



2023 Patient and Public Health Research Topic Priority-Setting Exercise Teams Orientation Meeting

Thursday, January 25th, 2024
3:00 PM – 4:00 PM EST





Nominated Principal Investigator

Andrea C. Tricco MSc, PhD is a scientist and director of the Knowledge Synthesis Team in the Knowledge Translation Program at St. Michael's Hospital of Unity Health Toronto. She is an Associate Professor at the University of Toronto in the Dalla Lana School of Public Health & Institute of Health Policy, Management, and Evaluation. She is also Co-Director & Adjunct Associate Professor for the Queen's Collaboration for Health Care Quality, Joanna Briggs Institute Centre of Excellence at Queen's University. Her research program focuses on advancing the science of knowledge synthesis and responding to information needs of decision-makers (including policy-makers, healthcare providers, and patients) through knowledge synthesis. Andrea currently holds a Tier 2 Canada Research Chair in Knowledge Synthesis.



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Land Acknowledgement



The SPOR Evidence Alliance Central Coordinating Office is located on land now known as Tkaronto (Toronto). Tkaronto is the traditional territory of many groups, including the Mississaugas of the Credit and the Chippewa/ Ojibwe of the Anishnaabe Nations; the Haudenosaunee, and the Wendat. It is now home to many diverse First Nations, Inuit and Métis peoples. We also acknowledge that Tkaronto is covered by Treaty 13 with the Mississaugas of the Credit and The Dish with One Spoon treaty between the Anishinaabe, Mississaugas and Haudenosaunee that connected them to share the territory and protect the land. All Indigenous Nations and peoples, Europeans and newcomers, have been invited into this treaty in the spirit of peace, friendship and respect.

We would like to honour the Elders and Knowledge Keepers, both past and present, and are committed to continuing to learn and respect the history and culture of the communities that have come before and presently reside here.

We acknowledge the harms of the past and present, and we dedicate ourselves to work with and listen to First Nations, Inuit and Métis communities in the spirit of reconciliation and partnership.



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Agenda

TIME	AGENDA ITEMS
3:00 PM – 3:05 PM (5 Minutes)	Ice Breaker Speaker: Andrea Tricco
3:05 PM – 3:25 PM (20 Minutes)	Considerations for Co-leadership and Partnership in Research Speaker(s): Andrea Tricco
3:25 PM – 3:45 PM (20 Minutes)	Resources, Work Plan and Budget Preparation, Administration Speaker: Wasifa Zarin
3:45 PM – 4:00 PM (15 Minutes)	Question Period

Ice Breaker

Type in the chat box ONE thing you are looking forward to this year?

Tapez dans la boîte de discussion UNE chose que vous attendez avec impatience cette année?



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Key Terminology

<p>Knowledge Synthesis</p>	<p>An umbrella term used to describe a range of research methods used to synthesize information from scientific literature.</p> <p>Knowledge synthesis uses objective, rigorous and transparent methods to bring together information from multiple studies that have looked at the same topic to make sense of their findings</p>
<p>Patient¹</p>	<p>The Canadian Institutes of Health Research (CIHR) uses patient to be inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends.</p>
<p>Public (citizen)²</p>	<p>Any interested representatives of the general public, consumers of health services, patients, caregivers, advocates and representatives from affected community and voluntary health organizations.</p>
<p>Patient and Public Engagement</p>	<p>Meaningful (<i>not tokenistic</i>) and active collaboration in governance, priority setting, conducting research, and knowledge translation to ensure patient and public voices and priorities play a role in shaping the evidence and care they receive.</p>

1. Strategy for Patient-Oriented Research - Patient Engagement Framework. Available from <https://cihr-irsc.gc.ca/e/48413.html>
2. CIHR Jargon Buster. Available from <https://cihr-irsc.gc.ca/e/48952.html>








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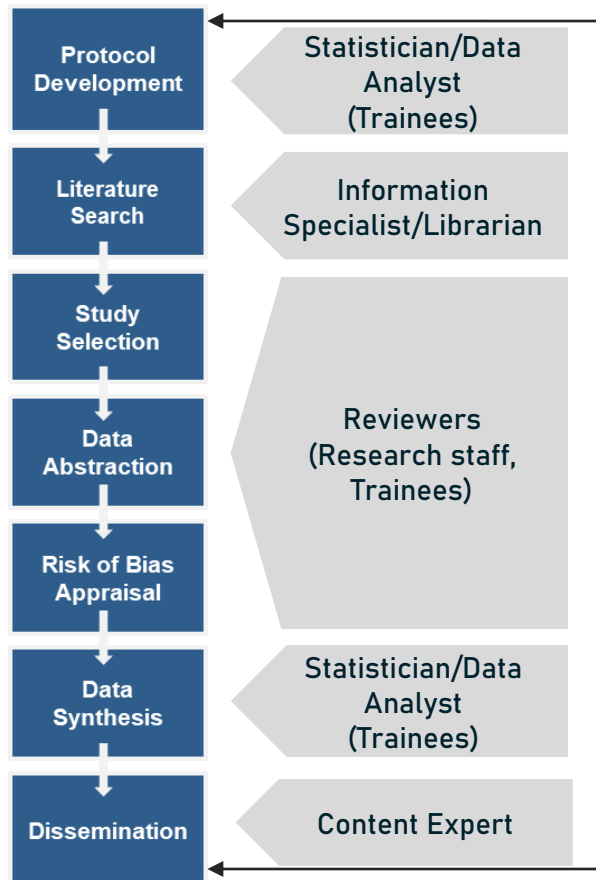
Spectrum of Patient and Public Engagement

	Inform	Consult	Discuss	Engage	Partner
					
What	Receive easy to understand, objective, and balanced information.	Provide feedback on research direction, progress, outcomes, analysis and interpretation.	Two-way information exchange and conversations.	Engage in each aspect of the decision in research and research-related activities	Shared decision-making responsibilities
How	<ul style="list-style-type: none"> • Plain language summary • Infographic 	<ul style="list-style-type: none"> • 1-on-1 interviews • Surveys • Focus groups • Workshop 	<ul style="list-style-type: none"> • Open forum • Large group meetings 	<ul style="list-style-type: none"> • Advisory committee • Consensus-building • Working group 	<ul style="list-style-type: none"> • Public/patient representation on decision-making committees
Goal	Communication information with no decision influence	Listening with no commitment to integrate feedback in decisions.	Dialogue to influence and inform decisions.	Engaging to shape final decisions.	Partnering to co-develop final decisions.

In co-leadership, patients & public steer the project direction with their researcher co-lead

How can we co-lead in knowledge synthesis?

Let's begin by taking a look at the different roles within a knowledge synthesis



Methodologist (scientific lead)

- Advanced methods knowledge, develops the research protocol, directs all steps of the review.

