

STEP 2 PROJECT CHARTER EXAMPLE

Systematization of the Accompanying Person program

CONTEXT IN WHICH THE IMPROVEMENT PROJECT IS HELD

Accompanying persons (APs) are women who have had one or more episodes of care at the CHUM, as part of a breast cancer predisposition or diagnosis. They are recognized for their expertise in dealing with health problems and using services. They are willing to share their experience to support new patients. They have received appropriate training for this role. Their expertise complements that of the clinical team. They are recruited, trained and coached by the CHUM.

Quebec is one of the provinces in Canada with the highest incidence and prevalence of cancer. In 2016, 21,300 people were diagnosed with cancer. In this context, cancer prevention and treatment are a public health priority. To address this, the MSSS has developed relevant and effective programs and tools.

Moreover, the importance of the patient partnership is increasingly recognized by the MSSS as one of the key levers for improving the quality and safety of health care and social services, since the current major reform of the Quebec healthcare system.

THE VISION OF PATIENT PARTNERSHIP

As a flagship institution in terms of patient partnership in Quebec, the CHUM has distinguished itself over the past 4 years by its avant-garde approach and expertise in developing and implementing projects that promote patient involvement at various levels of the organization.

Among other initiatives, the CHUM is putting forward a program to integrate resource patients, which aims to promote the participation of patients and their families as key players in improving the safety and quality of care and services.

A resource accompanying patient is a person who, at the end of an episode of care, wishes to put at the service of the organization the experiential knowledge he or she has acquired during the course of his or her clinical and organizational development, in order to contribute, alongside professionals and/or patients, to improving the quality/safety of the care and services offered.

These resource patients are recruited, trained and then invited to join working groups, according to their interpersonal and communication skills, in order to enrich the CHUM's service offering through their experiences of living with illness, and through the wealth of their expertise, which complements that of professionals and managers.

Many of these patients are invited to accompany CHUM patients with whom they share a similar care pathway, in order to share their experiential knowledge and offer support that complements that of healthcare professionals.

CLINICAL EXPERTISE - ONCOLOGY (CICC) - GENETICS

The *Centre intégré de cancérologie du CHUM (CICC)* is recognized by the *Direction générale de cancérologie (DGC)* of the *Ministère de la Santé et des Services sociaux* as a supra-regional center for the specialization and treatment of complex cancers. Specialists and professionals at the CICC work to advance clinical practices, both in terms of diagnostic examinations and proposed treatments. They are also involved in clinical, fundamental and evaluative research. They are grouped into 19 interdisciplinary teams, 16 of which are linked to tumor sites and three of which are dedicated to specific fields: palliative care, oncogenetics and radiation oncology.

The expertise of CHUM teams in the screening and treatment of hereditary female cancers, as conveyed by the teams and many of their patients, is widely recognized throughout the province. In fact, a number of initiatives and conferences are currently being offered to patients and their clinicians on various topics related to hereditary female cancers, through a network that brings together several of the province's hospitals.

Connecting patients with with the Rose Network resource patients diagnosed with a hereditary predisposition to cancer (most often associated with the BRCA1 and BRCA2 genes) is already providing access to certain information and resources for patients newly diagnosed with cancer or a hereditary predisposition to cancer. CHUM's genetics and gynecologic oncology clinics and departments are part of this initiative, although it is currently carried out on an ad hoc and informal basis by CHUM teams.

NURSING EXPERTISE

Nurses at the CICC have extensive experience in caring for people with female cancer or a genetic predisposition to this type of cancer. The CHUM's Designated Reference Center for Investigation (CRID) and the breast diseases and reconstruction clinic are under the leadership of a nurse clinician who is present with the patient and her family from the very start of follow-up in the clinic. Her expertise in this specialty is recognized throughout the network. She acts as a coordinator for both patients and other team members, and is responsible for teaching, listening and supporting patients.

STEP 2 PROJECT CHARTER EXAMPLE

Systematization of the Accompanying Person program

When a cancer diagnosis is made, the patient can be referred to a pivot nurse in oncology (PNO) if necessary. CHUM PNOs have in-depth expertise in oncology and in the site they specialize in, and are a role model for other PNOs in the network. The role of the PNO is fundamental in facilitating and guiding patients through the entire oncology trajectory. The key elements of her practice are customer support, coordination of the various stages of the trajectory, teaching and needs assessment, as well as preparation for surgery and vulgarization of medical care. More specifically, she ensures that the care plan (surgery, chemotherapy, radiotherapy and other therapies) runs smoothly, detects distress in patients and puts in place the caregivers who can best accompany the patient as required, as well as managing and dealing with the signs and symptoms associated with the disease and the ensuing treatments.

