



SPOR Evidence Alliance

Strategy for Patient-Oriented Research

**Alliance pour des données
probantes de la SRAP**

Stratégie de recherche axée sur le patient

Strategy for Patient-Oriented Research

SPOR

Putting Patients First

2023 Patient and Public Health Research Topic Priority-Setting Exercise

Details of the 63 Health Research Topics

Contact Information

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Glossary of Terms

5G – Fifth-generation of cellular broadband network

AGREE-REX – Appraisal of Guidelines for Research and Evaluation – Recommendation Excellence

AMSTAR-2 – A MeaSurement Tool to Assess systematic Reviews – version 2

ASD – Autism Spectrum Disorder

CGM – Continuous Glucose Monitors

CHF – Congestive Heart Failure

COVID-19 – Coronavirus Disease

CVI – Cerebral Visual Impairment

ED – Eating Disorder

HSV-2 – Herpes simplex virus-2

LGBTQ2S+ - Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, and Two-Spirit

QoL – Quality of Life

MCS – Multiple Chemical Sensitivity

RA – Rheumatoid Arthritis

RoB – Risk of Bias

SDM – Shared Decision-Making

SPOR – Strategy for Patient-Oriented Research

T1D – Type 1 Diabetes

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Arts and activities for older adults and/or those with chronic disease

Population	Older adults; older adults in long-term care; persons with chronic disease
Intervention/Exposure	Arts and health programming; mental and physical health and wellness programs
Comparator	Usual care in long-term care; no arts and health programming; no mental and physical health and wellness programs
Outcomes	QoL; healthcare expenditure; physical health outcomes; management of mental health symptoms (including depression and anxiety); patient experience; participation levels

Interview Details:

Why did you choose this topic and why is it important to you?

- Observed significant improvements in parent's personal enjoyment and QoL after working with a recreational therapist in a long-term care facility.
- Realized the importance and impact of mental well-being and physical health for older adults in long-term care facilities, including other non-physical activities (e.g., arts programming).
- Participated in dance programs with older adults and those with chronic illnesses and found it valuable (e.g., encourages physical movement, provides sense of community/peer network, and facilitates knowledge exchange).
- May be impactful for aging with dignity (in community or home).

What do you hope to learn from researching this topic?

- Literature that supports positive impacts of mental and physical health and wellness programs for older adults.
- Seeking an education-based element to increase education of available programming for older adults (thus increasing access to different programs).
- Improvements to health outcomes (physical and mental), QoL, cost-effectiveness.

- What other jurisdictions are doing, how programming can be scaled up and/or rolled out, and if they can be implemented for other ages/other health conditions.

Who needs to know about the findings?

- Older adults (transitioning to long-term care facilities) and their caregivers
- Advocacy groups (e.g., Indigenous groups, disability groups, aging in dignity groups)
- Healthcare professionals and staff at long-term care facilities
- Policy-makers/decision-makers
- Public

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Consider the healthcare cost of isolation.
- Arts and health programming should be appropriate, culturally safe, and accessible.

Arts and activities for older adults and/or those with chronic disease

Feasibility Assessment Results

Summary:

Two systematic reviews were identified during the scoping literature search. The following two reviews by Bouaziz et al (2017) and Desveaux et al (2014) were assessed using AMSTAR-2. A summary of the AMSTAR-2 assessments is provided in the table below.

Review #1: Bouaziz et al, 2017	Review #2: Desveaux et al, 2014
CRITICALLY LOW quality rating ● ○ ○ ○	LOW quality rating ● ● ○ ○
Critical flaw: Missing several checklist items Study design: Systematic review	Critical flaw: Missing 1 checklist item Study design: Systematic review

Conclusion:

This topic has low to critically low quality systematic reviews, which suggests that there is scope to conduct further research in this area.

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Effect of psilocybins on mental health

Population	Adults with clinical depression; adults with chronic pain
Intervention/Exposure	Psilocybin
Comparator	Common depression and anxiety medication (e.g., selective serotonin reuptake inhibitor); pain management drugs
Outcomes	QoL; management/treatment of depression, post-traumatic stress disorder and anxiety symptoms; pain management

Interview Details:

Why did you choose this topic and why is it important to you?

- They struggle with mental illness and chronic abdominal pain, and have been on many medications.
- Interested to see if psilocybins are an effective alternative treatment and if their use can be scaled up.

What do you hope to learn from researching this topic?

- Explore evidence on efficacy of psilocybins in comparison to standard medications for depression and/or chronic pain.
 - Efficacy on specific health and patient outcomes, including QoL and patient experience.

- Explore existing psilocybin policies in various jurisdictions and their impacts.

Who needs to know about the findings?

- Patients
- Healthcare providers
- Policy-makers
- General public
- Advocacy groups
- Allied health professionals
- Funding bodies


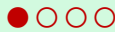
Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Not applicable

Feasibility Assessment Results

Summary:

Two systematic reviews were identified during the scoping literature search. The following two reviews by Li et al (2022) and Vargas et al (2020) were assessed using AMSTAR-2. A summary of the AMSTAR-2 assessments is provided in the table below.

Review #1: Li et al, 2022	Review #2: Vargas et al, 2020
LOW quality rating 	CRITICALLY LOW quality rating 
Critical flaw: Missing 1 checklist item Study design: Systematic review	Critical flaw: Missing 2 checklist items Study design: Systematic review

Conclusion:

This topic has low to critically low quality systematic reviews, which suggests that there is scope to conduct further research in this area.

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Factors promoting the inclusion of immigrant youth

Population	Immigrant youth, especially from racialized populations; foreign-born minors or minors with foreign-born parents
Intervention/Exposure	Factors promoting inclusion in services offered to immigrant youth and their families, in Québec or Canada
Comparator	Not applicable
Outcomes	Subjective mental health and well-being (QoL, well-being and inclusion perceptions)

Interview Details:

Why did you choose this topic and why is it important to you?

- Experience as a social worker and has been exposed to the difficult experiences of immigrant populations, particularly children.
- Believes that it is essential to take an interest in these concepts and to look at the services offered to immigrants from this perspective.

What do you hope to learn from researching this topic?

- To identify and understand underlying mechanisms in the best practices to promote the inclusion of young immigrants in Québec.

Who needs to know about the findings?

- Health and social service providers working with immigrant families: First line services, schools, social workers, etc.
- Research and public agencies that decide and influence policies on inclusion, such as the Ministry of Education and the Ministry of the Family, but also community organizations.
- Citizens (general public)

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Inclusion appears to be more subjective than objective.
- Qualitative, or meta-narrative, approach would be appropriate to identify the factors that promote the well-being and QoL of immigrant youth in order to get their experiential perspective. If it is difficult to gather the views of the young people themselves, it may be the views of practitioners or families.

Anything else you would like to share?

- Immigrant youth are part of their family bubble.
- Relevant to include services and resources that are offered to families to understand how they participate in youth inclusion.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Digital health literacy for older adults

Population	Older adults
Intervention/Exposure	Digital health literacy; digital health education
Comparator	No digital health literacy; no digital health education
Outcomes	QoL; knowledge levels; healthcare utilization

Interview Details:

Why did you choose this topic and why is it important to you?

- They have a professional background in digital health research through which they observed that:
 - a large population (e.g., older adults) lacks access to health technology due to lack of digital literacy, geographic restrictions, and other factors.
 - older adults tend to be the heaviest users of the healthcare system, requiring the most resources.
- Use of digital resources can help to reduce the load on hospitals and primary care.

What do you hope to learn from researching this topic?

- Seeking information on access to digital health (and increasing digital health literacy) that can help to identify:
 - where the load to healthcare providers can be reduced;
 - how to improve healthcare outcomes;
 - how to improve healthcare by integrating technology at the home-level; and
 - how to increase digital literacy knowledge levels for patients.

- Determine educational component (e.g., community programs, training, etc.) to be integrated for healthcare providers and patients.

Who needs to know about the findings?

- Regulatory colleges (e.g., College of Family Physicians of Canada, Royal College of Surgeons and Physicians of Canada)
- Digital Health Canada
- Telus Health

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Be cognizant of the objectives to reduce the workload for healthcare providers and bring healthcare to the home of patients.

Digital health literacy for older adults

Feasibility Assessment Results

Summary:

Three systematic reviews and one scoping review were identified during the scoping literature search. The following four reviews by Huang et al (2023), Kim et al (2023), Verma et al (2022) and Xie et al (2022) were assessed using AMSTAR-2. A summary of the AMSTAR-2 assessments is provided in the table below.

Review #1: Huang et al, 2023	Review #2: Kim et al, 2023
LOW quality rating ●●○○	CRITICALLY LOW quality rating ●○○○
Critical flaw: Missing 1 checklist item Study design: Systematic review	Critical flaw: Missing 2 checklist items Study design: Systematic review
Review #3: Verma et al, 2022	Review #4: Xie et al, 2022
CRITICALLY LOW quality rating ●○○○	CRITICALLY LOW quality rating ●○○○
Critical flaw: Missing several checklist items Study design: Scoping review	Critical flaw: Missing 2 checklist items Study design: Systematic review

Conclusion:

This topic has critically low to low quality systematic reviews and a critically low quality scoping review, which suggests that there is scope to conduct further research in this area.

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Minority and diverse representation in healthcare encounters

Population	Racialized populations/patients
Intervention/Exposure	Racialized healthcare providers or providers of similar gender/race/ethnic backgrounds as patients
Comparator	Non-racialized healthcare providers/usual care
Outcomes	QoL; patient experience; provider experience; patient health outcomes; healthcare costs; patient safety; community impacts

Interview Details:

Why did you choose this topic and why is it important to you?

- They have lived experience in the health sector from an immigrant perspective.
- There is minimal diversity within current healthcare teams.
 - There is little research about the difference in patient health outcomes when encountering diverse healthcare teams as opposed to non-diverse healthcare teams.
- In provision of patient care, patients feel more welcome, empowered, and understood when cared for by a diverse team.

What do you hope to learn from researching this topic?

- Learn about the following outcomes:
 - health outcomes at the individual level (patient safety and QoL);
 - impacts on community (productivity and cost); and
 - impacts on government (cost, healthcare provider shortages).

Who needs to know about the findings?

- Healthcare systems and providers
- Regulated health associations
- Government bodies

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?



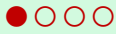
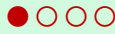
- The health outcomes of patients have the potential to be impacted.

Minority and diverse representation in healthcare encounters

Feasibility Assessment Results

Summary:

Four scoping reviews were identified during the scoping literature search. The following four reviews by Gerchow et al (2021), Palmer Kelly et al (2021), Shommu et al (2016), and Kalich et al (2015) were assessed using AMSTAR-2. A summary of the AMSTAR-2 assessments is provided in the table below.

Review #1: Gerchow et al, 2021	Review #2: Palmer Kelly et al, 2021
LOW quality rating 	CRITICALLY LOW quality rating 
Critical flaw: Missing 1 checklist item Study design: Scoping review	Critical flaw: Missing several checklist items Study design: Scoping review
Review #3: Shommu et al, 2016	Review #4: Kalich et al, 2015
CRITICALLY LOW quality rating 	CRITICALLY LOW quality rating 
Critical flaw: Missing several checklist items Study design: Scoping review	Critical flaw: Missing several checklist items Study design: Scoping review

Conclusion:

This topic has critically low to low quality scoping reviews, which suggests that there is scope to conduct further research in this area.

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Minority and diverse representation in policy-making

Population	Patients and caregivers from minority groups/populations
Intervention/Exposure	Integration of minority groups/voice/representation in healthcare policy-making; capturing experiences/feedback of patients from minority populations to influence policy
Comparator	Current involvement of minority populations in policy-making
Outcomes	Patient outcomes among minority populations; inclusion of minority populations and feedback from minority groups in policy-making/healthcare planning

Interview Details:

Why did you choose this topic and why is it important to you?

- They are frustrated that minority representation is lacking in policymaking.
 - This can impact healthcare planning and health outcomes for minority groups. Some barriers to providing feedback on policies include:
 - language;
 - lack of time or capacity;
 - lack of technological access/literacy;
 - perceived power differentials;
 - fear of repercussions for complaining; and
 - cultural differences.

What do you hope to learn from researching this topic?

- What is being done to capture the minority voice in policymaking (and research)?
- How can better feedback, with representation from minorities, be sought?

- Whose voices are consistently not being heard from?
- How to ensure feedback methods are trauma-informed and culturally-safe.

Who needs to know about the findings?

- Government bodies responsible for healthcare system improvement
- Policy-makers

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- “Nothing about us, without us” is a key phrase from the disability population.
 - We need to address the system barriers that prevent patients and their families from having a voice.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Identifying gaps and opportunities in endometriosis research

Population	People with endometriosis
Intervention/Exposure	Identifying gaps and opportunities in research; re-assessing clinical practice guidelines; associations with other diseases (e.g., mental health); survey assessment of endometriosis symptoms presenting at emergency room visits; identifying disease markers/presentation
Comparator	Current treatment/standard of care
Outcomes	QoL; management of endometriosis symptoms; chronic pain management

Interview Details:

Why did you choose this topic and why is it important to you?

