

Oncology

Passport

Québec 

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Oncology

Passport

Santé
et Services sociaux

Québec



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Direction des communications

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Masculine pronouns are used generically in this document.

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IMPORTANT PLEASE READ

Information provided in this booklet is for educational purposes only. It is not intended to replace the advice or guidance of a professional healthcare practitioner or as a substitute for medical care. Contact a qualified healthcare practitioner if you have any questions concerning your care.

WORD OF INTRODUCTION

This is the Oncology Passport for cancer patients, designed to help guide you through the various phases of your care experience. It can help you manage your appointments, treatments, exams, and various meetings with doctors, nurses, and other healthcare professionals. It also provides information on the symptoms you may experience during treatment and can help you decide when and whom to consult about your symptoms. You can use the passport to record information about your tests, exams, symptoms, and even your medication.

Everyone living with cancer receives an oncology passport. We have designed it to make your life easier and facilitate your contact with the care providers you deal with frequently in the healthcare system. It should be your constant companion when you go to the hospital, doctor's office, CLSC, or emergency room. Show it to your care providers; they will be interested in the information it contains. You can also download the Oncology Passport at **www.msss.gouv.qc.ca/cancer**.

This Oncology Passport is the result of experiences pooled together from people living with cancer and the work of a group of oncology nurses from different care sectors and various regions of Québec. Medical oncologists and oncology pharmacists have reviewed the recommendations arising out of the latest clinical practice based on research evidence.

People living with cancer have told us that they found the Oncology Passport to be a useful and effective tool. Healthcare professionals also encouraged us to develop this handy tool for you. Since the first version came out in 2008, we gathered feedback from the initial users, which went into producing this revised 2010 edition.

The Direction de la lutte contre le cancer of the Ministère de la Santé et des Services sociaux would like to thank everyone who believed in and took part in this project, and who, along with the Direction, wants every individual living with cancer to receive the best possible care.

Cancer affects everyone differently and your Oncology Passport reflects your personal approach. It is yours to use as you see fit. Don't hesitate to share your concerns, questions, or comments with your healthcare providers.

We wish you well as your journey begins...

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1 PERSONAL INFORMATION AND TELEPHONE NUMBERS

Name: _____ Telephone (home): _____

Telephone (work): _____ Telephone (cell): _____

Name and number of a relative or friend to contact in the event of an emergency: _____

Important telephone numbers

Oncology clinic: _____

Oncology Emergency: _____

Info-Santé: _____

24/7 service (you must register with your health and social services centre's CLSC):

2 HEALTH SNAPSHOT

Provide the information requested below to the best of your knowledge. If some information is missing, you can ask your doctor or nurse navigator for assistance.

ALLERGIES:

1. _____
2. _____
3. _____
4. _____
5. _____

- Type of reaction: 1. _____
- Type of reaction: 2. _____
- Type of reaction: 3. _____
- Type of reaction: 4. _____
- Type of reaction: 5. _____

PREVIOUS SURGERY: Yes ☐ No ☐

Name of surgery: _____

Date of surgery: _____

OTHER HEALTH PROBLEMS:

- ☐ Heart condition _____
- ☐ High blood pressure _____
- ☐ Diabetes _____
- ☐ Respiratory problem _____
- ☐ Kidney disorders _____

- ☐ Arthritis _____
- ☐ Epilepsy _____
- ☐ Anticoagulant treatment _____
- ☐ Other _____

3 PROFESSIONAL SUPPORT AND OTHER VALUABLE RESOURCES

The composition of your healthcare team depends on *your needs* and is designed to help you deal with your illness and make the most out of every day. Your healthcare providers work *together* to provide you with the best care and treatment. If you have any questions, don't hesitate to contact any member of your team.

The list of resources lets you see how your healthcare team is structured and what each team member does. We encourage you to enter the *names and contact information of your healthcare providers*.

HEALTHCARE TEAM

Pivot nurse

Acts as resource person throughout the course of the disease. Assesses your resources and healthcare needs. Informs and supports you.

Name:

Telephone number:

Fax:

Email:

Oncology clinic nurse

Administers treatments. Answers your questions about your treatments and concerns.

