

Caregiver Experience Survey

The survey will take approximately 20 minutes to complete. Please clearly check the circle that best corresponds to your answer for each question below. Once you have completed the survey, please return it to the researchers at the University of Toronto using the stamped and addressed return envelope.

Should you need any assistance at any time, ***or if you wish to complete the survey either online or over the telephone***, please contact the researchers from the University of Toronto at (416) 978-5017, or ifm.evaluation@utoronto.ca.

Section 1: We would like to know about the state of your health.

First, we'd like to find out what you think about your health. Each question has a choice of five answers. Please choose one answer that best describes your health ***TODAY***.

1. Mobility	<input type="radio"/> I have no problems in walking about	<input type="radio"/> I have slight problems in walking about	<input type="radio"/> I have moderate problems in walking about	<input type="radio"/> I have severe problems in walking about	<input type="radio"/> I am unable to walk about
2. Self-Care	<input type="radio"/> I have no problems washing or dressing myself	<input type="radio"/> I have slight problems washing or dressing myself	<input type="radio"/> I have moderate problems washing or dressing myself	<input type="radio"/> I have severe problems washing or dressing myself	<input type="radio"/> I am unable to wash or dress myself
3. Usual Activities (e.g. work, study, housework, family, or leisure activities)	<input type="radio"/> I have no problems doing my usual activities	<input type="radio"/> I have slight problems doing my usual activities	<input type="radio"/> I have moderate problems doing my usual activities	<input type="radio"/> I have severe problems doing my usual activities	<input type="radio"/> I am unable to do my usual activities
4. Pain / Discomfort	<input type="radio"/> I have no pain or discomfort	<input type="radio"/> I have slight pain or discomfort	<input type="radio"/> I have moderate pain or discomfort	<input type="radio"/> I have severe pain or discomfort	<input type="radio"/> I have extreme pain or discomfort
5. Anxiety / Depression	<input type="radio"/> I am not anxious or depressed	<input type="radio"/> I am slightly anxious or depressed	<input type="radio"/> I am moderately anxious or depressed	<input type="radio"/> I am severely anxious or depressed	<input type="radio"/> I am extremely anxious or depressed

PLEASE GO TO THE NEXT PAGE

Section 2: We would like to know about your experience as a caregiver.

Approximately «X months» ago, «patientname», hereafter referred to as the patient, was admitted to «hospital» and started on a care pathway called «ifm_program». This survey will ask you questions about **your experience as a caregiver** during this stay, as well as after the patient returned home.

To start, please choose the response that best describes how you have been feeling **since the patient was admitted to «hospital» approximately «X months» ago.**

	Never	Rarely	Sometimes	Quite frequently	Nearly always
6. Do you feel that because of the time you spend with the patient that you don't have enough time for yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Do you feel stressed between caring for the patient and trying to meet other responsibilities for your family or work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Do you feel strained when you are around the patient?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Do you feel uncertain about what to do about the patient?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Next, please answer the following questions about the patient's stay at «hospital» approximately «X months» ago.

	Never	Rarely	Sometimes	Quite frequently	Nearly always	Don't Know/ Don't Remember/ Not Applicable
10. During the hospital stay, how often did healthcare professionals listen to your concerns about the patient?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. During the hospital stay, how often were you made to feel involved in decision making by healthcare professionals?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Still thinking about your experience during the patient's stay in «hospital», we will now ask you a few questions about how well prepared you were to help the patient when leaving the hospital and returning home.

	Yes	No	Don't Know/ Don't Remember/ Not Applicable
12. Were you included in the planning for the patient's discharge?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Before leaving the hospital, were you given information on who to contact if you had questions or were worried about the patient's condition or treatment?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Before leaving the hospital, did anybody from the hospital staff give you information on caregiver support services (e.g. respite, caregiver support groups, educational seminars) or on how to care for yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Yes	No	Don't Know/ Don't Remember/ Not Applicable
15. Before leaving the hospital, did anybody from the hospital staff ask you if you were able or willing to help with the patient's care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Not at all	Partly	Quite a bit	Completely	Don't Know/ Don't Remember/ Not Applicable
16. Before leaving the hospital, were you given enough information on the patient's condition or treatment?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Before leaving the hospital, were you given enough information on how to provide care or help the patient at home?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	1	2	3	4	5	6	7	8	9	10	Don't Know/ Don't Remember/ Not Applicable
18. Using any number from 1 to 10, where 1 is a very poor experience and 10 is a very good experience, what number would you use to rate your experience during the patient's stay at «hospital»?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Now, we will ask you a few questions about your experience with the homecare and/or other healthcare professionals seen after the patient was discharged from **«hospital» up until now.**

