

From Start to Finish: Added Value of Patient Partners in the PriCARE Program.



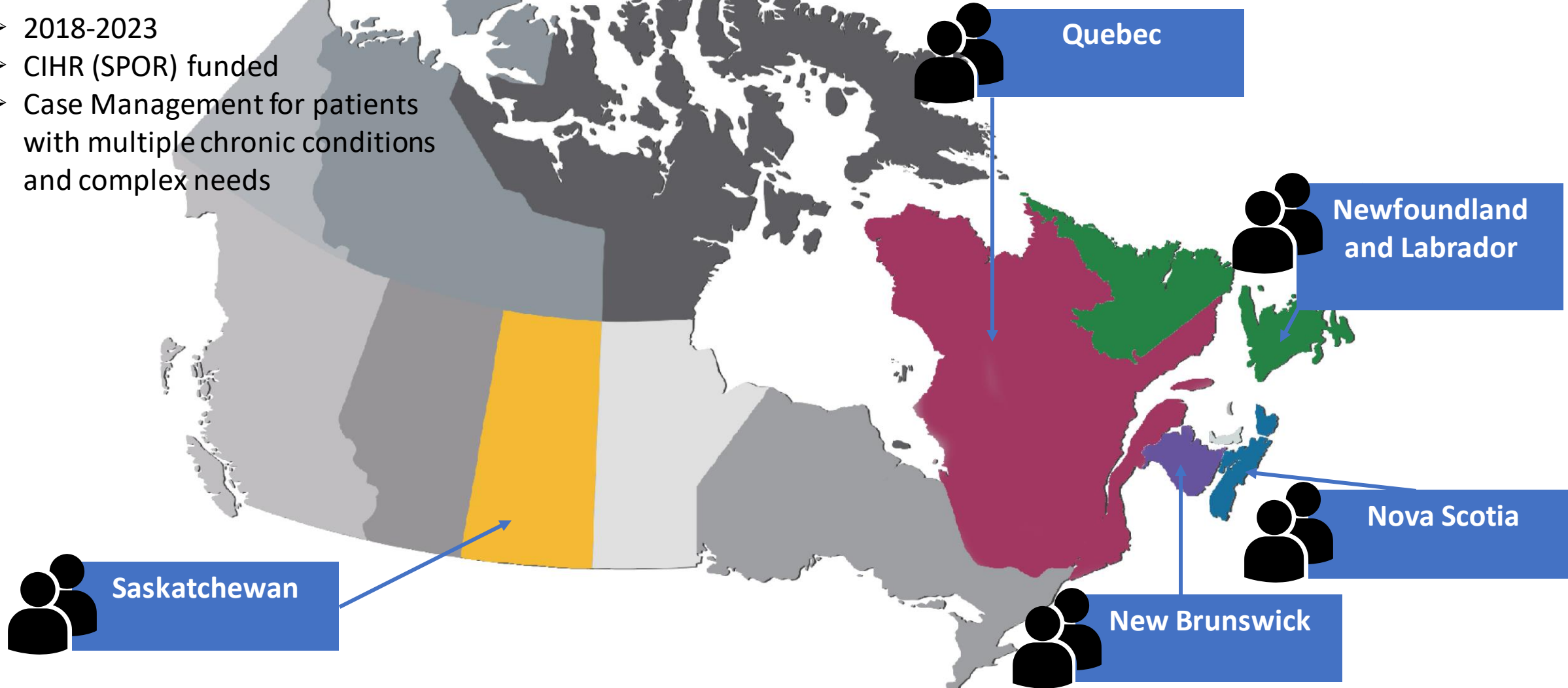
Presented by Judy Porter, Mike Warren and Dana Howse

- Judy Porter, André Gaudreau, Donna Rubenstein, Norma Rabbitskin, Jennifer Taylor, Mike Warren, Linda Wilhelm, Mathieu Bisson, Dana Howse, Mireille Lambert, Charlotte Schwarz, Shelley Doucet, Kris Aubrey-Bassler, Vivian R. Ramsden, Catherine Hudon



- Five provinces/five project teams
- 1-2 clinics per province
- 1-2 Patient Partners per province

- 2018-2023
- CIHR (SPOR) funded
- Case Management for patients with multiple chronic conditions and complex needs



