

2014-2021 ACTIVITY REPORT



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ABBREVIATIONS

CPPCP-RSQ: Communauté de pratique des patients et citoyens partenaires de la recherche en santé du Québec

FRQ: Fonds de recherche du Québec (Quebec Research Fund)

CIHR: Canadian Institutes of Health Research

MSSS: Ministère de la Santé et des Services sociaux du Québec (Quebec Ministry of Health and Social Services)

POR: Patient-oriented research

RUISSS: Réseau universitaire intégré en santé et services sociaux (Integrated University Health and Social Services Network)

SPOR: Strategy for Patient-oriented Research

LHS: Learning Health System

A WORD FROM MANAGEMENT

It's been six years already! Since its inception, Quebec's Unité de soutien de la Stratégie de recherche axée sur le patient (SRAP) has built valuable partnerships and beneficial synergies in patient-oriented research (POR). It has become a leading resource in Quebec for supporting learning systems.

2020 was a particularly challenging year due to the COVID-19 pandemic. However, it was also filled with good news and positive energy! The Unité's executive team moved to the Université de Sherbrooke's Longueuil Campus. It also officially appointed Dr. Antoine Groulx as the designated scientific director, supporting current scientific director Dr. Alain Vanasse.

In addition, it filed a renewal application with the CIHR. This was both an opportunity to take stock of the current situation and look to the future. We are proud of the extraordinary teamwork that has been done to ensure that the Unité continues its mission.

Our first mandate is coming to an end and we are more determined than ever to help build a learning health system that is continuously improving, with and for the population, benefitting both patients and health and social service staff. It is in this spirit that we are publishing an activity report for the community for the first time. We hope that our vision and service proposal inspire you so that as many people as possible can benefit from it.

We hope you enjoy reading it.



A stylized, handwritten signature in black ink.

Dr. Alain Vanasse
Scientific Director



A stylized, handwritten signature in black ink.

Dr. Antoine Groulx
Designated Scientific Director



A stylized, handwritten signature in black ink.

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General Director



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Dr. Annie LeBlanc
Component Director
Capacity Building



Dr. France Légaré
Component Director
Knowledge Translation



Dr. Pierre Pluye
Component Co-Director
Methodological Developments



Dr. Tibor Schuster
Component Co-Director
Methodological Developments

THANK YOU, TEAM!

We recognize the leadership of **Dr. Marie-Dominique Beaulieu**, who was the first person to provide scientific leadership for the Unit from 2014 to 2017!



Executive Team

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Myra Drolet
Sylvie Noël
Yves Couturier (Network-1)

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Joe Guillaume Pelletier

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Roxanne Dault

With us before 2021

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Carole Du Sault
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François Fournier
Geneviève David
Ginette Bélec
Janusz Kaczoroski
Martine Fournier
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THANK YOU, TEAM!

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Marie-Hélène Goulet
Marie Hirtle
Marie-Joelle Cossi
Marie-Josée Bernardi
Marie-Pascale Pomey
Marie-Pierre Gagnon
Mario Di Carlo

THANK YOU, TEAM!

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Yifan Bai
Ysendre Cozic-Fournier

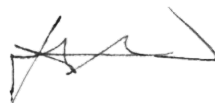
PATIENTS TAKE THE FLOOR

Many things have changed since the Unité de soutien SRAP du Québec was founded. Not only does the Unit support putting the findings of patient-oriented research into practice, it also gets patient partners involved to act as experts on its various committees. Their presence on the organization's steering committee played an important role in enabling patient partners to take their rightful place.

We have been asking for clarifications since 2014. We demanded real facts that significantly influenced communication within the Unit's Steering Committee and allowed everyone sitting on it to better understand the issues facing the organization. We also carried out interventions that led the Unit's senior managers to document and map out its organizational structure and the connections between its components. We are pleased with the progress we have made and are convinced of the validity of our approach, which we hope to continue implementing during a second phase starting in 2021 to improve care pathways for the Quebec population.



Zamzam Akbaraly



René Benoit

Patient Partners
Unit Steering Committee Members



POR

The Unité de soutien de la Stratégie de recherche axée sur le patient (SRAP) is the provincial stream of the national SPOR network funded by the Canadian Institutes of Health Research (CIHR).

What is POR?

Patient-oriented research (POR) establishes a partnership between patients, the public and any person or organization working in health and social services in the areas of research, care or social services.

POR is transforming patients from passive service receptors to proactive partners. They participate in research, health care and social services as co-researchers, partners in their care and experts on living with the disease.

Since its inception, the Unit has placed patient-oriented research at the heart of its initiatives.

This commitment helps ensure that studies focus on priorities identified by patients, which leads to better patient outcomes.

