

Creating Medication Management Resources for Parkinson Disease Using a Collaborative Community-Based Approach

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Background

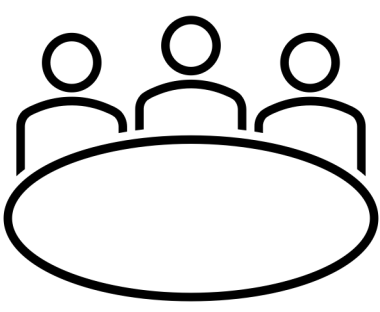
Parkinson disease (PD) is a chronic and progressive neurodegenerative condition. The wait time to see a movement disorder specialist is upwards of 9 to 12 months, leaving patients feeling unsupported and self-managing their medications without guidance. Together, individuals from the non-profit organization, Parkinson Wellness Projects (PWP), a movement disorder specialist, the University of British Columbia (UBC) - Faculty of Pharmaceutical Sciences, and an advisory committee comprised of those with PD and care partners/caregivers, collaborated to determine what medication-related challenges are encountered by the PD community.

Aim

To develop effective resources and supports that can be utilized by individuals affected by PD to help address challenges pertaining to medication management.

Methods

Adhering to community-based participatory action research principles, this five-step process was utilized:



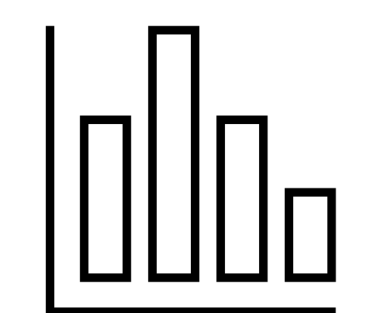
PD Community Advisory Committee: oversaw research and resource development



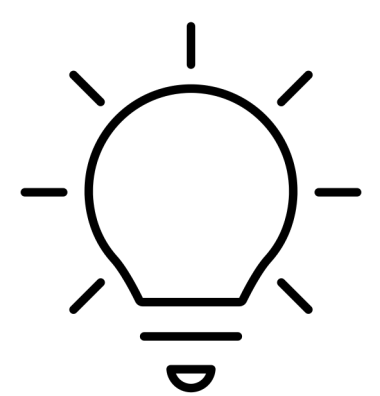
Scoping Review: identified existing patient-centred resources



Data Collection: utilized a mixed methods approach of focus groups and surveys



Data Analysis: analyzed quantitative data and qualitative themes



Resource Development: used findings to create resources that address patient needs

Results

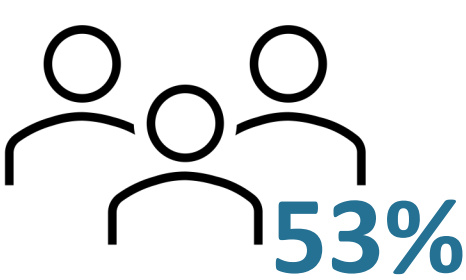
Patient survey responses on drug-related challenges



What challenges do you face when it comes to your PD medications?



How to adjust my medication based on my PD symptoms



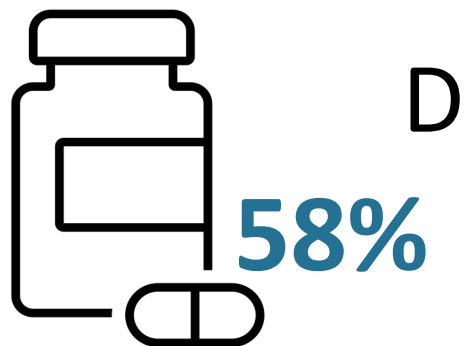
How to organize and schedule my medication based on my planned activities



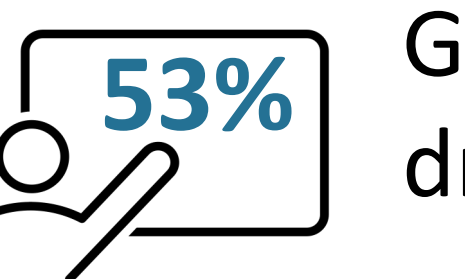
When to take my PD medication in relation to food



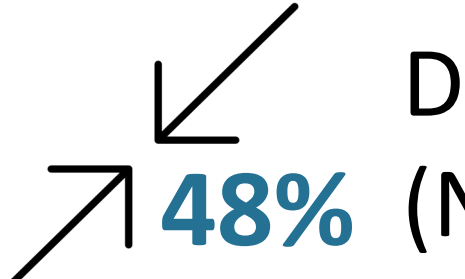
What type of pharmacist advice would be the most useful?



