

Patients as Partners in Research: There Is Plenty of Help for Researchers

ALISON M. HOENS, MSc, BScPT

*Department of Physical Therapy, University of British Columbia,
Vancouver, Canada*

*Centre for Health Evaluation and Outcomes Sciences, University
of British Columbia, Vancouver, Canada*

*Arthritis Research Canada, Milan Ilich Arthritis Research Centre,
Richmond, Canada*

JOLETTA BELTON, MSc

Special Features Editor

Endless Possibilities Initiative, Fraser, CO

Retrain Pain Foundation, Mamaroneck, NY

ALEX SCOTT, PT, PhD

Special Features Editor

*Department of Physical Therapy, University of British Columbia,
Vancouver, Canada*

CLARE L. ARDERN, PT, PhD

Editor-in-Chief

*Division of Physiotherapy, Karolinska Institute,
Stockholm, Sweden*

J Orthop Sports Phys Ther 2020;50(5):219-221. doi:10.2519/jospt.2020.0104

Thank you to all who read and responded to our call to action in our first editorial in this series about engaging patients as research team partners.³ We are delighted with the positive response! The first editorial in the series focused on *why* researchers should engage patient partners on research teams. In this, the second editorial in the series, we concentrate on *how* to engage patient partners.

Researchers who have had limited opportunity or have not yet had the opportunity to work with patient partners on a research team may worry about how to “do it right.” Common concerns include

1. When and how to invite patient partners into a study
2. How patient partners can contribute to research
3. If, when, and how to offer payment for patient partners’ contributions
4. How to document patient partners’ role in manuscripts

The following sections highlight a sample of resources researchers can use to address their concerns and authentically engage patients as partners in research.

Deciding Whether Researchers and Patients Are Ready for Partnership

How do you know if you are “ready” for patient partnership in research? Clinical Trials Ontario has developed 2 decision aids, one for researchers⁷ and another for patients.⁸ These interactive online tools lead users through a step-by-step deci-

sion tree to help all parties decide when it is right to partner on research.

How to Engage Patient Partners

The Action Catalogue (<http://actioncatalogue.eu/>) helps researchers identify and select their preferred method for engaging partners who are not already part of a research team. Researchers choose from a list of 32 criteria (eg, intent, level of engagement, skills, number of participants, budget, duration, roles, etc) and 57 evidence-based methods that support inclusive engagement.

The interactive map tool, developed by the George & Fay Yee Centre for Healthcare Innovation,¹⁰ provides ideas for how to engage patients (and other stakeholders) in different phases of the research cycle.

How Patient Partners Can Contribute: Defining Roles

Researchers need to collaborate with patient partners to define how each will contribute to a research project. Defining the patient partner's role should balance the needs of the project with the knowledge, experience, and skills of the patient partner. Every partnership is different, so patient partner roles cannot be predetermined by researchers if meaningful engagement is to occur.

For example, the first step in the research cycle is to establish the research question. The patient perspective regarding the research question can enhance the relevance and meaningfulness of research. Patient partners can (1) help identify the research question to be studied or (2) verify or help refine a question prespecified by the researchers.

One resource to guide the discussion regarding potential roles within each phase of the research cycle has been proposed by Izabela Szelest and has been included in a publication by the Can-SOLVE CKD Network.⁵ Another informative resource that illustrates the complementary roles of patient partners and researchers throughout the research cycle is outlined by Moss et al¹² (FIGURE).

The guiding principle when defining the patient partner's role is "meaningful engagement." Components of the "Workbook to Guide the Development of a Patient Engagement In Research (PEIR) Plan"¹³ can help the research team ensure that engagement is beneficial for and valued by all research team members.

How Patient Partners Can Contribute: Recruiting, Orienting, and Training

Including at least 2 patient partners

who reflect some diversity in the patient population (consider sex, age, condition/disease severity, geographical location, etc) can help to mitigate token patient engagement. A practical guide is "Patient Engagement: Heard and Valued."¹⁵

There are abundant training resources for patient partners and for researchers, including those hosted on the US-based INSPIRE Research Portal (<http://inspiresearch.org/>), UK-based INVOLVE training support,¹⁶ and Canadian-based, patient-oriented primary health care online modules.¹

Budgeting for Patient Partners' Contributions to Research

Respectfully engaging patient partners in research includes consideration of reimbursement for out-of-pocket expenses such as travel and parking, and compensation for time, effort, and expertise.¹⁴

