

**Supplementary Item 1 (Item S1): STROBE Statement: checklist of items that should be included in reports of observational studies**

	<b>Item No</b>	<b>Recommendation</b>	<b>Yes/No/NA, Page No.</b>
<b>Title and abstract</b>	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	Yes, page 1-2
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	Yes, Page 2-3
<b>Introduction</b>			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	Yes, Page 4-7
Objectives	3	State specific objectives, including any pre-specified hypotheses	Yes, Page 7
<b>Methods</b>			
Study design	4	Present key elements of study design early in the paper	Yes, Page 7
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Yes, Page 7-8
Participants	6	<i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	Yes, Page 7-8

Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	Yes, Page 8-9
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Yes, Page 9-10
Bias	9	Describe any efforts to address potential sources of bias	Yes, Page 8
Study size	10	Explain how the study size was arrived at	Yes, Protocol Page 7
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Yes, Page 10
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	Yes, Page 10-11
		(b) Describe any methods used to examine subgroups and interactions	Yes, Page 10-11
		(c) Explain how missing data were addressed	Yes, Page 10-11
		<i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy	NA

		(e) Describe any sensitivity analyses	NA
<b>Results</b>			
Participants	13*	(a) Report numbers of individuals at each stage of study— e.g., numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	No – screening logs at each site were not available
		(b) Give reasons for non-participation at each stage	No
		(c) Consider use of a flow diagram	NA
Descriptive data	14*	(a) Give characteristics of study participants (e.g., demographic, clinical, social) and information on exposures and potential confounders	Yes, Page 7-8, 22
		(b) Indicate number of participants with missing data for each variable of interest	Yes, Page 12-14, 24
		(c) <i>Cohort study</i> —Summarise follow-up time (e.g., average and total amount)	NA
Outcome data	15*	<i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	Yes, Page 11-14
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included	Yes, Page 11-14, 23- 24

		(b) Report category boundaries when continuous variables were categorised	Yes, Page 11-14, 23-24
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	NA
Other analyses	17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	Yes, Page 11-14
<b>Discussion</b>			
Key results	18	Summarise key results with reference to study objectives	Yes, Page 15-16
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Yes, Page 17
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Yes, Page 17
Generalisability	21	Discuss the generalisability (external validity) of the study results	Yes, Page 17
<b>Other information</b>			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Yes, Page 18

Supplementary Item 2 (Item S2): KDQOL-36 Questionnaire (SF-12: Questions 1 – 12 (converted to SF-utilities), KDQOL scores (PCS and MCS scores: Questions 1 – 12, burden of kidney disease: Questions 13 – 16, effects of kidney disease: Questions 17 – 28, symptoms of kidney disease: Questions 29 – 36)

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# Your Health – *and* – Well-Being

## Kidney Disease and Quality of Life (KDQOL™-36)

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.



*Thank you for completing these questions!*

# Your Health

**This survey includes a wide variety of questions about your health and your life. We are interested in how you feel about each of these issues.**

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

Excellent	Very good	Good	Fair	Poor
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**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  in a box on each line.]**

Yes, limited a lot	Yes, limited a little	No, not limited at all
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- 2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf .....  1 .....  2 .....  3**
- 3. Climbing several flights of stairs .....  1 .....  2 .....  3**

**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

4. Accomplished less than you would like..... <sub>1</sub>.....<sub>2</sub>
5. Were limited in the kind of work or other activities ..... <sub>1</sub>.....<sub>2</sub>

**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

6. Accomplished less than you would like..... <sub>1</sub>.....<sub>2</sub>
7. Didn't do work or other activities as carefully as usual..... <sub>1</sub>.....<sub>2</sub>

**8. 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

<sub>1</sub>      <sub>2</sub>      <sub>3</sub>      <sub>4</sub>      <sub>5</sub>

**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...**

		A good			
All	Most	bit	Some	A little	None
of the	of the				
time	time	time	time	time	time

9. Have you felt calm and peaceful? .....  1 .....  2 .....  3 .....  4 .....  5 .....  6
10. Did you have a lot of energy? .....  1 .....  2 .....  3 .....  4 .....  5 .....  6
11. Have you felt downhearted and blue? .  1 .....  2 .....  3 .....  4 .....  5 .....  6

**12. 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	Most	Some	A little	None
of the time				
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

# Your Kidney Disease

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

Definitely true	Mostly true	Don't know	Mostly false	Definitely false
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**13.** My kidney disease interferes too much with my life .....

