Patient Engagement in Health Research

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ALBERTANS 4 HEALTH RESEARCH

Alberta SPOR SUPPORT Unit

Alberta SPOR SUPPORT Unit
Patient Engagement Platform

Canadian Child Health Clinician Scientist Program

CCHCSP
PCCCSE

Programme canadien de cliniciens-chercheurs en santé de l'enfant

The Canadian Child Health Clinician Scientist Program (CCHCSP) is a national, multidisciplinary training program that supports highly qualified clinicians in developing the research skills required to pursue a career bridging the gaps between research and clinical care. Trainees receive funding, mentorship and progress review, along with a comprehensive career development curriculum.

THANK YOU CCHCSP SUPPORTERS!

SickKids FOUNDATION

BC CHILDREN'S HOSPITAL FOUNDATION

the Children's Hospital Research Institute of Manitoba

Alberta Children's HOSPITAL RESEARCH INSTITUTE

CHEO RESEARCH INSTITUTE

women & children's health research institute

STOLLERY CHILDREN'S HOSPITAL FOUNDATION

CCHCSP acknowledges the large network of volunteers (centre leaders, mentors, trainees, administrators) who make local and national program delivery possible.

Outline

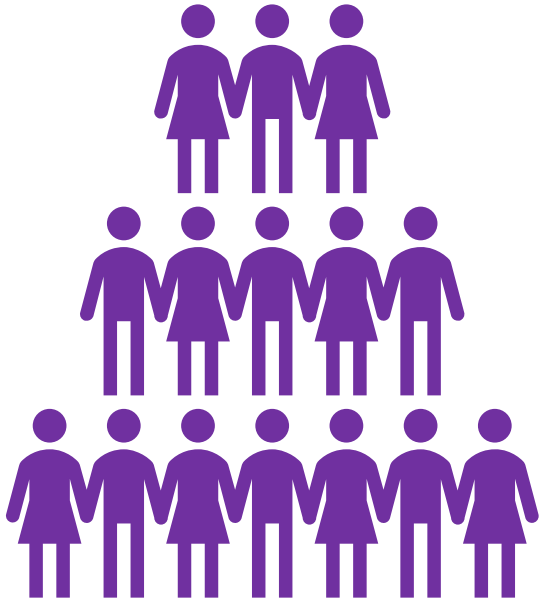
- Who is a patient ?
- Patient-oriented research
- Meaningful engagement of patients as partners
- Alberta SPOR Support Unit
- How to engage patients as partners ?
- How to request our services ?

Alberta SPOR SUPPORT Unit

Who is a patient?

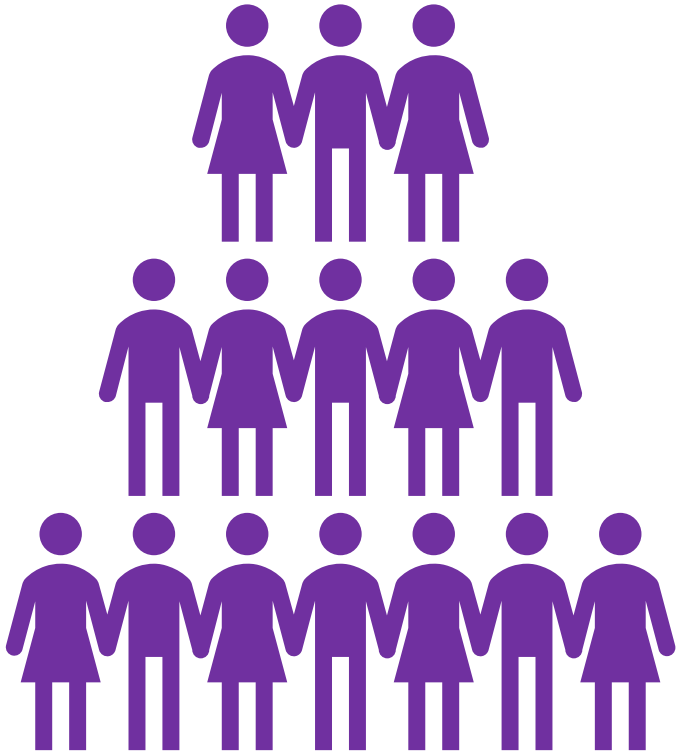
Video: https://www.youtube.com/watch?v=J8YIQbPDPAM

Who is a patient?



- Current or former patients
- Caregivers
- Family members
- Patient support groups

Who is a patient?



- Patient organizations
- Community groups
- Members of the public at large

Patient-Oriented Research

Patient-oriented research includes **at least one** of the following:

1. Meaningfully engages patients as partners
2. Focuses on patient-identified priorities
3. Has the potential to improve patient outcomes

Meaningfully engages patients as partners

- **Meaningful** and **active collaboration** in:
  - **governance**
  - **priority setting**
  - **conducting research**
  - **knowledge translation**

- Depending on the context, patient-oriented research may also **engage people** who bring the collective voice of specific, affected communities.

See: CIHR Patient Engagement Framework

Patient Engagement

Frameworks for Patient Engagement in research

IAP2 Spectrum of Public Participation

	Inform	Consult	Involve	Collaborate	Empower
Public Participation Goal	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision-making in the hands of the public.
Promise To The Public	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.
Example Techniques	• Fact sheets • Web sites • Open houses	• Public comment • Focus groups • Surveys • Public meetings	• Workshops • Deliberative polling	• Citizen advisory committees • Consensus-building • Participatory decision-making	• Citizen juries • Ballots • Delegated decision

