

# STEP 3 EXPERIENCE REVIEW - ACCOMPANYING PATIENT

## Questionnaire

**THE FIRST SECTION OF THIS QUESTIONNAIRE IS DESIGNED TO ASSESS YOUR EXPERIENCE AS AN ACCOMPANYING PATIENT (AP). THE QUESTIONS ASKED ARE DESIGNED TO ASSESS THE EXTENT TO WHICH THE INTERVENTION HAS HELPED YOU TO FULFIL YOUR ROLE AS AN AP.**

To what extent do you agree with each of the following statements?

	Very much agree	Rather disagree	Rather agree	Very much agree
The training you received was sufficient.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You felt sufficiently equipped to meet patients' needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You were able to attend conferences and continuing education activities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discussions and exchanges with other accompanying patients were sufficient.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You felt supported in the logistical organization of meetings with patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Means were put in place to inform the care team of your interventions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It was easy to communicate with the healthcare professionals involved.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You were able to attend care team meetings.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You felt part of the care team.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The people you accompanied had experiences similar to your own.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The number of accompaniments you carried out was adequate.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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	Very much in agreement	Rather in disagreement	Rather in agreement	Very much in agreement
You had certain advantages at the facility (parking, preferential rates).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### At least one member of the oncology care team (nurses, doctors, social workers, psychologists, etc.)...

	Very much agree	Somewhat disagree	Somewhat agree	Very much agree
...supported you in the logistical organization (room, documentation, etc.) of your meetings with patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...supervised your work with patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...took the time needed to answer your questions and discuss your work with you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...was available to give feedback to the people who benefited from your work.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### At least one member of the Virage team (nurses, doctors, social workers, psychologists, etc.)...

	Very much agree	Rather disagree	Rather agree	Very much agree
...supported you in the logistical organization (room, documentation, etc.) of meetings with patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...supervised your interventions with patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...took the time needed to answer your questions and discuss your interventions with you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...was available to give feedback to the people who benefited from your interventions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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#### Questionnaire

#### At least one team member CROIRE (nurses, doctors, social workers, psychologists, etc.)...

	Very much agree	Rather disagree	Rather agree	Very much agree
...supported you in the logistical organization (room, documentation, etc.) of meetings with patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...supervised your interventions with patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...took the time needed to answer your questions and discuss your interventions with you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...was available to give feedback to the people who benefited from your interventions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

#### At least one member of the Quebec Cancer Foundation team (nurses, doctors, social workers, psychologists, etc.)...

	Very much in agreement	Somewhat in disagreement	Somewhat in agreement	Very much in agreement
...supported you in the logistical organization (room, documentation, etc.) of your meetings with patients	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...supervised your work with patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...took the time needed to answer your questions and discuss your work with you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...was available to give feedback to the people who benefited from your work.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### STEP 3 EXPERIENCE REVIEW - ACCOMPANYING PATIENT

#### Questionnaire

**At least one member of the Quebec Cancer Foundation team (nurses, doctors, social workers, psychologists, etc.)...**

	Very much in agreement	Somewhat in disagreement	Somewhat in agreement	Very much in agreement
...supported you in the logistical organization (room, documentation, etc.) of your meetings with patients	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...supervised your work with patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...took the time needed to answer your questions and discuss your work with you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...was available to give feedback to the people who benefited from your work.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**At least one member of the PROCURE team (nurses, doctors, social workers, psychologists, etc.)...**

	Very much agree	Rather disagree	Rather agree	Very much agree
...supported you in the logistical organization (room, documentation, etc.) of meetings with patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...supervised your interventions with patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...took the time needed to answer your questions and discuss your interventions with you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...was available to give feedback to the people who benefited from your interventions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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### At least one member of the OGPAC team (nurses, doctors, social workers, psychologists, etc.)...

	Very much agree	Rather disagree	Rather agree	Very much agree
...supported you in the logistical organization (room, documentation, etc.) of meetings with patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...supervised your interventions with patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...took the time needed to answer your questions and discuss your interventions with you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...was available to give feedback to the people who benefited from your interventions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### At least one member of the Hope and Cope - L'espoir c'est la vie team (nurses, doctors, social workers, psychologists, etc.)...

