

Appendix D

Family member questionnaire about resident.

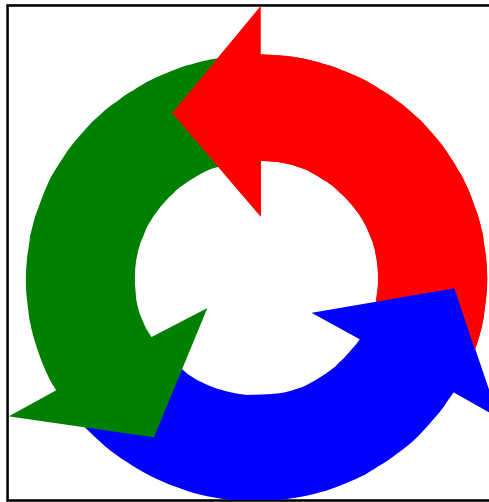
Note: Questionnaire was mailed to family contacts. Telephone followup done for non-respondents.

Family contact form.

(Used to select family members for sample.)

Measures, Indicators, and Quality of Life in Nursing Homes

Family Member Questionnaire



Study conducted by the
National Long-Term Care Center
University of Minnesota School of Public Health

and sponsored by

the Health Care Financing Administration
US Department of Health and Human Services

All questions apply to the resident named below and his or her experience at the nursing home named below.

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Before you start.....

A few points to help you fill this out:

- ☐ Remember to think of your particular relative when you answer the questions. You may have observed the life and care of others, but focus on the person named in the cover letter and on the label on the opposite page.
- ☐ Pay attention to time periods in the questions. If no time period is given, answer according to the last month or so.
- ☐ We are interested in your perceptions, even though you may feel a little uncertain of your answer. Go ahead and give us your best estimate or thought. Avoid using "Don't know" unless that is the only reasonable answer.

The first questions are about how much your relative does things for him/herself within his/her capabilities and wishes.	Often	Sometimes	Rarely	Never	Don't know	Does not apply
1. Is it easy for your relative to get around in his/her room by him/herself?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
2. Can your relative easily reach the things he/she needs or wants to use in his/her room?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
3. If your relative is away from his/her room anywhere else in the facility and needs a bathroom, can he/she get to one quickly?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
4. Can your relative groom <u>him/herself</u> and check his/her appearance when he/she wants?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
5. Can your relative easily reach toilet articles and other things she/she wants to use in the bathroom.	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
6. Could your relative do more to get <u>him/herself</u> dressed if he/she were given more time?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
7. Does your relative do as much to take care of his/her room and his/her own things as he/she wants.	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉

8. The first questions are about how comfortable your relative appears to be and the help given to make him/her more comfortable. How often does your relative:		Often	Sometimes	Rarely	Never	Don't know	Does not apply
	a. Feel too cold?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
	b. Feel too hot?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
	c. Stay so long in the same position that it hurts?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
	d. Feel in physical pain?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
	e. Feel bothered by noise when he/she is in his/her room?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
	f. Feel bothered by noise in the dining room and other parts of the nursing home?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
	g. Have difficulty seeing because of the lighting in his/her room?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
	h. Feel thirsty without something to drink?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
9. When your relative is feeling uncomfortable, do staff notice or pay attention without him/her asking?		9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
10. If something hurts your relative or causes him/her pain, can he/she get help quickly?		9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
11. During the day, are call lights answered promptly (within about five minutes)?		9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
12. During the evening, are call lights answered promptly (within five minutes)?		9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉

13. Is your relative satisfied with the cleanliness of the nursing home? (If relative cannot communicate, answer with your own opinion.)	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	
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The next questions are about the extent to which your relative has choice and control over his/her daily life.		Often	Sometimes	Rarely	Never	Don't know	Does not apply
14. Can your relative go to bed at the time he/she wants?		9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
15. Can your relative get up in the morning at the time he/she wants?		9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
16. Can your relative decide what clothes to wear?		9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
17. Can your relative choose to keep his/her door open or not?		9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
18. Does your relative feel pressured to go to organized activities even if he/she doesn't want to?		9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
19. Have you or your relative been successful in making changes in things you do not like?		9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
20.	a. How many baths or showers does your relative get in a week (0 - 9)? (If more than 9, write 9.)					9 ₇	9 ₉₉
	b. Does your relative get as many baths or showers as he/she wants (not too many or too few)? (If your relative cannot express his/her wants, do you think he/she gets as many as he/she needs.)	9 ₁ 9 ₂ 9 ₃	more than he/she wants fewer than he/she wants the right number			9 ₇	9 ₉₉
21.	a. How many walks does your relative get in a day either on foot or in a wheelchair (0 - 9)? A walk would be at least 5 minutes. (If more than 9, write 9.)					9 ₇	9 ₉₉
	b. Does your relative get as many walks as he/she wants?	9 ₁ 9 ₂ 9 ₃	more than he/she wants fewer than he/she wants the right number			9 ₇	9 ₉₉

