

Operationalization of a provincial unit to support
patient oriented research through a
multidisciplinary cluster of research resources,
policy knowledge, and patient perspectives.
The case of the Québec SUPPORT Unit

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Objectives

- ▶ Provide an overview of patient-oriented research SPOR SUPPORT Units
- ▶ Describe the operationalization model of the Québec Unit
- ▶ Provide insights and lessons learned

SPOR definitions

Patient

- An overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends

Patient-Oriented Research

- A continuum of research that engages patients as partners, focusses on patient-identified priorities and improves patient outcomes
- Conducted by multidisciplinary teams in partnership with relevant stakeholders
- Aims to apply the knowledge generated to improve healthcare systems and practices

Core Elements of SPOR



Support for People and Patient-Oriented Research and Trials (SUPPORT) Units



SPOR Networks



Capacity development



Improving the clinical trials environment



Patient engagement

What are SPOR SUPPORT Units?

Support for People and Patient-Oriented Research and Trials (SUPPORT) Units:

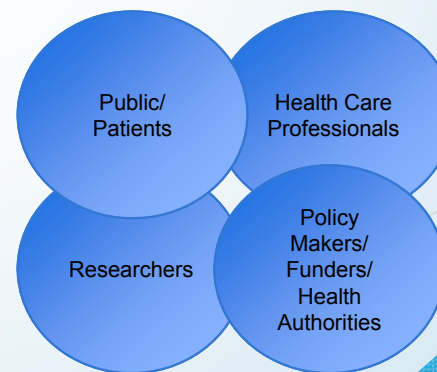
- Are locally accessible
- Are multidisciplinary clusters of specialized research resources, policy knowledge, and patient perspective.
- Provide the necessary expertise to pursue patient-oriented research and help lead reforms in response to locally-driven health care needs.

Overarching goal: foster the creation of learning health care environments

Vision

Key stakeholders such as patients, researchers, policy makers, funders and health care professionals will be involved in the development of all aspects of a SUPPORT Unit via a collaborative leadership approach.

This collaborative leadership and governance will ensure that all voices crucial for changing practice, implementing evidence and ensuring sustainability are integrated.



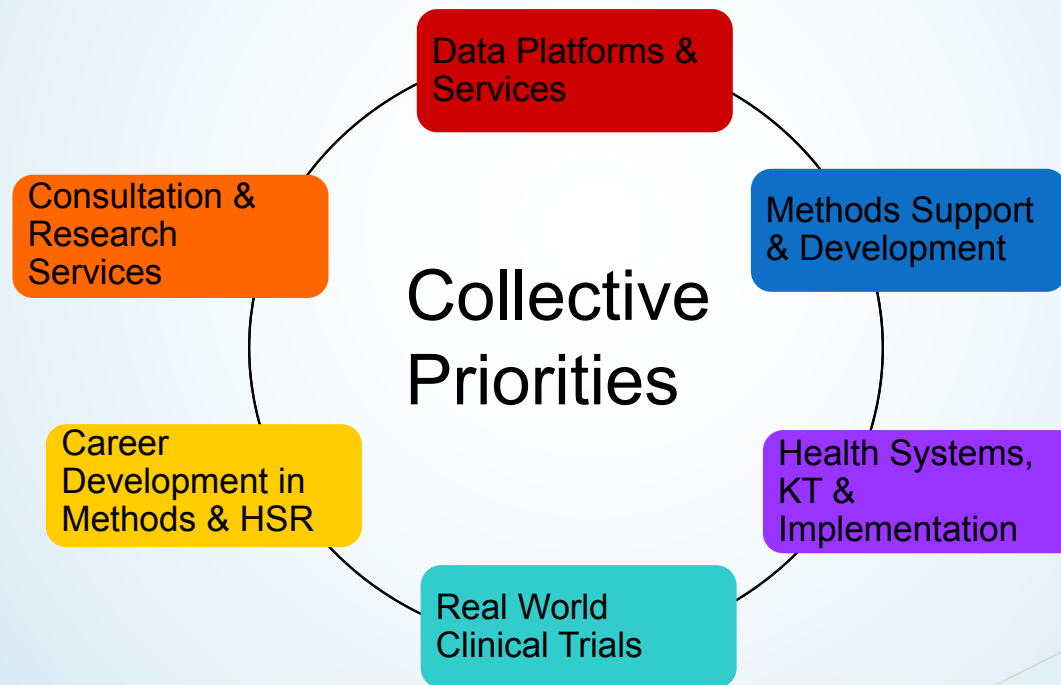
Qc SUPPORT Unit Mission

To support the creation and implementation of research projects in health and social services provided to the vast majority of the Quebec population, i.e., primary **health care and services (PHCS)** offered by health care and service providers in local jurisdictions close to patients.

Integrated care trajectories, mental health issues, and management and prevention of chronic illnesses related to population aging are some of the priority issues.

