



## Describing your patient partner roles and activities

We're interested in learning about your role as a patient partner and the activities you're involved in. Please remember that while we will be using the term *patient partner* to describe your involvement - you may know this as being an *advisor or council member or committee member* or some other name. Please also remember while we use the term patient this is intended to include all individuals who interact with the health system including patients, caregivers, family members, clients and others.

This first set of questions will ask you to reflect on when and how you first became a patient partner, and the activity you participated in.

First, we'd like to ask a general question to confirm that you are eligible for this survey.

**1. Have you ever participated in activities with an organization or government to help them understand your experiences with the health system?**

- Yes → Continue
- No → Thank you for your interest in this survey. Unfortunately, you are not eligible to participate.

**2. Thank you for confirming your eligibility. As we noted in the introduction, we will be using the term 'patient partner' for consistency throughout this survey. We are interested in understanding what terms people prefer to use to describe their role.**

**What term do you prefer to use when referring to your role with health organizations or government?**

**3. When did you begin your first activity as a patient partner?**

\_\_\_\_\_ (Year)

**4. What type of experience did you draw on in this first activity? (Select all that apply)**

- Experiences with the health system as an unpaid caregiver (e.g., taking care of a friend or family member)
- Experiences with the health system as a patient with an acute or chronic condition (e.g., patient with a life altering diagnosis)
- Experiences with the health system as a patient who accesses periodic care and/or screening (e.g., appointments with a family doctor, cancer screenings)
- Other, please specify: \_\_\_\_\_

**5. When you first started as a patient partner, which of the following most closely described your initial focus or interest? (Select all that apply)**

- Learning how the health system works to improve my own health care or the health care for my family member
- Improving an area of health care based on my positive experience with the health system
- Improving an area of health care based on my negative experiences with the health system
- Giving back as a result of my own positive experiences with the health system
- Sharing my expertise as a former health care worker
- Serving my community

- Creating new knowledge through research
  - Other, please describe
- 6. For this first patient partner role, what group, organization or government did you work with? Please name or describe it (e.g., hospital, long-term care organization, community clinic, research team, provincial health quality or patient safety organization, medical school, health charity, coalition, provincial government or private sector organization)**
- 7. How did you get involved in this first patient partner role? (Choose all that apply)**
- I was invited by someone in the organization
  - Somebody told me about it and encouraged me to apply
  - I saw a poster or advertisement for the role and I applied
  - I saw information about the opportunity on social media (e.g., Twitter, blogs)
  - I searched out the opportunity myself (e.g. called the agency, asked to join)
  - Other, please specify:
- 8. Briefly describe the activity that you participated in during this first interaction with the organization (e.g., if you attended meetings what did you do at these meetings? If you were involved in other activities, what were they?)**
- 9. Have you been involved in other activities with this organization?**
- Yes → Please describe these other activities
  - No
- 10. Have you continued to be active as a patient partner since this first patient partner experience?**
- Yes, I've been a patient partner since I started in my first activity
  - Yes, but I took some time off since I started my first activity → Why do you take time off?
  - No, I have not been active since this first activity → Why are you no longer active (then Skip to Q15)
  - Other, please specify:
- 11. Are you still working with the organization that you first started with as a patient partner?**
- Yes
  - No
- 12. Have you worked with any other organizations in your patient partner role?**
- Yes
  - No → Skip to Q14
- 13. Please name or describe up to 5 additional organizations that you have worked with, and briefly describe or list the activities you have been involved in with each.**
- 14. On average, how many hours per month do you spend on patient partnering activities?**
- Less than 5
  - 5 – 10
  - 11 – 20
  - 21 – 30
  - 31 – 40
  - More than 40

**15. Thinking about your overall role as a patient partner, which of the following most accurately describes you? (Select all that apply)**

- I see myself as a resource to the health system
- I see myself as an advocate
- I see myself as a collaborator
- I see myself as a peer with professionals
- I see myself as a token
- I see myself as an advisor
- I see myself as a patient leader
- I see myself as a change agent
- I see myself as an expert
- Other, please specify:

**16. How often have you been offered the following types of compensation in your patient partner activities? Note: We have included the reimbursement of expenses in the list below because it is commonly offered, however, we recognize that it is not a form of compensation.**

|   | Always | Often | Sometimes | Rarely | Never |
|---|--------|-------|-----------|--------|-------|
| Salary (e.g., compensation based on a pre-determined rate, e.g., hourly, monthly, annually)                         |        |       |           |        |       |
| Honorarium (e.g., one-time payments that may or may not be tied to the amount of work carried out or time involved) |        |       |           |        |       |
| Gift card   |        |       |           |        |       |
| Conference registration and/or associated expenses  |        |       |           |        |       |
| Material gifts (e.g., books)  |        |       |           |        |       |
| Reimbursement of expenses (e.g., money to cover parking costs, travel costs)  |        |       |           |        |       |
| Other, please describe  |        |       |           |        |       |

**17. How often do you feel you are adequately compensated for your patient partner activities? Please provide more detail in the comment box, if interested.**

- Always
- Often
- Sometimes
- Rarely
- Never

**18. Have you ever refused compensation? Please provide more detail in the comment box, if interested.**

- Yes
- No

**19. How often do your experiences and activities include working with other patient partners? (e.g., are other patient partners with you on a committee, in a discussion, etc). If interested, please provide more detail in the comment box.**

- Always
- Often
- Sometimes
- Rarely
- Never

**20. How important is it to you that you interact with other patient partners through your engagement activities rather than participate on your own? If interested, please provide more detail in the comment box.**

- Extremely important
- Very important
- Somewhat important
- Not very important
- Not important at all

**21. Have you established relationships with other patient partners outside of the activities that you've been involved in together?**

- No
- Yes → Please indicate the types of relationships you have formed with other patient partners and provide additional comments, if interested: (select all that apply)
  - I have formed personal friendships with other patient partners as a result of my engagements
  - I mentor or provide guidance to other patient partners
  - I seek guidance and mentorship from other patient partners
  - I am part of a patient partner network(s). Please provide details about the network you are a part of:
  - Other, please describe:

***We are interested in the skills and knowledge that you find useful in your patient partner role and how well you have been supported.***

**22. Which of the following skills and knowledge are useful for you to have in your patient partner role?**

| Skills and Knowledge   | I have and use this | This is useful for me in my role. I would like to acquire or develop this further | This isn't useful for me in my role | Unsure |
|--|---------------------|---|-------------------------------------|--------|
| Negotiation  |                     |   |                                     |        |
| Public speaking (e.g. presentations)   |                     |   |                                     |        |
| Computer skills  |                     |   |                                     |        |
| Ability to provide critical feedback   |                     |   |                                     |        |
| Listening  |                     |   |                                     |        |
| Writing  |                     |   |                                     |        |
| Research   |                     |   |                                     |        |
| Leadership   |                     |   |                                     |        |
| Knowledge of the health care system  |                     |   |                                     |        |
| Knowledge of the organization you are working with   |                     |   |                                     |        |
| Sharing my story/storytelling skills   |                     |   |                                     |        |
| Facilitation (e.g., how to run a good meeting)   |                     |   |                                     |        |
| Knowledge specific to the area I'm contributing to (e.g., health technology assessment, quality improvement, policy development) |                     |   |                                     |        |

**23. What supports have been most helpful to you in your patient partner role? For example, supports could include things like being oriented to your role, having a contact person in the organization you can contact, caregiving support, etc. (Please list up to three)**

***We are interested in learning more about your motivations for being a patient partner and how your work as a patient partner has impacted you and others.***