- Living with chronic pain associated with endometriosis.
- Symptoms of endometriosis were exhibited for many years until a diagnosis was finally established.
 - Feels endometriosis is not recognized properly in Canada; dismissed as a “woman’s disease” and believes it is an “invisible illness”.

What do you hope to learn from researching this topic?

- How to improve current clinical practice guidelines to:
 - address comorbidities and the need for multi-disciplinary treatment/approaches;
 - improve current referral system;
 - raise awareness in all healthcare professions and reduce medical gas lighting; and
 - improve pathways of care and communication.
- Identify gaps in research and healthcare systems
- Identify barriers and facilitators to diagnosis, treatment plans, communication and pathways of care in various clinical settings.
- Better understand origins of endometriosis (e.g., genetics).
- Explore accessible diagnosis and treatment options that are less invasive.

Who needs to know about the findings?

- Healthcare providers (not limited to gynecologists) and Professional Societies and Organizations (e.g., CanSAGE, Endometriosis Network Canada)
- Advocacy, disability, and patient Groups
- Policy-makers and funders
- Emergency room personnel

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Many groups of people are affected by endometriosis, including:
 - women;
 - trans and gender-diverse people; and
 - children.

Anything else you would like to share?

- Hysterectomy is not an effective cure, since endometrium tissues can continue growing.

Identifying gaps and opportunities in endometriosis research

Feasibility Assessment Results

Summary:

One systematic review and one scoping review were identified during the scoping literature search. The following two reviews by Sivajohan et al (2022) and Maple et al (2022) were assessed using AMSTAR-2. A summary of the AMSTAR-2 assessments is provided in the table below.

Review #1: Sivajohan et al, 2022	Review #2: Maple et al, 2022
CRITICALLY LOW quality rating ● ○ ○ ○	LOW quality rating ● ● ○ ○
Critical flaw: Missing 2 checklist items Study design: Scoping review	Critical flaw: Missing 1 checklist item Study design: Systematic review

Conclusion:

This topic has a critically low quality scoping review and a low quality systematic review, which suggests that there is scope to conduct further research in this area.

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Cost-effectiveness of home care versus assisted living facilities for individuals requiring additional supports

Population	Individuals requiring home care or assisted living facilities
Intervention/Exposure	Economic evaluation of home care costs (i.e., impact on productivity, well-being, QoL, overall health care)
Comparator	Economic evaluation of beds in clinical, institutional (long-term care, assisted living) settings
Outcomes	Healthcare costs; QoL

Interview Details:

Why did you choose this topic and why is it important to you?

- They have personal experience as a caregiver for a parent who was diagnosed with paranoid schizophrenia and was aging out of the mental healthcare system.
 - Given concerns about poor reputation of long-term care and COVID-19, parent moved in with them. They were unprepared and overwhelmed with workload.
 - Burden of caregiving had significant impact on wage earning, mental and emotional health, family workload, etc.
- Healthcare system does not have capacity to care for aging population resulting in a dependency on home-based caregiving, which lacks adequate supports.
- Work and good will of caregivers is being exploited by health care system.
 - Caregivers' personal resources decrease, but care recipients' needs may increase. Without support, people are forced to turn to institutions. This can be prevented if appropriate resources and supports can be provided.

What do you hope to learn from researching this topic?

- Quantify caregiving in family homes as part of overall health care infrastructure.
- Compare costs to institutional/organizational care with paid staff/infrastructure.
- Quantify cost and sustainability of moving beds from hospitals/long-term care/assisted living to homes.
- Quantifiable data on how caregivers are impacted and how they can be supported.
- Research could contribute to primary data collection system prototype to quantify work taken on by families.

Who needs to know about the findings?

- Caregivers
- Healthcare system (stakeholders)

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Policy of hospital to home, early hospital discharge, and aging in place are not supported by quantifiable data about how caregivers are impacted and how they can be supported.
- Lack of infrastructure.

Cost-effectiveness of home care versus assisted living facilities for individuals requiring additional supports

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Impact of endometriosis on mental health

Population	People with endometriosis; people with clinical depression
Intervention/Exposure	Mental health impacts
Comparator	Not identified
Outcomes	QoL; chronic pain management; depression and anxiety symptom management

Interview Details:

Why did you choose this topic and why is it important to you?

- Experienced severe pelvic pain during menstrual periods which significantly impacted their mental health (e.g., suicidal thoughts worsened when they were in pain).
 - Felt “crazy” and “medically gas lit” when healthcare providers could not provide answers/failed to recognize or believe the severity of their pain.
 - Received care only when they were trying to conceive.
 - Diagnosed with endometriosis after being referred to a pelvic pain center.
 - Pain was mostly relieved with a hysterectomy.
- Personal experience being gender-diverse and seeking care for endometriosis.
 - Language and knowledge around endometriosis and menstruation tends to be women-centric, and therefore may be exclusionary.
 - Gender-diverse people face challenges related to seeking healthcare (e.g., finding a queer-informed provider) and have higher rates of mental illness and suicidal

ideation, which is compounded by endometriosis.

What do you hope to learn from researching this topic?

- How to prioritize mental healthcare for people with pelvic pain and/or endometriosis, including:
 - follow-up and support; and
 - care leading to better overall outcomes.

Who needs to know about the findings?

- Medical students
- General practitioners
- General public

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- The impact of endometriosis goes beyond the health of people with endometriosis and/or pelvic pain, and includes:
 - lost productivity at work and financial impacts; and
 - increased costs due to a lack of awareness (e.g., pain management without specific treatment, exploratory surgeries).

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

Biologics and biosimilars for people with rheumatoid arthritis

Population	People with rheumatoid arthritis
Intervention/Exposure	Biologics in prevention of total joint replacement surgery
Comparator	Usual standard of care
Outcomes	QoL; need for total joint replacement surgery

Interview Details:

Why did you choose this topic and why is it important to you?

- They have lived experience with rheumatoid arthritis.
 - Had multiple total joint replacements and fusions to replace joints damaged by rheumatoid arthritis, prior to the first biologic drug being approved in Canada.
 - Feel that if they had access to biologic drugs sooner, they could have avoided surgeries.
- Ministries of Health and Canadian Agency for Drugs and Technologies in Health (CADTH) continuously question need to cover biologics for inflammatory arthritis, due to costs.
 - Biologics may actually be cost-effective if they prevent joint damage and the need for total joint replacement.
 - The rise in cheaper alternatives may also be cost-saving.
- Current treatment for rheumatoid arthritis needs to be timelier to prevent joint damage and disability.

What do you hope to learn from researching this topic?

- Have biologics prevented the need for total joint replacement for people with rheumatoid arthritis?
 - Explore trends (number of total joint replacements before and after biologics were made available) in patients with rheumatoid arthritis. Exclude total joint replacements due to osteoarthritis (only include diagnoses of inflammatory arthritis).

Who needs to know about the findings?

- Governmental bodies (e.g., CADTH, Health Canada)
- Healthcare professionals (e.g., orthopedic surgeons, rheumatologists)
- Private insurers
- Patients

Anything else you would like to share?

- There is potential for an economic evaluation of biologics and biosimilars (although there is current work being done on the economics of biosimilars).

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Association between endometriosis and allergies or other inflammatory conditions

Population	People with endometriosis
Intervention/Exposure	Association with allergies and/or inflammatory and/or autoimmune disease
Comparator	Not identified
Outcomes	QoL; clinical health outcomes

Interview Details:

Why did you choose this topic and why is it important to you?

- They have lived experience with endometriosis and allergies.
 - Noticed (e.g., through support groups and through family and friends) that autoimmune/inflammatory conditions are common in people with endometriosis.

What do you hope to learn from researching this topic?

- Learn more about endometriosis in general.
- Raise awareness for endometriosis as a condition that can affect someone beyond menstrual periods and related pain.

Who needs to know about the findings?

- Physicians and other healthcare providers
- Allergists
- General public
- Endometriosis advocacy groups and support systems
- Researchers

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Topic is common but not talked about enough.
 - Opening up this dialogue can improve support for those with endometriosis.

Anything else you would like to share?



- They are open to pivoting the scope of the research topic to other immunological-based topics (e.g., skin psoriasis or dermatitis).

Association between endometriosis and allergies or other inflammatory conditions

Feasibility Assessment Results

Summary:

Two systematic reviews were identified during the scoping literature search. The following two reviews by Shigeski et al (2019) and Bungum et al (2014) were assessed using AMSTAR-2. A summary of the AMSTAR-2 assessments is provided in the table below.

Review #1: Shigeski et al, 2019	Review #2: Bungum et al, 2014
HIGH quality rating 	CRITICALLY LOW quality rating 
Critical flaw: Addressed all checklist items Study design: Systematic review	Critical flaw: Missing several checklist items Study design: Systematic review

Conclusion:

This topic has a high quality systematic review published in 2019; therefore, there are opportunities for knowledge translation and dissemination.

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Peer navigation for organ transplant patients and their caregivers

Population	Organ transplant patients (donors and recipients); caregivers to organ transplant patients
Intervention/Exposure	Trauma-informed care; peer navigation or support programs (e.g., including peer-to-peer training);
Comparator	Standard supportive services for organ transplant recipients/caregivers
Outcomes	QoL (for patients and caregivers); management of anxiety and depression symptoms; quality of supportive services

Interview Details:

Why did you choose this topic and why is it important to you?

- Lived experience as a caregiver for husband who received an organ transplant.
- Felt a sense of community staying in the post-transplant treatment area and after returning home, they felt isolated living in a low-populated area.
- Having peers with training and oversight would be helpful to build a community to check in, provide tools for support, and to connect people.

What do you hope to learn from researching this topic?

- Learn more about compliance and about the trauma of patients and providers face.
- Feels that the trauma-informed mental health piece and compassion is missing in transplant research, and that psychological concerns of patients are not addressed.

Who needs to know about the findings?

- Basic training for patients and caregivers on navigating the healthcare system (e.g., how to keep a patient binder, how to take notes, health literacy)
- Physicians through training on how to facilitate these skills.

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- There is a need in healthcare to move towards trauma-informed care.
- It is important to consider what constitutes as trauma and why complex patients have trauma.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Reoccurrence of endometriosis after hysterectomy

Population	Patients with endometriosis
Intervention/Exposure	Hysterectomy
Comparator	Usual care; no hysterectomy; gold standard for endometriosis treatment
Outcomes	QoL; chronic pain management; post-hysterectomy growth management; newer/improved treatment options; low-cost treatment options; guidelines for standard of care; protocol for endometriosis diagnosis

Interview Details:

Why did you choose this topic and why is it important to you?

- They have stage 4 endometriosis and have had a complete hysterectomy.
 - They were (non-definitively) told lesions may generate estrogen and regrow. This is concerning as they were on hormone replacement therapy.
 - They find it difficult to find knowledge and medical help to address ongoing pain and health concerns; opinions from medical professionals vary considerably.
- They have heard stories from others with endometriosis facing issues with diagnosis/treatment.

What do you hope to learn from researching this topic?

- Understand the current gaps in endometriosis diagnosis and treatment.
 - This will help the medical community to become more aware, knowledgeable, and consistent in endometriosis practices.

Who needs to know about the findings?

- General practitioners
- Other healthcare professionals

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Endometriosis is not just a reproductive disease, but can affect the whole body.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Mental health supports for individuals experiencing homelessness

Population	Individuals experiencing homelessness
Intervention/Exposure	Mental health supports
Comparator	Current access to supportive services
Outcomes	QoL; depression and anxiety symptom management; mental health outcomes

Interview Details:

Why did you choose this topic and why is it important to you?

- Personal experiences with people without homes.
- Has found that there are barely any mental health supports that exist for people without homes.
- There is a need for trained healthcare providers to meet people without homes where they are at.

What do you hope to learn from researching this topic?

- If there are better alternatives offering mental health supports to people without homes.
- Ways to address societal attitudes and facilitate systemic change. Policy support and attitude shift is needed to facilitate long-term mental health support.

Who needs to know about the findings?

- Policy makers for top-down structural change.
- People who offer mental health support.

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Not applicable

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Identifying gaps and opportunities for patient/public partner engagement in research teams

Population	Patient/public partners involved in research teams as equal partners
Intervention/Exposure	Identifying barriers, facilitators, gaps, opportunities, guidelines, best practices, strategies, tools for addressing inequities faced by partners/public partners engaged as equal partners within the research community
Comparator	Current situation/method of patient partnership as research team members
Outcomes	Patient/public experiences (including caregivers) as equal partners on research teams; meaningful engagement/involvement of patients as partners on research teams; experiences of patient partners of colour as equal partners on research teams; equitable research patient partnerships; capacity development for patient partners on research teams

Interview Details:

Why did you choose this topic and why is it important to you?

- They have experience being engaged in research teams as a patient partner.
 - They do not feel that equity, diversity, and inclusion of patient partners is sufficient or consistent through the entire research process.
 - Patient partner engagement can feel tokenistic.
 - Power dynamics may cause intimidation; it may be unhelpful to bring up concerns (e.g., fear of being excluded, etc.).
- They are interested in exploring inequities faced by patients who partner on research teams, and seeing if research teams and institutes are addressing inequities in patient engagement as partners in research.

What do you hope to learn from researching this topic?

- What are best practices to improve the role of patients as equal partners on research teams?
 - What are current successes, strategies/tools/approaches, and barriers/facilitators?

