

**L'ENQUÊTE QUÉBÉCOISE SUR LA QUALITÉ DES  
SERVICES DE LUTTE CONTRE LE CANCER, 2008**

**QUESTIONNAIRE**

**Version anglaise**

**Direction des statistiques de santé**

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FOR CONSULTATION ONLY

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CERTAINES DES QUESTIONS UTILISÉES DANS LE QUESTIONNAIRE SONT LA PROPRIÉTÉ DE *NRC PICKER CANADA*. EN VERTU D'UNE ENTENTE AVEC CES DERNIERS, L'ISQ A L'AUTORISATION D'UTILISER, TRADUIRE, ADAPTER ET DIFFUSER CES QUESTIONS. *NRC PICKER* EST LE SEUL PROPRIÉTAIRE DE CES QUESTIONS, Y COMPRIS LES ADAPTATIONS OU LES COPIES D'ELLES, AINSI QUE LES DROITS DE PROPRIÉTÉ INTELLECTUELLE ASSOCIÉS AVEC ELLES. TOUTE UTILISATION DE CES QUESTIONS NÉCESSITE UNE AUTORISATION ÉCRITE DE *NRC PICKER*.

## Définitions

Several questions in this questionnaire concern health care providers who work with people who have cancer. By **health care providers**, we mean doctors, nurses, pivot nurses in oncology, pharmacists, social workers, psychologists, etc., with whom you may have had contact for cancer treatment. By **doctors**, we mean family doctor (or general practitioner), cancer specialists (for example, oncologist, hematologist/oncologist, radiation oncologist) and other specialists (for example, surgeon, dermatologist, gynecologist, urologist).

### SECTION A Questions générales

To begin, we are going to ask you some questions about the kind of cancer for which you received at least one of the following **treatments**, between April 1, 2005, and March 31, 2006 : **surgery**, **chemotherapy**, or **radiation therapy** (or **internal radiation therapy**).

**A1. What is the primary type of cancer for which you have received at least one treatment between April 1, 2005, and March 31, 2006?**

- |   |  |
|---|--|
| 01 <input type="checkbox"/> Brain                 | 12 <input type="checkbox"/> Bone                                   |
| 02 <input type="checkbox"/> Cervix                | 13 <input type="checkbox"/> Ovaries                                |
| 03 <input type="checkbox"/> Colon                 | 14 <input type="checkbox"/> Lung                                   |
| 04 <input type="checkbox"/> Uterus body           | 15 <input type="checkbox"/> Prostate                               |
| 05 <input type="checkbox"/> Stomach               | 16 <input type="checkbox"/> Rectum                                 |
| 06 <input type="checkbox"/> Liver                 | 17 <input type="checkbox"/> Kidney                                 |
| 07 <input type="checkbox"/> Leukemia (blood)      | 18 <input type="checkbox"/> Breast                                 |
| 08 <input type="checkbox"/> Non-Hodgkins lymphoma | 19 <input type="checkbox"/> Thyroid                                |
| 09 <input type="checkbox"/> Hodgkin's disease     | 20 <input type="checkbox"/> Unspecified type of cancer             |
| 10 <input type="checkbox"/> Melanoma (skin)       | 21 <input type="checkbox"/> Bladder                                |
| 11 <input type="checkbox"/> Oesophagus            | 95 <input type="checkbox"/> Other ( <b>please specify</b> ): _____ |

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**A2. Was the type of cancer, indicated in question A1 :**

- 01  A first-time cancer diagnosis (in other words, a cancer diagnosis treated for the first time)  
02  A recurrence or a repeat cancer diagnosis  
03  A second, distinct cancer diagnosis  
95  Other, **please specify** : \_\_\_\_\_

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**A3. When did you receive your cancer diagnosis for the type indicated in A1? If you are not sure, please put down your best guess.**

**NOTE :** If the cancer diagnosis for which you were treated was a recurrence, please give the date when you learned of the recurrence. If the cancer diagnosis was a second cancer diagnosis (or another cancer), please give the date when you learned of this second or other cancer diagnosis.

Month: \_\_\_\_\_ Year: \_\_\_\_\_

**NOTE :** Please fill out the rest of the questionnaire while only considering the type of cancer and date of diagnostic mentioned above.

**A4. Are you currently being treated for a cancer?**

- 01  Yes, I'm still being treated for the cancer diagnosis indicated in A1  
02  Yes, I'm being treated for a recurrence of the cancer indicated in A1 or for another cancer  
03  Yes, I'm being treated solely to relieve pain and increase my comfort  
04  No, my treatments are over, but I'm taking medication to prevent the cancer from coming back (for example, Tamoxifen, Rituxan)  
96  No, I'm no longer being treated for a cancer

## **SECTION B** Avant vos traitements

The following questions refer to **services you received before beginning your treatments**, including services related to the appearance of your symptoms, your formal cancer diagnosis, and treatment planning. These questions concern the cancer indicated in A1 and for which you received at least one treatment (surgery operation, chemotherapy, radiation therapy or internal radiation therapy) between April 1, 2005, and March 31, 2006.

