



UNIVERSITY OF ALBERTA
FACULTY OF MEDICINE & DENTISTRY



SPOR Platform Discussion

January 26, 2017

Questions: Dr. Jill Byrne (Director, Clinical Research; FoMD)
jill.byrne@ualberta.ca

I Do Clinical/Health Services Research, What Can ABSPORU Do For Me?

Finlay A. McAlister, MD MSc
On behalf of the ABSPORU Data Platform
Ross T. Tsuyuki, PharmD MSc
On behalf of the ABSPORU Consultation and Research Services Platform
Lisa Hartling, PhD
On behalf of the ABSPORU KT Platform



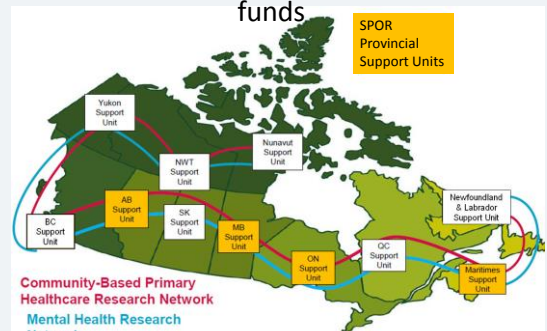
What is the Alberta SPOR SUPPORT Unit?

- The ABSPORU is a five year \$48 million federal-provincial partnership between AIHS 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) Unit across Canada.

First SPOR Unit established in Canada



ABSPORU – Infrastructure, but **not** operating funds



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.



Our Partners

- The Alberta SPOR SUPPORT Unit partners with:
 - Alberta Health
 - Alberta Innovates – Health Solutions
 - Alberta Health Services
 - Athabasca University
 - University of Alberta
 - University of Calgary
 - University of Lethbridge



Alberta SPOR SUPPORT Unit

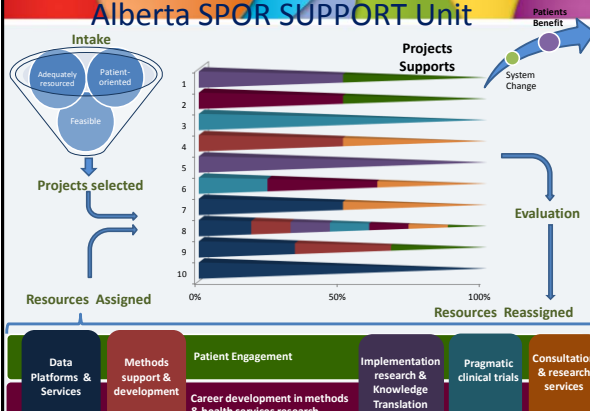
The Alberta SPOR SUPPORT Unit has seven core areas of expertise:

- RESEARCH MANAGEMENT** led by Dr. Virginia ...
- RESEARCH SUPPORT & DEVELOPMENT** led by Dr. ...
- RESEARCH PRIORITIZATION** led by Dr. ...
- RESEARCH EVALUATION** led by Dr. ...
- RESEARCH COMMUNITY ENGAGEMENT** led by Dr. ...
- RESEARCH CAPACITY BUILDING** led by Dr. ...
- RESEARCH COMMUNITY ENGAGEMENT** led by Dr. ...
- RESEARCH COMMUNITY ENGAGEMENT** led by Dr. ...

- Five platforms provide direct services to researchers.
- Two platforms, **Career Development and Pragmatic Clinical Trials**, help build capacity in Alberta's research community by providing a number of career development and training opportunities.



Alberta SPOR SUPPORT Unit



Intake

- Adequately resourced
- Patient-oriented
- Feasible

Projects selected

Resources Assigned

Projects Supports (1-10)

Evaluation

Resources Reassigned

System Change

Patients Benefit

Data Platforms & Services

Methods support & development

Patient Engagement

Implementation research & Knowledge Translation

Pragmatic clinical trials

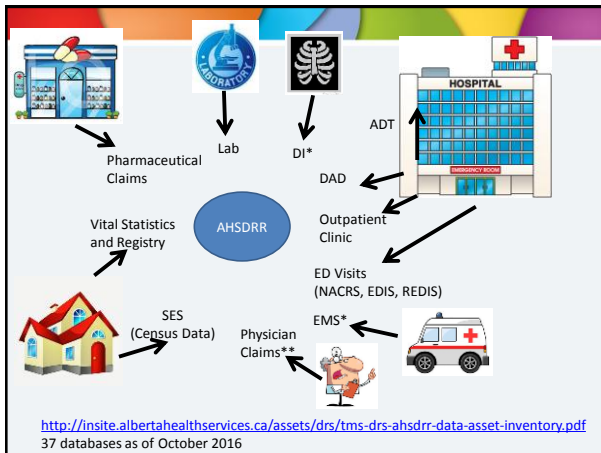
Consultation & research services

What does the ABSPORU Data Platform offer?

