



KIDNEY DISEASE AND QUALITY OF LIFE™

SHORT FORM

(KDQOL-SF™)

VERSION 1.3

Subject ID Patient Study Number: _____
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STUDY OF QUALITY OF LIFE FOR PATIENTS ON DIALYSIS

WHAT IS THE PURPOSE OF THE STUDY?

This study is being carried out in cooperation with physicians and their patients. The purpose is to assess the quality of life of patients with kidney disease.

WHAT WILL I BE ASKED TO DO?

For this study, we want you to complete a survey today about your health, how you feel and your background.

CONFIDENTIALITY OF INFORMATION?

We do not ask for your name. Your answers will be combined with those of other participants in reporting the findings of the study. Any information that would permit identification of you will be regarded as strictly confidential. In addition, all information collected will be used only for purposes of the study, and will not be disclosed or released for any other purpose without your prior consent.

HOW WILL PARTICIPATION BENEFIT ME?

The information you provide will tell us how you feel about your care and further understanding about the effects of medical care on the health of patients. This information will help to evaluate the care delivered.

DO I HAVE TO TAKE PART?

You do not have to fill out the survey and you can refuse to answer any question. Your decision to participate will not affect your opportunity to receive care.

INSTRUCTIONS FOR FILLING OUT SURVEY

- A. 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.
- B. 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.
- C. Please answer the questions by circling the appropriate number or by filling in the answer as requested.

Example:

During the past four weeks, how much back pain have you had?

(Circle One Number)

None	①
Very mild	2
Mild	3
Moderate	4
Severe	5

- D. Several items in the survey ask about the effect of kidney disease on your life. Some items will ask about limitations related to your kidney disease, and some items will ask about your well-being. Some questions may look like others, but each one is different. Please answer every question as honestly as possible. If you are unsure about how to answer a question, please give the best answer you can. This will allow us to have an accurate picture of the different experiences of individuals with kidney disease.

THANK YOU FOR COMPLETING THIS SURVEY

YOUR HEALTH

1. In general, would you say your health is:

(Circle One Number)

- Excellent 1
- Very good 2
- Good 3
- Fair 4
- Poor 5

2. **Compared to one year ago**, how would you rate your health in general **now**?

(Circle One Number)

- Much better now than one year ago 1
- Somewhat better now than one year ago 2
- About the same as one year ago 3
- Somewhat worse now than one year ago 4
- Much worse now than one year ago 5

3. 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?

(Circle One Number on Each Line)

	Yes, Limited <u>a Lot</u>	Yes, Limited <u>a Little</u>	No, Not Limited <u>at All</u>
a. Vigorous activities , such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing several flights of stairs ...	1	2	3
e. Climbing one flight of stairs	1	2	3
f. Bending, kneeling, or stooping	1	2	3
g. Walking more than a mile	1	2	3
h. Walking several blocks	1	2	3
i. Walking one block	1	2	3
j. Bathing or dressing yourself	1	2	3

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

(Circle One Number on Each Line)

	<u>Yes</u>	<u>No</u>
a. Cut down the amount of time you spent on work or other activities?	1	2
b. Accomplished less than you would have liked?.....	1	2
c. Were limited in the kind of work or other activities?.....	1	2
d. Had difficulty performing the work or other activities (for example, it took extra effort)?	1	2

5. 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)?

(Circle One Number on Each Line)

	<u>Yes</u>	<u>No</u>
a. Cut down the amount of time you spent on work or other activities?	1	2
b. Accomplished less than you would like?	1	2
c. Didn't do work or other activities as carefully as usual?	1	2

6. During the **past 4 weeks**, to what **extent** have your **physical health or emotional problems** interfered with your normal social activities with family, friends, neighbors, or groups?

(Circle One Number)

- | | |
|-------------------|---|
| Not at all | 1 |
| Slightly | 2 |
| Moderately | 3 |
| Quite a bit | 4 |
| Extremely | 5 |

7. How much **bodily** pain have you had during the **past 4 weeks**?

(Circle One Number)

- | | |
|-------------------|---|
| None | 1 |
| Very mild | 2 |
| Mild | 3 |
| Moderate | 4 |
| Severe | 5 |
| Very severe | 6 |

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

(Circle One Number)

- | | |
|--------------------|---|
| Not at all | 1 |
| A little bit | 2 |
| Moderately | 3 |
| Quite a bit | 4 |
| Extremely | 5 |

9. 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** . . .