https://www.iap2.org

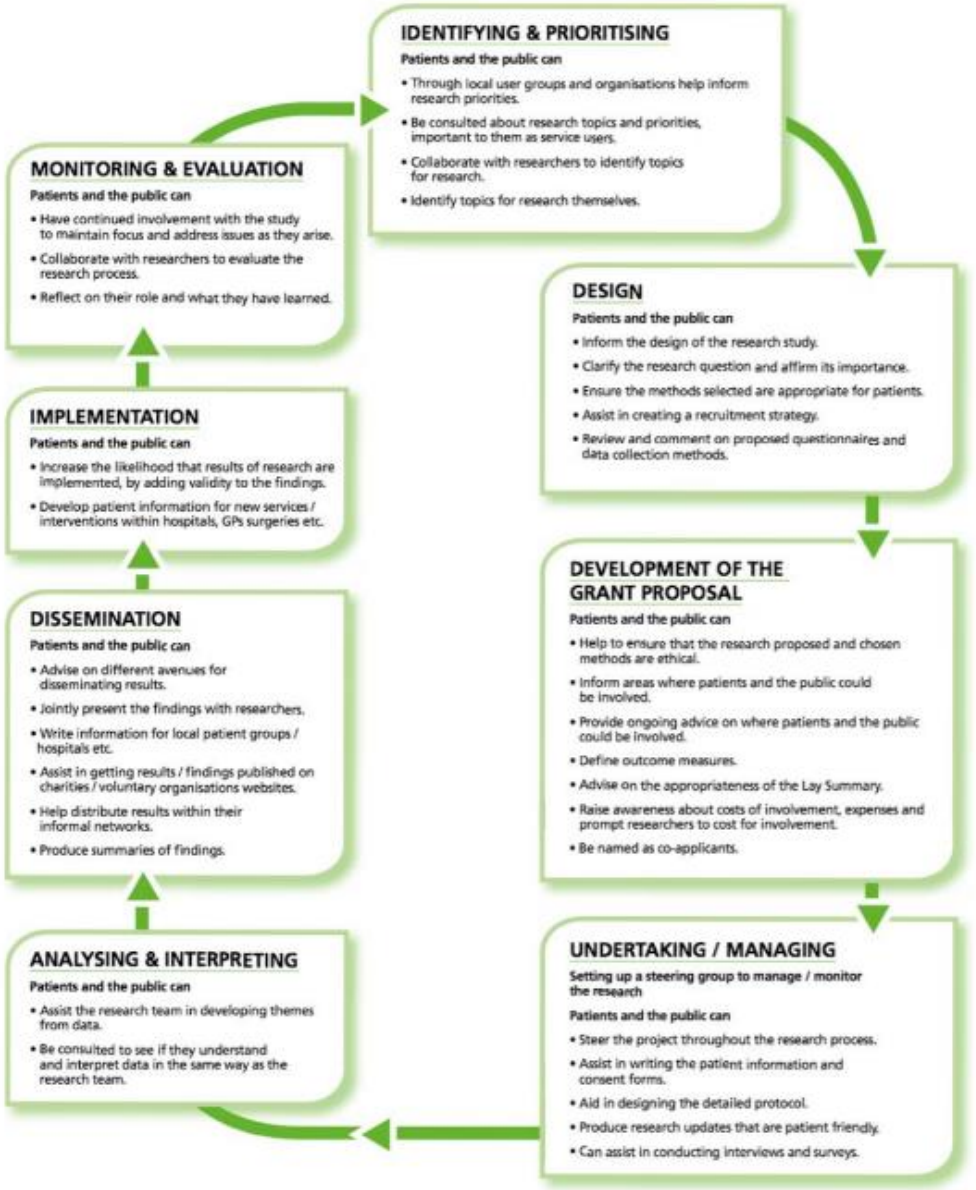


FIGURE 4 Example of study-focused framework for patient and lay involvement in research, reproduced with permission from the NIHR Research Design Service[51]

Greenhaul T et.al, **Frameworks for supporting patient and public involvement in research: Systematic review and co-design pilot**; Health Expectations, 2019

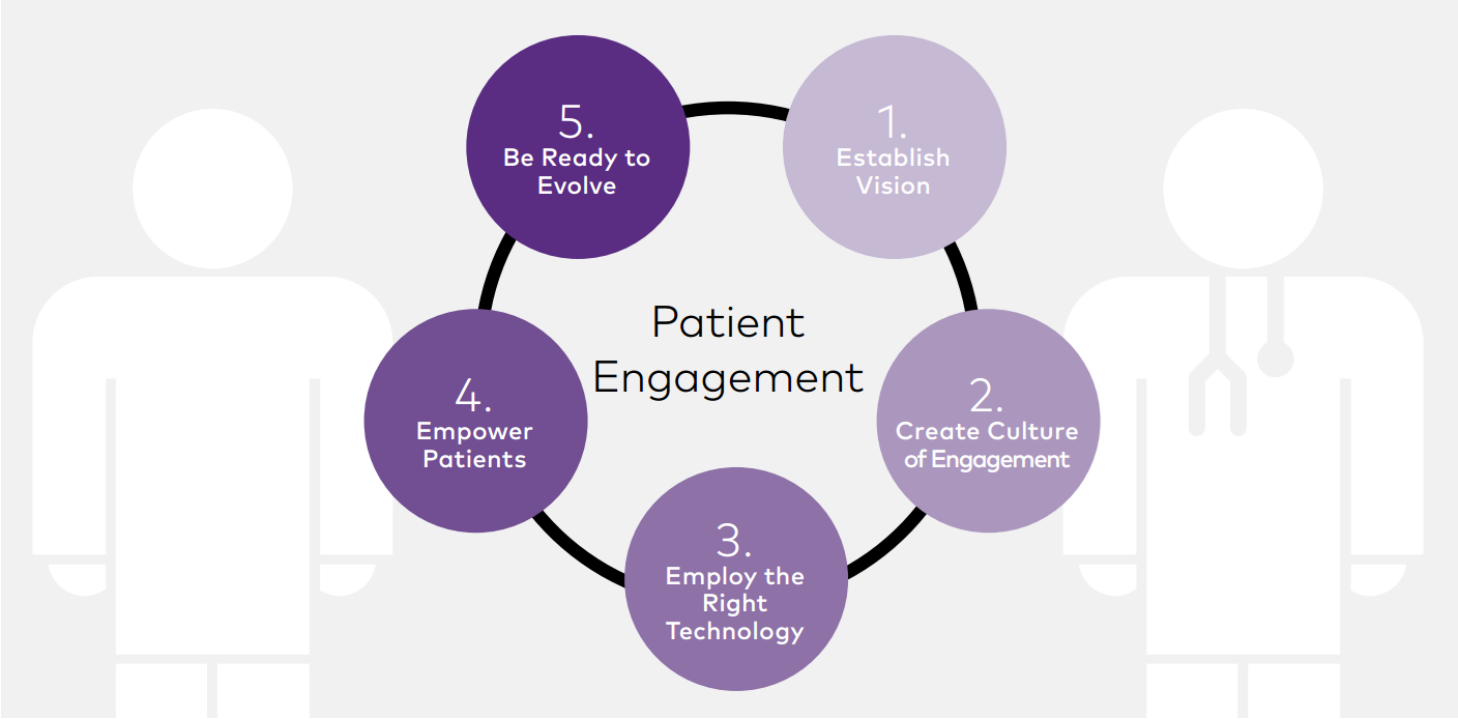
Scientific knowledge about the disease & Practical knowledge about living with the disease