Name:

Telephone number:

Fax:

Email:

Research nurse Assists you in the coordination of care related to a research protocol	Name: Telephone number: Fax: Email:
Oncologist This doctor specializes in cancer treatment	Name: Telephone number: Fax: Email:
Surgeon Performs surgical procedures to remove tumors.	Name: Telephone number: Fax: Email:
Radiation Oncologist This doctor specializes in using radiation to treat cancer	Name: Telephone number: Fax: Email:

Radiation Oncology Technician

Works in conjunction with a radiation oncologist to plan and administer radiation therapy treatments. Teaches patients how to deal with the side effects of the treatment.

Name:

Telephone number:

Fax:

Email:

Psychosocial Resources

Professionals such as social workers, psychologists, psychiatrists, spiritual-care professional, and others can provide support.

Name:

Telephone number:

Fax:

Email:

Name:

Telephone number:

Fax:

Email:

Oncology Pharmacist

Prepares your chemotherapy treatment and explains it in detail. Tells you about potential side effects and how to minimize them.

Name:

Telephone number:

Fax:

Email:

Other Healthcare Professionals Other team members such as physical therapists, occupational therapists, and nutritionists can assess your physical needs and advise you on ways to improve your quality of life.	Name: Telephone number: Fax: Email:
	Name: Telephone number: Fax: Email:
Volunteer Resources	Name: Telephone number: Fax: Email:
Other	Name: Telephone number: Fax: Email:

*** At the end of active treatment, your doctors and nurses will tell you who will be in charge of follow-up.**

COMMUNITY HEALTHCARE TEAM

CLSC

CLSC Resource Person

Name:

Telephone number:

Fax:

Email:

Family Physician

Plays a key role in monitoring your overall health

Name:

Telephone number:

Fax:

Email:

Pharmacist

Name:

Telephone number:

Fax:

Email:

Palliative-Care Team	Name: Telephone number: Fax: Email:
Dentist	Name: Telephone number: Fax: Email:
Other	Name: Telephone number: Fax: Email:
Community Volunteer Resources	Name: Telephone number: Fax: Email:

4 FOLLOW-UP SCHEDULE, APPOINTMENTS, AND EXAMS

Legend:

C	Chemotherapy	T	Blood tests
R	Radiotherapy	E	Exams
V	Visits	CLSC	CLSC

MD	Doctor	NUT	Nutritionist
NUR	Nurse	SW	Social worker
PNO	Pivot Nurse	PSYCH	Psychologist

MONTH: _____

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

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Legend:

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V	Visits	CLSC	CLSC

MD	Doctor	NUT	Nutritionist
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C	Chemotherapy	T	Blood tests
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V	Visits	CLSC	CLSC

MD	Doctor	NUT	Nutritionist
NUR	Nurse	SW	Social worker
PNO	Pivot Nurse	PSYCH	Psychologist

MONTH: _____

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

5 TREATMENT PLAN

Surgery

Your treatment plan may include surgery. Do not hesitate to ask a team member to help you to complete this section.

DATE	SURGICAL PROCEDURE	FOLLOW-UP AND RECOMMENDATIONS	COMMENTS

DATE	SURGICAL PROCEDURE	FOLLOW-UP AND RECOMMENDATIONS	COMMENTS

Chemotherapy & other treatments

When you go in for treatment, ask the nurse or pharmacist to enter the names of your chemotherapy medications and other drugs in the table below. This information will be valuable should you have side effects or symptoms after your treatment.

Date of first chemotherapy treatment: _____

DATE	CHEMOTHERAPY OR OTHER TREATMENT (including medications given before and after chemotherapy)	DRUGS TO BE TAKEN AT HOME AFTER TREATMENT	COMMENTS

DATE	CHEMOTHERAPY OR OTHER TREATMENT (including medications given before and after chemotherapy)	DRUGS TO BE TAKEN AT HOME AFTER TREATMENT	COMMENTS

DATE	CHEMOTHERAPY OR OTHER TREATMENT (including medications given before and after chemotherapy)	DRUGS TO BE TAKEN AT HOME AFTER TREATMENT	COMMENTS

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DATE	CHEMOTHERAPY OR OTHER TREATMENT (including medications given before and after chemotherapy)	DRUGS TO BE TAKEN AT HOME AFTER TREATMENT	COMMENTS

DATE	CHEMOTHERAPY OR OTHER TREATMENT (including medications given before and after chemotherapy)	DRUGS TO BE TAKEN AT HOME AFTER TREATMENT	COMMENTS

Radiotherapy

When you visit the radiotherapy department, ask the nurse, technician, or radiation oncologist to enter information about your radiotherapy treatment below.

