

# Lessons Learned from a Parkinson's Research Patient Advisory Board Model with Academic Centers

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## **ABSTRACT**

**Background:** There is minimal comparative effectiveness research in Parkinson's Disease (PD). Engaging people with PD in the research process through patient advisory boards (PAB) is one way to address this gap.

**Objectives:** To describe the project model and lessons learned from a PAB pilot project in 5 Parkinson's Foundation Centers of Excellence in comparative effectiveness research.

**Methods:** A virtual training and toolkit on patient engagement, PABs and comparative effectiveness research was created and used to implement PABs. Satisfaction and impact of the PAB training and pilot model was assessed via surveys.

**Results/Lessons Learned:** PAB participants (n=28) felt the training was comprehensive, their feedback was prioritized, and impacted the PAB goal of developing a comparative effectiveness research question. Recommendations include giving clinic staff protected time for patient engagement and providing funding.

**Conclusions:** The developed model led to an increase in participation in comparative effectiveness research and effectively trained staff, people with PD and care partners in patient engagement.

**KEYWORDS:** Community-Based Participatory Research, Community health partnerships, Community health research, Health outcomes, Diseases, Nervous System Diseases, Health Care, Organizations, Academic Medical Centers, Caregivers, Parkinson Disease, Patient participation, Comparative effectiveness research

## **Introduction**

Parkinson's disease (PD) is a chronic, neurodegenerative disease with no therapies to impact its progression or recent significant treatment breakthroughs to address symptoms.<sup>1</sup> There are likely many factors contributing to the failure to develop breakthrough therapies for PD, two of which may be the lack of comparative effectiveness research (CER) and lack of wide-spread patient engagement in PD research design and implementation. Involving people with Parkinson's (PWP) in the research process through models of patient engagement based in a community based participatory research approach (CBPR) is one way to address the lack of patient engagement and CER in PD and strengthen community-academic partnerships.<sup>2,3</sup> The primary risk factor for PD is age (median age of onset is 71 years). People can live many years with PD (a median of 10.3 years), and typically experience many non-movement symptoms including cognitive impairment, vision challenges, fatigue, and depression, extending beyond what people commonly think of as PD (i.e. tremor and stiffness).<sup>4,5,6</sup> The symptoms of Parkinson's present unique challenges to patient engagement in PD research and demonstrate how crucial it is to ensure effective models of patient engagement exist to prioritize people living with the disease and incorporate the voice of patients and the care partners (CP) supporting them throughout their disease progression.<sup>7</sup>

The Parkinson's Foundation defines patient engagement as the co-design and co-implementation of research between PWP, CP, and research teams throughout the research process and includes the co-creation of tools, best practices, metrics, and methodology to support this work. For fifteen years, the Foundation has trained PWP and CP to work with researchers and for six years has trained researchers in patient engagement. During this time, the Foundation developed a training for PWP and CP on the research process and how to partner with research

teams to co-create research studies based on models from the HIV and breast cancer communities.<sup>8</sup> While previously developed Foundation trainings and patient engagement methods supported ad hoc projects in academic research, individual “one and done” projects were not leading to sustained, systemic change and research teams still lacked knowledge and support in how to execute patient engagement.

To address this gap, in 2020 the Parkinson’s Foundation began a pilot project to create a replicable, sustainable model of patient engagement in academic PD CER at 5 of its 37 U.S. Centers of Excellence (COE). To be designated as a Parkinson’s Foundation COE, institutions are required to undergo a selective peer-review evaluation and meet standards of rigorous research, comprehensive care delivery, professional education, and patient outreach service criteria. A patient advisory board (PAB) model was chosen as the best method for advancing patient engagement in participating COE. A PAB involves bringing together a group of community members and researchers to determine how research is done through the discussion and alignment of community needs and priorities.<sup>9</sup> PABs have been shown to be effective in other disease areas to understand the patient experience and prioritize community focused research more comprehensively.<sup>10,11,12</sup> Further, they can lead to improvements in the research processes, patient reported outcome measures, diverse study recruitment, and amended project methods, outcomes, and goals.<sup>13-18</sup> The goal of this paper is to describe the framework and lessons learned from designing and implementing PABs in 5 Parkinson’s Foundation COE.

