# 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. W	hy do you want to engage patients?		2. Who do you want to engage with?	3. What might patient team members do?	
$\Diamond$	Gathering ideas for new research areas	$\Diamond$	Current patients	Identifying & Prioritising:	Data Collectio
	based on patients needs	$\Diamond$	Former patients	<ul> <li>Through community representation and organizations help inform research priorities</li> </ul>	<ul><li>♦ Draft/revise</li><li>♦ Assist with</li></ul>
$\Diamond$	Ensuring research is focused on the publics interest and concerns and that money and	$\Diamond$	Caregivers	<ul> <li>Be consulted about research topics and priorities important to them</li> </ul>	♦ Assist with Analysing and
	resources are used effectively	$\Diamond$	Family	♦ Collaborate and co-develop with researchers and	♦ Assist the r
$\Diamond$	Ensuring transparency and accountability	$\Diamond$	Public	other key groups topics for research <b>Design:</b>	from data    Be consulted.
$\Diamond$	Ensuring that the methods are acceptable	$\Diamond$	Patient support groups	<ul> <li>Inform the design of the research study</li> <li>Clarify the research question and affirm its im-</li> </ul>	interpret d  Output
	and sensitive to the situations of potential research participants	$\Diamond$	Patient organizations	portance  © Ensure the methods selected are appropriate for	pret the da  Dissemination
$\Diamond$	Making the language and content of infor-	$\Diamond$	Community groups	patients	♦ Advise on of
v	mation more appropriate and accessible	$\Diamond$	People who have experience with a specific con-	<ul><li>♦ Co-develop patient recruitment strategy</li><li>♦ Review and comment on proposed questionnaires</li></ul>	results
$\Diamond$	Increasing participation in research		dition, service, treatment. Please explain.	and data collection methods  Development of the Grant Proposal:	other appro
$\Diamond$	Collective data by, with and for patients			♦ Help to ensure that the research proposed and	♦ Write informal
$\Diamond$	Taking diverse perspectives into account when analysing data			<ul><li>chosen methods are ethical</li><li>Inform areas where patients and the public could be involved</li></ul>	hospitals, e  Assist in ge ties/ volun
$\Diamond$	Taking diverse perspectives into account when making decisions	<b>◊</b>	Any specific demographics of patients/former patients/ caregivers/ family/experienced	<ul> <li>◇ Define outcome measures</li> <li>◇ Advise on the appropriateness of the lay summary</li> <li>◇ Raise awareness about costs of involvement, ex-</li> </ul>	<ul><li>♦ Help distribution</li><li>♦ Produce su</li></ul>
	_		persons that are important for this work?	penses and prompt researchers to cost for involve-	<b>Implementation</b>
<b>\( \)</b>	Increasing the dissemination and uptake of research findings in practice or policy			ment.   Become co-applicants	<ul><li>Increase the implement</li></ul>
$\Diamond$	Meeting the requirements of funders		<del></del>	Preparation for execution of the study:	♦ Develop pa
$\Diamond$	Other:			<ul> <li>Assist with writing patient information and con- sent forms</li> </ul>	interventio  Monitoring an
		$\Diamond$	Do you want SCPOR to help connect you with the above individuals or groups? [] yes [] no	<ul> <li>Review ethics and operational approval applications prior to submission</li> </ul>	Have continuous maintain for maintain fo
				♦ Aid in designing the detailed protocol	♦ Collaborate

♦ Produce research updates that are patient friendly

- se study materials and protocols
- the recruitment of study participants
- conducting interviews and surveys

### **Interpreting Data:**

- esearch team in developing themes
- ed to determine if they understand and lata the same way as the research team
- ore approachable methods to help interita

- different avenues for disseminating the
- -author manuscripts, newsletters and opriate information outlets
- sent the findings with researchers
- mation for local patient groups/ etc.
- etting results/findings published on charitary organization websites
- oute results within their informal net-
- ummaries of findings

- e likelihood that results of research are ed, by adding validity to the findings
- atient information for new services/ ons within hospitals, clinics, etc.

# nd Evaluation:

- nued involvement with the study to ocus and address issues as they arise
- e with researchers to evaluate the research process
- A Reflect on their role and what they have learned

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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
- $\Diamond$ Work with existing provincial or regional patient advisory councils \*
- Work with existing patient groups
- $\Diamond$ Focus Group
- Town Hall Meeting
- Interviews/ Hearing Patient Stories
- $\Diamond$ Surveys
- $\Diamond$ Social media
- **Patient Shadowing**
- Other:

## 5. What level of engagement do you expect?

- $\Diamond$ 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.
- $\Diamond$ 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 decisionmaking 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. Ie. 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 patients and families engaged
- Depending on your funding source determine is \$100 per day (pro-rated) plus eligible expens- principles for patient engagement. es.

## Example:

- 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
- 1 full day focus group meeting for 20 patients = 20x100=\$ 2000
- Two hour, bi-monthly, Patient advisory council meetings with 8 members for a duration of 2 years = (100/7.5)x2\*12\*8=\$2560

Total = A+B+C = 2400+2000+2560\$6960 plus expenses

 T-4-1	
Total:	

## 7. How will you evaluate engagement?

From the beginning of your project discuss as a team will have engaged and the number of days you 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 honorarium rate. Note that the SCPOR rate the Strategy for Patient Oriented Research, guiding

- **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.

Adapted by: Saskatchewan Centre for Patient Oriented Research

Adapted from Newfoundland & Labrador SUPPORT Unit: Patient and Public Engagement Planning Template.

<sup>\*</sup> For information on existing advisory councils please contact the SCPOR Patient Engagement Platform.

<sup>\*</sup> 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.