

Welcome!

An introduction to patient engagement for grant applicants

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Agenda

This morning, we will discuss:

- Background of SPOR
- What is patient engagement
- Levels of engagement
- Sections of the grant application
- Patient engagement in the grant writing phase
- Examples of patient engagement plans
- Support and resources available

Background of SPOR: Strategy for Patient-Oriented Research

- Initiated by Gov't of Canada in 2011, funded through CIHR
Five year, multi-million dollar strategy
- Administered through provincial SUPPORT units:
Support for People and Patient-Oriented Research Trials Unit
- Heavily Influenced by movements in the UK and US – INVOLVE and PCORI, respectively

Strategy for Patient-Oriented Research (SPOR)

- Focused on improving outcomes for users of Canada's healthcare system
- Aims to create a research culture oriented around achieving real-world impacts for patients and their families

<http://www.cihr-irsc.gc.ca/e/48413.html>

What is patient engagement in research?

- Meaningful and **active** collaboration in **governance, priority setting, conducting research and knowledge translation.** (CIHR SPOR)
- Research being carried out **'with'** or **'by'** members of the public rather than **'to', 'about'** or **'for'** them (INVOLVE)
- Patients as **partners** in research is not the same as a patient being a research subject

What is Patient-Oriented Research?

Any research which:

- engages patients as partners
- focuses on patient-identified priorities
- improves patient outcomes

Where “patients” are defined as:

- in-patients
- out-patients
- caretakers
- families
- or any member of the public with a stake in improved outcomes

Levels of Engagement

- Patient engagement in research can be at many levels
- Engagement generally exists along a continuum ranging from fairly low levels of decision-making power to full empowerment
- The International Association of Public Participation has created a spectrum to illustrate levels of engagement – it is becoming an international standard

iap2 public participation spectrum

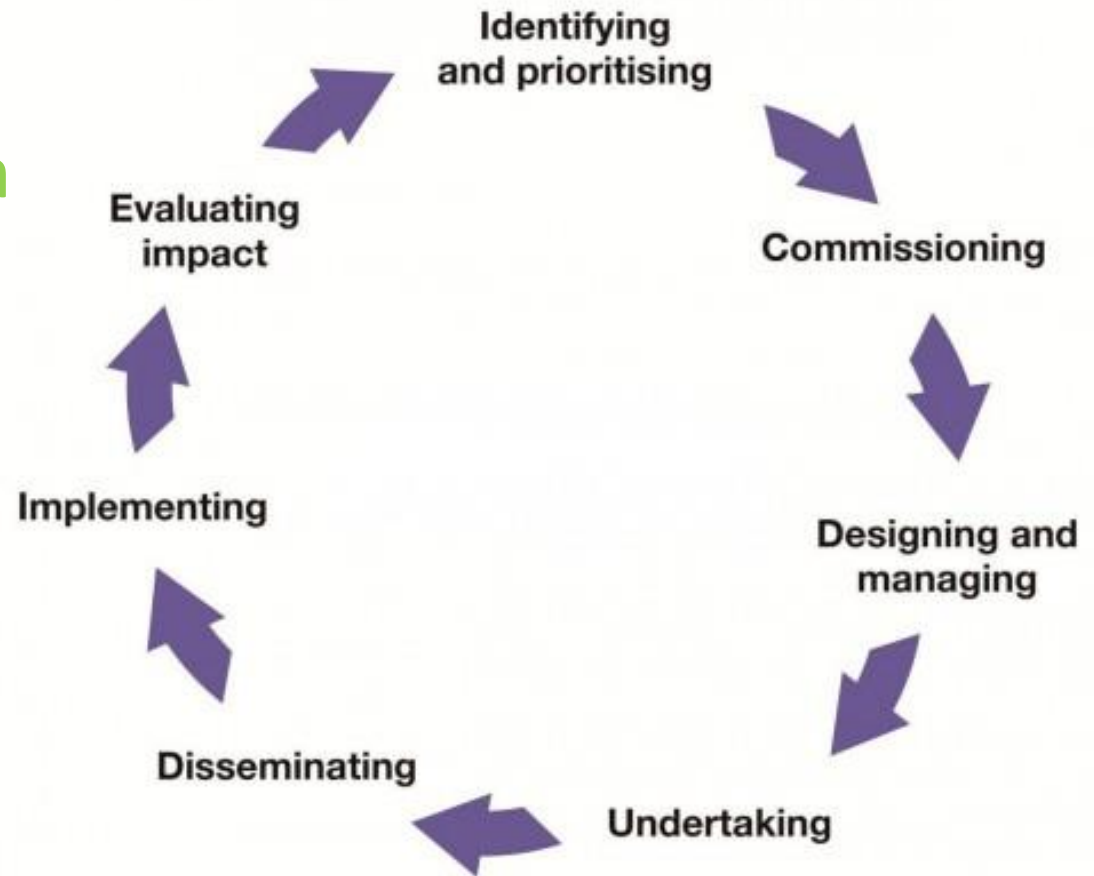
developed by the international association for public participation

