

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



Patient
Engagement
Platform

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Overview

In this section, you will learn

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

Who is a patient?

Patients are individuals with personal experience of a health issue, and informal caregivers, including family and friends.

What is health research?

Health research is research intended to find better ways to prevent and treat disease, ensuring that patients receive the right intervention at the right time.

What is patient oriented research?

Patient oriented research is research that engages patients as partners instead of as participants, focuses on patient-identified priorities, and improves patient outcomes.

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/>

What is the research activity life-cycle?

Research has five key stages: planning and preparation (getting ready for the research); study design (determining how the research is going to be conducted); study implementation (actually doing the research); data analysis (figuring out what the research says); and dissemination (telling everyone what the research discovered). Patients can be involved in each of these stages.

Why should I engage in health research?

Patient engagement in health research has advantages for both patient partners and researchers. Patients benefit by

- influencing what is explored and how it is researched and disseminated;
- developing their own voice—being empowered, respected, and valued;
- the building of trust and understanding with clinicians, researchers, or both; and,
- ultimately, receiving improved quality of care or experience with the implementation of more relevant research findings. (1, 6-9)

Researchers can benefit from engaging with patients in research through

- better understanding of and insight into the gaps and priorities in the research area;
- improved quality of research designs;
- increased participant enrolment and decreased attrition;
- wider impact and application of research findings;
- stronger rapport with patient communities; and
- overall improved research effectiveness. (1-5)

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 whole research cycle, from planning to dissemination. Some examples include

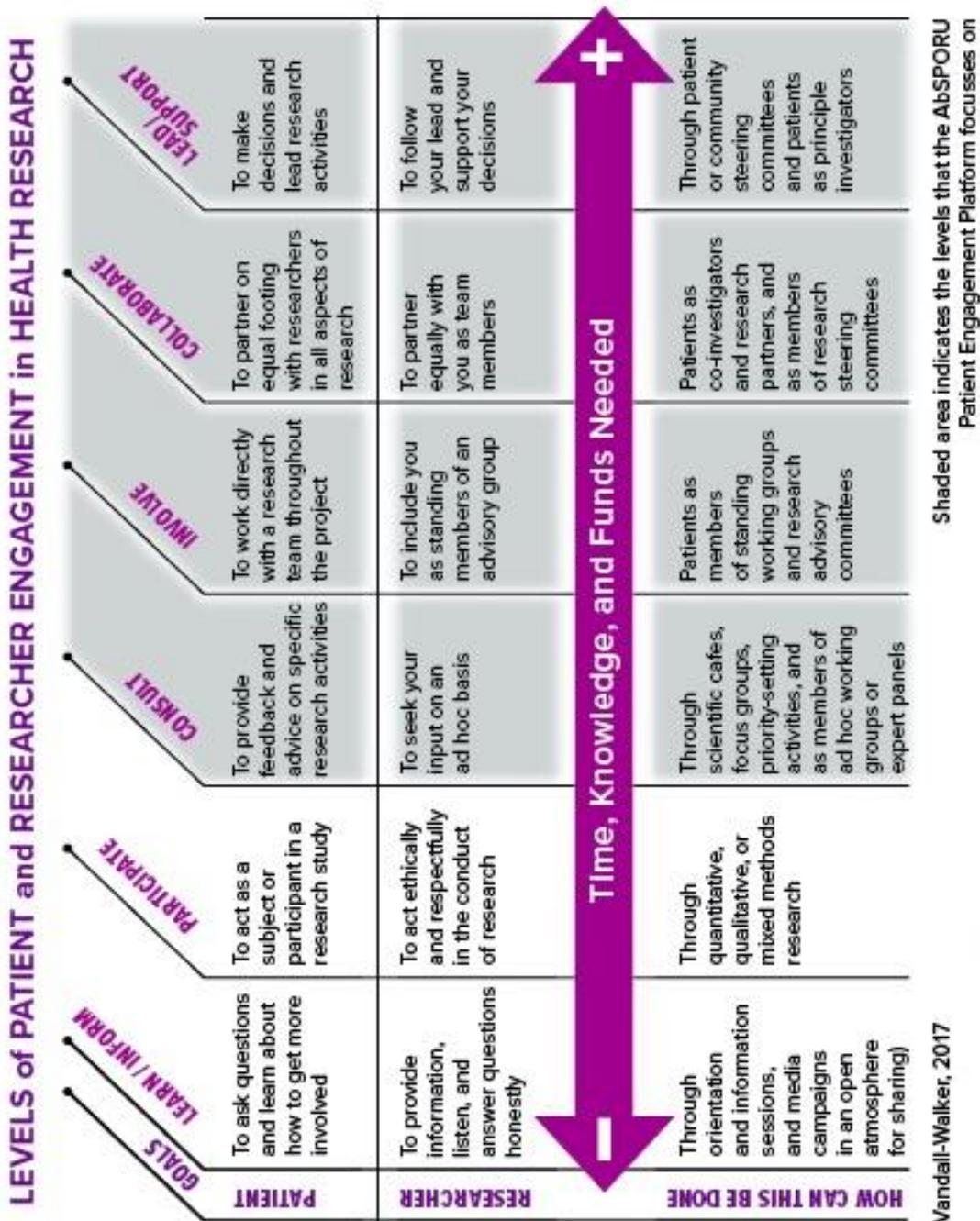
- applying as joint grant holders or co-applicants on a research project;
- identifying research priorities;
- providing input into surveys, patient information sheets, or other recruitment and data collection materials;
- recruiting participants;
- undertaking interviews with research participants;
- providing input on analysis of key themes and findings; and
- identifying novel opportunities to share research findings. (6)

