

CONFIDENTIAL ONCE COMPLETED

**STOP-ACEi Details**

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Assessment point: <input type="checkbox"/> Baseline (v 1) <input type="checkbox"/> Month 12 (v 5) <input type="checkbox"/> Month 24 (v 9) <input type="checkbox"/> Month 36 (v 13)	

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# Your Health – and – Well-Being

## Kidney Disease and Quality of Life (KDQOL-SF™ 1.3)

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



*Thank you for completing these questions!*

# **Study of Quality of Life For Patients on Dialysis**

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## **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.

# 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

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

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 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? [Mark an  in a box on each line.]**

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

**4. 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 ▼
a	Cut down the <u>amount of time</u> you spent on work or other activities .....	<input type="checkbox"/> 1.....	<input type="checkbox"/> 2
b	<u>Accomplished less</u> than you would like.....	<input type="checkbox"/> 1.....	<input type="checkbox"/> 2
c	Were limited in the <u>kind</u> of work or other activities .....	<input type="checkbox"/> 1.....	<input type="checkbox"/> 2
d	Had <u>difficulty</u> performing the work or other activities (for example, it took extra effort) .....	<input type="checkbox"/> 1.....	<input type="checkbox"/> 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)?**

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

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

Not at all	Slightly	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

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

None	Very mild	Mild	Moderate	Severe	Very severe
▼	▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

**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
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 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...**

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

- 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 has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?**

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

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

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
	▼	▼	▼	▼	▼
a I seem to get sick a little easier than other people .....	<input type="checkbox"/> 1	..... <input type="checkbox"/> 2	..... <input type="checkbox"/> 3	..... <input type="checkbox"/> 4	..... <input type="checkbox"/> 5
b I am as healthy as anybody I know ....	<input type="checkbox"/> 1	..... <input type="checkbox"/> 2	..... <input type="checkbox"/> 3	..... <input type="checkbox"/> 4	..... <input type="checkbox"/> 5
c I expect my health to get worse .....	<input type="checkbox"/> 1	..... <input type="checkbox"/> 2	..... <input type="checkbox"/> 3	..... <input type="checkbox"/> 4	..... <input type="checkbox"/> 5
d My health is excellent.....	<input type="checkbox"/> 1	..... <input type="checkbox"/> 2	..... <input type="checkbox"/> 3	..... <input type="checkbox"/> 4	..... <input type="checkbox"/> 5



# Your Kidney Disease

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

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a My kidney disease interferes too much with my life .....	▼	▼	▼	▼	▼
	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
b Too much of my time is spent dealing with my kidney disease .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
c I feel frustrated dealing with my kidney disease .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
d I feel like a burden on my family .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 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...**

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

**14. 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
▼	▼	▼	▼	▼

a	Soreness in your muscles?.....	<input type="checkbox"/> 1	.....	<input type="checkbox"/> 2	.....	<input type="checkbox"/> 3	.....	<input type="checkbox"/> 4	.....	<input type="checkbox"/> 5
b	Chest pain? .....	<input type="checkbox"/> 1	.....	<input type="checkbox"/> 2	.....	<input type="checkbox"/> 3	.....	<input type="checkbox"/> 4	.....	<input type="checkbox"/> 5
c	Cramps? .....	<input type="checkbox"/> 1	.....	<input type="checkbox"/> 2	.....	<input type="checkbox"/> 3	.....	<input type="checkbox"/> 4	.....	<input type="checkbox"/> 5
d	Itchy skin?.....	<input type="checkbox"/> 1	.....	<input type="checkbox"/> 2	.....	<input type="checkbox"/> 3	.....	<input type="checkbox"/> 4	.....	<input type="checkbox"/> 5
e	Dry skin?.....	<input type="checkbox"/> 1	.....	<input type="checkbox"/> 2	.....	<input type="checkbox"/> 3	.....	<input type="checkbox"/> 4	.....	<input type="checkbox"/> 5
f	Shortness of breath?.....	<input type="checkbox"/> 1	.....	<input type="checkbox"/> 2	.....	<input type="checkbox"/> 3	.....	<input type="checkbox"/> 4	.....	<input type="checkbox"/> 5
g	Faintness or dizziness?.....	<input type="checkbox"/> 1	.....	<input type="checkbox"/> 2	.....	<input type="checkbox"/> 3	.....	<input type="checkbox"/> 4	.....	<input type="checkbox"/> 5
h	Lack of appetite?...	<input type="checkbox"/> 1	.....	<input type="checkbox"/> 2	.....	<input type="checkbox"/> 3	.....	<input type="checkbox"/> 4	.....	<input type="checkbox"/> 5
i	Washed out or drained? .....	<input type="checkbox"/> 1	.....	<input type="checkbox"/> 2	.....	<input type="checkbox"/> 3	.....	<input type="checkbox"/> 4	.....	<input type="checkbox"/> 5
j	Numbness in hands or feet?.....	<input type="checkbox"/> 1	.....	<input type="checkbox"/> 2	.....	<input type="checkbox"/> 3	.....	<input type="checkbox"/> 4	.....	<input type="checkbox"/> 5
k	Nausea or upset stomach?.....	<input type="checkbox"/> 1	.....	<input type="checkbox"/> 2	.....	<input type="checkbox"/> 3	.....	<input type="checkbox"/> 4	.....	<input type="checkbox"/> 5
l	(Hemodialysis patient only)									
	Problems with your access site? ...	<input type="checkbox"/> 1	.....	<input type="checkbox"/> 2	.....	<input type="checkbox"/> 3	.....	<input type="checkbox"/> 4	.....	<input type="checkbox"/> 5
m	(Peritoneal dialysis patient only)									
	Problems with your catheter site?..	<input type="checkbox"/> 1	.....	<input type="checkbox"/> 2	.....	<input type="checkbox"/> 3	.....	<input type="checkbox"/> 4	.....	<input type="checkbox"/> 5

