Chair of Evaluation of
State-of-the-Art
Technology and Methods

Citizen and Patient Engagement
in the Transformation of
Organizations and Health Systems

PAROLE-Onco Program Implementation Guide

The Accompanying Patient, An Organisational Resource as a Lever for an Improved Experience in Oncology.

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CREDITS

FORWARD

This implementation guide is intended for all professionals, managers, and directors of health and social service facilities interested in implementing a program with accompanying patients (APs) in oncology, or who would like to revise and improve an existing program.

This guide was written especially for Quebec but can be adapted to other healthcare contexts. The guide is based on the lessons learned and tools developed during the implementation of the PAROLE-Onco program. The examples provided are based on the breast cancer trajectory, but the guide can be applied to all cancer trajectories.

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A special thought for Sylvie Desmarais, who believed in this project from the outset and worked as an accompanying patient until her last breath. **This guide is dedicated to her to thank her for having been an exceptional ambassador at every level of Quebec's health and social services system.**

CITATION OF THE DOCUMENT

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NOTE

To establish a common thread in the co-construction of the implementation guide, we have taken into account the experience acquired during the first phase of the PAROLE-Onco project, particularly in the context of breast cancer. However, this guide is designed to be applicable to implementation in all types of cancer, whether male or female, in order to meet the diverse needs of patients with different oncological pathologies. **Certain tools and video capsules are currently available in French only. English versions will be released in a subsequent phase.**

AP	Accompanying patient
CEPPP	Centre of Excellence on Partnership with Patients and the Public
CEVARMU	Centre of expertise for victims of traumatic amputation requiring reimplantation or emergency microsurgical revascularization (French: Centre d'expertise pour les victimes d'Amputation traumatique nécessitant une Réimplantation ou une revascularisation Microchirurgicale d'Urgence)
CIUSSS	Integrated university centre of health and social services (French: Centre intégré universitaire de santé et de services sociaux)
CHUM	Montreal University Hospital Center (French: Centre hospitalier de l'Université de Montréal)
CHUQ-UL	Laval University Hospital Center of Quebec (French: Centre hospitalier universitaire (CHU) de Québec-Université Laval)
CNESST	Commission for Labour Standards, Equity, Occupational Health and Safety (French: Commission des normes, de l'équité, de la santé et de la sécurité du travail)
CoP	Community of practice
CSP	Care and service partnership
INESSS	National Institute of Excellence in Health and Social Services (French: Institut national d'excellence en santé et en services sociaux)
OPP	Office of patient partnership
PAROLE-Onco	Accompanying Patients, an Organizational Resource for Leveraging an Improved Experience in Oncology
PAC	People affected by cancer
PPRO	Planning, programming, and research officer
QEPED	Quality, Evaluation, Performance and Ethics Department

PREFACE

MARIE-PASCALE POMEY, MADO DESFORGES AND MICHÈLE DE GUISE

The PAROLE-Onco program was born of a double opportunity. First, in 2015, a meeting between Marie-Pascale Pomey, a public health researcher, and Mado Desforges, a patient partner at the Faculty of Medicine and a resource patient partner at the *CIUSSS de l'Est-de-l'Île de Montréal*, led to the discovery that there was a convergence of the needs between people affected by cancer (PACs) and the researcher's research interests. The resource patient partner, who is in regular contact with women diagnosed with breast cancer, related how they have many questions, including about the cancer itself, its impacts on daily life (relationships with loved ones, impacts on work, financial impacts, etc.), the professionals and the physicians in various medical specialties, the organization of care and, of course, treatment. All of these issues, which are often difficult to communicate to healthcare professionals, mean that PACs lose control of their lives and the decisions concerning them. This leads to anxiety, which in turn undermines the ability of PACs to fully engage in their fight against cancer.

This exchange with Ms. Desforges led to the expansion of a project already underway in the surgery and rehabilitation department at the *Centre hospitalier universitaire de Montréal* (CHUM, a university hospital). At the time, an action-research project was nearing completion at the CHUM hand clinic, where accompanying persons had been incorporated into clinical teams to provide emotional, educational, informational, and navigational support [1]. In addition, to formalize the support that Ms. Desforges and others were providing spontaneously and unofficially, it was proposed that accompanying patients (APs) be introduced throughout the oncology care trajectory, with the support of a decision maker, Dr. Michèle de Guise. Dr. de Guise, who created the Health Promotion Department at CHUM, was at the time Director of Health Services and Technology Assessment at the *Institut national d'excellence en santé et en services sociaux* (INESSS).

At the same time, the Canadian Institutes of Health Research (CIHR) launched a call for projects as part of its health services improvement program for cancer, focused on the development of interventions co-constructed with patients.[1]

This was how the PAROLE-Onco research project came to receive four years of funding from CIHR. The project involves patient partners and researchers from various disciplines (medicine, nursing, management, anthropology, andragogy, ethics, law, psychology, public health and political science, and mental health).

This adventure has been an arduous journey. Talking about partnerships with PACs (why not?) is one thing, but allowing these people to become full-fledged members of the clinical team is something else entirely. It challenges existing lines of authority. Yet three institutions decided to take up the challenge: the *Centre hospitalier de l'Université de Montréal, the Centre intégré universitaire de santé et de services sociaux de l'Est-de-l'Île de Montréal* and the *Centre hospitalier universitaire de Québec-Université Laval*.

The results have demonstrated that complementing the expertise of a clinical team with the experiential knowledge of accompanying patients (APs) reduces the anxiety of people affected by cancer (PACs), increases their engagement in their care, and helps reduce health inequalities [2-5]. The APs also enable healthcare professionals to better respond to the needs of PACs, since they have access to privileged information about people's lives that PACs do not usually share with professionals. In addition, these professionals can obtain feedback on their practice and on the experience of cancer patients, in order to adjust their interactions and the organization of care. Such a project would not have been possible without the support of ethicists and legal experts, who helped us better understand the various issues associated with the arrival of this new player on the clinical team [6,7].

Given the positive outcomes of the PAROLE-Onco program, the *Programme Québécois de cancerologie* decided to include the role of «accompanying patient» at every stage of the cancer care pathway in its founding principles and priority orientations for 2023-2030.[2] This guide to implementing and sustaining the PAROLE-Onco program has been designed to support facilities interested in introducing PACs into the trajectories of their cancer services, as proposed by the Ministère de la Santé et des Services sociaux.

This project would not have been possible without the support of all the accompanying patients, clinical teams and co-administrators, as well as the directors of the three institutions that were involved in implementing this program. Their experiences, generously shared with us, are at the heart of the development of this guide.

We would like to thank all those who contributed to the development of this program. Through their commitment and collaboration, it has been possible to make a real difference in the lives of cancer patients and their family and friends. Their support is essential to the success of the PAROLE-Onco program.

PREFACE

VINCENT DUMEZ AND DR JEAN LATREILLE

VINCENT DUMEZ | The Patient Partnership Program first began at the University of Montreal's Faculty of Medicine in September 2010. At the time, we did not know that we were embarking on an adventure that would lead us to experiment with harnessing patient/caregiver knowledge in education and research, as well as in the care and service processes themselves. From the outset of the program, a number of healthcare facilities offered to be the first to implement these new practices directly in clinical settings, particularly in the specific context of continuous improvements to the quality of care and services. The results quickly proved to be positive, and today it is difficult to imagine embarking on such interventions without benefiting from the systemic and pragmatic knowledge of patients/caregivers, directly involved in the process as full partners.

Long before the creation of the Patient Partnership Program, the field of mental health had already shown us another, very rich and complementary way of engaging patient/caregiver knowledge in care and services by developing approaches based on informal caregiving. The initial assumption was simple: could patients/informal caregivers who had been through mental health-related ordeals and had regained a certain equilibrium accompany their peers through this experience, by becoming directly involved as companions in care and service processes? Other examples of peer support are also known and documented, notably between persons living with HIV/AIDS or hemophilia.

In any cases, the program's potential clinical effectiveness was equally well demonstrated in the more organizational context of quality improvement, whether in terms of shared clinical decision-making, health education, or development of self-care/self-determination skills, as it was in support of rehabilitation and social reintegration, to name but two contexts. This solid PAROLE-Onco program, which, of course, is part of this great tradition, would test this approach in a very complex and humanly difficult physical health context. If it worked, it was specifically because this approach was able to incorporate all the lessons learned in recent years about patient partnership implemented from the outset, whether in terms of recruitment, training, follow-up or change management.

This guide is intended as a vehicle for sharing best practices that have been co-constructed through research so that other teams can carry out their own implementations of the PAROLE-Onco program. The guide will therefore contribute to ever-wider deployment of the program if it can enhance clinical efficiency in our healthcare systems. The guide serves an even more important purpose, given that many health and social service facilities consider the implementation of such a program to be quite an avant-garde initiative. It is therefore necessary, more than ever before, to be methodologically rigorous. It also serves a clear sign of the inevitable emergence of the new role of accompanying patient, one that will profoundly change how we approach health care and services in the decades to come.

DR JEAN LATREILLE | Having cancer often becomes a journey filled with unexpected events, pitfalls, and challenges that call upon many of the person's inner resources, causing stress that is difficult to identify and master.

Peer support often becomes a safety net that allows the person to persevere, regain control, acquire some independence, and continue to be involved in their own care. This support can come from a variety of sources, including health professionals, volunteers, friends, family members, and support groups, but more and more, the support can come from people who have personally experienced cancer themselves, referred to as "accompanying persons." Some interventions are more significant than others and are usually required at pivotal moments throughout the care trajectory. No one can aspire to meet all of another person's needs.

Life paths are unique, varying from one person to the next. The role of the accompanying patient includes being present, listening, sharing, clarifying, putting things into perspective, and, lastly, supporting the other. Each AP makes a unique contribution to the affected person's well-being, based on their knowledge and experience. The APs, who have experienced cancer themselves or who have supported a loved one with cancer, have unique experiential expertise that is added to the collective knowledge of the team. These individuals are invited to share their discussions with patients with the interprofessional oncology teams. Their contribution proves to be very significant for the person with cancer during their journey.

Cancer patients who accompany others require support, supervision, and training, much as oncology healthcare professionals do. The knowledge gained from the «PAROLE-Onco» research project over the last few years has allowed us to document a successful implementation of the accompanying patient function in the oncology network.

The Quebec Cancer Program hopes to benefit from the experience of several health facilities to expand access to accompanying patients through the network and through partnerships between facilities.

I would like to thank all the people who, for many years, have helped make this project an example to follow, for the well-being of people affected by cancer. Thank you to the team who also helped develop this guide as a way to facilitate the implementation of the accompanying patient or accompanying person function. We hope it can serve as an inspiration to many.

DEVELOPMENT OF CARE AND SERVICE PARTNERSHIPS

Dominant until the 1990s, the paternalistic approach has gradually been replaced by the patient-centred approach. This began by taking greater account of patients' needs and encouraging professionals to inform and consult patients when developing their care plan, for example.

The 2010s saw the emergence of the care and service partnership (CSP), recognizing the experiential knowledge held by patients who are dealing with health problems and using services. This movement developed particularly in Quebec under the drive of the Department of Collaboration and Patient Partnership — now called the Office of Patient Partnership — at the University of Montreal's Faculty of Medicine. From this initiative was born, in 2016, the *Centre of Excellence on Partnership with Patients and the Public (CEPPP)* [8].

In Quebec, engagement of patients as partners in their care now constitutes an essential part of an adaptive and democratic system that allows patients and their loved ones to be involved in the decisions that concern them [9, 10].

WHAT VALUE DOES THE CSP ADD?

People who have lived through an illness develop knowledge linked to their experience of symptoms and the day-to-day management of their illness. They also develop a global vision of their care trajectory and the various players involved.

- The CSP recognizes this experiential knowledge as complementary to that acquired and developed by health professionals. This leads to the recognition that patients/users have the ability to make decisions for themselves, and to considering them as full members of the clinical team. The clinical team therefore consists of healthcare professionals (including physicians), accompanying persons and local managers.
- This experiential knowledge and the skills they have developed can be mobilized to improve the health and social services system in order to better meet patients' needs, improve professionals' working conditions, reduce costs, and improve the population's state of health [11].

HOW CAN PATIENTS MAKE A PRACTICAL CONTRIBUTION TO IMPROVING THE HEALTHCARE SYSTEM?

Participation in the healthcare system can occur at the strategic, organizational, and clinical levels [12].

- **At the strategic level,** patient partners participate in the development of public policies.
- **At the organizational level,** patient partners sit on committees working on optimizing the organization of services, among other things.
- **At the clinical level,** patient partners participate in the development of their care plan and in all decisions affecting them. Some of them may be called upon to support other patients as mental health peer support workers or as accompanying patients in various fields, including oncology.

BACKGROUND

Work carried out at CHUM's CEVARMU (the centre of expertise for victims of traumatic amputation requiring reimplantation or emergency microsurgical revascularization), as part of the PAROLE-CEVARMU program, had already shown that introducing accompanying patients (APs) for people affected by cancer (PAC) could have a positive impact on a patient's experience of care, anxiety, and response to treatment. Mental health studies have also shown the contribution made by peer support [12, 13].

The number of cancer diagnoses has been on the rise for several years and is expected to continue increasing because of screening delays that have been exacerbated by the pandemic [14]. Quebec has one of the highest cancer incidence and prevalence rates in Canada, and cancer is the leading cause of death [15,16].

