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

Contents

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

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.
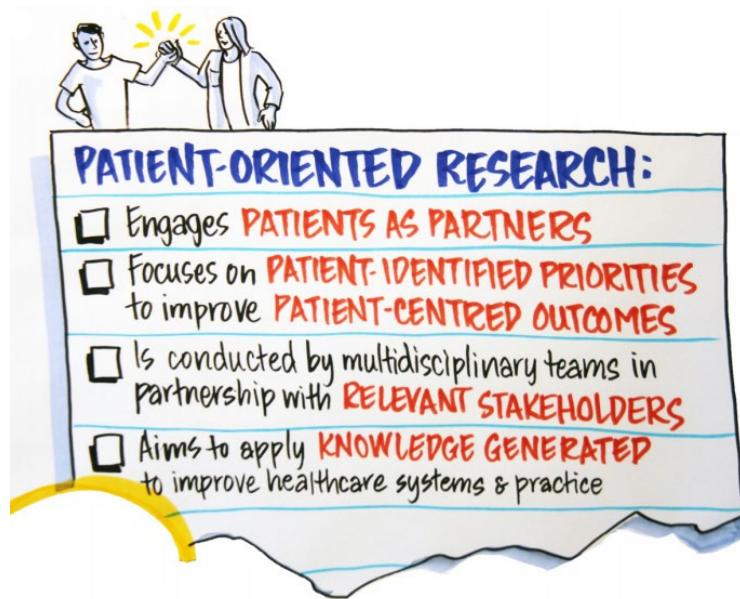
How do teams use the menu?

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: bcsupportunit@healthresearchbc.ca

Planning for POR

Practices	Strategies	Resources
Assess Readiness for the Project	❑ Conduct a **self-assessment** of team members' knowledge, skills, attitudes and attributes related to patient-oriented research.[8,14,68] ❑ 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] ❑ Account for **additional time** needed for recruiting, training and supporting patient partners/ stakeholders.[3,8,13,38,43,64] ❑ **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]	1, 8, 16, 30, 38, 55, 60
Form Sustainable Engagement Structures	❑ 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] ❑ 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] ❑ **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]	40, 41

Forming a POR Team

Practices	Strategies	Resources
Convey Project Goals	❑ 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] ❑ Have a conversation with patient partners/ stakeholders before the first engagement activity to clearly	60, 75

	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] ❏ 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]	
Clarify Roles	❏ **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, interests and experiences. [3,12,13,15,22,25,60,68,75] See also 'Utilize the Skillsets of All Team Members' ❏ 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, *it is not appropriate for patient partners to also be research participants*. [3,10,15,22,24,25,27,37,43,75] ❏ 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]	11, 17, 25, 38, 60
Manage Expectations	❏ 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] ❏ 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] ❏ 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] ❏ 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-	25, 38, 60

	assigning responsibilities and/ or parting ways.[1,14,18,25,38,43,51,64,68]	
Recruit Diverse Perspectives	❑ 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] ❑ 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] ❑ 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] ❑ 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 recruitment, crowdsourcing platforms or established patient organizations such as *Patient Voices Network*[5,57] .[1,3,8,14,15,27,38,43,57,64]	5, 14, 38, 42, 44, 57, 58
Engage Early & Regularly	❑ 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] ❑ 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] ❑ 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

Practices	Supporting Patient Partners & Stakeholders	
	Strategies	Resources
Designate an Engagement Liaison	❑ **Appoint one or two people** who have a designated role **managing engagement** activities.[1,3,12,14,37,38,39] ❑ 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] ❑ 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] ❑ 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	❑ 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] ❑ 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	❑ 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] ❑ **Maximize convenience** of engagement, for instance by: scheduling meetings around patient partners' availability, hosting meetings at 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] ❑ **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'	9, 38, 66, 72

