

## Appendix A

### Modality choice Barriers Survey Form

Date of visit: \_\_\_\_\_(MM/DD/YYYY)

## Primary Predictor Variable

### STAGE OF CHANGE ALGORITHM

FOR RENAL REPLACEMENT THERAPY MODALITY SELECTION DECISION MAKING

All subjects will have a medical diagnosis of CKD.

Do you currently have chronic kidney disease?

- Yes.
- No. [SUBJECT IS IN *PRECONTEMPLATIVE STAGE*]
- I don't know. My doctor said something about my kidneys, but I wouldn't say I have chronic kidney disease. [SUBJECT IS IN *PRECONTEMPLATIVE STAGE*]

How long ago did you start seeing a nephrologist (kidney doctor)? \_\_\_\_\_

Have you seriously considered going on dialysis?

- No, I've never really thought about it. [*PRECONTEMPLATIVE STAGE*]
- Yes, my doctor told me that someday I might have to go on dialysis and I think about it quite a bit. [*CONTEMPLATIVE STAGE*]
- Yes, I've been talking to people and reading about dialysis options [*PREPARATION STAGE*]
- Yes, I have already told my doctor what I would prefer. [*ACTION STAGE*]

Have you decided which type of dialysis that is best for you?

- Yes (continue to next section)
- No
- NA (continue to next section)
- I don't know

What was the type of dialysis you selected?

- In center hemodialysis
- Nocturnal in center hemodialysis
- Continuous ambulatory peritoneal dialysis
- Automated peritoneal dialysis
- Home hemodialysis

- NA

How long ago did you make your decision for the type of dialysis you chose? \_\_\_\_\_

When you made your decision what percentage of kidney function did you have? \_\_\_\_\_

Are you willing to go on dialysis if it is the only way to stay alive?

- Yes
- No

Are you considering a kidney transplant?

- Yes (continue with next two questions)
- No

Have you been evaluated for a kidney transplant?

- Yes
- No

Do you have an approved living donor?

- Yes
- No

## Covariates

A. Date of birth: \_\_\_\_\_(MM/DD/YYYY), Age \_\_\_\_\_years

B. Is your primary language something other than English?

	Yes (Please specify): _____
	No

C. Gender:

Male \_\_\_\_\_  
Female \_\_\_\_\_

D. Marital Status (Select One)

1. Single, Never Married
2. Married
3. Separated

4. Divorced
5. Widowed

\_\_\_\_\_

E. Race (Select One)

\_\_\_\_\_

1. White or Caucasian
2. Black or African American
3. American Indian/Alaska Native
4. Asian

5. Native Hawaiian/Other Pacific Islander
6. Other: \_\_\_\_\_
7. Don't Know

F. Ethnicity: Are you Hispanic or Latino? (Select One) \_\_\_\_\_

1. Not Hispanic
2. Hispanic/Latino

F. Knowledge of RRT modalities and CKD

For the following questions check the single most appropriate response:

i) In general, how would you rate your level of knowledge about your chronic kidney disease? (check the one best answer)

<input type="checkbox"/>	I have extensive knowledge about my condition
<input type="checkbox"/>	I have a great deal of knowledge about my condition
<input type="checkbox"/>	I have some knowledge about my condition
<input type="checkbox"/>	I have limited knowledge about my condition
<input type="checkbox"/>	I have very little or no knowledge about my condition

ii) When were you first told you had a problem with your kidneys?

<input type="checkbox"/>	In the past week
<input type="checkbox"/>	Past month
<input type="checkbox"/>	1 to 6 months ago
<input type="checkbox"/>	6 to 12 months ago
<input type="checkbox"/>	1 to 2 years ago
<input type="checkbox"/>	2 or more years ago

iii) Do you know what is causing your kidney disease?

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No

iv) What stage of chronic kidney disease do you have?

<input type="checkbox"/>	1
<input type="checkbox"/>	2
<input type="checkbox"/>	3
<input type="checkbox"/>	4
<input type="checkbox"/>	5
<input type="checkbox"/>	I don't know

v) In this 'next section, please think about various options that are available for patients with kidney disease. You may or may not have ever heard of these options. Please choose the response which most closely reflects how much knowledge you have about each option.

