

Activity Report

2021-2022



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A Word from Management

We are excited to share with you what our team has accomplished in the 2021-2022 year. This year was an opportunity to stand out in many areas, including our leadership in patient partnership. The Unit's patient partner community, *Expériences*, has become empowered. It has developed a vision to make the experiential knowledge of its members an integral part of the learning health system.

The Unit has demonstrated its growing influence with decision-makers. On the occasion of a Parliamentary Committee presentation for Bill 11 on increasing the supply of front-line services, the Unit's scientific-patient coleadership was able to highlight the importance of patient partnership. It also insisted on the need to build on science to improve health practices. In addition, four co-applicants from the Unit are sitting on the advisory table for the review of Bill 19 on access to data and the Executive Direction has participated in the review of the Québec Life Sciences Strategy as well as the advisory table on the evaluation of the SPOR program.

Concrete results of its communication efforts have also been observed. Its website has been translated into English to ensure equity and inclusiveness and to allow for greater outreach in Québec, Canada and internationally.



Catherine Wilhelmy
Patient partner, Scientific Codirection



Antoine Groulx
Scientific Codirection



Paul Nadeau
Patient Partner, Executive Codirection



Joe Guillaume Pelletier
Executive Codirection

In conjunction with these efforts, we are seeing a shift in the Unit's client base. The Unit's LHS support portal received nearly twice as many requests from decision-makers and network professionals compared to its best year since its inception. This demonstrates the impact of the messages in the network.

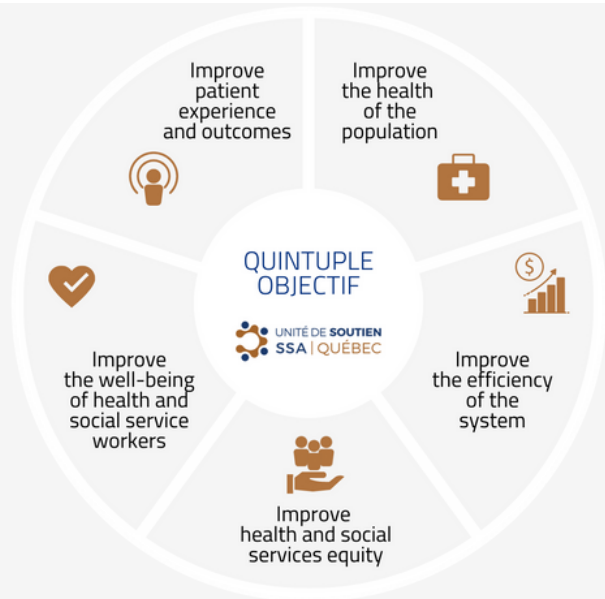
As of January 2023, the scientific codirectors are beginning a tour of the Réseaux universitaires de santé et de services sociaux (RUISSS) in order to encourage fruitful discussions with those working in the field and to highlight support needs.

Introduction

The Unité de soutien au système de santé apprenant (SSA) Québec is a provincial unit of the national SPOR network funded by the Canadian Institutes of Health Research (CIHR).

The Unit has unique capabilities to support the continuous improvement of the Québec Health and Social Services Network and to strive for the quintuple aim. It mobilizes and accompanies the research, health and social services communities, with and for the public, by focusing on three key approaches

- Working in partnership
- Building on data science
- Supporting change management