In this context, cancer prevention and treatment are a public health priority, and Quebec has set up a national cancer program to improve the quality of care and services offered to people affected by this disease [17].

Data has been collected on six dimensions to assess the experience of people affected by cancer in Quebec and across Canada: emotional support, information, care coordination, participation in decision-making, access to support services, and continuity of care. According to Rossy's 2017 study, emotional support is the most neglected of these dimensions.

In 2017, the Canadian Institutes of Healthcare Research (CIHR) launched a call for projects under the Partnerships for Health System Improvement in Cancer Control (PHSI) program. The PAROLE-Onco program (Accompanying Patients, an Organizational Resource for Leveraging an Improved Experience in Oncology / Personne Accompagnatrice, une Ressource Organisationnelle comme Levier pour améliorer l'Expérience en Oncologie) was selected and funded for a first phase of implementation.

During this initial phase, five institutions undertook the development of the project: the Centre hospitalier universitaire de Québec-Université Laval, the CIUSSS de l'Est-de-l'Île-de-Montréal, the Centre hospitalier de l'Université de Montréal, the CIUSSS Mauricie-Centre-du-Québec and the CISSS de la Gaspésie. However, only three have successfully implemented PAROLE-Onco on a long-term basis: Centre hospitalier universitaire de Québec-Université Laval, CIUSSS de l'Est-de-l'Île-de-Montréal and Centre hospitalier de l'Université de Montréal..

In 2022, a second phase of the project was financed by the Fonds de recherche du Québec - Santé (FRQS), Oncopole, enabling its expansion to include four new establishments: CISSS de la Côte-Nord, CISSS de la Montérégie-Centre, CISSS de la Montérégie-Est and CIUSSS de l'Estrie-CHUS. Thus, seven establishments in Quebec are currently participating in the implementation of PAROLE-Onco.

Initially focused on the breast cancer trajectory, the program is now being extended to other types of cancer, including gynecological, hematological, colorectal, prostate and lung cancers.

VISION AND OBJECTIVES

PAROLE-Onco is a personalized support program tailored to the needs of people with various types of cancer within different healthcare facilities (university hospitals, CISSS, CIUSSS). This program is part of the peer support movement, which provides support among peers around common life issues.

The aim of PAROLE-Onco is to help patients/users become partners in their own care, and to establish partnerships with health and social service professionals.

The program advocates co-construction with clinical teams, APs, managers, decision makers, community organizations, and researchers, from the design and implementation of AP interventions through to their evaluation. Co-construction is based on the complementary expertise and experiential knowledge of patients and professionals so that they can carry out joint activities based on a common understanding [18].

ACCOMPANYING PATIENTS (AP)

Accompanying patients are persons who:

- Have experienced at least one episode of care related to a genetic predisposition or a cancer diagnosis;
- Are recognized for their experiential knowledge of living with cancer and using services;
- Have expertise that complements that of the clinical team and are considered full members of the team;
- Have received training specifically for this role;
- Have volunteer status in the facility;
- Provide one-on-one support to new patients throughout their journey by talking about their own experience; and
- Present, if possible, a clinical history similar to that of the patients they are supporting.

The activities of the APs vary widely depending on the context and, in particular, on what is desired by the PAC, other APs and the clinical team. Their main activities are described in Table 1.

Table 1 Activites of APs

- Listen to the PAC and talk with them, either in person (at the point of care) or virtually (by phone or videoconference) about the health problem, treatments, or difficult subjects, such as announcing the diagnosis to their loved ones, the impact on daily life, etc.
- Support the PAC in preparing for appointments.
- Accompany the PAC to medical appointments and examinations.
- Refer the PAC to appropriate support resources (internal or external).
- Greet the PAC at the start of treatment or during surgery at the point of care.
- Sensitize the clinical team to the realities experienced by the PAC, when required.
- Participate in the development of educational materials and teaching activities to help the PAC better understand their disease and care pathways and, on the other hand, to help the professionals better understand the reality experienced by the PAC (e.g., develop health fact sheets or participate in instructional classes).
- Discuss a PAC's situation with a healthcare professional, when needed.
- Participate in a community of practice with other APs to discuss their interventions.
- Share one's expertise as a PAC while listening to the concerns raised.
- Explain the information that may have been exchanged with healthcare professionals in simpler terms, as needed.
- Encourage PACs to speak up and get involved in their care in order to become partners in their care.
- Break the PAC's isolation, and reassure and support them at various key moments in their care trajectory.
- Create a safe space and encourage free discussion by committing to respect the confidentiality of the information exchanged.

Table 2 Activities not carried out by APs

- Giving medical advice or counsel.
- Giving their opinion of treatment options.
- Comparing their treatments with those of the patient if they have the same cancer.
- Giving false hope.

BECOMING AN ACCOMPANYING PATIENT

Criteria (or conditions)

A PAC who wishes to become an AP must meet the following criteria to be able to fully assume her role, both toward the people affected by cancer whom she will be accompanying, and toward herself.

Table 3 Criteria for selecting APs

Area	Criteria
Care experiences	• Have experienced at least one episode of care as part of the patient's trajectory. • Be able to step back and be objective about one's illness and care trajectory. • Have received care in the facility where one wishes to be an AP. • Be psychologically and emotionally «stable.» • Have complied with the treatment and follow-up plan established by their clinical team.
Motivation	• Be available and motivated to actively engage with the clinical team and accompanied patients for the required program time. • Demonstrate a desire to help people and help reach a goal that transcends one's individuality.
Communication and collaborative skills	• Welcome the patients' questions, concerns, and emotions, and adjust care accordingly. • Possess listening skills, empathy, etc. • Express oneself clearly and simply. • Express a constructive attitude in one's interventions concerning the healthcare network in general. • Have a constructive, critical mind. • Be able to generalize one's experience to other care contexts.
Philosophy	• Understand the vision and implications of the healthcare and services partnership model. • Not be in conflict with the healthcare facility or anyone in the facility.

Furthermore, the AP must complete a training program and receives support throughout her practice (Identify, recruit, and train APs).

FOR PEOPLE AFFECTED BY CANCER

The announcement of a genetic predisposition or cancer comes as a shock and affects every aspect of one's life. The person is quickly confronted with a new reality, and must make important decisions that will have a major impact on their life. While medical concerns can be discussed with healthcare professionals, they are often less well equipped to deal with the impacts of the illness and treatment on the person's daily life. In addition, they have less time to spend on these topics, especially at the time of diagnosis or when treatment options are being explored.

APs can address the unmet needs of people affected by cancer (PAC). These needs vary for each PAC, but here are a few examples:

1. **Information and education:** Accompanying patients can help explain complex medical information, technical terms and medical procedures to PACs, and direct them to reliable sources of information about their condition.
2. **Emotional support:** Accompanying patients can offer emotional support to PACs by listening to their concerns, helping empower them and helping them find ways to cope with the emotional challenges associated with their medical condition.
3. **Navigating the healthcare system**: Accompanying patients can help PACs navigate the healthcare system by helping them book appointments, accompanying them to medical appointments, and helping them understand the administrative steps involved in their treatment.
4. **Shared decision making:** Accompanying patients can help PACs make informed decisions about their treatment by sharing their personal experiences and by encouraging them to ask their clinical team questions; they can also help PACs weigh the pros and cons of various treatment options.
5. **Autonomy and empowerment :** Accompanying patients can help PACs regain their autonomy and their power over their own health by encouraging them to take an active role in their treatment, helping them find community resources and support, and helping them develop skills for managing their condition on their own.

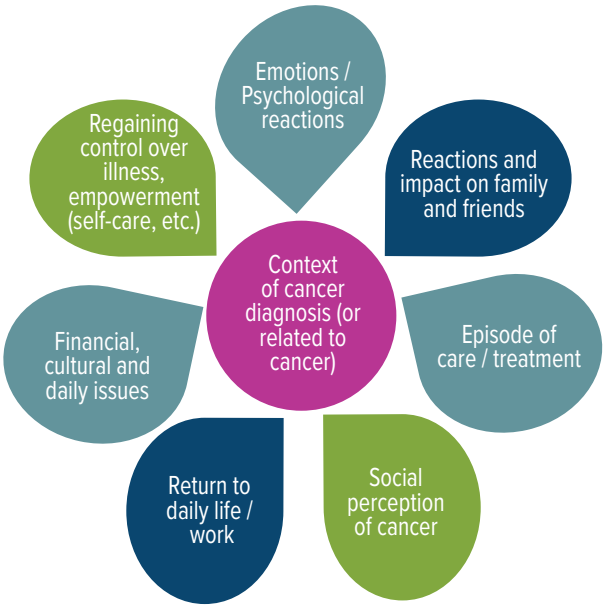
In essence, accompanying patients can help meet many of the needs of PACs by providing practical, emotional, and educational support throughout their healthcare journeys.

This is why a resource such as an AP provides unique support to PACs, and contributes to their quality of life by reducing their emotional burden and improving their experience with healthcare or social services. [10, 12, 19-21]. In fact, APs can make PACs feel more secure, thereby reducing their anxiety and enabling them to live and manage their emotions more effectively. As they feel more confident, PACs become more willing to talk to healthcare professionals and get involved in their own care. PACs can therefore feel supported, talk about their needs, and freely discuss their fears, hopes and concerns about their cancer.

APs therefore play a very broad role, facilitating communication, collaboration, and informed decision making. They participate in a PAC's therapeutic education (including by providing various references or resources) and supporting PACs in the decision-making process. They foster the transfer of information between PACs and caregivers, and vice versa. The support also equips PACs to take their place on the clinical team and to be actively involved in their care. In this way, accompaniment enables PACs to contribute to their own care, in partnership with the various healthcare professionals.

An overview of the issues addressed by APs is presented in the following figure.

Figure 1. Issues addressed by APs during their involvement



Testimonials from people affected by cancer

" Talking to someone who has been through the same thing and who takes the time to explain what is going to happen and answer our questions has been very beneficial to me. "
(Pascale, accompanied patient)

"The support received from my accompanying patient was an invaluable gift and an essential complement to the treatment received by PACs."
(Lucie, accompanied PAC)

"The resource person is, for me, an attentive ear who understands exactly what I'm going through. It is about shared experiences, discussions, encouragement... Feeling free to talk in confidence and without judgement!"
(Geneviève, accompanied PAC)

To ensure the confidentiality of the interview participants, a fictitious first name has been assigned to the people whose verbatim is presented in this guide. Other testimonials are available at the end of this guide.

FOR THE PROFESSIONALS ON THE CLINICAL TEAM

The presence of APs on a clinical team has the potential to improve the experience and the quality of care offered to the PACs being tested or treated for cancer.

APs respond to a need for emotional support that healthcare professionals often cannot meet because of time constraints and because they have not had the illness themselves. This lightens the workload for healthcare professionals, who can now carry out their consultations with PACs who are less anxious and more involved in their care.

By sharing the perspective of PACs, APs provide the clinical team's professionals with an additional resource, and this helps improve clinical and organizational practices.

By facilitating the transfer and circulation of information between professionals and PACs, APs enable the clinical team to become more efficient, save time and even restore meaning to their practice. APs provide a more comprehensive view of the person affected by cancer, fostering a follow-up that is more suitable to the implicit and explicit needs of PACs.

In addition, since APs benefit from the experience of many PACs, they can be mobilized as part of continuous improvement initiatives. [22]

For their part, PACs confide more easily in another PAC, either because they know that she understands them better, since she also has experience with cancer, or out of a desire not to disturb the clinical team. This often provides relevant information that the professionals on the clinical team would not otherwise have had, and they can act accordingly.

FOR THE ACCOMPANYING PATIENTS

PACs who become APs draw on all the knowledge they have acquired during their care journeys. This gives meaning to their story, while at the same time enabling others to benefit from it, for a more harmonious care experience. This commitment can also help them be better equipped for their own care journey, by strengthening their ability to work in partnership with their professionals and developing their autonomy and sense of self-determination.

Testimonials from healthcare professionals

"Usually, PACs find that it is a plus for them to have an AP."
(Michelle, pivot nurse in oncology)

"I think that it makes the job of a pivot nurse a bit easier, and it meets a need that we cannot currently address."
(Elsa, nurse)

"The added value for people affected by cancer is very, very clear, as is the added value for the teams, because a satisfied PAC, a PAC who is happier with the services received, is a PAC who is easier to treat. So, there's a very clear advantage."
(Pierre, management representative responsible for quality)

"It can make us reflect on the care journey we provide to patients. Either by offering workshops or training, or even by correcting certain situations."
(Sylvie, physician)

"In fact, with PAROLE-Onco there have been accompanying patients on several occasions during consultations and visits. We've had PACs who've come in accompanied, and I think that it helped. We saw the difference. PACs who sometimes didn't know how to approach us, what questions to ask, all of that. So it really helped these people affected by cancer, having that support."
(Guy, oncology surgeon)

Testimonials for accompanying patients

"It gives so much meaning to what I went through."
(Jeanne, AP)

"Thanks to this project, I met other APs and we support each other."
(Jeanne, AP)

"It's very rewarding to feel useful. There is a feeling of appreciation, and a feeling of having gone through a period in your life when you were afraid, afraid of dying, afraid of death, and the feeling of giving back. It gives you a feeling of well-being to help others. It allows you to give something to someone else. I have received in my life, and now I give."
(Suzanne, AP).

