

BMJ Open Understanding patient partnership in health systems: lessons from the Canadian patient partner survey

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ABSTRACT

Objectives To examine the sociodemographic characteristics, activities, motivations, experiences, skills and challenges of patient partners working across multiple health system settings in Canada.

Design Online cross-sectional survey of self-identified patient partners.

Setting Patient partners in multiple jurisdictions and health system organisations.

Participants 603 patient partners who had drawn on their experiences with the health system as a patient, family member or informal caregiver to try to improve it in some way, through their involvement in the activities of a group, organisation or government.

Results Survey respondents predominantly identified as female (76.6%), white (84%) and university educated (70.2%) but were a heterogeneous group in the scope (activities and organisations), intensity (number of hours) and longevity (number of years) of their role. Primary motivations for becoming a patient partner were the desire to improve the health system based on either a negative (36.2%) or positive (23.3%) experience. Respondents reported feeling enthusiastic (83.6%), valued (76.9%) and needed (63.3%) always or most of the time; just under half felt they had always or often been adequately compensated in their role. Knowledge of the health system and the organisation they partner with are key skills needed. Two-thirds faced barriers in their role with over half identifying power imbalances. Less than half were able to see how their input was reflected in decisions or changes always or most of the time, and 40.3% had thought about quitting.

Conclusions This survey is the first of its kind to examine at a population level, the characteristics, experiences and dynamics of a large sample of self-identified patient partners. Patient partners in this sample are a sociodemographically homogenous group, yet heterogeneous in the scope, intensity and longevity of roles. Our findings provide key insights at a critical time, to inform the future of patient partnership in health systems.

INTRODUCTION

In their call for a ‘patient revolution’ almost a decade ago, Richards *et al.*¹ argued for ‘a fundamental shift in the power structure in healthcare’.¹ Their revolution manifesto

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Examines, at the population level, the characteristics, activities and experiences of a large sample of self-identified patient partners.
- ⇒ Survey structure (closed-ended and open-ended responses) allowed for a comprehensive description of patient partner activities and experiences.
- ⇒ Reliance on an online snowballing approach and the research team’s networks to promote the survey (due to lack of a national registry of patient partners) limited survey reach
- ⇒ Survey was administered during the second major wave of COVID-19 in Canada, which may have limited and shaped survey responses.

viewed patients, families and communities as key partners needed to accelerate healthcare improvement efforts¹ aimed at reorienting health systems to improve experiences, quality and population health outcomes.^{2–4} Various labels have been assigned to this new partnership role—including patient partner, patient advisor, or some combination of patient, family and/or caregiver partner or advisor. Patient partner roles can now be found at all levels of the health system, from clinical and organisational to policy and governance⁵ and across a wide range of domains and sectors from education, training and research to service design, healthcare improvement, policy and regulation.^{5,6} In Canada, patient partnership has been formalised in health systems through provincial reviews and frameworks,^{7–9} legislation^{10–12} and strategic directions initiated at the national, provincial and regional levels.^{13–16} The precise number of patients in these roles in Canada is unknown, although rough estimates suggest they number in the thousands.^{14,17} While governments and organisations have implemented patient partnership in different ways, a common feature is patients being invited into largely hierarchical organisations to

contribute in ways they have never been asked to before. Limited evidence, to date, suggests that patient partners may be well positioned to influence healthcare processes and outcomes.^{2 18} The small number of (primarily) case studies that have explored the experiences of patient partners indicate that they view their roles positively. For example, reports of increased self-esteem and feelings of empowerment suggest supportive and enabling environments.² They have also experienced challenges in these roles, have sought greater involvement or felt that their involvement was important but tokenistic.²

As we enter a second decade of patient partnership in health systems, new terms such as ‘engagement-capable environments’⁶ and ‘patient leaders’¹⁹ have surfaced, hinting at a view of patient partners as part of the health workforce.²⁰ Yet we have no consolidated understanding of patient partners as an emerging resource. Who are they, what inspires them to undertake their work, what skills do they bring to that work and what supports might better sustain their efforts? Current knowledge about patient partners is localised to experiences within single organisations, provinces or sectors, largely compiled and analysed by sponsoring organisations.^{21 22} While these localised experiences are instructive, they fail to generate the comprehensive and cross-cutting learning that comes from the study of the population-level experiences and dynamics across a large swath of patient partners. The Canadian Patient Partner Survey, a nationwide survey of patient partners in Canada, is well positioned to address these knowledge gaps and to inform future directions for patient partnership in health systems. The aim of the survey was to gain an understanding of the roles, demographics and experiences of patient partners in Canada and to draw out broadly applicable lessons for other jurisdictions.

