



OMB No. 0925-0458 Expiration Date: 12/31/2013



NATIONAL INSTITUTES OF HEALTH CLINICAL CENTER

Warren G. Magnuson Clinical Center
Mark O. Hatfield Clinical Research Center

Please use the enclosed envelope and mail the completed survey to:
National Research Corporation
Survey Processing Center
PO BOX 82660
Lincoln, NE 68501-2660
1-800-733-6714

** 0060421-A12345 **



MR CHRISTOPHER JOHNSON
1245 Q ST
LINCOLN, NE 68508-1430

Dear Christopher Johnson:

As a patient volunteer at the National Institutes of Health Clinical Center, you are a critical member of the clinical research process. We are keenly interested in your perceptions of the quality of care and services that we provide to you. In fact, your input about our services is vital to the continued success of the Clinical Center. To measure our patients' perceptions of the Clinical Center, we conduct patient perception surveys. These surveys help us identify areas in the Clinical Center that are functioning well and areas in need of service improvement.

Enclosed in this packet is a questionnaire that was developed with, and endorsed by, the Clinical Center Patient Advisory Group. The Patient Advisory Group is comprised of current and former Clinical Center patients who advise me about issues that our patients face every day both as hospital patients and as clinical research volunteers.

Your experience as a patient in the Clinical Center is very important to us. Therefore, I ask that you take a few minutes to complete this survey. Your candid and honest answers will provide us with valuable information that we can use to help improve the care and services we provide at the Clinical Center.

We have contracted with National Research Corporation to assist us in administering the survey; the Clinical Center will be provided with the aggregate results. If you have questions regarding this survey, please contact Dr. David Henderson, Deputy Director for Clinical Care, at 301-496-3515.

Thank you for your assistance with this important survey and for your continued contributions to the clinical research mission of your National Institutes of Health.

John I. Gallin, M.D.
Director

Public reporting burden for this collection of information is estimated to average 30 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0458). **Do not return the completed form to this address.**



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** 0107077-A12345 **



MR CHRISTOPHER JOHNSON
1245 Q ST
LINCOLN, NE 68508-1430

Dear Christopher Johnson:

As a patient volunteer at the National Institutes of Health Clinical Center, you are a critical member of the clinical research process. We are keenly interested in your perceptions of the quality of care and services that we provide to you.

Recently you should have received a patient satisfaction survey. This survey will help us identify areas in the Clinical Center that are functioning well and areas in need of service improvement. If you have already completed the survey and sent it to the survey processing center we would like to thank you for taking the time to share your feedback. If you have not had the opportunity to complete the survey please take 10 minutes to complete the survey and return it in the self-addressed stamped envelope.

We have contracted with National Research Corporation to assist us in administering the survey; the Clinical Center will be provided with the aggregate results. If you have questions regarding this survey, please contact Dr. David Henderson, Deputy Director for Clinical Care, at 301-496-3515.

Thank you for your assistance with this important survey and for your continued contributions to the clinical research mission of your National Institutes of Health.

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78. Equipment and Facilities

79. Television
 Poor Fair Good Very Good Excellent Does Not Apply

80. Access to the internet
 Poor Fair Good Very Good Excellent Does Not Apply

81. Telephone
 Poor Fair Good Very Good Excellent Does Not Apply

82. In general, how would you rate your health?
 Poor Fair Good Very Good Excellent

83. How many times have you been hospitalized (either at the Clinical Center or in other hospitals) in the last six months?
 Once More than once

84. What was the last year of school you completed?
 Less than high school graduate College graduate
 High school graduate or GED Post college graduate education
 Some college, trade, or tech school

85. What is your age now?
 18 - 40 years 41 - 64 years 65 - 74 years 75 years or over

86. Are you...
 Female Male

87. If you could change one thing about the Clinical Center or if you have additional comments that you would like to share please use the space below. If you need additional space please attach an additional sheet of paper.



NATIONAL INSTITUTES OF HEALTH CLINICAL CENTER

Warren G. Magnuson Clinical Center
Mark O. Hatfield Clinical Research Center

Your Clinical Center visit...

Please fill in the bubble that best describes your experience during your most recent Clinical Center stay. Only the patient who was hospitalized should fill out this questionnaire.

ADMISSION...