Project Coordinator (support)

- Leads the coordination of the review, resource management, primary administrative and communications support

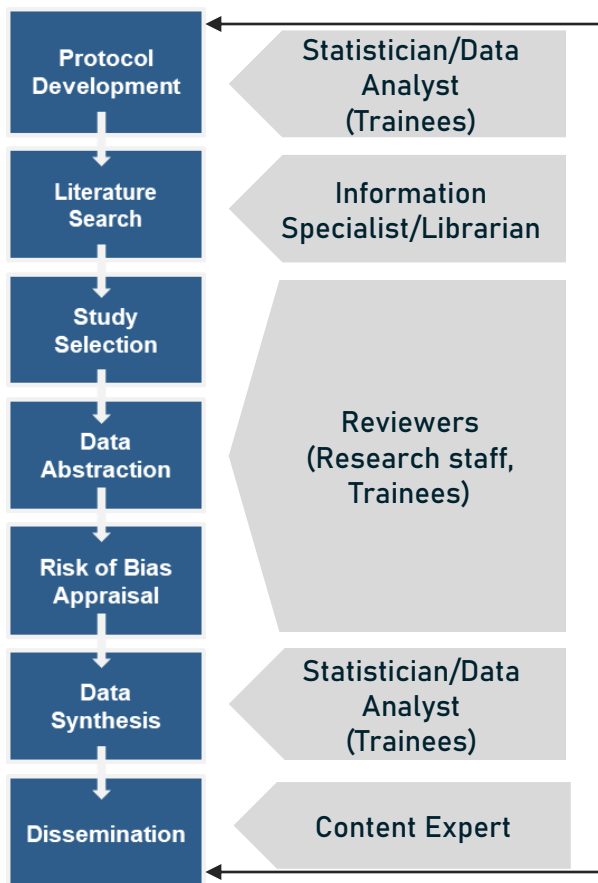
Content Expert(s) (advisory)

- Could be a patient/public, clinician, health system manager or policy-maker with subject matter expertise or lived experiences providing input in key stages (e.g., protocol development, interpretation, dissemination)



How can we co-lead in knowledge synthesis? (continued...)

Patient partner co-leads drive the research direction through their lived experience



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- Could be a clinician, health system manager or policy-maker with subject matter expertise providing input in key stages (e.g., protocol development, interpretation, dissemination)

Patient Partner (co-lead)

- ✓ Provides subject matter expertise through lived experience.
- ✓ Co-develop the research question, workplan and budget.
- ✓ Provide input on the search strategy
- ✓ Provide input on the study selection criteria
- ✓ Provide input on the data abstraction form.
- ✓ Provide input on the data analysis and presentation plan.
- ✓ Co-author all dissemination products.

Patient partners are not expected perform research staff duties



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Guidance on Partnership for Patients/Public

- The SPOR Evidence Alliance has developed a guidance document to support patient and public partners in engaging in health research in a meaningful and collaborative way.
- The document includes:
 - Key terminology
 - Overview of how patient and public partners can be engaged
 - Roles for patient and public partners

Patient and Public Partner Engagement in Research



Who are patients?

The Canadian Institutes of Health Research refers to patients with an inclusivity lens. Patients include not only those individuals who have personal experience of a health issue, yet also informal caregivers, including family and friends.¹

Who are citizens (public)?

The Canadian Institutes of Health Research defines citizen as any interested representatives of the general public, consumers of health services, patients, caregivers, advocates and representatives from affected community and voluntary health organizations.² We use citizen and public interchangeably.

What is patient and public engagement in health research?

Meaningful and active collaboration in decision-making, setting priorities, conducting research, and sharing (disseminating) research findings to ensure that the perspectives of patients and members of the public are considered in research priorities and in shaping the evidence and care they receive.

How will I be engaged?

Patient and public partner engagement exists along a spectrum, which includes inform, consult, collaborative, empower.³ Each of these engagement approaches provides unique yet inclusive opportunities for patient and public engagement, as shown below.


	Informed	Consulted	Involved	Collaborative	Empowered
What	Receive easy to understand, objective, and balanced information.	Provide feedback on research direction, progress, outcomes, analysis and interpretation.	Work closely throughout the research process so that your perspectives are consistently understood and considered	Engage in each aspect of the decision in research and research-related activities	Take on final decision-making responsibilities
How	<ul style="list-style-type: none"> • Plain language summary • Infographic 	<ul style="list-style-type: none"> • 1-on-1 interviews • Surveys • Focus groups • Workshop 	<ul style="list-style-type: none"> • Working group • Regular meetings 	<ul style="list-style-type: none"> • Advisory committee • Consensus-building • Participatory decision-making 	<ul style="list-style-type: none"> • Delegated decision

https://sporevidencealliance.ca/wp-content/uploads/2023/02/9.-SPOREA_Patient-and-Public-Engagement-for-Patient-Partners.pdf


Guidance of Partnership for Researchers

- The SPOR Evidence Alliance has developed a guidance document to support researchers in engaging patient and public partner members as partners in research.
- The document includes tips on:
 - How and when to meaningfully engage patient and public partners.
 - Budgeting for patient and public engagement.
 - Links to planning, communication, and evaluation.

Patient and Public Partner Engagement in Research



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What does patient and public partnership look like?

What it is?	What it is not?
✓ Working with patient and public partners to set the research agenda	✗ Enrolling patient and public partners as a study participant to test an intervention
✓ Working with patient and public partners to conceptualize the research question and design	✗ Interviewing patient and public partners in a focus group or other qualitative study designs
✓ Working with patient and public partners to develop key messages based on the findings	✗ Observing a population to collect information on health-related outcomes

How to create a positive environment for patient and public partner engagement?

Be curious and enthusiastic	Express support
Be open	Invite others to talk
Be genuine	Keep atmosphere calm/reduce tension, and encourage others
Share information, experiences, and ideas	Listen actively
Elaborate on each others' ideas	Summarize/paraphrase to check for understanding
Acknowledge contributions	Disagree in an agreeable way

https://sporevidencealliance.ca/wp-content/uploads/2021/08/7.-SPOREA-COVIDEND_Patient-and-Public-Engagement-for-Researchers.pdf

What is a Positive Environment for Patient and Public Engagement?



