

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

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 (0925-0648). **Do not return the completed form to this address.**

SURVEY INSTRUCTIONS

You should only fill out this survey if you were the patient during the hospital stay named in the cover letter. Do not fill out this survey if you were not the patient.

Answer all the questions by completely filling in the circle 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
 No → *If No, Go to Question 1*

You may notice a number on the survey. This number is used to let us know if you returned your survey so we don't have to send you reminders.

Please answer the questions in this survey about your stay at the hospital named on the cover letter. Do not include any other hospital stays in your answers.

YOUR CARE FROM NURSES

1. During this hospital stay, how often did nurses treat you with courtesy and respect?
 Never
 Sometimes
 Usually
 Always
2. During this hospital stay, how often did nurses listen carefully to you?
 Never
 Sometimes
 Usually
 Always
3. During this hospital stay, how often did nurses explain things in a way you could understand?
 Never
 Sometimes
 Usually
 Always

4. During this hospital stay, after you pressed the call button, how often did you get help as soon as you wanted it?
 Never
 Sometimes
 Usually
 Always
 I never pressed the call button

YOUR CARE FROM DOCTORS

5. During this hospital stay, how often did doctors treat you with courtesy and respect?
 Never
 Sometimes
 Usually
 Always
6. During this hospital stay, how often did doctors listen carefully to you?
 Never
 Sometimes
 Usually
 Always



7. During this hospital stay, how often did doctors **explain things** in a way you could understand?

- Never
- Sometimes
- Usually
- Always

THE HOSPITAL ENVIRONMENT

8. During this hospital stay, how often were your room and bathroom kept clean?

- Never
- Sometimes
- Usually
- Always

9. During this hospital stay, how often was the area around your room quiet at night?

- Never
- Sometimes
- Usually
- Always

YOUR EXPERIENCES IN THIS HOSPITAL

10. During this hospital stay, did you need help from nurses or other hospital staff in getting to the bathroom or in using a bedpan?

- Yes
- No → Go to Question 12

11. How often did you get help in getting to the bathroom or in using a bedpan as soon as you wanted?

- Never
- Sometimes
- Usually
- Always

12. During this hospital stay, did you need medicine for pain?

- Yes
- No → Go to Question 15

13. During this hospital stay, how often was your pain well controlled?

- Never
- Sometimes
- Usually
- Always

14. During this hospital stay, how often did the hospital staff do everything they could to help you with your pain?

- Never
- Sometimes
- Usually
- Always

15. During this hospital stay, were you given any medicine that you had not taken before?

- Yes
- No → Go to Question 18

16. Before giving you any new medicine, how often did hospital staff tell you what the medicine was for?

- Never
- Sometimes
- Usually
- Always

17. Before giving you any new medicine, how often did hospital staff describe possible side effects in a way you could understand?

- Never
- Sometimes
- Usually
- Always

WHEN YOU LEFT THE HOSPITAL

18. After you left the hospital, did you go directly to your own home, to someone else's home, or to another health facility?

- Own home
- Someone else's home
- Another health facility → Go to Question 21

19. During this hospital stay, did doctors, nurses or other hospital staff talk with you about whether you would have the help you needed when you left the hospital?

- Yes
- No

20. During this hospital stay, did you get information in writing about what symptoms or health problems to look out for after you left the hospital?

- Yes
- No



OVERALL RATING OF HOSPITAL

Please answer the following questions about your stay at the hospital named on the cover letter. Do not include any other hospital stays in your answers.

21. Using any number from 0 to 10, where 0 is the worst hospital possible and 10 is the best hospital possible, what number would you use to rate this hospital during your stay?

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

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

- Definitely no
- Probably no
- Probably yes
- Definitely yes

UNDERSTANDING YOUR CARE WHEN YOU LEFT THE HOSPITAL

23. During this hospital stay, staff took my preferences and those of my family or caregiver into account in deciding what my health care needs would be when I left.

- Strongly disagree
- Disagree
- Agree
- Strongly agree

24. When I left the hospital, I had a good understanding of the things I was responsible for in managing my health.

- Strongly disagree
- Disagree
- Agree
- Strongly agree

25. When I left the hospital, I clearly understood the purpose for taking each of my medications.

- Strongly disagree
- Disagree
- Agree
- Strongly agree
- I was not given any medication when I left the hospital

MORE QUESTIONS ABOUT YOUR STAY AT THE HOSPITAL

Please answer the following questions to provide us with a bit more detail about your experience.

ADMISSION INTO THE HOSPITAL

26. If you had to wait to go to your room, did someone from the hospital explain the reason for the delay?

- No
- Yes, somewhat
- Yes, mostly
- Yes, definitely
- Did not have to wait

27. How organized was the admission process?

- Not at all organized
- Somewhat organized
- Very organized
- Completely organized

HOSPITAL STAFF

28. During this hospital stay, before giving you any new medicine, how often did the hospital staff ask you about your allergies or other medications you may have been taking?

