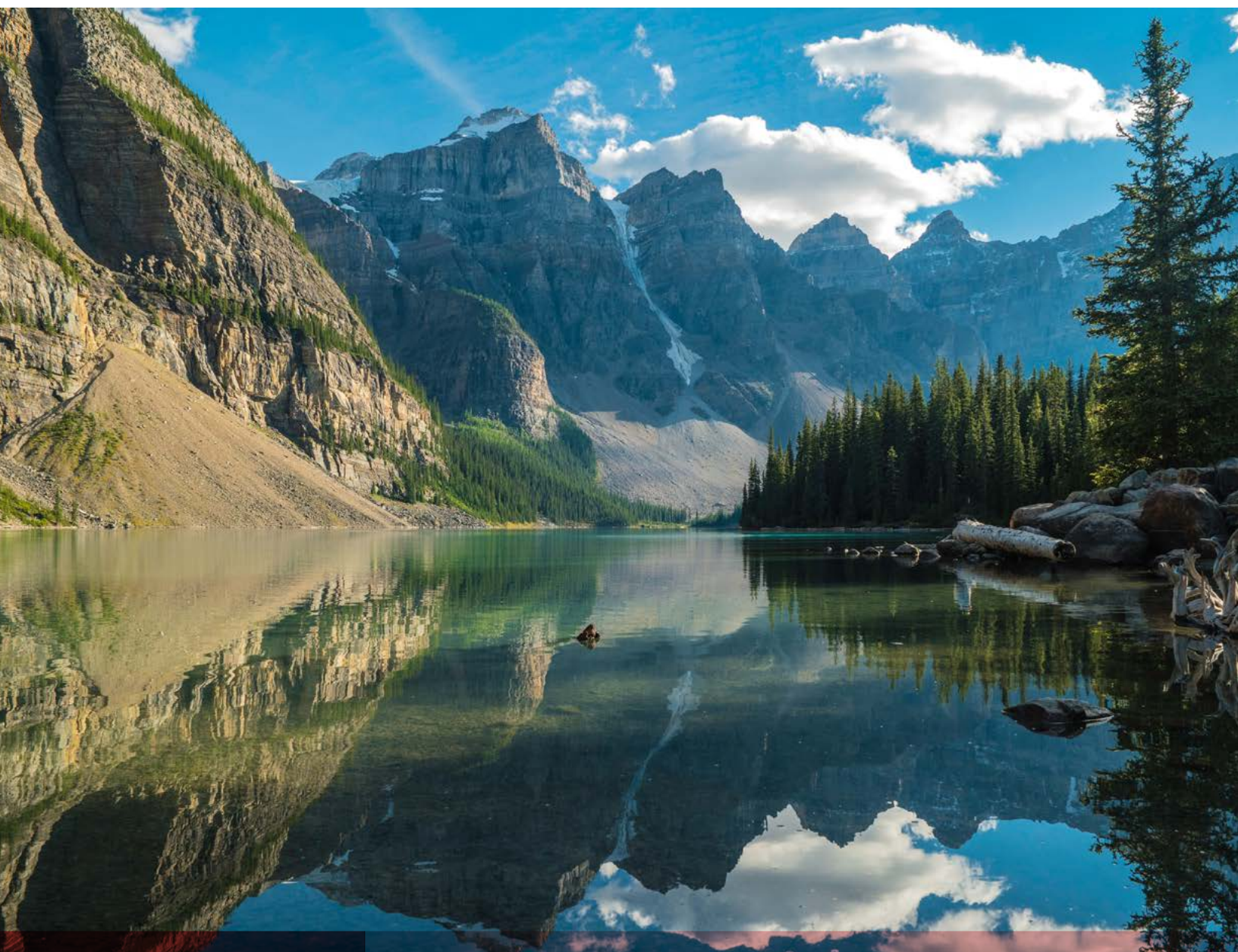


ALBERTA ROUNDTABLE REPORT

| Parkinson Canada



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ROUNDTABLE SERIES SUMMARY

The 2021 Parkinson Canada Roundtable Series consisted of eight regional roundtables, followed by a national session, over the course of three months. This effort brought together more than 150 voices from the Canadian Parkinson's community to gather understanding, insight, and clarity to support Parkinson Canada's advocacy efforts.