## **Methods**

### *Project Structure*

The total project timeline was 2.25 years (from January 2020 through May 2022) and involved the following components a) assembling a national collaborative to guide the project; b) building

and launching a virtual PAB training and toolkit; c) COEs completing the virtual training and executing the PABs; d) COEs developing a CER question and beginning project dissemination. The first year involved assembling the national collaborative, planning the project timeline, and building the PAB virtual training, toolkit and curriculum. The second year was dedicated to the PAB virtual training sessions and PAB project execution, where participating COEs were required to hold at least three PAB meetings. The final three months were spent finalizing the project and starting dissemination. The goal was for one PAB to develop a CER question by the completion of the project to demonstrate the viability of this model.

#### *National Collaborative*

A national collaborative of PD healthcare experts was assembled to develop the PAB model by planning and guiding the overall course of the project. National collaborative members included members of the COE network, those involved in previous Foundation patient engagement projects, and past PCORI awardees with PAB experience. It comprised 5 clinicians and experts in Neurology with different areas of expertise relevant to the project including patient engagement, working with diverse aging communities (ex. LGBTQ+ and non-White/non-Hispanic communities), and experience in health literacy and cognitive impairment. Two patient advocates were on the collaborative, one who is a person with PD and one who is a cancer survivor, who had extensive community organizing and patient engagement experience. Last, three experts in patient engagement from the Parkinson's Foundation led and organized the development of the national collaborative. The collaborative a) advised on recruiting representative participants to the PABs; b) created the structure, content and delivery of the online training course for PWP, CP, and site staff in patient engagement in research, patient advisory boards, and CER; c) produced a toolkit on PABs; d) ensured ongoing coaching support

for PAB development and implementation was available from the Parkinson's Foundation; e) oversaw the evaluation, assessment, and dissemination plans for the project; f) reviewed the virtual training for cultural competency and health literacy. The PWP helped initiate and design the concept for this project, helped produce the entire online training, and wrote best practices for working with people with cognitive impairment. Both patient advisors also served as faculty in teaching the PAB course content and assisted with the development and review of this manuscript.

#### *Funding and IRB Approval*

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#### *Participants and Recruitment*

PAB COE staff leaders were identified by asking COE leadership to choose staff who were interested in building the PAB. PWP and CP were recruited from existing Parkinson's Foundation Research Advocate volunteers and community members known to or cultivated by the COE. The project team developed and shared a recruitment and outreach plan with COE in the first year of the project that was designed using best practices for DEI. COE were required to work toward recruiting a PAB that reflected their community. The recruitment and outreach plan included key details such as, advisory board position expectations, tips for recruiting (e.g. leveraging existing networks to identify actively engaged community members and getting out

into the community to local groups), and engaging diverse and underserved populations by encouraging COE staff to go beyond those currently being seen at their COE to represent the broader PD community in their area.

#### *Virtual Training, Toolkit, and Support*

A virtual training with both synchronous and asynchronous sessions was developed along with a companion training manual. The training was eight, twice-weekly, hour-long sessions over four weeks. The goal was to establish research and patient engagement knowledge and to prepare participants for taking part in PABs.<sup>19</sup> PAB participants learned what patient engagement in research is, best practices for PABs, and how to create a research question. Additional components of the training can be found in Table 1.

A toolkit was created to provide templates and resources for planning and running PAB meetings with printable resources. Tools were collated from patient engagement and PAB projects in other disease areas that were available as duplicable resources.<sup>20, 21</sup> Contents of the toolkit included examples of mission and vision statements, roles and responsibilities documents, meeting planning checklists and agendas, educational materials, meeting facilitation and discussion guides, and examples of meeting notes.<sup>22, 23, 24, 25, 26</sup> The toolkit also included a guide to building a research question through community engagement.<sup>21, 27</sup> Finally, resources were provided on team building and special considerations such as diversity action plans.<sup>28</sup> The Parkinson's Foundation patient engagement staff and patient advisors were also available to work with PABs throughout the project through phone calls and ad-hoc meetings.

#### *Assessments/Outcomes*

We measured the following among PAB COE staff, PWP and CP. Results were analyzed using descriptive and frequency statistics.