- How to improve the equitable engagement of patients engaged as partners on research teams.

Who needs to know about the findings?

- Research community (as a whole):
 - Research teams
 - Policy-makers
 - Institutions/organizations engaging patient partners

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- This topic is asking to look at existing patient (definition includes caregivers) engagement as equal partners on research teams through an equity, diversity, inclusion lens.

Identifying gaps and opportunities for patient/public partner engagement in research teams

Feasibility Assessment Results

Summary:

Four scoping reviews were identified during the scoping literature search. The following four reviews by Rouncefield-Swales et al (2021), Van Schelven et al (2020), McCarron et al (2019) and Sangill et al (2019) were assessed using AMSTAR-2. A summary of the AMSTAR-2 assessments is provided in the table below.

Review #1: Rouncefield-Swales et al, 2021	Review #2: Van Schelven et al, 2020
CRITICALLY LOW quality rating ● ○ ○ ○	CRITICALLY LOW quality rating ● ○ ○ ○
Critical flaw: Missing several checklist items Study design: Scoping review	Critical flaw: Missing several checklist items Study design: Scoping review
Review #3: McCarron et al, 2019	Review #4: Sangill et al, 2019
LOW quality rating ● ● ○ ○	CRITICALLY LOW quality rating ● ○ ○ ○
Critical flaw: Missing 1 checklist item Study design: Scoping review	Critical flaw: Missing several checklist items Study design: Scoping review

Conclusion:

This topic has critically low to low quality scoping reviews, which suggests that there is scope to conduct further research in this area.

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Screening and diagnostic tools for Cerebral Visual Impairment

Population	People with Cerebral Visual Impairment (CVI)
Intervention/Exposure	Screening and diagnostic tools and procedures; clinical practice guidelines
Comparator	Current screening tools and procedures; no screening
Outcomes	Clinical health outcomes; screening rates and uptake

Interview Details:

Why did you choose this topic and why is it important to you?

- Has a child with CVI and is aware that CVI affects many peers and families.
- CVI has a lot of crossover with neurodevelopmental disability (NDD) and can account for many typical NDD behavioural symptoms.
- A lot of time and effort wasted with behavioural approaches and incomplete assessments that do not account for CVI.

What do you hope to learn from researching this topic?

- The rate of diagnosis of CVI in Canada
- How many medical professionals are capable of diagnosing CVI.

Who needs to know about the findings?

- Health professionals
- Patients and caregivers
- Educational system (e.g., educating staff)

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Potential scoping or systematic review.
- Development or updating current clinical practice guidelines.

Anything else you would like to share?

- Resources include: CVI Scotland (evidence-based and user-friendly resources, including webinars); CVI for TVI (teachers for visually impaired that provides resources and guides on how to make classrooms more accessible)

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search. We identified one Canadian clinical practice guideline on this topic published in 2019 ([Delpero et al. 2019](#)). However, we cannot comment on the clinical credibility and feasibility of the guideline since quality assessment using the AGREE-REX tool was not conducted.

Conclusion:

There is scope to conduct further research in this area.

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Digital health technology for patient education

Population	Patients with cardiac conditions
Intervention/Exposure	Patient education in a technological form (e.g., multimedia content, patient community forums, facilitation by healthcare professionals)
Comparator	No patient education; current patient education materials/methods
Outcomes	QoL; health behavior change outcomes (e.g., dietary habits, medication adherence); knowledge levels; cardiac/health functions; discharge education, patient knowledge

Interview Details:

Why did you choose this topic and why is it important to you?

- Professionally, they are a director of an online learning unit, and are well-versed in educational technology. They have lived experience as a patient undergoing two major cardiovascular operations, during which time they noticed gaps during the transition between hospital to home.
 - Education technology (if designed and applied appropriately) would be a benefit to patients; could be used to support patients and for patients to support themselves.
- They are currently working on a scoping review, looking at interventions for cardiac patients in the discharge/transition process.

What do you hope to learn from researching this topic?

- Trial a learning program in conjunction with a healthcare institution to learn how educational technology can assist healthcare delivery.
 - Identify what elements of the learning program are effective at the organizational and patient level.
 - Outcomes that can be assessed include the “quadruple aim metrics” (patient experience, healthcare costs, provider experience, population health).

Who needs to know about the findings?

- Patients and caregivers
- Healthcare providers

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- It is important for healthcare providers and policymakers to consider the thoughtful and intelligent use of existing technology that can make a difference without large costs. This has the potential to:
 - empower patients;
 - provide connectedness to other patients and healthcare professionals; and
 - use technology appropriately and with continuous improvement of existing processes (learning health system).

Digital health technology for patient education

Feasibility Assessment Results

Summary:

Two systematic reviews were identified during the scoping literature search. The following two reviews by Halldorsdottir et al (2020) and Emmerson et al (2018) were assessed using AMSTAR-2. A summary of the AMSTAR-2 assessments is provided in the table below.

Review #1: Halldorsdottir et al, 2020	Review #2: Emmerson et al, 2018
CRITICALLY LOW quality rating ● ○ ○ ○	LOW quality rating ● ● ○ ○
Critical flaw: Missing 2 checklist items Study design: Systematic review	Critical flaw: Missing 1 checklist item Study design: Systematic review

Conclusion:

This topic has critically low to low quality systematic reviews, which suggests that there is scope to conduct further research in this area.

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Geo-mapping database of sustainable health indicators in Québec

Population	Data sources, including all indicators that have already been computed, available for the greater Québec City area
Intervention/Exposure	What type of information is available, where/what publisher, how often, who has access to it, is it geo-locatable. How long has the information been available and how often is it collected/available
Comparator	Not applicable
Outcomes	Sustainable health and factors associated with or influencing it (e.g., environmental factors such as pollution)

Interview Details:

Why did you choose this topic and why is it important to you?

- Has witnessed researchers or research teams who set up a project where there is no inventory or directory of available data, leaving research teams to find this information on their own.
- Creating a directory with these contextual data sources could also promote comparability between different projects and interventions.
- The creation of the directory of available data described in this document would be the first necessary step in creating the tool.

What do you hope to learn from researching this topic?

- To promote citizen mobilization around knowledge of sustainable health factors.
- Hopes to easily make available relevant data to encourage and promote citizen involvement in the community and to support research, interventions and policies in sustainable health that can benefit the population of the Greater Québec City area.

Who needs to know about the findings?

- Citizens (general public)
- Municipal department heads who make local interventions or policies
- Government departments and agencies that provide services to the population, especially if they serve the region
- Community organizations and associations working on themes related to sustainable health
- Research centers, particularly in the various aspects covered by sustainable health

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- For the development of the directory, regular updates of the available data (including historical data) should be considered to ensure sustainability of the directory.

Anything else you would like to share?

- It would be relevant to select a few indicators or data sources to test the development of the tool.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Prevention and treatment of osteoporosis

Population	People with osteoporosis/osteopenia
Intervention/Exposure	Prevention and treatment (including supplements in addition to traditional pharmaceutical therapies); Omega 3 and 6 supplements on bone health
Comparator	No prevention and treatment; no supplements; standard of care
Outcomes	Clinical outcomes; chronic pain management; healthcare expenditure; QoL; public health prevention programming; complementary therapies; clinical guidelines

Interview Details:

Why did you choose this topic and why is it important to you?

- Interviewees are an allied healthcare practitioner who has volunteered for osteoporosis awareness and prevention and a family medicine resident with an interest in osteoporosis.
- They have also been diagnosed with osteoporosis, which they are managing with lifestyle self-management (e.g., taking vitamins D3 and K, increasing dairy consumption, bone-strengthening exercises).
- They feel there is a need for more research on lifestyle self-management for osteoporosis.

What do you hope to learn from researching this topic?

- Information on potential impact of supplements (e.g., Omega-3 and 6 supplements) and lifestyle changes that can improve outcomes for osteoporosis while complementing existing treatments.

Who needs to know about the findings?

- General population
- Patients
- Physicians
- Osteoporosis Canada

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Osteoporosis can impact all genders, though women are more at risk.
- There is a shift in health towards lifestyle self-management.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search. We identified one North American clinical practice guideline on this topic published in 2020 ([Shoback et al, 2020](#)). However, we cannot comment on the clinical credibility and feasibility of the guideline since quality assessment using the AGREE-REX tool was not conducted.

Conclusion:

There is scope to conduct further research in this area.

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Hydration of older adults in long-term care

Population	Older adults in long-term care
Intervention/Exposure	Monitored hydration programs
Comparator	Usual care
Outcomes	QoL; healthcare expenditure; clinical outcomes; frequency of falls

Interview Details:

Why did you choose this topic and why is it important to you?

- Their relative, who had Alzheimer's disease, sometimes demonstrated belligerent and uncooperative behavior.
 - Behavior appeared to improve with water intake leading them to be more cooperative, clearer, and have improved balance.
- They feel patients in long-term care homes are not encouraged to regularly drink enough fluids.
- There is limited research on dehydration in older people.

What do you hope to learn from researching this topic?

- Discover impacts of hydration on older adults, including QoL, falls, incident reports, hospital admissions.

Who needs to know about the findings?

- Policy-makers
- Advocacy groups
- Elderly people
- Long-term care providers

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Patients in long-term care homes face many challenges, especially related to their QoL.
 - A slight improvement in mood, balance, and cognitive function can make a difference in the life of someone in long-term care.

Anything else you would like to share?

- Dissemination of findings can include:
 - sharing packages with long-term care homes.
 - sharing findings at conferences
 - informational videos for policy-makers.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Hand hygiene of older adults in long-term care

Population	Older adults in long-term care
Intervention/Exposure	Monitored hand hygiene program
Comparator	Usual care
Outcomes	Infection rates; cost benefits

Interview Details:

Why did you choose this topic and why is it important to you?

- Worked in healthcare where campaigns to promote hand hygiene were geared toward healthcare workers and not patients (especially in long-term care homes).
 - Supervised handwashing was not usually performed in long-term care homes (exception: flu season).
- Limited information exists regarding hand hygiene practices among individuals living in long-term care settings.
- Supervised handwashing is a low cost intervention for patients in long-term care homes that can improve QoL.

What do you hope to learn from researching this topic?

- Produce data.
- Develop protocols for long-term care facilities.
- Educate patients, visitors, and staff.

Who needs to know about the findings?

- General public
- Patients
- Visitors
- Frontline staff
- Policy-makers

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- This is an area of research that has been neglected, and has the potential for high reward.

Anything else you would like to share?

- Hope that a low-cost intervention would support dignity, safety, and improve QoL.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Peer support networks for people with chronic pain

Population	People with chronic pain
Intervention/Exposure	Peer support network; personal pain care management
Comparator	No care management; no peer support network
Outcomes	QoL; chronic pain management

Interview Details:

Why did you choose this topic and why is it important to you?

- Faced a lot of barriers when receiving care for chronic pain management.
- Feels that people experiencing chronic pain are underserved, under resourced, and tend to hover in healthcare for years.
- Support networks allow individuals to share lived experiences and are a tool for knowledge exchange.

What do you hope to learn from researching this topic?

- Increase awareness among providers and the public on the social support aspect of chronic pain management.
- Explore how beneficial pain support groups are for those experiencing chronic pain.
- Explore how communities can support people living with chronic pain management, and the different dimensions of their pain.
- Explore approaches for how peer support networks can be scaled up and implemented.

Who needs to know about the findings?

- Communities
- Chronic pain and advocacy groups (e.g., arthritis associated pain groups)
- Healthcare and allied healthcare providers
- Researchers

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Methodologically, scoping reviews, jurisdictional scans or surveys of individuals in focus groups can be used.
- Explore ways in which support groups are developed and led.

Anything else you would like to share?

- Exemplars of peer support networks in other Canadian jurisdictions, which can be covered in a scoping review, such as the work being done by [Pain BC](#) and [Pain Canada](#).

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Tracking medical errors for patient safety

Population	Medical errors
Intervention/Exposure	Medical error checking system; tracking system
Comparator	Usual care
Outcomes	Patient care/experiences; health system outcomes; provider experiences

Interview Details:

Why did you choose this topic and why is it important to you?

- Their spouse was receiving medical treatment for heart surgery and hospital-acquired pneumonia.
 - They felt a lack of transparency and agency, and did not receive an admission of mistakes made by healthcare professionals.
 - Mistakes by healthcare professionals were not documented consistently through medical records and doctors' reports (this led to an investigation).
- A tracking system of medical errors needs to be implemented and/or scaled up.

What do you hope to learn from researching this topic?

- Scan other jurisdictions and their systems for tracking of medical errors.
- Ultimately, medical investigations need to be more comprehensive, including record-keeping of medical errors.

Who needs to know about the findings?

- Healthcare providers
- Patient advocacy groups
- Healthcare managers (in hospital and surgical settings)

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Not applicable

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Financial schemes to increase accessibility of health services for people experiencing socio-economic disadvantage

Population	People experiencing socio-economic disadvantage (including people working on minimum wage)
Intervention/Exposure	Financial approaches or services to encourage the provision of health services not covered by the RAMQ (RAMQ: Québec government basic health coverage)
Comparator	Lack of services
Outcomes	Any condition that requires health services not covered by the RAMQ

Interview Details:

Why did you choose this topic and why is it important to you?