Train Team Members	❏ 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] ❏ 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] ❏ 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]	9, 7, 19, 47, 49, 56, 59, 68, 73, 74, 76
Cover Expenses & Compensate Patient Partners	❏ 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] ❏ 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] ❏ Avoid having patient partners pay 'out-of-pocket' by having parking passes on hand, offering transit passes,	4, 16, 32, 33, 34, 45, 46, 53, 70

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]

❑ Clarify whether there will be any **costs incurred** related to engagement and explain processes for **submitting claims** for reimbursement, including whether original receipts are required and guidelines for eligible expenses.[4,8,12,16,20,25,30,36,37,38,57,60,75]

❑ 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
Build Relationships	❑ Invest time in **developing networks** and cultivating relationships with patients/ stakeholders *and* 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] ❑ 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] ❑ 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]	69
Promote Teamwork	❑ 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	23, 26, 38, 39, 60, 68

	listening and open dialogue.[1,3,8,12,13,15,20,29,36,37,38,39,43,51,52,60,65,68] ❏ 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] ❏ 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]	
Utilize the Skillsets of All Team Members	❏ 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] ❏ 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] ❏ 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]	17, 38
Share Information with Everyone	❏ **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 *BC SUPPORT Unit's Electronic Communities of*	2, 6, 14, 18, 29, 31, 35, 38, 44, 48, 57, 61, 63

Practices	Strategies	Resources
	Practice[6]).[1,3,14,17,20,22,38,51,60] ❑ **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] ❑ 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] ❑ 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] ❑ 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]	
Resolve Conflict	❑ Establish **protocols for raising concerns and resolving conflict** so that the procedures are transparent from the beginning.[22,25,29,38,43,64,68] ❑ 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] ❑ 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]	21, 23, 29, 38, 50

Closing the Loop

Practices	Strategies	Resources
Acknowledge Contributions	❑ **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]	18, 38

	❑ 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]	
	❑ 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]	
	❑ 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]	
Evaluate POR Strategies	❑ 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]	1, 3, 28, 38, 62, 71
	❑ 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]	
Document the Process	❑ **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]	18, 51, 67
	❑ Use an established **reporting framework**, such as *GRIPP2*[67], to contribute to building a standardized evidence base for POR.[13,52]	

❑ 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]

References & Resources

1. Alberta Health Services. (n.d.). A Resource Toolkit for Engaging Patient and Families at the Planning Table. Retrieved from https://www.albertahealthservices.ca/assets/info/pf/pe/if-pf-pe-engage-toolkit.pdf

2. Auckland District Health Board. (2019). Patient journey mapping. Health Service Co-Design. Retrieved from https://www.healthcodesign.org.nz/tool-kit/explore/patient-journey-mapping/

3. Ball, S., Harshfield, A., Carpenter, A., Bertscher, A. & Marjanovic, S. (2019). Patient and public involvement in research: Enabling meaningful contributions. Santa Monica, CA: RAND Corporation. Available from https://www.rand.org/pubs/research_reports/RR2678.html.

4. BC Centre for Disease Control. (2018). Peer payment standards for short-term engagements. Retrieved from http://www.bccdc.ca/resource-gallery/Documents/Educational%20Materials/Epid/Other/peer_payment-guide_2018.pdf

5. BC Patient Safety & Quality Council. (n.d.). Patient voices network: Engagement request form. Retrieved from https://patientvoicesbc.ca/healthcare-partners/engagement-request-form/

6. BC SUPPORT Unit. (2019). eCoPs: Electronic communities of practice.

7. BC SUPPORT Unit. (2019). Introductory workshops: Foundations in patient-oriented research (for all stakeholders).

8. BC SUPPORT Unit. (2019). Patient-oriented research pathways self-assessment readiness tool.

9. BC SUPPORT Unit. (2018). Patient partner appreciation policy.

10. BC SUPPORT Unit. (n.d.). How patient-oriented is your research? Retrieved from https://healthresearchbc.ca/wp-content/uploads/2022/10/How-patient-oriented-is-your-research.pdf

11. Belbin Associates. (2015). Belbin's team roles: How understanding team roles can improve team performance. Retrieved from https://www.mindtools.com/pages/article/newLDR_83.htm

12. Black, A., Strain, K., Wallsworth, C., Charlton, S., Chang, W., McNamee, K., & Hamilton, C. (2018). What constitutes meaningful engagement for patients and families as partners on research teams? *Journal of Health Services Research & Policy, 23*(3), 158-167.