(Circle One Number on Each Line)

	<u>All of the Time</u>	<u>Most of the Time</u>	<u>A Good Bit of the Time</u>	<u>Some of the Time</u>	<u>A Little of the Time</u>	<u>None of the Time</u>
a. Did you feel full of pep?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and blue?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

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

(Circle One Number)

- All of the time 1
- Most of the time 2
- Some of the time 3
- A little of the time 4
- None of the time 5

11. Please choose the answer that best describes how **TRUE** or **FALSE** each of the following statements is for you.

(Circle One Number on Each Line)

	<u>Definitely True</u>	<u>Mostly True</u>	<u>Don't Know</u>	<u>Mostly False</u>	<u>Definitely False</u>
a. I seem to get sick a little easier than other people	1	2	3	4	5
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

Ask the subject, "Do you or have you had any kidney problems."

If the subject says "Yes", continue with the questionnaire.

If the subject say "No": If the subject does not have any recollection of having kidney disease, please answer all kidney related questions as "Don't Know" and provide any comments here. Please move on to question 16.

YOUR KIDNEY DISEASE

12. How **TRUE** or **FALSE** is each of the following statements for you?

(Circle One Number on Each Line)

	Definitely <u>True</u>	Mostly <u>True</u>	Don't <u>Know</u>	Mostly <u>False</u>	Definitely <u>False</u>
a. My kidney disease interferes too much with my life	1	2	3	4	5
b. Too much of my time is spent dealing with my kidney disease	1	2	3	4	5
c. I feel frustrated dealing with my kidney disease	1	2	3	4	5
d. I feel like a burden on my family	1	2	3	4	5

13. These questions are about how you feel and how things have been going 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** . . .

(Circle One Number on Each Line)

	<u>None of the Time</u>	<u>A Little of the Time</u>	<u>Some of the Time</u>	<u>A Good bit of the Time</u>	<u>Most of the Time</u>	<u>All of the Time</u>
a. Did you isolate yourself from people around you?	1	2	3	4	5	6
b. Did you react slowly to things that were said or done?	1	2	3	4	5	6
c. Did you act irritable toward those around you?	1	2	3	4	5	6
d. Did you have difficulty concentrating or thinking?	1	2	3	4	5	6
e. Did you get along well with other people?	1	2	3	4	5	6
f. Did you become confused?	1	2	3	4	5	6

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

(Circle One Number on Each Line)

	<u>Not at All bothered</u>	<u>Somewhat bothered</u>	<u>Moderately bothered</u>	<u>Very Much bothered</u>	<u>Extremely bothered</u>
a. Soreness in your muscles?.....	1	2	3	4	5
b. Chest pain?.....	1	2	3	4	5
c. Cramps?	1	2	3	4	5
d. Itchy skin?	1	2	3	4	5
e. Dry skin?.....	1	2	3	4	5
f. Shortness of breath?.....	1	2	3	4	5
g. Faintness or dizziness?	1	2	3	4	5
h. Lack of appetite?	1	2	3	4	5
i. Washed out or drained?.....	1	2	3	4	5
j. Numbness in hands or feet?.....	1	2	3	4	5
k. Nausea or upset stomach?	1	2	3	4	5

14. (Continued) During the **past 4 weeks**, to what extent were you bothered by each of the following?

(Circle One Number on Each Line)

	Not at All	Somewhat	Moderately	Very Much	Extremely
	<u>bothered</u>	<u>bothered</u>	<u>bothered</u>	<u>bothered</u>	<u>bothered</u>

Hemodialysis Patient only

l. Problems with your access site?.....	1	2	3	4	5
--	---	---	---	---	---

Peritoneal Dialysis Patient only

m. Problems with your catheter site?.....	1	2	3	4	5
--	---	---	---	---	---

EFFECTS OF KIDNEY DISEASE ON YOUR DAILY LIFE

15. 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?