Case Management (CM) Steps

Assessment of the patient's needs and preferences

Development and maintenance of an "individualized services plan" (ISP)

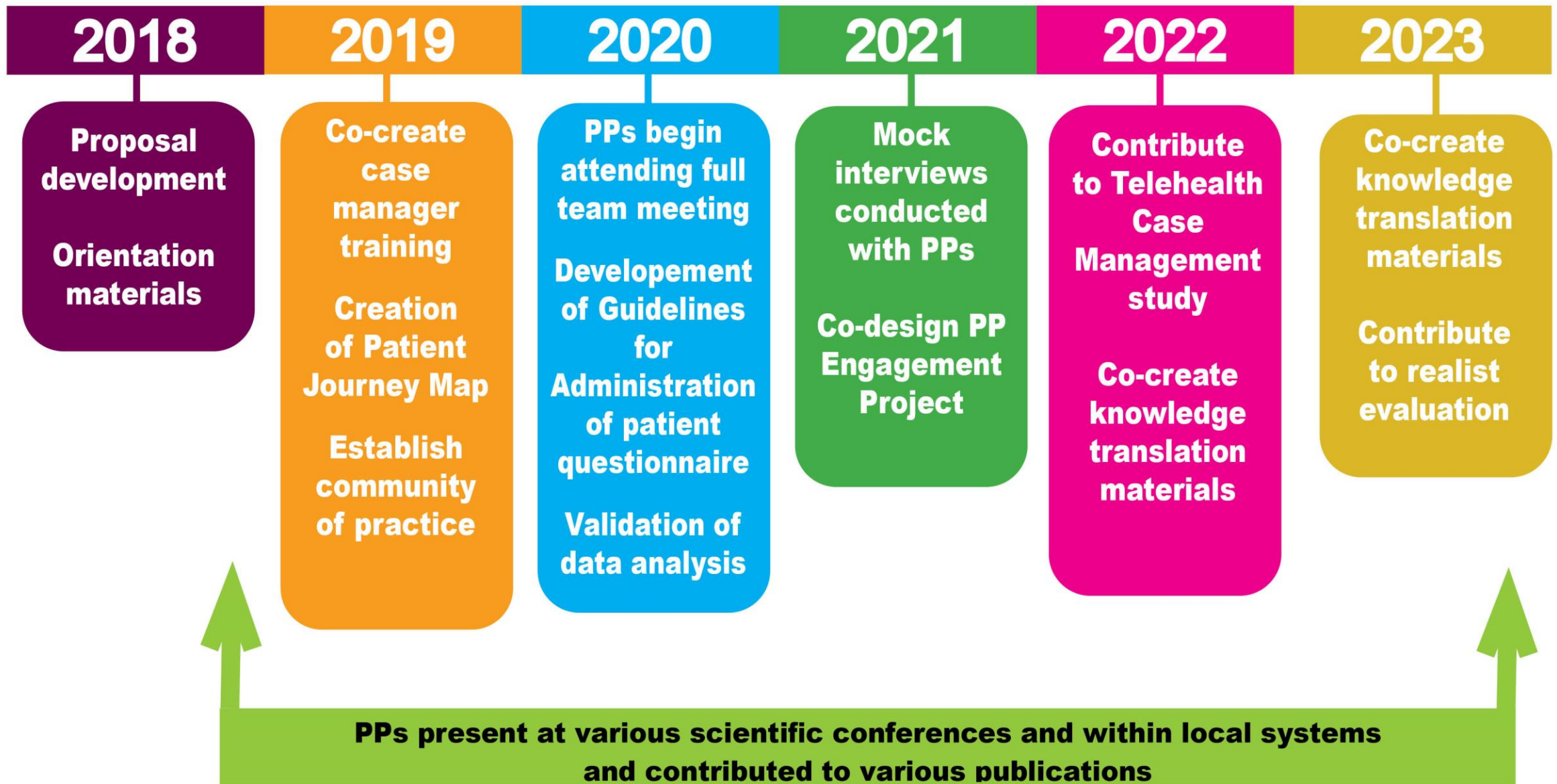
Coordination of services among health and social services partners