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	To provide the public with balanced and objective information to assist them in understanding the problems, alternatives and/or solutions.	To obtain public feedback on analysis, alternatives and/or decision.	To work directly with the public throughout the process to ensure that public issues and concerns are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision-making in the hands of the public.
PROMISE TO THE PUBLIC	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and issues are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for direct advice and innovation in formulating solutions and incorporate your advise and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.
EXAMPLE TOOLS	<ul style="list-style-type: none">• Fact sheets• Websites• Open houses	<ul style="list-style-type: none">• Public comment• Focus groups• Surveys• Public meetings	<ul style="list-style-type: none">• Workshops• Deliberate polling	<ul style="list-style-type: none">• Citizen Advisory committees• Consensus-building• Participatory decision-making	<ul style="list-style-type: none">• Citizen juries• Ballots• Delegated decisions

When to engage patients in research?

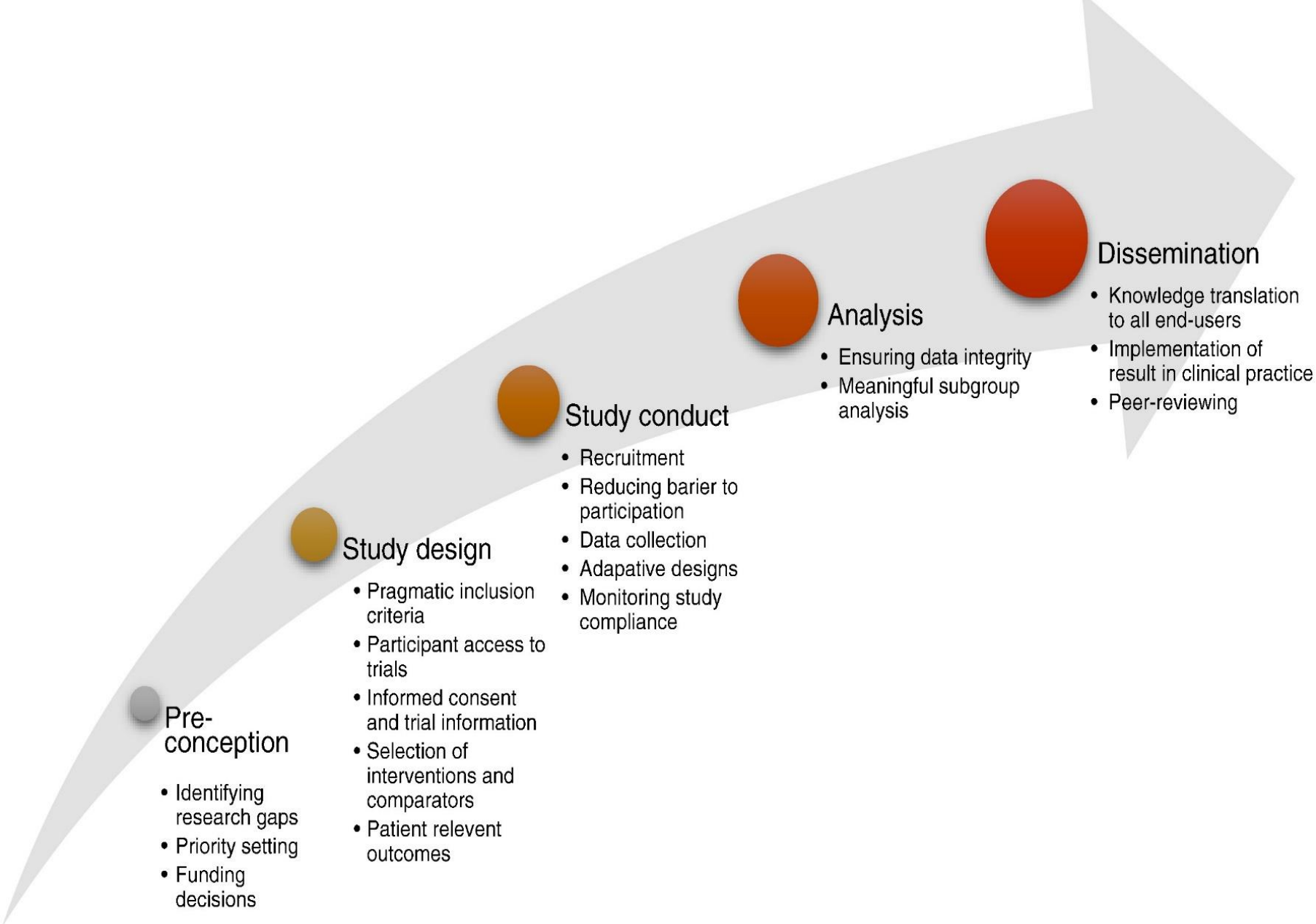
You can involve patients in different stages of the **research cycle**.

This might be at the beginning in setting the question all the way to analysing data and disseminating results



Adapted from INVOLVE: Briefing notes for researchers, February 2012

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



The grant application

Important considerations overall -

Weave patient engagement throughout and recognize that one size does not fit all – recall the different levels of engagement and stages of research

Be consistent in language and definition of ‘patients’

Make sure to describe exactly how patients will be engaged

Engaging patients as early as possible is generally recommended