- Open communication
- Mutual respect and trust between patient partners and researchers
- Openness of researchers to feedback and collaboration
- An accountable space that brings different perspectives to the table
- Reciprocal partnerships where both parties benefit
- Flexibility in compensation, collaboration and participation
- Summarizing/paraphrasing to check for understanding

Gonzalez M, Ogourtsova T, Zerbo A, Lalonde C, Spurway A, Gavin F, Shikako K, Weiss JA, Majnemer A. Patient engagement in a national research network: barriers, facilitators, and impacts. *Res Involv Engagem.* 2023 Mar 8;9(1):7. doi: [10.1186/s40900-023-00418-5](https://doi.org/10.1186/s40900-023-00418-5)



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Tips for Effective Communication and Building Relationships

- Building trust – taking time to establish mutually respectful relationships
- Being transparent – making sure everyone is aware of all the relevant information and what each person’s role is on the team
- Creating an accountable space – being aware of the power dynamics that may exist and work to dismantle these
- Defining roles – being clear about what you are expecting/seeking, but be flexible and open to discussion and change
- Sharing regular updates – being clear on how to send updates (e.g., phone, email, meetings) and frequency of updates (e.g., weekly, biweekly)



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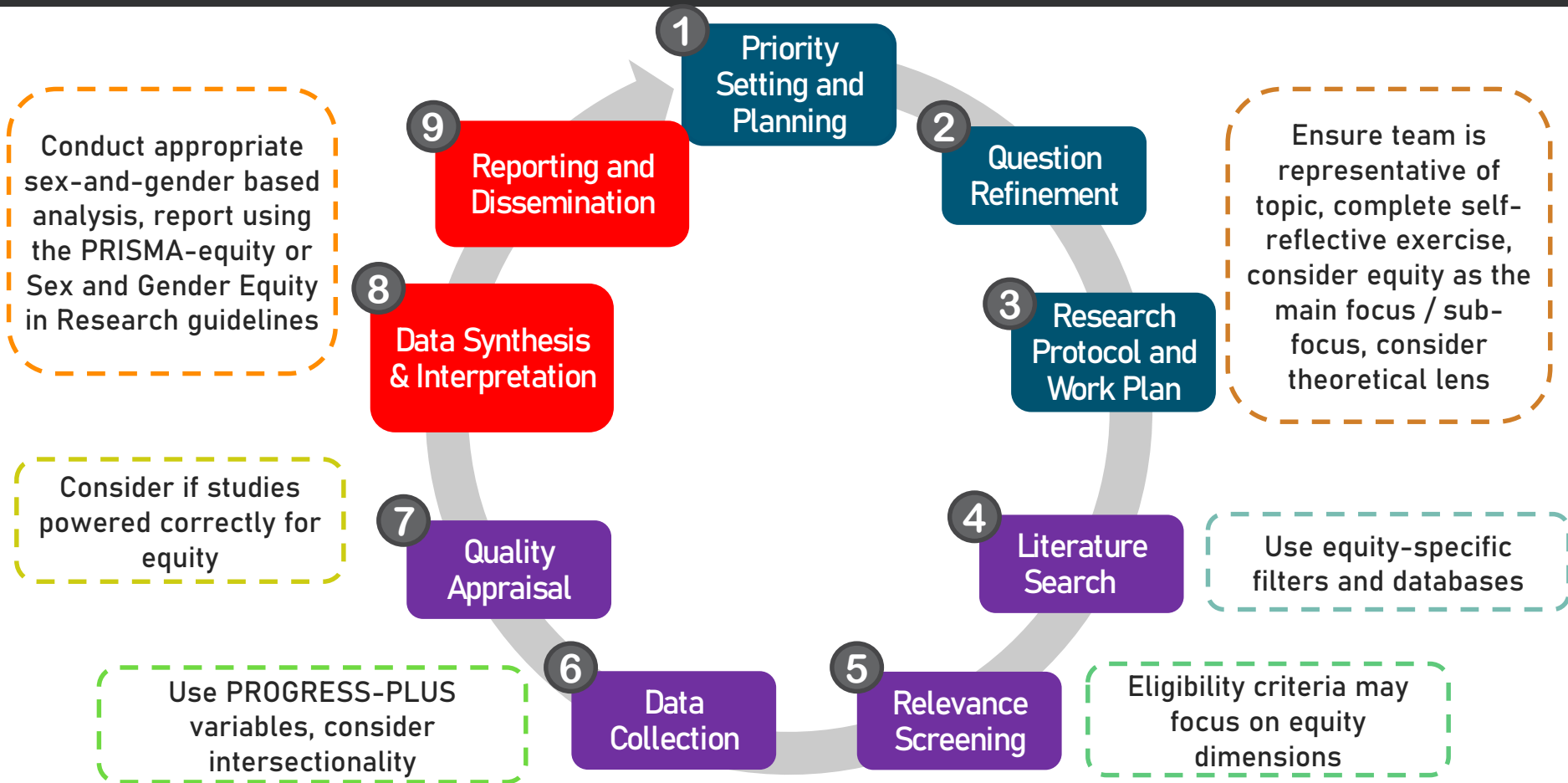
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How can we Embed EDI in Knowledge Synthesis?



Dewidar, Submitted to J Clin Epi, 2022; SPOREA Work Plan Template; PROGRESS Plus; SAGER Guidelines; PRISMA Equity

Intersectionality in Research

Strengthening the Integration of Intersectionality Theory in Health Inequality Analysis (SIITHIA) checklist

How to cite this document

Public Health Agency of Canada. How to integrate intersectionality theory in quantitative health equity analysis? A rapid review and checklist of promising practices. Ottawa, ON: PHAC; 2022.

Study/ Report section	Item	Promising practice	✓	
Introduction				
Background/ Rationale	1.	Provide a well-referenced definition of intersectionality theory, which alludes to its central principles*		
	2.	Describe inequalities that are consistently observed between population groups, and that are assumed to be avoidable, as "unjust/unfair" and requiring action.		
	3.	Describe the known determinants of the outcome of interest that operate at, and above, the individual level.		
	4.	State and describe underlying assumptions underpinning the study, including a reflexivity* or positionality* statement from the research team.		
	5.	Integrate and summarize evidence developed through research and analysis that involve populations that are affected by the inequalities under study or forms of knowledge that have been under-represented in public health practice.		
Objectives	6.	Draw on, and describe literature and complementary theoretical frameworks (including those from outside the field of health sciences), as needed, to justify and frame the research questions and objectives.		
	7.	Explore one or more objectives relevant to intersectionality theory, including:		
		a) Assessing effect modification or interaction between two or more measures capturing axes of marginalization, in determining health and social outcomes and inequalities.		
		b) Exploring to what extent observed health and social inequalities are explained by a given sub-set of characteristics or factors at the individual, community, or societal level.		
		c) Assessing changes in determinants, outcomes and inequalities therein (i.e., associations between determinants and outcomes), over time and across contexts.		
	8.	Engage with people and populations that are affected by the inequalities under study when establishing research questions and objectives.		
	Methods			
		9.	Engage with populations that are affected by the inequalities under study, when designing the methods.	
Data source(s)		Where possible and relevant to the research question:		
	10.	Collect or use data that allow a comparison of outcomes across intersecting social positions*.		
	11.	Collect or use data that allow for an assessment of heterogeneity in determinants and outcomes* across social or spatial units of aggregation (e.g., schools, regions).		