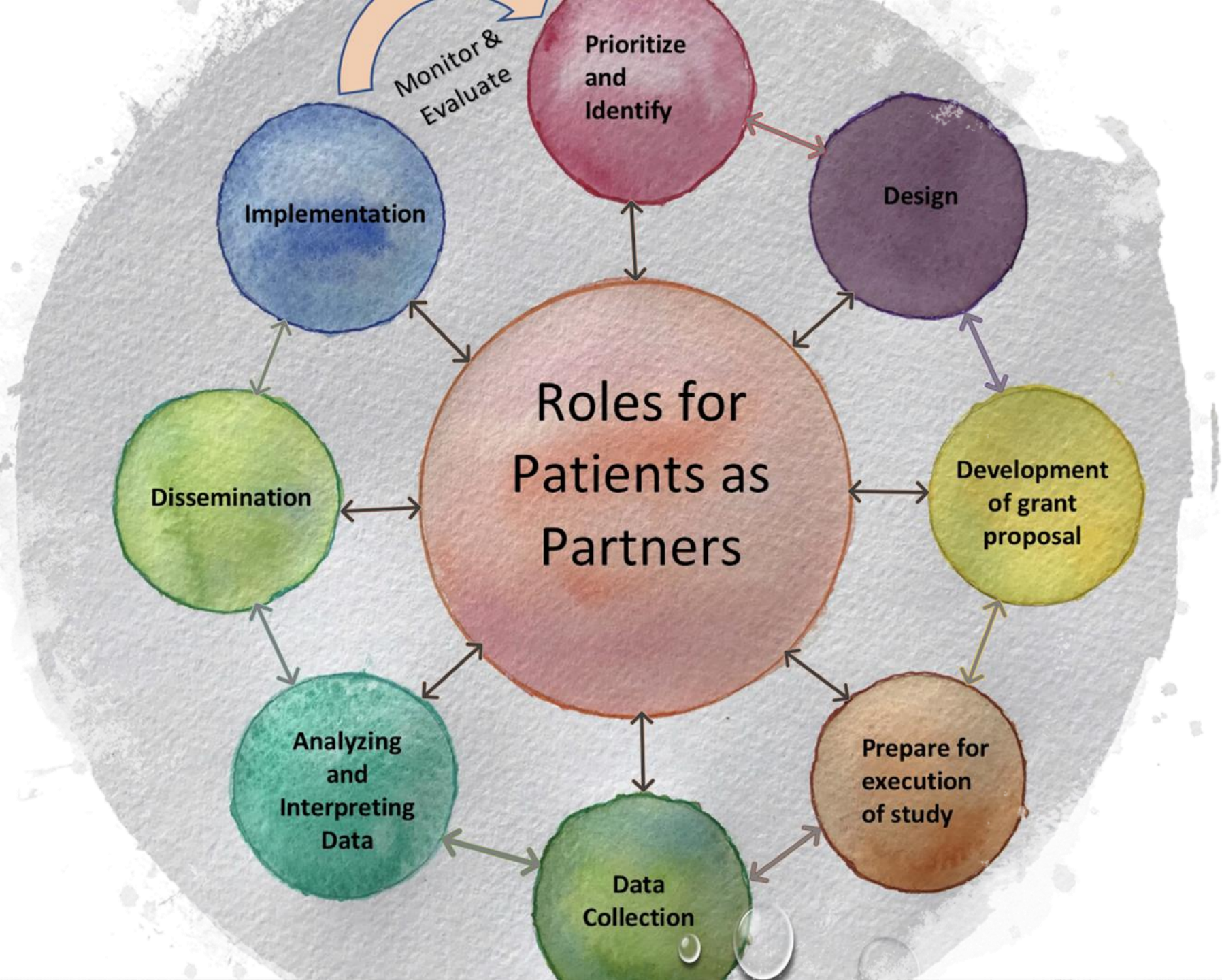
Effective Partnership:

- Shared values
- Acknowledged expertise
- Mutual Accountability

Meaningful and active collaboration

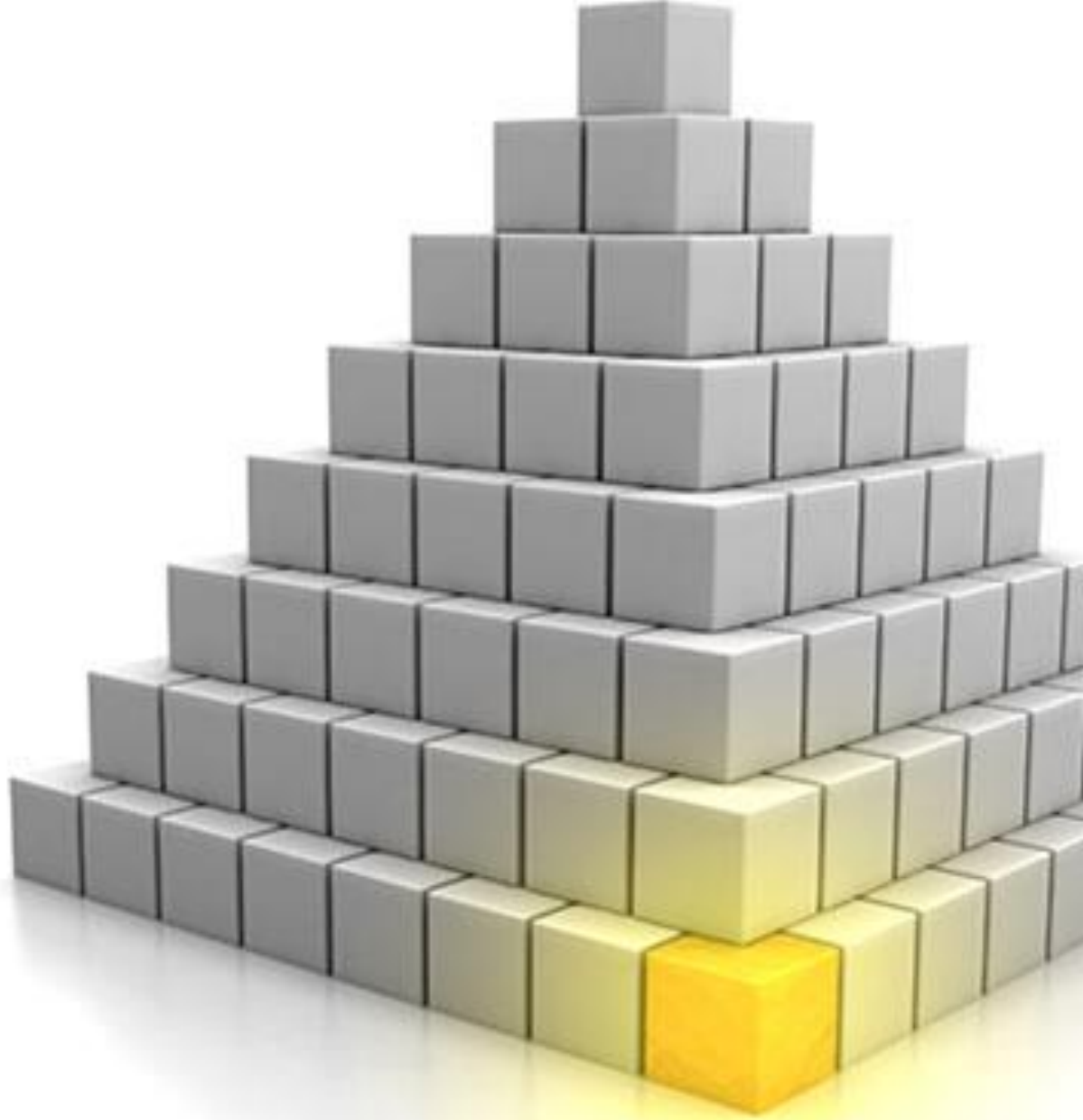
- Governance
- Priority-setting
- Conducting research
- Knowledge translation




Monitor & Evaluate
Prioritize and Identify
Design
Development of grant proposal
Prepare for execution of study
Data Collection
Analyzing and Interpreting Data
Dissemination
Implementation
Roles for Patients as Partners

The cornerstone for patient-oriented research

- Experience of **living with** an illness is essential for **understanding** that illness.



