



Engaging people with Parkinson's in determining and defining research priorities: The PDF Community Choice Research Award

Karlin Schroeder, M.A., Beth A. Vernaleo, Ph.D., Melissa Barry, M.A., David Blomquist, Diane Cook, Christiana Evers, M.P.A., James C. Beck, Ph.D., and Veronica L. Todaro, M.P.H.
Parkinson's Disease Foundation, New York, NY, USA

Objective

To understand how engaging people with Parkinson's disease (PD) and their care partners in determining and defining research priorities can help address the unmet needs of patients and advance research.

Introduction

The Parkinson's Disease Foundation (PDF), a division of the Parkinson's Foundation, is committed to ensuring that people living with Parkinson's disease are partners throughout the research process. This partnership begins with the creation of mechanisms to identify patient needs and priorities as determined by the patients themselves.

The Parkinson's Disease Foundation launched the Community Choice Research Award (CCRA) in 2013. The purpose of this award is to solicit the patient community to identify their priorities, turn priorities into research questions, and then fund a one and a half day workshop among scientific and clinical experts and people with Parkinson's. The focus of each workshop is a research priority as identified by the patient community.

Since 2013, PDF has funded four CCRA workshops and gathered leaders in the field of Parkinson's disease, specialists from related areas, pharmaceutical companies, and people living with Parkinson's. The identified research areas were chosen because they are not well-managed with current therapies, lack a substantial body of research in current literature regarding etiology or treatment, are particularly disabling aspects of PD that lead to reduced quality of life, and were suitable for the workshop format.

Methods

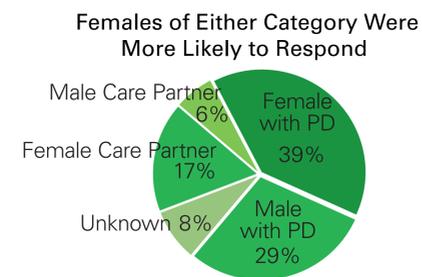
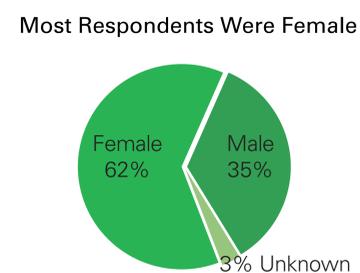
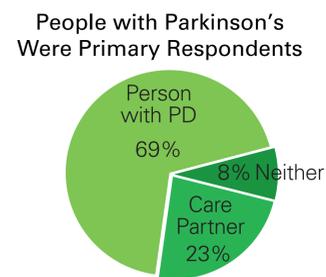
Determining Research Priority: A questionnaire was administered to people with PD and care partners via the PDF web site and in-person via electronic tablet at the 2013 World Parkinson Congress in Montreal, Canada. Research areas were reviewed and selected by PDF's scientific advisory board based on criteria as described above.

Determining Impact of Patient Involvement: A survey was administered to researchers and clinicians who attended the research priority meetings to determine their opinions on patient involvement.

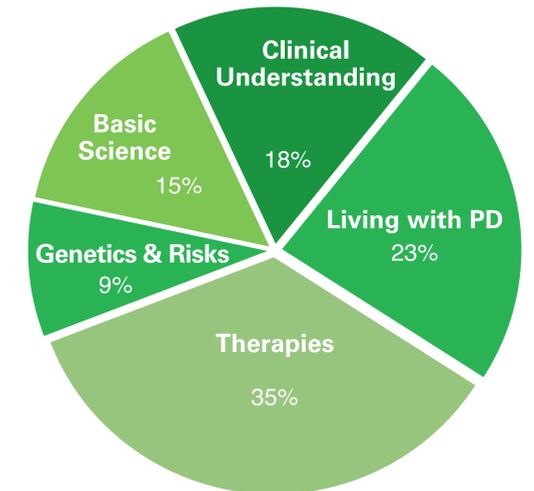
Patient Opinion on Unmet and Under-Researched Needs



Over 600 people have completed the online surveys. Relationship to Parkinson's and gender breakdowns are shown below. Similar to the PDF HelpLine, most respondents were female. Responses were far reaching, but could be categorized into five general areas (right). Unsurprisingly, Parkinson's Therapies represented the topic area within which the greatest number of responses could be categorized. Two issues, fatigue (Living with Parkinson's) and gastrointestinal dysfunction (Clinical Understanding), were selected by PDF reviewers using criteria described (see *Methods*) as topics to be funded.



Topics of Greatest Interest to People with Parkinson's Disease



Researcher and Clinician Opinion on Patient Engagement in CCRA Workshops:



Two conferences were held in the Fall of 2014 and two in Spring of 2016 to discuss the issues surrounding the research areas of fatigue, gastrointestinal dysfunction, dystonia and cognition. Researcher and clinician attendees included basic scientists, movement disorder and other specialty neurologists, psychiatrists, gastroenterologists, social workers and allied health professionals. Of those attendees surveyed (n=40), 95% responded that patient input enriched the meeting dialog; 87% thought that patient input influenced the outcome of the meeting; 92% felt that there is a role for patients in next steps related to the meeting outcomes (publishing papers on the current state of knowledge on the topic, working on developing research projects around ideas identified at the meeting and preparing educational materials for the community) and 78% were more inclined to include patients in future scientific conversations.

Did patient input enrich the meeting dialog?



Did patient input influence the meeting outcome?



Is there a role for patients in the meeting outcomes?



Are you likely to include patients in future scientific conversations?



Conclusion

Engaging people with PD and their care partners in determining research priorities can lead to identifying unmet needs that warrant attention by scientists. Researchers who collaborate with patients on defining research priorities find that it adds value, influences outcomes, and increases the likelihood of patient involvement in future scientific conversations.

Based on the success of the CCRA surveys and workshops PDF is implementing a third survey of the Parkinson's community at the 2016 World Parkinson Congress to identify a third set of two unmet needs that are under-researched and of importance to those affected by Parkinson's. These issues will be selected in Fall 2016 and will be the focus of CCRA workshops that will be organized in 2017.

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