- Useful tool for incorporating intersectionality in research
- Produced by the Public Health Agency of Canada

<https://www.canada.ca/content/dam/phac-aspc/documents/services/publications/science-research-data/how-integrate-intersectionality-theory-quantitative-health-equity-analysis/phac-siithia-checklist.pdf>



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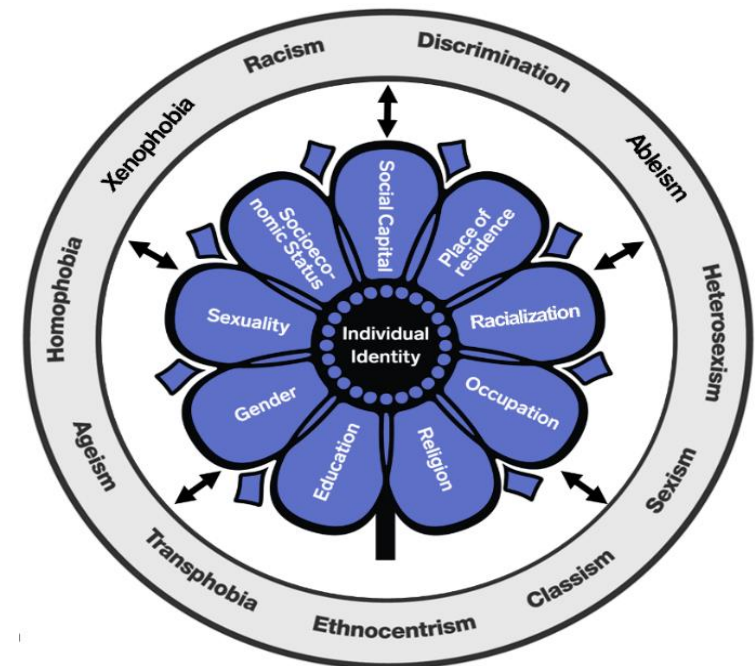
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How can we root our research in (EDI) principles?

- Co-create EDI values/guiding principles with the team
- Co-create terms of reference for the team
- Co-create policies with the team (e.g., patient partner appreciation, COIs)

Complete a **self-reflective exercise** (not to be shared) to think about your:

- own lived experience
- advantage or disadvantage, and
- position on the team



<https://sporevidencealliance.ca/about/governance-structure/>

<https://sporevidencealliance.ca/about/policies-procedures/>

https://sporevidencealliance.ca/wp-content/uploads/2021/08/4.-SPOREA_Reflective-EDI-Exercise-UPDATED.pdf



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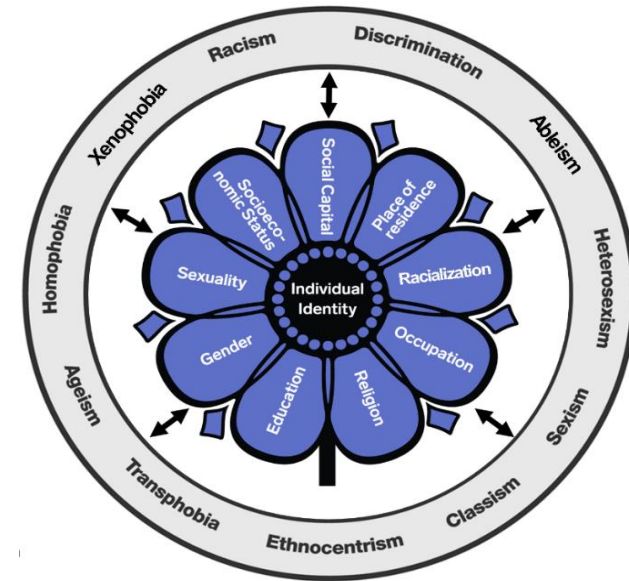
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Why Complete a Self-Reflective Exercise?

- Helps recognize the importance of individuals' social identities within the greater context of systems and structures of power that reflect macro systems of privilege and oppression.
- Some things to consider through this exercise:
 - Reflect on whether everyone who could be on the team has been asked if and how they would like to be involved. Think about how different perspectives that represent a range of intersecting categories have been examined.
 - Does your team reflect the makeup of the patient, community, and health care providers affected by the project topic?
 - Who is the patient, healthcare provider, and community affected by the project topic area? What would they want to get out of the project? How do you plan to get them involved?



https://sporevidencealliance.ca/wp-content/uploads/2021/08/4.-SPOREA_Reflective-EDI-Exercise-UPDATED.pdf



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Barriers to Patient and Public Engagement

- Tokenism
- Not taking the time to build trust and respect
- Lack of understanding of each person's motivations and perspectives
- Conflicting patient/public and researcher priorities
- Lack of preparation and training in research partnership
- Not setting expectations before starting an engagement
- Being the “only” patient or public partner on the team
- Power imbalances between researchers and patient or public partners
- Challenges related to ethnic, cultural, social, and organizational differences

Gonzalez M, Ogourtsova T, Zerbo A, Lalonde C, Spurway A, Gavin F, Shikako K, Weiss JA, Majnemer A. Patient engagement in a national research network: barriers, facilitators, and impacts. *Res Involv Engagem*. 2023 Mar 8;9(1):7. doi: [10.1186/s40900-023-00418-5](https://doi.org/10.1186/s40900-023-00418-5).



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Strategies to Improve Inclusivity and Diversity of Patients in Research Governance



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BLOG POST

Strategies to Improve Inclusivity and Diversity of Patients in Research Governance

A PCORI-funded learning network recently outlined key challenges and promising practices for improving the diversity and inclusion of patient representatives in research governance.

POSTED

Mar 01, 2022

BY

Elizabeth Cope, Ph.D.,

M.P.H. Prashila Dullabh,

M.D. Michelle Johnston-

Fleece, M.P.H. Claudia

Grossmann, Ph.D.

HSR Resources & Methods

Research Ethics & Governance

Patient & Consumer Engagement

Health Equity

SHARE



Partnership with communities and diverse patient representation are critical to earning and maintaining trust in the research and health care enterprises. Furthermore, diverse patient representation in research – where both research partners and study participants reflect the population being studied – is an essential ingredient for enhancing study conduct and ensuring not only study validity, but equitable uptake of and access to novel practices and therapies. This post outlines strategies for the engagement of diverse patients and caregivers in research governance, defined as “the processes, structures, and traditions that determine how power is exercised, how stakeholders have their say, how decisions are taken, and how decision-makers are held to account.” A previous blog post explored creating mutual benefit for researchers and research participants as a complementary mechanism to help achieve more inclusive patient representation in research.

Patients help shape the research process and hold the research enterprise (i.e., researchers, life sciences industry, policymakers, and other stakeholders) accountable for serving and protecting the interests of affected communities through their participation in governance bodies and activities. Diverse and inclusive governance structures can help center equity, align research priorities and aims, improve feasibility of conducting studies, identify relevant outcomes, and enhance uptake of findings. In order to be inclusive and representative, research governance should reflect the diversity of those affected by the condition or practice under study, with attention to race, ethnicity, gender identity, age, socioeconomic status, and disability.

