Strategy for Patient Oriented Research

Support Units
Disclosure

• I have no relationship that could be perceived as placing me in a real or apparent conflict of interest in the context of this presentation.
Presentation Objectives

✓ To Discuss:
  - Introduction to SPOR – National/Alberta Context
  - Overview of Alberta’s SPOR SUPPORT Unit.
  - Progress to Date
  - Next Steps

✓ To Answer Questions
ISSUE: There is a GAP between RESEARCH BASED KNOWLEDGE and HEALTH CARE PRACTICE

BARRIER: Research is often too far removed from health care clinicians, policy-makers, patients, and other key stakeholders.

SOLUTION: The Strategy for Patient-Oriented Research (SPOR) represents a coalition of federal, provincial and territorial partners – working in common cause and dedicated to the integration of research knowledge into care.

Patient-oriented research aims to ensure that the right patient receives the right intervention at the right time.
PATIENT-ORIENTED RESEARCH

• Focuses on patient-identified priorities

“Putting Patients First”

Patient-Oriented Research means tapping into what ultimately matters to patients:

✓ Improved health
✓ Improved access to the health care system
✓ Receiving the right treatment at the right time
✓ Being an active and informed partner in health care
✓ Quality of life that is tied to patient-oriented outcomes
SPOR CORE ELEMENTS

- Support for People and Patient-Oriented Research and Trials (SUPPORT) Units
- SPOR Networks
- Training and capacity development
- Improving the clinical trials environment
- Patient engagement
SPOR Principles

- Patients need to be involved in all aspects of the research to ensure questions and results are relevant and integrated into practice

- Decision-makers and clinicians need to be involved throughout the entire research process to ensure integration into policy and practice

- Funding under SPOR is based on a 1:1 matching formula with non-federal government partners to ensure relevance and applicability

- Effective patient-oriented research requires a multi-disciplinary approach

- SPOR is metric driven and incorporates performance measurement and evaluation as integral components of the initiative
SPOR NETWORKS

SPOR Networks: national collaborations of patients, health professionals, decision makers, health researchers and other stakeholders to generate evidence and innovations designed to improve patient health and health care systems

OBJECTIVES:

• Establishing priorities and developing a nation-wide agenda of outcomes-oriented research

• Developing and implementing evidence-informed practices, policies, services, products and programs to improve patient outcomes, access to care and quality, efficiency and effectiveness of health care

• Accelerating the translation of new knowledge into clinical applications, practice and policy

• Strengthening the capacity to conduct patient-oriented research through training and mentoring initiatives
SPOR SUPPORT UNITS

SPOR SUPPORT Units: provincial service centres providing support and expertise to those engaged in patient-oriented research including: a focus on data access, methodological and research services, knowledge translation, clinical trials and capacity development

STATUS UPDATE

- Alberta, Manitoba, Maritimes (PEI, NB, NS) and Ontario have been approved and are in the grant agreement process
- Newfoundland and Quebec are in the iterative review process
- British Columbia and Saskatchewan are developing proposals
- The Territories are working on a strategy to intersect with SPOR
TRAINING & CAPACITY

**SPOR Training and Capacity Development Strategy:** attracting, training and mentoring health care professionals and patient-oriented researchers including within SUPPORT Units and SPOR Networks

**Key Observations of the External Advisory Committee:**

- Canada needs a greater number and breadth of patient-oriented researchers
- A **systems problem** (vs. programmatic) problem in patient-oriented research training and career development – A **systems approach** is needed to maximize investments in patient oriented research training and career development.
- A consortium or network-type model can transform the system to create the patient oriented research jobs we need and the people trained to excel in them
The **Canadian Clinical Trials Coordinating Centre (CCTCC)** is being developed to:

- Measure, monitor and market clinical trial performance improvements
- Leverage existing work on accreditation, harmonization and streamlining ethics reviews and common contracts
- Develop a database of patient registries and consider national recruitment strategies
- Attract international investment in clinical trials
Patient Engagement: including patients in decision making and involving them directly in the research process

- Improved patient experience with the health system and health outcomes
- Patients influence and accelerate decision making and uptake of new practices
- Research is conducted in areas patients value
- Researchers understand the value of patient involvement and patients understand the value of research
- Provide input on identifying health research priorities
- Participate in the design and undertaking of research projects

Patients

Researchers, health care professionals and policy-makers work together with patients to ensure a patient-oriented approach that improves both practice and treatment
A National Integrated Network

Community-Based Primary Healthcare Research Network
Mental Health Research Network

Approved official Units 3/10/13
Bringing Research based Knowledge to Care

Adopted with Permission from Dr. Simon Sutcliffe
Realization of potential (%)

Improved Health Outcomes; Policy; Practice

Application

Discovery

Clinical validation

Population application

Infrastructure, Health Technology, Investment

Time (years)

Realization of potential (

Infrastruc

Clinical va
dation

Discovery

Population application

Application

Infrastruc
SPOR SUPPORT Units: Value Proposition:
Translation of knowledge into policy and practice

Steepening the ‘slope’

Speed of subject development within the constituency of interest

Preparedness & receptiveness of constituencies to receive, adapt & adopt

Shortening the ‘gap’
Mapping Alberta’s Strategy for Patient-Oriented Research: SUPPORT Units

Slope and Gap Functions:
- Data Platforms and Services;
- Methods Support and Development;
- Real World CTs;
- Consultation and Research Services
- Patient Engagement
- Career Development – HQP
- Health Systems, KT Implementation
Alberta SPOR SUPPORT Unit: Organizational Structure

As at: October 28, 2013

Black boxes comprise the AB SPOR SUPPORT Platforms

Alberta Innovates Health Solutions (AIHS) Board of Directors

CIHR SPOR SUPPORT Coordinating Group

Alberta SPOR SUPPORT Steering Committee

Alberta SPOR SUPPORT Unit Management Team

International Scientific Advisory Committee

Data Platforms and Services

Methods Support and Development

Pragmatic Clinical Trials

Health Systems, KT Implementation

Consultation and Research Services

Patient Engagement

Career Development in Methods and Health Systems Research

Other Groups

SCN/OCN Research Leads and Staff

Patients
Alberta SPOR Support Unit
Milestones and Deliverables

START-UP

August 1, 2013 – December 31, 2013
- Organizational Chart
- Steering Committee Terms of Reference
- Platform Leader Selection Process
- November 8, 2013 – Announcement of Alberta’s SPOR SUPPORT Unit...First in Canada!

GROWTH and DEVELOPMENT

January 1, 2014 to March 31, 2014
- Response to Administrative Review – completed
- Signing Agreement with CIHR
- Platform Lead Selection
- SPOR Management Team Development
- Business Plan/Value Proposition Development for each unit
- 3 Demonstration Projects
- Shift: Planning to Execution

IN PROGRESS

April 1, 2014 - on
- Delivering on Agreement with CIHR
- Detailed work plan; governance structure; training strategy; patient engagement plan; performance measurement strategy, capturing lessons learned/ sharing best practices – SPOR SUPPORT Unit Council

NEXT STEPS
Alberta SPOR SUPPORT Unit

Key Messages:

• Not Operating grants – but rather - enabling infrastructure – new capacities and approaches to research.
• Transformative, change focused
• Sustainability and Impact
• Coordinated – no duplication, substitution or extension
• Core philosophies – the translation of knowledge into policy and practice
Questions?

Thank you