

# Engaging Indigenous patient partners in patient-oriented research in Canada: challenges and lessons

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This presentation explores strategies and challenges for engaging Indigenous patient partners in patient-oriented research, based on:

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- The results of a small scale initiative, called the Indigenous patient partners Platform project (Canadian Institute of health research, 2017-2018)
- My observations as the co-leader of the Québec Support Unit's expertise in Indigenous health (2019-2024)



# The Québec Support Unit (SPOR entity)

The Québec Support Unit is a research infrastructure that aims to mobilize and equip the research community and the health and social services network to achieve greater equity, improved population health, more efficient use of resources and a better experience for patients and health and social services human resources.

The Support Unit's expertise in Indigenous health is co-led by **Marie-Claude Tremblay** (Laval University) and **Alex McComber** (McGill University).

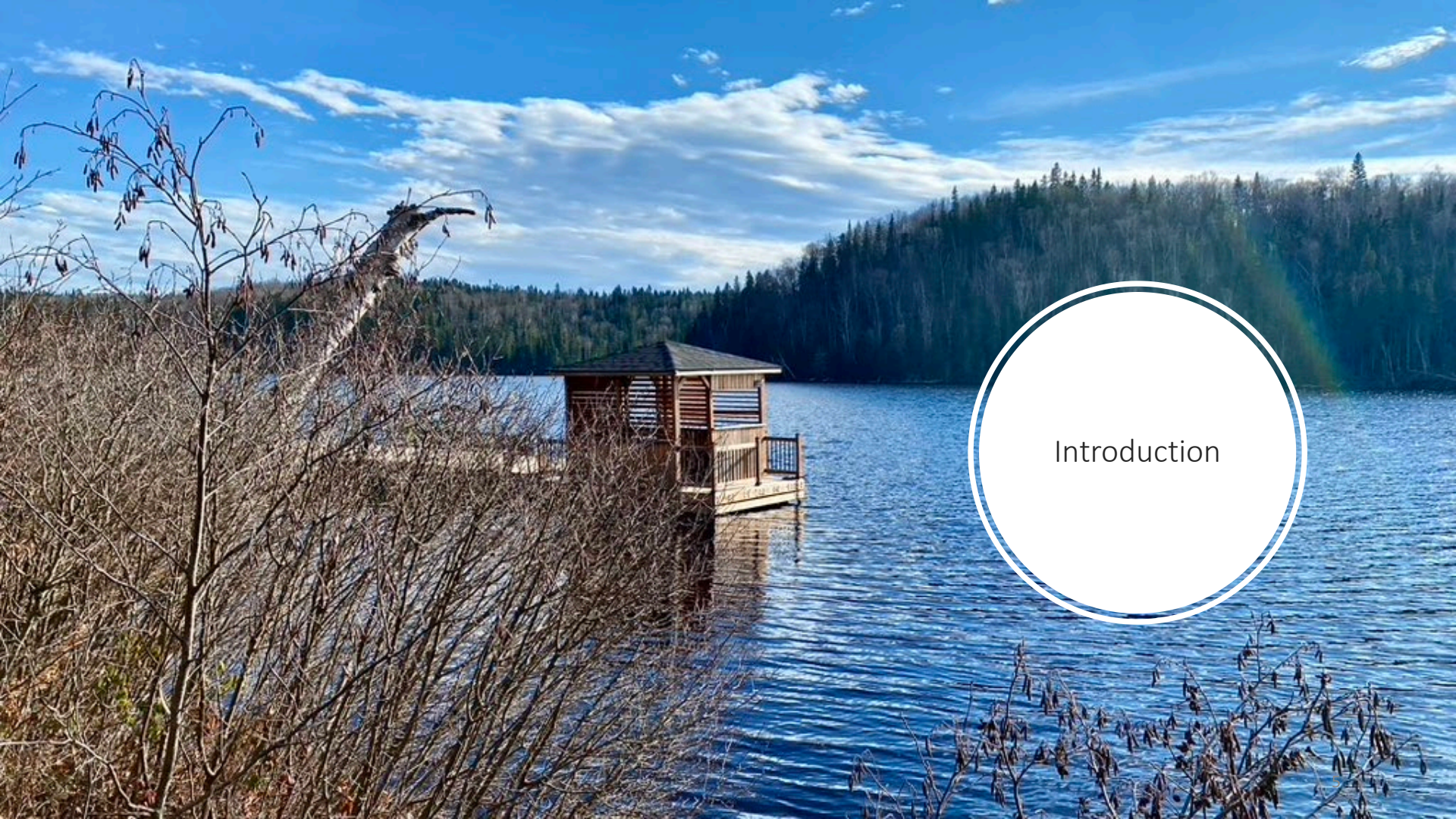


# The Québec Support Unit

- The Indigenous patient partners circles aim to provide feedback, advice and guidance to research teams wishing to develop respectful research partnerships with Indigenous peoples in Québec.
- They also develop training, tools and recommendations to support better Indigenous POR.