13. Boaz, A., Hanney, S., Borst, R., O'Shea, A., & Kok, M. (2018). How to engage stakeholders in research: Design principles to support improvement. *Health Research Policy and Systems, 16*(1), 60-60.

14. Canadian Foundation for Healthcare Improvement. (2013). Patient Engagement: Heard and valued: A handbook for meaningful engagement of patients that have not traditionally been heard in healthcare planning. Retrieved from https://www.cfhi-fcass.ca/sf-docs/default-source/patient-engagement/awesome_handbook-fraserhealth.pdf?sfvrsn=2

15. Canadian Institutes of Health Research Strategy for Patient-Oriented Research. (2019). Patient Engagement Framework. Retrieved from http://www.cihr-irsc.gc.ca/e/48413.html

16. Canadian Institutes of Health Research. (2019). Considerations when paying patient partners in research. Retrieved from http://www.cihr-irsc.gc.ca/e/51466.html

17. Can-SOLVE CKD. (2017). Engaging patients in the research process: A toolkit for project leads. Retrieved from https://www.cansolveckd.ca/wp-content/uploads/2018/07/patient-engagement-toolkit.pdf

18. Centre for Research in Public Health and Community Care. (2018). Guidance for researchers: Feedback from researchers to patient and public involvement (PPI) contributors. Retrieved from https://www.clahrc-eoe.nihr.ac.uk/wp-content/uploads/2016/05/Guidance-for-Researchers-PPI-Feedback_2018.pdf

19. CERTAIN Patient Advisory Network. (2016). INSPIRE research portal. Retrieved from http://inspireresearch.org/home

20. Cheung, P. P., de Wit, M., Bingham, C. O., Kirwan, J. R., Leong, A., March, L. M., … Grossec, L. (2016). Recommendations for the involvement of patient research partners (PRP) in OMERACT working groups: A report from the OMERACT 2014 Working Group on PRP. *J Rheumatol, 43*, 187–193.

21. Community Tool Box. (2018). Section 6: Training for conflict resolution. Retrieved from https://ctb.ku.edu/en/table-of-contents/implement/provide-information-enhance-skills/conflict-resolution/main

22. Concannon, T. W., Grant, S., Welch, V., Petkovic, J., Selby, J., Crowe, S., . . . for the Multi Stakeholder Engagement Consortium. (2019). Practical guidance for involving stakeholders in health research. *Journal of General Internal Medicine, 34*(3), 458-463.

23. Davies, L. & Ring, L. (2007). Building better teams: A toolkit for strengthening teamwork in community health centres: Resources, tips, and activities you can use to enhance collaboration. Association of Ontario Health Centres, Toronto. Retrieved from https://www.allianceon.org/sites/default/files/documents/Building%20Better%20Teams%20Toolkit%20--%202007.pdf

24. Domecq, J. P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., . . . Murad, M. H. (2014). Patient engagement in research: A systematic review. *BMC Health Services Research, 14*(1), 89-89.

25. Elliott, J., Lodemore, M., Minogue, V., & Wellings, A. (2019). Public co-applicants in research: Guidance on roles and responsibilities. Southampton: INVOLVE. Retrieved from

https://www.invo.org.uk/posttypepublication/public-co-applicants-in-research-guidance-on-roles-and-responsibilities/

26. Faulkner, A. (2010) Changing our Worlds: Examples of user-controlled research in action. INVOLVE, Eastleigh. Retrieved from https://www.invo.org.uk/wp-content/uploads/2011/09/INVOLVEChangingourworlds2010.pdf

27. Forsythe, L. P., Szydlowski, V., Murad, M. H., Ip, S., Wang, Z., Elraiyah, T. A., . . . Hickam, D. H. (2014). A systematic review of approaches for engaging patients for research on rare diseases. *Journal of General Internal Medicine, 29*(Suppl 3), 788-800.

