

Supplementary Material: Patient Survey Instrument



**Quantifying Treatment Preferences of Elderly Chronic Kidney Disease
Patients and their Family Caregivers**
Patient Questionnaire

For interviewer: Fill in the spaces that you can at the beginning of the interview, then enter Time Ended and Total Interview Time after completing the survey.

PARTICIPANT CODE: DATE OF SURVEY (DD/MM/YYYY): ____/____/____
(FROM CONSENT FORM)

TIME STARTED: _____ TIME ENDED: _____ TOTAL INTERVIEW TIME: _____ MIN

INTERVIEWER NAME: _____

SURVEY CONDUCTED IN: 1 ENGLISH 2 MANDARIN 3 MALAY 4 TAMIL

INTRODUCTION

We are conducting a survey to understand how patients and their family caregivers think about treatments for kidney failure. Even if you do not have kidney failure, we would like to know your opinions as a patient with chronic kidney disease. Your opinions are important to the success of this study. The survey usually takes about 30 minutes.

There are no right or wrong answers and you do not have to answer any questions that make you feel uncomfortable. Information about who you are and your answers will be kept confidential. Only group data will be reported.

INFORMATION FROM MEDICAL RECORDS

Interviewer: Please record the participant's information from patient's medical record file

GFR (Glomerular Filtration Rate) : ml/min

Age as of last birthday:

[Interviewer: Please end interview if age is less than 65 years and GFR > 59.]

SECTION S: SCREENING QUESTIONS

S1 Have you ever been diagnosed with chronic kidney disease?

1 Yes

2 No

3 Not sure

[Interviewer: Please end interview if the answer is not "Yes"]

S2 Are you currently on dialysis?

1 Yes

2 No

[Interviewer: Please end interview if participant answers "Yes"]

Abbreviated Mental Test (AMT)

READ OUT: Before starting the main questionnaire, we would just like to ask you a few questions. These questions are about memory. The questions may seem unusual, but they are routine questions we ask of everyone. Some of the questions are very easy and some are difficult, so do not be surprised if you have trouble with some of them.

Please try to answer these questions correctly and to the best of your knowledge.

Have you attained more than six years of school education?

1 Yes

2 No

Please remember the following phrase: "37 Bukit Timah Road." I will be asking you to repeat the phrase to me later.

Questions	Response	Correct only when:
a. What is the present year	Correct / Incorrect	Western calendar , i.e. 20__
b. What time is it now?	Correct / Incorrect	Within 1 hour
c. What is your age?	Correct / Incorrect	For Chinese, +1 yr is usually the norm and hence acceptable. Refer to patient list.
d. What is your date of birth?	Correct / Incorrect	Western year +/- month and day, refer to the SAC list. Refer to patient list
e. What is your home address?	Correct / Incorrect	Complete address excluding postal code, refer to patient list
f. Where are we now?	Correct / Incorrect	For community survey, "my home" or "my son's home" etc. is probably acceptable.
g. Who is Singapore's present Prime Minister?	Correct / Incorrect	Lee Hsien Loong
h. Show 'Showcard 1'. What is her occupation?	Correct / Incorrect	Nurse or doctor ok
i. Now, count backwards from 20 to 1	Correct / Incorrect	
j. Please recall memory phrase	Correct / Incorrect	

Interviewer: Please total up the number of questions correct. Then see the table below to determine if the respondent has passed the cognitive health section based on his or her age and education status. If they have too many questions wrong, please terminate the interview.

Questions correct: _____

Number of questions needed correct to continue to questionnaire:

	60-74 Years Old	75+ years Old
--	------------------------	----------------------

0 to 6 years of education	8 or more correct	6 or more correct
More than 6 years of education	9 or more correct	9 or more correct

[Interviewer: Please end interview if participant fails AMT]

SECTION A: BACKGROUND QUESTIONS

A1 Gender

1 Male 2 Female

A2 Which ethnic group do you belong to?