- Support Services for Research Involving **secondary analysis of existing Large Datasets** (*especially, but not limited to, administrative data*):
 - **Research Design**: methods, sample size, biostatistical plan, support letters for grants, assistance with Researcher Agreements
 - **Data Management**: data extraction, linkage, and cleaning
 - **Biostatistics**: consultations and/or analyses (if necessary, and in conjunction with **Methods Support platform**)
 - **Training** (in conjunction with **Training and Methods Support platforms**): emphasis on practicums, theses.

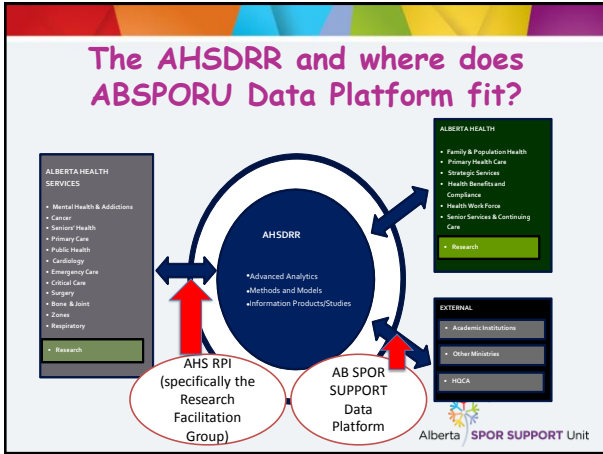
But Not

- Incubation/development of research questions and choice of study methods (primary vs. secondary data sources, RCT vs. cohort, etc)
- Support for primary data collection studies
- ➔ **Consultation and Research Services Platform**



25 pages of info on datasets in the AHSDRR

- Inpatient - Discharge Abstract Database (**DAD**)
 - Available from: April 1, 2002 to current
 - **Data refresh** occurrence: Monthly
- Laboratory (Lab R1 and R1.1)
 - Available from: LabFusion: Jan 1, 2009 to current. Meditech: Jan 1, 2009 to current. Millennium: Apr 1, 2012 to current. Sunquest: Apr 1, 2012 to current.
 - **Data refresh** occurrence: Daily (with up to 8 days latency)
- Provincial Registry
 - Available from: Fiscal Year End 1994 – March 31, 2014
 - **Data refresh** occurrence: Annually
- NACRS
 - Available from: April 1, 2010 to current
 - **Data refresh** occurrence: Monthly



Resources

- Infrastructure support:
 - DIMR: biostatisticians and data managers/analysts
 - Computers, stats software, CPE funds
- **NOT OPERATIONAL FUNDS, NOR MATCHING FUNDS**

How to access services: www.absporu.ca

Home » Initiatives & Partnerships

THE ALBERTA SPOR SUPPORT UNIT

The Alberta SPOR SUPPORT Unit is dedicated to the integration of research into care, so that the right patient receives the right care at the right time. We foster evidence-informed health care by bringing innovative diagnostic and therapeutic approaches to the point of care, to ensure greater quality, accountability, and accessibility of care.

Alberta SPOR SUPPORT Unit

Home Requests Application Forms FAQs Contact Us

Welcome to the Alberta SPOR SUPPORT Unit

How can we help you?

If you are an Alberta or Northwest Territories based researcher who has a project with a patient-oriented focus, the Alberta SPOR SUPPORT Unit (ASPORU) can help you connect with a network of services, expertise and resources to help accelerate your research. We offer training opportunities and services (rather than research operating grants) through seven ABSORU Platforms to support patient-oriented research from initial concepts through to analysis of a study.

What types of services can I apply for?

