

2020 - 2022

# Activity Report



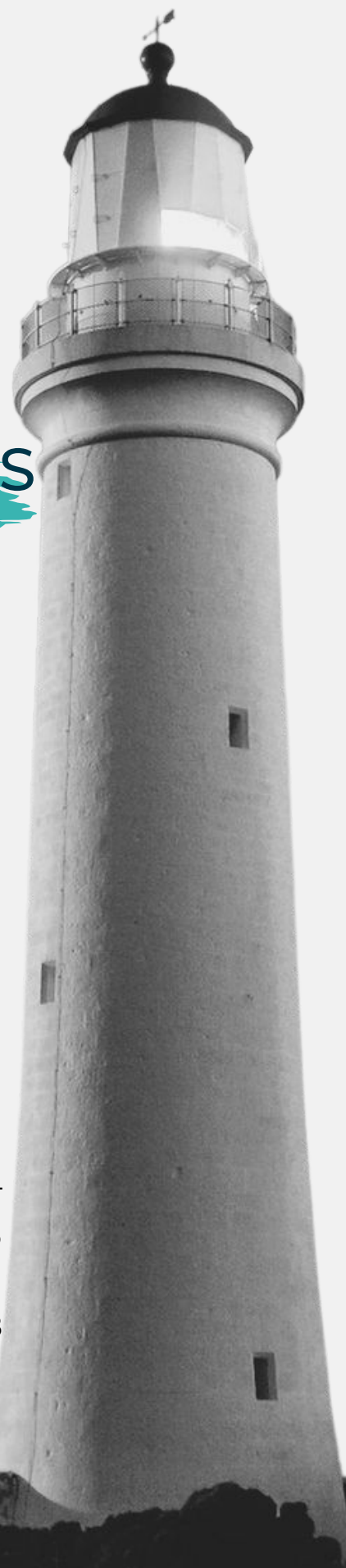
En partenariat avec :

Québec 

*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, in order to better support all caregiving stakeholders.*

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# A word from the Managing Committee Chair

We are very proud to present this first-ever report on the activities of the newly created Quebec Observatory on Caregiving (*Observatoire québécois de la proche aide*). Unique in its kind, the Observatory was born of a sustained and concerted government effort that led to its structure being enshrined in the new provincial *Act to recognize and support caregivers* — a development that ensures its activities will continue through the years to come.

Both as a caregiver and as a member of a non-government organization for caregivers of people with mental health issues, I consider this to be a significant step forward in the recognition of caregivers and of the importance of their role.

I am impressed and excited by the remarkable work already achieved since the Observatory's inception, and I sincerely believe its continued development will help improve the visibility of these dedicated caregivers, while giving rise to promising new practices to better support them.



Sylvie Constantineau  
Managing Committee Chair



# A word from the Observatory's Directors



As one who has been professionally involved in the field of caregiving for many years, I am delighted we now have an Observatory whose mission it is to make a reliable body of knowledge emerging from lived experience, practice and research widely accessible. Building on the expertise developed over time by the Integrated Health and Social Services University Network for West-Central Montreal (CIUSSS West-Central Montreal), this year the Observatory has been able to lay the solid foundations that will ensure the continuity of its mission into the long-term. I am particularly pleased to note the adoption of our first Strategic Development Plan, which has allowed us to clearly define our contribution and set priorities for action.

We have forged strong partnerships with our collaborators from all areas, including caregivers, the health & social services network, government and non-government organizations, and the scientific community.

I am extremely proud of the work accomplished by our small team in such a short time. And this is just the beginning! With dedicated members at every administrative level, I am hopeful and optimistic as I look ahead to our future projects.

A handwritten signature in black ink, appearing to read 'C. Starnino'.