Drug-drug interactions

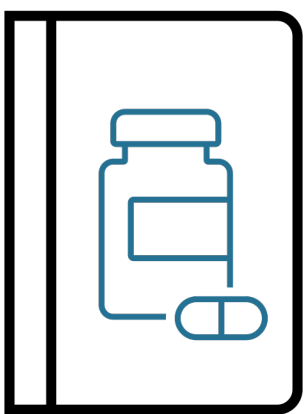


Guidance regarding sleep health, bowel health, dry mouth, excessive salivation, etc.



Drug interactions with natural health products (NHPs) and/or over-the-counter (OTC) medications

Thematic analysis of focus group and survey data revealed five key themes:



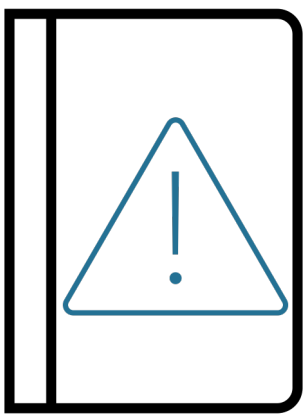
Understanding medication options

Patients are not sufficiently educated about the role of medication in managing PD



Managing medication adjustments

Patients are interested in self-managing their medication but lack the resources and help



Dealing with side effects

Patients want to possess knowledge on how to manage side effects of medications



Planning for future medication changes

Patients are concerned about how their medication will work as their PD progresses



Training for pharmacists

Many pharmacists are unable to provide tailored guidance to their patients

"I would like to know exactly what each [drug] does for me. Do I need all of them? Is there anything better?"

"How will I know when it's time to up the dose?"

"[I am] hesitant to increase [my] dose because [it] would increase side effects"

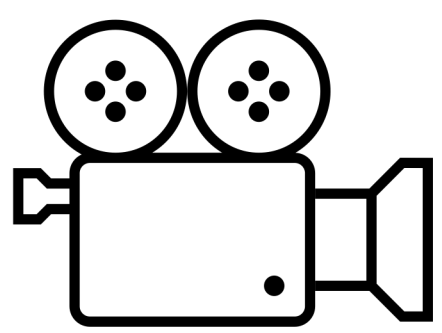
"What does the next stage of PD hold for my meds?"

"Pharmacist can only help with what the medications [are] and their side effects. [They do] not help with managing PD."

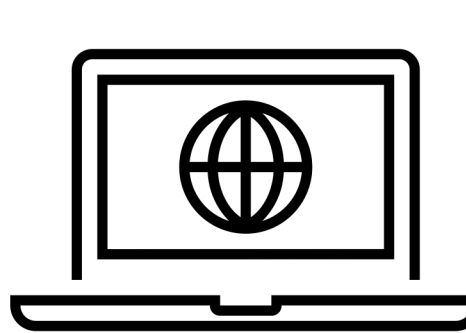
Tools & Resources Developed



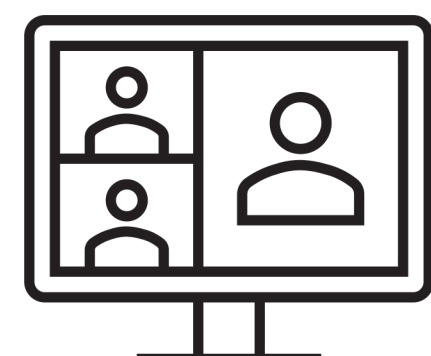
Analog tools for medication management



Video series covering medications and PD-specific exercises



Online shared decision-making tool



Supervised, student-led medication support groups

Lessons Learned

- A partnership between individuals with different backgrounds and experiences helps ensure that all perspectives are thoughtfully acknowledged.
- Creating an online shared decision-making tool that is both user-friendly and informative is essential.

Next Steps

- Share our resources with all interested parties
- Continue increasing awareness of all the accessible programs and services provided by PWP
- Find further ways to improve the delivery of support and medication guidance to the PD community

Acknowledgements

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