- The patient circles bring together members of various indigenous nations (Wolastoqey, Atikamekw, Kanien'kehá:ka, Innu, Inuit), living in rural, community or urban settings.







Introduction



# Context: Indigenous peoples in Canada

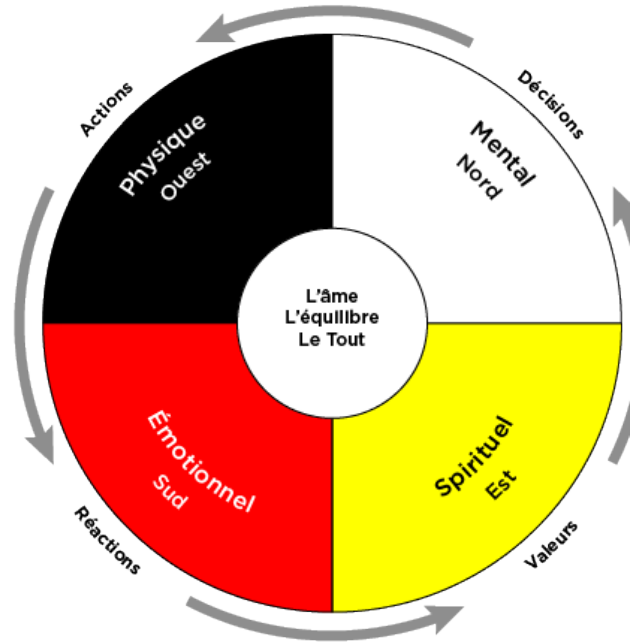
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- In Canada, the word “Indigenous” is the accepted term to refer to the original peoples who inhabited the land before contact with Europeans.
- Indigenous peoples include First Nations, Métis and Inuit (4.9% of the Canadian population).
- 630 communities, 50 languages and nations



# Indigenous concept of well-being


- Despite their great diversity, most Indigenous peoples share a vision of well-being rooted in balance, reciprocity, autonomy and harmony (the Pimatisiwin concept).
- The medicine wheel is a symbol that illustrates this holistic concept.
- Well-being is created and maintained in a quest for **balance between physical, mental, emotional and spiritual dimensions, supported by family and community.**



# Context: Indigenous peoples in Canada

- In Canada (as in many other countries), Indigenous peoples have been subjected to colonialism and genocide that have engendered numerous traumas
  - The Indian Act,
  - forced relocation and sedentarization on reserves,
  - the residential school system,
  - the 1960s scoop,
  - systemic racism,
  - social and economic exclusion,
  - unequal access to resources and power.
- As a result of all these adversities, Indigenous peoples experience significant health inequities compared to the rest of the population.