Source: CIHR

Our Mission

In 2015, the Unit's mission involved supporting the transformation of frontline clinical and organizational practices and integrating POR care and services. Since then, we have promoted, strengthened and developed POR in Quebec.



MARIE-DOMINIQUE POIRIER, PATIENT PARTNER

The patient-research partnership is based on my personal experience as a patient. This first-hand knowledge lets me approach research from a different angle—that of the patient—and allows me to make a small contribution to health care progress.

OUR VISION

The Unit strives to play an essential role in the continuous improvement of Quebec's health care system.

Recognition, Promotion and Development

The first phase of our work brought about a number of developments and choices, including:

- Recognizing the first-hand knowledge of patients, the public and all other concerned parties
- Promoting research in real-world contexts
- Developing implementation science
- Adopting the learning health system concept (LHS)

Fulfilling Our Ambitions

POR gives us the means to achieve our ambitions by making it possible to establish LHSs.

From now on, this vision will push us to embrace our quadruple aim of mobilizing researchers and health and social services **together with and for the benefit of the public**, in an effort to improve:

- The patient experience
- The health of the general population
- The efficiency of the system
- The well-being of health and social service workers



Dr. BRIGITTE GUERRIN

Your leadership and various discussions led me to reflect on another dimension of the disease—the emotional impact—that cannot be found in the scientific literature. I wonder whether suffering and hardship in the face of disease can lead to great generosity and kindness...but clearly you do an extraordinary job of bringing a human dimension to the disease, which isn't always the case. I am convinced that this collaboration with patient partners will make us better researchers with a greater understanding of the diseases that we want to diagnose and treat. We hope that we will be able to give them something in return and listen... especially when their time is so precious. A very sincere thank you.

THE UNIT IN NUMBERS

50 PEOPLE QUALIFIED IN POR

Over 50 researchers and professional POR support staff in Quebec

337 SERVICE REQUESTS

337 service requests, with over 90% receiving a favourable response

92.5% SATISFACTION RATE

Average satisfaction rate of 92.5% with the service platform

72 FELLOWS

Cohort of 74 POR fellows

30 POR TRAINING COURSES

30 specialized POR training courses

1 COMMUNITY OF PRACTICE

1 provincial community of practice for patient partners

39 TOOLS AND 4 PLATFORMS

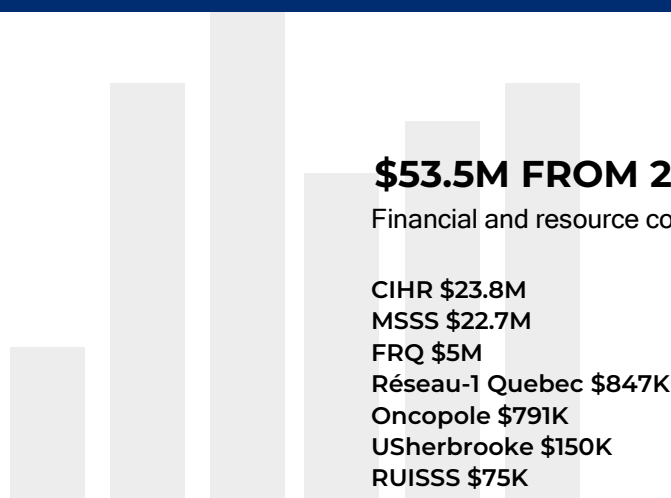
39 innovative tools and 4 research platforms

+250 PUBLICATIONS

Nearly 300 diverse scientific publications

+200% SUCCESS RATE IN CIHR COMPETITIONS

Double the success rate in CIHR competitions for teams supported by the Unit



OUR PROJECTS

A Pan-Quebec Team

- An executive team with a management, direction and communication role, hosted at the CIUSSS du Centre-Sud-de-l'Île-de-Montréal until March 2020 and now established at Université de Sherbrooke's Longueuil Campus
- Components that are activated by teams of experts in Quebec's four faculties of medicine and their affiliated research centres (McGill University, Université de Montréal, Université Laval, Université de Sherbrooke) to deploy the Unit's service offering
- Co-researchers throughout the Quebec university network

Our Road Map

The Unité de soutien SRAP du Québec is aptly named: it primarily provides support services. Little-known fact: in recent years, it has also successfully contributed to several other projects:

1. Participating in targeted programs in collaboration with the FRQ, MSSS and Oncopole
2. Completing a demonstration project on individuals who are frequent users of emergency services
3. Training expert consultants and tools relating to POR primary care.

Our Three Target Grant Competitions

The Unit has been actively involved in three grants programs requiring a patient-oriented approach to research, with patients acting as a partner or collaborator from the planning phase.

Transforming Quebec's Research Culture

We played an important role in these three competitions, right from the initial design. We supported around 40 competing teams and supported a dozen of the projects selected.

