CONFIDENTIAL ONCE COMPLETED

STOP-ACEi Details

Trial No.:	Centre:
DOB:	Assessment date: / / / / / / / / / / / / / / / / / / /
Assessment point: Baseline (v 1)	Month 12 (v 5) Month 24 (v 9) Month 36 (v 13)

Your Health

- and -

Well-Being

Kidney Disease and Quality of Life (KDQOL-SFTM 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

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.

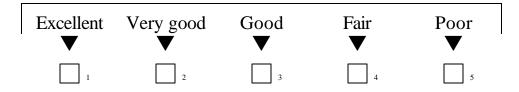
Do I have to take part?

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 \boxtimes in the one box that best describes your answer.]



2. <u>Compared to one year ago</u>, how would you rate your health in general <u>now</u>?

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

3. The following items are about activities typical day. <u>Does your health now limit</u> how much? [Mark an ∑ in a box on each	you in these activities? If so,
Vigorous activities, such as running, lifting	Yes, Yes, No, not limited a limited a little at all
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	. 1
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	. 1 2 3
Lifting or carrying groceries	
Climbing several flights of stairs	. 1 2 3
^e Climbing one flight of stairs	. 1
Bending, kneeling, or stooping	. 1
^g Walking more than a mile	1 2 3
h Walking several blocks	. 1 2 3
Walking one block	. 1 2 3
Bathing or dressing yourself	. 1 2 3

4.	During the <u>past 4 weeks</u> , have you had any with your work or other regular daily activi <u>physical health</u> ?	~ ·
		Yes No
ı	Cut down the <u>amount of time</u> you spent on work or other activities	12
,	Accomplished less than you would like	12
:	Were limited in the <u>kind</u> of work or other activities	1 2
I	Had <u>difficulty</u> performing the work or other activities (for example, it took extra effort)	
5.	During the past 4 weeks, have you had any	of the following proble
5.	During the <u>past 4 weeks</u> , have you had any with your work or other regular daily activi <u>emotional problems</u> (such as feeling depress	ties <u>as a result of any</u>
5.	with your work or other regular daily activi	ties <u>as a result of any</u>
	with your work or other regular daily activi	ties <u>as a result of any</u> sed or anxious)?
	with your work or other regular daily activity emotional problems (such as feeling depression of time you spent on work). Cut down the amount of time you spent on work	ties <u>as a result of any</u> sed or anxious)? Yes No \[\bigsize \] \[\bigsize \] \[\bigsize \] \[\bigsize \]
5.	with your work or other regular daily activities emotional problems (such as feeling depression of time). Cut down the amount of time you spent on work or other activities	ties <u>as a result of any</u> sed or anxious)? Yes No ▼ ▼ □ 1□ 2
a a	with your work or other regular daily activities emotional problems (such as feeling depression of the such as feeling depression of the such as feeling depression or other activities	ties <u>as a result of any</u> sed or anxious)? Yes No ▼ ▼ □ 1□ 2 □ 1□ 2

, T	at all	Slightly T	Moderately \blacktriangledown	Quite a bit	Extremely
	1		3	4	5
Iow mu	ıch <u>bodil</u> y	y pain have	e you had d	uring the <u>pas</u>	st 4 weeks?
No		ery ild M	ild Moder	ate Severe	Very severe
] 1	2	3	4 5	6
ormal ousewo	work (incork)?	luding bot		d <u>pain</u> interfe side the hom Quite a bit	
,	1	2	3	4	5

	How much of the tin	ie durir	ig the <u>pa</u>	ist 4 wee	<u>eKS</u>		
				A good bit of the time	of the	A little of the time	None of the 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 health or emotion (like visiting with	nal proble	<u>ms</u> interfer	ed with you	_	-
	All of the time o	Most f the time	Some of the time	A little of the time	None of the ti	
	1	2	3	4		5
11.	Please choose the of the following s			scribes how	<u>true</u> or <u>f</u>	<u>alse</u> each
		Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a	I seem to get sick a little easier than other people	▼	V	 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

