



PRACTICE CASE STUDY

PAROLE-Onco

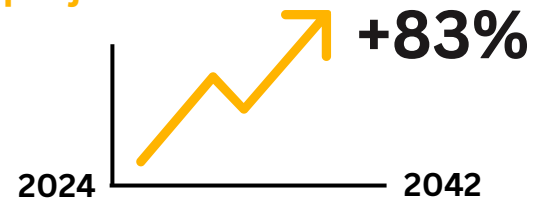
THEMES

- Accompanying patients (peer navigation)
- Peer support
- Improved patient experience
- Improved patient-provider communication
- Integrated clinical teams
- Psychosocial support
- Patient information & education
- Health equity

Cancer is the leading cause of death in Canada,¹ with Quebec having some of the highest incidence and prevalence rates in the country.²



1 in 2 of Canadians will be diagnosed with cancer during their lifetime, with cancer incidence projected to increase 83% until 2042.³



With the support of Canadian Institutes of Health Research and Quebec's cancer directorate within the Ministry of Health and Social Services, the **PAROLE-Onco** was implemented in 2019 in four healthcare organizations (HCOs) across Quebec to improve the experience of cancer patients through the **integration of accompanying patients (APs)** into clinical oncology teams.⁴

PAROLE-Onco currently has eight HCOs and is recognized as a **novel and complementary cancer care model** that offers cancer patients:

- Comprehensive emotional, informational, and educational support
- Navigation support throughout the care journey, including the diagnosis phase⁵
- Individualized interventions to support patients and their caregivers
- Assistance in clarifying medical information
- Facilitation of effective communication between patients and clinical professionals⁶

By integrating APs into the clinical teams, the model ensures that patients have continuous support from diagnosis through treatment and beyond, helping to alleviate the stress and anxiety associated with cancer care; but also to better understand the disease, the treatments and their side effects, as well as the activities that can help reduce these effects.





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“From the initial shock of the news (diagnostic), my accompanying patient proved to be essential support. His (the AP) regular telephone contact, weekly or at key moments, was particularly soothing. His telephone support was very effective, instantly dissipating stress, and his kind words were comforting.”

**-Accompanied
patient**

CHALLENGE

Half of Canadians can expect cancer diagnosis during their lifetime.⁷

In 2022, an estimated 60,000 Quebecers were diagnosed with cancer, averaging 158 new cases daily.⁸

This trend has been increasing and is expected to continue due to testing delays and backlogs from the pandemic.⁹ Along with an abrupt increase in cancer care costs, one of the significant challenges identified is the **lack of emotional support for cancer patients**, a need that has intensified during the pandemic **particularly for individuals from disadvantaged socio-economic backgrounds** who had additional difficulties accessing early diagnosis services and navigating the healthcare care system.¹⁰ Socio-economic disparities require adequate resource allocation, patient advocacy and stakeholder engagement.¹¹ Patients experience substantial **emotional distress, including depression, anxiety, and feelings of hopelessness**, yet there is a lack of structured emotional support within the healthcare system. Oncology nurses, who often play a crucial role in providing emotional care, report being overwhelmed and underprepared to address these needs effectively due to limited training and time constraints.¹² Moreover, not all patients have access to these nurses, the fragmented nature of current support services often leads to inconsistent care experiences, further exacerbating the emotional burden on patients. Without addressing the lack of comprehensive services, early cancer diagnosis initiatives are unlikely to achieve their intended impact.¹³ **Enhancing patient empowerment and advocacy is crucial** for achieving healthcare equity, particularly for women and other vulnerable populations who face significant challenges navigating the healthcare system and managing the burdens associated with a cancer diagnosis or genetic predisposition. Effective advocacy efforts and policies are essential to provide the necessary resources and assistance, **ensuring that all patients receive equitable care** and support throughout their healthcare journey.¹²



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“ I find it positive for patients to be with other people who have had cancer from which they have recovered, that there is long-term healing that exists. I find it encourages them to continue. ”

- **Accompanying patient**

SOLUTION

Targeted interventions and resource allocation are viable solutions to supporting all patients having equitable access to early diagnosis services, which will **improve overall cancer outcomes and reduce mortality rates**.¹⁰ In particular, streamlining these processes to ensure that they are **inclusive and accessible** to all patients is crucial for addressing disparities in care.