- Has lived experience with significant health concerns causing them to stop working and become socio-economically disadvantaged.
- Experienced negative physical and psychological impact because of not being able to receive financial schemes or program services, due to lack of funds.
- Allowing people in socio-economic disadvantaged situations to obtain financial scheme or program services could lead to an overall improvement for many and allow them to contribute to society.

What do you hope to learn from researching this topic?

- The consequences (in Québec) of not receiving services in the short, medium and long-term for people living in a situation of socio-economic disadvantage, who need health services not covered by the RAMQ (Québec's healthcare coverage).
- The kind of approaches, alternatives or financial services that could be put in place to address these consequences (e.g., SPOT Clinic).
- The barriers to accessing health services not covered by the RAMQ.

Who needs to know about the findings?

- INSPQ (Québec Public Health Institute)
- Public health authorities
- Chair on the reduction of inequalities at Université du Québec à Montréal
- Faculty of Medicine at Laval University
- General population

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?


- The long-term goal is to promote social justice in health.
- The lack of access to health services for this group of people has consequences for society.
- People living in socio-economic vulnerability are human beings in the same way as those who can afford the care required by their health situation.

Financial schemes to increase accessibility of health services for people experiencing socio-economic disadvantage

Feasibility Assessment Results

Summary:

One scoping review was identified during the scoping literature search. The following review by Harnagea et al (2017) was assessed using AMSTAR-2. A summary of the AMSTAR-2 assessment is provided in the table below.

Review #1: Harnagea et al, 2017
LOW quality rating 
Critical flaw: Missing 1 checklist item Study design: Scoping review

Conclusion:

This topic has a low quality scoping review, which suggests that there is scope to conduct further research in this area.

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Pain education reference guides for people with chronic pain

Population	Patients with chronic pain
Intervention/Exposure	Pain education reference guide (plain language and multilingual translations to English)
Comparator	No pain education
Outcomes	QoL; chronic pain management; patient-physician communication; knowledge levels; provider experiences; patient experiences

Interview Details:

Why did you choose this topic and why is it important to you?

- Living with chronic pain and when seeking help from healthcare practitioners, they did not have the language to effectively communicate and describe the pain, therefore it became challenging to receive the help they needed.
- They have multiple English-speaking peers who have had major surgeries, who struggled to describe their pain.
 - Even though they are high-functioning and self-advocating, they needed coaching from the interviewee to receive better care.
- People with poor health literacy may have increased difficult interactions with healthcare providers (i.e., poor patient-provider experiences).
 - It is critical to use language effectively to help diagnose and allow for better treatment.

What do you hope to learn from researching this topic?

- Interested in having a resource available for patients to support themselves; an easy-to-use guide available widely with visual printouts in various languages.

Who needs to know about the findings?

- Patients and caregivers
- Healthcare providers
- Various organizations and societies (e.g., pain management societies)
- Pharmacists and allied health clinics
- Funding bodies

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- It is important for healthcare providers and policymakers to make thoughtful and intelligent use of technology that can make a huge difference without huge cost.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Prodrome symptoms and treatment of HSV-2

Population	People with latent HSV-2 infection and prodrome symptoms
Intervention/Exposure	Treatment focused on prodrome symptoms related to HSV-2 infection, including depression
Comparator	Standard of care
Outcomes	QoL; detection/diagnosis of prodrome symptoms; management of depression symptoms

Interview Details:

Why did you choose this topic and why is it important to you?

- They have lived experience with HSV-2.
- There is a lack of information on causes underlying severe nerve pain in the prodrome stage of HSV-2 and a lack of information on why this occurs, what triggers it, and how it can be treated.

What do you hope to learn from researching this topic?

- Clinical prevention, primary care options, and treatment options (including therapies) for prodrome symptoms.
 - Prevalence information (e.g., how many people are experiencing prodrome symptoms).
- Understand triggers and prevention (aside from anti-viral drugs).

Who needs to know about the findings?

- Physicians (e.g., primary care)
- Patients
- Policy-makers

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Talking about prodrome symptoms in relation to HSV-2 can help reduce the stigma.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Impact of cannabis legalization on new cannabis users

Population	New cannabis users
Intervention/Exposure	Cannabis legalization; cannabis use
Comparator	No legalization of cannabis; no cannabis use
Outcomes	Impact on lifestyle (e.g., diet, physical activity), mental health, social isolation

Interview Details:

Why did you choose this topic and why is it important to you?

- Has lived experience as a caregiver for child with mental health issues and cannabis use has impacted their child's life path.

What do you hope to learn from researching this topic?

- Hopes to learn if cannabis use can have an impact on healthy lifestyle habits (e.g., diet, physical activity).

Who needs to know about the findings?

- General public
- Public health authorities
- Healthcare workers

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- This is a public health issue.
- It is therefore important to raise awareness about cannabis use, not only on its benefits but also its disadvantages and risks.

Anything else you would like to share?

- Healthy lifestyle habits are protective factors against mental health disorders. Cannabis seems to have an impact on lifestyle habits, such as diet and physical activity.
- It would be interesting to know the long-term impact on mental health, with a longitudinal study, ideally with a large population.
- It would also be interesting to explore social isolation among cannabis users.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Mental health supports for child amputees

Population	Children and youth amputees
Intervention/Exposure	Mental health supports for traumatic event loss of limbs
Comparator	Mental health supports for congenital loss of limbs
Outcomes	QoL; management of depression and anxiety symptoms

Interview Details:

Why did you choose this topic and why is it important to you?

- Lived experience as a parent of a pediatric cancer survivor and amputee. Feels that societal narratives perpetuate the idea that amputees are amazing, inspiring and can overcome obstacles and defy all odds.
- Their child struggled immensely with their mental health following the amputation.
- People are unaware of the long-term effects of amputation beyond the loss of limb (e.g., chronic pain).

What do you hope to learn from researching this topic?

- The difference in outcomes and mental health needs between congenital amputations and traumatic amputations due to illness or accident.
- How to improve ongoing care for traumatic amputations and families.

Who needs to know about the findings?

- Health professionals (e.g., those in medical teams and oncology units) for long term follow-up
- General public and education system

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- You may be able to cure the disease, but we cannot lose sight of the person's mental needs.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Flexibility in treatment guideline adherence for inclusion of patient goals

Population	Healthcare professionals; clinical practice guidelines
Intervention/Exposure	Differences/ flexibility in adherence to treatment guidelines (inclusion of patient goals)
Comparator	Adherence to treatment guidelines (usual care)
Outcomes	QoL; patient experience/care; healthcare costs; mortality; malpractice

Interview Details:

Why did you choose this topic and why is it important to you?

- Feels there is a negative impact from using algorithms in health care as algorithms can prevent practitioners from approaching treatment with nuance and creativity.
- It causes a lack of a tailored approach when treating different patients with different needs.

What do you hope to learn from researching this topic?

- If strict adherence to treatment guidelines (algorithms) negatively impact quality of patient care.
- If there is a negative impact of using algorithms in a medical context.

- If there is a negative impact on patients by having medical decision-making restricted by legal departments.

Who needs to know about the findings?

- Dissemination of findings can be done through the Strategic Clinical Network in Alberta.

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Need for a large patient survey to understand what is happening to them and receive consent for their data.
- Would want to consult the Strategic Clinical Network to decide on scope and who to engage with.

Feasibility Assessment Results

Summary:

One systematic review was identified during the scoping literature search. The following review by Wang et al (2022) was assessed using AMSTAR-2. A summary of the AMSTAR-2 assessment is provided in the table below.

Review #1: Wang et al, 2022
CRITICALLY LOW quality rating 
Critical flaw: Missing several checklist items Study design: Systematic review

Conclusion:

This topic has a critically low quality systematic review, which suggests that there is scope to conduct further research in this area.

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Continuous glucose monitors versus other monitors for diabetes management

Population	People with type 1 and 2 diabetes
Intervention/Exposure	Continuous glucose monitors (CGM)
Comparator	Other monitors for diabetes care (e.g., insulin pumps, flash glucose monitors)
Outcomes	Hemoglobin A1c (HbA1C) levels (blood sugar levels); QoL; symptom reduction/management

Interview Details:

Why did you choose this topic and why is it important to you?

- They have lived experience as a person with diabetes using an insulin pump.
- CGM are a recent technology for diabetes, offering benefits.
 - Evidence on benefits (e.g., efficacy, cost-effectiveness, benefits and challenges of CGM vs. other technologies) need to be explored.

What do you hope to learn from researching this topic?

- Efficacy and cost-effectiveness of CGM in comparison to insulin pumps.

Who needs to know about the findings?

- Patients and caregivers
- Diabetes advocacy groups
- Healthcare professionals
- Health system and technology manufacturers
- Funding bodies

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?


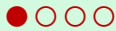

- The methodology could potentially involve a health technology assessment, including certain benchmarks (e.g., time, range hemoglobin A1C, etc.).
- A correlation study could assess how much the health system saves based on QoL outcomes and a cost-benefit analysis.

Continuous glucose monitors versus other monitors for diabetes management

Feasibility Assessment Results

Summary:

Three systematic reviews were identified during the scoping literature search. The following three reviews by Torres Roldan et al (2022), Luo et al (2021) and Langendam et al (2012) were assessed using AMSTAR-2. A summary of the AMSTAR-2 assessments is provided in the table below.

Review #1: Torres Roldan et al, 2022	Review #2: Luo et al, 2021	Review #3: Langendam et al, 2012
LOW quality rating 	CRITICALLY LOW quality rating 	HIGH quality rating 
Critical flaw: Missing 1 checklist item Study design: Systematic review	Critical flaw: Missing 2 checklist items Study design: Systematic review	Critical flaw: Addressed all checklist items Study design: Systematic review

Conclusion:

This topic has critically low to high quality systematic reviews, which suggests that there is scope to conduct further research in this area.

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Uses and applications of virtual reality in healthcare

Population	Healthcare provider; patients with disabilities and healthcare professionals
Intervention/Exposure	Knowledge transfer and application using virtual reality tools (e.g., Metaverse)
Comparator	Current methods of collaboration and knowledge transfer that are not virtual and do not use the Metaverse
Outcomes	Level of inclusion and engagement of patients with disabilities.

Interview Details:

Why did you choose this topic and why is it important to you?

- Has lived experience as a caregiver for a child suffering from a rare disease and uses a virtual reality helmet.
- Feels that there are obstacles to accessible safe and easily reachable meeting spaces for patients, who are not always able to travel to research centers.
- The use of virtual reality and the Metaverse offers an opportunity to improve the inclusion and engagement of patients in research projects and the community, and to reduce the difficulties and obstacles encountered by patients daily.

What do you hope to learn from researching this topic?

- Believes in the power of the Metaverse to accelerate the application and transfer of knowledge.

Who needs to know about the findings?

- Patient associations, patient advocacy groups, patient communities
- Governments
- Health professionals, the scientific community, researchers
- The professional and social world in general (companies, schools, cultural spaces, etc.)

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- They have designed a "Hub" for rare diseases in the Metaverse in which each member has access to their virtual office, a research center, a group of patients, a social club, a rehabilitation center and even conference rooms for holding virtual conferences.

Anything else you would like to share?

- The application of these virtual collaboration and inclusion solutions could also reduce carbon dioxide emissions linked to the actual organization of a national or international congress (e.g., travel, equipment, etc.). The use of virtual reality via the Metaverse is therefore part of a sustainable health approach.
- Opportunity to create jobs for people with disabilities who are still often excluded from the job market. In particular, through the creation of training workshops given by companies using virtual reality and the Metaverse.

Uses and applications of virtual reality in healthcare

Feasibility Assessment Results

Summary:

One scoping review was identified during the scoping literature search. The following review by Glegg et al (2018) was assessed using AMSTAR-2. A summary of the AMSTAR-2 assessment is provided in the table below.

Review #1: Glegg et al, 2018
CRITICALLY LOW quality rating ● ○ ○ ○
Critical flaw: Missing 2 checklist items Study design: Scoping review

Conclusion:

This topic has a critically low quality scoping review, which suggests that there is scope to conduct further research in this area.

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Impact of psilocybins on young adults undergoing stroke recovery

Population	Young adults undergoing stroke recovery
Intervention/Exposure	Psilocybin
Comparator	Usual care for stroke recovery
Outcomes	Cognitive function; brain health (e.g., MRI scans); QoL; physical and mental stroke recovery

Interview Details:

Why did you choose this topic and why is it important to you?

- They have personal experience of being ill; had a stroke at 27 years of age.
 - They feel psilocybins helped them greatly with physical and emotional recovery.

What do you hope to learn from researching this topic?

- General overview of the existing literature on psilocybins and health.
 - Find evidence of the positive impacts of psilocybins on stroke health and brain health (e.g., regenerating brain cells).

Who needs to know about the findings?

- Decision-makers, policymakers, health entities
- Healthcare providers
- Patients/public

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Mainstream medications have a limit, and (therefore) research should be done to explore alternatives as additional options provided to patients.
- Prevalence of strokes in younger and older populations warrants the exploration of psilocybins for recovery.

Anything else you would like to share?