Successful PE

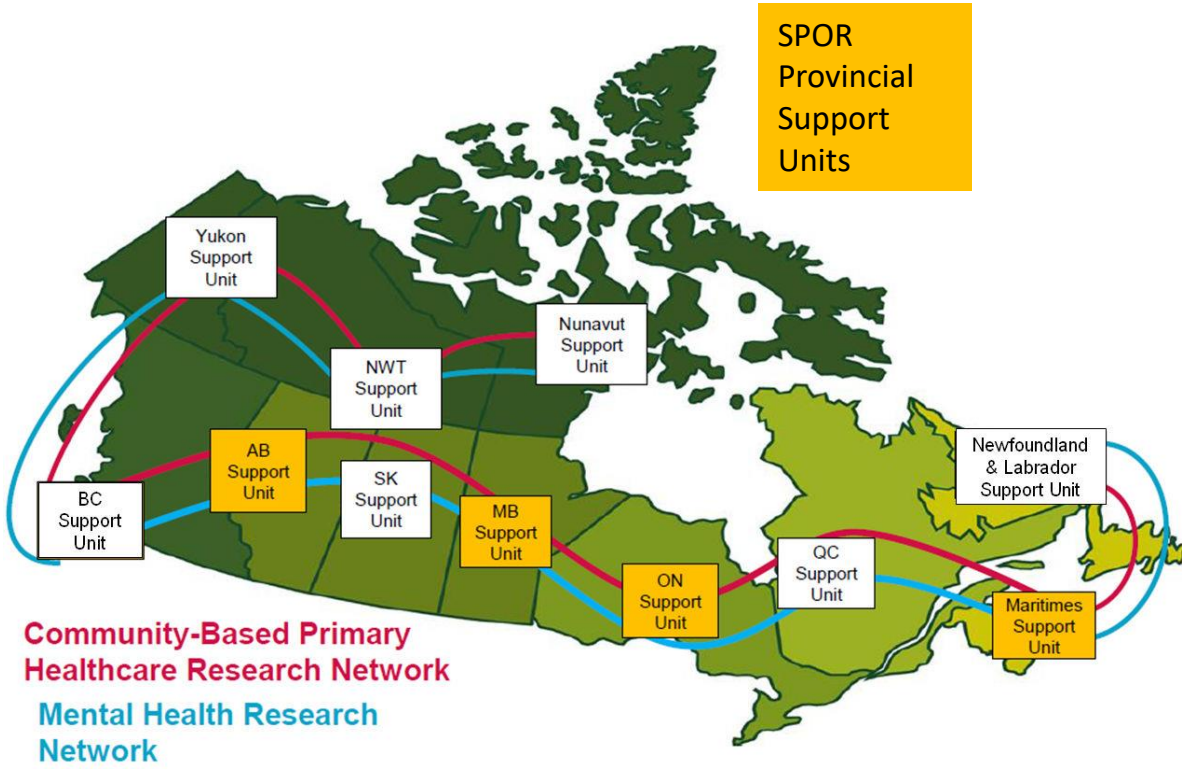
- Inclusive Mechanisms and Processes
- Multi-way Capacity Building
- Multi-way Communication and collaboration
- Experiential knowledge valued as evidence
- Patient-informed and directed research
- A shared sense of purpose

SPOR SUPPORT Units

- SPOR – Strategy for Patient-oriented Research

- The AbSPORU is a five year $48 million federal-provincial partnership between AI and CIHR (2015-2020).

- We are part of a network of SPOR (Strategy for Patient-Oriented Research) SUPPORT (Support for People and Patient-Oriented Research and Trials) Units across Canada.



Alberta SPOR Support Unit

✓ **Four platforms** :

- Patient Engagement Platform (Led by Dr.Maria Santana)
- Data & Methods Platform
- Capacity Development Platform
- Knowledge Translation Platform

Our partners

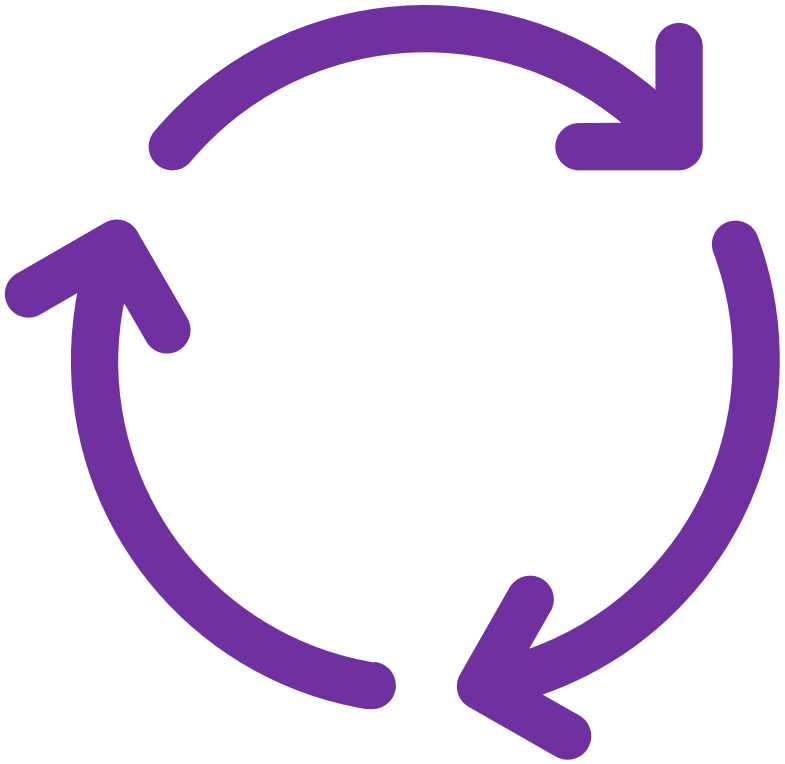
- The Alberta SPOR SUPPORT Unit partners with:
  - ✓ Alberta Health
  - ✓ Alberta Innovates
  - ✓ Alberta Health Services (SCNs)
  - ✓ Athabasca University
  - ✓ University of Alberta
  - ✓ University of Calgary
  - ✓ University of Lethbridge