Area of body treated: _____

Type of radiotherapy: ☐ External beam radiotherapy ☐ Brachytherapy

Expected number of treatments: _____

Expected duration of treatment (weeks): Start date: _____ End date: _____

DATE OR WEEK	RADIOTHERAPY TREATMENT	COMMENTS

DATE OR WEEK	RADIOTHERAPY TREATMENT	COMMENTS

DATE OR WEEK	RADIOTHERAPY TREATMENT	COMMENTS

DATE OR WEEK	RADIOTHERAPY TREATMENT	COMMENTS

6 WEIGHT & BLOOD TESTS

You may receive certain drugs that reduce blood-cell production. We will test your blood regularly to make sure your cell count is not low. Other tests may also be conducted.

Hemoglobin: This provides information about your red blood cells' ability to carry oxygen from the lungs to the rest of the body.

- If the value is too low, you may experience symptoms such as acute fatigue or weakness, dizziness, or persistent shortness of breath.

Neutrophils: White blood cells that fight infections.

- If the count is too low, you may develop an infection, which often results in fever.

Platelets: Help produce blood clots, which prevent prolonged bleeding in the event of injury.

- If the count is too low, you may bleed or bruise more than usual.

Weight: This information is used to adjust the dosage of your chemotherapy.

If you like, you can ask for your blood-test results and record them yourself below.

The values given in the table are for information purposes only; those at your oncology center may differ. If you have any concerns, don't hesitate to discuss them with your doctor.

Date	Weight (kg) Height (m)	Hemoglobin (120-160 g/L)	Neutrophils (2.1-6.7 X10 ⁹ /L)	Platelets (140-450 X10 ⁹ /L)	Other			

Date	Weight (kg) Height (m)	Hemoglobin (120-160 g/L)	Neutrophils (2.1-6.7 $\times 10^9$ /L)	Platelets (140-450 $\times 10^9$ /L)	Other			

Date	Weight (kg) Height (m)	Hemoglobin (120-160 g/L)	Neutrophils (2.1-6.7 X10 ⁹ /L)	Platelets (140-450 X10 ⁹ /L)	Other			

You are receiving red blood cell stimulating agents:

Name of medication: _____

Schedule	Dosage	Start Date	Stop Date (final dose)

You are receiving white blood cell stimulating factors:

Name of medication: _____

Schedule	Dosage	Start Date	Stop Date (final dose)

You are receiving anticoagulant drug (to thin your blood and prevent clot formation).

Name of medication: _____

Schedule	Dosage	Start Date	Stop Date (final dose)

7 CENTRAL VENOUS CATHETER

Ask your nurse to indicate the type of catheter used, if any:

☐ Catheter name: _____

Date of insertion: _____

Your nurse at the oncology clinic or CLSC will regularly rinse your catheter and change the dressing according to your center's practices.

If you experience the following severe symptoms:

- **Acute shoulder pain**, or ear or neck pain
or
- Pain or burning sensation, redness, **heat**, **swelling**, or **discharge** in the area around the point of entry of the catheter, accompanied by fever (over 38°C)

You should:

- Call this emergency number: _____
or
- Immediately go to the emergency room.

(continued on back)

If you experience the following symptoms:

- **Pain** or **burning sensation, redness, heat, swelling,** or **discharge** in the area around the catheter, without fever.
or
- The **catheter** is accidentally withdrawn, either partially or completely.

You should:

- Immediately notify the nurse at your health center: _____
or
- Call the emergency oncology number: _____
or
- Go to the emergency room.

8 LIST OF SYMPTOMS

The treatments you receive are intended to treat the disease, but they may sometimes result in the side effects listed below. However, your healthcare team may be able to suggest ways to relieve side effects, thereby improving your quality of life.

The following is a general list of symptoms that may arise depending on the treatment you receive. If you have one or more of them, it is important that you notify your contact people as soon as possible. During the day, contact your professional support team (p. 8 to 13). During the evening, call Info-Santé 8-1-1 or any other emergency number given to you by the treatment team. However, don't hesitate to call if you are concerned about any other symptoms or situations that may arise.

Please note that this table is only a guide. Remember that you can best assess what you are feeling. Trust your feelings. Do not stay at home and allow a situation to worsen and potentially lead to complications and/or delay your treatment.

If you have any of these symptoms but are unable to reach a healthcare provider to assess your physical condition, you must go to the emergency room.

SYMPTOM	REPORT IF... During the day: contact your professional support team (p.8 to 13). During the evening: call Info-Santé 8-1-1 or any other emergency number given to you by the treatment team.	GO TO THE EMERGENCY ROOM IF...
Fever during chemotherapy or radiotherapy treatments		• Temperature over 38°C for more than an hour OR • Temperature over 38.3°C In both cases, do not take anti-inflammatory drugs or acetaminophen, since they could mask the fever.
Fever 6 weeks or more after treatment has ended	• Temperature over 38.3°C	
Pain	• Known pain that is not relieved by current pain medication • New pain • Pain that keeps you from carrying out everyday activities • <i>Increased level</i> of pain	• New acute pain • Intolerable pain

SYMPTOM	REPORT IF... During the day: contact your professional support team (p. 8 to 13). During the evening: call Info-Santé 8-1-1 or any other emergency number given to you by the treatment team.	GO TO THE EMERGENCY ROOM IF...
Fatigue	• Persistent fatigue over several days • Fatigue that reduces your quality of life and prevents you from carrying out everyday activities • Shortness of breath after exertion	• Extreme sudden fatigue with chest pain, palpitations (sensation of increased heartbeat), or both
Shortness of breath (difficulty breathing)	• Difficulty breathing • Out of breath more easily than usual • Shortness of breath with cough with or without sputum • Shortness of breath that keeps you from carrying out everyday activities	• Sudden shortness of breath with chest pain • Sudden shortness of breath and inability to speak or lie down, or both • Shortness of breath with fever of more than 38°C for one hour or fever of more than 38.3°C
Anxiety	• Anxiety that affects your mood • Inability to think clearly or relax • Anxiety that prevents you from conducting everyday (family and social) activities • Difficulty sleeping, difficulty concentrating, frequent crying, loss of interest, loss of appetite	• Anxiety accompanied by trembling, tightness in throat, difficulty breathing • Panic attack

SYMPTOM	REPORT IF... During the day: contact your professional support team (p.8 to 13). During the evening: call Info-Santé 8-1-1 or any other emergency number given to you by the treatment team.	GO TO THE EMERGENCY ROOM IF...
Drowsiness (tendency to fall asleep easily)	• Drowsiness that keeps you from carrying out everyday activities • Difficulty staying awake	• Unusual difficulty waking the person
Insomnia (difficulty sleeping)	• Insomnia for three days • Insomnia that does not respond to prescribed medication or other interventions • Insomnia that keeps you from carrying out everyday activities	
Numbness	• Tingling or numbness in the hands or feet; insensitivity to hot or cold • Numbness that does not respond to prescribed medication • Difficulty walking • Difficulty holding objects	• Sudden difficulty walking

SYMPTOM	REPORT IF... During the day: contact your professional support team (p. 8 to 13). During the evening: call Info-Santé 8-1-1 or any other emergency number given to you by the treatment team.	GO TO THE EMERGENCY ROOM IF...
Bleeding	• Nose bleeds • Bloody urine • Bloody stool • Blood in sputum • Presence of multiple contusions (bruises) on skin	• Constant nosebleeds despite applying pressure for 10 minutes • Vomiting blood • For women: use of one or more sanitary pads per hour
Nausea (sick to your stomach)	• <i>Persistent</i> nausea despite prescribed medication • Vomiting • Nausea that prevents you from taking prescribed medication	
Vomiting	• Vomiting more than 3 times in 24 hours • Vomiting that does not respond to prescribed medication or other interventions	• Repeated vomiting that prevents you from drinking and eating • Inability to keep down food and liquids • Vomiting that prevents you from taking prescribed medication • Vomiting blood or black liquid • Vomiting with <i>intolerable</i> stomach pain • Vomiting with intolerable headache