Finally, patients undergoing treatment are also in contact with the nurses who are responsible for administering the treatments. Again, this is a unique area of expertise, as the treatments involved are generally complex. As a complement, she also offers support and teaching to patients this stage of the trajectory.

PSYCHOSOCIAL AND SEXOLOGY EXPERTISE

The oncology psychologist can intervene at any stage of the patient's care trajectory, based on a request from the patient's medical team professionals. Psycho-oncological intervention aims to support the patient in the process of adapting to his or her medical condition and treatments, by working on one or more of the psychological dimensions. In this way, the oncology psychologist can:

- Carry out a psychological assessment by means of a clinical interview and/or psychometric tests (Reserved activities, cf. Bill 28)
- Assess patients' difficulties and resources, which may be cancer-related or caused by the disease, in order to promote better adaptation to the patient's current situation
- Welcome emotional reactions associated with cancer and provide a safe space (e.g. following disclosure of a diagnosis)

PROJECT DESCRIPTION

Systematize the service offering of a program for accompanying persons (APs) for patients with similar oncology experiences, in collaboration with the clinical genetics teams, the CICC, which includes the gynecologic oncology, hematologic oncology and radiation oncology teams, the *Service de bénévolat, d'animation et de loisirs du CHUM (SBAL)*, the *Fondation Virage/Centre de bien-être du CHUM*, the *Secteur de la promotion de la santé du CHUM*, the *Direction des soins infirmiers (DSI)*, the *Direction des services multidisciplinaires (DSM)* regrouping psychosocial professionals dedicated to tumor sites, the *Direction de l'enseignement et de l'Académie du CHUM (DEAC)* and the *Centre of Excellence on Partnership with Patients and the Public (CEPPP)*.

Considered a full-fledged partner of the team, the resource AP is invited to meet patients hospitalized or undergoing treatment at the CICCs integrated cancer center or gene medicine department on a voluntary basis, to share her experience. What's more, since she has already lived through a care experience similar to that of the patients she meets, the resource AP is a key player in establishing a real partnership between patients and all members of the care team. On the one hand, she can facilitate the sharing of patients' experiential knowledge and professionals' clinical knowledge, by helping to validate each person's understanding of the others' knowledge. At the same time, she can put her own experiential knowledge at the service of patients, notably by supporting professionals in their efforts to put in place treatment plans that meet patients' needs and foster their feelings of self-efficacy.

TARGET CLIENTELE

The initiative will initially focus on providing accompaniment opportunities via resource APs for the following clientele:

- Women with a gene mutation predisposing to breast cancer (panel of 21 genes)
- New consultations at the CHUM in specialties related to breast cancer (Cf. trajectory: primary, recurrence, partial and total mastectomy)

PROJECT GOVERNANCE MODEL

The governance model is based on co-construction, with two groups with complementary mandates: an advisory group and a working group.

STEP 2 PROJECT CHARTER EXAMPLE

Systematization of the Accompanying Person program

PROJECT TEAM MEMBERS, ROLES AND RESPONSIBILITIES

CO-LEADER OF THE CLINICAL COMPONENT - CARE | RESPONSIBLE FOR MANAGING THE CLINICAL COMPONENT

- Act as the project's clinical leader
- Collaborate closely with the project's organizational co-leaders in planning, coordinating, scheduling and monitoring of the project
- Participate in the work of the working group
- Support clinical team professionals in the project's experimental phase
- Embody change as a role model (exemplarity)
- Ensure that the project is consistent with the development of nursing practice
- Collaborate in the coordination of research-related work and participate in the dissemination of results
- Collaborate in the identification of APs, their training and integration into the clinical team

CO-LEADER OF THE PSYCHO-SOCIAL COMPONENT | RESPONSIBLE FOR MANAGING THE PSYCHO-SOCIAL COMPONENT

- Act as psycho-social leader in the project
- Collaborate closely with the project's organizational and clinical co-leaders in planning, coordinating, and monitoring of the project
- Participate in the work of the working group
- Support psycho-social team professionals in the project's experimental phase
- Embody change as a role model (exemplarity)
- Collaborate in coordinating research-related work and participate in disseminating the results
- Collaborate in the identification of APs, their training and integration into the clinical team

CO-LEADER OF THE CLINICAL-MEDICAL COMPONENT | RESPONSIBLE FOR MANAGING AND COORDINATING THE MEDICAL COMPONENT OF THE PROJECT

- Act as medical leader in the project
- Participate in the advisory and working groups
- Support the medical profession in the project's experimental phase
- Embody change as a role model (exemplarity)
- Collaborate in coordinating research-related work and participate in disseminating the results

