



DEPARTMENT OF HEALTH & HUMAN SERVICES
National Institutes of Health

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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 visit 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. If a question does not apply, do not answer it.

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. Questions 1-25 in this survey are part of a national initiative to measure the quality of care in hospitals.

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

RECEPTION

1. Were clerks and receptionists at this facility as helpful as you thought they should be?⁵²⁶⁵⁵
 - ① No
 - ② Yes, somewhat
 - ③ Yes, mostly
 - ④ Yes, definitely
2. Did clerks and receptionists at this facility treat you with courtesy and respect?⁵²⁶⁵⁶
 - ① No
 - ② Yes, somewhat
 - ③ Yes, mostly
 - ④ Yes, definitely

3. During this outpatient visit, how often did your appointment/procedure/treatment begin on time?⁵³¹²⁶

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

4. If your appointment/procedure/treatment did not begin on time, did the staff keep you informed about delays?⁵³¹²⁷

- ① No
- ② Yes, somewhat
- ③ Yes, mostly
- ④ Yes, definitely
- Ⓢ Did not have to wait

YOUR CARE FROM NURSES

5. During your visit, were you seen by a nurse?⁵²⁶⁵⁷
 - ① Yes
 - ② No → Go to Question 11



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6. During this outpatient visit, how often did nurses treat you with courtesy and respect?

52658

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

7. During this outpatient visit, how often did nurses listen carefully to you?

52659

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

8. During this outpatient visit, how often did nurses explain things in a way you could understand?

52660

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

9. During this outpatient visit, how often were you able to discuss your worries or concerns with nurses?

52661

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

~~89~~ Did not have any worries or concerns

10. During this outpatient visit, how often did you have confidence and trust in the nurses treating you?

52662

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

YOUR CARE FROM DOCTORS

11. During this outpatient visit, were you seen by a doctor?

52663

- ① Yes
- ② No → Go to Question 17

12. During this outpatient visit, how often did doctors treat you with courtesy and respect?

52664

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

13. During this outpatient visit, how often did doctors listen carefully to you?

52665

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

14. During this outpatient visit, how often did doctors explain things in a way you could understand?

52666

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

15. During this outpatient visit, how often were you able to discuss your worries or concerns with doctors?

52667

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

~~89~~ Did not have any worries or concerns

16. During this outpatient visit, how often did you have confidence and trust in the doctors treating you?

52668

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

YOUR EXPERIENCES IN THIS HOSPITAL

17. During this outpatient visit, did you need medicine for pain?

52669

- ① Yes
- ② No → Go to Question 20

18. During this outpatient visit, how often was your pain well controlled?

52670

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

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

52671

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



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20. During this outpatient visit, were you given any medicine that you had not taken before?⁵²⁶⁷²

- ① Yes
- ② No → Go to Question 23

21. Before giving you any new medicine, how often did hospital staff tell you what the medicine was for?⁵²⁶⁷³

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

22. Before giving you any new medicine, how often did hospital staff describe possible side effects in a way you could understand?⁵²⁶⁷⁴

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

OVERALL RATING OF HOSPITAL

23. 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 outpatient visit?⁵²⁶⁷⁵

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

24. Would you recommend this hospital to your friends and family?⁵²⁶⁷⁶

- ① Definitely no
- ② Probably no
- ③ Probably yes
- ④ Definitely yes

UNDERSTANDING YOUR CARE WHEN YOU LEFT THE HOSPITAL

25. During this hospital visit, 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.⁵²⁶⁷⁷

- ① Strongly disagree
- ② Disagree
- ③ Agree
- ④ Strongly agree

26. When I left the hospital, I had a good understanding of the things I was responsible for in managing my health.⁵²⁶⁷⁸

- ① Strongly disagree
- ② Disagree
- ③ Agree
- ④ Strongly agree

27. When I left the hospital, I clearly understood the purpose for taking each of my medications.⁵²⁶⁷⁹

- ① Strongly disagree
- ② Disagree
- ③ Agree
- ④ Strongly agree
- ~~89~~ I was not given any medication when I left the hospital

MORE QUESTIONS ABOUT YOUR OUTPATIENT VISIT TO THE HOSPITAL

The next set of questions will give us more detailed information about how we can improve the care and treatment we provide.