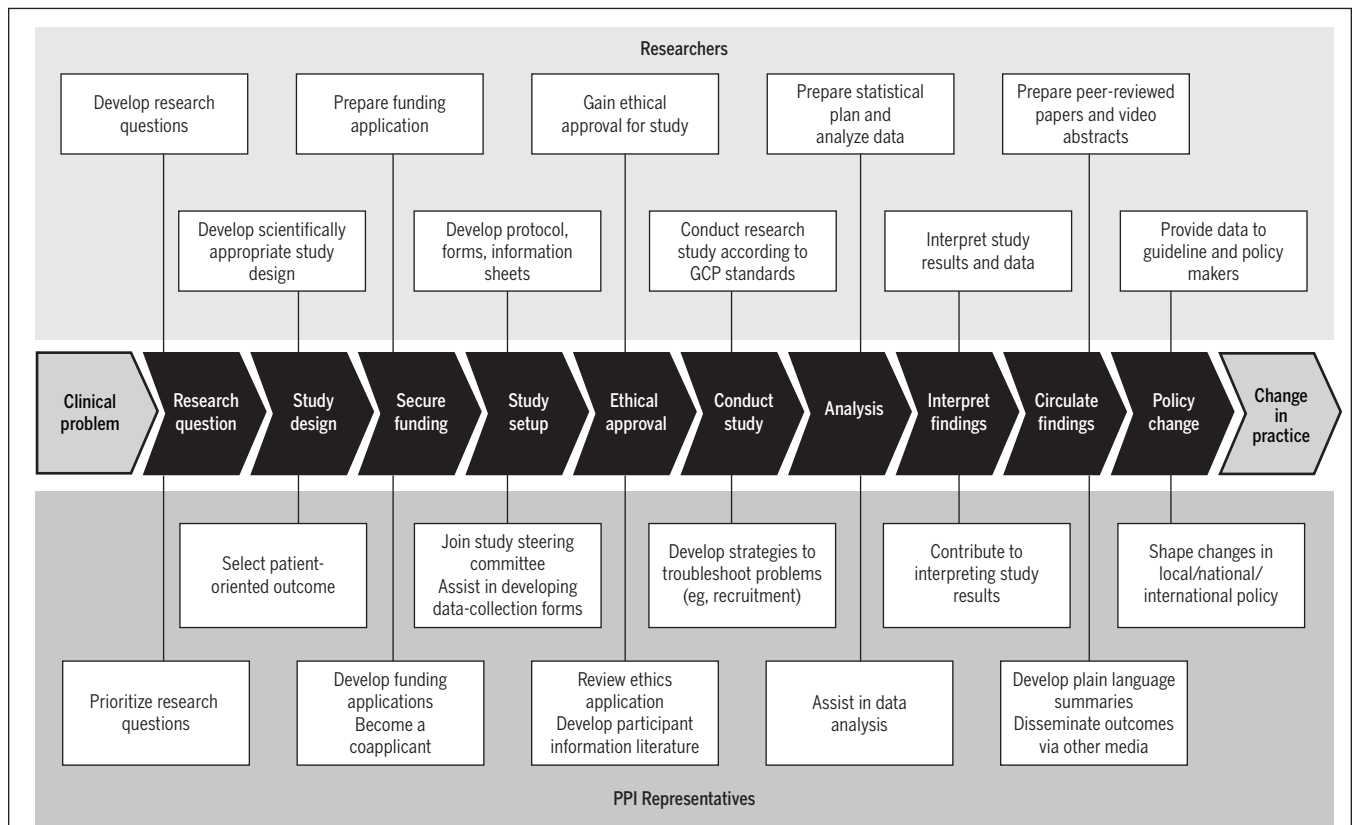


FIGURE. Patients and researchers can collaborate at every stage of the research process. Examples of complementary roles that can be assigned to patients and the public are illustrated. Abbreviations: GCP, good clinical practice; PPI, patient and public involvement. Reprinted with permission from Moss et al.¹² ©2016 Royal College of Obstetricians and Gynaecologists

“Should Money Come Into It? A Tool for Deciding Whether to Pay Patient-Engagement Participants”⁶ can help researchers propose appropriate remuneration for patient partners. This report provides a decision tool and questions for researchers and patient partners to consider in the decision-making process.

If the decision is to proceed with compensation, helpful tools to assist in budgeting include the website “budgeting for engagement”⁹ and the report “Peer Payment Standards for Short-term Engagements.”² Collectively, these tools can provide an evidence-informed and respectful foundation for developing the budget for a grant application.