Shared Principles

• Participatory Approach

Involve researchers, professional health and social services personnel, decision-makers, caregivers and patients in project design and implementation, interpretation of results and knowledge transfer.

• Training and Support

Foster the inclusion of patients as full partners in research projects.

OUR TARGET COMPETITIONS



COMPETITION 1: LA RAP EN APPUI AUX TRANSFORMATIONS CLINIQUES ET ORGANISATIONNELLES EN SOINS ET SERVICES DE PROXIMITÉ

- \$4M for four teams (one per RUISSS)
- Launched in July 2018 by the MSSS, the FRQ-S and the Unité de soutien SRAP du Québec
- Supporting ongoing changes in Quebec's patient-oriented health and social services network



COMPETITION 2: APPUI À LA MISE EN ŒUVRE DES RÉSEAUX DE SERVICES INTÉGRÉS DESTINÉS AUX JEUNES (RSIJ)

- \$4M in research
- Launched in February 2018 by the MSSS, the Graham Boeckh Foundation (GBF), the FRQ-S and the Unité de soutien SRAP du Québec Developing and evaluating pilot projects for mental and physical health services, adapted to meet the needs of youth aged 12 to 25
- Implementing the MSSS's *Aire Ouverte* (Open Space) initiative following the competition



COMPETITION 3: PATIENT PRIORITY

- \$800K for four projects
- Launched in November 2019 by the Oncopole, the FRQ-S and the Unité de soutien SRAP du Québec
- Aiming to improve care pathways and oncology services in Quebec

DEMO PROJECT

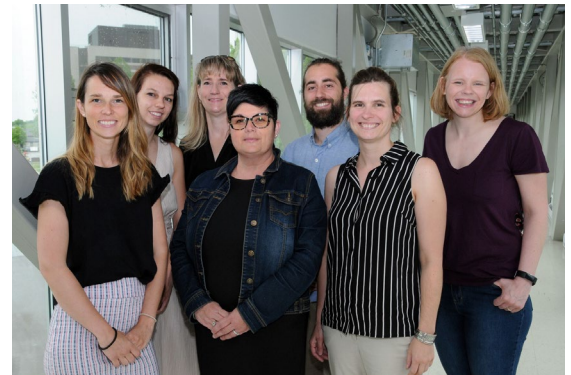
An Example of a Learning Health System

Project: Improve the ability to identify patients at risk of becoming frequent users of emergency services.

Launched in 2016 in support of the V1SAGES program, this flagship project helped demonstrate the value and benefits of the learning health system approach (LHS). Led by an interprofessional team involving patients and their loved ones, it embodied **a research continuum**, from structured data collection and valuation to producing tools to support decision-making and, ultimately, integrating the knowledge acquired into clinical and organizational practices.

Three Streams and Objectives

1. Improve the ability to identify patients at risk of becoming frequent users of emergency services
2. Further integrate the social and community streams with the health stream
3. Identify the decision-making issues for frequent users of services with complex needs



VERONIQUE SABOURIN, PATIENT PARTNER

I had a life expectancy of 18 years, and I'm now 45 years old. I've been receiving care since childhood. I was involved long before patient partnership was recognized and was given a name. It came naturally to me. I don't like to complain, I like to find solutions! This led to my interest in research and co-construction. I joined the demonstration project because our contributions are necessary. Patients can't exist without health care professionals, and the opposite is also true. This is precisely what I want: to demonstrate the relevance and added value of patient partnership.

DEMO PROJECT (CONTINUED)

Features

- Multidisciplinary and interprofessional team
- Active involvement of six patient partners in all phases of the project
- Support for most resources in the Unité de soutien SRAP du Québec

Process

- Systematic review, collection of data on decision-making needs and methods to integrate health and social streams
- Developing and validating clinical tools.

Results and Impacts

- Developing the [CONNECT-6](#) tool for identifying individuals at risk of becoming frequent users of emergency services, and implementing it in the clinical setting
- Improving training for clinical staff
- Optimizing nurses' role in monitoring patients with complex needs at risk of becoming frequent users of emergency services

Capacity Building

As part of the demonstration project, we provided POR capacity-building support to six patient partners, three researchers, six professional research staff members and ten members of the student community.

To this day, all of these people work in the POR field. This had a leverage effect, as several of them subsequently received training or career grants and substantial grants, including:

- A \$4M grant over four years to implement case management intervention similar to the [V1SAGES](#) program model in ten primary care clinics in five Canadian provinces
- A \$575K grant from the MSSS's Programme ciblé d'octrois de subventions, in partnership with the Unit and the FRQ-S
- Continuation of the demonstration project. The team is developing an online training series for clinical teams. In addition, they are aiming to scale the [V1SAGES approach](#) at other clinical institutions in Quebec



MARIE-EVE POITRAS, INF. PH. D.