### *TESTS AND DIAGNOSTIC PROCEDURES*

**B1. Did you have any signs or symptoms (such as a lump in your breast, blood in your urine) for the cancer indicated in A1?**

- 01  Yes ➤ **Go to question B3**  
02  No, I did not notice any signs or symptoms in particular ➤ **Go to question B2**

**B2. How did you learn that you had cancer?**

- 01  After a routine check-up or follow-up visit with my family doctor ➤ **Go to question B5**  
02  After a routine check-up or follow-up visit with a cancer specialist (for example oncologist, radiation oncologist) ➤ **Go to question B6**  
03  After a routine check-up or follow-up visit with another specialist (for example, dermatologist, gynecologist, urologist) ➤ **Go to question B6**  
04  After having a mammogram through the Québec Breast Cancer Screening Program ➤ **Go to question B6**  
95  Other, **please specify** \_\_\_\_\_ ➤ **Go to question B6**

**B3. When did you first notice signs or symptoms for the cancer indicated in A1? If you are not sure, please put down your best guess.**

Month: \_\_\_\_\_ Year: \_\_\_\_\_

**B4. How long was it between the appearance of your symptoms or your suspicions that you had cancer and your first visit to a family doctor (or general practitioner) ?**

- 01  Same day or next day
- 02  More than 2 days but within 1 week
- 03  More than 1 week but within 2 weeks
- 04  More than 2 weeks but within 1 month
- 05  More than 1 month but within 3 months
- 06  More than 3 months but within 6 months
- 07  More than 6 months but within 1 year
- 08  More than 1 year
- 94  I don't remember
- 96  I did not see a family doctor because I consulted a specialist directly ↗ **Go to question B6**
- 97  I did not see a family doctor because I went directly to a hospital emergency ward ↗ **Go to question B6**

**B5. After seeing this doctor, how long did you have to wait before getting your first appointment to see a specialist?**

- 01  Same day or next day
- 02  More than 2 days but within 1 week
- 03  More than 1 week but within 2 weeks
- 04  More than 2 weeks but within 1 month
- 05  More than 1 month but within 3 months
- 06  More than 3 months but within 6 months
- 07  More than 6 months but within 1 year
- 08  More than 1 year
- 94  I don't remember
- 96  I did not see a specialist ↗ **Go to question B7**

**B6. When did you first see a specialist for the cancer indicated in A1? If you are not sure, please give your best guess.**

Month: \_\_\_\_\_ Year: \_\_\_\_\_

**B7. Did the health care providers explain to you, in a way that was easy to understand, why you needed to have diagnostic tests and procedures?**

01  Yes, thoroughly

02  Yes, somewhat

03  No

96 I did not have any diagnostic tests or procedures ➔ **Go to question B9**

**B8. Did you pay out-of-pocket in order to have earlier access to diagnostic tests or procedures (such as x-rays, scans, MRI scans, ultrasound)?**

01  Yes

02  Yes, but my insurance paid some or all of the costs

03  No

### *YOUR DIAGNOSIS*

**B9. Who first told you of your cancer diagnosis?**

01  My family doctor

02  A cancer specialist (for example, hematologist, oncologist)

03  A surgeon

04  Another specialist (for example, dermatologist, gynecologist)

05  A pivot nurse in oncology

95  Someone else, **please specify** \_\_\_\_\_

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**B10. How were you told of your cancer diagnosis the first time?**

01  In person

02  By mail

03  Over the phone

95 Other, **please specify** \_\_\_\_\_

**B11. When you learned of your diagnosis, would you say the health care provider ...**

**A) was supportive enough?**

01  Yes

02  No

**B) allowed enough time?**

01  Yes

02  No

**C) answered your questions?**

01  Yes

02  No



**B12. When you received your cancer diagnosis or soon after, were you given any written information about the disease and the treatments you needed to have?**

- 01  Yes
- 02  No

**B13. After you received your cancer diagnosis, did someone put you in touch with any health care providers or organizations to help you cope with your fears and anxieties?**

◆ **You may check more than one answer**

- 01  Yes, with a support group or community-based organization
- 02  Yes, with a pivot nurse in oncology
- 03  Yes, with a psychologist
- 04  Yes, with a social worker
- 95  Yes, other (**please specify**): \_\_\_\_\_
- 96  No, I was not put in touch with any health care providers or organizations
- 97  No, I did not need any