Patient-oriented  
research and  
Indigenous  
patient partners

# Patient-oriented research and IPP

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- Patient-oriented research (POR) is an approach used to promote active patient involvement in health research
- Peoples involved in POR do not reflect the diversity of the population such research aims to serve, but rather **those who are more easily engaged with institutions, organizations and society.**
  - **Reproducing social and power inequities in research**
- Indigenous populations are among such groups generally underrepresented within POR.



# Patient-oriented research and IPP

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- There are particular **challenges** in involving Indigenous people as patient partners in research, linked to the **socio-historical and colonial context** :
  - Epistemic injustices due to the hierarchization of knowledge inherent in positivism, which positions scientific and Western knowledge systems above others;
  - Western knowledge systems contributing to the devaluation and rejection of indigenous knowledge systems, beliefs and visions;
  - Research perceived as another form of colonialism by Indigenous groups and communities.




# Patient oriented-research and IPP

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- Research teams/projects are not necessarily culturally safe contexts;
- Western research structures do not always allow to respect Indigenous ways of doing and knowing;
- In research teams, Indigenous peoples often bear the burden of educating researchers and other team members about their cultural realities;
- Or they carry the burden of being the sole person who represents Indigenous points of view in the project.







The Indigenous  
patient partners  
platform project

# The Indigenous patient partners Platform project (2017-2018)

A small-scale initiative aimed at **recruiting, orienting and supporting Indigenous patient partners to play an active role in health research in Québec (Canada).**

- **One-year engagement initiative** using a participatory approach involving researchers, Indigenous people living with type 2 diabetes, as well as Indigenous organizations in the province of Québec.

(Funded through a CIHR Collaboration grant, with matching funding from Diabetes Canada)

# The Indigenous patient partner platform project

- A core committee (Indigenous organizations) helped defining the goal and processes of the initiative.
- The core committee helped recruit 8 Indigenous patient partners (4 men and 4 women).
- From 2017-2018: Project members met eight times, mostly virtually (teleconference)
- **The meetings were designed to help IPP familiarize themselves with research, share their lived experiences and better understand their role as research patient partners.**

# The Indigenous patient partner platform project

- The project culminated in a **one-day, in-person training workshop**, which aimed to reinforce project members' capacities regarding POR.
- Training was developed in collaboration with Québec's Support Unit.





# The evaluation of the project

The evaluation of the Indigenous patient platform project aimed to garner lessons from the initiative and identify the best strategies to engage Indigenous patient partners in POR.

- Evaluation based on a case study design, using documentation analysis and qualitative interview with IPP and organizational partners
- Patients partners recruited and formed through the initiative were involved in results interpretation and knowledge dissemination.



# Results

The evaluation results offer lessons, pertaining to four components of patient engagement:


1. **Initiation of partnership**
2. **Interest development**
3. **Capacity building**
4. **Involvement in research**