## Baseline

- Demographics: age, gender, race and ethnicity, role (e.g., PWP, CP, COE staff), education, employment status, marital status, income, religion, PD diagnosis, prior involvement in research
- Health literacy: Short Assessment of Health Literacy (SAHL), a tool from the Agency for Healthcare Research and Quality to screen for health literacy in English-speaking adults. A score below 14 represents the cut-off point for low health literacy.
- Perceptions on COE care (PWP and CP)

## Baseline and Post Project

- Survey in English on knowledge, attitudes and behavior toward patient engagement processes and project outcomes. To develop this survey, a literature review of patient engagement, quality improvement, and PAB literature was conducted, where no validated or sufficient tools related to patient engagement and project outcomes were found. Questions were developed by the project team based on this literature review and were reviewed by members of the National Collaborative, including people who had worked on past PCORI projects, those with lived experience, and researchers. This survey was piloted with a PWP and administered via email.

## Results and Lessons Learned

### *PAB Results*

Table 2 provides the demographics of PAB participants (n=35; 21 PWP, 5 CP, and 9 COE Staff) and is included for additional context on lessons learned. All community participants except one had high health literacy and education levels skewed high (80.77% of PWP and CP had a Bachelor's or Master's degree). Participants in the post-project survey (n=28) agreed the PAB

training was comprehensive and provided the knowledge needed to take part in PAB meetings (PWP and CP 95.45%; Staff 100%) [Table 3]. Staff also reported the training improved their ability to work productively with PAB members (Strongly agree 66.67%; Somewhat agree 33.33%).

80% of participating COEs met the goal of conducting at least 3 PAB meetings, holding an average of 3.3 meetings. Some PABs met monthly while others chose to meet quarterly or on a different schedule. The most common patient engagement activity was setting research priorities (78.57%) [Table 3]. Other activities included practical considerations (50%), protocol design (35.71%), patient information (32.14%), and informed consent (21.43%). Most COEs reported using telephone or online meetings (78.57%), email discussions (42.86%), and group-in person interactions (25%) as methods of engagement.

PWP and CP felt satisfied with their experience participating in the PAB (81.82%). [Table 3] Most PWP and CP felt comfortable speaking up (90.91%) and confident when providing feedback (86.37%) on research related topics during PAB meetings, while 77.36% felt that meeting discussions were productive. The majority of PAB participants (88%) felt their feedback was prioritized, and trust the COE has good intentions to use the feedback they provided throughout the project (90.91%) [Table 4]. Overall PWP and CP felt their engagement positively impacted the project (72.72%). They reported their feedback was taken into consideration from the start of the project (81.81%), and 86.36% felt that their feedback was prioritized regarding project decisions. Project staff reported that the contributions of PWP changed their opinion of patient engagement in research (83.33%) and that the PAB was beneficial to their COE's research mission (83.33%).

### *Lessons Learned*

**Lesson 1: Identify leaders who value patient engagement to support efforts and needs, such as protected staff time.**

At the start of the project, the Foundation decided to pilot PABs at COE that voluntarily showed interest in this work and at one COE that already had a PAB in existence but was not focused on developing research questions. Identified COE were asked to self-identify staff leaders for their PABs. This resulted in a broad array of leaders based on who had both the time and relationships with the community to make the PAB successful. COE leaders included nurse researchers, COE coordinators, social workers and movement disorders clinician-researchers. The Foundation has learned from previous experiences that having COE self-identify the right leaders is a best practice, as these COE leaders have shown commitment to the work and a bond with their community. This also aligns with the overall principals of CBPR, that to conduct meaningful research, researchers need to have invested time into their local communities to obtain buy-in and best understand priorities.<sup>3</sup>

Most PAB participants had prior experience with patient engagement and research, with over 50% of PWP and CP reporting participating in prior research studies and all strongly or somewhat agreeing the COE provided high quality care and conducted research that aligned with community priorities [Table 5]. Further, all PAB participants viewed patient engagement as important, and most staff (73%) had already engaged PWP in research projects. While this likely positively impacted the success of the PABs, including people who value patient engagement and had previous experience was intentional. It has been the Foundation's experience that successfully expanding patient engagement to new environments requires leaders who already buy into or have some familiarity with patient engagement.