- Never
- Sometimes
- Usually
- Always
- No allergies/other meds

29. During this hospital stay, before giving you any medicine, how often did the hospital staff check your ID band or otherwise confirm your identity?

- Never
- Sometimes
- Usually
- Always
- Did not notice



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30. During this hospital stay, how often were you able to discuss your worries or concerns with nurses?
- Never
 - Sometimes
 - Usually
 - Always
 - Did not have any worries or concerns
31. During this hospital stay, how often did you have confidence and trust in the nurses treating you?
- Never
 - Sometimes
 - Usually
 - Always
32. During this hospital stay, how often were you able to discuss your worries or concerns with doctors?
- Never
 - Sometimes
 - Usually
 - Always
 - Did not have any worries or concerns
33. During this hospital stay, how often did you have confidence and trust in the doctors treating you?
- Never
 - Sometimes
 - Usually
 - Always
34. How often were the different doctors and nurses *consistent* with each other in providing you information and care?
- Never
 - Sometimes
 - Usually
 - Always
 - Did not notice
35. During this hospital stay, how often was your family or someone close to you able to talk to your doctor?
- Never
 - Sometimes
 - Usually
 - Always
36. During this hospital stay, how often did the hospital staff include your family or someone close to you in discussions about your care?
- Never
 - Sometimes
 - Usually
 - Always

37. During this hospital stay, how often was your family or someone close to you allowed to be with you as much as you wanted?
- Never
 - Sometimes
 - Usually
 - Always
38. During this hospital stay, how often was it easy for you to find someone on the hospital staff to talk to about your concerns?
- Never
 - Sometimes
 - Usually
 - Always
 - Did not want or need to talk
39. During this hospital stay, how often was there good communication between the different doctors and nurses?
- Never
 - Sometimes
 - Usually
 - Always
40. During this hospital stay, how often were you given enough input or say in your care?
- Never
 - Sometimes
 - Usually
 - Always

GOING HOME

41. During this hospital stay, did someone on the hospital staff explain when you would be allowed to leave?
- No
 - Yes, somewhat
 - Yes, mostly
 - Yes, definitely
42. During this hospital stay, did someone on the hospital staff explain what to do if problems or symptoms continued, got worse, or came back?
- No
 - Yes, somewhat
 - Yes, mostly
 - Yes, definitely



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43. During this hospital stay, did someone on the hospital staff explain the purpose of the medicines you were to take at home in a way you could understand?

- No
- Yes, somewhat
- Yes, mostly
- Yes, definitely
- No meds or explanation needed

HAND HYGIENE

Please answer the following questions about your experience regarding sanitation and hand washing practices you observed during this visit.

44. Did you observe any posted notices or signs about hand washing/sanitizing?

- Yes
- No

45. How often did nurses voluntarily wash or sanitize their hands before caring for you?

- Never
- Sometimes
- Usually
- Always

46. How often did doctors voluntarily wash or sanitize their hands before caring for you?

- Never
- Sometimes
- Usually
- Always

HOUSEKEEPING

Please answer the following questions about the housekeeping staff who may have cleaned your room, provided towels, etc. during this hospital stay.

47. Did any housekeeping staff visit your room?

- Yes
- No → Go to Question 50

48. How often did housekeeping staff treat you with *courtesy and respect*?

- Never
- Sometimes
- Usually
- Always

49. How often did housekeeping staff show respect for your privacy?

- Never
- Sometimes
- Usually
- Always

DINING SERVICES

Please answer the following questions about the bedside dining services you received during this hospital stay.

50. How often did the staff who brought you your food treat you with *courtesy and respect*?

- Never
- Sometimes
- Usually
- Always

51. How often did you get all of the food items you ordered?

- Never
- Sometimes
- Usually
- Always
- Not applicable

52. How often was the flavor of your food excellent?

- Never
- Sometimes
- Usually
- Always

53. How often was the freshness and appearance of your food excellent?

- Never
- Sometimes
- Usually
- Always

54. How often was the temperature of your food hot OR cold enough?

- Never
- Sometimes
- Usually
- Always

55. How often were you provided napkins, utensils, salt/pepper and the right condiments when your food was delivered?

- Never
- Sometimes
- Usually
- Always

56. Was there enough variety of food choices?

- No
- Yes, somewhat
- Yes, mostly
- Yes, definitely
- Not applicable



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CLINICAL RESEARCH PARTICIPATION

Please answer the following questions about the research study in which you participated during this hospital stay.

