



Observatoire
québécois de la
proche aide

The Quebec Observatory on
Caregiving is a hub for the
production, sharing and transfer
of reliable, essential and relevant
knowledge aimed at raising
awareness and fostering the
recognition of caregiving, the better
to support all caregiving stakeholders.

ACTIVITY REPORT 2024-2025

En partenariat avec :

Québec 

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1 A WORD FROM THE MANAGING COMMITTEE CHAIR

SYLVIE CONSTANTINEAU

MANAGING COMMITTEE CHAIR

In 2024-2025, the Observatory continued to build on the work of previous years.

As planned, we worked with the Centre of Excellence for Partnership with Patients and the Public (CEPPP) to assess how to better involve caregivers in the Observatory's various undertakings. Our aim was to get an impartial assessment, optimize their inclusion and improve the support they received throughout their involvement. The CEPPP's report has helped us identify areas for improvement that will strengthen an already strong collaboration.

As part of our ongoing efforts to improve awareness about caregivers, we also collected many first-hand accounts to expand our understanding of the caregiving experience and inform our publications. These stories provide a valuable counterpart to the work on trajectories discussed in this report.

In addition, the Observatory has agreed to be part of the efforts to make the health and social services system easier for caregivers to navigate (measure 17 of the government action plan).

In terms of influence, we're thrilled to note the steady increase in followers across our social media and distribution channels, pointing to a rising interest in our work.

The year ahead takes us into a new phase of strategic planning, one that must take into account the shift in dynamics brought about by the establishment of the government's new agency, Santé Québec. We must also consider the ongoing development of a national home support policy — an initiative that offers real hope in the face of the population's growing needs. Having much to contribute to this matter, we are keen to help highlight the essential role of caregivers in supporting family members and loved ones at home.

Planning for the coming years is shaping up to be rich in new developments.



2 A WORD FROM THE SCIENTIFIC DIRECTOR

OLIVIER BEAUCHET

SCIENTIFIC DIRECTOR OF THE OBSERVATORY

The year 2024-2025 saw us strengthen our strategic partnerships, including with the Institut national de santé publique du Québec (INSPQ) and the Institut national d'excellence en santé et services sociaux (INESSS). These collaborations support large-scale initiatives that range from monitoring caregiver health and well-being to assessing the implementation of the public policies enacted on their behalf.

The expert advisory committee was instrumental in guiding our reflection on the caregiving and recognition trajectories, two aspects that are key to better understanding the caregiver experience and improving access to the appropriate resources. Pooling our expertise has allowed us to make progress on issues that, until now, have remained largely unexplored.

Lastly, our scientific watch moved ahead with its mission of disseminating knowledge by gathering, analyzing and sharing the most recent publications on caregiving by Quebec researchers. The watch is an invaluable resource in terms of advancing research, informing action and providing solid evidence to support decision-making.

In closing, I would like to applaud the remarkable work of the entire team at the Observatory, whose commitment, thoroughness and creativity have made these results possible. The challenges facing us in the coming year, including our contribution to the next government action plan and the expansion of our trajectory approach, will call for the same level of mobilization.

Together, we will continue to drive forward the understanding and recognition of caregiving in Quebec.



3 A WORD FROM THE ADMINISTRATIVE DIRECTOR

TO NHU NGUYEN

ADMINISTRATIVE DIRECTOR OF THE OBSERVATORY

The past year saw me take the helm from my outstanding predecessor, Cindy Starnino, as Administrative Director of the Quebec Observatory on Caregiving. I am pleased to present the 2024-2025 Activity Report, which highlights key initiatives and achievements in our efforts to support Quebec's caregivers and caregiving stakeholders.

Our many partnerships continued to flourish throughout the year, generating productive synergies on promising projects launched to support caregiver health, wellness and life balance. There were many new partnerships, too, as reflected in the dozen-plus collaboration requests that have led to tangible initiatives.

With the instigation of preliminary reflections in anticipation of the next government action plan, caregiving in Quebec has crossed an important milestone. The Observatory and its team have contributed actively to the process, including by working with the Ministère de la Santé et des Services sociaux (MSSS) to organize the Journée nationale de concertation en proche aide, an important province-wide dialogue. Bringing together some 300 participants, the event was an opportunity to collectively consider the key themes that could inform the development of the action plan.

