



Driving patient engagement in Parkinson's clinical research: lessons learned in developing successful partnerships with study sponsors

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Introduction

The Parkinson's Disease Foundation (PDF) is committed to ensuring that people living with Parkinson's disease are partners throughout the research process. Identifying and operationalizing successful partnerships with study sponsors in government, industry and academia is essential. PDF and study sponsors have initiated formal collaborations to ensure the perspective and experience of people living with Parkinson's is incorporated into research decision-making. These collaborations include a wide range of decision points along the clinical research continuum.

Methods

Administration of an online survey to study sponsors (n=6) who have engaged in a collaboration with PDF and PDF Research Advocates to examine : 1. the impact of patient engagement within the context of the specific collaboration; 2. the broader organizational impact of the collaboration and 3. the barriers to patient engagement.

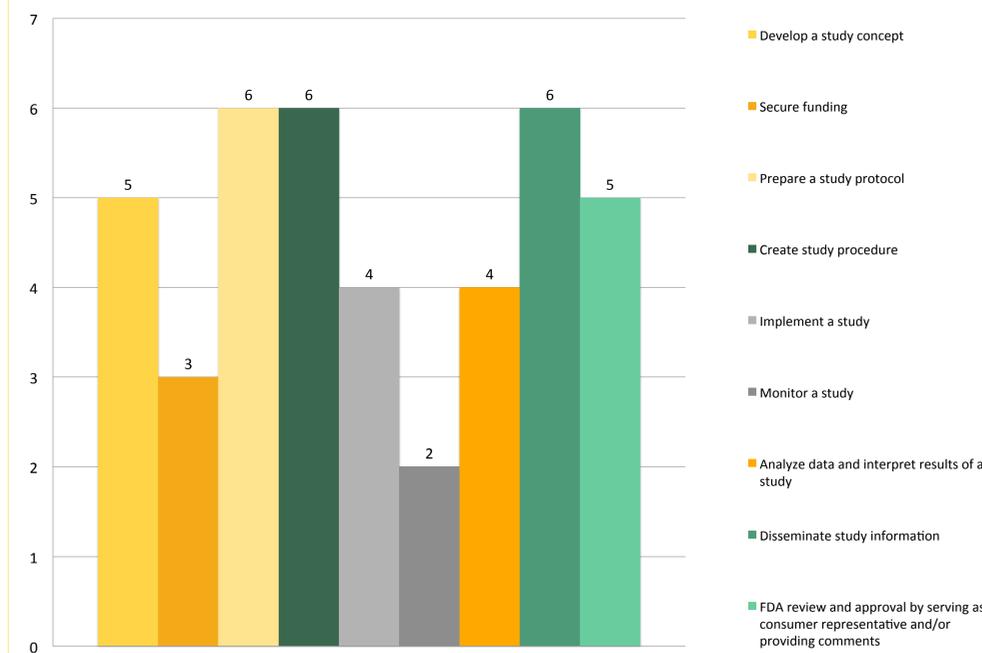
Respondents

- A principal investigator and clinical project manager from two studies funded by National Institute of Neurological Disorders and Stroke (NINDS)
- Biogen
- SRA International, contractor for Department of Defense (DoD)
- Eastern Research Group, Inc., contractor for Food and Drug Administration (FDA)
- Pfizer, Inc.

Conclusions

Across all sectors (academia, industry, government), engaging patients in research leads to tangible outcomes that benefit the research process. Working in collaboration, study sponsors and their affiliated organizations, advocacy groups and patient advocates can minimize, if not eliminate barriers to working together. Building relationships and learning about and respecting each others needs and priorities are key principles for creating a foundation for successful collaborations.

Study Sponsor Reported Role for Patient Input in the Research Process (n=6)



Respondent Suggestions

Advice to Research Teams

1. Get to know patients.
2. Use clear and simple language and iterative interactions.
3. Utilize patients. They add an informed and unique perspective that can benefit your work.
4. Look to the Parkinson's Disease Foundation for help.

Advice to Research Advocates

1. Get to know researchers.
2. Understand research timelines.
3. It is important to represent your community, not only your personal opinion.
4. Be creative.

Results

PDF Research Advocates have worked with survey respondents at various points of the research process. They reviewed grants, worked on study steering committees, provided feedback into the presentation of benefit-risk frameworks, critiqued patient-reported outcomes tools and provided input that informed pharmaceutical operations and technology strategy. Respondents reported that PDF Research Advocates improved informed consent, identified strengths and weaknesses in the research discussed, defined the impact of study decisions and provided keen insights into the needs and priorities of the Parkinson's community.

- 100 percent of respondents (n=6) reported PDF Research Advocates added input that was relevant to, and enriched thinking around, their project.
- For those partnerships where time was relevant, 100 percent of respondents (n=3) reported that collaboration with PDF Research Advocates helped move the project forward more quickly.
- 83 percent of respondents (n=6) were more inclined to engage patients after working with PDF Research Advocates.
- No barriers to patient engagement were reported.