

Subject # : _____

**Canadian Health Care Evaluation Project
(CANHELP)**

Individualized Caregiver Questionnaire

- Location of interview:
- Home or Retirement Home
 - Hospital
 - Palliative Care Unit
 - Long Term Care or Nursing Home
 - Other

Date : _____ - _____ - _____
 DD MMM YYYY

Instructions:

This questionnaire has 38 questions and should take about 30 minutes to complete. Once you have finished the questionnaire, you will receive a report with recommendations based on your answers. You can use these recommendations as a starting point for a conversation with your health care team.

Please think about the health care that your relative received ***during the past month*** from doctors, nurses and other health professionals. You will be asked how important various aspects of care are to you in terms of quality of care, and also how satisfied you are with the care your relative received.

For each statement, you will be asked to choose a number to indicate how important you regard that particular aspect of care to be – the higher the number, the more important it is. The 5 response options range from #1 **“Not at all Important”** (you do not consider that particular aspect of care important in terms of high quality care you would like your relative to receive), to #5 **“Extremely Important”** (you consider that aspect of care essential in terms of the care your relative receives when he is sick).

As well, you will be asked to choose a number to indicate how satisfied you are with the aspect of care your relative or yourself received ***during the past month*** -- the higher the number, the more satisfied you are. If you choose option #1 **“Not at all Satisfied”**, for example, you will be indicating that this aspect of the care your relative or yourself received did not meet any of your expectations of high quality care. At the other end of the scale, your choice of option #5 **“Completely Satisfied”** will indicate that this aspect of the care your relative or yourself received met or exceeded your expectations of quality care.

All information gathered will be completely confidential. Only the clinical team and research assistant will have access to the data collected. There are no right or wrong answers. **Completely honest answers are most helpful!**

For each item, during the past month: How <u>important</u> is this aspect of care? How <u>satisfied</u> are you with the care you have received?	Importance					Satisfaction				
	Not at all Important	Not very Important	Somewhat Important	Very Important	Extremely Important	Not at all Satisfied	Not very Satisfied	Somewhat Satisfied	Very Satisfied	Completely Satisfied
	1	2	3	4	5	1	2	3	4	5
Relationship with the Doctors										
1. You knew the doctor(s) in charge of your relative's care.										
2. The doctor(s) took a personal interest in your relative.										
3. The doctor(s) were available when you or your relative needed them (by phone or in person).										
4. You had trust and confidence in the <u>doctors</u> responsible for your relative's care.										
Characteristic of the Doctors and Nurses										
5. You had trust and confidence in the <u>nurses</u> responsible for your relative's care.										
6. The doctors and nurses who looked after your relative know enough about their health problems to give them the best possible care.										
7. The doctors and nurses looking after your relative were compassionate and supportive <u>of him or her</u> .										
8. The doctors and nurses looking after your relative were compassionate and supportive of <u>you</u> .										
9. Your relative was treated by those doctors and nurses in a manner that preserved his or her sense of dignity.										
Illness Management										
10. The tests that were done and the treatments that were given for your relative's medical problems.										
11. The physical symptoms your relative had (for example: pain, shortness of breath, nausea) were adequately assessed and controlled.										

For each item, during the past month: How <u>important</u> is this aspect of care? How <u>satisfied</u> are you with the care you have received?	Importance					Satisfaction				
	Not at all Important	Not very Important	Somewhat Important	Very Important	Extremely Important	Not at all Satisfied	Not very Satisfied	Somewhat Satisfied	Very Satisfied	Completely Satisfied
	1	2	3	4	5	1	2	3	4	5
12. The emotional problems your relative had (for example: depression, anxiety) were adequately assessed and controlled.										
13. The help your relative received with personal care (for example: bathing, toileting, dressing, eating).										
14. Your relative received good care when you were not able to be with him/her.										
15. The home care services your relative received.										
16. The health care workers worked together as a team to look after your relative.										
17. You were able to manage the financial costs associated with your relative's illness.										
18. With the environment or the surroundings that your relative was cared for in.										
19. The care and treatment your relative received was consistent with his or her wishes.										
Communication and Decision Making										
20. The doctor(s) explained things relating to your relative's illness in a straightforward, <u>honest</u> manner.										
21. The doctors explained things relating to your relative's illness in a way you <u>understand</u> .										
22. You received <u>consistent</u> information about your relative's condition from all the doctors and nurses looking after him/her.										
23. You received updates about your relative's condition, treatments, test results, etc. <u>in a timely manner</u> .										
24. The doctor(s) <u>listened</u> to what you had to say.										

For each item, during the past month: How <u>important</u> is this aspect of care? How <u>satisfied</u> are you with the care you have received?	Importance					Satisfaction				
	Not at all Important	Not very Important	Somewhat Important	Very Important	Extremely Important	Not at all Satisfied	Not very Satisfied	Somewhat Satisfied	Very Satisfied	Completely Satisfied
	1	2	3	4	5	1	2	3	4	5
25. Your discussions with the doctor(s) about where your relative would be cared for (in hospital, at home, or elsewhere) if he or she were to get worse.										
Your Involvement										
26. The level of confidence you felt <u>in your ability to help your relative</u> manage his/her illness.										
27. Your discussions with the doctor(s) about the use of life sustaining technologies (for example: CPR or cardiopulmonary resuscitation, breathing machines, dialysis).										
28. You have come to understand what to expect at the end stage of your relative's illness (for example: in terms of symptoms and comfort measures).										
29. Your role in decision-making regarding your relative's medical care.										
30. The discussions with your relative about wishes for future care in the event he or she is unable to make those decisions.										
31. You were able to talk comfortably with your relative about his or her illness, dying, and death.										
32. Your relationship with your relative was strengthened.										
Your Well Being										
33. The level of confidence you felt in <u>your relative's ability</u> to manage his/her own illness.										
34. You had enough time and energy to take care of yourself.										
35. You had family or friends to support you when you felt lonely or isolated.										

For each item, during the past month:	Importance					Satisfaction				
	Not at all Important	Not very Important	Somewhat Important	Very Important	Extremely Important	Not at all Satisfied	Not very Satisfied	Somewhat Satisfied	Very Satisfied	Completely Satisfied
<p>How <u>important</u> is this aspect of care?</p> <p>How <u>satisfied</u> are you with the care you have received?</p>	1	2	3	4	5	1	2	3	4	5
36. You were able to contribute to others in a meaningful way.										
37. You and your relative did special things you wanted to do (for example: resolve conflicts, complete projects, participate in special family events, travel).										
38. You were at peace.										