

COUNTRY	Doctor no	Patient no	PSC type

Chronic Kidney Disease Patient Information

Dear Sir / Madam

Your doctor is taking part in a research study that collects information about hundreds of patients across a number of countries. It will be used to find out more about patients who have suffered from chronic kidney disease and how to improve treatment.

As part of this study you have been invited to complete this CAHPS questionnaire. We hope you will find the questions interesting to answer. It should only take approximately 10 minutes to complete and you will not be contacted again. This is because all the information that you provide is completely confidential and no names or addresses are recorded.

If you do decide to take part, we would ask you to answer the questions alone, without the help of your doctor.

It is entirely up to you whether or not you take part and you are free to stop at any time without giving a reason. Answering this questionnaire will not affect your treatment in any way.

We would like to thank you in advance for your help in this study.

Survey Instructions

Answer each question by marking the box to the left of your answer.

You are sometimes told to skip over some questions in this survey. When this happens you will see an arrow with a note that tells you what question to answer next, like this:

- Yes → If Yes, go to #1 on page 1
 No

1. Where do you get your dialysis treatments?

- At home → **If At home, stop here.**
- At the dialysis center

2. How long have you been getting dialysis at this dialysis center?

- Less than 3 months → **If Less than 3 months, stop here.**
- At least 3 months but less than 1 year
- At least 1 year but less than 5 years
- 5 years or more

Your Kidney Doctors

3. For the questions that follow, “your kidney doctors” means the doctor or doctors most involved in your dialysis care now. This could include kidney doctors that you see inside and outside the center. In the last 3 months, how often did your kidney doctors listen carefully to you?

- Never
- Sometimes
- Usually
- Always

4. In the last 3 months, how often did your kidney doctors explain things in a way that was easy to understand?

- Never
- Sometimes
- Usually
- Always

5. In the last 3 months, how often did your kidney doctors show respect for what you had to say?

- Never
- Sometimes
- Usually
- Always

6. In the last 3 months, how often did your kidney doctors spend enough time with you?

- Never
- Sometimes
- Usually
- Always

7. In the last 3 months, how often did you feel your kidney doctors really cared about you as a person?

- Never
- Sometimes
- Usually
- Always

8. Using any number from 0 to 10, where 0 is the worst kidney doctors possible and 10 is the best kidney doctors possible, what number would you use to rate the kidney doctors you have now?

- 0 Worst kidney doctors possible
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 Best kidney doctors possible

9. Do your kidney doctors seem informed and up to date about the health care you receive from other doctors?

- ¹ Yes
- ² No

The Dialysis Center Staff

10. For the questions that follow, dialysis center staff do **not** include doctors. Dialysis center staff means nurses, technicians, dietitians, and social workers at this dialysis center. In the last 3 months, how often did the dialysis center staff listen carefully to you?

- ¹ Never
- ² Sometimes
- ³ Usually
- ⁴ Always

11. In the last 3 months, how often did the dialysis center staff explain things in a way that was easy to understand?

- ¹ Never
- ² Sometimes
- ³ Usually
- ⁴ Always

12. In the last 3 months, how often did the dialysis center staff show respect for what you had to say?

- ¹ Never
- ² Sometimes
- ³ Usually
- ⁴ Always

13. In the last 3 months, how often did the dialysis center staff spend enough time with you?

- ¹ Never
- ² Sometimes
- ³ Usually
- ⁴ Always

14. In the last 3 months, how often did you feel the dialysis center staff really cared about you as a person?

- ¹ Never
- ² Sometimes
- ³ Usually
- ⁴ Always

15. In the last 3 months, how often did dialysis center staff make you as comfortable as possible during dialysis?

- ¹ Never
- ² Sometimes
- ³ Usually
- ⁴ Always

16. In the last 3 months, did dialysis center staff keep information about you and your health as private as possible from other patients?

- ¹ Yes
² No

17. In the last 3 months, did you feel comfortable asking the dialysis center staff everything you wanted about dialysis care?

- ¹ Yes
² No

18. In the last 3 months, has anyone on the dialysis center staff asked you about how your kidney disease affects other parts of your life?

- ¹ Yes
² No

19. The dialysis center staff can connect you to the dialysis machine through a graft, fistula, or catheter. Do you know how to take care of your graft, fistula, or catheter?

- ¹ Yes
² No

20. In the last 3 months, which one did they use most often to connect you to the dialysis machine?

- ¹ Graft
² Fistula
³ Catheter → **If Catheter, go to #22**
⁴ Don't know → **If Don't know, go to #22**

21. In the last 3 months, how often did dialysis center staff insert your needles with as little pain as possible?

- ¹ Never
² Sometimes
³ Usually
⁴ Always
⁵ I insert my own needles

22. In the last 3 months, how often did dialysis center staff check you as closely as you wanted while you were on the dialysis machine?

- ¹ Never
² Sometimes
³ Usually
⁴ Always

23. In the last 3 months, did any problems occur during your dialysis?

- ¹ Yes
² No → **If No, go to #25**

24. In the last 3 months, how often were the dialysis center staff able to manage problems during your dialysis?

- ¹ Never
² Sometimes
³ Usually
⁴ Always

25. In the last 3 months, how often did dialysis center staff behave in a professional manner?

- ¹ Never
² Sometimes
³ Usually
⁴ Always

26. Please remember that, for these questions, dialysis center staff do **not** include doctors. Dialysis center staff means nurses, technicians, dietitians, and social workers at this dialysis center. In the last 3 months, did dialysis center staff talk to you about what you should eat and drink?

