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 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 al1 argued for ‘a fundamental shift in the power structure in healthcare’.1 Their revolution manifesto viewed patients, families and communities as key partners needed to accelerate healthcare improvement efforts2 aimed at reorienting health systems to improve experiences, quality and population health outcomes.3 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.6 In Canada, patient partnership has been formalised in health systems through provincial reviews and frameworks7–9 and strategic directions initiated at the national, provincial and regional levels.10–13 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. 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. 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’21 have surfaced, hinting at a view of patient partners as part of the health workforce.29 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?);
The survey were piloted tested with a varied sample of patient if desired. Both English and French versions of dents could use the ‘back’ button to review and/or change questions, with between 2 and 21 questions per page. Respon-

Survey, 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

Survey questions were written at a grade 9 reading level (82.9%) (table 1). The average respondent age was 57.5 years, compared with the average age of the Canadian population of 41.1. Nearly three-quarters had completed university-level education or higher (70.2%) compared with 26.1% of the general Canadian population and 43.3% reported a household income of CAD$90,000 or more, compared with 37.7% 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. 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. Just under half of respondents

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Respondent characteristics*</th>
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<tbody>
<tr>
<td>Characteristic</td>
<td>Statistic</td>
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<tr>
<td>Age</td>
<td>Mean (SD)</td>
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<td></td>
<td>Median (range)</td>
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<td>Gender</td>
<td>Female</td>
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<td>Male</td>
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<td>Transgender</td>
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<td>Non-binary</td>
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<td>Refuse</td>
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<td>Education</td>
<td>Completed university education or higher</td>
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<td>Race</td>
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<tr>
<td>Indigenous</td>
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<tr>
<td>Born in Canada</td>
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<tr>
<td>Self-reported health status</td>
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<td></td>
<td>Poor/Fair</td>
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<tr>
<td>Disabilities/health conditions</td>
<td>Chronic Illness</td>
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<tr>
<td>Employment</td>
<td>Employed full-time</td>
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<td></td>
<td>Retired</td>
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<td></td>
<td>Receiving disability and/or income replacement benefits</td>
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<tr>
<td>Residency</td>
<td>Urban</td>
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<td>Rural</td>
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<tr>
<td>Experience individual drew on for first engagement activity (all that apply)</td>
<td>Experience as an unpaid caregiver</td>
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<td></td>
<td>Patient with acute/chronic illness</td>
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<td>Patient who accesses periodic care/screening</td>
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*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. 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 CPSS 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. Nearly three-quarters had completed university-level education or higher (70.2%) compared with 26.1% of the general Canadian population and 43.3% reported a household income of CAD$90,000 or more, compared with 37.7% 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. 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. Just under half of respondents


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(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%)
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 (eg, technology, physical access, location) (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

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**Table 3** Supports and barriers to patient partners

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

*Non-responses have been removed from each data point; number of responses per question ranged from 447 to 556.
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. 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 field 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, Canada23 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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10 Legislative Assembly of the Province of Ontario. Bill 74, The People’s Care Act2019
11 Legislative Assembly of the Province of Ontario. Patients First Act, 2016
Correction: Understanding patient partnership in health systems: lessons from the Canadian patient partner survey


This article has been corrected since it was published online. The funding statement has been changed from “The study was funded by the Canadian Institutes for Health Information, Project Number 165883.” to “The study was funded by the Canadian Institutes of Health Research (CIHR), Project Number 165883.”

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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.

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

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?

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

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

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

<table>
<thead>
<tr>
<th></th>
<th>Always</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>Infrequently</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valued</td>
<td></td>
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<tr>
<td>Needed</td>
<td></td>
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<tr>
<td>Like I wasted my time</td>
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<tr>
<td>Disappointed</td>
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<tr>
<td>Self-conscious</td>
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<tr>
<td>Overwhelmed</td>
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<tr>
<td>Enthusiastic</td>
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<tr>
<td>Ignored</td>
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<tr>
<td>Exploited</td>
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</tbody>
</table>

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

<table>
<thead>
<tr>
<th></th>
<th>Always</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>Infrequently</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>See how your input was reflected in decisions or changes that were made</td>
<td></td>
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<tr>
<td>Provide feedback on how the engagement activity went</td>
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<tr>
<td>Provide feedback on the organization’s approach to engaging patients, clients, family members and/or caregivers</td>
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<td></td>
</tr>
</tbody>
</table>
27. Thinking about all of your experiences, what influence do you think you have had as a patient partner?

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

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 you have faced as a patient partner?

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

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.
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.

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

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?

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

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

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

<table>
<thead>
<tr>
<th></th>
<th>Always</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>Infrequently</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valued</td>
<td></td>
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<tr>
<td>Needed</td>
<td></td>
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<tr>
<td>Like I wasted my time</td>
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<tr>
<td>Disappointed</td>
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<tr>
<td>Self-conscious</td>
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<tr>
<td>Overwhelmed</td>
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<tr>
<td>Enthusiastic</td>
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<tr>
<td>Ignored</td>
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<tr>
<td>Exploited</td>
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</tbody>
</table>

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

<table>
<thead>
<tr>
<th></th>
<th>Always</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>Infrequently</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>See how your input was reflected in decisions or changes that were made</td>
<td></td>
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<tr>
<td>Provide feedback on how the engagement activity went</td>
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<tr>
<td>Provide feedback on the organization’s approach to engaging patients, clients, family members and/or caregivers</td>
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<td></td>
</tr>
</tbody>
</table>
27. Thinking about all of your experiences, what influence do you think you have had as a patient partner?

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

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?

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

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.