

Engaging and partnering with older adults in health research: The *why* and the *how*

Julia Abelson, PhD

Professor, Dept. of Health Evidence & Impact

Member, Centre for Health Economics and Policy Analysis



PUBLIC AND PATIENT
ENGAGEMENT
COLLABORATIVE



Biography

Interdisciplinary training: health systems/policy researcher

Health and social sciences: political science/ health policy theory + qualitative and survey research methods

Specific expertise: design, implementation and evaluation of approaches for involving citizens and patients in health systems decision making, policy and research

Outline

- 1. Background to the field** - history, rationale for engaging *community partners* in health research
- 2. Key concepts** - who to engage, how, when and in what?
- 3. From principles to practice** – embedding high-quality engagement practices into your research

1. Background to the field

- Involving community members, citizens and patients in health research and health system decision making is not new
 - long history of community-based, participatory research in health and social sciences; newer to biomedical and health systems/policy research
- Investments and requirements for doing this within Canadian health research community are more recent
- New rules of the game have created incentives (and challenges)


The patient engagement and partnership era (2010-present)



- Increasing worldwide attention to involving patients in various health system domains
 - quality improvement
 - planning and policy making
 - health technology assessment
 - health research
- Shift from patients as research subjects, consultees to more active participants, collaborators and partners

Major strategic investments

- re-orienting clinical and health systems research to the priorities of patients (U.K., U.S.A. and Canada, 2000-2021)



Briefing notes for researchers:
public involvement in NHS, public health and social care research

Supporting public involvement in NHS, public health and social care research



pcori Patient-Centered Outcomes Research Institute

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WHY PCORI WAS CREATED

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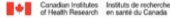
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Posted: September 10, 2014



Strategy for Patient-Oriented Research

SPOR

Putting Patients First

Strategy for Patient-Oriented Research

Patient Engagement Framework

Canada's Strategy for Patient-Oriented Research (SPOR)

Patient-oriented research is ultimately aimed at achieving benefits that matter to patients:

- *Improved health*
- *Improved access to the health care system*
- *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*
- *Make a contribution to improving the cost effectiveness of the health care system*

Patient Engagement and SPOR

- Patient-oriented research: continuum of research that engages **patients as partners**, focuses on **patient-identified priorities** and **improves patient outcomes**. Aims to **apply the knowledge generated to improve healthcare systems and practices**
- Patient engagement: **meaningful and active collaboration** with patients in governance, priority setting, conducting research and knowledge translation



2. Clarifying key concepts

Who to engage or partner with?

What do we mean by engagement and partnership?

What are our goals?

Different **people** in...
different **roles** for...
different **purposes**

Who to engage and partner with?

Those with experiential knowledge - *Patients, family members and caregivers* with health condition(s) or experience with aspects of care who can provide a specific set of perspectives

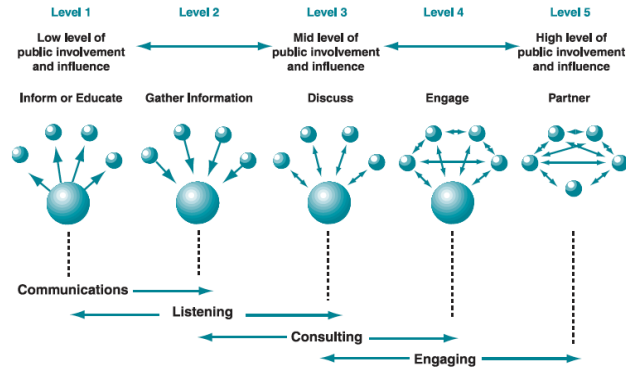
General population or specific groups – individual *citizens/community members* or groups with shared identity (e.g., geography, stage of life, vulnerabilities or limitations); may or may not have specific experience to draw from

Stakeholder groups – Groups with *organized interests* in the area (e.g., advocacy groups, provider organizations, industry)

(Abelson et al. 2016; Gauvin et al. 2014)

What do we mean by involvement, engagement, partnership and co-design?

