

Demographic Questionnaire – PPC & EDI Study

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

Opener

[Logos]

Demographic EDI Questionnaire for Patient Partner Compensation Study

Information and Consent

[CONSENT]

Title of Study

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

Information

Welcome! Thank you for taking part in this study. We are looking forward to talking to you soon. In the meantime, here is a questionnaire for you to complete that asks about your demographic characteristics (information about you and your perspectives). We collect this so we can better understand and describe the diversity of our participants. You do not need to give your name and your responses will be kept confidential.

The questionnaire is expected to take 5-10 minutes to complete. Required questions will be marked with a star.

Here are some quick definitions before we begin: Patient engagement in research

- Involves patients being meaningfully engaged in a research project. Patient partners may help with things like:
 - setting research priorities
 - research design
 - recruiting participants
 - collecting data
 - interpreting results
 - writing reports
 - 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.

- As a reminder, this study is focused on patient partner compensation in academic health research specifically

If you have any questions about the study, please feel free to contact the study's coordinator Samantha Fowler (samantha.fowler@HorizonNB.ca or 506-566-2728).

Thank you so much for participating. Let's get started!

—page break—

Age

[AGE]

1. What is your age?

1. Under 19 years
2. 19-29 years
3. 30-39 years
4. 40-49 years
5. 50-59 years
6. 60-69 years
7. 70-79 years
8. 80+ years

Instructions

- For respondents who indicate Under 19 years, send them to the disqualification page (message: "You did not qualify for the questionnaire, but thank you for your time!")
- Limit to 1 answer

Mandatory

Group

[GROUP]

2. Which of the following best describes your role?

1. A patient or caregiver who has been engaged as a patient partner in academic health research
2. A researcher affiliated with academic health research
3. University or other relevant stakeholder organization administration or finance representative
4. Research funding organization employee
5. Not listed (please explain): _____

Instructions

- Limit to 1 answer
- Mandatory
- For #5 message states: "A member from the research team will contact you to get further information regarding your response to 'which group best describes you.'"

Researcher's Role [researchers only]

[RESEARCHER]

3. Which of the following best describes your role as a researcher?

1. Professor
2. Research associate
3. Post-doctoral fellow
4. Graduate student (Master or PhD)
5. Research assistant
6. Other (please explain): _____

Instructions

- Use branching to display for researchers only
- Limit to 1 answer
- Mandatory

Researcher's PP Compensation [researchers only]

[RCOMP]

4. Are patient partners compensated for their engagement on your academic health research?

1. Yes always
2. Some of the time
3. No

Instructions

- Use branching to display for researchers only
- Limit to 1 answer
- Mandatory

Researchers Compensation [researchers only]

[RCOMPTYPE]

5. Which of the following apply to how patient partners engaged on your academic health research projects have been compensated? (check all that apply)

1. Monetary honorarium
2. Contractor income
3. Employment income
4. Cash
5. Direct bank deposit

6. Cheque
7. Gift cards
8. Gifts
9. In-kind exchanges or incentives
10. Donations to charity
11. Not offered compensation
12. Declined compensation
13. None of the above
14. Other (please explain): _____

Instructions

- Use branching to display for researchers who indicated they do compensate PPs “Yes always” or “Some of the time”
- Mandatory

University/Other Relevant Stakeholder Organization Staff’s Role

[university/other relevant stakeholder organization staff only]

[UNIVERSITY/OTHER RELEVANT STAKEHOLDER ORGANIZATION]

6. Which of the following best describes your role at your university?

1. Human resources
2. Finance
3. Administration
4. Program/project management
5. Other (please explain): _____

Instructions

- Use branching to display for university staff only
- Limit to 1 answer
- Mandatory

Researchers & University/Other Relevant Stakeholder Organization Staff Compensation [university/other relevant stakeholder organization staff only]

[COMPENSATIONTYPES]

7. Which of the following are types of patient partner compensation you have familiarity with? (check all that apply)

1. Monetary honorarium
2. Contractor income
3. Employment income
4. Cash
5. Direct bank deposit
6. Cheque

7. Gift cards
8. Gifts
9. In-kind exchanges or incentives
10. Donations to charity
11. Not offered compensation
12. Declined compensation
13. None of the above
14. Other (please explain): _____

Instructions

- Use branching to display for university/other relevant stakeholder organization staff
- Mandatory

Research Funding Organization Employee's Role [Research Funding Organization employees only]

[Research Funding Organization]

6. Which of the following best describes your role with your organization?

6. Human resources
7. Finance
8. Administration
9. Program/project management
10. Other (please explain): _____

Instructions

- Use branching to display for research funding organization employees only
- Limit to 1 answer
- Mandatory

Research Funding Organization Employee Compensation [research funding organization employees only]

[COMPENSATIONTYPES]

7. Which of the following are types of patient partner compensation you have familiarity with? (check all that apply)

15. Monetary honorarium
16. Contractor income
17. Employment income
18. Cash
19. Direct bank deposit
20. Cheque
21. Gift cards
22. Gifts

23. In-kind exchanges or incentives

24. Donations to charity

25. Not offered compensation

26. Declined compensation

27. None of the above

28. Other (please explain): _____

Instructions

- Use branching to display for university/other relevant stakeholder organization staff
- Mandatory

PP Experience [current patient partners only]

[PPEXPERIENCE]

8. How many times have you served as a patient partner on an academic health research project in the past?

Instructions

- Use branching to display for current PPs only
- Mandatory
- Drop down list of numbers 1 to 20+

PP Compensation History [current patient partners only]

[PPCOMPENSATIONHIS]

9. Which of the following apply to the compensation you received for your past patient engagement(s) on academic health research project(s)? (check all that apply)

Reminder: According to the Canadian Institutes of Health Research, compensation is 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.