METHODS

Study sample and recruitment

We developed, piloted and administered the Canadian Patient Partner Survey, an anonymous online survey of Canadian residents who self-identified as patient partners. The meaning of ‘patient partner’ was described in a detailed paragraph at the beginning of the survey which helped to establish survey eligibility: ‘people (patients, clients, family members and caregivers) who are drawing on their past or current experiences with the health system in some way, usually through their involvement in the activities of a particular health system group, organisation, or government’. Patient partners contributing only at the clinical level were excluded given the study’s focus on organisation and policy-level decisions. There is no known list of patient partners in Canada; thus, our sampling frame could not be clearly defined at the outset of the survey.

An online snowballing approach was used to recruit survey participants.²³ The snowballing recruitment process was designed to maximise diversity in the perspectives,

roles and experiences of respondents participating in the survey. A first round of emails was sent to members of the study team and external advisory committee, composed of patient partners, engagement researchers and health system professionals, who were asked to distribute the survey invitation widely through their networks. Survey recruitment information and links were also sent to health system organisations across Canada with requests to share them directly with their patient partners. The survey was also promoted on various social media platforms (Twitter, Facebook and LinkedIn) at multiple points during the recruitment phase with requests for those viewing the posts to share them with their networks. Survey completers were given the opportunity to enter a draw to win one of three CAD\$200 cash prizes.

Survey development

The survey was developed following a rigorous multi-step process. This included reviewing the literature to identify relevant pre-existing surveys and variables in the field, followed by extensive consultations with members of our research team (comprising experienced patient partners, an engagement practice leader and academic researchers with extensive experience in survey design methodology). We also sought the expertise of an external advisory committee including both Canadian and international representation and additional patient partners (external to the research team). The survey was piloted with 11 patient partners in four provinces, in French and English. Pilot study participants were identified using a maximum variation approach to ensure the survey’s face and construct validity with a wide range of patient partners working in different organisational and health system contexts. Pilot testing was carried out in two phases. Some participants were asked to review the survey independently and provide their overall feedback and in specific areas (ie, if response options adequately captured their experiences, what questions were missing, what was unclear). Others worked through the survey with a member of the research team in attendance (by zoom or by phone) to allow the participant to provide real-time feedback and to allow the research team member to directly assess comprehension and survey completion experience. The survey development process occurred over a 9-month period during which survey items and overall structure were iteratively refined resulting in a final version with strong face and construct validity. The full survey has been attached as online supplemental file 1.

The survey was structured around five analytical domains to describe the community of patient partners across Canada: (1) demographically (who are Canada’s patient partners? how diverse are they compared with the Canadian population and how heterogeneous are they as a group?); (2) functionally (how do they enter into their roles? what are the core activities of a patient partner/advisor? how many organisations are they partnering with and how long do they stay in these roles?);

Table 1 Respondent characteristics*

Characteristic	Statistic	All % (n)
Age	Mean (SD)	57.5 (14.4)
	Median (range)	60 (16–90)
Gender	Female	76.6 (412)
	Male	21.0 (113)
	Transgender	0.7 (4)
	Non-binary	0.2 (1)
	Refuse	1.5 (8)
Education	Completed university education or higher	70.2 (380)
Household income	> CAD\$90 000	43.3 (181)
Race	White	84 (462)
Indigenous	Yes	2.2 (6)
Born in Canada	Yes	82.9 (512)
Self-reported health status	Excellent/very good/good	74.3 (399)
	Poor/Fair	24.8 (132)
Disabilities/health conditions	Chronic illness	49.0 (269)
Employment	Employed full-time	17.5 (96)
	Retired	43.2 (237)
	Receiving disability and/or income replacement benefits	11.9 (72)
Residency	Urban	89.4 (457)
	Rural	10.6 (54)
Experience individual drew on for first engagement activity (all that apply)	Experience as an unpaid caregiver	48.9 (295)
	Patient with acute/chronic illness	62.0 (374)
	Patient who accesses periodic care/screening	46.8 (282)

*Non-responses have been removed from each data point; total number of responses per question ranged from 418 to 602.

(3) philosophically (what are their motivations for these roles?); (4) professionally (what skills and expertise do they bring to these roles? what additional skills do they need?); and (5) ethically (what challenges, harms and impacts have they faced in these roles?).