Protected time is also essential for implementing successful PABs, as this project required eight, 1-hour long training sessions and at least 3 PAB meetings over the course of one year. Additional time needs to be considered for PAB recruitment (approx. 10 hours), meeting preparation (1-2 hours per meeting), and additional administration time. The two PABs that were able to successfully meet the goals of the project had the needed, protected time to meet frequently. For example, one was already in existence and staff already had protected time dedicated to its running, while the other created monthly protected time for PAB meetings. The impact of COVID-19 also highlighted the need for protected staff time, as PAB work was necessarily deprioritized for health care workers, making the project less cohesive regarding learning and meeting regularly. For future PABs, it is recommended to work with sites to ensure protected time for staff to meet with PABs more frequently or over a longer period of time.

**Lesson 2: Plan for the time and space for understanding and meeting the unique needs of each patient population.**

Building in the time and space for engaging and recruiting representative communities is essential, especially when building relations with new communities. Current literature that shows PD is underrecognized and less commonly diagnosed in people of color, who, because of this, could be less likely to be receiving specialty PD care at COE.<sup>29</sup> While it was a project goal to recruit diverse communities and COE staff were given a handout by the project team on how to do this, due to COVID-19 COE staff were not able to spend the needed time in their communities to build relationships with populations they had not previously engaged. Having the adequate time to build additional relations in local communities could have allowed for the inclusion of more diverse populations and meeting people where they are to deliver the appropriate education and engagement, including to those with low health literacy.<sup>30</sup> However,

PAB representation did include a more racially and ethnically diverse community than typically seen in other PD community engagement projects. It is essential to build relationships in new communities early in the start of a PAB project, well before actual recruitment begins.

PAB COE staff also suggested that staff should be trained on patient engagement and PABs first before training PWP and CP in order to make recruitment for PABs more successful. Although the structure and requirements of the PAB project had been explained to both COE leadership and staff from the start of the project, a formal project orientation combined with being trained first would have allowed staff to describe the goals of the PAB and time commitment involved in order to better recruit and prepare participants.

Considering the learning needs of the engaged population is essential when deciding on the structure of a PAB and training. For example, PWP might need to attend PAB sessions with a care partner and might have motor limitations or cognitive and/or motor fluctuations that can make attendance and traveling more challenging. Several PAB members initially struggled to engage with the online learning system, and it would have been beneficial to have an initial orientation and increased support to address systemic barriers to accessing the course, such as lack of technology or low-tech literacy early in the training process<sup>31</sup>. A guide was developed for COEs regarding best practices for working with PWP with cognitive impairment and how to best structure meetings that would lead to inclusive participation. Further, holding most of the trainings in an asynchronous fashion was planned to provide flexibility in the time and pace of learning; however, it was difficult for participants to stay on track with this approach, even with regular reminders from the online learning system and individual outreach from the Foundation. In retrospect, synchronous, live sessions would have likely helped PWP with cognitive

challenges around multitasking and planning to stay on track while also demonstrating clearly to COE the schedule of protected time needed for staff.

### **Lesson 3: Consistent external support for PABs helps drive success.**

As PABs moved into meetings after the training, planned initial support and structured monitoring of PABs would have helped identify areas of success and challenges throughout the process of working towards a research question. Throughout the project, some PAB staff reported struggling with retention, finding meeting times that worked for everyone, and keeping meetings on topic to move towards a research question. In hindsight, challenges may have been alleviated through structured hands-on support by Foundation staff with expertise in patient engagement. For example, staff could have provided additional patient engagement tips, techniques and tools and helped set meeting agendas to move towards a research concept. Consistent support and constructive oversight of PABs would have also ensured that feedback loops were closed, as PWP and CP reported being unsure if their feedback actually changed research at the institution (27.28% PWP and CP) [Table 4]. This also could have ensured that the developed roles and responsibilities guidelines were followed more closely, which might have allowed all PAB participants to feel comfortable speaking up in meetings and better understand their role in the decision-making process, as 40.91% reported their role not being clearly defined [Table 3]. Having a patient representative co-lead meetings and ensuring roles and responsibilities guidelines are closely followed is key to a successful PAB.

In addition to adequate implementation support, adequate financial support is also a potential driver of success. Funding COEs to run PABs allowed for staff to have at least some protected time to dedicate to this work, although additional protected time was needed in most cases. Most staff reported that the financial support provided by the Parkinson's Foundation was

adequate (83.33%) [Table 4]. When asked if staff would be able to continue the PAB without additional financial support from the Parkinson's Foundation, 100% of respondents were unsure; however, 83.33% reported their COE was committed to continuing the PAB and 33.33% reported they would be applying for additional funding in the next 18 months.

