Item S1

Advance directives_patient

Record ID ______________________

These questions are to be completed by the patient only.

Do you know what an advance directive is?
- ○ Yes
- ○ No
- ○ I'm not sure

Do you have an advance directive?
- ○ Yes
- ○ No
- ○ I'm not sure

If you do not have an advance directive, why? (choose one)
- ○ Doesn't apply; I have an advance directive
- ○ I don't know what an advance directive is
- ○ I never thought about signing one
- ○ I don't need it because I'm in good health
- ○ I don't need it because my family knows my wishes
- ○ I don't need it because my doctor knows my wishes
- ○ Some other reason

What type of advance directive do you have?
- ☐ Living will
- ☐ Durable power of attorney for health care/Health care power of attorney/Health care proxy
- ☐ Other
- ☐ Unknown

What type of advance directive do you have? ______________________

When did you complete your advance directive? (What month)
- ○ January
- ○ February
- ○ March
- ○ April
- ○ May
- ○ June
- ○ July
- ○ August
- ○ September
- ○ October
- ○ November
- ○ December
- ○ I don't know

When did you complete your advance directive? (What year?) ______________________
(Year advance directive completed/signed (e.g. 2016); if unknown, enter "unknown")

Who has access to your advance directive? (can check multiple)
- ☐ My family
- ☐ My friends
- ☐ My lawyer(s)
- ☐ My doctor(s)
- ☐ Clergy
- ☐ Other

Where is your advance directive stored? (can check multiple)

- ☐ With me at home
- ☐ With my family
- ☐ With my friends
- ☐ With clergy
- ☐ At my hospital
- ☐ In my medical record
- ☐ A company (such as MedicAlert or U.S. Living Will Registry)
- ☐ Other

Do you know what a Massachusetts Medical Orders for Life-Sustaining Treatment (MOLST) form is?

- ◯ Yes
- ◯ No
- ◯ I'm not sure

Do you have a MOLST form?

- ◯ Yes
- ◯ No
- ◯ I'm not sure

When did you complete the MOLST form (what month)?

- ◯ January
- ◯ February
- ◯ March
- ◯ April
- ◯ May
- ◯ June
- ◯ July
- ◯ August
- ◯ September
- ◯ October
- ◯ November
- ◯ December
- ◯ I'm not sure

When did you complete the MOLST (what year)?

____

(Year MOLST form completed/signed (e.g. 2016), if unknown, enter "unknown")

Do you know what a Comfort Care/DNR Order Verification Form is?

- ◯ Yes
- ◯ No
- ◯ I'm not sure

Did you complete a Comfort Care/DNR Order Verification Form?

- ◯ Yes
- ◯ No
- ◯ I'm not sure

When did you complete the Comfort Care/DNR Order Verification Form (what month)?

- ◯ January
- ◯ February
- ◯ March
- ◯ April
- ◯ May
- ◯ June
- ◯ July
- ◯ August
- ◯ September
- ◯ October
- ◯ November
- ◯ December
- ◯ I'm not sure

When did you complete the Comfort Care/DNR Order Verification Form(what year)?

____

(Year Comfort Care form completed/signed (e.g. 2016), if unknown, enter "unknown")

These questions concern advance care planning. Please answer at baseline and 3-month follow up only.

	Yes	No	I don't know	Refused
Have you discussed your preferences for using or not using life-sustaining treatments with your substitute decision maker (a person who makes health care decisions on your behalf)?	○	○	○	○
Has your doctor talked to you and or a family member about your prognosis, or indicated how much time you have to live?	○	○	○	○
Have you and/or a family member discussed their preferences for using or not using medically appropriate life-sustaining treatments with your family doctor or other doctor?	○	○	○	○
Have you discussed your preferences for using or not using medically appropriate life-sustaining treatments with other family members?	○	○	○	○
Have you formally designated in writing (using appropriate legal documentation) someone you trust to be your substitute decision maker concerning medical treatment decisions in the event you are not able to do so? In case of power of attorney it should be related to health care.	○	○	○	○
Did a member of your health care team offer to arrange a time when you and your family could meet with the doctor to discuss the use of medically appropriate life-sustaining treatments they would want or not want in the event that your physical health deteriorates?	○	○	○	○

Do you have an advance directive or living will, or have you indicated in some other way (for example, verbally, through a video, and so on) the medical treatments you would want or not want in the event that you are unable to communicate for yourself as a result of a life-threatening health problem?	◯	◯	◯	◯
Have you and/or a family member discussed their preferences for using or not using medically appropriate life-sustaining treatments with other health care professionals (i.e. nurse social worker and spiritual carer)	◯	◯	◯	◯

Katz ADL_patient

Record ID ________________________________

(PATIENT ONLY) For each of the six activities below, select the description that best matches your ability to complete the task.

