



Observatoire
québécois de la
proche aidance

ACTIVITY REPORT 2023 . 2024

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.

En partenariat avec :

Québec 

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1
A WORD

FROM THE MANAGING

COMMITTEE CHAIR



Sylvie Constantineau

Managing Committee Chair

An annual review is always intended as a marker of significance, a pause that lets us take stock of where we got to in the past year. Such a review is all the more important when it concerns an endeavour as ambitious as establishing a multi-faceted Observatory, a place where tangible and intangible achievements merge to propel us forward.

Readers who want concrete examples of our progress will be happy to note that things are going very well indeed. Our efforts are starting to bear fruit, not just in terms of our digital communications (including our website, webinars, newsletter and infographics) but also in our Knowledge Portal, an ever-expanding catalogue of publications from a diversity of caregiving stakeholders. Together, these various elements help ensure the transfer of knowledge and are part of our ongoing drive to develop and improve.

The milestones of the past year also cover aspects that, if less tangible per se, are just as crucial to laying the groundwork as a complementary, value-added caregiving stakeholder. These include our presence at the Journée nationale de concertation, an annual forum where we presented on the Observatory and its activities; our work with the Centre d'excellence sur le partenariat avec les patients et le public (CEPPP) to develop a model that supports caregiver involvement in the Observatory's activities; the contacts we've made to augment collaborative undertakings with the government-appointed Partners Committee; and above all, our substantial efforts to consult and involve caregiving stakeholders in projects aimed at fostering a growing synergy among all those who can make a difference for caregivers.

All told, it's been another year rich in achievements and I would like to thank all those whose hard work has contributed to our success.

Sylvie Constantineau

2.

A WORD FROM THE ADMINISTRATIVE DIRECTOR



Cindy Starnino

Administrative Director of the Observatory

As the Observatory's administrative director, I'm very proud to present the highlights of 2023-2024 regarding the work and initiatives undertaken to benefit caregivers and those who work on their behalf.

The past year presented many opportunities to promote the Observatory's knowledge and expertise. Fuelled by the desire to recognize and raise awareness of the invaluable contribution of caregivers as well as of importance of supporting them and their various realities, our original publications of recent months have focused on two key themes: recognition and self-recognition; and caregiving trajectories.

The knowledge produced by other stakeholders also came to the fore with the launch of the Knowledge Portal, an online catalogue that provides one-click access to reliable and objective publications, thanks in no small part to exhaustive selection and assessment process carried out by our team to ensure the dissemination of quality information.

In 2023-2024, we also increased our impact and raised our visibility by harnessing social media, attending numerous knowledge transfer events and developing a communication plan based on extensive consultation with our stakeholders.

We also set out to consolidate our collaborative efforts with different caregiving stakeholders around structuring initiatives in the government action plan. The intersectoral collaboration and partnership framework we have developed attests to the fruitful alliances formed as part of promising initiatives to promote caregiver health and wellness and a better work/life balance.

In closing, I would like to thank our team for their unwavering diligence in terms of raising awareness about caregiving and rallying stakeholders around reliable and objective information. Our discussions with the latter have affirmed the growing awareness and appreciation of our specific role in the landscape of caregiving support.

We will continue to work with them to promote caregiver wellness for many years to come!

A handwritten signature in black ink that reads "C. Starnino".

3.

A WORD FROM THE SCIENTIFIC DIRECTOR



Olivier Beauchet

Scientific Director of the Observatory

This past year has seen the Observatory, supported by its Expert Advisory Committee, launch a series of remarkable scientific initiatives aimed primarily at improving caregiver recognition in Quebec, work that highlights the critical importance of acknowledging and supporting those who take care of loved ones.

The effort has focused in part on formalizing the elements needed to produce a detailed statistical portrait of caregiving in Quebec, in partnership with the public health surveillance and planning directorate of the ministère de la Santé et des Services sociaux (MSSS) and the Institut national de santé publique du Québec (INSPQ). This portrait will provide essential information to guiding public policies and support programs. A good deal of focus has also gone into the discussion about caregiving definitions in a bid to shed light on the nuances and diversities of this often-complex reality.

Additionally, work on caregiving trajectories has begun to identify the challenges that caregivers face and the resources they need to continue their role while maintaining their wellbeing. The scientific watch bulletin has proved an invaluable resource, providing regular updates on advances in the field and serving as an efficient means of sharing knowledge.

Lastly, by partnering with major institutions, the Observatory promotes the kind of multidisciplinary approach and concerted action that will ensure maximum impact for its activities, publications and outreach in the drive to better support Quebec's caregivers.