For me, patient partnership is the very essence of health research. It fulfills my desire as a clinician and researcher to help improve the quality of care for and with patients! It is essential in every way and at all stages of the research process.

THE INSTINCT TO CO-DEVELOP



JULIE GODBOUT, NURSE VISAGE TEAM CASE MANAGER

Being a case manager has radically changed my relationship with clients. I used to see myself a bit like a teacher who provided knowledge to patients who just had to follow my advice and recommendations, because it was the right thing to do to be healthy! [...] Now, I see myself as a resource, partner and coach.

Of course we have knowledge to pass on to patients, but they are ultimately responsible for making decisions about their lives and health. [...] The case manager is there to support them, offer services, help them make decisions and navigate the health care system. They allow for a more thorough assessment of the individual's needs.

Case management has also allowed me to develop relationships with other professionals and community resources, to better understand their roles and when and how to contact them when needed.

[...] Now when they have a patient with complex needs or a difficult situation, their instinct is to talk to other professionals. A co-development group was even set up to provide a forum to discuss these situations. Concrete solutions and concerted actions have emerged. Now that I'm replacing people in other fields, I miss these meetings.

PROJECTS: TRAINING



JOINT POR FELLOWSHIP PROGRAM

Since 2014, this program has helped the student community, postdoctoral fellows, health professionals and researchers hone their skills, gain valuable expertise and expand their POR collaboration network. We administer this program in partnership with the FRQ, MSSS, Fédération des médecins omnipraticiens du Québec, Programme de résidence du Clinicien (Clinical Scholar Residency Program) and the four faculties of medicine in Quebec.

This program enables recipients to:

- Participate in POR training activities and POR science days
- Receive scientific communications and outreach grants in connection with POR
- Collaborate on POR working groups, committees and projects
- Receive mentorship and support from POR experts

From 2014 to 2019, our training program hosted:

- 48 fellows in training (master's, Ph.D and postdoctorate)
- 10 family physicians
- 11 medical residents (Clinician Scholar Program)
- 3 students participating in the demonstration project

> [Learn about the Training Fellowship Program](#)



CITIZEN LECTURES

Public health education lectures on polypharmacy offered in 25 public libraries in Montreal and Quebec City were attended by over 360 people. They represent proof of concept for popularizing and disseminating research findings to the general public.

> [Learn more](#)

PROJECTS: TRAINING



TABLE DE TRAVAIL PROVINCIALE DE LA SRAP EN RENFORCEMENT DES CAPACITÉS

In 2017, the Unit initiated a working group involving the capacity-building expertise of various Quebec SPOR entities. This group identifies issues relating to POR capacity building, implements actions and promotes sharing and collaboration. It is the only example in Canada where all SPOR entities in a single province come together around the same table.

It includes all SPOR mentoring networks and chairs in Quebec, including:

- The Réseau québécois de la recherche sur la douleur (RQRD)
- BRILLEnfant
- ACCESS Open Minds Diabetes Action Canada
- The SPOR Evidence Alliance
- Chaire de mentorat SRAP des IRSC sur les essais cliniques comportementaux novateurs
- Réseau-1 Québec
- Patient Partners

Impact

- Creating synergy between SPOR networks in Quebec;
- Implementing initiatives between networks, by and for all networks, including:
 - The Unit's mandate to provide POR training to French-language partners at Diabetes Action Canada
 - Launching the Forum jeunes leaders de la RAP, an annual event designed to instill knowledge and skills and provide mentorship to young researchers



TRAINING WITH THE UNIT

We provide POR training to researchers, health and social services professionals, decision-makers, patients, the student community and federal and provincial organizations. Since 2014, we have offered:

- 25 patient partnership training courses, tools to support decision-making, health economics, research literacy, etc.
- 149 educational activities offered to nearly 2,000 individuals
- Increased participation and an increasingly diverse clientele

> [Learn About the Training Courses](#)

PROJECTS: TRAINING



ÉCOSANTÉ

Écosanté (Ecohealth) is a group of health economists who develop training programs and provide support through economic assessments and health economics. Services are available to researchers, health professionals, administrators, patients and their loved ones and anyone else who is involved in the health and social services field.

The Écosanté initiative provides the following tools:

- Tutorials and training workshops

A series of 4 training modules for the general public and a series of 12 advanced training modules and tutorials. This content is available online.

- Key resource mapping

The document “Cartographie des ressources en économie et évaluation économique en santé” provides a list of various types of academic training, para-governmental bodies and other institutions, along with various economic assessment and health economics specialists, primarily in Quebec. It also contains references to Canadian and international organizations in the field, along with books, newspapers and websites of interest.