1..... 2..... 3..... 4..... 5

**14.** Too much of my time is spent dealing with my kidney disease .....

1..... 2..... 3..... 4..... 5

**15.** I feel frustrated dealing with my kidney disease .....

1..... 2..... 3..... 4..... 5

**16.** I feel like a burden on my family .....

1..... 2..... 3..... 4..... 5

**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
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17. Soreness in your muscles? .....  1 .....  2 .....  3 .....  4 .....  5
18. Chest pain? .....  1 .....  2 .....  3 .....  4 .....  5
19. Cramps? .....  1 .....  2 .....  3 .....  4 .....  5
20. Itchy skin? .....  1 .....  2 .....  3 .....  4 .....  5
21. Dry skin? .....  1 .....  2 .....  3 .....  4 .....  5
22. Shortness of breath? .....  1 .....  2 .....  3 .....  4 .....  5
23. Faintness or dizziness? .....  1 .....  2 .....  3 .....  4 .....  5
24. Lack of appetite? ...  1 .....  2 .....  3 .....  4 .....  5
25. Washed out or drained? .....  1 .....  2 .....  3 .....  4 .....  5
26. Numbness in hands or feet? .....  1 .....  2 .....  3 .....  4 .....  5
27. Nausea or upset stomach? .....  1 .....  2 .....  3 .....  4 .....  5
- 28<sup>a</sup>. (Hemodialysis patient only)  
Problems with your access site? ...  1 .....  2 .....  3 .....  4 .....  5
- 28<sup>b</sup>. (Peritoneal dialysis patient only)  
Problems with your catheter site?..  1 .....  2 .....  3 .....  4 .....  5

# Effects of Kidney Disease on Your Daily Life

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**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
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- 29.** Fluid restriction?.....  1 .....  2 .....  3 .....  4 .....  5
- 30.** Dietary restriction?.....  1 .....  2 .....  3 .....  4 .....  5
- 31.** Your ability to work around the house? .....  1 .....  2 .....  3 .....  4 .....  5
- 32.** Your ability to travel? .....  1 .....  2 .....  3 .....  4 .....  5
- 33.** Being dependent on doctors and other medical staff?.....  1 .....  2 .....  3 .....  4 .....  5
- 34.** Stress or worries caused by kidney disease? .....  1 .....  2 .....  3 .....  4 .....  5
- 35.** Your sex life? .....  1 .....  2 .....  3 .....  4 .....  5
- 36.** Your personal appearance? .....  1 .....  2 .....  3 .....  4 .....  5

## Supplementary Item 3 (Item S3): ICECAP-O Questionnaire

### ABOUT YOUR QUALITY OF LIFE

By placing a tick (✓) in ONE box in EACH group below, please indicate which statement best describes your quality of life at the moment.

#### 1. Love and Friendship

- |  |                          |   |
|--|--------------------------|---|
| I can have all of the love and friendship that I want      | <input type="checkbox"/> | 4 |
| I can have a lot of the love and friendship that I want    | <input type="checkbox"/> | 3 |
| I can have a little of the love and friendship that I want | <input type="checkbox"/> | 2 |
| I cannot have any of the love and friendship that I want   | <input type="checkbox"/> | 1 |

#### 2. Thinking about the future

- |   |                          |   |
|---|--------------------------|---|
| I can think about the future without any concern        | <input type="checkbox"/> | 4 |
| I can think about the future with only a little concern | <input type="checkbox"/> | 3 |
| I can only think about the future with some concern     | <input type="checkbox"/> | 2 |
| I can only think about the future with a lot of concern | <input type="checkbox"/> | 1 |

#### 3. Doing things that make you feel valued

- |  |                          |   |
|--|--------------------------|---|
| I am able to do all of the things that make me feel valued   | <input type="checkbox"/> | 4 |
| I am able to do many of the things that make me feel valued  | <input type="checkbox"/> | 3 |
| I am able to do a few of the things that make me feel valued | <input type="checkbox"/> | 2 |
| I am unable to do any of the things that make me feel valued | <input type="checkbox"/> | 1 |

#### 4. Enjoyment and pleasure

- |   |                          |   |
|---|--------------------------|---|
| I can have all of the enjoyment and pleasure that I want      | <input type="checkbox"/> | 4 |
| I can have a lot of the enjoyment and pleasure that I want    | <input type="checkbox"/> | 3 |
| I can have a little of the enjoyment and pleasure that I want | <input type="checkbox"/> | 2 |
| I cannot have any of the enjoyment and pleasure that I want   | <input type="checkbox"/> | 1 |

#### 5. Independence

- |   |                          |   |
|---|--------------------------|---|
| I am able to be completely independent      | <input type="checkbox"/> | 4 |
| I am able to be independent in many things  | <input type="checkbox"/> | 3 |
| I am able to be independent in a few things | <input type="checkbox"/> | 2 |
| I am unable to be at all independent        | <input type="checkbox"/> | 1 |

Tick  
one  
box  
only in  
each  
section

### **Supplementary Item 4 (Item S4): Background Questions**

- Q1. What is your full name? \_\_\_\_\_
- Q2. What is your date of birth? \_\_\_\_\_ (dd/mm/yyyy)
- Q3. Gender (*please tick one*)
- Male
- Female
- Q4. What is your main residential postcode? \_\_\_\_\_
- Q5. What was your country of birth? \_\_\_\_\_
- Q6. What is the highest level of education you have completed? (*please tick the box that best describes you*)
- Primary school
- Some high school
- Completed high school
- Completed Diploma/ TAFE course
- Completed University Degree
- Q7. Do you have private health insurance? (*please tick one*)
- Yes
- No
- Don't know
- Q8. What type of kidney treatment are you **currently** having? (*please tick one*)
- Hemodialysis (satellite or hospital)
- Hemodialysis at home
- Peritoneal dialysis
- Non-dialysis renal supportive care

Q9. If you are currently on dialysis when did you first start dialysis?

\_\_\_\_\_ (mm/yyyy)

Q10. Have you ever had a kidney transplant before? *(please tick one)*

Yes  No

Q11. The next two questions are about the **ICECAP-O survey**. On the scale below please rate how easy this survey was to complete *(circle a number between 1 and 5)*

Very easy	Somewhat easy	Neutral	Somewhat difficult	Very difficult
1	2	3	4	5

Q12. Did this survey measure the things that you consider important to your quality of life? *(circle a number between 1 and 5)*

Completely agree	Somewhat agree	Neutral	Somewhat disagree	Completely disagree
1	2	3	4	5

Q13. If you responded with ‘somewhat disagree’ or ‘completely disagree,’ would you like to tell us what you think the **ICECAP-O survey** was missing?

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Q14. The next two questions are about the **SF-12 survey**. On the scale below please rate how easy this survey was to complete (*circle a number between 1 and 5*)

Very easy	Somewhat easy	Neutral	Somewhat difficult	Very difficult
1	2	3	4	5

Q15. Did this survey measure the things that you consider important to your quality of life? (*circle a number between 1 and 5*)

Completely agree	Somewhat agree	Neutral	Somewhat disagree	Completely disagree
1	2	3	4	5

Q16. If you responded with ‘somewhat disagree’ or ‘completely disagree,’ would you like to tell us what you think the **SF-12 survey** was missing?

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## Supplementary Item 5 (Item S5): SF-6D domains

Level	SF-6D
	<i>Physical Functioning</i>
1	Your health does not limit you in <i>vigorous activities</i>
2	Your health limits you a little in <i>vigorous activities</i>
3	Your health limits you a little in <i>moderate activities</i>
4	Your health limits you a lot in <i>moderate activities</i>
5	Your health limits you <i>a little in bathing and dressing</i>
6	Your health limits you <i>a lot in bathing and dressing</i>
	<i>Role limitations</i>
1	You have <i>no</i> problems with your work or other regular daily activities as a result of your physical health or any emotional problems
2	You are limited in the kind of work or other activities as a result of your physical health
3	You accomplish less than you would like as a result of emotional problems
4	You are limited in the kind of work or other activities as a result of your physical health and accomplish less than you would like as a result of emotional problems
	<i>Social functioning</i>
1	Your health limits your social activities <i>none of the time</i>
2	Your health limits your social activities <i>a little of the time</i>
3	Your health limits your social activities <i>some of the time</i>
4	Your health limits your social activities <i>most of the time</i>
5	Your health limits your social activities <i>all of the time</i>
	<i>Pain</i>
1	You have <i>no</i> pain
2	You have pain but it does not interfere with your normal work (both outside the home and housework)
3	You have pain that interferes with your normal work (both outside the home and housework) <i>a little bit</i>
4	You have pain that interferes with your normal work (both outside the home and housework) <i>moderately</i>
5	You have pain that interferes with your normal work (both outside the home and housework) <i>quite a bit</i>
6	You have pain that interferes with your normal work (both outside the home and housework) <i>extremely</i>
	<i>Mental health</i>
1	You feel tense or downhearted and low <i>none of the time</i>
2	You feel tense or downhearted and low <i>a little of the time</i>
3	You feel tense or downhearted and low <i>some of the time</i>
4	You feel tense or downhearted and low <i>most of the time</i>
5	You feel tense or downhearted and low <i>all of the time</i>
	<i>Vitality</i>
1	You have a lot of energy <i>all of the time</i>
2	You have a lot of energy <i>most of the time</i>
3	You have a lot of energy <i>some of the time</i>
4	You have a lot of energy <i>a little of the time</i>
5	You have a lot of energy <i>none of the time</i>