

BUILDING TOWARDS CONSENSUS ON COMPENSATION AND CONFLICT IN PATIENT-ORIENTED RESEARCH

ACTION REPORT

JANUARY 2023



ACKNOWLEDGEMENTS

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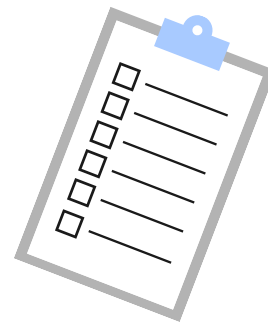
This project was funded by
Michael Smith Health Research BC

Thank you
To all of our participants

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EXECUTIVE SUMMARY



BACKGROUND

Patient-oriented research (POR) describes the process of involving patients and their caregivers as collaborators and partners on research teams. In response to calls for patient partners to receive compensation for their contributions, research teams have sought financial support from various sources. Increasing numbers of patients and patient organizations are receiving financial support through industry, like pharmaceutical or medical device companies, as well as non-profit advocacy groups. Although these sources of funding have opened up new opportunities for patients to be involved in research, it is unclear how stakeholders in POR understand and manage conflicts of interest (COIs).

METHODS

Our project seeks to critically explore the compensation of patient partners in POR and to gain insights into how COIs are, and could be, managed. We conducted a scoping literature review to identify relevant studies related to patient compensation and COIs in POR. Our scoping review included five stages and reviewed 74 articles. We also hosted a live chat on Twitter to gather a range of perspectives from patients and stakeholders. At the same time, we conducted nine in-depth semi-structured interviews with health researchers and patient partners via Zoom between October 2021 and September 2022. The interviews were transcribed verbatim and analyzed using a thematic analysis method. The interview data was used to plan and deliver a one-day priority-setting workshop. Harmonized research ethics board approval was received before any data was collected, and all participants granted written and verbal consent. The overarching goal of our work is to foster meaningful collaborations with key stakeholders to identify priorities, values, and gaps as they relate to compensation and conflict in POR.

Specifically, this work has two principal objectives:

- 1) To examine the perspectives and practices for compensation and conflict in POR.
- 2) To develop relevant and responsive questions and priorities to inform future consensus-building activities and research.

EXECUTIVE SUMMARY



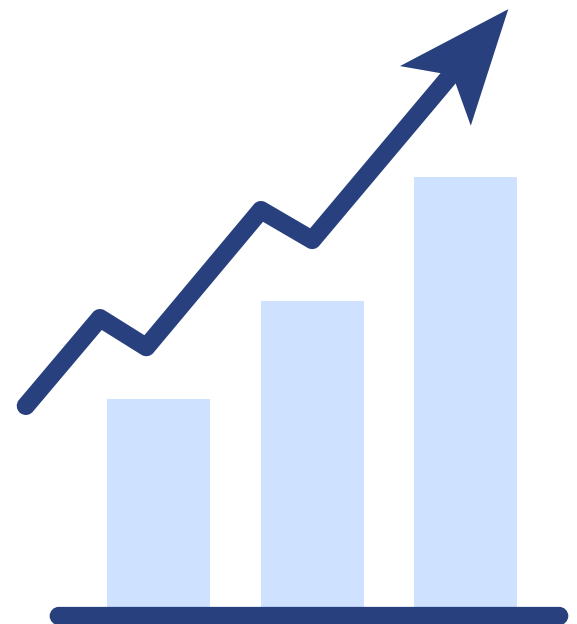
PROGRESS TO DATE

The first phase of our research was the scoping literature review, which is now complete. The second phase of research included 1) the tweet chat with the public and 2) the interviews with researchers and patient partners. For both of these consultation activities, we invited key stakeholders from across British Columbia, including patients, researchers, and healthcare decision-makers to share their experiences and identify key research questions, gaps, and priorities. The third phase of research was the priority-setting workshop which took place on December 2nd, 2022 and brought together researchers, knowledge users, patients, and community stakeholders to collectively determine how we can address and manage issues of compensation and COI in POR. The next step in this project will be developing a guidebook of resources that researchers and patient partners can use to identify and manage issues relating to compensation and COIs.