TOOLBOX - SECTION 1

Introducing the PAROLE-Onco program (FRENCH ONLY)

- Testimonials from patients who have been supported
- Testimonials from PA
- PAROLE-Onco training
- Presentation of the PAROLE-Onco program to patients by a healthcare professional (video by Dr. Fortin)
- PAROLE-Onco capsule (women)
- PAROLE-Onco capsule (men)
- CHUM Report: Being supported through illness | Radio-Canada
- « I saw it as a way to give back to the next person | TVA Nouvelles
- PAROLE-Onco co-construction workshop – Example of PAROLE-Onco deployment in France
- PAROLE-Onco self-supporting training

IMPLEMENTATION PHASES	ACTIONS TO TAKE	TIPS AND LEVERS
PHASE 1 Assess and create a suitable environment	Present the program Verify the interest Evaluate resources	• Receive support from senior management and managers • Identify stakeholders interested in getting involved at the clinical level • Identify one or more APs interested in getting involved in the governance
PHASE 2 Co-construct the implementation of the program	Establish program governance Identify the AP's intervention trajectory Establish a timeline Develop program visibility Designate a coordinator for the APs and the program	• Ensure common understanding and vision and remove concerns and resistance • Designate a project leader for each care trajectory • Survey AP's experiences regularly to develop a sense of belonging
PHASE 3 Implement the intervention	Integrate AP into the teams, activities, and committees Set up the foundations of the intervention Propose the offer of service to patients Testing AP's intervention with patients Adjust and evaluate the intervention	• Remind teams frequently encouraging them to refer patients to AP • Ensure fluid communication between stakeholders • Have an AP on-site during diagnosis and pre-operative meeings • Ensure a reasonable time frame for recruiting APs to avoid demotivation
PHASE 4 Deploy the program	Promote the program Recruit additional APs Consolidate governance Ensure patient / AP balance Form a community of practice	• Allocate premises for AP to standardize their presence • Encourage feedback from AP to professionals • Involve AP in activities and continuing medical education of doctors • Plan annual meetings between APs from different programs and establishments
PHASE 5 Ensure the sustainability of the program	Ensure continuous improvement of the program Ensure the continuing training of AP and professionals Maintain stakeholders motivation Expansion to other tumor sites	• Raise awareness of the project and promote it on a regular basis • Have stability in human resources • Maintain the AP community of practice • Ensure AP / patient balance • Continually engage AP • Maintain commitment from general management

OBJECTIVE

To evaluate the facility's capacity for and openness to implementing a peer-support program. This evaluation covers:

- The importance of the program having the support of senior management and managers;
- Identifying a clinical team in oncology that sees the interest in introducing accompanying patients (APs) for PACs and that wishes to incorporate them into their team;
- Identifying a clinical leader who would be in contact with the entire clinical team to ensure optimal implementation of the program and who will personally help implement it in his or her activities.

ACTIONS

Present the program

Prepare a presentation of the program's main principles to managers and healthcare professionals that is designed to raise awareness among the clinical teams and departments concerned. It includes the following:

- The unmet needs of PACs;
- The objectives of the PAROLE-Onco program;
- The APs' activities;
- The contributions made by APs for PACs;
- The contributions made by APs for the clinical team;
- The potential ethical and legal problems and the planned responses (see Section 3 on ethical and legal considerations);
- The resources required to start the program;
- Testimonials.

This presentation can be given by people who have implemented the program in other facilities, or by someone wishing to deploy it in their own facility. The profiles of these presenters may vary: APs, research teams that have already evaluated the program, managers, healthcare professionals, partnership specialists, etc. **A professional-AP pair is the preferred solution for this presentation.**

EVALUATE THE INTEREST

After the presentation, it is suggested to identify some professionals (physicians, pivot nurses, psychologists, etc.) who recognize the potential contribution that APs can make to the care trajectory in which they are involved, and who are willing to introduce them into their practice.

The PAROLE-Onco program requires involvement at all levels of a facility's governance:

- At the senior management level, it is preferable to have actors who will promote and encourage this type of initiative and have the necessary resources available.
- At the management level, managers also have an important role to play to support adoption of this new practice by clinicians by: favouring it, promoting it, and providing the additional resources required and planned by senior management.
- At the level of the professionals, their involvement is needed so that patients are referred to APs and to ensure that they will work with them. [10].

To evaluate the interest in the program, the following questions can be asked, informally, to clinical teams and management.

For clinical teams

		Yes	No
1	Has the clinical team ever worked with partner patients before?		
2	Has the clinical team ever worked with accompanying patients?		
3	Are the professionals interested in working with APs?		

In addition, an adapted AHRQ questionnaire can be used to assess professionals' perceptions of the arrival of APs (TOOLBOX - Section 2, Step 1, next page).

For management teams

		Yes	No
4	Have the oncology program managers ever worked with patient partners?		
5	Have the oncology program managers ever worked with accompanying patients?		
6	Do oncology program managers want to implement such a program?		
7	Is the program supported by senior management?		

Negative answers to questions 1, 2, 4 and 5 are not critical, but informative. However, if negative responses are given to questions 3, 6, and 7, presenting the program along with testimonials from PAC participants may support greater acceptance and engagement with the program.

MOBILIZE EXISTING RESOURCES

To set up the program, resources can be used to support partnership development within the facility, where such resources exist. This expertise can be mobilized to recruit, train and supervise APs.

If expertise needs to be developed, support can be obtained from Centre d'excellence sur le partenariat avec les patients et le public (CEPPP) and to benefit from a training course (in French only) offered by the Faculty of Continuing Education of the Université de Montréal.

To determine the resources required, questions can be asked of the clinical and management teams. In addition, a PAROLE-Onco familiarization workshop can be offered to potential participants. The aim is to ensure that all interested parties receive the same information and can ask any questions they may have about the program's implementation. Tools for facilitating this workshop are provided in the Toolbox. The Guide d'implantation du partenariat de soins et de services can also support this step by offering concrete guidelines for establishing a partnership culture.

		Yes	No
8	Does your facility have people whose job it is to help recruit and train patient partners ?		
9	Does your facility have people whose job it is to help recruit and train accompanying patients ?		
10	Has the facility had any experience of involving patient partners on committees or with professionals ?		
11	Has the facility had any experience of involving support staff on committees or with professionals ?		

Negative answers to questions 8 and 9 raise the question of whether people within the company can take on this role. There are a number of resources in this area, including the MMD 6380 – Fondements du partenariat patient course [23] and a training course offered by the Unité de soutien au système de santé apprenant (SSA). Questions 10 and 11 are informative and serve primarily to identify potential resource people to support the implementation of PAROLE-Onco.

TIPS AND LEVERS FOR CREATING A FAVORABLE ENVIRONMENT

GOUVERNANCE	
Gain the support of senior management.	√
Gain the support of cancer managers.	√
CULTURE	
Clarify that APs do not replace any healthcare professional, but complement the service offering.	√
Create a space where professionals can discuss their perceptions of the arrival of APs.	√
RESOURCES	
Identify professionals, accompanying patients as well as managers wishing to get involved.	√
Mobilize existing resources in support of the partnership.	√

INDICATORS

- % of people to whom the program has been presented
- % of people interested

Readiness: pre-implementation score

TOOLBOX - SECTION 2, STEP 1

Assessing and creating a favorable environment

- PAROLE-Onco: What is it?
- Introducing PAROLE-Onco program to managers and clinicians
- Introducing PAROLE-Onco program to accompanying patients
- Introducing PAROLE-Onco program to people affected by cancer
- PAROLE-Onco brochure
- PAROLE-Onco leaflet
- Organizational readiness to implement change
- PAROLE-Onco FRANCE co-construction workshop (example)
- Perception of integration of accompanying patients questionnaire (Start)
- Perception of integration of accompanying patients questionnaire (End)
- Strengths, Weaknesses, Opportunities, Threats analysis (SWOT)

OBJECTIVE

To implement winning conditions for deploying the program in a facility.

ACTIONS

1. IMPLEMENT PROGRAM GOVERNANCE

I First, it is proposed to set up a **working committee** and a s**trategic committee** and then appoint a **project manager** and an **AP coordinator**.

WORKING COMMITTEE

Mandate

The working committee is responsible for:

- Identifying the people connected to the project at the clinical and organizational levels to inform them of the project and how they can get involved;
- Establishing and implementing the various stages of AP implementation in the program;
- Reporting on project implementation to the strategic committee.

Composition

The working committee consists of four to twelve people from the oncology clinical team, care and service partnership resource people and accompanying patients.

A summary of the working committee's composition and actions is presented in Table 1.

Working Methods

The committee is part of the cancer program. Its members meet regularly to monitor the implementation and adjust the strategies. Meetings are more frequent at the beginning of the process (at least once every two weeks). The project manager and AP coordinator can then suggest a frequency of meetings suitable to the needs and availability of committee members.

The committee can function as a continuous improvement committee (CAC) [22], which sets itself S.M.A.R.T. (Specific, Measurable, Achievable, Realisable and Time-defined) objectives to rapidly introduce APs (Examples of S.M.A.R.T. objectives) and improve the PAC experience. It is advisable to set three-, six- and nine-month objectives, and to establish a work schedule.

In the recommendations for good practice, it is strongly encouraged to recruit at least two APs to sit on the committee, so as to always have an AP present at meetings and encourage their participation and input in discussions. [10]

Table 1 Composition and actions of the working committee

Composition	Actions to be coordinated
- At least one AP - One or both co-managers of the oncology program - The project manager - The AP coordinator - One or two healthcare professionals (physicians, specialized nurse practitioners, nurse navigators, nurses, psychologists, social workers, etc.).) - A partnership specialist	• Designate a project manager; • Recruit an AP coordinator; • Identify professional champions (physicians, pivot nurses in oncology, psychologists, etc.) willing to make referrals and integrate APs into their practice; • Define the various parties' roles and responsibilities with the help of the improved RASCCI*; • Provide training to the professionals; • Recruit and train APs; • Follow-up on implementation; • Evaluate the implementation; • Propose continuous improvements (see details in Step 5).

* RASCCI improved [26], acronym for Realization, Approval, Support, Consultation, Co-construction and Information.

STRATEGIC COMMITTEE

Mandate

The strategic committee's mandate is to support the working committee as it implements the program, and to ensure its widespread use and sustainability.

Composition

The Management Committee or Clinical Coordination Committee can serve as a strategic committee for the program. This committee is made up of people who have a comprehensive view of the facility, as well as hierarchical links with the members of the working committee. However, it may be necessary to create a dedicated committee for the PAROLE-Onco program. This committee could consist of representatives from the various departments involved in the program (e.g., President - General Manager or his or her representative, Director of Nursing, Director of Multidisciplinary Services, professionals, director responsible for quality, chief finance officer, oncology co-manager). Once the program has been rolled out, two PACs may join the committee.

Working methods

This committee is regularly informed by e-mail of the progress of its work (at least every 3 months). It can be consulted, if necessary, on important issues.

Table 2 Composition and actions of the strategic committee

Composition (representatives of the departments involved in the program)	Actions to coordinate
- At least one AP - President – General Manager (or his or her representative) - Director of Nursing - Director of Multidisciplinary Services - Professionals - Director responsible for quality - Chief finance officer - Oncology co-managers	• Facilitate the implementation of the PAROLE-Onco program by ensuring that the necessary resources are available; • Regularly be informed of progress made in the project; • Advise the working committee on the strategies to be implemented; • Promote the PAROLE-Onco program throughout the facility • Participate in sharing lessons learned • Ensure program sustainability (see details in Step 5); • Ensure links with the provincial oncology program

EXAMPLES OF QUESTIONS TO ASK IN A MEETING OF THE STRATEGIC COMMITTEE

What problems have been encountered that need to be discussed?

What lessons have been learned that could assist implementation of the PAROLE-Onco program in other trajectories or in programs other than oncology?

How can the work done by APs, clinical team professionals and co-managers be recognized?

What strategies could be deployed in the facility to promote the program?

CO-MANAGERS

Mandate
Co-managers are responsible for encouraging all professionals on the clinical team to refer PACs to the program.

Composition
This pair is comprised of the physician responsible for the program and the manager who works alongside him or her.

Working Methods
The co-managers support implementation of all the stages, in particular the strategies put in place by the working committee to mobilize the clinical team's professionals.

EXAMPLES OF QUESTIONS THAT CO-MANAGERS NEED TO ASK THEMSELVES

What actions need to be put in place to support the working committee?

How can we value the work done by APs, clinical team professionals and managers?

What strategies can we put in place in the cancer program to promote the program to PACs?

What strategies should be implemented in the oncology program to promote the program to professionals?

What lessons have been learned that could encourage the implementation of PAROLE-Onco in other oncology trajectories?

PROJECT MANAGER

Mandate
The roles and responsibilities of the project manager are to:

- Act as manager of the project;
- Use project management tools (Gantt chart, project chart, etc.). See documents Gestion de projet en santé. and RASCCI matrices.
- Work closely with both committees to plan, coordinate, schedule and monitor implementation;
- Support clinical team professionals during the project implementation phase and ensure program consistency with clinical practices;
- Participate in committee organization, leadership and work (preparation of agendas and reports as required);
- Ensure that the various implementation stages are completed and the SMART objectives are met on schedule;
- Report to the strategic committee on the progress made in the project, communicate follow-up indicators and inform members of any situations requiring support or arbitration;
- Coordinate the activities with other partnership activities.

Profil
Experienced in managing projects that require the involvement of a wide range of people and patient partners, the project manager may be a senior consultant, a department head, a planning, programming, and research officer (PPRO) from one of the departments involved, the AP coordinator, or another qualified person. Ideally, this person is a manager or project management specialist.

