Patient-Oriented Research — Project Planning Tool

Instructions: Start by reviewing the Strategy for Patient Oriented Research, Patient Engagement Framework. This template is used to guide the discussion about how patients may be engaged in your research project. Complete this template as early in the project identification phase as possible. Include patients in the creation of this plan if possible. This template may be used throughout the life of project to amend or identify new or additional patient engagement opportunities. Use questions 1 to 7 to then write the project patient engagement plan using page 3 as a template.

1. Why do you want to engage patients?
   - Gathering ideas for new research areas based on patients needs
   - Ensuring research is focused on the publics interest and concerns and that money and resources are used effectively
   - 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
   - Collective 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
   - Other:

   - Current patients
   - Former patients
   - Caregivers
   - Family
   - Public
   - Patient support groups
   - Patient organizations
   - Community groups
   - People who have experience with a specific condition, service, treatment. Please explain.
   - Any specific demographics of patients/former patients/caregivers/family/experienced persons that are important for this work?

2. Who do you want to engage with?
   - Do you want SCPOR to help connect you with the above individuals or groups? [ ] yes [ ] no

   - Patient organizations
   - Community groups
   - People who have experience with a specific condition, service, treatment. Please explain.
   - Any specific demographics of patients/former patients/caregivers/family/experienced persons that are important for this work?

3. What might patient team members do?
   - Identifying & Prioritising:
     - Through community representation and organizations help inform research priorities
     - Be consulted about research topics and priorities important to them
     - Collaborate and co-develop with researchers and other key groups topics for research
   - Design:
     - Inform the design of the research study
     - Clarify the research question and affirm its importance
     - Ensure the methods selected are appropriate for patients
     - Co-develop patient recruitment strategy
   - Development of the Grant Proposal:
     - Help to ensure that the research proposed and chosen methods are ethical
     - Inform areas where patients and the public could be involved
     - Define outcome measures
     - Advise on the appropriateness of the lay summary
     - Raise awareness about costs of involvement, expenses and prompt researchers to cost for involvement.
   - Data Collection:
     - Draft/review study materials and protocols
     - Assist with the recruitment of study participants
     - Assist with conducting interviews and surveys
   - Analysing and Interpreting Data:
     - Assist the research team in developing themes from data
     - Be consulted to determine if they understand and interpret data the same way as the research team
   - Dissemination:
     - Develop more approachable methods to help interpret the data
   - Implementation:
     - Increase the likelihood that results of research are implemented, by adding validity to the findings
   - Monitoring and Evaluation:
     - Have continued involvement with the study to maintain focus and address issues as they arise
     - Collaborate with researchers to evaluate the research process
     - Reflect on their role and what they have learned

Adapted by: Saskatchewan Centre for Patient Oriented Research
Adapted from Newfoundland & Labrador SUPPORT Unit: Patient and Public Engagement Planning Template.
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4. What engagement methods will you use?

There are many ways to engage patients/groups in research. Consider which of the following you may use. Note that you may use several methods at various stages of the project.

- Patient on research team (SCPOR recommends 2 patients per research team.)
- Patient Advisory Council
- Work with existing provincial or regional patient advisory councils *
- Work with existing patient groups
- Focus Group
- Town Hall Meeting
- Interviews/Hearing Patient Stories
- Surveys
- Social media
- Patient Shadowing
- Other:

__________________________________________________________

* For information on existing advisory councils please contact the SCPOR Patient Engagement Platform.

5. What level of engagement do you expect?

- 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 in each aspect of the decision-including the development of alternatives and the identification of the preferred solutions.
- Level 4: COLLABORATE: To partner with the patient throughout the process to ensure that patient concerns and aspirations are consistently understood and considered.
- Level 5: EMPOWER: To place final decision-making in the hands of the patient.

* Achieving a higher level of engagement is optimal. Note that the levels of engagement may vary for each patient or patient group therefore you may have more than one level of engagement within your project. I.e. You may have groups of patients you want to INFORM while the patient on your research team may be engaged at the EMPOWER level.

6. What budget is needed?

- Estimate the number of patients/families you will have engaged and the number of days you will have patients and families engaged
- Depending on your funding source determine the honorarium rate. Note that the SCPOR rate is $100 per day (pro-rated) plus eligible expenses.
- Example:
  
  A) 2 advisors on the research team participating in 4 days of engagement in each of the planning, conducting and disseminating phases of the research cycle would equate to = 2x12x100= $2400
  
  B) 1 full day focus group meeting for 20 patients = 20x100= $2000
  
  C) Two hour, bi-monthly, Patient advisory council meetings with 8 members for a duration of 2 years = (100/7.5)x2

  $6960 plus expenses

- Total:

7. How will you evaluate engagement?

From the beginning of your project discuss as a team how you will monitor and evaluate patient involvement and its impact throughout the project. Start by considering if the plan you have created aligns with the Strategy for Patient Oriented Research, guiding principles for patient engagement.

- 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.

* Tools are being developed nationally to support this and will be available in 2016-2017. Contact the SCPOR Patient Engagement Platform or CIHR for more information.

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