

Evidence-Informed Practices and Strategies for Patient-Oriented Research (POR): A ‘Menu’ for Research Teams

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October 2019

Cite as: Kent, A. (2019). Evidence-informed practices and strategies for patient-oriented research (POR): A ‘menu’ for research teams. BC SUPPORT Unit: Vancouver.

This project has been undertaken by the [BC SUPPORT Unit](#), a Unit of the [BC Academic Health Science Network](#) funded by the [Canadian Institutes of Health Research \(CIHR\)’s Strategy for Patient-Oriented Research \(SPOR\)](#)

Who should use this resource?

The purpose of this resource is to support **research teams considering or moving into Patient-Oriented Research (POR)** by offering a ‘menu’ of evidence-informed practices and strategies for effective engagement. The term ‘menu’ was selected to represent the flexibility that this resource has to offer and to move away from the prescriptive ‘one-size-fits-all’ approach of a checklist. A research team would not be expected to incorporate every practice and strategy identified; the extent to which teams draw from this list will vary depending on a range of factors, including stakeholder priorities, available resources and capacity, size of team, length of engagement, and whether engagement is the primary or secondary goal of the research.

The body of literature on POR has rapidly expanded over the last decade. However, a significant portion of the available literature presents abstract principles and frameworks for conceptualizing engagement, and the evidence base for specific practices is primarily anecdotal and lacking empirical evaluation.^{3,65} There is a need for practical guidelines for operationalizing POR.^{20,24,75} In an effort to fill this gap, this resource presents a synthesis of academic literature and grey literature on the topic of POR, including case studies, descriptive articles, systematic reviews, reports, frameworks and toolkits. Sources were identified through secondary analysis of a previously conducted literature review, for which the study protocol has been published.⁵⁴ Through full-text review and thematic analysis of included sources, promising practices and strategies from the literature were consolidated into a menu. This menu is not an exhaustive list, but a starting point for discussion and innovation.

What is Patient-Oriented Research?

POR refers to a continuum of research and knowledge translation activities that **engage patients as partners, focus on patient-identified priorities and aim to improve healthcare systems and health outcomes.**¹⁰ Patient engagement enhances the relevance of the research and improves its translation into policy and practice.¹⁵ POR is conducted by multidisciplinary teams made up of four stakeholder groups: (1) patients, (2) researchers, (3) health care providers and (4) health system decision-makers.¹⁵ The term ‘patient’ is used to refer to an overarching stakeholder group that includes individuals with personal or lived experience of a health issue as well as caregivers, family and friends.¹⁵ Although this resource has a health research focus, it is equally applicable for collaborative research in other fields; users are encouraged to replace “patient” with whichever word most resonates for them. Learn more about POR here: <https://bcsupportunit.ca/about>



How do teams use the menu?

Users are encouraged to **go through this menu as a team and in collaboration with patient partners and stakeholders** (if relationships are already established). The menu is ideally suited for use in the initial stages of conceiving a research or knowledge translation project to initiate conversations about how POR will be enacted.

To help guide teams, the menu is organized into the following headings: Planning for POR (p. 4); Forming a POR Team (p. 4); Supporting Patient Partners & Stakeholders (p. 6); Working Together (p. 8); and Closing the Loop (p. 10). These headings and their corresponding practices are generally organized in a sequence that follows a traditional POR research plan; however, they do not need to be followed from beginning through end or even in a linear order.

Under each heading, broad categories of POR 'Practices' are listed along the left column; these practices can be operationalized through specific 'Strategies' that are described in the middle column. Key ideas from each strategy are highlighted in bold for ease of reading. The Practices and Strategies are also supported by recommended 'Resources', which are identified in the right column. Each Strategy has a checkbox beside it for users to identify which ones are most useful and/ or appropriate for their needs. Again, research teams are not expected to incorporate every practice and strategy.

Discussions can help form the foundation for a workplan (see for instance *PEIRS Workbook to Guide the Development of a Patient Engagement in Research (PEIR) Plan*⁶⁰). A workplan could identify practices and strategies selected by the team, considerations for any adaptations necessary for the particular research context, a projected timeline as well as who is responsible for implementing or overseeing tasks. It is recommended that this menu and any resulting workplan be revisited periodically as the project unfolds to monitor progress and recalibrate if necessary.