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**B14. After receiving your cancer diagnosis, were you put in touch with a health care provider who, throughout your illness, could evaluate your needs, or assess your situation, or give you information or support, if needed?**

◆ **You may check more than one answer**

- 01  Yes, with a pivot nurse in oncology
- 02  Yes, with a cancer specialist (for example, an oncologist)
- 03  Yes, with my family doctor
- 04  Yes, with another specialist (for example, a dermatologist)
- 95  Yes, with another health care provider (**please specify**): \_\_\_\_\_
- 96  No, I was not put in touch with a health care provider

*YOUR TREATMENT PLANNING : SURGERY AND/OR CHEMOTHERAPY AND/OR RADIATION THERAPY (OR INTERNAL RADIATION THERAPY)*

**B15. Were you involved in the treatment decision-making as much as you would have wanted?**

- 01  Yes, thoroughly
- 02  Yes, somewhat
- 03  No

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**B16. Were the various stages of your treatments explained to you?**

- 01  Yes, thoroughly
- 02  Yes, somewhat
- 03  No

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**B17. Did the health care providers involve your family or friends in decisions about your treatment?**

- 01  Yes
- 02  No, I did not want my family or friends to be involved
- 03  No, but I would have liked that the health care providers involved my family and friends
- 96  No, there was no need to involve them
- 97  I had no family or friends who were able or willing to be involved

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**B18. Did the health care providers take your family or living situation into account in planning for your treatments?**

- 01  Yes, thoroughly
- 02  Yes, somewhat
- 03  No
- 96  No, they do not have to take into account my family or living situation

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**B19. Was there a health care provider or a staff member in charge of making your appointments (for tests, treatments, examinations) and sending along your patient record if necessary?**

- 01  Yes, a pivot nurse in oncology
- 02  Yes, a nurse
- 03  Yes, a clerk or a secretary
- 95  Yes, someone else (please specify): \_\_\_\_\_
- 96  No

**B20. Did you feel comfortable talking about complementary, non traditional or alternative therapies (for example, massage, acupuncture, homeopathy) with your health care providers?**

- 01  Yes, thoroughly
- 02  Yes, somewhat
- 03  No, I did not feel comfortable to talk about it
- 96  No, I did not feel the need to talk about it
- 97  No, I did not use complementary, non-traditional or alternative therapies

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**B21. Did anyone ask you to participate in a cancer treatment research project?**

- 01  Yes, and I agreed
- 02  Yes, but I could not participate because I did not meet eligibility criteria
- 03  Yes, and I refused
- 04  No

The questions below deal with the following **treatments** : **surgery, chemotherapy** and **radiation therapy** (or **internal radiation therapy**). Please refer to the cancer diagnosis, indicated in A1, for which you received at least one treatment between April 1, 2005, and March 31, 2006. Your full course of treatments, however, may have extended over a longer period. In such cases, you are asked to consider your full course of treatments as a whole.

If your cancer is a recurrence of a previous cancer diagnosis, please consider only those treatments that targeted the recurring cancer as you complete this section of the survey. For those whose cancer is a second cancer diagnosis (or another cancer), please consider only those treatments that targeted the second or other cancer diagnosis as you complete this section of the survey.

### SURGERY

**C1. After receiving your cancer diagnosis indicated in A1, did you have at least one surgical operation to remove one or more tumours?**

**Note: In this survey, biopsies are not considered surgical operations.**

- 01  Yes, I've had an operation  
 02  Yes, I've had more than one operation  
 03  No ➔ **Go to question C9**

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**C2. Was this surgery (or one of these surgeries) a day-surgery?**

**Note: A day-surgery can take place in a hospital (or a clinic), but does not require you staying overnight.**

- 01  Yes  
 02  No

**Questions C3 to C8 refer solely to your first surgical operation.**

**C3. When were you operated on for the first time? If you are not sure, please give your best guess.**

Month: \_\_\_\_\_ Year: \_\_\_\_\_

**C4. Where did you have this first surgical operation?**

- 01  In a hospital in my area  
 02  In a hospital outside my area  
 95 Other (**please specify**): \_\_\_\_\_

**C5. Did your health care providers consider your travel concerns when planning your first surgical operation?**

- 01  Yes, thoroughly
  - 02  Yes, somewhat
  - 03  No
  - 96  No, it was not necessary
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**C6. Did your health care providers talk to you about the risks and possible side effects of your first surgical operation?**

- 01  Yes, thoroughly
- 02  Yes, somewhat
- 03  No

**C7. After your surgical operation, did the doctor inform you to the outcome or the results of your surgery?**

- 01  Yes
- 02  No → **Go to question C9**

**C8. Was the outcome or result of your surgical operation explained to you in a way that was easy for you to understand?**

