



Observatoire
québécois de la
proche aide

ACTIVITY REPORT

2022-2023

En partenariat avec :

Québec 

Summary

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, to better support all caregiving stakeholders.

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A word from the Managing Committee Chair

The Managing Committee remains focused on the Observatory's output and its capacity to regularly deliver resources to support caregivers. As the following pages will make clear, this year once again saw major efforts go into the various areas under development at the Observatory.

There are two things of which I am particularly proud:

- ▶ The release of the first productions in support of caregivers, e.g., those that set out to encourage recognition of the important role played by caregivers and self-recognition as a caregiver by those who assume that role.
- ▶ The colossal work undertaken to launch our Knowledge Portal: a pooled resource that makes quality productions from caregiving stakeholders easily accessible and widely available.

Advances like these are ongoing, bringing us ever closer to the Observatory's mission of serving as an information hub and a catalyst for caregiver recognition and support.

Of course, much remains to be done; setting up an observatory is a lengthy task. To these ends, we met twice with Quebec Health and Seniors Minister Sonia Bélanger, who assured us of her firm belief in the need to maintain efforts to support family caregivers and of her unwavering support for our mission.

In closing, while all this work is very much a team effort, I would like to thank in particular Christiane Montpetit, staff coordinator and a key architect of the Observatory's implementation. As the year draws to a close, she is preparing to take her well-earned retirement. We warmly wish her all the best.



A handwritten signature in black ink that reads "Sylvie Constantineau".

Sylvie Constantineau
Managing Committee Chair

A word from our directors

Administrative Director

As the administrative director of the Quebec Observatory on Caregiving, I am very proud to present this overview of our activities for 2022–2023.

This year saw the Observatory make its presence felt on the caregiving landscape, with the rollout of a strong visual identity and a free, accessible, user-friendly website housing our first original productions. We also began disseminating our work and activities through newsletters.

The Observatory pooled its expertise around various structural initiatives, partnerships and collaborations with different caregiving stakeholders who are part of the government's action plan for caregivers. These multiple initiatives attest to successful teamwork within the framework of various forward-looking projects to improve the lives of caregivers.

In terms of circulating the knowledge and expertise of the field's many stakeholders, the Observatory gave serious consideration to how best to amplify third-party publications. This entailed developing guidelines for the selection process and announcing the launch of the Knowledge Portal, a single platform bringing together these varied publications.

This report also shows how the Observatory has maintained and strengthened its collaborative approach to governance, notably by forming an Expert Advisory Committee whose members represent a wide array of caregiving profiles and knowledge backgrounds.

To conclude, my sincere thanks go out to our team and their unflagging efforts to offer original, reliable and objective productions aimed at raising both awareness of caregiving and the visibility of the Observatory. I have every confidence that the Quebec Observatory on Caregiving is here to stay and that it will only continue to develop, deploying its mission for many years to come, working in tandem with its partners and the different caregiving stakeholders.



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

Cindy Starnino
Administrative Director of the Observatory

Scientific Director

In 2022–2023, the Quebec Observatory on Caregiving launched an ambitious strategy to raise awareness of what caregiving is and who caregivers are. From the get-go, the Observatory has been on a mission to define caregiving in all its complexity, diversity and repercussions, and put these notions into circulation. Various tools, including a website and a comprehensive infographic, as well as collaborations with key partners have been undertaken to make these concepts more readily understandable.

The year was also noteworthy for the productive encounters that brought together individuals with diverse views and from differing areas of expertise. The newly created Expert Advisory Committee supported the Observatory's team by assessing the quality and relevance of the work undertaken in the area of knowledge production. This inclusive approach is what guarantees the quality and value of the studies and recommendations the Observatory presents to Quebec society.

Close working relations were established with such authorities as the Ministère de la Santé et des Services sociaux (MSSS) and the Institut national de santé publique du Québec (INSPQ). These strategic partnerships were created to provide the government with reliable data on caregiving, the better to clarify caregivers' needs and foster the development of appropriate public policies.

In strengthening these alliances, the Observatory positions itself as an essential reference in the field. Our job is twofold: we actively contribute to raising awareness among the general public as to the vital role of caregiving while providing essential information to those who take on this role.

Through its ongoing efforts to promote the inclusion and recognition of caregivers, the Observatory is helping to build a society whose bywords are solidarity and caring.



A stylized, handwritten signature in black ink, consisting of a large, looping 'O' and 'B' followed by a long horizontal stroke.

Olivier Beauchet
Scientific Director of the Observatory

Observatory on Caregiving

Mission and roles



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

For whom?