The Unit in transition

2014-2021 / 2021-2026

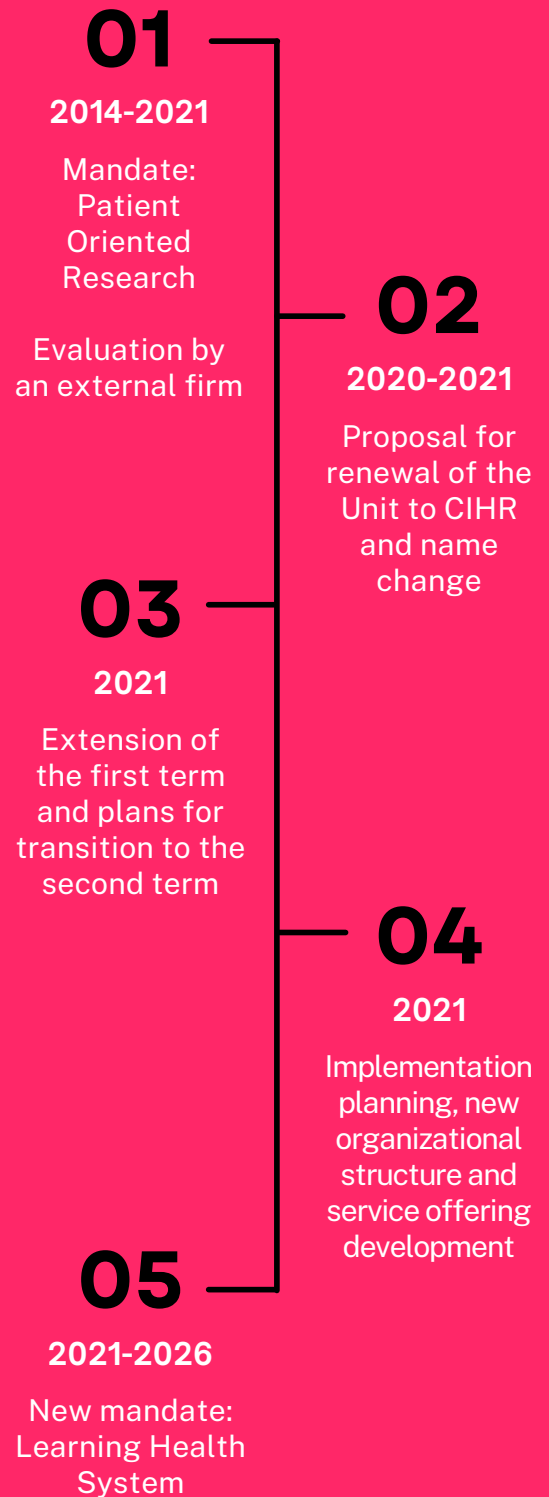
The year 2021-2022 was one of activity structuring and transformation for the teams. The Unit began the transition from a Patient-Oriented Research Support Unit to a Learning Health System Support Unit. Beyond the name change, the Unit has evolved its mission, which now aims to make the health care system a learning system, always with the patient partnership as its driving force.

Since then, proud of the ground that has been covered and the knowledge that has been gained, the Unit has developed an ambitious 2021-2026 implementation plan to support its vision of a learning health system.



2021-2026 Priorities

- Activation of SSA-RUISSS teams
- Coaching of teams around the LHS theme
- Implementation of a performance measurement process
- Development and implementation of targeted grants to improve care trajectories
- Planning of the sustainability of the Unit



Governance

This year, the Unit adopted a new governance framework that includes patient partners at all levels.

Patients are therefore an integral part of the Unit's decision-making structure at all levels: operational, tactical and strategic.