The PAROLE-Onco program supports individuals diagnosed with cancer by connecting them with an accompanying patient (AP) who has undergone a similar experience.⁶

The program started with four HCOs with breast cancer and now **covers eight Québec Health Care Organizations and several types of cancer**. The APs play a crucial role in facilitating **effective communication between the patient, their family, and their healthcare team**, tailored to the patient's expectations and capabilities. Acting as a liaison between multiple parts of the system, **APs inform clinical teams about the unique needs of the patients**, alleviate some of the workload of oncology teams and increase sensitivity towards the experiences of patients.⁵ The role of the AP is grounded in the ethical foundations of resilience, listening skills, and altruism, while also addressing both interpersonal and interprofessional relationships within the healthcare system.¹⁴ Often compared with patient navigators in other parts of Canada and patient experts in France, AP's most significant contribution builds on their **unique knowledge¹⁵ and direct experience with cancer**. APs play a significant role in helping patients understand medical information, manage their emotions, and feel more in control of their care journey. They also play a role in better understanding the disease and the treatment. Additionally, APs assist the cancer patients preparing for medical appointments to ensure all questions and concerns are addressed and help the patient understand the information provided by healthcare professionals, thereby **enhancing their overall comprehension of the diagnosis and treatment** and their ability to commit to their own care.^{4,5,6} All APs are trained in active listening, the limits of their roles, ethical issues related to support and the roles of each healthcare professional.



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ACHIEVEMENTS

Multiple studies demonstrated the efficiency and efficacy of the APs on the patients, their families, the oncology teams and the overall cancer care system as a service provider that often lacks the necessary resources to successfully address the patients' needs.^{4,5,6,16,17}

The most important achievements of this intervention are:

- Practical advice
- Patient empowerment
- Improved quality of life
- Improved quality and safety of care
- Patient provider communication
- Reduced health inequities¹⁶

Recent studies highlight that APs enhance patients' sense of empowerment and self-efficacy, and reduce psychological distress, contributing to a **more positive cancer care experience**.^{20,21} APs play a significant role in helping patients understand medical information, manage their emotions, and feel more in control of their care journey.²⁰ Additionally, it was found that multiple encounters with APs, as opposed to a single meeting, significantly improve the patients' understanding and emotional well-being.²⁰ Similarly, APs facilitate **better communication between patients and healthcare providers**, and help patients articulate their concerns and needs more effectively, which is crucial for improving patient satisfaction and outcomes.²¹

APs were **particularly beneficial for patients from disadvantaged socio-economic backgrounds** who often struggle more with communicating with healthcare professionals, navigating their care pathway, accessing comprehensible information about their health issues, and expressing their needs during consultations.^{17,18} However, these patients don't always recognize their needs and do not ask for additional help.





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FURTHER INFORMATION

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It should be noted that some patients reported difficulties in accessing APs due to a lack of awareness and systematic integration into the care process while others were not aware of the services APs could offer.

While legal concerns were identified in relation to the professional status of the APs who are not bound by the deontological code applicable to the medical professionals and in some clinical sites, APs are not allowed to participate in clinical team discussions without the express prior authorization of the patients,¹⁹ but they can exchange information with healthcare professionals that can help professionals better meet patients' needs.

Overall, **PAROLE-Onco represents a significant and innovative approach to improving the patient experience and the effectiveness of clinical teams.** From a clinical perspective, the implementation of PAROLE-Onco emphasized the importance of **creating supportive environments** where patients feel safe expressing their needs and concerns. This underscores the value of implementing tailored support interventions that address the specific needs of cancer patients, ultimately contributing to **improved patient experiences and outcomes in the clinical setting.**

NEXT STEPS

Moving forward, it is essential to delve deeper into the impact of the PAROLE-Onco program and **explore strategies to seamlessly integrate APs into clinical teams.** Future efforts should focus on securing an adequate selection, high-quality training of APs, and implementing communication campaigns within healthcare institutions to inform patients about the PAROLE-Onco program.²² The **program should be systematically offered to all patients** throughout their care pathway, providing a personalized approach to cancer navigation that promotes direct communication between patients and accompanying patients to enhance the patient experience and the professional quality of practice.

The program is currently being rolled out in Belgium and France, and will soon be implemented in Switzerland and Sweden.



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