

Patient Engagement in Health Research: A How-to Guide for Researchers



Patient
Engagement
Platform

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Contents

Overview	1
Why should I engage patients in health research?	1
How is patient engagement defined?	2
What does patient engagement in health research look like?	3
How does the “patient and researcher engagement in health research” strategy differ from other participatory research approaches?	4
How do I know I’m ready to engage patients in health research?	6
How do I use this Guide?	8
 Step 1: Why	 10
Why engage patients in health research?	10
What knowledge or perspectives do you seek from patients at the individual level?	11
Is research ethics approval required to engage patients in health research?	12
 Step 2: Who	 14
Who should I consider engaging in my research?	14
How many patients do I need to engage?	15
How do I decide how patients should be involved?	16
How do I find people to engage in my research?	19
 Step 3: How	 21
What do I need before I engage with patients in my research?	21
What practical items should I consider before with engaging patients in my research?	22
How do I engage patients across the research activity cycle?	22
What are the most common tactics used to engage with patients in research?	28
How do I know which patient engagement tactic is the best for my team’s research study?	39
How do I budget for patient and researcher engagement in health research?	40

Step 4: Engage	42
What tips can I use to help me engage with patients?	42
What do I do if things go wrong?	44
Step 5: Evaluate	45
Why should I evaluate how we engaged with patients in our research?	45
How do I plan for evaluating success in engaging with patients in research?	46
What outcomes and measures should I consider when evaluating patient and researcher engagement?	48
Annotated Bibliography Patient Engagement in Health Research	50
References	58
Appendix A—Competencies, Readiness, and Training Guide	61
Appendix B—Patient Engagement Worksheets	67

Figures

Figure 1. Levels of Patient and Researcher Engagement in Health	5
Figure 2. Patient and Researcher Engagement in Health Research Competency Domains	7
Figure 3. Five Steps for Researchers Engaging with Patients in Health Research	9

Overview

In this section, you will learn

- key terminology for understanding patient and researcher engagement in health research;
- the benefits and challenges of engaging with patients in health research;
- examples of how patients and researchers are engaged across the research cycle; and
- how to use this Guide.

Why should I engage patients in health research?

Health care delivery that does not accommodate patients' active engagement is no longer an option, and the emphasis on patient engagement is moving into research as well. Several funding bodies, as well as research ethics committees and peer-reviewed journals, now require that researchers describe their plans for engaging with patients in health research. However, doing so, and doing so effectively, is challenging. The Strategy for Patient-Oriented Research (SPOR) was launched nationally by the Canadian Institutes of Health Research (CIHR) in 2011 to address this knowledge to action gap. (1)

Researchers benefit from engaging patients in research through

- improved quality of research design;
- increased participant enrolment and decreased attrition;
- wider impact and application of research findings;
- stronger rapport with patient communities;
- better understanding of and insight into gaps and priorities in the research area; and
- overall improved research effectiveness. (2-6)

Patients benefit from being engaged in research by

- influencing the questions that are explored and researched;
- developing their own voice by knowing they are valued and have power to influence;

- gaining confidence about research and other life skills;
- building trust and rapport with clinicians, researchers, or both; and
- receiving improved care through the implementation of research findings more relevant to them. (2, 7-10)

Some challenges that have been noted about engaging patients in research are

- researchers' lack of knowledge about how patients can be involved;
- a lack of training or guidance for researchers wanting to work in partnership with patients;
- the increased investment of time, effort, money, and other resources needed for research that engages patients;
- a lack of systemic coordination and linkages between patients, researchers, policy makers, and funding bodies. (3, 11, 12)

FIND OUT MORE

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

SPOR SUPPORT | Unit Alberta Patient Engagement Platform
<http://www.aihealthsolutions.ca/initiatives-partnerships/spor/patient-engagement-platform/>

How is patient engagement defined?

Defining key concepts and terms is critical to creating a common understanding of patient engagement in health research. However, different nations use different language to describe the patient engagement enterprise. For example, in the US, terminology focuses on “patient-centered” activities; in the UK, on “patient involvement”; and in Australia, on “community engagement.” (13)

The definitions below establish the terminology used throughout this document. (14)

KEY TERM	DEFINITION
Patient	<ul style="list-style-type: none"> • Individual with personal experience of a health issue or situation; and informal caregiver, including family member or friend
Patient engagement	<ul style="list-style-type: none"> • Involvement of patients engaged with researchers in activities of governance, priority setting, conduct of research, knowledge translation, and evaluation
Patient-oriented research	<ul style="list-style-type: none"> • A continuum of research by multidisciplinary teams that engage patients as partners, focuses on patient-identified priorities, and improves patient outcomes.

FIND OUT MORE

Jargon Buster | CIHR (Canada)

<http://www.cihr-irsc.gc.ca/e/48952.html>

Patient-Centered Outcomes Research Institute | PCORI (US)

<https://www.pcori.org/>

National Institute for Health Research | INVOLVE (UK)

<http://www.invo.org.uk/>

What does patient engagement in health research look like?

Patients can be engaged with researchers across the research cycle, from governance and planning, to dissemination and evaluation. Some examples include

- applying as joint grant holders or co-applicants on a research project;
- identifying research priorities;
- providing input into surveys, patient information sheets, or other research materials;
- recruiting participants;
- undertaking interviews with research participants;
- providing input related to analysis; and
- identifying novel opportunities to share research findings. (7)

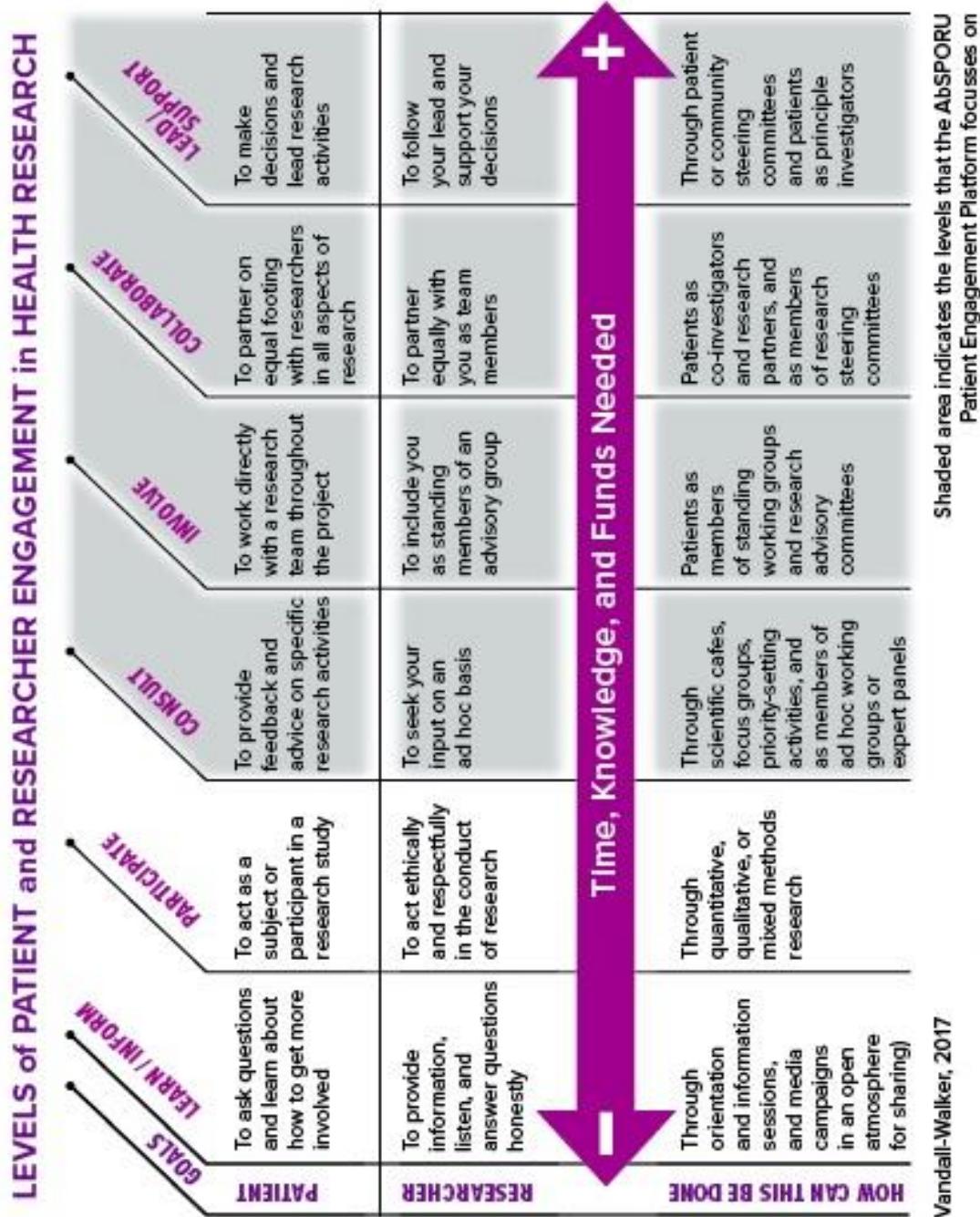
It is important to note that not all forms of engagement are considered equal (see the schematic of the Levels of Patient and Researcher Engagement, Figure 1). (15) The deeper the level of engagement, the greater the influence the patient has in decision making, and the more time, knowledge and funds are required by both patients and researchers.

How does the “patient and researcher engagement in health research” strategy differ from other participatory research approaches?

Patient and researcher engagement in health research uses an approach similar to that of traditional participatory research models, such as Participatory Action Research (PAR) or Community Action Research (CAR). Both patient and researcher engagement and PAR value participation and action by both those studying and those being studied, emphasizing collective inquiry about a specific experience or to address a common problem. However, more traditional PAR approaches involve using the researcher to resolve conflicting viewpoints among different stakeholders, limiting ownership of the participants’ contributions. (17)

In contrast, patient and researcher engagement embodies engagement or partnership in research that is not only community oriented and conflict resolution focused, but that can encompass all approaches to the conduct of research, both qualitative and quantitative, including clinical trials. This breadth of scope means that patients and researchers work in partnership with one another to produce outcomes that support or enable improved health outcomes and health care experiences.

As indicated in Figure 1, below, patient and researcher engagement in health research can occur at different levels, with the deeper levels of engagement associated with patients making research decisions and leading research activities. Patient engagement strategies foster opportunities to partner with patients using various levels of engagement across the spectrum of health research activities—from planning to dissemination.

Figure 1. Levels of Patient and Researcher Engagement in Health Research (15)

Vandall-Walker, 2017

How do I know I'm ready to engage patients in health research?