Bathing
- ◯ Bathes self completely or needs help bathing only a single part of the body such as the back, genital area or disabled extremity.
- ◯ Need help with bathing more than one part of the body, getting in or out of the tub or shower. Requires total bathing.

Dressing
- ◯ Gets clothes from closets and drawers and puts on clothes and outer garments complete with fasteners. May have help tying shoes.
- ◯ Needs help with dressing self or needs to be completely dressed.

Toileting
- ◯ Goes to toilet, gets on and off, arranges clothes, cleans genital area without help.
- ◯ Needs help transferring to the toilet, cleaning self or uses bedpan or commode.

Transferring
- ◯ Moves in and out of bed or chair unassisted. Mechanical transfer aids are accepted.
- ◯ Needs help in moving from bed to chair or requires a complete transfer.

Continence
- ◯ Exercises complete self control over urination and defecation.
- ◯ Is partially or totally incontinent of bowel or bladder.

Feeding
- ◯ Gets food from plate into mouth without help. Preparation of food may be done by another person.
- ◯ Needs partial or total help with feeding or requires parenteral feeding.

ADL total points ________________________________

Lawton-Brody IADL_patient

Record ID ______________________________

(PATIENT ONLY) For each category, select the item description that most closely resembles the patient's highest function level.

Ability to Use Telephone	◯ Operates telephone on own initiative-looks up and dials numbers, etc. ◯ Dials a few well-known numbers ◯ Answers telephone but does not dial ◯ Does not use telephone at all
Shopping	◯ Takes care of all shopping needs independently ◯ Shops independently for small purchases ◯ Needs to be accompanied on any shopping trip ◯ Completely unable to shop
Food Preparation	◯ prepares, and serves adequate meals independently ◯ Prepares adequate meals if supplied with ingredients ◯ serves and prepares meals, or prepares meals, or prepares meals but does not maintain adequate diet ◯ Needs to have meals prepared and served
Laundry	◯ Does personal laundry completely ◯ Launders small items-rinses stockings, etc. ◯ All laundry must be done by others
Housekeeping	◯ Maintains house alone or with occasional assistance (e.g. "heavy work domestic help") ◯ Performs light daily tasks such as dish washing, bed making ◯ Performs light daily tasks but cannot maintain acceptable level of cleanliness ◯ Needs help with all home maintenance tasks ◯ Does not participate in any housekeeping tasks
Mode of Transportation	◯ Travels independently on public transportation or drives own car ◯ Arranges own travel via taxi, but does not otherwise use public transportation ◯ Travels on public transportation when accompanied by another ◯ Travel limited to taxi or automobile with assistance of another ◯ Does not travel at all
Responsibility for Own Medications	◯ Is responsible for taking medication in correct dosages at correct time ◯ Takes responsibility if medication is prepared in advance in separate dosage ◯ Is not capable of dispensing own medication

Ability to Handle Finances	◯ Manages financial matters independently (budgets, writes checks, pays rent, bills, goes to bank), collects and keeps track of income ◯ Manages day-to-day purchases, but needs help with banking, major purchases, etc. ◯ Incapable of handling money
Total score	__________________________________

Please think about how effective your kidney medication/dialysis has been. On a scale from 0 to 10, where 0 means completely ineffective and 10 means completely effective, how effective would you say your kidney medication/dialysis has been?	◯ 0 ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 ◯ Don't know ◯ Refused
Who first raised the idea of starting dialysis?	◯ Me ◯ Health care provider ◯ Don't know ◯ Refused
A personal health care provider is the health care provider who knows you best. This can be a general doctor, a specialist doctor, a nurse practitioner, or a physician assistant. Do you have someone you think of as your personal health care provider?	◯ Yes ◯ No ◯ Don't know ◯ Refused
On a scale from zero to 10, where 0 means do not trust at all and 10 means trust completely, how much do you trust your personal health care provider's judgments about your medical care?	◯ 0 ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 ◯ Don't know ◯ Refused
(If baseline survey) During the past 12 months, how many times have you been hospitalized overnight or longer? (If 3-month or 6-month follow-up): How many times have you been hospitalized overnight or longer since our last interview?	__________________________________
Do you think that your clinician knows the kinds of treatment you would want if you got too sick to speak for yourself?	◯ No ◯ Probably yes ◯ Definitely yes
When you are talking with your doctor about the kinds of treatment you want if you get very sick, do you feel that your doctor cares about you as a person?	◯ No ◯ Probably yes ◯ Definitely yes
When you are talking with your doctor about the kinds of treatment you want if you get very sick, do you feel that your doctor listens to what you say?	◯ No ◯ Probably yes ◯ Definitely yes
When you are talking with your doctor about the kinds of treatment you want if you get very sick, do you feel that your doctor gives you enough of his or her attention?	◯ No ◯ Probably yes ◯ Definitely yes
I feel that my doctor understands my background and values.	◯ Strongly agree ◯ Somewhat agree ◯ Somewhat disagree ◯ Strongly disagree
How would you rate the overall quality of the discussions you've had with your doctor/clinician about the kinds of treatment you would want if you got too sick to speak for yourself?	◯ Poor ◯ Fair ◯ Good ◯ Very good ◯ Excellent
I often feel as if my doctor looks down on me and the way I live my life.	◯ Strongly agree ◯ Somewhat agree ◯ Somewhat disagree ◯ Strongly disagree
Who have you designated to be your substitute decision maker (e.g. Spouse, Adult Child, etc. Do not write a person's name.)?	__________________________________ (Who has the patient identified as their SDM (e.g., spouse, adult child, friend, relative, etc. Not a name))