It is important to note that there are many ways of engaging in health research. The deeper the degree of participation, the greater the influence the patient has in decision making (see the schematic “Levels of Patient and Researcher Engagement” presented in Figure 1). The same is true for the amount of time and knowledge required by both patients and researchers to carry out the particular type of engagement.

Your story here?

This Guide is a work in progress, and we are hoping that patients and researchers who have engaged in patient-oriented health research will provide us with information about their own experiences. If you have a story about what patient engagement in research looked like in your experience, please contact us!

Figure 1. Levels of Patient and Researcher Engagement in Health Research (13)



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

As a patient—a person who has had contact with the health care system either because you experienced a health-related issue, or were a caretaker, family member or friend of someone who did so—you have knowledge and opinions that can be valuable to the research process. You know what worked and what did not; what information you would have liked to receive; and what questions you wish you had been in a position to ask. You probably have opinions about the care provided, and how it could have been improved; and about research that could have helped provide you with some additional knowledge. In addition, you have experiences from your personal and work lives that can also be useful in collaborative research.

Of course, just because you have valuable knowledge and opinions does not mean that you are eager to become involved in health research. For all its positive contributions to science, engaging in research can be time consuming and sometimes frustrating. But if you are reading this Guide, you are most probably already aware of the importance of patient engagement in health research, and you may even have the desire to engage in and support the changes to health care that can only come about through research. What you need now is knowledge about the practicalities. That is what this Guide is designed to provide.