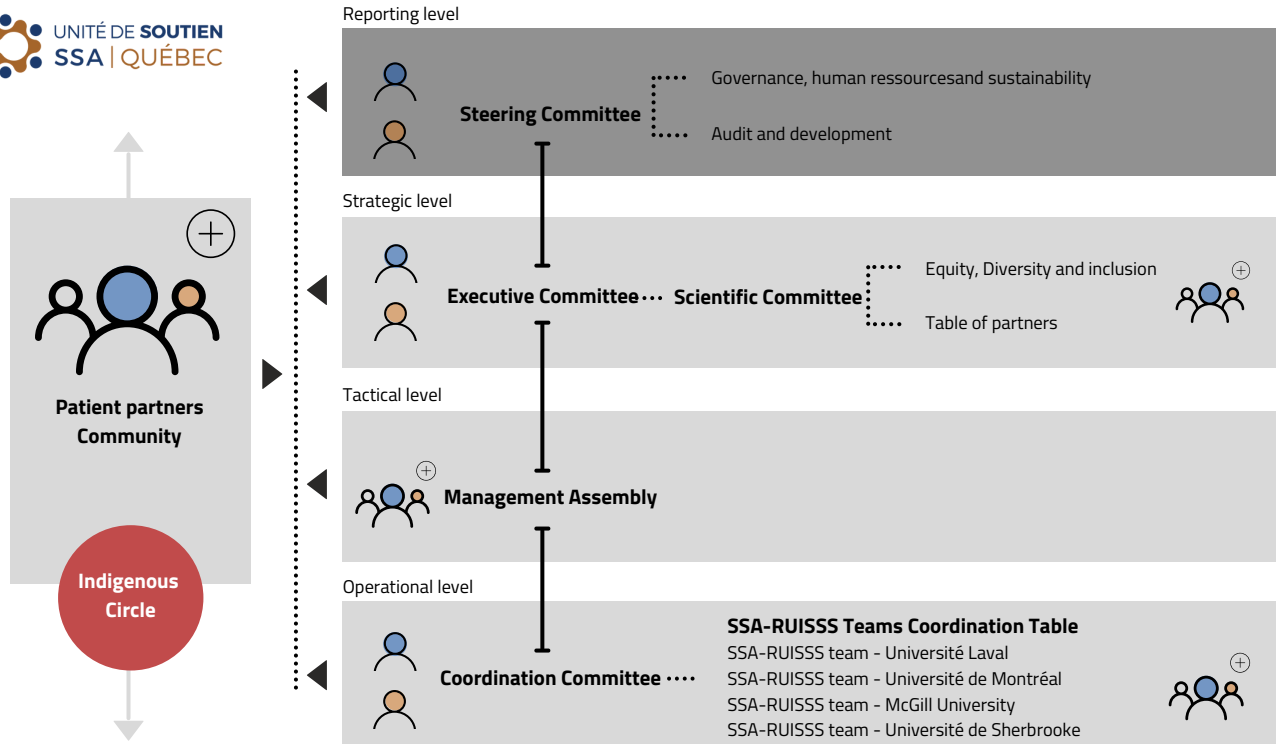
The Unit has also set up an External Partners' Table, whose diverse membership ensures that it is anchored in the field and is close to the decision-making bodies.

The mandate of this table is to advise the scientific committee, particularly on the needs of the health and social services sector.

The governance of the Unit also includes a statutory meeting with representatives of the Research and Internal Coordination Direction of the Ministère de la Santé et des Services sociaux (MSSS).

A few accomplishments of the Direction and the committees

- Update of the communication guidelines
- Draft of a patient-partner compensation policy
- Implementation of a new project tracking and management system
- Launch of a new service request form (LHS Portal)
- Creation of Sustainability and Equity, Diversity and Inclusion sub-committees
- Implementation of a new partnership agreement between the various participating institutions (including four faculties of medicine and several affiliated research centers)

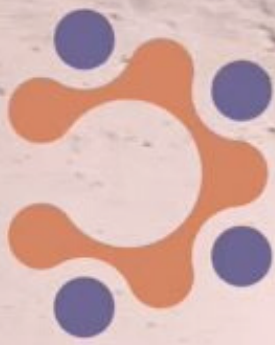


Excerpt from the *Expériences Magazine*

This magazine was developed by the patient partner community of the same name. The *Expériences* community includes patient partners actively involved in governance, strategy, training, and research teams. To date, two issues have been published.



Je suis plus que le cancer



UNITÉ DE SOUTIEN SSA | QUÉBEC

Ensemble pour un système de santé qui apprend

TESTIMONY

Amélie Bouchard, Literacy Facilitator

"I think it's super important for the community organizations to be involved in research, decisions and consultations in the health and social services system because the community sector is closest to the most excluded people."

TESTIMONY

Carole Dupuis, Patient Partner participating in literacy training

"I share my story, people ask me questions, I answer with pride, I love it (...)

Before, when I went to see my doctor or my pharmacist, I didn't tell them that I didn't understand. I was ashamed. I was living with guilt inside me."

about patient partnership

Portrait of the engagement

Here is how the stakeholder groups engaged with the Unit's activities this year

Level of engagement

Inform - Provide stakeholders with sound, objective information that will help them understand the issues, options, opportunities or solutions being considered.

Consult - Obtain feedback from stakeholders on analysis, options or decisions to be made.

Integrate - Work directly with stakeholders throughout the process to ensure that concerns and expectations are always understood and addressed.

Collaborate - Work in partnership with stakeholders at all stages of the decision-making process, including identifying options and determining the preferred solution.