	Never	Rarely	Sometimes	Quite frequently	Nearly always	Don't Know/ Don't Remember/ Not Applicable
19. Since the patient's discharge, were there times when you felt abandoned by the healthcare system or didn't know where to turn for help?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Since the patient's discharge, were members of the home care team available when you needed them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Since the patient's discharge, were home care visits arranged in a manner that was convenient for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Since the patient's discharge, did the home care team seem informed and up-to-date about the care the patient received in the hospital?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Since the patient's discharge, did the doctors or staff at the place where the patient usually gets medical care (e.g. the patient's family doctor) seem informed and up-to-date about the care the patient received in the hospital?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Yes	No	Don't Know/ Don't Remember/ Not Applicable
24. Since the patient's discharge, did anybody from the homecare team conduct an assessment of the supports you need to help care for the patient?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. Since the patient's discharge, did anybody from the homecare team give you information on caregiver support services (e.g. respite, caregiver support groups, educational seminars) or on how to care for yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. Since the patient's discharge, did anybody from the homecare team ask you if you were able or willing to help with the patient's care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	1	2	3	4	5	6	7	8	9	10	Don't Know/ Don't Remember/ Not Applicable
27. Using any number from 1 to 10, where 1 is a very poor experience and 10 is a very good experience, what number would you use to rate your experience with the services provided after the patient's discharge from hospital?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section 3: We would like to know how much time you spent caring for the patient and about any costs you may have incurred since the patient was admitted to the hospital

Now, we are going to ask you a few questions about the amount of time you have spent helping the patient. ***IN AN AVERAGE WEEK, since the patient was admitted to « hospital» approximately «X months» ago,*** how much time did you spend on the following tasks?

	0 hours a week	Less than 5 hours a week	5 hours to less than 10 hours a week	10 hours to less than 20 hours	20 hours or more (Please specify number of hours)
28. Helping the patient by providing medical treatment, such as changing bandages, administering medications, or other medical procedures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> _____ hours
29. Helping the patient with personal care (e.g. bathing, dressing, toileting, hair and nail care); transportation (e.g. to do shopping or errands, or to get to medical appointments or social events); or housework (e.g. meal preparation, meal clean-up, house cleaning, laundry, or sewing)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> _____ hours
30. Helping the patient with scheduling or coordinating care-related tasks such as making appointments or hiring professional help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> _____ hours

	0 hours a week	Less than 5 hours a week	5 hours to less than 10 hours a week	10 hours to less than 20 hours	20 hours or more (Please specify number of hours)
31. IN AN AVERAGE WEEK, since the patient was admitted to the hospital, how many hours of help have you provided to the patient?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> _____ hours
32. IN AN AVERAGE WEEK, since the patient was admitted to the hospital, how many hours of help has the patient received from other friends or family members?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> _____ hours

Now, we are going to ask you a few questions about any expenses you may have had in association with the patient's care. ***Since the patient was admitted to «hospital» approximately «X months» ago***, about how much of your own money or the patient's money, not including amounts reimbursed by insurance, was spent on:

	\$0	\$1-199	\$200-500	More than \$500 (Please specify amount)
33. Home modifications to accommodate the patient's needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> \$_____
34. Hiring people to help with the patient's daily activities or medical care (e.g. wound care)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> \$_____
35. Hiring people to spend time with the patient or care for the patient so you can take a break or spend time on other responsibilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> \$_____
36. Specialized aids or devices for the patient's use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> \$_____
37. Prescription or non-prescription drugs for the patient's use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> \$_____
38. Mental health services for the patient such as counseling or psychotherapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> \$_____
39. Physical health services for the patient such as physiotherapy, chiropractor, or deep tissue massage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> \$_____
40. Other expenses resulting from the patient's health issues such as transportation and parking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> \$_____

	Yes	No	Prefer not to answer
41. Since the patient was admitted to «hospital» approximately «X months» ago, have you experienced financial hardship because of your caregiving responsibilities? (E.g. in paying rent, borrowed money)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Now we are going to ask you about your current employment situation, and if it has been affected by your caregiving responsibilities **since the patient was admitted to «hospital» approximately «X months» ago.**

42. Please describe your current work situation:

- I am currently employed/self-employed/at school
- I am currently on leave to care for the patient
- I am no longer employed/studying as a result of my caregiving (Please specify for how long _____)
- I am not working for reasons not related to caregiving
- I am retired

43. Since the patient was admitted to «hospital» *approximately «X months» ago*, how much work time did you miss because of your caregiving responsibilities?

- Less than 1 work day
- 1 to 5 work days
- 6 to 10 work days
- 11 to 15 work days
- 16 to 20 days
- More than 20 work days (Please specify number of work days _____)
- Not Applicable
- Don't Know/Don't remember

44. Were you paid for this time off?

- Yes
- No
- Some paid, some unpaid (Please specify percentage of time off that was paid _____)
- Not Applicable
- Don't Know/Don't remember

45. Since the patient was admitted to «hospital» *approximately «X months» ago*, how many times have you been *UNABLE* to participate in your usual activities other than paid work (e.g. volunteer work, study, housework, family, or leisure activity) because of your caregiving responsibilities?

