NL SUPPORT & Quality of Care NL

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Outline

Who we are
• SPOR

What we’ve done
• Development of the Indigenous Communities Grant

What we’re trying to do
• Proposed Governance Structure
• Actively involve all communities in NL in our work
• Develop a student stipend to support Indigenous health research

Discussion/Feedback
• How should we engage Indigenous communities? What could that look like in our context?
• Who should we start with within each community to discuss engagement?
• What should our next steps be?
Who we are
Patient-Oriented Research

Patient-Oriented Research (POR) is research that:

1. Addresses patient priorities
2. Engages patients as partners
3. Improves patient outcomes

It’s research conducted WITH rather than ON patients.

Patients bring expertise in the form of lived experience.

Requires:

• Patient Engagement
• Knowledge Translation
Patient Engagement (PE)

• Meaningful collaboration with patients in research

• Patients can be engaged in governance, priority setting, developing the research questions, conducting research, and sharing results

• Helps to ensure that the research being conducted is relevant to the patients that it affects and improves the impact of related health system changes
What is a patient?

CIHR defines patients as including:

- Individuals with personal experience of a health issue
- Informal caregivers, such as family and friends

Patients can also provide the perspectives of a specific community
Knowledge Translation (KT)

• Getting research into the hands of the people who can use it (knowledge users)

• There are two phases of effective KT:

  1. Integrated (iKT): Proactively identifying and working with knowledge users throughout the project
  2. End of grant: Sharing results when the project is finished
What is a knowledge user?

Knowledge users are individuals who will be able to use research results to make informed decisions about health policies, programs and/or practices.

For example:

- Practitioners
- Policy maker
- Educators
- Decision makers
- Health care administrators

- Community leaders
- Individuals in a health charity
- Patient groups
- Private sector organizations
- Media outlets
Quality of Care NL/Choosing Wisely NL

- Research programs of NL SUPPORT
- **Quality of Care NL**: Right treatment, right patient, right time
- Work in partnership with **Choosing Wisely Canada**
- **QCNL/CWNL** drives evidence-based health care practice and efficient use of resources
Core Components of SPOR II

- Data Platform & Services
- Learning Health System
- Capacity Development
- Patient Engagement
Meet our Patient Advisory Council
What we’ve done
Indigenous Communities Development Grant
What we’re trying to do
Core Components of SPOR II

- Data Platform & Services
- Learning Health System
- Capacity Development
- Patient Engagement
Proposed Governance Structure

Oversight Committee

Executive Committee

CORE 1
Data Platform & Services

CORE 2
Learning Health Systems

CORE 3
Capacity Development

CORE 4
Patient Engagement

PROJECT COMMITTEE:
Data Management, Analysis & Measurement

IMPLEMENTATION COMMITTEE:
Knowledge Translation, & Communications

TRAINING & POR SKILLS COMMITTEE

PATIENT ENGAGEMENT COMMITTEE

1. Clinical Leaders
2. Patient Advisory Council
3. Indigenous Communities

Quality of Care NL
Patient Representation

Oversight Committee - 3 reps

Executive Committee

CORE 1
Data Platform & Services

CORE 2
Learning Health Systems

CORE 3
Capacity Development

CORE 4
Patient Engagement

PROJECT COMMITTEE:
Data Management, Analysis & Measurement
Minimum of 2 reps

IMPLEMENTATION COMMITTEE:
Knowledge Translation, & Communications
Minimum of 2 reps

TRAINING & POR SKILLS COMMITTEE
Minimum of 2 reps

PATIENT ENGAGEMENT COMMITTEE
Minimum of 2 reps
Funding for Indigenous health research

• Student stipend to support Indigenous Health Research
  – Indigenous students will be prioritized to receive this funding
  – Projects must address Indigenous health
Discussion
Lessons Learned

• Translating documents may be beneficial
• Use more pictorial and oral forms of communication
• Initial contact via email is not always appropriate
  – Telephone may be better
• No response = no interest
• Communities are currently overwhelmed with requests (especially contacts within governmental structures)
  – COVID-19 has also shifted the priorities of many communities
• The term “research” may have negative connotations
• Acknowledging that no one person can speak on behalf of an entire community and one community can’t represent the perspectives of all Indigenous peoples
Discussion

• How should we engage Indigenous communities? What could that look like in our context?
• Who should we start with within each community to discuss engagement?
• What should our next steps be?
If you are interested in becoming engaged in the work of NL SUPPORT and/or would like more information, please contact:

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