

Patient Engagement and Canada's SPOR Initiative

A Resource Guide for Research Teams and Networks

Prepared by Julia Abelson, PhD

McMaster University

For the Ontario SPOR SUPPORT Unit

March 2015 (version 1.0)

Table of Contents

Background and purpose of the document.....	3
Key concepts & terms.....	5
High-level evidence summary.....	9
Guidance for researchers	12
Comprehensive ‘all-in-one’ resources.....	12
Patient recruitment resources.....	13
Patient compensation resources.....	15
Training and supports for researchers.....	16
Evaluation frameworks and tools	17
List of selected patient engagement resources.....	18
References.....	20

Acknowledgements

I would like to thank Dr. Antoine Boivin for his thoughtful comments on an earlier draft of this document and Asha Behdinan for her assistance with the literature review and preparation of the final document.

Background and purpose of the document

In 2011, the Canadian Institutes of Health Research announced Canada's Strategy for Patient-Oriented Research (SPOR). The vision of SPOR is to improve health outcomes and enhance patients' health care experience through the integration of evidence at all levels in the health care system (CIHR, 2011).

A primary goal of Canada's SPOR is "for patients, researchers, health care providers and decision-makers to actively collaborate to build a sustainable, accessible and equitable health care system and bring positive changes in the health of people living in Canada" (SPOR Patient Engagement Framework, 2014). Patient-oriented research, as described in the Strategy, refers to a continuum "that engages patients as partners, focuses on patient-identified priorities and improves patient outcomes" (SPOR PE Framework, 2014). The engagement of patients at various stages and levels of the research enterprise is seen as integral to the development, implementation and ultimate success of the SPOR initiative and its core elements (e.g., SUPPORT Units and Networks).

The idea of 'doing research with' lay individuals and communities has a long and rich tradition in the public health and social science research disciplines (Entwistle, 1998; Minkler, 2003; Baum et al. 2006). More recently, efforts to incorporate citizen and patient perspectives in clinical and health services research have been linked to social and political trends calling for democratic accountability of political institutions and challenges to the biomedical research community's control over the research process (Entwistle, 1998).

Since the 1990s, patients have become more actively involved in setting health research agendas in a variety of research communities such as breast cancer, AIDS, rehabilitation and midwifery (Entwistle, 1998). Despite these early examples, patient engagement in health research in Canada is at a nascent stage of development. This is also true in the U.S., which established its Patient Centered Outcomes Research Institute (PCORI) in 2010, just a year before Canada's SPOR was announced. By comparison, patient and public involvement in health research has had a much longer history in the U.K. Most of the academic literature on the subject has been published by U.K. researchers and important institutional markers exist such as INVOLVE, a national, government-funded organization, dedicated to supporting active public involvement in NHS, public health and social care research, and the recent launch of *Patient Involvement and Engagement*, the world's first co-led patient-research journal.

Recognizing the much less developed field in Canada, this document has been prepared with the objective of supporting researchers, decision makers and other relevant stakeholders involved in a wide range of SPOR-related activities.

In particular, this document seeks to:

- 1) Clarify key concepts and terms relevant to involving patients in health research such as what we mean by patients, the public and stakeholders, and the different levels and types of involvement and the rationales and perceived benefits of patient involvement;
- 2) Describe, at a very high level, the current state of the evidence about patient engagement with respect to the effectiveness of different methods in relation to process and outcome measures;
- 3) Assemble in one place, a selection of resource documents collected from leading patient engagement organizations around the world to provide basic guidance for researchers about principles and methods for involving patients in health research.

This document is intended to be a 'living' resource guide to be updated on a regular basis to reflect new developments in the field and the growing foundation for public and patient engagement in the Canadian health research community.

1. KEY TERMS AND CONCEPTS

Being clear about what we mean by patient engagement and related concepts is critical to supporting the *practice* and *science* of patient engagement. Due to the value-laden and multi-faceted nature of patient engagement, it is common to see the following terms used inconsistently and interchangeably in the literature: *communication, consultation, collaboration, involvement, participation, deliberation* or *engagement* of members of the *public, citizens, patients, service users, consumers* or *community*. This ambiguity may lead to conflicting goals and visions for patient engagement and more practically, conflicting views about who should be engaged, who is being represented, what role they should play, at which stages in the research process, and using which types of engagement mechanisms (Gauvin et al. 2014).

