \*Missing=2

a. I am afraid my doctor may not believe I am in pain and treat my pain.

<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
27 (14.2)	3 (12.0)	<b>Strongly agree</b>
29 (15.3)	5 (20.0)	<b>Agree</b>
11 (5.8)	3 (12.0)	<b>Neither agree or disagree</b>
49 (25.8)	5 (20.0)	<b>Disagree</b>
61 (32.1)	9 (36.0)	<b>Strongly disagree</b>
13 (6.8)	0 (0.0)	<b>Do not know</b>

b. I would only take pain medicines when the pain is severe

<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
77 (40.3)	10 (40.0)	<b>Strongly agree</b>
79 (41.4)	5 (20.0)	<b>Agree</b>
4 (2.1)	0 (0.0)	<b>Neither agree or disagree</b>
15 (7.9)	3 (12.0)	<b>Disagree</b>
11 (5.8)	6 (24.0)	<b>Strongly disagree</b>
5 (2.6)	1 (4.0)	<b>Do not know</b>

c. I am afraid I will become addicted to pain medicines over time



<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
29 (15.1)	3 (12.0)	<b>Strongly agree</b>
30 (15.6)	2 (8.0)	<b>Agree</b>
12 (6.3)	4 (16.0)	<b>Neither agree or disagree</b>
55 (28.7)	3 (12.0)	<b>Disagree</b>
60 (31.3)	12 (48.0)	<b>Strongly disagree</b>
6 (3.1)	1 (4.0)	<b>Do not know</b>

- d. I would take the lowest amount of medicine possible to save larger doses for when the pain is worse

<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
65 (33.9)	8 (32.0)	<b>Strongly agree</b>
64 (33.3)	1 (4.0)	<b>Agree</b>
12 (6.3)	4 (16.0)	<b>Neither agree or disagree</b>
28 (14.6)	5 (20.0)	<b>Disagree</b>
16 (8.3)	4 (16.0)	<b>Strongly disagree</b>
7 (3.7)	3 (12.0)	<b>Do not know</b>

- e. I am afraid I would be given too much pain medicine

<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
14 (7.3)	1 (4.0)	<b>Strongly agree</b>
22 (11.5)	1 (4.0)	<b>Agree</b>
20 (10.4)	0 (0.0)	<b>Neither agree or disagree</b>
77 (40.1)	9 (36.0)	<b>Disagree</b>
52 (27.1)	11 (44.0)	<b>Strongly disagree</b>
7 (3.7)	3 (12.0)	<b>Do not know</b>

22. Have you heard of hospice services?

African Americans N (%)	Non-African Americans N (%)	
168 (87.5)	24 (96.0)	Yes
24 (12.5)	1 (4.0)	No (if no skip to Q23 & 24)

23. How did you learn about hospice services? \*Missing= 3

African Americans N (%)	Non-African Americans N (%)	
118 (71.5)	12 (50.0)	I know someone who used hospice services
5 (3.0)	0 (0.0)	I have used hospice services myself
1 (0.6)	2 (8.3)	I am/was a hospice volunteer
14 (8.5)	3 (12.5)	I heard from a healthcare professional
13 (7.9)	5 (20.8)	I read literature/newspaper/TV/radio/other media
12 (7.3)	2 (8.3)	I heard from others
2 (1.2)	0 (0.0)	No response

24. If you were dying, would you want hospice support? \*Missing=3

African Americans N (%)	Non-African Americans N (%)	
87 (53.1)	15 (60.0)	Yes
29 (17.7)	1 (4.0)	No
47 (28.7)	8 (32.0)	Do not know/not sure
1 (0.61)	1 (4.0)	No response

**Spiritual Well-Being**

25. Do you consider yourself...? (If not religious/spiritual, skip Q26 and Q27)

African Americans N (%)	Non-African Americans N (%)	
81 (42.2)	9 (37.5)	Very religious/spiritual
95 (49.5)	9 (37.5)	Somewhat religious/spiritual
8 (4.2)	2 (8.3)	Not very religious/spiritual
5 (2.6)	4 (16.7)	Not religious/spiritual
1 (0.52)	0 (0.0)	Do not know
1 (1.0)	0 (0.0)	No response

26. How often do you attend religious or spiritual services?

African Americans N (%)	Non-African Americans N (%)	
41 (21.8)	0 (0.0)	Always
41 (21.8)	6 (27.3)	Very Often
53 (28.2)	7 (31.8)	Sometimes
37 (19.7)	7 (31.8)	Rarely
15 (8.0)	2 (9.1)	Never
1 (0.53)	0 (0.0)	Do not know