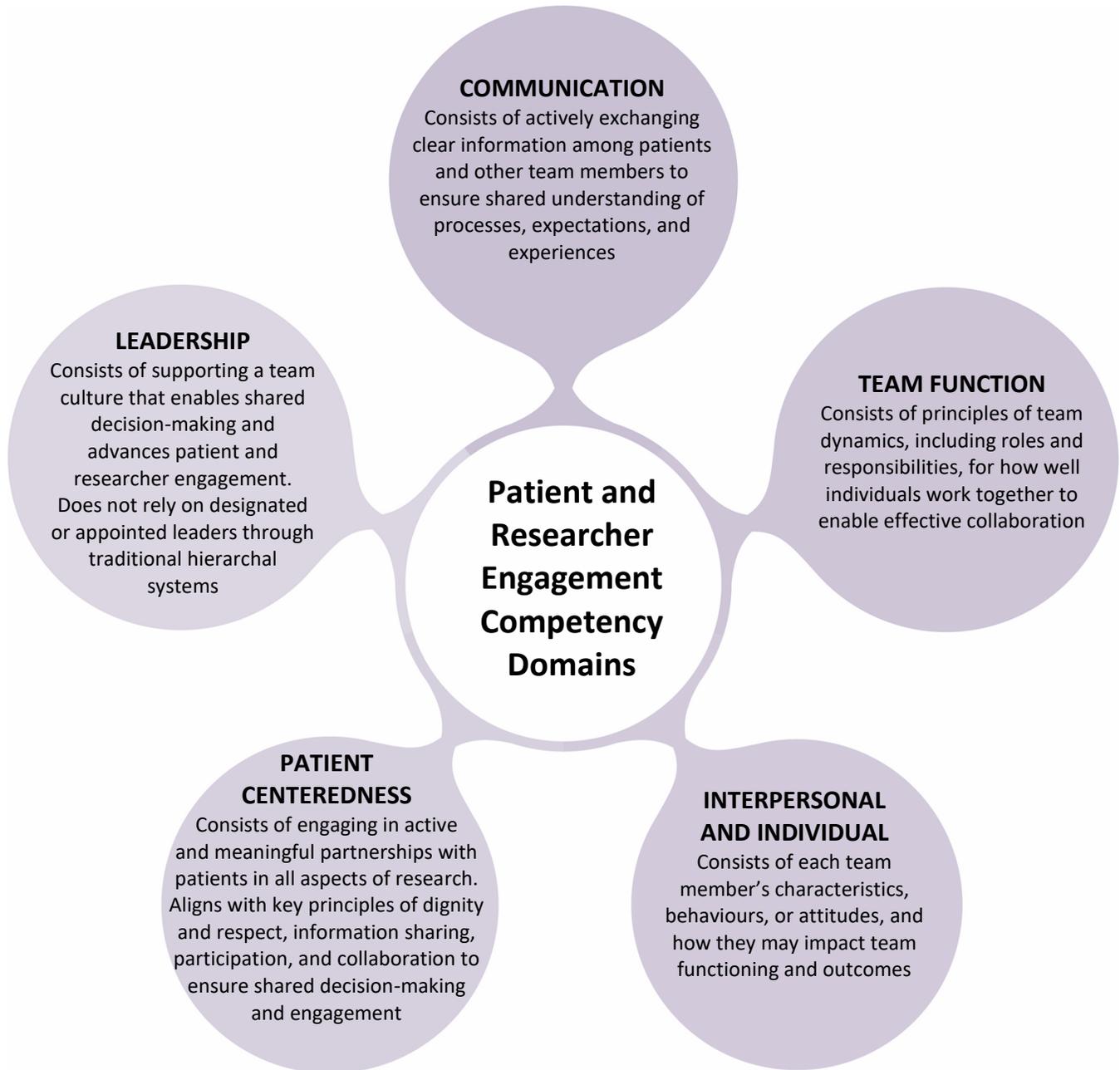
In Figure 2, below, you will see details of five “competency domains” for patients and researchers engaging in health research. “Competencies” are skills, knowledge, attitudes or behaviours, and beliefs that are needed to support the activities and goals of patient engagement. Remember, as you review Figure 2, that no one goes into the research process with all of the competencies identified. The process itself builds them. The end result—a collaborative partnership between patient and researcher—can be a powerful tool for improving health care for all.

Your story here?

If you have a story about how you recognized that you were ready to engage in health research, please contact us!

In fact, if you have a story about any aspect of your engagement in health research, please share it with us. We won't be showing any more of these boxes, in this version, but we are eager to add your information as we receive it.

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



If you are looking for additional information about patient engagement methods, you may wish to consult the resources below. They come from two well-established patient engagement platforms: the Patient-Centered Outcomes Research Institute (PCORI) in the US, and the INVOLVE Advisory Group in the UK. Patient engagement is a truly international endeavour!