CIHR's jargon buster (<http://www.cihr-irsc.gc.ca/e/48952.html>) provides a number of helpful definitions for key SPOR-related terms:

Patient

An overarching term that includes individuals with personal experience of a health issue and informal caregivers, including family and friends.

Patient Engagement

Meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation. Depending on the context, patient-oriented research may also engage people who bring the collective voice of specific, affected communities.

Patients are not always easily distinguishable from *citizens*. As noted in the following definitions, CIHR takes an inclusive view of the term citizen as encompassing patients, health system users as well as a wide range of organizations that represent the interests of these individuals and groups.

Citizen

Encompasses interested representatives of the general public, consumers of health services, patients, caregivers, advocates and representatives from affected community and voluntary health organizations.

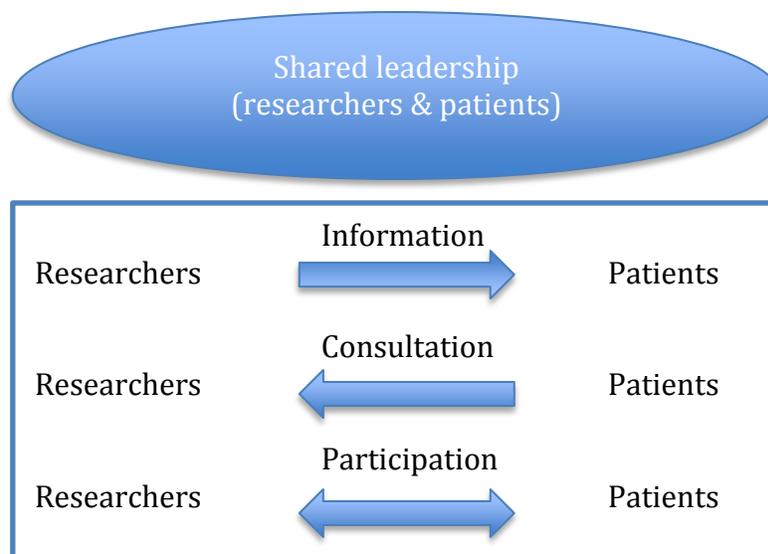
Citizen Engagement

The meaningful involvement of citizens in its activities, from agenda setting and planning to decision making, implementation and review.

The terms defined above are not perfectly consistent with terms used in the academic literature or by organizations in the engagement field. For example, INVOLVE – the NHS funded organization that promotes the active involvement of patients in health research - uses the term *public involvement* in all of its documentation although their definition of ‘public’ is similar to CIHR’s definition of citizen. These broadly-defined concepts of citizen and public overlap in part with another commonly used term – *stakeholder* - which is often defined as organized interests whether they be consumer, patient or community interests or the interests of health care providers or industry.

Confusion often arises with the various terms used to describe the involvement of citizens and patients in different activities and stages of health research. Numerous typologies have been developed to illustrate different levels or methods of engagement (IAP2 2014; Gauvin et al. 2010; Arnstein, 1969; Rowe and Frewer, 2005). Rowe and Frewer’s typology captures the core elements of most typologies and offers a simple yet instructive way to think about different methods of engagement. The three elements of the typology focus on researchers: i) sharing *information* with citizens or patients through various communication vehicles; ii) eliciting citizens’ or patients’ ideas through various *consultation* techniques; or iii) collaborating with citizens or patients interactively through *participatory* processes. Added to Rowe Frewer’s typology is the concept of shared leadership, where patients and researchers are full partners at the governance level and negotiate the goals and methods of engagement (Boivin et al. 2015).

Figure 1: Engagement typology



The NHS's INVOLVE provides helpful terminology and examples of the kinds of public involvement activities that could take place in the research process.

Involve (overarching term)

Where members of the public are actively involved in research projects and in research organisations.

Examples of *public involvement* are:

- as joint grant holders or co-applicants on a research project
- identifying research priorities
- as members of a project advisory or steering group
- commenting and developing patient materials
- undertaking interviews with research participants
- user and/or carer researchers carrying out the research.

