

Alberta SPOR SUPPORT Unit



What is the Alberta SPOR SUPPORT Unit?

- SPOR: Strategy for Patient-Oriented Research
- SUPPORT Unit: Support for People and Patient-Oriented Research and Trials
- The Alberta SPOR SUPPORT Unit is a five year, \$48 million federal-provincial partnership between Alberta Innovates and CIHR (2015-2020).
- We are part of a network of SPOR SUPPORT Units across Canada.

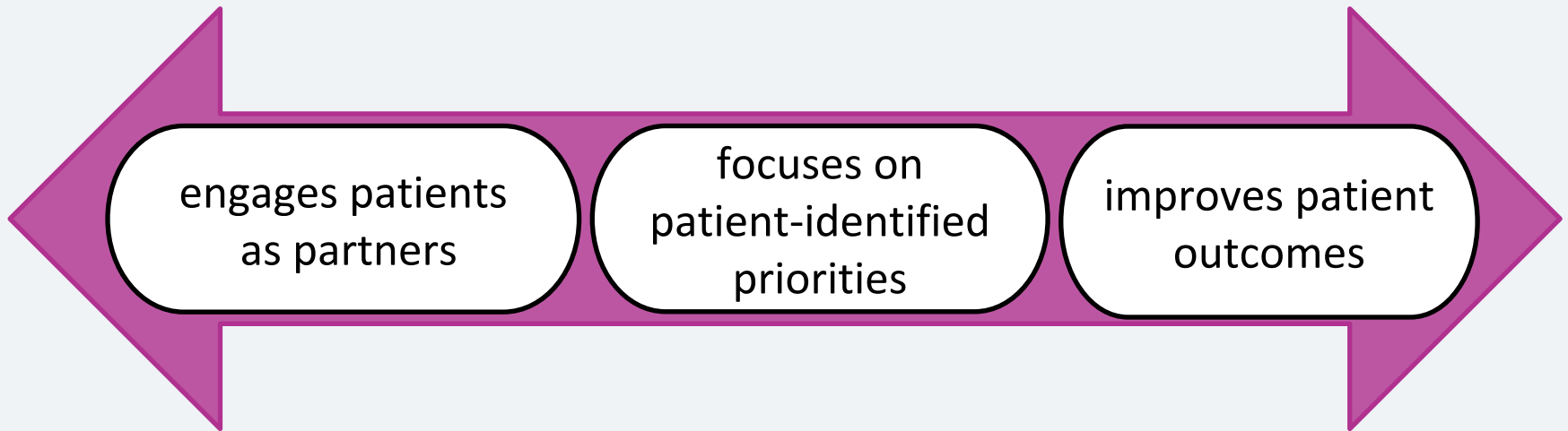
First SPOR
Unit
established
in Canada

Our Vision and Goal

- **Vision:** Advance knowledge to improve patient health and health care.
- **Goal:** Increase the quantity and quality of patient-oriented health research.

Patient Oriented Research

A *continuum of research* conducted by multi-disciplinary teams...



that aims to *apply knowledge generated* to improve healthcare systems & practices

(CIHR Strategic Patient Oriented Research)

Alberta SPOR SUPPORT Unit

The Alberta SPOR SUPPORT Unit has seven core areas of expertise:



PATIENT ENGAGEMENT
led by Dr. Virginia Vandall-Walker aims to support patient engagement in research.



METHODS SUPPORT & DEVELOPMENT
led by Dr. Hude Quan aims to support researchers in developing innovative research methods for undertaking patient-oriented research.



KNOWLEDGE TRANSLATION
led by Dr. Lisa Hartling aims to advance understanding in how to translate evidence into practice.



PRAGMATIC CLINICAL TRIALS
jointly led by Dr. Michael Hill and Dr. Lawrence Richer aims to provide expertise for completing real-world clinical trials which may change health outcomes.



CAREER DEVELOPMENT
jointly led by Dr. Dean Eurich and Dr. Marilynne Hebert aims to enhance training and career development in methods and health service research.



CONSULTATION & RESEARCH SERVICES
led by Dr. Ross Tsuyuki aims to provide you with the tools, resources and expertise necessary for the successful completion of patient-oriented research.



DATA led by Dr. Finlay McAlister aims to provide you with the support and resources for undertaking patient-oriented research using secondary analysis of existing large datasets.