Related Content

PROFESSIONAL DEVELOPMENT

Current Controversies and Emerging Methods

Jul 20, 2021

BLOG POST

The Relationship between Health and Place: Expanding Use of Place-Based Disadvantage Indices Beyond COVID-19

Nov 09, 2021

BLOG POST

Engagement Science: Introducing Inclusive Research Practices & Potential Impacts

Jan 08, 2019

- Evidence suggests the most under served populations are not engaged in research
- Important to consider the diversity of the patients you are engaging with.
- This provides some guidance on increasing inclusivity and diversity of patient partners.

<https://academyhealth.org/blog/2022-03/strategies-improve-inclusivity-and-diversity-patients-research-governance> !



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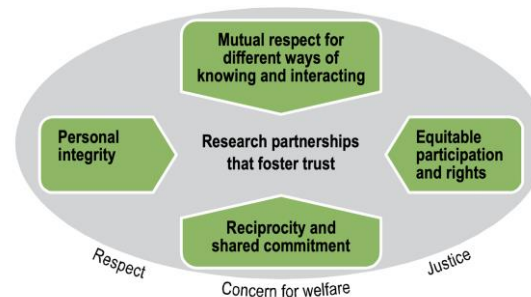
Ethics Guidance for Developing Partnerships with Patients and Researchers (EGDPPR)



https://cihr-irsc.gc.ca/e/documents/ethics_guidance_partnerships-en.pdf

- EGDPPR has identified four core considerations for ethical partnerships:
 - ✓ mutual respect for different Ways of Knowing and interacting
 - ✓ equitable participation and rights
 - ✓ reciprocity and a shared commitment to producing relevant research results
 - ✓ personal integrity

Figure 1. Core considerations for ethical research partnerships



Available Resources for Research Teams on the SPOR Evidence Alliance Website

We have developed a series of templates and guidance documents for our research teams: <https://sporevidencealliance.ca/resources-for-research-teams/>

■ Guidance Tools and Resources

- [Reflective Equity, Diversity and Inclusion Exercise](#)
- [Guidance on Engaging Patient and Public Partners in Research as a Researcher](#)
- [Guidance on Being a Patient and Public Partner in Research](#)
- [Resource List for Rapid Review Methods Guidance](#)
- [Right Review Tool](#)
- [Menu of Knowledge Dissemination Approaches](#)

■ Templates

- [Work Plan Template](#)
- [Study Budget Template](#)
- [Progress Update Template](#)
- [Report Template](#)
- [Research Brief Template](#)
- [Plain Language Summary Template](#)



Research Program Manager



Wasifa Zarin (MPH) is the Program Manager of the Strategy for Patient-Oriented Research (SPOR) Evidence Alliance, based at the St. Michael's Hospital site of Unity Health Toronto. Wasifa earned her Master of Public Health in epidemiology from the Dalla Lana School of Public Health at the University of Toronto. With a keen interest in the science of evidence synthesis and its uptake in the decision-making process and has contributed to a range of knowledge products for decision-makers locally (Ontario Drug Policy Research Network), nationally (Health Canada), and internationally (World Health Organization). Wasifa oversees the operations, communications, and strategic development of the SPOR Evidence Alliance.



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Project Kick-Off Steps

- Meet with your project co-leads to get to know each other
- Set clear expectations of co-leadership and partnership (e.g., terms of reference, roles and responsibilities matrix)
 - Reflect on whether everyone who could be on the team has been asked if and how they would like to be involved.
- Discuss project goals, timelines and deliverables:
 - Work plan and budget due on **February 16, 2024**
 - Quarterly project updates to the central coordinating office
 - Manuscript submission at the end of the project
 - 1-page plain language summary at the end of the project
 - Project to be completed by **March 31, 2025**

Watch the Fireside Chat on Patient/Public Partner Driven Research with Partnership and Co-Leadership to learn more about the co-leads' experience from the pilot initiative: <https://youtu.be/EcFlSU7bddE>

Project Kick-Off Steps (continued...)

- **Work plan and budget must be co-developed by the researcher and patient partner co-leads**
 - Submitted work plan and budget will be reviewed by a member of the SPOR Evidence Alliance with expertise in knowledge synthesis and a member of the central coordinating office
- **All feedback will be shared with the teams on **March 8, 2024****
 - All required changes to the work plan and budget to be submitted within 1-week (**March 15, 2024**)
- **Final work plan and budget will be used to set up funding agreement between the **Unity Health Toronto** and **project team's host institution.****
 - As a CIHR-funded research initiative, we can only transfer funds to CIHR eligible institutions authorized to administer funds (e.g., Canadian University, academic research centres, teaching hospitals)
 - See full list here: <https://cihr-irsc.gc.ca/e/36374.html>

Tips for Work Plan Preparation

■ Project Team

- Does the team include adequate number of research and/or technical staff?
- Is there a scientific librarian involved who can review and support the literature review process?
- **EDI:** Does your team reflect the makeup of the patient, community, and health care providers affected by the project topic?

■ Research Question

- Is the research question clear? Are PICOST (Population, Intervention, Control, Outcomes, Study Design, Time) elements or equivalent clearly defined?
- Is the research strategy clearly defined?
- **EDI:** Consider equity as the main focus / sub-focus, consider EDI theoretical lens as applicable

■ Research Approach

- Is the methodological approach appropriate to answer the research question? Use [Right Review Tool](#), for support if needed.

Tips for Work Plan Preparation (continued...)

■ Methods Details

- Sources of data – please list all databases and other sources of data (e.g., bibliographic databases such as MEDLINE, grey literature sources, focus groups, key informant interviews).
 - **EDI:** Consider equity-specific filters and databases
- Data collection – provide details on how information will be searched and who will perform the search, data elements to be collected, who will be responsible for collecting the data, will specific training be required prior to data collection, specific forms or tools to be used to collect the data, whether the study requires REB approval, how will information be verified for accuracy, where and how information will be stored.
 - **EDI:** Use PROGRESS-PLUS variables, consider intersectionality
- Data analysis and synthesis – please describe how data will be analyzed, interpreted, and presented (e.g., tables, graphs)
 - **EDI:** Conduct appropriate sex-and-gender based analysis, report using the PRISMA-equity or Sex and Gender Equity in Research guidelines



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Tips for Work Plan Preparation (continued...)