If you and your team elect to use the tool, please let us know. We'd be pleased to hear how it is being taken up by research teams and stakeholders!

Use this webform for easy feedback: <https://redcap.bcahsn.ca/surveys/?s=RJPHXCE7AH> or feel free to contact us with any comments, questions or feedback at: info@bcsupportunit.ca

Planning for POR

Practices	Strategies	Resources
<p>Assess Readiness for the Project</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Conduct a self-assessment of team members’ knowledge, skills, attitudes and attributes related to patient-oriented research.^{8,14,68} <input type="checkbox"/> Make a list of existing assets and resources as well as gaps (e.g. expertise, funding, office space, technology, structural supports, commitment from leadership, etc.).^{1,13,36,38,57,60} <input type="checkbox"/> Account for additional time needed for recruiting, training and supporting patient partners/ stakeholders.^{3,8,13,38,43,64} <input type="checkbox"/> Budget for patient partner compensation and engagement expenses (e.g. travel, and accommodation, childcare, translation/ interpretation, conference attendance).^{3,4,8,14,30,37,39,43,60,64} 	<p>1, 8, 16, 30, 38, 55, 60</p>
<p>Form Sustainable Engagement Structures</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Formalize an overarching engagement structure or model, such as an advisory council, to facilitate stakeholder involvement beyond the lifespan of a single project or engagement activity.^{3,14,37,39,43} <input type="checkbox"/> Work with host institutions (e.g. universities, health authorities) to establish institutional policies or partnership agreements that outline commitments, such as provision of workspace and equipment, access to internet and shared drives, online platforms, institutional email addresses, security passes or ID cards, etc.^{3,25,27,29,52} <input type="checkbox"/> Build capacity for stakeholder groups to engage in patient-oriented research (e.g. collaborate on grant applications, extend invitations to training opportunities, share resources and templates).^{3,13,14} 	<p>40, 41</p>

Forming a POR Team

Practices	Strategies	Resources
<p>Convey Project Goals</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Ask patient partners/ stakeholders about their interest in the research topic and what they hope to achieve to ensure alignment with project aims and create a shared sense of purpose.^{1,15,22,36,60} <input type="checkbox"/> Have a conversation with patient partners/ stakeholders before the first engagement activity to clearly communicate and confirm a mutual understanding of: the purpose and scope of the research, timeline and activities, rationale for engagement and potential benefits of engagement, goals and desired outcomes, etc.^{3,7,12,13,14,20,22,37,38,43,57,60} <input type="checkbox"/> Create a visual map to depict research activities, key milestones, assigned responsibilities, timelines and outcomes as well as how each component relates to the “bigger picture.”^{22,29,38,75} 	<p>60, 75</p>
<p>Clarify Roles</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Ask patient partners and stakeholders how they envision their roles, their desired level of engagement and what they hope to contribute to the project. Suggest possible roles that match their knowledge, skills, 	<p>11, 17, 25, 38, 60</p>