FIND OUT MORE

Engagement rubric for applicants | PCORI (US)

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

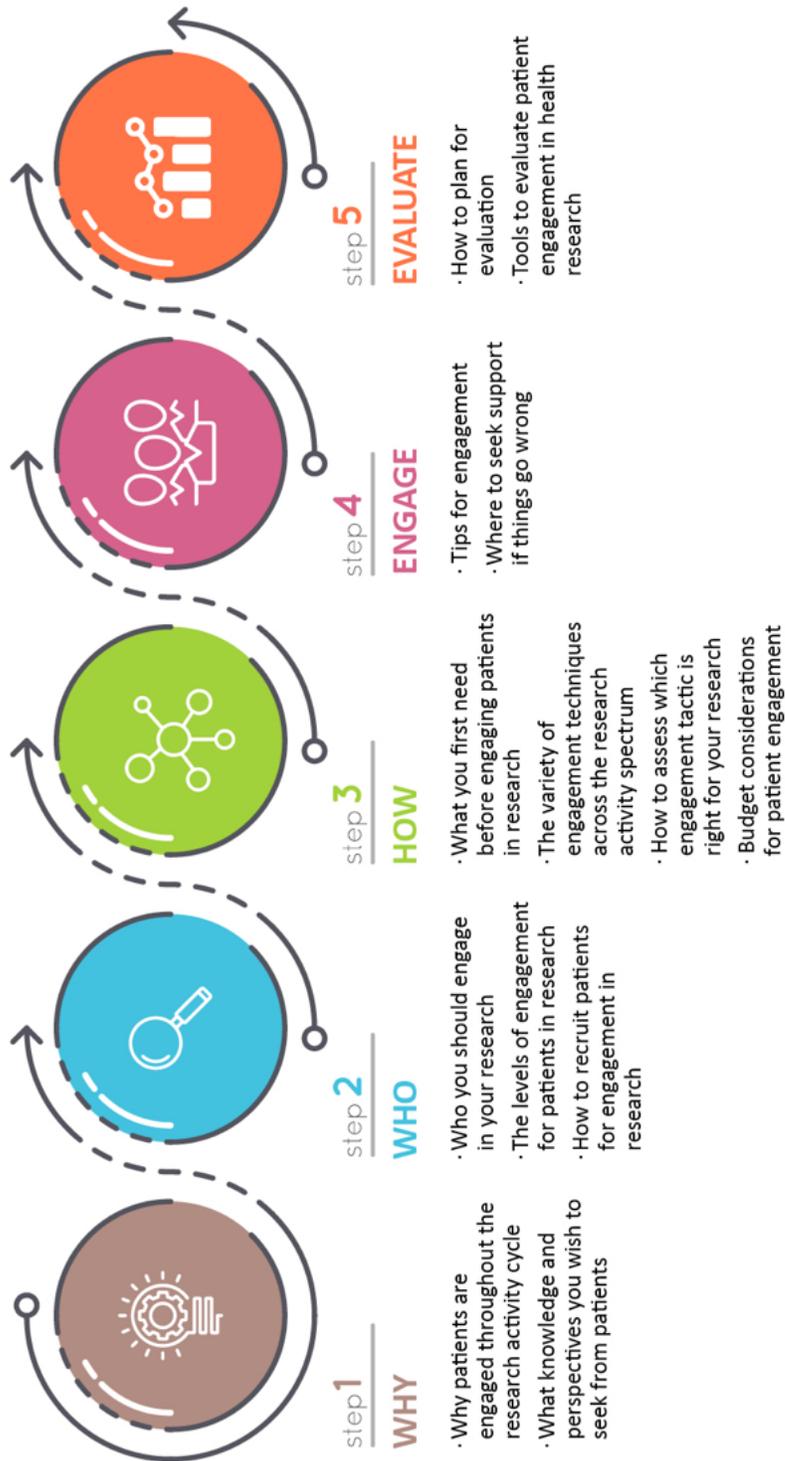
Briefing notes for researchers | INVOLVE (UK)

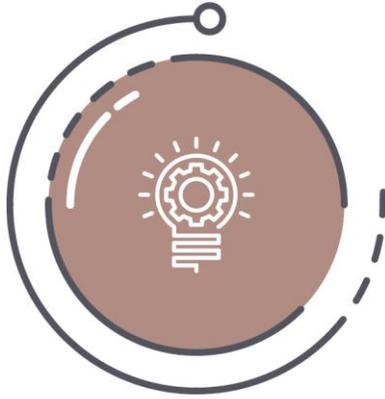
<http://www.invo.org.uk/posttypepublication/involve-briefing-notes-for-researchers/>

How do I use this Guide?