Your readiness can be assessed using the Prosci ADKAR model of change-management tool, shown in the schematic below. (18)

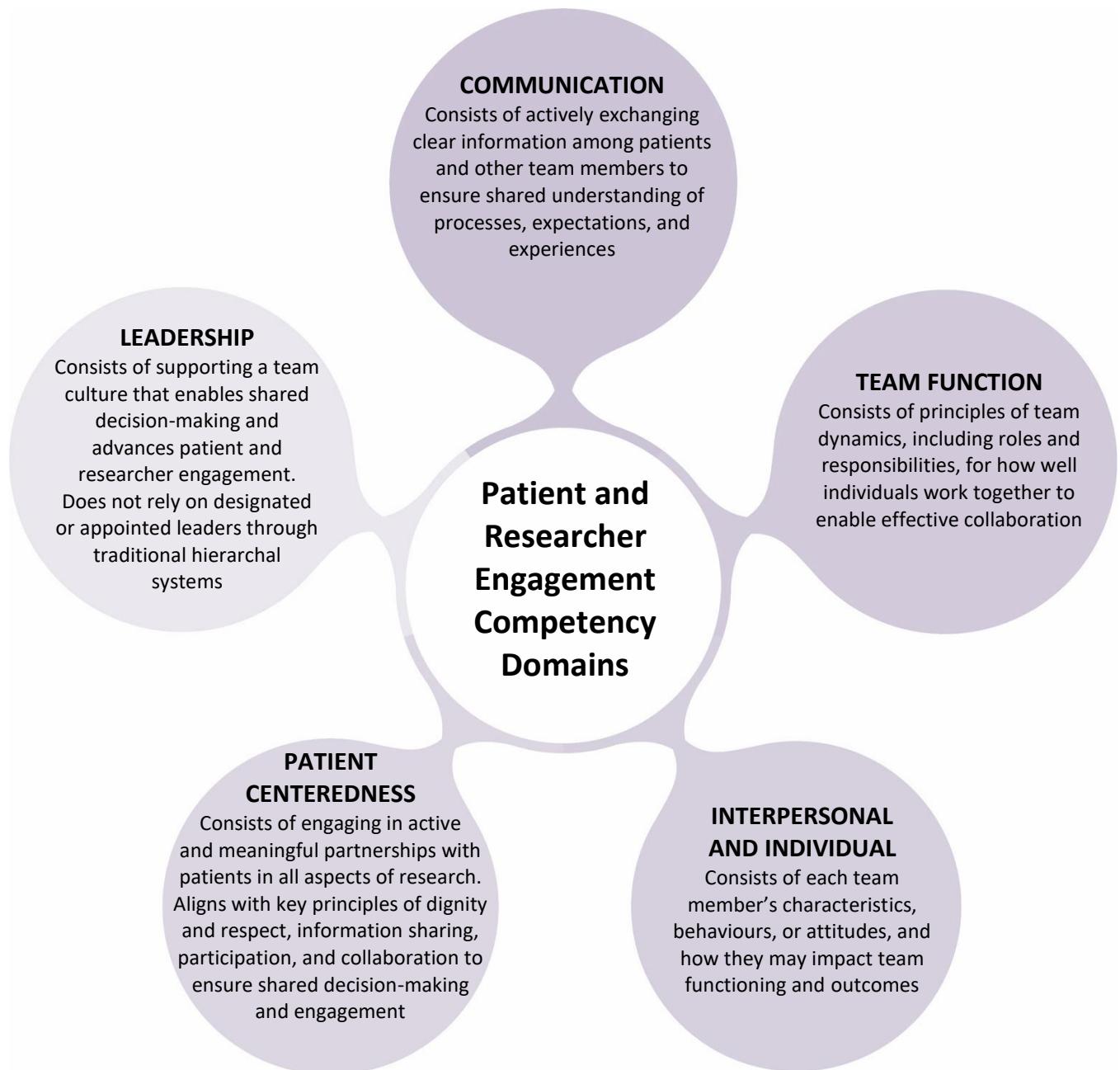
- A** Awareness of the need for engaging with patients in health research
- D** Desire to participate in and support the change
- K** **Knowledge of how to engage with patients (approaches, principles, best practices, training, and education)***
- A** Ability to implement and evaluate or monitor engagement strategies, skills, and competencies
- R** Reinforcement of engagement with patients (benefits realization, evidence, outcomes, funding opportunities)

* This Guide is designed to provide researchers with such knowledge.

Readiness for engaging with patients in health research also requires consideration of specific competencies; that is, skills, knowledge, attitudes or behaviours, and beliefs that are needed to support the activities and goals of patient engagement. Specific competencies have been outlined for the researcher *and* for the patient, thus focusing on the objective of establishing, building, and enhancing collaborative partnerships between these groups.

An overview of the five competency domains that together support patient and researcher engagement in health research is provided in Figure 2, below. Each domain consists of a competency statement—a description of the desired result of the individual competencies of both researchers and patients. You may find it useful to look ahead and understand the abilities of a competent researcher and patient who can engage successfully across the different levels. A detailed description of competencies, along with readiness tools, can be found in Appendix A of this Guide. The competencies may also be useful as part of the evaluation of patient and researcher engagement opportunities (see “Step 5: Evaluation”).

To achieve a basic proficiency in patient engagement, competency requires continuous education and training for both researchers and patients. That is why it is important to assess one’s strengths and readiness to engage before beginning.

Figure 2. Patient and Researcher Engagement in Health Research Competency Domains

How do I use this Guide?

In this Guide, the five key steps to engaging patients throughout your research project are outlined: Why, Who, How, Engage, and Evaluate (see Figure 3, below). The discussion of each stage includes an overview of current evidence, methods of engagement, patient and researcher competencies, tips for engagement, key examples, and engagement tools that can be used to optimize the process. Use the infographic provided in Figure 3 to guide you through the process.

If you are looking for additional guides to further your learning about patient and researcher engagement, link to the resources noted below from the Patient-Centered Outcomes Research Institute (PCORI) and INVOLVE, patient engagement initiatives in the US and UK, respectively.

FIND OUT MORE

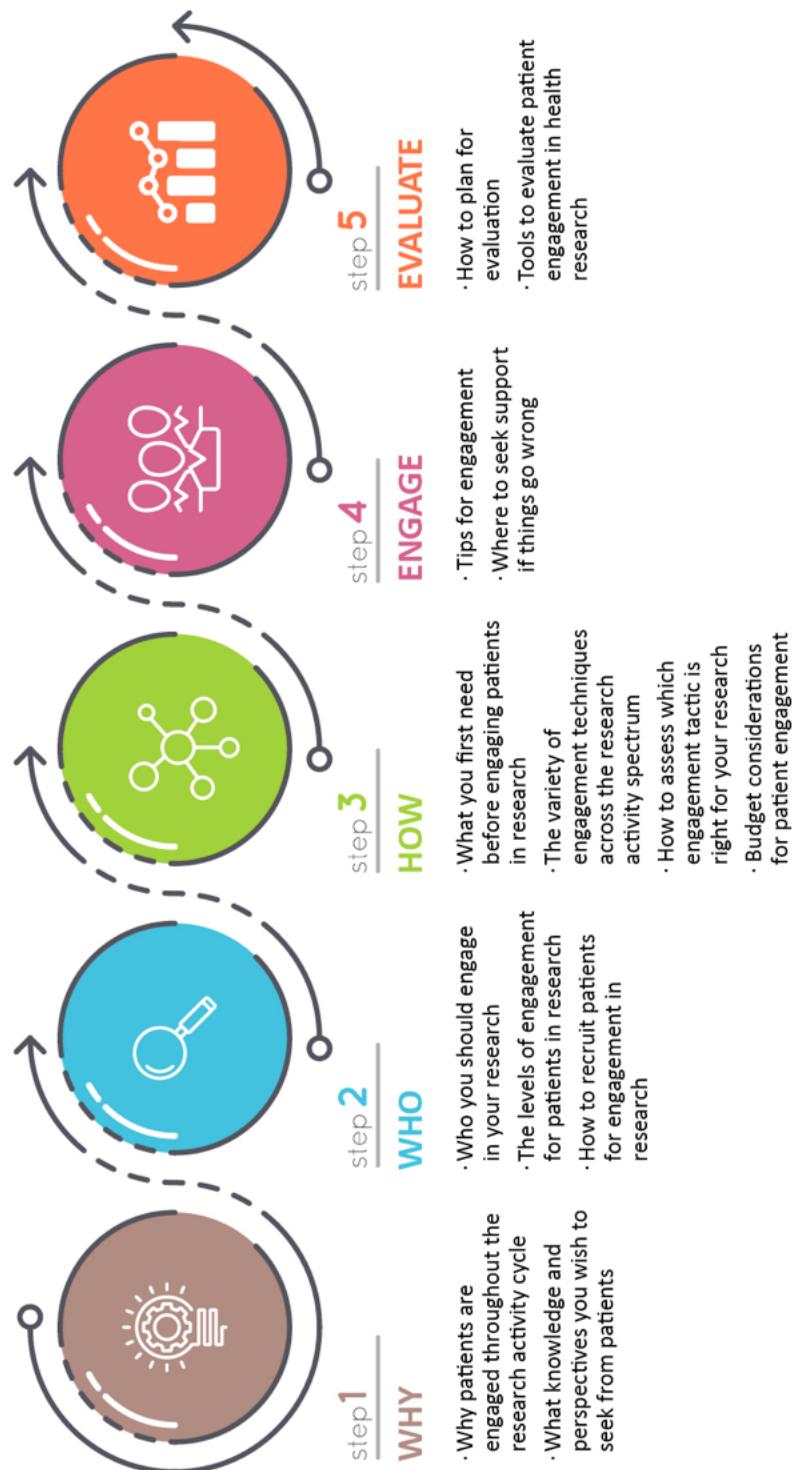
Engagement rubric for applicants | PCORI (US)

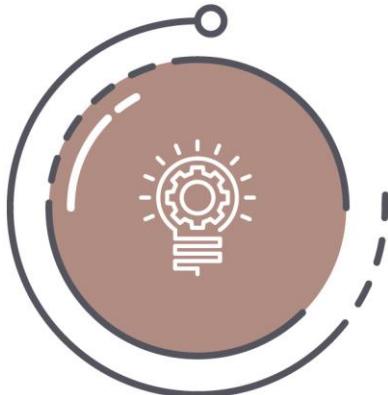
<http://www.pcori.org/sites/default/files/Engagement-Rubric.pdf>

Briefing notes for researchers | INVOLVE (UK)

<http://www.invo.org.uk/posttypepublication/invoke-briefing-notes-for-researchers/>

Figure 3. Five Steps for Researchers Engaging with Patients in Health Research





step 1

WHY

Why engage patients in health research?

Before deciding who you will engage with or what activity you will need patients to be engaged in, an important first step after assessing your own and other team members' strengths and readiness is to consider why you want to engage with patients in the first place.

What knowledge and perspective are you looking for from patients? (20) Consider the examples below.