CO-LEADERS OF THE ORGANIZATIONAL COMPONENT | RESPONSIBLE FOR MANAGING THE ORGANIZATIONAL COMPONENT OF THE PROJECT

- Act as organizational leaders in the project
- Collaborate closely with the project's clinical and psycho-social leader in planning, coordination, scheduling and monitoring of the project
- Support the collaboration of resource patients in the work of the advisory and working groups
- Participate in the organization, facilitation and work of the advisory and working groups (preparation of meeting agendas and minutes as required)
- Coordinate activities aimed at formalizing the process of recruiting, empowering (training), follow-up and coaching of APs
- Make the link between the project and the clinical practices required to foster partnership with patients
- Collaborate in coordinating research-related work and participate in disseminating the results
- Participate in research team meetings and circulate information within the two groups (advisory and working)
- Participate in coordinating the drafting of the summary report and in disseminating the results

STEP 2 PROJECT CHARTER EXAMPLE

Systematization of the Accompanying Person program

RESEARCH CO-LEADERS | RESPONSIBLE FOR MANAGING THE RESEARCH COMPONENT OF THE PROJECT

- Act as liaison between the clinical, psychosocial, organizational and research components
- Support the clinical and organizational co-leaders in the work of the two groups (advisory and work) (e.g. preparation of agendas and minutes, then in the stages of implementing the intervention)
- Participate in the coordination of work and meetings related to the research
- Contribute to the identification of factors facilitating or hindering the implementation of the intervention
- Contribute to the evaluation of the intervention
- - Procedures with ethics committees
- - Carry out data collection
- - Transfer of knowledge between APs, patients and professionals
- - Drafting tools and publications

ACCOMPANYING PERSONS | RESPONSIBLE FOR ACTING AS ACCOMPANYING PERSON FOR PATIENTS AND THEIR FAMILIES

- Sharing her experiential knowledge as a patient
- Sharing her experiential knowledge as a resource patient and drawing on her experience of involvement in other oncology projects (e.g. BraDay, screening for distress, ROSE network, etc.)
- Ensure that patients' experiential knowledge, preferences and needs are listened to and taken into account at every stage of the project
- Participate actively in the work of the advisory and working groups
- Participate in the coherent implementation of the deliverables with the reality of patients and accompanying persons
- Participate in deploying various deliverables and in project outreach
- Participate in the accompaniment, support and coaching of recruited APs in the deployment of the intervention
- Participate, under the responsibility of the psychology department, in supervision workshops and group discussions regarding the therapeutic relationship, ethics, etc.

CENTRE INTÉGRÉ DE CANCÉROLOGIE DU CHUM (CICC) | RESPONSIBLE FOR ENSURING THAT THE PROJECT IS CONSISTENT WITH THE CICC'S ORIENTATIONS

- Participate in the work of the advisory group
- Facilitate access to CICC resources to carry out the work
- Facilitate implementation of the intervention in the trajectory
- Collaborate with Dr. Pomey on the research component

PSYCHOLOGY/SEXOLOGY DEPARTMENT, SPIRITUAL CARE DEPARTMENT AND MULTIDISCIPLINARY SERVICES DEPARTMENT (DSM) | RESPONSIBLE FOR ENSURING THE PROJECT IS CONSISTENT WITH DSM ORIENTATIONS

- Participate in the work of the advisory group
- Ensure the project's coherence with the professional services it provides
- Support the development of training
- Act as a facilitator with the DSM
- Collaborate in the implementation and operation of supervision workshops regarding the therapeutic relationship

STEP 2 PROJECT CHARTER EXAMPLE

Systematization of the Accompanying Person program

SERVICE DU BÉNÉVOLAT ET ACTIVITÉS DE LOISIR (SBAL/CBE) | RESPONSIBLE FOR ENSURING THAT THE PROJECT IS CONSISTENT WITH SBAL ORIENTATIONS

- Participate in the work of the advisory and working groups
- Participate in the organization of AP training
- Coordinate activities aimed at formalizing the AP pairing process during intervention, training, follow-up and coaching of APs
- Collaborate in identifying APs

DIRECTION DE L'ENSEIGNEMENT ET DE L'ACADÉMIE (DEAC) | RESPONSIBLE FOR SUPPORTING THE DEVELOPMENT OF TRAINING IN LINE WITH DEAC GUIDELINES

- Participate in the work of the advisory and working groups
- Coordinate work related to the development of training in collaboration with the project's co-leaders
- Facilitate the planning and deployment of training

GENE MEDICINE DEPARTMENT | RESPONSIBLE FOR ENSURING THE PROJECT'S COHERENCE WITH GENE MEDICINE

- Participate in the work of the advisory and working groups
- Collaborate in identifying APs (prevention trajectory)
- Facilitate the program's implementation in the gene medicine department

