

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

## EVIDENCE REPORT

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# ACKNOWLEDGEMENTS

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## 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 will be 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

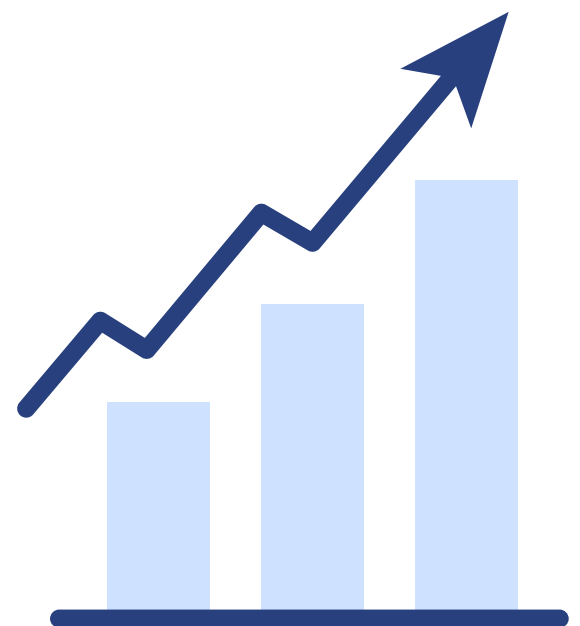
The first phase of our research was the scoping literature review, which is now complete. The second phase of research included 1) the tweet chat with patients and stakeholders and 2) the interviews with researchers and patient partners. For both of these consultation activities, we invited key stakeholders from across British Columbia, including patients, researchers, and others, to share their experiences and identify key research questions, gaps, and priorities.

Our next phase of this study will include a priority-setting workshop which will bring together researchers, knowledge users, patients, and community stakeholders to collectively determine how we can address and manage issues of compensation and COI in POR.

**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,



# METHODS: ACTIVITY 1

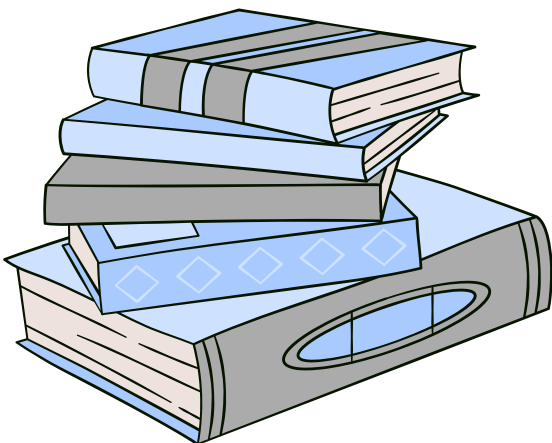
## Scoping Literature Review

We conducted a scoping literature review to identify relevant studies related to patient compensation and COIs in POR.

Our scoping review was co-led by a patient partner who contributed in all stages of research to ensure the relevance and meaningfulness of our study.

**This review was done in five stages:**

- 1) Identifying search terms and headings after a preliminary literature review,
- 2) Identifying relevant studies,
- 3) Selecting studies,
- 4) Charting the data, and
- 5) Collating, summarizing, and reporting results.



**The studies we chose had to meet these criteria:**

- Written in English,
- Published after 2000,
- Relevant to COI in POR,
- Contain quantitative or qualitative data, and
- Available in their full-text version.

# METHODS: ACTIVITY 1

## WHAT WE FOUND

Our review included 74 articles and found four main themes:

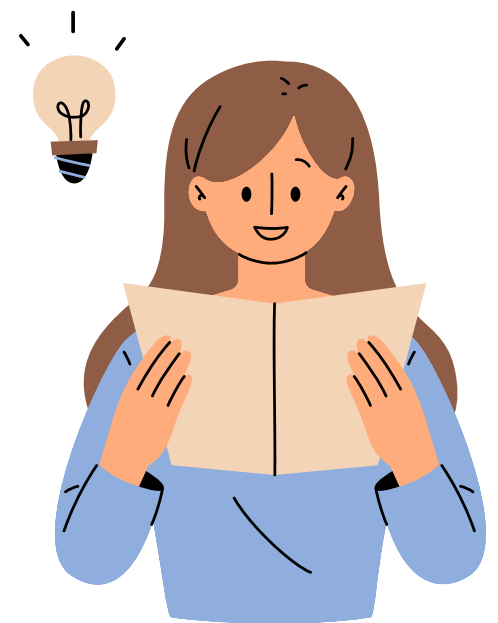
- Definitions of COI vary in the literature, but the potentials for COIs in health research is widespread.
- After a COI is identified, it must be managed and the literature presents six categories of management strategies.
- Collaboration in health research with industry and other groups can be positive but also presents significant risk of COI,
- Few articles in the review relate specifically to COI in patient-partnered and patient-oriented research,

## OUR CONCLUSIONS

Based on this scoping review, we developed three recommendations:

- 1) **Develop consensus** on what constitutes COI in POR
- 2) **Do more research** on identifying and managing COI in POR teams
- 3) **Co-design resources** and tools to support COI disclosure and mitigation

## Scoping Literature Review



# METHODS: ACTIVITY 2

Tweet chats, also called Twitter chats, are informal conversations about a specific topic that take place at a set time on Twitter. Typically, they involve a host posing a series of questions to the community. Community members participating in the tweet chat reply to those questions, interacting with the host account and with one another. Tweet chats can be a useful tool for researchers who want to directly reach and have informal conversations with members of the public.