After we analyzed the interview data, four key themes were identified:

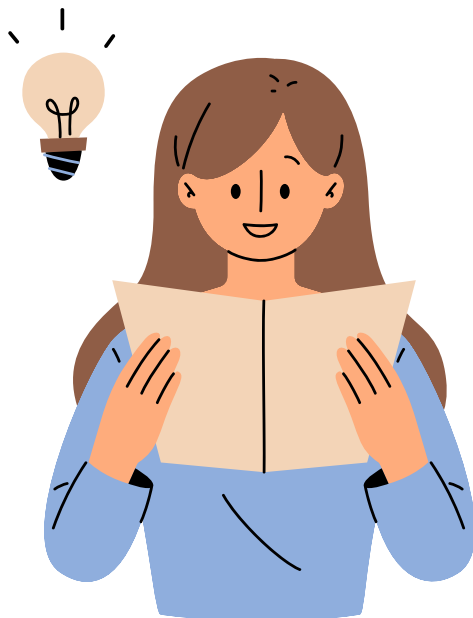
- 1) How research teams can support meaningful patient engagement
- 2) Compensation related to fairness
- 3) Conflicts of interest in POR
- 4) Compensation as a conflict of interest in POR

In this report, we give an overview of the key messages of the research.



PRIORITY-SETTING FOR FUTURE IMPACT

In November 2022, we began our process of priority settings. At our priority-setting meeting on December 2nd, 2022, we discussed the findings of our work so far and worked as a group to generate some priorities around compensation and COI in POR for future impact.



Our goal for these priorities was for them to be actionable and specific enough to provide direction to key organizations and stakeholders engaged in POR. In addition, we worked together to rank these ideas and identify the actions that are most important and could bring about the most change.

THE PRIORITY-SETTING PROCESS

Priority-setting meetings can include a variety of activities, including guided discussion, consensus methods, and voting. During the meeting, we invited all participants to contribute, creating an inclusive space to discuss issues and potential actions. We used a Deliberative Dialogue approach.

BEFORE THE MEETING

As well as receiving an evidence brief, participants were asked to review the participant information sheet provided and contact us with any questions. Written and/or verbal consent was also obtained from all participants. Additionally, we provided a video that offered an easy-to-understand explanation of the priority-setting process and a brief summary of findings.

DURING THE MEETING

Plain language was used throughout. During the meeting, members of our team aided meeting facilitation, technological support, support for participants, and note-taking. Participants were invited to reach out at any time if additional support was needed. Our meeting began with some introductions, followed by a review of the process and findings to date. We then broke out into smaller groups to discuss each of the themes and then came together to identify priorities and vote on those we felt were the most important or timely.