	I want to engage patients at the individual level	I want to engage patients at the organizational level	I want to engage patients at the systems level
Example	Patients provide information about preferences for treatment plan	Patients act as members of an advisory council	Patients provide recommendations about research priorities to support funding decisions

The following discussion addresses engaging with patients at the individual level.

What knowledge or perspectives do you seek from patients at the individual level?

Consider how patients might contribute at different phases of the research cycle.

Research Cycle Activity	Rationale
1. Planning and preparation	<ul style="list-style-type: none">• Gather ideas for new research areas based on patient needs and interests• Ensure research is focused on the public's interest and concerns• Review research tools• Help meet funder requirements
2. Study design	<ul style="list-style-type: none">• Review research tools• Ensure methods are feasible and sensitive to the situations of potential research participants
3. Study implementation	<ul style="list-style-type: none">• Help increase recruitment into the research study
4. Data analysis	<ul style="list-style-type: none">• Take diverse perspectives into account when analyzing data and when making decisions
5. Dissemination	<ul style="list-style-type: none">• Influence the language and content of information to be more appropriate and accessible before disseminating• Increase dissemination and uptake of evidence into practice or policy

Is research ethics approval required to engage patients in health research?

Researchers often ask about ethics approval requirements for engaging patients in health research. Different provinces and territories across Canada have different requirements. Exploration of these requirements is currently underway across the country to identify the specific procedures outlined for each jurisdiction.

In any case, it is prudent for researchers to address any ethical issues that may arise from patients being involved with research, from conception to dissemination. Researchers should fully describe how patients will contribute to the research (at each planned level of engagement), and what access to information they may have (e.g., anonymized data). (21) Patients who are research partners should be listed as members of the research team.

FIND OUT MORE

Partnering with citizens in research | Patients Canada

http://www.patientscanada.ca/site/patients_canada/assets/pdf/researcher_orientation_to_patient_partners - pub 2016.pdf

Framework for Citizen Engagement | Canadian Institute of Health Research

<http://www.cihr-irsc.gc.ca/e/41270.html>

Patient Engagement and Research Ethics Guidelines | Newfoundland and Labrador SUPPORT Unit

<https://www.dropbox.com/s/cwuvftkqn4nngzo/Patient%20Engagement%20and%20Research%20Ethics%20Guidelines%20NL%20SUPPORT%20and%20REB.PDF?dl=0>

ENGAGEMENT SPOTLIGHT

Title: Patient and Researcher Engagement in Health Research:
A Parent's Perspective (Alberta)

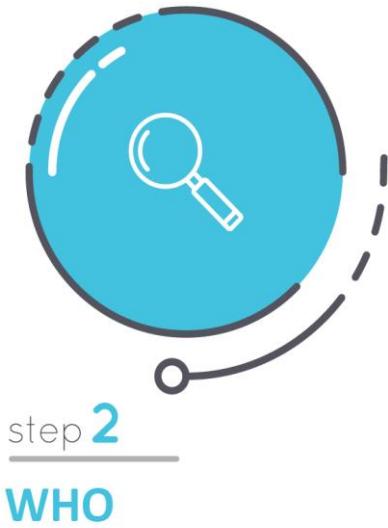
Who: Clinicians and researchers in Alberta, Canada.

What: The Letters Study showcases an example of meaningful patient and researcher engagement, where parents of children receiving care from a pediatric pulmonologist had the opportunity to share their voice in designing, implementing and disseminating a research study.

How: At the end of an appointment with a pulmonologist, parents receive a letter informing them about their child's condition, treatment, and recommendations for follow up. The Letters Study engaged with parents to see if an information letter was useful and accurately reflected their child's condition and treatment plan.

Results: One parent (Ms. Saunders) shared her thoughts and feelings about being engaged as a parent *"My personal experiences were met with genuine care and interest by the team members and my suggestions were implemented and built upon. It was a true demonstration of the power of collaboration and an amazing first experience for me . . ."*. This example demonstrates the powerful dynamic possible between researchers and patients in health research.

Amirav, I., Vandall-Walker, V., Rasiah, J., & Saunders, L. (2017). Patient and researcher engagement in health research: A parent's perspective. *Pediatrics*, 140(3), 1-4. doi:/10.1542/peds.2016-4127.



In this section, you will learn

- who you should consider engaging in your research;
- the levels of engagement for patients and researchers; and
- how to recruit patient partners for engagement in research.

Who should I consider engaging in my research?

Once you know why you want to engage patients in research, the next step is to consider who you will engage. A variety of people can—and should—be involved as partners in your research, depending on the research purpose. Special consideration should be given to including as wide a range of individuals as possible, to ensure diversity of input. In the table below, possible patient partners are identified, and brief explanations are given for why it is desirable to engage with them in research studies.

Patient	Rationale
Current or former patients Caregivers Family members Patient support groups	<ul style="list-style-type: none"> • People with lived experience of a specific condition, treatment, service, or event
Patient organizations Community groups	<ul style="list-style-type: none"> • People who provide a representative patient voice and advocate for issues relevant to patient populations and conditions of interest • People who provide a representative patient voice for those populations whose voice is often missing in research
Members of the public at large	<ul style="list-style-type: none"> • Concerned citizens who are interested in engaging in research to contribute to the well being of the population

How many patients do I need to engage?

There is no ideal number of patients to engage in research—but relying on one patient is problematic. (7) Tokenism, which may be perpetuated with a small number of patients, is a major barrier to quality patient engagement. To ensure that differing patient perspectives are included throughout the research, consider the recommendations below. (22)

- Involve as many patients as possible to include a wider perspective in your research.
- Patients should come from a broad range of backgrounds. Consider diverse genders, ages, types of expertise, socio-economic levels, and other demographic factors.
- Aim to include populations that researchers find hard to reach. This consideration is especially important at a system- or province-wide engagement level. Make it easier for patients to participate by meeting their needs in terms of time of day and day of the week (consider evening and weekend meetings), providing childcare, paying for transportation, or meeting them in their communities; and consider paying participants an honorarium.

FIND OUT MORE

Fairness and Equity in Research Participation | Government of Canada

<http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter4-chapitre4/>

Health Equity Impact Assessment | Ontario Ministry of Health and Long-Term Care

<http://www.health.gov.on.ca/en/pro/programs/heia/>

How do I decide how patients should be involved?

Clearly and jointly define roles, duties, and expectations among patients, researchers, and other stakeholders involved in your research. (3, 23) Patients must feel free to choose how and when they will engage, and to what level, to promote their autonomy and commitment throughout the study (9).

The researcher should consider the patient's motivation, willingness, and ability to engage at the required level, as well as their ability to move beyond simply sharing their own personal experience, to applying that experience so as to benefit society, including the care of others. (3) Consider ensuring that patients and researchers are a good fit for each other by completing a prescreening or interviewing process with predefined questions.

Patient attitudes and strengths can be assessed considering the criteria presented in the table below. (24)

Skills	Criteria
Understanding value of engagement	<ul style="list-style-type: none"> • Patient believes that the patient and family perspective is as important as the researcher's perspective. • Patient believes they bring a valuable perspective to the relationship with the researcher.
Supporting others	<ul style="list-style-type: none"> • Patient shares experiences as patient or family member. • Patient is non-judgmental and accepting of others. • Patient can cope well with their feelings and emotional issues. • Patient recognizes the needs and feelings of others.
Working with others	<ul style="list-style-type: none"> • Patient is willing to get involved with other people for a common goal. • Patient can handle confidential information without sharing it with others. • Patient can listen as well as contribute. • Patient does not necessarily expect praise for their work, but does expect respect and valuing of their perspective. • Patient can challenge his or her assumptions and those of others.
Working collaboratively	<ul style="list-style-type: none"> • Patient treats each research team member as an individual and avoids letting past negative experiences or attitudes influence contributions or decisions. • Patient is able to deal with conflict and disappointment constructively. • Patient has experience to share and will contribute accordingly. • Patient has realistic expectations for themselves and others.

Engaging with patients on your research team requires consideration of inclusivity, mutual respect, and opportunities to co-design the research process. Taking the time to build a relationship for meaningful engagement is critical for successful patient and researcher engagement.

FIND OUT MORE

Meaningful recruitment of patient and family advisors | Canadian Foundation for Healthcare Improvement

http://www.cfhi-fcass.ca/sf-docs/default-source/collaborations/PEP_Brief_Recruitment_EN.pdf?sfvrsn=0

Patients as Partners in Research Planning Guidelines | Patients Canada

http://www.patientscanada.ca/site/patients_canada/assets/pdf/planningguidelines_pub_2016.pdf

A resource toolkit for engaging patient and families at the planning table | Alberta Health Services Patient Engagement

<http://www.albertahealthservices.ca/assets/info/pf/pe/if-pf-pe-engage-toolkit.pdf>

It is also imperative that researchers meet the patient where he or she is—a patient may still be within care and treatment, or supporting someone who is. There are limitations to relying on patients who may need to prioritize their activities differently during this time. Outlining practical information can help the patient make the decision of whether they are able to participate, how, to what level. (25) Some suggestions are given below.

Practical Information for patients interested in engaging in health research

- Information about what they can offer to the research
- An overview of the research process and why the patient perspective is essential
- Contact information for who can answer their questions if they feel unclear about the expectations for their role
- Specific information about the project:
 - Is the project still in the application process or is it funded and underway?
 - How long is the project?
 - Where is the PI located, and where is the team located?
 - Who are the members of the team?
 - What is the commitment of time and effort the patient needs to make?
 - Is there separate funding for compensating patients and caregiver partners?

How do I find people to engage in my research?

Identifying, recruiting, and selecting who you will engage with in your research study takes time—but that time spent up front will pay dividends for the rest of the project. Most often, a convenience sampling strategy is effective for recruiting patient partners. (7)

Methods of Convenience Sampling Recruitment of Patient Partners

- Identifying patients during their care who may be interested in engagement in health research
 - Asking community members or patients you are already familiar with about additional people who might be interested in engaging
 - Advertising in clinical departments, such as outpatient clinics
 - Using social media
 - Connecting with local or national patient support groups or voluntary organizations
-

FIND OUT MORE

Partnering with citizens in research | Patients Canada

http://www.patientscanada.ca/site/patients_canada/assets/pdf/researcher_orientati on_to_patient_partners - pub_2016.pdf

Vat, L., Ryan, D., & Etchegary, H. (2017).

Recruiting patients as partners in health research: A qualitative descriptive study.