- ▶ Caregivers
- ▶ Non-governmental organizations (NGOs)
- ▶ Government authorities
- ▶ The scientific community
- ▶ The health & social services network
- ▶ The general public

How?

- ▶ Through four strategic pillars:
 - Knowledge monitoring and production — by collecting and analyzing data on caregiving.
 - Knowledge mobilization and transfer — by adapting the knowledge gathered and/or produced by the Observatory and ensuring it reaches its intended audiences.

- Stakeholder relations — by fostering dialogue and cooperation with all those involved in caregiving and engaging them in the Observatory's mission.
- Expertise and advising — by assessing, guiding and/or recommending improvements in the caregiving sector, drawing on multiple forms of knowledge, skills and know-how.

Teams and committees

The Observatory's development, coordination and administrative support has been entrusted to the CIUSSS West-Central Montreal.

Administrative Director: Cindy Starnino, strategic consultant representing the CIUSSS West-Central Montreal

Scientific Director: Dr. Olivier Beauchet, Faculty of Medicine, Université de Montréal

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

[Christiane Montpetit](#), Executive Coordinator, AAD
[Margaux Reiss](#), research professional, project officer for the Knowledge Monitoring and Production pillar

[Alexis Pearson](#), research professional, project officer for the Knowledge Mobilization & Transfer and Stakeholder Relations pillars

[Camille Girard-Marcil](#), research professional

[Cassandra Bois](#), research professional

[Diana Monzon-Sanchez](#), communications intern

[Virginie Tuboeuf](#), administrative technician

[Rym Zakaria](#), librarian

Other committees

The Observatory also relies on the input of three committees whose members represent a range of sectors and forms of expertise:

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 the Monitoring Committee (Comité de suivi de l'action gouvernementale pour le soutien aux personnes proches aidantes) and the Partners Committee (Comité de partenaires concernés par le soutien aux personnes proches aidantes). For the members list, [click here](#) or [see Appendix 1](#).

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 can attain a high level of quality and achieve the desired impact. For the members list, [click here](#).

Coordinating Committee

This committee oversees the implementation of the Managing Committee's orientations, the strategic plan and the annual work plan. For the members list, [click here](#).

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, 2022 to March 31, 2023. The report covers the full range of our activities and summarizes our achievements and progress made over the course of one year.

After the sustained effort to put the Observatory on a solid footing, the past year was a time to start building on what had been established. A noteworthy achievement in this sense was the finalization and introduction of the Observatory's collaborative approach to governance, which is based on representing multiple types of knowledge.

The year 2022–2023 also saw the contribution of new insights into caregiving with the release of the Observatory's first original productions. With this came a [new website](#), a striking new

visual identity and new distribution channels, all of which have helped cement our position on the Quebec caregiving landscape. The dialogue with various caregiving stakeholders, specifically with regard to cooperation mechanisms, also continued. Lastly, the past twelve months have been marked by a surge in the dissemination of Quebec caregiving expertise in general and that of the Observatory's members specifically, not just through partnerships and projects linked to structural initiatives in the [government's action plan for caregivers](#), but also through the creation of the Observatory's Expert Advisory Committee.

To find out more about our activities in 2022–2023, the following sections summarize the main undertakings linked to our cross-cutting priority and strategic pillars.



Cross-cutting priority

To build stakeholder confidence, cohesion and engagement in the Observatory, the past year saw us strengthen our foundations and our collaborative approach to governance. Our actions and activities attest to this consolidation process, which translates into the inclusion and representation of diverse member profiles and forms of knowledge in our governance structures. It also includes various appointments and designations, all of it enriched by the opportunities we have taken to present and discuss our governance approach with multiple caregiving stakeholders.



The strengthening of our foundations and collaborative governance to build trust and promote stakeholder engagement



Reinforcement of our connections through appointments and designations

- **Appointment** (by the minister) of the Observatory's **Managing Committee Chair**, Sylvie Constantineau, and its **Vice-Chair**, Marc Rochefort, two members from non-governmental organizations
- **Appointment** of Managing Committee Vice-Chair Marc Rochefort as the Observatory's **representative on the Partners Committee**¹
- **Appointment** of two government representatives, Nathalie Tremblay (MSSS) and Philippe Bériault (Ministère des Finances), to the **Managing Committee**

¹ Comité de partenaires concernés par le soutien aux personnes proches aidantes established by the *Act to recognize and support caregivers*.