Guided as ever by the desire to acknowledge and raise awareness of the substantial contribution of caregivers, as well as by the importance of supporting them in their varying situations, our original publications of recent months focused on two primary topics: caregiver recognition/self-recognition; and caregiving trajectories.

To conclude, I would like to express my gratitude to our incredible team, who once again this year were exemplary in their diligence and commitment to raising awareness about caregivers and mobilizing caregiving stakeholders around reliable and objective information. Our discussions with the latter have affirmed the growing awareness and appreciation of our specific role.

We will continue to work closely with these partners to promote the well-being of caregivers in their every area of life.

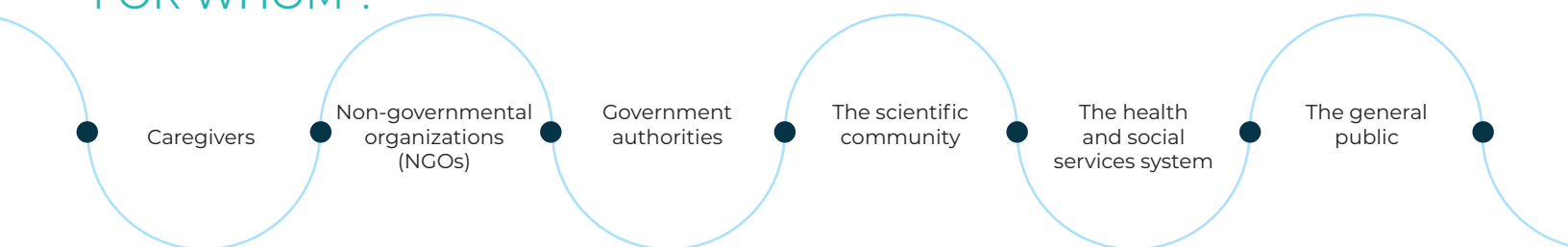


4 THE OBSERVATORY AT A GLANCE

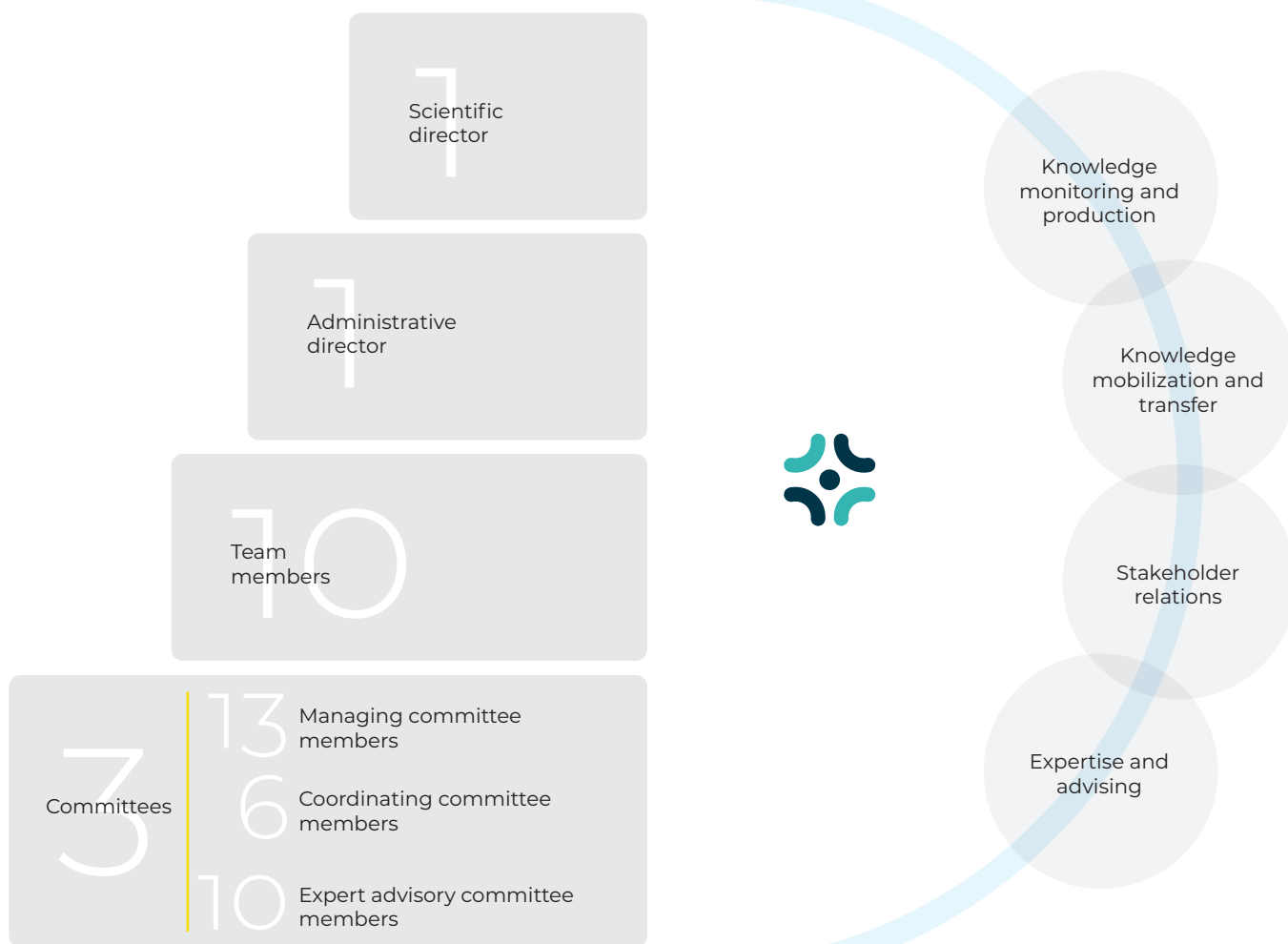
MISSION

To provide reliable and objective information regarding caregiving through observation, monitoring, analysis and knowledge sharing.

FOR WHOM ?



WHO ARE WE?



5 ACTIVITY REPORT

The team at the Quebec Observatory on Caregiving is proud to present this report on its activities for the period from April 1, 2024 to March 31, 2025. The report summarizes our initiatives and highlights a year that, rich in partnerships, teamwork, publications and consultations, has been marked by significant progress on many fronts for Quebec's caregivers.

The year 2024-2025 was particularly important for caregiving in Quebec, not least due to the start of strategic thinking toward the next government action plan — a process launched at the Journée nationale de concertation in October 2024. Working with the MSSS's Direction des Aînés et des proches aidants (directorate for seniors and caregivers), we set up a high-level dialogue that convened different partners around key challenges such as caregiving in oncological or end-of-life contexts; balancing work, life and caregiving responsibilities; caregiving trajectories; and life after the care journey.