- 1. Was your Clinical Center visit planned (e.g., according to your protocol, first visit) or unplanned due to a complication?
 Planned Unplanned
- 2. Length of Stay
 0 - 3 days 4 - 6 days 7 - 9 days 10 or more days
- 3. How organized was the admission process?
 Not at all organized Somewhat organized Very organized
- 4. Do you feel you had to wait an unnecessarily long time to go to your room?
 Yes, definitely Yes, somewhat No
- 5. If you had to wait to go to your room, did someone from the hospital explain the reason for the delay?
 Yes No Did not have to wait
- 6. How would you rate the courtesy of the staff who admitted you?
 Poor Fair Good Very Good Excellent

DOCTORS...

- 7. Was there one particular doctor in charge of your care in the hospital?
 Yes No Not sure
- 8. When you had important questions to ask a doctor, did you get answers you could understand?
 Yes, always Yes, sometimes No Did not have questions
- 9. If you had any anxieties or fears about your condition or treatment, did a doctor discuss them with you?
 Yes, completely Yes, somewhat No Did not have anxieties or fears
- 10. Did you have confidence and trust in the doctors treating you?
 Yes, always Yes, sometimes No
- 11. Did doctors talk in front of you as if you weren't there?
 Yes, often Yes, sometimes No
- 12. How would you rate the courtesy of your doctors?
 Poor Fair Good Very Good Excellent
- 13. How would you rate the availability of your doctors?
 Poor Fair Good Very Good Excellent

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS SURVEY.

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NURSES...

14. When you had important questions to ask a nurse, did you get answers you could understand?

- Yes, always Yes, sometimes No Did not have questions

15. If you had any anxieties or fears about your condition or treatment, did a nurse discuss them with you?

- Yes, completely Yes, somewhat No Did not have anxieties or fears

16. Did you have confidence and trust in the nurses treating you?

- Yes, always Yes, sometimes No

17. Did nurses talk in front of you as if you weren't there?

- Yes, often Yes, sometimes No

18. How would you rate the courtesy of your nurses?

- Poor Fair Good Very Good Excellent

19. How would you rate the availability of your nurses?

- Poor Fair Good Very Good Excellent

HOSPITAL STAFF...

20. Sometimes in a hospital or clinic, one doctor or nurse will say one thing and another will say something quite different. Did this happen to you?

- Yes, always Yes, sometimes No

21. Did you have enough say about your treatment?

- Yes, definitely Yes, somewhat No

22. Did your family or someone else close to you have enough opportunity to talk to your doctor?

- Yes, definitely No Family did not want or need to talk
 Yes, somewhat No family or friends were involved

23. How much information about your condition or treatment was given to your family or someone close to you?

- Not enough Too much Family did not want or need information
 Right amount No family or friends involved

24. Was it easy for you to find someone on the hospital staff to talk to about your concerns?

- Yes, definitely Yes, somewhat No Did not want to talk/no concerns

25. When you needed help getting to the bathroom, did you get it in time?

- Yes, always Yes, sometimes No Did not need help

26. How many minutes after you used the call button did it usually take before you got the help you needed?

- 0 minutes/right away 6-10 minutes 16-30 minutes Never used call button
 1-5 minutes 11-15 minutes More than 30 minutes Never got help