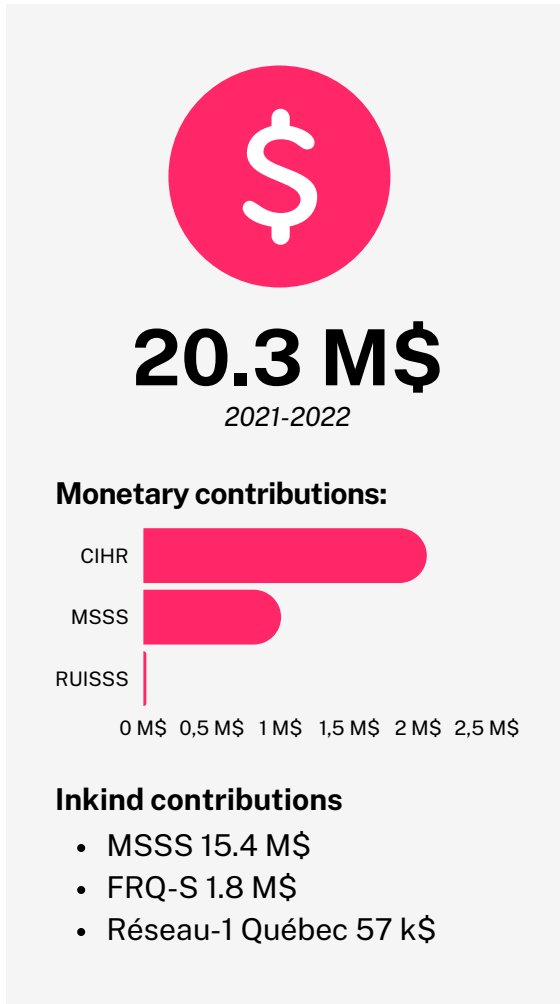
Delegate - Entrust stakeholders with the final decision making.

Type of stakeholder	Inform	Consult	Integrate	Collaborate	Delegate
Patients or users of the health care system	x	x	x	x	x
Professional staff in health care, the health system or public health	x		x	x	x
Health care managers	x	x	x	x	x
Health professional organizations	x	x	x	x	
Federal and Provincial Representatives	x			x	
Community or municipal organizations				x	
User groups or charities	x				
Industry				x	
Medias	x				
Researchers or academics	x	x	x	x	x
Research funding agencies	x	x	x	x	x

2021/2022

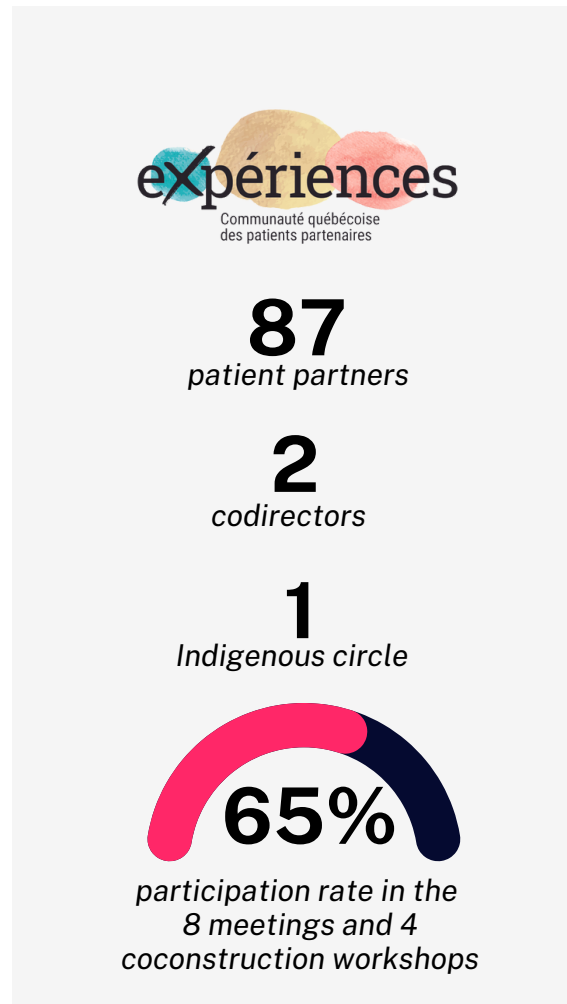
The Unit in figures

avril 2021 - mars 2022



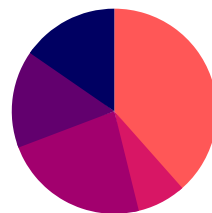
Highlights

- 45 team members qualified in learning health systems
- 28 fellows out of a total of 125 to date
- 284 registrations for training on the *Espace Proximité* platform
- 4 newsletters
- 3 communities of practice



