

Supplemental Material

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USRDS Study about Treatment Preferences Survey for Family Members and Friends

Supplemental Table 1: Characteristics of patients enrolled in USTATE with and without an enrolled family member (n, %)

		Patients with enrolled family member (n=172)	Patients without enrolled family member (n=825)	P value
Age (SD), years		61 (15)	63 (14)	0.045
Female sex		82 (48)	358 (43)	0.30
Race	White	95 (55)	470 (57)	0.49
	Black	50 (29)	220 (27)	
	Other*	20 (12)	109 (13)	
	Missing	7 (4)	26 (3)	
Hispanic, %	Hispanic	12 (7)	52 (6)	0.93
	Missing	3 (2)	13 (2)	
Highest educational level, %	Less than high school	18 (11)	110 (13)	0.02
	Graduated from high school	42 (24)	289 (35)	
	Some college, community college or trade school	40 (23)	129 (16)	
	Graduated from college, community college or trade school	60 (35)	247 (30)	
	Graduate degree or some post-graduate education	12 (7)	43 (5)	

	Missing	0 (0)	7 (1)	
Self-reported health status, %	Excellent or very good	30 (17)	166 (20)	0.38
	Good	60 (35)	320 (39)	
	Fair or poor	82 (48)	337 (41)	
	Missing	0 (0)	2 (0)	
Years on dialysis, %	<1 year	66 (38)	214 (26)	0.003
	1-5 years	77 (45)	400 (49)	
	>5 years	28 (16)	209 (25)	
	Missing	1 (1)	2 (0)	

* Asian, Native Hawaiian or other Pacific Islander or American Indian or Alaskan Native or belonged to more than one race

Supplemental Table 2: Agreement between responses of family members and patients to survey questions about the patient among family members who indicated they were the patient's surrogate decision-maker n (%)

Question	Variable configuration	Responses	Responses of enrolled family members included in the analytic sample (n=70)	Responses of patients (n=70)	Kappa	% Agreement	P value
If the patient had to decide right now do you think he/she would want CPR if his/her heart were to stop beating?	All responses	Definitely yes	37 (53)	39 (56)	0.24	54%	0.001
		Probably yes	16 (23)	15 (21)			
		Probably no	2 (3)	8 (11)			
		Definitely no	10 (14)	8 (11)			
		Not sure	5 (7)	NA			
		Missing	0	0			
	Dichotomous response	Definitely or probably yes	53 (75)	54 (77)	0.21	74%	0.045
		Definitely or probably no	12 (17)	16 (23)			
		Not sure	5 (7)	NA			
		Missing	0	0			
If the patient had to decide right now do you think he/she would	All responses	Definitely yes	12 (17)	21 (30)	0.04	27%	0.29
		Probably yes	16 (23)	19 (27)			
		Probably no	12 (17)	18 (26)			

want to be placed on a breathing machine if he/she were to become so sick he/she could not breathe on their own?		Definitely no	23 (33)	12 (17)			
		Not sure	7 (10)	NA			
	Dichotomous response	Definitely or probably yes	28 (40)	40 (57)	0.22	60%	0.04
		Definitely or probably no	35 (50)	30 (43)			
		Not sure	7 (10)				
		Missing	0 (0)				
What do you think the patient would value if he/she were seriously ill or dying?	All responses	Extending life	17 (24)	15 (21)	0.10	46%	0.12
		Relieving pain and discomfort	42 (60)	35 (50)			
		Not sure	11 (16)	20 (29)			
	Definitive responses	Extending life	17 (29)	15 (30)	0.06	65%	0.34
		Relieving pain and discomfort	42 (71)	35 (70)			
If the patient had to decide right now, where do you think he would prefer to die if circumstances		At home or the home of a relative	46 (66)	45 (64)	0.04	58%	0.38
		Other response	19 (27)	24 (34)			
		Missing	5 (7)	1 (1)			