**Cindy Starnino**  
Administrative Director of the Observatory



Over the course of the past two years, the COVID-19 pandemic has underscored as never before the vital role of caregivers in the provision of care. Ensuring that this role is recognized and better supporting caregivers are top priorities for the Quebec Observatory on Caregiving. To these ends, the Observatory must work closely with its partners to identify and propose priority actions; take a scientific approach to gathering and producing reliable knowledge; and ensure that knowledge is produced with integrity and in keeping with ethical guidelines. All of these are tasks that fall to the Scientific Director of the Observatory. But above and beyond this wealth of information intended to assist caregivers, we will be sure not to overlook the opportunity to share the knowledge and know-how from the experiences of those united by the fundamental humanist value of “taking care of one another.”

A handwritten signature in black ink, appearing to read 'O. Beauchet'.

**Dr. Olivier Beauchet**  
Scientific Director of the Observatory  
Faculty of Medicine, Université de Montréal

# 1 The Quebec Observatory on Caregiving

## Origins

The idea of founding an observatory focused on caregiving in Quebec dates back some time. It was envisioned as a structure that would recognize caregivers' contributions while providing access to reliable, objective information on the various aspects of caregiving and their repercussions. Shared by supporters within the government, non-government and scientific sectors, this vision was championed by Marguerite Blais, minister responsible for seniors and caregivers, and integrated into recent government advancements to recognize and support caregivers.

As a result, the Quebec Observatory on Caregiving was formally brought into existence, and the composition of its managing committee defined, in October 2020 through the *Act to recognize and support caregivers* (articles 28 and 29). In preparation, the Ministère de la Santé et des Services Sociaux (MSSS) had, in 2019, mandated the Integrated Health and Social Services University Network for West-Central Montreal (CIUSSS West-Central Montreal) to develop the Observatory and provide coordination and administrative support. The creation of the Quebec Observatory on Caregiving aligns with the national caregiver policy adopted in April 2021, while support for founding the Observatory represents one of the 61 action items identified in the 2021–2026 government action plan for caregivers adopted in October 2021. Members of the managing committee were named by the minister in November 2021, with the chair and vice-chair appointed in May 2022.

This, the Observatory's very first activity report, highlights its main activities and outputs from the date of its launch through March 31, 2022. It also presents the Observatory's managing committee, its team, and the various other committees put in place to support its many different projects and activities. Lastly, it attests to the fruitful collaborations between the founding partners and those who have come on board as the Observatory continues to develop.

## Mission

(as per Article 35 of the *Act to recognize and support caregivers* [the “Act”])

Enshrined in the *Act to recognize and support caregivers* (“the Act”), the purpose of the Observatory is to provide reliable and objective information regarding caregiving through observation, monitoring, analysis and knowledge sharing.



## Functions

(as per Articles 35 and 36 of the Act)

- **Collect, integrate, compile, analyze and disseminate information on caregiving.**
- **Monitor** the evolution of caregivers’ needs as well as effective and innovative practices, measures and actions to support caregivers.
- Facilitate the **transfer of knowledge.**
- Facilitate **collaborations** regarding caregiving.
- **Advise the Minister.**

## Strategic divisions

The Observatory’s mission and functions guide the actions taken under its four strategic divisions:



①

Monitoring and knowledge production

②

Knowledge mobilization and transfer

③

Stakeholder relations

④

Consulting



## Vision

To be a hub for the production, sharing and transfer of reliable, essential and relevant knowledge aimed at raising awareness and fostering the recognition of caregiving, in order to better support all caregiving stakeholders.

## Values

The Observatory **cooperates** with other caregiving experts in a dynamic of co-construction and co-development of knowledge and practices. This spirit of cooperation stems from a recognition of differing but complementary types of knowledge — namely, scientific, experiential, practical and contextual. The Observatory fosters contributions from all stakeholders, whose needs and interests it serves by facilitating sharing of ideas and perspectives, interdisciplinarity, intersectorality, cohesion and the development of a shared body of knowledge.

The Observatory **validates** current caregiving knowledge from different areas of expertise, including the expertise of caregivers. Accordingly, it strives to ensure that its output and activities represent added value for each of its target audiences.