22.	a. How much say did your relative have in picking or changing his/her last roommate. (If he/she has not had a roommate in the last month, check "Does not apply.")	9 ₁ 9 ₂ 9 ₃	a lot some not much	9 ₇	9 ₉₉
	b. If your relative had a roommate in the last month, how satisfied is he/she with the most recent roommate? (If no roommate in the past month, check "Does not apply.")	9 ₁ 9 ₂ 9 ₃ 9 ₄	very satisfied somewhat satisfied somewhat unsatisfied very unsatisfied	9 ₇	9 ₉₉

The next questions are about your relative's dignity.		Often	Sometimes	Rarely	Never	Don't know	Does not apply
23. Do staff call your relative by the name he/she prefers?		9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
24. Do staff treat your relative politely?		9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
25. Do staff treat you and other family members politely?		9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
26. Do you feel your relative and other residents are treated with respect?		9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
27. Do staff here handle your relative gently while giving care to him/her?		9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
28. Do staff respect your relative's modesty?		9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
29. If your relative does not want a staff member of the opposite sex bathing him/her, is that wish respected?		9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
30. Do the people who work at the nursing home talk to the residents as if they were children?		9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
31. Do staff remember to do the things you or your relative ask them to do?		9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
32. Do staff take time to listen to you or your relative when you have something to say?		9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉

We have a few questions about your relative's spiritual well-being.						
33. Does your relative enjoy religious services at the nursing home?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
34. Can your relative speak to a clergy person (for example a priest, minister, or rabbi) when he/she wishes?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
35. In your opinion, are your relative's spiritual needs being fulfilled?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉

The next questions are regarding interesting things for your relative to see and do.	Often	Sometimes	Rarely	Never	Don't know	Does not apply
36. Does your relative enjoy the organized activities at the nursing home?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
37. Does your relative wish there were more interesting things to do at this nursing home?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
38. Outside of religious services, does your relative have enjoyable things to do at the nursing home during the weekends?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
39. Does your relative complain that the days seem long or time hangs heavily?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
40. When your relative wants to do something or go somewhere he/she finds interesting, do staff help make that possible?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
41. Despite his/her health condition, does your relative do anything to help others, such as other residents, family members, the nursing home, or the outside community?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
42. About how often does your relative get outdoors? (Don't count entering a car to go somewhere)	9 ₁ 9 ₂ 9 ₃ 9 ₄ 9 ₅	every day several times a week about once a week less than once a week less than once a month			9 ₇	9 ₉₉

43. Does your relative get outdoors:	9 ₁ 9 ₂ 9 ₃	as much as he/she wants too much not enough	9 ₇	9 ₉₉
44. During the past three months, did your relative leave the grounds of the nursing home (not counting a medical appointment)? Count excursions planned by the facility or by the resident and/or family.	9 ₁ 9 ₂	Yes No	9 ₇	9 ₉₉

The next questions concern how enjoyable life is for your relative	Often	Sometimes	Rarely	Never	Don't know	Does not apply
45. Does your relative like the food at the nursing home?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
46. Does your relative enjoy mealtimes at the nursing home?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
47. Does your relative get his/her favorite foods at the nursing home?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
48. Does your relative get a good night's sleep at the nursing home?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
49. Taken all together, do the staff at the nursing home really know about your relative's interests and what he/she likes?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
50. Do one or more staff at the nursing home know your relative as a person?	9 ₁ 9 ₂ 9 ₃	Yes , one staff member does Yes , more than one staff member does No , nobody on staff knows my relative as a person				9 ₉₉
51. a. Since coming to this nursing home, has your relative continued with any particular activities, pastimes, interests, or hobbies that have interested him/her during his/her lifetime?	9 ₁ 9 ₂	Yes No			9 ₇	9 ₉₉
b. If yes, please give an example.						
52. a. Since coming to the nursing home, has your relative found any new enjoyable activities, pastimes, or interests?	9 ₁ 9 ₂	Yes No			9 ₇	9 ₉₉
b. If yes, please give an example:						

