

Strategy for Patient-Oriented Research

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Putting Patients First

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Capacity Development Framework

2015

Acknowledgements

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Introduction

Patient-oriented research is the cornerstone of evidence-informed health care and encompasses both clinical and health services research as well as the synthesis, dissemination and integration of this new knowledge into the health care system and into clinical practice. Patient-oriented research is not only about what research we do but how we do it; the essence of patient-oriented capacity is not just what capacity we have, but how we use it. Canada's Strategy for Patient-Oriented Research (SPOR) is about ensuring that the right patient receives the right intervention at the right time and consists of a coalition of federal, provincial and territorial partners including patients and caregivers, researchers, health practitioners, policy makers, health authorities, academic institutions, charities and the private sector.

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Capacity for patient-oriented research within SPOR requires that all partners are trained, aligned, prepared, and working collaboratively towards the common goal of increased access to high quality health care and improved patient outcomes. In order to accomplish this, there needs to be strategies in place to guide and foster a culture of learning and collaborating within patient-oriented research and the health care system as well as a clear plan for the future. Capacity development is embedded into SPOR activities, including the SPOR SUPPORT Units and SPOR Networks; however, there is a need to consider this key issue as a distinct element in order to develop a coherent framework to guide these activities and develop a common, collaborative approach to capacity development.

As a first step to understanding capacity development in SPOR, a SPOR External Advisory Committee on Training and Career Development was created. This committee performed extensive research on this topic, including a large workshop with stakeholders, which informed the development of their *Report on Training and Career Development in Patient-Oriented Research*. Building on this report, CIHR held an additional workshop to develop a common vision for patient-oriented research capacity in Canada. This SPOR Capacity Development Framework stems from this work and reflects consultations with the SPOR SUPPORT Units and Networks as well as the workshop participants.

Purpose

This SPOR Capacity Development Framework is meant to be collectively adopted and serve as a guide for capacity-building activities of all SPOR partners, including CIHR, in the development of each partner's individual capacity development action plans. Each component of SPOR (e.g. each SUPPORT Unit and Network) is expected to identify their community's capacity development needs and priorities, and develop concrete objectives, targets and activities to meet these needs. Each partner is expected to develop their own capacity-development action plans which align with this framework and contain plans for resource allocation, oversight, performance measurement and sustainability. This Framework is intended to be a living document that will be reviewed and updated as required to maintain its relevance. It is hoped that this Framework will also be useful to other parties interested in building capacity in patient-oriented research.

This framework has strong links to the SPOR Patient Engagement Framework, as both patient engagement and capacity development underpin SPOR. We invite you to refer to the SPOR Patient Engagement Framework for further information on patient engagement.

Issues and needs

The SPOR External Advisory Committee on Training and Career Development completed extensive literature reviews and found consensus around the essential characteristics of successful training and career environments in patient-oriented research. The following are adapted from their Report on Training and Career Development in Patient-Oriented Research.

Essential characteristics of **training environments** in patient-oriented research:

- Multidisciplinary mentorship
- Training in multiple environments
- Professional skills development
- Best practices and resource sharing

Essential characteristics of **career support** in patient-oriented research:

- Balance and value of clinical and academic goals
- Explicit and equitable job expectations, resource provision and compensation
- Expectation of, and support for, systematic mentorship

Canada is facing a challenge in its capacity to translate the results of health research into clinical practice and health care decision-making, which are essential for effective health care. There is insufficient capacity to translate the results of discoveries generated by basic biomedical research in the laboratory into care settings, as well as limited capacity to synthesize, disseminate and integrate research results more broadly into clinical practice and health care decision- and policy-making.

A number of factors contribute to this challenge, among which the following have been identified as priorities for this Framework:

- limited involvement of patients and communities in health research
- lack of incentives for researchers to pursue research topics with real world applications
- limited opportunities to establish multidisciplinary teams which include clinicians
- lack of certain specialized expertise such as non-physician clinician scientists, methodologists, biostatisticians and health economists.

A systems-wide approach is needed to bring about a culture change, link partners together and effectively support training and career development in patient-oriented research.

There is a need to begin effecting a culture of learning and improving in order to catalyze broader changes to the health system. Capacity-building is a critical building block in achieving the goal of fostering a collaborative environment where patients are empowered, clinicians engage with patients, researchers and policy-makers, and researchers work collaboratively across disciplines

“For clinicians, particularly non-physicians, there are limited opportunities to combine both research and clinical work, and even fewer which effectively support both roles in practice. For most health clinician-scientists, this lack of jobs – especially outside academic health science centres - is the top challenge.”

- Report from the SPOR External Advisory Committee on Training and Career Development

Vision

To grow, support and sustain the capacity for a collaborative, interdisciplinary and innovative patient-oriented research environment capable of addressing evolving health care questions, contributing to enhancing patients' health care experience and improving health outcomes.

Objective

The SPOR Capacity Development Framework is designed to provide a shared vision, key principles and considerations for capacity development to guide the activities of all SPOR partners in this area.

Definitions

The definitions below represent a shared understanding of the terminology used throughout this framework and other SPOR initiatives.

Patient-Oriented Research:

Patient-oriented research refers to a continuum of research that engages patients as partners, focusses on patient-centric priorities and improves patient outcomes individually and in communities such as vulnerable populations. This research, conducted by multidisciplinary teams in partnership with relevant stakeholders, aims to apply the knowledge generated to improve healthcare systems and practices.

Patient:

Patient is an overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends.

SPOR Partner:

SPOR partners are key stakeholders collaborating in patient-oriented research, such as relevant ministries within the provinces and territories, patients, researchers, health practitioners, policy makers, decision-makers, health organizations, provincial/territorial health authorities & funders, academic institutions, charities, professional societies and the private sector.

Patient-oriented research capacity means

- *Patients have the capability and support to meaningfully contribute to and participate in research*
- *The health research enterprise supports viable career paths for patient-oriented researchers and health professionals*
- *All participants in patient-oriented research receive the proper training and support*
- *Patients, researchers, health practitioners, administrators, and policy-makers work collaboratively towards common goals*
- *Relevant and transformative knowledge is generated and applied to improve health outcomes*

Capacity Development in SPOR Networks and SUPPORT Units

All of SPOR's present and future core elements are required to adhere to the principle of capacity development and develop concrete action plans. The following are some non-exclusive examples:

- i. **SUPPORT Units:** Each SUPPORT Unit will develop and implement a training and capacity development strategy which includes measurable objectives, clearly identified needs, plans and delivery mechanisms.
- ii. **SPOR Research Networks:** Networks will establish concrete plans and targets for the capacity building, training and mentorship programs in order to develop capacity for patient-oriented research within their particular area of focus.

Both SUPPORT Units and SPOR Networks will track and report on results of their training and capacity development activities.

Guiding Principles for Capacity Development

The following principles are intended to guide the overarching efforts of all SPOR partners in developing capacity for successful patient-oriented research, which are expected to happen at an individual level as well as organizational level.

Ensuring capacity for meaningful patient engagement

Ensure that patients and communities have the capacity to be engaged in all stages of research, and that researchers and health professionals recognize the value of patient inclusion in research and have the capacity to effectively collaborate with patients.

Mobilizing existing expertise

Build capacity for patient-oriented research by tapping into the diverse skill sets already in existence and reorienting them to be able to participate fully in patient-oriented research. This could include opportunities for training, collaboration and mentorship across all domains within health research.

Supporting careers

Build capacity in areas of identified need such as clinical investigators, biostatisticians and health economists by raising the profile of those career opportunities that are particularly conducive to patient-oriented research and creating supportive environments that include training and mentorship opportunities.

Collaborating

Support a collaborative, interdisciplinary approach to patient-oriented research by fostering integration, respect and mentorship among patients, researchers, health practitioners, administrators, and policy-makers.

Building capacity to apply research to real world problems

Enhance capacity to translate the knowledge gained through research and collaboration into practice, and to generate evidence informed by practice. Partners can then better identify the right problems, propose solutions relevant to patients and real world situations and implement, adapt and scale up effective solutions.

Core Considerations for Capacity Development

These Core Considerations are intended to be used in conjunction with the Guiding Principles to design the individual capacity development actions proposed by each SPOR participant. Each action proposed should be related to one or more guiding principles, and take into consideration the commitment of all necessary parties, the diverse needs of the stakeholders involved, and the tools and resources available or required to ensure success.

1. Commitment

In order for capacity development to be effective, all stakeholders must be open and committed to contributing, implementing, learning and growing. All partners participating in SPOR must be committed to working collaboratively and dedicated to taking on leadership roles in effecting change in the health care landscape. Success will be dependent on the dedicated time and support from all SPOR partners in order to encourage, promote and reward the efforts of all those involved in building capacity for patient-oriented research.

2. Diverse needs

Patient-oriented research encompasses a large variety of interdependent stakeholders including patients, researchers, policy makers, health systems leaders, and health professionals, to be engaged in the research activities. Each of these stakeholders would have different needs with regards to training, engagement and careers in effective patient-oriented research. Each participant has the potential to act as both learner and teacher to the rest of the team, meaning that everyone has something to contribute to the whole and that all parties will become more effective as they increase their understanding of the system and its various components and participants. Moreover, it is important to recognize that certain groups of people have experienced institutional disadvantages and therefore we need to ensure equity and to eliminate barriers to their access and participation. Approaches to capacity development must be tailored to the different needs and perspective to ensure that everyone can participate fully and receive maximum benefits from patient-oriented research.

3. Tools and resources

There are a number of existing tools, resources and best practices in patient-oriented research and in capacity development; it is important that we identify, share and learn from these to build upon their proven success. In addition to learning from existing practices, new tools and resources will be built, customized and implemented as SPOR progresses. As best practices are identified or developed, it is important to seek out collaborative opportunities, as appropriate, with the partners that have developed and/or implemented these practices to learn from their experience and expertise. To meet the evolving challenges in building patient-oriented research capacity, it is imperative to maintain an environment open to continuous learning and improvement.

The action plans are expected to vary based on the identified needs of the target community for each participant and the corresponding capacity development objectives and targets. As such, frameworks for communication, resource allocation, implementation, performance measurement, change management and sustainability will vary accordingly and are to be articulated in the individual action plans.

Desired Outcomes of Capacity Development in SPOR

Outcomes of the capacity development efforts will be seen in the long term. By growing and supporting capacity for patient-oriented research, it is expected that research will be conducted by multi-disciplinary teams, in collaboration with all stakeholders, where patients, researchers and health practitioners work together to contribute to improved and sustainable health systems and outcomes.

Long-term (10-year) outcomes of successful capacity development would include:

- *A learning health system that integrates research practices into health care and decision-making*
- *Collaborative, integrated research teams and training environments*
- *Attractive, sustainable career paths available for those engaged in patient-oriented research*
- *Patients and other stakeholders effectively working together to meet shared patient-oriented research capacity goals*
- *Diverse resources aligned, connected and coordinated*

Participants of the SPOR Workshop on Capacity Development, held in Toronto on March 31, 2014, described a future state for patient-oriented research. The medium- and long-term outcomes are based on the results of these discussions.

Medium-term outcomes

- Diverse resources are connected and coherently working towards common goals
- Health leaders are demonstrably increasing priority, ownership of POR
- Patients (individuals and communities) are integrated into POR teams as partners and leaders
- Best practices are identified and continue to scale up and improve

“Needs and priorities will evolve over the next five years, with a likely shift from filling immediate gaps to investing in longer-term human resources development. As one respondent explained: For now, we are focusing on existing individuals and adding to their skill set - but in five years there’s going to be a new creature that doesn’t exist today. Our real goal is to develop new opportunities and thinking and careers.”

- Excerpted from pre-workshop interviews as documented in the discussion document for the 2014 SPOR Workshop on Training and Career Development

Conclusion

Patient-oriented research capacity is not just what capacity we have, but how we use it. SPOR aims to combine existing knowledge and expertise with effective collaboration, training, mentoring and support so that each participant in SPOR will be able to contribute their individual expertise to a broader research enterprise, to participate in and contribute effectively to a multidisciplinary, multi-professional patient-oriented research community and facilitate the application of research into practice. This framework, meant to guide the activities of the SPOR partners, is a first step towards achieving this goal.

SPOR Capacity Development Framework

VISION

To grow, support and sustain the capacity for a collaborative, interdisciplinary and innovative patient-oriented research environment capable of addressing evolving health care questions, contributing to enhancing patients' health care experience and improving health outcomes.

GUIDING PRINCIPLES



CORE CONSIDERATIONS



DESIRED OUTCOMES



Appendix 2: Core Competencies

The following core competencies were developed in consultation with various stakeholders. They can be seen as abilities that are important to creating an environment for conducting successful patient-oriented research. SPOR partners and SPOR-funded entities should use this list to inform their local capacity building efforts, such as building a training strategy, creating learning milestones, etc.

These core competencies apply to all people participating in patient-oriented research, including patients (an overarching term inclusive of individuals with personal experience of a health issue and their informal caregivers, including family and friends), health care professionals, decision-makers, policy-makers, researchers, and trainees. Certain core competencies may be more readily developed by some individuals depending on the situation, but in general, all participants should aim to develop these abilities and attitudes. Also, the core competencies should not be seen as pre-requisites in order to begin conducting patient-oriented research, but rather, they should be treated as goals and areas for capacity development over a period of time.

Participants are able to communicate effectively with others.

- Actively listen to other participants.
- Interact in a way that is respectful, non-judgmental and culturally safe.
- Contribute positively to discussions using their worldview and be able to look beyond one's personal experience.
- Find and use common language that all participants can understand and follow.

Participants are able to work with others in collaborative teams.

- Work cooperatively with others as part of a team or group towards a common goal.
- Discuss and define roles and responsibilities.
- Explore each other's perspective and experience.
- Share power to build trust.
- Build relationships by demonstrating respect, honesty and integrity.
- Recognize potential ethical issues that may arise.

Participants are able to describe how the health system works within their own province and within Canada.

- Demonstrate knowledge of how decisions are made and the key players involved.
- Describe how the health system provides and funds services at the national, provincial and local levels and how these levels are related.
- Demonstrate the ability to find information about the health care system in Canada.

Participants are able to describe health research.

- Describe the purpose of health research.
- Describe who conducts research studies and how research teams are formed and funded.
- Describe the stages of the research study, i.e., determining the research question, designing research tools, conducting research, analyzing results, and sharing the findings.
- Acknowledge that different methods can be used to conduct research.
- Articulate the importance of ethical considerations, especially with engaging patients.
- Describe the research funding process.

Participants are able to define and describe patient-oriented research.

- Describe the concept of research as a continuum (i.e., from bench to bedside).
- Articulate that patients must be engaged as partners with meaningful and active roles.
- Understand the uniqueness of each patient experience and ensure that patient-oriented research must integrate a diversity of patient perspectives.
- Articulate that patient-oriented research must focus on patient-identified priorities.
- Articulate that patient-oriented research must aim to improve patient outcomes.
- Articulate that patient-oriented research is conducted by multidisciplinary teams in partnership with relevant stakeholders.
- Articulate that patient-oriented research aims to apply the knowledge generated to improve healthcare systems and practices.

Participants are able to describe the evolution of patient roles in health care and health research.

- Describe the kinds of roles that patients in the past and what roles they can and are playing now.
- Describe how the movement towards patient partnerships in health care has led to a similar movement in health research.
- Understand that creating meaningful roles for patients in research represents a culture shift in general.

Participants are able to demonstrate an understanding that patients can bring added value to research.

- Demonstrate an understanding that the patient perspective is unique from research, clinical and policy perspectives.
- Describe the value of patients' experiential knowledge as evidence.
- Describe the areas where patients can provide added value in the process, i.e., the project design (including research question and objectives), the research method(s), the development of research tools, recruitment, data collection, data analysis, writing up the results, and disseminating the research results.
- Describe ways in which experiential knowledge impacts the research, such as improving the credibility of results, empowering the different participants involved, improving enrollment and retention, and increasing opportunity to share the results, etc.