EXAMPLES OF PROJECT MANAGER PROFILES

CHUQ : coordinator of the Oncogenetic Resource Network for the support and education of people with an hereditary risk of cancer

CHUM: an advanced practice nurse

CIUSSS de l'Est-de-l'Île-de-Montréal: Department Manager – Partner Space in Oncology

CISSS de la Montérégie-Est: planning, programming and research officer (PPRO) assigned to patient partner engagement at the clinical level

AP COORDINATOR

Mandate

The AP coordinator plays various roles (see Table 3), including:

- Participating in the recruitment of at least two APs;
- Coordinating the contributions of APs;
- Placing APs in contact with PACs;
- Supporting the clinical teams in their roles with APs;
- Providing feedback (occasionally or on a regular basis) to clinical teams after APs' interventions.

A detailed summary of the roles is shown in the table below and in a video.

Profile

The person in this role knows the clinical team well and can easily communicate with its members. He/she has good communication skills and is present in the field to encourage healthcare professionals (including physicians) to refer PACs to APs. Ideally, the coordinator is an AP and serves as the link between APs, PACs and the clinical team.

See detailed job description here

Table 3 AP coordinator role

Area	Roles
AP support	• Participate in recruiting, training and supporting APs; • Welcome APs new to the program; • Respond to APs' questions and requests; • Ensuring that APs work in the best possible conditions; • Welcoming APs who are experiencing difficulties during certain accompaniments (death, personality, understanding of a treatment, etc.) and, if necessary, consulting with a specialist.) and, if necessary, consult a competent person depending on the situation; • Accompany, with the support of the partnership managers if necessary, the cohort of APs and PACs, ensuring everyone's satisfaction; • Promote contacts between APs by animating a community of practice (CoP).
Connecting APs and PACs	• Collect referrals or requests made by professionals and synthesize the necessary information on the PAC to be supported for APs; • Offer PAC support to APs on a secure platform; • Ensure that APs have the necessary information. to carry out their accompaniment in the best possible conditions; • Ensure that relevant information gathered by APs is passed on to professionals; • Keep a register or dashboard that records all accompaniments that take place (indicating in particular the person who referred, the moment in the care trajectory of the PAC, the AP(s) doing the accompanying).
Support for clinical teams in their role with APs	• Ensure that professionals and physicians are aware of APs' profiles; • Encourage contact between APs and the clinical team, for example by inviting professionals and physicians to the community of practice; • Communicate APs' concerns to professionals and physicians; • Communicate professionals' and physicians' concerns to APs.
Feedback after accompaniments to clinical teams	• Establish a communication loop with clinical teams (routinely and in emergencies) that corresponds to everyone's needs; • Ensure that relevant information held by APs is passed on to clinical teams and entered in the patient's file if necessary; • Draw up a monthly report on activities carried out: number of accompaniments; support activities between APs; activities with healthcare professionals; ; • Communicate the report to the clinical team including the APs.

EXAMPLES OF THE PROFILES OF AP COORDINATORS

CHUQ: a PA

CHUM: a person from the VIRAGE Foundation [11] and, more recently, an advanced practice nurse, former co-manager of CHUM's Integrated Oncology Centre

CIUSSS de l'Est-de-l'Île-de-Montréal: a patient partner responsible for the Partner Space in Oncology [12]

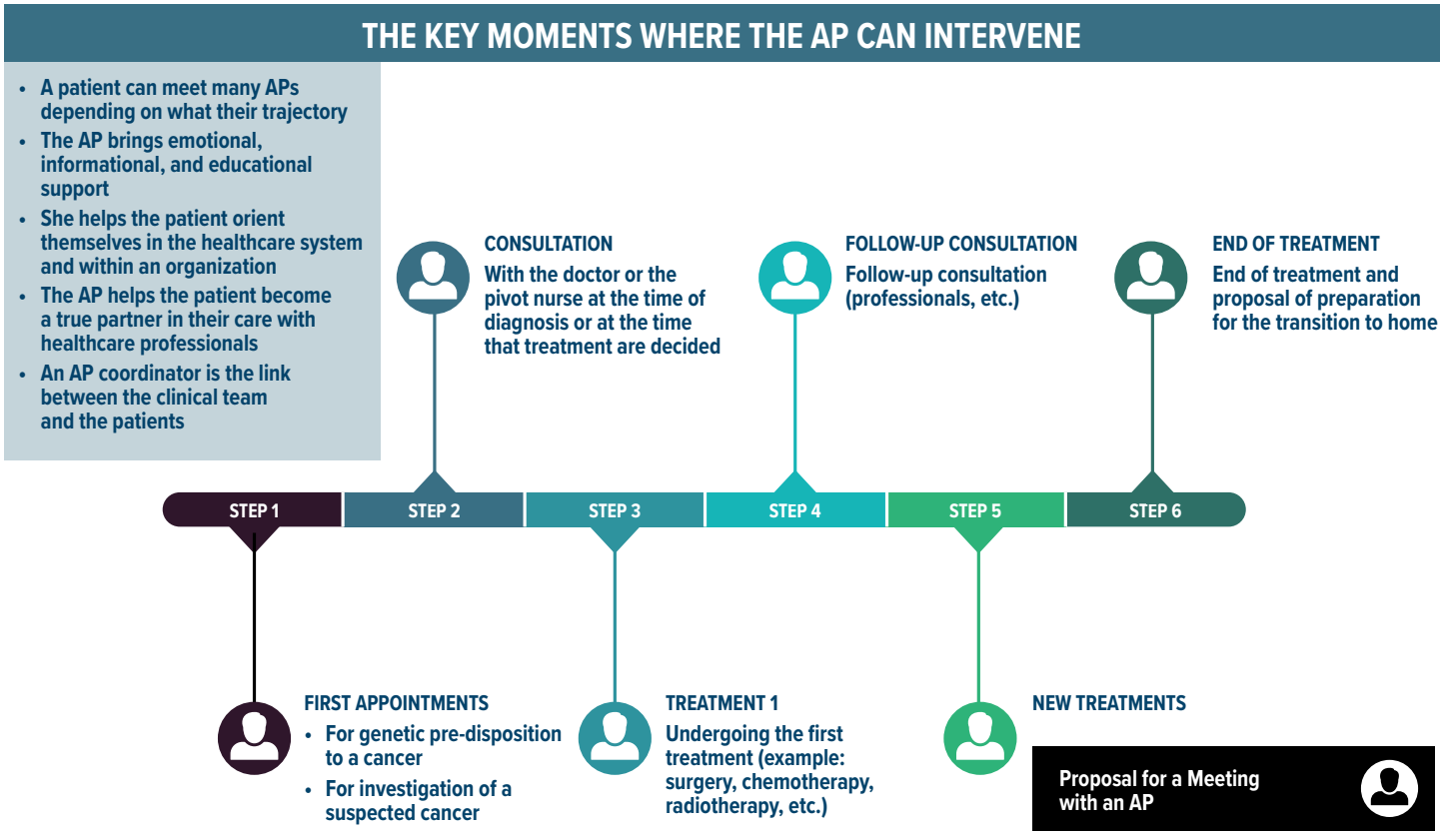
CISSS de la Montérégie-Est: a Planning, Programming and Research Officer (PPRA) dedicated to engaging patient partners in clinical activities.

2. DETERMINING THE INTERVENTION TRAJECTORY AND THE TIMES WHEN THE AP COULD BE INTEGRATED

Once the type of cancer where the program will be implemented has been identified, APs can be introduced at different points in the trajectory (investigation, announcement of diagnosis, radiotherapy, pre-operative assessment, etc.). The time of announcement of diagnosis (or even of investigations) could be favored in order to begin support as early as possible (cf. Figure 2).

The PAROLE-Onco program can be applied just as much to investigations for genetic or diagnostic predispositions as to any other type of treatment; it can even extend to end-of-life care. Its aim is to provide the best possible support to PACs throughout their care trajectories. It can also begin at the investigation stage and be aimed at the caregivers of PACs.

Figure 2 Example of the key moments in the breast cancer trajectory when APs can intervene



3. IDENTIFY, RECRUIT, AND TRAIN APs (Back to Step 1)

To initiate PAROLE-Onco, one or two APs has to be recruited. [27] This process can be carried out by members of the Quality, Evaluation, Performance and Ethics Department (QEPED), by the structure in charge of partnership, or by the cancer department itself. The complete process comprises 4 stages: (1) identification of potential APs; (2) selection of APs; (3) training of APs; and (4) support and recognition of APs' contributions. Some departments prefer to recruit one person full-time, while others prefer to recruit several profiles at the same time to cover the different situations that patients may experience. The rest of the guide focuses on a situation where there are more than two APs, but all the steps presented here also applies to the case where the department recruits just one person. Criteria for selecting APs can be found at Toolbox Step 2 and also at table 3.

Step 1: Identification

Clinical teams can identify future APs from among the PACs they are monitoring. They will be able to base their recruiting on the criteria presented above (see table 3), particularly once the PACs have taken a step back from their disease.

APs can also identify future APs. Indeed, among the PACs they accompany, they can identify PACs who might be of interest and meet the selection criteria at the end of their interventions

Diversity and inclusion considerations

The integration of accompanying patients (APs) takes into account issues of diversity, equity and inclusion. The recruitment of APs takes into consideration the characteristics of the population served, taking into account gender, age, culture, language, etc. This ensures more effective accompaniment. This ensures that support is more representative and sensitive to different trajectories. To achieve this, targeted strategies can be put in place, such as partnerships with community organizations or the creation of culturally and linguistically adapted tools. Such an approach fosters equity of access, a sense of trust and an improved care experience.

TESTIMONIAL: HOW A PAC BECOMES AN AP

In the summer of 2020, Diane received support from an accompanying patient (AP) from the PAROLE-Onco project. Diane already had the skills of a partner patient in her care, as one of the objectives of the PAROLE-Onco program is to help the accompanied women become partners in their care so that they can get through this episode in their lives under the best possible conditions. Calm and serene in the face of her illness, she did not hesitate to ask her clinical team questions in order to better understand her diagnosis and the treatment options in her care trajectory. After a third meeting, her AP asked her if she would like to accompany other women with breast cancer, after her treatments were over, of course, and, above all, when she felt ready. She said that she would think about it. One and a half years later, following an interview and training, she joined the group of women involved in the PAROLE-Onco program. Diane has become an invaluable asset to women with breast cancer.

EXAMPLE OF HOW TO IDENTIFY NEW ACCOMPANYING PATIENTS

APs or professionals can identify PACs who could become APs. PACs can also express their interest to the APs or professionals on the clinical team. The people responsible for partnership then ensure, with the clinical team, that the person is clinically fit for the role before selecting and training them.

Step 2 : Selection

An interview is conducted by two people – one of whom has expertise in partnering and another who is an accompanying patient or partner – to ensure that the criteria are met.

Part of the interview should include a discussion specifically with the active AP so that she can share her experience and give the future AP a clear idea of what this role entails. The future AP will also be able to ask questions.

In addition, if the suggestion for a PAC does not come from their treating physician, it must be confirmed with the physician that the PAC could become an AP.

Subsequently, if the person in charge of partnership, the AP, and the physician believe that the future AP meets the selection criteria, this person is then offered the opportunity to undergo training.

As part of the selection process, a criminal record check may be carried out. APs are also encouraged to inform the facility of any criminal convictions/charges that could alter an initial declaration.

Step 3: Training

Online training including synchronous and asynchronous sessions ensures that all PACs participating in the PAROLE-Onco program receive the same basic training. Access details are available on the Faculté d'éducation permanente (FEP) de l'Université de Montréal website. This training is aimed at future oncology APs and active APs, who are encouraged to update their knowledge periodically. Facilities can develop additional information according to their needs. Table 4 shows the various modules offered in French and English.

Table 4 Training modules

Module	Description
1	Familiarize oneself with the fundamentals of the Care and Services Partnership (CSP) and the role played by APs in the CSP.
2	Understand one's environment and how to position oneself in it.
3	Accompany PACs.
4	How to deal with the ethical and legal challenges.

Step 4: Accompaniment and recognition

APs are accompanied by the program coordinator, who supports them in their interventions. The coordinator also ensures that APs receive feedback on their interventions from PACs and healthcare professionals.

When an AP begins in this role, she is paired with a more experienced AP who serves as a coach for the first few months. After three months, a reassessment of her ability to be an AP is carried out by her peers and the program coordinator. If the person does not satisfy the conditions, she is then offered the opportunity to participate in other activities.

Currently, in Quebec, APs do not receive any compensation for accompaniment services, but they are reimbursed for expenses related to their activities as APs (parking, meals, travel, etc.). This situation may change in the future.

This whole process guarantees a high quality program, thereby fostering PACs' confidence in the PAROLE-Onco program.

Step 5: Promoting the Program

The program would benefit from more promotion to make it better known. To this end, facilities could adopt communication strategies aimed at professionals and PACs.

- For professionals, including physicians: make presentations at their interdisciplinary meetings, invite professionals to join health professionals' communities of practice, provide program bookmarks/brochures, have clinician representatives sit on various committees, etc.
- For PACs: messages projected on screens in waiting rooms, PAROLE-Onco bookmarks/brochures, occasional presence of APs in waiting rooms, etc.
- Presentation of the program and news on its development in the facility's newsletter to all employees and physicians.