Establishment of an inclusive governance model that recognizes diverse profiles and forms of knowledge

- Ongoing work by the Managing Committee (10 members who met five times) and launch of the Expert Advisory Committee (9 members)
 - ▶ **Cross-sectoral membership**
 - 4 members from an NGO
 - 2 members from a government organization and 1 other member still to be recruited
 - 2 caregivers and 2 other members still to be recruited
 - 2 members from practice settings
 - 8 members who are researchers
 - ▶ **Members with multiple forms of expertise**
 - In relation to the profiles of informal caregivers: those who care for people undergoing loss of autonomy or who have a degenerative illness, an intellectual disability, cancer or a mental health disorder; young caregivers; parents who are caregivers
 - In relation to health & social services disciplines/fields: social work, medicine, geriatrics, nursing sciences, sociology, physiotherapy, psychology, gerontology, psychoeducation
- Representation and inclusion of **different types of knowledge** (scientific, experiential, practical, contextual)
 - ▶ Publication of the *Processus de sélection et de diffusion des publications tierces*, which came together through an extensive consultation process on the part of our various committees
- Start of involvement in the **Comité provincial en proche aideance pour les communautés ethnoculturelles et de langue anglaise**²
 - ▶ 2 meetings in 2022-2023
 - ▶ Participation in **consultations with ethnocultural organizations** in February 2023

² Comité provincial en proche aideance pour les communautés ethnoculturelles et de langue anglaise, affiliated with the University Institute for Ethnocultural Communities (SHERPA) at CIUSSS West-Central Montreal.



Engaging presentations on governance

- Collaborative workshop with **19 caregiving NGOs**
- **3 meetings** with government ministers and their cabinets:
 - ▶ Marguerite Blais, June 2022
 - ▶ Sonia Bélanger, December 2022 and January 2023
- Publication of our governance structure on our website



Knowledge Monitoring and Production

In terms of Knowledge Monitoring and Production, the past year saw the Observatory work to promote a shared and informed view of caregiving among key stakeholders. A knowledge production and publication plan was developed based on input from multiple stakeholders. Our first original productions were prepared and distributed, thus allowing us to contribute new insights to the caregiving community. Mechanisms for scientific monitoring and the inclusion of third-party publications were also implemented.



Knowledge collection, analysis and monitoring; work with stakeholders to establish a shared, informed vision of caregiving



The establishment of a concerted plan for productions and publications

- Identification of **131 topics** following consultations with a number of caregiving stakeholders (interviews and workshops with 21 NGOs, Mentimeter survey with 61 participants from varied backgrounds and 392 responses) and development of the **first production and publication plan**
- Identification by the Expert Advisory Committee of a priority theme:
 - ▶ **Caregiving trajectories**



Release of the Observatory's first original insightful productions

- **Caregiver statistics**
 - ▶ Publication of the section "[Caregiving in Quebec: a few figures](#)" on the Observatory's website
 - ▶ Progress on a gender-based analysis of statistical data³ (publication planned for spring 2023)

³ Data compiled by the Institut de la statistique du Québec in February 2022 from Statistics Canada's 2018 *General Social Survey – Caregiving and Care Receiving*. Online. <https://statistique.quebec.ca/en/document/informal-caregiving-in-quebec-in-2018>



- **Caregiver recognition and self-recognition**
 - ▶ Publication of the section “[Definitions of caregiving](#)” on the Observatory’s website
 - ▶ Publication of the interactive infographic “[What is a caregiver? Would you know one to see one?](#)”
 - ▶ Work continued on inspiring practices to foster the recognition and self-recognition of caregivers (publication planned for fall 2023)
- **Caregiver support**
 - ▶ Publication of the first fact sheet on [financial support for caregivers](#), aimed at decision-makers and professionals
 - ▶ Work in progress on a state of knowledge on caregiving trajectories



Following caregiving experts and stakeholders

- Launch of scientific monitoring
 - ▶ **53 Quebec researchers** from **8 fields or sectors** (medicine, physiotherapy, psychiatry, psychoeducation, sociology, nursing sciences, social work) interested primarily in caregiving
- Review of third-party publications
 - ▶ Automated screening of **123 national and international organizations** that produce different types of caregiving knowledge
 - ▶ Manual review of third-party publications through visits to **112 organizational websites**

Knowledge Mobilization and Transfer

With regard to Knowledge Mobilization and Transfer, our aim for 2022–2023 was to ensure that the knowledge gathered would be adapted and made accessible to our different target audiences through our new distribution channels. Initiatives over the year that helped raise the Observatory's visibility included the creation and distribution of our visual identity, the launch of our [website](#) and Facebook page, the publication of our first two newsletters, and early reflections on our communication plan.