If you have read this far, you are interested in engaging with researchers in health research! Much of the rest of this Guide outlines the five key steps to engaging in health research projects: Why, Who, When, Engage, and Evaluate. You may find the infographic presented in Figure 3, below, helpful in guiding you through the process.

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





step 1

WHY

In this section, you will learn

- why patients need to be engaged throughout the research activity cycle;
- what knowledge and perspectives patients can bring to health research; and
- what ethical guidelines should be considered when taking part in research.

Why do researchers want to engage patients in health research?

Health care 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 patients in health research.

What are researchers looking for in a patient partner?

Researchers typically look for patients who have had a health experience in the researcher's area of expertise (e.g., critical care, cancer, heart attack, broken bones). There are many skills that are valuable to the research team—see Appendix A of this Guide for a list.

What knowledge or perspectives can patients contribute to a health research project?

Patients can contribute at every stage of the research cycle. Some examples are included in the table below.

| Research Cycle Activity | Rationale |
|-----------------------------|---|
| 1. Planning and preparation | <ul style="list-style-type: none"> Gather ideas for new research areas based on patient needs Ensure research is focused on the patient's interest and concerns |
| 2. Study design | <ul style="list-style-type: none"> Ensure methods are acceptable and sensitive to the situations of potential research participants |
| 3. Study implementation | <ul style="list-style-type: none"> Increase participation in the research project |
| 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"> Make language and content of information more appropriate and accessible before disseminating it Increase dissemination and uptake of evidence into practice or policy |

What are the dangers in being a “patient representative”?

Unfortunately, many research believe that they can invite one or two patients as partners on their project team, and that those people will “represent” the voice of all individuals with a similar health experience. Patient partners must remember that they can share their own experiences, and they can collect data from people who have had similar experiences, but they are not the authorized voice for all individuals with that health experience. It is OK to remind researchers of that distinction!

What ethical considerations should I be aware of when engaging in a health research project?

Benefits and Harms

The term “benefits” refers to any positive effects on an individual’s or group’s welfare; “harms” refers to any negative effects. As you make the decision about becoming

engaged as a partner in research, you will be considering the potential wider benefits of the research itself, but you must also assess the potential impact of the research activity on your own physical, mental, and spiritual health, and on your physical, economic, and social circumstances.

Patients, researchers, institutions, and funders may have diverse conceptions about the potential benefits and harms of the research activity. Patients can play a very valuable role by alerting researchers, institutions, and funders to potential unexpected benefits and harms that may be experienced by patients and their communities.

Remember, too, that the deeper your level of involvement, the greater the potential benefits and harms.

Confidentiality of Information

Some of the information gathered throughout the research process may be provided to patient partners with the expectation that it will be kept confidential; for example, applications submitted for scientific or ethics review, and information that could reveal the identities of research participants. Patients, researchers, institutions, and funders need to ensure that all involved have the capacity to uphold all expectations of confidentiality, and that appropriate policies and procedures are in place.

Before engaging in a research project, it is a good idea to ask about a research agreement that outlines the roles and responsibilities of each member of the team. You are also encouraged to read through Canada's Tricouncil Policy Statement (TCPS-2), which deals with ethics in research on humans:

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

Power Dynamics and Imbalances

The process of engaging patients in research can be affected by power imbalances with respect to such things as

- status, resulting from differences in community or social status, research expertise, compensation, and affiliations (e.g., among members of a committee or research team);
- control, resulting from responsibilities for the funding for the research, and other “accountabilities” (by law and policy) at the level of the funder, institution, or research project, as well as possible community expectations; and
- information, resulting from differences in research expertise and experience, and access (e.g., to academic journals).

Patients and researchers bring a variety of expertise and competencies to the research project. Through mutual respect, trust, and valuing of alternate knowledge systems and ways of knowing, tensions around power imbalances can be resolved.

Conflicts of Interest and Commitments

A basic question that patients should ask themselves before engaging in a health research project is, “Do I have any interests or commitments that could interfere with my ability to act in the best interests of the research process, project, or team?” Conflicts of interest and commitment arise when there is an incompatibility between two or more of the duties, responsibilities, or interests (personal or work-related) of an individual or institution as they relate to the research activity. Such incompatibilities must be severe enough that one duty, responsibility or interest cannot be fulfilled without compromising others. Conflicts of interest and commitment can be potential, actual, or perceived.

