

Renal Support Network's 2007 Patient Survey Results

This survey was given to patients with chronic kidney disease so that congressional representatives and medical professionals may know how patients feel about some of the current issues that affect their lives and the quality of care they receive.

1. Please read the statements below and choose the one that best describes you.	TOTAL	PERCENT
I have kidney disease not yet requiring dialysis or transplantation.	34	4%
I am currently being treated with hemodialysis.	640	77%
I am currently being treated with peritoneal dialysis.	52	6%
I have a kidney transplant.	90	11%
I do not have kidney disease.	12	2%
Total	828	100%
2. If you are currently on dialysis, how long have you been on dialysis?	TOTAL	PERCENT
Less than 1 year.	157	19%
1-3 years.	225	27%
3-5 years.	129	16%
More than 5 years.	192	23%
I am not currently on dialysis.	125	15%
Total	828	100%
3. If you are <u>not currently on dialysis</u> , have you ever been treated with dialysis?	TOTAL	PERCENT
I am currently on dialysis.	674	81%
No, I have never been on dialysis.	46	6%
Yes, I was previously on hemodialysis.	53	6%
Yes, I was previously on peritoneal dialysis.	14	2%
Yes, I have previously been on both hemodialysis and peritoneal dialysis.	41	5%
Total	828	100%
4. The government pays for some of the medications you receive on dialysis. They are looking at ways to provide the medications more efficiently. They think one way to do that would be to require that some medications be given by an injection into the skin with a needle. We want to know what you think about this idea. Please look at the answer choices below and pick the statement you agree with the most:	TOTAL	PERCENT
It is okay for the government to require that some medications are injected into my skin with a needle to save money	77	9%

How I take my medications should be a decision that is made by me and my doctor	701	85%
No opinion	50	6%
Total	828	100%
5. There are thousands of patients in the United States with chronic kidney disease (CKD) who do not yet require dialysis or transplantation. Congress is currently considering a bill that would provide funding for educational sessions to patients on Medicare who have advanced CKD (i.e., stage 4 CKD).		
Please look at the answer choices below to let us know whether you favor or oppose having the government provide patients with educational sessions that would teach them how to slow the progression of the disease and how to prepare for dialysis or transplantation:		
	TOTAL	PERCENT
Strongly favor	509	61%
Somewhat favor	180	22%
Somewhat oppose	32	4%
Strongly oppose	31	4%
No opinion	76	9%
Total	828	100%
6. Do you have diabetes and require injections of insulin?	TOTAL	PERCENT
Yes	199	24%
No	629	76%
Total	828	100%
7. Most patients who are on hemodialysis get a medication to treat anemia each time they go to the dialysis center. One way to receive this medication is for the nurse to put the medication in the tubing of your hemodialysis machine. Another way you could get this medication is for you or the nurse to inject the medication directly into your skin (arms, legs, stomach) with a needle.		
Please look at the answer choices below and choose how you would want to receive your anemia medication during hemodialysis if your doctor asked which you would prefer (please answer only if you have been treated with hemodialysis):		
	TOTAL	PERCENT
I would want to have my anemia drug given to me in the tubing of the hemodialysis machine while I am getting my treatment.	650	84%
I would want to have my anemia drug injected into my skin with a needle.	36	5%
No opinion - either way would be fine with me.	87	11%
Total	773	100%

<p>8. There are several different ways that people can receive dialysis, including hemodialysis provided at a dialysis facility, and peritoneal or hemodialysis performed by the patient at their home.</p> <p>Approximately 90% of patients are treated at a dialysis facility. Since fewer patients dialyze at home, the government is considering to conduct a study to determine the barriers that may prevent patients from choosing a home dialysis option.</p> <p>This study may help to understand how to overcome those barriers.</p> <p>Please look at the answer choices below to let us know whether you favor or oppose having the government conduct a study:</p>		
	TOTAL	PERCENT
Strongly favor	279	34%
Somewhat favor	242	29%
Somewhat oppose	83	10%
Strongly oppose	97	12%
No opinion	127	15%
Total	828	100%
<p>9. Patients with stage 5 chronic kidney disease who need to start dialysis have many options on how they will get dialysis. The most common type of dialysis is in-center hemodialysis.</p> <p>Another option is to get your dialysis at home (peritoneal or home hemodialysis).</p> <p>When you and your doctor were deciding how to get your dialysis, were peritoneal dialysis and home hemodialysis discussed with you as an option?</p>		
	TOTAL	PERCENT
Yes, peritoneal dialysis was discussed	176	21%
Yes, home hemodialysis was discussed	44	5%
Both home dialysis options were discussed	380	46%
No, I was not told about other dialysis options	157	19%
I can't remember if I was told about home dialysis	71	9%
Total	828	100%
<p>10. Medicare's end-stage renal disease (ESRD) program pays for dialysis and other treatments related to kidney disease. It is the only Medicare program that does not have an automatic cost-of-living update each year to adjust for inflation.</p> <p>Please look at the answer choices below to let us know whether you favor or oppose having the government treat the ESRD program like other Medicare programs by providing a yearly cost-of-living update for dialysis facilities.</p>		
	TOTAL	PERCENT
Strongly favor	547	66%