Engage patients where you can – BUT, make sure to discuss with patients where and how they wish to contribute

Make sure to describe how research reflects competition objectives and the definition of patient-oriented research

Sections of the grant application

Identify participants

Lay summary

Project description

Budget

Attachments

- Who is on the team?
- What patient perspectives are needed?
- Across the whole project or at specific stages?
- What is the role of patient partners?

Sections of the grant application

Identify participants

Lay summary

Project description

Budget

Attachments

- Avoid jargon
- Think about reading level
- Do you have a patient partner who might want to write this?
- Describe contribution of engagement – how are patients going to be partners?

Sections of the grant application

Identify participants

Lay summary

Project description

Budget

Attachments

- All the usual elements – objectives, hypotheses, measures, analysis plan, KT, timeline...
- BUT ALSO – be clear about where and how patients will be engaged
- Are there specific patient engagement activities that can be described (e.g., creation of a patient advisory council? Review of study materials? Help with recruitment?)

Sections of the grant application

Identify participants

- Budget for engagement

Lay summary

Reimbursement

Appreciation/compensation

Costs for patient activities

Project description

- Discuss upfront compensation and reimbursement policies with patient partners

Budget

Attachments

Sections of the grant application

Identify participants

- Letters of support?

Lay summary

- Patient engagement plans?

Project description

- Patient written statements?

Budget

Attachments

Patient engagement in the grant writing phase

This can take many forms - patients helping to define research questions, choose study instruments, writing lay summaries and reviewing drafts

Two recent examples from my work:

- Project 1: Why don't BRCA carriers in Newfoundland and Labrador receive adequate prevention and screening?