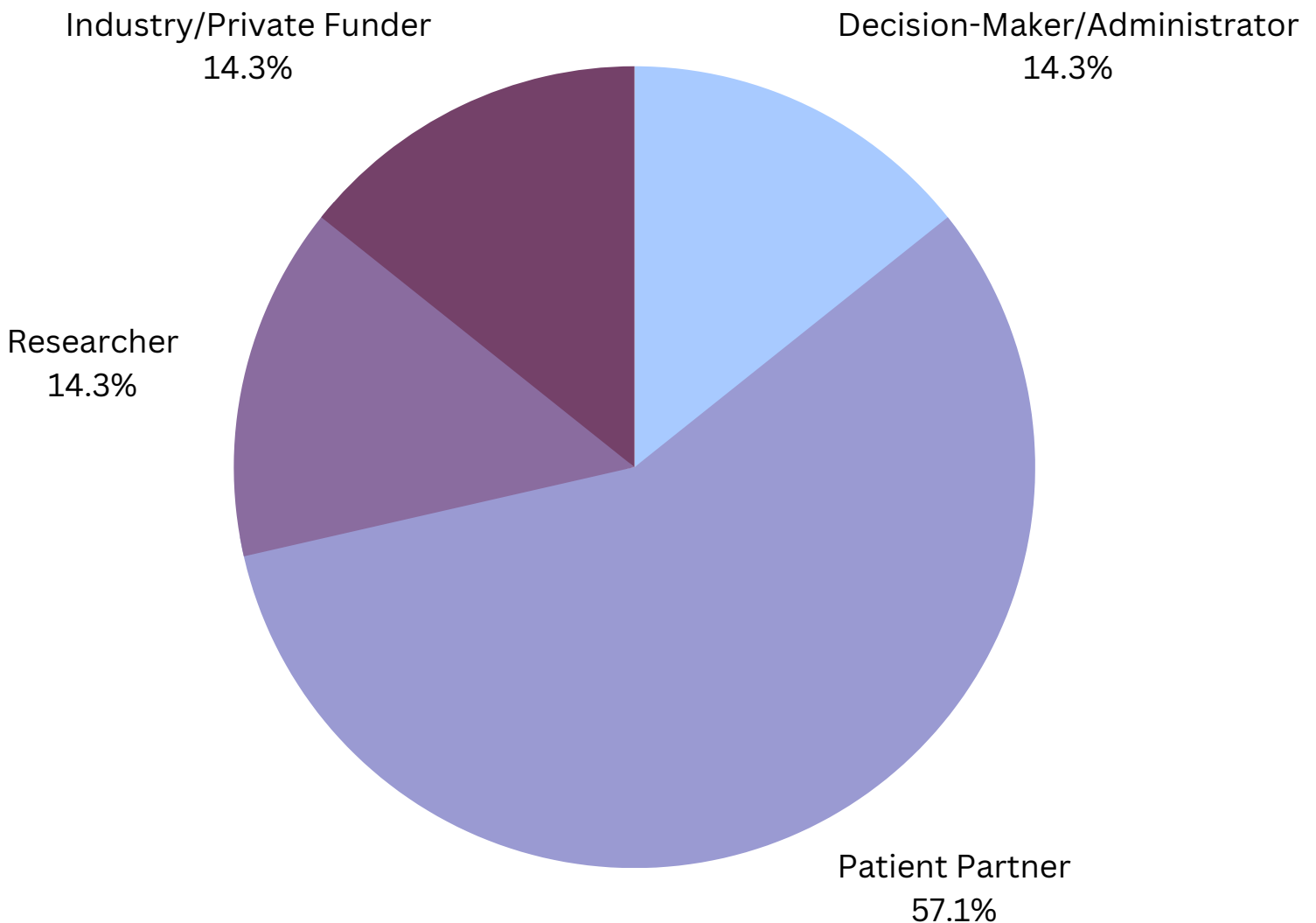
WHAT HAPPENS NOW?

Our team has summarized these discussions and priorities and are looking forward to reviews and feedback from participants. Once we have a finalized document, we will complete our report and share it with the wider POR community. We will also develop a guidebook of resources that researchers and patient partners can use to identify and manage issues relating to compensation and COIs.

THE PARTICIPANTS

We invited a diverse range of stakeholders. Our workshop had a total of 8 participants from an array of health-related fields, including patient partners. All participants provided informed consent before data collection.

We asked participants in what role they were attending the priority-setting workshop. Participant responses are summarized below. All participants had been in their roles for at least three years, and 71% of participants had been in their roles for more than 10 years.



THE DISCUSSIONS

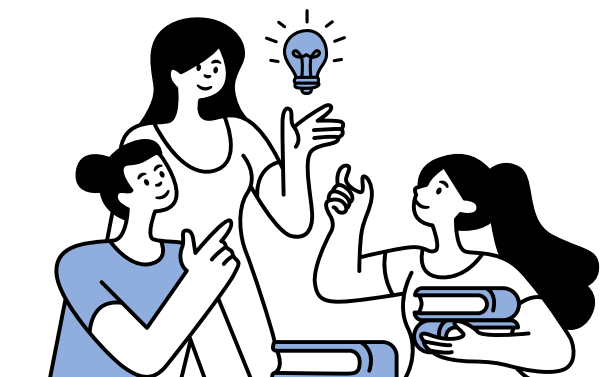
After reporting the key highlights from the documents provided (including the Evidence Report), we began with a roundtable discussion where we first asked participants to introduce their primary role (e.g., patient partner, researcher, etc.) and what institution they are affiliated with (if applicable). As well, we facilitated an ice-breaker activity which helped to build connections, mitigate power relationships, and familiarize participants with the ranking and voting process.