As you make your decision, consider the questions below.

- Do I, as a patient, have personal, business, or other relationships in my community that could conflict with my role in the research project, and inhibit me from acting in the best interests of the research? Have I disclosed them to others involved in the research and, where appropriate, to others in my patient group or community? Can I rearrange my involvement in the research to avoid such conflicts?
- Does the research team, institution, or funding organization have policies and processes for identifying and managing actual and potential conflicts of interest?

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)

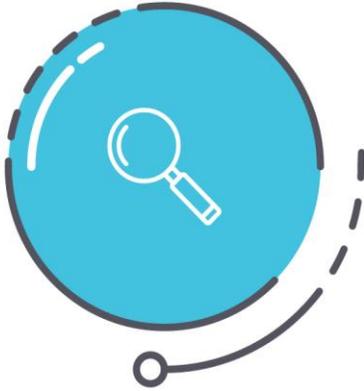
Who: Clinicians and researchers in Alberta, Canada.

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.



step 2

WHO

In this section, you will learn

- what research projects you should get involved in;
- the levels of engagement for patients in research; and
- how to find research projects.

How do I decide how I should be involved?

The members of a research team must clearly and jointly define roles, duties, and expectations of patient partners, researchers, and other stakeholders involved in the research. (2, 21) As a patient partner, you must feel free to choose how and when you will engage; this freedom of choice promotes your autonomy and commitment throughout the study (9). Remember, too, that tokenism is a major barrier to quality patient engagement. Look for projects that champion inclusivity, mutual respect, and opportunities to co-design the research. Taking time to build trusting, respectful relationships for meaningful engagement is critical for successful patient engagement.

FIND OUT MORE

Fairness and Equity in Research Participation | Government of Canada

<http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-epc2/chapter4-chapitre4/>

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

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

Consider your motivation, willingness, and ability to engage at the required level, and to move beyond sharing your own personal experience to applying that experience to benefit society, including the care of others. (2) Talk with the researchers in advance to ensure that the project is a good fit for you. You can assess your attitudes and strengths against the criteria listed below. (22)

| Skills | Criteria |
|---------------------------------------|---|
| Understanding the value of engagement | <ul style="list-style-type: none"> • Patient believes that the patient and family perspective is as important as the researcher's. • Patient believes they bring a valuable perspective to the relationship with the researcher. |
| Supporting others | <ul style="list-style-type: none"> • Patient shares their experiences as patient or family member. • Patient is non-judgmental and accepting of others' opinions and experiences. • 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 their own 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 attitudes or experiences 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. |

It is also imperative that researchers meet you where you are at. For example, as a patient, you may still be within care and treatment, or supporting someone who is, and you may need to prioritize your activities differently during this time. Seek out practical information to help you make the decision of whether you are able to participate, how, and how deeply. Some suggestions are given below.

Practical information for patients interested in engaging in health research

- Information about what you can offer to the research
- An overview of the research process and why the patient perspective is essential
- Contact information for who can answer your questions if you feel unclear about the expectations for your 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 principle investigator located, and where is the team located?
 - Who are the members of the team?
 - What is the commitment of time and effort you need to make?
 - Is there separate funding for compensating patients and caregiver partners? (23)

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>

How do I find research to engage in?

So how do potential patient partners and enthusiastic researchers find one another? The following suggestions will help you get started.

If you are in care, ask your care providers about possible research opportunities. They may know of a research project, or may remember your interest when they hear of one. Informal caregivers may also have opportunities to discuss the possibilities with members of the health care team. Remember, too, that researchers may advertise in clinical departments, such as outpatient clinics.

Ask community members or other patients about any experiences they may have had in health research. And your “community” need not be limited to those you know face-to-face. Social media may provide the link you need; for example, check out the AbSPORU PE Platform Facebook page! Local and national patient support groups often know about research opportunities as well.