1 Chinese 3 Indian
2 Malay 4 Other (Please specify:_____)

A3 What is your current marital status?

1 Married 4 Divorced
2 Separated 5 Never married
3 Widowed

A4 What is your highest education level completed?

1 No formal education 5 Junior college/ Polytechnic/ Diploma
2 Primary 6 University and above
3 Secondary 7 Don't know/ Can't remember
4 Vocational/ ITE

A5 Have you ever been diagnosed with any of the following illnesses/health conditions? Please check all that apply.

Illness/Conditions	Yes	No	Not Sure
1. Diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Cerebrovascular Disease such as stroke	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Heart Failure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Heart attack, heart blood vessel narrowed or blocked	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Irregular heartbeat, also called dysrhythmia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Other heart conditions, such as heart valve problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Chronic Obstructive Pulmonary Disease such as emphysema or chronic bronchitis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Liver Disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Gastrointestinal Bleeding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Poor circulation or blocked blood vessels	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION B: KIDNEY FAILURE TREATMENT OPTIONS

Dialysis

Healthy kidneys remove harmful waste from the blood. Without kidneys, the waste would build up and people would get sicker and eventually die. When kidneys start failing, people may choose to go on dialysis. Dialysis uses a machine to remove some of the waste from the blood so that people can do more of their daily activities and hopefully stay healthy longer.

There are two kinds of dialysis. For blood dialysis (also called haemodialysis), patients need to go to a hospital or a dialysis centre. Water-bag dialysis (also called peritoneal dialysis) can be done at home. Patients on either type of dialysis also have to make changes to their diet, drink less liquid and take medicines.

B1 Have you heard of water-bag dialysis?

1 Yes 2 No 3 Not sure

B2 Have you heard of blood dialysis?

1 Yes 2 No 3 Not sure

Non-dialysis management

Non-dialysis management is also an option for kidney failure. Under non-dialysis management, the patient uses diet and medicines without dialysis. It does not remove waste from the blood as dialysis does. Instead, it tries to control symptoms and maintain quality of life while the disease runs its natural course.

B3 Did you know that non-dialysis management is also an option for patients with kidney failure?

1 Yes 2 No 3 Not sure

B4 Have you participated in a counselling session with a Renal Coordinator given at the kidney clinic?

1 Yes 2 No 3 Not sure

SECTION C: INTRODUCTION TO TREATMENT FEATURES

In this section we will ask you to think about some features of treatments for kidney failure. Even if you do not have kidney failure, please assume that you have kidney failure when answering the following questions. The treatment features are:

- *Type of treatment*
- *Expected survival with this treatment*
- *Quality of daily life*
- *Expected out-of-pocket health care cost per month*

Type of treatment

Later in this survey, we will ask you to think about three types of treatment for kidney failure:

- **In-centre blood dialysis:**
 - You would need to go to a dialysis centre 3 times a week and each dialysis treatment will take 4 hours.
 - You would receive 2 needle sticks per session (6 needle sticks per week) which can be painful.
 - The risk of infection from receiving blood dialysis is very small.
- **Water-bag dialysis at home:**
 - You would need to have dialysis every day at home. You can do water-bag dialysis either 4 times throughout the day or for 8 hours at night while you sleep.
 - You would have no pain during water-bag dialysis.
 - The risk of infection from receiving water-bag dialysis is very small but may be higher for patients with hygiene problems.
- **Non-dialysis management only:**
 - You would not be using dialysis. Instead, you would take food supplements and medicines, and limit liquids to control your symptoms.
 - The symptoms will get worse over time.

C1 If you were to start *blood dialysis* in the next couple months, what is the most likely way you would travel to a dialysis centre?

- 1 Bus and/or MRT
- 2 Taxi
- 3 Private car
- 4 Walking without using any other transportation
- 5 Others, please specify: _____

C2 If you were to start *blood dialysis* in the next couple months, how often would someone be able to help you to go to the dialysis centre?