This set of questions has to do with goals of care discussion. Please answer at baseline and 6-month follow up only.

	Yes	No	I don't know	Refused
Has a member of the health care team talked to you and/or your substitute decision maker about your prognosis, or indicated how much time you have to live?	○	○	○	○
Has a member of your health care team talked to you and/or your substitute decision maker about the outcomes, benefits, and burdens (or risks) of life-sustaining medical treatments?	○	○	○	○
Has a member of your health care team talked to you and/or your substitute decision maker about the outcomes, benefits, and burdens of focusing on comfort care as the goal of your treatment? (For example, speaking to you about palliative care or treating symptoms like pain without trying to cure or control your underlying illness).	○	○	○	○
Has a member of your health care team offered to arrange a time when you, your substitute decision maker, and/or your family can meet with the doctor to discuss your treatment options and plans?	○	○	○	○
Has a member of your health care team asked if you or your substitute decision maker had prior discussions or has written documents about use of life-sustaining treatments?	○	○	○	○

Has a member of your health care team asked you, your substitute decision maker, and/or your family about what is important to you/them (such as values, spiritual beliefs, and/or other practices) as you/they consider health care decisions at this stage of your life?	○	○	○	○
Has a member of your health care team given you the opportunity to express your fears or discuss what concerns you?	○	○	○	○
Has a member of your health care team asked you and/or your family if you/they had any questions or needed things clarified regarding your overall goals of care?	○	○	○	○
Has a member of your health care team asked you about what treatments you prefer to have or not have if you develop a life-threatening illness?	○	○	○	○
Have you been informed that you may change your mind regarding decisions around the goals of care?	○	○	○	○
Have you and your family been offered an opportunity to discuss with members of your health care team issues around capacity and consent with regard to advance care planning? Specifically, what actions would take place in the event that you lose capacity to consent to care?	○	○	○	○
Have you and your family been offered support from the allied health care team (e.g. spiritual carers, social workers, and clinical nurse specialists) as needed?	○	○	○	○

Has a member of your health care team provided you and/or your family with information about "goals of care discussion" to look at before conversations with the doctor?	◯	◯	◯	◯

Has a member of your health care team helped you and/or your family access legal documents to communicate your Advance Care Plans?

◯ Yes ◯ No ◯ I don't know
◯ Refused

Goals of care_patient

Record ID ______________________

These questions are to be completed by the patient only.

You suffer from a severe stroke or heart attack. You are very seriously ill and your mind is no longer sound. For example, you do not know what is going on and you cannot speak for yourself. The doctors and nurses believe that you are unlikely to recover and that continuing life-sustaining treatment, including dialysis, is no longer helpful to you. The costs and burdens of life-sustaining treatment are now very high. Your doctor is asking your family member (or health care agent) what goals of care should be. What should the goals of care be focused on?

- ○ The goals of care should be focused on delaying my death. I want to continue life-sustaining treatment.
- ○ The goals of care should be focused on my comfort and peace. I do not want life sustaining treatment, including dialysis. Instead, I want treatment to make me as comfortable as possible and would like my family and faith community to pray for me.
- ○ I am not sure.

You develop advanced dementia, and you can no longer be yourself. For example, you are not aware of your feelings, not able to make decisions, and not able to recognize other persons, including your loved ones. Your dementia is no longer responding to treatment. Your doctor is asking your family member (health care agent) what goals of care should be. What should the goals of care be focused on?

- ○ The goals of care should be focused on delaying my death. I want to continue life-sustaining treatment.
- ○ The goals of care should be focused on my comfort and peace. I do not want life-sustaining treatment, including dialysis. Instead, I want treatment to make me as comfortable as possible and would like my family and faith community to pray for me.
- ○ I am not sure.

Demographic info_patient

Record ID ______________________

These questions are to be completed by the patient only.

What is the highest grade or year of school you completed?