POR funded grant 2017; led by Dr. Lesa Dawson and myself

- Project 2: Using behavioral theory to develop an e-intervention to help manage Type 2 Diabetes

Grant application not yet written, but aim is to submit Fall 2018

Patient engagement in the grant writing phase

Project 1 - Why don't BRCA carriers in Newfoundland and Labrador receive adequate prevention and screening?

This project includes three patient partners, all of whom are affected by BRCA – inherited breast/ovarian cancer

Partners were contacted prior to anything being written

We held a morning workshop to brainstorm ideas for the project and decide on the priority questions for the grant

At the end of that workshop, the team had a good idea of the research question(s), and several ideas for study instruments

The PIs created a rough draft of the project plan which was emailed to patient partners for their feedback

Patient engagement in the grant writing phase

Why don't BRCA carriers in Newfoundland and Labrador receive adequate prevention and screening? (Con't)

Several drafts were distributed to the full team, comments incorporated and revisions created

Patient partners also specifically reviewed potential study instruments (surveys and interview guides)

The PIs chose four potential instruments based on patient priorities – this reduced patient partner burden

Final instruments were chosen by patient partners

They are currently reviewing our Masters student's ethics application and interview guide

Patient engagement in the grant writing phase

Project 2: Using behavioral theory to develop an e-intervention to help manage Type 2 Diabetes

Grant application not yet written, but aim is to submit Fall 2018

The team began by recognizing we needed to talk to people who live with diabetes – what are their challenges in managing the condition? What helps? Would they use some kind of e-intervention (e.g., an app?)

We reached out to local diabetes associations, cooking classes, allied healthcare professionals (e.g., dieticians) to begin talking about the project

To date, we have spoken with about 10-12 people who live with diabetes (or their partners) to flesh out the challenges and facilitators and to explore interest in e-technology in this context; we have also spoken with several healthcare professionals

This information has already informed a Masters student's project, and will inform the writing of the grant and the development of the app

Advice from our patient partners

In preparing this session, I emailed three of our patient partners who have been team members on grant applications over the last couple of years

I asked if they would provide their thoughts on how patients could be engaged in the grant application process

Here is what two of them had to say....

Reflections from one of our patient partners

“In my own experience, I felt it was a significant move on the part of the research team to - at the very outset - present its overall proposal in lay terms to a support group for their feedback and questions. My role then was as a liaison between the research team and the support group of which I am a part. This took place before the submission of the application. Similar feedback sessions would be helpful throughout the research should the application be successful and should be indicated in the body of the application that this process of communication will be a vital part of the patient engagement role definition.”

Reflections from one of our patient partners (con't)

“One of the very initial decisions that researchers have to make is how the recruitment of patient partners will be conducted. In order for the process to be meaningful, it will be incumbent on the PI to have established well in advance what role(s) the patient partners will be expected to play and how. This will vary with the type of research, the complexity from a scientific perspective, the logistics of involving persons who may not be readily accessible in terms of time, distance to travel, financial considerations etc. Not to mention the personal interest and educational readiness to be part of complex methodology etc. which often can be intimidating.”

Reflections from one of our patient partners (con't)

“It needs to be clearly delineated that `patient engagement` is different from `patients as subjects` in the research, as important as the latter is. One of the easily confused aspects I found in the assessment stage of the grant application process was deciphering the patient as subject, from the patient as integral team member.”

Reflections from another of our patient partners

- “It’s important to engage patients (as defined) at the early stages of the proposal, if possible. That will help flesh out the proposed research and make it more patient-oriented.
- Take efforts to best match patients with projects in order to get the most value from patient engagement. It shouldn’t be a case of “any patient will do”.
- Patients with a closer connection to the research will likely be more engaged in the project and outcomes. Also, they will be more likely to remain involved and committed to the project.
- Depending on their personal and professional experience, patients can also bring extra skills to the proposal development stage e.g., proposal writing, team building, implementation strategy and KT expertise. And in some cases writing/communications skills and expertise. It’s often about selling an idea as much as it is about identifying research capability.”