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	<p>interests and experiences. ^{3,12,13,15,22,25,60,68,75} See also ‘Utilize the Skillsets of All Team Members’</p> <ul style="list-style-type: none"> <input type="checkbox"/> Be open to the range of possibilities for the roles/ titles of patient partners. Possible roles could include: advisors, paid employees, knowledge users, co-investigators, joint grant holders, principal investigators, etc. Note that for most studies, <i>it is not appropriate for patient partners to also be research participants.</i> ^{3,10,15,22,24,25,27,37,43,75} <input type="checkbox"/> Create a written document (e.g. terms of reference) to clearly define each person’s role within the research team and describe respective responsibilities/ scope of authority. ^{1,3,8,12,22,25,29,36,37,38,39,43,52,57,64,65} 	
<p>Manage Expectations</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Discuss as a team mutual goals and expectations before the start of a project, and consider documenting agreements in study protocols, a collaborative agreement or terms of reference. ^{3,14,18,20,24,29,38} <input type="checkbox"/> Establish realistic expectations for the project (e.g. funding uncertainty, start and end dates, what can and cannot be achieved through research, scope for influence). ^{13,14,18,22,43} <input type="checkbox"/> Ensure patient partners and stakeholders understand what the engagement process entails in terms of workload and time commitments (e.g. frequency/ duration) ^{1,3,12,16,20,22,24,25,27,37,38,43,57,60} <input type="checkbox"/> Inform team members that they can step away with dignity at any time if they need a break or need to withdraw due to changing health status, new professional roles or other commitments. Establish protocols for giving notice, identifying replacements, re-assigning responsibilities and/ or parting ways. ^{1,14,18,25,38,43,51,64,68} 	<p style="text-align: center;">25, 38, 60</p>
<p>Recruit Diverse Perspectives</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Avoid overreliance on a single patient by involving at least two patient partners, with the understanding that individuals represent their own perspectives, not the viewpoints of all patients. ^{1,3,12,14,20,22,36,38,43,52,57} <input type="checkbox"/> Identify the appropriate stakeholders for your project based on who is impacted as well as who has relevant knowledge/ experience, including but not limited to: patients/ potential patients, parents/ family members, caregivers, clinicians, decision-makers, policy makers, interest groups (as applicable/ appropriate). ^{10,13,14,15,22,25,36,37,38,39,43,57,65} <input type="checkbox"/> Reach out to under-represented demographic groups and seldom-heard voices to represent various realms of diversity, considering for instance: sex, gender, sexuality, age, ability/ mobility, language, literacy, socio-economic status, culture, religion, ethnicity/ race, Indigeneity, citizenship, geographic region, disease duration/ severity (as applicable/ appropriate). ^{1,3,12,14,15,17,20,25,38,39,57} <input type="checkbox"/> Employ multiple and creative recruitment techniques tailored to the intended audience to attract diverse patient partners; consider one or more of the following channels: word-of-mouth, media outlets, social media, conferences or public events, posters in health centres/ pharmacies/ community-based agencies, key informants/ peer-to-peer 	<p style="text-align: center;">5, 14, 38, 42, 44, 57, 58</p>

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	recruitment, crowdsourcing platforms or established patient organizations such as <i>Patient Voices Network</i> ^{5,57} . ^{1,3,8,14,15,27,38,43,57,64}	
Engage Early & Regularly	<ul style="list-style-type: none"> <input type="checkbox"/> Engage patient partners and other stakeholders as early as possible, ideally starting with identifying the research topic, so they are an equal partner and share ownership.^{3,8,13,14,15,37,43,57,64,65} <input type="checkbox"/> Schedule regular (e.g. quarterly) engagement activities (e.g. team meetings, check-ins), with opportunities for face-to-face/ in-person contact as much as possible.^{18,29,36,37,51,57} <input type="checkbox"/> Consult patient partners/ stakeholders on their availability and/ or desired levels of involvement over the course of the project, and agree upon frequency and duration of engagement (e.g. one-off, ad hoc, long-term).^{3,10,20,36,57} 	17

Supporting Patient Partners & Stakeholders

Practices	Strategies	Resources
Designate an Engagement Liaison	<ul style="list-style-type: none"> <input type="checkbox"/> Appoint one or two people who have a designated role managing engagement activities.^{1,3,12,14,37,38,39} <input type="checkbox"/> Maintain a consistent point-of-contact for patient partners (e.g. answering questions, sending meeting invitations and key documents, supporting expense claims, receiving and providing bi-directional feedback).^{1,12,17,18,25,38,43,68} <input type="checkbox"/> Situate a liaison in an office that is accessible to patient partners (e.g. on-site, in community) to encourage face to face contact.⁵¹ <input type="checkbox"/> Have a back-up plan or protocols in case the designated person(s) has to leave their role.²⁵ 	17
Provide Administrative, Logistical & Other Support	<ul style="list-style-type: none"> <input type="checkbox"/> Designate one or more individuals to be responsible for administrative logistics, including filling out expense claims, reimbursing team members in a timely manner, coordinating and troubleshooting necessary technology (e.g. webconference).^{1,3,4,16,38,43} <input type="checkbox"/> Arrange for emotional support, counselling services or Elders if warranted, particularly in cases where the nature of the research is sensitive or distressing.^{30,43,57,64} 	16 , 17 , 30
Remove Barriers & Encourage Engagement	<ul style="list-style-type: none"> <input type="checkbox"/> Take into account patient partners' health-related, ability/mobility, language/literacy, allergy/ dietary and/ or practical needs; and minimize barriers to engagement (e.g. host meetings in accessible venues, create culturally safe environments, provide childcare/ care attendants, offer transit passes/ parking passes, arrange for interpreters and translation services, provide printed materials in large print, use toll-free phone numbers, etc.).^{1,4,8,12,14,25,27,30,36,38,39,43,57,60,64} <input type="checkbox"/> Maximize convenience of engagement, for instance by: scheduling meetings around patient partners' availability, hosting meetings at 	9 , 38 , 66 , 72