To complement this, the program is publicized in the community through PAC associations, family medicine practices, community organizations, etc. Social media such as Facebook, X, Instagram, and LinkedIn can be used to spread news testimonials, photographs and videos.

It is also possible to organize events such as conferences, workshops, and open houses on the subject.

The local media can also be invited to attend the launch of the program to relay the message to the community.

The facility's communications department should develop a communications plan and evaluate its effectiveness.

EXAMPLES OF COMMUNICATION TOOLS

These tools can be used to promote the AP service or for the intervention itself:

- PowerPoint presentations to clinical teams and various oncology department committees;
- Activities presented by email or the intranet;
- Articles published in the in-house newsletter;
- Production of bookmarks and leaflets made available in the offices of physicians and other healthcare professionals;
- Creation of a form for recording AP intervention notes in the PAC's file.

TIPS AND KEYS TO PROMOTE PROGRAM IMPLEMENTATION

GOVERNANCE	
Keep upper management informed on a regular basis	√
Keep the main departments involved in the project informed through the Strategic Committee.	√
Ensure that the Working Committee meets on a regular basis.	√
CULTURE	
Identify clinical teams that wish to incorporate APs.	√
Create a space where professionals can share their points of view on incorporating APs in the care trajectory.	√
Clarify everyone's roles and responsibilities.	√
Develop a shared understanding and vision.	√
Address the concerns and resistance of the various stakeholders.	√
Ensure that all decisions are taken with the APs.	√
RESOURCES	
Recruit a project manager and an AP coordinator.	√
Recruit at least 2 APs.	√
Ensure access to an information system for exchanging confidential information.	√
Mobilize communications professionals to promote the program both internally and externally.	√
TOOLS AND METHODS	
Adapt tools to suit the context and the message to be conveyed, while involving APs.	√
Create communication tools (examples: brochures, flyers, PowerPoint presentations, videos, podcasts, etc.)	√
Measure the impact of the communication strategy on the various stakeholders.	√

INDICATORS

A number of indicators can be tracked to monitor program implementation, such as:

- % absenteeism at working committee meetings;
- % absenteeism at strategic committee meetings;
- % of people trained in partnership on these two committees;
- Project manager and AP coordinator recruited;
- Realistic timetable co-constructed with APs;
- S. M.A.R.T. objectives achieved and updated;
- Number of promotional activities carried out;
- % of people familiar with the program among professionals, managers and PACs in the care trajectory

TOOLBOX - SECTION 2, STEP 2

Co-constructing program implementation

- Support guide for patient support partners (PSPs) in breast cancer (CHUM example) - French
- Accompanying Patient's Notes
- Examples of S.M.A.R.T. objectives
- Community of Practice for breast cancer accompanying patients Charter
- Video: *Le rôle de coordination des accompagnements* (The role of accompanying patients coordinator)
- Breast cancer pathway to receive support from an AP
- Procedures for patient and AP meetings
- Support Registry
- Job description for AP coordinator
- Selection criteria for users and APs
- Project Charter example

(Return page 14)

OBJECTIVE

Start the APs' interventions with PACs

We recommend starting with a project involving one or a few teams in order to test the intervention mechanisms and take into account the specific features of each facility.

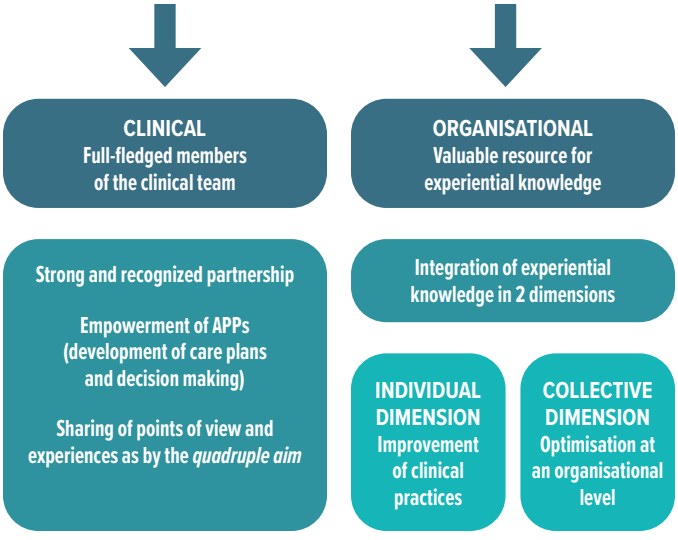
ACTIONS

1. INCORPORATE APs INTO CLINICAL TEAMS, ACTIVITIES, AND COMMITTEES

- Present the profile of recruited APs to the clinical team and answer their questions, for example with the help of a photo gallery of the APs (example given in the Toolbox).
- Offer teams the opportunity to meet the APs in person so that they can put faces to names. This allows the teams to refer patients to people they know. These contacts can be made at interdisciplinary meetings, clinical coordination committee meetings or other clinical meetings.
- Offer APs the opportunity to participate in various activities at the facility related to the specific care trajectory, such as training classes, continuous improvement committees, [22], etc.
- Clarify everyone's role, taking the time needed for clinical team members and APs to be able to work together cohesively.
- Discuss with the APs the various activities they are interested in.

PRACTICAL TOOL: Modalités de participation et d'intégration des personnes accompagnatrices (PA) aux réunions interdisciplinaires

ACCOMPANYING PARTNER PATIENTS: INCLUSION IN 2 SECTORS



A number of optimal conditions must be taken into account to ensure successful integration:

- Respect the APs' level of commitment and availability to carry out their interventions and take part in meetings. The meetings must take place at times that reflect their availability.
- Allow the APs to choose not to begin or to end their services with a PAC for personal reasons (based on physical or psychological capabilities) that may have an impact on their relationship with the PAC.

Examples of activities that APs can perform

With APs	With the team
- Perform consultations with the patients in person or remotely - Prepare the patient for their medical appointments - Accompany the patient during appointments - Animate or co-animate activities for patients (group sessions, accompaniment to therapeutic sessions (preparation for chemo)	- Discuss the situation of a patient with the team - Share the realities lived by patients with the team in the goal of improving individual and collective practices - Participate in the evaluation of professional practices in the context of continuaous education of doctors.

The activities of APs may vary from one facility to the next, depending on internal policies. These activities can therefore be discussed in advance among the members of the clinical team, the managers, and the APs. They should form part of the contract signed between the APs and the facility, bearing in mind that this contract may change over time, depending on the activities.

2. DEPLOY THE INTERVENTION

The working committee and the project manager help:

1. Identify professional champions;
2. Train the stakeholders in the partnership: the APs, the clinical team, the managers;
3. Co-construct the intervention's implementation with all stakeholders (intervention loop), meaning:
   a. The professionals, including the physicians,
   b. The managers,
   c. The APs,
   d. The people affected by cancer.

Produce the intervention deployment kit:

4. a. A leaflet presenting the PAROLE-Onco program,
   b. A request form filled out by the healthcare professionals (including physicians) for the accompaniment,
   c. A template document for informing the APs about the PACs to be accompanied,
   d. The AP's logbook, used to summarize the accompaniment intervention.

ETHICAL ISSUE:

How can we ensure the confidentiality of the personal information shared among PACs, accompanying patients, and healthcare professionals?

When recruiting APs, the facility enters into a written contract with them, stipulating that all information shared with healthcare professionals and the PACs is confidential.

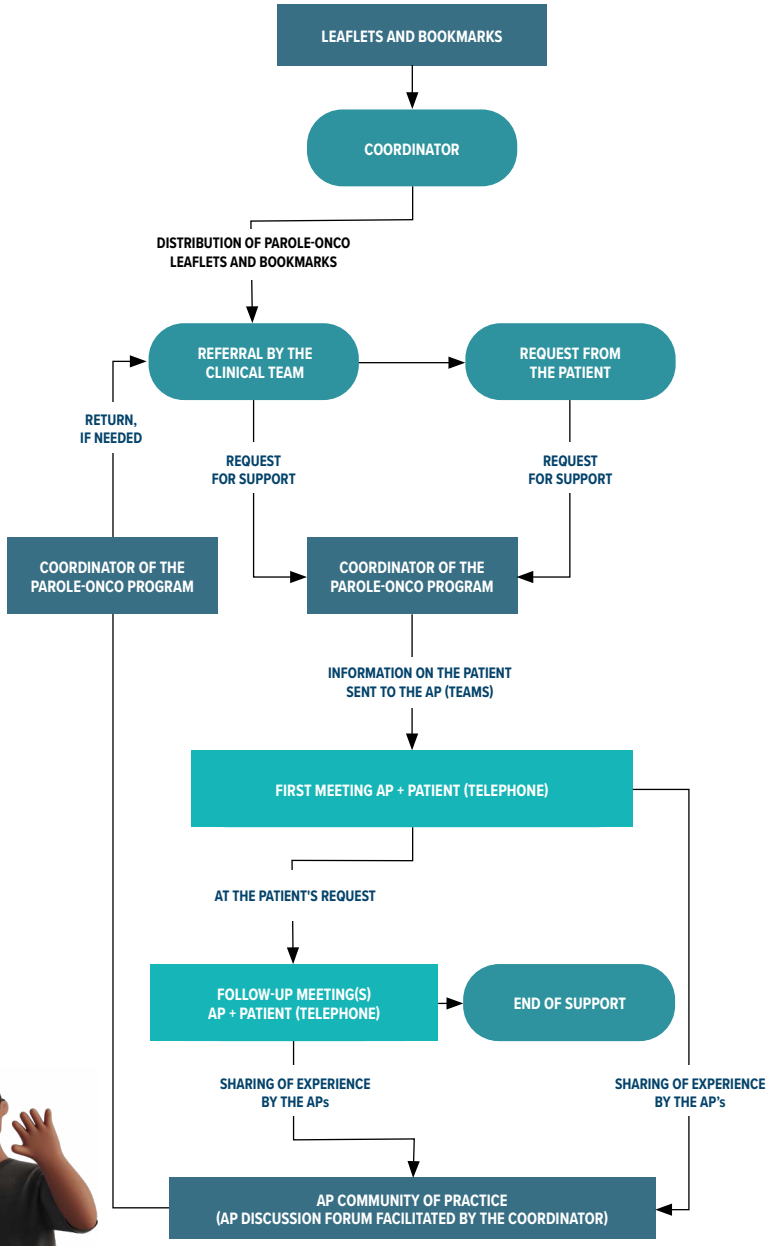
When a PAC agrees to meet with an AP, this represents a verbal agreement. During this meeting, the AP presents her role, the data to which she has access and the rules around confidentiality (see ETHICAL ISSUE next page) and (ETHICAL AND LEGAL CONSIDERATIONS).

During the intervention, if the AP deems it necessary to pass along important or urgent information to the professionals on the clinical team, she first asks the PAC to agree (except in exceptional circumstances).

PACs may refuse or terminate an AP's accompaniment at any time, without justification. In the event of a problem with an AP, the PAC may lodge a complaint.

PACs may refuse or terminate support at any time without justification. In the event of a problem with an AP, the PAC may lodge a complaint .

PAROLE-ONCO BREAST CANCER PATHWAY TO RECEIVE SUPPORT FROM AN ACCOMPANYING PATIENT (AP)



For a research project, steps are added on presenting the project, obtaining the PAC's consent, and sending questionnaires.

3. OFFER THE SERVICE TO PAC's

Research shows that PACs do not necessarily identify their needs. This is especially true of those who are most in need, such as people in vulnerable situations [1]. This is why it is recommended to systematically propose a meeting with an AP; the PAC then decides whether or not to continue seeing the AP. Professionals are therefore encouraged to present the opportunity to be accompanied by an AP; if the PAC agrees, the professionals make the request. Professionals are informed of the procedure for referring PACs in order to facilitate implementation of the intervention.

When the AP contacts the PAC, she explains her role and offers to meet with them in person, or else by telephone or videoconference.

- **In person:** the AP has access to a physical location at the clinic and meets the PAC in a consultation during her visit with the professionals. The AP on site will therefore need to be informed of the schedule of consultations for which she may be involved..
- **By phone or videoconference:** the AP is informed that a PAC wishes to meet her after being in contact with the professional. The AP who has experienced the clinical pathway closest to that of the person to be accompanied contacts the PAC by telephone or videoconference (using a user-friendly platform such as Zoom or Teams), whichever she prefers. The first contact will be made by telephone, and both methods (telephone or Zoom/Teams) will be offered to the PAC on this occasion for subsequent meetings.

4. EVALUATE, ADJUST, AND CONTINUE THE INTERVENTION

After some twenty PACs have benefited from the accompaniment of an AP, the working committee conducts a review of the experience to analyze the situation and report its findings to the clinical team for discussion. The evaluation of such an experience is pragmatic, taking into account the context, in particular. The team must therefore adapt to this complexity and remain flexible. [28, 30]

The evaluation may involve following up on qualitative data (interviews or focus groups) and quantitative data (questionnaires) with professionals, APs and PACs to gather their perceptions of how the program is being implemented. See Toolbox - Section 2, step 3 on next page for Interview and/or group discussion guides

Depending on the results, adjustments are made, for example, by redefining the S.M.A.R.T. objectives.

The **working committee** also informs the **strategic committee** of the progress made at this stage (including S.M.A.R.T. objectives), and mobilizes it to address the strategies to be implemented, where necessary.

During and after this evaluation, the PACs continue to be accompanied.

Impact assessments can be introduced for PACs. They can measure their anxiety, quality of life, ability to cope with cancer or to partner with healthcare professionals, etc.