**Innovation** emerges from the Observatory's ongoing exchanges with the various caregiving stakeholders: not just in terms of the new findings generated from the merging of different forms of expertise, but also in the pioneering of novel approaches to how this knowledge is monitored, produced, mobilized and transferred.

The Observatory strives for **excellence** in its full range of output and activities by keeping to an approach grounded in rigour, professionalism and objectivity. Working with science and other knowledge bases, the Observatory uses sound reasoning and the most accurate evidence to support decision-making, stimulate action and fuel research.

## For whom?

### Different target audiences:

The Observatory sets out to inform, raise awareness, educate and facilitate decision-making and action among both caregivers and the many different governmental, non-governmental and scientific stakeholders who support them. It also seeks to reach the general public, since caregiving is a reality that will affect almost everyone at some point in their lives, be it as a caregiver or care receiver.

## To what aims?

In keeping a close watch on relevant, useful caregiving information and communicating its findings to its various target audiences, the Observatory fosters the recognition of caregivers and those who support them by:

- Offering a credible, accessible and central repository of reliable, objective knowledge on caregiving along with original publications and activities produced with its partners.
- Highlighting and disseminating research, best practices and promising initiatives developed in Quebec, Canada and abroad.
- Drawing on evidence-based practices and pooled knowledge to issue guidelines and recommendations for assessing the impact of caregiving policies and actions.
- Establishing structures and opportunities for concerted action and the sharing of knowledge between caregivers and the many stakeholders who support them



# 2 The people at the heart of the Observatory

## Managing committee

The role of this committee, whose members are appointed by the Minister, is to determine the Observatory's scientific directions, general objectives and policies as well as the annual activities it intends to carry out. It also assesses the relevance, priority status and scientific quality of the Observatory's programs and activities, and works closely with the government action follow-up committee and the partners committee (art. 30 of the Act).

### Sylvie Constantineau

Managing Committee Chair

Member from a non-governmental organization (NGO) — Arborescence, pour les proches en santé mentale (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, School of Social Work (since  
November 2022), 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

TBA: A caregiver from a First Nations or Inuit community



## The Observatory's support staff

### Christiane Montpetit

Executive Coordinator, Academic Affairs and Research Ethics Directorate,  
CIUSSS West-Central Montreal

### Margaux Reiss

Research professional, project officer for the  
Monitoring and Knowledge production  
division, CIUSSS West-Central Montreal

### Alexis Pearson

Research professional, project officer for the  
Knowledge mobilization and transfer and  
Stakeholder relations divisions,  
CIUSSS West-Central Montreal

### Virginie Tuboeuf

Administrative technician,  
CIUSSS West-Central Montreal

### Rym Zakaria

Librarian, CIUSSS West-Central Montreal

## Expert advisory committee

(Currently in development, but outlined in the governance structure adopted by the managing committee in December 2021.)

Under Scientific Director Dr. Olivier Beauchet, this committee brings its specific expertise to bear on the Observatory's key priorities and specific topics, with a view to ensuring quality output and having the desired impact.

### Anne Bourbonnais

Researcher, Faculty of Nursing, Université de Montréal

### Isabelle Courcy

Researcher, Département de sociologie, Université de Montréal

### Sahon Chimène Dro

Member from the health & social services network — 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

### Lucyna Lach

Researcher, School of Social Work, McGill University

### Sylvie Lambert

Researcher, Ingram School of Nursing, McGill University

### Aude Villatte

Researcher, Département de psychoéducation et de psychologie, Université du Québec en Outaouais

### Denise Juneau

Caregiver

Other members still to be invited:

Another caregiver

Representative from a government ministry or organization involved in supporting caregivers

Member representing regional caregiving coordinators in the health & social services network

