Advance care planning preferences questionnaire in End Stage Kidney Disease Settings

A. Patient Questionnaire

A1. Illness-information preferences

	Never	Rarely	Sometimes	Often	Always
A.1.1. Do you prefer to know about your illness?					
A.1.2. Do you prefer to know about the severity of your illness?					
A.1.3. Do you prefer to know about the future course of your illness?					
A.1.4. Do you prefer to know about your treatment options?					
A.1.5. Do you prefer to know the success/side-effects of your treatment options?					
A.1.6. Do you prefer to know about the future symptoms?					
A.1.7. Do you prefer to know about the future complications due to illness or due to its treatment?					
A.1.8. Do you prefer to know about your expected length of survival?					

A2. Decision-making preferences

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
A.2.1. Future health care preferences and options should be discussed and planned					
A.2.2. I prefer my future health care preferences to be documented as an advanced care plan					
A.2.3. I prefer to be part of all decision-making discussions concerning my current and future healthcare options					
A.2.4. I would prefer to make all the health care decisions myself					
A.2.5. I would prefer family to make all the health care decisions					
A.2.6. I would prefer health care provider (doctors/dialysis team) to make all the health care decisions					
A.2.7. I would prefer myself, my family, and healthcare providers (doctors/dialysis team) are involved in the decision-making process					
A.2.8. I like my preferences, decisions and wishes made about my future treatment and general care process is respected and implemented					

B. Caregiver Questionnaire

B1. Illness-information preferences

	Never	Rarely	Sometimes	Often	Always
B.1.1. Do you prefer for your patient to know about his/her illness?					
B.1.2. Do you prefer for your patient to know about the severity of his/her illness?					
B.1.3. Do you prefer your patient to know about the future course of his/her illness?					
B.1.4. Do you prefer your patient to know about his/her treatment options?					
B.1.5. Do you prefer your patient to know the success/side-effects of his/her treatment options?					
B.1.6. Do you prefer your patient to know about his/her future symptoms?					
B.1.7. Do you prefer your patient to know about his/her future complications due to illness and its treatment?					
B.1.8. Do you prefer your patient to know about his/her expected length of survival?					

B2. Decision-making preferences

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
B.2.1. Future health care preferences and options should be discussed and planned					
B.2.2. I prefer my patient's future health care preferences should be documented as an advanced care plan					
B.2.3. I prefer my patient to be part of all discussions concerning decision-making about his/her current and future healthcare options					
B.2.4. I would prefer the patient to make all the health care decisions					
B.2.5. I would prefer the family to make all the health care decisions					
B.2.6. I would prefer health care provider to make all the health care decisions					
B.2.7. I would prefer a shared decision-making process where patient, family, healthcare providers are involved in the decision-making process					
B.2.8. I like my patient's preferences, decisions and wishes made about his/her future treatment and the general care process is respected and implemented					

C. Nephrology team

C. Information related to Advance care planning

C.1 Please describe your role

(1) Nephrologist
(2) Nephrology Trainee / RRT student
(3) Dialysis Technician
(4) Nephrology Nurse
(5) Others ____________ (Please Specify)

C.2 Have you participated in training about Advance Care Planning?

Yes
No

C.3 Approximately how many patients do you see in each group on an average monthly?

	<50	50-100	>100
Patients with ESKD on Dialysis			
Patients with ESKD not on Dialysis			
Patients with ESKD undecided about treatment			

C.4 Following best describes my practice on the discussion on Goals of care among patients with ESKD their families.

	Never	Rarely	Sometimes	Often	Always
Patients with ESKD on Dialysis					
Patients with ESKD not on Dialysis					
Patients with ESKD undecided about treatment					

C.5 Following best describes my practice on the discussion of Advance Care Planning (ACP) among patients with ESKD their families.

	Never	Rarely	Sometimes	Often	Always
Patients with ESKD on Dialysis					
Patients with ESKD not on Dialysis					
Patients with ESKD undecided about treatment					

C.6 Likelihood of discussions about Advance Care Planning (ACP) with patient with ESKD and their families.

a) Definitely
b) Probably
c) Possibly
d) Probably not
e) Definitely not

C.7. Please indicate your level of agreement with the following statements

	Strongly disagree	Disagree	Undecided	Agree	Strongly Agree
The need to discuss ACP does not arise in my setting					
ACP discussions are not part of my role					
I do not have access to appropriate ACP training for CKD patients					

C.8 Likelihood of engaging in Advance Care Planning (ACP) discussions in the future?

a) Definitely
b) Probably
c) Possibly
d) Probably not
e) Definitely not

C.9 Please indicate how skilled you feel, or would feel, in doing the following with your patients.