- 1 All the time
- 2 Most of the time
- 3 Some of the time
- 4 Never

C3 [SKIP IF C2 = 4] Who would be most likely to take you to the dialysis centre?

- | | |
|--|---|
| <input type="checkbox"/> 1 Husband or wife | <input type="checkbox"/> 5 Maid |
| <input type="checkbox"/> 2 Son or daughter | <input type="checkbox"/> 6 Friend |
| <input type="checkbox"/> 3 Son-in-law or daughter-in-law | <input type="checkbox"/> 7 Nurse or other health worker |
| <input type="checkbox"/> 4 Other family member | <input type="checkbox"/> 8 Others, specify: _____ |

C4 If you were to start *water-bag dialysis* in the next couple months, how often would someone be able to help you to have dialysis at home?

- 1 All the time
- 2 Most of the time
- 3 Some of the time
- 4 Never

C5 [SKIP IF C4 = 4] Who would be most likely to help you with *water-bag dialysis* at home?

- | | |
|--|---|
| <input type="checkbox"/> 1 Husband or wife | <input type="checkbox"/> 5 Maid |
| <input type="checkbox"/> 2 Son or daughter | <input type="checkbox"/> 6 Friend |
| <input type="checkbox"/> 3 Son-in-law or daughter-in-law | <input type="checkbox"/> 7 Nurse or other health worker |
| <input type="checkbox"/> 4 Other family member | <input type="checkbox"/> 8 Others, specify: _____ |

Expected survival

Later in the survey, we will ask you to think about how long older adults live with kidney failure. Now we would like to get your opinion on an imaginary patient's survival under different circumstances.

Mr/Ms Law is _____ years old and has kidney failure. He/She has similar other health problems as you do. He/She can choose either dialysis or non-dialysis management to treat the symptoms from kidney failure.

C6 What is your best guess as to how many more years someone like Mr/Ms Law will live using...

i. Dialysis?

_____ years Not sure/ Don't know

ii. Non-dialysis management only (no switching to dialysis)?

_____ years Not sure/ Don't know

C7 [ASK IF ANY C6 = Don't know] Under which treatment do you think Mr/Ms Law would have a longer life?

- 1 Dialysis
- 2 Non-dialysis management only
- 3 Not sure/ Don't know

C8 Until what age do you think a person who is your age and gender without chronic kidney disease is likely to live (please provide your best guess)?

years old

Not sure/ Don't know

Quality of daily life

Later in the survey, we will ask you to think about the quality of daily life using the following definitions:

- **Poor:** It is not possible for you to do activities that are important to you.
- **Fair:** You can do some activities that are important to you.
- **Good:** You can do most activities that are important to you.
- **Very Good:** You can do all of the activities that are important to you.

C9 Over the past month, how would you rate your quality of daily life based on the definitions above?

- 1 Poor
- 2 Fair
- 3 Good
- 4 Very good

C10 What do you think your quality of daily life would be like if you had kidney disease and you were using ...

i. Blood dialysis?

- 1 Poor
- 2 Fair
- 3 Good
- 4 Very good
- 5 Not sure/ Don't know

ii. Water-bag dialysis?

- 1 Poor
- 2 Fair
- 3 Good
- 4 Very good
- 5 Not sure/ Don't know

iii. Non-dialysis management only?

- 1 Poor
- 2 Fair
- 3 Good
- 4 Very good
- 5 Not sure/ Don't know

C11 [ASK IF ANY C10 = Don't know] Which treatment do you think offers the best quality of daily life?

- 1 Water-bag dialysis at home
- 2 In-centre blood dialysis
- 3 Any form of dialysis
- 4 Non-dialysis management only
- 5 They are all about the same
- 6 Don't know

Expected out-of-pocket medical cost per month

Out-of pocket costs refer to the total amount you or your family have to pay for all medical costs after

- Deductions from MediSave account (personal or family)
- Claims from MediShield and any other health insurance
- Other subsidies (e.g. Medifund, National Kidney Foundation)

Later in the survey, we will ask you to think about **out-of-pocket costs in a typical month for all your health problems**, including kidney failure.