For the Observatory, 2024-2025 was also an opportunity to maintain the dialogue with various caregiving stakeholders as well as to diversify our partnerships around structuring initiatives aimed at benefitting caregivers. Furthermore, we continued to promote external research and expertise by adding to our [Knowledge portal](#).

In terms of our influence, the past year saw a notable increase to subscriber and user numbers across our various distribution channels. We also intensified our presence at numerous knowledge-building events.

Lastly, we strengthened our capacity to mobilize and transfer essential caregiving knowledge by expanding our scientific watch in addition to publishing works on various key issues, including caregiver recognition/self-recognition and caregiving trajectories.

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5.1 THE YEAR'S HIGHLIGHTS

APRIL 2024

Presentation

[Panel on young caregivers, organized by the Communauté de pratique Proche aideance](#)

JUNE 2024

Publication

Fact sheet on recognition
[Helping caregivers self-identify: Strategies for professionals and practitioners](#)

SEPTEMBER 2024

Publication

Two caregiving trajectories

Young caregivers 

Parent caregivers of autistic children 

OCTOBER 2024

Co-organizer

[Journée nationale de concertation](#)

Presentation

- Opening panel on the day's topics, in cooperation with the partners' committee
- Dialogue workshop on caregiving trajectories

Presentation

[Opening panel of the intersectoral conference on family and friends in mental health care](#), organized by CAP santé mentale

JANUARY 2025

Publication

[First quarterly list of the scientific watch](#)