> [Learn About Écosanté](#)

ANNIE POIRIER, PATIENT PARTNER AND RESEARCH PROFESSIONAL

Should health be researched at any cost? [...] The constant growth in health care costs is leading decision-makers to examine the economics of health technologies, programs and policies. Health economics assessments are tools to aid in decision-making and can be addressed from several perspectives, i.e., the payer, patients and society. This requires reconciling several different perspectives.

PROJECTS: EXPERT CONSULTANTS



PATIENT PARTNERSHIP OUTREACH

We have participated in several international activities, including the international partnership summit. We have also been part of Canada's leadership in terms of tools and assessment frameworks, along with measuring impacts.

We have positioned Quebec as a Canadian and international leader in assessing and researching partnerships with patients and the public. For instance, patient partners were involved in these outreach efforts at the following events:

- An activity at Montreal's Centre hospitalier universitaire Sainte-Justine
- A symposium at the Université de Sherbrooke - Longueuil Campus
- A symposium on Artificial Intelligence at the Université de Montréal



TRANSFORMING PRACTICES AND CULTURE USING POR

We have prompted a profound transformation of patient-oriented research practices at the micro, meso and macro levels by launching various activities and initiatives:

- Ethical coaching guides
- Compensation and integration guides at research centres
- Peer committees
- Strategic fundraising competitions



GILLES GAUTHIER, PATIENT PARTNER

Patient partnership is the basic concept that allows health care staff to understand that patients need to be involved in their entire care process by keeping them informed and respecting their choices.

PROJECTS: EXPERT CONSULTANTS



COMMUNITY OF PRACTICE FOR PATIENTS AND CITIZEN PARTNERS IN HEALTH RESEARCH IN QUEBEC (CPPCP-RSQ)

We mobilized, integrated and sustained a provincial community of about twenty patients, caregivers and citizen partners in connection with major research and health system transformation initiatives in Quebec. The CPPCP-RSQ is experienced and capable of engaging in all stages of research.

It has three objectives:

- Supporting the exchange and capacity building of patients and citizen partners in health research in Quebec
- Driving the emergence of structuring initiatives for these same health research partners in Quebec
- Acting as an advisory resource to the Unit's general and scientific management (Direction générale et scientifique)



EXPERTISE IN PATIENT-PUBLIC PARTNERSHIPS

We have developed a sustainable capacity for patient and public engagement across the province. We have also developed awareness and deployment capabilities by establishing the following entities:

- A network of experts and patient partners throughout Quebec's RUISSs
- 5 training modules on partnering with patients on research
- Tools to help initiate POR and recruitment of patients and patient partners (videos, training modules, reference documents and compensation policies)
- An evaluation framework and tools to measure processes and the impact of partnerships between patients, the public and research

> [Learn more](#)

PROJECTS: EXPERT CONSULTANTS



CLARET

CLARET is a project that studies ways to implement meta consent, allowing patients to provide access to their health data. CLARET is studying informed consent on several research projects at the same time and how often patients should receive invitations to provide consent. Using surveys and focus groups comprised of people from all levels of society, the CLARET project is studying the implementation of a meta consent approach.

The MSSS mandated the Unit to define and validate the parameters required to establish a transparency portal for citizens that would facilitate transparency, acceptability and access to health data for research purposes.

> [Learn About CLARET](#)



COLLECTING IDEAS

The collection of ideas “S’outiller pour favoriser la participation des usagers, des proches, des citoyens et des communautés à l’amélioration continue de la qualité des soins et des services,” on using tools to promote the participation of users , family and friends, citizens and communities in the continuous improvement of quality of care and services, offers specific information to different groups of users. The purpose of collecting this data is to equip those concerned to continuously improve the quality of care and services in individual, organizational and community settings. This initiative was carried out in collaboration with the MSSS , INESSS, the Institut universitaire de première ligne en santé et services sociaux du CIUSSS de l’Estrie and the Unit.

Implementing these ideas in care and social services settings aims to ensure that the right care or service is provided to the right people, at the right time and at a reasonable cost. Activities to integrate these tools were held in all CISSSs and CIUSSSs across Quebec.

> [Consulting the Recueil](#)

GIVING BACK



JOCELYN BERNARD, PATIENT PARTNER

My involvement left me with a sense of accomplishment from my active participation in these projects, which for me represented a way of “giving back”. [...] Firstly, the sense of belonging that I lost after my stroke due to losing my job and professional status.

Secondly, the sense of accomplishment I gained from participating in the project to evaluate the assessment tool on the need to adapt home bathrooms for people who have lost their autonomy (Algo), a tool intended for health professionals [...]. Following this project, I had the honour of being invited to the thesis defence of the researcher with whom I collaborated on this wonderful achievement [...].