- **Knowledge User/Patient Partner Engagement Plan**
 - We encourage each project to include **two patient/public partners** (one lead and one support). If you have pre-existing relationships with relevant patients/citizens, then feel free to include them and if not, we are happy to match you with patient/citizen partners who have the relevant lived experience for the research topic.
 - Patient/public partner contributions are compensated per our [Patient Partner Appreciation Policy](#)** . As of January 1st, 2024 our hourly rate has changed to \$40/hour.
 - Patient/public partners are included as coauthors on knowledge products (e.g., report, publications).
 - Communication with patient/citizen partners is of utmost importance and we recommend letting them know expectations and timelines advance.
 - Ensure project budget allocates sufficient funds for co-leadership and partnership



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Patient/Public Engagement Template

Patient and Public Engagement Planning Template



Instructions: Patient engagement is about meaningful engagement of patients/public in the research process (not just as subjects of research). This template has been designed to assist with the development of Patient/Public Engagement plans for health research but can be used to plan other projects. Begin with box #1 and work through to box #10 to address the components of the engagement planning process. Select all that apply and discuss the template with your research team (including your patient/public partners!).

(1) WHY¹

Why do you want to involve people with lived/living experience?

- Gathering ideas for new research areas based on the needs of people with lived/living experience of the area you are studying
- Ensuring research is focused on the interests and concerns of people with lived/living experience of the condition and/or system being studied, and that money and resources are used efficiently
- Ensuring transparency and accountability
- Ensuring that the methods are acceptable and sensitive to the situations of potential research participants
- Making the language and content of information more appropriate and accessible
- Increasing participation in research
- Collecting data with and for patients/members of the public
- Taking diverse perspectives into account when analyzing data
- Taking diverse perspectives into account when making decisions
- Increasing the dissemination and uptake of research findings in practice or policy
- Meeting the requirements of funders
- _____

Consider: If there is a useful role for patient/public partners. Are there options to choose from or are decisions already made?

(2) WHO¹

Who do you need to involve?

- In-patients
- Out-patients
- Former patients
- Caregivers
- Family
- Public
- Patient support group
- Patient organization
- Community group
- People who have experience with a specific condition, service or treatment
- _____

Consider: The broad and different views and experiences you will need. Engage people as “independent citizens” not as “experts” or representatives of specific stakeholder groups.

Tip: Involve more than one person. This allows you to involve different people at different stages of the research process, and allows people to choose how they want to be involved.

- Developed by the NL SUPPORT Unit
- Includes a framework to help you map out the why, who, when, what, how of your engagement plan including budget considerations.
- Available here: <https://nlsupport.ca/wp-content/uploads/2022/07/Patient-and-Public-Engagement-Planning-Template-2023.pdf>



Patient Engagement in Research Scale

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DOI: 10.1111/hex.13227

ORIGINAL RESEARCH PAPER

WILEY

Shortening and validation of the Patient Engagement In Research Scale (PEIRS) for measuring meaningful patient and family caregiver engagement

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Abstract

Objective: To shorten the Patient Engagement In Research Scale (PEIRS) to its most essential items and evaluate its measurement properties for assessing the degree of patients' and family caregivers' meaningful engagement as partners in research projects.

Methods: A prospective cross-sectional web-based survey in Canada and the USA, and also paper-based in Canada. Participants were patients or family caregivers who had engaged in research projects within the last 3 years, were ≥ 17 years old, and communicated in English. Extensive psychometric analyses were conducted.

Results: 119 participants: 99 from Canada, 74 female, 51 aged 17-35 years and 50 aged 36-65 years, 60 had post-secondary education, and 74 were Caucasian/white. The original 37-item PEIRS was shortened to 22 items (PEIRS-22), mainly because of low inter-item correlations. PEIRS-22 had a single dominant construct that accounted for 55% of explained variance. Analysis of PEIRS-22 scores revealed the following: (1) acceptable floor and ceiling effects ($< 15\%$), (2) internal consistency (ordinal $\alpha = 0.96$), (3) structural validity by fit to a Rasch measurement model, (4) construct validity by moderate correlations with the Public and Patient Engagement Evaluation Tool, (5) good test-retest reliability ($ICC_{2,1} = 0.86$) and (6) interpretability demonstrated by significant differences among PEIRS-22 scores across three levels of global meaningful engagement in research.

Conclusions: The shortened PEIRS is valid and reliable for assessing the degree of meaningful patient and family caregiver engagement in research. It enables standardized assessment of engagement in research across various contexts.

Patient or public contribution: A researcher-initiated collaboration, patient partners contributed from study conception to manuscript write-up.

- Quality of partnership can be assessed using the Patient Engagement In Research Scale
- There is a 22-item short form (PEIRS-22)
- Helpful Patient Engagement Evaluation tool
- Workbook to plan engagement based on the PEIRS framework in available here:
https://www.arthritisresearch.ca/wp-content/uploads/2018/06/PEIR-Plan-Guide.pdf?_ga=2.70969296.1909033060.1667851335-2007855859.1663196399

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Reporting Patient Engagement

RESEARCH METHODS AND REPORTING

OPEN ACCESS

GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research

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Additional material is published online only. To view please visit the journal online.

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GRIPP2 (short form and long form) is the first international guidance for reporting of patient and public involvement in health and social care research. This paper describes the development of the GRIPP2 reporting checklists, which aim to improve the quality, transparency, and consistency of the international patient and public involvement (PPI) evidence base, to ensure that PPI practice is based on the best evidence

ABSTRACT

BACKGROUND
While the patient and public involvement (PPI) evidence base has expanded over the past decade, the quality of reporting within papers is often inconsistent, limiting our understanding of how it works, in what context, for whom, and why.

OBJECTIVE
To develop international consensus on the key items to report to enhance the quality, transparency,

and consistency of the PPI evidence base. To collaboratively involve patients as research partners at all stages in the development of GRIPP2.

METHODS
The EQUATOR method for developing reporting guidelines was used. The original GRIPP (Guidance for Reporting Involvement of Patients and the Public) checklist was revised, based on updated systematic review evidence. A three round Delphi survey was used to develop consensus on items to be included in the guideline. A subsequent face-to-face meeting produced agreement on items not reaching consensus during the Delphi process.

RESULTS
143 participants agreed to participate in round one, with an 86% (123/143) response for round two and a 78% (112/143) response for round three. The Delphi survey identified the need for long form (LF) and short form (SF) versions. GRIPP2-LF includes 34 items on aims, definitions, concepts and theory, methods, stages and nature of involvement, context, capture or measurement of impact, outcomes, economic assessment, and reflections and is suitable for studies where the main focus is PPI. GRIPP2-SF includes five items on aims, methods, results, outcomes, and critical perspective and is suitable for studies where PPI is a secondary focus.

CONCLUSIONS
GRIPP2-LF and GRIPP2-SF represent the first international evidence based, consensus informed guidance for reporting patient and public involvement in research. Both versions of GRIPP2 aim to improve the quality, transparency, and consistency of the international PPI evidence base, to ensure PPI practice is based on the best evidence. In order to encourage its wide dissemination this article is freely accessible on *The BMJ* and *Research Involvement and Engagement* journal websites.