FEBRUARY 2025

Webinar

[Recognizing parent caregivers, in association with L'accompagnateur](#)

Workshop facilitation

The mental health caregiver trajectory, bringing together caregivers, peer helpers, researchers and community organizations (Ami Québec, Arborecence Québec, Cap santé mentale, La Boussole)


MARCH 2025

Presentation

[Journées de l'APPUI 2025](#)

Publications

- [Report on the ethical issues of caregiver recognition](#)
- 2 summary sheets

2nd annual scientific watch bulletin 

5.2 ACTIVITIES AND PUBLICATIONS

Throughout the year, we continued to highlight caregiving knowledge and expertise through our scientific watch, our original publications on the topics of caregiver recognition and caregiving trajectories, and the expansion of our knowledge portal.

SCIENTIFIC WATCH

The scientific watch on caregiving, whose aim is to track, collect and analyze the most recent publications in the field. By monitoring changing realities and needs, the watch serves to inform research, action and the decisions made on the caregivers' behalf.

168 Quebec caregiving **researchers** (65 added in 2024-25)

145 caregiving **researchers** in the rest of Canada

70 articles analyzed in the annual scientific watch bulletin

412 articles inventoried

Creation of a quarterly reference list

CAREGIVING TRAJECTORIES

Caregiving trajectories, whose aim is to identify key moments experienced by caregivers with similar profiles and analyze the factors that may influence their experiences. The insights thus gained increase the likelihood of offering the right services to the right person at the right time.

2 trajectories completed

Young caregivers

Parents caregivers of autistic children

4 ongoing trajectories

Caregiving in oncological contexts, in collaboration with Sylvie Lambert

Caregiving in mental health contexts

Caregiving in palliative care/end-of-life contexts, in collaboration with the Centre for Research and Expertise in Social Gerontology (CREGÉS)

Caregiving in contexts of ethnocultural diversity or immigration, in collaboration with the SHERPA University Institute

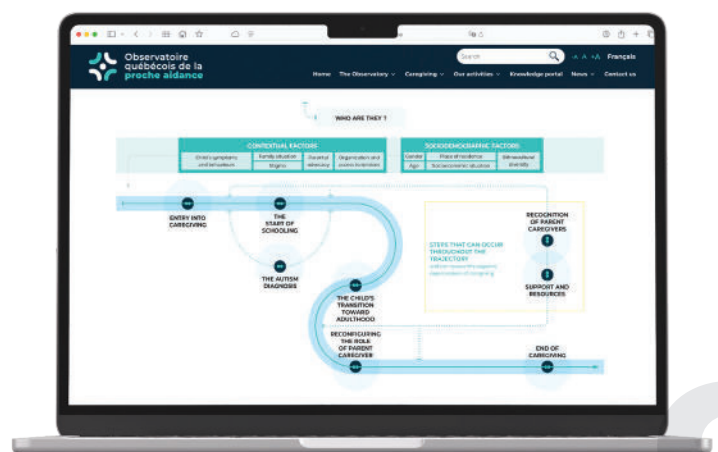
Workshop on the mental health caregiving trajectory. This event brought together caregivers, peer helpers, researchers, community organizations (AMI-Québec, Arborescence Québec, CAP santé mentale, La Boussole)

Workshop on caregiving trajectories at the Journée nationale de concertation

13 collaborations with caregivers, scientists and the community sector

Presentation at the Journées de l'Appui

CAREGIVING
TRAJECTORY



CAREGIVER RECOGNITION AND SELF-RECOGNITION

Widely acknowledged as the essential first step in supporting caregivers, recognition — both by others and by the caregivers themselves — broadens awareness of their needs and improves their access to the various available supports and services.