Platforms for the QC SPOR SUPPORT Unit

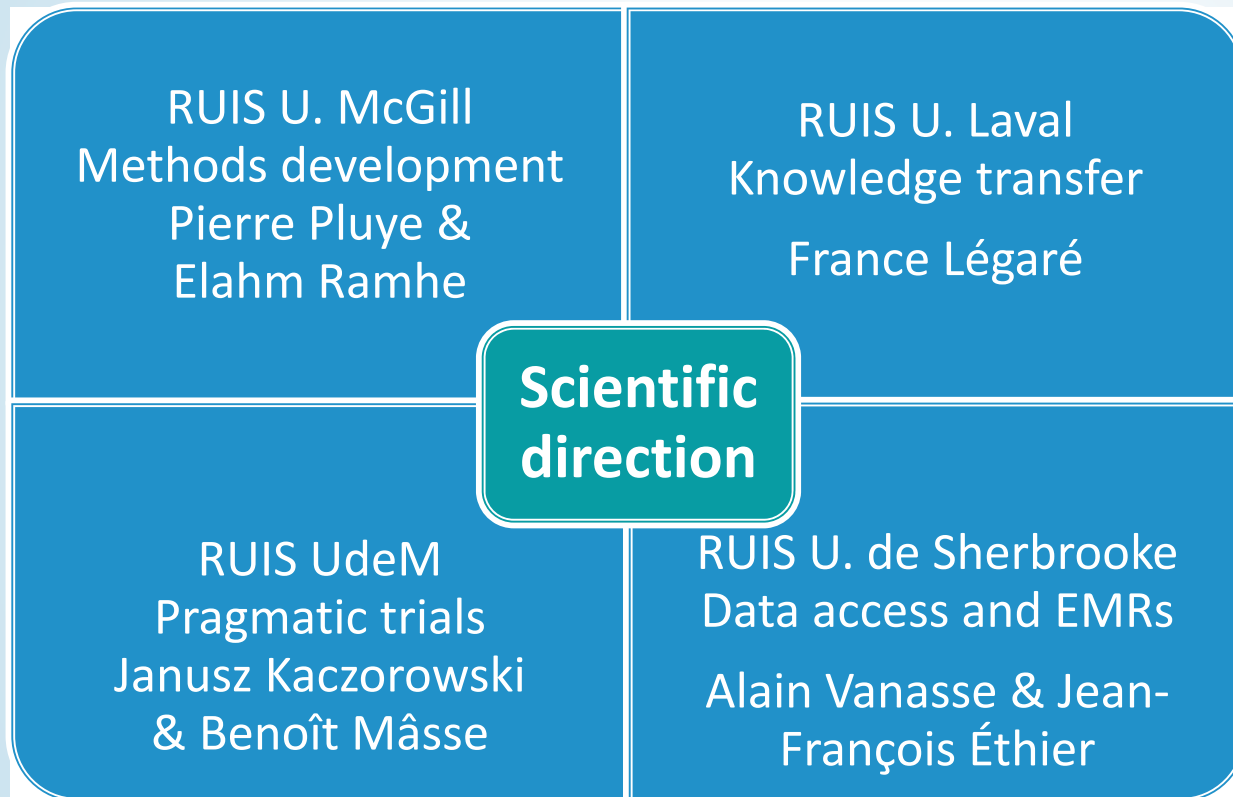
Six core functions are being implemented



The Québec SUPPORT Unit

- ▶ Status: completing the start-up phase
- ▶ Work accomplished
 - ▶ Detailed working plan finalized
 - ▶ Strategy to integrated patient engagement at all levels of the unit

The Four University leads



Our priorities

- ▶ Implementing a strategy that makes the best use of enhanced data in Quebec :
 - ▶ “Spoke and hub” approach
 - ▶ Remote access
- ▶ Enhancing the capacity to use EMRs for research in PC
- ▶ Developing patient-oriented research (POR) methods
 - ▶ Patient reported outcomes
 - ▶ E-Health applications to support pragmatic trials in the community
- ▶ Connecting effectively with clinicians and decision makers



How did we build consensus and operationalize the Unit?



Strengths of the Qc SUPPORT Unit

- Coalition between FRQS, MSSS, key institutions of the health care system, universities, and the community
- Integration of social and health care research and services
- Expertise in patient and public engagement for a vibrant engagement and KT platform

Challenges

- ▶ Developing a common understanding of POR
- ▶ Going out of our comfort zone
- ▶ Engaging with community-based primary care professionals
- ▶ Connecting the scientific community with the primary care sector
- ▶ Integrating social health services
- ▶ Barriers to data access

An iterative process

- ▶ Engaging all members and stakeholders to be part of the discussion
- ▶ 2 full day workshops for stakeholders and participants to engage in collaborative leadership
- ▶ Structured communication and touch-points, including:
 - ▶ Standing monthly working group meetings (in person and by videoconference)
 - ▶ Regular calls / in person meetings to support the leads of each of the 4 platforms
 - ▶ Alternating meeting locations to cover the provincial representation
 - ▶ Material/document review, email communication
 - ▶ Prepared agendas, discussion topics and approach to lead to the operationalization deadline
- ▶ Engaged our partners (government, industry, public, private, associations)



WE WANT YOU!