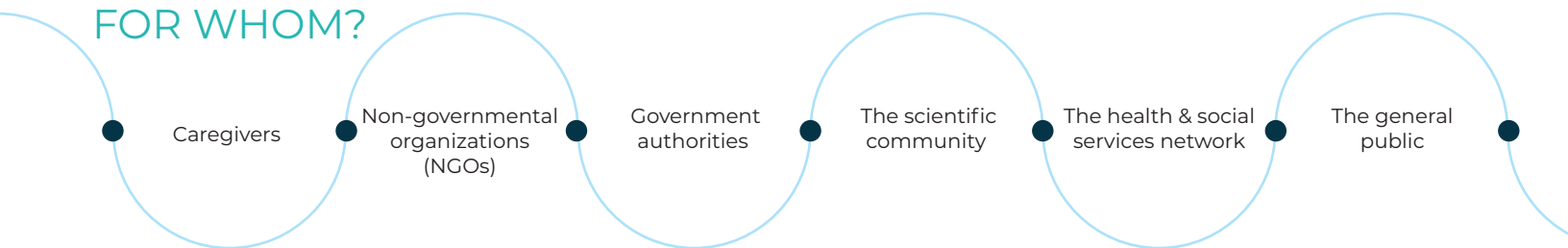
A handwritten signature in black ink, appearing to be 'O. Beauchet', written in a cursive style.

THE QUEBEC OBSERVATORY ON CAREGIVING

MISSION

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

FOR WHOM?



WHO ARE WE?¹

1 Knowledge monitoring and production

Collecting and analyzing data on caregiving.

1

scientific director

11

team members

1

administrative director

2 Knowledge mobilization and transfer

Adapting the knowledge gathered and/or produced by the Observatory and ensuring it reaches its intended audiences.

3 Stakeholder relations

Fostering dialogue and cooperation with all those involved in caregiving and engaging them in the Observatory's mission.

COORDINATING COMMITTEE

6

members

MANAGING COMMITTEE

12

members

EXPERT ADVISORY COMMITTEE

13

members

4 Expertise and advising

Assessing, guiding and/or recommending improvements in the caregiving sector, drawing on multiple forms of knowledge, skills and know-how.

¹ For details on our team and committee members, please see Appendix 1.

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, 2023 to March 31, 2024. The report covers the full range of our activities and summarizes our achievements and progress made over the course of one year.

The year 2023-2024 represented a high point for caregiving in Quebec, marking as it did the midway point of the 2021-2026 government action plan for caregivers. With the notion of recognition enshrined in its title (in French: Reconnaître pour mieux soutenir), the plan puts particular emphasis on acknowledging caregivers and their essential contribution by developing and transferring knowledge on the matter. The Observatory's activities over the past year align with this approach, notably in our original productions — particularly reports on caregiver recognition and statistical analyses —

released and distributed through our various channels, as well as in the launch of our Knowledge Portal. We have also furthered knowledge development by launching initiatives to support a caregiving/work/studies balance, looking into caregiving trajectories, and releasing our first communication plan.

Other significant events in Quebec in 2023-2024 include the first in-person Journée de concertation nationale, which brought together different caregiving stakeholders to bolster cooperation, spur action around measures to benefit caregivers and promote Quebec's caregiving expertise. For the Observatory, 2023-2024 was above all an opportunity to maintain the dialogue with various caregiving stakeholders as well as to form promising partnerships around structuring initiatives aimed at benefitting caregivers.

4.1 THE OBSERVATORY IN FIGURES

COMMUNICATION CHANNELS AND ACTIVITIES

789 newsletter subscribers

22 Facebook followers

7,479 Knowledge Portal users

17 LinkedIn followers

8,400 website users

6 presentations at knowledge transfer events

2 major reports

3 infographics

2 webinars

1 [scientific watch bulletin](#)

1 [Intersectoral collaboration and partnership framework](#)

1 stakeholder map with 350 caregiver organizations and 103 researchers

6 partnerships formed around 5 structuring projects

21 meetings with NGOs

4 Managing Committee meetings

4 Expert Advisory Committee meetings

4 participations in events

ORIGINAL, INFORMATIVE PRODUCTIONS

INSPIRING ACTIVITIES AROUND COLLABORATIONS, PARTNERSHIPS AND STAKEHOLDER RELATIONS

4.2 ORIGINAL, INFORMATIVE PRODUCTIONS

The past year allowed us to highlight the knowledge of different caregiving stakeholders through both our own original publications and the launch of our Knowledge Portal, a user-friendly platform that makes wide-ranging information on caregiving widely accessible.