- 01  Yes, thoroughly
- 02  Yes, somewhat
- 03  No

**CHEMOTHERAPY**

**C9. Did you receive chemotherapy treatments for your cancer diagnosis indicated in A1?**

◆ **You may check more than one answer**

- 01  Yes, intravenously
- 02  Yes, orally (for example, medications)
- 95  Other (**please specify**): \_\_\_\_\_
- 96  No → **Go to question C17**

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**C10. When did you begin your chemotherapy treatments? If you are not sure, please give your best guess.**

Month: \_\_\_\_\_ Year: \_\_\_\_\_

**C11. Where did you receive the majority of your chemotherapy treatments?**

- 01  In a hospital in my area
- 02  In a hospital outside my area
- 03  At home, under hospital supervision ➤ **Go to question C16**
- 04  At home, under CLSC supervision ➤ **Go to question C16**
- 95 Other (please specify): \_\_\_\_\_

**C12. How long, on average, did it take you to go from your home to where you were receiving the majority of your chemotherapy treatments?**

- 01  Under half an hour
- 02  More than half an hour but within an hour
- 03  More than 1 hour but within 3 hours
- 04  More than 3 hours

**C13. Did your health care providers consider your travel concerns when planning your chemotherapy treatments?**

- 01  Yes, thoroughly
  - 02  Yes, somewhat
  - 03  No
  - 96  No, it was not necessary
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**C14. When you went to the hospital for your chemotherapy treatments, on average, how long did you have to wait between your scheduled appointment time and the time the treatment began?**

- 01  Under half an hour
  - 02  More than half an hour but within an hour
  - 03  More than 1 hour but within 3 hours
  - 04  More than 3 hours
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**C15. Did you find the chemotherapy treatment facilities suitable (for example, with respect to cleanliness, noise levels, comfort)?**

- 01  Yes, thoroughly
- 02  Yes, somewhat
- 03  No

**C16. Did your health care providers talk to you about the possible side effects of your chemotherapy treatments?**

- 01  Yes, thoroughly
- 02  Yes, somewhat
- 03  No
- 96  I did not need any explanations

*RADIATION THERAPY (or INTERNAL RADIATION THERAPY)*

**C17. Did you have radiation therapy (or internal radiation therapy) for your cancer diagnosis indicated in A1?**

- 01  Yes  
02  No ➔ **Go to question C23**

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**C18. When did you begin your radiation therapy treatments (or internal radiation therapy)? If you are not sure, please give your best guess.**

Month: \_\_\_\_\_ Year: \_\_\_\_\_

**C19. Where did you receive the majority of your radiation therapy treatments (or internal radiation therapy)?**

- 01  In a hospital in my area  
02  In a hospital outside my area  
95  Other (please specify): \_\_\_\_\_

**C20. How long, on average, did it take you to go from your home to where you were receiving the majority of your radiation therapy treatments (or internal radiation therapy)?**

- 01  Under half an hour  
02  More than half an hour but within an hour  
03  More than 1 hour but within 3 hours  
04  More than 3 hours

**C21. Did your health care providers consider your travel concerns when planning your radiation therapy treatments (or internal radiation therapy)?**

- 01  Yes, thoroughly  
02  Yes, somewhat  
03  No  
96  No, it was not necessary

**C22. Did your health care providers talk to you about the possible side effects of your radiation therapy treatments (or internal radiation therapy)?**

- 01  Yes, thoroughly  
02  Yes, somewhat  
03  No  
96  I did not need any explanations

## THE CARE AND SERVICES YOU RECEIVED DURING YOUR TREATMENTS

Note that several of the following questions concern **health care providers** who work with people who have cancer. By **health care providers** we mean doctors, nurses, pivot nurses in oncology, pharmacists, social workers, psychologists, etc., with whom you may have had contact for cancer treatment. By **doctors** we mean family doctor (or general practitioner), cancer specialists (for example, oncologist, haematologist/oncologist, radiation oncologist) and other specialists (for example, surgeon, dermatologist, gynecologist, urologist).

