

Focus Group Guide
(University & Other Interest-holding Organization Administration & Finance Staff)
—
PPC & EDI Study

Compensation-Related Barriers and Facilitators to Patient Engagement in Canadian Academic Health Research and Intersections with Equity, Diversity, and Inclusion

[Start PowerPoint for those joining with video]

Welcome (1 minute)

Hello everyone, my name is [name]. I am one of the team members for the study on patient partner compensation and inclusion in academic health research. I will be [leading our discussion/co-leading our discussion/taking notes/helping with the chat function/offering additional support/etc.] Also joining me is another team member who I will let introduce themselves. [Co-facilitator introduces themselves and their role]. We would like to thank you for agreeing to participate in this focus group.

In a few minutes, you will all introduce yourselves. You may use your first name or a made-up name if you prefer. You can change how your name appears in Zoom by clicking on the three dots next to your name. If you feel comfortable, I encourage you to include your pronouns by your name. Please let me know if you have any questions.

Topic Information (5 minutes)

So we're all on the same page, I'll go over a few definitions with you for context:

- As a reminder, this focus group is focused on patient partner compensation in academic health research specifically
- Patient¹
 - A term that includes individuals with personal experience of a health issue and informal caregivers, including family and friends.
- Patient engagement in research
 - Involves patients being meaningfully engaged in a research project.² Patient partners may help with things like:
 - setting research priorities
 - research design
 - recruiting participants
 - collecting data
 - interpreting results
 - writing reports

¹ <https://cihr-irsc.gc.ca/e/48413.html>

² <https://cihr-irsc.gc.ca/e/48413.html>

- sharing findings
 - The difference between patient partners and patients as research participants is that patient partners are engaged in the research process and inform and/or conduct the research. Patients who are research participants are part of the research. For this study, we are focusing on patient partners.
- Compensation³
 - The act of awarding something to someone in exchange for a service. While this is often monetary compensation in the form of salary or stipends, it can also be in the form of services, honoraria, gifts or in-kind exchanges or incentives.
- Equity, Diversity, and Inclusion (EDI)⁴
 - *Equity* is removing systemic barriers and biases to let all individuals have equal opportunity
 - *Diversity* is differences in race, colour, place of origin, religion, immigrant and newcomer status, ethnic origin, ability, sex, sexual orientation, gender identity, gender expression, age, etc.
 - *Inclusion* is when we ensure all individuals are valued and respected for their contributions and are equally supported

Guidelines (5 minutes)

Before we begin, I would like to spend a few moments talking about basic ground rules, confidentiality, and technical aspects of our discussion.

Basic ground rules

- Everyone's views are welcomed
- We will do our best to ensure that everyone has a chance to speak
- We may step in if the conversation is going off-topic
- For transcription purposes, I would ask that for the first few comments, you say your first name or your made-up name so that we will recognize your voice. We may give you a gentle reminder to do so
- If you feel uncomfortable at any time, feel free to send one of us a private message or drop off the call if you need and we will check in with you afterward.

Confidentiality

- We ask that you keep the opinions you heard today confidential. Having said this, we cannot guarantee that everyone here will honour this request. Therefore, we ask that you only make comments you would feel comfortable making in a public setting
- We would like to remind you that this focus group will be recorded to increase accuracy and to reduce the chance of misinterpreting your comments. You will be notified when the recording begins.
- The recording (audio and video) will be deleted after transcription so that the information you share today will no longer be connected to you in any way

Technical points

³ <https://cihr-irsc.gc.ca/e/51466.html>

⁴ <https://www.sshrc-crsh.gc.ca/funding-financement/nfrf-fnfr/edi-eng.aspx#2>

- We would appreciate if you turn on your camera so everyone can feel comfortable with one another, but you are not required to do so
- You can use the chat feature to participate
- Closed captioning is turned on for accessibility purposes. If you would like to follow along with the dialogue simply click the button at the bottom of your screen to turn this feature on

If you have any questions about your consent to participate please let us know.

[End PowerPoint]

Recording (1 minute)

OK, unless you have any questions, we can begin. I am now turning on the recording.

[The researcher turns on the recording function in Zoom as well as a backup recorder to capture sound coming through the computer speakers as a backup.]

Introductions (1 minute)

I would like to invite you to introduce yourself to one another using your first name or a made-up name and the province you live in.

Commented [1]: Possible alternative wording: 0.5 I would like to invite you to introduce yourself to one another using 1) your first name or a made-up name, 2) the province you live in, and... 3) briefly about your role relating to working with patient partners on research teams.

Guiding Focus Group Questions (approximately 60+ minutes)

To start, I'd like everyone to introduce yourself 1) using the name you'd prefer us to use for this session, 2) the Province you live in, and 3) briefly share about your role relating to patient engagement.

1. What is your experience of compensating patient partners engaged on research teams you've supported?
 - a. What has been your experience in providing compensation to patient partners from diverse backgrounds (related to equity, diversity, and inclusion)?
2. Can you walk us through what the process looks like on your end when a patient partner on a research team is compensated?
 - a. Who is responsible for doing what tasks (e.g., an assistant, a Finance person)?
 - b. What role do you play?
3. In your experience, what has worked well when you've provided compensation to patient partners on research teams?
 - a. What are the strengths of your institution in compensating patient partners?
4. In your experience, what are the biggest challenges when you've provided compensation to patient partners on research teams?
 - a. What challenges does your institution face in compensating patient partners?
 - b. Optional Probes (ensure not brought up in a leading way)

- EDI

5. How would you suggest these challenges may be overcome?

a. Probe for each challenge they identified in Q4

b. Optional Probes

- Solutions that fit within current limitations
- Solutions that are blue-skying (if there were no constraints, what would this look like)
- EDI

6. Is there anything that we haven't covered that you thought we would discuss?

[When questions have been completed, ask participants whether they feel anything has been forgotten or if they wish to make any additional comments.]

Wrap up (2 minutes)

That concludes our discussion for today. Thank you again so much for participating.

Examples/Prompts

a. Types of compensation

- Monetary honorarium
- Contractor income
- Employment income
- Cash
- Direct bank deposit
- Cheque
- Gift cards
- Gifts
- In-kind exchanges or incentives
- Donations to charity
- Not offered compensation
- Declined compensation
- Other (please explain)

b. Examples of diversity:

- First Nation, Métis, Inuit, or Indigenous other
- Gender diverse individual
- Individual facing housing insecurity or homelessness
- Individual living in low income

- LGBTQIA+ community member (Lesbian, Gay, Bisexual, Transgender, Queer and/or Questioning, Intersex, Asexual, and other affirming ways individuals self-identify)
- Member of a racialized group
- Newcomer to Canada within the past 5 years
- Person with a disability (visible or invisible)
- Two-Spirit
- Woman
- An equity-deserving group not covered above

c. Possible Challenges

- Rates
 - Are they sufficient
 - Are they consistent (within and across projects)
 - Are there higher amounts for seniority
- Types of work covered (e.g., inside meetings, outside of meetings)
- Monetary payments versus honoraria (e.g., gift cards, donations to charity, in-kind exchanges or incentives)
- Administrative paperwork
- Payment speed
- Payment frequency
- Contracts
- Tax implications (for government benefits such as disability, pension, social assistance, etc.)
- Contractor versus employee versus unique positioning
- Contractor's liability insurance
- Social insurance numbers (SIN) and banking information
- Research budgets
- Co-authorship
- Compensation presented as a choice (guilt in accepting) versus assume yes unless PP says otherwise
- Uncertainty if even getting paid
- Language or literacy barriers with compensation paperwork