- ◯ No formal education
- ◯ Grade 1
- ◯ Grade 2
- ◯ Grade 3
- ◯ Grade 4
- ◯ Grade 5 (Elementary school)
- ◯ Grade 6
- ◯ Grade 7
- ◯ Grade 8 (Middle school)
- ◯ Grade 9
- ◯ Grade 10
- ◯ Grade 11 (Some high school)
- ◯ Grade 12 or GED (High school graduate)
- ◯ Grade 13
- ◯ Grade 14 (Some college or technical school)
- ◯ Grade 15
- ◯ Grade 16 (College graduate)
- ◯ Grade 17 or more (Postgraduate)
- ◯ Don't know
- ◯ Refuse

What is the year of your birth? ______________________
(Enter year (e.g. 2016); Don't know; or Refused)

Are you currently married or living with a partner?

- ◯ Yes
- ◯ No
- ◯ Don't know
- ◯ Refused

Are you separated, divorced, widowed, or have you never been married?

- ◯ No
- ◯ Separated
- ◯ Divorced
- ◯ Widowed
- ◯ Never married
- ◯ Don't know
- ◯ Refused

Are you Hispanic or Latino?

- ◯ Yes
- ◯ No
- ◯ Don't know
- ◯ Refused

Which one or more of the following would you say represents your race?

- ☐ White
- ☐ Black or African American
- ☐ Asian
- ☐ Native Hawaiian or other Pacific Islander
- ☐ Native American or Alaskan Native
- ☐ Other
- ☐ Don't know
- ☐ Refused

Thinking about you and any other members of your household, what is your combined annual household income, meaning the total pre-tax income from all sources in 2015?	◯ Less than $25,000 ◯ Between $25,000 and $49,999 ◯ Between $50,000 and $74,999 ◯ Between $75,000 and $99,999 ◯ More than $100,000
Do you identify as male or female?	◯ Male ◯ Female ◯ Don't know ◯ Refused

KDQOL-36_patient

Record ID ______________________

These questions are to be completed by the patient only.

In general, would you say your health is: [Mark an X in the one box that best describes your answer.]

- ○ Excellent
- ○ Very good
- ○ Good
- ○ Fair
- ○ Poor

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? [Mark an X in a box on each line.]

	Yes, limited a lot	Yes, limited a little	No, not limited at all
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	○	○	○
Climbing several flights of stairs	○	○	○

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	Yes	No
Accomplished less than you would like	○	○
Were limited in the kind of work or other activities	○	○

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	Yes	No
Accomplished less than you would like	○	○
Didn't do work or other activities as carefully as usual	○	○

During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- ○ Not at all
- ○ A little bit
- ○ Moderately
- ○ Quite a bit
- ○ Extremely

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Have you felt calm and peaceful?	◯	◯	◯	◯	◯	◯
Did you have a lot of energy?	◯	◯	◯	◯	◯	◯
Have you felt downhearted and blue?	◯	◯	◯	◯	◯	◯

During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

- ◯ All of the time
- ◯ Most of the time
- ◯ Some of the time
- ◯ A little of the time
- ◯ None of the time

How true or false is each of the following statements for you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
My kidney disease interferes too much with my life	◯	◯	◯	◯	◯
Too much of my time is spent dealing with my kidney disease	◯	◯	◯	◯	◯
I feel frustrated dealing with my kidney disease	◯	◯	◯	◯	◯
I feel like a burden on my family	◯	◯	◯	◯	◯

During the past 4 weeks, to what extent were you bothered by each of the following?

	Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
Soreness in your muscles?	◯	◯	◯	◯	◯
Chest pain?	◯	◯	◯	◯	◯
Cramps?	◯	◯	◯	◯	◯
Itchy skin?	◯	◯	◯	◯	◯
Dry skin?	◯	◯	◯	◯	◯
Shortness of breath?	◯	◯	◯	◯	◯
Faintness or dizziness?	◯	◯	◯	◯	◯
Lack of appetite?	◯	◯	◯	◯	◯
Washed out or drained?	◯	◯	◯	◯	◯
Numbness in hands or feet?	◯	◯	◯	◯	◯

Nausea or upset stomach?	○	○	○	○	○
(Hemodialysis patient only) Problems with your access site?	○	○	○	○	○
(Peritoneal dialysis patient only) Problems with your catheter site?	○	○	○	○	○

Some people are bothered by the effects of kidney disease on their daily life, while others are not. How much does kidney disease bother you in each of the following areas?

	Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
Fluid restriction?	○	○	○	○	○
Dietary restriction?	○	○	○	○	○
Your ability to work around the house?	○	○	○	○	○
Your ability to travel?	○	○	○	○	○
Being dependent on doctors and other medical staff?	○	○	○	○	○
Stress or worries caused by kidney disease?	○	○	○	○	○
Your sex life?	○	○	○	○	○
Your personal appearance?	○	○	○	○	○