**C23. When you had pain or discomfort (for example, nausea, vomiting) during the course of your treatments, were they :**

- 01  Severe
  - 02  Moderate
  - 03  Mild
  - 96  I had no pain or discomfort ➦ **Go to question C25**
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**C24. Did the health care providers do everything they could to control your pain or discomfort?**

- 01  Yes, thoroughly
  - 02  Yes, somewhat
  - 03  No
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**C25. During the course of your illness, did your health care providers assess the ability of your friends and family to assist you with your activities of daily living (for example, making meals, personal care)?**

- 01  Yes
- 02  No
- 96  I had no family or friends who were able or willing to assist me 97
- 99  I did not need any help

**C26. Did your health care providers make sure that you had the necessary resources and equipment (for example, home care visits, wheelchair, sitz bath) to help you carry out your activities of daily living?**

- 01  Yes
- 02  No
- 96  I did not need these kinds of resources or equipments

**C27. Did your health care providers explain clearly the purpose and benefits of the medications you were to take once you were back home?**

- 01  Yes, thoroughly
- 02  Yes, somewhat
- 03  No
- 96  I did not need any explanations
- 97  I had no medications to take

**C28. During the course of your treatments, did someone tell you whom you could contact evenings, nights and weekends, should you have problems related to your health or your cancer treatments?**

**NOTE : By contact, we mean a telephone call or a visit.**

**◆ You may check more than one answer**

- 01  Yes, I was told to contact a family doctor (or general practitioner)
- 02  Yes, I was told to contact a cancer specialist or another specialist
- 03  Yes, I was told to contact my pivot nurse in oncology
- 04  Yes, I was told to contact Info-Santé
- 05  Yes, I was told to contact a CLSC
- 06  Yes, I was told to contact a hospital emergency ward
- 07  Yes, I was told to contact a hospital patient care unit
- 95  Other (**please specify**): \_\_\_\_\_
- 96  No, I was not told who to contact

**C29. During the course of your treatments, did you feel that you were treated with respect by your health care providers?**

- 01  Yes, always
- 02  Yes, most of the time
- 03  No

**C30. During the course of your treatments, did any health care providers ever talk about your case in front of you as if you were not there?**

- 01  Yes, often
- 02  Yes, sometimes
- 03  Yes, once
- 04  No, never

**C31. During the course of your treatments, was information about your care and the state of your health given to you in private or without others being able to hear it?**

- 01  Yes, always
- 02  Yes, most of the time
- 03  No



**C32. During the course of your treatments, did you feel that health care providers were respectful of your privacy (for example, drawing curtains, covering you up)?**

- 01  Yes, always
- 02  Yes, most of the time
- 03  No

**C33. Do you think your health care providers knew enough about the therapies available for treating your cancer?**

- 01  Yes, thoroughly
- 02  Yes, somewhat
- 03  No

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**C34. As far as you know, was a medical error committed by a health care provider during your treatments (for example, mistakes with intravenous fluid drips, mistakes during surgery, diagnostic mistakes)?**

- 01  Yes, a doctor or a health care provider notified me of a medical error
- 02  Yes, I observed a medical error
- 03  No, there were no medical errors that I know
- 95  Other (**please specify**): \_\_\_\_\_
- 98  I do not know

**C35. How often were your health care providers familiar with your medical history?**

- 01  Always
- 02  Most of the time
- 03  Sometimes
- 04  Never

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**C36. Was your family doctor, in your opinion, adequately informed of the various procedures and treatments that you received to treat your cancer?**

- 01  Yes, thoroughly
- 02  Yes, somewhat
- 03  No
- 96  I was the one who kept my family doctor informed
- 97  I did not have a family doctor

**C37. During the course of your treatments, were the results of your examinations or tests ever lost or misplaced?**

- 01  Yes
- 02  No

**C38. How often were you given confusing or contradictory information about the state of your health or your treatments?**

- 01  Never
- 02  Sometimes
- 03  Usually
- 04  Always

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**C39. Were you assisted by the staff member or health care providers in dealing with other hospitals or organizations, for example, in making appointment or transferring your medical record to a hospital outside your area or a CLSC when it was required?**

- 01  Yes, thoroughly
- 02  Yes, somewhat
- 03  No
- 96  No assistance was necessary

**C40. When you had important questions to ask a health care provider, did you get answers that you could understand?**

- 01  Yes, always
- 02  Yes, most of the time
- 03  No
- 96  I did not need to ask any questions

**C41. When your family or friends wanted to talk to a health care provider, could they do so easily?**

- 01  Yes, thoroughly
- 02  Yes, somewhat
- 03  No
- 96  My family or friends did not want to talk to the health care providers
- 97  I did not want my family or friends to talk to the health care providers

**C42. Did you get the impression that the health care providers involved in your care and treatments were working as a team?**

- 01  Yes, thoroughly
- 02  Yes, somewhat
- 03  No

**C43. During the course of your treatments, were you given helpful information about changes that might occur in :**

**A) ...your physical appearance ?**

- 01  Yes, thoroughly
- 02  Yes, somewhat
- 03  No
- 96  I did not need any information

**B) ... your sexual activity ?**

- 01  Yes, thoroughly
- 02  Yes, somewhat
- 03  No
- 96  I did not need any information

**C) ... your emotions ?**

- 01  Yes, thoroughly
- 02  Yes, somewhat
- 03  No
- 96  I did not need any information

