

# ESRD Beneficiary Survey

## SCREENER - INTRODUCTION

Hello, my name is [INTERVIEWER NAME]. I'm calling on behalf of the Centers for Medicare and Medicaid Services the Medicare Agency. We're conducting a survey of people with kidney failure. You have been selected at random to be included in this important study.

Now I will read you a statement regarding the Paperwork Reduction Act:

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is XXXX-XXXX. The time required to complete this information collection is estimated to average 15 minutes per response, including the time to review instructions, search existing data resources, gather the data needed, and complete and review the information collection. If you have comments concerning the accuracy of the time estimate(s) or suggestions for improving this form, please write to: CMS, 7500 Security Boulevard, Attn: PRA Reports Clearance Officer, Mail Stop C4-26-05, Baltimore, Maryland 21244-1850.

Participation in the study is voluntary and should take about 15 minutes. You may skip any questions you do not want to answer.

[add confidentiality and privacy statement – nonintrusive]

**1a. In the last 3 months have you received dialysis treatment?**

- <sup>1</sup>  YES
- <sup>2</sup>  NO [If NO, SKIP TO END]
- <sup>-7</sup>  REFUSED
- <sup>-8</sup>  DON'T KNOW

**1b. Have you had a kidney transplant since March of 2011?**

- <sup>1</sup>  YES [If YES, SKIP TO END]
- <sup>2</sup>  NO
- <sup>-7</sup>  REFUSED
- <sup>-8</sup>  DON'T KNOW

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## EXTENDED SURVEY

These first questions are about the type of dialysis treatment you get.

**2. Where do you currently get your dialysis treatments...**

[IF NEEDED: If you get dialysis treatments in more than one setting, please tell us where you usually get dialysis treatments.] [INSTRUCTIONS TO INTERVIEWER: If respondent says it is owned by a hospital, but the dialysis center is not located physically within the hospital, it is still considered at a hospital]

- <sup>1</sup>  At home,
- <sup>2</sup>  At a dialysis center, or
- <sup>3</sup>  At a hospital?
- <sup>-7</sup>  REFUSED – SKIP to Q4
- <sup>-8</sup>  DON'T KNOW – SKIP to Q4

**3. How long have you been getting dialysis treatments at {home/a dialysis center/a hospital}? Would you say...**

- <sup>1</sup>  Less than 3 months,
- <sup>2</sup>  At least 3 months but less than 1 year,
- <sup>3</sup>  At least 1 year but less than 5 years, or
- <sup>4</sup>  5 years or more?
- <sup>-7</sup>  REFUSED
- <sup>-8</sup>  DON'T KNOW

[PROGRAMMER, IF Q2=1, FILL DISPLAY WITH "home"; IF Q2=2 FILL DISPLAY WITH "a dialysis center"; IF Q2=3, FILL DISPLAY WITH "a hospital".]

**4. What type of dialysis treatment do you currently get? Hemodialysis through the vein or peritoneal dialysis through the belly?**

- <sup>1</sup>  HEMODIALYSIS
- <sup>2</sup>  PERITONEAL DIALYSIS →Skip to 6
- <sup>-7</sup>  REFUSED
- <sup>-8</sup>  DON'T KNOW

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5. The dialysis center staff can connect you to the dialysis machine through a graft, fistula, or catheter. In the last 3 months, which one did they use most often to connect you to the dialysis machine?

<sup>1</sup>  GRAFT

<sup>2</sup>  FISTULA

<sup>3</sup>  CATHETER

<sup>-7</sup>  REFUSED

<sup>-8</sup>  DON'T KNOW

6. (Old 7) How many hours do your dialysis treatments usually last?

\_\_\_\_\_

**OP1. Please describe your experience with getting your kidney care over the last three months. [PROGRAMMER NOTE, ASK OF FLAGGED OPEN ENDED CASES ONLY]**

7. (Old 14) Now we are going to ask you about your kidney doctors. Your kidney doctors are the doctors most involved in your dialysis care now. This could include kidney doctors that you see inside and outside of a clinic, hospital, or dialysis center. In the last 3 months, how often did your kidney doctors listen carefully to you? Would you say...

