

Supplementary Online Content

O'Hare AM, Kurella Tamura M, Lavalley DC, et al. Assessment of self-reported prognostic expectations of people on dialysis: United States Renal Data System Study of Treatment Preferences (USTATE). Published online July 8, 2019. *JAMA Intern Med*. doi:10.1001/jamainternmed.2019.2879

eTable 1. Characteristics of prevalent in-center hemodialysis patients

eTable 2. Adjusted association of patient characteristics with prognostic expectations

eFigure. Cohort derivation

eAppendix. USRDS Study about Treatment Preferences (UState) 2 Patient Questionnaire

This supplementary material has been provided by the authors to give readers additional information about their work.

1 eTable 1: Characteristics of prevalent in-center hemodialysis patients

	All patients (n=307,602)	Transplant recipients (n=33,713)
Age group, %		
<45 y	14.2	35.6
45-59 y	29.0	42.4
60-74 y	34.6	21.0
75 y	22.2	1.0
Female gender, %	45.3	36.7
Race, %		
White	55.1	51.7
Black	38.0	39.7
Asian	3.4	5.1
American Indian or Alaskan Native	1.5	1.5
Native Hawaiian or other Pacific Islander	1.1	1.2
Other or missing	0.9	0.9
Ethnicity, %		
Hispanic	15.7	21.0

Missing	0.6	0.3
Time since ESRD onset, %		
<6 months	12.8	13.9
6-12 months	11.4	13.4
1-2 years	17.7	20.9
2-5 years	32.1	35.4
5-10 years	17.5	13.8
>10 years	8.5	2.6

2 Abbreviations: SD standard deviation; ESRD end-stage renal disease

3

4 eTable 2: Adjusted association of patient characteristics with prognostic expectations

	Prognostic expectations			
	Adjusted odds ratio (95% confidence interval)			
	<5 years (n=112)	5-10 years (n=150)	>10 years (n=330)	Uncertain (n=404)
Age >75 years	1.0 (referent)	0.7 (0.4, 1.2)	0.2 (0.1, 0.3)	0.7 (0.4, 1.1)
Female gender	1.0 (referent)	0.8 (0.5, 1.3)	1.3 (0.8, 2.1)	0.8 (0.5, 1.2)
Race				
White	1.0 (referent)	1.0 (referent)	1.0 (referent)	1.0 (referent)
Black	1.0 (referent)	1.7 (0.85, 3.48)	2.2 (1.1, 4.1)	2.6 (1.4, 4.9)
Other	1.0 (referent)	0.8 (0.3, 1.8)	1.2 (0.6, 2.5)	2.0 (1.0, 3.9)
Hispanic ethnicity	1.0 (referent)	1.0 (0.3, 3.4)	2.2 (0.8, 6.0)	1.5 (0.5, 4.1)
Fair or poor self-reported health status	1.0 (referent)	0.5 (0.3, 0.8)	0.2 (0.1, 0.3)	0.4 (0.3, 0.6)
> 2 years on dialysis	1.0 (referent)	1.4 (0.8, 2.3)	1.0 (0.6, 1.5)	1.0 (0.7, 1.6)
College or postgraduate education	1.0 (referent)	1.3 (0.8, 2.2)	1.0 (0.6, 1.5)	0.6 (0.4, 1.0)
Spiritual beliefs definitely important	1.0 (referent)	2.0 (1.2, 3.3)	1.7 (1.0, 2.7)	1.4 (0.9, 2.2)

5 Adjusted for self-reported age, sex, race, ethnicity, health status, time on dialysis, highest educational level and spirituality. For race
6 we report the results of multinomial regression in which patients of white race with a prognostic expectation of <5 years serve as the
7 referent category for all comparisons.