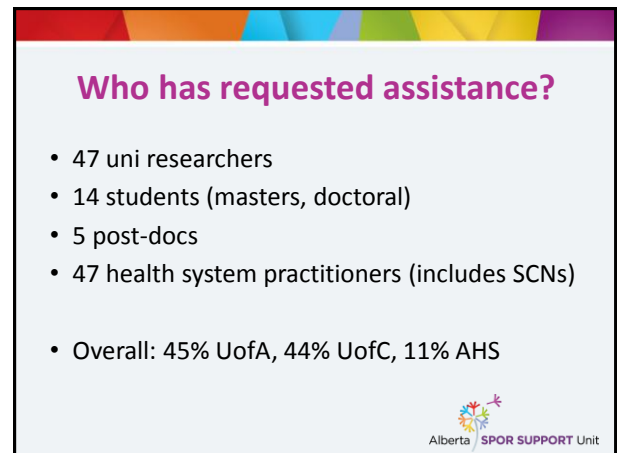
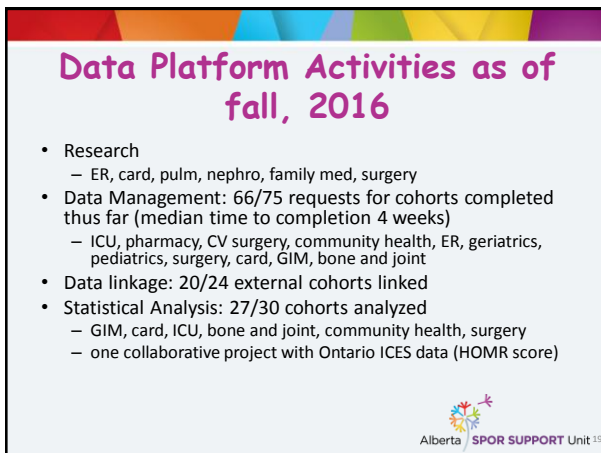
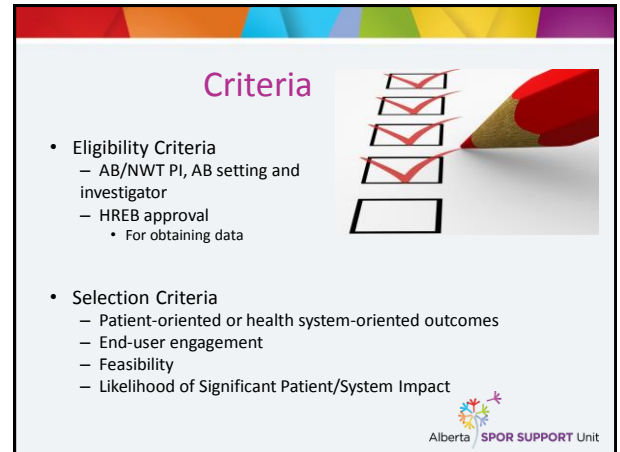
There are two types of requests that you can apply for:

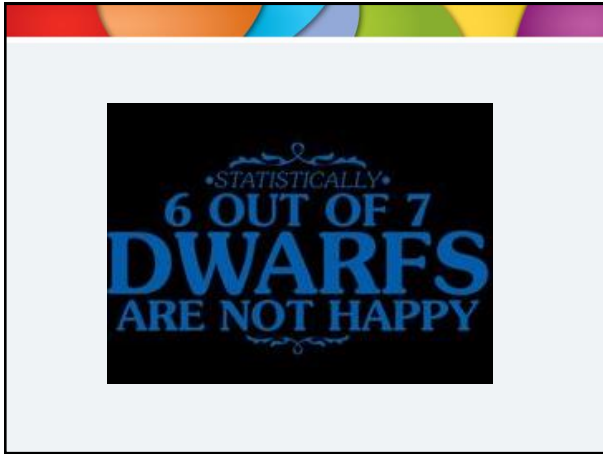
Project Services: ABSORU platforms provide a variety of services to help accelerate your research, from initial concept through to analysis of a study. A detailed description of each platform and the services they offer can be found at absporu.ca.

Letter of Support: ABSORU platforms can provide you with a letter of support (e.g. for submission to grant funding agencies). We encourage requests to be submitted as early as possible to allow sufficient time to review your project and customize the letter we may provide.

What do I need to submit?

Project Services: complete the request form, which provides us with information about your research project and the services you are requesting. Request form is available in French and Spanish. For more information, please contact us at abs@absporu.ca.