<sup>1</sup>  Never,

<sup>2</sup>  Sometimes,

<sup>3</sup>  Usually, or

<sup>4</sup>  Always?

<sup>-7</sup>  REFUSED

<sup>-8</sup>  DON'T KNOW

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**8. (Old 15) In the last 3 months, how often did your kidney doctors explain things in a way that was easy to understand? Would you say...**

- <sup>1</sup>  Never,
- <sup>2</sup>  Sometimes,
- <sup>3</sup>  Usually, or
- <sup>4</sup>  Always?
- <sup>-7</sup>  REFUSED
- <sup>-8</sup>  DON'T KNOW

**9. (Old 16) In the last 3 months, how often did your kidney doctors show respect for what you had to say?**

- <sup>1</sup>  NEVER
- <sup>2</sup>  SOMETIMES
- <sup>3</sup>  USUALLY
- <sup>4</sup>  ALWAYS
- <sup>-7</sup>  REFUSED
- <sup>-8</sup>  DON'T KNOW

**10. (Old 17) In the last 3 months, how often did your kidney doctors spend enough time with you?**

- <sup>1</sup>  NEVER
- <sup>2</sup>  SOMETIMES
- <sup>3</sup>  USUALLY
- <sup>4</sup>  ALWAYS
- <sup>-7</sup>  REFUSED
- <sup>-8</sup>  DON'T KNOW

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**11. (Old 26) In the last 3 months, did you and your kidney doctors talk about starting or stopping a prescription medicine?**

- <sup>1</sup>  YES
- <sup>2</sup>  NO → If NO, go to Q15
- <sup>-7</sup>  REFUSED
- <sup>-8</sup>  DON'T KNOW

**12. (Old 27) Did you and your kidney doctors talk about the reasons why you might want to take a prescription medicine?**

- <sup>1</sup>  Yes
- <sup>2</sup>  No
- <sup>-7</sup>  REFUSED
- <sup>-8</sup>  DON'T KNOW

**13. (Old 28) Did you and your kidney doctors talk about the reasons why you might not want to take a prescription medicine?**

- <sup>1</sup>  Yes
- <sup>2</sup>  No
- <sup>-7</sup>  REFUSED
- <sup>-8</sup>  DON'T KNOW

**14. (Old 29) When you talked about starting or stopping a prescription medicine, did your kidney doctors ask what you thought was best for you?**

- <sup>1</sup>  YES
- <sup>2</sup>  NO
- <sup>-7</sup>  REFUSED
- <sup>-8</sup>  DON'T KNOW

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**15. (Old 30) 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

[PROGRAMMER, FILL Q16 IF Q2=1 (HOME DIALYSIS), DO NOT SHOW DISPLAY; IF Q2=2 (DIALYSIS AT A CENTER) FILL DISPLAY WITH "dialysis center"; IF Q2=3 (DIALYSIS AT A HOSPITAL), FILL DISPLAY WITH "hospital dialysis center".]

**16. (Old 34) Now we are going to ask you to think about all the people on your kidney care team. This includes nurses, technicians, and social workers at the [PROGRAMMER PLEASE INCLUDE DISPLAY FOR -- dialysis center, / hospital dialysis center]. In the last 3 months, how often did your kidney care team treat you with courtesy and respect? Would you say...**

<sup>1</sup>  Never,

<sup>2</sup>  Sometimes,

<sup>3</sup>  Usually, or

<sup>4</sup>  Always?

<sup>-7</sup>  REFUSED

<sup>-8</sup>  DON'T KNOW

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### PROGRAMMER BOX 2:

IF Q2=1 (CURRENTLY GETTING DIALYSIS TREATMENT AT HOME) SKIP TO #21

ELSE, GO TO #18.