Provision of education and self-management support for patients and families

TWO *DIFFERENT* LENSES



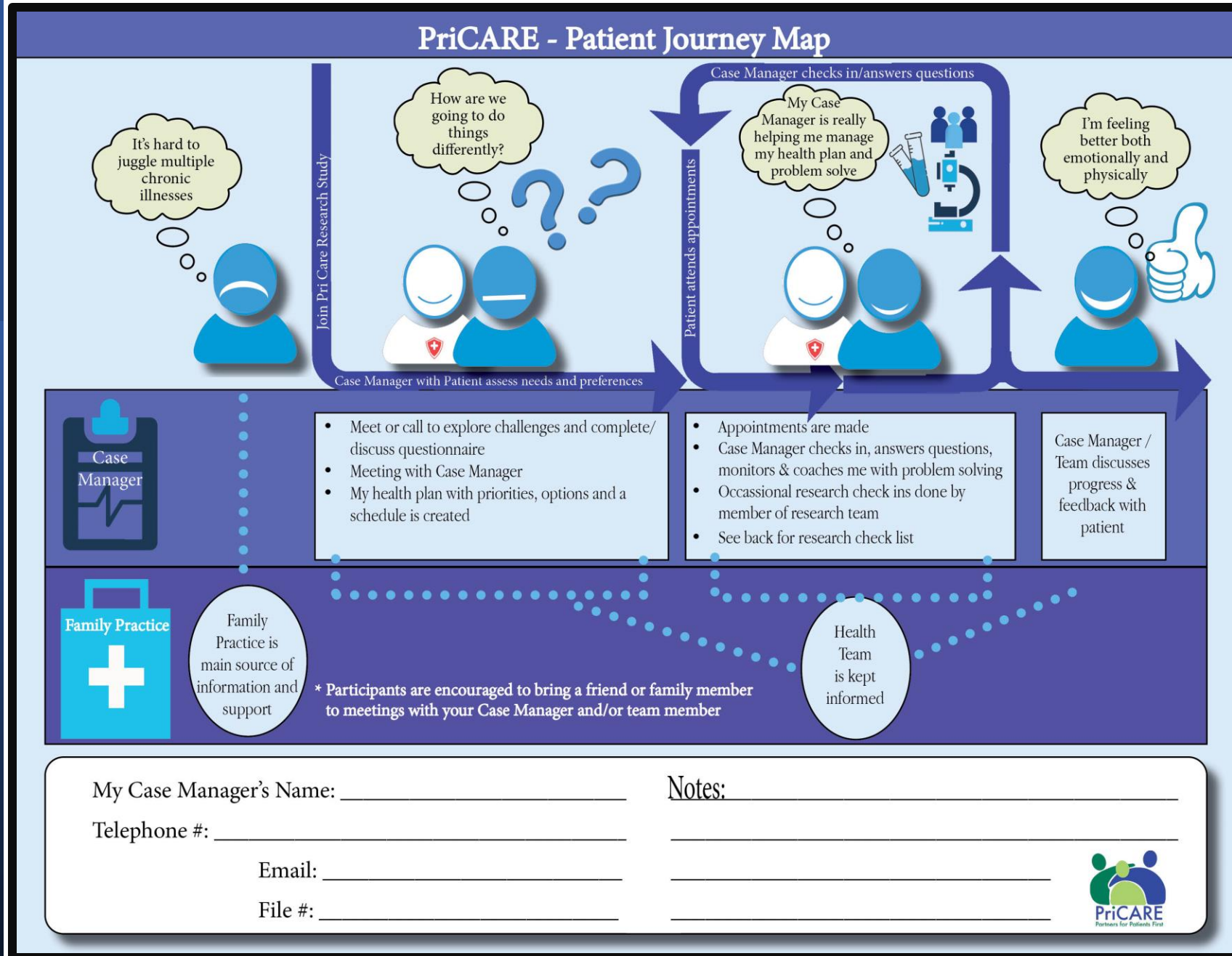
START TO FINISH: Patient Partners (PPs) add value to PriCARE



Shared
learning
through
Lived
experience




Patient Journey Map



Patient Partner Involvement

Danish A., Cassidy M., Dumont-Samson O., Lambert-Harvey M., Porter J., Rubenstein D., Sabourin V., Chouinard M.C., Hudon C. Guidelines for administration of the PriCARE Patient questionnaires, 2020.