**D) ...your relationship with your spouse or partner and your family life?**

- 01  Yes, thoroughly
- 02  Yes, somewhat
- 03  No
- 96  I did not need any information

**E) ... your nutritional needs?**

- 01  Yes, thoroughly
- 02  Yes, somewhat
- 03  No
- 96  I did not need any information

**F) ... your work or usual activity ?**

- 01  Yes, thoroughly
- 02  Yes, somewhat
- 03  No
- 96  I did not need any information

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**C44. Did a health care provider give you information about community resources or support groups for people with cancer?**

◆ **You may check more than one answer**

- 01  Yes, I received some written information about this (a list, resource directory, etc.)
- 02  Yes, I received some verbal information about this
- 03  No

**C45. Did a health care provider or a staff member give you information about the availability of financial aid to pay some or all of the cost of services, medical equipment, or devices that were necessary during the course of your treatments (for example, expenses for medications, transportation, wigs)?**

- 01  Yes
- 02  No, but I would have liked to have had such information
- 96  No, and I did not need information like that

**C46. During the course of your treatments, did you consult any of the following health care providers or use any of the services listed below?**

**A) Occupational therapist or physical therapist**

- 01  Yes
- 02  No, but I would have like to
- 96  No, and I did not want to

**B) Nutritionist or dietician**

- 01  Yes
- 02  No, but I would have like to
- 96  No, and I did not want to

**C) Pharmacist**

- 01  Yes
- 02  No, but I would have like to
- 96  No, and I did not want to

**D) Psychologist**

- 01  Yes
- 02  No, but I would have like to
- 96  No, and I did not want to

**E) Social worker**

- 01  Yes
- 02  No, but I would have like to
- 96  No, and I did not want to

**F) Alternative, non traditional or complementary therapies (for example, meditation, massage, acupuncture)**

- 01  Yes, I did use this kind of service
- 02  No, but I would have liked to
- 96  No, and I did not want to

**G) Self-help group or support group or patient association**

- 01  Yes, I did use this kind of service
- 02  No, but I would have liked to
- 96  No, and I did not want to

**H) Transportation services (for example, a volunteer driver, financial assistance for transport from home to a treatment center)**

- 01  Yes, I did use this kind of service
- 02  No, but I would have liked to
- 96  No, and I did not want to

**I) Lodging or guest quarters (for example, using a lodging in the Québec**

*Cancer Foundation [Fondation québécoise du cancer])*

- 01  Yes, I did use this kind of service
- 02  No, but I would have liked to
- 96  No, and I did not want to

**J) Visiting homemaker services (for example, for housework)**

- 01  Yes, I did use this kind of service
- 02  No, but I would have liked to
- 96  No, and I did not want to

**K) Home health care services (for example, CLSC nurses visits, changing bandages)**

- 01  Yes, I did use this kind of service
- 02  No, but I would have liked to
- 96  No, and I did not want to

**L) Spiritual counselling (for example, priest, minister, preacher)**

- 01  Yes, I did use this kind of service
- 02  No, but I would have liked to
- 96  No, and I did not want to

**C47. The course of your treatments, did you not consult a health care provider or use a service because the cost was too high?**

- 01  Yes
- 02  No ➔ Go to question C49

**C48. What health care provider or service did you not consult or use because the cost was too high?**

◆ You may check more than one answer

- 01  Occupational therapist or physical therapist
- 02  Nutritionist or dietician
- 03  Psychologist
- 04  Social worker
- 05  Alternative, non traditional or complementary therapies (for example, meditation, massage, acupuncture)
- 06  Medications
- 07  Transportation services (for example, financial assistance for transport from home to a treatment center)
- 08  Visiting homemaker services (for example, for housework)
- 09  Lodging or guest quarters (for example, using a lodging in the Québec Cancer Foundation)
- 10  Home health care services (for example, CLSC nurses visits, changing of bandages)
- 95  Other, (please specify): \_\_\_\_\_

**NOTE : Sometimes appointments and scheduled procedures must be postponed. In this question, we are interested only in the appointments and procedures that were postponed for administrative or technical reasons, such as operating room closures, staff shortages, or equipment breakdowns. Please refer to the cancer you mentioned in question A1.**

**C49. Were any of your appointments and procedures ever postponed for ...**

**A) Your diagnostic tests or procedures?**

- 01  Yes, once
- 02  Yes, 2 or 3 times
- 03  Yes, more than 3 times
- 04  No
- 96  I did not have any diagnostic tests or procedures for the cancer diagnosis indicated in A1

**B) Your first surgical operation (excluding biopsies)**

- 01  Yes, once
- 02  Yes, 2 or 3 times
- 03  Yes, more than 3 times
- 04  No
- 96  I did not have any surgical operation for the cancer diagnosis indicated in A1