Application form

– Contact information

1 Primary Contact (primary contact for which questions about your application will be directed to)


Name	
Phone Number	
Email	
Mailing Address	

2 Principal Investigator (complete if different from the primary contact identified above)

Name	
Phone Number	
Email	
Mailing Address	

3 Investigator Team (if applicable)

Name	Email	Phone Number



Application form

– Study information

4 Study Title (to be used)

5 Study Stage (Please indicate the current stage of your study)

<input type="checkbox"/> Priority setting	<input type="checkbox"/> Preparing ethics application	<input type="checkbox"/> Disseminating (End of Project)
<input type="checkbox"/> Project recruitment/feasibility	<input type="checkbox"/> Collecting data	<input type="checkbox"/> Other (please specify below)
<input type="checkbox"/> Preparing grant application	<input type="checkbox"/> Analyzing data	

Other (specify):

6 Research Ethics Approval (If you can see the [Research Ethics Approval](#) section of our website for more details, is ethics approval required for your study?) No Yes

If YES, has ethics approval been obtained? No Yes

If YES, please provide the ethics approval number with your submission to the panel.

If ethics approval is required for your study, please provide a full written or audio description of the research to be conducted during the panel meeting to support the ethics review.

7 Timeline (Please specify the date and provide a short justification of when the requested services and/or expertise from the Alberta SPOR Support Unit (Mathematics) are required.)

Date: (DD/MM/YYYY)

Justification:

8 Resources (Please include all that apply. Detail both the funding opportunities/resources available to you. Human resources can include the operational team members who are/will be lined up to help with the project (e.g. research assistants, research fellows, administrative, etc.)


Grant funded Match funding or organizational support Unfunded Human Resources Other (describe)

Application form

– Study information

9 Lay Abstract (Briefly describe the research plan in lay language suitable for a lay reader with no experience in your research area) (200 characters)

10 Project Description (Please use the following as a starting point: Background, Justification, Research Question, Approach, Identification, Qualities or Novelty/Methods. This should be suitable for a reader with no specialist understanding of your research area. All areas should be addressed when completing an application to ensure support for the granting agency in terms of feasibility of the project and a match for the panel as possible. Provide as much detail as you have available in your methodology including procedures/setting, timeline in a research plan if applicable, data sources, sample size estimates and any additional URL(s) (e.g. www.1000characters.com)



Application form

11 Patient-Oriented Research (POR)
 POR refers to a continuum of research that engages patients as partners, focusses on patient-identified priorities and improves patient outcomes. This research, conducted by multidisciplinary teams in partnership with relevant stakeholders, aims to apply the knowledge generated to improve healthcare systems and practices.

Please indicate which aspect of POR your research applies to: (select all that apply)

<input type="checkbox"/> Engages patients as partners	<input type="checkbox"/> Has the potential to improve patient outcomes
<input type="checkbox"/> Focuses on patient-identified priorities	<input type="checkbox"/> Seeking support from the Patient Engagement Platform (please provide further details in Section 15)

Describe how your research meets the aspect(s) selected above.

Application form


– Required support from ABSPORU

14 Support Requested from the Alberta SPOR SUPPORT Unit
 Please indicate if you are seeking support for a project involving primary data collection or use of secondary data, if applicable. This will help us to determine which platforms are most relevant to provide you with support.

Have you been in contact with a Platform already? Yes No

If YES, please indicate which Platform(s):

<input type="checkbox"/> Data	<input type="checkbox"/> Methods Support & Development	<input type="checkbox"/> Consultation & Research Services
<input type="checkbox"/> Patient Engagement	<input type="checkbox"/> Knowledge Translation	



Application form

– Platform services


For assistance with patient engagement

Patient Engagement Platform	
<p>Project Refinement & Feasibility</p> <ul style="list-style-type: none"> <input type="checkbox"/> Reading list about Patient Engagement in research <input type="checkbox"/> Advice re: general plan for Patient Engagement <input type="checkbox"/> Advice about Patient Partners in: <ul style="list-style-type: none"> <input type="checkbox"/> Governance <input type="checkbox"/> Preparatory/Planning <input type="checkbox"/> Design/Execution <input type="checkbox"/> Translation/Dissemination <input type="checkbox"/> Advice regarding evaluating Patient Engagement efforts <input type="checkbox"/> Grant review 	<p>Project Services</p> <ul style="list-style-type: none"> <input type="checkbox"/> Priority setting advice <input type="checkbox"/> Publicizing/mobilizing/matching <input type="checkbox"/> Mentoring <input type="checkbox"/> Facilitation <input type="checkbox"/> Education/training <input type="checkbox"/> Governance <input type="checkbox"/> PE tools