allowed him/her to choose?							
What role do you think the patient would want to have in decision-making?		Patient-centered	39 (56)	33 (47)	0.09	49%	0.20
		Shared	26 (37)	30 (43)			
		Physician-centered	5 (7)	4 (6)			
		Missing	0 (0)	3 (4)			
How long would you guess people of similar age with similar health conditions to the patient usually live?	All responses	<5 years	15 (21)	11 (16)	0.24	43%	<0.001
		5-10 years	19 (27)	13 (19)			
		>10 years	21 (30)	22 (31)			
		Not sure	15 (21)	24 (34)			
		Missing	0 (0)	0 (0)			
	Definitive responses	<5 years	15 (27)	11 (24)	0.31	56%	0.004
		5-10 years	19 (35)	13 (28)			
		>10 years	21 (38)	22 (48)			

Supplemental Table 3: Agreement between responses of family members and patients to survey questions about the patient among family members who indicated they were extremely confident in their knowledge n (%)

Question	Variable configuration	Responses	Responses of enrolled family members included in the analytic sample (n=55)	Responses of patients (n=55)	Kappa	% Agreement	P value
If the patient had to decide right now do you think he/she would want CPR if his/her heart were to stop beating?	All responses	Definitely yes	36 (66)	35 (64)	0.35	65%	<0.001
		Probably yes	5 (9)	12(22)			
		Probably no	3 (6)	3 (6)			
		Definitely no	10 (18)	5 (9)			
		Not sure	1 (2)	NA			
		Missing	0 (0)	0 (0)			
	Dichotomous response	Definitely or probably yes	41 (75)	47 (86)	0.36	79%	0.003
		Definitely or probably no	13 (24)	8 (15)			
		Not sure	1 (2)	NA			
		Missing	0 (0)	0 (0)			
If the patient had to decide right now do you think he/she would	All responses	Definitely yes	12 (22)	23 (42)	0.12	34%	0.07
		Probably yes	13 (24)	10 (18)			
		Probably no	9 (16)	10 (18)			

want to be placed on a breathing machine if he/she were to become so sick he/she could not breathe on their own?		Definitely no	16 (29)	12 (22)			
		Not sure	5 (9)	NA			
	Dichotomous response	Definitely or probably yes	25 (46)	33 (60)	0.12	56%	0.20
		Definitely or probably no	25 (46)	22 (40)			
		Not sure	5 (9)				
		Missing	0 (0)				
What do you think the patient would value if he/she were seriously ill or dying?	All responses	Extending life	18 (33)	11 (20)	0.14	47%	0.05
		Relieving pain and discomfort	34 (62)	27 (49)			
		Not sure	3 (6)	17 (31)			
	Definitive responses	Extending life	18 (35)	11 (29)	0.21	69%	0.10
		Relieving pain and discomfort	34 (65)	27 (71)			
If the patient had to decide right now, where do you think he would prefer to die if circumstances		At home or the home of a relative	41 (75)	32 (58)	0.21	63%	0.04
		Other response	10 (18)	23 (42)			
		Missing	4 (7)				

allowed him/her to choose?							
What role do you think the patient would want to have in decision-making?		Patient-centered	35 (64)	33 (60)	0.25	63%	0.02
		Shared	18 (33)	20 (36)			
		Physician-centered	2 (4)	1 (2)			
		Missing	0 (0)	1 (2)			
How long would you guess people of similar age with similar health conditions to the patient usually live?	All responses	<5 years	7 (13)	5 (9)	0.30	50%	<0.001
		5-10 years	13 (24)	9 (16)			
		>10 years	17 (31)	23 (42)			
		Not sure	17 (31)	18 (33)			
		Missing	1 (2)	0 (0)			
	Definitive responses	<5 years	7 (19)	5 (14)	0.42	64%	0.001
		5-10 years	13 (35)	9 (24)			
		>10 years	17 (46)	23 (62)			

Supplemental Table 4: Agreement between responses of family members and patients to survey questions about the patient among patients aged 75 years and older n (%)