(Circle One Number on Each Line)

	<u>Not at All bothered</u>	<u>Somewhat bothered</u>	<u>Moderately bothered</u>	<u>Very Much bothered</u>	<u>Extremely bothered</u>
a. Fluid restriction?	1	2	3	4	5
b. Dietary restriction?	1	2	3	4	5
c. Your ability to work around the house?	1	2	3	4	5
d. Your ability to travel?	1	2	3	4	5
e. Being dependent on doctors and other medical staff?	1	2	3	4	5
f. Stress or worries caused by kidney disease?.....	1	2	3	4	5
g. Your sex life?.....	1	2	3	4	5
h. Your personal appearance?	1	2	3	4	5

The next three questions are personal and relate to your sexual activity, but your answers are important in understanding how kidney disease impacts on people's lives.

16. Have you had any sexual activity in the **past 4 weeks**?

(Circle One Number)

No 1

---> Please skip to Question 17

Yes 2



How much of a problem was each of the following in the **past 4 weeks**?

(Circle One Number on Each Line)

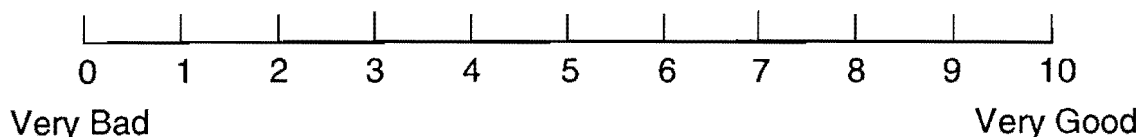
	<u>Not a Problem</u>	<u>A Little Problem</u>	<u>Somewhat of a Problem</u>	<u>Very Much a Problem</u>	<u>Severe Problem</u>
a. Enjoying sex?	1	2	3	4	5
b. Becoming sexually aroused?	1	2	3	4	5

For the following question, please rate your sleep using a scale ranging from 0 representing "very bad" to 10 representing "very good."

If you think your sleep is half-way between "very bad" and "very good," please circle 5. If you think your sleep is one level better than 5, circle 6. If you think your sleep is one level worse than 5, circle 4 (and so on).

17. On a scale from 0 to 10, how would you rate your sleep overall?

(Circle One Number)



18. How often during the **past 4 weeks** did you...

(Circle One Number on Each Line)

	<u>None of the Time</u>	<u>A Little of the Time</u>	<u>Some of the Time</u>	<u>A Good bit of the Time</u>	<u>Most of the Time</u>	<u>All of the Time</u>
a. Awaken during the night and have trouble falling asleep again?	1	2	3	4	5	6
b. Get the amount of sleep you need?	1	2	3	4	5	6
c. Have trouble staying awake during the day?	1	2	3	4	5	6

19. Concerning your **family and friends**, how satisfied are you with ...

(Circle One Number on Each Line)

	<u>Very Dissatisfied</u>	<u>Somewhat Dissatisfied</u>	<u>Somewhat Satisfied</u>	<u>Very Satisfied</u>
a. The amount of time you are able to spend with your family and friends?.....	1	2	3	4
b. The support you receive from your family and friends?.....	1	2	3	4

20. During the **past 4 weeks**, did you work at a paying job?

(Circle One Number)

Yes 1

No 2

21. Does your health keep you from working at a paying job?

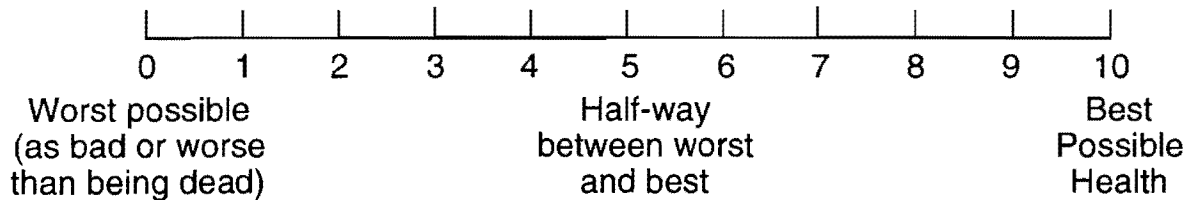
(Circle One Number)

Yes 1

No 2

22. Overall, how would you rate your health?

(Circle One Number)



SATISFACTION WITH CARE

23. Think about the care you receive for kidney dialysis. In terms of your satisfaction, how would you rate the friendliness and interest shown in you as a person?