- Current but limited research on psilocybins and stroke shows promise with regenerating brain cells.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Higher quality patient encounters for people with chronic progressive diseases

Population	People/adults with chronic progressive diseases and physicians supporting patients with chronic disease
Intervention/Exposure	Processes and systems for higher quality patient-clinical encounters (e.g., communication strategies to encourage engagement, resources, supportive services – language support)
Comparator	Usual care (clinician decision-making)
Outcomes	Patient care/experiences; QoL; provider experiences; quality of patient encounters with healthcare professionals/system

Interview Details:

Why did you choose this topic and why is it important to you?

- Interviewees have a passion for improving patient experience and safety.
 - Inspired by [Healthcare Excellence Canada's 'How Safe is Your Care' webinar](#), [Greg's wings](#) and numerous patient stories heard by the members of this team during patient-led research projects through [PaCER](#) and as patient advisors with Alberta Health Services.
- Have determined that higher quality encounters between patients and providers contribute to better and safer outcomes, but there is lack of evidence about how to achieve, assess, and sustain higher quality patient/provider encounters.

What do you hope to learn from researching this topic?

- Identify key factors and barriers that impact high-quality health encounters.
 - To better understand what is happening at the encounter level (need to develop robust definitions of key terms, such as “high quality encounters” and “patient safety”).
- Develop and validate a definition of high-quality encounters from the patient and provider side of the encounter
- Identify a user-friendly process to support higher quality encounters and safer outcomes

for patients with chronic progressive diseases and their clinicians.

- Determine appropriate study design, methodology, and indicators to capture all aspects of the patient/provider encounter in a simple, replicable way.
 - Find validated tools for assessing the quality of patient/provider encounters (what are the pros and cons of developing new tool).
 - Measure quantitative data to demonstrate effectiveness in patient safety/experience.
 - Develop pre- and post- evaluation approaches.

Who needs to know about the findings?

- Healthcare providers and support staff
- Patients and families
- Alberta Health Services

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- The work should be co-designed and co-led by patients and providers, with sharing of power.
- Developed product should be transferable, sustainable, and easy to implement.

Anything else you would like to share?

- Interviewees have actively sought funding and secured funding for a portion of the project.

Higher quality patient encounters for people with chronic progressive diseases

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Healthcare professionals' awareness of breast cancer rehabilitation

Population	Individuals who underwent breast cancer surgery
Intervention/Exposure	Healthcare professionals' decision-making process and guidelines for rehabilitation referrals
Comparator	Standard of care
Outcomes	QoL; rehabilitation outcomes

Interview Details:

Why did you choose this topic and why is it important to you?

- They are a physiotherapist who was diagnosed with breast cancer. Through connections and self-referral, they started physiotherapy early.
 - They joined a support group and discovered no one in the group was referred to a physiotherapist by a practitioner.
- It is important to receive timely rehabilitation after breast cancer surgery. Disabilities that women are left with can be prevented with timely intervention.

What do you hope to learn from researching this topic?

- What is preventing physicians from having an in-depth discussion about rehabilitation?
- What are guidelines surrounding post-surgery care, and what are triggers and best practices?

Who needs to know about the findings?

- Patients
- Physicians
- Nurses
- Navigators/case-managers
- Family doctors

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Would like them to recognize that by doing this, we are getting women back into the workforce and continue to feel capable of continuing to care for themselves and their children (if applicable).
- If physiotherapists are embedded into care team, patient will likely come out with better physical and mental outcome and can return to pre-diagnosis life.

Anything else you would like to share?

- Dissemination via lay summaries is of interest.
- Share findings through social media, cancer centres, and medical conferences.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Health care provider knowledge of type 1 diabetes management

Population	People with type 1 diabetes (T1D) in resource-limited settings
Intervention/Exposure	T1D-specific management by healthcare professionals; identifying healthcare professionals' knowledge limitations and barriers to diabetes management; limitations to T1D management due to changes in healthcare policy
Comparator	No T1D management; current T1D management provided by healthcare professionals
Outcomes	Patient experience/care; provider experiences; healthcare costs; healthcare provider knowledge

Interview Details:

Why did you choose this topic and why is it important to you?

- They have personal experience caring for their child who had T1D.
 - When their child became an adult, they lost access to pediatric care, and adult treatment (e.g., endocrinologist, insulin) needed to be paid out-of-pocket.
- There are limitations to healthcare services for T1D; overrepresentation of type 2 diabetes in healthcare and policy issues causes barriers and disparities for people with T1D.
 - Diabetic ketoacidosis (DKA) is a life-threatening condition more common in type 1 diabetics; people at risk for DKA often end up in the hospital in a serious state.
- A needs assessment with 27 people with T1D showed main concerns being:
 - Access to drugs and devices.
 - Lack of awareness of doctors about options for T1D treatments.
 - Lack of education from healthcare providers.

What do you hope to learn from researching this topic?

- What are the disparities in care and outcomes for T1D and why do these disparities exist? Specifically:
 - Why is there a lack of earlier diagnosis and intervention?
 - How many people are ending up in states of serious DKA in the hospital, and why?

Who needs to know about the findings?

- General practitioners
- Policy-makers

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Overrepresentation of type 2 diabetes (in population and care services) is a disservice to those with T1D.

Anything else you would like to share?

- Lives of people with T1D are greatly affected; these people need help.
 - Effects related to T1D (e.g., limb amputations) have wide-reaching costs (e.g., healthcare, disability, lost productivity).

Health care provider knowledge of type 1 diabetes management

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Peer support for families of people with Alzheimer's

Population	Families and loved ones (or caregivers) of patients with Alzheimer's disease (or of patients in geriatric care more generally)
Intervention/Exposure	Peer support programs for families/peer navigators
Comparator	No peer support
Outcomes	Healthcare experience for patients, patients' family and clinicians; health and well-being for patients' family and caregivers, health quality, costs

Interview Details:

Why did you choose this topic and why is it important to you?

- Has lived experience as a caregiver of a person living with mental illness and as a caregiver of a person living with Alzheimer's disease.
- Families supporting a loved one with Alzheimer's or a similar disease (e.g., dementia) can experience difficult situations and could benefit from that kind of support.
- Peer support can bring important relief and contribute to the well-being of families of people with mental health issues, by bringing empathy and help coming from someone having lived a similar situation.
- Peer support workers can also act as a link with healthcare teams and health services, which could positively contribute to health care and care experience.

What do you hope to learn from researching this topic?

- Demonstrate the benefits of peer support programs for families on patients, their

families, loved ones and carers, and clinicians.

- Help support organizations to implement peer support programs support for families, for instance by understanding challenges and opportunities.

Who needs to know about the findings?

- Policy-makers
- Clinical directorates at living facilities for older people.
- CIUSSS (integrated university health and social services centers) and CISSSs (Integrated health and social services centers) should be involved in facilitating peer support for families.

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Peer support is getting more widespread.
- It is an approach that is getting more widely known and frequently requested by patients and their loved ones. Having research results about peer support could contribute to increase the reach of this approach.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

Accountability tools and procedures of clinical and home care settings for older adults

Population	Older adults in clinical and home care settings
Intervention/Exposure	Assessing treatment of older adults; accountability tools and procedures of home care givers
Comparator	Current standard of care amongst older adults in hospital/home care settings
Outcomes	QoL; accountability measures

Interview Details:

Why did you choose this topic and why is it important to you?

- They have personal experience of self, partner, and peers as older adults in the healthcare system.
 - Their complaints were often dismissed by doctors; blamed on “old age”.
- They have a poor impression of home care.
 - Workers are inconsistent, difficult to reach, under-trained and uninterested.
- They feel there is existing research and evidence on the inadequate treatment of older adults, but there is a significant gap in system-level reform.

What do you hope to learn from researching this topic?

- Reassessing the treatment of older adults in various clinical settings and home care to:
 - see policies and practices implemented and followed (e.g., clinical practice guidelines);
 - increase respect and importance given to older adults; and
 - focus on patient experience beyond health outcomes.
- An emphasis on firsthand personal accounts from healthcare providers and receivers, not only administrators.

Who needs to know about the findings?

- Provincial Regional Health Authorities and Units
- Healthcare providers at different levels

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?



- They had positive experiences with some Winnipeg Regional Health Authority programs:
 - [PRIME](#) program for older adults in Winnipeg, Manitoba.
 - [Self and Family Managed Care](#) program.

Accountability tools and procedures of clinical and home care settings for older adults

Feasibility Assessment Results

Summary:

One systematic review and one scoping review were identified during the scoping literature search. The following two reviews by Lette al (2020) and Stall et al (2014) were assessed using AMSTAR-2. A summary of the AMSTAR-2 assessments is provided in the table below.

Review #1: Lette et al, 2020	Review #2: Stall et al, 2014
LOW quality rating 	CRITICALLY LOW quality rating 
Critical flaw: Missing 1 checklist item Study design: Scoping review	Critical flaw: Missing 2 checklist items Study design: Systematic review

Conclusion:

This topic has a critically low quality systematic review and a low quality scoping review, which suggests that there is scope to conduct further research in this area.

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Patient safety related to COVID-19 vaccines

Population	Patient safety related to COVID-19 vaccines
Intervention/Exposure	Monitoring system for adverse reactions and safety due to COVID-19 vaccines (including boosters)
Comparator	No monitoring system/current monitoring system
Outcomes	COVID-19 vaccine symptoms; infection rate; adverse health reactions and outcomes; patient outcomes (physical, emotional, social, cognitive health); mortality; immune system impacts

Interview Details:

Why did you choose this topic and why is it important to you?

- They are a mental health counselor by profession. They facilitate a support group for people injured by the COVID-19 vaccine.
 - Many of these people are no longer able to work, and have been impacted in many ways (e.g., financially, emotionally, socially, etc.).
- COVID-19 has impacted everyone in the world. COVID-19 vaccine safety requires considerable “unpacking”.

What do you hope to learn from researching this topic?

- Due to COVID-19 vaccination:
 - How many people have been injured?
 - What is the extent of their injuries?
 - What healthcare (including mental healthcare) did they receive?

- How have injuries impacted their physical, emotional, social, cognitive, and financial health?
- Why are young men vulnerable to myocarditis and pericarditis?
- What are the long-term effects of multiple COVID-19 vaccines on the strength of the immune system?

Who needs to know about the findings?

- Public
- Physicians and healthcare workers

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- The COVID-19 pandemic has affected every Canadian, therefore this topic is important considering its timeliness.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Primary prevention of suicide risk in men aged 60 and over

Population	Men aged 60+ with suicidal thoughts
Intervention/Exposure	Prevention and promotion in public health
Comparator	No prevention and promotion interventions in public health
Outcomes	Suicide risk

Interview Details:

Why did you choose this topic and why is it important to you?

- Interested in suicide prevention for over 30 years.
- People are getting older and the cohort in which suicide deaths are increasing is mainly older men. Yet, the focus is still mainly on young people and the LGBTQ2+ community.
- Would like to be more proactive in terms of research, prevention and intervention to adequately reach this older population.

What do you hope to learn from researching this topic?

- Explore through focus groups what are the experiences of older men who have had suicidal thoughts, and what they would have needed at the time when they had suicidal thoughts.
- Determine when, with whom, and where to provide the interventions. When it comes to socializing, men do things differently than women, and we need to take this into account.

Who needs to know about the findings?

- Decision-makers, regardless of political level
- Population, so reaching out to journalists to raise awareness
- Any groups working with older people
- Réseau FADOC
- Groups where men are involved: Clubs Optimiste, Lions Club, Chevaliers de Colomb, etc.
- Healthcare professionals

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- They would like to be involved in the process in different ways, either by facilitating focus groups or by being a patient partner.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Caregivers and care practitioners' knowledge of hospice and palliative care

Population	Caregivers and care practitioners of complimentary services to palliative care services
Intervention/Exposure	Communication pathways/palliative care networks for accessing end-of-life care and resources for caregivers and healthcare professionals
Comparator	Usual care
Outcomes	Knowledge of palliative care pathways; provider experience

Interview Details:

Why did you choose this topic and why is it important to you?

- They have a background as an end-of-life doula.
- There is a general sense that patients do not know how to access palliative care.
- There is not enough conversation between various end-of-life service providers.

What do you hope to learn from researching this topic?

- What communication pathways for palliative care currently exist?
 - Where and how is the communication breaking down?
 - Are there success stories and lessons learned?
- Foundational evidence to:
 - Eventually develop a communication pathway/social network/navigational tool;
 - Understand which communication pathways do/do not exist.
- Province by province nuanced approach to work, given regional differences in palliative care pathways.
 - As an exemplar, an initial provincial framework might be used that is

responsive, flexible and culturally sensitive.

Who needs to know about the findings?

- General public
- Palliative/end-of-life care providers
- Patient advocacy groups and cultural societies (e.g., Indigenous groups)

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- This is a grassroots-developed need that has come from healthcare providers and those outside of the healthcare system (e.g., families, doulas, funeral homes).
 - Interdisciplinary group requires an interdisciplinary approach to the research.

Anything else you would like to share?



- Would like findings to be shared in many ways:
 - Final report with executive summary (to be used as advocacy tool)
 - Creative, culturally relevant knowledge translation beyond written information (e.g., presentations, stories, visuals, theatre)

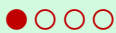
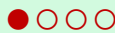
Caregivers and care practitioners' knowledge of hospice and palliative care

Feasibility Assessment Results

Summary:

Three scoping reviews and one systematic review were identified during the scoping literature search. The following four reviews by Vellani et al (2021), Broady et al (2018), Cahill et al (2017) and Threapleton et al (2017) were assessed using AMSTAR-2. A summary of the AMSTAR-2 assessments is provided in the table below.