27. How often does your religion or spirituality help you face your fears or do what you were afraid to do?

African Americans N (%)	Non-African Americans N (%)	
102 (54.6)	8 (36.4)	Everyday
23 (12.3)	2 (9.1)	A few times a week
26 (13.9)	5 (22.7)	A few times a month
22 (11.8)	6 (27.3)	Rarely
9 (4.8)	1 (4.6)	Never
5 (2.7)	0 (0.0)	Do not know

28. How many times in your life have you been seen at an emergency room? \*Missing=5

African Americans N (%)	Non-African Americans N (%)	
5 (2.7)	0 (0.0)	0
4 (2.1)	1 (4.0)	1
16 (8.6)	2 (8.0)	2
12 (6.4)	5 (20.0)	3
17 (9.1)	5 (20.0)	4
19 (10.2)	3 (12.0)	5
13 (7.0)	0 (0.0)	6

7 (3.7)	0 (0.0)	<b>7</b>
4 (2.1)	1 (4.0)	<b>8</b>
2 (1.1)	0 (0.0)	<b>9</b>
31 (16.6)	1 (4.0)	<b>10</b>
2 (1.1)	2 (8.0)	<b>12</b>
3 (1.6)	2 (8.0)	<b>15</b>
23 (12.3)	2 (8.0)	<b>20</b>
1 (0.53)	0 (0.0)	<b>24</b>
6 (3.2)	0 (0.0)	<b>30</b>
1 (0.53)	0 (0.0)	<b>40</b>
8 (4.3)	1 (4.0)	<b>50</b>
1 (0.53)	0 (0.0)	<b>60</b>
1 (0.53)	0 (0.0)	<b>65</b>
1 (0.53)	0 (0.0)	<b>70</b>
8 (4.3)	0 (0.0)	<b>100</b>
1 (0.53)	0 (0.0)	<b>220</b>
1 (0.53)	0 (0.0)	<b>999</b>

29. How many times in your life have you ever been hospitalized? *Missing=4*

<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
9 (4.8)	4 (16.0)	<b>0</b>
18 (9.6)	1 (4.0)	<b>1</b>
29 (15.4)	3 (12.0)	<b>2</b>
19 (10.1)	5 (20.0)	<b>3</b>
25 (13.3)	2 (8.0)	<b>4</b>
29 (15.4)	6 (24.0)	<b>5</b>
11 (5.9)	1 (4.0)	<b>6</b>

6 (3.2)	0 (0.0)	<b>7</b>
1 (0.53)	1 (4.0)	<b>8</b>
2 (1.1)	0 (0.0)	<b>9</b>
14 (7.5)	0 (0.0)	<b>10</b>
5 (2.7)	0 (0.0)	<b>12</b>
3 (1.6)	0 (0.0)	<b>15</b>
6 (3.2)	1 (0.0)	<b>20</b>
3 (1.6)	1 (0.0)	<b>25</b>
3 (1.6)	0 (0.0)	<b>30</b>
1 (0.53)	0 (0.0)	<b>35</b>
2 (1.1)	0 (0.0)	<b>40</b>
2 (1.1)	0 (0.0)	<b>50</b>
1 (0.53)	0 (0.0)	<b>60</b>

29a. How many nights have you spend in a hospital in the last year?

<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
122 (63.5)	19 (76.0)	<b>0</b>
8 (4.2)	0 (0.0)	<b>1</b>
15 (7.8)	1 (4.0)	<b>2</b>
11 (5.7)	1 (4.0)	<b>3</b>
9 (4.7)	0 (0.0)	<b>4</b>
4 (2.1)	1 (4.0)	<b>5</b>
3 (1.6)	1 (4.0)	<b>7</b>
1 (0.53)	0 (0.0)	<b>10</b>
2 (1.0)	1 (4.0)	<b>12</b>
3 (1.6)	0 (0.0)	<b>14</b>
1 (0.53)	0 (0.0)	<b>15</b>
1 (0.53)	0 (0.0)	<b>16</b>
2 (1.0)	0 (0.0)	<b>20</b>
2 (1.0)	0 (0.0)	<b>21</b>
1 (0.53)	0 (0.0)	<b>25</b>
3 (1.6)	1 (4.0)	<b>30</b>
2 (1.0)	0 (0.0)	<b>90</b>
1 (0.53)	0 (0.0)	<b>120</b>
1 (0.53)	0 (0.0)	<b>180</b>

29b. How many of these hospitalization were psychiatric hospitalizations? For example, behavior problems or depression.