CHUM'S DESIGNATED REFERENCE CENTER FOR INVESTIGATION (CRID), BREAST DISEASES AND RECONSTRUCTION CLINIC, CICC | RESPONSIBLE FOR ENSURING THAT THE PROJECT IS CONSISTENT WITH DSI ORIENTATIONS

- Participate in the work of the working group
- Collaborate in identifying APs

DIRECTION DES SOINS INFIRMIERS (DSI) | RESPONSIBLE FOR ENSURING THAT THE PROJECT IS CONSISTENT WITH DSI ORIENTATIONS

- Participate in the work of the advisory group
- Make links between the project and the various research projects of the DSI
- Facilitate resolution of problems linked with the DSI
- Act as a facilitator for the DSI
- Collaborate on research

DIRECTION DE LA QUALITÉ, DE L'ÉVALUATION, DE LA PERFORMANCE ET DE L'ÉTHIQUE CLINIQUE (DQEPE) | RESPONSIBLE FOR ENSURING THE PROJECT'S CONSISTENCY WITH DQEPE ORIENTATIONS

- Participate in the work of the advisory group
- Participate in supervision workshops regarding the therapeutic relationship

RESEARCHER IN CHARGE OF THE PROJECT | RESPONSIBLE FOR THE RESEARCH COMPONENT OF THE PROJECT AS PRINCIPAL INVESTIGATOR

- Coordinate the initial context analysis and ongoing evaluation of the collaboration between APs and professionals
- Formulate recommendations for sustaining and extending the care partnership model, developed in oncology, based on the results obtained and the expectations of key decision-makers in the healthcare network
- Participate in drafting the summary report and disseminating the results
- Participate in the work of the advisory and working groups

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MAIN OBJECTIVES OF THE IMPROVEMENT PROJECT

- By May 2019, to have recruited 3 to 6 resource APs to carry out interventions with patients.
- By September 2019, to have implemented the resource AP intervention.
- By May 2021, to observe an improvement, for patients who have benefited from a resource AP, in the patient experience (20% increase), quality of life (20% increase) and an increase in emotional well-being and adaptation to the demands of the care trajectory.

MAJOR PROJECT MILESTONES

1. Develop and describe the intervention
 - Theme to be addressed and intervention modality
 - Develop AP training
 - Team preparation and change management
2. Recruit and train APs
3. Implement the intervention
 - Implement the intervention: support teams and APs
 - Harmonize with existing structures (logistics)
4. Monitor and evaluate the intervention

INTERNAL STAKEHOLDERS

1. Genetic medicine team
2. Surgery team
3. Radiation oncology team
4. Hematologic oncology team
5. Direction de l'enseignement et de l'Académie du CHUM (DEAC)
6. The CHUM's Designated Reference Center for Investigation (CRID)
7. The Direction des soins infirmiers (DSI) (pre-op, day center, CLSC) and teaching clinics
 - Pre-admission
 - Pre-radiation therapy
 - Pre-chemotherapy
 - Hospitalization
 - Breast reconstruction
 - Day center
 - Leave
8. Oncology research nurse (breast cancer)
9. The CHUM's Centre intégré de cancérologie (CICC)
10. Outpatient Oncology Center
11. Social Services
12. Psychology and Sexology
13. Psychiatry

STEP 2 PROJECT CHARTER EXAMPLE

Systematization of the Accompanying Person program

14. Physiotherapy
15. Palliative Care Service (pain management)
16. Spiritual Care Team
17. Users' Committee
18. Service de bénévolat, d'animation et loisirs du CHUM
 - Kinesiologists
19. Fondation Virage/Centre de bien-être du CHUM
20. DQEPE health promotion department
21. CRCHUM
22. The CHUM's Direction des communications et de l'Accès à l'information

EXTERNAL STAKEHOLDERS

1. Quebec Cancer Foundation
2. Canadian Cancer Society
3. Quebec Breast Cancer Foundation
4. Ovaire espoir
5. Ovarian Cancer Canada
6. Belle et bien dans sa peau
7. Hope & Cope (Jewish General Hospital)
8. CanSupport (MUHC)
9. The Center of Excellence for Patient and Public Partnership (CEPPP)
10. Rose Network
11. Fonds Jason (30 years and under)

STRENGTHS, WEAKNESSES, OPPORTUNITIES AND THREATS ANALYSIS

The Strengths, Weaknesses, Opportunities and Threats analysis enables us to identify "mitigation strategies" to help us achieve our objectives.

This document is inspired by the collaborative program
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