Eligibility to receive support from SPOR Units

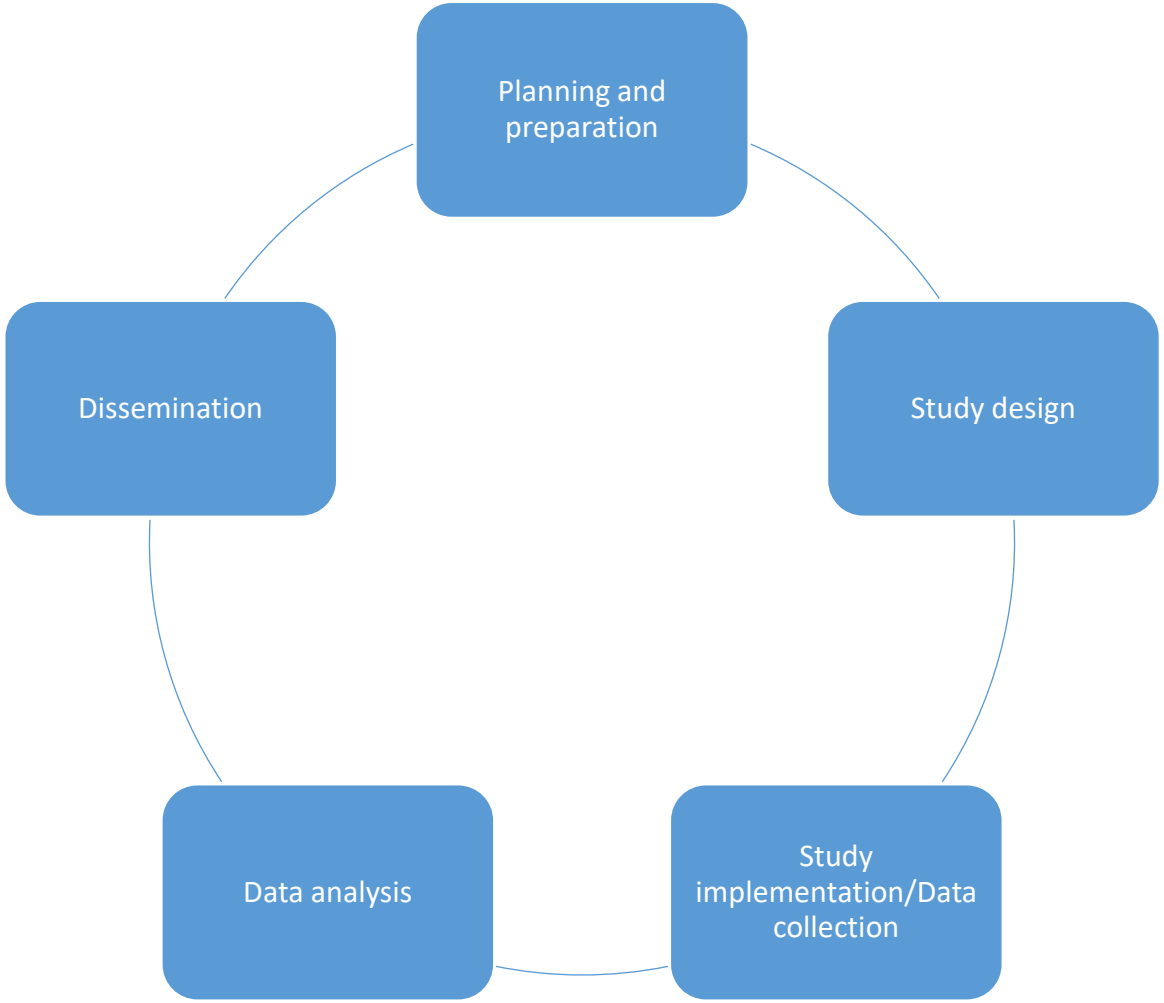
- Eligibility Criteria
  - Research setting and/or investigator
  - Patient-oriented
  - End-user engagement
  - Potential of Patient/System Impact

Check AbSPORU.ca for more information

How can I engage patients in my Project ?

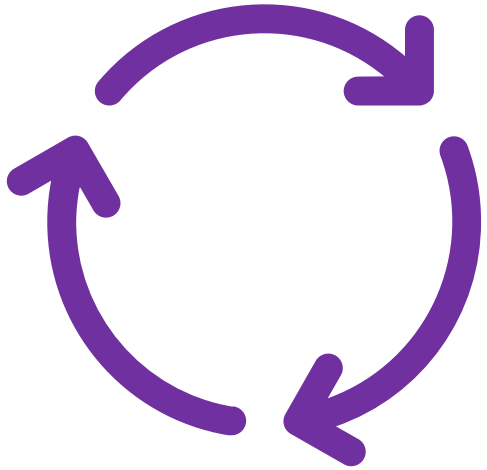


Patient Partners and Research Cycle



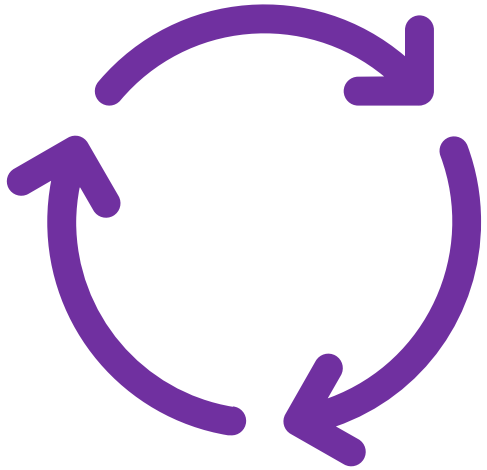
Remember: patient partners are not research subjects

Planning and preparation



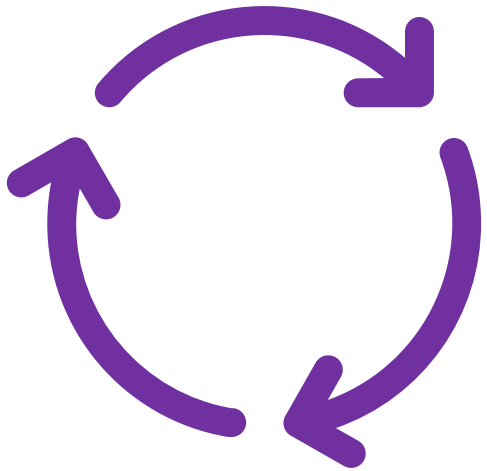
- Help with conceptualizing your project
- Review your proposal
- Help identifying more patient-partners
- Help with writing lay abstract
- Be part of your grant application
- Provide letters of support

Study design



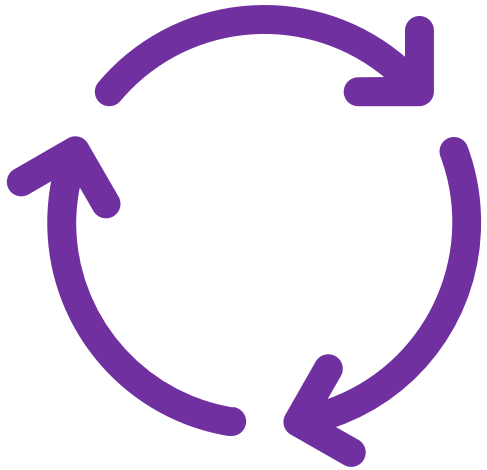
- Review research tools
- Ensure methods are feasible and sensitive to the situations of potential research participants
- Provide feedback on ways to recruit participants
- Ensure interventions are acceptable by research participants
- Identify outcomes of interest