1 ongoing projects : improving young caregiver recognition through comic strips, in partnership with AMI-Québec, Proche aidance Québec, CAP santé mentale and the Regroupement des aidantes et aidants naturels de Montréal (RAANM)

1 report on the ethics of caregiver recognition

1 infographic on strategies for professionals and practitioners re. caregiver self-identity

1 video on recognition

5 joint initiatives with community organizations and caregivers

2 fact sheets

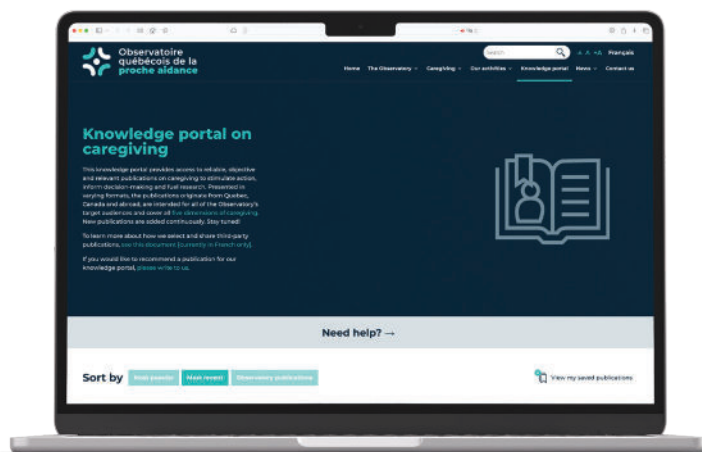
1 webinar in collaboration with L'accompagnateur

KNOWLEDGE PORTAL

An online library whose extensive collection of reliable and objective information on caregiving is easily accessed through its user-friendly format

100 publications highlighted

1332 users of the portal



5.3 INFLUENCE

NEWSLETTER

931

subscribers (+142 in 2024-25)

65 %

open rate



WEBSITE

14 000

users (9,800 new users in 2024-25)

20 %

of users in a given month consulted the site at least once a week

4,207 views

Knowledge portal

Most-viewed pages

4,051 views

Caregiving in Quebec

3,887 views

Interactive infographic: [What is a caregiver?](#)
[Would you know one to see one?](#)

SOCIAL MEDIA

Facebook

459

followers
(+230 in 2024-25)

92

publications

LinkedIn

577

followers
(+407 in 2024-25)

72

publications

5.4 PUBLIC ACTIVITIES

CO-ORGANIZER OF THE JOURNÉE NATIONALE DE CONCERTATION

Presentation (during the **panel to introduce the day's topics**) in collaboration with the partners committee

7 working sessions to inform the upcoming government action plan

workshop on the **caregiving trajectory**

27 collaborators led the workshops

425 participants

PRESENTATIONS

Young caregivers panel with the Communauté de pratique Proche aidance

CAP santé mentale

Webinar by L'accompagnateur

Journées de l'APPUI

PARTICIPATION IN VARIOUS EVENTS

Event held by the **Table de concertation régionale** sur les personnes proches aidantes de Montréal (TCRPAM) (regional roundtable on caregivers in Montreal)

Heart & Stroke summit

Mental Health Forum — AMI-Québec

Launch of L'Appui's "**CAP 18**" tool (a digital platform for parent caregivers dealing with the administrative complexities of special needs children turning 18)

CIUSSS West-Central Montreal **forum on caregiving**

Launch of the SHERPA University Institute **report**

Launch of the CAP Santé mentale tool, "**CAP Mieux-être**" (digital app to support caregivers in mental health contexts)



5.5 PARTNERSHIPS, COLLABORATIONS AND OUTREACH

INTERNAL CONSULTATION THROUGH OUR COMMITTEES

- 4 managing committee meetings
- 4 expert advisory committee meetings
- 9 coordinating committee meetings

CARTOGRAPHY

388 organizations identified in the cartography (+41 in 2024-25)

PARTNERSHIP AND COLLABORATION REQUESTS

27 partnership and collaboration requests processed through our collaboration framework and 15 of these were prioritized and led to activities

GOVERNMENT-APPOINTED PARTNERS COMMITTEE

Participation of the Observatory's managing committee vice-chair in partners committee meetings

Co-organization of a joint panel as part of the Journée nationale de concertation

PARTNERSHIPS WITH CAREGIVERS

18 personal accounts from caregivers that went on to inform 7 publications

Knowledge and skills building among caregivers and governing bodies working together in a partnership-based approach (measure 7 of the government action plan), in cooperation with the Centre of Excellence for Partnership with Patients and the Public (CEPPP)

1 analysis of caregiver partnerships within the Observatory, based on 12 interviews