SYMPTOM	REPORT IF... During the day: contact your professional support team (p.8 to 13). During the evening: call Info-Santé 8-1-1 or any other emergency number given to you by the treatment team.	GO TO THE EMERGENCY ROOM IF...
Diarrhea	• More than three watery stools a day • Diarrhea that does not respond to prescribed medication • Blood in stools or (tarry) dark stools	• More than ten episodes of diarrhea (watery stools) a day • Diarrhea with <i>intolerable</i> stomach or rectal pain • Diarrhea with fever of more than 38°C for one hour or fever of more than 38.3°C
Constipation	• No bowel movements for three days • Constipation that does not respond to prescribed medication • Stools that are very hard, difficult to evacuate • Stomachache or cramping • Swollen or bloated stomach • No passing of gas	• No bowel movements for three days with intolerable stomachache, nausea (sick to your stomach) and vomiting, bloated stomach, no passing of gas
Loss of appetite	• Loss of appetite lasting more than three days • Rapid weight loss	

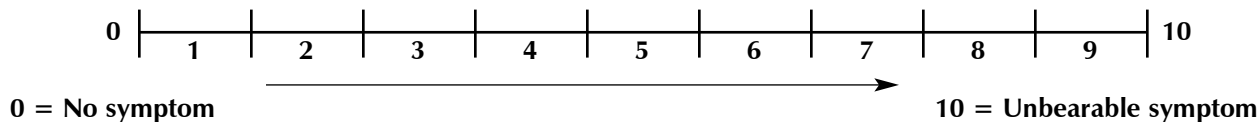
SYMPTOM	REPORT IF... During the day: contact your professional support team (p.8 to 13). During the evening: call Info-Santé 8-1-1 or any other emergency number given to you by the treatment team.	GO TO THE EMERGENCY ROOM IF...
Stomatitis (red spots, mouth ulcers)	• Red spots, ulcers in mouth with pain and difficulty swallowing or eating • Mouth pain that does not respond to prescribed medication or other interventions	• Ulcers, red spots in mouth that prevent the swallowing of liquids, including drugs, for more than 24 hours • Lesions in the mouth with fever of more than 38°C for one hour or fever of more than 38.3°C
Esophagitis, gastritis (pain in digestive tract, stomach)	• Pain, burning sensation in throat, neck, chest, or stomach • Difficulty eating • <i>Reflux</i> of liquid in throat or mouth • Esophagitis, gastritis that does not respond to prescribed medication	• Vomiting blood
Skin reaction	• Presence of redness, rash or pimples, dryness, itchiness, tenderness, skin that is irritated, cracking, peeling or oozing	

9 MONITORING SYMPTOMS AT HOME

If you monitor your symptoms at home, this scale from 0 to 10 can help you to determine and record the levels of severity and keep track of the methods you use to relieve them.

You should have this information on hand when going to your clinic or telephoning for assistance, since attending medical staff could find it of help in identifying the best steps for relieving your symptoms.

The following example uses pain as an example. The scale can be applied to any symptom you experience.



Example for table below: Enter the date on the indicated line. If you have no pain, enter 0 in the “pain” column. If you have any level of pain, enter the relevant number based on the scale above. Follow the same procedure for all other symptoms.

Date	Pain	Fatigue	Shortness of breath	Anxiety	Insomnia	Numbness	Nausea	Vomiting	Diarrhea	Constipation	Loss of appetite	Red spots in mouth	Other	What did you do to relieve the symptom?

Date	Pain	Fatigue	Shortness of breath	Anxiety	Insomnia	Numbness	Nausea	Vomiting	Diarrhea	Constipation	Loss of appetite	Red spots in mouth	Other	What did you do to relieve the symptom?

Date	Pain	Fatigue	Shortness of breath	Anxiety	Insomnia	Numbness	Nausea	Vomiting	Diarrhea	Constipation	Loss of appetite	Red spots in mouth	Other	What did you do to relieve the symptom?