The survey included a combination of continuous and categorical variables using Likert scales and drop-down menus with both closed and open-ended questions. Survey questions were written at a grade 9 reading level and jargon was minimised through extensive review and pilot testing of both the survey content and the online survey platform.

Data collection

The survey was available in both English and French via LimeSurvey, an online survey platform available to all McMaster University researchers. The survey included four pages of questions, with between 2 and 21 questions per page. Respondents could use the 'back' button to review and/or change their answers if desired. Both English and French versions of the survey were piloted tested with a varied sample of patient

partners (eg, more vs less experienced working in different sectors) in British Columbia, Ontario, Quebec and Nova Scotia. The survey was open for responses between October and December 2020.

Data analysis

Structured data (ie, multiple choice) were cleaned and duplicates removed. User-created identification codes ensured the generation of unique survey responses. The data analysis used simple descriptive techniques including contingency and cross-tabulation analyses within Stata. Where appropriate, combining some variables yielded composite measures. Respondents had extensive opportunities throughout the survey to include additional, clarifying information through open-ended questions and text boxes to elaborate on quantified responses. An inductive approach allowed categories to be identified from the data.²⁴ Excel was used to manage the categorisation of all qualitative data.

Patient and public involvement

Patient partners contributed to all aspects of the larger Canadian Patient Partner Study and survey. The research team's two patient partner members (CC and MAL) are co-leads of a national peer-led patient partner network and have participated in all study phases (study conceptualisation and grant application preparation, survey conceptualisation and questionnaire development, pilot testing, data collection and interpretation, manuscript preparation). Additional patient partners contributed to the survey development and 11 patient partners participated in the pilot testing phase. All survey respondents self-identified as patient partners.

RESULTS

Respondent characteristics

A total of 603 individuals participated in the CPPS survey. The median time to complete the survey was 37 min. As discussed previously, a response rate could not be calculated due to the unknown number of patient partners in Canada. Survey respondents most often identified as female (76.6%), white (84%) and born in Canada (82.9%) (table 1). The average respondent age was 57.5 years, compared with the average age of the Canadian population of 41.1.²⁵ Nearly three-quarters had completed university-level education or higher (70.2%) compared with 26.1%²⁶ of the general Canadian population and 43.3% reported a household income of CAD\$90 000 or more, compared with 37.7%²⁷ of the general Canadian population. The majority of respondents (89.4%) live in an urban area of Canada, compared with 83.8% of the general Canadian population.²⁸ While some (17.5%) respondents are employed full time (which may have included their patient partner roles if individuals view that as their full-time work), many (43.2%) indicate that they are retired. Nearly half (49.0%) reported having a chronic illness. Three-quarters (74.3%) claimed good to excellent overall health, compared with 85.4% of the general population.²⁹ Just under half of respondents

Table 2 Patient partners' activities and experiences

Characteristic	Statistic	All* % (n)
Actively engaged as a patient partner	Yes	85.0 (534)
Actively engaged with original organisation	Yes	80.9 (423)
No of organisations partnered with	1	44.4 (268)
	2–5	37.8 (228)
	6 or more	17.7 (107)
Year began as a patient partner	Prior to 2010	18.2 (106)
	2010–2015	34.6 (202)
	After 2015	47.3 (276)
Initial focus/interest	Improving healthcare based on negative experience	36.2 (213)
	Giving back/improving healthcare based on positive experience	23.3 (137)
	Learning about health system to improve care for myself/family member	10.7 (63)
	Serving my community	10.2 (60)
No of hours per month spent on patient partner activities	10 or less	53.9 (280)
	11–40	35.4 (184)
	More than 40	10.8 (56)
Adequately compensated for work	Always/often	49.9 (255)
Established relationships with other patient partners outside of engagement activities	Yes	53.7 (301)

*Non-responses have been removed from each data point; number of responses per question ranged from 511 to 603.

(48.9%) also reported having experience as an unpaid caregiver.

Patient partner role trajectories and activities

Most respondents reported being active in their patient partner role at the time of the survey (85.0%) and continuing to work with the same organisation they first partnered with (80.9%) (table 2). Just under half began their patient partnering work within the last 5 years (47.3%) with a sizeable group (18.2%) reporting experience of 10 years or more.