Application form

For projects involving large secondary datasets


Methods Support & Development Platform	
<p>Project Refinement & Feasibility</p> <ul style="list-style-type: none"> <input type="checkbox"/> Discussion of data possibilities <input type="checkbox"/> Identification of variables <input type="checkbox"/> Identification of data sources <input type="checkbox"/> Advice on development of innovative methods <input type="checkbox"/> Advice on data collection methods <input type="checkbox"/> Protocol development <input type="checkbox"/> ICD coding algorithms <input type="checkbox"/> Risk adjustment methodologies 	<p>Project Services</p> <ul style="list-style-type: none"> <input type="checkbox"/> Methods support <input type="checkbox"/> Risk adjustment



Application form

Data Platform (for examination of publicly held datasets such as AHS DIMR data holdings)

Project Refinement & Feasibility	Project Services
<ul style="list-style-type: none"> <input type="checkbox"/> Identification of a cohort of patients <input type="checkbox"/> Information on database and variable time periods <input type="checkbox"/> Identification of data sources <input type="checkbox"/> Development of biostatistical plans for analysis <input type="checkbox"/> Information on repository owners and access protocols <input type="checkbox"/> Case volume estimates <input type="checkbox"/> Running pilot test data <input type="checkbox"/> Data release agreements 	<ul style="list-style-type: none"> <input type="checkbox"/> Data procurement <input type="checkbox"/> Data cleaning <input type="checkbox"/> Linking and merging of data <input type="checkbox"/> Generation of control groups <input type="checkbox"/> Analysis and dissemination of study results <input type="checkbox"/> Outcomes modelling <input type="checkbox"/> Data visualization



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Application form

15 Support Required
Please provide more details of the support you require, indicating how the support will benefit your research project. (1500 characters)

Please indicate if you are an:

Early career researcher

Researcher new to Alberta

If **yes**, please submit a short form CV with your application (template available for download).



CRS activities to date

- Launched November 2015
- 24 pre-consults
 - 10 led to portal applications
 - 14 active pre-consults
- Services requested
 - 93 % Design/Methods
 - 21% Analytical plan preparation
 - 7% Sample size calculation



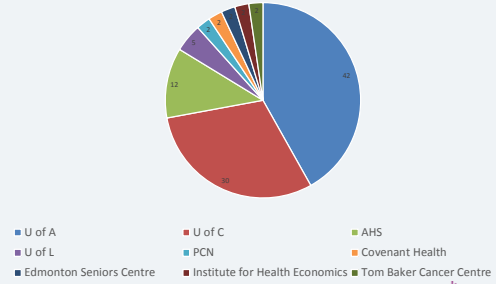
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Portal applications

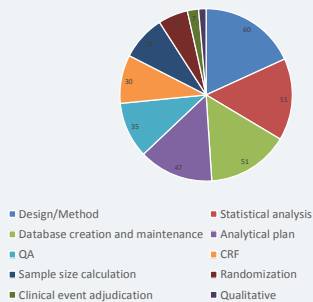
- Applicants are students, residents, postdocs, nurses, clinicians, professors
- 33% were early career researchers
- 7% were new to Alberta



Application sources



Services requested



Application form

For projects involving primary data collection (original data that is being collected for the first time to answer the research question(s)) using qualitative and/or quantitative methods

Consultation & Research Services Platform

- Project Refinement & Feasibility**
- Research question refinement
 - Project design consultation
 - Methods consultation
 - Grant review
 - Pilot projects
 - Development of analytical plans
 - Sample size calculations

- Project Services**
- Development of case report forms
 - Database development and maintenance
 - Randomization
 - Data entry
 - Quality assurance
 - Statistical analysis
 - Clinical event adjudication



Knowledge Translation (KT) Platform

Our long-term vision for Alberta SPOR KT Platform is increased capacity in the Alberta health care research environment for effective, evidence-based work in KT and integration of KT into patient-oriented research (POR) activities.

Knowledge Translation

- A dynamic and iterative process that includes the **synthesis, dissemination, exchange** and ethically-sound **application of knowledge** to improve the health of Canadians, provide more effective health services and products and strengthen the healthcare system.
- This process takes place within a complex system of interactions between researchers and knowledge users which **may vary in intensity, complexity and level of engagement depending on the nature of the research and the findings as well as the needs of the particular knowledge user** (Graham, 2010).

CIHR definition (www.cihr-irsc.gc.ca/e/29418.html)



KT Platform: Scope

- We offer consultation, support and training in:
 - Knowledge synthesis (KS)
 - Knowledge translation (KT)
 - Implementation science (IS)
- We work with researchers across Alberta who require assistance with their patient-oriented research projects.