8

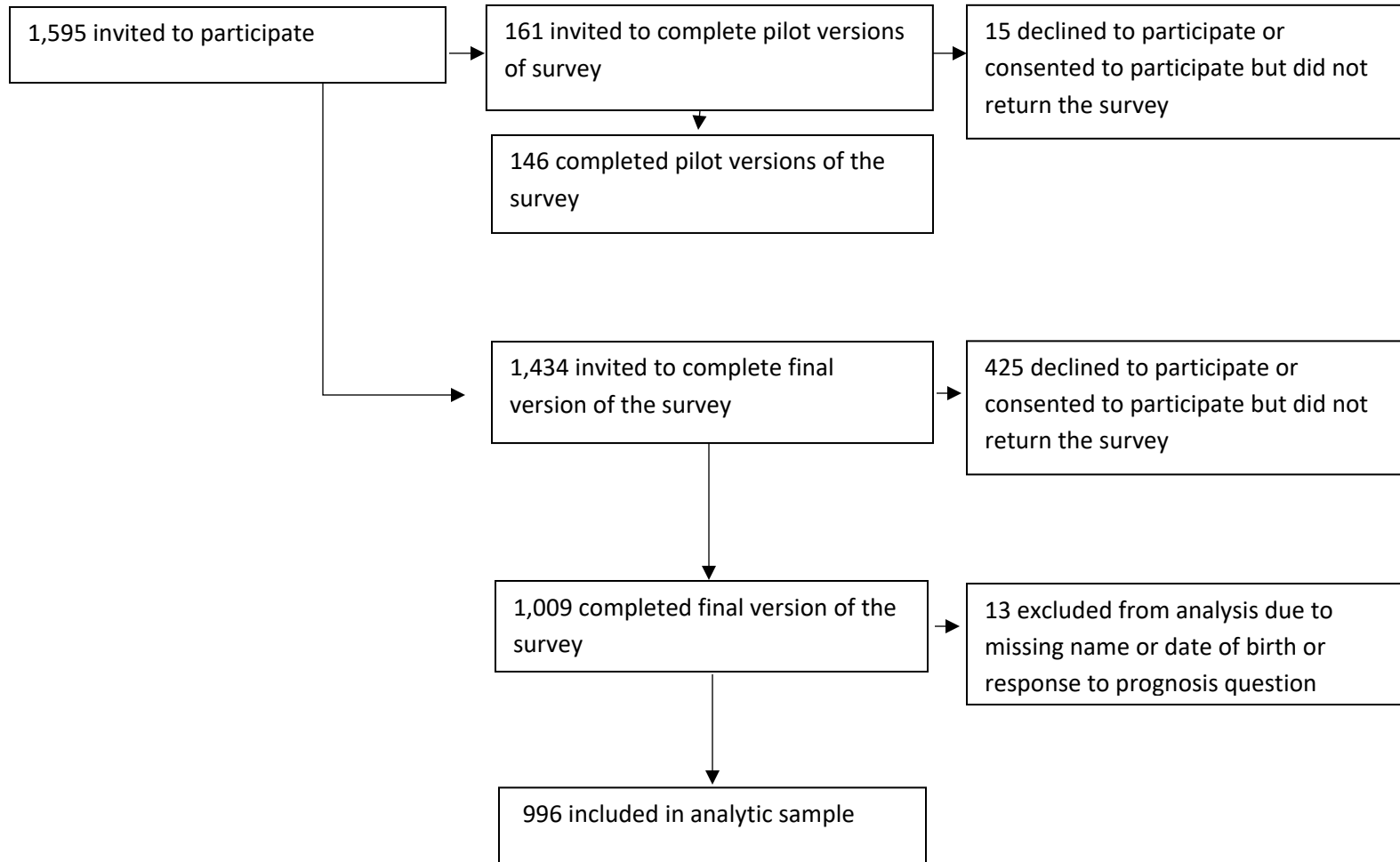
9

10 eFigure: Cohort derivation

11

12

13



1 **USRDS Study about Treatment Preferences (UState)**
2 **Patient Questionnaire**

3 Thank you for taking part in our study to improve care for patients with kidney
4 disease. We want to hear about the experiences of people receiving dialysis.
5 We hope that by improving our understanding of the experiences of patients on
6 dialysis and their families that we will be able to better help patients receive the
7 type of care they need and want.