Question	Variable configuration	Responses	Responses of enrolled family members included in the analytic sample (n=33)	Responses of patients (n=33)	Kappa	% Agreement	P value
If the patient had to decide right now do you think he/she would want CPR if his/her heart were to stop beating?	All responses	Definitely yes	14 (42)	15 (46)	0.35	55%	0.001
		Probably yes	7 (21)	8 (24)			
		Probably no	1 (3)	5 (15)			
		Definitely no	7 (21)	5 (15)			
		Not sure	4 (12)	NA			
		Missing	0 (0)	0 (0)			
	Dichotomous response	Definitely or probably yes	21 (64)	23 (70)	0.36	72%	0.03
		Definitely or probably no	8 (24)	10 (30)			
		Not sure	4 (12)	NA			
		Missing	0 (0)	0 (0)			
If the patient had to decide right now do you think he/she would	All responses	Definitely yes	3 (9)	8 (24)	0.08	31%	0.21
		Probably yes	6 (18)	7 (21)			
		Probably no	8 (24)	11 (33)			

want to be placed on a breathing machine if he/she were to become so sick he/she could not breathe on their own?		Definitely no	12 (36)	7 (21)			
		Not sure	4 (12)	NA			
	Dichotomous response	Definitely or probably yes	9 (27)	15 (46)	0.28	66%	0.06
		Definitely or probably no	20 (61)	18 (55)			
		Not sure	4 (12)				
		Missing	0 (0)				
What do you think the patient would value if he/she were seriously ill or dying?	All responses	Extending life	4 (15)	2 (9)	-0.05	46%	0.65
		Relieving pain and discomfort	22 (85)	20 (91)			
		Not sure	7 (21)	11 (33)			
	Definitive responses	Extending life	4 (15)	2 (9)	-0.10	77%	0.68
		Relieving pain and discomfort	22 (85)	20 (91)			
If the patient had to decide right now, where do you think he would prefer to die if circumstances		At home or the home of a relative	22 (67)	25 (76)	-0.13	59%	0.76
		Other response	8 (24)	7 (21)			
		Missing	3 (9)	1 (3)			

allowed him/her to choose?							
What role do you think the patient would want to have in decision-making?		Patient-centered	14 (42)	18 (55)	0.26	56%	0.03
		Shared	16 (49)	11 (33)			
		Physician-centered	3 (9)	3 (9)			
		Missing	0 (0)	1 (3)			
How long would you guess people of similar age with similar health conditions to the patient usually live?	All responses	<5 years	8 (24)	6 (18)	0.03	27%	0.36
		5-10 years	13 (39)	8 (24)			
		>10 years	5 (15)	8 (24)			
		Not sure	7 (21)	11 (33)			
		Missing	0 (0)	0 (0)			
	Definitive responses	<5 years	8 (31)	6 (27)	0.12	41%	0.23
		5-10 years	13 (50)	8 (36)			
		>10 years	5 (19)	8 (36)			

Supplemental Table 5: Agreement between responses of family members and patients to survey questions about the patient among patients in fair or poor health n (%)

Question	Variable configuration	Responses	Responses of enrolled family members included in the analytic sample (n=82)	Responses of patients (n=82)	Kappa	% Agreement	P value
If the patient had to decide right now do you think he/she would want CPR if his/her heart were to stop beating?	All responses	Definitely yes	51 (62)	55 (67)	0.22	61%	0.003
		Probably yes	17 (21)	14 (17)			
		Probably no	2 (2)	7 (9)			
		Definitely no	6 (7)	5 (6)			
		Not sure	6 (7)	NA			
		Missing	0 (0)	1 (1)			
	Dichotomous response	Definitely or probably yes	68 (83)	69 (84)	0.34	85%	0.001
		Definitely or probably no	8 (10)	12 (15)			
		Not sure	6 (7)	NA			
		Missing	0 (0)	1 (1)			
If the patient had to decide right now do you think he/she would	All responses	Definitely yes	22 (27)	31 (38)	0.14	37%	0.03
		Probably yes	20 (24)	20 (24)			
		Probably no	11 (13)	15 (18)			