Two platforms help build capacity:

- Career Development
- Pragmatic Clinical Trials

Five platforms provide direct services:

- Consultation & Research Services (CRS)
- Data
- Knowledge Translation (KT)
- Methods Support & Development
- Patient Engagement (PE)



We can help you every step of the way



Research Process / Lifecycle

	Consultation and research services	Data	Knowledge Translation (KS, KT, IS)	Methods	Patient Engagement
Identifying & prioritizing	√	√	√	√	√
Designing study	√	√	√	√	√
Executing study	√	√	√	√	√
Analyzing results	√	√	√	√	√
Disseminating results			√		√
Monitoring & evaluating uptake and use		√	√		√

Identifying & Prioritizing

CRS

- Research question refinement

Data

- Case volume estimates
- Data feasibility

KT

- Advice on question clarity, feasibility (scope), consideration of relevant audiences (who), and involvement of the right people (KT)
- Identification of review methods and specific research questions (KS)

Methods

- Advice on measuring patient-centered care
- Advice on data collection methodology
- Training on novel methodologies
- Advice on writing a methodology section

PE

- Coaching to choose an appropriate priority setting process, facilitation support to execute the process

Designing Study

CRS

- Project design & methods consultations
- Development of analytical plans
- Sample size calculation
- Grant review

Data

- Design and methodology consultation
- Identification of data sources
- Data Extraction and Analysis Plan

KT

- Advise KT Plan design, who to consider, how and where to include them; guide consideration of barriers and facilitators (KT)
- Specific review methodology advice/assistance (KS)

Methods

- Help developing innovative methods for using data
- Developing Ideas for innovative tools to conduct POR
- Advice on developing proposals/protocols
- Developing methodology
- Developing & validating ICD coding algorithms for defining disease
- Developing risk adjustment methodologies

PE

- Training on how to meaningfully engage patients, mentoring support for including patients on the research team

Executing Study

CRS

- Development of case report forms (data collection sheets)
- Database development & maintenance
- Randomization
- Quality assurance

Data

- Administrative approval
- Extraction and linking of data
- Cohort matching

KT

- Direction on appropriate relevancy for audience, their roles, and where to engage (KT)
- Access to research librarian, methodologist, research assistants, statistician (KS)

Methods

- Providing quality assessment and validation of ICD coding algorithms for defining disease
- Risk adjustment

PE

- Training on how to meaningfully engage patients, mentoring support for including patients on the research team

Analyzing Results

CRS

- Statistical analysis
- Clinical event adjudication

Data

- Analysis of data
- Visualization

KT

- Advise on who should be involved in analysis, guide engagement and relevancy to end users and possible application (KT)
- Statistical support for meta-analysis; methodology support for qualitative or narrative synthesis (KS)

Methods

- Risk adjustment
- Data visualization
- Data interpretation

PE

- Training on how to meaningfully engage patients, mentoring support for including patients on the research team

Disseminating and Translating Results

CRS

Data

KT

- Guidance on who, when, where, how, and the appropriate tools to best share knowledge; overcome barriers and utilize facilitators (KT)
- Support for KT and implementation activities
- Advice and assistance with SR formatting standards for publication (KS)

Methods

PE

- Training on how to meaningfully engage patients, mentoring support for including patients on the research team

Monitoring & Evaluating

CRS

Data

- Monitoring system change in health system

KT

- Advise on KT Plan evaluation and identify appropriate measures maintaining relevancy and usability for end users (KT)
- Update of review search as required (KS)

Methods

PE

- Purpose built evaluation framework for measuring patient engagement in research

Accessing Services

VISIT
ABSPORU.CA

APPLY FOR
SERVICES

SERVICE
MATCHING

*Connecting your
project to the right
people & resources*

ACCESS
SERVICES

*Training, Expert Advice,
& Research Services*

IMPROVED
OUTCOMES



Accomplishments

- Infrastructure
 - “one-stop” (virtual) location
 - individualized value-added service
 - connection to world-class data and resources (people and information)

Accomplishments

60+
HQP

"It's really amazing, as a graduate student, to have access to a group of PhD-trained experts who are available to give you as much help and advice as you need for your project. The SPOR staff really know their stuff and can give you input and direction on many aspects of your research."

Accomplishments

55 data
sets

“Data is seen as the lifeblood for some researchers. So reducing access to Alberta health-related data from three months to five weeks is something to get excited about.”

“The Alberta SPOR SUPPORT Unit is making a huge difference in our access to data, which had been very challenging before.”

Accomplishments

170
patient
partners


“The PE Platform has been instrumental in supporting patient-oriented research networks in Alberta including the Primary and Integrated Healthcare Innovation Network (PIHCIN). They have assisted in patient/citizen project recruitment, have provided expertise and resources describing how to meaningfully engage members of the community, as well as partnered with numerous PIHCIN project teams.”