1 presentation to the Observatory's managing committee

5 working sessions

STRATEGIC PARTNERSHIPS

Monitoring plan to track caregiver health and wellness (measure 2 of the government action plan): work is ongoing with the MSSS's Direction générale adjointe de la surveillance et de la planification en santé publique (public health surveillance and planning directorate) and the Institut national de santé publique du Québec (INSPQ)

- 8 working sessions

Statistical survey to develop a profile of caregiver health and wellness (measure 2 of the government action plan): work is ongoing with the Direction générale adjointe de la surveillance et de la planification en santé publique and the Institut de la statistique du Québec (ISQ)

- 2 orientation committee meetings to develop the survey questionnaire

Assessment of progress on the national caregiving policy (measure 33 of the government action plan): work is ongoing with the Institut national d'excellence en santé et en services sociaux (INESSS)

- 3 meetings

3 advisory committee meetings aimed at helping caregivers navigate the health and social services system (measure 17 of the government action plan)

Participation in the follow-up committee on caregiving in ethnocultural and English-speaking communities

Participation in working groups on developing terminology for caregiver training

Participation in the advisory committee for the SHERPA's research project on male caregivers who are immigrants or descended from migrants

6 LOOKING AHEAD TO 2025-2026

Continue developing **caregiving trajectories** and disseminating knowledge transfer products to inform stakeholders about key transition points and share best practices for supporting caregivers through these transitions.

Caregiving in **oncological** contexts, in collaboration with Sylvie Lambert

Caregiving in **mental health** contexts

Caregiving in **palliative and end-of-life care**, in collaboration with CREGÉS

Caregiving in contexts of **ethnocultural diversity** or **immigration**, in partnership with the SHERPA

Caregiving in the context of **Alzheimer's** disease or **dementia**, in collaboration with Véronique Dubé

Caregiving in **hospital settings**, in collaboration with Marie-Hélène Morin

Maintain **collaborations aimed at caregiver recognition**

- Recognizing young caregivers through the **publication of comics**, in partnership with AMI-Québec, Proche aideance Québec, CAP santé mentale and the RAANM

Work with various stakeholders toward a common understanding of caregiving by developing a **shared glossary**

Continue involvement and co-building initiatives with caregivers by establishing **engagement processes** based on the work of Centre of Excellence on Partnering with Patients and the Public (CEPPP)

Promote the Observatory and its mission by implementing a communications plan

Continue **collaboration** and **partnership** activities

Maintain key strategic partnerships

Actively promote and strengthen collaborative relationships with the partners committee and governmental action monitoring committee

Take active part in activities and events organized by our stakeholders

Highlight the Observatory's role as an expert advisor by disseminating its reference framework

Augment our contribution to discussions aimed at **shaping the next governmental action plan** on caregiving

Pursue the Observatory's development by taking steps to **implement the next strategic plan**

7 APPENDICE: TEAMS AND COMMITTEES

OBSERVATORY'S TEAM

The Observatory's development, coordination and administrative support have been entrusted by the Ministère de la Santé et des Services sociaux (MSSS) to the CIUSSS West-Central Montreal.

- Administrative direction
 - **Cindy Starnino**, Administrative Director of the Observatory, strategic consultant representing the CIUSSS West-Central Montreal (until November 2024)
 - **To Nhu Nguyen**, Administrative Director of the Observatory, representing the CIUSSS West-Central Montreal (as of December 2024)
- Scientific direction : **Dr Olivier Beauchet**, Faculty of Medicine, Université de Montréal
- Staff, Academic Affairs and Research Ethics, CIUSSS West-Central Montreal
 - **Mélanie M. Gagnon**, team manager and chief of knowledge translation
 - **Margaux Reiss**, team leader, project officer for the Knowledge Monitoring and Production pillar
 - **Alexis Pearson**, research professional, project officer for the Knowledge Mobilization & Transfer and Strategic Relations pillars
 - **Jennifer Lorena Cohen Reyes**, research assistant (until October 2024)
 - **Janie Dussault**, research professional
 - **Valentina Maninat**, administrative processes specialist (since October 2024)
 - **Camille Girard-Marcil**, research professional
 - **Diana Monzon-Sanchez**, communications professional
 - **Florence Potvin**, knowledge mobilization and transfer professional
 - **Virginie Tuboeuf**, administrative technician (until October 2024)
 - **Rym Zakaria**, librarian

The Observatory is also guided by three internal committees whose members represent different sectors and forms of expertise: the managing committee, the expert advisory committee and the coordinating committee.