C12 We would like you to indicate what you think your out-of-pocket costs for all your health problems will be in a typical month if you had kidney failure and if you were using....

i. Blood dialysis?

\$_____ Not sure/ Don't know

ii. Water-bag dialysis?

\$_____ Not sure/ Don't know

iii. Non-dialysis management only?

\$_____ Not sure/ Don't know

C13 [ASK IF ANY C12 = Don't know] Under which treatment do you think you will have the highest out-of-pocket cost for all your health problems in a typical month?

- 1 Water-bag dialysis at home
- 2 In-centre blood dialysis
- 3 Non-dialysis management only
- 4 Don't know

Doctor's Recommendation

Doctors may recommend a particular treatment for kidney failure. The recommendation might or might not be based on the same concerns you and your family have about your health and health care.

C14 When making decisions about your health and health care, who usually makes the final decisions?

- | | |
|--|---|
| <input type="checkbox"/> 1 Me only | <input type="checkbox"/> 5 Me and my doctor only |
| <input type="checkbox"/> 2 My family only | <input type="checkbox"/> 6 My family and my doctor only |
| <input type="checkbox"/> 3 My doctor only | <input type="checkbox"/> 7 Me, my family and my doctor |
| <input type="checkbox"/> 4 Me and my family only | <input type="checkbox"/> 8 Other. Please specify:_____ |

C15 When making decisions about your health and health care, who do you want to make the final decisions?

- | | |
|--|---|
| <input type="checkbox"/> 1 Me only | <input type="checkbox"/> 5 Me and my doctor only |
| <input type="checkbox"/> 2 My family only | <input type="checkbox"/> 6 My family and my doctor only |
| <input type="checkbox"/> 3 My doctor only | <input type="checkbox"/> 7 Me, my family and my doctor |
| <input type="checkbox"/> 4 Me and my family only | <input type="checkbox"/> 8 Other. Please specify:_____ |

C16 If there is a disagreement about the care of chronic kidney disease, whose opinion do you think will be most important in deciding what to do?

- 1 My own
2 My family's
3 My doctor's

SECTION D: WHICH SCENARIO WILL YOU CHOOSE?

In the next 9 questions, we will show you two possible treatments for kidney failure. Even if you do not have kidney failure, please assume that you have kidney failure when answering these questions. Please tell us which treatment you would choose if these were the only options available for you. Assume that once you make a decision it is final; you cannot change your mind later.

Please think carefully about your choice. Your answers will help increase our understanding of trade-offs that patients make when faced with decisions about treatment for kidney failure.

Please think about whether you and your family can afford paying the cost of the treatment before making your choice.

There are no right or wrong answers.

EXAMPLE QUESTION

If these were the only treatment options, which one would you choose?		
	Profile A	Profile B
Type of treatment	In-centre blood dialysis (3 times a week)	Non-dialysis management
Expected survival	6 years	3 years
Quality of daily life	Fair	Fair
Expected out-of-pocket cost per month	S\$ 2,500 per month	S\$ 450 per month

If you choose **Treatment A**, you would have dialysis at a centre 3 times a week, and each dialysis treatment will take 4 hours. The expected survival would be 6 years and you would have a fair quality of daily life. Expected costs would be S\$2,500 per month for all your health care costs.

If you choose **Treatment B**, you would receive supplements and medication to manage your symptoms. The expected survival would be 3 years and you would have a fair quality of daily life. Expected costs would be S\$450 per month for all your health care costs.

You do not need to provide an answer for this question. This is just an example.

D1. If these were the only treatment options, which one would you choose?