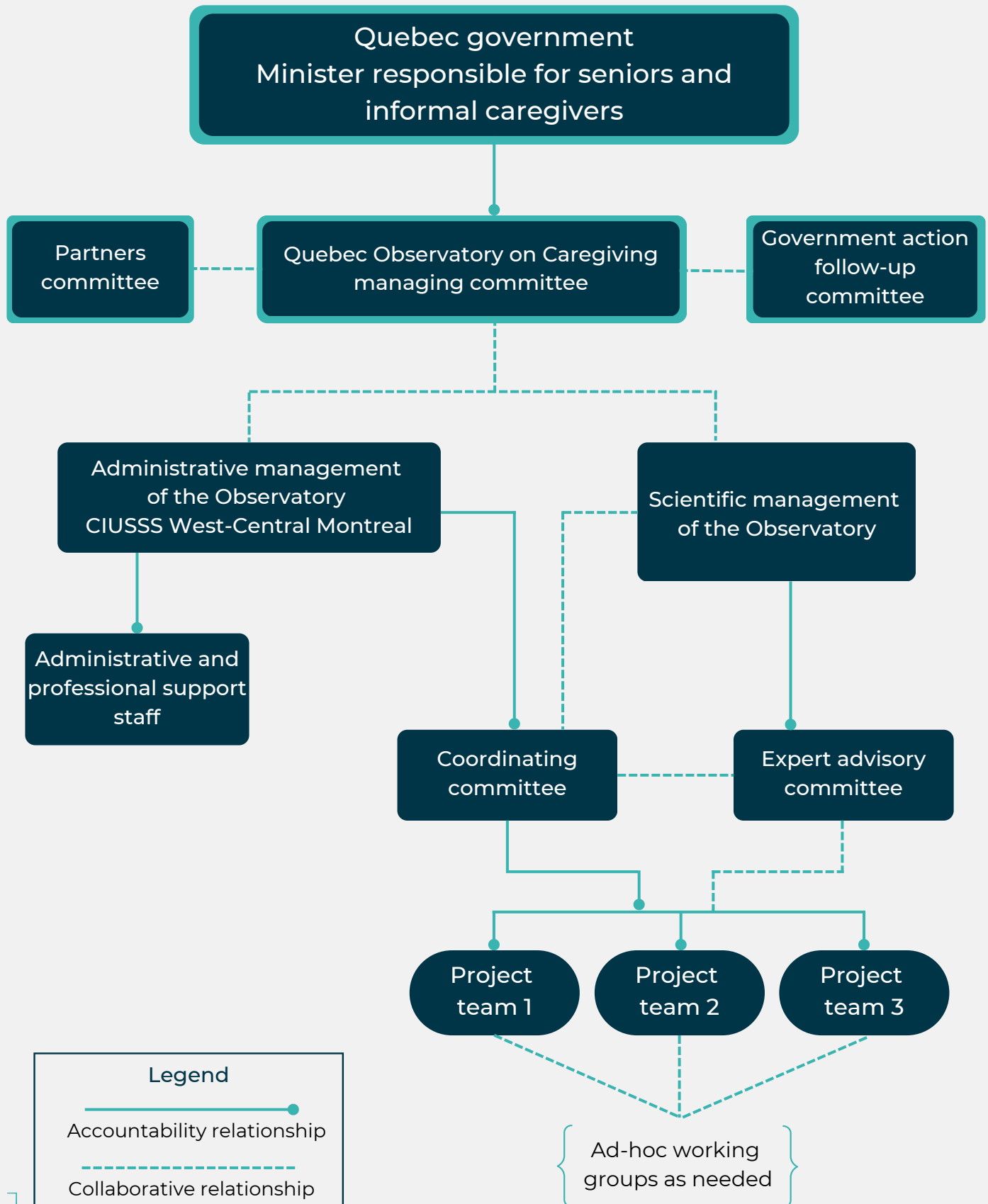
## Coordinating Committee

The Observatory's activities are coordinated by a committee consisting of its administrative and scientific directors, various team members and:

### Michèle Archambault

representative, Direction générale des Aînés et des Proches aidants, MSSS

# The Quebec Observatory on Caregiving: organizational structure

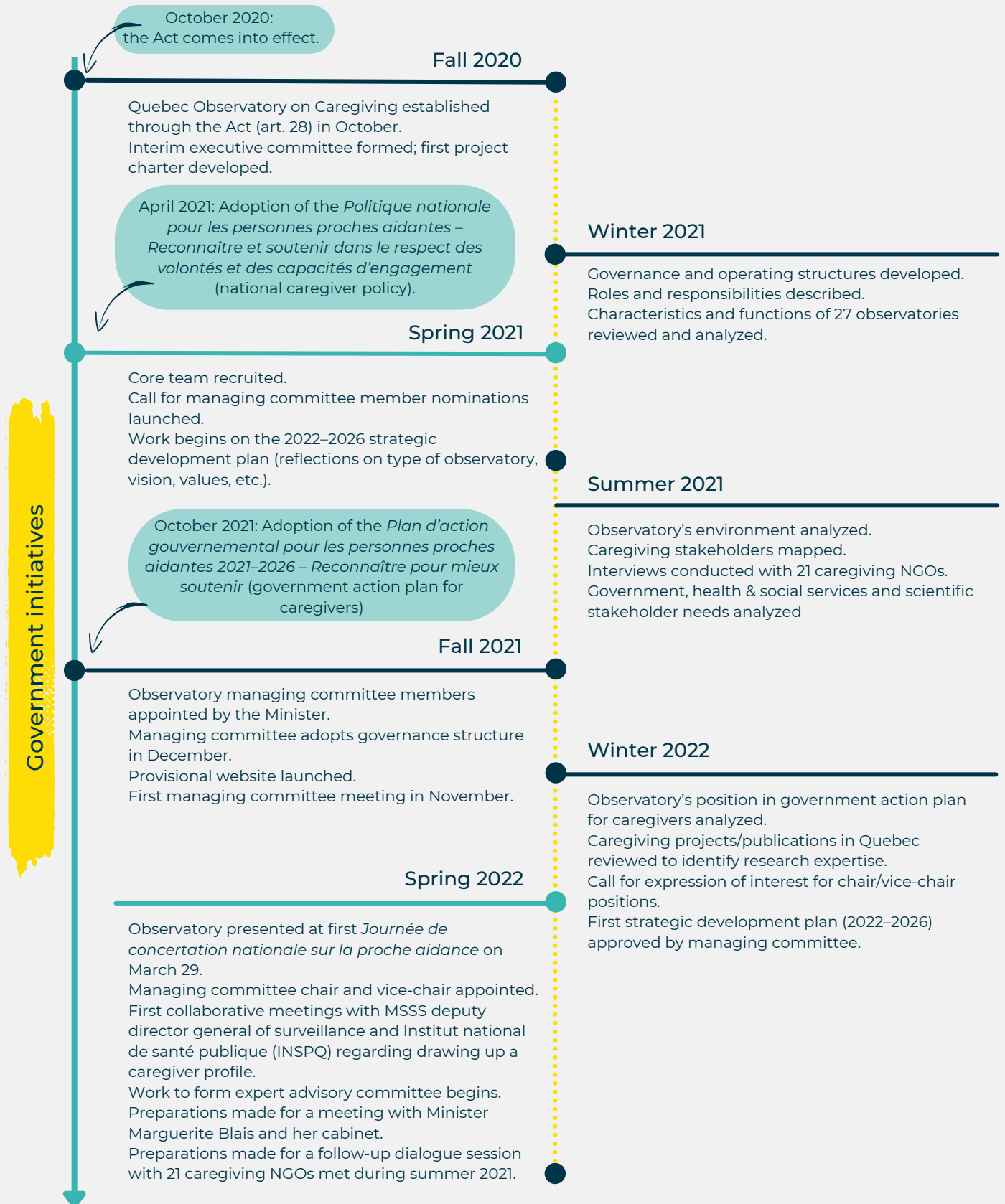


# 3 A strong and lasting foundation

Mandated by the Ministère de la Santé et des Services Sociaux, the CIUSSS West-Central Montreal has been responsible from the very start for developing the Observatory and establishing its operating structure. Under the Act (articles 35, 36 and 37), the national caregiver policy and the government action plan in association with the multiple caregiving stakeholders, the Quebec Observatory on Caregiving bears significant responsibilities. The first two years were thus devoted to establishing a solid footing to get the Observatory up to speed and allow it to take its rightful place among the many different caregiving interests.