- ¹ Yes
- ² No

27. In the last 3 months, how often did dialysis center staff explain blood test results in a way that was easy to understand?

- ¹ Never
- ² Sometimes
- ³ Usually
- ⁴ Always

28. As a patient, you have certain rights. For example, you have the right to be treated with respect and the right to privacy. Did this dialysis center ever give you any written information about your rights as a patient?

- ¹ Yes
- ² No

29. Did dialysis center staff at this center ever review your rights as a patient with you?

- ¹ Yes
- ² No

30. Have dialysis center staff ever told you what to do if you experience a health problem at home?

- ¹ Yes
- ² No

31. Have any dialysis center staff ever told you how to get off the machine if there is an emergency at the center?

- ¹ Yes
- ² No

32. Using any number from 0 to 10, where 0 is the worst dialysis center staff possible and 10 is the best dialysis center staff possible, what number would you use to rate your dialysis center staff?

- 0 Worst dialysis center staff possible
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 Best dialysis center staff possible

The Dialysis Center

33. In the last 3 months, when you arrived on time, how often did you get put on the dialysis machine within 15 minutes of your appointment or shift time?

- ¹ Never
- ² Sometimes
- ³ Usually
- ⁴ Always

34. In the last 3 months, how often was the dialysis center as clean as it could be?

- ¹ Never
- ² Sometimes
- ³ Usually
- ⁴ Always

35. Using any number from 0 to 10, where 0 is the worst dialysis center possible and 10 is the best dialysis center possible, what number would you use to rate this dialysis center?

- 0 Worst dialysis center possible
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 Best dialysis center possible

Treatment

The next few questions ask about your care in the last 12 months.

36. You can treat kidney disease with dialysis at a center, a kidney transplant, or dialysis at home. In the last 12 months, did either your kidney doctors or dialysis center staff talk to you as much as you wanted about which treatment is right for you?

- ¹ Yes
- ² No

37. Are you eligible for a kidney transplant?

- ¹ Yes → **If Yes, go to #39**
- ² No
- ³ Don't know → **If Don't know, go to #39**

38. In the last 12 months, have either your kidney doctors or dialysis center staff explained to you why you are not eligible for a kidney transplant?

- ¹ Yes
- ² No

39. Peritoneal dialysis is dialysis given through the belly and is usually done at home. In the last 12 months, did either your kidney doctors or dialysis center staff talk to you about peritoneal dialysis?

- ¹ Yes
- ² No

40. In the last 12 months, were you as involved as much as you wanted in choosing the treatment for kidney disease that is right for you?

- ¹ Yes
- ² No

41. In the last 12 months, were you ever unhappy with the care you received at the dialysis center or from your kidney doctors?

- ¹ Yes
- ² No → **If No, go to #45**

42. In the last 12 months, did you ever talk to someone on the dialysis center staff about this?

¹ Yes

² No → **If No, go to #45**

43. In the last 12 months, how often were you satisfied with the way they handled these problems?

¹ Never

² Sometimes

³ Usually

⁴ Always

44. Medicare and your state have special agencies that check the quality of care at this dialysis center. In the last 12 months, did you make a complaint to any of these agencies?

¹ Yes

² No

About You

45. In general, how would you rate your overall health?

¹ Excellent

² Very good

³ Good

⁴ Fair

⁵ Poor

46. In general, how would you rate your overall mental or emotional health?

¹ Excellent

² Very good

³ Good

⁴ Fair

⁵ Poor

47. Are you being treated for high blood pressure?

¹ Yes

² No

48. Are you being treated for diabetes or high blood sugar?

¹ Yes

² No

49. Are you being treated for heart disease or heart problems?

¹ Yes

² No

50. What is your age?

- 1 18 to 24
- 2 25 to 34
- 3 35 to 44
- 4 45 to 54
- 5 55 to 64
- 6 65 to 74
- 7 75 or older

51. Are you male or female?

- 1 Male
- 2 Female

52. What is the highest grade or level of school that you have completed?

- 1 8th grade or less
- 2 Some high school, but did not graduate
- 3 High school graduate or GED
- 4 Some college or 2-year degree
- 5 4-year college graduate
- 6 More than 4-year college degree

53. Are you of Hispanic or Latino origin or descent?

- 1 Yes, Hispanic or Latino
- 2 No, not Hispanic or Latino

54. What is your race? Please mark one or more.

- 1 American Indian or Alaska Native
- 2 Asian
- 3 Black or African American
- 4 Native Hawaiian or Other Pacific Islander
- 5 White

55. What language do you mainly speak at home?

- 1 English
- 2 Spanish
- 3 Both English and Spanish equally
- 4 Some other language

Please print: _____

56. Did someone help you complete this survey?

- 1 Yes
- 2 No → **If No, stop here.**

57. Who helped you complete this survey?

- 1 A family member
- 2 A friend
- 3 A staff member at the dialysis center
- 4 Someone else

Please print: _____

58. How did that person help you? Please mark one or more.

- 1 Read the questions to me
- 2 Wrote down the answers I gave
- 3 Answered the questions for me
- 4 Translated the questions into my language
- 5 Helped in some other way

Please print: _____

THANK YOU FOR COMPLETING
THIS FORM