Study implementation



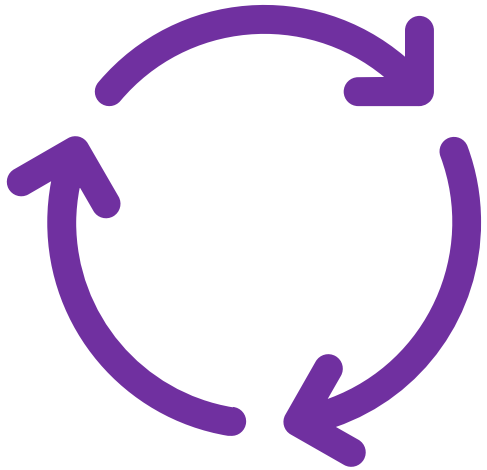
- Create participant recruitment material
- Help increase recruitment into the research study
- Help with data collection
- Conduct interviews/focus groups for qualitative projects

Data analysis



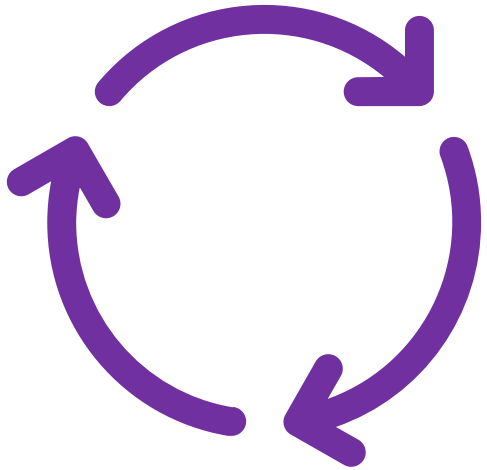
- Take diverse perspectives into account when analyzing data and when making decisions
- Provide explanation on trends in your data from patient's perspective
- Help you with coding/thematic analysis in qualitative studies
- Provide comments on data visualization

Dissemination



- Influence the language and content of information to be more appropriate and accessible before disseminating
- Advocate for uptake of evidence in local health system
- Reach out to various patient advocacy groups to increase uptake of evidence into policy
- Co-present at academic conferences
- Co-author peer reviewed publications

What about REB approval?

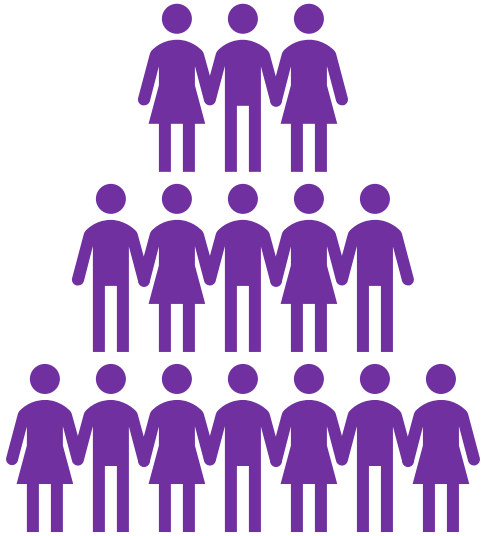


- Different provinces and territories have different requirements, but they're not usually a barrier.
- Researchers should fully describe how patients will contribute to the research, and what access to information they may have.
- Patients who are research partners should be listed as members of the research team.
- **Remember: patient partners are not research subjects.**

How do I budget for PE in my grant?

- **Reimbursement**: Covering the direct costs and expenses associated with participating in research and research related activities including travel, parking and child care.
- **Compensation**: Payment for the time, skills, lived experience and expertise patient partners bring to a research project or related activity.
- Compensation can including direct payment, in-kind contributions (conference travel, etc.), cash, or honoraria.
- Consideration about diversity of protocols
- Opting out of payment should be an option
- Alberta SPOR guidelines use $25/hr as a benchmark

How many patients do I need to engage?



- No ideal number of patients to engage in research
- Relying on one patient can be problematic
- Involve as many patients as possible to include a wider perspective in your research, but easy to manage
- Patients should come from a broad range of backgrounds
- Aim to include populations that researchers find hard to reach
- **Remember: Tokenism is not patient engagement**

Patient Engagement Examples

Bele et al, (2020) Investigating integration of Patient-reported Outcome Measures (PROMs) in pediatric clinical care for asthma

- ✓ Helped with recruitment strategies
- ✓ Co-designing KidsPRO platform
- ✓ Co-design KidsPRO user guides
- ✓ Co-design KidsPRO logo
- ✓ Provide feedback on systematic review
- ✓ Patient recruitment*
- ✓ Will be co-presenting the results*

KidsPROS

Patient Engagement Examples

Fiest et al. (2019). Co-designing a Patient and Family Caregiver-Oriented Transitions in Care Bundle. 2019-2023. *Canadian Institutes of Health Research Transitions in Care Team Grant.* $1,107,400.

- ✓Facilitated a Tier II priority setting meeting (Sept 2018)
- ✓Co-created a poster (May 2019 KT Canada Scientific Meeting Conference)
- ✓Article being written (~8months)
- ✓Grant submitted & provided a letter of support (~Jan 2019)
- ✓Attended & contributed to a stakeholders meeting (Sept 2019)

Patient Engagement Examples

Innovative Pediatric Clinical Trials (SPOR-funded entity) – 4 Pediatric Clinical Trials Sites in Emergency Departments across Canada (in Alberta – Richer et al.)

- ✓ Co-design patient informed recruitment strategy (Aug 2019 – Dec 2019)
  - ✓ Develop a protocol for sites
- ✓ Co-facilitate patient engagement workshop (Sept 2019)
  - ✓ Develop overarching patient engagement strategy
- ✓ Produce two articles (~12months)
- ✓ Support training at site(s) or with coordinators

You are not alone!

Support from Patient Engagement Platform

- ✓ Access capacity development and team training resources
- ✓ Access patient partners through online patient network (*www.albertans4healthresearch.ca*)
- ✓ Assess patient engagement readiness
- ✓ Determine a budget for patient engagement
- ✓ Develop patient engagement plan
- ✓ Evaluate patient engagement experience
- ✓ Identify and mentor patient liaison
- ✓ Link and match researchers to patients and patient groups
- ✓ Mentor/coach patients and researchers in engagement activities

AWARDS

- Accelerator Award
- Patient Partner Conference Travel Award

Resources

- ✓How-To-Guide Researcher version
- ✓How-To-Guide Patient Partner version
- ✓Ethical Guidelines for Patient Engagement
- ✓Terms of Reference for Patient Engagement
- ✓Patient Partner Appreciation Guidelines
- ✓Cost-calculators for budgetary consideration
- ✓Co-authorship for patient-partners
- ✓Evaluation of Patient Engagement

How to request our services

www.absporu.ca

Alberta SPOR SUPPORT Unit

Data + Services | Capacity Development | Events | Patient Engagement | Knowledge Translation | Resource Library | About Us

Welcome to the Alberta Strategy for Patient Oriented Research SUPPORT Unit (AbSPORU)

AbSPORU is dedicated to transforming health outcomes in Alberta through Patient-Oriented Research (POR).

POR actively engages patients and other stakeholders in research that focuses on patient-identified priorities and improves patient outcomes.