Health Canada's Public Involvement Continuum



Adapted from Patterson Kirk Wallace

IAP2 Spectrum of Public Participation



IAP2's Spectrum of Public Participation was designed to assist with the selection of the level of participation that defines the public's role in any public participation process. The Spectrum is used internationally, and it is found in public participation plans around the world.

		INCREASING IMPACT ON THE DECISION				
		INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL		To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
	PROMISE TO THE PUBLIC	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

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Design Thinking Process



 Sep 18, 2018  [News](#)

PATIENT VIEWS ON “LADDERS OF ENGAGEMENT”

A patient-developed paper on what it means to partner in health research

OSSU’s Patient Partners Working Group have been leading OSSU’s work in developing patient-led answers to the questions most pertinent to patient partners in research across Ontario. One of the main issues that kept resurfacing for patient partners in the province was around how individuals are engaged in projects in ways that are meaningful to them. Most academic discourse on this subject, and the SPOR Patient Engagement Framework, build on the idea of spectrums (or ladders) of engagement for patient partnered research projects; from approaches to inform patients at one end of the spectrum to movements to empower patients at the other. In this paper, developed for the Patient Partners Working Group by a Jennifer Johannesen (a patient partner in research herself), the



What are the goals for engagement and partnering?

Quality goals (outcomes driven)

Higher-quality, more responsive research

Legitimacy goals (process driven)

Better decision making (e.g., more inclusive, legitimate, accountable)

Developmental goals (capacity driven)

Increased competency and capacity to contribute to individual and collective decision-making

Ethics goals (rights driven)

Engagement is a right

Abelson et al. 2016. Public and Patient Involvement in HTA: Framework for Action. *IJTAHC*, 32:4.



3. From principles to practice:

Embedding high-quality engagement practices into your research

Key areas to work through:

- Scope and level of engagement/partnership
- Recruitment and selection
- Clarification and negotiation of roles
- Orientation and supports for community research partners *and* researchers

Involving public and patients in research:

What aspects of the research will you involve your partners in?

Setting priorities for research

- what research questions and outcomes are important to users?

Proposal writing (and applying for funding)

- help with the development of the engagement/partnership strategy + other relevant sections of the proposal

Study execution

- assistance with various aspects of study design, recruitment, data collection and analysis

Dissemination, Implementation & Evaluation

- work within relevant user networks to share the study results
- help with public-friendly versions of results
- input into decision tools, user guidelines
- input into assessment and uptake of new technologies, programs, future research

Involving the public and patients in research: *What roles and responsibilities will they have?*

- In the overall **governance** and/or **execution** of the research (committee members or co-chairs)
- As **contributors** to different stages of the research
 - *deliberative engagement* processes to inform research priorities, outcomes of interest
 - *consultants* in the development and implementation data collection tools
 - *co-designing* interventions, dissemination outputs

Identification and selection of community research partners

Key considerations

- who do you want to involve and how will you find them?
- what perspectives, experiences, population or community characteristics do you want them to reflect or represent?
- how many partners or contributors do you need to achieve your goals?

Commonly used sources

- market research firms and online panels (e.g., Asking Canadians)
- health charities and disease-specific organizations
- health system organizations (patient and family advisory councils, patient partners and advisors)
- community-based organizations

Clarifying and negotiating roles

- As early as possible and check in periodically
- Clarify expectations for involvement in all stages of the research process
- Allow enough time for discussions about roles to show respect and commitment to meaningful involvement

Orientation and supports

What do research partners need to contribute meaningfully?

- a good understanding of the research goals and process, and their roles in it (including timelines)
- basic understanding of relevant research terminology and concepts needed to carry out their roles
- sense that they are a respected member of the team
- a supporting infrastructure for their participation (mentoring, administrative support, social/health support)

How can researchers facilitate this?