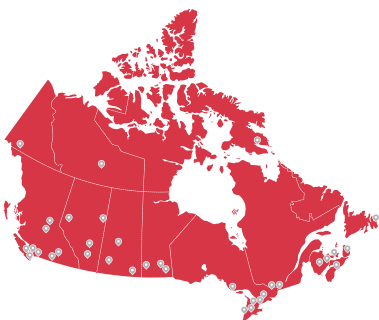
The purpose of the roundtables was to listen to the realities and unmet needs of the Parkinson's community and capture the key issues surrounding Parkinson's healthcare from provincial, territorial, and national perspectives. To support validation of the findings, Parkinson Canada strove for diverse participant representation. People living with Parkinson's, care partners, healthcare professionals, and regional Parkinson's organizations were all invited to participate in the roundtables.

Each roundtable was approximately three hours long and included, speakers, large group discussions, and smaller breakout conversations. Moderators facilitated the conversation and note-takers were present to accurately capture input and insights from the participants. For the purposes of privacy and encouraging an open dialogue, these roundtable sessions were not recorded, and quotations used within this document are anonymously attributed.

This regional report has been created to summarize the unique realities faced by members of the Parkinson's community in Alberta. Following the in-depth discussions from the National Roundtable and building off the eight regional roundtables, Parkinson Canada has identified key priorities for the Parkinson's community to consider to better improve the overall health and quality of life for those living with Parkinson's in Canada.

- Identify and address gaps for additional training and knowledge transfer to qualified healthcare professionals about Parkinson's, which will allow for earlier diagnosis and treatment of Parkinson's.
- Examine the systemic issues and barriers throughout the healthcare system to determine what steps can be taken to increase the number of healthcare practitioners available to support people with Parkinson's.
- Advance equitable access to care and improved treatments for all Canadians living with Parkinson's.

These priorities will provide a roadmap to the organization in developing our future advocacy work in supporting Canadians affected by Parkinson's.



The roundtable series brought together **more than 150 voices** from the Canadian Parkinson's community.

INTRODUCTION

UNDERSTANDING PARKINSON'S

Parkinson's is a chronic, progressive disease of the brain caused by the loss of certain brain cells producing a chemical called dopamine. These dying brain cells are in areas of the brain involved in coordinating movement. Individuals with Parkinson's may experience a resting tremor, slowness of movement, muscle rigidity, and balance problems. While Parkinson's is commonly thought of as a movement disorder, non-motor symptoms such as anxiety & depression, sleep issues, and cognitive impairment, including dementia, can also occur. The average age of diagnosis for Parkinson's is 60 years old, but some people are diagnosed prior to 50 and referred to as having early onset Parkinson's.

Currently, there is no cure for Parkinson's or treatments that can stop or slow the progression of the disease. There are only therapies to help manage the symptoms. Most Parkinson's medications work to maintain levels of dopamine in the brain. The gold standard medication for Parkinson's, Levodopa, helps to make up for the dopamine lost due to brain cell degeneration. Levodopa was developed in the 1960s. Surgical procedures like deep brain stimulation (DBS) and the insertion of a Duodopa® pump can also be options for people living with Parkinson's.

In addition, the following therapies can help manage Parkinson's symptoms, physical therapy and exercise for mobility, flexibility, and balance; occupational therapy for daily activities; speech therapy to help with voice and swallowing; and mental health services for depression and anxiety.

Every Parkinson's experience is unique, with symptoms and progression varying from person to person. Living with Parkinson's requires a holistic approach to care, which includes all aspects of an individual's life.