(Circle One Number)

- Very Poor 1
- Poor 2
- Fair 3
- Good 4
- Very Good 5
- Excellent 6
- The Best 7

24. How **TRUE** or **FALSE** is each of the following statements?

(Circle One Number on Each Line)

	<u>Definitely True</u>	<u>Mostly True</u>	<u>Don't Know</u>	<u>Mostly False</u>	<u>Definitely False</u>
a. Dialysis staff encourage me to be as independent as possible	1	2	3	4	5
b. Dialysis staff support me in coping with my kidney disease	1	2	3	4	5

BACKGROUND INFORMATION

25. Do you currently take prescription medications regularly (4 or more days a week) that are prescribed by your doctor for a medical condition? Please don't count over the counter medications like antacids or aspirin.

(Circle One Number)

No 1
Yes 2

---> Please skip to Question 26



25a. How many different prescription medications do you currently take?

Number of Medications: _____

**This does not include over-the-counter medications such as Tylenol, Ibuprofen, Aleve, ect

26. How many days total in the **last 6 months** did you stay in any hospital overnight or longer? **(If none, please write in 0)**

Number of Days: _____

27. How many days total in the **last 6 months** did you receive care at a hospital, but came home the same day? **(If none, please write in 0)**

Number of Days: _____

28. What caused your kidney disease?

(Circle All That Apply)

- Don't know 1
- Hypertension (High Blood Pressure) 2
- Diabetes 3
- Polycystic Kidney Disease 4
- Chronic Glomerulonephritis 5
- Chronic Pyelonephritis 6
- Other (please specify): _____ 7
- _____

29. When were you born?

		/			/		
Month			Day			Year	

30. What is the highest level of school you have completed?

(Circle One Number)

- 8th grade or less 1
- Some high school or less 2
- High school diploma or GED..... 3
- Vocational school or some college 4
- College degree 5
- Professional or graduate degree 6

31. What is your gender?

(Circle One Number)

- Male 1
- Female 2

32. How do you describe yourself?

(Circle One Number)

- African American or Black 1
 - Hispanic or Latino 2
 - Native American or American Indian 3
 - Asian or Pacific Islander 4
 - White 5
 - Other (please specify): _____ 6
- _____

33. Are you currently married?

(Circle One Number)

- No 1
- Yes 2

34. During the last 30 days, were you:

(Circle One Number)

- | | |
|--|---|
| Working full-time..... | 1 |
| Working part-time..... | 2 |
| Unemployed, laid off, or looking for work..... | 3 |
| Retired..... | 4 |
| Disabled..... | 5 |
| In school..... | 6 |
| Keeping house..... | 7 |
| None of the above..... | 8 |

35. What kind of health insurance do you have?

(Circle One Number)

- | | |
|---|---|
| None, I have no health insurance | 1 |
| Medicare only | 2 |
| Medicare and any other insurance | 3 |
| Medicaid or Medi-Cal only | 4 |
| Private, fee-for-service health insurance (e.g., Prudential, Aetna, etc.) | 5 |
| HMO, PPO, IPA or other prepaid plan (e.g., Kaiser, Cigna, FHP, etc.) | 6 |
| Other (please specify) | 7 |

36. What was your total household income (from all sources) before taxes in the **LAST CALENDAR YEAR**, including yourself, your partner, and others you regard as family who live in your household? (Please remember your answers are confidential.)

(Circle One Number)

- | | |
|--------------------------|---|
| Less than \$5,000 | 1 |
| \$5,001-\$10,000 | 2 |
| \$10,001-\$20,000 | 3 |
| \$20,001-\$40,000 | 4 |
| \$40,001-\$75,000 | 5 |
| More than \$75,000 | 6 |
| Don't know | 7 |

37. Did someone help you fill out this survey?

(Circle One Number)

- | | |
|--|---|
| Yes, a physician or other health care provider | 1 |
| Yes, a family member or friend | 2 |
| Yes, someone else | 3 |
| No | 4 |

38. What is today's date?

<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>
Month			Day			Year	

THANK YOU FOR TAKING PART IN THIS STUDY.