Key caregiver statistics (using an age- and gender-based analysis) presented in a [report](#) and [two infographics](#).

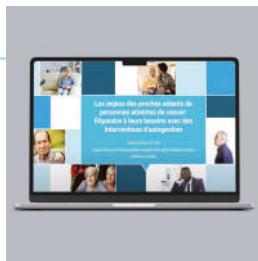


Caregiver recognition/self-recognition

- Publication of the interactive [infographic](#), “What is a caregiver? Would you know one to see one?”
- Publication of a [report](#) and [webinar](#) on caregiver recognition and self-recognition, including a summary of the current definitions, facilitators and obstacles to caregiver recognition and self-recognition, as well as the practices to promote it.



A webinar (in French) on the unmet needs of those who care for cancer sufferers and how to best support them. Presented in association with the Communauté de pratique Proche aideance.



Launch of Knowledge Portal, an online catalogue of reliable, objective publications on caregiving.

- Ongoing monitoring of caregiving publications to continuously expand the portal.
- Making the [process to select and disseminate third-party publications](#) (in French only) available online.
- Meetings with 10 NGOs to introduce the portal and strengthen ties with a view to future partnerships.
- Over 100 publications currently highlighted in the portal.²
- 7,479 users since its launch in June 2023.



Scientific watch

- **Launch of a scientific watch** of caregiving researchers in Quebec.
- **Publication of our first scientific watch bulletin** to track new articles published by researchers in the field of caregiving.



² One article may reference numerous publications.

4.3 PROMISING WORKS IN PROGRESS

In addition to these publications, the year 2023-2024 saw us launch a bunch of promising projects to support caregivers and caregiving stakeholders.

A summary sheet on balancing work/studies with caregiving responsibilities was written in consultation with several caregiving stakeholders.

The literature on caregiving trajectories was reviewed to determine pivotal moments and the best practices for supporting transitions in the lives of caregivers, including:

- Young caregivers
- Caregivers of cancer patients
- Caregivers of people with intellectual disabilities or autism spectrum disorders

The literature watch on caregiving in Canada and internationally was expanded.

The communication plan was deployed in view of establishing the Observatory's reputation and raising awareness of its mission and the importance of its role. Various means were used to identify the best strategies for developing the communication plan, including consultations with 10 stakeholders representing five types of target audiences, along with a SWOT analysis.³

The term “caregiving trajectory” refers to the moments and transitions in the caregiving relationship (itself defined as the provision of support to another person, whether or not this role is desired) experienced by a caregiver during one or more episodes of caregiving in his or her life.

³ SWOT: strengths, weaknesses, opportunities, and threats (to the structure).

4.4 COMMUNICATION CHANNELS AND VISIBILITY ACTIVITIES

The past year also presented numerous opportunities to raise our visibility and extend our influence, chiefly through our various communication channels and our participation in different knowledge transfer events.

3 newsletters

Subscribers: **789**
Click-through rate: **65%**

1 Website

Site visitors: **8,400**
Returning visitors: **1,800**
First visits: **8,200**

Top pages

- [Knowledge Portal](#) homepage
- [Caregiving in Quebec: A few figures](#)
- Interactive [infographic](#), "What is a caregiver? Would you know one to see one?"

2 social media pages

229 Facebook followers
97 Facebook posts
170 LinkedIn followers
16 LinkedIn posts

6 Presentations at knowledge transfer events

- Presentation at the ACFAS conference (Montreal)
- Presentation of the half-day session on strategic priority 2 of the Plan d'action gouvernemental pour les personnes proches aidantes 2021-2026 (led by the MSSS – online)
- Presentation and booth at the Journée de concertation nationale sur la proche aide (Quebec City)
- Presentation during two panel discussions at the Canadian Caregiving Summit, hosted by the Canadian Centre for Caregiving Excellence (CCCE) (Ottawa)
- Presentation as part of the Gender-Based Analysis plus (GBA +) training course led by the MSSS and the Secrétariat à la condition féminine (online)

4 Participation in knowledge transfer events

- Present at the Young Carers symposium organized by Ami Québec (Montreal)
- Booth at the Place aux proches aidants event organized by the Table de concertation régionale sur les PPA de Montréal (TCRPAM) (Montreal)
- Booth at the 2023 National Caregivers Week forum, CIUSSS West-Central Montreal (Montreal)
- Presence at the Rendez-vous Famille Choisie, held by the Fondation Émergence (Montreal)

1 We produced a [pamphlet](#) introducing the Observatory and a [leaflet](#) of our key milestones since our launch; both were aimed at publicizing our work to different caregiving stakeholders at various events.