Source: INVOLVE Briefing note #2

Approaches to involvement

Consultation – seeking views to inform decision making (can occur at any point in the research process)

Collaboration – on-going partnership between researchers and patients (or members of the public); decision making is shared; broad approach that can be used in a wide range of research activities at many stages of the research project

User-controlled research – decision making is in the hands of service users and their organizations; some distinguish user-controlled from user-led research which might be controlled by researchers

Source: INVOLVE Briefing note #7

The goals for patient engagement

Being clear about *why* you want to involve patients in research will help you determine *who* to involve and *how* best to involve them. There are three commonly cited goals for involving the public in health research (Esmail, Moore & Rein, 2015)

The first is a **democratic accountability** goal based on the principle that people who are affected by research have a right to contribute to determining what and how publicly funded research is carried out. This is embedded in the notion of public involvement as citizenship.

Linked to this citizenship goal is the related **developmental** goal where patient engagement increases public understanding of health research, which strengthens their competence and capacity to contribute to decision making for themselves and their families.

Patient engagement in health research is also promoted to contribute to **improved research quality and relevance**. This is based on the view that patients bring different and unique perspectives to research from those of researchers and health care providers. In particular, their experiences living with a particular disease or condition positions them well to contribute to the prioritizing of health research topics, identifying relevant health outcomes and assisting with the preparation of patient materials. They may also be able to assist with the provision of access to relevant patient populations and with the dissemination of research at the end of the research study.

Building a Common Language for Patient Engagement

Pulling all of these concepts together helps us work towards a common language for patient engagement (Abelson et al. 2015).

GOALS FOR PATIENT ENGAGEMENT			
<ul style="list-style-type: none"> • Increased transparency and accountability of health research • Improved understanding of health research • Improved research quality and relevance 			
WHO TO INVOLVE?	WITH WHICH METHODS?		
	Communication	Consultation	Participation
Citizens (interested members of the general public without direct experience with a particular disease or health condition)			
Patients, families, caregivers (with experience with a specific disease or health condition)			
Stakeholder group (with an organized interest in a particular disease or condition)			

2. High-level review of the evidence

In the early 2000s, Boote and colleagues (2002) published one of the earliest reviews of consumer involvement in health research. In addition to their critical review of the existing conceptual and empirical literature, the authors helpfully mapped out a research agenda that included four questions in need of theoretical and empirical attention:

- i) how can consumer involvement in health research be further conceptualized?
- ii) how and why does consumer involvement influence health research?
- iii) How can the influence of consumers in health research be measured and evaluated?
- iv) what factors are associated with 'successful consumer involvement in health research?

These questions have been the subject of on-going investigation over the last decade, including several recently completed systematic, bibliometric and realist reviews focused on answering some of these questions (Brett et al. 2012; Jagosh et al. 2012; Boote et al. 2012; Domecq et al. 2014).

In the most recent and comprehensive review published to date, Domecq et al. (2014) provides practical guidance to researchers for designing and carrying out meaningful patient engagement in health research informed by the following review questions:

1. What are the best ways to identify patient representatives?
2. How do you engage them in designing and conducting research?
3. What are the observed benefits of patient engagement?
4. What are the harms and barriers of patient engagement?

Data from 142 studies were analyzed using a meta-narrative approach. Patient engagement was seen to be feasible in all research phases although it was more commonly carried out at the research design stage (agenda setting and protocol development) than in the execution or knowledge translation stages. The most *common forms of consultative involvement were focus groups, interviews, and surveys*. More active *collaborative* forms include serving on a board or advisory council, or attending regular meetings with researchers. Most studies used volunteer rather than randomly sampled patients due to the small numbers of participants being sought. The *lack of comparative evidence about different methods prevented any recommendations from being made about the suitability of a particular engagement or recruitment method*. Challenges to patient engagement included the extra time and funding required for patient engagement, worries about “tokenistic engagement” and “scope creep” resulting in the identification of patient concerns that could not be

feasibly addressed by the research. These need to be balanced against the reported benefits of improved patient enrolment, decreased attrition and improved dissemination of research findings to relevant patient communities.

Brett et al. (2012) recently published the first systematic review of research studies that assessed the impact of patient and public involvement on health and social care research. Covering a 15-yr time period (1995-2009), 66 published and grey literature studies were included in the review. The positive impacts identified related to the ways in which patient and public involvement enhanced the quality and appropriateness of research. Impacts were reported for all stages of research, including: i) the development of user-focused research objectives, user-relevant research questions, and user-friendly information, questionnaires and interview schedules; ii) more appropriate recruitment strategies; iii) consumer-focused interpretation of data; and iv) enhanced implementation and dissemination of study results. Challenges of user involvement on impact were also identified such as ethical dilemmas arising from users' concerns with the acceptability of the study design to service users and researchers' concerns about the robustness and validity of the research design (Table 1).