	Very much agree	Rather disagree	Rather agree	Very much agree
...supported you in the logistical organization (room, documentation, etc.) for meetings with patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...supervised your work with patients.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...took the time needed to answer your questions and discuss your work with you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...was available to give feedback to the people who benefited from your work.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

# STEP 3 EXPERIENCE REVIEW - ACCOMPANYING PATIENT

Questionnaire

**Was the logbook you were given to keep track of your work useful?**

- Strongly disagree
- Somewhat disagree
- Somewhat agree
- Strongly agree

**Were other tools made available to you?**

- Yes
- No

**Other tool at your disposal #1** \_\_\_\_\_

**This tool was useful to you.**

- Strongly disagree
- Somewhat disagree
- Somewhat agree
- Strongly agree

**Were other tools made available to you?**

- Yes
- No

**Other tool at your disposal #2** \_\_\_\_\_

**This tool was useful to you.**

- Strongly disagree
- Somewhat disagree
- Somewhat agree
- Strongly agree

**Were other tools made available to you?**

- Yes
- No

**Other tool at your disposal #3** \_\_\_\_\_

**This tool was useful to you.**

- Strongly disagree
- Somewhat disagree
- Somewhat agree
- Strongly agree

# STEP 3 EXPERIENCE REVIEW - ACCOMPANYING PATIENT

## Questionnaire

Were other tools made available to you?

- Yes
- No

Other tool at your disposal #4 \_\_\_\_\_

This tool was useful to you.

- Strongly disagree
- Somewhat disagree
- Somewhat agree
- Strongly agree

**THE PURPOSE OF THIS SECTION IS TO IDENTIFY THE INFORMATION YOU WERE PROVIDED WITH TO HELP YOU CARRY OUT YOUR ROLE AS AN ACCOMPANYING PATIENT.**

### ORGANIZATIONAL ASPECTS

Did you receive the information you needed regarding...

	No	Yes, in part	Yes, completely	I didn't need it	Doesn't apply
... your role has an accompanying patient?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...the role of the various healthcare professionals?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...the role of external and internal organizations?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...the care trajectory?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...patient rights (e.g.: refusing treatment, asking questions)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...where and how to get to medical appointments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...financial support for patients and assistance with transport?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...the PAROLE-Onco research project?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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## Questionnaire

Have you received any further information on organizational aspects?

- Yes
- No

If yes, please specify. \_\_\_\_\_

### RELATIONAL ASPECTS

Did you receive the information you needed regarding...

	No	Yes, partly	Yes, completely	I didn't need it	Doesn't apply
...interpersonal skills and know-how?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...familiarity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...dealing with unexpected situations?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...conflict management?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...the therapeutic relationship?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Did you receive other information regarding relational aspects?

- Yes
- No

If yes, please specify. \_\_\_\_\_

### CLINICAL ASPECTS

Did you receive the information you needed regarding...

	No	Yes, partly	Yes, completely	I didn't need it	Does not apply
....the doctor's diagnosis of cancer/genetic predisposition?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...oncogenetics?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...genetic testing?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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	No	Yes, partly	Yes, completely	Didn't need it	Doesn't apply
...treatment options for cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...means of risk reduction in carriers of a genetic mutation that increases the risk of cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...surgical and reconstructive options in the case of cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...breast prostheses?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...hormonal issues?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...reproductive issues?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...fatigue following treatment?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...pain and discomfort after surgery?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...pain and discomfort after treatment?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...possible emotions?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...stress and anxiety management?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...impact on physical appearance and self-esteem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...decision-making processes?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...urinary and erectile dysfunction issues?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Have you received any further information on clinical aspects?

- Yes  
 No

If yes, please specify. \_\_\_\_\_

# STEP 3 EXPERIENCE REVIEW - ACCOMPANYING PATIENT

## Questionnaire

### IMPACT ON DAILY LIFE

Did you receive the information you needed regarding...