<b>Renal Replacement Therapy option</b>	<b>No knowledge</b> (Never heard of it)	<b>A little bit of knowledge</b>	<b>Some Knowledge</b>	<b>A lot of knowledge</b> (know everything I need about it)
In center Hemodialysis				
Nocturnal In center Hemodialysis				
Continuous Ambulatory Peritoneal Dialysis (CAPD)				
Automated peritoneal dialysis (APD)				
Home Hemodialysis				
Kidney Transplant				
Conservative Management				

#### G. Health Care Utilization:

How many times did you see your nephrologist in the past year?  
 \_\_\_\_\_ times (if this is your first visit, enter 0)

H. Type of health insurance (list all that apply)? \_\_\_\_\_

- |                 |                      |
|-----------------|----------------------|
| 1. Medicaid     | 3. Private Insurance |
| 2. Medicare     | 4. No insurance      |
| 5. Other: _____ |                      |

#### I. Self-report Charlson Comorbidity Index (With verification from electronic medical record)

**Do you have any of the following medical conditions?**

Congestive heart failure  
 Myocardial infarction (Heart attack)  
 Cerebrovascular disease or stroke

Yes	No

Angioplasty or heart bypass  
 History of hypertension or high blood pressure  
 Diabetes  
 Chronic obstructive pulmonary disease or Asthma requiring medication  
 Cancer


**J. Additional Medical History**

a) Do you have a rheumatic or musculoskeletal condition that limits your doing of daily activities or to be independent? \_\_\_\_\_ (Y/N)

b) Do you have the strength to lift a 2 kg (4.4lb) bag? \_\_\_\_\_  
 (Y/N/Don't know)

**K. Surgical History**

a) Have you had abdominal surgery? \_\_\_\_\_ (Y/N)

b) If so, what was the nature of the surgery? \_\_\_\_\_

c) Where are the incision(s)? \_\_\_\_\_

d) Do you have any known hernias? (Y/N) \_\_\_\_\_

e) If so where are they located? \_\_\_\_\_

**L. Caregiver or Assistance with Home Dialysis**

a) Do you have someone that can help you do PD or home hemodialysis? (Y/N)

b) If YES: Please describe this person's relationship to you  
 \_\_\_\_\_

c) If YES: please tell me how many minutes they live from you  
 \_\_\_\_\_

d) If YES: Please tell me how many hours per day they can be with you  
 \_\_\_\_\_  
 \_\_\_\_\_

**M. Health Literacy**

**Please circle the most applicable response to each item below.**

	Always	Often	Sometimes	Occasionally	Never
A. How often do you have problems learning about your medical condition because of difficulty understanding written information?	1	2	3	4	5

Questions	0	1	2	3	4
A. How often do you have a drink containing alcohol?	Never (end of Audit if selected)	Monthly or less	2-4 times a month	2-3 times a week	4 or more times a week
B. How many drinks containing alcohol do you have on a typical day when you are drinking?	1 or 2	3 or 4	5 or 6	7 to 9	10 or more
C. How often do you have six or more drinks on one occasion?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily

0 1 2 3 4 5 6 7 8 9 10  
No worry Extremely worried

For this section, please check the best response for each question below (1 indicates 'strongly disagree' and 5 indicates 'strongly agree'):

How important are/were these factors in choosing a type of dialysis?

Factors	Importance			
	Not at all	A little Important	Somewhat Important	Very Important
i) Not wanting to do dialysis at home				
ii) Swimming in lakes or hot tubs				
iii) Medical reasons or not feeling well				
iv) Issues with your home (Built Environment)				
v) Distance to a dialysis center				
vi) Issues with a pet				
vii) Home dialysis would be too difficult				
viii) Having enough support from others				
ix) Issues with your job				
x) Others' opinions				
xi) How you will look (visible catheter or access, weight gain, )				
xii) Fears (afraid to have dialysis)				

xiii) Being treated differently because of dialysis				
xiii) Feeling overwhelmed				

## T. Decisional Balance

i) What are some of the cons/negatives about choosing a type of dialysis?

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ii) What are some of the pros/positives about choosing a type of dialysis?

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iii) What is the thing that most worries you about having to go on dialysis?

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U. The following questions ask you to think about some things that may or may not be helpful to patients who have kidney problems and might need to go on dialysis. We are interested in hearing from you about how helpful you think these things might be.

i) How helpful would it be to talk with other patients who have started the different types of dialysis? (Not at all helpful/A little helpful/ Somewhat helpful/Very helpful)\_\_\_\_\_

ii) Have you talked to any other patients who have started on dialysis? (Y/N) \_\_\_\_\_

iii)How helpful would it be for you to talk to another person who has already made a decision about dialysis? (Not at all helpful/A little helpful/ Somewhat helpful/Very helpful)\_\_\_\_\_

iv)How helpful would it be to speak with a patient who has had a kidney transplant? (Not at all helpful/A little helpful/ Somewhat helpful/Very helpful)

v) Have you spoken with a patient who has had a kidney transplant? (Y/N) \_\_\_\_\_

vi)How helpful is it to have your doctor explain all the details of different types of dialysis? (Not at all helpful/A little helpful/ Somewhat helpful/Very helpful)

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vii)Has your doctor explained all the different types of dialysis? (Y/N)\_\_\_\_\_

viii)How helpful would it be to visit a dialysis center? (Not at all helpful/A little helpful/ Somewhat helpful/Very helpful)\_\_\_\_\_

ix) Have you visited a dialysis center? (Y/N)



## V. Complementary and Alternative Medicine

i) In the past 12 months, how often have you used complementary or alternative medicines (vitamins, herbs, special foods) to try and keep your kidneys healthy?