1. I was appropriately compensated for my time
2. I was under compensated for my time
3. I was offered compensation for my time but declined
4. I was not offered compensation for my time

Instructions

- Use branching to display for current PPs only
- Mandatory

PP Compensation Type [current patient partners only]

[PPCOMPENSATIONTYPE]

10. Which of the following types of compensation have you received for your past patient engagement(s) on academic health research project(s)? (check all that apply)

1. Monetary honorarium
2. Contractor income
3. Employment income
4. Cash
5. Direct bank deposit
6. Cheque
7. Gift cards
8. Gifts
9. In-kind exchanges or incentives
10. Donations to charity
11. Other (please explain): _____

Instructions

- Use branching to display for PPs who indicated they received compensation
- Mandatory

—page break—

Province

[PROVINCE]

11. In which Canadian* province or territory do you currently live?

1. Alberta [PROVINCE_AB]
2. British Columbia [PROVINCE_BC]
3. Manitoba [PROVINCE_MB]
4. New Brunswick [PROVINCE_NB]
5. Newfoundland and Labrador [PROVINCE_NL]
6. Northwest Territories [PROVINCE_NT]
7. Nova Scotia [PROVINCE_NS]
8. Nunavut [PROVINCE_NU]
9. Ontario [PROVINCE_ON]
10. Prince Edward Island [PROVINCE_PE]
11. Quebec [PROVINCE_QC]
12. Saskatchewan [PROVINCE_SK]
13. Yukon [PROVINCE_YT]

** We acknowledge that the land we call Canada is the traditional territory of Indigenous peoples*

Instructions

- Limit to 1 answer
- Mandatory
-

Education

[EDUCATION]

12. What is your highest level of education?

1. Less than 12th grade (no diploma)
2. High school diploma (or equivalent)
3. Some education after high school, no degree
4. College degree or trades diploma
5. Undergraduate degree (bachelor's),
6. Postgraduate degree (master's or doctorate)

Instructions

- Limit to 1 answer
- Not mandatory

—page break—

Gender

[GENDER]

13. What best describes your current gender identity?

1. Indigenous or other cultural gender identity
2. Man
3. Non-binary, agender, bigender, gender fluid, questioning, etc.
4. Woman
5. Prefer to self-describe: _____

Instructions

- Limit to 1 answer
- Not mandatory

LGBTQIA+ Identification

[LGBTQIA]

14. Do you identify as a member of the LGBTQIA+ community? (Lesbian, Gay, Bisexual, Transgender, Queer and/or Questioning, Intersex, Asexual, and other affirming ways individuals self-identify)

1. Yes
2. No

Instructions

- Limit to 1 answer
- Not mandatory

—page break—

Person with a Disability

[DISABILITY]

15. Do you identify as a person with a disability? (There are a variety of disabilities, which can be visible or invisible. Some examples include cognitive, communication, intellectual/developmental, learning, mental health, physical/mobility, and sensory)

1. Yes
2. No

Instructions

- Limit to 1 answer
- Not mandatory

Indigenous Peoples

[INDIGENOUS]

16. Do you identify as First Nations, Inuk/Inuit and/or Métis? (select all that apply)

1. Yes, First Nations
2. Yes, Inuk/Inuit
3. Yes, Métis
4. No
5. Do not know
6. Prefer not to answer

Instructions

- Limit to 1 answer
- Not mandatory

Indigenous Peoples

[TWOSPIRIT]

17. Do you identify as Two-Spirit?

7. Yes
8. No

Instructions

- Branch to display is "Yes" to INDIGENOUS question
- Limit to 1 answer
- Not mandatory

Race

[RACE]

18. Do you identify as a member of a racialized group?

1. Yes
2. No

Instructions

- Limit to 1 answer
- Not mandatory

Newcomer

[NEWCOMER]

19. Are you a newcomer who came to Canada within the past 5 years?

1. Yes
2. No

Instructions

- Limit to 1 answer
- Not mandatory

—page break—

Employment

[EMPLOYMENT]

20. Which of the following describes your level of employment? (check all that apply)

1. Employed full-time (including self-employed)
2. Employed part-time (including self-employed)
3. Unemployed (not receiving government benefits)
4. Unemployed (receiving government benefits)
5. Retired
6. Student
7. Other (please explain): _____

Instructions

- Check all that apply
- Not mandatory

Income

[INCOME]

21. Compared to others in Canada, what do you feel your income is:

1. Lower than most people's income
2. About the same as most people's income
3. Higher than most people's income

Instructions

- Limit to 1 answer
- Not mandatory

Housing

[HOUSING]

22. Are you facing housing insecurity or homelessness?

1. Yes
2. No

Instructions

- Limit to 1 answer
- Not mandatory

ADDITIONALGROUP

[ADDITIONAL]

23. If you identify with an equity-deserving group not covered above, please list it here

—page break—

Open feedback

[FEEDBACK]

24. Do you have any clarifying comments you would like to share about any of your answers above?

Instructions

- Open text box
- Not mandatory

—page break—

Closing

Thank you so much for your response! We appreciate you being part of this research study.

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