Somewhat favor	130	16%
Somewhat oppose	24	3%
Strongly oppose	43	5%
No opinion	84	10%
Total	828	100%
<p>11. Congress is currently debating whether to provide financial rewards to dialysis facilities based on the quality of care provided to patients if they reach standardized clinical measures.</p> <p>Please look at the answer choices below to let us know whether you favor or oppose having the government establish a quality initiative that would offer financial rewards to dialysis facilities that provide improved quality of care to patients with kidney disease:</p>		
	TOTAL	PERCENT
Strongly favor	476	57%
Somewhat favor	203	25%
Somewhat oppose	31	4%
Strongly oppose	39	5%
No opinion	79	9%
Total	828	100%
<p>12. Currently, dialysis centers are paid a fixed amount for each dialysis treatment, and then paid an additional amount for some additional treatments (such as certain medications) based on each individual patient's need.</p> <p>The government is considering a new method of paying for dialysis services that they believe will be more efficient and that is more like other Medicare payment systems (like hospitals, for example). This new payment method is called bundling and would involve paying dialysis centers an increased amount of money for each dialysis treatment by including in the payment things like medications and lab tests that are currently billed separately. (Keep in mind, hospitals are paid one fee by Medicare when you are in the hospital, and hospitals can't bill for anything separately.)</p> <p>Some people are opposed to bundling because they think "the change" could decrease the quality of care provided to patients. Others think that bundling will not affect the quality of care and that it would be a more efficient way for the government to pay for dialysis.</p> <p>Are you concerned or not concerned that attempts to bundle may result in a decrease in the quality of care that you receive?</p>		
	TOTAL	PERCENT
Yes, I am concerned that "bundling" may decrease the quality of care	350	42%
No, I am not concerned that "bundling" may decrease the quality of care	107	13%
Don't know enough about the issue to provide a response.	371	45%

Total	828	100%
<p>13. One potential effect of a bundled payment system is that dialysis patients may have to get some of the less common laboratory tests done outside the dialysis facility. This may require patients to visit another medical facility for additional blood work.</p> <p>Whether or not you are currently on dialysis, please look at the answer choices below and select how difficult it would be to travel to another location other than the dialysis facility to get some of your laboratory testing done.</p>		
	TOTAL	PERCENT
Very difficult	404	49%
Somewhat difficult	294	36%
Not too difficult	85	10%
Not at all difficult	45	5%
Total	828	100%
<p>14. For people who are entitled to Medicare ONLY because of their kidney failure (that is, they are not receiving SSDI benefits or have not turned 65 yet), Medicare pays for transplant medication for 36 months post-kidney transplant. After 36 months, kidney transplant recipients need to find health care coverage to help pay for the cost of their immunosuppressant medication.</p> <p>Immunosuppressant medication, also called anti-rejection medication, is used to prevent the body from rejecting a transplanted organ.</p> <p>Are you concerned or not concerned about your ability to receive the immunosuppressant medication to prevent organ rejection?</p>		
	TOTAL	PERCENT
Yes, I am concerned.	517	62%
No, I am not concerned.	121	15%
Don't know enough about the issue to provide a response.	190	23%
Total	828	100%
15. What is your age?	TOTAL	PERCENT
Less than 21 years	3	<1%
21-30 years	12	1%
31-40 years	71	9%
41-50 years	160	19%
51-60 years	206	25%
61 years or more	376	45%
Total	828	100%

16. What is your gender?	TOTAL	PERCENT
Male	394	48%
Female	434	52%
Total	828	100%
17. What is your ethnicity?	TOTAL	PERCENT
American Indian/Alaska Native	21	3%
Asian	35	4%
Black or African American	176	21%
Latin or Hispanic	31	4%
White	535	65%
Native Hawaiian or Other Pacific Islander	9	1%
Other, please specify	21	2%
Total	828	100%

This Survey was Conducted by the Renal Support Network.

www.RSNhope.org

The Renal Support Network (RSN) was founded in 1993 by Lori Hartwell—a longtime CKD survivor—to instill health, happiness, and hope into the lives of others affected by CKD. RSN is a nonprofit, patient-focused, patient-run organization that strives to help patients develop their personal coping skills, special talents, and employability by educating and empowering them, as well as their family members, to take control of the course and management of the disease.