28. Forsythe, L., Heckert, A., Margolis, M. K., Schrandt, S. & Frank, L. (2018). Methods and impact of engagement in research, from theory to practice and back again: Early findings from the patient-centered outcomes research institute. *Quality of life research, 27*(1),17-31.

29. Gadlin, H. & Bennet, L. M. (2013). Tools for preempting discord. Retrieved from http://i2sconference.digitalposter.com.au/posters-list/628

30. George and Fay Yee Centre for Health Care Innovation. Budgeting for Patient Engagement. Retrieved from https://chimb.ca/sub-sites/1-patient-engagement?page=79-budgeting-for-engagement"

31. Government of BC. Plain language course. Retrieved from https://www2.gov.bc.ca/gov/content/governments/services-for-government/policies-procedures/web-content-development-guides/writing-for-the-web/plain-language-guide/plain-language-course

32. Government of Canada. (2019). Personal income tax. Retrieved from https://www.canada.ca/en/services/taxes/income-tax/personal-income-tax.html

33. Greer, A.M. & Buxton, J.A. (2017). A guide for paying peer research assistants: Challenges and opportunities. Vancouver, BC Centre for Disease Control. Retrieved from: http://towardtheheart.com/assets/uploads/1502392095pS7Cr8pMMC3xed4576edy2mHGOyNxJnLFCmcbzU.pdf

34. Greer, A.M., Newman, C., Burmeister, C., Burgess, H., Coll, M., Choisil, P.,LeBlanc, B., Lacroix, K., Lampkin, H., Amlani, A., Pauly, B., & Buxton, J.A. (2017). Peer Engagement Principles and Best Practices: A Guide for BC Health Authorities and other Providers (version 2). Vancouver, BC: BC Centre for Disease Control. Retrieved from: http://www.towardtheheart.com/assets/uploads/1516141269o4KkCMkq2ytmhxVyGjcQ9DSWtUoI1d8FLnzYdIv.pdf

35. Group Health Research Institute. (n.d.). Program for readability in science and medicine: Online training. Retrieved from https://prism.kpwashingtonresearch.org/course_introduction/splash_page_before_registration.html

36. Hamilton, C. B., Hoens, A. M., Backman, C. L., McKinnon, A. M., McQuitty, S., English, K., & Li, L. C. (2018). An empirically based conceptual framework for fostering meaningful patient engagement in research. *Health Expectations, 21*(1), 396-406.

37. Harrison, J. D., Auerbach, A. D., Anderson, W., Fagan, M., Carnie, M., Hanson, C. ... Weiss, R. (2019). Patient stakeholder engagement in research: A narrative review to

describe foundational principles and best practice activities. *Health Expectations, 22*(3), 307-316.