Thirdly, my various patient partnership activities also allowed me to fulfill a need to feel respected by giving me the opportunity to actively collaborate on research teams, which was extremely valuable for me [...]. This involvement as a patient partner was what prompted me to get involved with the Institut universitaire de première ligne en santé et services sociaux (IUPLSSS) and participate in the “La force du Nous” (Strength of Us) Committee and sit on the Institute’s Executive Committee as a user member.



PROJECTS: TOOLS



REAFFECTMD

In April 2020, the ReaffectMD platform was designated as the official platform to monitor and reassign physicians across Quebec to address emerging needs relating to COVID-19. It already has over 2,000 users.

> [Learn More](#)



UNDERSTANDING RESEARCH

The bilingual “Understanding Research” bilingual platform aims to make research and scientific information available to the public. It uses text and videos to explain the stages of health research and covers a variety of themes, including:

- Research ethics
- Literature reviews
- Application of knowledge
- Research methods and specifications
- The participatory approach

> [Learn About the Portal](#)



ACCÈS RECHERCHE

ACCÈS RECHERCHE is a platform for accessing research facilitation services, developed in partnership with Réseau-1 Québec, to provide research capacity to frontline clinical settings, as well as advisory services to researchers on methodology, clinical realities, writing protocols, recruitment, dissemination, letters of support and cost estimates. It is a living laboratory, offering the Réseaux de recherche axée sur les pratiques de première ligne (RRAPPL)’s services in order to provide a learning health system for care and outreach services.

This network includes over 50 frontline clinics in Quebec that serve over 500,000 patients.

> [Access the platform](#)

PROJECTS: TOOLS



ENGAGE

ENGAGE is a website that aims to get researchers, the student community and the general public involved in participatory and engaged research, including the most vulnerable people and those with low literacy levels who have less of a voice or are less visible in health research.

This website was co-built by community-based organizations with expertise in action research and members of the Canadian and international research community.

It offers visual and auditory tools and promotes methods and approaches to help get the entire population involved in research. The following visual methods have been proposed:

- Photovoice
- Participatory mapping
- Digital storytelling
- Guided tours
- Podcasts
- Photo comics
- Problem tree

> [Learn About ENGAGE](#)



AMÉLIE BOUCHARD, SOCIAL WORKER PARTNER

[...] You feel a strong sense of pride and accomplishment when you are part of a team of people with shared values who work for increased social justice for the most marginalized people in our society [...]. We place the same emphasis and importance on community experts as we do on academic expertise. It is so rare that we have the opportunity to write down and share the wealth of innovative practices we possess. I invite everyone to contribute to this great initiative, including community members and researchers!

PROJECTS: TOOLS



DYNAMIC DESCRIPTION OF FRONTLINE SERVICES

Description dynamique des services (Dynamic Service Description or DDS) is an interactive web application that provides an integrated and updated overview of frontline services in Quebec.

It was developed to fulfill a need expressed by patients, practitioners, researchers, and faculty of medicine administrators and their affiliated research centres.

DDS is a tool dedicated to the continuous improvement of frontline services in Quebec. From the patient's perspective, it provides an intuitive, visual and user-friendly overview of frontline services by region. It was merged with the CIRANO website, which now updates the DDS.

> [Access DDS](#)



PROMS AND PROMIS®

PROMs (patient-reported outcome measures) are self-reported measures of how patients are feeling and functioning.

PROMs provide insight into common symptoms and functional impacts of chronic diseases. These measures help staff to quickly identify what needs to be discussed with patients who are struggling with loneliness or anxiety and who may require a meeting and would benefit from additional services.

We supported the first steps in implementing the PROMIS® system, in English and in French, to improve patient-oriented research and care.

Our collaboration with NIH-PROMIS (Patient Reported Outcomes Measurement Information System) was central to the Unit's work. PROMIS® uses advanced psychometric methods to transform the way in which health is measured and includes over 300 self-reporting measures of overall physical, mental and social health, such as quality of sleep, social isolation and physical functioning of the body. PROMIS® is the tool of choice for patient-oriented research worldwide.