**24. How important are the following factors when you are making a decision to get involved in a patient engagement activity?**

| Factors  | Extremely important | Very important | Neither important nor unimportant | Not very important | Not important at all |
|--|---------------------|----------------|-----------------------------------|--------------------|----------------------|
| Understanding what is expected   |                     |                |                                   |                    |                      |
| Fit with your focus and interests  |                     |                |                                   |                    |                      |
| Opportunity to learn new skills and knowledge                                    |                     |                |                                   |                    |                      |
| Opportunity to build new relationships or strengthen existing ones               |                     |                |                                   |                    |                      |
| The group I would be working with  |                     |                |                                   |                    |                      |
| Amount and type of work expected of you  |                     |                |                                   |                    |                      |
| Compensation offered   |                     |                |                                   |                    |                      |
| Supports available to carry out my role  |                     |                |                                   |                    |                      |
| Opportunity to make an impact on the organization or project I was involved with |                     |                |                                   |                    |                      |
| Opportunity to make an impact on the health system                               |                     |                |                                   |                    |                      |
| Opportunity to have my voice heard   |                     |                |                                   |                    |                      |

**25. Thinking about all of your experiences as a patient partner, how often have you felt...**

|                       | Always | Most of the time | Some of the time | Infrequently | Never |
|-----------------------|--------|------------------|------------------|--------------|-------|
| Valued                |        |                  |                  |              |       |
| Needed                |        |                  |                  |              |       |
| Like I wasted my time |        |                  |                  |              |       |
| Disappointed          |        |                  |                  |              |       |
| Self-conscious        |        |                  |                  |              |       |
| Overwhelmed           |        |                  |                  |              |       |
| Enthusiastic          |        |                  |                  |              |       |
| Ignored               |        |                  |                  |              |       |
| Exploited             |        |                  |                  |              |       |

**26. In the various patient partnering activities you've been involved in, how often have you been able to do the following:**

|   | Always | Most of the time | Some of the time | Infrequently | Never |
|---|--------|------------------|------------------|--------------|-------|
| See how your input was reflected in decisions or changes that were made   |        |                  |                  |              |       |
| Provide feedback on how the engagement activity went  |        |                  |                  |              |       |
| Provide feedback on the organization's approach to engaging patients, clients, family members and/or caregivers |        |                  |                  |              |       |

**27. Thinking about all of your experiences, what influence do you think you have had as a patient partner?**

| Influences  | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly Agree |
|---|-------------------|----------|----------------------------|-------|----------------|
| Improved communication between patients/caregivers and health systems |                   |          |                            |       |                |
| Affected the thinking of people in positions of influence             |                   |          |                            |       |                |
| Improved the health system for future patients and/or caregivers      |                   |          |                            |       |                |
| Affected decisions in healthcare                                      |                   |          |                            |       |                |
| Paved the way for others  |                   |          |                            |       |                |
| Created new knowledge   |                   |          |                            |       |                |
| Unsure if I have had any influence                                    |                   |          |                            |       |                |
| I have not had any influence  |                   |          |                            |       |                |

**28. Do you think the lived experience you bring to your patient partner activities make you an expert? Please explain in the box below**

- Yes
- No

**29. What is the most stressful thing about being a patient partner?****30. What have you gained the most from your experience as a patient partner?****31. What are the biggest barriers have you faced as a patient partner?**

| Barriers  | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly Agree |
|---|-------------------|----------|----------------------------|-------|----------------|
| Not being heard, feeling dismissed  |                   |          |                            |       |                |
| The assumption that I represent all patients  |                   |          |                            |       |                |
| Power imbalances  |                   |          |                            |       |                |
| Unclear expectations about my role  |                   |          |                            |       |                |
| Accessibility (e.g. technology, physical access, location)                                    |                   |          |                            |       |                |
| Scheduling and logistics  |                   |          |                            |       |                |
| Use of acronyms and jargon  |                   |          |                            |       |                |
| Learning about patient partner opportunities  |                   |          |                            |       |                |
| Costs associated with my role (e.g. software, scientific journals, wardrobe, internet access) |                   |          |                            |       |                |
| Discrimination  |                   |          |                            |       |                |
| I have not faced any barriers as a patient partner  |                   |          |                            |       |                |
| Other, please specify   |                   |          |                            |       |                |

**32. If you wish, please provide more details about the barriers you faced and/or how you overcame them.****33. Has there ever been a time when you gave serious thought to quitting your role(s) as a patient partner?**

- No
- Yes → What prompted this?