Review #1: Vellani et al, 2021	Review #2: Broady et al, 2018
MODERATE quality rating 	CRITICALLY LOW quality rating 
Critical flaw: Partially addressed all checklist items Study design: Scoping review	Critical flaw: Missing 2 checklist items Study design: Scoping review

Review #3: Cahill et al, 2017	Review #4: Threapleton et al, 2017
CRITICALLY LOW quality rating 	CRITICALLY LOW quality rating 
Critical flaw: Missing several checklist items Study design: Systematic review	Critical flaw: Missing several checklist items Study design: Scoping review

Conclusion:

This topic has a critically low quality systematic review and critically low to moderate quality scoping reviews, which suggests that there is scope to conduct further research in this area.

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Digital patient portals for people with cancer

Population	People with brain cancer, or cancer in general
Intervention/Exposure	Use of a (digital) patient portal allowing access to health information and data
Comparator	Usual care; health/illness management without this technology (i.e. without a digital patient portal)
Outcomes	QoL; mental health outcomes

Interview Details:

Why did you choose this topic and why is it important to you?

- Has lived experience as a cancer patient with limited energy experiencing the burden of dealing with many appointments and administrative tasks.
- Interested in the impact of digital innovations on society.
- With the advent of digital technologies, a window of opportunity is opening to find solutions to reduce some of these administrative tasks.

What do you hope to learn from researching this topic?

- Which actors developed these portals and to what extent were patients consulted in the design of these platforms?
- Are these platforms accessible for all patients or only for certain groups (the more affluent, those with digital and health literacy, etc.)?
- If they are accessible (portals), why are they not more 'publicized'?
- What are the facilitators and barriers to their implementation?
- Are they more publicly or privately funded?

Who needs to know about the findings?

- SPOR Evidence Alliance
- SSA Québec Support Unit
- Patient advocacy groups, including the Québec Coalition Priorité Cancer
- Decision-makers at the Québec Ministry of Health and Social Services, CISSS (integrated health and social services centres) and CIUSSS (integrated university health and social services centres)

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?



- A digital portal would make it possible to manage appointments, test results, the information that is agreed to share and with which professionals.
- Would also like the panel to bear in mind that the QoL and health of people with cancer goes beyond medical treatment.

Digital patient portals for people with cancer

Feasibility Assessment Results

Summary:

Two systematic reviews were identified during the scoping literature search. The following two reviews by Gyawali et al (2023) and Hasnan et al (2022) were assessed using AMSTAR-2. A summary of the AMSTAR-2 assessments is provided in the table below.

Review #1: Gyawali et al, 2023	Review #2: Hasnan et al, 2022
LOW quality rating 	LOW quality rating 
Critical flaw: Missing 1 checklist item Study design: Systematic review	Critical flaw: Missing 1 checklist item Study design: Systematic review

Conclusion:

This topic has low quality systematic reviews, which suggests that there is scope to conduct further research in this area.

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Impact of 5G radiation on health outcomes

Population	People living in areas of higher concentration of 5G (or similar) towers
Intervention/Exposure	5G (or similar) frequency radiation
Comparator	People living in areas of lower concentration of 5G (or similar) towers; health outcomes prior to 5G tower use
Outcomes	Clinical health outcomes

Interview Details:

Why did you choose this topic and why is it important to you?

- A 5G tower was built 4 miles from the interviewee's family home and interviewee became concerned with radiation waves from a health and environment perspective.
- Concerns with the lack of choice in patient safety due to being exposed without consent to potential radiation in their surrounding areas.

What do you hope to learn from researching this topic?

- Which situation is better: lower radiation waves at a closer proximity or stronger radiation waves at a farther proximity and how this can be quantified and/or measured?
- What the risks are and if their better alternatives to 5G towers for our health.
- Who is monitoring radiation to say that it is safe?

Who needs to know about the findings?

- Federal and provincial/territorial government bodies involved in health, e.g., Health Canada, Environment Canada, Health Excellence Canada
- General public and health advocacy groups

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- An example from British Columbia, in which an advocacy group pushed to prohibit 5G towers within a certain radius of child daycare centers.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Identifying barriers and facilitators to accessing primary care services in Newfoundland and Labrador

Population	Patients and public accessing care in Newfoundland and Labrador
Intervention/Exposure	Identifying barriers and facilitators to accessing primary care services
Comparator	Collaborative care clinics and other healthcare services available other than a family physician
Outcomes	Health system outcomes; healthcare costs; provider experiences; access to primary care; barriers/facilitators to healthcare practitioners entering primary care practice; current status of primary care access in Newfoundland and Labrador

Interview Details:

Why did you choose this topic and why is it important to you?

- They have lived experience as a primary caregiver to an older parent with multiple complex conditions requiring ongoing care.
 - Parent lost access to family physician and was placed on a very long waitlist for a new doctor in their small community.
- Primary care provider access is an ongoing and significant issue in Newfoundland and Labrador (NL).
 - NL is geographically diverse with a population with varying healthcare needs (e.g., aging population, high burden of chronically ill patients).

What do you hope to learn from researching this topic?

- What is the current state of primary care access in NL, and how does it compare to other regions?
 - Barriers and facilitators to healthcare professionals entering primary care practice.

- What are the current strategies to correct barriers; are they effective?
- Measure the results of current strategies and action plans in NL (e.g., Health Accord NL).
- What solutions have been implemented in other areas (that NL can learn from)?

Who needs to know about the findings?

- Public
- Patient partners (across Canada)
- Policy-makers
- Healthcare providers
- Advisory council members

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Primary care access is an issue that is relevant across Canada.
 - Results of this work could inform future decision-making, and improve health outcomes for many people in NL and across Canada.

Identifying barriers and facilitators to accessing primary care services in Newfoundland and Labrador

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Reassessment of clinical practice guidelines for individuals experiencing and at risk of eating disorders

Population	Individuals at risk of eating disorders
Intervention/Exposure	Revising weight restriction criterion for diagnosis and in clinical practice guidelines
Comparator	Weight restriction criterion for eating disorder diagnoses; other assessments
Outcomes	Clinical health outcomes; diagnosis rates; access to eating disorder treatment

Interview Details:

Why did you choose this topic and why is it important to you?

- Personal experiences with an eating disorder (ED); experiences of friends and peers met through the recovery process; experiences shared through online communities.
- ED diagnosis criterion is based strictly on weight and the behavioural symptoms overtly displayed at the time of diagnosis. When diagnosis is heavily focused on weight, rather than eating or other behavioral symptoms, it strengthens the fear in sufferers that they must weigh or have certain symptoms for their ED to be validated.
- Specialized intensive treatments (e.g., in-patient) are largely geared towards people with anorexia nervosa, who fit the criterion of being 'underweight' according to body mass index (BMI).

What do you hope to learn from researching this topic?

- Origin, epidemiology, and impact of ED within health and social systems.
- Capacity for treatment providers to increase accessibility and inclusivity of varying treatment approaches to support survivors and sufferers of ED.
- Raising awareness to the misunderstanding of the scope of ED (e.g., not focusing solely on weight) and the psychological distortion that affects eating behavior, self-perception, and self-efficacy.

Who needs to know about the findings?

- Health professionals and those who support health professionals (e.g., nurses).
- Policy makers who can bring about tangible change.

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Potential methodology can include scoping and literature review to understand existing research and knowledge gaps, mixed-methods, and statistics of the impacts of ED.

Reassessment of clinical practice guidelines for individuals experiencing and at risk of eating disorders

Feasibility Assessment Results

Summary:

One systematic review was identified during the scoping literature search. The following review by Feltner et al (2022) was assessed using AMSTAR-2. A summary of the AMSTAR-2 assessment is provided in the table below.

Review #1: Feltner et al, 2022
CRITICALLY LOW quality rating ● ○ ○ ○
Critical flaw: Missing 2 checklist items Study design: Systematic review

We identified two North American clinical practice guidelines on this topic published in 2022 ([Crone et al, 2022](#); [Davidson et al, 2022](#)). However, we cannot comment on the clinical credibility and feasibility of the guidelines since quality assessments using the AGREE-REX tool was not conducted.

Conclusion:

This topic has a critically low quality systematic review, which suggests that there is scope to conduct further research in this area.

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Impacts of climate change on chronic conditions

Population	Individuals experiencing chronic illness; individuals impacted by structural marginalization (discrimination, geography, etc.); general population (patients and health care practitioners)
Intervention/Exposure	Assessment of impacts of climate change on patients; healthcare practitioners' knowledge of impacts of climate change on health
Comparator	Current approaches to addressing climate change on health (or lack thereof)
Outcomes	Patient outcomes; patient/healthcare practitioner knowledge; QoL

Interview Details:

Why did you choose this topic and why is it important to you?

- They have a background as a social worker in healthcare settings; have 13 years patient experience with chronic illness; interest in environmental justice.
 - Gained insight into how inequities affect how individuals interact with healthcare system and disproportionate impacts of climate change on vulnerable and/or marginalized patients and groups.
 - Collaborated with [Centre for Collaborative Healthcare and Education](#).
- They noted that other jurisdictions may be used as exemplars in climate preparedness (e.g., British Columbia has a [Climate Preparedness and Adaptation Strategy](#)).

What do you hope to learn from researching this topic?

- Increased awareness on the importance of climate change in healthcare systems and delivery.
- Mobilize existing knowledge to tailor strategies to:
 - Better support vulnerable populations.
 - Improve care from systemic, organizational, and provider level.
- Increased qualitative research (e.g., surveys with patients, focus groups with patients and providers).

Who needs to know about the findings?

- Patients
- Healthcare providers
- Healthcare systems
- Policy-makers
- Advocacy groups (e.g., Canadian Association of Physicians for the Environment)
- Professional associations and colleges

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

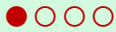
- Not applicable

Impacts of climate change on chronic conditions

Feasibility Assessment Results

Summary:

One systematic review was identified during the scoping literature search. The following review by Witt et al (2015) was assessed using AMSTAR-2. A summary of the AMSTAR-2 assessment is provided in the table below.

Review #1: Witt et al, 2015
CRITICALLY LOW quality rating 
Critical flaw: Missing several checklist items Study design: Systematic review

Conclusion:

This topic has a critically low quality systematic review, which suggests that there is scope to conduct further research in this area.

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Anaphylaxis and adverse health outcomes due to surgical implants

Population	People with mental hypersensitivity receiving medical implants; people with autoimmune disease
Intervention/Exposure	Use of other metals/materials for medical implants and surgery
Comparator	Usual care (nickel implants)
Outcomes	QoL; patient care/experience; healthcare costs; healthcare provider knowledge; medical training/screening; patient outcomes; adverse health outcomes;

Interview Details:

Why did you choose this topic and why is it important to you?

- They were not asked or tested for metal allergies, nor were informed of metal nature of medical device(s) before undergoing surgery or medical procedures
- Consequently, they developed significant complications, including additional allergies, and faced medical gas lighting. They are now long-term disabled.
- Feel there may be a link between their metal implants and later autoimmune disease diagnosis.

What do you hope to learn from researching this topic?

- Identify existing guidelines and protocols relating to metal device use in surgery.
- Improvement or assessments of existing clinical practice guidelines and/or pre-screening for surgery to minimize risk of using metal implants or other alternatives to metals in surgery.
- Identify gaps in literature.

Who needs to know about the findings?

- Patients/public
- Manufacturers
- Healthcare providers
- Mental health professionals
- Patient advocacy groups

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- A scoping review may be needed to identify knowledge gaps.

Anything else you would like to share?

- This acquired physical disability affects daily health and function, mental health, and overall well-being.
- Results may prompt manufacturers to use alternative materials.
 - Despite package inserts from manufacturers stating they are not to be used in patients with nickel allergies (as life-threatening complications may ensue), this is disregarded and they are used due to a lack of alternatives.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Identifying gaps and opportunities in healthcare systems in Canada

Population	Healthcare system; healthcare professionals in Canada
Intervention/Exposure	Identifying gaps and opportunities in healthcare systems and governance arrangements (e.g., integration of skilled healthcare workers); examining healthcare systems in other countries (e.g., Europe); reducing healthcare practitioner shortages
Comparator	Current Canadian healthcare system gaps
Outcomes	Areas for improved efficiencies and increased access to care in the Canadian healthcare system

Interview Details:

Why did you choose this topic and why is it important to you?

- They are originally from Europe and note surprising differences between the healthcare system in Canada compared to Europe, including:
 - Feels that the Canadian system is slow and inefficient.
 - Feels that many people in Canada are left in limbo between different healthcare providers, referral systems, primary care system, etc.
- There is a need for action and change to the Canadian healthcare system, including investments in traineeship for physicians and other medical professionals.

What do you hope to learn from researching this topic?

- What are the barriers to improving the healthcare system?
- What are the failures in the Canadian healthcare system and why do these exist?
- What are the barriers for foreign-trained healthcare professionals?

- Can Canada learn from other healthcare models?

Who needs to know about the findings?