Our guiding discussion question was:

- What resonated with you from the Evidence Report?

Here is what we heard:

- Overall lack of clear COI definitions
- There is a need to develop tools to build patient partner allyship
- Patient partners lived experience is often valued, but they may have secondary skillsets that should be valued and appropriately compensated
- Compensation as a COI is primarily from the perspective of researchers
- There is a need for funders and finance departments to understand POR principles and best practices




FOCUSED DISCUSSION

IDENTIFYING CONFLICTS OF INTEREST

Our guiding questions were:

- What activities could POR teams engage in to identify financial COI?
- What strategies can help patient-oriented researchers identify and manage COIs?
- What activities could POR teams engage in to identify non-financial COI?

We heard:

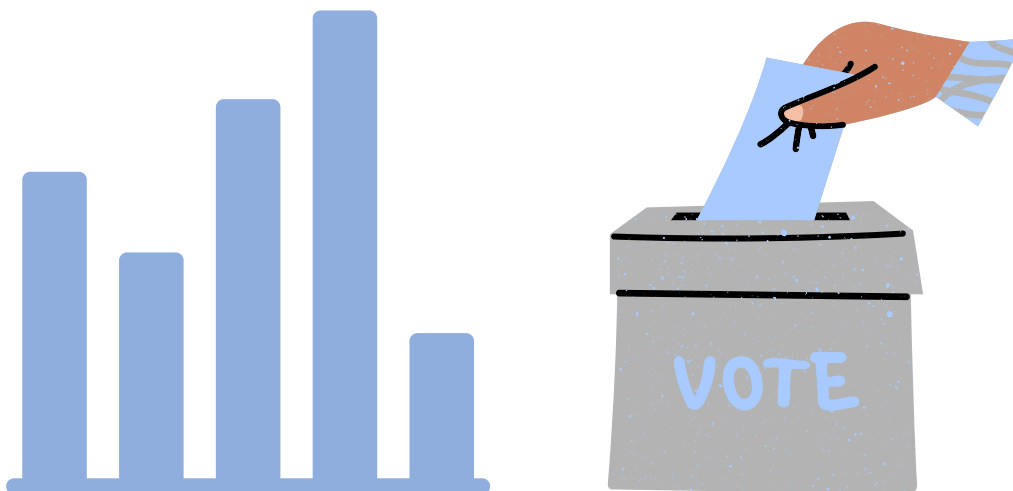
- We need clear definitions of financial and non-financial COIs
 - A good practice is to have clear conversations around compensation between the research team and patient partners from the very beginning, before patient partners agree to the project
 - Financial compensation for patient partners should be included in grant applications
 - We need transparent process for creating and amending budgets and engagement plans; funders must stop cutting allocations for engagement and knowledge translation
 - We need to develop disclosure processes, primarily for the research team, because transparency is crucial
- 

FOCUSED DISCUSSION POLL

After discussing the best ways for researchers and patient partners to identify and manage COIs, we determined six methods to be the most useful and ranked them in order of importance.

The key points ranked in order of importance are:

1. Transparent process for budgets and engagement plans
2. Clear definitions of financial and non-financial COIs
3. Relationship transparency
4. Similar disclosure practices for all involved
5. Written agreements that address non-financial or financial conflicts and outline management strategies and expectations
6. Researchers disclosing their COIs and encouraging discussion



BREAKOUT DISCUSSIONS

RESEARCHERS AND KNOWLEDGE USERS

Our guiding questions were:

- What tools or resources would work best in your work?
- How are COIs understood in POR?
- What other ways to manage COIs should team members consider?
- How do researchers address financial arrangements/funding within POR teams?
- How might industry funded projects create new or additional considerations?
- How should researchers minimize the existence or impact of these conflicts when recruiting patient partners?