MANAGING COMMITTEE

This committee determines the Observatory's scientific directions, general objectives and policies as well as its annual activities. It also assesses the relevance, priority status and scientific quality of the Observatory's programs and activities, working closely with two government-appointed committees: the Comité de suivi de l'action gouvernementale pour le soutien aux personnes proches aidantes (government action monitoring committee) and the Comité de partenaires concerné par le soutien aux personnes proches aidantes (partners committee).

- **Sylvie Constantineau**, committee chair, member from a non-governmental organization (NGO)
- **Marc Rochefort**, committee vice-chair, member from an NGO
- **Dr. Olivier Beauchet**, Scientific Director of the Observatory, Faculty of Medicine, Université de Montréal
- **Cindy Starnino**, Administrative Director of the Observatory, strategic consultant representing the CIUSSS West-Central Montreal (until November 2024)
- **To Nhu Nguyen**, Administrative Director of the Observatory, Director of Academic Affairs and Research Ethics, CIUSSS West-Central Montreal (as of December 2024)
- **Mélanie Couture**, researcher, Department of Psychology, Université de Sherbrooke
- **Véronique Dubé**, researcher, Faculty of Nursing Sciences, Université de Montréal
- **Sophie Éthier**, researcher, School of Social Work and Criminology, Université Laval
- **Sylvie Lambert**, researcher, Ingram School of Nursing, McGill University
- **Elizabeth Obregon**, member from an NGO
- **Carole Tavernier**, caregiver
- **Nathalie Tremblay**, government member, Ministère de la Santé et des Services sociaux
- Coming appointments: a caregiver from a First Nations and/or Inuit community and a member representing a ministry concerned with caregiver support

EXPERT ADVISORY COMMITTEE

Under Scientific Director Dr. Olivier Beauchet, this committee brings its specific expertise to bear on the identification of key priorities and specific topics. The varied expertise of its members serves to clarify objectives and priority themes and thus ensure the quality and impact of the Observatory's programs.

- **Dr. Olivier Beauchet**, Scientific Director of the Observatory, Faculty of Medicine, Université de Montréal
- **Anne Bourbonnais**, researcher, Faculty of Nursing Sciences, Université de Montréal
- **Isabelle Courcy**, researcher, Department of Sociology, Université de Montréal
- **Magalie Dumas**, member from a non-governmental organization, Assistant Executive Director of L'Appui
- **Martine Gélinas**, member from the health & social services system, social worker, specialist in clinical activities, home support and rehabilitation under the SAPA and DI-TSA-DP, CIUSSS de l'Est-de-l'Île-de-Montréal
- **Lucyna Lach**, researcher, School of Social Work, McGill University
- **Sylvie Lambert**, researcher, Ingram School of Nursing, McGill University
- **Marie Larose**, member representing specialized caregiving coordinators, CIUSSS de la Capitale-Nationale
- **Denise Juneau**, caregiver
- **Aude Villatte**, researcher, Department of Psychoeducation and Psychology, Université du Québec en Outaouais
- Coming appointments: member of an organization or ministry concerned with caregiver support

COORDINATING COMMITTEE

This committee oversees application of the guidelines from the Observatory's managing committee as well as from its strategic plan and annual work plan.

The committee consists of the Observatory's administrative and scientific management unit, various team members, and:

- **Michèle Archambault**, representative, Direction générale des Aînés et des Proches aidants, Ministère de la Santé et des Services sociaux (MSSS)
- **Charlotte Boudreau-Drouin**, caregiving consultant, Direction générale des Aînés et des Proches aidants, Ministère de la Santé et des Services sociaux (MSSS)



ACTIVITY REPORT 2024-2025

The Observatory's development,
coordination and administrative support
has been entrusted to the

**Centre intégré universitaire
en santé et services sociaux du
Centre-Ouest-de-l'Île-de-Montréal**

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