27. Did a doctor or nurse explain the results of tests in a way you could understand?

- Yes, completely Yes, somewhat No No tests were done

28. Were your scheduled tests and procedures performed on time?

- Yes, always Yes, sometimes No No tests/procedures

29. Did you feel like you were treated with respect and dignity while you were in the hospital?

- Yes, always Yes, sometimes No

68. Food Services

d. Accuracy of receiving the food items you ordered

- Poor Fair Good Very Good Excellent Does Not Apply

e. Taste of the food

- Poor Fair Good Very Good Excellent Does Not Apply

f. Temperature of the food

- Poor Fair Good Very Good Excellent Does Not Apply

g. Overall quality of food

- Poor Fair Good Very Good Excellent Does Not Apply

69. Housekeeping

a. Cleanliness of your room

- Poor Fair Good Very Good Excellent

b. Friendliness and courtesy shown to you by housekeeping staff

- Poor Fair Good Very Good Excellent

70. Transporters

a. Courtesy and helpfulness

- Poor Fair Good Very Good Excellent Does Not Apply

71. Other Hospital Staff

a. Courtesy of parking attendants

- Poor Fair Good Very Good Excellent Does Not Apply

b. Courtesy of people who took your x-rays

- Poor Fair Good Very Good Excellent Does Not Apply

c. Courtesy of people who took your blood samples

- Poor Fair Good Very Good Excellent Does Not Apply

72. Courtesy of security guards

- Poor Fair Good Very Good Excellent Does Not Apply

73. Courtesy of information desk

- Poor Fair Good Very Good Excellent Does Not Apply

74. Facilities

a. Cleanliness of the facility

- Poor Fair Good Very Good Excellent

75. Location and clarity of signs around the NIH Clinical Center

- Poor Fair Good Very Good Excellent

76. Ease of finding your way around the NIH Clinical Center

- Poor Fair Good Very Good Excellent

77. Comfort of waiting areas

- Poor Fair Good Very Good Excellent



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58. When you used the call button, did nurses respond as quickly as you thought they should?

- Yes, always Yes, sometimes No Did not use call button

GOING HOME...

59. Did someone on the hospital staff explain the purpose of the medicines you were to take at home in a way you could understand?

- Yes, completely No No medicines at home
 Yes, somewhat Did not need explanation

60. Did someone tell you about medication side effects to watch for when you went home?

- Yes, completely No No medicines at home
 Yes, somewhat Did not need explanation

61. Did they tell you what danger signals about your illness or operation to watch for after you went home?

- Yes, completely Yes, somewhat No Not applicable

62. Did they tell you when you could resume your usual activities, such as when to go back to work or drive a car?

- Yes, completely Yes, somewhat No Not applicable

63. Did the doctors and nurses give your family or someone close to you all the information they needed to help you recover?

- Yes, definitely No Family did not want or need information
 Yes, somewhat No family or friends involved

OVERALL IMPRESSION...

64. How would you rate how well the doctors and nurses worked together?

- Poor Fair Good Very Good Excellent

65. Overall, how would you rate the care you received at the hospital?

- Poor Fair Good Very Good Excellent

66. Would you recommend this hospital to your friends and family?

- Yes, definitely Yes, probably No

67. Did the actual care and services you received exceed your expectations, meet your expectations, or fall below your expectations?

- Exceeded my expectations Fell below my expectations
 Met my expectations I did not have any expectations

Please fill in the bubble that best describes your evaluation of each one of the following areas:

68. Food Services

a. Did you receive food services?

- Yes No (Go to #69)

b. Courtesy and helpfulness of staff who served your food

- Poor Fair Good Very Good Excellent

c. Variety of menu items

- Very Good Fair Very Poor Does Not Apply
 Good Poor Don't Know

PAIN...

30. Were you ever in any pain?

- Yes No (Go to #37)

31. When you had pain, was it usually severe, moderate, or mild?

- Severe Moderate Mild

32. Did you have a machine that you could use to give yourself pain medicine?

- Yes (Go to #35) No

33. Did you ever request pain medicine?

- Yes No (Go to #35)

34. How many minutes after you requested pain medicine did it usually take before you got it?

- 0 minutes/right away 11-15 minutes Never got medicine
 1-5 minutes 16-30 minutes Did not request pain medicine
 6-10 minutes More than 30 minutes

35. Do you think that the hospital staff did everything they could to help control your pain?

- Yes, definitely Yes, somewhat No

36. Overall, how much pain medicine did you get?

- Not enough Right amount Too much Did not request pain medicine

SURGERY...

37. Did you have surgery at the Clinical Center?

- Yes No (Go to #42)

38. Did the surgeon explain the risks and benefits of the surgery in a way you could understand?

- Yes, completely No I did not want anything explained
 Yes, somewhat Explained to spouse or someone else

39. Did the surgeon or any of your other doctors answer your questions about the surgery in a way you could understand?

- Yes, completely Yes, somewhat No I did not have any questions

40. Did a doctor or nurse tell you accurately how you would feel after surgery?

- Yes, completely Yes, somewhat No

41. Were the results of the surgery explained in a way you could understand?

- Yes, completely Yes, somewhat No Explained to spouse or someone else

CLINICAL RESEARCH QUESTIONS...