Documenting Patient Partnership in Research

JOSPT requires authors to include a statement about how (if at all) patient partners were involved in the research. Two resources to guide researchers on what to report, how to report, and how much detail to include are the GRIPP2 reporting checklists¹⁷ and the article “Framework for Advancing the Reporting of Patient Engagement in Rheumatology Research Projects.”¹¹

Summary: Demystifying Patient Partnership in Research

If including patients as equal partners in health care research is increasingly regarded as “the right thing to do,”³ then it is important that researchers and patients “do it right.” The research community should be aware of, use, and share resources that support best practices in this domain. In this editorial, we highlighted a selection of resources to help

researchers and to demystify patient partnerships in research.

We encourage researchers to approach local organizations that specialize in patient engagement in research when planning a research project (eg, the Patient-Centered Outcomes Research Institute [<https://www.pcori.org/>], the website “Strategy for patient-oriented research,”⁴ and INVOLVE [<https://www.invo.org.uk/>]).

If you have additional resources, suggestions, questions, or stories about partnering with patients in research, please reach out to us via e-mail (jospt@jospt.org) or our social media channels (@JOSPT). ●

REFERENCES

1. BC SUPPORT Unit. Patient-Oriented Research Training and Learning – Primary Health Care (PORTL-PHC) online modules (for all stakeholders). Available at: <https://bcsupportunit.ca/resources/patient-oriented-research-training-and-learning-primary-health-care-portl-phc-online>. Accessed January 22, 2020.
2. Becu A, Allan L. Peer Payment Standards for Short-term Engagements. Vancouver, Canada: BC Centre for Disease Control; 2018.
3. Belton J, Hoens A, Scott A, Ardern CL. Patients as partners in research: it's the right thing to do. *J Orthop Sports Phys Ther*. 2019;49:623-626. <https://doi.org/10.2519/jospt.2019.0106>
4. Canadian Institutes of Health Research. Strategy for patient-oriented research. Available at: <https://cihr-irsc.gc.ca/e/41204.html>. Accessed January 22, 2020.
5. Can-SOLVE CKD Network. Engaging Patients in the Research Process: A Toolkit for Project Leads. Vancouver, Canada: Can-SOLVE CKD Network; 2017.
6. The Change Foundation. Should Money Come Into It? A Tool for Deciding Whether to Pay Patient-Engagement Participants. Toronto, Canada: The Change Foundation; 2015.
7. Clinical Trials Ontario. Investigator decision aid. Available at: <https://www.ctontario.ca/patients-public/resources-for-engaging-patients/investigator-decision-aid/>. Accessed January 22, 2020.

8. Clinical Trials Ontario. Patient decision aid. Available at: <https://www.ctontario.ca/patients-public/resources-for-engaging-patients/patient-decision-aid/>. Accessed January 22, 2020.
9. George & Fay Yee Centre for Healthcare Innovation. Budgeting for engagement. Available at: <https://chimb.ca/sub-sites/1-patient-engagement/?page=79-budgeting-for-engagement>. Accessed January 22, 2020.
10. George & Fay Yee Centre for Healthcare Innovation. The interactive map tool. Available at: <https://chimb.ca/sub-sites/1-patient-engagement?page=75-how-to-engage#>. Accessed January 22, 2020.
11. Hamilton CB, Leese JC, Hoens AM, Li LC. Framework for advancing the reporting of patient engagement in rheumatology research projects. *Curr Rheumatol Rep*. 2017;19:38. <https://doi.org/10.1007/s11926-017-0666-4>
12. Moss N, Daru J, Lanz D, Thangaratnam S, Khan KS. Involving pregnant women, mothers and members of the public to improve the quality of women's health research. *BJOG*. 2017;124:362-365. <https://doi.org/10.1111/1471-0528.14419>
13. PEIRS Project Team. Workbook to Guide the Development of a Patient Engagement In Research (PEIR) Plan. Richmond, Canada: Arthritis Research Canada; 2018. Available at: <https://www.arthritisresearch.ca/wp-content/uploads/2018/06/PEIR-Plan-Guide.pdf>
14. Richards DP, Jordan I, Strain K, Press Z. Patient partner compensation in research and health care: the patient perspective on why and how. *Patient Exp J*. 2018;5:art 2. <https://doi.org/10.35680/2372-0247.1334>
15. Snow B, Tweedie K, Pederson A, Shrestha H, Bachmann L. Patient Engagement: Heard and Valued—A Handbook for Meaningful Engagement of Patients That Have Not Traditionally Been Heard in Healthcare Planning. Surrey, Canada: Fraser Health Authority; 2013.
16. Staley K, Hanley B, Faulkner A. Developing Training and Support for Public Involvement in Research. Eastleigh, UK: INVOLVE Coordinating Centre; 2012.
17. Staniszewska S, Brett J, Simera I, et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *Res Involv Engagem*. 2017;3:13. <https://doi.org/10.1186/s40900-017-0062-2>