Research Involvement and Engagement, 3:15 pp. doi: [10.1186/s40900-017-0067-x](https://doi.org/10.1186/s40900-017-0067-x)
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5611573/>

ENGAGEMENT SPOTLIGHT

Title: Recruiting patients as partners in health research: A qualitative descriptive study

Who: Members of the general public in rural and urban Newfoundland and Labrador

What: Describe ways that patient partners (versus subjects) have been recruited by researchers and patient engagement leads

How: Interviews with researchers and patient engagement leads in Canada and the United Kingdom

Results: Four key recruitment strategies to engage patients in health research:

1. social marketing;
2. community outreach;
3. health system; and
4. partnering with other organizations (e.g., advocacy groups)

Vat, L., Ryan, D., & Etchegary, H. (2017). Recruiting patients as partners in health research: A qualitative descriptive study. *Research Involvement and Engagement*, 3, 15 pp.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5611573/>



step **3**

HOW

In this section, you will learn

- what you need before engaging patients in research;
- a variety of engagement tactics to apply across the research activity cycle;
- how to decide which engagement tactic is right for your research; and
- how to budget for patient engagement in health research.

What do I need before I engage with patients in my research?

Having planning documents in place beforehand can help prevent common challenges that may arise throughout the research process when you are engaging patients at the “Involve” level or higher. Worksheets to support these processes can be found in Appendix B of this Guide.

Documents to prepare before you begin engaging patients in research

- Terms of reference for research team or working group
 - Meeting ground rules
 - Guidelines for how input from patients will be recorded and shared
 - Guidelines for raising a concern or complaint
 - Confidentiality agreements
 - Authorship agreements
-

What practical items should I consider before engaging patients in my research?

Consider the items listed below when planning for engagement.

Planning for engagement

- Transportation, food, lodging etc.
 - Equipment, supplies
 - Participant compensation and reimbursement of expenses
 - Time of day and day of the week
 - Agenda or plan for the event
 - Participant satisfaction feedback method (including researcher feedback)
 - Timeframe
-

How do I engage with patients across the research activity cycle?

Patients can be engaged throughout the research cycle. The following section describes the ways in which patients can be involved, and the benefits of such involvement. Subsequent sections focus on the different tactics that can be used throughout the research activity cycle. Worksheets to support these processes can be found in Appendix B of this Guide.

STAGE 1. Planning and Preparation

This stage of the research cycle is critical from a patient engagement perspective, as it allows the patient perspective to be included in determining the research topic, in alignment of priorities and in identification of research questions. (26) The earlier you engage with patients, the better. This is the most powerful way to influence what will be researched. (27)

Engaging patients at this stage of research can

- ensure that the project and results will be useful and important to patient and other stakeholder communities; and
- minimize the risk that certain patients will be included or excluded due to non-relevant selection criteria

FIND OUT MORE

JLA Priority Setting Partnership (PSP) Guidebook | James Lind Alliance (UK)
<http://www.jla.nihr.ac.uk/jla-guidebook/>

Manafò, E., Petermann, L., Vandall-Walker, V., Mason-Lai, P. Patient and public engagement in priority setting: A systematic rapid review of the literature. *PLOS ONE*. 2018, Mar. 13(3). <https://doi.org/10.1371/journal.pone.0193579>

ENGAGEMENT SPOTLIGHT

Title: Engaging patients and clinicians in establishing research priorities for Gestational Diabetes Mellitus (GDM)

Who: Patients and clinicians in Alberta, Canada

What: Engaging with women with GDM and clinicians to identify uncertainties about the management of GDM

How: Various survey formats to support a four-step James Lind Alliance (JLA) process

Results: Seventy-five individuals submitted 389 uncertainties in the area of GDM. After final priority setting process, the final top 10 research priorities included questions about a simpler, more accurate and convenient screening test; risk factors for GDM; improving postpartum diabetes screening; the impact of GDM on the future health of the children; lifestyle challenges and mental health issues; safety, effectiveness, and impact of diet, medical treatments, or both; appropriate timing for delivery; and how care is provided, organized, and communicated.

Rees, S., Chadha, R., Donovan, L., Guitard, A., Koppula, S., Laupacis, A., . . . Johnson, J. (2017). Engaging patients and clinicians in establishing research priorities for Gestational Diabetes Mellitus. *Canadian Journal of Diabetes*, 41(2), 156-163. <https://doi.org/10.1016/j.jcjd.2016.08.219>

STAGE 2. Study Design

In this stage of the research cycle, patients provide input, as appropriate, about the methods and processes by which the study is carried out. This input can help build and strengthen the relevance, quality, and attention to ethical considerations of the research. (7) The insight provided by patients can also help recruit, promote, and retain patients who are participating in the study, as the study will clearly be *for* patients *with* patient input. (8)

Engaging patients at this stage of research can

- promote recruitment and retention of the participant sample;
 - ensure that written materials developed are user friendly and in plain language format;
 - ensure that the patient perspective is incorporated and maintained throughout the study; and
 - ensure that patient engagement is properly budgeted for through the duration of the research project.
-

ENGAGEMENT SPOTLIGHT

Title: BedMed: A patient engagement demonstration project

Who: Pragmatic Trials Collaborative (PTC) and AbSPORU PE Platform

What: The BedMed Project is a primary-care based, pragmatic clinical trial that seeks to evaluate antihypertensive medication timing in adults with high blood pressure.

How: Leaders from PTC and the PE Platform met to collaborate on the BedMed Project. They agreed to use BedMed as a PE Platform demonstration project that models active, meaningful, patient engagement in a health research project, and illustrates one method of building capacity in patients and researchers working to partner effectively together in health research.

Results: The BedMed research team has found patient engagement through a Working Group structure to be a valuable method for continuous improvement in POR design and implementation.

BedMed Project: A patient engagement demonstration project. Partnership between Pragmatic Trials Collaborative and AbSPORU Patient Engagement Platform. August, 2017.

For general information on BedMed, see Pragmatic Trials Collaborative: Measuring what matters. Trials in progress: Bedmed. <http://www.pragmatictrials.ca/bedmed>

STAGE 3. Study Implementation

Engaging patients in study implementation can be challenging. A common assumption is that a patient may not be able to contribute substantially because of a limited level of research expertise and knowledge. However, this assumption does not necessarily recognize the capacity of many patients. Training for researchers and patients—and ongoing support for both groups—are required to ensure that patient contributions are continuously recognized and included. After being engaged in study planning,

patients are most likely engaged in the project in an advisory capacity to continue to help steer the research by providing a patient lens. (8)

Engaging patients at this stage of research can also

- sustain and further increase recruitment, thus ensuring study viability;
 - help reduce barriers to participation for subjects and participants; and
 - help interpret recruitment materials from a patient perspective.
-

FIND OUT MORE

Get trained to become a patient researcher | PaCER (Calgary, AB)

<https://pacerinnovates.ca/get-trained/>

ENGAGEMENT SPOTLIGHT

Title: Support for living a meaningful life with osteoarthritis: A patient-to-patient research study

Who: Patients with osteoarthritis (OA)

What: Patients with OA and trained in engagement methods used adapted qualitative methods to co-design and conduct the study.

How: OA patients ($N = 25$) participated in a three-step peer-to-peer process: a focus group clarified and explored the topic and guided the creation of the interview guide used in the second phase.

Results: Using a collaborative analysis process, the researchers identified eight concepts that they then brought to a last focus group. Participants reviewed the findings, identifying implications for arthritis care in Alberta, Canada.

Miller, J., Teare, S., Marlett, N., Shklarov, S., & Marshall, D. (2016) Support for living a meaningful life with osteoarthritis: A patient-to-patient research study. *Patient*, 9(5), 457-464.
doi: 10.1007/s40271-016-0169-9.

STAGE 4. Data analysis

While there are fewer examples in the literature of how patients are currently being meaningfully engaged in this aspect of the work, researchers are also encouraged to engage with patients in the analysis of the study data. However, patient involvement does not have to be limited to the analysis of data. Once the analysis is complete, patients can help contextualize results by interpreting them in a meaningful way to patients and stakeholder groups. Successful dissemination hinges on earlier involvement of patients, especially in data analysis.

Engaging patients at this stage of research can

- lend unique and varied perspectives to data interpretation;
- identify missing themes in analysis;
- highlight findings more relevant to the public; and
- influence the extent to which information is accessible to a public audience.

ENGAGEMENT SPOTLIGHT

Title: “Part of the Team”: Mapping the outcomes of training patients for new roles in health research and planning

Who: Patients with various chronic conditions

What: One-year training in adapted qualitative research methods, including an internship where patients designed and conducted five peer-to-peer inquiries into a range of health experiences

How: Grounded theory using an outcome mapping framework

Results: Key stakeholders indicated increased capacity of patients to engage in health-care research and planning and the introduction and acceptance of new, collaborative roles for patients in health research. The uptake of new patient roles in health-care planning began to impact attitudes and practices.

Shklorov, S., Marshall, D., Wasylak, T., & Marlett, N. (2017) “Part of the Team”: Mapping the outcomes of training new patients for new roles in health research and planning. *Health Expectations*, 20(6), 1428-1436. <https://doi.org/10.1111/hex.12591>

STAGE 5. Dissemination

This stage of research is a critical one, for both researchers and patients. The patient engagement adage “Nothing about us, without us” underscores the importance of including patients in the plans to disseminate study findings to ensure findings are communicated in an understandable and useable way.

Engaging patients at this stage of research can

- keep patients informed throughout project, reporting positive and negative results;
- reach different audiences that may be interested in patient perspective; and
- make it possible to move away from traditional models of dissemination and consider novel opportunities.

FIND OUT MORE

GRIPP2 Reporting Checklist for Patient Engagement | (UK)

<http://www.bmj.com/content/358/bmj.j3453>

ENGAGEMENT SPOTLIGHT

Title: Quality of Care Newfoundland (NL)

Who: Quality of Care NL is a Faculty of Medicine program in partnership with the Newfoundland Labrador Medical Association (NLMA)

What: Quality of Care NL is focused on the appropriate use of health care resources in the province, so that the right intervention is provided to the right patient at the right time.

How: Working collaboratively with patients to obtain input through informal discussions and interactive workshops, Quality of Care NL has developed non-traditional dissemination resources for use by patients and providers.

Results: The inventory of dissemination can be found for patients
<http://qualityofcarenl.ca/patients/your-health/>
and providers
<http://qualityofcarenl.ca/healthcare-professionals/resources/>

For general information on Quality of Care NL, see <http://qualityofcarenl.ca>

What are the most common tactics used to engage with patients in research?

Depending on the purpose and objectives for engaging with patients, several facilitation tactics can be used to engage with patients in small and large group meetings. It is a good idea initially to use an experienced facilitator who is familiar with engaging widely and with differing audiences, to help guide the process.

The level of engagement you choose depends on the inputs and resources you have available. As a general rule, as you progress through the levels of patient and researcher engagement (Figure 1, above), the more time, money, skill (i.e., competence) and support is required.

Consider the options in the table below, organized according to the levels of engagement designated “Consult,” “Involve,” and “Collaborate.” (28).