38. Health PEI. (2016). Engagement Toolkit. Retrieved from http://www.gov.pe.ca/photos/original/hpei_engagetool.pdf
39. Hickey, G., Brearley, S., Coldham, T., Denegri, S., Green, G., … & Turner, K. (2018). Guidance on co-producing a research project. Southampton: INVOLVE. Retrieved from https://www.invo.org.uk/wp-content/uploads/2019/04/Copro_Guidance_Feb19.pdf
40. Institute for Patient and Family Centered Care. (n.d.) A toolbox for creating sustainable partnerships with patients and families in research. Retrieved from https://www.ipfcc.org/bestpractices/sustainable-partnerships/index.html
41. Institute for Patient and Family-Centered Care. (n.d.). A patient and family advisory council workplan: Getting started. Retrieved from http://www.ashnha.com/wp-content/uploads/2018/03/4-PFAC-Workplan-Getting-Started-Copy.pdf
42. INVOLVE. (2019). 'Make it clear' campaign. Retrieved from https://www.invo.org.uk/makeitclear/
43. INVOLVE. (2019). Developing training and support. Retrieved from https://www.invo.org.uk/resource-centre/training-resource/
44. INVOLVE. (2019). Learning needs and tools. Retrieved from https://www.invo.org.uk/resource-centre/learning-and-development/learning-needs-and-tools/
45. INVOLVE. (2019). Payment and recognition for public involvement. Retrieved from https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/
46. INVOLVE. (2016). Involving children and young people in research: Top tips and essential key issues for researchers. INVOLVE, Eastleigh. Retrieved from http://www.invo.org.uk/wp-content/uploads/2016/01/involvingcyp-tips-keyissues-January2016.pdf
47. INVOLVE. (2012). Briefing notes for researchers: Involving the public in NHS, public health and social care research. INVOLVE, Eastleigh. Retrieved from http://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf
48. INVOLVE. (2012). Strategies for diversity and inclusion in public involvement: Supplement to the briefing notes for researchers. INVOLVE, Eastleigh. Retrieved from http://www.invo.org.uk/wp-content/uploads/2012/06/INVOLVEInclusionSupplement1.pdf
49. INVOLVE. (2011). What you need to know about payment: An introductory guide for members of the public who are considering active involvement in NHS, public health or social care research. INVOLVE, Eastleigh. Retrieved from http://www.invo.org.uk/wp-content/uploads/2011/06/INVOLVEpaymentdocument2011.pdf
50. IREX. (n.d.). Conflict resolution and peer mediation toolkit. Retrieved from https://www.irex.org/sites/default/files/node/resource/conflict-resolution-and-peer-mediation-toolkit.pdf
51. Kendall, C., Fitzgerald, M., Kang, R. S., Wong, S. T., Katz, A., Fortin, M., . . . Liddy, C. (2018). "Still learning and evolving in our approaches": Patient and stakeholder

engagement among Canadian community-based primary health care researchers. *Research Involvement and Engagement, 4*(1), 1-16.

52. Kirwan, J. R., de Wit, M., Frank, L., Haywood, K. L., Salek, S., Brace-McDonnell, S., . . . Bartlett, S. J. (2016). Emerging guidelines for patient engagement in research. *Value in Health, 20*(3), 481-486.

53. Langlois, A., Tatham, C., Carter, A., Chittock, B., Lauscher, D. McDougall, P., Osborne, C. & Parashar, S. (n.d.). Compensating peer research associates in HIV community-based research. Retrieved from https://pacificaidsnetwork.org/files/2015/05/PAN-CAHRposter2015_web.pdf

54. Mallidou, A. A., Frisch, N., Doyle-Waters, M. M., MacLeod, M. L. P., Ward, J., & Atherton, P. (2018). Patient-oriented research competencies in health for patients, healthcare providers, decision-makers and researchers: Protocol of a scoping review. *Systematic Reviews, 7*(1), 101-101.

55. Mental Health Research Network & INVOLVE. (2013). Budgeting for involvement: A practical guide and cost calculator to plan and budget for public involvement in your research. Retrieved from www.involve.nihr.ac.uk/resource-centre/involvement-cost-calculator/

56. Panel on Research Ethics. TCPS 2: CORE: Tutorial. Retrieved from https://tcps2core.ca/welcome

57. Patient Voices Network. (n.d.). A guide to patient engagement. Available from https://patientvoicesbc.ca/resources/a-guide-to-patient-engagement/

58. Patient-Centered Outcomes Research Institute. (2017). Patient and Stakeholder Engagement in Research: Strategies for Initiating Research Partnerships. Webinar Recording. Retrieved from https://www.pcori.org/events/2017/patient-and-stakeholder-engagement-research-strategies-initiating-research-partnerships