Our Tweet chat happen on March 10, 2021 from 11am to 12pm (Pacific). Participants included patient partners, academic researchers, patient organization representatives, and health authority representatives. At least 36 Twitter accounts engaged (interacting with polls, 'liking,' etc.), and 24 accounts participated in the conversations, either tweeting or replying using the #COIinPOR hashtag. The chat generated 167 tweets.

Find the Tweet chat archived on the BC SUPPORT Unit Wakelet account.

[Part 1](#) and [Part 2](#).

## Live Tweet Chat





# METHODS: ACTIVITY 3

## *Interviews*

### WHAT ARE INTERVIEWS?

Interviews are conversations that focus on a topic for the purposes of a research project. They help us understand complex health and research issues, including how to manage COIs in POR.



Semi-structured individual interviews, lasting around 45 minutes, were conducted over Zoom. These interviews draw on opportunities for shared learning and growth. In doing this, we worked to understand how to identify and manage issues of COI and compensation in POR.

To recruit our sample, we shared a summary of this research with our partners. In addition, we recruited community stakeholders, including patient partners engaged in research. Data analysis was guided by the Qualitative Description approach, with data being coded and then analyzed thematically.

### HOW IS THIS DATA ANALYZED?

When data is analyzed, researchers review the information in detail, looking for similarities, differences, or areas where information is conflicting or unclear.

A researcher will identify important issues or statements (a process called coding) and will then group these together to create themes. Analyzing this type of data is very time consuming and can take months and sometimes years. After the data is analyzed, researchers describe the data, often using direct quotes to give examples or draw attention to important issues.

# FINDINGS

## WHAT WE HAVE LEARNED SO FAR

A total of nine people took part in the interviews. Our participants included researchers, decision-makers, and patient partners. The interviews explored the identification and management of issues relating to compensation and COIs in POR. Our interviews were designed to critically explore the compensation of patients in POR and to gain insights into how COIs are, and could be, managed.



# FINDINGS: THEME 1

Both researchers and patient partners discussed the importance of meaningful engagement of patients in POR. Our participants expressed that ensuring patient engagement is meaningful contributes to the ability to manage COIs and issues of compensation.

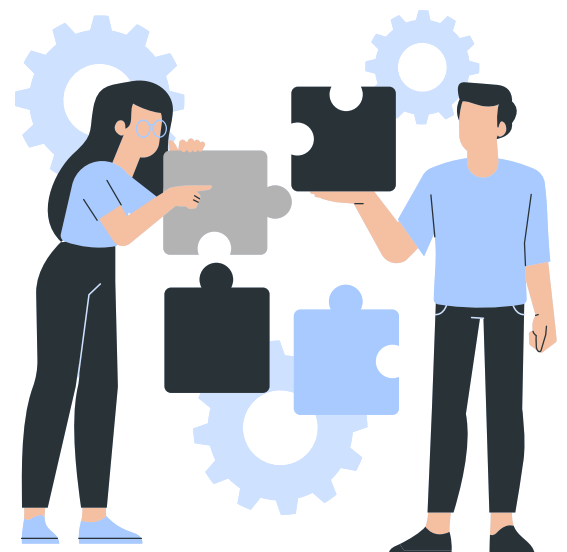
The way that meaningful engagement was described by participants varied depending on whether the participant identified as a researcher or patient partner. Meaningful patient engagement for researchers was closely linked to the work done by patient partners. For patients, meaningful engagement was often linked to feeling valued.

Participants that identified as patient partners often discussed comfort levels. The general sentiment was that participants want research teams to focus on inclusivity and awareness of their biases.

There was also a distinct connection between accessibility of participation and compensation with differing opinions of whether compensation should reflect differing barriers to participation or not. This sub-theme was often presented by participants as an issue of fairness.

## *Supporting Meaningful Patient Engagement*

*“Creating the space and time and acknowledgement of the individuals’ lived experience as their expertise, making sure they’re being engaged. The terms of engagement is clear.” (P008)*



# FINDINGS: THEME 2

In describing issues of compensation, nearly all participants discussed it in terms of monetary compensation. The primary concern shared by all participants was the concept of fairness.

One major concern shared by the many participants was the issue of whether, and how, compensation should reflect expertise. This sentiment was also related to the question of whether compensation should be a wage or honorarium, with opinions varying drastically between participants. The majority of participants who discussed this issue asserted that wage vs. honorarium depends on the nature and amount of work being done.