In addition, Albertans can sign into the PE Platform Registry, where research opportunities for patients are available to choose from. See www.bit.ly/peRegistry

You can also sign into the Clinical Trials Alberta Registry, Be the Cure, at <https://bethecure.ca/>

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

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 in research;
- a variety of engagement tactics that are applied across the research activity cycle;
- how to decide which engagement tactic is right for you; and
- about compensation for becoming a patient partner in a research project.

What do I need before I engage in a health research project?

Having planning documents in place beforehand can help prevent common challenges that may arise throughout the research process when patients are becoming engaged at the “Involve” level or higher. [Worksheets to support these processes can be found in Appendix B of this Guide.] Ask about whether these documents are already available for review and input, whether the full research team will be developing them jointly (and when), or whether there are no plans to put them in place.

Documents to review / provide input into before you begin engaging in research

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

What practicalities should I consider before engaging in a health research project?

Consider the items listed below when planning for engagement in research.

- Meetings, face-to-face, teleconference, or both
- Transportation, food, lodging etc.
- Equipment, supplies
- Participant compensation and reimbursement of expenses
- Agendas or plans for the event
- Participant satisfaction feedback method
- Timeframe

How do I engage across the research activity cycle?

Patients can be engaged throughout the research cycle. In the following section, ways in which you can be involved, and the benefits of such involvement are described. In subsequent sections, the focus is 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 includes the patient perspective in determining the research topic, alignment of priorities, and identification of research questions. (24) The earlier you become engaged, the better. This is the most powerful way to influence what will be researched. (25)

Engaging 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 because of 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/>

ENGAGEMENT SPOTLIGHT

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

Who: Patients and clinicians in Alberta, Canada

What: Engage 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., Laupacias, 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.cjcd.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. (6) The insight provided by patients can also help promote and retain patients who are participating in the study, as the study will clearly be designed *by* patients, *for* patients. (7)

By engaging at this stage of research, you 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.

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 in study implementation can be challenging. A common assumption has been 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

partners 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 patients; and
- help interpret literature 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

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
- ensure that 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.

Shklarov, 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. 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.

The patient engagement adage “Nothing about us, without us” underscores the importance of including patients in the plans to disseminate study findings to ensure that findings are communicated in an understandable and usable 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 by researchers to help patients to engage in research?

Depending on the purpose and objectives for engaging with patients, several facilitation tactics can be used by researchers to promote engagement with patients in small and large group meetings. It is a good idea, initially, for researchers 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 and your research team members choose depends, to a large degree, on the inputs and resources you have available. As a general rule, as you progress through engagement spectrum (see Figure 1, above), the more time, money, skill (i.e., competence) and support you will need.

Remember, engaging at the “Participation” level, as a research subject or participant, and not as a research team member, is a critically important and valuable level of engagement, and may be what interests you initially.

Consider the options in the table below, organized according to the levels of engagement designated “Consult,” “Involve,” and “Collaborate.” (26).

| 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 identify 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 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 identify 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> | <ol style="list-style-type: none"> 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 | <ol style="list-style-type: none"> 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- | 2. Study Design |

| Level of Engagement: Collaborate | | | |
|---|--|--|--------------------------------|
| Engagement Tactic | Purpose | Description | Research Stage Examples |
| | | established times and 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 are patients compensated for engaging in health research?

Budgeting for patient engagement depends on the *number of patients* (including family members and caregivers) involved, and the *number of days* patients will be in the study. Depending on the funding source, researchers may be able to offer 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, patients should be compensated for their out-of-pocket expenses (e.g., parking and mileage).

Compensation is a sensitive subject, and discussions are ongoing. AbSPORU's PE Platform is spearheading the development of a compensation document, and we encourage you to check our Facebook page for further information. The most important thing at this point, however, is for you to find out about reimbursement and compensation plans for the project you are interested in, and decide if you can become engaged, given those criteria.

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 researchers seeking to engage with patients; and
- what to do if things go wrong.

What strategies can researchers use to help them engage with patients?

The following lists consist of tips provided to researchers to help them to engage meaningfully with patients throughout the research activity cycle. These engagement tips are organized according to the stages of the research cycle to help them think about engaging with patients continuously, but researchers are reminded that they are not limited to any one stage. Read through the lists, and think carefully about the implications of these points for the collaborative relationships you will seek to build with the team; for what you should expect when beginning the engagement process; and for the probabilities of success for the team relationship. Consider additional points to add to the list.