The implementation process makes it possible to start on a small scale and gradually acquire the experience and skills that will be mobilized for Step 4.

EXAMPLE OF HOW DR. ISRAËL FORTIN (RADIATION ONCOLOGIST AT MAISONNEUVE-ROSEMONT HOSPITAL) INTRODUCES APs TO HIS PACs DIAGNOSED WITH BREAST CANCER:

"I usually introduce the PAROLE-Onco program very simply at the end of the consultation:

We're a full team to support you on your journey. You already know my nurse, but we also have a clinical team with psychologists, social workers and nutritionists, should you need them. We're also fortunate to have an accompanying patient on our clinical team! Like you, she was diagnosed with breast cancer and trained to be part of our clinical team. If you agree, she will contact you in the next few days by phone to explain the support that she can provide. This call will take just a few minutes of your time. The vast majority of our PACs very much appreciate this phone meeting. However, if after this call you feel that you don't need it, just let the AP know."

Excerpt from video.

ETHICAL ISSUE:

How do we ensure that confidentiality is maintained?

When training APs, fictional situations should be presented to test how information is shared. The APs should also be asked to sign, in their contract, a clause to ensure that data confidentiality will be maintained. As part of the community of practice, APs can also be regularly reminded of the rules of confidentiality and allowed to ask questions related to this topic. Lastly, it is important to ensure that any technological interfaces used to share personal data comply with IT security standards for the protection of personal data.

TIPS AND KEYS FOR IMPLEMENTING THE INTERVENTION

GOVERNANCE	
Keep senior management informed on a regular basis.	√
Keep the departments involved in the project informed on a regular basis.	√
Ensure that the working committee meets on a regular basis.	√
CULTURE	
Implement the program gradually.	√
Continue to develop a shared understanding and vision.	√
Ensure that you address all the concerns of the various stakeholders.	√
Communicate regularly with APs to evaluate their experience and develop their sense of belonging.	√
Regularly remind professionals of the importance of referring PACs to APs.	√
Ensure free-flowing communication between all the actors.	√
Ensure that all decisions are made with the APs.	√
RESOURCES	
Ensure that the AP coordinator has access to all the resources needed to fulfill his or her mandate.	√
Provide space for APs if needed.	√
Mobilize communications people to provide feedback on this first phase.	√
TOOLS AND METHODS	
Develop the kit to establish a process for placing APs in touch with PACs and provide feedback to the professionals.	√
Create communication tools (e.g., flyers, PowerPoint presentations, videos, podcasts).	√
Evaluate the effects on PACs, APs, and professionals.	√
Evaluate the impact of the communication strategy on the various stakeholders.	√

INDICATORS

- % of PACs approached relative to the number of PACs who agreed to participate
- % of professionals who agreed to refer PACs
- % of APs and PACs satisfied with the experience
- % of PAC with improved health outcomes

TOOLBOX - SECTION 2, STEP 3

Implementing the intervention

- Request for support from healthcare professionals
- Information on PAC to be communicated to AP (+ example)
- Participation and integration of APs in interdisciplinary meetings
- AP questionnaires
  - Logbook
  - Personal information
  - Care path
  - Experience review
  - Compassion Wear Test (CWT)
- PAC questionnaires
  - Personal information
  - Care path (long version)
  - Cancer coping skills
  - Quality of life SF-6
  - HAD Scale (Hospital Anxiety and Depression)
  - Accompaniment feedback
  - Accompanying Patient support assessment
  - CADICEE tool
- Questionnaires for healthcare professionals, senior management and managers
  - Personal information
  - Questionnaire on the perception of the integration of accompanying patients (beginning of implementation)
  - Questionnaire on the perception of the integration of accompanying patients (end of implementation)
- Interview and/or group discussion guides
  - Group discussion guide - professionals
  - Group discussion guide - leaders' team (start)
  - Group discussion guide - leaders' team (end)
  - Group discussion guide - accompanying patients
  - Group discussion guide - patients supported by APs
- Accompagnying patient logbook – code of conduct (CHUM example)
- Registration form – volunteer patient partner (CHUM example)
- Privacy policy (CHUM example)
- Complaint filing process (CHUM example)
- Legal and Ethical considerations

OBJECTIVE

Deploy the program and continue to adapt it to the needs of PACs, APs, professionals, and the facility's managers in order to improve and institutionalize it. During this step, one can envision proposing APs throughout the entire duration of a care trajectory and offering the AP intervention to other types of cancer patients.

ACTIONS

1. PROMOTE THE PROGRAM

Whether finalizing the service offering of the PAROLE-Onco program in one care trajectory or starting it in another, the various steps proposed in Phase 2 will need to be repeated. If the project manager or coordinator has a very heavy workload, it may be necessary to recruit another one.

The presentation of the program can be improved based on the experience acquired in Phase 3 and the program's results.

In addition, strategies should be implemented to publicize the progress made in implementing the PAROLE-Onco program in the facility. This can take the form of presentations by the AP coordinator, or by sharing testimonials from PACs, APs, professionals, or managers, preferably alongside an accompanied PAC. In addition, the work carried out in the facility needs to be communicated to the public and to other actors in the health and social services system (see the strategies proposed in Step 2, point 4).

2. RECRUIT NEW APs

At this stage, it will probably be necessary to recruit additional APs, either to cover more of the same trajectory or to start covering a new one. The procedures proposed in point 3 of Step 2 apply here in the same way, while ensuring that APs are recruited with a variety of sociodemographic and economic profiles (type of trajectory, age, family situation, cultural background, economic status, etc.). This diversity makes it possible to associate PACs with APs who have a similar profile (e.g., same age group, similar family composition, type of oncological surgery or reconstruction, similar treatments) and to cover the various themes that the accompanied PACs would like to address.

The process presented in Step 2 can be enhanced by APs who have acquired some experience.

- During the identification phase, they can suggest PACs they have followed who have a profile that would enable them to become APs themselves;
- During the selection phase, they can take part in the selection interview. It is the APs who are in the best position to judge whether or not the person is suitable for the AP role;
- During the training phase, they can co-lead the training provided to future APs;
- During the accompaniment and recognition phase, they draw on their experience with the future APs, enabling them to: follow or assist them in the intervention; participate in the community of practice; and assess, after a few weeks, whether the individual is suited to the role.

3. FORM A COMMUNITY OF PRACTICE

As part of their activities, and to enable them to share their views on their practice, a Community of Practice (CoP) will be set up specifically for APs. This community, led by the AP coordinator, meets on a regular basis (at least once a month).

The CoP gives APs the opportunity to talk about their experience in the intervention, their questions, their challenges and their achievements, in order to consolidate their knowledge and support reflective practice. This enables them to improve their skills and receive advice from their peers.

During these meetings, the confidentiality of the data exchanged is guaranteed (for example, the names of the PACs are not given, unless someone has agreed to this beforehand). A CoP charter will need to be developed.

This community of practice is also a forum for discussions with healthcare professionals and managers, who are regularly invited to address various issues.

4. CONSOLIDATE GOVERNANCE

At this stage, program governance can evolve according to the scale of the proposed deployment. For example, more than one working committee is created. Coordination between working committees, provided by the cancer department's co-manager or another person from one of the departments, ensures continuity and a shared vision.

The strategic committee continues to be the reference structure for supporting and monitoring deployment of the PAROLE-Onco program. Feedback on its implementation and evaluations of its effects play a vital role at this stage. These two committees work closely with the various departments.

The coordinator and project manager support the roll-out. Depending on the scale of deployment, new coordinators may be recruited. The project manager may also be changed to someone at a different hierarchical level in the facility if the project grows in size.

Each month, the AP coordinator(s) prepare a report on the activities carried out, which they forward to all the stakeholders. The report includes, among other things, the number of accompaniments, the support activities between the APs, and the activities with healthcare professionals.

A committee of APs could also be created to advise on improving the quality of care. Points for improvement noted by APs during their interventions or discussed in their community of practice could be brought to this committee.

ETHICAL ISSUE:
If a PAC wishes to lodge a complaint against an AP, or against any professional, they can contact the local complaints and quality of services department. Given the potential for civil litigation, it is recommended that the facility provide the APs with liability insurance. Such coverage enables registration with the *Commission des normes, de l'équité, de la santé et de la sécurité du travail (CNESST)* in order to benefit from the protection provided under the *Act respecting industrial accidents and occupational diseases.*

In the absence of a community of practice, peer-to-peer coaching is recommended. This would be even better if supervised by a psychologist.

TIPS AND KEYS FOR DEPLOYING THE PROGRAM

GOVERNANCE	
Keep upper management informed on a regular basis.	√
Keep the departments involved in the project informed on a regular basis.	√
Ensure that the working committee meets on a regular basis.	√

CULTURE	
Implement the program gradually.	√
Continue to develop a common understanding and vision.	
Respond to all the concerns of the various stakeholders.	√
Communicate regularly with new APs to evaluate their experience and develop a sense of belonging.	√
Regularly remind professionals of the importance of referring PACs to APs, in particular within the new care trajectories.	√
Ensure smooth communication between all actors.	√
Ensure that all decisions are made with APs.	√
Ensure that the APs' feedback to professionals is used to improve the quality and organization of care.	√

RESOURCES	
Ensure that the AP coordinator is able to take on the coordination of new trajectories.	√
Recruit APs according to the new trajectories and ensure a variety of profiles.	√
Provide space for APs as needed.	√
Mobilize people in communication with AP support to publicize the service offer in the new trajectories.	√

TOOLS AND METHODS	
Implicate experienced APs throughout the recruitment process.	√
Enhance the toolkit to set up the mechanism for putting APs in touch with PACs and feedback to professionals for these new trajectories.	√
Create communication tools (examples: brochures, leaflets, PowerPoint presentations, videos, podcasts) for these new trajectories.	√
Carry out recognition activities for APs (annual AP day, for example).	√
Measure the effects on PACs, APs and professionals.	√
Measure the impact of the communication strategy on the various stakeholders.	√
Present evaluation results to professionals, APs and managers.	√

INDICATORS

- Number of APs recruited/trajectory
- % of APs trained
- % of professionals trained in the targeted trajectories
- % of APs still involved after one year
- % of PACs accompanied by an AP, by trajectory
- % of APs satisfied with the experience
- % of PACs satisfied with the experience
- % of PACs with an improved health status or care experience (quality of life, self-determination, partnership, anxiety, etc.)
- Number of accompaniments per PAC
- Number of accompaniments per trajectory
- Average length of accompaniments
- % of themes discussed by the AP and PAC pairings
- Breakdown by category: professionals who refer PACs
- % of PACs who refuse accompaniment
- % of PACs with accompaniment
- % of PACs with more than one accompaniment

TOOLBOX - SECTION 2, STEP 4

Deploying the program along the trajectory

- Example of inter-institutional collaboration for the benefit of patients
- PAROLE-Onco video (women)
- PAROLE-Onco video (men)

(Return page 10)

OBJECTIVE

Make the PAROLE-Onco program sustainable within the facility by ensuring continuous improvement of the program and maintaining the motivation of clinical team members. This step also aims to cover all cancer trajectories.

"To ensure the program's sustainability, it is important to use validated strategies for sustainability and scalability. Légaré et al. (2021) emphasize the importance of conceptual frameworks and tools for the adoption and scaling up of innovations, taking into account barriers and facilitators. "[29]

ACTIONS

1. EXTEND THE PROGRAM TO ALL TYPES OF CANCER

In this step, the program is implemented for all types of cancer, based on the facility's needs and the various sub-steps proposed in Steps 3 and 4. All oncology clinical teams are potential candidates for the program, and each type of cancer has its own care trajectory

2. CONTINUOUSLY IMPROVE THE PROGRAM

The members of the strategic and working committees are responsible for program evaluation and continuous improvement.

They should regularly evaluate the following:

- The quality of the services provided
- The experience of the PACs
- The effects on PACs
- The experience of the APs
- The effects on APs
- The experience of the professionals
- The gap between the SMART objectives set and those achieved
- The scope of program
- Program-related issues

The success of the PAROLE-Onco program depends on its ability to adapt quickly to changes in the care setting. To achieve this, it is important to:

- Ensure that APs follow a minimum number of PACs to sustain their commitment to the program;
- Ensure that the training given to APs is kept up to date;
- Continuously evaluate program activities and effects;
- Discuss the results with the strategic committee at least once a year;
- Discuss the results in working committee(s) at least twice a year;
- Review the constitution, roles, responsibilities and tools of governance committee members.

During program evaluation meetings, the strategic committee, working committee(s), project manager and AP coordinator conduct self-assessments of their performance. They analyze their strengths and weaknesses, with the aim of improving governance efficiency and thus better serving the PACs, APs and healthcare professionals.

3. PROVIDE CONTINUING EDUCATION TO APS AND HEALTHCARE PROFESSIONALS

Ongoing training enhances the reach of the program and the intervention offered to PACs by giving APs and healthcare professionals the opportunity to update their knowledge on new developments in partnership, including program developments. For APs, this may include updates on treatment modalities.

ETHICAL ISSUE:
How to avoid conflicts of interest ?

To avoid any conflict of interest, APs do not accept bequests or donations from a PAC. APs avoid personal relationships during interventions carried out as part of a facility's program. They do not harm the facility's reputation and respect the directives given by the care teams, unless they are irremediably incompatible with the ethical principles applicable to APs. APs are encouraged to report situations that run counter to the best interests of PACs. For more information, consult the document on the legal and ethical considerations related to AP participation, the associated checklist, and the podcast in the Toolbox - Step 5

To cultivate the interest of APs and support them in their work, it is important to provide them with complementary workshops or training courses throughout the year, in line with their needs.