Reflections from another of our patient partners (con't)

- “Engaging patients can also open doors to identify other patients who may be able to assist with the project - or future projects. Overall, there is a need to build a pool of good patient partners.
- Treat the patient as a team member and partner, not as simply a means to obtain funding. Make it a meaningful opportunity - but not a burdensome commitment - for them.
- Patients can add value if carefully selected, properly engaged and supported.”

Examples of patient engagement plans

Currently finishing two projects, each of which has a patient partner

But...their involvement has been at different stages and they have different roles

- Breast cancer surgical treatment choices – patient and surgeon opinions (patient partner, “Jane”)
- Universal tumor testing for Lynch syndrome – perspectives of key stakeholders (patient partner, “John”)

Breast cancer project

An example of recruiting a patient to be a member of the research team before the study protocol was fully designed

Jane was recruited by my co-PI who knew her professionally years ago

Jane came to the first team meeting (before the grant was written) and from then on, has had a full voice in every decision made about the project – just like every other team member

Jane's expertise comes in being a person who has made a surgical decision for breast cancer – lived experience

Jane's role

To contribute to the initial discussions about the project where methods and measures were decided

To advise on the ethical and practical implications of the methods

To help collect data

To help analyse focus group transcripts (happening now)

To help plan the knowledge translation event at the end of the study (also happening now)

In contrast, tumor testing project

John has had colon cancer and was not recruited at the beginning of the study

This study includes consulting with pathologists and genetic counselors across the country (via online surveys), but also a patient survey here in NL

John was brought into the study at Phase 3 – the patient survey, well over a year from the study start

He was also recruited by word of mouth as I talked about the project with colleagues

John's role

John's lived experience is as a patient who would be eligible to complete the survey

A Masters student and myself met with John before any survey item was drafted

He advised on ethical and acceptable ways of getting the surveys to patients

He was instrumental in drafting the survey, in particular the opening paragraph explaining tumor testing. We were too complex, he parsed the text to a manageable reading level

John's experience

John has refused offers to take part in the whole project, explaining the patient survey is what is important to him and where his lived experience can best be used

He would like to see the results of the other two phases and have a chance to help draft end-of-study recommendations

My student and I met with John late 2017 to share preliminary data/results and discuss knowledge translation activities - e.g., we will be meeting with the Cancer Centre's family/patient advisory board to present these results in 2018

Patient engagement plans

PCORI – Patient Centred Outcomes Research Institute
Several patient engagement plans of funded projects on their website

<http://www.pcori.org/sites/default/files/PCORI-Sample-Engagement-Plans.pdf>

A useful resource for brainstorming ideas for your own plans and engagement activities

Let's briefly review one plan

Sample Patient engagement plan (PCORI)

Project Title: Effect of Glucose Monitoring on Patient and Provider Outcomes in Non-Insulin Treated Diabetes

“The stakeholders who play a critical role in providing care, advocacy, and education for persons with diabetes include patient groups, community members/at risk individuals, policy makers, providers, industry, and professional organizations. To obtain a broad yet appropriately sized swath of this community, we have chosen eight key stakeholder groups (see Figure 1). These include a state-based Diabetes Advisory Council, a state-based family medicine patient advisory board, a state-based Physicians Network, a regional Community Advisory Board, a diabetes advocacy organization, a national diabetes education program, a state-based diabetes patient registry and representatives from two glucose monitor manufacturers.”