We heard:

- There are barriers for researchers to fairly and equitably compensate patient partners, especially related to their funding regulations
- Difficulties navigating dual relationships with patient partners; for example, as both researcher and treating clinician
- Many documents have been developed to help with establishing trusting relationships and having conversations about compensation; there are fewer resources about COI
- The Patient Experience Research Committee (PERC) can offer advice and expertise, they are paid by the SUPPORT Unit
- There is a need for compensation guidelines for youth as participants
- There is a need for compensation guidelines that provide a range of options and recognize varied contributions and expertise

BREAKOUT DISCUSSIONS

PATIENT PARTNERS

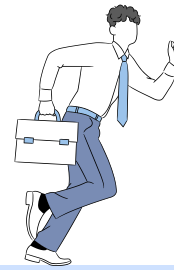
Our guiding questions were:

- What tools or resources would work best in your work?
- From a patient partner's point of view, what kinds of details related to COI are most important for researchers to disclose?
- What obligations do patient partners have to manage their COIs when engaging as a research team member?
- How should patient partners learn about what COIs are and how to manage them—before and after they join a research team?
- What are patient advocacy organizations' obligations to identify, disclose, and manage COIs when partnering with patient-oriented research team members?

We heard:

- There is a need for research teams to engage with patient partners early and often; develop an engagement plan before grant application
- There is a need for greater transparency and the development of disclosure guidelines
- Disclosure needs to be ongoing as positions, expectations, and relationships change throughout the project
- Case studies and mentorship programs are useful
- Transparency of budgets is desired by patient partners
- Research teams need to engage broadly because one patient partner cannot represent an entire group of people

MOVING TO ACTION



Tangible strategies that support action and best practices.

Who needs to hear about this work?

- All those engaged in POR
- Funding institutions/organizations and policy-makers
- University financial departments
- Program managers and directors
- Those working on patient- and family-centered care initiatives in health authorities

How can we best share the outcomes of our work?

- Infographics
- Central website
 - with keywords “patient partner financial compensation” for easy searching
- Training and education sessions
- Conference presentations at the BC Support Unit's Putting Patients First conference
- Email prompts directed to the research site

What forms of knowledge translation work best?

- Central website
- Infographics
- Training
 - mentorship program, training modules, training videos
- Several different communication methods for greater accessibility

NEXT STEPS



Step 1 - Action Report

We have created an action report that outlines tangible solutions. We are now asking for feedback from participants which will be used to finalize the report.

We have created an action report that outlines the priorities generated in our priority-setting workshop. Our goal was to identify priorities that are actionable and specific enough to provide direction to researchers and patient partners.

We are now seeking reviews and feedback from participants to ensure that we captured the priorities. This action report will highlight tangible solutions and help to inform the guidebook.



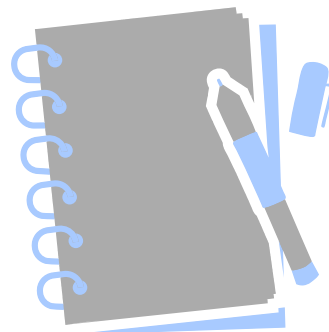


Step 2 - **Guidebook with Resources**

We will create a functional resource that researchers and patient partners can use to identify and manage issues relating to compensation and conflicts of interest.

We will be developing a guidebook of educational resources based on the feedback on the action report. This will be a resource that researchers and patient partners can use to identify and manage issues of compensation and conflicts of interest.

We will seek review and feedback from participants to ensure that this guidebook is a practical and helpful resource.



YOUR FEEDBACK MATTERS!

- *Does this report reflect the content and messaging from the workshop?*
- *What about these results resonates strongly with you?*
- *What do you think is missing?*
- *Who do you think needs to hear these results and recommendations?*
- *What do you think should happen with these results?*



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