Level of Engagement: Consult			
Engagement Tactic	Purpose	Description	Research Stage Examples
Survey/questionnaire	Administered to a sample of patients to learn about the experience of a larger population	Opportunity to gain insight from patients about their experiences	3. Study Implementation 4. Data Analysis 5. Dissemination
One-to-one meetings	To obtain patient stories and information about their experiences	A resource-intensive but rewarding opportunity for patient stakeholders to feel open and comfortable in expressing their views and telling their stories Can have targeted questions or be an open forum for discussion Useful for building rapport	1. Planning and Preparation 2. Study Design 3. Study Implementation
Appreciative inquiry	To identify and leverage resources and positive experiences that have contributed to success in the past	Used in stakeholder engagement to identify “what works” by inviting participants to recount individual success stories about the relationship between a researcher and the stakeholders These stories serve to inspire a more positive approach to the relationship, and more creativity. Once discovered, these stories are shared throughout the research team. What is	5. Dissemination

Level of Engagement: Consult			
Engagement Tactic	Purpose	Description	Research Stage Examples
		<p>“wrong”, “inadequate” or “not good enough” moves out of awareness as the organization taps into positive possibilities rather than past failings.</p> <p>Appreciative inquiry is based on the idea that a positive future can be built on successes of the past.</p>	
Focus group	To obtain stakeholder perceptions and opinions	Small group of carefully selected individuals engage in facilitated discussions	<ol style="list-style-type: none"> 1. Planning and Preparation 2. Study Design 3. Study Implementation 4. Data Analysis 5. Dissemination
Delphi process	To build consensus about patient priorities	<p>A method of obtaining agreement forecasts or other parameters by a group of people without need for face-to-face group process</p> <p>Can be done anonymously, so people feel comfortable expressing themselves.</p>	4. Data Analysis

Level of Engagement: Involve			
Engagement Tactic	Purpose	Description	Research Stage Examples
Interview matrix	To develop strategies for moving forward	Opportunity for patient stakeholders to reflect actively on their experiences and share ideas with others	1. Planning and Preparation 3. Study Implementation 5. Dissemination
Appreciative inquiry	To identity and leverage resources and positive experiences that have contributed to success in the past	Used in stakeholder engagement to identify “what works” by inviting participants to recount individual success stories about the relationship between a researcher and the stakeholders These stories serve to inspire a more positive approach to the relationship, and more creativity. Once discovered, these stories are shared throughout the research team. What is “wrong”, “inadequate” or “not good enough” moves out of awareness as the organization taps into positive possibilities rather than past failings. Appreciative inquiry is based on the idea that a positive future can be built on successes of the past.	1. Planning and Preparation 3. Study Implementation

Level of Engagement: Involve			
Engagement Tactic	Purpose	Description	Research Stage Examples
Nominal group technique	To generate and organize ideas quickly	A larger group breaks down into small groups to discuss clearly articulated questions. Ideas are noted on 5-8 cards per group. The cards are grouped into logical categories and displayed on wall. Groups can prioritize ideas using “voting” with paper dots. Ideas are shared with larger group in a “marketplace” display.	4. Data Analysis
Open Space (OS) meetings / technology	To give everybody on the research team the opportunity to surface and engage about his or her issues, concerns or ideas	In OS meetings and events, participants create and manage their own agendas of parallel working sessions around a central theme of strategic importance. OS events have no keynote speakers, no pre-announced schedules or workshops, no panel discussions. Instead, sitting in a large circle, participants learn in the first hour how they are going to create their own conference. Anyone who wants to initiate a discussion or activity writes it down on	2. Study Design

Level of Engagement: Involve			
Engagement Tactic	Purpose	Description	Research Stage Examples
		a large sheet of paper in big letters, then stands up and announces it to the group. After selecting one of the many pre-established times and places, they post their proposed workshop on a wall. When everyone who wants to has announced and posted their initial offerings, participants mill around the wall, putting together their personal schedules for the remainder of the conference. The first meetings begin immediately.	
Scenario planning	To stimulate creative thinking and communication of complex ideas	A small panel of stakeholders, including decision-makers and experts are guided by a facilitator to identify key issues relevant to the topic under discussion. From these key issues, trends and driving forces are determined. The most important possible trends are then fleshed out into contingent futures.	2. Study Design 4. Data Analysis

Level of Engagement: Collaborate			
Engagement Tactic	Purpose	Description	Research Stage Examples
Appreciative inquiry	To identity and leverage resources and positive experiences that have contributed to success in the past.	<p>Used in stakeholder engagement to identify “what works” by inviting participants to recount individual success stories about the relationship between a researcher and the stakeholders</p> <p>These stories serve to inspire a more positive approach to the relationship, and more creativity. Once discovered, these stories are shared throughout the research team. What is “wrong”, “inadequate” or “not good enough” moves out of awareness as the organization taps into positive possibilities rather than past failings.</p> <p>Appreciative inquiry is based on the idea that a positive future can be built on successes of the past.</p>	1. Planning and Preparation 2. Study Design 5. Dissemination
Consensus building	To collaborate in decision-making and partnership-building among diverse research stakeholders	With the assistance of an unbiased mediator or facilitator, participants are guided through a structured process of raising issues, understanding each	1. Planning and Preparation 2. Study Design 4. Data Analysis 5. Dissemination

Level of Engagement: Collaborate			
Engagement Tactic	Purpose	Description	Research Stage Examples
		other's views, and then co-operatively developing an agreed-upon resolution.	
Consensus conference, Citizens' jury	To stimulate informed public debate	A panel of stakeholders is brought together and asked to investigate a particular question. The panel selects and then publicly cross-examines experts, and produces a report of its findings. Most often used when considering questions relating to new science or technology	1. Planning and Preparation
Community of practice	To bring people together to share, learn, and cultivate new possibilities for their research	A group of stakeholders is brought together to share knowledge, experiences, tools, and lessons learned, so as to contribute to a growing area of research.	1. Planning and Preparation 2. Study Design
Planning for Real	To make decisions collaboratively in local communities	"Planning for Real," a process trademarked by the Neighbourhood Initiatives Foundation, uses large-scale maps and three-dimensional models to promote discussion of planning and community development options.	1. Planning and Preparation

Level of Engagement: Collaborate			
Engagement Tactic	Purpose	Description	Research Stage Examples
Visioning	To stimulate creative thinking and collaborative planning	In visioning, individuals and groups develop a vision for the future, then go through a process of “back casting” to translate the vision into more concrete goals and action plans	1. Planning and Preparation 3. Study Implementation
Open Space (OS) meetings / technology	To give everybody on the research team the opportunity to surface and engage about his or her issues, concerns or ideas	In OS meetings and events, participants create and manage their own agendas of parallel working sessions around a central theme of strategic importance. OS events have no keynote speakers, no pre-announced schedules or workshops, no panel discussions. Instead, sitting in a large circle, participants learn in the first hour how they are going to create their own conference. Anyone who wants to initiate a discussion or activity writes it down on a large sheet of paper in big letters and then stands up and announces it to the group. After selecting one of the many pre-established times and	2. Study Design

Level of Engagement: Collaborate			
Engagement Tactic	Purpose	Description	Research Stage Examples
		places, they post their proposed workshop on a wall. When everyone who wants to has announced offerings, participants mill around the wall, putting together their personal schedules for the remainder of the conference. The first meetings begin immediately.	
World café or carousel	To generate ideas, share knowledge, stimulate creative thinking, and explore action possibilities with quite large groups.	Seated at tables of four or five, set up informally in a café style, people discuss a question linked to the overall theme. Drawing and writing on the table cloth to record ideas. Each table is hosted by one person who stays there. After 30 minutes, people move to a new table and are encouraged to link and carry over ideas from one conversation to the next, and to build on ideas discussed by previous groups. After several rounds a final synthesis is drawn together through a whole group discussion.	1. Planning and Preparation

Level of Engagement: Collaborate			
Engagement Tactic	Purpose	Description	Research Stage Examples
Priority Setting Partnerships (PSPs)	To build consensus about patient priorities / research questions / uncertainties	Designed to identify and prioritize public-, patient-, and clinician-shared uncertainties about the effects of treatments and experiences across health conditions and situations	1. Planning and Preparation
Dialogue model	To identify needs and priorities of patients as basis for dialogue about research to improve health practice	Involves question exploration, consultation and prioritizing with patients, the better to integrate their perspectives into programming and eventual dissemination	1. Planning and Preparation 3. Study Implementation
Global Evidence Mapping (GEM)	To identify research questions that, for high-priority questions, are mapped to available evidence	Develop and prioritize questions in collaboration with patients. A separate evidence search is completed with data extraction, and a mapping between patient identified priorities and research questions is weighted against current evidence to determine gaps and future research directions	1. Planning and Preparation

How do I know which patient engagement tactic is the best for my team's research study?

It is important to assess the engagement tactic to see if it meets your team's research objective and purpose for engaging with patients. Keeping the purpose of your team's engagement in mind, ask yourselves the questions given below when comparing different tactics. (28)

Assessing engagement tactics

- Do we have access to the tools and personnel needed to implement this technique?
 - Do we have the expertise to implement this technique successfully, or do we need outside support?
 - Is there sufficient time to implement the technique successfully?
 - Does the technique have a proven track record of success in similar situations or with similar audiences?
 - Does the technique coincide with what we have learned about our team's stakeholders and how they want to be involved?
 - Will the technique meet legal and policy requirements?
 - What risks are associated with this technique?
 - At what point in the decision-making process will this technique be used?
-

Other important considerations include the inputs or resources listed below.

Time	<ul style="list-style-type: none">• How much time do we have to commit to engaging with patients in our research?
Funding	<ul style="list-style-type: none">• How much funding do we have to allocate to engaging with patients?
Competencies	<ul style="list-style-type: none">• What competencies do we need as researchers?• What competencies are needed by potential patients with whom we are trying to engage?
Support / endorsement	<ul style="list-style-type: none">• How well supported is patient and researcher engagement in research in our organization?

How do I budget for patient and researcher engagement in health research?

Budgeting for patient and researcher engagement depends in large measure on the competence of the patients and researchers to engage together. Additional workshops and training might be needed to promote greater competence for meaningful engagement, and therefore must be budgeted for. Budgeting should also include a line for refreshments for meetings—to help build rapport, and thereby trust. One idea is to consider hosting a potluck event.

Budgeting for patient and researcher engagement depends as well on the *number of patients* (including family members and caregivers) you will engage with, and the *number of days* patients and family members will be engaged in the study. Depending on your funding source, you may wish to consider an honorarium (i.e., an expression of appreciation) or other remuneration of some sort. A compensation rate should be determined, and expenses added. At a bare minimum, you should reimburse patients for their out-of-pocket expenses (e.g., parking and mileage), and provide refreshments at the meetings.