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.

Designing

- Start early with “pre-engagement.” Trust cannot be built overnight. Researchers are encouraged to Integrate themselves into existing community networks. Trust is one of the key factors in the decision to be made by patients from hard-to-reach groups about 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.
- 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.
- 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 to liaise with patient partners.

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 recognize the contributions made by patient research partners to the project.
- Encourage patients to share their opinions and provide adequate time for them to participate.
- 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 engagement is a new and evolving initiative. AbSPORU and the PE Platform are prepared to support researchers and patients to promote equitable and effective patient engagement. The tips given below may be useful in addressing issues that may affect the success of patient and researcher engagement. (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.
-

step **5****EVALUATE**

In this section, you will learn

- how to plan for evaluation; and
- existing tools for evaluating patient engagement in health research.

Why should researchers evaluate how they engaged with patients in research?

There are several reasons why researchers should conduct evaluations of the processes and outcomes of their patient engagement initiatives. Some of them are listed below. (14) Patient-partner input to these evaluations are crucial.

- **Pragmatic:** To increase the utility of the knowledge created
- **Political:** To promote fairness through equitable involvement in the evaluation process
- **Philosophical:** To produce valid knowledge of underlying social phenomena

The focus of evaluation efforts may emphasize the pragmatic benefits specifically, while indirectly contributing to the political and philosophical domains of patient engagement in health research.

How do researchers plan for evaluating success in engaging patients in research?

Researchers are told that keeping a record of how patients are engaged in research and of the implications of this engagement for research (especially the unintended benefits and consequences) is important. Keeping these records can help monitor that patients are engaged throughout the study, and so contribute to their continued engagement; and can help when drafting a report to funders and in the dissemination of research findings.

An evaluation of patient engagement should contribute to a better understanding of the experiences of the patients and researchers, 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 experiences as well.

Researchers are advised to consider the questions below when planning for evaluation. (27)

- What is the aim of engaging with patients in the research study?
- What theoretical rationale or influences relating to patient 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 engagement of patients at the various stages of the research?
- What might be the positive and negative outcomes of engaging with patients in the study? How might these outcomes impact the results of the study? How might they impact the patients?
- What influence or contextual factors might enable or hinder the process or impact of patient engagement?
- What considerations or advancements to the theoretical development of patient engagement in health research have emerged?
- What does the engagement with patients in the study add to our knowledge of best practices in patient and researcher engagement?
- Was the engagement exercise mutually beneficial?

As always, consider the implications of these questions for your own engagement, You may wish to keep your own notes throughout the study—even though you will be discussing your experience with researchers as the project proceeds, having notes of your experience can help ensure that no critical points are missed in the evaluation phase.

Researchers are also advised that 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 the needs of the research team. 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. Researchers are advised to consider how they plan to evaluate the patient engagement opportunity from the outset. The tools identified in the “Find out More” section below can 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 research teams consider when evaluating patient and researcher engagement?

Researchers are advised of the importance of identifying the goals and purposes of engaging with patients, and of connecting 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:

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

An example of an evaluation framework is given in the table 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. | <p>Questionnaires with team members before and after the engagement processes; and follow-up interviews after study completion</p> |
| <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. | <p>Patient and researcher surveys before and after the engagement process</p> |
| <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). | <p>Robust patient and engagement evaluation frameworks and summaries of contributions to evaluation activities and results</p> |
| <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) | <p>Presence of posters, reports or research, and other dissemination vehicles on the promising impacts of patient engagement in health research</p> |
| <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 | <p>Presence of researchers on PE Platform Working Group</p> |

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 • 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>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, 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 71-76 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 <ul style="list-style-type: none"> • | Identify populations of interest | • Define characteristics of study participants | | • |
| | Identify research gaps / priorities | <ul style="list-style-type: none"> • Inform research priorities • Identify research topics | | |
| | Formulate research questions | • 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: Cost: Level: Support: | Time: Cost: Level: Support: | Time: Cost: Level: 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: Cost: Level: Support: | Time: Cost: Level: Support: | Time: Cost: Level: Support: |

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