KT Platform: Rationale

- Our plan was developed based on an extensive needs assessment with members of the community we serve, across the province and all stakeholder organizations

KT Platform: Rationale

- Needs:
 - Training and professional development
 - Consultations
 - KT expertise and technical support
 - Means to develop and implement KT interventions
 - Community of practice
 - Timely and targeted knowledge syntheses
 - Common language and understanding

KT Platform: Critical activities

- 3C Model:
 - Consultation services
 - Community of practice
 - Capacity Building

KT Platform: Critical activities

- Consultation services
 - Responding to applications submitted through the Research Alberta portal that are:
 - Focused on work in KS/KT/IS
 - POR projects where support is needed to develop integrated or end-of-project KT plans

KT Platform: Critical activities

- Community of practice
 - A community of practice model being used to build linkages and networks among Alberta researchers interested in KS/KT/IS research or integrating these concepts into their POR.

KT Platform: Critical activities

- Capacity building
 - Training and professional development activities, including dedicated working groups, to:
 - Increase researchers' awareness of KS/KT/IS science
 - Develop researchers' abilities and capacity to move KS/KT/IS science forward
 - Embed KS/KT/IS considerations in POR

KT Platform Services

Administrative Director

Denise Thomson, MA, MBA



KS Consultations

Meghan Sebastianski, PhD



KT & IS Consultations

Gabrielle Zimmermann, PhD



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Application form

For assistance with knowledge translation, synthesis & implementation science

Knowledge Translation Platform

Project Refinement & Feasibility

Knowledge Synthesis

- Literature searching
- Systematic reviews
- Rapid reviews
- Scoping reviews
- Practice guidelines
- Critical appraisal

Knowledge Translation (KT) & Implementation Science

- Integrated Knowledge Translation (IKT)
- End of Grant/Project KT
- KT Implementation Strategies

Project Services

Knowledge Synthesis

- Literature searching
- Statistics (Meta-analysis)
- Systematic reviews
- Rapid reviews
- Scoping reviews
- Practice guidelines
- Critical appraisal
- Mentoring
- Grant Review

Knowledge Translation (KT) & Implementation Science

- Integrated Knowledge Translation (IKT)
- End of Grant/Project KT
- KT Implementation Strategies
- Stakeholder management
- Mentoring
- Grant Review

For More Information

- Email spor@albertainnovates.ca
- Or visit absporu.ca

Alberta  SPOR SUPPORT Unit

 SPOR
Supporting Patient-Oriented Research

 CIHR IRSC

 Alberta
Innovates
Health
Solutions

Patient-Oriented Research

Patient-oriented research refers to a continuum of research that engages patients as partners, focusses on patient-identified priorities and improves patient outcomes. This research, conducted by multidisciplinary teams in partnership with relevant stakeholders, aims to apply the knowledge generated to improve healthcare systems and practices (CIHR, 2014).



Patient-Oriented Research

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

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



Focuses on patient-identified priorities

Priorities maybe identified through

- Core Outcome Sets (the minimum that should be measured and reported in in all clinical trials of a specific condition) that have been developed with stakeholder involvement
- Focus groups
- James Lind Alliance association top 10 uncertainties or un answered questions about a condition (priorities set by patients, carers and clinicians)
- Online priority setting activities



Meaningfully engages patients as partners

SPECTRUM OF PATIENT ENGAGEMENT IN RESEARCH
Increasing Levels of Patient Involvement

	LEARN/FORM	CONSULT	INVOLVE	COLLABORATE	LEAD
Patients' Goal?	To learn about research & getting involved to act	To more formally provide opinion/ feedback	To work directly & honestly with research team	To partner on equal footing with researchers in all aspects of research	To make decisions and lead research activities
Researcher promise to the Patient	"We will provide you with information and hear & answer questions"	"We will value you & see your input"	"We will work directly with you"	"We will partner equally with you"	"We will follow your lead & support your wishes"
How can this be done?	In an open atmosphere for sharing knowledge and asking questions; sometimes one-on-one; Through Orientation, Education, Sessions & Research	Through priority setting, cafes, focus groups, working groups	Working groups, cafes, health panels	Patients as co-members of Patient Committees	Patient Advisory Committees/ Patient led research



Has the potential to improve patient outcomes

Examples include

- Patient Reported Outcome Measures (PROMS)
- Patient Reported Experience Measures (PREMS)
- Patient satisfaction
- Quality of life
- Management of symptoms and pain
- Potential clinical improvements
- Length of stay
- Cost effectiveness