42. Before you agreed to participate in a research protocol, did a doctor explain the protocol requirements including both risks and benefits in a way you could understand?

- Yes, completely Yes, somewhat No

43. Prior to signing the informed consent form, did the research team talk with you about the details of the study on which you were enrolled?

- Yes, completely Yes, somewhat No



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44. Did time pass between when the research team talked with you about the study and the informed consent process and when you signed the form?

- No, I signed the form immediately
- Yes, less than 1 hour
- Yes, more than 1 hour but less than 2 hours
- Yes, more than 2 hours but on the same day
- Yes, 2 - 7 days later
- Yes, more than 1 week later

45. Did the informed consent form that you signed explain the details of the study for which you are enrolled?

- Yes, completely
- Yes, somewhat
- No

46. Thinking back is there any part of the research study that you wish you had known more about before you signed the informed consent to participate in the study?

- Yes
- No

47. If yes, what part (please check all that apply)

- Serious risks
- Common but not serious risks
- Procedures involved in the study
- Amount of time participation would require
- Amount of money to be paid for participating
- Who to call if I had problems
- Other

48. On a scale of 1 to 10, where 1 is not at all informed and 10 is extremely informed, how well informed do you feel about the study you are on?

- 1 Not at all informed 2 3 4 5 6 7 8 9 10 Extremely informed
- -
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49. Did you feel pressure from physicians, nurses, or other people at the NIH to sign up for the study you are on?

- A great amount of pressure
- A moderate amount of pressure
- A small amount of pressure
- No pressure

50. If, for any reason, you decided that you wanted to withdraw from the protocol in which you are enrolled, when could you stop participation?

- Once the first test is completed
- If I obtain the physician's approval
- When I am between courses of treatment
- To change to another study
- Only when the protocol is over
- I can stop at any time I want
- I do not know

51. When you decided to participate in the study you are on, what was the most important reason for participating? (Please use any number from 1 to 10, where 1 is the MOST IMPORTANT reason.)

a. Find out more about my disease

- 1 Most important 2 3 4 5 6 7 8 9 10 Least important
- -
 -
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b. Get the newest treatments

- 1 Most important 2 3 4 5 6 7 8 9 10 Least important
- -
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c. No other medical options available

- 1 Most important 2 3 4 5 6 7 8 9 10 Least important
- -
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d. Get health care at no cost

- 1 Most important 2 3 4 5 6 7 8 9 10 Least important
- -
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51. When you decided to participate in the study you are on, what was the most important reason for participating? (Please use any number from 1 to 10, where 1 is the MOST IMPORTANT reason.)

e. To benefit others

- 1 Most important 2 3 4 5 6 7 8 9 10 Least important
- -
 -
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f. NIH reputation for providing quality clinical care

- 1 Most important 2 3 4 5 6 7 8 9 10 Least important
- -
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g. My physician encouraged me to come to NIH

- 1 Most important 2 3 4 5 6 7 8 9 10 Least important
- -
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h. To earn money

- 1 Most important 2 3 4 5 6 7 8 9 10 Least important
- -
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i. My friends participated in research at NIH

- 1 Most important 2 3 4 5 6 7 8 9 10 Least important
- -
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j. Some other reason

- 1 Most important 2 3 4 5 6 7 8 9 10 Least important
- -
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52. Besides participating in the research study at the NIH Clinical Center, what other treatment options do you have available to you? (Mark all that apply.)

- No other options are available
- Another research study at the NIH Clinical Center
- Research studies at other medical centers
- Treatments or care I was receiving before I came to the NIH Clinical Center

PATIENT SAFETY...

53. How often did you need to explain to staff something about your condition or treatment that you thought they should already know?

- Often
- Sometimes
- Never

54. Did you ever receive the wrong medicine or the wrong dosage of medicine?

- Yes, often
- Yes, sometimes
- No
- Did not receive any medicine during visit

55. Did a family member or someone close to you ever have to do something or say something to staff to assure that your medical needs were attended to?

- Yes, often
- Yes, sometimes
- No
- Did not have family member or someone close to me present

56. Did staff ask your name and date of birth before giving you any medicines, treatments, or tests?

- Yes, always
- Yes, sometimes
- No

57. Did staff appear to be in too much of a hurry?

- Yes, often
- Yes, sometimes
- No



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