# Activity timeline



# 2020–2022 Highlights

## Cross-cutting priority

### Establish a collaborative governance structure to support operations and allow expertise to be shared

One of our most important achievements to date has been the development of a governance structure defining roles and responsibilities within a context of administrative and scientific co-management, in addition to establishing the managing, coordinating and expert advisory committees. Such a structure not only supports the Observatory's performance, but also gives concrete form to the values of collaboration and validation by investing each committee with different forms of expertise, be it from caregivers, scientists or governmental and non-governmental groups involved in caregiving. A core support team was also hired to coordinate activities, productions and seminal works.

After a first meeting in November 2021, the managing committee met on four occasions to orient the Observatory's strategic development and establish annual priorities. The coordinating committee, in turn, began meeting every two weeks as of fall 2020 to orchestrate overall efforts. Work to establish the mandate and determine the composition of the expert advisory committee also got underway with a first meeting scheduled for June 2022.

## Monitoring and knowledge production

### Developing and structuring content; launching collaborations tied to structural initiatives identified in the government action plan

The Observatory deployed a broad range of efforts in structuring its initiatives related to monitoring and producing knowledge. Firstly, the characteristics and functions of 27 observatories—including 14 from Quebec, 2 from elsewhere in Canada, and 11 on the international level—were systematically reviewed and analyzed. It emerged that the Quebec Observatory on Caregiving is the only such entity dedicated solely to caregiving in all its varied aspects. The exercise also informed reflection on the appropriate functions and the specific type of observatory that was called for. Other work in this division included the following: developing objectives and goals for each monitoring unit; determining a mandate for and establishing an expert advisory committee; identifying and classifying themes and aims relating to the five core dimensions of caregiving (what is caregiving, realities of caregiving, repercussions of caregiving, analysis of caregiving support, society and caregiving); identifying annual priority themes; and starting production on original publications related to caregiver recognition/self-recognition and the notion of caregiving.

The team also reviewed the caregiving-related scientific publications produced and funded research projects carried out in Quebec since the 1990s. Through this effort, 53 Quebec researchers whose work focused primarily on caregiving were identified, as were some 50 other researchers for whom caregiving was a significant but secondary focus. There is no doubt that this body of work and wealth of expertise will prove to be of great value. A careful analysis of the government's action plan and its 61 associated action items was also carried out, with a two-pronged aim: to determine suitable collaborators and partners for the Observatory; and to identify the work to be carried out by third parties, particularly university research institutes, that will result in essential knowledge on the lived realities and needs of the vast range of caregivers and care receivers. This valuable knowledge will be documented and disseminated by the Observatory through its online knowledge directory.

Lastly, in recent months the Observatory has joined an ongoing effort to monitor caregivers' health. This work is being led by the MSSS's public health surveillance and planning department in partnership with the Institut national de santé publique du Québec (INSPQ). Among other outcomes, the work will facilitate the development of a theoretical framework that can be used to characterize the health and well-being of Quebec caregivers, as set out in Measure 2 of the 2021–2026 government action plan for caregivers.

## Knowledge mobilization and transfer

### Developing the Observatory's communications and knowledge transfer strategy

A top priority has been developing a strategy for communications and knowledge transfer. Other observatories were reviewed with a view to analyzing their respective approaches to knowledge transfer and identifying inspiring practices. To ensure the Observatory's visibility and convey essential information about its mission, mandate and team, an initial online presence was established on the CIUSSS West-Central Montreal website. This interim webpage allowed interested parties to register on the Observatory's contact list and receive the latest Observatory news as work progressed toward the planned launch of a new website in fall 2022. At the same time, a communications company that could support efforts to develop a distinctive brand identity and build an official website was sought. An agreement was reached in spring 2022, allowing work with the selected company to begin.