## RESEARCH ARTICLE

## Open Access

### Engaging indigenous patient partners in patient-oriented research: lessons from a one-year initiative

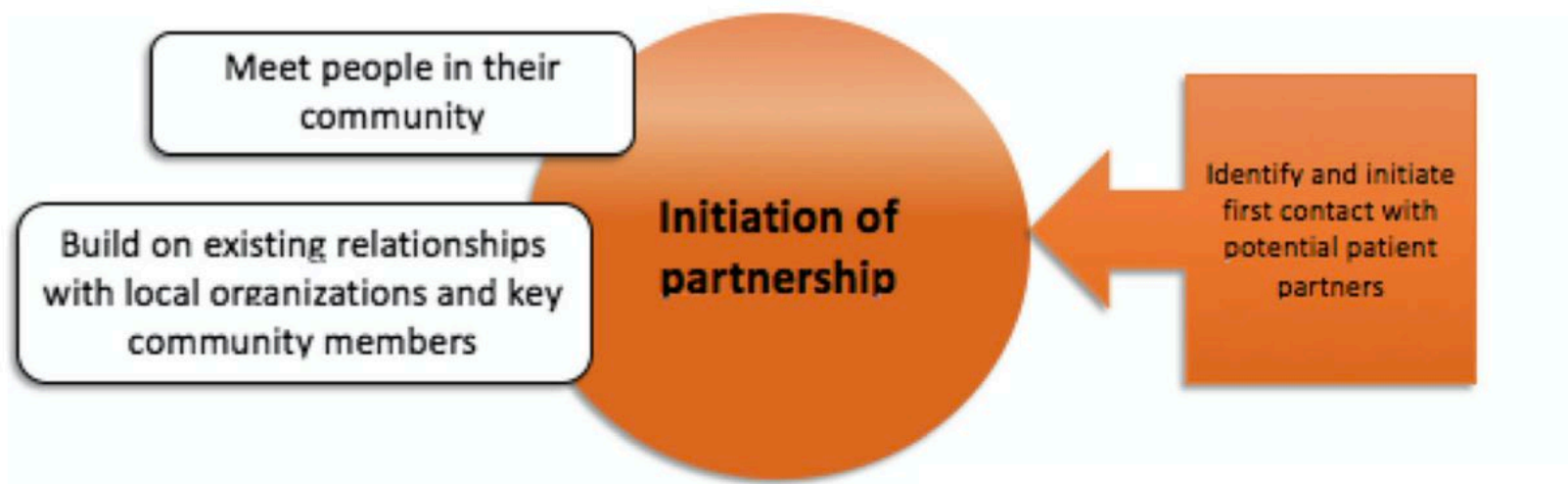


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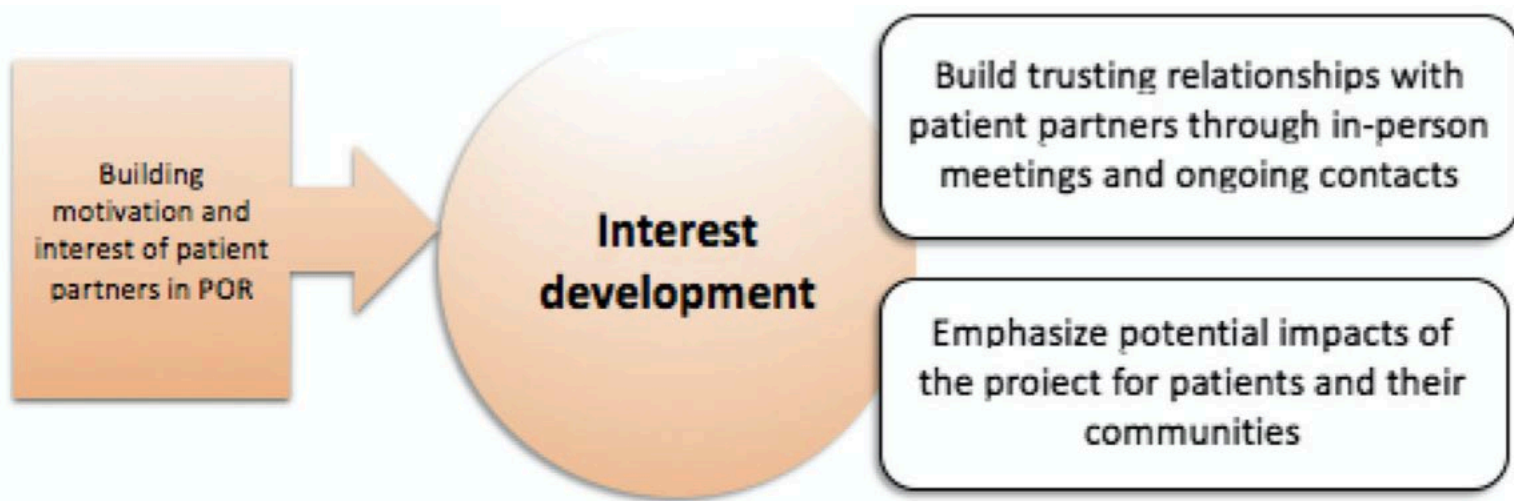
#### Abstract