> [Learn More](#)

PROJECTS: TOOLS



PARS3

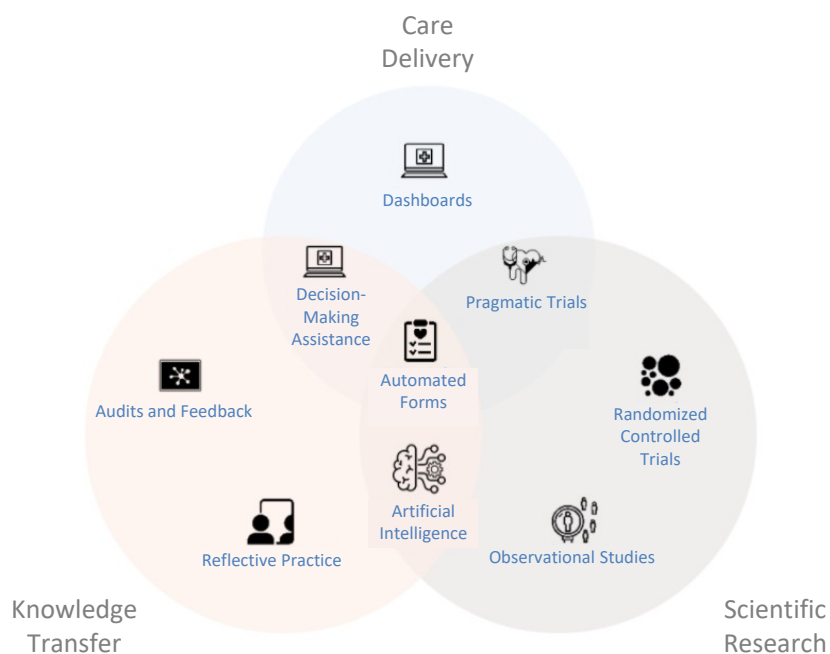
PARS3 is a safe and ethical learning platform intended for health care and health research teams working on projects that require authorized access to data from multiple sources. PARS3 makes it possible to process data that is distributed through separate computer systems and to share it with various networks in a consistent and comprehensible manner. It is a public asset whose use is not limited to research. PARS3 is a useful tool for supporting the entire learning health system cycle.

It contains several different types of data, including administrative, clinical, research and environmental .

Numerous interventions, have demonstrated the added value of the platform since its creation:

- MSSS mandate to deploy PARS3 for frontline services throughout Quebec and to use it for several other MSSS projects
- Deployment with clinical data from a Dossier of Clinical Information (DCI) in Paris, a frontline electronic medical record in collaboration with Omnimed, and the REDCap public health research data cohort(Research Electronic Data Capture)
- Structuring the algorithms of the Canadian SPOR data platform in the PARS3 ontological model

> [Learn About PARS3](#)



PROJECTS: TOOLS

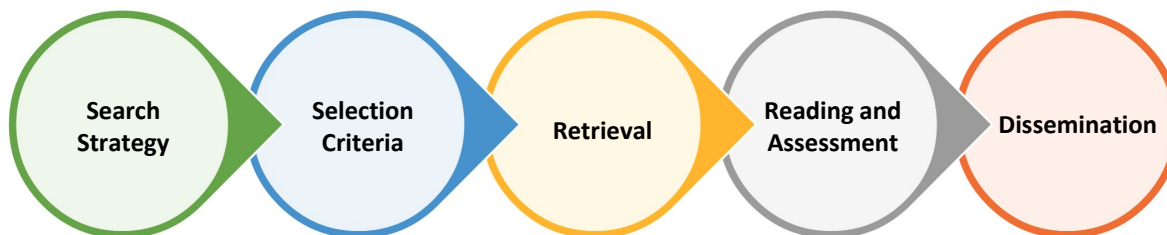


ESRAP

eSRAP is a collaborative monitoring system to monitor and share the latest literature on patient-oriented research.

eSRAP facilitates collaborative selection of relevant publications and access to selected publications. The tool aims to optimize monitoring efforts and knowledge sharing. It is founded on the concept of strength in numbers, and our experts believe that it's easier to stay informed as a group and share the task than to do it individually.

> [Learn More](#)



Health Pathway – Enriched Data

TORSADE COHORT

TorSaDE is a cohort specifically designed to study patient care pathways and patients with sensitive conditions requiring ambulatory care.

In partnership with the Institut de la statistique du Québec (ISQ), this project aims to make data on care pathways for a cohort representative of the Quebec population available to researchers.

The TorSaDE cohort consists of respondent data from various cycles of the Canadian Community Health Survey (CCHS), combined with their medical and administrative data for a 20-year period (from 1996 to 2016).

With this project, we were able to:

- Develop the conceptual and operational “6Ws” to analyze care pathways
- Develop a sex and gender indicator
- Develop a case selection library on conditions likely to require ambulatory care
- Receive over \$2M in additional grants
- Create a community of practice dedicated to studying care pathways

> [Learn More](#)

PROJECTS: TOOLS



REFLEXD

ReflexD is a clinical audit and feedback tool intended to transform care and monitoring practices for people with diabetes. It is compatible with PARS3 and stands out in the following ways:

- It applies PARS3 to electronic medical records and provides useful and concrete data to promote reflective practices
- It won a public and young physician award at the 2019 QCAM Symposium

> [Learn About ReflexD](#)



NEXT STEPS 2021–2026

Several projects are now in full swing. Learn about them and stay tuned!