The EQUATOR network has developed high standard reporting guidelines such as the CONSORT (Consolidated Standards of Reporting Trials) statement and the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) statement enhancing the quality of research reporting, but no guidance has been developed specifically for the reporting of patient and public involvement (PPI). This prompted the development of the original Guidance for Reporting Involvement of Patients and the Public (GRIPP), which tackled inconsistent reporting by helping researchers, patients, carers, and the public to improve the quality, consistency, and transparency of PPI reporting, to strengthen the

LAY SUMMARY

Patient and public involvement in health and social care research is increasingly important, helping to ensure that the research focuses on issues relevant to patients and the public. A wide variety of research papers with public involvement has been published over the past decade, yet many of these papers give little information about how members of the public were involved and what the result of this involvement was. This means that learning from these studies is limited. Working closely with patients and the public, we have developed guidance for people writing about public involvement to suggest what details to report. We carried out a thorough assessment of studies in this area and used a Delphi survey to ask 143 people who are knowledgeable about this topic for their opinions about what should be included in the guidance. The Delphi method consists of a series of questionnaires over a specific time period to find out whether there is agreement among experts about the topic under discussion. We found strong agreement on a number of issues to include in the guidance from the 112 people who completed three rounds of Delphi questionnaires. We also held a one day meeting to find out whether any additional issues for which we hadn't reached agreement should be included in the guidance.

As a result of this three stage project, we developed two versions of the guidance, a short version of the guidance (GRIPP2-SF), which can be used when reporting public involvement in any study, and a long version (GRIPP2-LF) to use when the study is mainly about public involvement in research. Our aim in developing this guidance is to promote good quality reporting of public involvement, to inform good practice and create effective public involvement.

thebmj | *BMJ* 2017;358:j3453 | doi:10.1136/bmj.j3453

BMJ: first published as 10.1136/bmj.j3453 on 2 August 2017. Downloaded from <http://www.bmj.com/> on 20 September 2022 at University of Toronto Libraries AT/IC. Protected by copyright.

Guidance for Reporting Involvement of Patients and the Public (GRIPP-2) reporting checklist:

- A structured tool to report on how and where patient partners were engaged in the research project that is being reported
- The Short-Form of the tool was deemed more user-friendly and useful than the long-form
- Available here: <https://www.bmj.com/content/358/bmj.j3453>



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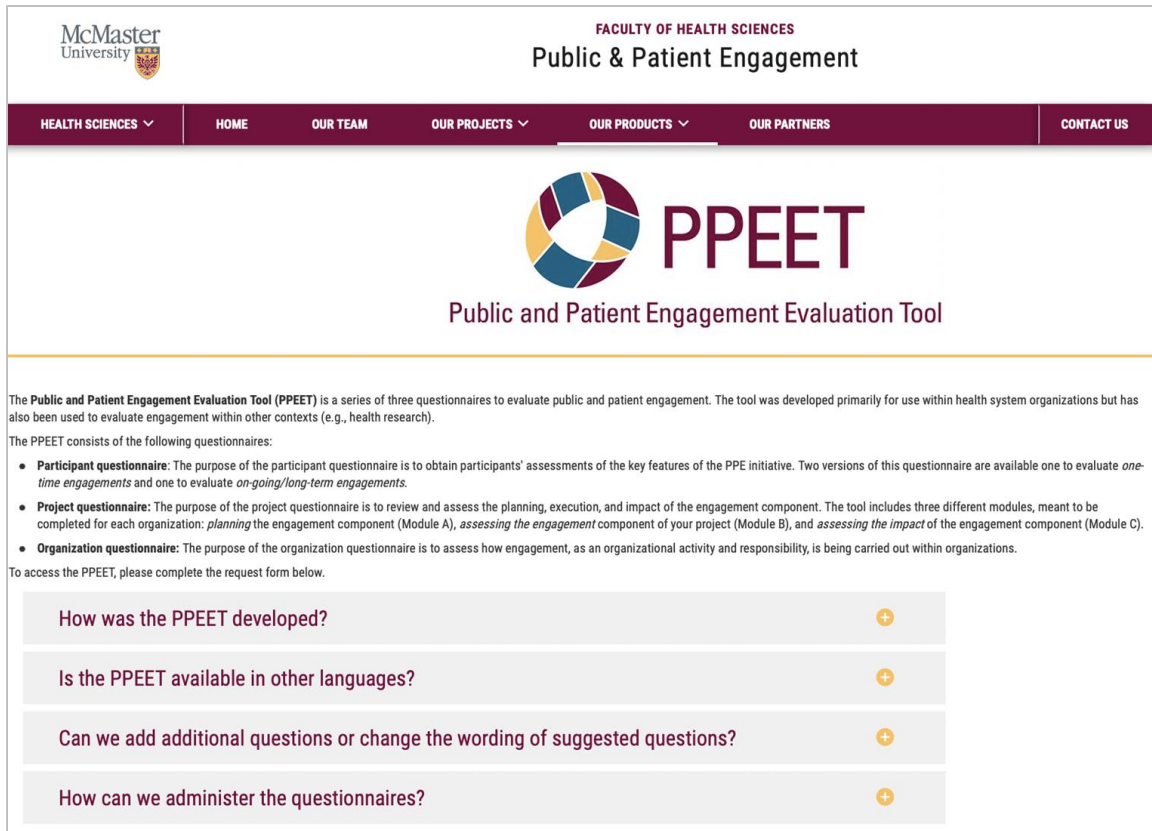
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Public and Patient Engagement Evaluation Tool (PPEET)




The screenshot shows the homepage of the PPEET website. At the top left is the McMaster University logo. The main header reads 'FACULTY OF HEALTH SCIENCES Public & Patient Engagement'. A navigation bar includes links for 'HEALTH SCIENCES', 'HOME', 'OUR TEAM', 'OUR PROJECTS', 'OUR PRODUCTS', 'OUR PARTNERS', and 'CONTACT US'. The central graphic features a circular logo with four colored segments (blue, yellow, red, green) and the text 'PPEET Public and Patient Engagement Evaluation Tool'. Below this, a paragraph explains that the PPEET is a series of three questionnaires for evaluating public and patient engagement. A list of three questionnaires follows: Participant, Project, and Organization. At the bottom, there are four expandable sections with plus signs, each containing a question: 'How was the PPEET developed?', 'Is the PPEET available in other languages?', 'Can we add additional questions or change the wording of suggested questions?', and 'How can we administer the questionnaires?'.

McMaster University

FACULTY OF HEALTH SCIENCES
Public & Patient Engagement

HEALTH SCIENCES ▾ HOME OUR TEAM OUR PROJECTS ▾ OUR PRODUCTS ▾ OUR PARTNERS CONTACT US

 PPEET
Public and Patient Engagement Evaluation Tool

The **Public and Patient Engagement Evaluation Tool (PPEET)** is a series of three questionnaires to evaluate public and patient engagement. The tool was developed primarily for use within health system organizations but has also been used to evaluate engagement within other contexts (e.g., health research).

