Parkinson Canada

Patient Engagement in Parkinson's Research Workshop Report - Montreal

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Parkinson Canada's second Patient Engagement in Parkinson's Research Workshop took place in Montreal on July 24. Following on from a successful first workshop in Toronto in April, our workshop in Montreal was attended by 40 people affected by Parkinson's. This included people living with Parkinson's, care partners, and family members. The workshop was also attended by 15 Parkinson's researchers from across Quebec. Similar to our Toronto event, most workshop attendees had little or no previous experience with patient engagement, further highlighting the critical need for more opportunities to bring different members of the Parkinson's research community together.

The patient engagement workshops are part of a series of new events and initiatives designed to raise awareness and support for patient-informed research across Canada. In developing our patient engagement in research strategy, Parkinson Canada is looking for new ways to incorporate the perspectives and priorities of people living with Parkinson's in research. This includes building capacity for greater involvement of people with Parkinson's in the design, delivery, analysis, and dissemination of Parkinson's research. By viewing people with Parkinson's as partners in research, our goal is to transform conversations around what kind of research is funded and how people with lived experience can, and should be, included in the research process.

The workshop was opened with presentations by Angelica Asis, VP of Research at Parkinson Canada, and Dora Rodriguez, Director of Research Development at Parkinson Québec, who explained how the organizations are supporting research and facilitating participation and engagement for people with Parkinson's. Dr. Jude Bek provided an overview of concepts, definitions, and methods of patient engagement and involvement in research. We then heard from a panel of invited speakers who shared their experience and reflections on Parkinson's research and patient engagement.

Caroline Thornton discussed how the different symptoms and effects of Parkinson's can impact on research participation, highlighting examples from her own experience and providing suggestions for researchers to facilitate participation and engagement for people with Parkinson's. We also heard from Julie Prévéreault , Executive Director at Parkinson Montreal-Laval, who discussed motivating factors and different approaches to patient engagement. Dr Madeleine Sharp, Assistant Professor in Neurology at McGill University, talked about involving people with lived experience at different levels within her research, highlighting how discussions with patients can inspire research questions, while also noting some challenges faced by researchers when trying to conduct meaningful engagement. Finally, Olivier Jérôme from CATALIS Québec explained how CATALIS supports research engagement and participation across different health conditions, and showed how research participation opportunities can be made more accessible through a user-informed website.

A Q&A session with the panelists included some thought-provoking discussions about how research participation can be made more appealing, the need to educate and support researchers to engage more effectively with patients, and the changing trajectory of Parkinson's research in the age of artificial intelligence.

Conversations continued into the lunch break, which was followed by a group discussion session, where people with lived experience and researchers worked together to consider challenges and opportunities in patient engagement and what types of resources would be useful to support patient-researcher partnerships.

Following the workshop, both people with Parkinson's and researchers said they appreciated the opportunity to meet and interact with each other, and that they would like more time to share discussions and ask questions.

> **"I found the workshop immensely valuable. Also the opportunity to network with patients and researchers was greatly appreciated. [Person with Parkinson's attending the workshop]"**

KEY MESSAGES AND NEXT STEPS

Our previous workshop identified a number of themes to help shape our patient engagement strategy, including the importance of communication and accessibility of information about research and participation opportunities, the impact and outcomes of involving patients in research, and considerations to make research more inclusive and relevant to a more diverse population. From the Montreal workshop, we identified some further important themes to consider. In particular, the following insights were highlighted:

Impact of practicality issues and symptoms on engagement and participation

- People with Parkinson's noted that it is often difficult for them to participate in research because of time commitments, travel requirements, medication schedules, or physical or emotional challenges relating to their symptoms (e.g., fatigue, anxiety). Discussions emphasized the importance of considering participants' individual circumstances and providing flexible options for participation and engagement where possible.

The need for an active role for people with Parkinson's in research

- It was noted that people with Parkinson's have valuable experience and knowledge to bring to research. They can help to advance research efforts by taking an active role in educating researchers about living with Parkinson's, as well as supporting and encouraging others to get involved. Caregivers also have unique insights into the effects of Parkinson's and their perspectives can help to enhance research. The important contributions of people with lived experience should be recognized through keeping research partners informed throughout and beyond the project, as well as providing appropriate compensation for their time.

KEY MESSAGES AND NEXT STEPS

Challenges faced by researchers seeking to conduct meaningful engagement

- Although we often consider how to support patients to engage more with researchers, the workshop highlighted that there are also challenges facing researchers who wish to increase their engagement with patients. These include a limited understanding of the practicalities of living with Parkinson's, a lack of time and resources to dedicate to engagement activities, and working in research areas that do not typically involve patient contact. We therefore need to consider how to provide resources and supports for all members of the community to engage more effectively with each other.

These insights provide a deeper understanding of what needs to be done to achieve effective research partnerships. As an organization, we are already working on some new initiatives to enhance patient involvement and engagement in research in Canada. These include developing an online resource hub, planning further engagement events in-person or online, and further integrating patient input into our research funding priorities and grant review process.