59. Patient-Oriented Research Training and Learning – Primary Health Care. (2019). Online training modules (for all stakeholders). Retrieved from https://bcsupportunit.ca/resources/patient-oriented-research-training-and-learning-primary-health-care-portl-phc-online

60. PEIRS Project Team. (2018). Workbook to guide the development of a Patient Engagement In Research (PEIR) Plan. Retrieved from http://www.arthritisresearch.ca/wp-content/uploads/2018/06/PEIR-Plan-Guide.pdf

61. Plain English Campaign. (2019). Retrieved from www.plainenglish.co.uk

62. Popay, J., Collins, M. & the PiiAF Study Group. (2014). The public involvement impact assessment framework guidance. Available from https://ceppp.ca/en/evaluation-toolkik/public-involvement-impact-assessment-framework-piiaf/

63. Ridpath, J. R., Greene, S.M., & Wiese, C.J. (2007). Program for readability in science and medicine: Readability Toolkit, 3rd ed. Seattle: Group Health Research Institute. Retrieved from https://prism.kpwashingtonresearch.org/documents/PRISMReadabilityToolkit_ThirdEdv6_062210.pdf

64. Shen, S., Doyle-Thomas, K. A. R., Beesley, L., Karmali, A., Williams, L., Tanel, N., & McPherson, A. C. (2017). How and why should we engage parents as co-researchers in health research? A scoping review of current practices. *Health Expectations, 20*(4), 543-554.

65. Shippee, N. D., Domecq Garces, J. P., Prutsky Lopez, G. J., Wang, Z., Elraiyah, T. A., Nabhan, M., . . . Murad, M. H. (2015). Patient and service user engagement in research: A systematic review and synthesized framework. *Health Expectations, 18*(5), 1151-1166.

66. Social Care Institute for Excellence. (2019). Making events and meetings accessible. Retrieved from https://www.scie.org.uk/co-production/supporting/making-events-accessible

67. Staniszewska, S., Brett, J., Simera, I., Seers, K., Mockford, C., Goodlad, S., . . . Tysall, C. (2017). GRIPP2 reporting checklists: Tools to improve reporting of patient and public involvement in research. *BMJ, 358,* j3453-j3453.

68. Strategy for Patient-Oriented Research. (2018). Foundations in patient-oriented research. Module 3: Building Partnerships and consolidating teams. Facilitator guide.

69. Students as Partners, Teaching, Learning and Support Office, University of Manchester. (n.d.). Peer support icebreakers. Retrieved from https://documents.manchester.ac.uk/display.aspx?DocID=7582

70. The Change Foundation. (2019). Should money come into it? A tool for deciding whether to pay patient- engagement participants. Available from https://www.changefoundation.ca/patient-compensation-report/

71. The Standards Development Partnership. (2018). National standards for public involvement. Retrieved from: http://www.invo.org.uk/wp-content/uploads/2018/03/71110_A4_Public_Involvement_Standards_v4_WEB.pdf

72. Toronto Artscape Inc. (n.d.). Who are my stakeholders and how do I engage them?. Retrieved from http://www.artscapediy.org/Creative-Placemaking-Toolbox/Who-Are-My-Stakeholders-and-How-Do-I-Engage-Them.aspx

73. U.S. Department of Health and Human Service. Basic research concepts. Retrieved from https://ori.hhs.gov/basic-research-concepts-brc-introduction

74. University of Glasgow. (n.d.). Understanding health research: A tool for making sense of health studies. Retrieved from https://www.understandinghealthresearch.org/

75. Witteman, H. O., Chipenda Dansokho, S., Colquhoun, H., Fagerlin, A., Giguere, A. M. C., Glouberman, S., ... Volk, R. J. (2018). Twelve lessons learned for effective research partnerships between patients, caregivers, clinicians, academic researchers, and other stakeholders. *Journal of General Internal Medicine, 33*(4), 558-562.

76. Yale University. (2015). Fundamentals of qualitative research methods. Retrieved from https://www.youtube.com/watch?v=wbdN_sLWl88