**17. (Old 35) In the last 3 months, how often did your kidney care team spend enough time with you? Would you say...**

- <sup>1</sup>  Never,
- <sup>2</sup>  Sometimes,
- <sup>3</sup>  Usually, or
- <sup>4</sup>  Always?
- <sup>-7</sup>  REFUSED
- <sup>-8</sup>  DON'T KNOW

**18. (Old 36) In the last 3 months, how often did your kidney care team make you as comfortable as possible during dialysis?**

- <sup>1</sup>  NEVER
- <sup>2</sup>  SOMETIMES
- <sup>3</sup>  USUALLY
- <sup>4</sup>  ALWAYS
- <sup>-7</sup>  REFUSED
- <sup>-8</sup>  DON'T KNOW

**19. (Old 37) In the last 3 months, how often did your kidney care team check you as closely as you wanted while you were on the dialysis machine?**

- <sup>1</sup>  NEVER
- <sup>2</sup>  SOMETIMES
- <sup>3</sup>  USUALLY
- <sup>4</sup>  ALWAYS
- <sup>-7</sup>  REFUSED
- <sup>-8</sup>  DON'T KNOW

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**20. (Old 40) Using any number from 0 to 10, where 0 is the worst kidney care team possible and 10 is the best kidney care team possible, what number would you use to rate your kidney care team?**

0 Worst kidney care team possible

1

2

3

4

5

6

7

8

9

10 Best kidney care team possible

**21. (Old 22) Are you eligible for a kidney transplant?**

<sup>1</sup>  YES → If YES go to Q24

<sup>2</sup>  NO

<sup>-7</sup>  REFUSED

<sup>-8</sup>  DON'T KNOW

**22. (Old 23) In the last 3 months, did your kidney doctors or anyone on your kidney care team explain why you are not eligible for a kidney transplant?**

<sup>1</sup>  YES

<sup>2</sup>  NO

<sup>-7</sup>  REFUSED

<sup>-8</sup>  DON'T KNOW

**23. (Old 24) In the last 3 months, did your kidney doctors or anyone on your kidney care team talk with you as much as you wanted about a kidney transplant?**

<sup>1</sup>  YES

<sup>2</sup>  NO

<sup>-7</sup>  REFUSED

<sup>-8</sup>  DON'T KNOW



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**24. (Old 25) Peritoneal dialysis is dialysis given through the belly and is usually done at home. In the last 3 months, did your kidney doctors or anyone on your kidney care team talk with you as much as you wanted about peritoneal dialysis?**

<sup>1</sup>  YES

<sup>2</sup>  NO

<sup>-7</sup>  REFUSED

<sup>-8</sup>  DON'T KNOW

**25. (Old 44) In the last 3 months, did your kidney doctors or anyone on your kidney care team talk to you about what you should eat and drink?**

<sup>1</sup>  YES

<sup>2</sup>  NO

<sup>-7</sup>  REFUSED

<sup>-8</sup>  DON'T KNOW

**26. (Old 46) In the last 3 months, did your kidney doctors or anyone on your kidney care team work with you to set specific goals for managing your health?**

<sup>1</sup>  YES

<sup>2</sup>  NO → If NO go to Q28

<sup>-7</sup>  REFUSED

<sup>-8</sup>  DON'T KNOW

**27. (Added question) In the last 3 months, did your kidney doctors or anyone on your kidney care team offer you help to reach these goals?**

<sup>1</sup>  YES

<sup>2</sup>  NO

<sup>-7</sup>  REFUSED

<sup>-8</sup>  DON'T KNOW

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**28. (Old 47) In the last 3 months, did your kidney doctors or anyone on your kidney care team ask you about your mental or emotional health?**

<sup>1</sup>  YES

<sup>2</sup>  NO

<sup>-7</sup>  REFUSED

<sup>-8</sup>  DON'T KNOW

**29. (Old 60) In the last 3 months, did your kidney doctors or anyone on your kidney care team ask you about how your kidney disease affects other parts of your life?**

<sup>1</sup>  YES

<sup>2</sup>  NO

<sup>-7</sup>  REFUSED

<sup>-8</sup>  DON'T KNOW

**OP2. Thinking about your experience with your kidney doctors and your kidney care team, please describe the care you received over the last three months. [PROGRAMMER NOTE, ASK OF FLAGGED OPEN ENDED CASES ONLY]**

Now we are going to ask you about how much your health affects other parts of your life and daily activities. 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?