**Background:** Patient-oriented research (POR) is a specific application of participatory research that promotes active patient engagement in health research. There is a growing concern that people involved in POR do not reflect the diversity of the population such research aims to serve, but are rather those more ‘easily’ engaged with institutions, organizations and society. Indigenous peoples are among such groups generally underrepresented in POR. The “Indigenous patient partners platform project” was a small-scale initiative aimed to address the issue of the underrepresentation of Indigenous people in patient-oriented research by recruiting, orienting and supporting Indigenous patient partners in Québec (Canada). This article reports on the findings of an evaluation conducted at the end of the project to garner lessons and identify strategies for engaging Indigenous patient partners in patient-oriented research.

# Results

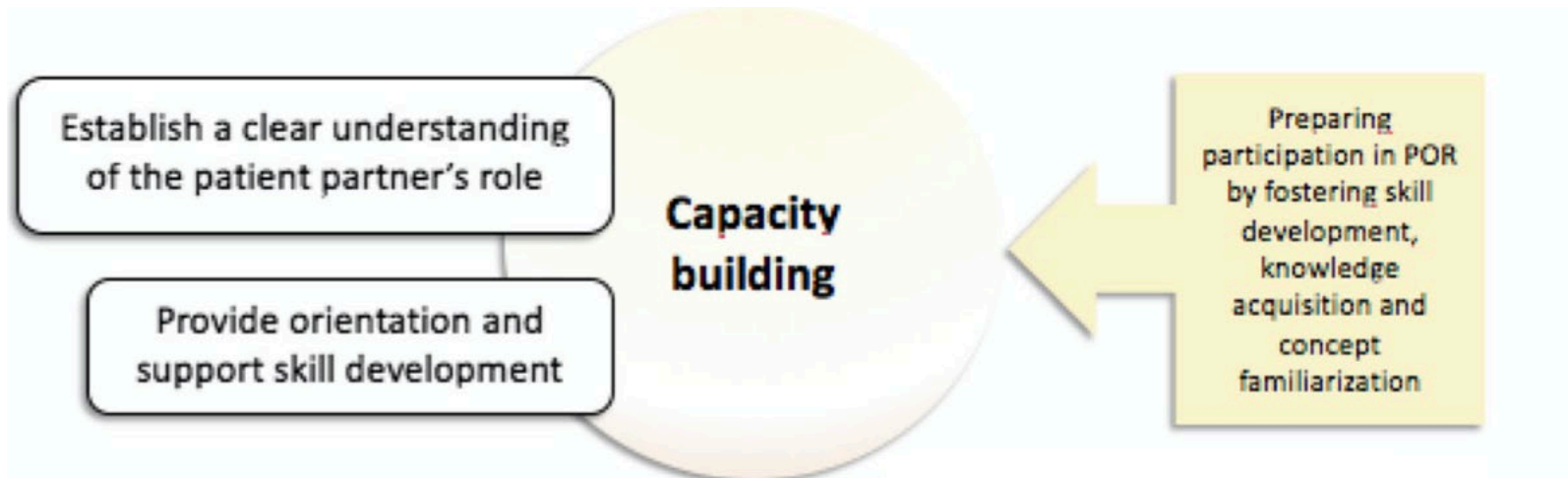


# Results

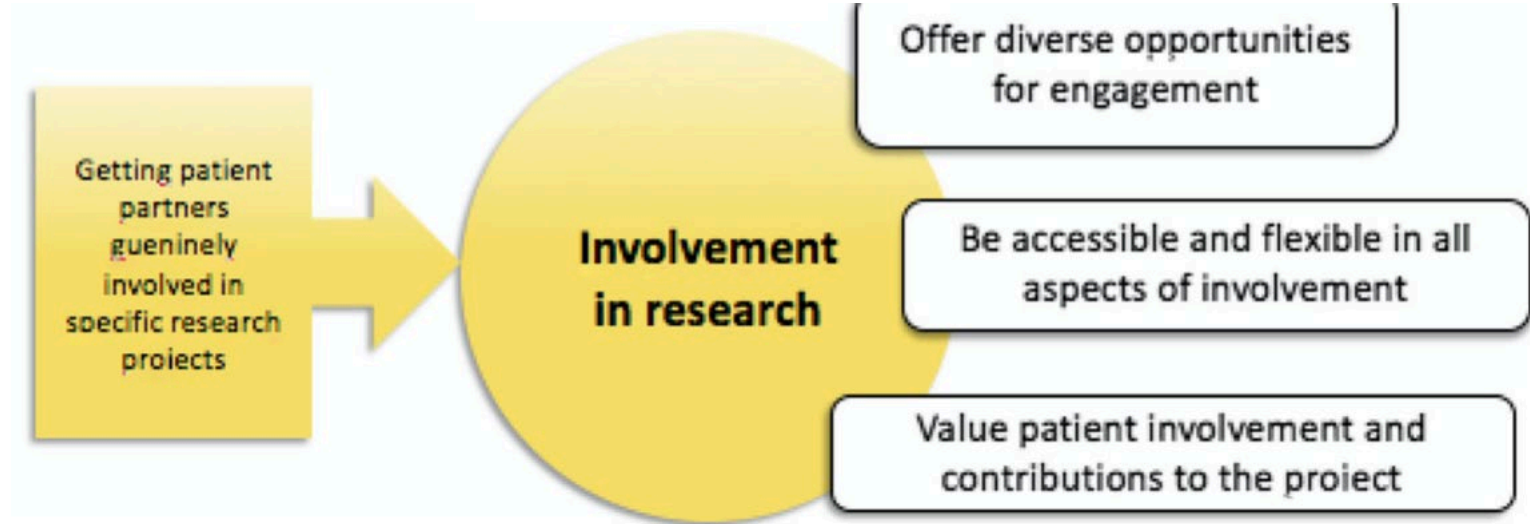




# Results



# Results



A scenic landscape of a lake at sunset or sunrise. The sky is filled with dramatic, layered clouds in shades of blue, grey, and white, with a hint of orange and yellow near the horizon. The water is calm, reflecting the sky and the surrounding green forest. In the foreground, a sandy shore is visible with a piece of driftwood and a blue metal grate. A large white circle with a thin black border is overlaid on the left side of the image, containing the text "Conclusions".

# Conclusions

# Specific challenges

1. Not considering Indigenous populations as a homogenous ethnic group.
  - Need to create a common safe space to encompass this diversity
2. Understanding fully the influence of historical and social context in which engagement occurs for Indigenous patient partners.