Introduction of new distribution channels to raise the Observatory's profile and share the knowledge gathered



Rollout of a strong brand image

- **Visual identity** created with PF Communications
 - ▶ A logo conveying the human focus of the Observatory's mission (i.e., that of serving as a hub for the production, sharing and transfer of knowledge about caregiving)
 - ▶ Consultations with support staff and committees (**20 participants** with different profiles)



Introduction of new, user-friendly and diversified distribution channels

- Launch of the Observatory's [website](#)
 - ▶ Consultations and testing with **29 participants** (including 3 caregivers, 4 people from the non-governmental sector, 12 from the health & social services network, 2 from government, 6 from the scientific community and 2 knowledge transfer experts)
 - ▶ **2,542 users** between April 1, 2022 and March 31, 2023
- Distribution of our two first newsletters
 - ▶ 1 special edition for National Caregivers Week 2022
 - ▶ **518 subscribers** as of March 31, 2023
- Creation of the Observatory's Facebook page
 - ▶ **2 posts per week** since its launch
 - ▶ 76 followers since its launch and growing



Reflection on how new knowledge can be amplified

- Creation of the [Knowledge Portal](#) to highlight the different forms of knowledge produced by a range of caregiving stakeholders
 - ▶ Launch planned for spring 2023
- Early reflections on a [comprehensive communication plan](#), working with our staff, committee members and contributors



Stakeholder Relations

In terms of Stakeholder Relations, our aim this past year has been to get to know the many different caregiving stakeholders, to better foster productive collaborations. We gained a better understanding of our environment by creating a stakeholder map, which will be updated annually and specifies fields of action and expertise. We also kept up the dialogue with different stakeholders through online consultations held via our website and by organizing or attending various meetings. Together with our reflections on how to work together most effectively, our efforts to forge and develop partnerships and joint undertakings around concrete projects and around the government action plan show our sustained commitment to working closely with the caregiving community.



Gaining an in-depth understanding of our environment; encouraging dialogue and promising collaborations with different caregiving stakeholders



A key tool: the stakeholder map

- **305 organizations** (NGOs, government and research organizations) were **documented** in Québec (247), elsewhere in Canada (39) and internationally (19)
- Starting a media watch; continuing scientific monitoring and third-party publication screening



Creation of opportunities to get to know our stakeholders and vice versa

- Creation of a [contact](#) form on our website and a dedicated email address for the Observatory
- Participation in caregiving-related events:
 - ▶ **The press conference** to announce the Observatory's launch
 - ▶ Rehabilitation Scientific Day at the Lethbridge-Layton-Mackay Rehabilitation Centre
 - ▶ The symposium on **caregiving in a context of diversity** by the Alliance des communautés culturelles pour l'égalité dans la santé et les services sociaux (ACCESSS)
 - ▶ The event "**Journée de l'Appui: Proche aidance en chœur**"



- Organization of group and individual meetings
 - ▶ 1 group workshop with **19 NGOs**
 - ▶ **Meetings with 5 NGOs** (L'Appui, Proche aidance Québec, Federation of Quebec Alzheimer Societies, Association québécoise des retraité[e]s des secteurs public et parapublic, Fondation Émergence)
 - ▶ Planning is underway for an NGO tour in spring 2023



Joint initiatives to benefit caregivers

- Partnership created to address **structural initiatives in the government action plan** (Ministère de la Santé et des Services sociaux [MSSS], Institut national de santé publique [INSPQ] and Institut national d'excellence en santé et services sociaux [INESSS])⁴
- Joint initiative launched with the **Centre d'Excellence sur le Partenariat Patient-Public (CEPPP)**⁵
 - ▶ 2 preliminary work meetings
 - ▶ 2 training sessions for members of our committees planned for spring and fall 2023
- **Joint initiative** launched with the CIUSSS de l'Estrie-CHUS **Communauté de Pratique (CdP) en proche aidance**
 - ▶ 2 work meetings and participation in the CdP's launch
 - ▶ 1 webinar on **young caregivers**
 - ▶ 1 webinar on **caregivers of care receivers with cancer** (planned for June 2023)
- Early reflections with other caregiving stakeholders around the question of **developing a model for partnership and collaboration** so that activities may be prioritized (to be continued in 2023–2024)
 - ▶ Model informed by meetings held with many caregiving stakeholders

⁴ For more information, see **Expertise and Advising**.

⁵ Measure 7 of the *Plan d'action gouvernemental pour les personnes proches aidantes 2021–2026: Reconnaître pour mieux soutenir*, Ministère de la Santé et des Services sociaux.