	High level of competence	Moderately high level of competence	Average level of competence	Low level of competence	No level of competence
Discussing advance care planning					
Assisting patients to complete an advance directive					
Discussing prognosis					
Discussing death and dying					
Discussing potential future withdrawal or withholding of dialysis					
Discussing whether or not to attempt CPR or intensive care					

C.10 Please indicate how comfortable you are, or would be, in discussing the following with your patients.

	Very uncomfortable	Uncomfortable	Neutral	comfortable	Very comfortable
Discussing advance care planning					
Assisting patients to complete an advance directive					
Discussing prognosis					
Discussing death and dying					
Discussing potential future withdrawal or withholding of dialysis					
Discussing whether or not to attempt CPR or intensive care					

C.11 At your primary workplace, Likelihood of discussing Advance Care Planning with the following groups of patients?

	Never/ Hardly ever	sometimes	Most of the time	Always/ almost always	Unsure	My workplace does not look after this group of patients
Patients on Dialysis						
Patients with end-stage on supportive care approach						
Patients with CKD undecided about treatment approach (Dialysis or Supportive Care)						

D. Factors influencing involvement of healthcare workers in advance care planning in patients with CKD.

D.1 Please rate the degree to which you perceive the following to be barriers to Advance Care Planning (ACP) at your workplace

	Not a barrier	Somewhat of a barrier	Neutral	Moderate barrier	Extreme barrier
Lack of clinician time					
Lack of awareness about ACP among HCW					
Lack of awareness among Patient and Families					
Patients and/or family discomfort in discussing end of life care					
Fear of losing hope among patient and family					
Collusion among patient and family (Family withholding information about disease and prognosis from patient)					
Health professional discomfort in discussing end of life care					
Health professional lack of expertise in discussing ACP					
Difficulty involving communication with families					
Discouragement from colleagues or administration					
Lack of policy or procedures for ACP					
Environmental problems (e.g. lack of private space)					
Cultural or language barriers					
Socio-economic status					
Educational status of patient and family					

D.2 Please rate the degree of agreement regarding the factors that might facilitate Advance Care Planning (ACP) at your work place.

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
Education about ACP for health professionals in the renal unit, clinic or ward					
Assign a HCW in team who is trained to discuss ACP					
More renal specific ACP programs/ patient education materials					
Integrating palliative care services into renal program					

D.3 Which health professionals should be targeted for Advance Care Planning (ACP) training within your renal unit, clinic or ward? Tick all that apply

a. Nephrologists
b. Nephrology registrars
c. Renal nurses
d. Social workers
e. Dialysis technicians

D.4 To what extent do you think the following information is important in CKD specific Advance Care Planning education materials and/or discussions, over and above those in general resources (e.g. information about CPR/ventilation and surrogate decision making)?

	Not Important At All	Of Little Importance	Of Average Importance	Very Important	Absolutely Essential
Information about disease trajectory in CKD (including potential for cognitive decline)					
Information about prognosis on dialysis					
Information on the option to withdraw from dialysis					
Practicalities of dialysis withdrawal					
Information about conservative care, including symptom management					

D.5 When do you think is the best time to begin to discuss advance care planning with patients with CKD? Please tick only one option.

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
With all patients when they are considering their treatment options (e.g. different types of dialysis or supportive care)					
With all patients before they start dialysis as part of pre-dialysis education					
With all patients after they have started dialysis					
Only when the patient has poor prognostic factors or is starting to become more unwell (such as being elderly, presence of significant co-morbidities)					
Patients with co-morbidities or complications or if you wouldn't be surprised if they died within 12 months, or patients choosing a conservative pathway to care)					

D.6. Which patients do you think will benefit from Advance Care Planning (Select one or more)

	Not Important At All	Of Little Importance	Of Average Importance	Very Important	Absolutely Essential
All Chronic Kidney Disease patient					
All Chronic Kidney Disease patients above 70 years of age					
All Chronic Kidney Disease patients who are on dialysis					
All Chronic Kidney Disease patients with known comorbidities					
All Chronic Kidney Disease patients who are unable to do activities of daily living					
All Chronic Kidney Disease patients who have a poor performance status					

D.7. If you have any other suggestions about how Advance Care Planning could be improved for patients with stage 4 or 5 CKD who are considering their treatment options, are receiving dialysis or who have chosen a conservative care pathway. Would you like us to approach you for a detailed interview?

a) Yes
b) No