EXAMPLE

Considerations

- Honorarium = \$125/day
- Number of patients across research activity cycle = 14 (2 patient members on research team; 10 patients involved in priority setting; 2 patients involved in dissemination opportunities)
- Number of days patients will be engaged = 7

Calculation

- a. 4 full days patient team members on the research team; $(125 * 4) * 2 = \$1,000$
- b. 1 full day focus group priority setting meeting; $(125) * 10 = \$1,250$
- c. 2 full days dissemination planning $(125 * 2) * 2 = \$500$

Total

$$a + b + c = \$2,750 + \text{expenses (including meeting refreshments)}$$

FIND OUT MORE

Patient Engagement Appreciation Guidelines | Newfoundland and Labrador SUPPORT Unit

http://www.mun.ca/research/conferences/CARA_Patient_Engagement_Ethics.pdf

Should money come into it? A tool for deciding whether to pay patient-engagement participants | Change Foundation (Ontario)

<http://www.changefoundation.ca/patient-compensation-report/>



step **4**

ENGAGE

In this section, you will learn

- tips for engagement; and
- where to seek support if things go wrong.

What tips can I use to help me engage with patients?

The following lists consist of tips to help you to engage meaningfully with patients throughout the research activity cycle. These engagement tips are organized according to the stages of the cycle to facilitate thinking about engaging with patients continuously, but it is important to note that they are not limited to any one stage.

Planning

- Develop transparent processes.
- Provide clear rules for engagement within group settings.
- Establish formal processes for voting.
- Establish clear processes for resolving conflict.
- Establish authorship expectations.
- Plan for socializing to get to know each other—and over food and drink.
- Consider taking team-building exercises and workshops (e.g., through the AbSPORU PE Platform).
- Work with the PE Platform on your engagement plan.

Designing

- Start early with “pre-engagement.” Trust cannot be built overnight. Integrate yourself into existing community networks. Trust is one of the key factors in the decision to be made by individuals from hard-to-reach groups of whether or not to participate in the research process.
- Communicate early and often.
- View patient partners as competent, autonomous individuals, not as vulnerable patients, to remove the stigma that being involved in a health situation may impose.
- Eliminate hierarchy and status. Use first names for all researchers and patients, rather than, for example, “Dr.”; eliminate degrees and titles.
- Use plain language for descriptions of key concepts and the research project, and when recording summaries of calls or meetings involving patient representatives. More complex terminology and acronyms may slowly be integrated as needed.
- Actively listen to patient responses. Read body language and think about non-verbal ways to build trust.
- Have a single contact person on the research team for patient partners.
- Use opportunities to socialize to build rapport and trust. Refreshments can help here, but must be budgeted for.

Implementing, Analyzing, and Evaluating

- Speak the same language (i.e., use “lay” language whenever possible).
- Be flexible.
- Remember that “research” is an emotionally charged word for some.
- Communicate in a culturally and linguistically appropriate manner.
- Provide constructive feedback to affirm that patient research partners are contributing to the project.
- Encourage patients to share their opinions and provide adequate time for them to engage.
- Keep questions simple and straightforward.

FIND OUT MORE

Real engagement for real improvement | Canadian Foundation for Healthcare Improvement

http://www.cfhi-fcass.ca/sf-docs/default-source/collaborations/PEP_Brief_RealEngagement_EN.pdf?sfvrsn=0

Ready, set, engage: Preparing for engagement | Canadian Foundation for Healthcare Improvement

http://www.cfhi-fcass.ca/sf-docs/default-source/on-call/PEP_Brief_Readiness_EN.pdf?sfvrsn=0

What do I do if things go wrong?

Patient and researcher engagement is a new and evolving initiative. AbSPORU is prepared to support researchers and patients to promote equitable and meaningful patient engagement opportunities. The tips given below maybe useful to address issues that may affect the success of engaging with patients. (3)

Strategies to address problems

- Acknowledge that there is a problem.
 - Listen to any concerns and openly discuss them with those concerned, along with any concerns that you might have.
 - Allow space and time for all involved to reflect.
 - Refer back to any relevant documents that you may have developed.
 - Ensure that support is available, such as follow-up phone calls or meetings to discuss matters privately, as needed.
 - Consider using a skilled external facilitator.
-



EVALUATE

Why should I evaluate how we engaged with patients in our research?

There are several reasons why a researcher should conduct evaluations of the patient engagement initiative. Some of them of evaluation are listed below. (17)

- **Theoretical:** To help prove or disprove the theoretical assumptions underlying the patient and researcher engagement, and to help clarify the nature of patient and researcher engagement
- **Scientific:** To produce valid knowledge of underlying social phenomena related to patient and researcher engagement
- **Political:** To promote fairness through equitable involvement in the evaluation process
- **Pragmatic:** To increase the utility of the knowledge created
- **Practice:** To help determine best practices in patient and researcher engagement in research

Within your research, the focus of evaluation efforts may emphasize the pragmatic and practice-related benefits specifically, while indirectly contributing to the political, scientific, and theoretical and philosophical domains of patient and researcher engagement in health research.

How do I plan for evaluating success in engaging with patients in research?

Keeping a record of how patients and researchers are engaged, and of the implications of this engagement for your research (especially the unintended benefits and consequences) is important. It helps ensure that patients and researchers are engaged throughout the study, and also helps when drafting a report to funders, and in the dissemination of research findings.

An evaluation of patient and researcher engagement should contribute to a better understanding of the experiences of the patient and researcher, and when appropriate, the organization that helps fund or facilitate the research. Engagement should be measured quantitatively (e.g., number of people engaged), as well as qualitatively (e.g., patient and researcher satisfaction and other feedback about the engagement opportunity). Evaluation is not limited to the perspective of patients, but should also include researcher views as well.

When planning for evaluation, you may find it helpful to consider the questions below. (29)

- What is the aim of engaging with patients in the research?
- What theoretical rationale or influences relating to patient and researcher engagement were considered in developing the study?
- Who are the patients, carers, and public members involved as team members in the study?
- What is the level or nature of involvement of patient partners at the various stages of the research?
- What might be the positive and negative outcomes of engaging patients and researchers in the study? How might these outcomes impact the results of the study? How might they impact the patient?
- What influence or contextual factors might enable or hinder the process or impact of patient and researcher engagement?
- What considerations or advancements to the theoretical development of patient and researcher engagement in health research have emerged?
- What does the patient and researcher engagement of our study add to our knowledge of best practices in patient and researcher engagement?
- Was the engagement exercise mutually beneficial?

It is always a good idea to consult, and if feasible, work with an experienced evaluator who can support the development of an evaluation framework and plan how best to support your needs. Budgeting for evaluation support, including data collection, is critical to ensuring capacity for this stage of research.

Even though evaluation is listed as the fifth and final step in this Guide, planning for evaluation takes place before research begins, not after it ends. It is a good idea to consider how you plan to evaluate the patient engagement opportunity from the outset. Consider one of the tools identified in the “Find out More” section below to help guide the evaluation process.

FIND OUT MORE

Patient and Public Engagement Evaluation Tool | McMaster University (Canada)
<https://iap2usa.org/resources/Documents/Research/Evaluation%20Tool%20-%20PublicandPatientEngagementEvaluationTool.pdf>

Researcher Surveys: Evaluating the Patient Partnership in Research | Patients Canada
https://www.patientscanada.ca/site/patients_canada/assets/pdf/researchersurveys_2016.pdf

Patient/Caregiver Surveys: Evaluating the Patient Partnership in Research | Patients Canada
https://www.patientscanada.ca/site/patients_canada/assets/pdf/patientsurveys_2016.pdf

Evaluation Framework | Involve (UK)
<https://www.involve.org.uk/knowledge-base/evaluation-framework/>

Dissemination and Implementation Toolkit | PCORI (US)
<https://www.pcori.org/sites/default/files/PCORI-DI-Toolkit-February-2015.pdf>

What outcomes and measures should I consider when evaluating patient and researcher engagement?

It is important that you, as the researcher, identify the goals and purposes of engaging patients, and then connect these goals to possible indicators and data sources to support evaluation. This linkage is known as an “evaluation framework.”

The AbSPORU has identified five critical areas for consideration when evaluating patient engagement (modified below by the addition of the term “researcher”):

- building awareness of the process and impact of patient and researcher engagement;
- co-creating linkages between patients and researchers to support meaningful patient and researcher engagement opportunities;
- collaborating towards meaningful and robust patient and researcher engagement evaluation frameworks with existing PE leaders, such as the PE Platform in AbSPORU;
- creating and mobilizing knowledge on the promising impacts of patient and researcher engagement; and
- fostering leadership to accelerate patient and researcher engagement.

An example of an evaluation framework may be useful to support your evaluation plan. Such an example is given below.

Goal / Purpose	Possible Indicators / Measures	Data Sources
<p><i>Building awareness</i> Capacity building and learning</p>	<ul style="list-style-type: none"> • Alberta citizens / patients and researchers have increased awareness of patient engagement. • Citizens with “lived experience” have greater knowledge of and empathy for broader community needs. • Alberta researchers partner with patients to design, implement, and evaluate research pilots or projects that effectively and meaningfully embed patient engagement in a range of relevant roles in future research. 	Questionnaires with team members before and after the engagement processes; and follow-up interviews after study completion
<p><i>Co-creating linkages</i> Improved relationship between researchers and patients</p>	<ul style="list-style-type: none"> • A growing number of Alberta researchers and patient / citizen groups are building relationships around shared research interests in patient engagement projects. 	Patient and researcher surveys before and after the engagement process
<p><i>Collaborative evaluation</i> Improved leveraging of evaluation support and resources</p>	<ul style="list-style-type: none"> • Robust patient and researcher engagement evaluation frameworks are available, as are purpose / contribution statements for the evaluation activities and results (i.e., formative and developmental). 	Robust patient and engagement evaluation frameworks and summaries of contributions to evaluation activities and results
<p><i>Knowledge creation and mobilization</i> Increased knowledge mobilization from patients and patient groups</p>	<ul style="list-style-type: none"> • Innovative researchers (i.e., early adopters / champions) are co-publishing with patients • Citizens / patients are partners in many relevant knowledge translation roles (e.g., design of knowledge mobilization strategy) 	Presence of posters, reports or research, and other dissemination vehicles on the promising impacts of patient engagement in health research
<p><i>Fostering leadership</i> Championing patient and researcher engagement across health disciplines</p>	<ul style="list-style-type: none"> • A cohort of researcher, clinician, and patient champions are emerging to accelerate PE in POR system change 	Presence of researchers on PE Platform Working Group

Annotated Bibliography | Patient Engagement in Health Research

The following references may be useful to support your exploration of patient and researcher engagement in health research.

Background

Baker, G. [2014]. Evidence boost: A review of research highlighting how patient engagement contributes to improved care. Available from <http://www.cfhi-fcass.ca/SearchResultsNews/2014/08/14/evidence-boost-a-review-of-research-highlighting-how-patient-engagement-contributes-to-improved-care>

Note: The comments below are a direct and complete quote from the summary given on the website identified.