Table 1 Summary of evidence by themes from systematic review

Beneficial impacts

Initial stages of research: PPI helped identify relevant topics for the research agenda, assisted in prioritizing topics for the research agenda and provided pragmatic criticism of the research protocol in perceiving whether research was relevant or appropriate to users

Undertaking research: PPI helped assess the appropriateness, wording and timing of research instruments (e.g. questionnaires, interview schedules) to the community and helped adapt the language of the instruments and information to suit the lay audience. PPI also assisted with recruitment to the study and improved response rates.

Furthermore, PPI helped gain deeper and more personal insights because of the rapport users had with participants
Analysis and write-up: PPI helped ensure emerging themes and trends were interpreted from the user perspective as well as the academic researcher perspective, assisted in identifying relevant knowledge gaps, and final research reports benefited from being grounded in user experiences

Dissemination and implementation: PPI helped with the dissemination and implementation of research findings owing to the dedication to and influence of users to the community. Studies reported that dissemination was delivered in a more poignant and user-friendly way

Challenging impacts

Initial stages of research: Studies indicated that PPI led to scientific and ethical conflict in protocol design, which may have been due to a lack of knowledge and understanding of PPI. PPI may lead to a tokenistic nature of users' involvement and can cause power struggles between researchers and users

Data collection stage of research: PPI studies have reported the difficulty in recruiting a diverse range and representative sample of users to a project, the difficulty in balancing traditional academic criteria for reliability and user perspectives in a protocol for research and the difficulty in maintaining user confidentiality within meetings, where users may discuss personal experiences

The challenges reported by researchers in running PPI focus groups included users influencing each other, which may result in an over-emphasizing of particular problems; groups being dominated by strong characters and their perspectives; groups being overshadowed by personal experience stories, when the aim was to identify research topics, and groups seen as a forum to get other people to accept their understanding of the disease

Dissemination and implementation: PPI led to research findings being disseminated before the academic papers are published, thereby jeopardizing academic publication

Time and Cost: PPI led to increased time and cost owing to the practical aspects of planning and managing the user involvement in the research, the time and cost of building up relationships within the community and setting up user groups, the training and education for both users and researchers and the additional time needed for users to read and comment on documentation

PPI, patient and public involvement.

Source: Brett et al. *Health Expectations*. 2012; 17:637-650.

A major conclusion of the review is the weak evidence base concerning impact and the need for further development of: i) the way in which impact is reported; ii) a clearer conceptual understanding of the nature of impacts and methods for assessing impacts both qualitatively and quantitatively. Patient engagement is a complex intervention requiring appropriate evaluation that carefully considers the independent and interactive relationships between the context within which the engagement takes place, the processes carried out and the outcomes achieved.

Opportunities to advance the science of patient engagement

While it is assumed that patient engagement leads to “better research”(Nass, 2012) much remains to be learned about the methods and impact of patient engagement. As described here, systematic reviews have documented a growth in patient engagement research in recent years. However, the majority of existing studies are small scale, with poor descriptions of the actual engagement process, few comparisons, and limited follow-up over long periods of time. As a result, the research community remains divided about the potential benefits and limitations of patient engagement (Snape, 2014), and uncertainty remains about how to support effective patient engagement in research.

The SPOR strategy will generate significant opportunities to advance the *science* of patient engagement. First, a number of patient engagement projects will be concurrently run throughout the country, offering opportunities for comparisons across projects using different methods of engagement and implementation contexts. Furthermore, SPOR networks will be funded for up to 5 years, creating opportunities for longer follow-up than what is usually possible in short-term projects. Finally, SUPPORT units have a mandate to advance the methods of patient-oriented research, and to evaluate their activities, which could support national research collaborations and methodological development work that is usually difficult to carry out.

3. Guidance for researchers

As SUPPORT units fulfill their role of facilitating the *practice* of patient engagement in research, there are numerous areas that need to be covered (e.g. recruitment, compensation policy, training, methods and evaluation). The methods, capacity and patient engagement working groups in each SUPPORT Unit will contribute in important ways but there are numerous helpful resources that have already been developed that researchers can benefit from.

In the sections below, we list and describe some of these resources ranging from comprehensive 'how to' guides to those that address particular topics related to patient engagement, including: i) patient recruitment; ii) patient compensation policies; iii) training of patients and researchers; and iv) evaluation frameworks and tools.

Comprehensive 'all-in-one' resources

Two organizations stand out as providing excellent all-purpose resources to support research teams in their early thinking and planning for patient engagement.

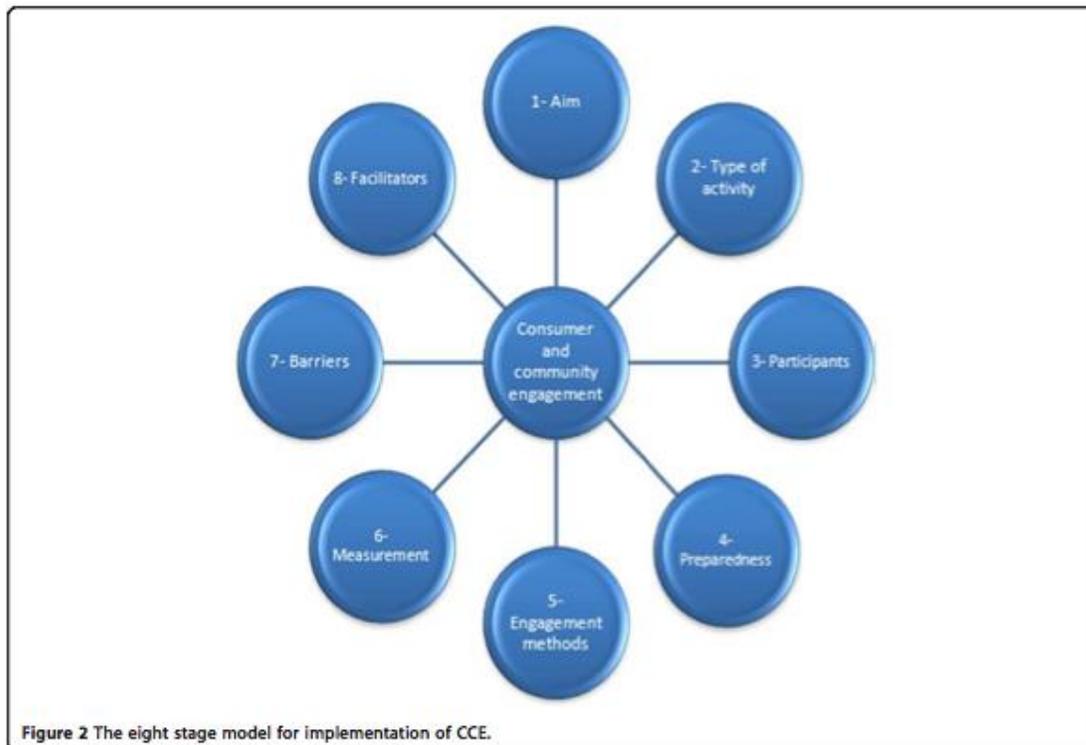
INVOLVE in the U.K. has a comprehensive set of resources available on its website. Its [Briefing notes for researchers](#) document, published in 2012, is the most comprehensive all-in-one document.

PCORI in the U.S. has published a [Patient and Family Engagement Rubric](#), which includes four elements:

- Planning the study
- Conducting the study
- Disseminating the study results
- PCOR engagement principles

As a support to PCORI's work, Nass, Levine and Yancy (2012) produced a [white paper](#) that included an evidence-based review of best practices, processes and methods for patient engagement that have been studied and implemented internationally, to be adapted and used to promote patient involvement in research topic generation in the U.S. While the focus of the paper is on methods for patient involvement in research topic generation, there are helpful sections in the report that summarize core principles for engagement patients and the public in health care research, how to decide whether to engage the public or patients, at what level and with what methods.

Finally, Sarrami-Foroushani et al. (2014) offer an 8-stage model for implementing consumer and community engagement based on a large scoping review. The model includes provisions for assessing the context within which engagement is being implemented which is critical to determining its success and offers guidance at each stage of the engagement process, e.g., identifying goals, the engagement activity, participants, methods, measurement, etc.



Source: Sarrami-Foroushani et al. BMC Health Services Research 2014, 14:402

Patient Recruitment Resources

The recruitment of patients to contribute actively to the research process can be a challenging prospect for researchers, especially those who have had little or no previous experience involving patients in their research studies. In some Canadian provinces, patient partner programs have been established for the purposes of linking patients to various health-system initiatives, including research, medical education and quality improvement activities (listed below).

Ontario does not currently have an institutionalized resource of this kind. Patients Canada and the Change Foundation's PANORAMA panel have been fulfilling some of these roles over the last 2-3 years along with Patient and Family Advisory Councils now in place in many health care facilities and provincial agencies. It is worth noting that these newly established patient organizations and panels have had a broader

focus on health system improvement and change rather than a more specific focus on patients engagement in research. In contrast, the long-established Cochrane Consumer Network has an active base of patients and consumers across Canada with extensive experience “contributing to evidence-based health care” through the production of systematic reviews and clinical guidelines.

In addition to ‘purpose built’ patient panels, consideration should also be given to the vast array of patient organizations in Ontario and across the country as a potential resource for the research community. While careful attention needs to be given to the mandate and funding sources of these organizations, these groups are already organized around specific patient populations and, as such, may be more appropriate for some research teams to work with. SUPPORT units might consider creating an inventory of patient organizations (if such an inventory does not already exist) and creating a panel of representatives, drawn from these groups, that SUPPORT Units could liaise with.

Existing patient panels or networks (provincial and national)

- [BC’s Patients as Partners | Patient Voices Network](#) (administered by Impact BC)
 - Community of 1500 patients, family members and caregivers
 - Different health system roles (individual care, health services delivery/evaluation, health system governance)
- [University of Montreal’s Patient Partner Program](#)
 - 250 patients acting as partners in health education, healthcare improvement and health research
- [Cochrane Consumer Network](#) (large and organized by disease/condition)
 - Consumer involvement in Cochrane reviews through prioritizing topics for new reviews, assessing relevance of review questions, identifying relevant outcomes, commenting on plain-language summaries, disseminating Cochrane’s work, recruiting other consumers)
- [Patients Canada](#) (small and primarily based in Ontario)
 - 20-40 active members meet once a month to review patient stories and identify areas to target for health system improvement; strong web presence (7,000 twitter followers); 1000-2000 members; Chair (Michael Decter)

- [Change Foundation's PANORAMA panel](#)
 - 32 patients or caregivers from across Ontario with extensive experience navigating the health system

Panels in development

- CIHR – planning to create one for internal purposes
- Health Quality Ontario – planning to establish one focused on health quality improvement

Patient Compensation Resources

The remuneration of patients is a thorny issue and organizations are addressing this issue in different ways with no single, unified approach. There seems to be general support for the principle that people should be reimbursed for their time and expenses but how this is done varies. Separating out the different roles and tasks being performed can be a helpful way of establishing general rules of thumb for compensation (e.g., governance roles on advisory committees several times a year vs. more regular involvement in various stages of a research project or in the training of patients and/or researchers). It is also important to discuss and decide on remuneration early on *with* patients to ensure that patients' additional sources of income (e.g., pensions, social assistance, disability payments) are not negatively affected by receiving payment for their contributions.

CHANGE FOUNDATION (Ontario, Canada)

- released a tool in March 2015 for deciding whether to pay patient-engagement participants [Should money come into it?](#)

INVOLVE (U.K.)

- [involvement cost calculator](#) (helps with budget planning for patient engagement in various roles)

PCORI (US)

- approach to compensation is guided by the principles of equity and parity
- if everyone else at the table is getting compensation (real or in-kind), there needs to be equity
- if there are groups that have not historically been involved, compensation can help promote this (e.g., marginalized groups, low SES)
- include in budget at an appropriate level
- use creative approaches: stipends, employment at university
- recognized that earned income may be a problem for participants on disability and social assistance

CIHR (Canada)

- carrying out an internal scan and analysis of internal practices re compensation and what processes are needed to integrate a policy within Grants and Awards guide that could be applicable to all CIHR grants

Other organizations to consult with on this topic

Canadian Foundation for Healthcare Improvement (CFHI)

Patient Voices Network (BC)

Patient Partner Program (University of Montréal)

- major health care delivery, teaching and research organizations (e.g., Centre for Addictions and Mental Health, Bloorview Research Institute)
- large health authorities with active public and patient engagement portfolios (e.g., Vancouver Coastal Health (BC), Winnipeg Regional Health Authority (MB), Capital District Health Authority (NS))

Training and Supports for Researchers and Patients

Researcher-patient collaborations and partnerships need to be supported in order to be successful. Consideration needs to be given to the appropriate training and supports that are required for the various roles and interactions in which patients and researchers will be engaging which can range from governance roles to active involvement in the research process. Resources that fall into this category cover a broad range from basic 'ground rules for engagement', which are often shared at the beginning of meetings, to comprehensive training curricula. Organizations that have established patient partner programs in place are good resources for information about training (see below). CIHR is leading the development of a generic patient preparation curriculum and convened a consensus-building workshop to inform its work on March 30-31 2015. As background to the workshop, a targeted environmental scan of approaches to prepare patients to engage in patient-oriented health research was prepared, which will be made publicly available in the very near future (contact the OSSU team to obtain this document).