In addition to financially supporting the running of the PAB, financial support for implementing a co-created comparative effectiveness research question may also facilitate the success of PABs. At the suggestion of the National Collaborative, the Foundation created a grant program for PABs mid-project to support the implementation of a small, single site CER study to ensure continuity of the PAB and study execution. At the conclusion of this project, it was also determined that future rounds of PABs would receive more funding per year as patient engagement requires dedicated time and resources for success. It should be noted that while additional funding was provided, it is clear that providing additional funding alone is not enough to sustain lasting efforts related to patient engagement.

## **Conclusion**

Through this PAB project, the Foundation aimed to build on past successes in creating patient engagement training programs by identifying and bringing together collaborators and developing tailored resources and tools to build a sustainable, replicable model that could make patient engagement in CER a key component of academic institutions' scientific programs. Results indicate this pilot PAB model was successful, as the project achieved the goal of having PWP and CP engage in research decision-making by formalizing a model of patient engagement and giving COEs structure and funding to do patient engagement. Overall, project participants found the training to be useful and comprehensive for preparing them to participate in PABs at their COE. PWP and CP found their input and feedback to be prioritized by COE staff and staff found

the engagement of PWP and CP to be useful in the research process. This pilot project provides a successful initial framework for training and implementing PABs in academic medical centers and was a successful first step to address a significant gap by building a replicable, scalable model of patient engagement embedded in academic research institutions.



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Table 1. PAB Training Structure and Content

Course Chapter	Chapter Content
1. Welcome to Parkinson’s Foundation Patient Advisory Boards	Provided a welcome to the course, project schedule, and an introduction to course instructors. Participants learned how to navigate the online learning environment, which included an overview of how to use Zoom and who to contact for technical support.
Live Kick-off Event	Live introduction to the project and participating centers.
2. Advantages to Patient Engagement and Community Based Participatory Research	Participants learned to recognize the role of people with Parkinson’s and care partners in representing communities in guiding research. <sup>20,21</sup> What patient engagement in research is and the benefits was also discussed, and participants to learned to identify the benefits and challenges to implementing patient advisory boards. <sup>19,21,22,26,28</sup>
3. The Research Process for Patient Advocates	Participants learned about research ethics and the different types of research, including the phases of clinical trials. Other key components of the research process were covered, such as interpreting research design questions, the different roles of research participants, variables of research design, and the design of research analysis. <sup>19,27</sup>
4. Patient Advisory Board Best Practices	This chapter covered best practices on the logistics of planning, implementing, and assessing PABs, including strategies for planning and implementing PAB meetings, conducting patient advocate trainings, and appraising the impact of PABs. <sup>21,22</sup>
5. Parkinson’s Foundation Centers of Excellence	This chapter provided an overview and introduction to the different participating COEs.
6. Advisory Board Curriculum Overview	This chapter covered the different aspects of developing a PAB curriculum. Participants learned how to identify the key components of a curriculum, design curriculum topics, compose learning objectives, and formulate assessments and discussion questions related to the learning objectives. <sup>20,22,23,24</sup>
7. Communication (Live)	Essential communication skills for conducting PABs were covered for both community members and COE staff. Community members learned how to conduct and participate in constructive conversations about study ideas and research. COE staff learned the ability to talk about research in lay language and facilitate discussions about research with the community.

8. Drafting a Research Question (Live)	Participants learned skills to draft a research question as a team. <sup>25</sup>
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Table 2. PAB Demographics and Participant Characteristics

