

Final Follow-Up Visit Folder

For DCC Use Only
Rev. 1 10/15/92

Form #44
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f. Modification of Diet in Renal Disease Study MDRD Study Survey for Randomized Patients

Your honest thoughts and feelings about the MDRD Study are important to us. Your answers to this survey will help us learn what you liked and did not like about the MDRD Study. Your answers will also help us to better prepare for future studies. Please answer all of the questions, place your Study Survey Form in the envelope with the Nutrition Program Survey, and seal it. The sealed envelope will be sent unopened to the MDRD Data Coordinating Center in Cleveland, Ohio.

No one at your clinical center will see your answers to this survey. Your answers will be kept strictly confidential.

Please circle a Y for yes and N for no.

1. Study Intervention

- | | | |
|--|---|---|
| A. Were you asked to make changes in the foods you eat to meet MDRD goals for protein intake? | Y | N |
| B. Were you asked to make changes in the foods you eat to meet MDRD goals for phosphorus intake? | Y | N |
| C. Were you asked to make changes in the foods you eat to meet MDRD goals for blood pressure? | Y | N |
| D. Were you asked to change your weight to meet MDRD goals for blood pressure? | Y | N |
| E. Were you asked to change your exercise to meet MDRD goals for blood pressure? | Y | N |
| F. Were you asked to change your prescribed medicines to meet MDRD goals for blood pressure? | Y | N |

October 23, 1992

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2. Why did you decide to take part in the MDRD Study?

- | | | |
|--|---|---|
| A. Free medical services. | Y | N |
| B. Close, frequent medical monitoring. | Y | N |
| C. Reassurance. | Y | N |
| D. Hope for physical improvement. | Y | N |
| E. To help others with kidney disease. | Y | N |
| F. To take part in research. | Y | N |
| G. My doctor recommended it. | Y | N |
| H. My family wanted me to be in the study. | Y | N |
| I. It seemed harmless. | Y | N |
| J. Curiosity - I wanted to give it a try. | Y | N |
| K. Had time available. | Y | N |
| L. Other (please state) _____ | | |

3. Have any of the items below been a problem for you in the MDRD Study?

- 1 = Never
2 = Rarely
3 = Sometimes
4 = Often
5 = Always

- | | | | | | |
|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | A. Travel to and from the clinic |
| 1 | 2 | 3 | 4 | 5 | B. Parking |
| 1 | 2 | 3 | 4 | 5 | C. Location of clinic |
| 1 | 2 | 3 | 4 | 5 | D. Long waits for clinic visits |
| 1 | 2 | 3 | 4 | 5 | E. Hurried clinic visits |
| 1 | 2 | 3 | 4 | 5 | F. Too much time spent in clinic visits |
| 1 | 2 | 3 | 4 | 5 | G. Too many clinic visits |

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3. Have any of the items below been a problem for you in the MDRD Study? (continued)

- 1 = Never
- 2 = Rarely
- 3 = Sometimes
- 4 = Often
- 5 = Always

- | | | | | | |
|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | H. Inconvenient scheduling of visits |
| 1 | 2 | 3 | 4 | 5 | I. Changes in the staff at the MDRD Clinic |
| 1 | 2 | 3 | 4 | 5 | J. Work-related problems |
| 1 | 2 | 3 | 4 | 5 | K. Family problems related to my attending visits |
| 1 | 2 | 3 | 4 | 5 | L. Family problems related to my eating pattern |
| 1 | 2 | 3 | 4 | 5 | M. Side effects from blood pressure medicine |
| 1 | 2 | 3 | 4 | 5 | N. Side effects from keto acids |

4. Who do you feel was helped by your taking part in the MDRD Study?

- | | | |
|-------------------------------------|---|---|
| A. Myself | Y | N |
| B. Scientists | Y | N |
| C. The MDRD staff | Y | N |
| D. Other people with kidney disease | Y | N |
| E. My family members | Y | N |
| F. My friends | Y | N |
| G. Other (please state) _____ | | |

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5. How did the MDRD Study help you?

