

Patient and Public Engagement Planning Template

Instructions: Patient engagement is about meaningful engagement of patients/public in the research process (not just as subjects of research). This template has been designed to assist with the development of Patient/Public Engagement plans for health research but can be used to plan other projects. Begin with box #1 and work through to box #10 to address the components of the engagement planning process. Select all that apply and discuss the template with your research team (including your patient/public partners!).

(1) WHY¹

Why do you want to involve people with lived/living experience?

- Gathering ideas for new research areas based on the needs of people with lived/living experience of the area you are studying
- Ensuring research is focused on the interests and concerns of people with lived/living experience of the condition and/or system being studied, and that money and resources are used efficiently
- Ensuring transparency and accountability
- Ensuring that the methods are acceptable and sensitive to the situations of potential research participants
- Making the language and content of information more appropriate and accessible
- Increasing participation in research
- Collecting data with and for patients/members of the public
- Taking diverse perspectives into account when analyzing data
- Taking diverse perspectives into account when making decisions
- Increasing the dissemination and uptake of research findings in practice or policy
- Meeting the requirements of funders
- _____

Consider: If there is a useful role for patient/public partners. Are there options to choose from or are decisions already made?

(2) WHO¹

Who do you need to involve?

- In-patients
- Out-patients
- Former patients
- Caregivers
- Family
- Public
- Patient support group
- Patient organization
- Community group
- People who have experience with a specific condition, service or treatment
- _____

Consider: The broad and different views and experiences you will need. Engage people as “independent citizens” not as “experts” or representatives of specific stakeholder groups.

Tip: Involve more than one person. This allows you to involve different people at different stages of the research process, and allows people to choose how they want to be involved.

Patient and Public Engagement Planning Template

(3) WHEN¹

When and how can patients be involved?

Research Process:

Identifying and Prioritizing

Patients' experiences of a condition can help generate new ideas or clarify questions that you may have about new studies.

Design

Patients can inform the design of data collection tools, for example piloting a questionnaire. Patients can help develop communication materials that are clear to patients and the public.

Grant Writing

Patients can help support proposals and collaborate on grant applications.

Data Collection and Analysis

Patients can use their lived experience to help to collect data from peers and/or highlight information that is important to them in the data analysis process.

Dissemination

Patients can advise on who to share research findings with and the different ways to communicate with them.

Implementation and Evaluation

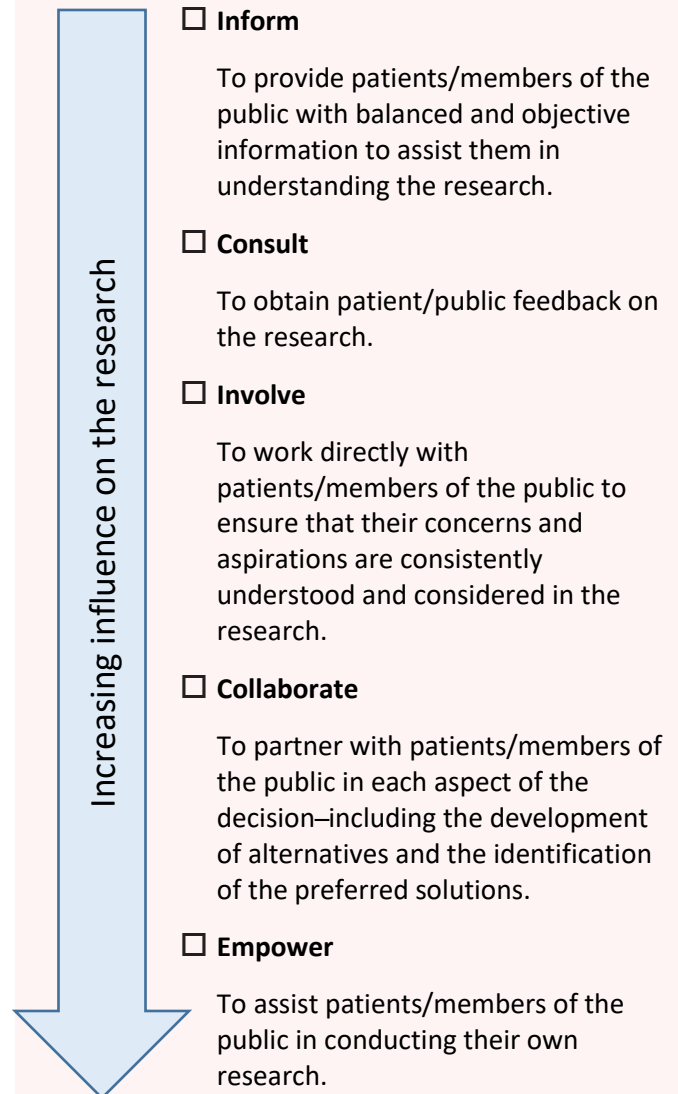
Patients can help develop, implement, and evaluate interventions, and can advise on ways to ensure that implementation is successful.

Tip: You can involve patients in different stages of the research cycle. It is most effective to involve patients as early as possible; however, it is never too late.

Tip: Having user input before the ethics application shows you have considered patient concerns.

(4) WHAT IS YOUR GOAL?

Levels of engagement^{2,3}



(5) HOW^{2,4}

Levels of engagement²

Level 1: Inform

- Website
- Factsheet
- Report card
- Press release
- Presentation
- Mail out
- _____

Level 3: Involve

- Debate
- Panel
- Shadowing
- Workshop
- Café scientifique⁶
- Deliberative polling
- _____

Level 5: Empower

- Patient jury
- Patient-led research
- Search conference
- Think tank
- Delegated decision-making
- _____

Level 2: Consult

- Focus group (different from focus groups used for data collection⁵)
- Survey
- Interview
- Story telling
- Social media
- Forum
- Town hall/public meeting
- _____

Level 4: Collaborate

- Patient Advisory Council
- Round tables
- World café
- Participatory decision-making
- _____

Consider: Assess your strengths and readiness. Each level requires different researcher and patient/public competencies. Training can be recommended. Check the NL SUPPORT website for [training opportunities](#) or contact nlsupport@mun.ca.

Consider: Your goals in relation to your approach. You may have a different strategy for each stage of the research cycle or each group/person you are engaging with. You may combine approaches.

Patient and Public Engagement Planning Template

(6) WHERE^{1,7}

Where to identify potential patients?

- Contact NL SUPPORT to see if there are any existing advisors with health care experiences interested in your project
- Ask your contacts; you may already have ideas and relationships
- Consult existing patient/public advisory councils
- Ask health professionals to help identify people with lived experience
- Talk to local or national patient support groups, voluntary organizations, or advocacy organizations
- Advertise in plain language in reception areas, public buildings, local newspapers, newsletters, and the radio
- Use social media such as Facebook, Twitter or Instagram
- Include information about opportunities for patients/the public and families to participate as advisors in data collection surveys
- Ask community members or patients about people who might be interested in getting involved
- Ask town councils or community and service leaders
- _____

Patient and Public Engagement Planning Template

(7) RESOURCES

What resources are required?

Recruitment and Support Resources:

- Media
- Financial
- Information technology (IT)
- Volunteer
- Knowledge broker/knowledge translation expert
- Patient engagement expert
- Designer
- Facilitator
- Location
- Management support
- Leadership support
- Training support
- _____

Consider Diversity in the Recruitment Process:

- Those who do not speak English as a first language
- Children/youth
- Seniors (65 Years +)
- 2SLGBTQIA+ individuals
- People living with chronic illnesses
- People with disabilities
- People living in rural communities
- People with sensory impairments
- Newcomers to Canada
- Those living with culturally diverse backgrounds
- People with mobility or other accessibility issues
- People with low levels of literacy
- People with mental illness and/or substance use disorders
- _____

Tip: Contact nlsupport@mun.ca if you are looking for help recruiting patient/public partners.

Consider: How you can support the people you are engaging by considering equity, diversity, inclusion and accessibility.

(8) BUDGET⁸

What budget is needed?

Compensation for Partners:

- Honoraria
- Salaries (in certain cases)
- Vouchers or tokens
- Fee, donation or gift to a group or network
- Funding for additional training and learning
- Honorary appointment
- _____

Additional Partner Expenses to Consider:

- Travel
- Subsistence
- Child care
- Caregiver costs (when engaging someone who needs a caregiver present – youth, for example)
- Personal assistants
- Overnight accommodation
- Home office costs
- _____

Staffing and Support Costs:

- Administrative support
- Public involvement coordinator
- Independent facilitator
- Peer researchers/interviewers
- _____

Engagement Activities that Might Require a Budget:

- Recruitment costs (marketing, poster design, printing, ad space, etc.)
- Training costs
- Venues and catering
- Equipment and books
- Access to facilities
- Conferences fees
- _____

Other Costs:

- Criminal record checks
- Language translation and interpretation
- Support for people with impairments
- _____

Tip: Explore the resources listed below for more information about budgeting for patient/public engagement.

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(9) IMPLEMENTATION⁹

Describe how you will implement your strategy

Take into account the guiding principles:

Inclusiveness

Patient engagement in research integrates a diversity of patient perspectives and research is reflective of their contribution.

Support

Adequate support and flexibility are provided to patient participants to ensure that they can contribute fully to discussions and decisions. This implies creating safe environments that promote honest interactions, cultural competence, training, and education. Support also implies financial compensation for their involvement.

Mutual Respect

Researchers, practitioners and patients acknowledge and value each other's expertise and experiential knowledge.

Co-build

Patients, researchers and practitioners work together from the beginning to identify problems and gaps, set priorities for research and work together to produce and implement solutions.

(10) EVALUATION¹

Patient and public involvement should be evaluated from both the patients' and the researchers' points of view.

From the beginning of your project think how you are going to monitor and evaluate patient and public involvement and its impact throughout the project.

Help to build the evidence base and let others know about what worked well, what didn't and the impact of patient/public involvement in your research by:

- Including the information in your research reports
- Publishing information on the impact in journal articles
- Contacting NL SUPPORT to include an article in our newsletter
- _____

Consider: The CEPPP Learning Together: Evaluation framework for PPE in research when creating your evaluation tools (see Resources below).

Consider: The already established tools in the Patient/Public Engagement Evaluation Toolkit (see Resources below).

Tip: Whatever reward you decide upon, remember to thank people for their contributions and tell them how they impacted the project.

Tip: Ask for support. For guidance on getting started, important things to consider and how to recruit patients, contact nlsupport@mun.ca.

Tip: See below for more elements to consider to optimize patient/public engagement in research.

Patient and Public Engagement Planning Template

REFERENCES AND RESOURCES

This Patient and Public Engagement Planning Template has been designed by NL SUPPORT: Newfoundland and Labrador's SPOR SUPPORT unit. SUPPORT stands for "Support for People and Patient-Oriented Research and Trials." NL SUPPORT is part of The Canadian Institutes for Health Research's Strategy for Patient-Oriented Research (SPOR) – a nationwide initiative focused on improving outcomes for users of Canada's health care system by fostering and supporting a research culture oriented around achieving real-world impacts for patients and their families. We are happy to receive feedback on this template. Please let us know if you have any questions or suggestions. Contact our Training and Capacity Development/Patient Engagement Lead, Chelsey McPhee at chelsey.mcphee@med.mun.ca or 709-864-6654.

Adapted from: Vat, LE. (2016). Patient and Public Engagement Template. NL SUPPORT: Newfoundland and Labrador's Support for People and Patient-Oriented Research and Trials Unit.

References:

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- ² [International Association for Public Participation. IAP2 Spectrum \(2007\)](http://c.ymcdn.com/sites/www.iap2.org/resource/resmgr/imported/IAP2%20Spectrum_vertical.pdf)
[http://c.ymcdn.com/sites/www.iap2.org/resource/resmgr/imported/IAP2%20 Spectrum_vertical.pdf](http://c.ymcdn.com/sites/www.iap2.org/resource/resmgr/imported/IAP2%20Spectrum_vertical.pdf)
- ³ Bremmer, G. (2020). The research-modified International Association for Public Participation (IAP2) spectrum. Found at: <https://i2insights.org/2020/01/07/research-modified-iap2-spectrum/>
- ⁴ Kovacs, Burns, et al. (2014). 'Practical' resources to support patient and family engagement in healthcare decisions: a scoping review. *BMC Health Services Research*, *14*(175). <http://www.biomedcentral.com/1472-6963/14/175>
- ⁵ Doria, N., Condran, B., Boulous, L., Curtis Maillet, D. G., Dowling, L., & Levy, A. (2018). Sharpening the focus: differentiating between focus groups for patient engagement vs. qualitative research. *Research Involvement and Engagement*, *4*(19). Found at <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-018-0102-6>
- ⁶ Canadian Institutes of Health Research, Café Scientifique Program. Found at <https://cihr-irsc.gc.ca/e/53133.html>
- ⁷ Alberta Health Services. A Resource Toolkit for Engaging Patient and Families at the Planning [Table, April 2014](http://www.albertahealthservices.ca/info/patientexperience.aspx)
<http://www.albertahealthservices.ca/info/patientexperience.aspx>
- ⁸ INVOLVE: Budgeting for involvement: practical advice on budgeting for actively involving the public in research [studies, July 2013](http://www.invo.org.uk/posttypepublication/budgeting-for-involvement/) <http://www.invo.org.uk/posttypepublication/budgeting-for-involvement/>
- ⁹ Canadian Institutes of Health Research – Strategy for Patient-Oriented Research. Patient Engagement Framework (2014) <http://www.cihr-irsc.gc.ca/e/48413.html>

Patient and Public Engagement Planning Template

Resources:

- Visit <https://onlinelibrary.wiley.com/doi/pdf/10.1111/hex.13417> for an example of how to operationalize the levels of patient/public engagement
- Visit <https://cihr-irsc.gc.ca/e/51466.html> for considerations when paying patient partners in research
- Visit <https://nlsupport.ca/wp-content/uploads/2022/07/NL-SUPPORT-Patient-Partner-Appreciation-March-2023-FINAL-signed.pdf> for an example of ways to compensate patient/public partners
- Visit https://sporevidencealliance.ca/wp-content/uploads/2019/08/SPOR-EA_Patient-Partner-Appreciation-Policy-and-Procedure.pdf for another example of ways to compensate patient/public partners
- Visit <https://ceppp.ca/en/uncategorized/learning-together-evaluation-framework-for-patient-and-public-engagement-ppe-in-research/> for an evaluation framework for patient and public engagement in research. This is an excellent tool to use for patient/public engagement planning as well as it outlines indicators for successful engagement.
- Visit <https://ceppp.ca/en/evaluation-toolkit/> for a repository of tools to evaluate patient and public engagement in research



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