- a. Never
- b. A few times
- c. Sometimes
- d. Very often
- e. Always/ routinely/ daily

ii) In the past 12 months, how often have you used complementary activities (yoga, acupuncture, meditation) to try to keep your kidneys healthy?

- a. Never
- b. A few times
- c. Sometimes
- d. Very often
- e. Always/ routinely/ daily

## W. Dialysis Decision Making

For this section, please check the best response for each question below (1 indicates 'strongly disagree' and 5 indicates 'strongly agree'):

Questions	1	2	3	4	5
i) I want to work with my doctors to make a decision about dialysis					
ii) I want to be deeply involved in deciding about dialysis					
iii) My doctor could do more to involve me in making a dialysis decision.					
iv) The doctors and nurses devote enough time and energy into helping me decide about dialysis.					
v) I want to have more dialysis choices.					
vi) I am concerned about how dialysis will affect my family.					
vii) I am concerned about how dialysis will interfere with my social life.					
viii) I am concerned about the amount of time it will take once I am on dialysis.					
ix) Being able to urinate means that I have some kidney function left.					
x) Being able to urinate makes me feel healthier.					
xi) Travel time to an in center dialysis unit is a part of my dialysis decision.					
xii) Travel time to a peritoneal dialysis unit is a part of my dialysis decision.					

X. What is your annual household income?

- a. Less than \$10,000 per year
- b. \$10,000 to \$25,000 per year
- c. \$25,001 to \$40,000 per year
- d. \$40,001 to \$55,000 per year
- e. \$55,001 to \$70,000 per year
- f. \$70,001 to \$85,000 per year
- g. \$85,001 to \$100,000 per year
- h. More than \$100,000 per year
- i. Refused to Answer

Y. What is the highest level of education you have completed? (Check one box)

<input type="checkbox"/>	Less than high school
<input type="checkbox"/>	Some high school
<input type="checkbox"/>	High school graduate
<input type="checkbox"/>	Some college
<input type="checkbox"/>	College graduate
<input type="checkbox"/>	Graduate/ professional school

## Appendix B

Table. CKD Patient Ratings Importance of Lifestyle Factors in Making a Dialysis Decision, % (N=55)				
	Not at all Important	A little Important	Somewhat Important	Very Important
i) Not wanting to do dialysis at home	35.2	13.0	11.1	40.7
ii) Swimming in lakes or hot tubs	75.9	9.3	1.9	13.0
iii) Medical reasons or not feeling well	18.5	14.8	24.1	42.6
iv) Issues with your home (Built Environment)	66.7	13.0	5.6	14.8
v) Distance to a dialysis center	37.0	11.1	16.7	35.2
vi) Issues with a pet	86.8	1.9	5.7	5.7
vii) Home dialysis would be too difficult	37.7	18.9	11.3	32.1
viii) Having enough support from others	44.4	9.3	14.8	31.5
ix) Issues with your job	81.5	5.6	3.7	9.3
x) Others' opinions	77.8	5.6	9.3	7.4
xi) How you will look (visible catheter or access, weight gain, )	52.8	22.6	7.6	17.0
xii) Fears (afraid to have dialysis)	33.3	16.7	18.5	31.5
xiii) Being treated differently because of dialysis	70.4	13.0	9.3	7.4
xiii) Feeling overwhelmed	42.6	13.0	18.5	25.9

**Appendix Table A1. Factor Analysis Results N = 55**

	<b>Involvement</b>	<b>Provider Factor</b>	<b>Social Concerns</b>	<b>Urination</b>
I want to work together with my doctors to make a decision about dialysis.	<i>0.93184</i>	0.03316	-0.00924	-0.03365
I want to be deeply involved in deciding about dialysis.	<i>0.92688</i>	-0.10626	0.01453	-0.01832
My doctor could do more to involve me in making a dialysis decision.	0.08118	<i>0.86961</i>	0.12643	-0.08809
The doctors and nurses could devote more time and energy into helping me decide about dialysis. (REV)	-0.15214	<i>0.88134</i>	-0.10321	0.07607
I am concerned about how dialysis will affect my family.	0.17216	0.07082	<i>0.63313</i>	0.24431
I am concerned about how dialysis will interfere with my social life.	-0.07161	-0.03570	<i>0.93876</i>	-0.11314
I am concerned about the amount of time it will take once I am on dialysis.	0.18062	0.16366	<i>0.65084</i>	0.16994
Being able to urinate means that I have some kidney function left.	-0.07615	-0.08054	0.18650	<i>0.72007</i>
Being able to urinate makes me feel healthier.	0.01666	0.06590	-0.14886	<i>0.90232</i>
* Primary factor loadings are shown in italics.				