As we move forward with AbSPORU, we are concentrating on bridging the gaps among data, research evidence and health care practice. The collaborations between AbSPORU and AHS Strategic Clinical Networks™ (SCNs), Alberta Health, Alberta Innovates plus other learning health system proponents will continue to contribute to our collective success.

Who is eligible for AbSPORU services and resources?

Researchers who want to:

- learn or request assistance on including patients and patient partners in their research, or
- enhance their patient-oriented research

Patients and patient partners who want to:

- help researchers by becoming team members and/or partners with research teams, or
- become involved in research studies.

The research must:

- be conducted in Alberta or the Northwest Territories and seek to impact patients and/or the healthcare system.
- have a patient-oriented focus, which AbSPORU can help researchers identify.

Review our service descriptions and request a service or letter of support by completing the forms below:

- **Service Descriptions**– people with expertise in many research service areas are available to assist in your Patient-Oriented Research.
- **Service Application** – complete the application form to access services. Ensure all mandatory fields are complete to avoid delay.
- **Letter of Support** – can be provided to confirm the feasibility of a planned project and included with a grant application. This usually occurs after AbSPORU has been involved in one of the services listed above.

Questions? Contact AbSPORU at absporu@albertainnovates.ca

Service request form

- ✓Contact information and role
- ✓Study information
- ✓Funding information
- ✓Study description
- ✓SCNs and SPOR involvement
- ✓Services from PE platform

Quality Assurance

- Not Applicable
- Developing, validating or quality assessment
- ICD coding algorithms

Knowledge Synthesis

- Not Applicable
- Literature searching
- Rapid review
- Scoping review
- Statistics (meta-analysis)
- Systematic review

Knowledge Translation

- Not Applicable
- Developing a Knowledge Translation plan (end-of-grant or end of project)
- Developing an Integrated Knowledge Translation proposal

Implementation Science

- Not Applicable
- Assessing barriers and facilitators to implementation
- Developing a sustainability plan
- Developing an implementation plan
- Evaluating implementation
- Identifying appropriate implementation strategies

Patient Engagement

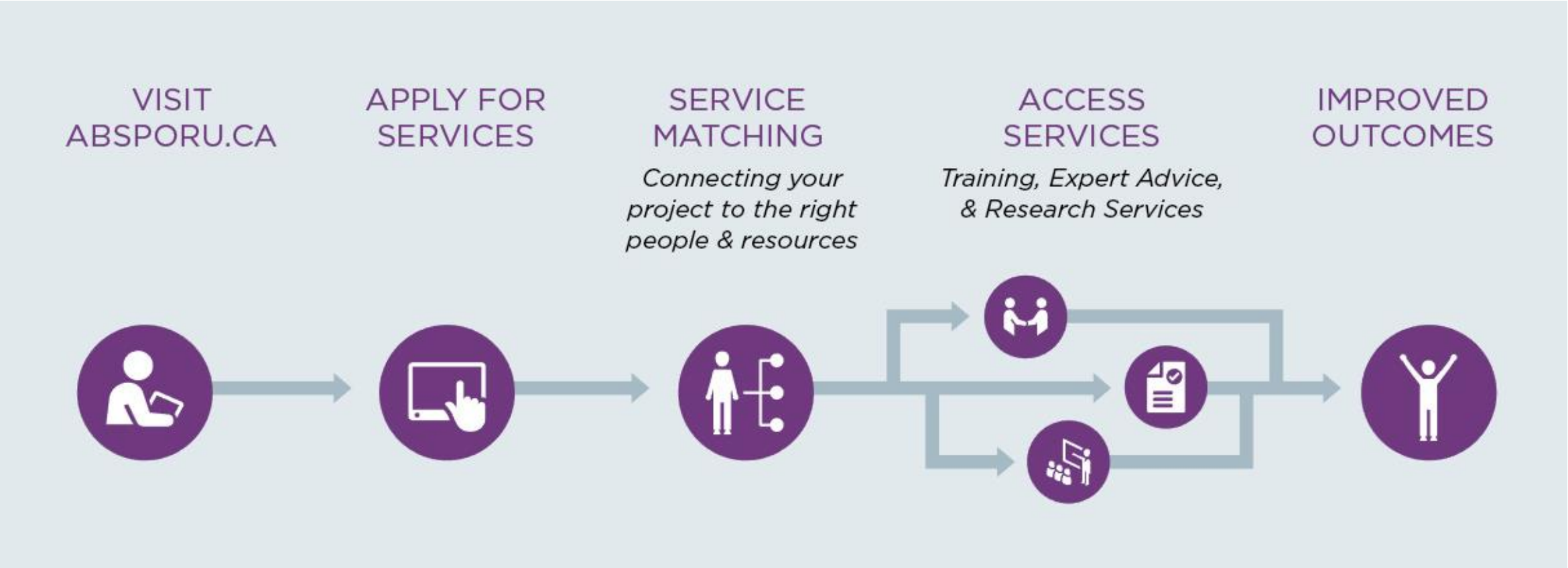
- Not Applicable
- Access capacity development and team training resources
- Access patient partners through Patient Registry
- Assess patient engagement readiness
- Determine a budget for patient engagement
- Develop Patient Engagement Plan
- Evaluate patient engagement experience
- Identify and mentor patient liaison
- Link and match researchers to patients and patient groups
- Mentor/coach patients and researchers in engagement activities

Stakeholder Engagement

- Not Applicable
- Clinicians (KT, PE)
- Patients / Caregivers / Citizens (PE)
- Policy Makers / Administrators (KT, PE)
- Researchers (KT, PE)

Processing your requests

Complete the form and send to : absporu@albertainnovates.ca



www. Albertans4HealthResearch.ca

Alberta SPOR SUPPORT Unit | Patient Engagement Platform | CIHR IRSC | Alberta Innovates Health Solutions

Albertans4HealthResearch.ca

Opportunities

Activity	Shifts	Start	End
Canadian COVID-19 Emergency Department Rapid Response Network (CCEDRRN)	1		
Child and parent perceptions of play therapy	1		
Evaluation of a website about Patient-Researcher Partnerships	1		
Evaluation of a website to support patients with chronic kidney disease	1		
Healthcare needs of Women with Polycystic Ovary Syndrome	1		
Parents Empowering Neurodiverse Kids: Strongest Families Neurodevelopmental Study	1		
Patient Experience of Lung Cancer: A Qualitative Study	1		
Patient Important Gastrointestinal Bleeding in the ICU	1		
Preventing Heart Attacks in Alberta	1		
Reducing Ventricular/Lumbar Drain and Ventricular Shunt Insertion Infections in the Adult Neurosurgery, Trauma and ICU Patient Population in Alberta (Treatments for Hydrocephalus)	1		
Toward Optimal Use of Blood Tests for Hospitalized Patients	1		

I would like to volunteer

Fill in an application

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Tweets by @AbSPORU_PEP

Opportunities - Toward Optimal Use of Blood Tests for Hospitalized Patients

Re-Purposing the Ordering of 'Routine' laboratory Tests on medical teaching units
(RePORT study)
University of Calgary

Background
Blood tests are valuable tools used by clinicians to help diagnose and treat their patients. However, overuse of these tests, particularly in hospitalized patients, leads to patient discomfort, disruption in sleep patterns, and can negatively impact their medical outcomes therefore it is important for clinicians and patients to engage in meaningful conversations about why and how often blood tests are drawn.
Our team previously brought together a national group and developed recommendations on the use of blood tests for hospitalized patients. Through education of healthcare teams about these recommendations, and by providing summarized feedback to them on their ordering patterns, we have shown that we can safely reduce blood test overuse.
We are now proposing a new study to engage with patients about their perspectives on the appropriate use of blood testing and to share widely the effects of education and feedback on blood testing with 6 hospitals in Canada. By learning and understanding the views of patients and healthcare teams around these efforts, these results can help to inform how to best integrate tools to optimize blood test into healthcare system operational processes and can help determine the true impacts of our efforts in reducing blood test use . This can also help to answer questions related to its cost-effectiveness. Our eventual goal is widespread integration of such tools so that blood testing in hospitals becomes more purposeful.