**30. (Old 62) In the last 3 months, how often have you been bothered by fluid restrictions? Would you say...**

<sup>1</sup>  Never,

<sup>2</sup>  Sometimes,

<sup>3</sup>  Usually, or

<sup>4</sup>  Always?

<sup>-7</sup>  REFUSED

<sup>-8</sup>  DON'T KNOW

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**31. (Old 63) In the last 3 months, how often have you been bothered by dietary restrictions?**

Would you say...

- <sup>1</sup>  Never,
- <sup>2</sup>  Sometimes,
- <sup>3</sup>  Usually, or
- <sup>4</sup>  Always?
- <sup>-7</sup>  REFUSED
- <sup>-8</sup>  DON'T KNOW

**32. (Old 70) In the last 3 months how often have you felt downhearted and blue?**

- <sup>1</sup>  NEVER
- <sup>2</sup>  SOMETIMES
- <sup>3</sup>  USUALLY
- <sup>4</sup>  ALWAYS
- <sup>-7</sup>  REFUSED
- <sup>-8</sup>  DON'T KNOW

**33. (Old 92) In the last 3 months, how many days total did you stay in any hospital overnight?**

\_\_\_\_\_ days

**34. (Old 93) Excluding scheduled treatments, tests, or dialysis, in the last 3 months, how many days total did you receive care at a hospital, but came home the same day?**

\_\_\_\_\_ days

**35. (Old 94) In the last 3 months how many dialysis related infections did you have?**

\_\_\_\_\_ infections

**OP3. Please describe how your kidney care treatment has affected your overall health?  
[PROGRAMMER NOTE, ASK OF FLAGGED OPEN ENDED CASES ONLY]**

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**36. (Old 95) In general, how would you rate your overall physical health? Would you say...**

- 1  Excellent,
- 2  Very good,
- 3  Good,
- 4  Fair, or
- 5  Poor?
- 7  REFUSED
- 8  DON'T KNOW

**37. (Old 96) In general, how would you rate your overall mental or emotional health? Would you say...**

- 1  Excellent,
- 2  Very good,
- 3  Good,
- 4  Fair, or
- 5  Poor?
- 7  REFUSED
- 8  DON'T KNOW

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Now we are going to ask you about the insurance you may have and the cost of your dialysis treatment.

**38. (Old 78) Some people who are eligible for Medicare or Medicaid also have another type of insurance. Do you have any of the following types of health insurance...**

[YES/NO/REFUSED/DON'T KNOW TO EACH]

- <sup>1</sup>  Medigap or Medicare Supplement?
- <sup>2</sup>  Medicare Special Needs Plan?
- <sup>3</sup>  Medicare Advantage?
- <sup>4</sup>  Insurance through your or your spouse's employer or former employer?
- <sup>5</sup>  Insurance through the VA?
- <sup>6</sup>  Insurance that you purchased directly?
- <sup>7</sup>  Any other type of health insurance?

**39. (Old 80) Are you covered for your prescription drugs through any of the following health plans?**

[YES/NO/REFUSED/DON'T KNOW TO EACH]

- <sup>1</sup>  Medicare Part D [IF NEEDED: The Medicare prescription drug plan]?
- <sup>2</sup>  Medicaid?
- <sup>3</sup>  Low Income Subsidy?
- <sup>4</sup>  A private prescription drug plan or any other kind of plan?