KEY PARKINSON'S TERMINOLOGY

Movement Disorder Specialist (MDS): A neurologist who has completed additional fellowship training in the area of movement disorders.

Wait time: Time an individual must wait to see a healthcare professional.

Care partner: Another term for caregiver.

Multidisciplinary care: This term can have wide-reaching definitions but for the purposes of this report, it refers to accessing a diverse range of healthcare professionals as part of the management of Parkinson's. Multidisciplinary care models can also involve components such as care coordination, education, and self-management support.

Integrated care: A healthcare model where healthcare professionals from different specialities communicate

and interact in the joint management of care. There can be many different degrees of integration from simply exchanging notes to more in-depth collaboration.

Deep Brain Stimulation (DBS): A neurosurgical procedure where electrodes are implanted deep into the brain and electrical stimulation is delivered through a pacemaker-like device. This electrical stimulation impacts dysfunctioning brain circuits and helps in the management of Parkinson's symptoms.ⁱ

Duodopa®: A gel mixture of levodopa-carbidopa (Parkinson's medications) administered continuously through a pump into the small intestine. It allows a constant and more consistent amount of levodopa to be present in the body.ⁱⁱ

AN OVERVIEW OF PARKINSON'S IN CANADA

Parkinson's disease has the fastest growing rates of death and disability compared to other neurological disorders such as dementias, MS, and stroke and Canada has one of the highest prevalence rates of Parkinson's compared to other countries.ⁱⁱⁱ

It is estimated there were more than 100,000 people in Canada living with Parkinson's in 2021.^{iv,v} That number will grow by about 30 people tomorrow and the day after that until we reach 50 new diagnoses per day within 10 years.^{iv,v}

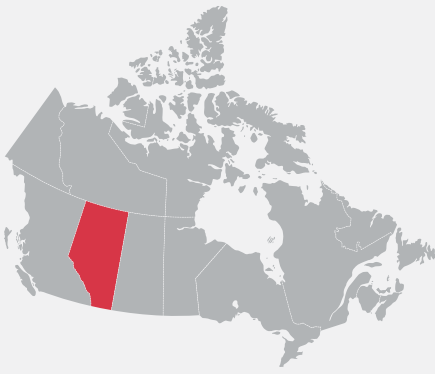
One in five people living in Canada with Parkinson's wait a year or more to receive a formal diagnosis after reporting their symptoms to a medical professional.^{vi} Prolonged wait times to receive diagnosis have serious implications for an individual's quality of life and increase the likelihood for both physical and mental health deterioration.

In 2018, the national wait time average to see a Parkinson's specialist, also known as a Movement Disorder Specialist (MDS), was 11 months with some regions reporting wait times of more than two years.^{vii} It is estimated that there is only one MDS for every 1,400 people living with Parkinson's in the country and most of these specialists are in major urban centres within the provinces, posing a geographical barrier for rural Canadians with Parkinson's.^{viii}

Currently, there are no MDSs in Prince Edward Island or in any of the territories. Furthermore, there are also no general neurologists in the territories. People living with Parkinson's in these regions must see travelling neurologists who visit intermittently, or they must attend appointments with clinicians in other provinces.

According to a 2018 IPSOS poll conducted by Parkinson Canada, many Canadians living with Parkinson's pay a portion of healthcare expenses out-of-pocket.^{vi} This includes critical healthcare services like medications and physiotherapy. Furthermore, nearly 75 per cent of survey respondents report paying a portion of exercise class expenses out-of-pocket.^{vi}

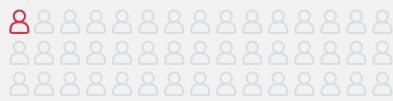
AN OVERVIEW OF PARKINSON'S IN ALBERTA



There are over **10,000** people living with Parkinson's in Alberta.



The provincial average wait time to meet with a Parkinson's specialist was **one - two years** in 2018.



There is **one** Parkinson's specialist for every **735** people with Parkinson's in the province.