Roles and Responsibilities
We are seeking a patient partner to join our team as an applicant/collaborator on the project proposal to CIHR. This patient partner will have a leadership role in informing and developing the patient engagement approaches and strategies of the project including establishing and sustaining a patient advisory council.

Time Commitment
If the grant application is successful, the project will start April 2021 with 1 hour team meetings every 3 months for 3 years.

Reimbursement/Compensation
There is no compensation being offered for the grant submission stage however if the application is successful patient partners will, going forward, be compensated for their time and contributions to the study from the project grant budget.

For more information or to apply please contact:
Anshula Ambasta
aambasta@ucalgary.ca

I would like to volunteer

Fill in an application

Already use MyImpactPage.com to volunteer with this organization?
Log in to your account

Get Social

Share this

Tweets by @AbSPORU_PEP

absporu.ca

Sep 14, 2020

Patient Engagement Platform Retweeted

Sadia Ahmed
@Sadiaahmed1221

Replying to @SherryVera6 and 4 others

the event page here:
absporu.ca/event/absporu-...

Embed | View on Twitter

Community Engagement

- Government organizations
- Community Members
- NGO's
- Albertans
- YOU
- Different levels of Government
- Community Organizations
- Urban and Rural

Patient and Community Engagement Research (PaCER)

The PaCER training program teaches learners how to conduct research with, by and for patients in their communities. This program enables patients to tell their stories with the goal of incorporating research-informed patient voices into health system research, planning and policy.

Two primary goals of the PaCER training program are to:

Incorporate a research-based patient perspective into healthcare and health research

Teach non-traditional learners research skills and how to conduct patient-engagement research

Join our Journal Club

THE ALBERTA SPOR SUPPORT UNIT'S
PATIENT ENGAGEMENT PLATFORM
INVITES YOU TO THE...

PATIENT ENGAGEMENT JOURNAL CLUB

Article: Banerjee, C., Brehm, G., Hanberg, H., Hylton, C., Maverley, D., Swendson, Y., & Zelinsky, S.(2013). ***The Hidden Pathways of Chronic Illness*** (Unpublished internship report). University of Calgary

Download from: https://bit.ly/3tvXHHR

All are welcomed !!

Wednesday, February 17th, 2021, 10:00 - 11:30 AM

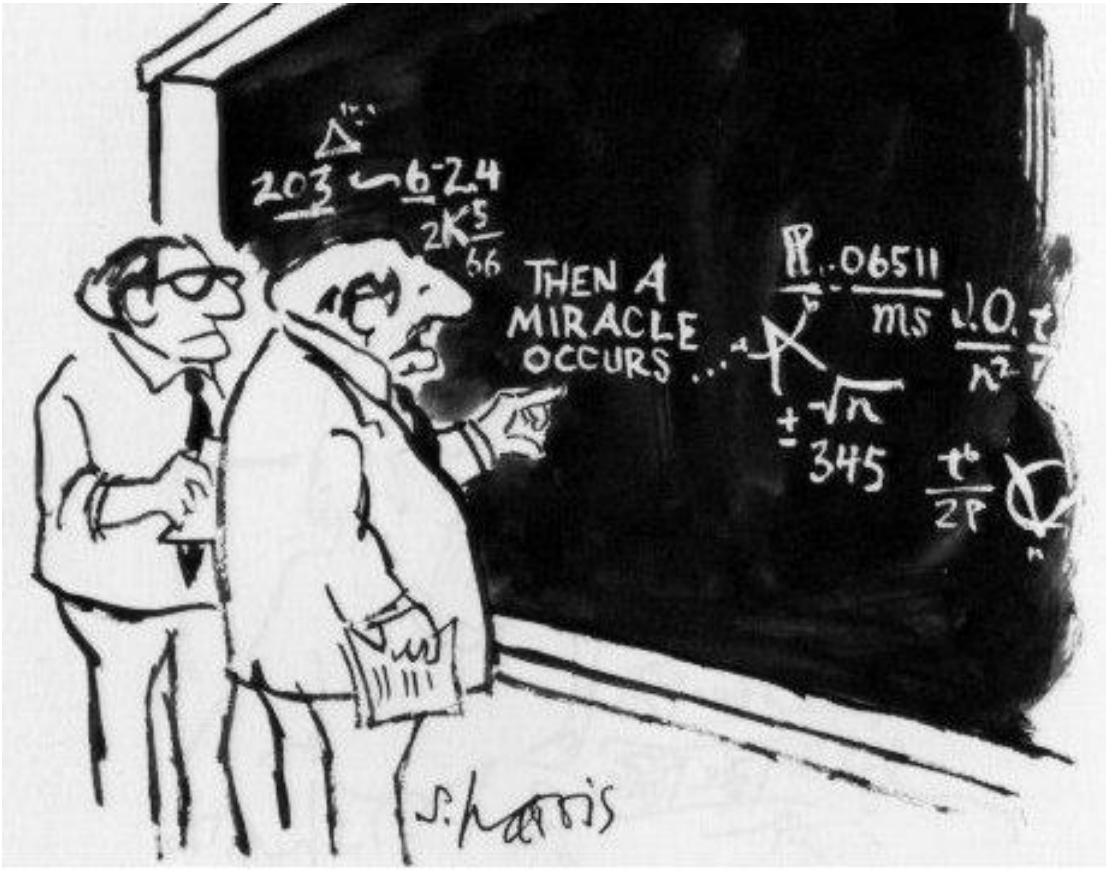
Please Register @: https://bit.ly/3sgSFhT

Zoom meeting link and teleconference number will be sent to you after registration !

ALBERTANS HEALTH RESEARCH

Alberta SPOR SUPPORT Unit
Patient Engagement Platform

YOU HAVE QUESTIONS?



"I think you should be more explicit here in step two."

from *What's so Funny about Science?* by Sidney Harris (1977)

We have answers!

Later? Contact us:

- ✓Email: absporu@albertainnovates.ca
  sumedh.bele@ucalgary.ca
- ✓Or visit: www.absporu.ca

Acknowledgements

Funded by