- Unsure

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- There is a need for a step-wise approach to determine:
 - What the current problems are.
 - What the key messages for decision-makers are.
 - What action needs to be taken.
 - What follow-up needs to be initiated.
- Aging and related suffering are a part of life that everyone will face; too many people are left in limbo and are suffering because they aren't receiving the care they need.
- Healthcare is a universal human right and should therefore be accessible.
- Canada needs to utilize current available talent.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Emotional intelligence education in children

Population	Children (daycare, pre-school, primary school)
Intervention/Exposure	Teaching emotions and emotion management strategies in childhood
Comparator	Current situation without teaching emotions
Outcomes	Better management of emotions by children

Interview Details:

Why did you choose this topic and why is it important to you?

- Has lived experience with a panic disorder and struggled managing emotions. Their child has schizophrenia and often felt powerless trying to manage their emotions.
- Consulted psychologists and undergone therapy, but the methods used have done little to help them overcome their difficulties, sometimes even increasing their feeling of helplessness faced with their suffering.
- Became aware after numerous readings of the importance of emotions and in particular of emotional intelligence.

What do you hope to learn from researching this topic?

- Learning emotions and strategies to manage them from childhood could allow children to better manage them and during the rest of their lives.
- Learning emotions from childhood has the potential to reduce the number of people suffering from mental disorders.

Who needs to know about the findings?

- General population
- Government (including the Ministry of Education)
- Education sector (teachers, pre-school, primary schools)
- Health professionals

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- They are a patient partner for the Québec program for mental disorders)

Anything else you would like to share?

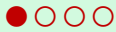
- They would like to also assess whether the learning of emotions by the parents of children participating in the research could also be beneficial, as today's parents do not always have ability to manage their own emotions.

Emotional intelligence education in children

Feasibility Assessment Results

Summary:

One systematic review was identified during the scoping literature search. The following review by Fenwick-Smith et al (2018) was assessed using AMSTAR-2. A summary of the AMSTAR-2 assessment is provided in the table below.

Review #1: Fenwick-Smith et al, 2018
CRITICALLY LOW quality rating 
Critical flaw: Missing 2 checklist items Study design: Systematic review

Conclusion:

This topic has a critically low quality systematic review, which suggests that there is scope to conduct further research in this area.

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Spatial epidemiology in identifying environmental toxins and their health impacts

Population	People with autoimmune conditions; exposure to environmental toxins for people with autoimmune conditions; chemical sensitivity in people with autoimmune conditions
Intervention/Exposure	Spatial epidemiology in identifying environmental toxins and their health impacts
Comparator	No spatial epidemiology
Outcomes	Population health outcomes

Interview Details:

Why did you choose this topic and why is it important to you?

- They are curious about the relationship between people who have multiple chemical sensitivity (MCS) and people who have autoimmune conditions. They would like to learn about:
 - why people with MCS may be more reactive to environmental toxicants.
 - the causes of MCS or autoimmune conditions, which can lead to a better understanding of how to prevent/reduce risk factors.

What do you hope to learn from researching this topic?

- Use spatial mapping technique to determine the potential correlation of MCS and autoimmune conditions.
- Understanding the association between certain chemicals and the development of

MCS/autoimmune conditions may lead to better health education (e.g., understanding risks), and better health management and public health and safety measures.

Who needs to know about the findings?

- Patients/public
- Healthcare professionals
- Government entities and regulatory bodies
- Autoimmune condition advocacy groups

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Not applicable

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Patient engagement in clinical ethics consultations

Population	People participating in clinical ethics consultations
Intervention/Exposure	Patient engagement in clinical ethics consultations
Comparator	No patient partners/engagement
Outcomes	Healthcare experience for patients, their loved ones and caregivers, and healthcare providers; processes of clinical ethics

Interview Details:

Why did you choose this topic and why is it important to you?

- Has lived experience as a patient partner who has been involved in CISSS (integrated health and social services centres) committee for clinical ethics. CISSS innovates by including a patient partners in clinical ethics consultations.
- There is a real benefit to involve patient partners in clinical ethics consultations.
- Patient partners are in a position of vulnerability when they interact with the healthcare system, even more so in the complex situations that lead to the involvement of the ethics committee.

What do you hope to learn from researching this topic?

- Describe and measure the impact of patient partners' participation to clinical ethics consultations: on healthcare experience for patients, their loved ones and caregivers, and healthcare providers; on the processes of clinical ethics.
- If the impact is positive, explore the possibility of scaling up this practice.

Who needs to know about the findings?

- Laval CISSS
- Centre of Excellence on Partnership with Patients and the Public
- Provincial community of practice for patient partners

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Can never draw enough attention to the role that patients' vulnerability in relation to the healthcare system plays in their decisions about their care and their care relationships.
- This plays into complex situations, where the relationship between patients and healthcare providers is often asymmetric or perceived as such. By being outside of this position of vulnerability, the patient partner can shed a new light to help all actors make sense of the situation.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Multi-household parenting arrangement and child health

Population	Children from co-parenting/separated households
Intervention/Exposure	Multiple household parenting arrangements impact on child health
Comparator	Single household parenting arrangements impact on child health
Outcomes	QoL (parents and children); healthcare utilization, mental and physical health (e.g., anxiety, loneliness, access to regular health care); continuity of care

Interview Details:

Why did you choose this topic and why is it important to you?

- Has lived experience as a caregiver of child who experiences a split-parenting arrangement and health issues.
- Feels that the legal system tends to split parenting 50/50, but this may not be in the best interests of a child's physical and mental health.

What do you hope to learn from researching this topic?

- Inform health and legal policy on decisions surrounding children in split-parent situations.
- Inform health provider education on how to support and advocate for medical decisions as a health care practitioner.

Who needs to know about the findings?

- Health policy, health care and legal systems, to inform decision-making.
- Healthcare providers need to be educated on how to manage split-parent dynamics and advocate for the best interests of the patient.
- Parents, to access resources to advocate for their child.

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Consider various patient stories and situations and its potential impact on a child's health.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Integrated team-based primary care in rural communities

Population	Individuals in rural, isolated communities
Intervention/Exposure	Integrated, team-based primary care in rural communities; culturally-safe primary care
Comparator	Usual care; current standard of care/healthcare system
Outcomes	QoL; patient care/experience; provider experience; population health outcomes; healthcare costs; healthcare utilization; access to emergency healthcare alternatives for rural communities

Interview Details:

Why did you choose this topic and why is it important to you?

- They reside in a small community in rural Saskatchewan which has limited healthcare capacity.
 - Individuals seeking care for major concerns must travel to the closest cities (one hour away), or to Regina or Saskatoon.
- Feels that where you live in Canada determines your experience and access to the healthcare system.
 - Frustrated with barriers to accessing care as a patient (e.g., no connection of health records of visits with different providers).

What do you hope to learn from researching this topic?

- How to increase open and transparent access and delivery of primary healthcare in a rural setting.
 - Informing/educating patients and communities on how and where to access care.
 - Improve system flow and integration.
- Understand current state of care through community-based participatory research, with front-line providers, patients, and policymakers collaborating to provide perspectives.

Who needs to know about the findings?

- Patients and communities
- Saskatchewan's Ministry of Health and Health Authorities

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Indigenous partnerships will be crucial to this project to inform culturally-safe and relevant care.

Anything else you would like to share?


- If this goes forward, they see a possibility to collaborate on a Canadian project with the Canadian Primary Care Research Network.

Integrated team-based primary care in rural communities

Feasibility Assessment Results

Summary:

One systematic literature review was identified during the scoping literature search. The following review by Rainsford et al (2017) was assessed using AMSTAR-2. A summary of the AMSTAR-2 assessment is provided in the table below.

Review #1: Rainsford et al, 2017
LOW quality rating 
Critical flaw: Missing 1 checklist item Study design: Systematic literature review

Conclusion:

This topic has a low quality systematic literature review, which suggests that there is scope to conduct further research in this area.

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Cognitive deficits associated with severe mental disorders

Population	People with a severe mental health disorder; cognitive deficits related to severe mental health disorders
Intervention/Exposure	Awareness of cognitive deficits in mental health disorders
Comparator	Usual care
Outcomes	Awareness level; QoL; Treatment of cognitive symptoms

Interview Details:

Why did you choose this topic and why is it important to you?

- Has lived experience with several health problems in his life, including a severe mental health disorder.
- Cognitive deficits associated with severe mental disorders have major impacts on everyday life, whether in school or in employment.
- There is a lack of awareness of cognitive deficits in severe mental health disorders among healthcare professionals. During clinical encounters, cognitive deficits are rarely considered as symptoms that can be treated.

What do you hope to learn from researching this topic?

- Hopes to learn the extent to which doctors are aware of cognitive deficits in this population.

Who needs to know about the findings?

- Family medicine groups (e.g., family physicians, nurses, social workers, pharmacists, psychologists).
- Family members of people living with a mental health problem.

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Scientific literature is the greatest vectors of stigma come from our carers, without them being aware of it.
- It is important to consider the person as whole. A greater focus on cognitive deficits, in addition to being in phase with the recovery approach, promotes the integration of people in society (e.g., return to work, school, etc.).

Anything else you would like to share?

- There is a necessity in increasing physicians' awareness that those who are living with a serious mental health disorder may experience cognitive deficits that significantly impact their daily lives.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Detection of human trafficking in clinical settings

Population	Human trafficking victims
Intervention/Exposure	Physician-led detection of human trafficking in clinics and emergency departments (including training, etc.)
Comparator	No physician-led detection
Outcomes	Healthcare costs; provider experiences; detection rates

Interview Details:

Why did you choose this topic and why is it important to you?

- Canada had [2,977 police-reported incidents of trafficking from 2010-2020](#). The vast majority (96%) of detected victims of human trafficking were women and girls. In all, one in four (25%) victims were under the age of 18.
- Some of these victims will come into contact with a healthcare provider while being trafficked.
- Trafficking is an issue that affects many aspects of health.

What do you hope to learn from researching this topic?

- Explore tangible, trauma-informed tools that can help physicians interact with victims/survivors, detect human trafficking and intervene.

- Possibility of a code attached to human trafficking.

Who needs to know about the findings?

- Physicians (e.g., emergency room personnel)
- Engage with local stakeholders, professionals, victims and survivors.

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Not applicable

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Impact of plastic use on health outcomes

Population	General population
Intervention/Exposure	Impact of plastic use on health outcomes
Comparator	Not identified
Outcomes	Population health outcomes; hormonal health; guidelines for use of plastics and impacts on health

Interview Details:

Why did you choose this topic and why is it important to you?

- They are concerned about the use of plastics.

What do you hope to learn from researching this topic?

- How do plastics impact health (including hormonal health)?

Who needs to know about the findings?

- Public
- Researchers
- Plastics manufacturing industry
- Food industry

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Humans are exposed to plastics frequently.
- There are different types of plastics; curious to discover what can be done to discover what types of plastics are negatively impacting humans.

Feasibility Assessment Results

Summary:

One rapid review and one scoping review were identified during the scoping literature search. The following two reviews by Danopoulos et al (2022) and Rahman et al (2021) were assessed using AMSTAR-2. A summary of the AMSTAR-2 assessments is provided in the table below.

Review #1: Danopoulos et al, 2022	Review #2: Rahman et al, 2021
LOW quality rating ● ● ○ ○	LOW quality rating ● ● ○ ○
Critical flaw: Missing 1 checklist item Study design: Rapid review with meta-regression analysis	Critical flaw: Missing 1 checklist item Study design: Scoping review

Conclusion:

This topic has low quality scoping review and rapid review, which suggests that there is scope to conduct further research in this area.

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Patient engagement in health education curriculum

Population	Patient partners
Intervention/Exposure	Patient partners engaging in curriculum planning, implementation, and evaluation of patient-centered care education and delivery
Comparator	No patient partner engagement; usual care
Outcomes	Population health outcomes; provider experiences; patient care/experiences

Interview Details:

Why did you choose this topic and why is it important to you?

- Interviewees have experiences as nurse educators/administrators and as patient partners.
- They have identified a need to engage patients and families as equal collaborators across all levels of healthcare; embedding patient- and family-centered care into patient-provider interactions. It is important to properly educate healthcare providers on the competencies and qualities needed of them, form a patient/family centered perspective.
 - In most education programs, patient- and family-centered care is not taught in collaboration with patients, or patients are treated as guests but not full partners.
 - For patient- and family-centered care to become a reality within the health system, patients and families must be embedded into curriculum as co-designers and co-educators, in the planning, design, implementation, and evaluation of curricula.

What do you hope to learn from researching this topic?

- To determine what the governance structures and processes needed are to ensure patients, families, and communities are engaged as partners in the co-design, implementation and evaluation of health education curricula.
 - What are the structural barriers and how can they be overcome? What are the facilitators?

- How to support cultural shift of healthcare and education towards patient-centered care.
- What are the core competencies of patient- and family-centered care that matter most to patients, families, and communities that should be embedded in health education curriculum (and standardized across Canada)?

Who needs to know about the findings?