	People Living w/ PD (n=21)	Care Partners (5)	COE Center Staff (9)
Age, mean (SD)	69.1 (9.85) years	59.6 (17.60) years	46.22 (18.33) years
Age of PWP that you care for (SD)		66.40 (9.45) years	
Gender identity			
Male	47.62%(10)	20% (1)	100% (9)
Female	52.38% (11)	80% (4)	
Race/Ethnicity			
White	76.19% (16)	100% (5)	66.67% (6)
Hispanic/Latino	14.29% (3)		11.11% (1)
Asian	4.76% (1)		
Black/African American	4.76% (1)		33.33% (3)
American Indian or Alaska Native			11.11% (1)
Other race/ethnicity	4.76% (1)	20% (1)	
Marital Status			
Married	80.95% (17)	60% (3)	
Divorced	4.76% (1)		
Single	9.52% (2)	40% (2)	
Widowed	4.76% (1)		
Education			
Bachelors	61.90% (13)	40% (2)	11.11% (1)
Masters	14.29% (3)	60% (3)	55.56% (5)
High School	9.52% (2)		
Doctorate	9.52% (2)		
Professional	4.76% (1)		22.22% (2)
Associates			11.11% (1)
PD Specifics			
Time Since Diagnosis, mean (SD)	8.76 (4.99) Years		
Newly diagnosed	9.52% (2)		
Young Onset (Before 55)	23.81% (5)		
Employment Status			
Retired	80.96%(17)	40% (2)	11.11% (1)
Employed full-time	9.52% (2)	40% (2)	88.89% (8)
Employed part-time	4.76% (1)		
Unable	4.76% (1)		
Self-employed		20% (1)	
Income			

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Less than \$25,000	4.76% (1)		
\$25,000 to \$49,999	28.57% (6)		11.11% (1)
\$50,000 to \$99,999	23.81% (5)		22.22% (2)
\$100,000 to \$199,999	23.81% (5)	40% (2)	55.56% (5)
\$200,000 or more	4.76% (1)		11.11% (1)
Prefer not to answer	14.29% (3)	60% (3)	
Religion			
Protestant	14.29% (3)		
Roman Catholic	42.86% (9)	40% (2)	
Jewish	19.05% (4)		
Hindu	4.76% (1)		
Muslim		20% (1)	
Other	19% (4)	20% (1)	
Prefer not to answer		20% (1)	
Health Knowledge Score	17.15	17.8	
Rural			
Yes	28.57% (6)	20% (1)	

Table 3. PAB Training and Execution

	People Living with PD and Care Partners (22)	Staff (6)
All topics that came up in PAB meetings were covered in the PAB training.		
Strongly agree	40.91% (9)	33.33% (2)
Somewhat agree	54.55% (12)	66.67% (4)
Somewhat disagree	4.55% (1)	
How often did you speak up or participate in PAB meetings and activities?		
Less than once per meeting	9.09% (2)	
Once or twice per meeting	40.91% (9)	
Three or more times per meeting	50.00% (11)	
As a PAB member, my role in the decision- making process was clearly defined.		
Strongly agree	27.27% (6)	
Somewhat agree	31.82% (7)	
Somewhat disagree	40.91% (9)	
As a PAB member, I felt that meeting discussions were productive.		
Strongly agree	31.82% (7)	
Somewhat agree	45.45% (10)	
Somewhat disagree	13.64% (3)	
Strongly disagree	9.09% (2)	
As a PAB member, I felt comfortable speaking up and providing feedback on research related topics.		
Strongly agree	54.55% (12)	
Somewhat agree	36.36% (8)	
Somewhat disagree	4.55% (1)	
Strongly disagree	4.55% (1)	
As a PAB member, I trust that the center has good intentions to use the feedback I have provided throughout this project.		
Strongly agree	54.55% (12)	
Somewhat agree	36.36% (8)	
Somewhat disagree	4.55% (1)	
Strongly disagree	4.55% (1)	
Were you satisfied with your experiences as a PAB member?		
Very satisfied	31.82% (7)	



Somewhat satisfied	50.00% (11)	
Somewhat dissatisfied	13.64% (3)	
Very dissatisfied	4.55% (1)	
The PAB training improved my ability to productively work with the PAB members.		
Strongly agree		66.67% (4)
Somewhat agree		33.33% (2)
Did Parkinson's Foundation provide adequate support to host the PAB?		
Yes		83.33% (5)
Unsure		16.67% (1)
People Living with PD, Care Partners, and Staff (28)		
What PAB patient engagement activities did you participate in?		
Setting research priorities	78.57% (22)	
Practical considerations	50.00% (14)	
Protocol design	35.71% (10)	
Patient information	32.14% (9)	
Informed consent	21.43% (6)	
Information to trial participants	17.86% (5)	
Protocol Synopsis	14.29% (4)	
Grant/fellowship review	10.71% (3)	
Post-study communication	10.71% (3)	
Ethical review	7.14% (2)	
Fundraising for Research	3.57% (1)	
Study Reporting	3.57% (1)	
Health technology assessment	3.57% (1)	
Other	25% (7)	
What methods for patient engagement were used?		
Telephone or online meeting	78.57% (22)	
Email	42.86% (12)	
Group in-person interactions	25% (7)	
Surveys or questionnaires	14.29% (4)	
Online forum	3.57% (1)	
Other	7.14% (2)	