<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
159 (85.5)	21 (87.5)	<b>0</b>
17 (9.1)	1 (4.2)	<b>1</b>
3 (1.6)	2 (8.3)	<b>2</b>
2 (1.1)	0 (0.0)	<b>3</b>
1 (0.54)	0 (0.0)	<b>4</b>
1 (0.54)	0 (0.0)	<b>5</b>
1 (0.54)	0 (0.0)	<b>6</b>
1 (0.54)	0 (0.0)	<b>7</b>
1 (0.54)	0 (0.0)	<b>17</b>

29c. How many nights have you spent psychiatrically hospitalized in the past year?

<b>African Americans N (%)</b>	<b>Non-African Americans N (%)</b>	
172 (95.6)	23 (95.8)	<b>0</b>
2 (1.1)	0 (0.0)	<b>1</b>
1 (0.6)	0 (0.0)	<b>2</b>
1 (0.6)	0 (0.0)	<b>3</b>
1 (0.6)	0 (0.0)	<b>7</b>
1 (0.6)	0 (0.0)	<b>10</b>
1 (0.6)	1 (4.2)	<b>14</b>
1 (0.6)	0 (0.0)	<b>30</b>

**Supplement Table 3. Significantly different survey responses by race (N=217)<sup>a</sup>**

<b>Adult Palliative Care Survey Item<sup>b</sup></b>	<b>African-American (n =192) N (%)</b>	<b>Non-African- American (n =25) N (%)</b>	<b>P<sup>c</sup></b>
If someone could tell me when I would die, I would want to know			0.0411
Agree/Strongly Agree	73 (41.2)	5 (20.0)	
Otherwise <sup>d</sup>	104 (58.8)	20 (80.0)	
How important would family and friends visiting be to you if you were dealing with your own dying?			0.0171
Somewhat important/Very Important	160 (86.5)	17 (68.0)	
Otherwise <sup>e</sup>	25 (13.5)	8 (32.0)	
How important would being at peace spiritually be to you if you were dealing with your own dying?			0.0352
Somewhat important/Very Important	187 (97.1)	22 (88.0)	
Otherwise <sup>e</sup>	4 (2.1)	3 (12.0)	
How did you learn about hospice services?			0.0039
I know someone who used hospice services myself	118 (72.4)	12 (50.0)	
I have used hospice services myself	5 (3.1)	0 (0.0)	
I am/was a hospice volunteer	1 (0.6)	2 (8.3)	
I heard from a health care professional	14 (8.6)	3 (12.5)	
I read literature/newspaper/TV/radio/other media	13 (8.0)	5 (20.8)	
I heard from others	12 (7.4)	2 (8.3)	
If death were likely to happen in the next few weeks, and you could choose where to die, where would you MOST want to die?			0.0285
At home	116 (60.7)	19 (76.0)	
In a hospital	37 (19.4)	1 (4.0)	
Other (assisted living/nursing home/residential hospice)	6 (3.1)	3 (12.0)	
Do not know	32 (16.8)	2 (8.0)	

I would only take pain medicines when the pain is severe. 0.0113

Agree/Strongly Agree	156 (83.9)	15 (62.5)
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Otherwise <sup>d</sup>	30 (16.1)	9 (37.5)
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I would take the lowest amount of medicine possible to save larger doses for later when the pain is worse. 0.0067

Agree/Strongly Agree	129 (69.7)	9 (40.9)
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Otherwise <sup>d</sup>	56 (30.3)	13 (59.1)
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<sup>a</sup>6 participants who declined to give race were excluded.

<sup>b</sup>“Don’t know” was excluded from each question and changed the sample size for each question.

<sup>c</sup>All P values computed using Pearson chi-square test or Fisher Exact Test

<sup>d</sup>Otherwise: Neither agree nor disagree, Disagree, Strongly Disagree

<sup>e</sup>Otherwise: Neither important nor unimportant, Not very important, Not at all important