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	<p>community-based agencies where patient partners access services, providing webconference/ teleconference options to access meetings remotely, ensuring sufficient time to review materials and contribute, etc.).^{1,3,8,14,25,30,36,37,38,43,51,57,60,64}</p> <ul style="list-style-type: none"> <input type="checkbox"/> Offer incentives or gestures of appreciation, such as providing refreshments at meetings.^{14,30,36,38,64,9} See also ‘Cover Expenses & Compensate Patient Partners’ 	
<p>Train Team Members</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Welcome all new members into the research team with an appropriate induction (e.g. welcome letter, orientation session) and information package (e.g. study protocols, directory with contact information). Help familiarize individuals with the research study and their role within it so they can fully engage.^{1,3,12,13,25,27,29,37,52,75} <input type="checkbox"/> Work with patient partners to identify learning needs according to their roles, agree upon suitable training opportunities that are not overly onerous, and arrange for financial support. Opportunities may include one-on-one or group mentorship (e.g. pairing with an experienced patient partner), workshops on POR, training in specialized methods, online learning resources and modules, relevant seminars or conferences, etc.^{1,3,8,12,14,15,18,25,27,36,37,38,43,52,64} <input type="checkbox"/> Emphasize that training opportunities are for all team members (patient partners, stakeholders, co-investigators, principal investigators, staff, trainees) to equip individuals and build collective capacity for effective POR.^{1,3,12,15,27,29,37,38,52,60,65,68} 	<p>9, 7, 19, 47, 49, 56, 59, 68, 73, 74, 76</p>
<p>Cover Expenses & Compensate Patient Partners</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Consult funding guidelines and host institution’s internal policies to ensure all payment and compensation practices comply (e.g. eligible expenses, forms of payment that can be issued, whether SIN numbers or other personal information needs to be collected, procedures for submitting expense claims, typical timeframes for expense reimbursement, etc.). Seek guidance from appropriate representatives within your institution and/ or within the community to uphold locally specific cultural protocols for paying and gifting Indigenous patient partners, Elders and Knowledge Holders.^{4,8,16,25,60} <input type="checkbox"/> Be upfront about what payment options are available and advise patient partners on any potential implications for accepting payment (e.g. taxable earnings, income/ disability assistance entitlement), so they can decide whether they will be able to engage and/ or whether they wish to be compensated. Agree upon an appropriate form of compensation, amount, payment schedule and how payment will be issued (e.g. cash, cheque, direct deposit).^{4,8,12,16,25,30,43,57,75} <input type="checkbox"/> Avoid having patient partners pay ‘out-of-pocket’ by having parking passes on hand, offering transit passes, pre-booking travel, etc. Where advance payment cannot be arranged, have systems in place to alleviate paperwork and expedite reimbursement.^{1,3,4,25,30,38,43,57} <input type="checkbox"/> Clarify whether there will be any costs incurred related to engagement and explain processes for submitting claims for reimbursement, 	<p>4, 16, 32, 33, 34, 45, 46, 53, 70</p>