### C) Your chemotherapy treatments

- 01  Yes, once
- 02  Yes, 2 or 3 times
- 03  Yes, more than 3 times
- 04  No
- 96  I did not have any chemotherapy treatment for the cancer diagnosis indicated in A1

### D) Your radiation therapy treatments (or internal radiation therapy)?

- 01  Yes, once
- 02  Yes, 2 or 3 times
- 03  Yes, more than 3 times
- 04  No
- 96  I did not have any radiation therapy treatment (or internal radiation therapy) for the cancer diagnosis indicated in A1

**C50. During the course of your treatments, when you needed assistance right away because of cancer-related health problems, which of the services below was the most helpful to you?**

◆ **Please check only one answer**

- 01  Hospital emergency department ward
- 02  Walk-in clinic
- 03  Medical services of a CLSC or a Centre de santé et de services sociaux (CSSS)
- 04  Family doctor (or general practitioner)
- 05  Cancer specialist or another specialist
- 06  Pivot nurse in oncology
- 07  Nurse from a Family medicine group practice (or Groupe de médecine familiale)
- 08  Hospital cancer care clinic
- 95  Other service (**please specify**): \_\_\_\_\_
- 96  I did not need assistance right away

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**C51. Had you wanted to express dissatisfaction regarding services or care received, would you have known how to file a complaint?**

- 01  Yes
- 02  No

**C52. Overall, how would you rate the quality of care received since the date you were diagnosed with the cancer indicated in A1?**

- 01  Poor
- 02  Passable
- 03  Good
- 04  Very good
- 05  Excellent

Now we are going to ask you some questions about follow-up after your cancer treatments ended. By **medical follow-up**, we mean the consultations or visits that you had with a family doctor (or general practitioner, a cancer specialist (for example, oncologist, hematologist/oncologist, radiation oncologist) or other specialist (for example, gynecologist, urologist) in order to monitor the evolution of your health.

**D1. Once all your treatments were finished for the cancer indicated in A1, was there any medical follow-up organized for you (for example, check-ups, tests)?**

- 01  Yes
- 02  No, no medical follow-up was organized ➤ **Go to question D8**
- 96  No, because I did not need a medical follow-up ➤ **Go to question D8**
- 97  No, because I have not yet finished my treatments ➤ **Go to section E**

**D2. In the 12 months following the end of your treatments, who was the doctor primarily in charge of your medical follow-up ?**

- 01  A cancer specialist (for example, hematologist/oncologist, oncologist)
- 02  My family doctor
- 03  Another specialist (for example, dermatologist, gynecologist)
- 95  Other (**please specify**): \_\_\_\_\_
- 96  My treatments ended less than 12 months ago

**D3. Currently, who is the doctor primarily in charge of your medical follow-up?**

- 01  A cancer specialist (for example, hematologist/oncologist, oncologist)
- 02  My family doctor
- 03  Another specialist (for example, dermatologist, gynecologist)
- 95  Other (**please specify**): \_\_\_\_\_
- 96  No doctor is currently in charge of my medical follow-up → **Go to question D8**

**D4. Currently, how often do you see this doctor for medical follow-up??**

- 01  Every month
- 02  Every 2 or 3 months
- 03  Every 4 months
- 04  Every 6 months
- 05  As needed
- 95  Other (**please specify**): \_\_\_\_\_



**D5. When you go for follow-up visits, do you feel that the time the doctor spends with you is :**

- 01  Too long ?
- 02  Too short ?
- 03  About right ?

**D6. Does your doctor seem attentive and thorough enough to detect a recurrence of your illness if one were to occur?**

- 01  Yes, completely
- 02  Yes, somewhat
- 03  No
- 98  I do not know

**D7. Has the doctor explained to you the warning signs and/or symptoms to watch out for that signal a possible recurrence of your illness ?**

- 01  Yes, thoroughly
- 02  Yes, somewhat
- 03  No

**D8. Once your various treatments were over, were you able to get psychological support from a health care provider and/or a self-help support group to restore your quality of life?**

- 01  Yes
- 02  No, but I would have liked to
- 96  No, I did not need that kind of support

**E1. Since your cancer diagnosis, indicated in A1, have you made any changes in the following lifestyle habits or practices?**

**A) Played more sports or did more physical activities**

- 01  Yes  
02  No  
96  I was already in the habit of exercising

**B) Lost weight**

- 01  Yes  
02  No  
96  I had no excess weight to lose

**C) Changed dietary habits**

- 01  Yes  
02  No  
96  I did not need to change my diet

**D) Reduced tobacco use**

- 01  Yes  
02  No  
96  I was not a smoker

**E) Reduced drug use**

- 01  Yes  
02  No  
96  I did not take drugs before

**F) Drank less alcohol**

- 01  Yes  
02  No  
96  I was not a drinker or I drank in moderation

**G) Managed or reduced stress**

- 01  Yes  
02  No  
96  I already knew how to manage my stress

**H) Reduced my exposure to sunlight**

- 01  Yes  
02  No  
96  I already spent little time in the sun or I protected myself appropriately from the sun