The next questions are about social relationships, friendships, or family contacts that your relative has.	Often	Sometimes	Rarely	Never	Don't know	Does not apply
53. To your knowledge, do any staff stop just to have a friendly conversation with you or your relative?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
54. Do you and other family find the nursing home an easy and pleasant place to visit?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
55. Would you be comfortable bringing a child to visit your relative at the nursing home?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
56. How easy or hard does the facility make it for you or others to take your relative out? Is it:	9 ₁ 9 ₂ 9 ₃	usually hard sometimes hard/ sometimes easy usually easy			9 ₇	9 ₉₉
57. Does your relative consider any other resident to be a close friend?	9 ₁ 9 ₂	Yes No			9 ₇	9 ₉₉
58. Does your relative consider any staff member to be a friend?	9 ₁ 9 ₂	Yes No			9 ₇	9 ₉₉

The next questions are about privacy or the lack of privacy.						
59. Can your relative find a place to be alone here when he/she wishes?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
60. Can your relative make a phone call in private? (If he/she cannot speak on the phone, check "does not apply.")	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
61. Can you or other family members find a place to visit your relative in private?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
62. Do the people who work at the facility knock and wait for a reply before entering your relative's room?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
63. Do you or your relative feel that people working or living at the nursing home know too much about your relative's personal business?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉

These next questions are about how safe and secure your relative feels in the nursing home.	Often	Sometimes	Rarely	Never	Don't know	Does not apply
64. Is this nursing home a place where a resident or family member can know what to expect on a typical day?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
65. Do you and your relative understand the rules and routines of the nursing home?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
66. Do you feel that your relative's possessions are safe?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
67. Do your relative's clothes get lost or damaged in the laundry?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
68. Do you feel confident your relative can get help when he/she needs it?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
69. If your relative doesn't feel well, can he/she get a nurse or a doctor quickly?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
70. Does your relative have trouble understanding the aides and other staff when they talk to him/her because of the way staff speaks your relative's language?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
71. Does your relative have trouble making staff understand him/her because of the way staff speaks your relative's language?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
72. Do you think your relative feels afraid because of the way he/she or another resident has been treated?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
73. Does your relative feel comfortable making complaints?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉
74. Do you feel your relative's nursing home is a safe place to live?	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	9 ₉₉

The next questions are about any physical restraints that may have been used for your relative.	
75. To your knowledge, have bed rails been used for your relative in the last month?	<div>9₁ Yes</div> <div>9₂ No GO TO QUESTION 77</div>
76. Does your relative show discomfort with bedrails, such as complaining about them, trying to get out, trying to climb over?	<div>9 Often</div> <div>9 Sometimes</div> <div>9 Rarely</div> <div>9 Never</div> <div>9 Don't know</div> <div>9 Does not apply</div>
77. Not counting bedrails, have any other kinds of physical restraints been used for your relative in the last month? <i>These include vest restraints, ties to hands or feet, lap restraints, or gerichairs or other chairs that prevent rising.</i>	<div>9₁ Yes</div> <div>9₂ No GO TO QUESTION 79</div>
78. Does your relative show discomfort with physical restraints? <i>Discomfort means complaining about them, struggling, banging on chair tables, or making visible attempts to escape the restraints.</i>	<div>9 Often</div> <div>9 Sometimes</div> <div>9 Rarely</div> <div>9 Never</div> <div>9 Don't know</div> <div>9 Does not apply</div>
79. In your opinion, are physical restraints used more than necessary for your relative?	<div>9₁ Yes</div> <div>9₂ No</div>
80. In your opinion, are physical restraints used less than necessary for your relative?	<div>9₁ Yes</div> <div>9₂ No</div>

81. Now we have some questions about how your relative has felt in the last two weeks. For each way of feeling, please give your best guess as to whether your relative has felt that way often, sometimes, rarely, or never.		Often	Sometimes	Rarely	Never	Don't know
a. Lonely	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	
b. Happy	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	
c. Bored	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	
d. Angry	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	
e. Contented	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	
f. Worried	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	
g. Interested in things	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	
h. Sad	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	
i. Afraid	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	
j. Looking forward to the future	9 ₁	9 ₂	9 ₃	9 ₄	9 ₇	