Nearly **50%** of care partners in Alberta feel they do not have sufficient access to information or resources.



43% of individuals with Parkinson's pay out of pocket for medication costs.

It is estimated that there are over 10,000 people in Alberta living with Parkinson's. ^{ix} In 2018, the average wait time to see a Parkinson's specialist was one to two years, which was longer compared to other provinces. ^{vii}

It is estimated that there is only one Parkinson's specialist for every 735 people living with Parkinson's in Alberta. ^{viii}

There are 14 Parkinson's specialists in Alberta and all of them are in the province's two major cities, Calgary and Edmonton, posing geographical access barriers to residents living in rural areas. ^{vii}

Nearly 50 per cent of care partners in Alberta feel they do not have sufficient access to information or resources to properly care for the person with Parkinson's in their lives. ^{vi}

There are many living with Parkinson's in Alberta who are required to pay out of pocket for critical healthcare services. It is estimated over 50 per cent of individuals pay out of pocket for exercise programs and 37 per cent pay for physiotherapy. ^{vi} Furthermore, 43 per cent of individuals report paying a portion of their medication costs out of pocket. ^{vi}

ROUNDTABLE DISCUSSION THEMES

Three major themes were focused on during the roundtables. Summarized under each theme are the commonly held perspectives of the participants.

DIAGNOSIS WAIT TIMES

When participants of the Alberta Roundtable were polled, 80% felt that diagnosis wait times are a challenge in the province. A member in the group from a Parkinson's community organization shared her belief that a part of the issue with diagnosis wait times is the actual complexity of the disease and not necessarily due to a lack of Parkinson's specialists.

This sentiment was echoed by another member in the group who also works at the same Parkinson's community organization. She went on to add that while they believe there are delays with getting into meet with a movement disorders specialist, it is much faster for people to go to a community neurologist to receive a diagnosis.

There were some in the group living with Parkinson's who shared their experience with receiving diagnosis. One individual shared how it took him seven years of going to see a neurologist before they were finally able to give him a proper Parkinson's diagnosis.

“When it comes to diagnosis, it is important for specialists to educate neurologists and general practitioners on how to recognize symptoms of Parkinson's in the initial stages.”

- Movement Disorders Specialist, Calgary, Alberta

A movement disorders specialist who was in attendance discussed how with her clinic, wait times have been significantly reduced since she began working. She went on to add that typically it is the community neurologist who will make the initial diagnosis of Parkinson's, and usually patients are only referred to her clinic when there is uncertainty about the diagnosis or about how to manage the disease.

ACCESS TO CARE

The next topic of discussion was access to care. A person with Parkinson's shared his belief of the importance of people with Parkinson's being a part of a multidisciplinary healthcare team.

It was then mentioned how important it is to have care partner support when it comes to managing Parkinson's symptoms and attending various appointments. Another member in the group living with Parkinson's shared how when he initially was diagnosed, he would attend appointments with doctors and healthcare providers alone, but it was not until after his wife started to go with him that he felt much more supported and at ease.

One of the attendees who works at a Parkinson's community organization discussed how non-profits are "medically adjacent" and foster relationships with medical teams and can provide their clients with resources and help connect them to healthcare services. It was her belief that her organization is an important part of a Parkinson's healthcare team, even though they do not provide any medical care directly.

The conversation then shifted towards virtual healthcare. Several members of the group agreed that since the beginning of the COVID-19 pandemic, virtual medical appointments have been incredibly convenient and have spared people a lot of time and financial costs with not having to travel. Particularly for those living in more rural parts of the province who would have to travel to either Calgary or Edmonton to attend most of the appointments with specialists.

"I was able to meet with all members of my healthcare team in one video call and it was great. I did not meet with only one doctor and think 'oh I wish I had said that.' The whole experience was much faster and convenient."