**I) Other**

- 01  Yes, **Please specify:** \_\_\_\_\_  
02  No

**E2. Since your cancer diagnosis, have you had help from a health care provider to make changes in your lifestyle habits?**

- 01  Yes  
02  No, but I would have liked to  
93  No, because I did not need help from a health care provider  
96  No, because I did not need to change my lifestyle habits ↗ **Go to question E4**  
97  No, I did not want to change my lifestyle habits ↗ **Go to question E4**

**E3. Are there any other factors, as listed below, that have helped you make changes in your lifestyle habits ?**

**A) Support from my family or friends**

- 01  Yes  
02  No  
96  Does not apply

**B) The new anti-smoking law (that is, smoking is no longer permitted in most public places)**

- 01  Yes  
02  No  
96  Does not apply

**C) A new program or policy at school or at work intended to encourage people to get in shape**

- 01  Yes  
02  No  
96  Does not apply

**D) A self-help group or a patient association**

- 01  Yes  
02  No  
96  Does not apply

**E) The example set by people I know**

- 01  Yes
- 02  No
- 96  Does not apply

**F) Prayer or spiritual guidance**

- 01  Yes
- 02  No
- 96  Does not apply

**G) Other**

- 01  Yes (please specify): \_\_\_\_\_
- 02  No

**E4. Since being diagnosis with cancer, have you advised any of your friends or family**

**A) ... to have screening examinations (that is, tests that detect illness)?**

- 01  Yes, I did it
- 02  No, but I am thinking about it
- 03  No, I do not think it is useful

**B) ... to make changes in their lifestyle habits?**

- 01  Yes, I did it
- 02  No, but I am thinking about it
- 03  No, I do not think it is useful

**SECTION F** Votre situation personnelle actuelle

To conclude the questionnaire, the answers to the questions below will provide a general profile of your life circumstances. Please note that your answers will remain strictly confidential and will be used only for statistical purposes.

**F1. Do you have a family doctor?**

- 01  Yes
- 02  No

**F2. Compared to other people your age, would you say the state of your health is ...**

- 01  Excellent
- 02  Very good
- 03  Good
- 04  Average
- 05  Poor

**F3. What language do you speak most often at home?**

- 01  French
- 02  English
- 96  Other (please specify): \_\_\_\_\_

**F4. Were you born in Canada?**

- 01  Yes ➔ **Go to question F6**
- 02  No

**F5. How many years have you lived in Canada?**

\_\_\_\_\_ years

**F6. What is the highest level of education you have attained?**

- 01  No diploma
- 02  High school diploma
- 03  Vocational (training school) or trade school diploma or certificate
- 04  Business college diploma
- 05  CÉGEP diploma (junior college, classical education)
- 06  University degree
- 95  Other (please specify): \_\_\_\_\_

**F7. What was the approximate combined total income before taxes of your household over the past twelve months?**

◆ **Include only the income of people who permanently resided in your home**

- 01  Less than \$10,000
- 02  From \$10,000 up to \$20,000
- 03  From \$20,000 up to \$30,000
- 04  From \$30,000 up to \$40,000
- 05  From \$40,000 up to \$50,000
- 06  From \$50,000 up to \$60,000
- 07  From \$60,000 up to \$80,000
- 08  \$80,000 or more

**F8. How do you perceive your economic situation compared with other people your age?**

- 01  I consider myself well-off
- 02  I consider my income adequate to meet my basic needs and those of my family
- 03  I consider myself poor
- 04  I consider myself very poor

**F9. Which of the following best describes your family situation?**

◆ **Include only people who usually reside in your home**

- 01  I live alone
- 02  I live in a couple without children at home
- 03  I live in a couple with a child/children at home
- 04  I live with a child/children at home
- 05  Other (please specify): \_\_\_\_\_

**F10. Which item best describes your employment status?**

- 01  Full-time worker
- 02  Part-time worker
- 03  Student
- 04  Retired person
- 05  Homemaker
- 06  On paternity/maternity (parental) leave
- 07  Receiving unemployment insurance
- 08  Receiving social assistance (welfare)
- 09  Other (please specify): \_\_\_\_\_

**F11. Who completed this survey?**

- 01  I completed it myself
- 02  I completed it with the help of another person

**Comments.**

**This concludes the survey. Thank you for your participation.**