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	<p>including whether original receipts are required and guidelines for eligible expenses.^{4,8,12,16,20,25,30,36,37,38,57,60,75}</p> <ul style="list-style-type: none"> <input type="checkbox"/> Offer patient partners payment for their time and efforts in the form of honoraria, stipend, hourly pay or salary (as appropriate). Non-monetary alternatives for compensation include in-kind contributions (e.g. tuition for a course, conference registration), gifts/ gift cards, or donations to a charity of choice.^{3,4,8,12,14,16,25,30,36,37,43,51,52,60,64,75} 	
Working Together		
Practices	Strategies	Resources
<p>Build Relationships</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Invest time in developing networks and cultivating relationships with patients/ stakeholders <i>and</i> their communities/ affiliated organizations prior to research inception; also explore opportunities for long-term partnerships beyond the lifespan of a single project.^{1,3,14,22,39,43,51} <input type="checkbox"/> Co-develop partnership agreements that outline shared values and principles for the working relationship, such as reciprocity, mutual respect, co-ownership, trust and accountability.^{8,24,25,36,39,75} <input type="checkbox"/> Build in team activities to get to know team members, nurture relationships and redress power differentials; activities could include: convening an in-person full-team meeting as early as possible, facilitating icebreaker exercises, using nametags and introduction circles at meetings, introducing yourselves with stories instead of titles, setting aside time for informal socializing, planning research retreats or team lunches, etc.^{1,3,12,13,14,36,37,38,39,43,51,57,60,68,75} 	<p>69</p>
<p>Promote Teamwork</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Foster a research environment and team culture that cultivates shared commitments to foundational principles of POR. For example, co-develop and agree upon terms of engagement or ground rules to establish a safe, judgement-free atmosphere that promotes active listening and open dialogue.^{1,3,8,12,13,15,20,29,36,37,38,39,43,51,52,60,65,68} <input type="checkbox"/> Reflect on whether engagement methods are privileging people with more education, power, influence, or confidence; and create space for all voices to be heard. For example: occasionally break into small group discussions with people in similar roles; privately check-in with individuals who are quiet, without putting them on the spot; routinely invite questions or comments from team members joining remotely; offer pre- or post- meeting debriefs; suggest alternatives for team members who prefer to comment one-on-one, in writing, or after reviewing additional information; etc.^{1,8,12,14,20,29,36,37,38,39,43,51,52,60,68,75} <input type="checkbox"/> Embrace collaboration, shared decision-making (e.g. voting, consensus) and joint ownership of both successes and shortcomings—without placing blame.^{1,3,8,14,29,38,39,43,52,60,64,68} 	<p>23, 26, 38, 39, 60, 68</p>

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<p>Utilize the Skillsets of All Team Members</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Convey mutual respect for diverse knowledge bases, lived experiences and unique perspectives. Recognize that patient partners have valuable expertise through living with a condition, undergoing treatments and navigating the health system.^{1,8,12,13,14,15,20,36,38,39,51,64,68} <input type="checkbox"/> Work with patient partners to explore their professional and personal skillsets that can be leveraged to support the research (e.g. social networking, social media abilities, web content development or management, writing and presentation skills, etc.).^{12,14,17,36,39,60,68} <input type="checkbox"/> Create opportunities for patient partners to support carrying out research activities if they are interested (e.g. recruiting participants, piloting data collection instruments, administering surveys, conducting interviews, interpreting results, formulating recommendations, preparing plain language summaries, delivering presentations, co-authoring publications, etc.).^{1,3,8,10,12,15,17,18,20,22,24,36,43,52,64,65} 	<p>17, 38</p>
<p>Share Information with Everyone</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Tailor communications to patient partners' and stakeholders' information needs and preferences. Agree upon what types of information are useful (e.g. lay summaries, data visualizations, briefing notes) as well as how communication will be sustained (e.g. in-person, phone, email, online collaboration platforms such as <i>BC SUPPORT Unit's Electronic Communities of Practice</i>⁶).^{1,3,14,17,20,22,38,51,60} <input type="checkbox"/> Circulate copies of relevant materials (e.g. grant proposal, ethics protocol, workplan, meeting schedule, minutes) at appropriate stages, giving enough time for review and input if applicable.^{1,3,18,20,38,43} <input type="checkbox"/> Use plain language and minimize use of jargon, without oversimplifying content— important technical terms and acronyms can be defined in a glossary of terms.^{1,3,8,12,14,20,36,37,38,51,57,65,68,75} <input type="checkbox"/> Provide clear information about meeting logistics (e.g. dates, times, location, dial-in information, agenda, meeting materials), and notify attendees of any changes well in advance. Follow up with individuals who are unable to attend to share minutes.^{1,20,29,38,43,57,60} <input type="checkbox"/> Send regular (i.e. quarterly) updates to all team members and stakeholders through e-newsletters or progress reports. Report back to all patient partners and stakeholders once the outcomes of grant applications or ethics submissions are announced as well as once a project is complete to share results, including feedback, explanations or next steps if applicable.^{1,3,12,17,18,25,38,43,52,57,65} 	<p>2, 6, 14, 18, 29, 31, 35, 38, 44, 48, 57, 61, 63</p>
<p>Resolve Conflict</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Establish protocols for raising concerns and resolving conflict so that the procedures are transparent from the beginning.^{22,25,29,38,43,64,68} <input type="checkbox"/> Create safe and supportive spaces for all involved to express divergences of opinion, acknowledge tensions, reflect on negative experiences, bridge divides, address sources of conflict as they arise, and prevent future incidents.^{1,7,8,39,43,57,64,65,68,75} <input type="checkbox"/> Reach out to appropriate individuals (e.g. human resources department, professional facilitator) who can act as a neutral mediator to support conflict resolution, if warranted.^{1,25,30,37,38,43,57} 	<p>21, 23, 29, 38, 50</p>