**Supplement Table 4. Significantly different survey responses by age (N=223)**

<b>Adult Palliative Care Survey<sup>a</sup></b>	<b>Young Adult 22–39 years old (n = 44) N (%)</b>	<b>Adult 40–60 years old (n = 128) N (%)</b>	<b>Elderly 61–77 years old (n = 51) N (%)</b>	<b>P<sup>b</sup></b>
How afraid if at all, are you of dying suddenly, such as an accident, or being killed?				0-0007
Afraid	27 (61.3)	50 (40.0)	11 (22.5)	
Otherwise <sup>c</sup>	17 (38.6)	75 (60.0)	38 (77.6)	
Dying is an important part of life.				0-0118
Agree	32 (74.4)	115 (92.0)	43 (91.5)	
Otherwise <sup>d</sup>	11 (25.6)	10 (8.0)	4 (8.5)	
How important would family and friends visiting be to you if you were dealing with your own dying?				0-0332
Important	42 (95.5)	98 (76.7)	43 (87.8)	
Otherwise <sup>e</sup>	2 (4.56)	25 (20.3)	6 (12.3)	
How important would fulfilling personal goals/pleasures be to you if you were dealing with your own dying?				0-0208
Important	42 (95.5)	113 (89.7)	37 (77.1)	
Otherwise <sup>e</sup>	2 (4.6)	13 (10.3)	11 (22.9)	
How important would reviewing your life history with your family be to you if you were dealing with your own dying?				0-0053
Important	36 (81.8)	90 (71.4)	26 (52.0)	
Otherwise <sup>e</sup>	8 (18.2)	36 (28.6)	24 (48.0)	
How often do you attend religious or spiritual services?				0-0426
Always to sometimes	22 (55.0)	91 (72.8)	39 (78.0)	
Rarely or never	18 (45.0)	34 (27.2)	11 (22.0)	

<sup>a</sup>“Don’t know” was excluded from each question and changed the sample size for each question.

<sup>b</sup>All P values were computed using Pearson chi-square test or Fisher Exact Test.

<sup>c</sup>Otherwise: Neither afraid nor not afraid, Not very afraid, Not at all afraid

<sup>d</sup>Otherwise: Neither agree nor disagree, Disagree, Strongly Disagree

<sup>e</sup>Otherwise: Neither important nor unimportant, Not very important, Not at all important

**Supplement Table 5. Significantly different survey responses by gender (N=219)<sup>a</sup>**

<b>Adult Palliative Care Survey<sup>b</sup></b>	<b>Females ( n = 94) N (%)</b>	<b>Males ( n = 125) N (%)</b>	<b>P<sup>c</sup></b>
How afraid if at all, are you of dying suddenly, such as an accident, or being killed?			0.0076
Afraid	46 (50.0)	39 (32.0)	
Otherwise <sup>d</sup>	46 (50.0)	83 (68.0)	
If someone could tell me when I would die, I would want to know.			0.0149
Agree	40 (47.6)	37 (30.8)	
Otherwise <sup>e</sup>	44 (52.4)	83 (69.2)	
How important would comfort from church services or persons such as a minister, priest, imam, or rabbi be to you if you were dealing with your own dying?			0.0033
Important	79 (87.8)	85 (70.8)	
Otherwise <sup>f</sup>	11 (12.2)	35 (29.2)	
How important would planning your own funeral be to you if you were dealing with your own dying?			0.0035
Important	81 (88.0)	88 (71.5)	
Otherwise <sup>f</sup>	11 (12.0)	35 (28.5)	
How important would reviewing your life history with your family be to you if you were dealing with your own dying?			0.005
Important	74 (79.6)	76 (61.8)	
Otherwise <sup>f</sup>	19 (20.4)	47 (38.2)	
How important are knowing how to say goodbye to you when you think about dying?			0.0445
Important	91 (96.8)	108 (90.0)	
Otherwise <sup>f</sup>	3 (3.2)	12 (10.0)	

<sup>a</sup>4 participants who were transgender were removed due to the size is less than 5.

<sup>b</sup>“Don’t know” was excluded from each question and changed the sample size for each question.

<sup>c</sup>All P values were computed using Pearson chi-square test or Fisher Exact Test.

<sup>d</sup>Otherwise: Neither afraid nor not afraid, Not very afraid, Not at all afraid

<sup>e</sup>Otherwise: Neither agree nor disagree, Disagree, Strongly Disagree

<sup>f</sup>Otherwise: Neither important nor unimportant, Not very important, Not at all important