	Profile A	Profile B
Type of treatment	In-centre blood dialysis (3 times a week)	Non-dialysis management
Expected survival	3 years	3 years
Quality of daily life	Good	Good
Expected out-of pocket cost per month	\$1,500	\$1,000
If these were the only options, which would you choose?	<input type="radio"/>	<input type="radio"/>

D2. If these were the only treatment options, which one would you choose?

	Profile A	Profile B
Type of treatment	In-centre blood dialysis (3 times a week)	Non-dialysis management
Expected survival	10 years	1 year
Quality of daily life	Very good	Very good
Expected out-of pocket cost per month	\$700	\$500
If these were the only options, which would you choose?	<input type="radio"/>	<input type="radio"/>

D3. If these were the only treatment options, which one would you choose?

	Profile A	Profile B
Type of treatment	Water bag dialysis at home (Every day or night)	Non-dialysis management
Expected survival	3 years	1 year
Quality of daily life	Poor	Good
Expected out-of pocket cost per month	\$3,000	\$250
If these were the only options, which would you choose?	<input type="radio"/>	<input type="radio"/>

D4. If these were the only treatment options, which one would you choose?

	Profile A	Profile B
Type of treatment	In-centre blood dialysis (3 times a week)	Water bag dialysis at home (Every day or night)
Expected survival	1 years	10 years
Quality of daily life	Very good	Poor
Expected out-of pocket cost per month	\$1,500	\$700
If these were the only options, which would you choose?	<input type="radio"/>	<input type="radio"/>

D5. If these were the only treatment options, which one would you choose?

	Profile A	Profile B
Type of treatment	Water bag dialysis at home (Every day or night)	Non-dialysis management
Expected survival	6 years	1 year
Quality of daily life	Poor	Fair
Expected out-of pocket cost per month	\$7,000	\$500
If these were the only options, which would you choose?	<input type="radio"/>	<input type="radio"/>

D6. If these were the only treatment options, which one would you choose?

	Profile A	Profile B
Type of treatment	Water bag dialysis at home (Every day or night)	Non-dialysis management
Expected survival	6 years	3 years
Quality of daily life	Fair	Poor
Expected out-of pocket cost per month	\$3,000	\$2,000
If these were the only options, which would you choose?	<input type="radio"/>	<input type="radio"/>

D7. If these were the only treatment options, which one would you choose?

	Profile A	Profile B
Type of treatment	In-centre blood dialysis (3 times a week)	Non-dialysis management
Expected survival	1 year	3 years
Quality of daily life	Very good	Good
Expected out-of pocket cost per month	\$1,500	\$1,000
If these were the only options, which would you choose?	<input type="radio"/>	<input type="radio"/>

D8. If these were the only treatment options, which one would you choose?

	Profile A	Profile B
Type of treatment	Water bag dialysis at home (Every day or night)	Non-dialysis management
Expected survival	10 years	3 years
Quality of daily life	Poor	Good
Expected out-of pocket cost per month	\$700	\$1,000
If these were the only options, which would you choose?	<input type="radio"/>	<input type="radio"/>

D9. If these were the only treatment options, which one would you choose?

	Profile A	Profile B
Type of treatment	In-centre blood dialysis (3 times a week)	Non-dialysis management
Expected survival	3 years	1 year
Quality of daily life	Fair	Fair
Expected out-of pocket cost per month	\$3,000	\$250
If these were the only options, which would you choose?	<input type="radio"/>	<input type="radio"/>

D10 If your doctor strongly recommended ____ and if you could afford this treatment, would you take the doctor recommended treatment?