GUIDELINES FOR ADMINISTRATION

Patient questionnaires

La flexibilité dans le partenariat en recherche axée avec et pour les patients



Patient Engagement Works

Patient and researcher experiences of patient partnership in research



NAPCRG 2021 Annual Meeting

Dana Howse, Judy Porter, André Gaudreau, Charlotte Schwarz, Donna Rubenstein, Véronique Sabourin, Cathy Scott, Mike Warren, Linda Wilhelm, Kris Aubrey-Bassler, Fred Burge, Maud-Christine Chouinard, Shelley Doucet, Mathieu Bisson, Alannah Delahanty-Pike, Olivier Dumont-Samson, Mireille Lambert, Catherine Hudon

Meaningful patient-oriented research: Working together on a collaborative multi-provincial study

Linda Wilhelm, Jennifer Taylor and Charlotte Schwarz



Patient engagement in research on a case management intervention with chronic diseases and complex care needs



BACKGROUND
A case management intervention for patients with chronic diseases and complex care needs is being developed and evaluated. The intervention is designed to address the needs of patients with chronic diseases and complex care needs. The intervention is designed to be patient-centered and to involve patients in the development and evaluation of the intervention.

OBJECTIVE
The objective of this research is to evaluate the impact of patient engagement on the development and evaluation of a case management intervention for patients with chronic diseases and complex care needs.

EXPECTED RESULTS
The expected results of this research are that patient engagement will lead to a more patient-centered and effective case management intervention.

CONCLUSION
The conclusion of this research is that patient engagement is an important component of the development and evaluation of a case management intervention for patients with chronic diseases and complex care needs.

ENHANCING RESEARCH THROUGH MEANINGFUL ENGAGEMENT WITH PATIENT PARTNERS



DEVELOPING CLEAR EXPECTATIONS
Establishing a clear relationship between researchers and patient partners is essential for successful research. This involves setting clear expectations for the roles of both parties and ensuring that the research is meaningful and relevant to the patient partners.

LEARNINGS
Authentic and impactful patient partnership involves with culture of openness and support. Co-development is beneficial to research and involves memorizing research standards with the lived experience of patient partners.

OUTCOMES
• INTEGRATED KNOWLEDGE
• UNDERSTANDING
• CLARITY
• LEARNINGS
• SUSTAINABILITY
• PATIENT RELEVANCE

Open access

BMJ Open Protocol for a mixed-method analysis of implementation of case management in primary care for frequent users of healthcare services with chronic diseases and complex care needs

Alya Danish¹, Maud-Christine Chouinard², Kris Aubrey-Bassler³, Fred Burge⁴, Shelley Doucet⁵, Vivian R Ramsden⁶, Mathieu Bisson⁷, Monique Cassidy⁸, Brian Condran⁹, Mireille Lambert¹⁰, Carla Penney¹¹, Veronique Sabourin¹², Mike Warren¹³, Catherine Hudon¹⁴



CASE MANAGEMENT

WHO?
Patients and Case Managers (Nurses)

WHAT?
COORDINATION
Needs Goals Wellness Plan Supports Self-Management

WHY?
"I feel that our patients are in extremely good hands with the teams that our Case Manager coordinates" - Doctor

COLLABORATION
Family and Social Supports Healthcare Professionals Healthcare Facilities Community Resources

"I felt like I was starting to fall through the cracks of the system but now I feel listened to and heard." - Patient

"Help! I'm being through the cracks!"




Reconciling Validity and challenges of patient Questionnaires

A Patient Partners Perspective :


Presented by Judy Porter and Donna Rubenstein

- Catherine Hudon, Alya Danish, Mireille Lambert, Dana Howse, Monique Cassidy, Olivier Dumont-Samson, Véronique Sabourin, Shelley Doucet, Vivian R. Ramsden, Mathieu Bisson, Maud-Christine Chouinard, Judy Porter, Donna Rubenstein





Integrating research in primary care settings: challenges and lessons from the PriCARE case management study in Nova Scotia PHC



Case management in primary care for frequent users of healthcare services with chronic diseases and complex care needs: protocol of an implementation and realist evaluation