Adapted from PCORI Sample Engagement Plans – example of how patient partners provided input and influenced the research project

Stakeholders	Input Provided	How it shaped our design
State family medicine board	Emphasize quality of life questions	Added quality of life to outcomes
Local advisory board	<ul style="list-style-type: none"> • Important outcomes: quality of life, hypoglycemia, health care service use, patient empowerment; • CME for providers important; • Query provider/patient community care 	<ul style="list-style-type: none"> • Hypoglycemia added as an outcome; • CME added for providers; • Added survey questions about patient-provider communication

Successful patient engagement – CAN-SOLVE CKD Network

Can-SOLVE CKD is a pan-Canadian patient-oriented kidney research network.

Can-SOLVE CKD is one of five chronic disease networks funded by the Canadian Institutes of Health Research through the [Strategy for Patient-Oriented Research](#).

A [Patient Council](#) and [Indigenous Peoples' Engagement and Research Council](#) guide all Can-SOLVE CKD activities to ensure they address and respect the unique needs and perspectives of patients, including Indigenous peoples. Research questions are based on key issues identified by patients over three years of priority-setting discussions.

More than 120 researchers across Canada will take part in [18 patient-centered research projects](#) spanning basic science, clinical and population health research.

Patient Council – CAN-SOLVE CKD Network

- It is composed of more than 30 patients affected by a broad range of medical conditions (e.g., diabetes, heart disease, polycystic kidney disease) as well as family caregivers and kidney donors.
- The council meets on a monthly basis to provide input and guidance on all aspects of Can-SOLVE CKD, from setting priorities to supporting patient engagement in the collection and communication of research evidence.
- Patient Council members are actively involved in all network activities through four working groups:

Curriculum & Training for Patient Participation in Research Working Group

Knowledge Translation, Communications & Outreach Working Group

Measurement & Metrics Working Group

Research Projects & Recruitment Working Group

Useful resources

- [INVOLVE - http://www.invo.org.uk/](http://www.invo.org.uk/)
- Established in 1996, funded by the National Institute for Health Research in the UK
- Very readable, concise “Briefing Notes” for researchers
- Good database of examples

Useful resources

- PCORI - www.pcori.org
- Patient Centered Outcomes Research Institute, since 2010 in the US
- Also a good database of examples
- And guidance on numerous issues – e.g., evaluation rubric

Useful Resources

- [NL Support's patient engagement planning template](http://www.nlsupport.ca/getdoc/da3b71fb-0a0b-4923-9e59-fcf23b361fb6/Tools.aspx)
<http://www.nlsupport.ca/getdoc/da3b71fb-0a0b-4923-9e59-fcf23b361fb6/Tools.aspx>
- [Recruitment Tip Sheet](http://www.invo.org.uk/wp-content/uploads/2012/04/Recruitment-tips-sheet.pdf), INVOLVE
<http://www.invo.org.uk/wp-content/uploads/2012/04/Recruitment-tips-sheet.pdf>
- [Tools for patient partnerships](https://www.patientscanada.ca/index.cfm?id=76578) Patients
Canada <https://www.patientscanada.ca/index.cfm?id=76578>
- Local ethics and patient appreciation guidelines (contact NL SUPPORT)

Useful resources

- NL SUPPORT's Patient Advisory Council is available for consultation. This may allow additional patient perspectives
- Next meeting Feb 15, 2018 (online)
- Local Appreciation
Guidelines: <https://medium.com/support-letters/do-i-need-ethics-approval-for-patient-engagement-efb83c2c34b> (blog) and guidelines (<https://www.dropbox.com/s/cwuvftkqn4nngzo/Patient%20Engagement%20and%20Research%20Ethics%20Guidelines%20NL%20SUPPORT%20and%20REB.PDF?dl=0>)

How can we help you?

- Orientation and feasibility
- Developing a patient engagement plan
- Recruitment and matching
- Facilitation and mentorship
- Guidance with patient compensation
- Evaluation of patient engagement activities
- And more



How can we help you?

- Patient-Oriented training program (online sessions)
- Foundational curriculum in Patient-Oriented Research (in person)
- Seminars, workshops and other sessions on request
- Patient-Oriented Research grants
- Educational funding



Contact us

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