- invest in early support of user members in their roles
- on-going communication
- respect for their roles and contributions and any limitations related to health conditions, mobility, vulnerabilities

Relevant resources

Top 10 Patient Engagement Resources

By Trish Roche



CHI KT Platform

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Feb 21, 2020 · 7 min read



Partnering principles and strategies: A guidance document for researchers, patients and caregivers

Authors: Julia Abelson | Rebecca Ganann | Gail Heald-Taylor | Maureen Markle-Reid | Penelope Petrie | Parminder Raina

The following guidance document is to be used to plan for and involve **Patient, Caregiver, and Public Research Partners** in the activities and projects facilitated by the McMaster Institute for Research on Aging (MIRA) Collaborative for Health & Aging, for example, the interpretation of findings from a systematic review. Below, we outline the core principles that should guide the involvement of Patients, Caregivers and Public Research Partners in activities of the Collaborative and the best practices for carrying this out.



Clear communication – The purpose of the MIRA Collaborative for Health & Aging and roles/opportunities for Patients, Caregivers and Public Research Partners are clearly communicated.

Information exchange – Information is shared in a context of trust where Patient, Caregiver, and Public Research

<https://miracollaborative.ca/2020/10/13/guiding-principles/>



Advancing the science of engagement:

Key findings from evidence reviews

- More focus on doing than assessing
- Rich case studies citing context-specific benefits (for specific populations, diseases/conditions, types of research)
- Growing evidence base about effectiveness and impact
 - Engagement of people with lived experience can improve study enrolment
 - Level/type of engagement appears to influence proximal outcomes (e.g., discrete outputs, care processes)

Emerging evidence about the implementation and impact of older adults as research partners



Institute for
Research on Aging

COLLABORATIVE FOR HEALTH & AGING



RESEARCH BRIEF

Older people as research partners: a systematic review of implementation and impact

KEY POINTS

- We know more about what older adults do in their research partner roles than about the impacts of their involvement.
- The impacts that older adults have had as research partners include the creation of new and continuation of existing partnerships.
- Impact evaluation is an emerging science.

What is this research about?

Older adults are frequently called on to help design, carry out and share the knowledge produced from health research projects. Despite their active roles in research, little is known about the specifics of how they have been engaged and with what impact.

The MIRA | Collaborative for Health & Aging's Patient Engagement Working Group by leadership of Drs. Rebecca Ganann and Julia Abelson set out to explore these questions

disability, dementia, and self-harm, and experiences as caregivers.

Patient and public partners were most likely to be engaged in the execution of research and least likely to be engaged in the preparatory stages of research. In about half of included studies, patient or public research partners were engaged to translate research findings. In four studies, older adult research partners were engaged across all stages of research (see table).



The importance of evaluation (selected resources)

- Public and patient engagement toolkit (on-line platform of evaluation frameworks and tool <https://ceppp.ca/en/our-projects/evaluation-toolkit/#care>)



Centre of Excellence on Partnership
with Patients and the Public

- Public and Patient Engagement Evaluation Tool (PPEET)

<https://ppe.mcmaster.ca/our-products/public-patient-engagement-evaluation-tool>



Public and Patient Engagement Evaluation Tool



Additional resources and contact details



The screenshot shows the top portion of a website. At the top left is the McMaster University logo. In the center, it says 'FACULTY OF HEALTH SCIENCES' above 'Public & Patient Engagement'. On the right, there are search and menu icons. Below this is a dark red navigation bar with links: HEALTH SCIENCES, HOME, OUR TEAM, OUR PROJECTS, OUR PRODUCTS, OUR PARTNERS, and CONTACT US. The main content area has a heading 'Welcome to the Public and Patient Engagement Collaborative Website' followed by a circular logo with the text 'PUBLIC AND PATIENT ENGAGEMENT COLLABORATIVE'. Below the logo is a paragraph of text: 'The Public and Patient Engagement (PPE) Collaborative was established in 2011. Our research and service activities focus on the role of patients and publics in health system policy making and health research, with a specific focus on the evaluation of these efforts. This website has been designed as a portal to access the latest research and news from the PPE Collaborative and to share tools for use in practice. Please use the links above to learn more about the PPE Collaborative.' At the bottom of the screenshot, it says 'You can also get updates about the PPE Collaborative's work on Twitter.'

Email: abelsonj@mcmaster.ca

Research team contact: lauratripp@mcmaster.ca

Website: <https://ppe.mcmaster.ca>