4.5 INSPIRING ACTIVITIES AROUND COLLABORATIONS, PARTNERSHIPS AND STAKEHOLDER RELATIONS

As an information hub, the Observatory sets out to be a unifying, inclusive space for sharing knowledge working in sync with other caregiving stakeholders in Quebec and elsewhere, with a view to being mutually supportive and bringing to the fore the advances to date in the field. Our activities in 2023-2024 aligned with this vision through the rollout of a rich reflection process that formed the basis of the intersectoral collaboration and partnership framework; through updates to the stakeholder map; and through inspiring partnerships around structuring projects.

1 [Intersectoral collaboration and partnership framework](#) created to help guide decisions on how to prioritize joint initiatives suggested by the Observatory or its stakeholders. The framework promotes mutually beneficial collaborations between the Observatory and its stakeholders in keeping with the missions, visions and roles of the participating parties and in respect of their varying capacities.

1 updated stakeholder map bringing together:

- **350** stakeholders in Quebec, Canada and internationally (**43** added in 2023-2024)
- **103** Quebec researchers focused on caregivers

Occasions to get to know our stakeholders and raise our own visibility

- **21** meetings with caregiving NGOs
- **2** meetings of the follow-up committee on caregiving in ethnocultural and English-speaking communities
- Participation of the Observatory's managing committee vice-chair in Partners Committee meetings

Dialogue within the Observatory's committees⁵

- **4** Managing committee meetings
- **4** Expert advisory committee meetings
- **13** Coordinating committee meetings

5 development projects led in tandem with **6** partners:

- **The monitoring plan** to track changes in caregiver health and wellness (linked to Measure 2 of the government action plan), an ongoing collaboration with the public health surveillance and planning directorate of the ministère de la Santé et des Services sociaux (MSSS) and the Institut national de santé publique du Québec (INSPQ).
 - **14** project team meetings
 - **8** task force meetings to develop the monitoring plan
 - **2** follow-up committee meetings
- **The statistical survey** to establish a portrait of caregiver health and wellness (linked to Measure 2 of the government action plan), an ongoing collaboration with the public health surveillance and planning directorate of the ministry of Health and Social services (MSSS) and the Institut de la statistique du Québec (ISQ)
 - **6** steering committee meetings to develop the survey
- **The process to assess the attainment of national caregiver policy objectives** (linked to Measure 33 of the government action plan), an ongoing collaboration with the Institut national d'excellence en santé et services sociaux (INESSS).
 - **4** work team meetings
 - **2** follow-up committee meetings
- **The knowledge and skills development initiative** to further caregivers and governance body stakeholders to work together in a partnership-based approach (linked to Measure 7 of the government action plan), an ongoing collaboration with the Centre d'excellence sur le partenariat avec les patients et le public (CEPPP).
 - **1** managing committee training session and 2 work meetings
- A joint initiative regarding **co-productions and the merging of knowledge** is ongoing with the Communauté de pratique (CdP) Proche aide du CIUSSS de l'Estrie-CHUS.
 - **5** work meetings
 - **2** webinars produced jointly⁵

⁵ For more information, see "Original, informative productions."

⁶ For more information on each committee's mandate, see Appendix 1.

In 2023-2024, we concretized our vision through such achievements and activities as:

Varied output (reports, infographics, webinars) and the launch of the Knowledge Portal to provide diversified, reliable and objective knowledge to caregivers and caregiving stakeholders.

The many projects launched regarding caregiving trajectories and balancing work/ studies with caregiving responsibilities, as well as the rollout of a communication plan aimed at further promoting the Observatory and its activities.

The various distribution channels — website, newsletters, social media (Facebook/LinkedIn) — used to disseminate information to our target audiences.

Our presence at numerous external knowledge transfer events.

The release of our intersectoral collaboration and partnership framework, the furtherance of numerous partnerships, and meetings with a range of caregiving stakeholders.

The Observatory is heading into 2024-2025 on a high note. The desire to serve as a rallying point where knowledge can be pooled and communicated and where efforts can be aligned with other caregiving stakeholders continues apace, in view of achieving such aims as:

- **Expanding the current knowledge on caregiver recognition and self-recognition**, particularly as regards ethical issues and populations less apt to self-identify as caregivers (e.g. young caregivers, caregivers from ethnocultural communities), through the dissemination of infographics and other publications.