want to be placed on a breathing machine if he/she were to become so sick he/she could not breathe on their own?		Definitely no	14 (17)	16 (20)			
		Not sure	15 (18)	NA			
	Dichotomous response	Definitely or probably yes	42 (51)	51 (62)	0.22	64%	0.03
		Definitely or probably no	25 (31)	31 (38)			
		Not sure	15 (18)				
		Missing	0 (0)				
What do you think the patient would value if he/she were seriously ill or dying?	All responses	Extending life	23 (28)	22 (27)	0.14	45%	0.03
		Relieving pain and discomfort	39 (48)	37 (45)			
		Not sure	20 (24)	23 (28)			
	Definitive responses	Extending life	23 (37)	22 (37)	0.18	65%	0.11
		Relieving pain and discomfort	39 (63)	37 (63)			
If the patient had to decide right now, where do you think he would prefer to die if circumstances		At home or the home of a relative	55 (67)	53 (65)	0.07	59%	0.27
		Other response	18 (22)	29 (35)			
		Missing	9 (11)				

allowed him/her to choose?							
What role do you think the patient would want to have in decision-making?		Patient-centered	50 (61)	39 (48)	0.05	48%	0.31
		Shared	25 (31)	35 (43)			
		Physician-centered	7 (9)	3 (4)			
		Missing	0 (0)	0 (0)			
How long would you guess people of similar age with similar health conditions to the patient usually live?	All responses	<5 years	15 (18)	11 (13)	0.08	33%	0.12
		5-10 years	16 (20)	14 (17)			
		>10 years	27 (33)	29 (35)			
		Not sure	24 (29)	28 (34)			
		Missing	0 (0)	0 (0)			
	Definitive responses	<5 years	15 (26)	11 (20)	0.19	50%	0.05
		5-10 years	16 (28)	14 (26)			
		>10 years	27 (47)	29 (54)			

USRDS Study about Treatment Preferences Survey for Family Members and Friends

Thank you for taking part in our study to improve care for patients with kidney disease. We want to hear about your experiences as a friend or family member of a patient on dialysis. We hope we will be able to better help patients receive the type of care they need and want by improving our understanding of the experiences of patients on dialysis and their friends/family members.

This questionnaire includes a number of questions. Some ask about your role in the care of your friend/family member on dialysis and also about your knowledge and understanding of his/her care preferences if he/she were to become very sick. Other questions are about your own health and some general information so that we can describe the people who are participating in this study. It will take about 30 minutes to complete these questions.

Some of the questions may not apply to you because people with many kinds of experiences will be answering these questions. Please feel free to skip any questions that you do not want to answer, or that you feel do not apply to you. Some of the questions may seem quite similar to each other because we have included questions from a number of other surveys. We appreciate your patience going through all the questions even if they seem similar. All of your answers are confidential and will not be shared with your friend/family member on dialysis.

Thank you very much for taking the time to complete this survey.

Your name

Your name: _____
First Middle Family name

Referred by Subject ID #: _____

Today's date

Today's date: _____ / _____ / _____
Month Day Year

Please tell participant the recording will begin at this point.

Section A: This section asks about your relationship to and role in the care of the person on dialysis enrolled in this study

A1. What is your relationship with <name of enrolled patient>? (**Check only one answer**)

- ☐ I am his/her spouse or partner
- ☐ I am his/her parent
- ☐ I am his/her child
- ☐ I am his/her sibling
- ☐ I am another relative
- ☐ I am his/her friend.

A2. Do you live with <name of enrolled patient>? (**Check only one answer**)

- ☐ I live with him/her
- ☐ I live within 40 miles of him/her
- ☐ I live more than 40 miles away from him/her

A3. How often do you participate or provide oversight in caring for <name of enrolled patient>? (**Check only one answer**)

- ☐ None of the time
- ☐ Some of the time
- ☐ Most of the time
- ☐ All of the time

A4. Are you the friend/family member who is most involved in the care of <name of enrolled patient>?