The PPEET consists of the following questionnaires:

- **Participant questionnaire:** The purpose of the participant questionnaire is to obtain participants' assessments of the key features of the PPE initiative. Two versions of this questionnaire are available one to evaluate *one-time engagements* and one to evaluate *on-going/long-term engagements*.
- **Project questionnaire:** The purpose of the project questionnaire is to review and assess the *planning, execution, and impact* of the engagement component. The tool includes three different modules, meant to be completed for each organization: *planning the engagement component* (Module A), *assessing the engagement component* of your project (Module B), and *assessing the impact* of the engagement component (Module C).
- **Organization questionnaire:** The purpose of the organization questionnaire is to assess how engagement, as an organizational activity and responsibility, is being carried out within organizations.

To access the PPEET, please complete the request form below.

How was the PPEET developed? +

Is the PPEET available in other languages? +

Can we add additional questions or change the wording of suggested questions? +

How can we administer the questionnaires? +

Available for anyone to easily adapt and use to gain perspectives from patient partners and others on the team (including researchers and 'organizational' perspectives)

<https://ppe.mcmaster.ca/resources/public-and-patient-engagement-evaluation-tool/>



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Guidance on authorship with and acknowledgement of patient partners in patient-oriented research

Richards et al. *Research Involvement and Engagement* (2020) 6:38
https://doi.org/10.1186/s40900-020-00213-6

Research Involvement and Engagement

COMMENTARY Open Access

Check for updates

Guidance on authorship with and acknowledgement of patient partners in patient-oriented research

Dawn P. Richards^{1,2*}, Kathryn A. Birnie^{1,3†}, Kathleen Eubanks¹, Therese Lane¹, Delane Linkewich¹, Lesley Singer², Jennifer N. Stinson^{1,4} and Kimberly N. Begley¹

Abstract

The Strategy for Patient-Oriented Research Chronic Pain Network was founded in 2016 and is a patient-oriented research network funded by the Canadian Institutes of Health Research. The Network incorporates patient partners throughout its governance and operations meaning that patient partners may contribute to research projects in ways that warrant scientific authorship as defined by the International Committee of Medical Journal Editors. The Network did a brief informal review of research on patient authorship in 2019, but could not find any practical documentation to guide its members on this topic. Note the term patient partner here refers to a patient (or caregiver or other person with lived experience) who is a partner or collaborator on a research team. This guidance does not address patients as participants in a research study. This guidance has been co-written by a group of researchers and patient partners of the Chronic Pain Network in an effort to address this gap. It is intended for both researchers and patient partner audiences. This guidance is meant to facilitate conversations between researchers and patient partners about authorship and/or acknowledgement regarding research projects on which they collaborate. While the overall principles of academic authorship and acknowledgement remain unchanged, nuances for interpreting these principles through the lens of patient engagement or patient-oriented research is provided. Teams that carry out patient-oriented research projects will require different preparation to empower all team members (researchers and patient partners) to discuss authorship and acknowledgement. To facilitate these conversations, we have included an overview of the scientific publishing process, explanation of some common terms, and sets of considerations are provided for both patient partners and researchers in determining the range of team member contribution from acknowledgement to authorship. Conversations about authorship can be difficult, even for established research teams. This guidance, and the resources discussed within it, are provided with the intention of making these conversations easier and more thoughtful.

Keywords: Authorship, Acknowledgement, Guidance, Patient engagement, Patient involvement, Patient-oriented research, Patient partner, Publication

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An overview of the scientific publishing process, explanation of some common terms, and sets of considerations for patient partners and researchers in determining the range of team member contribution from acknowledgement to authorship.

<https://tspace.library.utoronto.ca/handle/1807/101500>



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Tips for Work Plan Preparation (continued...)

■ Knowledge Translation Plan

- Consult the [Menu of Knowledge Dissemination Approaches](#) to view common strategies for sharing knowledge with your intended audience.
 - Identify your target audiences (knowledge users).
 - Products or tools to be disseminated
 - Your plan for dissemination
 - How you anticipate the products or tools to be used.
 - We recommend a 1-page summary tailored to your knowledge user.
 - Consider alternate mediums to spread your message (e.g., Twitter, YouTube, LinkedIn)
 - Consider content accessibility best practices when developing products (e.g., Web Content Accessibility Guidelines (WCAG) 2.0)

■ COI declaration

- Teams must complete the [web-based COI declaration form](#)

■ Timeline

- Projects should be completed by **March 2025**
- Consider feasibility of your proposed work within the timeline.



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Budget Guidelines

✓ Things to Include

- Personnel Cost:
 - Research staff salary expenses including benefits
 - Student stipend
- Travel
 - Within 5% of total project
- Materials, supplies and other expenses
 - Direct costs of research
- Knowledge translation costs (e.g., publication fees, conference costs)
- Patient/public partner compensation**

✗ Ineligible

- >5% of total budget (\$2500) allocated to travel
- Charitable donations
- Indirect cost (e.g., research administration)
- PI salary

**A \$1,000 stipend for each patient/public partner co-lead is required in addition to their hourly honorarium. As of January 1st, 2024, our hourly rate has changed to \$40/hour. Our [Patient and Public Partner Appreciation Policy and Protocol](#) is currently being updated.

Funds Transfer and Management

- Once the work plan and budget has been approved, we will establish an institutional agreement between our host institution (Unity Health Toronto) and research team's institution.
- This agreement must be fully established before any payment can be transferred.
 - Payment will be made via electronic fund transfer
 - Invoice must be submitted to Unity Health Toronto to initiate fund transfer
- Research teams are responsible for monitoring and managing their research expenses, including disbursing payments for patient/public honoraria.
- Financial reporting – annual F300 (per CIHR requirements)

- The Central Coordinating Office will circulate a copy of the recording and slide deck
- A Frequently Asked Questions (FAQ) document will be prepared and circulated
- Deadline for Work Plan and Budget: **February 16th, 2024**
- We will also host 2 learning and exchange meetings in **April and May**
- In-house self-paced learning modules will be shared:
 - **For researchers:** Knowledge synthesis for knowledge users (17 modules)
 - **For patients/public:** Patient partner engagement in knowledge synthesis (3 modules)

Next Steps



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Analysing and making evidence to practice

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Additional Resources

- [Cochrane's Learning Collection for Consumer Involvement](#)
- [Introduction to GIN Systematic Reviews](#)
- [Other SPOR Evidence Alliance Patient-Driven Research Projects](#)
- [Patient partners' perspectives of meaningful engagement in synthesis reviews: A patient-oriented rapid review](#)
- [Patient engagement in the SPOR Evidence Alliance: Reflection and learnings](#)
- [Stakeholder Engagement in Evidence Synthesis](#)



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Thanks to the members of the Central Coordinating Office

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Research Program Manager



Sharmila Sreetharan MSc
Research Coordinator



Angelika Aziz BSc
Research Assistant



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Questions?



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