8 This questionnaire covers a number of topics. Some questions are about your
9 health and emotions. Another set of questions are about the care preferences
10 you may have now or if you become very sick. Other questions ask for general
11 information about you, so that we can find out more about the people who are
12 participating in this study. It will take about 30 minutes to complete these
13 questions.

14 Because many types of people will be answering these questions, some
15 questions may not apply to you. Please feel free to skip any questions that you
16 do not want to answer, or that you feel do not apply to you. Because we have
17 used questions from other surveys, some of the questions may seem quite
18 similar to each other. All of your answers are confidential and will not be shared
19 with anyone else.

20
21 Thank you very much for taking the time to complete this survey.
22
23
24
25

26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46

Personal information

Your name: _____

First Middle Family name

Your date of birth: ____/____/____

Mo. / Day / Year

Your social security number: _____ (only include if you agree that your social security number can be used for linkage to USRDS)

Is someone helping you to answer these questions?

Yes

No

Today's date:

Today's date: ____/____/____

Month Day Year

47 **Section A: Your Overall Health and Symptoms**

48 This section asks about your overall health and symptoms that you have had
49 in the last week.

50 **A1.** In general, would you say your health is: *(Check only one answer)*

51 Excellent

52 Very good

53 Good

54 Fair

55 Poor

56 **Questions A2-A19:** Please check either the “yes” or “no” boxes to the right of
57 each symptom listed below to report whether or not you have had that symptom
58 **over the last week**

	Symptom	Have you had this symptom in the last week?	
		Yes	No
A2.	Pain		
A3.	Shortness of breath		
A4.	Weakness or lack of energy		
A5.	Nausea (feeling like you are going to vomit or throw up)		
A6.	Vomiting (throwing up)		

	Symptom	Have you had this symptom in the last week?	
		Yes	No
A7.	Poor appetite		
A8.	Constipation		
A9.	Mouth problems		
A10.	Drowsiness		
A11.	Poor mobility		
A12.	Itching		
A13.	Difficulty sleeping		
A14.	Restless legs or difficulty keeping legs still		
A15.	Feeling anxious		
A16.	Feeling depressed		
A17.	Changes in your skin		
A18.	Diarrhea		
A19.	Which symptom has bothered you the most over the past week? Describe:		

59

60

Please go on to the next page----->

Section B: Your Needs

This section asks about your spiritual, educational and care needs.

61

62 **Questions B1-B18:** Please check either the “yes” or “no” box to the right of
63 each question below. Although we will not be able to meet your needs as part of
64 this survey, your answers to these questions are helpful for our research.

I would like to learn more about:		Yes	No
B1.	How to be in touch with other patients with kidney disease		
B2.	What I can do about pain		
B3.	Relaxation or stress management		
B4.	Treating the symptoms of kidney disease (itching, nausea, fatigue)		

I would like help with:		Yes	No
B5.	Making plans in case I become very ill		
B6.	Learning to cope with feelings of sadness		
B7.	Sharing my thoughts and feelings with those close to me		
B8.	Finding spiritual resources		

65

I would like help with:		Yes	No
B9.	Worries I have about the effect of my illness on my family		
B10.	Finding meaning in my life now		
B11.	Finding hope		
B12.	Overcoming my fears		
B13.	Organizing my appointments and treatments		
III. I would like to have someone to talk to about:		Yes	No
B14.	Talking about my care plan and treatments		
B15.	Treatment options for the future		
B16.	The meaning of life		
B17.	Dying and death		
B18.	Finding peace of mind		

66

67

68 **Section C: Planning for Serious Illness**

69 **This section asks about planning for your future healthcare if you were**
70 **to become very sick in the future.**

71
72
73 **C1.** Do you have a person who could make medical decisions for you if you
74 were to become very sick and were unable to speak for yourself? (*This is known*
75 *as a surrogate decision-maker, durable power of attorney, or DPOA*) (**Check**
76 **only one answer**)