☐ Yes

☐ No

A5. How many friends or family members help to care for <name of enrolled patient>? (*This number should include you if you help to care for him/her*)

☐ 0

☐ 1

☐ 2

☐ Other _____ (write in number)

Section B: This section asks about your knowledge of the person on dialysis enrolled in this study's engagement in planning for future illness

B1. Has <name of enrolled patient> spoken with you about whom they would want to make medical decisions for him/her if he/she were to become very sick and were unable to speak for him/herself? (*This is known as a surrogate decision-maker, durable power of attorney, or DPOA*) (**Check only one answer**)

☐ Yes

☐ No

B2. Has <name of enrolled patient> signed official papers naming you as the person who will make medical decisions for him/her if he/she were to become very sick and unable to speak for him/herself? (*This is known as a surrogate decision-maker, durable power of attorney, or DPOA*). (**Check only one answer**)

☐ Yes

☐ No

☐ I'm not sure

B3. Has <name of enrolled patient> spoken with you about the kinds of situations that might reduce his/her quality of life so much that life would not be worth living? (**Check only one answer**)

☐ Yes

☐ No

B4. Has <name of enrolled patient> spoken with you about the kinds of treatments he/she would want or not want if he/she were to become very sick and was unable to speak for him/herself? **(Check only one answer)**

☐ Yes

☐ No

B5. Has <name of enrolled patient> signed official papers about his/her wishes for care if he/she were to become very sick and was unable to speak for him/herself? (e.g., living will or advance directive) **(Check only one answer)**

☐ Yes

☐ No

☐ I'm not sure

B6. Has <name of enrolled patient> ever had a conversation with you about stopping dialysis if he/she were to become sicker or if his/her goals changed? **(Check only one answer)**

☐ Yes

☐ No

B7. Has <name of enrolled patient> ever had a conversation with you about whether he/she would want to receive hospice care if he/she were to become sicker or if his/her goals changed? (This is care that is focused on trying to keep people comfortable toward the end of life rather than trying to prolong life.) **(Check only one answer)**

☐ Yes

☐ No

Section C: This section asks about your understanding of your friend/family member's values, preferences and expectations for the future

C1. How true is the following statement for <name of enrolled patient> "His/her religious or spiritual beliefs are what really lie behind his/her whole approach to life."
(Check only one answer)

- ☐ Definitely true
- ☐ Tends to be true
- ☐ Tends not to be true
- ☐ Definitely not true
- ☐ I'm not sure

C2. If <name of enrolled patient> were to become very sick in the future and was unable to speak for him/herself, do you think he/she would prefer a plan of medical care that focuses on extending life as much as possible, even if it means having pain and discomfort, or do you think he/she would want a plan of medical care that focuses on relieving pain and discomfort as much as possible, even if that means not living as long? **(Check only one answer)**

- ☐ Extending life, even if that means having more pain and discomfort
- ☐ Relieving pain and discomfort as much as possible, even if that means not living as long
- ☐ I'm not sure which he/she would choose

C3. If <name of enrolled patient> had to decide right now, do you think he/she would want CPR (cardiopulmonary resuscitation) if his/her heart were to stop beating? (**Check only one answer**)

☐ Definitely yes

☐ Probably yes

☐ Probably not

☐ Definitely not

☐ I'm not sure

C4. If <name of enrolled patient> had to decide right now, do you think he/she would want to be placed on a breathing machine (ventilator or respirator) if he/she were to become so sick that he/she could not breathe on their own? (**Check only one answer**)

☐ Definitely yes

☐ Probably yes

☐ Probably not

☐ Definitely not

☐ I'm not sure

C5. If <name of enrolled patient> had to decide right now, where do you think he/she would prefer to die if circumstances allowed him/her to choose? (**Check only one answer**)

☐ In his/her own home

☐ In the home of a relative or friend

☐ In a hospital

☐ In a nursing home

☐ Other: _____(describe)

C6. If <name of enrolled patient> were to become very sick and had to make a decision about whether to accept treatments to prolong his/her life that might increase his/her suffering, what role do you think he/she would want to have in that decision? (**Check only one answer**)

☐ He/she would prefer to make the final selection about which treatments he/she will receive.