Respondents most commonly began their patient engagement work with hospitals (34.4%) or provincial health organisations (14.4%). Just under half (44.4%) had partnered with one organisation, just over one-third (37.8%) reported affiliations with 2–5 organisations and

a small group (17.7%) reported working with at least six organisations. Respondents reported participating in a wide range of activities with the organisations with which they partner. Their experiences as patient partners included attending meetings, sharing feedback/opinions, sharing experiences/stories/perspectives and assisting with research activities.

Over half of respondents (53.9%) reported that their patient partner activities consumed 10 or fewer hours/month. A small group (10.8%) were heavily engaged with partnering activities consuming up to 40 or more hours/month; a large proportion of this group (60.7%) reported working with at least six organisations.

Motivations, perceived value and secondary benefits of patient partnering

To gain insights into their motivations and priorities, we asked respondents to identify their initial focus of interest in becoming a patient partner and the factors they consider important in choosing to get involved in an engagement activity (table 2). Over one-third of respondents (36.2%) identified their initial focus as a desire to improve the health system because of a negative experience; just under a quarter were motivated to improve or give back based on a positive experience (23.3%). Other motivations were split roughly evenly between learning how the health system works to improve their own or a family member's healthcare (10.7%) or serving their community (10.2%). When making subsequent decisions about which engagement activities to take on, respondents prioritised the opportunity to make an impact on the health system (62.4%), or the organisation or project they were involved with (56.1%) and having a clear understanding of what is expected of them in their role (60.1%).

In reflecting on their overall experiences as patient partners, respondents reported a high degree of personal reward such as feeling enthusiastic (83.6%), valued (76.9%) and needed (63.3%) always or most of the time. However, just under half stated that they felt they had always or often been adequately compensated in their partnering activities (49.9%). Patient partners also appear to accrue other benefits from their role. Just over half of respondents (53.7%) reported developing relationships with other patient partners outside of their engagement activities; most of these involved the formation of personal friendships (78.1%). Additionally, about half reported that they had joined a patient partner network (50.2%), sought mentorship/guidance from another patient partner (49.5%) or provided mentorship/guidance to others (54.8%).

Supports and barriers to patient partners

We inquired about what knowledge and skill areas might provide useful supports to patient partners in their role (table 3). Over half (52.3%) of respondents reported that having knowledge of the healthcare system was something they had found useful, and almost half (45.9%)

Table 3 Supports and barriers to patient partners

Characteristic	Statistic	All* % (n)
Knowledge and skills useful to your role (Have and use, would like to acquire/develop this further)	Knowledge of the healthcare system	52.3 (291)/45.9 (255)
	Knowledge related to the area I'm contributing to	40.0 (219)/52.2 (286)
	Knowledge of the organisation I'm working with	53.1 (293)/44.8 (247)
	Research	46.1 (250)/36.0 (195)
	Facilitation	48.4 (264)/34.1 (186)
Barriers faced (Strongly agree/agree)	Power imbalances	50.7 (265)
	Use of acronyms and jargon	46.1 (245)
	Unclear expectations	40.2 (212)
	Not feeling heard, feeling dismissed	34.8 (185)
	Scheduling and logistics	31.6 (163)
	Learning about patient partner opportunities	28.8 (149)
	The assumption I represent all patients	27.8 (144)
	Accessibility (eg, technology, physical access, location)	27.4 (142)
	Costs associated with my role	23.8 (122)
	Discrimination	12.8 (65)
	I have not faced any barriers	34.4 (164)
Most helpful supports	Staff support from organisation (contact person, administrative support)	55.1 (283)
	Orientation/training	29.8 (153)
	Relationships with other patient partners	12.5 (64)
Thoughts about quitting	Yes	40.3 (213)

*Non-responses have been removed from each data point; number of responses per question ranged from 447 to 556.

also identified this as an area where they would like to increase their knowledge. Similarly, respondents indicated that knowing about the organisation they are partnering with (53.1%) and the area they are contributing to (40.0%) was useful to them in their partnering roles, as well as areas where they would like to learn more (52.2% involvement area and 44.8% organisation, respectively). When asked to identify the three most helpful supports to them in their roles, the most common responses were staff support from the organisation (eg, having a contact person, having administrative support) (55.1%), access to ongoing training and/or an orientation session (29.8%) and relationships with other patient partners (12.5%).

About two-thirds (65.6%) of respondents reported that they faced barriers in their role. Just over half identified power imbalances (50.7%); the use of acronyms and jargon (46.1%) and unclear expectations (40.2%) were also commonly cited. The assumption that they represent all patients (27.8%), accessibility (27.4%) and costs associated with their role (23.8%) were also mentioned. A sizeable number (40.3%) also indicated they had considered quitting patient partnership at some point.