With regard to knowledge transfer methods, the team consulted with caregiving partners during the *Journée de concertation nationale en proche aide* and began developing a strategy for communicating with and engaging the Observatory's target audiences.



## Stakeholder relations

### Developing the Observatory's vision and strategic directions and mobilizing stakeholders around its mission

The release of the Observatory's 2022–2026 Strategic Development Plan represented a significant milestone. The first of its kind, the plan puts government efforts related to caregiving into context, presents the Observatory's mission, vision and values, and lays out its strategic orientations and actions for the next four years. Its inspiring and unifying vision was developed in tandem with various caregiving stakeholders, and through extensive reflection and dialogue with committee members from varied backgrounds, including caregivers.

Substantial efforts went into drafting, editing and validating the Plan and its presentation to stakeholders. Firstly, to properly situate the Observatory within the caregiving landscape, the team analyzed the caregiving environment and assessed the needs of those active in the government, scientific, health care and social services sectors. Interviews were also carried out with 21 NGOs, while strategic reflections on the Plan's broad orientations and the actions to be undertaken in the coming years formed the topic of many committee meetings. The Observatory's participation in the *Journée de concertation nationale sur la proche aidance* (March 29, 2022), which regrouped all partners identified in the 2021–2026 government action plan, provided an ideal opportunity for presenting key elements of the Plan, as well as sounding out information needs, interest for specific caregiving-related themes and determining the preferred modes of knowledge transfer. A half-day follow-up meeting with representatives of the NGOs who took part in the interviews was also planned for April 2022 to review of the Plan's overall directions and identify opportunities for future collaboration.

# 4 Perspectives

The Quebec Observatory on Caregiving is an emerging organization that seeks to rally those involved in caregiving around a common, unifying vision: to be a hub for the production, sharing and transfer of reliable, essential and relevant knowledge aimed at raising awareness and fostering the recognition of caregiving, in order to the better support all caregiving stakeholders.

Priorities that the Observatory has identified as critical for fulfilling this mission include developing new knowledge through cross-pollination of existing knowledge and expertise; tracking and monitoring caregiver needs and realities; evaluating the impact of government actions and policies; and facilitating knowledge transfer.