- 1 Definitely would
- 2 Probably would
- 3 Probably would not
- 4 Definitely would not

SECTION E: CURRENT HEALTH STATUS

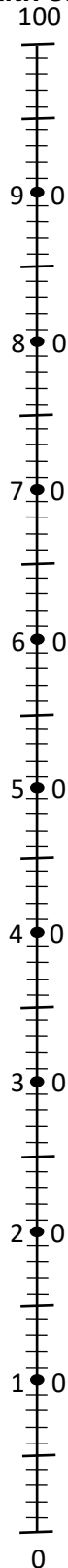
E1	By placing a tick in one box [✓] in each group below, please indicate which statements best describe your own health state <u>today</u> .
i. Mobility	<input type="checkbox"/> 1 I have no problems in walking about <input type="checkbox"/> 2 I have some problems in walking about <input type="checkbox"/> 3 I am confined to bed
ii. Self-Care	<input type="checkbox"/> 1 I have no problems with self-care <input type="checkbox"/> 2 I have some problems washing or dressing myself <input type="checkbox"/> 3 I am unable to wash or dress myself
iii. Usual Activities (e.g. work, study, housework, family or leisure activities)	<input type="checkbox"/> 1 I have no problems with performing my usual activities <input type="checkbox"/> 2 I have some problems with performing my usual activities <input type="checkbox"/> 3 I am unable to perform my usual activities
iv. Pain/Discomfort	<input type="checkbox"/> 1 I have no pain or discomfort <input type="checkbox"/> 2 I have moderate pain or discomfort <input type="checkbox"/> 3 I have extreme pain or discomfort
v. Anxiety/Depression	<input type="checkbox"/> 1 I am not anxious or depressed <input type="checkbox"/> 2 I am moderately anxious or depressed <input type="checkbox"/> 3 I am extremely anxious or depressed

E2 To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the BLACK BOX below to whichever point on the scale indicates how good or bad your health state is today.

**Your own
health state
today**

**Best
imaginable
health state**



**Worst
imaginable
health state**

SECTION F: ADDITIONAL BACKGROUND QUESTIONS

F1 What is your CURRENT employment situation:

- | | |
|---|---|
| <input type="checkbox"/> 1 Paid full-time | <input type="checkbox"/> 6 Retired due to health problems |
| <input type="checkbox"/> 2 Paid part-time | <input type="checkbox"/> 7 Retired – non-health reasons |
| <input type="checkbox"/> 3 Self-employed | <input type="checkbox"/> 8 Unemployed, looking for work |
| <input type="checkbox"/> 4 Homemaker | <input type="checkbox"/> 9 Unemployed, not looking for work |
| <input type="checkbox"/> 5 Volunteer | |

F2 What type of housing are you living in?

- | | |
|---|---|
| <input type="checkbox"/> 1 HDB/ JTC flat (1-2 room) | <input type="checkbox"/> 5 Condominium/ Private flat |
| <input type="checkbox"/> 2 HDB/ JTC flat (3 room) | <input type="checkbox"/> 6 Bungalow/ semi-detached/ terrace house |
| <input type="checkbox"/> 3 HDB/ JTC flat (4 room) | <input type="checkbox"/> 7 Shophouse |
| <input type="checkbox"/> 4 HDB/ JTC flat (5 room and above/
HUDC/ Executive) | <input type="checkbox"/> 8 Others, specify_____ |

F3 How many persons live in your household?

[Interviewer: This includes all who live in the household presently, as well as those who have this address recorded in their NRIC, excluding tenants. e.g. including yourself, maid and those who are temporarily hospitalised, children who are living in a hostel within Singapore, and household members who are currently in National Service/ Reservist training, etc.]

Number of persons

F4 How many persons in your household earn income?

[Interviewer: Exclude domestic helpers.]

Number of persons

F5 What is your religion?

- | | |
|--------------------------------------|---|
| <input type="checkbox"/> 1 Christian | <input type="checkbox"/> 6 Sikh |
| <input type="checkbox"/> 2 Buddhist | <input type="checkbox"/> 7 Other, specify:_____ |
| <input type="checkbox"/> 3 Taoist | <input type="checkbox"/> 8 No religion |
| <input type="checkbox"/> 4 Muslim | <input type="checkbox"/> 9 Free thinker |
| <input type="checkbox"/> 5 Hindu | |