**34. Given the impact of COVID-19 on our daily lives, we are interested in how the pandemic has affected your activities as a patient partner. Has the COVID-19 pandemic had an impact on your patient partner activities?**

- Yes → Please describe how your patient partner activities have been influenced by the pandemic.
- No

**Demographics: Who are Canada's patient partners?**

We want to learn more about the patient partner community in Canada. Please help us by answering the following questions about yourself. Please remember that this survey is anonymous.

**35. How old are you? \_\_\_\_\_ years**

**36. Please provide the first three letters/numbers of your postal code (e.g., L7M)**

\_\_\_\_\_

**37. Where you born in Canada?**

- Yes
- No → What year did you arrive in Canada? \_\_\_\_\_

**38. What gender category do you identify with: (please select all that apply)**

- Man
- Woman
- Transgender
- Non-Binary
- Other, please specify:
- I prefer not to answer

**39. What is the highest level of education you have completed?**

- Less than high school
- High school diploma
- College
- Apprenticeship
- University → Please indicate your highest degree and the area of study:
- Other, please specify:
- I prefer not to answer

**40. Which race category best describes you? Check all that apply:**

- Black (Examples: African, Afro-Caribbean, African Canadian descent)
- East/Southeast Asian (Examples: Chinese, Korean, Japanese, Taiwanese descent or Filipino, Vietnamese, Cambodian, Thai, Indonesian, other Southeast Asian descent)
- Indigenous (First Nations, Inuk/Inuit, Métis) → Do you identify as First Nations, Inuk/Inuit and/or Métis?
- Latino (Examples: Latin American, Hispanic descent)
- Middle Eastern (Examples: Arab, Persian, West Asian descent (e.g., Afghan, Egyptian, Iranian, Lebanese, Turkish, Kurdish))
- South Asian (Examples: East Indian, Pakistani, Bangladeshi, Sri Lankan, Indo-Caribbean descent)
- White (Example: European descent)
- Other, please specify:
- Do not know
- Prefer not to answer

**41. In general, would you say your health is....**

- Excellent
- Very good
- Good
- Fair
- Poor
- Prefer not to answer

**42. Do you have any of the following disabilities or underlying health conditions? (Please select all that apply)**

- No disabilities or health conditions
- Sensory disability (i.e. hearing or vision loss)
- Chronic illness
- Drug or alcohol dependence
- Developmental disability
- Physical disability
- Learning disability
- Mental illness
- Other, please specify
- Do not know
- Prefer not to answer

**43. Which of the following best describes you.... (Please select all that apply)**

- Full-time employed
- Part-time employed
- Self-employed
- Unpaid Caregiver
- Full-time student
- Part-time student
- Receiving disability benefits
- Receiving income replacement benefits (e.g., Employment Insurance, Ontario Works)
- Retired
- Full-time volunteer
- Part-time volunteer
- On a leave (e.g., parental leave, short-term leave)
- I prefer not to answer
- Other, please specify

**44. What is your best estimate of your total household income, before taxes and deductions, from all sources during the year ending December 31, 2019? [Income can come from various sources such as from work, investments, pensions or government. Examples include Employment Insurance, social assistance, child benefits and other income such as child support, spousal support (alimony) and rental income.]**

- \$0 to \$29,999
- \$30,000 to \$59,999
- \$60,000 to \$89,999
- \$90,000 to \$119,999
- \$120,000 to \$149,999
- \$150,000 or more
- Do not know
- Prefer not to answer



**45. How many people (including yourself) does your household income support?**

- \_\_\_\_\_

**46. Have you ever worked as a healthcare provider?**

- Yes, I am currently practicing as a healthcare provider. Please indicate your role:
- Yes, I was a healthcare provider in the past. Please indicate your role:
- Yes, I am training to become a healthcare provider. Please indicate your role:
- No, I am not a healthcare provider.

**Survey wrap-up**

- 47. Thank you for sharing your experiences as a patient partner with us through this survey. This survey is the first to examine patient partner roles in depth in Canada. Is there anything that we haven't asked you that you would like us to know about your experience as a patient partner? If so, please share below.**