HOSPITAL STAFF

28. During this outpatient visit, 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?⁵²⁶⁸⁰

- ① Never
- ② Sometimes
- ③ Usually
- ④ Always
- ~~89~~ No new medicine



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29. During this outpatient visit, before giving you any medicine, how often did the hospital staff check your ID band or otherwise confirm your identity?⁵²⁶⁸¹

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always
- 88 Did not notice
- 89 No medicine given

30. If you had worries or concerns during your treatment, how often did someone on the staff discuss them with you? ⁵²⁶⁸²

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always
- 89 Did not have any worries or concerns

31. How often were the staff members consistent with each other in providing you information and care?⁵²⁶⁸³

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

32. During this outpatient visit, how often did the hospital staff include your family or someone close to you in discussions about your care?⁵²⁶⁸⁴

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

33. During this outpatient visit, how often was your family or someone close to you allowed to be with you as much as you wanted?⁵²⁶⁸⁵

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

34. During this outpatient visit, how often was it easy for you to find someone on the hospital staff to talk to about your concerns?⁵²⁶⁸⁶

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always
- 89 Did not want or need to talk

35. How often was there good communication between the different staff members treating you?⁵²⁶⁸⁷

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

36. During this outpatient visit, how often were you given enough input or say in your care?⁵²⁶⁸⁸

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

37. How often did you have enough privacy?⁵²⁶⁸⁹

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

GOING HOME

38. During this outpatient visit, did someone on the hospital staff explain what to do if problems or symptoms continued, got worse, or came back?⁵²⁶⁹⁰

- 1 No
- 2 Yes, somewhat
- 3 Yes, mostly
- 4 Yes, definitely

39. During this outpatient visit, did someone on the hospital staff explain the purpose of the medicines you were to take at home in a way you could understand?⁵²⁶⁹¹

- 1 No
- 2 Yes, somewhat
- 3 Yes, mostly
- 4 Yes, definitely
- 89 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.

40. Did you observe any posted notices or signs about hand washing/sanitizing?⁵²⁶⁹⁸

- 1 Yes
- 2 No



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41. How often did nurses voluntarily wash or sanitize their hands before caring for you?⁵²⁶⁹⁹

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

42. How often did doctors voluntarily wash or sanitize their hands before caring for you?⁵²⁷⁰⁰

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

CLINICAL RESEARCH PARTICIPATION

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

43. Was the study explained to you in a way that you knew what you were being asked to do as a research subject?⁵³⁰⁸²

- ① No
- ② Yes, somewhat
- ③ Yes, mostly
- ④ Yes, completely

44. Were the details about the research study described in way that you could understand?⁵³⁰⁸³

- ① No
- ② Yes, somewhat
- ③ Yes, mostly
- ④ Yes, completely
- ⑤ Do not remember

45. Did someone explain the risks and benefits of joining the study in a way that you could understand?⁵³⁰⁸⁴

- ① No
- ② Yes, somewhat
- ③ Yes, mostly
- ④ Yes, completely
- ⑤ Do not remember

46. Were the details about the study included in the informed consent form?⁵³⁰⁸⁵

- ① No
- ② Yes, somewhat
- ③ Yes, mostly
- ④ Yes, completely
- ⑤ Do not remember

47. Were the risks and benefits of joining the study included in the informed consent form?⁵³⁰⁸⁶

- ① No
- ② Yes, somewhat
- ③ Yes, mostly
- ④ Yes, completely
- ⑤ Do not remember

48. Was the informed consent form written in a way that you could understand?⁵³⁰⁸⁷

- ① No
- ② Yes, somewhat
- ③ Yes, mostly
- ④ Yes, completely
- ⑤ Do not remember

49. During your discussion about the study, did you feel pressure from the research team to join the study?⁵³⁰⁸⁸

- ① No
- ② Yes, somewhat
- ③ Yes, mostly
- ④ Yes, completely

50. After the study was explained to you, did you have enough time to think about your decision before signing the informed consent form?⁵³⁰⁸⁹

- ① No
- ② Yes, somewhat
- ③ Yes, mostly
- ④ Yes, completely

51. Did the informed consent form prepare you for what to expect during the study?⁵³⁰⁹⁰

- ① No
- ② Yes, somewhat
- ③ Yes, mostly
- ④ Yes, completely

52. Did you ever consider leaving the study?⁵³⁰⁹¹

- ① No
- ② Yes, briefly
- ③ Yes, a great deal
- ④ Yes, I left the study

53. Did you feel you were a valued partner in the research process?⁵³⁰⁹²

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

54. Would you have liked to receive a summary of the results of the study?⁵³⁰⁹³

- ① No
- ② Yes
- ③ Received a summary of the study



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55. Was the summary of the results of the study written in a way you could understand?⁵³⁰⁹⁴