**40. (OLD 81, 85) In the last 3 months, were you ever worried or concerned about the cost of your dialysis treatments, tests, or prescription medicines?**

- <sup>1</sup>  YES
- <sup>2</sup>  NO
- <sup>-7</sup>  REFUSED
- <sup>-8</sup>  DON'T KNOW

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**41. (OLD 82, 86) In the last 3 months, did you and your kidney doctors or anyone on your kidney care team talk about the cost of your dialysis treatments, tests, or prescription medicines?**

<sup>1</sup>  YES

<sup>2</sup>  NO

<sup>-7</sup>  REFUSED

<sup>-8</sup>  DON'T KNOW

**42. (OLD 83, 87) In the last 3 months, did you delay or not get dialysis treatments, tests, or medicines prescribed for you?**

<sup>1</sup>  YES

<sup>2</sup>  NO → If NO, go to #44

<sup>-7</sup>  REFUSED

<sup>-8</sup>  DON'T KNOW

**43. (OLD 84, 88) Was cost or lack of insurance a reason why you delayed getting dialysis treatments, tests, or prescription medicines?**

<sup>1</sup>  YES

<sup>2</sup>  NO

<sup>-7</sup>  REFUSED

<sup>-8</sup>  DON'T KNOW

**OP4. How have you been impacted by the cost of your kidney care? [PROGRAMMER NOTE, ASK OF FLAGGED OPEN ENDED CASES ONLY]**

The last few questions are about you.

**44. (Old 97) Are you of Hispanic or Latino origin or descent?**

<sup>1</sup>  YES, HISPANIC OR LATINO

<sup>2</sup>  NO, NOT HISPANIC OR LATINO

<sup>-7</sup>  REFUSED

<sup>-8</sup>  DON'T KNOW

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**45. (Old 98) Please tell me which one or more of the following you would use to describe yourself. Would you describe yourself as...**

- <sup>1</sup>  Native Hawaiian or Other Pacific Islander,
- <sup>2</sup>  American Indian or Alaska Native,
- <sup>3</sup>  Asian,
- <sup>4</sup>  Black or African American, or
- <sup>5</sup>  White?
- <sup>-7</sup>  REFUSED
- <sup>-8</sup>  DON'T KNOW

**46. (Old 99) What is the highest grade or level of school that you have completed?**

- <sup>1</sup>  8TH GRADE OR LESS
- <sup>2</sup>  SOME HIGH SCHOOL, BUT DID NOT GRADUATE
- <sup>3</sup>  HIGH SCHOOL GRADUATE OR GED
- <sup>4</sup>  SOME COLLEGE OR 2-YEAR DEGREE
- <sup>5</sup>  4-YEAR COLLEGE GRADUATE
- <sup>6</sup>  MORE THAN 4-YEAR COLLEGE DEGREE
- <sup>-7</sup>  REFUSED
- <sup>-8</sup>  DON'T KNOW

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**47. (Old 100) Are you now...**

- <sup>1</sup>  married,
- <sup>2</sup>  living with a partner in a marriage-like relationship,
- <sup>3</sup>  widowed,
- <sup>4</sup>  divorced,
- <sup>5</sup>  separated, or
- <sup>6</sup>  never married?
- <sup>-7</sup>  REFUSED
- <sup>-8</sup>  DON'T KNOW

**48. (Old 101) What was your household annual income from all sources before taxes?**

- <sup>1</sup>  Less than \$10,000
- <sup>2</sup>  \$10,001 to \$20,000
- <sup>3</sup>  \$20,001 to \$30,000
- <sup>4</sup>  \$30,001 to \$40,000
- <sup>5</sup>  \$40,001 to \$50,000
- <sup>6</sup>  \$50,001 to \$60,000
- <sup>7</sup>  \$60,001 to \$70,000
- <sup>8</sup>  \$70,001 to \$80,000
- <sup>9</sup>  \$80,001 to \$90,000
- <sup>10</sup>  \$90,001 to \$100,000
- <sup>11</sup>  \$100,001 or more
- <sup>-7</sup>  REFUSED
- <sup>-8</sup>  DON'T KNOW

**49. (Old 102) Including yourself, how many people living in your household are supported by your total household income?**

\_\_\_\_\_ **NUMBER OF PEOPLE {Range 1-20}**



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**THANK YOU FOR TAKING THE TIME TO ANSWER THE END STAGE RENAL MEDICARE BENEFICIARY SURVEY. IF YOU HAVE ANY QUESTIONS, PLEASE DO NOT HESITATE TO CONTACT US AT [     ].**

**THANK YOU.**