- New web platform for our POR fellows community of practice
- New LHS training
- POR competency framework
- National POR assessment framework
- Application for data visualization
- New target competitions
- Questionnaire on patient fees (CoPaQ)

FOR MORE INFORMATION

Thanks to its highly qualified team, the Unit has published and disseminated numerous books and tools. Here are a few that are particularly relevant and easy to understand. They are available online just a few clicks away!

01

Guide to patient-citizen research partnerships

The international scientific community and government agencies are beginning to recognize the value of patient involvement in research. Consult the patient-citizen research partner guide to learn about the basics of patient-oriented research and the guiding principles of this new public-patient partnership approach.

02

Survey and webinar on the consequences of the lack of access to information

In collaboration with ASPQ (Association pour la santé publique du Québec), we announced the results of a survey that demonstrated that two thirds of Quebecers find it extremely or fairly important that the government make the data that it collects and produces available for research to improve the health of the population. Watch the webinar on the consequences of the population's lack of access to health information during the pandemic and find out why we are advocating to place greater value on data.

03

COVID-19 Videos

COVID-19 has shaken Quebec and the rest of the world. Discover our series of videos designed to ensure the continuity of POR, even and perhaps especially during the pandemic. We provide insight into the patient partnership, and research and caregiver support during the COVID-19 crisis.

04

Research Literacy Portal

Research is both fascinating and daunting. Familiarize yourself with basic research concepts on the "Understanding Research" platform. It is intended for patients, administrators, clinicians and others who are interested in research and collaboration with researchers. You will also find explanations, definitions and tutorials.

OUR PARTNERSHIPS

RUISSSSs are the territories associated with Quebec's four faculties of medicine. They were created to promote the co-development, complementarity and integration of care missions, along with teaching and research at health care establishments with university designations and at universities with which these establishments are affiliated.



The Unit initiative is co-funded by the **Canadian Institutes of Health Research** and the **Government of Quebec** to build infrastructure to support patient-oriented research. We will be offering structured programming in Quebec in the coming years, mainly due to a recent investment by the **MSSS** in the area of clinical and organizational data valorization and thanks to the generous training program grant from the **Fonds de recherche du Québec** for POR succession training.

Toward a Quebec Ecosystem

With its 2021-2026 programming, the Unit intends to contribute, along with its partners and collaborating organizations, to building a true ecosystem of province-wide connections across the health care system, the research network, various organizations dedicated to spreading knowledge and other provincial SPOR entities.

The Unit's expertise specifically helps promote collaboration between the big four **Réseaux universitaires de santé et de services sociaux** (RUISSSSs), their faculties of medicine (Université Laval, McGill University, Université de Montréal and Université de Sherbrooke) along with their research teams.

The connection between these traditionally highly competitive institutions is a notable success in and of itself and can be attributed to the Unit's establishment and operations.

Dr. Alain Vanasse, Scientific Director



OUR COLLABORATIONS

- ACCESS Open Minds
- Diabetes Action Canada (DAC)
- Association pour la santé publique du Québec (ASPQ)
- Centre Déclic
- Centre d'excellence en partenariat patient public (CEPPP)
- Centre interuniversitaire de recherche en analyse des organisations (CIRANO)
- Centre interuniversitaire québécois de statistiques sociales (CIQSS)
- Interdisciplinary Research Group in Health Informatics (GRIIS)
- Institut national d'excellence en santé et services sociaux (INESSS)
- Institut national de santé publique du Québec (INSPQ)
- Institut de la statistique du Québec (ISQ)
- Institut universitaire de première ligne en santé et services sociaux CIUSSS de l'Estrie -CHUS
- Institut universitaire de première ligne en santé et services sociaux CIUSSS de la Capitale-Nationale
- The Quebec Network for Research on Aging (RQRV)
- SPOR units and networks in other provinces

OUR SERVICE PROPOSAL

The Unit strives to play an essential role in the continuous improvement of Quebec's health care system. To achieve this, we offer three types of services that allow research to meet clinical needs.

This service offering is deployed in several ways. Our teams are versatile and can work together to support projects that meet our eligibility criteria and help us fulfill our mission. During our first mandate, we developed the following expertise:

- Access to data
- Methodological developments
- Real-world clinical and evaluative studies
- Research on health and social systems, knowledge application and implementation
- Capacity building
- Research strategies for partnership with patients and the public

In order to streamline data, knowledge and practices, the Unit will expand its expertise in 2021, namely in terms of learning health systems, health economics, data valorization, equity, diversity and inclusion, Indigenous health and patient-reported outcome measures.



Training



Expert Consultants



Tools