Closing the Loop

Practices	Strategies	Resources
<p>Acknowledge Contributions</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Respond promptly to team members to let them know their comments have been received and efforts will be made to incorporate any input. Follow-up in a reasonable timeframe to explain how their feedback was used or why it was not used.^{1,3,17,14,18,29,36,57} <input type="checkbox"/> Give honest but sensitive constructive feedback to patient partners/ stakeholders on their contributions. Feedback may be directed to the whole team or specific to individuals.^{1,3,15,18,36,38} <input type="checkbox"/> Discuss preferred approaches for recognizing team members' contributions and showing that they are appreciated. Create a system for validating their time and efforts; this may take the form of verbal recognition, a written thank you card, a certificate of participation, nominations for awards, etc.^{3,8,12,16,17,18,36,37,38,39,57,60,64,68,75} <input type="checkbox"/> Agree upon how team members will be acknowledged in reports, publications and presentations to attribute credit to their work as appropriate and consistent with authorship eligibility guidelines (e.g. acknowledgements section, co-authorship and/ or lead authorship). Care should be taken to avoid inadvertently identifying patient partners when reporting research on sensitive topics.^{16,18,20,25,29,43,52,60} 	<p>18, 38</p>
<p>Evaluate POR Strategies</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Engage the entire research team in co-designing an evaluation plan early in the research process to outline a blueprint for how you will monitor progress, assess the quality of the engagement process, and/ or evaluate short- and long- term impacts of POR. Collectively agree upon evaluation measures, data, methods, timelines and individuals responsible for evaluation tasks.^{1,3,13,17,25,37,38,39,43,51,60,64,65} <input type="checkbox"/> Step back and reflect at regular intervals (e.g. interim reports, routine check-ins, reflective diaries, collecting feedback from patient partners and stakeholders) to identify what is working well and areas for improvement. Use this information to recalibrate the research plan and modify the POR strategies, as needed.^{1,3,13,18,22,29,37,38,39,43,51,57,60,65} 	<p>1, 3, 28, 38, 62, 71</p>
<p>Document the Process</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Document POR activities, including a description of the purpose, context, number and characteristics of patient partners/ stakeholders involved, strategies adopted, how patient partners/ stakeholders are involved at each stage, as well as outcomes of engagement.^{1,3,14,43,52,64} <input type="checkbox"/> Use an established reporting framework, such as <i>GRIPP2</i>⁶⁷, to contribute to building a standardized evidence base for POR.^{13,52} <input type="checkbox"/> Tell the story of the POR process and find ways to share success/ lessons learned with stakeholders and broader audiences (e.g. final report, publications, presentations, media interviews).^{1,3,22,38,43} 	<p>18, 51, 67</p>

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