LHS Portal: 66 support requests for 112 services

- Partnership
- Data to Knowledge
- Data Management
- Capacity Building
- Change Management



octobre 2020 - mars 2022*



13 798

unique visitors on the website



18 184

views

A popular new website

The Unit's new website has been live since summer 2020. User experience was at the heart of the team's goals during this project. Since October 2020, the number of unique visitors to the site has nearly doubled from 14,075 to 27,873 (+198%).



+167 %

interaction rate

Ongoing media socialization

The Unit is experiencing a noteworthy uptick on social media. Of particular interest is the significant increase in interactions with its content (likes, clicks, comments, shares), a clear indicator of the relevance of the Unit's messages to people.



+84 %

reactions

*Exceptionally, the Unit's first communication plan covered more than twelve months.

A close-up photograph of a car's side-view mirror. The mirror is dark-colored and reflects a blurred scene of a road with a yellow light and a red light in the distance. The background is a soft, out-of-focus landscape with warm tones.

TESTIMONY

Catherine Wilhelmy, Patient Partner, Scientific Codirection of the Unit

"The patient fills the blind spot of any health care worker. That of living with disease."

TESTIMONY

Antoine Groulx, Scientific Codirection of the Unit

"The learner is everyone. There are not those who know, and those who don't. It's a collaborative effort by all."

Targeted grants

In collaboration with the Ministère de la Santé et des Services sociaux du Québec (funding for competitions 1, 2 and 4) and the Fonds de recherche du Québec - Santé

The targeted grant program to improve care trajectories is a critical component of the Unit's activities. During 2021-2022, the Unit accompanied research teams on the following projects.

<p>01</p> <p>4.75 M 2022-2025</p> <p><u>MND Living Labs</u></p> <p>Innovative research to facilitate transitions and trajectories for people living with a Major Neurocognitive Disorder and their families.</p>	<p>02</p> <p>4 M 2018-2023</p> <p><u>POR in support of clinical and organizational transformations in community care and services</u></p> <p>Transformation of clinical and organizational practices into integrated community-based care and services, in support of the changes underway in the health and social services network.</p>
<p>03</p> <p>600 k 2022-2023</p> <p><u>Priorité patient</u></p> <p>Improving the trajectory of care and services in oncology in Québec. A committee of patient partners has been mandated to identify issues on which research teams are invited to work closely with patient partners.</p>	<p>04</p> <p>4.7 M 2022-2027</p> <p><u>Support for the implementation of integrated service networks for youth (RSIJ)</u></p> <p>Knowledge creation and support of a continuous improvement culture by enhancing the <i>Aire ouverte</i> initiative and making it part of a learning health system. 12 to 25 year olds are welcomed in <i>Aire ouverte</i> spaces and receive health and social services adapted to their needs.</p>

Pan-Canadian Projects

A few examples



Initiatives led by CIHR

We have contributed to these initiatives:

- Project to identify Francophone patient partners in Canada (outside Québec)
- Consensus activities related to the project to develop an evaluation framework and an evaluation guide of SPOR

Collaborations with other provincial SPOR units

We have worked with:

- British Columbia (BC SUPPORT UNIT)
- Saskatchewan (SCPOR)

Communities of Practice

The Unit is a member of:

- SPOR Support Unit Council (SSUC)
- Patient Engagement, Communication, Indigenous Health and Learning Health System Communities of Practice
- National Capacity Building and Performance Measures Table

Other SPOR Funded Entities

We have collaborated with the following entities:

- Diabetes Action Canada (DAC)
- Réseau-1 Québec
- CHILD-BRIGHT
- ACCESS Open Minds
- National Training Entity (NTE)
- Health Data Research Network Canada (HDRN Canada)
- SPOR Evidence Alliance