57. Was the study explained to you in a way that you knew what you were being asked to do as a research subject?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely

58. Were the details about the research study described in way that you could understand?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely
- Do not remember

59. Did someone explain the risks and benefits of joining the study in a way that you could understand?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely
- Do not remember

60. Were the details about the study included in the informed consent form?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely
- Do not remember

61. Were the risks and benefits of joining the study included in the informed consent form?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely
- Do not remember

62. Was the informed consent form written in a way that you could understand?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely
- Do not remember

63. During your discussion about the study, did you feel pressure from the research team to join the study?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely

64. After the study was explained to you, did you have enough time to think about your decision before signing the informed consent form?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely

65. Did the informed consent form prepare you for what to expect during the study?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely

66. Did you ever consider leaving the study?

- No
- Yes, briefly
- Yes, a great deal
- Yes, I left the study

67. Did you feel you were a valued partner in the research process?

- Never
- Sometimes
- Usually
- Always

68. Would you have liked to receive a summary of the results of the study?

- No
- Yes
- Received a summary of the study

69. Was the summary of the results of the study written in a way you could understand?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely
- Did not receive a summary of the results

70. Did the information and discussions you had before participating in the research study prepare you for your experience in the study?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely



71. If you wanted to leave the study, do you think you would have been allowed to do so by the research team?

- No
- Yes

72. If you considered leaving the study, did you feel pressure from the research team to stay?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely

73. Were you ever told that you could stop being in the study, at any time, and for any reason?

- No
- Yes

74. Below is a list of possible reasons for joining a research study. When you considered joining the study how important were these reasons for you?

- a. To find out more about my disease

Very important	Somewhat important	Not very important	Not important at all
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- b. Because no other medical options were available

Very important	Somewhat important	Not very important	Not important at all
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- c. To gain access to new treatment/therapy

Very important	Somewhat important	Not very important	Not important at all
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- d. To obtain free health care

Very important	Somewhat important	Not very important	Not important at all
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- e. To help others

Very important	Somewhat important	Not very important	Not important at all
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- f. Because of the NIH Clinical Center's reputation

Very important	Somewhat important	Not very important	Not important at all
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- g. Because I am concerned about the topic of study

Very important	Somewhat important	Not very important	Not important at all
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- h. To obtain education and learning

Very important	Somewhat important	Not very important	Not important at all
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

74. Below is a list of possible reasons for joining a research study. When you considered joining the study how important were these reasons for you?

- i. Because of a positive experience in another study

Very important	Somewhat important	Not very important	Not important at all
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- j. Because of family influence/involvement

Very important	Somewhat important	Not very important	Not important at all
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- k. To earn money/payment

Very important	Somewhat important	Not very important	Not important at all
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- l. Because my caregiver encouraged me

Very important	Somewhat important	Not very important	Not important at all
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- m. Other reasons

Very important	Somewhat important	Not very important	Not important at all
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

75. Below is a list of possible reasons for leaving a research study. How important were these reasons for you in considering leaving the study?

- a. Pain or discomfort related to participation

Very important	Somewhat important	Not very important	Not important at all
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- b. Worried about risks of treatment

Very important	Somewhat important	Not very important	Not important at all
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- c. Side effects that occurred during study

Very important	Somewhat important	Not very important	Not important at all
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- d. Invasion of privacy

Very important	Somewhat important	Not very important	Not important at all
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- e. Too much time spent waiting around

Very important	Somewhat important	Not very important	Not important at all
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- f. Time commitment required

Very important	Somewhat important	Not very important	Not important at all
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
- g. Family/work issues unrelated to study

Very important	Somewhat important	Not very important	Not important at all
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



75. Below is a list of possible reasons for leaving a research study. How important were these reasons for you in considering leaving the study?

- h. Interactions with research team
- | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|
| Very important | Somewhat important | Not very important | Not important at all |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
- i. Not getting test results
- | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|
| Very important | Somewhat important | Not very important | Not important at all |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
- j. Undue pressure to stay in study
- | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|
| Very important | Somewhat important | Not very important | Not important at all |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
- k. Problems with study payment
- | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|
| Very important | Somewhat important | Not very important | Not important at all |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
- l. Unexpected tests and procedures that occurred during study
- | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|
| Very important | Somewhat important | Not very important | Not important at all |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
- m. Transportation/parking
- | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|
| Very important | Somewhat important | Not very important | Not important at all |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
- n. Other reasons
- | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|
| Very important | Somewhat important | Not very important | Not important at all |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

We would greatly appreciate your feedback about the following.

76. Is there anything else you would like to say about the care you received or your research participation during this visit?

ABOUT YOU

There are only a few remaining items left.

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

- Excellent
- Very Good
- Good
- Fair
- Poor

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

- Excellent
- Very Good
- Good
- Fair
- Poor

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

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

80. Are you of Spanish, Hispanic or Latino origin or descent?

- No, not Spanish/Hispanic/Latino
- Yes, Puerto Rican
- Yes, Mexican, Mexican American, Chicano
- Yes, Cuban
- Yes, other Spanish/Hispanic/Latino

81. What is your race? Please choose one or more.

- White
- Black or African American
- Asian
- Native Hawaiian or other Pacific Islander
- American Indian or Alaska Native

82. What language do you mainly speak at home?

- English
- Spanish
- Chinese
- Russian
- Vietnamese
- Portuguese
- Some other language (*please print*): _____



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THANK YOU!

Please return the completed survey in the postage-paid envelope.

Mail the completed survey to: NRC Health, Survey Processing Center, PO Box 82660, Lincoln, NE 68501-2660. NRC Health phone: 1-800-733-6714.

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