METHODOLOGY

© Hudon, MC Chouinard, K Aubrey-Bassler, F Burge, S Doucet, VR Ramsden, S Bisson, M Brodeur, PL Bush, C Campbell, Y Chouinard, B Gaudreau, E Deschênes, MF Dubois, L Edwards, S Gaudier, G Gauthier, P Gauthier, R Gibson, J Guibout, L Guénette, F Légaré, J Labbe, G Lavoie, S Longtin, P Marin, P Pluyne, TG Poole, ME Poitras, N Rattakapan, P Robarge, DA Roy, J Roy, V Sabourin, T Sampalli, A Sautner, C Spence, J Spence, R Waite, M Warren, J Young

Case management in primary care for frequent users of healthcare services with chronic diseases and complex care needs: the PriCARE study



Maximizing
the Added
Value of
Patient
Partner
Engagement

**Key Best Practices and
Recommendations
from our PriCARE experience**



1

Foster a Team Culture of Understanding, Respect & Trust

- Create of an inclusive, safe, and welcoming environment.
- Full participation in the work including decision making.
- Offer training opportunities.
- Create a safe space for PP to identify concerns and ideas.
- Develop and ongoing review of expectations and roles (Onboarding)
- Strong leadership from Researchers and PPs is critical.



2

Effective and Ongoing Communications

(From start to finish)

- Starts with proposal development.
- Includes: PP ToR and creation of Community of Practice.
- Communications include: language, scientific terminology, technology.
- Keep lines of communication always open – check-ins, meetings.



3

Recognize the Value Patient Partners Bring to the Team

- Appreciate the varied skills PP bring to the team both lived experience and professional skills.
- Remunerate & give credit.
- Provide opportunities for PP to contribute to (or lead on) publications, conferences and KT materials.



4

Patient Partners come prepared to participate

- Participate in POR & PE training (if needed).
- Come prepared and engage.
- Be clear on your expectations.
- Share experiences and skills.
- Reach out for help when required.



Health Expectations (2022) article

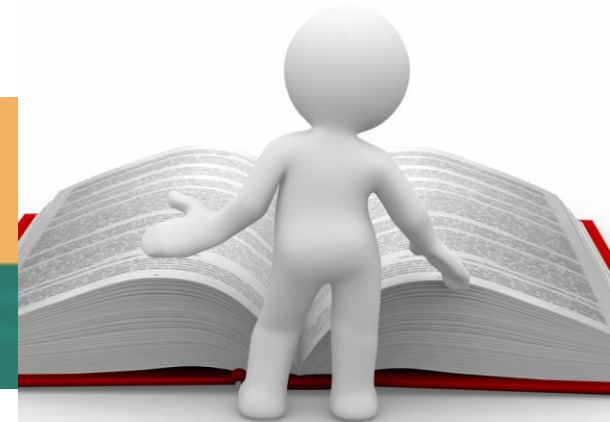
ORIGINAL ARTICLE

Health Expectations. 2022;25:2365–2376.

WILEY

Patient and researcher experiences of patient engagement in primary care health care research: A participatory qualitative study

Sophie Béland MSc¹ | Mireille Lambert MA² | Alannah Delahunty-Pike MSc³ |
Dana Howse PhD⁴ | Charlotte Schwarz MA⁵ | Maud-Christine Chouinard PhD⁶ |
Kris Aubrey-Bassler MD, MSc⁴ | Fred Burge MD³ | Shelley Doucet PhD⁵ |
Alya Danish PhD⁷ | Olivier Dumont-Samson MA¹ | Mathieu Bisson MA¹ |
Alison Luke PhD⁵ | Marilyn Macdonald PhD⁸ | André Gaudreau⁹ | Judy Porter⁹ |
Donna Rubenstein⁹ | Véronique Sabourin⁹ | Cathy Scott⁹ | Mike Warren⁹ |
Linda Wilhelm⁹ | Catherine Hudon MD, PhD^{1,10} 



QUESTIONS?



Catherine Hudon Catherine.hudon@usherbrooke.ca
(Principal Investigator)

Dana Howse dhowse@mun.ca
Judy Porter novaskoshun@hotmail.com
Mike Warren mjw709@gmail.com



For more information:
<https://v1sages.recherche.usherbrooke.ca/en/pricare-program/>