- Person with Parkinson's, Edmonton, Alberta

On the other end of the spectrum, a movement disorders specialist in the group discussed how she does believe that online platforms, such as ZOOM, have made it fast and convenient to meet with her patients, but there are still patients who would like to be able to come in and see her in person and express concerns that they may not be receiving the same level of care as if they were being examined face-to-face. Furthermore, there are times that a clinician may want to have a patient come in to be assessed in person, but some patients are now reluctant to want to go in due to concerns with the pandemic.

“I love to have the virtual option, but also medicine is about having the physical examination. I would hate to go two years without seeing a patient, because they prefer to do virtual, and then find out they have something that should have been addressed sooner but was missed.”

- Movement Disorders Specialist, Calgary, Alberta

The topic was then raised about how attending appointments with healthcare providers is typically much easier for those who live in major cities versus rural communities. Expenses that are associated with travel can be quite high for people who may have a limited income and while there may be some government programs aiding with travel to medical appointments, they are not available to everyone.

One of the members in the group who works at a Parkinson's community organization then stated how important it is for care partners to have the proper education on Parkinson's. She went on to add how concerned she is that there does not seem to be much education or resources provided after initial diagnosis to patients and their care partners. Their organization will receive calls from people who are worried or uncertain about where to go for support, and their team at the non-profit ensure they provide as much education and resources as possible.

A member of the group with Parkinson's agreed with this statement and shared a few personal anecdotes on times in the past when he felt healthcare providers were lacking in education about Parkinson's.

One incident occurred while he was having a procedure done at the hospital and he noticed how the nurse was getting impatient with him for taking time to go from lying down to sitting up. He informed the nurse that he has Parkinson's, and she still was visibly frustrated. He went on to add that he has had a similar experience at the dentist.

MODEL OF CARE

The final topic of the roundtable was on a model of care for Parkinson's. It was initially raised by a member in the group that a multidisciplinary care model would be much easier to develop in a major city, rather than in a rural community. It would be more challenging to build a location that offers multiple healthcare professionals under one roof when most healthcare professionals are based in large city centres.

Another member in the group with Parkinson's shared that his family doctor will charge \$100 for each referral to a specialist or other healthcare provider and how this can become expensive. Being based in a rural community, he understands that you may not be able to get every healthcare service that you require without having to travel, but there should be a much broader selection of services offered close to where he lives.

“Parkinson's rates are growing, even in my small community. Parkinson's support groups are good and really help. My support group facilitator helps people get appointments and advocates for them.”

- Person with Parkinson's, Alberta

One of the Parkinson's community organization attendees then shared with the group some of the tough conversations that she has had in the past with members of the provincial government. Some of the feedback that she has received when inquiring about increased funding for Parkinson's with government has varied between sentiments such as, people living with Parkinson's are not voters, Parkinson's is incurable so there is no need to invest further into it, and there are people who have worse illnesses and advocate louder who get prioritized.

Another member in the group then suggested that Parkinson Canada should look to collaborate with other Parkinson's community organizations across the country to strengthen advocacy efforts to help see change from the government.

CONCLUSION

KEY PRIORITIES

During the Parkinson Canada Roundtable Series, members of the Canadian Parkinson's community spoke honestly about their current challenges and were both enthusiastic and hopeful that their shared insights will move towards meaningful action.

Upon concluding its roundtable series and after months of engaging with people living with Parkinson's, care partners, healthcare professionals, and other Parkinson's community organizations from across the country, we have gathered insights and have identified the following key priorities for improving the quality of life for people living with Parkinson's in Canada.

- Gaps have been identified in the support of the development and promotion of Parkinson's curriculum and awareness for family physicians and allied healthcare professionals. **Work needs to be done to address these gaps and provide additional training and knowledge transfer to qualified healthcare providers, which will allow for earlier diagnosis and treatment of Parkinson's.**
- Systemic issues exist within healthcare across Canada, which means people living with Parkinson's are underserved given the limited number of Parkinson's Nurse Specialists and Movement Disorder Specialists. **Systemic issues and barriers throughout the healthcare system need to be examined to determine what steps can be taken to increase the number of healthcare providers available to support people with Parkinson's.**
- **Equitable access to care and treatments for all Canadians living with Parkinson's is essential.** This includes exploring the availability and wait times for life-changing treatments and access to Health Canada approved medications.