[Patient and Community Engagement Research \(PACER\)](#) (University of Calgary, Alberta)

- a research training program within the Institute for Public Health (IPH) at the University of Calgary
- through an intensive training program, patients are supported to engage in research, and to integrate this evidence-informed research into the health care system and clinical practice.

[Patients as Partners in Arthritis program](#)

- provides highly motivated, trained patient volunteers to facilitate an increase in the understanding of all aspects of arthritis.
- accomplished through small group sessions led by a trained patient(s) that includes not only a technique for a musculoskeletal (bone and joint) examination but also real life experiences of living with the disease

[INVOLVE online database for development training and support](#)

[BC's Patients as Partners | Patient Voices Network](#) (administered by Impact BC)

[University of Montreal's Patient Partner Program](#)

Evaluation Frameworks and Tools

SUPPORT units can play an important role in supporting methodological developments to facilitate opportunities for rigorous research and evaluation of patient engagement within SPOR. The development of evaluation frameworks and tools that research teams and networks can use is one such area.

A helpful starting point for this work is the PCORI evaluation framework and surveys for patients and stakeholders, researchers and research networks that have been developed (included in resources section).

List of Selected Patient Engagement Resources (with hyperlinks to websites)

1. Frameworks and strategy documents

CIHR. Strategy for Patient-Oriented Research Patient Engagement Framework
<http://www.cihr-irsc.gc.ca/e/48413.html>

2. Rubrics, glossaries and 'how to manuals'

PCORI Engagement Rubric
<http://www.pcori.org/sites/default/files/PCORI-Engagement-Rubric-with-Table.pdf>

CIHR glossary of funding-related terms
<http://www.cihr-irsc.gc.ca/e/34190.html>

INVOLVE Briefing Notes for Researchers
<http://www.invo.org.uk/posttypepublication/involve-briefing-notes-for-researchers/>

3. Patient recruitment resources

Patient Voices Network/ Impact BC
<https://www.patientsaspartners.ca/network>

Patient Partner Program (University of Montreal)
http://medecine.umontreal.ca/doc/PPS_Rapport_2011-2013.pdf

Patients Canada
<http://www.patientscanada.ca/>

4. Patient compensation guidance documents

Should Money Come Into It? A Tool for Deciding Whether to Pay Patient-Engagement Participants. The Change Foundation. March 11, 2015.
<http://www.changefoundation.ca/site/wp-content/uploads/Should-money-come-into-it.pdf>

5. Patient/researcher training resources

CIHR environmental scan (available in early-mid April 2015 – available from OSSU)

6. Evaluation Frameworks and Tools

PCORI Evaluation Framework Overview
<http://www.pcori.org/assets/2014/04/PCORI-Draft-Evaluation-Framework-042214.pdf>

PCORI WE-ENACT Patient & Stakeholder Survey

<http://www.pcori.org/sites/default/files/PCORI-WE-ENACT-Patient-Stakeholder-Survey-Item-Pool.pdf>

PCORI WE-ENACT Research Survey

<http://www.pcori.org/sites/default/files/PCORI-WE-ENACT-Researcher-Survey-Item-Pool.pdf>

7. Other relevant resources (OHRI slide deck – What does patient-oriented research look like? Shea et al. December 19th, 2014 – available from OSSU)