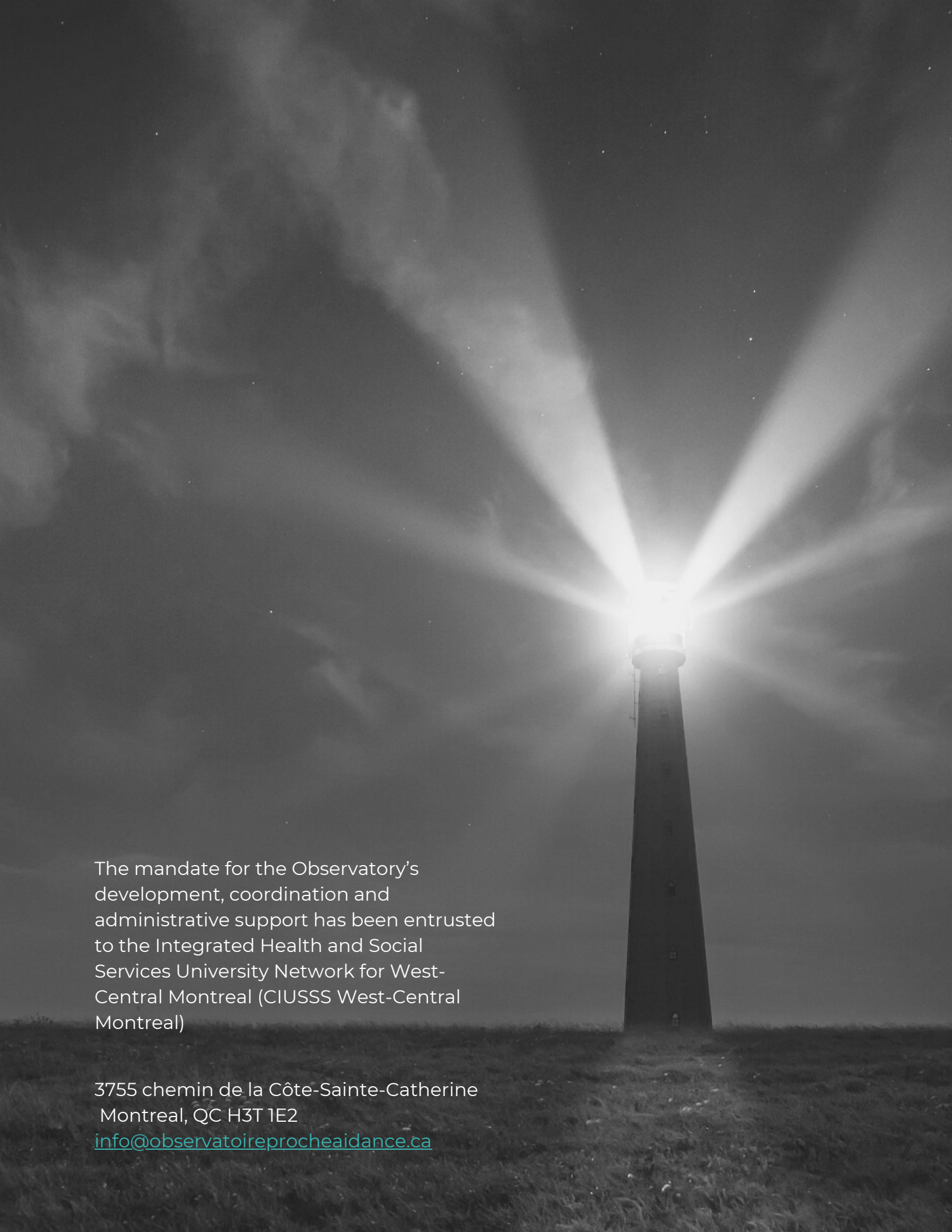
More specifically, over the coming year, the Observatory will focus on:

- Launching a new website and producing a first newsletter.
- Finalizing the Observatory's first original productions to:
  - Present the concept of caregiving in a dynamic, accessible way
  - Validate the currently available statistics on caregivers
  - Document knowledge related to caregiver recognition and self-recognition along with best practices for promoting this recognition
  - Document and develop caregiving trajectories to identify critical milestones and best practices for supporting periods of transition
- Developing monitoring units to track scientific advances, third-party productions and social media activities.
- Establishing guidelines for sharing the knowledge produced by third parties, with a view to structuring the Observatory's knowledge directory and setting out the criteria for selecting and disseminating knowledge so as to ensure its reliability, neutrality, objectivity and relevance and quality.
- Developing a framework (governance/methodology) for the Observatory's consulting division and, together with Minister Sonia Bédard, exploring the required level of decision support.
- Collaborating with partners on key measures of the 2021–2026 government action plan. This includes work to monitor caregiver health carried out in cooperation with the MSSS Direction générale adjointe de la surveillance et de la planification en santé publique and the Institut national de santé publique du Québec (INSPQ). It also includes working with the Institut national d'excellence en santé et services sociaux (INESSS) to develop an evaluation approach and determine indicators for measuring progress related to the official goals set out in the Quebec government's national caregiver policy.
- Reinforcing ties with the partners committee.
- Building alliances and partnerships around concrete projects.

# Acknowledgements

The Observatory has emerged from the ideas and unstinting efforts of the many individuals without whom the project would not have been possible. In addition to its chair and vice-chair, its administrative director and scientific director, its managing and expert advisory committee members, its support team and Michèle Archambault, who coordinates work in favour of caregivers at the Direction générale des Aînés et des Proches aidants at the MSSS, special thanks are due to those who, in their different ways, have staunchly supported its founding and early efforts: Marguerite Blais, Natalie Rosebush, Mélanie Kavanagh, Vincent Defoy, Dr. Lawrence Rosenberg, Francine Dupuis, Julie Lemieux and Mathilda Abi Antoun.





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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