· 2 projects to encourage self-identification:

1 aimed at young caregivers

1 aimed at caregivers from ethnocultural communities

- **Continuing to document and develop caregiving trajectories** and share knowledge with stakeholders regarding key moments in caregiver life paths and the best practices for supporting transitions.
- **Expanding the scientific watch** on caregiving to include Canadian and international publications and releasing an annual bulletin that reports on caregiving trends.
- **Working with other caregiving stakeholders, establish a lexicon** of caregiving terms.
- **Documenting and promoting caregiver expertise and perspectives** by compiling personal accounts into a database and establishing knowledge co-construction and sharing mechanisms.
- **Using the communication plan to boost visibility** of the Observatory and its mission.
- **Continuing our collaboration and partnership activities:**
 - Implementing the intersectoral collaboration and partnership framework, using the established prioritization criteria to gauge which collaborations or partnerships to pursue.
 - Consolidating collaborative relationships with the committees established under the Act to recognize and support caregivers, i.e., the partners committee and the government action monitoring committee.
 - Actively participating in activities and events organized by our stakeholders.
 - Planning a mobilizing activity for caregiving stakeholders focused on knowledge transfer.
- **Finalizing the Expertise and advising reference framework.**

6.1 TEAMS AND COMMITTEES

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



Support staff,
Academic Affairs and Research Ethics Directorate (AAD),
CIUSSS West-Central Montreal

Mélanie M. Gagnon,
team manager and chief of knowledge translation (since July 2023)

Christiane Montpetit,
team manager and executive coordinator (until July 2023)

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 Stakeholders Relations pillars

Cassandra Bois,
communications professional

Jennifer Lorena Cohen Reyes,
research assistant

Janie Dussault,
research professional

Camille Girard-Marcil,
research professional

Diana Sanchez,
communications professional

Florence Potvin,
research professional

Virginie Tuboeuf,
administrative technician

Rym Zakaria,
librarian

The Observatory also relies on the input of **three internal committees** whose members represent different sectors and forms of expertise.



6.1.1 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/activities and works closely with two external committees established under the Act to Recognize and Support Caregivers: the Comité de suivi de l'action gouvernementale pour le soutien aux personnes proches aidantes (government action monitoring committee) and the Comité de partenaires concernés par le soutien aux personnes proches aidantes (partners committee).

- **Sylvie Constantineau**

Managing Committee Chair,
Member from a non-governmental organization (NGO)
Arborescence (formerly the Association québécoise des parents et amis de la personne atteinte de maladie mentale [AQPAMM])

- **Marc Rochefort**

Managing Committee Vice-Chair,
Member from a non-governmental organization (NGO)
Regroupement provincial des comités des usagers (RPCU)

- **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

- **Philippe Bériault**

Government member
Ministère des Finances

- **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,
Heart and Stroke Foundation of Canada

- **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

6.1.2 EXPERT ADVISORY COMMITTEE

Under Scientific Director Dr. Olivier Beauchet, this committee brings its specific expertise to bear on the Observatory's key priorities and specific topics. The varied expertise of its members serves to clarify objectives and priority themes so that Observatory programs and activities may attain a high level of quality and have the desired impact.

- **Dr Olivier Beauchet**

Scientific Director of the Observatory,
Faculty of Medicine,
Université de Montréal

- **Anne Bourbonnais**

Researcher,
Faculty of Nursing,
Université de Montréal

- **Isabelle Courcy**

Researcher,
Department of Sociology,
Université de Montréal

- **Jessica Darilus**

Caregiver

- **Sahon Chimène Dro** (until January 2024),

Member from the health & social services system
Home support social worker,
Physical disability service,
CIUSSS de l'Est-de-l'Île-de-Montréal

- **Magalie Dumas**

Member from an NGO – Assistant Executive Director,
L'Appui pour les proches aidants

- **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 programs,
CIUSSS de l'Est-de-l'Île-de-Montréal

- **Lucyna Lach**

Researcher,
School of Social Work,
McGill University

- **Mathieu Lacombe**

Caregiver

- **Sylvie Lambert**

Researcher,
Ingram School of Nursing,
McGill University

- **Marie Larose**

Member representing specialized
Caregiving coordinators,
CIUSSS de la Capitale-Nationale

- **Aude Villatte**

Researcher,
Department of Psychoeducation and Psychology,
Université du Québec en Outaouais

- **Denise Juneau**

Caregiver

- Coming appointments: member of an organization or ministry concerned with caregiver support

6.1.3 COORDINATING COMMITTEE

The Coordinating Committee oversees application of the guidelines set out by the Observatory's Managing Committee and in 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)



Observatoire
québécois de la
proche aide



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**

3755, chemin de la Côte-Sainte-Catherine
Montreal (Québec) H3T 1E2

info@observatoireprocheaide.ca