# Effects of Kidney Disease on Your Daily Life

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**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?**

Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
▼	▼	▼	▼	▼

a	Fluid restriction?....	<input type="checkbox"/>	1 .....	<input type="checkbox"/>	2 .....	<input type="checkbox"/>	3 .....	<input type="checkbox"/>	4 .....	<input type="checkbox"/>	5
b	Dietary restriction?.	<input type="checkbox"/>	1 .....	<input type="checkbox"/>	2 .....	<input type="checkbox"/>	3 .....	<input type="checkbox"/>	4 .....	<input type="checkbox"/>	5
c	Your ability to work around the house? .....	<input type="checkbox"/>	1 .....	<input type="checkbox"/>	2 .....	<input type="checkbox"/>	3 .....	<input type="checkbox"/>	4 .....	<input type="checkbox"/>	5
d	Your ability to travel? .....	<input type="checkbox"/>	1 .....	<input type="checkbox"/>	2 .....	<input type="checkbox"/>	3 .....	<input type="checkbox"/>	4 .....	<input type="checkbox"/>	5
e	Being dependent on doctors and other medical staff?.....	<input type="checkbox"/>	1 .....	<input type="checkbox"/>	2 .....	<input type="checkbox"/>	3 .....	<input type="checkbox"/>	4 .....	<input type="checkbox"/>	5
f	Stress or worries caused by kidney disease? .....	<input type="checkbox"/>	1 .....	<input type="checkbox"/>	2 .....	<input type="checkbox"/>	3 .....	<input type="checkbox"/>	4 .....	<input type="checkbox"/>	5
g	Your sex life? .....	<input type="checkbox"/>	1 .....	<input type="checkbox"/>	2 .....	<input type="checkbox"/>	3 .....	<input type="checkbox"/>	4 .....	<input type="checkbox"/>	5
h	Your personal appearance? .....	<input type="checkbox"/>	1 .....	<input type="checkbox"/>	2 .....	<input type="checkbox"/>	3 .....	<input type="checkbox"/>	4 .....	<input type="checkbox"/>	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



If no, please skip to Question 17

Yes .....2

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

	Not a problem	A little problem	Somewhat of a problem	Very much a problem	Severe problem	
a	Enjoying sex? .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3 .....	<input type="checkbox"/> 4 .....	<input type="checkbox"/> 5
b	Becoming sexually aroused? .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3 .....	<input type="checkbox"/> 4 .....	<input type="checkbox"/> 5

**17. 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 mark the box under the number 5. If you think your sleep is one level better than 5, mark the box under 6. If you think your sleep is one level worse than 5, mark the box under 4 (and so on).**

**On a scale from 0 to 10, how would you rate your sleep overall?  
[Mark an  in one box.]**

Very bad											Very good
▼											▼
0	1	2	3	4	5	6	7	8	9	10	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

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

	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
a Awaken during the night and have trouble falling asleep again?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
b Get the amount of sleep you need?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
c Have trouble staying awake during the day?...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

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

	Very dissatisfied	Somewhat dissatisfied	Somewhat satisfied	Very satisfied
a The amount of time you are able to spend with your family and friends?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
b The support you receive from your family and friends?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

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

Yes	No
▼	▼
<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>

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

Yes	No
▼	▼
<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>

**22. Overall, how would you rate your health?**

Worst possible (as bad or worse than being dead)		Half-way between worst and best					Best possible			
▼					▼					▼
0	1	2	3	4	5	6	7	8	9	10
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



# 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?

Very poor	Poor	Fair	Good	Very good	Excellent	The Best
▼	▼	▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7

24. How true or false is each of the following statements?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false	
	▼	▼	▼	▼	▼	
a	Dialysis staff encourage me to be as independent as possible .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3 .....	<input type="checkbox"/> 4 .....	<input type="checkbox"/> 5
b	Dialysis staff support me in coping with my kidney disease .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3 .....	<input type="checkbox"/> 4 .....	<input type="checkbox"/> 5

*Thank you for completing these questions!*