- Healthcare providers
- Regulators
- Accreditation bodies
- Advocacy groups
- Non-governmental organizations (providing services to patients who face inequities)
- Health educators and students
- Institutional/program administration
- Governmental departments for education and health

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- There are two focuses in this work: (1) policy; and (2) competencies.
- Patient partners need to help identify the priorities and scope for this project.
- Indigenous communities need to be engaged in this work (to ensure trauma-informed care and culturally appropriate practice is embedded within curriculum).
 - This work might not be accomplished in one research project.

Patient engagement in health education curriculum

Feasibility Assessment Results

Summary:

One systematic review was identified during the scoping literature search. The following review by Gordon et al (2019) was assessed using AMSTAR-2. A summary of the AMSTAR-2 assessments is provided in the table below.

Review #1: Gordon et al, 2019
CRITICALLY LOW quality rating ● ○ ○ ○
Critical flaw: Missing 2 checklist items Study design: Systematic review

Conclusion:

This topic has a critically low quality systematic review, which suggests that there is scope to conduct further research in this area.

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Pain associated with gynecological procedures

Population	People accessing routine gynecological procedures; Pain management and medical trauma
Intervention/Exposure	Patient-reported experiences of pain and medical trauma
Comparator	Not identified
Outcomes	QoL; patient care/experience; reported medical trauma

Interview Details:

Why did you choose this topic and why is it important to you?

- They have experience in online communities where there is space for knowledge exchange and storytelling of pain and traumatic encounters.
- Interested in supporting patient-focused care which includes:
 - Trauma-informed care that is sensitive to past trauma and ensures further encounters do not exacerbate existing trauma.
 - Culturally safe care, especially for vulnerable populations.

What do you hope to learn from researching this topic?

- How well informed are patients in various healthcare settings?
 - What options are offered and what is offered to alleviate pain?
 - What did patients expect and was that accurate to their experience?
- What is the discrepancy between research and medical practice?
 - Research may report pain in certain procedures, but pain management may not be reflected in clinical practice guidelines.

- Considerations for how people with certain conditions (e.g., endometriosis, adenomyosis, pelvic floor dysfunction, vulvodynia) may experience more pain than others.
- Knowledge translation tools needed to bridge this gap.
- Personal accounts from patients
 - Understanding varying experiences of pain for different contexts

Who needs to know about the findings?

- Vulnerable populations
- Advocacy groups
- Health professionals (who provide and/or assist with gynecological procedures)

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Pain of women and gender-diverse people is often dismissed by medical professionals.
 - Pain might be deemed not significant enough if they do not complain.
 - May be perceived as “hysterical” or “emotional” if they do complain.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

LGBTQ2S+ trauma-informed care in schools

Population	Students, people and healthcare professionals with lived LGBTQ2S+ experiences
Intervention/Exposure	Engagement of healthcare/educational professionals and people with lived LGBTQ2S+ experiences in developing creative and trauma-informed activities and resources
Comparator	No engagement; current resources available to LGBTQ2S+ students and teachers
Outcomes	QoL; mental health symptoms; provider experiences; patient care/experiences; healthcare costs; population health outcomes; available student/teacher resources

Interview Details:

Why did you choose this topic and why is it important to you?

- The LGBTQ2S+ community faces a disproportionate number of concerns (e.g., abuse, gender-based violence, school success, poverty, homelessness, mental health, etc.)
- As a teacher who started a pride club, many students discussed and brought up their trauma, mental health struggles, and other concerns.
- They conducted an informal survey and found that 60% of students identify within the LGBTQ2S+ community (including unsure and questioning).

What do you hope to learn from researching this topic?

- Support an action plan for professionals to document and address statistical outcomes (e.g., school programming for sexuality/queer education, pride club activities).
- Identify various barriers (e.g., rural communities).
- Acknowledge the disparities that the LGBTQ2S+ community faces and identify where help is needed.

Who needs to know about the findings?

- Healthcare providers, educators, counselors, etc., as it is important for them to receive trauma-informed education on how to support LGBTQ2S+ youth.
- Young people (students, alumni), pride captains (logistical coordinators), community service providers, school boards, and professionals (e.g., psychologists, therapists) should be involved in the research.
- The Minister of Education, provincial lead of gender-based violence, and federal funding entities that support the needs of LGBTQ2S+ youth to receive the information from the findings.

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Potential for jurisdictional scan, mixed-methods study.
- Pull from success stories in other jurisdictions.

LGBTQ2S+ trauma-informed care in schools

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Association between Autism Spectrum Disorder and Congestive Heart Failure

Population	People with autism spectrum disorder (ASD)/ADHD/learning disabilities
Intervention/Exposure	Association/impact between autism and congestive heart failure (CHF)
Comparator	CHF among those without autism
Outcomes	Clinical health outcomes; prevalence of CHF

Interview Details:

Why did you choose this topic and why is it important to you?

- They have lived experience with Autism spectrum disorder (ASD) and four chronic diseases: interstitial cystitis, Crohn's disease, endometriosis, and congestive heart failure (CHF).
 - No explanation received for potential cause of chronic conditions.
 - Felt healthcare providers were basing diagnosis of chronic conditions on the behavioural symptoms of their ASD (e.g., aversion to certain food causing pain due to Crohn's disease, rather than a behavioural symptom).
- Feels healthcare providers are misinformed or unaware about nuances of ASD.
 - Has often been talked over and not given opportunity to make own decisions (e.g., assumption that they could not make informed health decisions on their own).

What do you hope to learn from researching this topic?

- Association of ASD and chronic diseases, and the causation of these conditions.
- Increased awareness of people with ASD having chronic conditions.
- How to tailor treatment plans for people with ASD and chronic conditions.

Who needs to know about the findings?

- Patient advocacy groups
- Healthcare providers
- Specialists and groups related to chronic diseases
- General public

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- ASD is non-linear and presents differently from individual to individual.

Association between Autism Spectrum Disorder and Congestive Heart Failure

Feasibility Assessment Results

Summary:

One scoping review was identified during the scoping literature search. The following review by Cashin et al (2016) was assessed using AMSTAR-2. A summary of the AMSTAR-2 assessment is provided in the table below.

Review #1: Cashin et al, 2016
CRITICALLY LOW quality rating ● ○ ○ ○
Critical flaw: Missing 2 checklist items Study design: Scoping review

Conclusion:

This topic has a critically low quality scoping review, which suggests that there is scope to conduct further research in this area.

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Support systems for in- and out-patient services for young people

Population	Young people with severe health concerns
Intervention/Exposure	Identifying support systems for in-patient and out-patient services for young people
Comparator	Usual care
Outcomes	QoL; patient care/experiences for youth; clinical health outcomes

Interview Details:

Why did you choose this topic and why is it important to you?

- Has lived experience as a young person navigating the healthcare system.
- Felt constantly overlooked and dismissed by health care professionals, leading to a delayed diagnosis.
- Felt that inpatient and outpatient care was inadequate, with minimal support and guidance by healthcare professionals.

What do you hope to learn from researching this topic?

- How young people who are experiencing severe health issues can be better supported both as in patients and as outpatients, whether or not a firm diagnosis has been reached.
- Generate evidence that changes policies and can be tailored to young people.
- Provide a different avenue for young people experiencing health concerns to receive adequate outpatient support.

Who needs to know about the findings?

- Policy-makers
- Patient advocacy groups
- Healthcare professionals (e.g., social workers, nutritionists, etc.)

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?


- Feels that many of those in policy-making positions tend to be privileged, well-educated, and likely don't know what it's like to experience barriers in the healthcare system.
- It is important to make room for these voices, and for policymakers to grasp the struggles people face in the healthcare system.

Support systems for in- and out-patient services for young people

Feasibility Assessment Results

Summary:

One systematic review was identified during the scoping literature search. The following review by Barnett et al (2023) was assessed using AMSTAR-2. A summary of the AMSTAR-2 assessment is provided in the table below.

Review #1: Barnett et al, 2023
HIGH quality rating 
Critical flaw: Addressed all essential checklist items Study design: Systematic review

Conclusion:

This topic has a high quality systematic review published in 2023; therefore, there are opportunities for knowledge translation and dissemination.

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Spatial epidemiology of pediatric cancers in Canada

Population	Pediatric cancers by geographic region in Canada
Intervention/Exposure	Environmental/industrial pollutants
Comparator	No/lack of environmental/industrial pollutants
Outcomes	Population health outcomes; incidence/prevalence of pediatric cancers (e.g., neuroblastoma)

Interview Details:

Why did you choose this topic and why is it important to you?

- They completed a small-scale, single-site study on this topic as a graduate student.
 - Curious about relationship between cancer (especially pediatric neuroblastoma) and industrial pollutants.
 - Spatially mapped out neuroblastoma cases based on residential address at time of diagnosis.
 - Results showed statistically significant risk of industrial pollutants for children with malignant neuroblastoma compared to benign cancer (ganglioneuroma).
 - Small study size made it difficult to conclude significance.
 - As data was taken from open-access sources that may not be reliable (may use estimates rather than exact quantities for pollution).

What do you hope to learn from researching this topic?

- Understand history of exposures in young children, especially if parents/caregivers did not have any lifestyle or genetic risk factors.

Who needs to know about the findings?

- Policy-makers
- Educators
- General public

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Not applicable

Anything else you would like to share?

- Would like to focus on neuroblastoma, though information is relevant to know for all cancers.
- People are reluctant or resistant to recognizing health impacts of toxic chemicals or other environmental factors.

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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Shared decision-making tools for patients in clinical settings

Population	Patients in clinical settings (e.g., clinics, hospitals)
Intervention/Exposure	Shared decision-making tools (e.g., patient decision aids); identifying gaps and opportunities in shared decision-making
Comparator	Current decision-making engagement
Outcomes	Patient care/experiences; QoL; patient knowledge levels; patient experiences; access to healthcare; impacts of shared decision-making tools (e.g., patient decision aids)

Interview Details:

Why did you choose this topic and why is it important to you?

- They have had arthritis since childhood, and had many encounters with the healthcare system over their lifetime.
- They believe shared decision-making (SDM) is not systematically implemented with patients, and many patients still need to advocate for themselves.
 - This affects patients' access to the healthcare system, their understanding of health conditions and options, and decision-making for their own health.
- They recognize the effort in developing tools (e.g., patient decision aids, coaching), but do not see the effect on real outcomes.

What do you hope to learn from researching this topic?

- Determine if there is enough research to properly understand patients' views on the decision-making process.
- Bring awareness for the value of SDM and the patient experience.

Who needs to know about the findings?

- Patients/public
- Healthcare providers
- Government bodies
- Policy-makers

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?



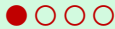



- Even if clinicians believe they are doing SDM, they may not be, as clinicians might not be giving patients enough information about various options.

Shared decision-making tools for patients in clinical settings

Feasibility Assessment Results

Summary:

Two systematic reviews, three scoping reviews, and one rapid review were identified during the scoping literature search. The following six reviews by Aoki et al (2022), Hamilton et al (2021), Scalia et al (2021), Shinkunas et al (2016), Cincidda et al (2015) and Scholl et al (2011) were assessed using AMSTAR-2. A summary of the AMSTAR-2 assessments is provided in the table below.

Review #1: Aoki et al, 2022	Review #2: Hamilton et al, 2021	Review #3: Scalia et al, 2021
HIGH quality rating 	MODERATE quality rating 	CRITICALLY LOW quality rating 
Critical flaw: Addressed all checklist items Study design: Systematic review	Critical flaw: Partially addressed all checklist items Study design: Scoping review	Critical flaw: Missing 2 checklist items Study design: Rapid review
Review #4: Shinkunas et al, 2016	Review #5: Cincidda et al, 2015	Review #6: Scholl et al, 2011
LOW quality rating 	MODERATE quality rating 	LOW quality rating 
Critical flaw: Missing 1 checklist item Study design: Scoping review	Critical flaw: Partially addressed all checklist items Study design: Systematic review	Critical flaw: Missing 1 checklist item Study design: Scoping review

Conclusion:

This topic has moderate to high quality systematic reviews, a critically low rapid review, and low to moderate quality scoping reviews; therefore, there are opportunities for knowledge translation and dissemination.

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Effectiveness of shockwave therapy for Chronic Fatigue Syndrome

Population	People with chronic fatigue syndrome
Intervention/Exposure	Shockwave therapy
Comparator	Other therapies/treatments; usual care
Outcomes	QoL; chronic pain management

Interview Details:

Why did you choose this topic and why is it important to you?

- Visits patients with Chronic Fatigue Syndrome.
- Has found that there is no single specific treatment and limited therapeutic options available.
- Shockwave therapy is an existing physical treatment that can have therapeutic effects when applied to tissues, using high frequency waves of varying intensity.

What do you hope to learn from researching this topic?

- Interested in clinical/physical level, measurements of effectiveness using scores and/or questionnaires (e.g., measuring energy levels or aerobic capacity pre-/post-treatment) of shockwave therapy.
- Also interested in knowing the mechanism of Chronic Fatigue Syndrome.

Who needs to know about the findings?

- Healthcare providers who may apply shockwave therapy and physical treatments (e.g., physiotherapists, rehab specialists).
- Healthcare insurance companies, if found effective.

Is there anything that you feel a panel of patients, caregivers, healthcare providers, and policy-makers should keep in mind when reviewing this topic?

- Not applicable

Feasibility Assessment Results

Summary:

No reviews were identified during the scoping literature search.

Conclusion:

There is scope to conduct further research in this area.

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