Excerpt from the Expériences Magazine

The mission of the *Expériences magazine* is to create a space for free expression by gathering, in various forms, testimonies of lived experiences regarding the disease and care

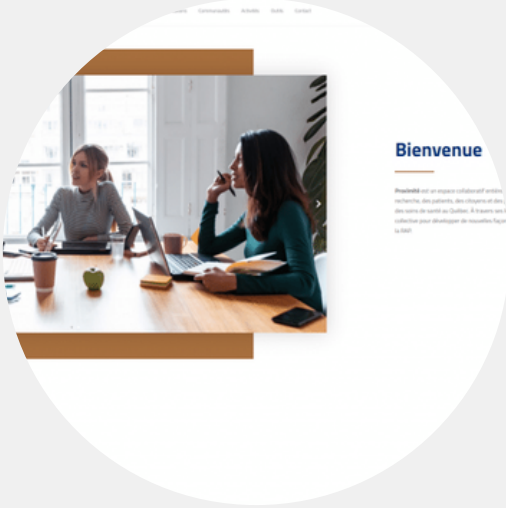
PSYCH PILLS

SAM HALL

My mind has been corrupted
by simple blue and white pills
Where do I go from here?
The snow collects on my window sill
Promising a fresh new beginning
I step out into the winter air
My head whispers the events hadn't been fair
Of a breakdown
Rubbing shoulders with friends I have made
During hospital days.
Everyone in white
Crying inside
Knowing they will never be the same
The corruption of drugs to make you sane
The addiction of psych drugs
to drive away the rain
And in the end, you'll talk just fine.
A simple life is what you'll have
Easy does it, you don't want to fall
Through the gemmed web of curiosity
Of creativity
What does one expect when you've had ECT

RÉFLEXION

ALEXANDRE
GENEST



Launch of the *Espace Proximité* platform

Our Capacity Building team has launched the *Espace Proximité* platform. It is a collaborative space dedicated to patient-oriented research (POR) and the learning health system. It includes:

- Communities of Practice
- Trainings
- Tools and resources
- Networking opportunitun



Trainings to prepare for a medical consultation

These three free trainings, presented in the form of short narrated presentations, allow the development of skills to engage more actively in health consultations:

- Communicating better with health and social services staff
- Making a shared decision with health and social services staff
- Evaluating the quality of health information available on the Internet

The videos are in French.



Understanding research

Our Data to knowledge team has enhanced the Understanding Research website with new video clips. These popularized contents are available in French and in English and aim at providing a better understanding of the research world, research methods and terms used in research.

The videos are available online.



TESTIMONY

Marie-Hélène Goulet, Young Learning Health Systems Leader, SSA-
RUISSS Université de Montréal

"Having had access to so many trainings and conferences when I was a fellow in the Unité de soutien, these shaped the researcher I have become as they changed the way I do research.

While I had the opportunity to implement several research strategies while on fellowship, it was when I had to develop my own research programming that I saw the impact. As a young faculty member, I am now able to propose projects that I am passionate about with methods that are consistent with my personal and professional values, such as patient and clinician partnerships, mixed methods, and organizational participatory approaches."



Participatory research video FAQ

Here is an example of a request for support that our Capacity Building team responded to by providing expertise, including techno-pedagogical advice, in this project to help set up a participatory research project. The following contents are online:

- 18 videos
- 16 experts
- 1 glossary and other complementary content



Patient Partner Community *Expériences*

In 2021, the patient partner community activated by the Unit became self-sustaining, it recruited new members and adopted the name *Expériences*. Among its annual accomplishments:

- New governance (60 hub members, 22 assembly members and 5 executive members).
- Launch of the magazine of the same name
- Launch of a provincial tour
- Planning of short, medium and long term activities with the goal of recruiting and participating in provincial, national and international committees.



Indigenous patient circle

The Indigenous Patient Circle will help develop respectful and meaningful relationships with Indigenous patient partners, representing a wide range of communities, nations and social identities. The circle will be a self-governing, self-determining community that provides a safe place for its members to share and guide the implementation of the Unit's Indigenous health program.

