

Involving patients with Parkinson's disease in research benefits everyone

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Although there is a growing trend to involve patients in clinical research, specific guiding principles for engaging individuals with Parkinson's disease have not been established. The authors of this Call to Action

published in the *Journal of Parkinson's Disease* emphasize the value of incorporating patient perspectives in clinical Parkinson's disease studies and recommend how to include patient researchers effectively.

"Including [patients](#) helps to design better studies by addressing relevant research questions and defining outcomes that actually matter to patients," explained lead author Marjan J. Meinders, Ph.D., Radboud University Medical Center, Department of Neurology, Center of Expertise for Parkinson & Movement Disorders, Nijmegen, The Netherlands. "It can help ensure that protocols are tolerable and that the trial outcomes actually matter to patients. Yet, much remains to be learned about the best methods and exact impacts of patient engagement in research in general, and more specifically, about the specific challenges that come with Parkinson's disease.

Although various international governmental funding bodies have translated the existing literature on patient engagement in research into frameworks for engagement, specific guiding principles for Parkinson's disease are thus far lacking.

This Call to Action for empirical research draws on the lived experiences of co-authors Anne C. Donnelly, DPH, and Margaret Sheehan, JD, both members of the Patient Council, Michael J. Fox Foundation for Parkinson's Research, New York, NY, U.S.. These individuals with Parkinson's disease have served as expert patients in a project that aimed at incorporating patient preferences into the design and evaluation of a clinical trial. Their experiences confirm those of other patient researchers in the Parkinson's community, who emphasize the importance of patient involvement in research.

"Parkinson's disease comes with specific challenges. For example, issues such as depression, apathy, fatigue, or frontal executive dysfunction may be factors that could hamper effective patient participation in research,"

noted Ms. Sheehan. "Many patients experience diurnal fluctuations, with a worsening of symptoms during the day. This would imply that group meetings to discuss the research project in the late afternoon or evening could be a challenge. Medication could create further challenges, for example when patients are troubled by compulsions, which are secondary to treatment with dopamine receptor agonists."

"There is also the issue of the tremendous inter-individual variability across different individuals living with Parkinson's disease," added Dr. Donnelly. "So, inclusion of just a limited number of patient researchers will inevitably only offer a restricted perspective of the overall needs of the worldwide Parkinson's disease population. Researchers should be aware of these Parkinson-specific challenges and develop strategies so that patient researchers can actually make the impact that is so greatly needed."

Inspired by the experiences of the patient researchers, the authors propose a set of measures and recommendations that can be considered when involving patients with Parkinson's disease. These include: recognizing that travel may be difficult for some and holding online conference calls to enable a wider group to participate; understanding that some patients have very quiet voices and giving them a chance to repeat themselves; pairing the patient with an expert when speaking in a public setting; using patience and handouts to help people with a diminished ability to remember and concentrate; and scheduling calls and meetings when patients are less likely to experience off time and fatigue.

"Evaluations of studies in which patients are involved report cost savings because of faster recruitment, lower drop-out rates due to successful engagement strategies, and consequently, faster completion of the clinical trial," noted co-author Professor Bastiaan R. Bloem, MD, Ph.D., Radboud University Medical Center, Department of Neurology; Center

of Expertise for Parkinson & Movement Disorders, Nijmegen, the Netherlands. "Researchers perceive their work as more rewarding, enjoyable, and meaningful when patients are actively involved. Patients can also take a shared responsibility for ascertaining that the study findings actually find their way to the scientific community and wider general audience via accessible publications."

The authors challenge investigators involved in health-related Parkinson's disease research to look ahead and purposely address emerging best practice standards for engaging patients in clinical study design and execution.

"Importantly, systematic identification of certain barriers and facilitators for active [patient engagement](#) and finding solutions on how to remove barriers are greatly needed to further develop guiding principles for effectively involving patient researchers. Ultimately, all researchers should regard patient participation and co-creation in research as a vital aspect of learning and improving the value of research in Parkinson's disease," the authors concluded.

Parkinson's disease is a slowly progressive disorder that affects movement, muscle control, and balance. It is the second most common age-related neurodegenerative disorder affecting about 3% of the population by the age of 65 and up to 5% of individuals over 85 years of age.

More information: Marjan J. Meinders et al, Including People with Parkinson's Disease in Clinical Study Design and Execution: A Call to Action, *Journal of Parkinson's Disease* (2022). [DOI: 10.3233/JPD-223190](#)

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