  - Need to equalize the power dynamics as much as possible
3. Working with ill-prepared institutions to manage patient partnership in research (ex. financial compensation payment and reimbursements).
  - Need to heighten the capacity of our institutions to work with these kinds of partnership



# Specific lessons

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- Community ties are crucial in recruiting, sustaining and motivating patient partners;
- Relationship-building is key: Prioritize relationship-building to develop trust and create a balanced power dynamic;
- Flexibility in the engagement process is essential to respect everyone's pace and allow for different types of engagement;
- Consistently valuing patient partner contribution and participation, knowledge and experience, as well as traditional expertise;
- Create a safe environment where sharing and inclusion are favored, experiences are valued.

# Conclusions: Remaining paradoxes

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- Indigenous people do not, or rarely, conceive of their participation in individual terms. They have collective motivations, visions and interests.
- Research principles for respectful and reciprocal research with Indigenous populations are difficult to apply in the context of POR.
- **An avenue could be to move from patient engagement to community engagement in research.**
- This would enable community perspectives to be taken into account rather than individual points of view, allowing a more solid approach to understanding and acting on the health of populations

# Funding and Acknowledgements

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**Mikwetc! Merci! Thank you!**

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**Fonds de recherche  
Santé**



Migwetc, thank you, merci!

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# References