

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?	2. Who do you want to engage with?	3. What might patient team members do?	
◇ Gathering ideas for new research areas based on patients needs	◇ Current patients	Identifying & Prioritising:	Data Collection:
◇ Ensuring research is focused on the publics interest and concerns and that money and resources are used effectively	◇ Former patients	◇ Through community representation and organizations help inform research priorities	◇ Draft/revise study materials and protocols
◇ Ensuring transparency and accountability	◇ Caregivers	◇ Be consulted about research topics and priorities important to them	◇ Assist with the recruitment of study participants
◇ Ensuring that the methods are acceptable and sensitive to the situations of potential research participants	◇ Family	◇ Collaborate and co-develop with researchers and other key groups topics for research	Analysing and Interpreting Data:
◇ Making the language and content of information more appropriate and accessible	◇ Public	Design:	◇ Assist the research team in developing themes from data
◇ Increasing participation in research	◇ Patient support groups	◇ Inform the design of the research study	◇ Be consulted to determine if they understand and interpret data the same way as the research team
◇ Collective data by, with and for patients	◇ Patient organizations	◇ Clarify the research question and affirm its importance	◇ Develop more approachable methods to help interpret the data
◇ Taking diverse perspectives into account when analysing data	◇ Community groups	◇ Ensure the methods selected are appropriate for patients	Dissemination:
◇ Taking diverse perspectives into account when making decisions	◇ People who have experience with a specific condition, service, treatment. Please explain.	◇ Co-develop patient recruitment strategy	◇ Advise on different avenues for disseminating the results
◇ Increasing the dissemination and uptake of research findings in practice or policy	_____	◇ Review and comment on proposed questionnaires and data collection methods	◇ Author/co-author manuscripts, newsletters and other appropriate information outlets
◇ Meeting the requirements of funders	◇ Any specific demographics of patients/former patients/ caregivers/ family/experienced persons that are important for this work?	Development of the Grant Proposal:	◇ Jointly present the findings with researchers
◇ Other: _____ _____	_____	◇ Help to ensure that the research proposed and chosen methods are ethical	◇ Write information for local patient groups/hospitals, etc.
	◇ Do you want SCPOR to help connect you with the above individuals or groups? <input type="checkbox"/> yes <input type="checkbox"/> no	◇ Inform areas where patients and the public could be involved	◇ Assist in getting results/findings published on charities/ voluntary organization websites
		◇ Define outcome measures	◇ Help distribute results within their informal network
		◇ Advise on the appropriateness of the lay summary	◇ Produce summaries of findings
		◇ Raise awareness about costs of involvement, expenses and prompt researchers to cost for involvement.	Implementation:
		◇ Become co-applicants	◇ Increase the likelihood that results of research are implemented, by adding validity to the findings
		Preparation for execution of the study:	◇ Develop patient information for new services/interventions within hospitals, clinics, etc.
		◇ Assist with writing patient information and consent forms	Monitoring and Evaluation:
		◇ Review ethics and operational approval applications prior to submission	◇ Have continued involvement with the study to maintain focus and address issues as they arise
		◇ Aid in designing the detailed protocol	◇ Collaborate with researchers to evaluate the research process
		◇ Produce research updates that are patient friendly	◇ 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.