For patient partners, a primary discussion point was whether services provided to reduce the burden of participation were actually compensation or just accessibility practices that should be done anyway. For researchers, a major concern was the systemic barriers to providing equitable compensation, such as restrictions on giving cash as compensation.

## Compensation

"This will create something that will have some financial benefit to others who are involved ... and so I do think it's important because the reality is that we live in a capitalist society and if I'm the free labour at a table full of people who are not ... then they will necessarily see me as having less value."  
(P003)



# FINDINGS: THEME 3

Conflicts of interest were not discussed as thoroughly as the other themes, but participants gave many personal examples of COIs. Most COIs were discussed in the context of relationships, either familial or medical relationships between researchers and patients. Researchers discussed COIs more often than patient partners.

Participants expressed the need to address COIs in their own work and they expressed a similar need for concrete guidelines that can be shared between groups and organizations, and tools to mitigate COIs, such as a list of resources or tools that they can apply as they see fit.

"It's the responsibility of the person who may be in conflict to bring that forward and then each situation will be discussed and managed ... my understanding is then it gets discussed and you bring in whomever needs to be brought into the conversation to make a determination."

(P004)

## Conflicts of Interest

"I mean conflicts of interest are only conflicts of interest if they're not transparent. Right, it's perception that creates conflict or the lack of transparency that creates conflict. So I've seen conflict in every single area in which I've worked in health."

(P002)



# FINDINGS: THEME 4

Compensation as a COI was primarily discussed by participants that identified as researchers rather than those that identified as patient partners. This theme was often described through examples, which differed between participants. Examples included patient partners transferring from volunteer to paid positions, patient partners being compensated through pharmaceutical companies, and patient partners potentially taking advantage of compensation. Some participants who identified as researchers expressed significant concern in this area.

Similar to theme three, participants expressed the need to address compensation as a COI through concrete guidelines for navigating relationships and potential COIs in relation to compensation.

“I think we’re all in conflict by not having diversity in the research enterprise and so I mean compensation is kind of downstream of participation, right.”  
(P002)

## *Compensation as a Conflict of Interest*

“Which hat am I wearing and what happens when a patient partner becomes employed by the organization? So that’s starting to touch on the compensation part of this discussion, right.”  
(P003)



# NEXT STEPS



## *Step 1 - Priority Setting Workshop*

Our priority-setting workshop will include a variety of activities, including guided discussion, consensus methods, and voting to identify the research priorities.



## *Step 2 - Action Report*

Using the priorities set in Step 1, we will create an action report that outlines tangible solutions.



## *Step 3 - 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.

# Step 1 – Priority-Setting Workshop

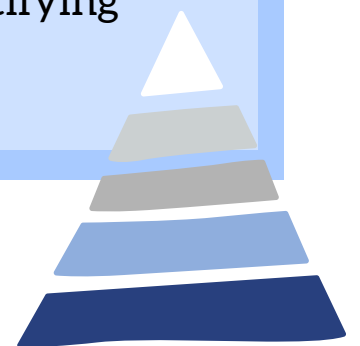
## THE PRIORITY-SETTING PROCESS

Priority-setting meetings include a variety of activities, including guided discussion, consensus methods, and voting. Using a Deliberative Dialogue approach during the meeting, we will invite all participants to contribute, creating an inclusive space.

**Before the meeting:** We ask participants to read this evidence brief, review the participation sheet we provide, contact us with any questions, and complete a consent form we provide.

**During the meeting:** We will use plain language will be used throughout. Members of our team will offer facilitation, technological, emotional, and note-taking support. Our meeting will begin with introductions, followed by a review of the process and findings to date. We will then break out into smaller groups to discuss each of the themes and then come together to identify priorities and vote on them.

**After the meeting:** Our team will summarize these discussions and priorities and then send to participants for review and feedback. When we have a finalized document, we will complete our action report and share this with the wider research community. We will also develop a guidebook with resources to support identifying and managing COI in POR.



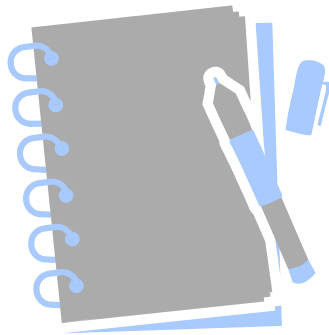


## Step 2 – Action Report

During the priority-setting workshop, we will work as a group to generate some priorities for future impact. We will then create an action report that outlines these priorities.

Our goal is to identify priorities that are actionable and specific enough to provide direction to researchers and patient partners. The action report will highlight tangible solutions and help to inform the guidebook.

We will seek review and feedback from participants to ensure we captured the priorities.



## Step 3 – Guidebook with Resources

We will be developing a guidebook of educational resources based off of 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.

***We would love to hear  
from you!***



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