- Dialogue initiated with 8 patient partners



TESTIMONY

Amédé Gogovor, Postdoctoral Fellow

"The patient partnership represents both an inspiration and a justification for my research projects. This is made possible through the Unité de soutien SSA Québec as a platform for training, recruiting patient partners and belonging to a community of practice for the advancement of patient-centered research for optimal and equitable outcomes."

TESTIMONY

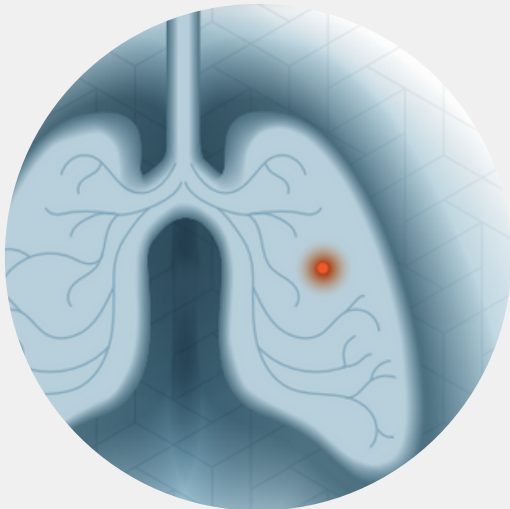
Christine Loignon, Researcher in charge of the Partnership Antenna, SSA-RUISSS team Université de Sherbrooke

"If you involve, from the beginning in the research, different partners, including citizens and patients, you transform things as you go along [...] It brings a knowledge of experience that clinicians and researchers don't have at all."



Partner Portal

Our Partnership team has enhanced a portal that was created through coconstruction. This portal, now populated by approximately 130 patients, has a co-governing structure with 50% of the committee seats held by community-based partner members.



Decision support tool for lung cancer screening in Québec

Our Change Management team contributed to the development of this decision support tool for the population eligible for lung cancer screening in Québec and for clinical staff. It is intended to help the eligible population make an informed choice about whether or not to participate in screening.

The tool is available [online](#).



Guide and questionnaire for measuring gender in research

Our Data to Knowledge team has developed two tools for measuring gender in human research:

- Creation Guide for a Composite Gender Index (a method to be applied after data collection when only sex assigned at birth has been measured)
 - The guide is available [in French](#)
- [Questionnaire to measure gender identity, gender roles, and sexual orientation in research](#) (a self-reported measure to be incorporated before data collection)



PARS3 Data Platform and White Paper

PARS3 is a secure and ethical learning platform for health care and research teams on projects that require authorized access to data from multiple sources. In 2021-2022, our Data Management team has:

- Made the platform ready for deployment (TGV certification, security analysis, demonstration)
- Contributed to the pan-Canadian white paper on the social acceptability of health data



Updates and maintenance of existing tools

In 2021-2022, our teams maintained and improved several tools:

- Understanding Research website (new videos)
- eSRAP© collaborative monitoring system (update and perpetuation)
- BayesiCALLY web application (promotional video)
- Dynamic description of front-line services (DDS) in Québec (update and perpetuation by CIRANO)
- Methods for Rapid and Rigorous TransCultural Adaptation (RR-TCA) (update)
- TorSaDE population-based data cohort (update and add data)

Coming soon 2022-2023

Working on it!

Here are a few initiatives that will be covered in our next activity report.



Mapping Québec's expertise in learning health systems (LHS)

WHAT

- We have made an inventory of existing LHS resources and expertise in Québec
- We have identified strengths and areas for improvement.

WHY

- To inspire the work of co-building for the implementation of the LHS teams in the RUISSSSs.
- To support the design, implementation and evaluation of LHS in Québec.



PATlenTS Project

Life Trajectory Improvement and Innovation Partnerships in Transition to Sustainable Health

WHAT

- We have explored themes in response to needs identified by the field (4 RUISSSSs).
- We have conducted action research projects with immediate added value for the system.

WHY

- To support the improvement of care and service trajectories with SSA-RUISSS teams in collaboration with RUISSSSs and their institutions.

Must read and watch



Key events

Watch the recordings of our events and see the results of the survey!