It is also important to plan for replacements in the event that one or more of the key players leave the program.

4. MAINTAIN THE MOTIVATION OF ALL STAKEHOLDERS

The program is promoted to PACs and professionals on an ongoing basis. For healthcare professionals, this means emailing reminders and regularly presenting the program's impacts to the clinical teams.

It would also be appropriate to present the main results and indicators each year at the program's statutory meeting and to the oncology department.

To promote the program to PACs, we recommend putting up posters or distributing flyers in offices and using the display screens in waiting rooms and social networking sites. It is also good practice to publish articles and advertisements in the facility's internal magazine, if there is one, but also to share the results during the cancer program's scientific activities.

Physicians and other professionals need to be reminded of the importance of regularly talking to PACs about the program, and ensuring that they have all the necessary tools, such as leaflets/signets, at their disposal. The distribution of leaflets/binders to professionals is always a good opportunity to tour services and remind them of the services offered.

Other ideas, such as sending e-mail reminders, organizing regular meetings, talking about successes, recognizing the importance of APs, highlighting their contribution and organizing activities for them keep stakeholders motivated.

Program results can also be showcased as part of the accreditation process.

TIPS AND KEYS FOR IMPLEMENTING AND DEPLOYING THE PROGRAM

GOVERNANCE	
Maintain the commitment of general management.	√
Keep general management informed on a regular basis.	√
Keep the main departments affected by the project informed.	√
Ensure that the working committee meets on a regular basis.	√

CULTURE	
Implement the program gradually.	√
Continue to develop a shared understanding and vision.	√
Ensure that the stakeholders' concerns are addressed.	√
Communicate regularly with new APs to assess their experience and encourage a sense of belonging.	√
Regularly remind professionals of the importance of referring PACs to APs, especially in new trajectories.	√
Ensure smooth communication between all parties.	√
Ensure that all decisions are being taken with APs.	√
Ensure that the APs' feedback to professionals is used to improve the quality and organization of care.	√
Encourage the participation of APs in the facility's various improvement committees.	√
Encourage the participation of APs in continuing education activities for professionals, especially physicians, for evaluations of their practice.	√

RESOURCES	
Ensure that the AP coordinator is able to coordinate the new trajectories.	√
Recruit APs based on the new trajectories and ensure that they represent a variety of profiles.	√
Provide one or more rooms for the APs.	√
Ensure the stability of human resources in place (coordinator, project manager, APs).	√
Constantly ensure that the number of APs available meets the demand.	√
Mobilize people in communications, with the support of APs, to publicize the service offering in the new trajectories.	√

TOOLS AND METHODS	
Involve experienced APs throughout the recruiting process.	√
Develop the kit used to implement the mechanism for placing APs in touch with PACs and for providing feedback to the professionals in the new trajectories.	√
Create communication tools (e.g., brochures, leaflets, PowerPoint presentations, videos, podcasts) for these new trajectories.	√
Organize recognition activities for the APs (e.g., annual AP day).	√
Create spaces where APs from different facilities can discuss their practices.	√
Host recognition activities for APs.	√
Measure the effects of all trajectories on the PACs, APs and professionals.	√
Measure the impact of the communications strategy on the various stakeholders.	√
Present evaluation results to professionals, APs and managers.	√

INDICATORS

- Number of APs recruited
- Rate of APs trained
- Rate of professionals who have taken the training
- AP retention rate
- % of PACs who met with an AP
- APs' rate of satisfaction with the experience
- PACs' rate of satisfaction with the experience

TOOLBOX - SECTION 2, STEP 5

Ensuring program sustainability

- Legal and ethical considerations
- Podcast: Qui sont les patients accompagnateurs ? Et quels enjeux entourent leur statut? With Catherine Régis and Marie-Pascale Pomey on H-podcast

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The status and roles of APs raise some ethical and legal issues. This can interfere with implementation of the program. This section addresses the rights and responsibilities of APs with the goal of providing a legal framework that will protect all stakeholders to the best of our ability. Five considerations are proposed here, to be taken into account during the implementation and development of the PAROLE-Onco program. They are presented in more detail in two articles [31, 32, 36-38].

PROTECTING THE INDIVIDUALS INVOLVED IN ACCOMPANYING PATIENT PROGRAMS

In order to deploy the PAROLE-Onco program in a climate that promotes trust, it is recommended that mechanisms are implemented that will allow patients, APs and professionals to feel protected. This protection relies on two distinct yet complementary legal mechanisms: (1) accompanied patients can seek compensation for a fault committed by a member of the clinical team who benefits from insurance protection in the event of such a lawsuit before the civil courts; and (2) accompanied patients can turn to the local Complaints and Service Quality Commissioner if they are dissatisfied with the services they received, or should have received, in the public health network. Both of these mechanisms are potentially applicable to the services provided by APs. To achieve this, here follows a few recommendations.

The facility defines the APs' activities in its internal policies and ensures that the APs limit themselves to these activities to avoid any confusion of roles. This is ensured in particular by the initial and continuous training of APs, which provides a framework for their activities. It also results in an explicit presentation by APs of their activities to patients and the clinical team. The activities of APs are part of the internal policies for introducing partner patients into various areas of the facility, which also include the roles and responsibilities of clinical teams enrolling APs.

It is recommended that the facility provide insurance coverage to APs to protect against potential civil litigation.

In addition, if an accompanied patient wishes to file a complaint against an AP, he or she can do so with the person in charge of complaints, such as the local Complaints and Service Quality Commissioner in Quebec.

FREE, INFORMED AND ONGOING CONSENT

The facility ensures that patients who receive support from an AP do so in a free and informed manner and that they can end it without any justification being required. To enable free and informed decision-making, patients receive information on the APs' scope of practice so that both APs and patients can make their decisions regarding the support services. Patients are encouraged to be accompanied by an AP to obtain information from the healthcare team so that they can exercise informed consent regarding the care and services they receive. The interventions help pair patients with APs of similar ethnocultural profiles.

APs may refuse to provide support services or cease support, provided that their decision is not based on discriminatory or malicious motives.

APs may be required to stop providing support if a significant deterioration in physical or psychological capacities is noted and this may have an impact on the relationship with the supported patient, endangering the AP or the supported patient.

RESPECT FOR PRIVACY AND CONFIDENTIALITY

APs cannot disclose information acquired during their support services except with the consent of the supported patient or in exceptional cases involving emergencies affecting the patient's health. In the vast majority of cases, they do not have direct access to the medical records of a supported patient, unless the patient consents to sharing their medical records. However, they have access to clinical data in the file to help them provide support under the best possible conditions.

Patients give oral consent for this information to be transmitted when they agree to be accompanied. APs may, with the patient's consent, contribute notes to the patient's medical record if deemed helpful. If the clinical team requests that an AP discuss a supported patient, the supported patient also needs to agree.

PUBLIC CONFIDENCE IN ACCOMPANYING PATIENT PROGRAMS

The PAROLE-Onco program establishes a basis for building public trust. To achieve this, APs are recruited on the basis of criteria that are predetermined and known to the candidates, including their skills in terms of support, their profiles, and their motivations, which must not be opportunistic (for example, to have better treatment themselves). Candidates are also informed of their scope of practice, as well as the possibility that their interventions may not be as successful as they may like. They are also told that they should not feel guilty if the support fails.

Before recruiting an AP, it is suggested that the facility perform a criminal background check to ensure that candidates have not been charged with or convicted of any offence or criminal act relevant to the skills required for their functions. APs are also encouraged to notify the facility of any criminal convictions/charges that alter their initial declaration.

To avoid any conflict of interest, APs cannot accept a bequest or donation from an accompanied patient. On a relational level, APs have supportive relationships with accompanied patients. This involves receiving certain confidential information with professionalism, refusing multiple invitations, or even determining the appropriateness of sharing personal contact information.

APs act with loyalty to the facility, which implies acting with honesty, not placing themselves in a conflict-of-interest situation, protecting confidential information, fulfilling a duty of discretion, and not harming the facility's business or reputation. They follow the directives of the care teams, unless they are irremediably incompatible with the statement of ethical principles applicable to APs. APs are encouraged to report situations that go against the best interests of patients.

RECOGNIZING THE CONTRIBUTION MADE BY ACCOMPANYING PATIENTS

APs may or may not be compensated for their support services. If they are not compensated, their activity cannot be classified as employment or self-employment. Often, they are compensated for the expenses (parking, meals, travel, etc.) generated during their interventions.

To ensure the safety and well-being of APs, they can be registered with the Commission des norms, de l'équité, de la santé et de la sécurité du travail (CNESST) to benefit from the protection provided by the Act respecting industrial accidents and occupational diseases.

The facility designates someone to be responsible for integrating APs in order to facilitate their arrival in the care team, detect any problems, and represent them if necessary. It is important to ensure a balanced distribution of APs among the teams and the implementation of a service to connect APs with each other.

The facility respects the ability of APs to commit and be available by adopting standards that will avoid having meetings scheduled during APs' working hours or at times unsuited to their physical capabilities; holding meetings in their absence when the issues discussed directly concern them; and over-soliciting APs.[36-38]

Figure 3: Summary of Ethical and Legal Considerations for Implementation of the PAROLE-Onco Program

ETHICAL CONSIDERATIONS

- Ensure that patients and APs act within a moral and respectful framework.
- Ensure trust and transparency between patients and APs.
- Protect the confidentiality of patient information.

LEGAL CONSIDERATIONS

- Provide a legal framework to protect the rights and responsibilities of all stakeholders.
- Ensure the implementation of recourse mechanisms in the event of a dispute.
- Legally protect paatients, APs, and healthcare establishments.

CONCLUSION

The beneficial effects of the presence of accompanying patients on the experience and quality of life of cancer patients have been clearly demonstrated. Accompanied PACs are less anxious and have a better understanding of what they are going through. They benefit from having the ear of someone who understands them, because their accompanying person has had a similar experience. The clinical teams have the opportunity to rely on a person of trust who can meet some of their patients' needs, other than clinical needs. In short, the role of the AP, combined with that of the clinical team, provides a "360-degree view of the PAC's needs," in the words of Dr. Israël Fortin.

Even before I met my radiation oncologist, Dr. Israël Fortin, I had done some research on him. To my surprise, I was able to read a brief biography of his career up to 2019. I was greatly impressed by his PAROLE-Onco program, which offers patients undergoing treatment for breast cancer someone to accompany them who had had breast cancer herself. Finally, a man who understood me, a doctor who understood women, a doctor who understood cancer patients. He was my hero. I was ready to become an accompanying patient without even having been accompanied.

During my first conversation with a member of his care team, the resident explained the program to me and offered me the opportunity to be part of this PAROLE-Onco program. I accepted with great pleasure, assuring him that I didn't need to be accompanied to be part of this initiative. I told her that I could have used someone to help me from the start of my process in November 2019, so I started my chemotherapy treatments and then the surgery process. It was too late for me, but not for others.

At the very beginning of my care process, I felt safe in the knowledge that the hospital would be my center of care for all aspects of my health, whether for cancer or any other needs for the next year. I also had access to a pharmacist, dietician and psychologist in the oncology unit. Information would be passed on to my family doctor.

In the chemotherapy treatment room, there was a volunteer who talked to all the patients, and when I saw her coming, I pretended to be asleep, I didn't want to talk, I was incapable of it. All my energy was spent living one day at a time, swimming in the murky waters of unfamiliar situations and processes: treatments and side effects, fears but above all the fear of surviving this cancer. I had to trust a group of strangers who were there to supposedly save my life.

During the Covid pandemic, there were no emotional support or sponsorship services, only one information session, a week before starting chemotherapy. I thought to myself, "no big deal" as I wasn't a "therapy for the sick" kind of person. This process would have depressed me more than anything else, not to mention that I wouldn't have had the physical or emotional strength to take part and experience the misfortune of others without being able to help. Chemotherapy was very difficult, and I kept pushing myself to overcome the "chemical" depression caused by the side effects. But I still hoped to make friends in the chemo room, but no one would look at each other, often evasive glances and sometimes terror in these women's eyes. It was the same at the Résidence Cantin (it was my summer camp) where I stayed for a month for the duration of my radiotherapy treatments, since I was living two hours from the hospital. Nobody talked to each other, nobody looked at each other, nobody wanted to hear each other's stories (except me).

On the 5th day after chemo, I started my survival plan. Given my career, I was a leader, training sales, marketing and technical support teams for architects in large North American companies in the field of industrial and commercial design. I rolled up my sleeves and applied everything I'd been teaching for over 30 years. To do so, I had to be tenacious, courageous and resilient, overcoming obstacles and finding solutions.

Anything to survive. I was extremely well supported by the oncology team at the hospital, including a super pivot nurse.

Despite all my efforts, my guidance and the services offered, there was a missing link in the chain to help me through the tough times, to keep me grounded and surviving without being at the beck and call of my husband, friends and family. They were suffering too, and I felt guilty. But I wanted people to respect my need to keep the secret of my cancer to myself and to decide who I would tell. The pressure to be respected

was unacceptable. People's comments, even those full of good intentions, the atrocious stories of their acquaintances and especially old stories. Also, cancer bothers some people in a selfish way; we take up space and they feel obliged to call us, which is very sad for the patient. For me, it was fear of the unknown; the word Cancer meant death, shame. Why is this happening to me, did I deserve this, am I going to die, lie so as not to worry others about my condition, we're very alone.