☐ He/she would prefer to make the final selection of treatment after seriously considering the doctor's opinion

☐ He/she would prefer that the doctor and he/she share the responsibility for deciding which treatments are best.

☐ He/she would prefer that the doctor make the final decision about which treatments will be used, but seriously consider his/her opinion.

☐ He/she would prefer to leave all treatment decisions to the doctor.

C7. How confident are you that you know what kind of care <enrolled patient> would want to receive if he/she were very sick and unable to speak for him/herself? **(Check only one answer)**

☐ Extremely

☐ Quite a bit

☐ Somewhat

☐ A little

☐ Not at all

C8. How long would you guess people of similar age with similar health conditions to <name of enrolled patient> usually live? **(Check only one answer)**

☐ Less than 6 months

☐ Between 6 months and 1 year

☐ Between 1 and 2 years

☐ Between 2 and 5 years

☐ Between 5 and 10 years

☐ Over 10 years

☐ I'm not sure

Section D: This section will ask for information about you so that we will be able to describe the characteristics of people who completed this questionnaire.

D1. What is your age? _____(years)

D2. What is your gender?

☐ Female

☐ Male

☐ Other: _____ (describe)

D3. What ethnicity do you consider yourself? (***Check only one answer***)

☐ Non-Hispanic

☐ Hispanic

D4. What race do you consider yourself? (***Check only one answer***)

☐ White

☐ Black or African American

☐ Asian

☐ American Indian or Alaskan native

☐ Native Hawaiian or other Pacific Islander

☐ Other: _____ (describe)

D5. What is the highest level of education you have completed? (***Check only one answer***)

☐ 8th grade or less

☐ Some high school

☐ Graduated from high school

☐ Graduated from college, community college or trade school

☐ Other: _____ (describe)

D6. How true is the following statement for you? “My religious or spiritual beliefs are what really lie behind my whole approach to life.” **(Check only one answer)**

- ☐ Definitely true
- ☐ Tends to be true
- ☐ Tends not to be true
- ☐ Definitely not true

D7. Over the past 2 weeks, how often have you felt like you had no interest or pleasure in doing things? **(Check only one answer)**

- ☐ Not at all
- ☐ Several days
- ☐ More than half the days
- ☐ Nearly every day

D8. Over the past 2 weeks, how often have you felt down, depressed or hopeless? **(Check only one answer)**

- ☐ Not at all
- ☐ Several days
- ☐ More than half the days
- ☐ Nearly every day

D9. In general, would you say your own health is: (***Check only one answer***)

☐ Excellent

☐ Very good

☐ Good

☐ Fair

☐ Poor

Section E: This section asks for your comments

Would you rather have completed this survey online (yes/no) or filled out the survey by hand and mailed in the form (yes/no) than by phone?

Do you have any thoughts or opinions about planning for future care that are important to you or <name of enrolled patient> on dialysis that we may have missed? Please feel free to tell us in your own words in the space provided below.

We would like to obtain your feedback on the questionnaire so that we can improve it. Your answers to the following questions will help us do this.

How long did it take you to complete this questionnaire? _____(minutes)

Were there any questions that were difficult to understand? *If so, please list the question number(s):*

Were there any questions that were upsetting? *If so, please list the question number(s):*

Can you explain to us what upset you about this/these question(s)?

Are there any questions you think we should have asked that were not included in the questionnaire? *If so, please tell us what these would have been.*

This is the end of this questionnaire. Thank you for taking the time to complete this questionnaire. If you have any questions, feel free to call us at: (206)616-8574

Thank you again for your help.