Perceived influence through their role

Respondents were asked to describe the types of influence they believed they had exerted through their patient partnering, across all experiences (table 4).

About one-third were sceptical of having any influence; they were either unsure (25.7%) or did not believe they had any influence at all (7.7%). Nearly three-quarters of respondents perceived that their work had positive impacts, on the thinking of people in positions of influence (73.3%) and on communication between patients/caregivers and their health systems (72.2%). Over two-thirds also believed that their partnership work had improved the health system for future patients and/or caregivers (68.1%), and just over half agreed or strongly agreed they had affected health system decisions (56.1%). When asked specifically how often they were able to see how their input was reflected in decisions or changes, a sizeable group (42.1%) indicated this happened always or most of the time. Respondents also reported a sense of perceived influence through opportunities to evaluate and provide feedback on engagement activities (57.3%) and the organisation's overall approach to engagement (53.5%).

We also probed about respondents' experience and expertise as a potential source of influence. A majority of respondents (61.7%) identified that the lived experience they bring to their patient partner roles makes them an expert, yet when asked if they see themselves as an expert, only 22.7% agreed. Respondents who viewed themselves as experts tended to be more deeply involved in patient

Table 4 Patient partners' perceived influence in role

Characteristic	Statistic	All* % (n)
Perceived influence (agree/strongly agree)	Improved communication between patients/caregivers and health systems	72.2 (379)
	Affected the thinking of people in positions of influence	73.3 (389)
	Improved the health system for future patients and/or caregivers	68.1 (361)
	Affected decisions in healthcare	56.1 (292)
	Paved the way for others	73.4 (384)
	Created new knowledge	73.7 (383)
	Unsure I had any influence	25.7 (133)
	I didn't have any influence	7.7 (39)
See impact of their engagement (always/most of the time)	See how your input was reflected in decisions or changes that were made	42.1 (225)
	Provide feedback on how the engagement activity went	57.3 (306)
	Provide feedback on the organisation's approach to engagement	53.5 (285)

*Non-responses have been removed from each data point; number of responses per question ranged from 505 to 553.

partnering, with 64.1% working more than 10 hours per month and 27.0% working with at least six organisations.

Within group analyses

We conducted exploratory analyses of responses related to patient partner activities, experiences, supports, barriers and influences by sociodemographic (age, race, gender, income, urban/rural, patient/caregiver and self-reported health status) and did not identify any meaningful within-group differences.

DISCUSSION

This national survey of patient partners is the first of its kind to develop a comprehensive understanding of the growing patient partner role in health systems. Jurisdictions around the world, including Canada, have been experimenting with expanded roles for patients, families and caregivers in their health systems, with anecdotal or localised information to guide planning and decision making in this area. Our findings offer several key messages to address this knowledge gap.

First, our findings contribute to the ongoing discourse about the representativeness of patient partners, how well they reflect the diversity and experiences of current and future health system users and whether this is a desirable or feasible goal.^{30 31} Our sample of patient partners was a sociodemographically homogenous group; most respondents were retired White females over age 50, with high socioeconomic status. On age and gender dimensions, they reflect a large cross-section of health system users (ie, older adults) and those in caregiving roles (women). However, on other important dimensions (eg, race, education and income), they do not. This 'lack of diversity' in patient partnership has been the subject of recent, focused attention in the patient partnership field³² as health systems grapple with long-standing concerns about the exclusion of historically under-represented and equity-deserving populations. Organisations should

consider these findings and their implications for the recruitment and retention of patient partners who are more representative of the populations they are serving. A more nuanced view of how patient partners view themselves regarding their ability or desire to represent various subpopulations of patients and caregivers or communities in their work is also needed. An important part of this work will be understanding how recruitment approaches and institutional norms result in reaching different populations and potentially excluding some.

Second, our survey results also identified considerable heterogeneity in the patient partner role, most notably in scope, intensity and longevity. While over half of our respondents engage episodically with one or two organisations, a small but very heavily engaged group of patient partner respondents are spending more than 40 hours/month in this role, with multiple organisations. These demarcations in patient partnering trajectories call for more in-depth analysis to explore the experiences, advantages, challenges and supports needed in these different roles.