Table 4. Impact of Patient Engagement and Future PAB Plans

	People Living with PD and Care Partners (22)	Staff (6)
As a PAB member, my feedback was taken into consideration for project decisions from the start of the project.		
Strongly agree	36.36% (8)	
Somewhat agree	45.45% (10)	
Somewhat disagree	13.64% (3)	
Strongly disagree	4.55% (1)	
As a PAB member, my feedback was taken into consideration regarding decisions about how to best move forward with the project.		
Strongly agree	50.00% (11)	
Somewhat agree	22.73% (5)	
Somewhat disagree	22.73% (5)	
Strongly disagree	4.55% (1)	
As a PAB member, I felt that my feedback was prioritized regarding project decisions.		
Strongly agree	27.27% (6)	
Somewhat agree	59.09% (13)	
Somewhat disagree	9.09% (2)	
Strongly disagree	4.55% (1)	
As a PAB member, I feel that my engagement positively impacted this project.		
Strongly agree	36.36% (8)	
Somewhat agree	36.36% (8)	
Somewhat disagree	22.73% (5)	
Strongly disagree	4.55% (1)	
Since the creation of the PAB, how important do you feel that the inclusion of people with Parkinson's was to the research process (patient engagement)?		
Strongly important	86.36% (19)	100% (6)
Somewhat important	13.64% (3)	
Did you feel that the contributions of people with Parkinson's changed your opinion of patient engagement in research?		
Yes		83.33% (5)
Unsure		16.67% (1)

Was the PAB beneficial to your center's research mission?		
Yes		83.33% (5)
Unsure		16.67% (1)
Was the financial support provided by the Parkinson's Foundation adequate to pilot a PAB at your center?		
Yes		83.33% (5)
No		16.67% (1)
Without ongoing financial support from Parkinson's Foundation, will your center be able to continue the PAB in the future?		
Unsure		100% (6)
Will your center be applying for funding to implement your PAB project(s) in the next 18 months?		
Yes		33.33% (2)
Unsure		66.67% (4)
Is your center committed to continuing the PAB moving forward?		
Yes		83.33% (5)
Unsure		16.67% (1)
Will the PAB continue to focus on research?		
Yes		83.33% (5)
Unsure		16.67% (1)

Table 5. Baseline Perceptions of Center Care and Patient Engagement Experience

	People Living with PD (21)	Care Partners (5)	COE Center Staff (11)
<b>Center Care Perceptions</b>			
This center does its best to make patients health better.			
Strongly agree	76.19% (16)	100% (5)	
Somewhat agree	23.81% (5)		
Patients receive high quality care from this center.			
Strongly agree	80.95% (17)	100% (5)	
Somewhat agree	19.05% (4)		
This center conducts research that is relevant to the majority or all people with PD.			
Strongly agree	66.67% (14)	100% (5)	
Somewhat agree	33.33% (7)		
This center puts my medical priorities above other considerations when treating my medical problems.			
Strongly agree	66.67% (14)	60% (3)	
Somewhat agree	23.81% (5)	20% (1)	
Somewhat disagree	4.76% (1)		
Not applicable	4.76% (1)	20% (1)	
<b>Patient Engagement Experience and Perceptions</b>			
How important is the inclusion of people with Parkinson's to the research process (patient engagement)?			
Strongly important	100% (21)	100% (5)	100% (11)
Have you ever engaged in research other than as a study participant or patient?			
Yes	28.57% (6)	20% (1)	
No	71.43% (15)	80% (4)	
Have you ever engaged people with people with Parkinson's in research projects other than as study participants?			
Yes			73% (8)

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<p>No To your knowledge, has your center ever engaged people with Parkinson's in research projects other than as study participants?</p> <p>Yes No Unsure</p>			<p>27% (3)</p> <p>58.33% (7)</p> <p>18.18% (2)</p> <p>18.18% (2)</p>
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