77 I have not thought about this

78 I have thought about this, but have not decided who this would be

79 I know who this would be, but have not asked him/her

80 I have asked someone, but have not signed official papers naming
81 him/her as the person who will make medical decisions for me

82 I have signed official papers naming someone to make medical
83 decisions for me (e.g., as part of a living will or advance directive), but
84 have not discussed this with him/her

85 I have signed official papers naming someone to make medical
86 decisions for me (e.g., as part of a living will or advance directive), and
87 have discussed this with him/her
88
89
90

91 **C2.** Have you thought about the kinds of treatments that you would want or not
92 want if you were to become very sick and were unable to speak for yourself?
93 **(Check all answers that apply)**

94 I have not thought about this

95 I have thought about this, but have not talked to anyone about it

96 I have talked about this with a friend or family member, but have not
97 signed official papers

98 I have talked about this with a doctor or other healthcare provider, but
99 have not signed official papers

100 I have signed official papers documenting my preferences (e.g., living
101 will or advance directive), but have not talked with any friends or family
102 members about this

103 I have signed official papers documenting my preferences (e.g., living
104 will or advance directive), and have talked with at least one friend or family
105 member about this

106
107
108

109 **C3.** If you were to become very sick in the future and were unable to speak for
110 yourself, would you prefer a plan of medical care that focuses on extending life
111 as much as possible, even if it means having more pain and discomfort, or
112 would you want a plan of medical care that focuses on relieving pain and
113 discomfort as much as possible, even if that means not living as long? (**Check**
114 **only one answer**)

115 Extending life, even if that means having more pain and discomfort

116 Relieving pain and discomfort as much as possible, even if that
117 means not living as long

118 I'm not sure which I would choose

119
120

121 **C4.** If you had to decide right now, would you want CPR (cardiopulmonary
122 resuscitation) if your heart were to stop beating? (**Check only one answer**)

123 Definitely yes

124 Probably yes

125 Probably not

126 Definitely not

127
128

129

130 **C5.** If you had to decide right now, would you want to be placed on a breathing
131 machine (ventilator or respirator) if you became so sick that you could not
132 breathe on your own? (**Check only one answer**)

133 Definitely yes

134 Probably yes

135 Probably not

136 Definitely not

137

138

139 **C6.** If you had to decide right now, where would you prefer to die if
140 circumstances allowed you to choose? (**Check only one answer**)

141 In my own home

142 In the home of a relative or friend

143 In a hospital

144 In a nursing home

145 Other: _____ (describe)

146

147

148

149 **C7.** If you were to become very sick in the future and were facing a decision
150 about whether to accept treatments to prolong your life that might increase your
151 suffering, what role would you want to have in that decision? (**Check only one**
152 **answer**)

153 I prefer to make the final selection about which treatments I will
154 receive

155 I prefer to make the final selection of my treatment after seriously
156 considering my doctor's opinion.

157 I prefer that my doctor and I share responsibility for deciding which
158 treatments are best for me.

159 I prefer that my doctor makes the final decision about which
160 treatments will be used, but seriously considers my opinion.

161 I prefer to leave all treatment decisions to my doctor.
162

163 **C8.** Have you ever thought about stopping your dialysis treatments? (**Check**
164 **only one answer**)

165 Yes

166 No

167

168 **C9.** Have you ever had a discussion about the option of stopping dialysis if you
169 were to become sicker, or if your goals changed? (**Check all answers that**
170 **apply**)

171 Yes, with my kidney doctor

172 Yes, with my primary care doctor

173 Yes, with a nurse

174 Yes, with a social worker

175 Yes, with another healthcare provider: _____(describe)

176 Yes, with a friend or family member

177 No, I have never had a discussion about this with anyone

178

179

180

181 **C10.** Have you ever thought about whether you might want to receive hospice
182 care if you were to become sicker or if your goals changed? (This is care that is
183 focused on trying to keep people comfortable toward the end of life rather than
184 trying to prolong life.) (**Check only one answer**)