**Supplement Table 6. Significantly different survey responses by sexual orientation (N=223)**

Adult Palliative Care Survey <sup>a</sup>	Non-Heterosexual (n = 75) n (%)	Heterosexual (n = 148) n (%)	P <sup>b</sup>
How afraid if at all, are you of dying alone?			0.0397
Afraid	39 (53.4)	55 (38.7)	
Otherwise <sup>c</sup>	34 (46.6)	87 (61.3)	
How important would comfort from church services or persons such as a minister, priest, imam, or rabbi be to you if you were dealing with your own dying?			0.002
Important	47 (66.2)	121 (84.6)	
Otherwise <sup>d</sup>	24 (33.8)	22 (15.4)	
I would only take pain medicines when the pain is severe.			0.0091
Agree	52 (70.3)	121 (85.2)	
Otherwise <sup>e</sup>	22 (29.7)	21 (14.8)	
Do you consider yourself religious/spiritual?			0.0093
Religious/spiritual	62 (83.8)	137 (94.5)	
Not religious/not spiritual	12 (16.2)	8 (5.5)	
How often do you attend religious or spiritual services?			0.0017
Always to sometimes	41 (56.9)	111 (77.6)	
Rarely or never	31 (43.1)	32 (22.4)	

<sup>a</sup>“Don’t know” was excluded from each question and changed the sample size for each question.

<sup>b</sup>All P values were computed using Pearson chi-square test.

<sup>c</sup>Otherwise: Neither afraid nor not afraid, Not very afraid, Not at all afraid

<sup>d</sup>Otherwise: Neither important nor unimportant, Not very important, Not at all important

<sup>e</sup>Otherwise: Neither agree nor disagree, Disagree, Strongly Disagree

**Supplement Table 7. Significantly different survey responses by education (N=223)**

<b>Adult Palliative Care Survey<sup>a</sup></b>	<b>Some college or higher (n = 130) n (%)</b>	<b>High school or lower (n = 93) n (%)</b>	<b>P<sup>b</sup></b>
How strongly do you agree or disagree that dying is an important part of life?			0.0391
Agree	117 (92.1)	73 (83.0)	
Otherwise <sup>c</sup>	10 (7.9)	15 (17.1)	
I would only take pain medicines when the pain is severe.			0.0238
Agree	96 (75.0)	77 (87.5)	
Otherwise <sup>c</sup>	32 (25.0)	11 (12.5)	
I am afraid I would be given too much pain medicine.			0.0202
Agree	16 (13.5)	24 (26.1)	
Otherwise <sup>c</sup>	103 (86.6)	68 (73.9)	

<sup>a</sup>“Don’t know” was excluded from each question and changed the sample size for each question.

<sup>b</sup>All P values were computed using Pearson chi-square test.

<sup>c</sup>Otherwise: Neither agree nor disagree, Disagree, Strongly Disagree

**Supplement Table 8. Significantly different survey responses by income (N=218)<sup>a</sup>**

<b>Adult Palliative Care Survey<sup>b</sup></b>	<b>Equal or below federal poverty line (n = 86) n (%)</b>	<b>Higher than federal poverty line (n = 87) n (%)</b>	<b>Declined to Report (n = 45) n (%)</b>	<b>P<sup>c</sup></b>
How concerned are you that the family's money won't last.				0.0045
Concerned	31 (87.4)	36 (42.9)	29 (67.4)	
Otherwise <sup>d</sup>	52 (62.7)	48 (57.1)	14 (32.6)	
How important would being able to stay in your own home be to you if you were dealing with your own dying?				0.0117
Important	76 (92.7)	66 (75.9)	33 (80.5)	
Otherwise <sup>e</sup>	6 (7.3)	21 (24.1)	8 (19.5)	
How important would fulfilling personal goals/pleasures be to you if you were dealing with your own dying?				0.0066
Important	70 (84.3)	73 (84.9)	44 (100.0)	
Otherwise <sup>e</sup>	13 (15.7)	13 (15.1)	0 (0.0)	
How important would reviewing your life history with your family be to you if you were dealing with your own dying?				0.0249
Every day to a few times a month	63 (73.3)	50 (58.1)	34 (79.1)	
Rarely or never	23 (26.7)	36 (41.9)	9 (20.9)	
I am afraid I would be given too much pain medicine.				0.0249
Agree	15 (17.9)	11 (13.8)	14 (33.3)	
Otherwise <sup>f</sup>	69 (82.1)	69 (86.3)	28 (66.7)	

<sup>a</sup> Income had 5 missing data.

<sup>b</sup> "Don't know" was excluded from each question and changed the sample size for each question.

<sup>c</sup> All P values were computed using Pearson chi-square test or Fisher Exact Test.

<sup>d</sup> Otherwise: Neither concerned nor unconcerned, Not concerned, Not at all concerned

<sup>e</sup> Otherwise: Neither important nor unimportant, Not very important, Not at all important

<sup>f</sup> Otherwise: Neither agree nor disagree, Disagree, Strongly Disagree