- | | | |
|--|---|---|
| A. Treatment and information from kidney doctors | Y | N |
| B. A "second opinion" on my kidney disease | Y | N |
| C. Treatment and information from dietitians | Y | N |
| D. Meeting with other people with kidney disease | Y | N |
| E. Meeting with other concerned people | Y | N |
| F. More knowledge of my physical condition | Y | N |
| G. Close monitoring of my physical condition | Y | N |
| H. Free exams | Y | N |
| I. Free lab results | Y | N |
| J. Free medicine | Y | N |
| K. Personal awareness and education | Y | N |
| L. Peace of mind | Y | N |
| M. Other (please state) _____ | | |

6. You have met with several staff people during your MDRD clinic visits. How do you rate their treatment of you? Please circle the number that matches your rating for each staff person listed below.

- 1 = Excellent
- 2 = Good
- 3 = Average
- 4 = Below Average
- 5 = Poor

- | | | | | | |
|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | A. Study doctors |
| 1 | 2 | 3 | 4 | 5 | B. Study dietitians |
| 1 | 2 | 3 | 4 | 5 | C. The person who did your GFR measurements |
| 1 | 2 | 3 | 4 | 5 | D. The study coordinator |
| 1 | 2 | 3 | 4 | 5 | E. Other study staff people |

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7. The MDRD Study has placed a number of demands on you. Please rate the items below on a scale from 1 to 5 where:

1 = NOT at all unpleasant or difficult;
5 = EXTREMELY unpleasant or difficult.

- 1 2 3 4 5 A. GFR
- 1 2 3 4 5 B. Blood tests
- 1 2 3 4 5 C. 24-hour urine collection
- 1 2 3 4 5 D. Three-day food records
- 1 2 3 4 5 E. Quality of well-being telephone interview
- 1 2 3 4 5 F. Psychological Questionnaire (SCL-90-R)
- 1 2 3 4 5 G. Blood pressure measurement
- 1 2 3 4 5 H. Changes in eating habits
- 1 2 3 4 5 I. Blood pressure medicine

8. For each statement below, please show how much you agree or disagree on a scale from 1 to 5 where:

1 = Strongly Agree
2 = Agree Somewhat
3 = Undecided
4 = Disagree Somewhat
5 = Strongly Disagree

- 1 2 3 4 5 A. My decision to take part in the MDRD Study was a good idea.
- 1 2 3 4 5 B. The results of the MDRD Study will be of great value to people with kidney disease.
- 1 2 3 4 5 C. Taking part in the MDRD Study helped my kidney disease.

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8. For each statement below, please show how much you agree or disagree on a scale from 1 to 5 where: (continued)

- 1 = Strongly Agree
2 = Agree Somewhat
3 = Undecided
4 = Disagree Somewhat
5 = Strongly Disagree

- 1 2 3 4 5 D. I would make changes in my own life if the final results of the MDRD Study showed that I would be more healthy.
- 1 2 3 4 5 E. Taking part in the MDRD Study helped my health in general.
- 1 2 3 4 5 F. The protein and phosphorus levels of my study diet were clear to me.
- 1 2 3 4 5 G. I was successful in meeting my dietary goals.
- 1 2 3 4 5 H. I am happy with the study diet to which I was assigned.
- 1 2 3 4 5 I. Following my study diet made me feel much better.
- 1 2 3 4 5 J. My study goal for blood pressure was clear to me.
- 1 2 3 4 5 K. I was successful in meeting my blood pressure goals.
- 1 2 3 4 5 L. I am happy with the study goal for blood pressure which I was assigned.
- 1 2 3 4 5 M. Keeping my blood pressure below the level of my study goal has made me feel much better.
- 1 2 3 4 5 N. My family and friends supported my taking part in the study.
- 1 2 3 4 5 O. For those now employed outside the home: My employer supported my taking part in the MDRD Study.

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9. If you were asked in the future to take part in a study like MDRD, do you think you would volunteer? Y N
10. Would you recommend taking part in a study like MDRD to a friend or a family member who was thinking about volunteering? Y N
11. Date form completed _____/_____/_____

Please feel free to write any other comments in the space below or on the back of this form. These comments will be read and summarized confidentially by the people who work at the MDRD Data Coordinating Center at The Cleveland Clinic Foundation in Cleveland, Ohio. Your comments will not be shown to any of the staff members at your MDRD clinic.