185 Yes

186 No

187
188 **C11.** Have you ever had a discussion about the option of receiving hospice care
189 if you were to become sicker or if your goals changed? (This is care that is
190 focused on trying to keep people comfortable toward the end of life rather than
191 trying to prolong life.) (**Check all answers that apply**)

192 Yes, with my kidney doctor

193 Yes, with my primary care doctor

194 Yes, with a nurse

195 Yes, with a social worker

196 Yes, with another healthcare provider: _____(describe)

197 Yes, with a friend or family member

198 No, I have never had a discussion about this with anyone
199
200

201 **C12.** How long would you guess people your age with similar health conditions
202 usually live? (**Check only one answer**)

203 Less than 6 months

204 6 to 12 months

205 1 to 2 years

206 2 to 5 years

207 5 to 10 years

208 More than 10 years

209 I'm not sure

210

211

212

213

214

215

216

217

218

219

220

221

222

223

224

Section D: About You

The next questions provide us with information about you so that we will be able to describe the people who completed this questionnaire.

225

226 **D1. What is your gender?**

227 Female

228 Male

229 Other: _____ (describe)

230

231

232 **D2. What ethnicity do you consider yourself? (*Check only one answer*)**

233 Non-Hispanic

234 Hispanic

235

236

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

238 White

239 Black or African American

240 Asian

241 American Indian or Alaskan native

242 Native Hawaiian or other Pacific Islander

243 Other: _____ (describe)

244

245 **D4.** What is the highest level of education you have completed? (**Check only**
246 **one answer**)

247 8th grade or less

248 Some high school

249 Graduated from high school

250 Graduated from college, community college or trade school

251 Other: _____ (describe)

252

253

254 **D5.** How true is the following statement for you? “My religious or spiritual
255 beliefs are what really lie behind my whole approach to life.” (**Check only one**
256 **answer**)

257 Definitely true

258 Tends to be true

259 Tends not to be true

260 Definitely not true

261

262

263 **D6.** Which religion/spiritual group do you belong to? (**Check all answers that**
264 **apply**)

265 Christian

266 Buddhist

267 Muslim

268 Jewish

269 None

270 Other: _____ (describe)
271
272

273 **D7.** What type of dialysis treatment are you currently receiving? (**Check only**
274 **one answer**)

275 Hemodialysis

276 Peritoneal dialysis
277
278
279

280 **D8.** How long have you been on dialysis? (**Check only one answer**) If you
281 *can't decide which of two categories your answer fits into, please choose the*
282 *higher of the two categories.*

283 Less than 6 months

284 6 to 12 months

285 1 to 2 years

286 2 to 5 years

287 5 to 10 years

288 More than 10 years

289 Other: _____ (describe)
290
291
292
293

Section E. Contact Information for Family Members

296 As part of this study, we are hoping to contact one or more of your family
297 members or friends to invite them to participate in this study.

298 I do not have anyone to ask

299 I don't want the study team to contact my family members or friends

300 If you are willing for the study team to contact close friends and/or family
301 members, please list contact information for one or more adult family members
302 or friends to invite to participate in this study below. Please list the family
303 member or friend who is most involved in your care first.

304 **Name of friend or family member:** _____

305 **Mailing Address:** _____

306 _____

307 _____

308 **Best telephone # (with area code):** _____

309 **Email address:** _____

310 **Relationship to you:** _____

311 _____

312 **Name of friend or family member:** _____

313 **Mailing Address:** _____

314 _____

315 _____

316 **Best telephone # (with area code):** _____

317 **Email address:** _____

318 **Relationship to you:** _____

319 **Section F: Comments?**

320

321 Do you have any thoughts or opinions about planning for future care that are important to you
322 that we may have missed? Please feel free to tell us in your own words in the space provided
323 below.

324 _____

325 _____

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

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

330 _____

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

332 _____

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

334 _____

335 _____

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

338 _____

339 _____

340 ***This is the end of this questionnaire. Thank you for taking the time to complete this***
341 ***questionnaire. If you have any questions, feel free to call us at: 206.616.8574***

342 ***Thank you again for your help!***