Improving patient experience and incorporating patient input into the design of healthcare services have emerged as critical priorities for many healthcare systems but progress has been limited. Greater engagement of patients and families in organizational roles and care teams has helped a number of healthcare organizations to improve quality, safety and patient experience. Insights from exemplar organizations suggest broader opportunities to improve health system performance. This brief provides a context and summary of research findings on case studies of patient engagement for health system improvement across organizations in four countries.

Key Findings

- Many organizations have discovered that involving patients and families in quality improvement, patient safety and service redesign initiatives accelerates both patient engagement and the work of improvement teams.
- Patient engagement in improvement efforts may improve outcomes.
- Effective patient and family-centered care and engagement require changes in values and relationships, but these, in turn, depend on creating structures, roles and policies that support these values and relationships.
- Successful patient engagement initiatives had staff that managed local work effectively and communicated its importance, relevance and contributions to leadership.
- Leadership for patient engagement and to develop patient and family-centered care is critical to its success.

Duffett, L. (2017). Patient engagement: What partnering with patient in research is all about. *Thrombosis Research*, 150, 113-120. doi:
<https://doi.org/10.1016/j.thromres.2016.10.029>

Note: The comments below are a direct and complete quote from the abstract of this article.

The inclusion of patients on important decisions related to healthcare has marked a significant “patient revolution” during the last several decades. Patients now play active roles in personal health decisions, healthcare delivery and policy making, and the development of clinical practice guidelines. Such inclusion of patients' values has resulted in largely positive effects. The next wave of this “patient revolution” is active and meaningful engagement with patients in health related research. Similar to other aspects of healthcare, it is increasingly recognized that experienced patients, their families, and caregivers, have a wealth of knowledge that comes from living and experiencing a medical condition. By understanding and valuing this experience-based knowledge, research priority setting, research study design, trial conduct, analysis of results and knowledge dissemination can be positively influenced. Patients can challenge our assumptions, align research with the needs of patients, increase transparency and trust in research, and lead to research that has a greater impact on the ultimate care of patients. This new approach to research is timed well with a larger movement towards simple, pragmatic clinical trials better reflecting realistic patient care. While there is still much to be learned about the best methods and exact impacts of patient engagement in research, preliminary results are promising and future venous thromboembolism research will likely benefit from the adoption of patient engagement in research.

Frank, L., Forsythe, L., Ellis, L., Schrandt, S., Sheridan, S., Gerson, J., . . . Daugherty, S. (2015). Conceptual and practical foundations of patient engagement in research at the Patient-Centered Outcomes Research Institute. *Quality of Life Research*, 24(5), 1033-1041. Available from <https://link.springer.com/article/10.1007/s11136-014-0893-3>

Note: The comments below are a direct and complete quote from the abstract of this article.

Purpose

To provide an overview of PCORI's approach to engagement in research.

Methods

The Patient-Centered Outcomes Research Institute (PCORI) was established in 2010 to fund patient-centered comparative effectiveness research. Requirements for research funding from PCORI include meaningful engagement of patients and other

stakeholders in the research. PCORI's approach to engagement in research is guided by a conceptual model of patient-centered outcomes research (PCOR), that provides a structure for understanding engagement in research.

Results

To understand and improve engagement in research PCORI is learning from awardees and other stakeholders. Those efforts are described along with PCORI's capacity building and guidance to awardees via the Engagement Rubric. PCORI's unique model of engaging patients and other stakeholders in merit review of funding applications is also described. Additional support for learning about engagement in research is provided through specific research funding and through PCORI's major infrastructure initiative, PCORnet.

Conclusion

PCORI requires engagement of stakeholders in the research it funds. In addition PCORI engages stakeholders in activities including review of funding applications and establishment of CER research infrastructure through PCORnet. The comprehensive approach to engagement is being evaluated to help guide the field toward promising practices in research engagement.

Shen, S., Doyle-Thomas, K., Beesley, L., Karmali, A., Williams, L., Tanel, N., & McPherson, A. (2016). How and why should we engage parents as co-researchers in health research? A scoping review of current practices. *Health Expectations, 20*(4), 543-554. Available from <https://doi.org/10.1111/hex.12490>

Note: The comments below are a direct and complete quote from the abstract of this article.

Background

The importance of engaging parents in health research as co-researchers is gaining growing recognition. While a number of benefits of involving parents as co-researchers have been proposed, guidelines on exactly how effective engagement can be achieved are lacking. The objectives of this scoping review were to (i) synthesize current evidence on engaging parents as co-researchers in health research; (ii) identify the potential benefits and challenges of engaging parent co-researchers; and (iii) identify gaps in the literature.

Methods

A scoping literature review was conducted using established methodology. Four research databases and one large grey literature database were searched, in addition to hand-searching relevant journals. Articles meeting specific inclusion criteria were

retrieved and data extracted. Common characteristics were identified and summarized.

Results

Ten articles were included in the review, assessed as having low-to-moderate quality. Parent co-researchers were engaged in the planning, design, data collection, analysis and dissemination aspects of research. Structural enablers included reimbursement and childcare. Benefits of engaging parent co-researchers included enhancing the relevance of research to the target population, maximizing research participation and parent empowerment. Challenges included resource usage, wide-ranging experiences, lack of role clarity and power differences between parent co-researchers and researchers. Evaluation of parent co-researcher engagement was heterogeneous and lacked rigour.

Conclusions

A robust evidence base is currently lacking in how to effectively engage parent co-researchers. However, the review offers some insights into specific components that may form the basis of future research to inform the development of best practice guidelines.

Planning

Sheridan, S., Schrandt, S., Forsythe, L., Advisory Panel on Patient Engagement (2013 inaugural panel), Hilliard, T., & Paez, K. (2017). The PCORI Engagement Rubric: Promising Practices for Partnering in Research. *Annals of Family Medicine, 15(2), 165-170.* Available from <http://www.annfammed.org/content/15/2/165>

Note: The comments below are a direct and complete quote from the abstract of this article.

Purpose

Engaging patients, caregivers, and other health care stakeholders as partners in planning, conducting, and disseminating research is a promising way to improve clinical decision making and outcomes. Many researchers, patients, and other stakeholders, however, lack clarity about when and how to engage as partners within the clinical research process. To address the need for guidance on creating meaningful stakeholder partnerships in patient-centered clinical comparative effectiveness research, the Patient-Centered Outcomes Research Institute (PCORI) developed the PCORI Engagement Rubric (Rubric).

Methods

PCORI developed the Rubric drawing from a synthesis of the literature, a qualitative study with patients, a targeted review of engagement plans from PCORI-funded project applications, and a moderated discussion and review with PCORI's Advisory Panel on Patient Engagement.

Results

The Rubric provides a framework for operationalizing engagement to incorporate patients and other stakeholders in all phases of research. It includes: principles of engagement; definitions of stakeholder types; key considerations for planning, conducting, and disseminating engaged research; potential engagement activities; and examples of promising practices from PCORI-funded projects.

Conclusions

PCORI designed the Rubric to illustrate opportunities for engagement to researchers interested in applying for PCORI funding and to patients and other stakeholders interested in greater involvement in research. By encouraging PCORI applicants, awardees, and others to apply the rubric, PCORI hopes to shift the research paradigm from one of conducting research on patients as subjects to a pursuit carried out in collaboration with patients and other stakeholders to better reflect the values, preferences, and outcomes that matter to the patient community.

Impact

Barber, R., Boote, J., Parry, G., Cooper, C., Yeeles, P., & Cook, S. (2011). Can the impact of public involvement on research be evaluated? A mixed methods study. *Health Expectations, 15(3), 229-241.* Available from <https://doi.org/10.1111/j.1369-7625.2010.00660.x>

Note: The comments below are a direct and complete quote from the abstract of this article.

Background

Public involvement is central to health and social research policies, yet few systematic evaluations of its impact have been carried out, raising questions about the feasibility of evaluating the impact of public involvement.

Objective

To investigate whether it is feasible to evaluate the impact of public involvement on health and social research.

Methods

Mixed methods including a two-round Delphi study with pre-specified 80% consensus criterion, with follow-up interviews. UK and international panellists came from different settings, including universities, health and social care institutions and charitable organizations. They comprised researchers, members of the public, research managers, commissioners and policy makers, self-selected as having knowledge and/or experience of public involvement in health and/or social research; 124 completed both rounds of the Delphi process. A purposive sample of 14 panellists was interviewed.

Results

Consensus was reached that it is feasible to evaluate the impact of public involvement on 5 of 16 impact issues: identifying and prioritizing research topics, disseminating research findings and on key stakeholders. Qualitative analysis revealed the complexities of evaluating a process that is subjective and socially constructed. While many panellists believed that it is morally right to involve the public in research, they also considered that it is appropriate to evaluate the impact of public involvement.

Conclusions

This study found consensus among panellists that it is feasible to evaluate the impact of public involvement on some research processes, outcomes and on key stakeholders. The value of public involvement and the importance of evaluating its impact were endorsed.

Esmail, L., Moore, E., & Rain, A. (2015). Evaluating patient and stakeholder engagement in research: Moving from theory to practice. *Journal of Comparative Effectiveness Research*, 4(2), 133-145. Available from https://www.researchgate.net/publication/274372073_Evaluating_patient_and_stakeholder_engagement_in_research_Moving_from_theory_to_practice

Note: The comments below are a direct and complete quote from the abstract of this article.

Despite the growing demand for research that engages stakeholders, there is limited evidence in the literature to demonstrate its value—or return on investment. This gap indicates a general lack of evaluation of engagement activities. To adequately inform engagement activities, we need to further investigate the dividends of engaged research, and how to evaluate these effects. This paper synthesizes the literature on hypothesized impacts of engagement, shares what has been evaluated, and identifies steps needed to reduce the gap between engagement's promises and the underlying evidence supporting its practice. This assessment provides explicit guidance for better

alignment of engagement's promised benefits with evaluation efforts, and identifies specific areas for development of evaluative measures and better reporting processes.

Dissemination

Staniszewska, S., Brett, J., Mockford, C., & Barbar, R. (2011). The GRIPP checklist: Strengthening the quality of patient and public involvement reporting in research. *International Journal of Technology Assessment in Health Care, 27(4), 391-399.* doi: 10.1017/S0266462311000481

Note: The comments below are a direct and complete quote from the abstract of this article.

Objectives

The aim of this study was to develop the GRIPP (Guidance for Reporting Involvement of Patients and Public) checklist to enhance the quality of PPI reporting.

Methods

Thematic analysis was used to synthesize key issues relating to patient and public involvement (PPI) identified in the PIRICOM and PAPIRIS systematic reviews. These issues informed the development of the GRIPP checklist.

