

## DEMOGRAPHY FORM

Centre number      Subject initials      Sequential patient number

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Date Form Completed: \_\_ / \_\_ / \_\_\_\_

***Now we would like you to provide some details about you. Your answer are treated in confidence. Please ensure that your study number is entered above.***

1. **What is your sex?**       Female       Male       Prefer not to say
2. **When did you first have haemodialysis**    Month \_\_\_\_\_ Year \_ \_ \_ \_
3. **What is the highest level of education you have received?** (Please tick ONE circle)
  - No formal qualification .....
  - Professional qualification
  - 'O' level / GSCE equivalent
  - Apprenticeship and/or NVQ (National Vocational Qualification)
  - 'A' level / highers equivalent
  - Degree and/or higher
4. **How would you describe your ethnic origins?** (Please tick ONE circle)
  - White               Mixed               Asian or Asian British       Black or Black British
  - Other (please specify) .....
5. **What is your marital status?** (Please tick ONE circle)
  - Married                               Living with companion       Single
  - Widowed/widower               Divorced                       Prefer not to say
6. **Who else do you live with, in your home?** (Please tick ALL that apply)
  - Children               Parent(s)               Other relatives               Friends
  - Other (please specify) .....



**7. Which of the following best describes your current work status?** (Please tick ONE circle)

- Working full-time (for 30 hours or more per week)
- Working part-time (for less than 30 hours per week)
- Unemployed due to illness or disability
- Unemployed for another reason
- Retired due to illness or disability
- Retired for another reason
- Home maker (housewife/househusband)
- Other (please comment) .....

**8. Has your work status changed because of your kidney problem?**

- Yes
- No

If Yes, please state how it has changed.....

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**9. Did someone help you complete the questionnaire?**

- Yes
- No

**10. About how long did it take you to complete the questionnaire?**

.....

**Name**.....

**Address** .....

Protocol Reference (26) Adapted from the Yorkshire Dialysis Decision Aid study (Patient acceptability of the Yorkshire Dialysis Decision Aid (YoDDA) booklet: a prospective non-randomized comparison study across 6 predialysis services. Perit Dial Int. 2015 Oct 1. Pii: pdi.2014.00274.)

**1. Cousineau CARER BURDEN 10-Item Version Self-Perceived Burden Scale**

		None of the time 1	A Little of the time 2	Some of the time 3	Most of the time 4	All of the time 5
1	I worry that the health of my caregiver could suffer as a result of caring for me					
2	I worry that my caregiver is overextending him/herself in helping me					
3	I am concerned that it costs my caregiver a lot of money to care for me					
4	I feel guilty about the demands that I make on my caregiver					
5	I am concerned that my caregiver is helping me beyond their capacity					
6	I am concerned that I am "too much trouble" to my caregiver					
7	I am concerned that because of my illness, my caregiver is trying to do too many things at once					
8	I am confident that my caregiver can handle the demands of caring for me					
9	I think that I make things hard on my caregiver					
10	I feel that I am a burden to my caregiver					

Protocol Reference (21) Cousineau N, McDowell I, Hotz S, xe, bert P. Measuring Chronic Patients' Feelings of Being a Burden to Their Caregivers: Development and Preliminary Validation of a Scale. Medical Care. 2003;41(1):110-8.

## 2. ILLNESS INTRUSIVENESS RATINGS SCALE

The following items ask about how much your illness and/or its treatment interfere with different aspects of your life. **PLEASE CIRCLE THE ONE NUMBER THAT BEST DESCRIBES YOUR CURRENT LIFE SITUATION.** If an item is not applicable, please circle the number one (1) to indicate that this aspect of your life is not affected very much. **Please do not leave any item unanswered. Thank you.**

### How much does your illness and/or its treatment interfere with your:

**1. HEALTH**

Not very much	1	2	3	4	5	6	7	Very much
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**2. DIET (i.e. the things you eat and drink)**

Not very much	1	2	3	4	5	6	7	Very much
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**3. WORK**

Not very much	1	2	3	4	5	6	7	Very much
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**4. ACTIVE RECREATION (e.g. sports)**

Not very much	1	2	3	4	5	6	7	Very much
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**5. PASSIVE RECREATION (e.g. reading, listening to music)**

Not very much	1	2	3	4	5	6	7	Very much
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**6. FINANCIAL SITUATION**

Not very much	1	2	3	4	5	6	7	Very much
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**7. RELATIONSHIP WITH YOUR SPOUSE OR PARTNER**

Not very much	1	2	3	4	5	6	7	Very much
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**8. SEX LIFE**

Not very much	1	2	3	4	5	6	7	Very much
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**9. FAMILY RELATIONS**

Not very much	1	2	3	4	5	6	7	Very much
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**10. OTHER SOCIAL RELATIONS**

Not very much	1	2	3	4	5	6	7	Very much
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**11. SELF-EXPRESSION/SELF – IMPROVEMENT**

Not very much	1	2	3	4	5	6	7	Very much
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**12. RELIGIOUS EXPRESSION**

Not very much	1	2	3	4	5	6	7	Very much
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**13. COMMUNITY AND CIVIC INVOLVEMENT**

Not very much	1	2	3	4	5	6	7	Very much
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Protocol Reference (25): Devins GM, Binik YM, Hutchinson TA, Hollomby DJ, Barre PE, Guttman RD. The emotional impact of end-stage renal disease: importance of patients' perception of intrusiveness and control. *International journal of psychiatry in medicine*. 1983;13(4):327-43.

**THE RENAL TREATMENT SATISFACTION QUESTIONNAIRE : RTSQ**

The following questions are concerned with the treatment for your renal condition (which may include some form of dialysis, tablets, dietary and/or fluid restrictions) and your experience over the past few weeks. Please answer each question by circling a number on each of the scales. **Thank you.**

**1. How satisfied are you with your current treatment?**

Very Satisfied	6	5	4	3	2	1	0	Very Dissatisfied
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**2. How well controlled do you feel your renal condition is now?**

Very well controlled	6	5	4	3	2	1	0	Very poorly controlled
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**3. How convenient have you been finding your treatment to be recently?**

Very convenient	6	5	4	3	2	1	0	Very inconvenient
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**4. How flexible have you been finding your treatment recently?**

Very flexible	6	5	4	3	2	1	0	Very inflexible
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**5. How satisfied are you with the amount of freedom you have with your present treatment?**

Very Satisfied	6	5	4	3	2	1	0	Very Dissatisfied
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**6. How satisfied are you with your understanding of your renal condition?**

Very Satisfied	6	5	4	3	2	1	0	Very Dissatisfied
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**7. How satisfied are you with the time taken by your present form of treatment?**

Very Satisfied	6	5	4	3	2	1	0	Very Dissatisfied
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**8. How satisfied are you with the amount of discomfort or pain involved with your present form of treatment?**

Very Satisfied	6	5	4	3	2	1	0	Very Dissatisfied
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**9. How satisfied are you with the extent to which your treatment fits in with your lifestyle?**

Very Satisfied	6	5	4	3	2	1	0	Very Dissatisfied
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**10. Would you recommend this form of treatment to someone else with your kind of renal condition?**

Yes, I would definitely recommend the treatment	6	5	4	3	2	1	0	No, I would definitely not recommend the treatment
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**11. How satisfied would you be to continue with your present form of treatment?**

Very Satisfied	6	5	4	3	2	1	0	Very Dissatisfied
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Protocol Reference (24) : The Renal Treatment Satisfaction Questionnaire (RTSQ): A Measure of Satisfaction With Treatment for Chronic Kidney Failure

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### 3. Vascular Access Questionnaire.

	Vascular Access Questionnaire :	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
	During the past 4 weeks how much were you bothered by each of the following problems related to your vascular access.					
A	Pain					
B	Bleeding					
C	Swelling					
D	Bruising					
E	my vascular access interfered with my daily activities					
F	I was bothered by the appearance of my vascular access					
G	my vascular access interfered with my sleep					
H	my vascular access caused me problems when I was bathing or showering					
I	my vascular access had problems					
J	my vascular access was difficult to care for					
K	I was worried about being hospitalised because of my vascular access					
L	I was worried about how long my vascular access will last					

Protocol Reference (18) The questionnaire is adapted from Quinn RR et al, J Vasc. Access 2008;9:122-8.