References

- Abelson J. et al. 2015. A framework for patient and public involvement in Ontario's health technology assessment process. Draft manuscript.
- Arnstein SR. A ladder of citizen participation. *Journal of the American Institute of Planners*. [Online] 1969; 35(4):216-224. Available from: <http://www.tandfonline.com/doi/abs/10.1080/01944366908977225#.VPKSG8b5vdc>
- Baum F, MacDougall C, Smith, D. Participatory action research. *Journal of Epidemiology & Community Health*. [Online] 2006; 60:854-857. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2566051/pdf/854.pdf>
- Boivin, A. 2015. Advancing the Science of Patient Engagement in Research. Presentation to the Ontario SUPPORT Unit Patient Engagement Roundtable. Toronto, Ontario, March 12th, 2015.
- Boote J, Telford R, Cooper C. Consumer involvement in health research: A review and research agenda. *Health Policy*. [Online] 2002; 61:213-236. Available from: <http://www.sciencedirect.com/science/article/pii/S0168851001002147>
- Boote J, Wong R, Booth A. "Talking the talk or walking the walk?" A bibliometric review of the literature on public involvement in health research published between 1995 and 2009. *Health Expectations*. [Online] 2012; 18:44-57. Available from: <http://onlinelibrary.wiley.com/doi/10.1111/hex.12007/full>
- Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, et al. Mapping the impact of patient and public involvement on health and social care research: A systematic review. *Health Expectations*. [Online] 2012; 17:637-650. Available from: <http://onlinelibrary.wiley.com/doi/10.1111/j.1369-7625.2012.00795.x/full>
- Canadian Institutes of Health Research. Strategy for Patient-oriented research – patient engagement framework. Government of Canada. [Internet]. Available from: <http://www.cihr-irsc.gc.ca/e/48413.html>.
- Canadian Institutes of Health Research. Canada's Strategy for Patient-Oriented Research. Government of Canada. [Internet]. Available from: <http://www.cihr-irsc.gc.ca/e/44000.html>
- Domecq JP, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N, et al. Patient engagement in research: A systematic review. *Health Services Research*. [Online] 2014; 14(89):1-9. Available from: <http://www.biomedcentral.com/1472-6963/14/89>

Entwistle VA, Renfrew MJ, Yearley S, Forrester J, Lamont T. Lay perspectives: Advantages for health research. *BMJ*. [Online] 1998; 316:463-466.

Esmail L, Moore E, Rein A. Evaluating patient and stakeholder engagement in research: moving from theory to practice. *Journal of Comparative Effectiveness Research*. 2015; 4(2):133-45. Available from: <http://www.futuremedicine.com/doi/pdf/10.2217/cer.14.794>

Gauvin FP, Abelson J, Lavis JN. Evidence Brief: Strengthening Public and Patient Engagement in Health Technology Assessment in Ontario. Hamilton, Canada: McMaster Health Forum, 8 May 2014.

Gauvin FP, Abelson J, Giacomini M, Eyles J, Lavis JN. "It all depends": Conceptualizing public involvement in the context of health technology assessment agencies. *Social Science & Medicine*. [Online] 2010; 70(10):1518-1526. Available from: <http://www.sciencedirect.com/science/article/pii/S0277953610001188>

International Association for Public Participation. IAP2 Public Participation Spectrum. International Association for Public Participation 2014; Available from: http://c.ymcdn.com/sites/www.iap2.org/resource/resmgr/files/iap-006_brochure_a3_internat.pdf

Jagosh J, Macaulay AC, Pluye P, Salsberg J, Bush PL, Henderson J, et al. Uncovering the benefits of participatory research: Implications of a realist review for health research and practice. *The Milbank Quarterly*. [Online] 2012; 90(2):311-346. Available from: <http://onlinelibrary.wiley.com/doi/10.1111/j.1468-0009.2012.00665.x/full>

Minkler M, Wallerstein N, eds. *Community-based participatory research for health*. San Francisco: Jossey-Bass, 2003.

Nass P, Levine S and Yancy, C. Methods for Involving Patients in Topic Generation for Patient-Centered Comparative Effectiveness Research – An International Perspective. Research Priorities White Paper (PCORI-SOL-RPWG-001) for the Patient-Centered Outcomes Research Institute (PCORI), 2012. Available from: <http://www.pcori.org/assets/Methods-for-Involving-Patients-in-Topic-Generation-for-Patient-Centered-Comparative-Effectiveness-Research---An-International-Perspective.pdf>

Rowe G and Frewer L. A typology of public engagement mechanisms. *Science, Technology & Human Values* 2005; 30(2):251-90.

Snape D, Kirkham J, Britten N, Froggatt K, Gradinger F, Lobban F, et al. Exploring perceived barriers, drivers, impacts and the need for evaluation of public involvement in health care and social care research: A modified Delphi study. *BMJ Open*. [Online] 2014; 4:e004943. Available from: <http://bmjopen.bmj.com/content/4/6/e004943.short>