- ① No
- ② Yes, somewhat
- ③ Yes, mostly
- ④ Yes, completely
- ⑤ Did not receive a summary of the results

56. Did the information and discussions you had before participating in the research study prepare you for your experience in the study?⁵³⁰⁹⁵

- ① No
- ② Yes, somewhat
- ③ Yes, mostly
- ④ Yes, completely

57. If you wanted to leave the study, do you think you would have been allowed to do so by the research team?⁵³⁰⁹⁶

- ① No
- ② Yes

58. If you considered leaving the study, did you feel pressure from the research team to stay?⁵³⁰⁹⁷

- ① No
- ② Yes, somewhat
- ③ Yes, mostly
- ④ Yes, completely

59. Were you ever told that you could stop being in the study, at any time, and for any reason?⁵³⁰⁹⁸

- ① No
- ② Yes

60. 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?¹⁶⁶⁰

a. To find out more about my disease⁵³⁰⁹⁹

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

b. Because no other medical options were available⁵³¹⁰⁰

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

c. To gain access to new treatment/therapy⁵³¹⁰¹

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

d. To obtain free health care⁵³¹⁰²

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

60. 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?¹⁶⁶⁰

e. To help others⁵³¹⁰³

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

f. Because of the NIH Clinical Center's reputation⁵³¹⁰⁴

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

g. Because I am concerned about the topic of study⁵³¹⁰⁵

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

h. To obtain education and learning⁵³¹⁰⁶

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

i. Because of a positive experience in another study⁵³¹⁰⁷

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

j. Because of family influence/involvement⁵³¹⁰⁸

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

k. To earn money/payment⁵³¹⁰⁹

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

l. Because my caregiver encouraged me⁵³¹¹⁰

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

m. Other reasons⁵³¹¹¹

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

61. Below is a list of possible reasons for leaving a research study. How important were these reasons for you in considering leaving the study?¹⁶⁴⁵

a. Pain or discomfort related to participation⁵³¹¹²

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

b. Worried about risks of treatment⁵³¹¹³

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④



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61. Below is a list of possible reasons for leaving a research study. How important were these reasons for you in considering leaving the study?¹⁶⁴⁵

c. Side effects that occurred during study⁵³¹¹⁴

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

d. Invasion of privacy⁵³¹¹⁵

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

e. Too much time spent waiting around⁵³¹¹⁶

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

f. Time commitment required⁵³¹¹⁷

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

g. Family/work issues unrelated to study⁵³¹¹⁸

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

h. Interactions with research team⁵³¹¹⁹

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

i. Not getting test results⁵³¹²⁰

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

j. Undue pressure to stay in study⁵³¹²¹

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

k. Problems with study payment⁵³¹²²

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

l. Unexpected tests and procedures that occurred during study⁵³¹²³

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

m. Transportation/parking⁵³¹²⁴

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

n. Other reasons⁵³¹²⁵

Very important	Somewhat important	Not very important	Not important at all
①	②	③	④

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

ABOUT YOU

63. In general, how would you rate your overall health?⁵²⁶⁹²

- ① Excellent
- ② Very Good
- ③ Good
- ④ Fair
- ⑤ Poor

64. In general, how would you rate your overall mental or emotional health?⁵²⁶⁹³

- ① Excellent
- ② Very Good
- ③ Good
- ④ Fair
- ⑤ Poor

65. What is the highest grade or level of school that you have completed?⁵²⁶⁹⁴

- 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

66. Are you of Spanish, Hispanic or Latino origin or descent?⁵²⁶⁹⁵

- ① No, not Spanish/Hispanic/Latino
- ② Yes, Puerto Rican
- ③ Yes, Mexican, Mexican American, Chicano
- ④ Yes, Cuban
- ⑤ Yes, other Spanish/Hispanic/Latino



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67. What is your race? Please choose one or more.⁵²⁶⁹⁶

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

68. What language do you mainly speak at home?⁵²⁶⁹⁷

- ① English
- ② Spanish
- ③ Chinese
- ④ Russian
- ⑤ Vietnamese
- ⑥ Some other language (please print):

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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