Event: Access to data: transparency and digital consent (in French)

- October 28, 2021
- 5 presentations in a scientist-patient pair
- 1 deliberative workshop
- 6 recommendations

Population Survey on Health System Improvement and Health Information Sharing

- Between February 18 and 20, 2022
 - By Léger Firm
 - 1007 adults residing in Quebec
-
- 86% of people are interested in getting involved to help improve the health care system
 - The well-being of health care teams and scientific studies should guide decision making
 - 72% of Quebecers are willing to give consent online rather than on paper

Summit: Building Québec's Learning Health System Together (some content available in English)

- March 24, 2022
- + More than 700 registrations
- 29 speakers including 9 patient partners
- 12 presentations, 2 panels, 1 poster competition and 2 interactive workshops

Videos



Latest releases



Find out what's a learning health system in 60 seconds



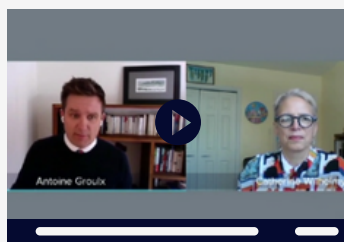
Our scientific co-leadership in parliamentary committee (in French)



Testimony of a team working in partnership in health and social services (in French)



From medicine to the learning health system: the journey of Dr. Antoine Groulx (in French)



Who is the Unité de soutien au système de santé apprenant Québec? (in French)



Do you know the patient partner community *Expériences*? (in French)



5 winners of the Learning Health System Poster Competition

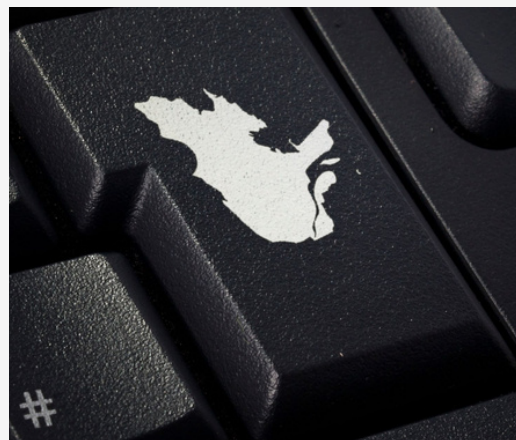
Partners

Striving to support the continuous improvement of our health system and the care and services provided to the population.

Towards a Québec Ecosystem

The Unit intends to contribute, with its partners and collaborating organizations, to the construction of a true province-wide ecosystem that links

- the health network
- the research network
- the various knowledge mobilizing organizations
- other provincial SPOR entities



Nos partenaires fondateurs



Support offer

Who are you?

- Researcher
- Policy maker
- Health or social services professional
- Patient or caregiver



TRAINING



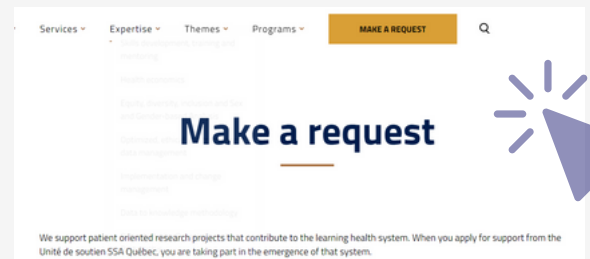
CONSULTATION



TOOLS

Do you have a project...

- Focused on patient partnership?
- Contributing to the learning health system?
- Improving clinical or organizational practices?



ssaquebec.ca/en/make-a-request

5 axis and expertise deployed throughout Québec



PARTNERSHIP



CAPACITY BUILDING



DATA MANAGEMENT



DATA TO KNOWLEDGE




CHANGE MANAGEMENT



Acknowledgements

We warmly thank the members of our team who are dedicated to the continuous improvement of the health system and the care and services provided to the population of Québec.

- **Executive team**
- **Axis**
 - Partnership
 - Data Management
 - Data to Knowledge
 - Change Management
 - Capacity Building
- **SSA-RUISSS teams**
 - Université Laval
 - McGill University
 - Université de Montréal
 - Université de Sherbrooke
- **Coordination, Steering and Scientific Committees**
- **Management Assembly**
- **Community of Patient Partners *Expériences***
- **Executive and Scientific Directions**



Working together for a Learning
Health System

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