Accomplishments

- Consultations and services



950+



45% academic
45% health system
practitioners
10% trainees



56% U of A
27% U of C
14% AHS
1% U of L
2% other

Accomplishments

- Consultations and services

Letters of support

Grant review

Linkages (data, patients)

Design and methodological support

Project support

KT and implementation

Accomplishments

- Improving POR awareness and reach:



*-dedicated
outlet to
disseminate
knowledge and
contribute to
science of POR*

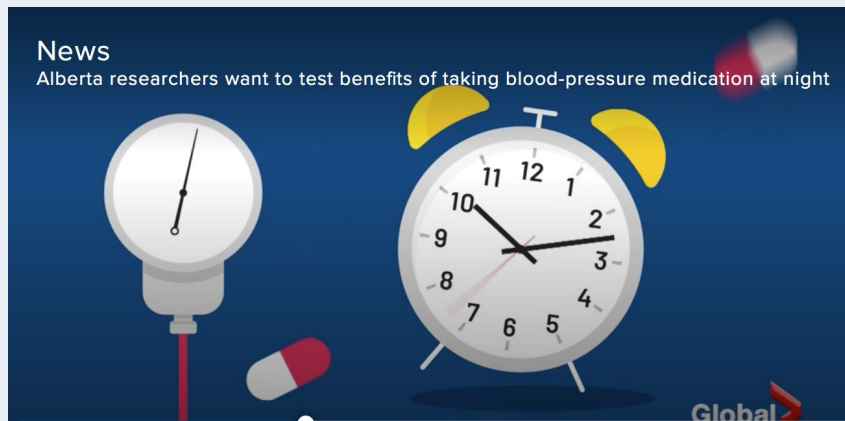
Accomplishments

- National activities and collaborations
 - Pan-Canadian Real World Health Data Network
 - Canadian Clinical Trials Coordinating Centre
 - SPOR Evidence Alliance
 - National Patient Engagement Working Group
 - CIHR Patient Engagement Framework
 - National Knowledge Translation Working Group
 - Sharing resources and best practices

An example

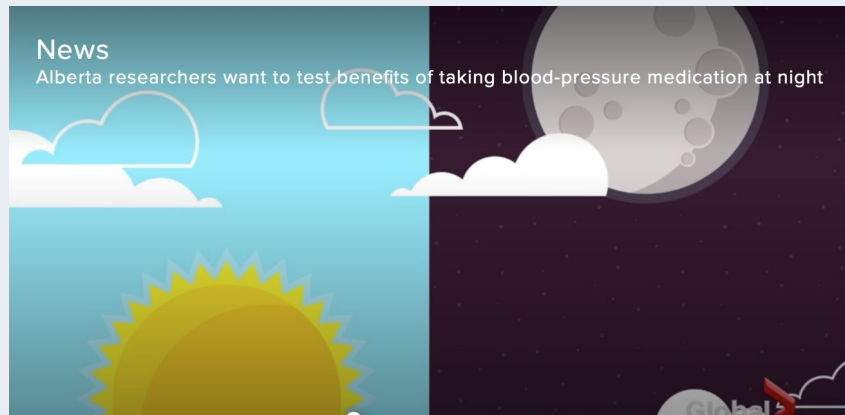
BedMed The High Blood Pressure Study

Research suggests it might be possible to improve health outcomes for people living with high blood pressure.



“With patients' consent, the Alberta SPOR SUPPORT Unit Data Platform can now look at hospital and emergency room records for trial-relevant outcomes (like heart attacks, strokes, or deaths) and compile information much faster for researchers, like Dr. Garrison. Through BedMed, he is also helping to ensure that patient priorities are taken into account in the direction of the research.”

Finlay McAlister, Professor, University of Alberta, Department of Medicine, Lead, Data Platform, AbSPORU



“Having experienced what it means to fully engage patients in research, I would never go back. We have better study design, better study materials, assistance troubleshooting compliance problems mid-trial, and an incredible energy and renewal of purpose every time the group meets.”

Scott Garrison, Associate Professor, University of Alberta, Department of Family Medicine, Director, Pragmatic Trials Collaborative and leader of the BedMed Project

- Enabling dedicated access to secondary use data resources
- Staff growth from 1 to 13 (8 SPOR funded) PhD/MSc Statisticians / Data Scientists
- Completed projects increased from 86 in FY16/17 to 157 in FY18/19
- Reduced time to access data from months to weeks
- Collaboration on several inter-provincial projects
- Member of SPOR Canadian Data Platform
- Support for clinical trials using administrative data in areas including hypertension, critical care, kidney disease, EMS and addictions
- Established collaboration with AHS and U of C Centre for Health Informatics (CHI) including addition of machine learning expertise

Benefits

- For researchers:
 - “one-stop” location
 - individualized value-added service
 - connection to world-class data and resources (people and information)
- For patients:
 - a stronger voice in healthcare research
- For Alberta & Canada
 - improved health outcomes
 - a strengthened health care system

Thank you