- Never
- 1-5 times
- 6-10 times
- More than 10 times (Please specify the number of times _____)
- Not Applicable
- Don't Know/Don't remember

Now we are going to ask you about healthcare or social services that you used **since the patient was admitted to «hospital» approximately «X months» ago.**

46. Did you use any respite services?

- Yes, I used respite services (Please state how many hours _____)
- No, I did not use any respite services
- No, I was not aware of respite services

47. Did you use any caregiver support services (caregiver support groups, educational seminars)?

- Yes, I used caregiver support services (I used _____ services, for _____ hours)
- No, I did not use any caregiver support services

Section 4: Background Information

48. We want to understand how your caregiving experience may be related to your own health outcomes (such as visits to primary care or emergency department visits). Learning about caregivers' health and healthcare use is key to improving the healthcare system for family caregivers by providing them with the right support at the right time.

If you agree, your health card number, date of birth and survey results will be sent to the Institute for Clinical Evaluative Sciences (ICES). This is a not-for-profit organization authorized by Ontario privacy laws to hold records on health services received by Ontario residents. Your health card number and date of birth will be used to link your survey to health records held at ICES.

YOUR PRIVACY WILL BE ENTIRELY PROTECTED. Once the linkage is made, the numbers will be changed so that the researchers do not have health card numbers in the data that they analyze. We remind you that the electronic copy of survey data will be stored securely using encryption technology and made available only to persons conducting the study. Only summary results will be used in any reports or publications resulting from this study.

BY PROVIDING YOUR HEALTH CARD NUMBER AND BIRTH DATE YOU ARE PROVIDING CONSENT FOR LINKAGE OF YOUR SURVEY WITH HEALTH INFORMATION AT ICES.

We remind you that all parts of this survey are voluntary. If there are questions that you would rather not answer, you can leave them blank.

Health Card Number #

Version Code (if Health Card has one, this may be 1 or 2 letters)

Birth Date (YYYY/MM/DD)

____ / ____ / ____

49. How long have you been a caregiver to this patient?

Please specify length of time: _____

50. What is your age?

_____ years

- Under 18 years
- 18 to 44 years
- 45 to 64 years
- 65 to 74 years
- 75 years and older
- Prefer not to answer

51. What is your gender?

- Male
- Female
- Prefer to self-identify _____
- Prefer not to answer

52. What is the highest level of education that you have completed?

- Primary school or some high/secondary school
- High school diploma or equivalency certificate
- College, CEGEP, or professional trade school diploma/certificate or some university
- Undergraduate university degree (e.g. B.A., B.Sc.)
- Graduate or professional university degree above the Bachelor's level (e.g. M.Sc., Ph.D., MD, J.D./LL.B.)
- Prefer not to answer

53. What was your income (or retirement income) (before tax) for the past 12 months?

- No income
- Less than \$5,000
- \$5,000 to \$9,999
- \$10,000 to \$14,999
- \$15,000 to \$19,999
- \$20,000 to \$29,999
- \$30,000 to \$39,999
- \$40,000 to \$49,999
- \$50,000 to \$59,999
- \$60,000 to less than \$79,999
- \$80,000 to less than \$99,999
- \$100,000 or more
- Prefer not to answer

54. What was your household income (before tax) for the past 12 months?

- No income
- Less than \$5,000
- \$5,000 to \$9,999
- \$10,000 to \$14,999
- \$15,000 to \$19,999
- \$20,000 to \$29,999
- \$30,000 to \$39,999
- \$40,000 to \$49,999
- \$50,000 to \$59,999
- \$60,000 to less than \$79,999
- \$80,000 to less than \$99,999
- \$100,000 or more
- Prefer not to answer

55. What is your relationship to patient? He or she is my...

- Spouse/partner
- Parent, step parent, or parent-in-law
- Son/daughter, step-child, foster child, or child-in law
- Sibling or step-sibling
- Grandchild, step-grandchild, or grandchild-in-law
- Grandparent, step-grandparent, or grandparent-in-law
- Friend or neighbor
- Other, please specify _____

56. How close do you live to the patient?

- In the same household
- In the same building
- Less than 10 minutes by car
- 10 minutes to less than 30 minutes by car
- 30 minutes to less than 1 hour by car
- 1 hour to less than 3 hours by car
- 3 hours or more by car
- Other, please specify distance _____

57. How would you describe your racial or ethnic group?

- East Asian (e.g. Chinese, Japanese, Korean)
- South Asian (e.g. Indian, Pakistani, Sri Lankan)
- South-East Asian (e.g. Malaysian, Filipino, Vietnamese)
- African (e.g. Ghanaian, Kenyan, Somali)
- Caribbean Black (e.g. Barbadian, Jamaican)
- North American Black (e.g. Canadian, American)
- First Nations
- Caribbean Indian (e.g. Guyanese with origins in India)
- Indigenous/Aboriginal
- Inuit
- Latin American (e.g. Argentinean, Chilean, Salvadoran)
- Metis
- Middle Eastern (e.g. Egyptian, Iranian, Lebanese)
- European (e.g. English, Italian, Portuguese, Russian)
- North American White (e.g. Canadian, American)
- Mixed heritage (e.g. Black-African & White-North American) Please specify mix: _____
- If others, please specify: _____
- Prefer Not to Answer

58. Would you like to share any comments or thoughts about your experience as a caregiver since the patient was admitted to «hospital» approximately «X months» ago? Please note that your comments might be used in reports/publications but will not refer to you by name.