10 LIST OF MEDICATIONS

Your local or hospital pharmacy may be able to print out a list of drugs you have been prescribed. **ASK FOR A PRINTOUT AND KEEP IT IN THE FLAP OF YOUR PASSPORT.**

Before your chemotherapy treatment, you should tell your hematologist/oncologist and oncology pharmacist about any nonfood substance (**NATURAL PRODUCTS, VITAMINS, AND OTHERS**) you consume, even occasionally. Certain substances can interact with your chemotherapy drugs either by reducing the effectiveness of the treatment or increasing treatment side effects.

Indicate below any nonfood substance you consumed in the past six months or still consume.

Date	Substance	Reason

11 RESOURCE INFORMATION

Fondation québécoise du cancer

People living with cancer and their loved ones can have information, resources, and services from the foundation at no charge and confidentially by calling 1 800 363-0063 or visiting the foundation Web site at www.fqc.qc.ca.

- Clearinghouse and information resource center: This center maintains a broad variety of up-to-date information in both electronic and print formats about resources throughout Québec. The center can also send you information at no charge.
- French-language Internet portal for cancer information
- Ligne Info-cancer: Providing answers to your questions.
- Telephone peer support: When you need someone to talk to
- Accommodations network in Montréal, Trois-Rivières, Sherbrooke, and Gatineau.

Just one number: 1 800 363-0063, Monday to Friday, 9 a.m. to 5 p.m. – Web site: www.fqc.qc.ca

Canadian Cancer Society

The Canadian Cancer Society offers many services to support and inform people living with cancer and their families:

- Cancer Information Service staffed by well-trained specialists who can answer your questions and provide quality information over the telephone or by e-mail.
- Cancer J'écoute is a personalized service that pairs an individual with cancer (or a family member) with a qualified volunteer who has lived through a similar experience.
- Support, visualization, and art-expression in the CCS's 14 regional offices.
- Financial assistance (transportation, parking, surgical bra, compression sleeves, intervention to prevent lymphedema, etc.) and material assistance, including loans of wigs and free temporary breast prostheses.
- Lodge in Montréal to accommodate cancer patients from outside the city.
- Straightforward pamphlets about many cancers and their treatment.
- A directory of services available in your community.
- A documented Web site featuring electronic versions of pamphlets and an extensive medical encyclopedia.

A single number: 1 888 939-3333 – Web site: www.cancer.ca

Leucan

Leucan's mission is to promote the well-being, cure, and recovery of children living with cancer and to provide support to their families.

While supporting clinical research and Quebec's four pediatric-oncology centers, Leucan accompanies children and their families through all the steps of the disease and, when necessary, through the bereavement process. Its many services and programs are geared to take care of each family member.

- Intake, support, and follow-up services
- Financial assistance
- Massage-therapy program
- Directed services in most of Québec's pediatric-oncology centers
- Social and recreational activities, including the Vol d'été Leucan-CSN camp
- School awareness program
- Bereavement follow-up program

A single number: 1 800 361-9643 – Website: www.leucan.qc.ca

Resources available in your area (organizations providing support for people living with cancer, etc.)

[illegible]

12 NOTES

Questions: _____

Notes: _____

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Notes:

[illegible]



YOUR OPINION

Please help us improve the passport by giving your opinion on the following statements:

1) Overall, the Oncology Passport is useful.

Yes ☐

No ☐

2) The passport contains enough information for me to take part in my treatment plan.

Yes ☐

No ☐

3) The information is presented logically.

Yes ☐

No ☐

4) The general layout of the Oncology Passport is attractive.

Yes ☐

No ☐

5) It is easy to enter information in the passport and consult it.

Yes ☐

No ☐

Please do not hesitate to share your comments and suggestions with us.

Comments & Suggestions _____

Please mail the passport evaluation to the following address:

Ministère de la Santé et des Services sociaux
Direction de la lutte contre le cancer
1075, chemin Sainte-Foy, 7^e étage
Québec (Québec) G1S 2M1

or send it by e-mail to:

passeportoncologie@msss.gouv.qc.ca