Expertise and Advising

As regards Expertise and Advising, our overall aim is to support intersectoral decision-makers by evaluating, advising on or recommending improvements to the caregiving field, drawing on multiple forms of knowledge, skills and know-how. The year 2022–2023 marked a turning point for this pillar thanks to two key developments: namely, the establishment of the Expert Advisory Committee; and the start of work to develop a reference framework for advisory expertise within the Observatory. The framework will define for whom, on what grounds and in what form expert opinions and recommendations are to be issued. This past year also saw us enhance the Observatory's renown as an expert resource through our participation, in an advisory capacity, in various committees or strategic initiatives of the government action plan.



Development of the Expertise and Advising pillar to disseminate Quebec caregiving expertise



Solid, lasting foundations based on multiple forms of knowledge, skills and know-how

- Creation of the **Expert Advisory Committee**
 - ▶ 9 members from **various sectors and different areas of expertise**
 - ▶ **4 work meetings** in 2022–2023
- Start of work on a **reference framework** on **advisory expertise**
 - ▶ Literature review on how to provide advisory expertise and scientific recommendations completed
 - ▶ Analysis and writing underway
 - ▶ Stakeholder consultations (MSSS, Partners Committee) planned for 2023–2024



An expertise and advisory role propagated through partnerships

- **Partnership** with the **MSSS health status surveillance directorate and INSPQ** to create a conceptual framework and draw up a portrait of caregivers⁶ in Quebec
 - ▶ 2 preliminary work meetings
 - ▶ **2 meetings** with the monitoring committee
 - ▶ **7 meetings** with the project committee
 - ▶ **Expert advisory committee participation** in developing the documentation strategy
 - ▶ Participation of the working group to develop a plan for thematic monitoring (spring 2023)
- **Partnership** with the **INESSS** to identify assessment criteria and indicators through which to measure the success of the objectives stated in the national caregivers' policy⁷
 - ▶ **4 preliminary work meetings** leading to a framework paper
 - ▶ Participation planned in two project committees in 2023–2024
 - ▶ Support in identifying caregiving and public policy experts
- **Participation** of researcher and **Managing Committee member** Sophie Éthier on the steering committee for the project “Apprendre à aider, sans s’oublier, tout au long de la maladie d’Alzheimer” led by the Federation of Quebec Alzheimer Societies

⁶ Measure 2 of the *Plan d'action gouvernemental pour les personnes proches aidantes*.

⁷ Measure 33 of the *Plan d'action gouvernemental pour les personnes proches aidantes*.

Perspectives

The year 2022–2023 was marked by sustained efforts to develop the Observatory by building on the foundations laid during its first two years.

It also saw the Observatory move closer to its vision: namely, to serve as a hub for the production, sharing and transfer of reliable, essential and relevant knowledge aimed at raising awareness and fostering the recognition of caregiving, to better support all stakeholders.

A vision expressed through the **gathering** of different kinds of **knowledge** and by their **dissemination** through our first original publications: works that define caregiving, give it a statistical profile and promote caregiver support and recognition, all of it in view of establishing a shared notion of caregiving.

This vision also took shape over the past year in the form of **new and user-friendly distribution channels** — for example, the Observatory's **website, newsletter and Facebook page**.

Our vision is informed by **an in-depth understanding of our environment** as well as our **ongoing dialogue** and **promising collaborations** with a wide range of caregiving stakeholders.

It is also based on the development and **propagation** of our **expertise** through our Expert Advisory Committee and our engagement in major undertakings involving multiple stakeholders.

This vision will continue to guide us through 2023–2024, a year that holds the promise of significant developments through:

- The publication of a report on the latest caregiving statistics
- The publication of a document on practices that foster caregiver recognition and self-recognition
- Our ongoing partnerships and collaborations with the MSSS, INSPQ, INESSS, CEPPP and CdP
- Launch of the Knowledge Portal, created to amplify and disseminate third-party publications on caregiving
- Launch of an advisory group of caregivers wishing to contribute to the Observatory's work
- Development of an expert advisory reference framework
- Development of a model for partnership and collaboration
- Development of a communication plan

And much more.

Appendix 1

Managing Committee

Sylvie Constantineau, Managing Committee Chair, Member from a non-governmental organization (NGO) — Arborescence: for loved ones in mental health

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, École de travail social, Université de Sherbrooke

Véronique Dubé, Researcher, Faculty of Nursing, 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 a non-governmental organization (NGO) — Heart and Stroke Foundation of Canada

Carole Tavernier, Caregiver

Nathalie Tremblay, Government member — Ministère de la Santé et des Services sociaux

Nomination to come: A caregiver from a First Nations or Inuit community (TBD)



Observatoire québécois de la **proche aide**

The mandate for the Observatory's development, coordination and administrative support has been entrusted to the Integrated Health and Social Services University Network for West-Central Montreal (CIUSSS West-Central Montreal)

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