82.	Considering your relative's life at this nursing home, how would you rate his/her overall quality of life in each of the following areas:	Excellent	Good	Fair	Poor	Don't know	Does not apply
	a. Feeling physically comfortable.	9	9	9	9	9	9
	b. Doing as much for him/herself as he/she wants.	9	9	9	9	9	9
	c. Having the privacy he/she wants.	9	9	9	9	9	9
	d. Having choice and control over his/her life.	9	9	9	9	9	9
	e. Feeling his/her dignity is respected.	9	9	9	9	9	9
	f. Having interesting and enjoyable things to see and do.	9	9	9	9	9	9
	g. Feeling life is enjoyable	9	9	9	9	9	9
	h. Following his/her own interests and preferences	9	9	9	9	9	9
	i. Having good friendships and relationships	9	9	9	9	9	9
	j. Feeling secure and safe	9	9	9	9	9	9
	k. Meeting his/her spiritual and religious needs	9	9	9	9	9	9
	l. His/her life as a whole	9	9	9	9	9	9

The next questions are about your overall satisfaction.	Very satisfied	Somewhat satisfied	Somewhat unsatisfied	Very unsatisfied
83. Overall how satisfied are you with the services and programs at this facility?	9	9	9	9
84. How satisfied are you with the physical layout and characteristics of your relative's room and bath?	9 ₁	9 ₂	9 ₃	9 ₄
85. How satisfied are you with the physical environment in the facility, not counting your relative's room and bath?	9 ₁	9 ₂	9 ₃	9 ₄

86. How likely would you be to choose this place for yourself in similar circumstances?

9₁

9₂

9₃

9₄

The next questions are about general policies and practices at the nursing home as you have experienced them.	Yes	No	Don't know
87. Did your relative or any family members get an orientation to the nursing home at the time he/she moved in?	9 ₁	9 ₂	9 ₇
88. Have you or any family member ever been <u>invited</u> to a care conference?	9 ₁	9 ₂	9 ₇
89. Have you or any family member ever <u>participated</u> in a care conference?	9 ₁	9 ₂	9 ₇
90. Have you or any family member ever been <u>invited</u> to a family council meeting?	9 ₁	9 ₂	9 ₇
91. Have you or any family member ever <u>participated</u> in a family council meeting?	9 ₁	9 ₂	9 ₇
92. Did your relative or any family members ever get a policy manual from the nursing home?	9 ₁	9 ₂	9 ₇
93. Did you or other family ever receive instruction or help from the facility on how to transfer your relative to a car?	9 ₁	9 ₂	9 ₇
94. Have you or any family member been asked to give your input into what activities are being offered?	9 ₁	9 ₂	9 ₇

The last questions are factual ones about you and your relative.

95. How is your relative in the nursing home related to you? Is he/she:

9 your parent 9 your grandparent 9 your brother/sister 9 your husband/wife
 9 your mother-in-law/father-in-law 9 your aunt/uncle 9 other

96. How far away do you live from your relative's nursing home? (Check the best answer)

9 within a short walk 9 within an hour's drive
 9 further away than an hour 9 it would be a long trip by plane or car

97. Typically, how often do you see your relative in the nursing home? (Check the best answer)

9 every day 9 several times a week 9 about once a week

98. How long is a typical visit with your relative?

9 less than 15 minutes 9 15-30 minutes 9 1-2 hours 9 over 2 hours

99. Typically how often do you talk to your relative on the phone?

9 every day

9 several times a week

9 about once a week

9 several time
a month

9 at least once a month

9 less than once a month

9 N/A, relative does not communicate

100. What is your relative's highest educational level:

9 no schooling

9 some college

9 grade school or less (less than 8th grade

9 bachelor's degree

9 some high school (9 - 11 grades)

9 graduate education

9 high school graduate

9 other

9 technical training or trade school

101. Which, if any, best describes your relative's religious affiliation?

9 Protestant

9 Muslim

9 Catholic

9 Other

9 Jewish

9 none

102. What is your relative's current marital status? If he/she has been both widowed and divorced, use most recent status.

9 never married

9 separated

9 married

9 divorced

9 widowed

103. Does your relative have living children?

9 Yes

9 No

104. Does your relative have living grandchildren?

9 Yes

9 No

105. What best describes your relative's ethnic group?

9 American Indian or Alaska Native

9 Hispanic

9 Asian/Pacific Islander

9 White (Caucasian), not of Hispanic origin

9 Black, not of Hispanic origin

9 Other

Please add anything that you think is relevant, positive or negative, about your relative's quality of life in the nursing home.

[illegible]

This completes our questionnaire. Thank you so much for your help.

If you have any questions or comments about the study, please contact:

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