Third, our results uncovered some important dynamics at play in the patient partner population. On the one hand, respondents conveyed a strong sense of perceived value and influence. Yet half of them report being inadequately compensated and just under half have given thought to quitting their role. These tensions require further investigation to inform the supporting infrastructure needed for this role. Some of the supports and barriers identified by survey respondents, such as knowledge deficits, may be straightforward to address. Others will be more challenging to remedy. Notable among them are power imbalances (mentioned by half of our respondents), which were central to the call for a patient revolution a decade ago and will be foundational to advance many aspects of patient partnership. An additional consideration in moving forward will be the lessons learned about patient engagement and partnering

during the COVID-19 pandemic, including the benefits and challenges of remote online engagement as health system organisations look to expand patient partnership with underrepresented communities.³³

Strengths and weaknesses

This is the first study of its kind to survey and develop a comprehensive understanding of patient partners working across a variety of health systems and organisations (ie, across different Canadian provinces and territories with different political cultures and institutional arrangements). We note several limitations in our study. First, with no current national registry of patient partners, we relied on snowball sampling and team member networks to promote the survey. This approach may have limited our reach, particularly with looser and differentially connected groups of patient partners, a known characteristic of this field. As a result, the individuals who answered the survey may not represent all patient partners in Canada and future work is needed to further explore how to reach groups that may have been missed. Second, the survey was conducted in the Fall of 2020, during the second wave of COVID-19 in Canada; this may have shaped the experiences of patient partners recorded in their responses. The pandemic may have also limited who participated in our survey, given new demands and stresses on individuals. Third, given that many individuals bring multiple perspectives to their role as a patient partner (eg, patient, family member, informal caregiver) we were unable to examine the data by respondent background to understand how these different experiences and backgrounds may have shaped their views.

Few similar studies have been conducted in this field. A survey of patient partners in Alberta, Canada²¹ found similar results related to the demographic characteristics of respondents, with patient partners in that sample also being mainly older, well-educated females who were retired and living in urban areas.

Conclusion

The Canadian Patient Partner Survey is the first comprehensive effort at understanding the characteristics, activities and experiences of a national sample of patient partners working with a wide range of health system organisations across multiple sectors. Its findings provide key insights and lessons learned about patient partnership at an important time in health systems in Canada and around the world as they grapple with numerous systemic issues amplified by COVID-19, including notable inclusivity gaps between communities who experience the worst health outcomes and their level of engagement in the health policies affecting them. As we transition to the next stages of the current pandemic and beyond, understanding the profile, career paths, motivations and experiences of current patient partners will be essential to prioritising future goals for patient partnership and the collaborations needed for the patient revolution to achieve its vision of healthcare transformation.

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Contributors JA conceived the idea of the survey and oversaw all aspects of its development. CC, ML, MAL, PR, LT, MV, JP, DC, P-GF, DS and GW contributed substantively to the design of the survey including item development, structure and layout. JA, LT and DC led the data analysis. CC, ML, MAL, PR, MV, JP, DC, P-GF, DS and GW reviewed interim analyses and contributed to key analytical decisions. JA and LT drafted the original manuscript. CC, ML, MAL, PR, MV, JP, DC, P-GF, DS and GW reviewed and contributed to multiple revisions of the manuscript, and have approved the final version. JA and MV are the coprincipal investigators of the Canadian Patient Partner Study. JA is the guarantor, accepts full responsibility for the work, had access to all the data and was responsible for the decision to publish. JA attested that all listed authors met authorship criteria and that no others meeting the criteria had been omitted.

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Patient consent for publication Not applicable.

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Correction: *Understanding patient partnership in health systems: lessons from the Canadian patient partner survey*

Abelson J, Canfield C, Leslie M, *et al.* Understanding patient partnership in health systems: lessons from the Canadian patient partner survey. *BMJ Open* 2022;12:e061465. doi:10.1136/bmjopen-2022-061465

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BMJ Open 2022;12:e061465corr1. doi:10.1136/bmjopen-2022-061465corr1





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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?

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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)
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 - 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?)**
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- Yes, I've been a patient partner since I started in my first activity
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12. **Have you worked with any other organizations in your patient partner role?**
- Yes
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 - 5 – 10
 - 11 – 20
 - 21 – 30
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- 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:

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Honorarium (e.g., one-time payments that may or may not be tied to the amount of work carried out or time involved)					
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Conference registration and/or associated expenses					
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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
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18. Have you ever refused compensation? Please provide more detail in the comment box, if interested.

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 - 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:
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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				
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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)

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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
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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.**



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Compensation offered					
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	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.**