	No	Yes, in part	Yes, completely	I didn't need it	Doesn't apply
...consequences on children?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...consequences on married life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...consequences on sex life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...consequences on professional life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...consequences on finances?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...the consequences on insurance?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...the consequences on spiritual life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...the return to work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...the return to daily life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...the way of announcing a diagnosis to loved ones?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...social perception (other people's reactions)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...strategies for coping with treatment in the best possible conditions?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...how to regain control over the disease?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Did you receive any other information regarding the impact on daily life?

- Yes  
 No

If yes, please specify. \_\_\_\_\_

### STEP 3 EXPERIENCE REVIEW - ACCOMPANYING PATIENT

Questionnaire

**THE FOLLOWING SECTION IS DESIGNED TO HELP YOU BETTER UNDERSTAND HOW YOU COMMUNICATED WITH THE TEAM AS AN ACCOMPANYING PATIENT.**

How were you informed that you had a new accompaniment request?

	Never	A few times	Usually	Always
In person, at a formal meeting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In person, informally	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
By telephone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In writing, on a form	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
By e-mail	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If another means was used, please specify which \_\_\_\_\_

Did you follow up with a member of the care team following your accompaniments?

- Yes, systematically
- Yes, only if important elements to bring back to the team
- No

If another means was used, please specify which \_\_\_\_\_

If yes, how did you follow up on your accompaniments with the care team?

	Never	A few times	Usually	Always
In person, at a formal meeting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In person, informally	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
By telephone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Par écrit, sur un formulaire à cet égard	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
By e-mail	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If another means was used, please specify which \_\_\_\_\_

## STEP 3 EXPERIENCE REVIEW - ACCOMPANYING PATIENT

### Questionnaire

#### How did you carry out your interventions?

	Never	A few times	Usually	Always
Always In person, in a dedicated office at the healthcare facility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In person, in another part of the healthcare facility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In person, during a medical appointment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In person, outside the healthcare facility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
By telephone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
By secure teleconference (Reacts)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If another means was used, please specify which \_\_\_\_\_

#### DOCUMENTING THE ACCOMPANYING PERSON'S CONTRIBUTION

This section aims to document the accompanying person's contribution to the care trajectory of the accompanied patient. In your opinion, what is the accompanying person's contribution ? Check all that apply.

- Giving information
- Giving support
- Sharing experiences
- Facilitating communication between the care team and the accompanied patient
- Helping to make the patient's point of view known to the care team
- Improving understanding of information shared between the patient and the care team
- Helping to remember information
- Preparing the patient for medical appointments
- Accompany patients to medical appointments
- Help patients participate in decision-making
- Bring a new perspective to decision-making
- Direct patients to various resources
- Help develop a relationship of trust between the patient and the care team
- Help patients become partners in their own care
- Listen to patients
- No, the accompanying patient makes no particular contribution to the care trajectory
- Other

If the accompanying patient makes other contributions, please specify. \_\_\_\_\_

## STEP 3 EXPERIENCE REVIEW - ACCOMPANYING PATIENT

### Questionnaire

#### IMPACTS

The purpose of this section is to document the impacts (positive or negative) that your involvement as an accompanying patient has had on yourself

**Has your involvement as an accompanying patient had any positive impacts for you?**

- Yes  
 No

**If yes, what are they?**

- Giving meaning to my past experience  
 Giving back to others what I have received  
 Making myself useful  
 Valuing myself  
 Breaking my isolation  
 Developing new skills  
 Other

**If other, please specify.** \_\_\_\_\_

**Has your involvement as an accompanying patient had a negative impact on you?**

- Yes  
 No

**If yes, what are they?**

- Not feeling sufficiently supported in my intervention  
 Not having had the necessary training  
 Not having had the necessary information  
 Not fully understanding my contribution  
 Not feeling integrated into the care team  
 Reliving my illness  
 Having too many responsibilities  
 Having too many constraints  
 Not feeling up to the task  
 Other

**If other, please specify which ones.** \_\_\_\_\_

**Finally, do you think this type of meeting would be worth deploying to help more patients and caregivers?**

- Yes, absolutely  
 Yes, but with a review of certain modalities  
 Rather no, it's not really of interest  
 No, not at all

**Please specify the modalities to be reviewed** \_\_\_\_\_

**THANK YOU FOR YOUR PARTICIPATION AND COLLABORATION !**