Your Kidney Disease

12. How <u>true</u> or <u>false</u> 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	▼	▼	▼	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.	going during the past	about how you feel and how things have been at 4 weeks. For each question, please give the nes closest to the way you have been feeling.
	How much of the tim	ne during the <u>past 4 weeks</u>
a	Did you isolate your-	None A little Some bit of Most All of of the of the time time time time time time
	self from people around you?	
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 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? Somewhat Moderately Very much Extremely Not at all bothered bothered bothered bothered bothered Soreness in your muscles?.... Chest pain? Cramps? Itchy skin?.... Dry skin?..... Shortness of breath?.... 3..... Faintness or dizziness?..... Lack of appetite?... Washed out or drained?..... Numbness in hands or feet?..... Nausea or upset stomach?.... (Hemodialysis patient only) Problems with your access site? ... 1 2 3 4 (Peritoneal dialysis patient only) Problems with your catheter site?..

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?

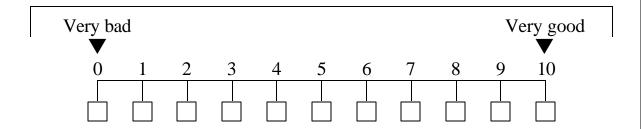
		Not at all bothered	Somewhat bothered	•	Very much bothered	•
a	Fluid restriction?	1	2	3	4	5
b	Dietary restriction?.		2	3	4	5
c	Your ability to work around the house?	1	2	3	4	5
d	Your ability to travel?	1	2	3	4	5
e	Being dependent on doctors and other medical staff?	1	2	3	4	5
f	Stress or worries caused 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

but	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		· ·		eeks?	
			$.1 \longrightarrow [$	If no, please	skip to Ques	tion 17
	How much of a proveeks?	roblem wa	s each of	the followin	ng in the <u>pa</u>	ast 4
				Somewhat of a problem	much a	
a	Enjoying sex?	1	2	3	4	5
b	Becoming sexually aroused?	1	2	3	4	5

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

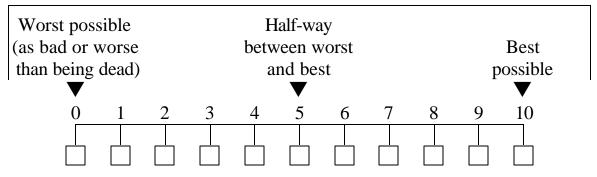
If you think your sleep is half-way between "very bad" and "very good," please mark the box under the number 5. If you think you sleep is one level better than 5, mark the box under 6. If you think your sleep is one level worse than 5, mark the box under 4 (and so on).

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



		e <u>past 4 w</u>	<u>eeks</u> di	id you			
			A little 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?	V	V	V	4	V	V
b	Get the amount of sleep you need?	1		3	4	5	6
c	Have trouble staying awake during the day?	1	2	3	4	5	6
19.	Concerning your <u>fam</u>	aily and fr	iends l	h a a-4			
		-		now sau newhat	Somewh		t h Very
a	The amount of time you are able to spend with your family and friends?	Very dissatisfie	Son d diss	newhat atisfied		nat '	Very tisfied
a b	you are able to spend with your family and	Very dissatisfie ▼	Sor d diss	mewhat atisfied	Somewh satisfie	nat '	Very tisfied ▼
	you are able to spend with your family and friends?	Very dissatisfie ▼	Sor d diss	mewhat atisfied	Somewh satisfie	nat '	Very tisfied ▼

20. During the <u>pa</u>	nst 4 weeks, did you w	ork at a paying job?
	Yes ▼	V
	1	2
21. Does your he	alth keep you from wo	orking at a paying job?
21. Does your he	alth keep you from wo	
21. Does your he		
21. Does your he	Yes ▼	No V
21. Does your he	Yes ▼	No V



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		
	1	2	3	4	5	6	7		
4.	How <u>tr</u>	<u>ıe</u> or <u>false</u>	is each of	the follov	ving state	ments?			
b		staff e me to ependent ble	Definitely true	Mostly true ▼	Don't know ▼	Mostly false ▼	Definitely false ▼		
	coping w	ith my	1	2	3	4	5		
	Th	ank vou	t for coi	mpleting	these	question	es!		