These priorities will help provide a roadmap to the organization in developing our future advocacy work in support of Canadians living with Parkinson's.

NEXT STEPS

The roundtable series was an opportunity to hear from the Parkinson's community and get direction on advocacy needs to help inform the development of an advocacy strategy for the organization. These roundtables and reports are the first step in this process and will be the foundation of future advocacy efforts.

The next step is the development of a Parkinson Canada Advocacy Strategy based on these key priorities, which will outline how the organization, along with all Canadians, can play a role in advocating for those affected by Parkinson's.

We will continue to build relationships with key stakeholders and government officials to raise awareness about the gaps that currently exist in Parkinson's healthcare. In addition, we will continue to collaborate with community organizations across the country to address these advocacy issues and work towards our mission of transforming the lives of people living with Parkinson's in Canada.

ACKNOWLEDGEMENTS

PARKINSON ADVISORY COUNCIL (PAC)

Parkinson Canada is grateful to Parkinson Advisory Council members Bob Kuhn and Joe van Koeverden, who participated in all roundtables.

COMMUNITY ORGANIZATION COLLABORATION

Parkinson Canada recognizes we are stronger together and appreciate the support for the roundtables from the following organizations:

Parkinson Association of Alberta

Parkinson Society British Columbia

Parkinson Society Newfoundland & Labrador

Parkinson Society Southwestern Ontario

Parkinson Quebec

U-Turn Parkinson's

ABOUT PARKINSON CANADA

People with Parkinson's are at the centre of everything we do. Our mission is to transform the lives of people living with Parkinson's.

Parkinson Canada funds critical research, provides information and support, increases awareness, and advocates for improved health care outcomes for people living with Parkinson's across Canada.

<https://www.parkinson.ca/>

APPENDIX

ⁱ Deep Brain Stimulation. (n.d.). Sunnybrook Health Sciences Centre. Retrieved January 7, 2022 from <https://sunnybrook.ca/content/?page=deep-brain-stimulation>

ⁱⁱ Duodopa® Therapy. (n.d.). University Health Network Krembil Brain Institute. Retrieved January 7, 2022 from https://www.uhn.ca/Krembil/Treatments_Procedures/Duodopa_therapy

ⁱⁱⁱ Dorsey, E. R., Elbaz, A., Nichols, E., Abd-Allah, F., Abdelalim, A., Adsuar, J. C., ... Collado-Mateo, D. (2018). Global, regional, and national burden of Parkinson's disease, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet Neurology*. doi:10.1016/s1474-4422(18)30295-3

^{iv} Public Health Agency of Canada. Canadian Chronic Disease Surveillance System (CCDSS), Data Tool 2000–2016, 2018 Edition. Ottawa (ON): Public Health Agency of Canada; 2019.

^v Neurological Health Charities Canada (NHCC), Health Canada, Public Health Agency of Canada (PHAC), Canadian Institute of Health Research (CIHR). MAPPING CONNECTIONS: An Understanding of Neurological Conditions in Canada. Sept. 2014. pg.68.

^{vi} People with Parkinson's Face Gaps in the Availability of Health Services [Data Set] (March 28, 2018). IPSOS Public Affairs. Retrieved December 17, 2021 from <https://www.ipsos.com/en-ca/news-polls/parkinson-canada-stakeholder-survey-2018>

^{vii} Parkinson Canada National Environmental Scan conducted in Fall 2018

^{viii} Mathematical estimate based on ^{v, vii}

^{ix} Mathematical estimate based on ^{iv}

The Roundtables and Ontario Roundtable Report were supported in part with funding from AbbVie.

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