Results

The key issues identified included limited conceptualization of PPI, poor quality of methods reporting, unclear content validity of studies, poor reporting of context and process, enormous variability in the way impact is reported, little formal evaluation of the quality of involvement, limited focus on negative impacts, and little robust measurement of impact. The GRIPP checklist addresses these key issues.

Conclusion

The reporting of patient and public involvement in health research needs significant enhancement. The GRIPP checklist represents the first international attempt to enhance the quality of PPI reporting. Better reporting will strengthen the PPI evidence-base and so enable more effective evaluation of what PPI works, for whom, in what circumstances and why.

Evaluation

Abelson, J., Li, K., Wilson, G., Shields, K., Schneider, C., & Boesveld, S. (2016). Supporting quality public and patient engagement in health system organizations: Development and usability testing of the Public and Patient Engagement Evaluation Tool. *Health Expectations, 19(4)*. 817-827. Available from <https://doi.org/10.1111/hex.12378>

Note: The comments below are a direct and complete quote from the abstract of this article.

Objectives

Only rudimentary tools exist to support health system organizations to evaluate their public and patient engagement (PPE) activities. This study responds to this gap by developing a generic evaluation tool for use in a wide range of organizations.

Methods

The evaluation tool was developed through an iterative, collaborative process informed by a review of published and grey literature and with the input of Canadian PPE researchers and practitioners. Over a 3-year period, structured e-mail, telephone and face-to-face exchanges, including a modified Delphi process, were used to produce an evaluation tool that includes core principles of high-quality engagement, expected outcomes for each principle and three unique evaluation questionnaires that were tested and revised with input from 65 end users.

Results

The tool is structured around four core principles of “quality engagement”: (i) integrity of design and process; (ii) influence and impact; (iii) participatory culture; and (iv) collaboration and common purpose. Three unique questionnaires were developed to assess each of these four evaluation domains from the following perspectives: (i) those who participate in PPE activities; (ii) those who plan, execute or sponsor PPE activities within organizations; and (iii) those who provide the leadership and capacity for PPE within their organizations.

Conclusions

This is the first known collaboration of researchers and practitioners in the co-design of a comprehensive PPE evaluation tool aimed at three distinct respondent groups and for use in a wide range of health system organization settings.

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Appendix A—Competencies, Readiness, and Training Guide

	RESEARCHER		PATIENT	
Communication	<p><i>Learn / Inform</i></p> <ul style="list-style-type: none"> • Open to questions • Uses plain language when needed (oral and written) • Adapts information to appropriate reading level • Listens, hears, and clarifies meanings of questions • Communicates using different media and technology <p><i>Consult</i></p> <ul style="list-style-type: none"> • Actively listens and hears different perspectives • Explains in plain language and asks questions in language congruent with audience • Speaks confidently in front of others 	<p><i>Involve</i></p> <ul style="list-style-type: none"> • Listens actively • Negotiates common goals • Communicates effectively and continuously <p><i>Collaborate</i></p> <ul style="list-style-type: none"> • Uses partnership language of <i>with</i> patients and not <i>to</i> or <i>for</i> patients • Shares collective experiences • Provides constructive feedback 	<p><i>Learn / Inform</i></p> <ul style="list-style-type: none"> • Willing to learn • Accepts information or material as presented • Desires knowledge and understanding, both superficial and in-depth • Seeks clarification of unclear information • Speaks confidently in front of others • Provides open and honest feedback <p><i>Consult</i></p> <ul style="list-style-type: none"> • Represents his or her own perspective or views • Recognizes that his or her perspective is not representative of others, community or disease 	<p><i>Consult</i></p> <ul style="list-style-type: none"> • Speaks confidently in front of others • Provides open and honest feedback • Represents his or her own perspective or views • Recognizes that his or her perspective is not representative of others' views, community or disease <p><i>Involve</i></p> <ul style="list-style-type: none"> • Listens for and respects other perspectives

	RESEARCHER	PATIENT
Team function	<p><i>Involve</i></p> <ul style="list-style-type: none"> • Establishes productive relationships • Clearly articulates roles, responsibilities • Explores patient's expectations and motivations • Matches patient's expected level of participation to engagement with team • Prepares and supports patients to be actively involved as research team members • Facilitates conflicting and diverse opinions • Acts in an inclusive manner • Adept at reading non-verbal cues <p><i>Collaborate</i></p> <ul style="list-style-type: none"> • Establishes meaningful relationship of mutual trust and understanding • Shares all project information 	<p><i>Involve</i></p> <ul style="list-style-type: none"> • Forms productive relationship • Identifies and communicate expectations • Deals effectively with conflict adheres to or abides by research ethics protocols • Understands roles and responsibilities

	RESEARCHER	PATIENT
Interpersonal or individual	<p><i>Learn / Inform</i></p> <ul style="list-style-type: none"> • Aware of diversity of needs <p><i>Consult</i></p> <ul style="list-style-type: none"> • Open to critical feedback • Open and transparent • Empathetic • Incorporates principles of patient centeredness (respect, dignity, information sharing and participation) • Actively seeks patient's ideas / opinions / perspective <p><i>Involve</i></p> <ul style="list-style-type: none"> • Patient • Flexible to the barriers, constraints and personal obstacles • Accessible and responsive <p><i>Support</i></p> <ul style="list-style-type: none"> • Implements decisions of patients • Proceeds with patient advice and recommendations • Flexible and adaptable • Acts in advisory role in patient-led research 	<p><i>Learn / Inform</i></p> <ul style="list-style-type: none"> • Understands that some decisions have been made • Accepts that patient input may not be required <p><i>Consult</i></p> <ul style="list-style-type: none"> • Reasonably available as required • Interested in learning more about research <p><i>Involve</i></p> <ul style="list-style-type: none"> • Patient • Prepared for meetings • Works well with others • Prepared to invest time and energy • Accepts diverse opinions • Maintains confidentiality <p><i>Collaborate</i></p> <ul style="list-style-type: none"> • Sees beyond own experiences to the big picture • Understands research processes and implications • Can act as an advisor • Sees the value of their commitment • Thinks critically • Maintains partnership • Thinks strategically • Thinks creatively • Influences others • Sustains commitment • Prepared to undertake research

	RESEARCHER	PATIENT
Patient centeredness	<p><i>Involve</i></p> <ul style="list-style-type: none"> • Incorporates patient perspectives • Establishes safe, welcoming environment • Understands needs for psychological, emotional, and physical safety • Appreciates all individuals' strengths, contributions, and input • Understands a patient is not representative of his or her community • Creative in approaches to involving patients 	

	RESEARCHER	PATIENT
Leadership	<p><i>Involve</i></p> <ul style="list-style-type: none"> • Fosters and encourages diversity • <i>Collaborate/Partner</i> • Integrates patients into research team early in the research process • Co-develops and co-designs research • Shares decision making • Intervenes if there is a lack of inclusion, respect, and trust within team • Shares successes and recognition • Acts in role as a mentor or “buddy” to other researchers seeking to engage patients • Advocates for patient’s collaboration in research • Engages continuously <p><i>Support</i></p> <ul style="list-style-type: none"> • Supports patient-led research 	<p><i>Collaborate</i></p> <ul style="list-style-type: none"> • Advocates for research • Mentors or trains other patients • Makes decisions <p><i>Empower</i></p> <ul style="list-style-type: none"> • Demonstrates leadership

Appendix B – Patient Engagement Worksheets

The following pages can be detached from this document and used as worksheets to guide patient engagement strategies.

Important: These pages may not print correctly from the PDF version of this Guide. To print a working copy, identify pages 73-78 in the “Pages” section of your print dialogue box, and select the radio button next to “Landscape.”

Examples of Engagement Tactics				
	Research Activities	Who	How	Evaluate
• STAGE 1. PLANNING AND PREPARATION	Identify populations of interest	<ul style="list-style-type: none"> Define characteristics of study participants 	•	•
	Identify research gaps / priorities	<ul style="list-style-type: none"> Inform research priorities Identify research topics 		
	Formulate research questions	<ul style="list-style-type: none"> Support development of research questions and outcomes to be studied 		
	Consider dissemination and evaluation efforts	<ul style="list-style-type: none"> Inform dissemination efforts Inform evaluation efforts 		
Resources		Time:	Time:	Time:
		Cost:	Cost:	Cost:
		Level:	Level:	Level:
		Support:	Support:	Support:

		Examples of Engagement Tactics		
Research Activities		Who	How	Evaluate
• STAGE 2. STUDY DESIGN	Identify participant inclusion criteria	<ul style="list-style-type: none"> Review ethical considerations, and identify and advise on potential issues and solutions 		
	Define participant access to trials	<ul style="list-style-type: none"> Ensure transparency, practicality and feasibility in recruitment Provide suggestions on budget for patient engagement, including considerations on time 		
	Develop informed consent and trial information	<ul style="list-style-type: none"> Suggest ways to build trust between patients and researchers throughout study Help develop written information 		
	Select interventions and comparators	<ul style="list-style-type: none"> Identify meaningful intervention opportunities that are realistic for patients 		
	Identify outcomes	<ul style="list-style-type: none"> Identify meaningful outcomes relevant to patients 		
Resources		Time: Cost: Level: Support:	Time: Cost: Level: Support:	Time: Cost: Level: Support:

Examples of Engagement Tactics				
	Research Activities	Who	How	Evaluate
STAGE 3: STUDY IMPLEMENTATION •	Identify recruitment strategy	• Participate in recruitment of participants	•	•
	Collect data	• Collect data through interviews / support or focus groups		
	Adapt study designs	• Develop research tools and information		
	Monitor study compliance	• Gather and review documentary evidence		
Resources		Time:	Time:	Time:
		Cost:	Cost:	Cost:
		Level:	Level:	Level:
		Support:	Support:	Support:

		Examples of Engagement Tactics		
Research Activities		Who	How	Evaluate
• STAGE 4. DATA ANALYSIS	Ensure data integrity	<ul style="list-style-type: none"> Participate in data analysis and interpretation 	•	
	Complete a subgroup analysis	<ul style="list-style-type: none"> Provide input on key themes and findings 		
Resources		Time:	Time:	Time:
		Cost:	Cost:	Cost:
		Level:	Level:	Level:
		Support:	Support:	Support:

		Examples of Engagement Tactics		
Research Activities		Who	How	Evaluate
• STAGE 5. DISSEMINATION	Translate knowledge to all end users	<ul style="list-style-type: none"> • Develop progress reports or newsletters • Work with patients to develop dissemination plans • Identify opportunities for novel information sharing 		
	Implement results—clinical practice	<ul style="list-style-type: none"> • Identify partner organizations for dissemination • Plan dissemination efforts, post-study • Participate in dissemination efforts 		
Resources		Time:	Time:	Time:
		Cost:	Cost:	Cost:
		Level:	Level:	Level:
		Support:	Support:	Support:

