

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 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.



1 WHY¹

Why do you want to involve patients?

- Gathering ideas for new research areas based on patients needs
- Ensuring research is focused on the public's interests and concerns 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 by, with and for patients
- Taking diverse perspectives into account when analysing 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 patients. Is the topic appropriate? 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 organisation
- 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 allow people to choose how they want to be involved.

3 WHEN¹

When and how can patients be involved?

Research process:

- Identifying priorities: patients' experiences of a condition can help generate new ideas or clarify questions that you may have about new studies.
- Grant writing and review process: patients can help support proposals and collaborate on grant applications.
- Design and managing: 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.
- Data collection and analysis: patients can help to collect and analyse data
- Dissemination: patients can advise on who to share research findings with and the different ways to communicate with them.
- Implementation: patients can help develop and implement interventions.
- Evaluating: patients involvement should be evaluated from both the patients' and the researchers' point of view.

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?

Degree of engagement²

- Level 1 Inform: To provide the patient with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.
- Level 2 Consult: To obtain patient feedback on analysis, alternatives and/or decisions.
- Level 3 Involve: To work directly with the patient throughout the process to ensure that patient concerns and aspirations are consistently understood and considered.
- Level 4 Collaborate: To partner with the patient in each aspect of the decision -including the development of alternatives and the identification of the preferred solutions.
- Level 5 Empower: To place final decision-making in the hands of the patient.

Consider: assess your strengths and readiness, each level requires competences from researchers and patients. Training can be recommended. Check the NL SUPPORT website for training opportunities www.nlsupport.ca or contact Eva Vat eva.vat@med.mun.ca

5 HOW^{2,3}

Degree of engagement²

Level 1 Inform

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

Level 2 Consult

- Focus group
- Survey
- Interview
- Story telling
- Social media
- Forum
- Town hall / public meeting
-

Level 3 Involve

- Debate
- Panel
- Shadowing
- Workshop
- Cafe scientific
- Deliberative polling
-

Level 4 Collaborate

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

Level 5 Empower

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

Consider: your goals in relation to your approach. You may have a different strategy for each stage of the research cycle. You may combine approaches.

6 WHERE^{1,4}

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 advisory councils
- Ask physicians and other providers to identify patients
- Talk to local or national patient support groups, voluntary organisations or advocacy organizations
- Advertise in plain language in reception areas, public buildings, local newspapers and the radio
- Use online social media such as Facebook or Twitter
- Include information about opportunities for patients and families to participate as advisors in patient surveys
- Ask community members or patients about people who might be interested in getting involved
- Ask town councils, community and service leaders
-

Consider: recruitment for diversity:

- | | |
|-----------------------------------------------------------------------------|---------------------------------------------------------------------------|
| <input type="checkbox"/> Those who do not speak English as a first language | <input type="checkbox"/> People with sensory impairments |
| <input type="checkbox"/> Children / Youth | <input type="checkbox"/> Newcomers to Canada |
| <input type="checkbox"/> Seniors (65 Years +) | <input type="checkbox"/> Those living with culturally diverse backgrounds |
| <input type="checkbox"/> Gay, lesbian, bisexual and transgender | <input type="checkbox"/> People with mobility issues |
| <input type="checkbox"/> People living with chronic illnesses | <input type="checkbox"/> People with low levels of literacy |
| <input type="checkbox"/> People with disabilities | <input type="checkbox"/> People with mental illness and/or addictions |
| <input type="checkbox"/> Those living in rural communities | <input type="checkbox"/> |

Consider: you may combine strategies. NL SUPPORT is conducting a study on 'recruitment strategies'. Contact NL SUPPORT for more information. We can also connect you with our Patient Advisory Council members. eva.vat@med.mun.ca

7 RESOURCES

What resources are required?

- Media
- Financial
- IT
- Volunteer
- Knowledge broker
- Patient engagement expert
- Designer
- Facilitator
- Location
- Management support
- Leadership support
-

8 BUDGET⁵

What budget is needed?

Payment and rewards:

- Fees to individuals
- Vouchers or tokens for individuals
- Fee, donation or gift to a group or network
- Funding for additional training and learning
- Honorary appointment
-

Expenses for members of the public:

- Travel
- Subsistence
- Childcare
- Caregiver costs
- Personal assistants
- Overnight accommodation
- Home office costs
-

Activity:

- Finding people
- Training and learning costs
- Venues and catering
- Equipment and books
- Access to facilities
- Conferences fees
-

Involvement staffing:

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

Other costs:

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

Tip: whatever reward you decide upon, remember to thank people for their contributions.

Consider: a Canadian compensation framework is in development, contact NL SUPPORT for the latest updates.

9 IMPLEMENTATION⁶

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 – i.e., patients are bringing their lives into this.
- 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.

Tip: ask for support. For guidance on getting started, important things to consider and how to recruit patients contact NL SUPPORT eva.vat@med.mun.ca 709 864 6654 www.nlsupport.ca

10 EVALUATION¹

Patient and public involvement should be evaluated from both the patients' and the researchers' point of view. This will help make improvements for next time and contribute to the evidence base.

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 and what didn't and the impact of involvement in your research by:

- including the information in your research reports
- publishing information on the impact in journal articles
- contacting NL SUPPORT to put an article in our newsletter
-

Consider: a national evaluation framework is in development, contact NL SUPPORT for the latest updates.

REFERENCES AND RESOURCES

- ¹ INVOLVE: Briefing notes for researchers, February 2012 <http://www.invo.org.uk/posttypepublication/involve-briefing-notes-for-researchers/>
- ² International Association for Public Participation. IAP2 Spectrum (2007) http://c.ymcdn.com/sites/www.iap2.org/resource/resmgr/imported/IAP2%20Spectrum_vertical.pdf
- ³ Kovacs Burns et al. 'Practical' resources to support patient and family engagement in healthcare decisions: a scoping review. BMC Health Services Research 2014, 14:175 <http://www.biomedcentral.com/1472-6963/14/175>
- ⁴ Alberta Health Services. A Resource Toolkit for Engaging Patient and Families at the Planning Table, April 2014 <http://www.albertahealthservices.ca/info/patientexperience.aspx>
- ⁵ 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/>
- ⁶ Canadian Institutes of Health Research – Strategy for Patient-Oriented Research. Patient Engagement Framework (2014) <http://www.cihr-irsc.gc.ca/e/48413.html>

This Patient and Public Engagement Planning Template has been designed by NL SUPPORT: Newfoundland and Labrador's Support for People and Patient-Oriented Research and Trials Unit. NL SUPPORT is part of The Canadian Institutes for Health Research (CIHR)'s Strategy for Patient-Oriented Research (SPOR). A nationwide initiative focused on improving outcomes for users of Canada's healthcare 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: Eva Vat, NL SUPPORTS' Training and Capacity lead email: eva.vat@med.mun.ca phone: 709 864 6654

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