It was difficult socially too, life passing us by. Sometimes it goes by in slow motion, other times at lightning speed. We believe this will be the last moment before we die. Christmas with the family, a walk in the sun in a park, the last pizza in your favorite restaurant, being with your husband, petting your cat. Who would take care of my 96-year-old mother if I died before her?

Nobody understood me, because it's also a disease that you can't see, it's invisible. No one else can understand a woman afflicted with breast cancer except another woman who has lived through one, not even the pivot nurse or the doctor who have thousands of hours of experience with patients.

Even though we're all different people who have travelled different paths in our lives, our reactions are different, but at a certain point during our treatments, there's a crossroads of paths and emotions that are identical and that make us "click" together for life. A complete stranger looks at me the same way when we share that we both have breast cancer.

We have a transparent thread that runs from one heart to the other; we are sisters. He knits himself a string of pearls that stretches from one country/culture to another.

And then there's the judgment, the way people analyze us, asking what we've done to contract this great disease that's slowly killing us. Some people are afraid of catching it if they hear about it.

Fear of dying, of having your life cut short when you haven't finished living it, of preparing for retirement and then, poof! it blows up in your face and this could be the end. For others, it's having cancer when they're pregnant or shortly after giving birth.

All my career, I've worked inordinate hours year after year to make the companies I've worked for a success, as if they were my own and we were all just numbers. My radiation oncologist had explained to me that it's a bit of a lottery to have cancer, the number on the lottery ticket had been drawn and it's yours. But I don't understand, I'm not done living, I don't want to lose my hair, have my breasts removed, I don't want to be sick, for my environment to see me suffering from the consequences of my cancer.

The moment the word CANCER comes out of the doctor's mouth, there's a flash in our brain. We hear nothing but indescribable sounds coming out of the mouth of the person in front of us.

Me, I'm going to die ... everything we've done so far has been for nothing, since there's time to be happy, to enjoy retirement, to rest, and above all to do what we haven't done all these years for ourselves. It's not going to happen, the questions follow, like "my job", "my finances", "my husband", "I'm going to be sick as a dog", "how do I announce this", "who's going to want me", "if I survive, I'll never be like the others again?

We are given the following explanation: "Oh, madam, there may be many causes for your cancer, but in your case, anovulants for over twenty years (because I had very difficult periods from the age of 13). Having had a miscarriage (I cried so much). No children (impossible to have children because of endometriosis). Hormones for over 6 years (no one told me to stop after 5 years).

But why me? I never wanted any of this and now I'm being punished once again and now with breast cancer!

I wanted children ... I'm furious. You're overweight, lady (I've been to more than 6 doctors to try to find the reason for what's been happening to me over the past 9 months) ... and now I've got stage 3 hormone-dependent breast cancer.

It all made sense, except for this woman doctor who announced the diagnosis with such a cold, haughty tone of voice, pointing her finger at me to make me feel guilty.

Luckily, my surgical oncologist told me, "Ms. Carole, you won't like your year, but our mission here is to kill this cancer. We

have a 70% chance of saving you. I'll see you in 5 months after chemo, and don't worry, we'll rebuild you. Get used to me, we're going to see each other for the next 5 years (now 10 years)." It was from there that I let go and blew a little wind into my sail for the strength to carry on, to let myself go to be cared for by a team of cancer professionals. I counted down the days in my calendar until I saw my doctor again, because I knew it would be a new beginning then. It would be the beginning of the end for this cancer, before graduating from cancer school.

We're tired of calling the pivot nurse, the list of questions at each of our meetings with the oncologist, we don't want to disturb and it's hard not to talk about emotions, except in the context of explaining a behavior / symptom like depression, swollen legs, fever, nausea.

I'm going to live with legs and feet as swollen as big sausages for the rest of my life, aching all over, my complexion is green as a frog, my nails are gray, I'm swollen, I'll never go back to the way I was... it'll never stop. I look in the mirror and I don't recognize myself. Who am I?

Towards the end of my chemo treatments, I insist that the oncologist give me an ultrasound to find out where I stand with my lump under my breast and all the lymph nodes under my arm. The radiologist told me on the spot that no cancer was apparent, putting her hand on my shoulder, "Madame Carole, you must continue your treatments until the end. I left the room, took refuge in the bathroom and cried like a child. Until this year, I return to this place after my annual check-ups and I look at myself in the mirror with a look that is inexplicable, but I don't cry.

I also experienced a disastrous tragedy: 3 weeks after my diagnosis, my best friend of over 25 years' friendship was also diagnosed with three different cancers, including brain cancer, and died less than three months later. It was the end of the world, and I was unable to accompany her through her illness, to the brink of death, or to attend her funeral. I made a promise to Chantal that if my life was saved, I would volunteer for as long as possible to "move on to the next one", and in her memory.

So, going back to my first meeting with the radiation oncologist, he explained to me that I absolutely had to be accompanied by a patient-accompanist to better understand, I agreed but stressed that I didn't need one. At every appointment, he asked me a lot of questions about what I was going through. Later, he asked me to write down my story from the time I received the call to return for another mammogram and then a 2nd ultrasound. He explained that he had to make a presentation to the hospital doctors about his PAROLE-Onco support program, and that he wanted them to hear the story of a woman with breast cancer. He wanted to explain the importance of the patient companion program. He tells me he cried when he read the story, and he cries when he tells me this. Despite my illness, I was important to him, I was special, and he understood me. That's how I felt at that moment, and I too had tears in my eyes, but of gratitude, my Hero.

Then along came my guardian angel Ginette, my accompanying patient. I was her first patient, a first for both of us, and I still feel special. She takes time for me, a stranger ... even if I thought from the start that I didn't need anyone, I was wrong. By sharing her experience with me, not so much physically (not the same type of cancer), but socially, endurance, people's perception of us, our perception of ourselves, what people do for us, our fears, our beliefs, shame, loneliness etc., Ginette opened up to me. Ginette opened up to me very generously, as a stranger.

In short, at first she asked me questions to get to know me, but she also told me her story. I asked her questions because I didn't know what to say, closed up like an oyster wanting to keep my pearl intact at all costs. Two and a half hours later, she had pressed the button to open the doors of the elevator of my emotions... which allowed me

to cross the threshold and take responsibility for myself. I wasn't so different from her, I wasn't different from the others, I wasn't crazy, I was completely "normal". I was just sick. You can 't fix normal!!!

I talked to him so much that afterwards I had nothing to say to anyone... to anyone. But I didn't know I had anything to say to anyone for such a long time. We always want to keep a strong front in front of others, but Ginette understood that!

She understood all that, my Ginette! I wanted to be a 'Ginette' for someone else, to help, to listen, to support. I wanted to pay it forward. This reinforced my promise to 'pass it on'.

She understood the little gestures that touched me, such as the warm welcome I received from the care team at radiotherapy, and the radiation oncologist who looked me in the eye when I spoke to him. In the early days, my husband would make my cheese sandwich with lettuce, cut into wedges and fill my "lunch bag" during COVID because I wouldn't be able to eat much other than this, yogurt and applesauce. I could make my own lunch, but I was "special" because my husband did it for me. He was obliged to leave me at the hospital door without accompanying me to the treatments because of the COVID, which was the hardest thing for him. Four hours later I'd come out of the treatments with my scalp frozen in an ice helmet so as not to lose my hair, my libido through the roof, wanting to eat everything in my path for two days. Then, for the next five days, I'm sad all the time, doing the "pancake" on the sofa. I have Lola, my 18-year-old cat, my everyday companion, who comforts me with her warmth, knowing that I'm not doing well.

I really needed a Patient Companion, and today my radiation oncologist and I laugh about it when I'm asked to share, train and present.

I never thought I'd get to where I am now, sharing with you the Canadian-European project.

The care teams did everything they could to save my life, so I'm giving to the next.

But it doesn't stop when the treatments end. Then followed the long years of post-treatment illness, lymphedema, capsulitis, chemo-brain, weakened immune system, serial infections, digestive / gastrointestinal system, hormone therapy, osteoarthritis, surgeries, yet another reconstruction in spring 2025 and above all the hope of getting a lymph node transplant.

All the patients I've accompanied to date have a similar story to mine, some even worse. They are all so relieved after each of our conversations, a trust is established, a relationship of being, like a friend, a confidante for life.

I'm able to pierce through each patient's shield of emotions, minimize the fears they carry in their hearts at the start of the telephone conversation and guide them in the direction of a gentler, reassuring path to make their lives easier and equip them during and after treatment. I'm the solution woman, and that's why I'm able to internalize their drama and not let it destroy me personally, I move on to solutions.

I have to adjust quickly after about 15 minutes of conversation to know which path I'm going to take to take the patient to a new stage in their illness and feel that she's regaining control of the situation. They are part of the journey, participating in their care process.

I've helped women of different cultures, ethnicities, religions, elderly, sometimes the only way to communicate with her was via Google Translate, penniless ladies, without family, losing their jobs, families who believe that the devil has afflicted them with breast cancer, others that their spouses are divorcing them, the inability of their environment to understand and accept. A large percentage of couples divorce or abandon their relationship during the first months of treatment. Some patients believe they can beat cancer with herbs and teas, others believe it's a message from life and must let themselves die, while others refuse treatment for lack of information and knowledge. But that's the reality.

It's not a doctor's job to accompany their patient, except in the doctor/patient relationship. It's impossible to ask this of a doctor, except to demonstrate empathy and understanding.

It's a team effort with the accompanying patient to inform the health-care team of the patient's progress and the additional resources needed to help the patient heal faster, by offering complementary services.

Don't you think that all women with cancer deserve an accompanying patient?

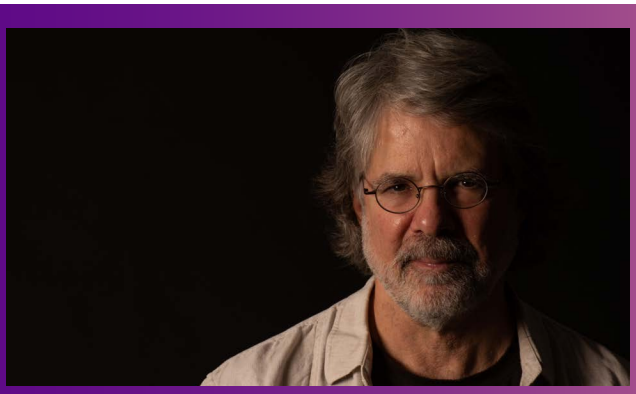
Do you believe that it's the responsibility of the doctor, oncologist, surgeon, nurse, nurse navigator, psychologist and others to do this accompanying work? Or should we leave them to navigate the labyrinths of the medical system alone, as I have done for years?

Can we understand, respect and treat patients according to their needs, based on their financial situation, level of education and age, rather than lumping them all together?

I, Carole, am not my cancer, and that's why I can help other women.

Thank you,

Carole Lespérance, accompanying patient,
breast cancer.



A few different sensations, unusual in my body, different from ordinary everyday life, PSA a little high but not so bad, a nice smooth prostate to the touch; we're not taking any chances, we're going to have a biopsy, the doctor tells me. And then, bang! the word cancer appears with the word prostate. Everything turns, the word is: dizzying. What's going on? Yes, I'm now part of the statistics. A worrying diagnosis, but optimistic messages about future treatments. Meeting with the radiation oncologist, meeting with the surgeon, both options are possible and favorable. It's not easy to make a decision, despite the presence of a truly available medical team and a supportive, empathetic and encouraging entourage. I find it hard to explain and express what's going on inside me. It's not like what you read in the papers, on the Internet or anywhere else; it's happening inside me.

The CHUM announces a conference on the subject; I call and a volunteer in charge of the support group calls me back. There's an immediate connection, an almost instantaneous understanding. "I've been through what you're going through; there are solutions, there are ways out of this disease." They don't sound the same when they've been through the same thing. These words sound good: "patient-partner". This person has been a patient like me, this person knows how to listen with patience and, above all, is a team player with me, like a true partner. Yes, it feels good, yes, it helps, yes, it gives you a grip on life and, above all, it gives you hope!

Marc, accompanied patient,
prostate cancer.

A few years ago, I went through one of the most difficult periods of my life: a prostate cancer diagnosis. It was a journey filled with uncertainty and fear. Even with good support from my doctor, I faced it alone, without someone to tell me: I've been there, and you can do it.

Today, I have the privilege of being that voice for others. As a volunteer with PAROLE-Onco at CHUM, I accompany people with prostate cancer through their therapeutic process. I listen to their fears, celebrate their victories, no matter how small, and walk alongside them on the road to recovery.

This work is deeply personal for me. It's not about sharing my story, but about offering empathy, strength and encouragement to those who need it most. No one should face such a journey alone.

Pasquale, accompanying patient,
prostate cancer

Testimonials from accompanying patients

"It gives so much meaning to what I've been through." **(Jeanne, PA)**

"Thanks to this project, I've met other APs and we help each other out." **(Jeanne, PA)**

"It's very rewarding to feel useful. There's a feeling of self-worth, and also a feeling of when you've been through a period in your life when you were afraid, afraid of dying, afraid of death, and the feeling of giving back. It's a feeling of well-being to help others. It allows us to give to the next. I've had, I've received in my life and now I'm giving back." **(Suzanne, PA)**

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