Best Practices for Recruitment
Parkinson's Advisors in Research and Training Pilot: A Patient Advisory Board Model

Goal: Recruit and vet people with Parkinson's and care partners for a virtual Parkinson's research-based patient advisory board (PAB). Please aim to fill 5-9 openings on your institution's board.

Key Characteristics to Look for in Recruits
- Patience
- Enthusiasm
- Flexibility
- Respectfulness towards others
- Rich experience with Parkinson's and/or research
- Knowledge of/ability to integrate community perspectives and priorities
- Dedication and commitment to PD research

Advisory Board Position Expectations
- Be willing to serve as advisory board member for one year
- Go through Parkinson's Foundation patient advisory board training
- Participate in all quarterly PAB meetings
- Express your thoughts and ideas, keeping the community perspective in mind
- Listen to, understand and respect the perspectives of others
- Respect any group rules for discussion and meetings

How to Recruit
- Identify Parkinson's Foundation Research Advocates, if available
- Utilize networks already in place
    o Share advisory board opportunities with people with Parkinson's you see at your Center of Excellence
    o Other researchers at your institution who may see people with Parkinson's can share advisory board opportunities with patients
    o Social workers can share advisory board opportunities with their networks
    o Allied health professionals (physical therapists, speech therapists, etc.) can share opportunities with their patients
- Go out into the community – this may be difficult due to COVID-19
    o Churches – virtual church services and events are in session
    o Libraries – library websites may be a good place to post an announcement or bulletin
    o Regional or local Parkinson's organizations
    o Many Parkinson's groups are now virtual. Consider contacting your local group for a visitor or speaking opportunity
        ▪ Parkinson's support groups

- Parkinson's exercise groups
- Dance groups (e.g. Mark Morris Dance for PD)
- Rock Steady Boxing classes
  - LSVT clinicians
  - Federally qualified health centers
  - Aging centers/rec centers/aging villages

Engaging Diverse and Underserved Populations
Diversity encompasses race, ethnicity, socio-economic status, gender and sexual-orientation and geography.
- Consider who has not "at the table," both historically and currently, and work toward including those perspectives
- Keep in mind your local community
  - Boards should work towards being representative of the broader community of people with Parkinson's beyond those who are seen at COEs. Please take into consideration the demographic makeup of your area, which the Parkinson's Foundation will provide.

Process of Recruitment
- Outreach materials will be created, and active recruitment will commence
- Participants will call a centralized number to indicate interest
- Centers will be provided a list of participants to be screened
  - Parkinson's Foundation will work with centers to generate uniform screening questions.
- Final participants will be invited to the boards
- Other opportunities for engagement will be provided for those not chosen

Timeline
- **June – July:** Develop recruitment plan and materials, work with Foundation to determine training date
- **August – November:** Recruit participants
- **December:** Make final selections
- **January – March:** Participant trainings held virtually

Best Practices for Working with Populations with Cognitive Impairment Parkinson's Advisors in Research and Training Pilot: A Patient Advisory Board Model

Goal: Support people with Parkinson's through any stages of cognitive impairment to be as fully engaged in the advisory board as possible.

Introduction: Mild cognitive impairment affects 20-50% of people with Parkinson's. Of those, up to 70% may develop dementia. Cognitive impairment may include the following:

- Challenges with executive function (planning steps, organizing ideas, multitasking).
- Slowness of thinking.
- Difficulty with word finding.
- Brain fog.
- Intersection with other symptoms also common to Parkinson's such as depression and sleep and motor issues such as speech challenges.
- Intersection with "OFF" times (when medication is wearing off).
- Intersection with socio-demographic factors such as health literacy

Evidence shows people with cognitive impairment can engage in decision making potentially quite far into the impairment with the right support.

Best Practices: The following best practices for working with people with cognitive impairment were created through discussion groups with people with PD, researchers and clinicians, literature and landscape reviews and experiential learning.

- **Presentation**

Provide well organized materials in advance.
Use clear font and graphics.

- **Language**

Present in simple bullet points (not dense language).
Use common word the community understands.
Keep sentence structure simple.
Ensure questions flow well and are properly ordered.

- **Structure of Feedback Interactions**

Provide opportunities to give feedback in multiple ways – verbally, written, in real time or before or after meeting.
Build in ample time for participants to provide answers.

Allow for breaks.

- **Teamwork**

Ensure all members of the research team are prepared.
Work with partners – find an ally who can support the person with cognitive impairment.

- **Environment**

Consider the time of day to avoid holding meetings when cognitive impairment may be worse (ex: early mornings).
Create a supportive, comfortable environment, free from distractions.
Engage people when they are feeling their best, well-rested and relaxed.

- **Holistic Approach**

Consider if the cognitive challenges are a chronic issue of thinking or if there something else happening such as a speech challenge, pain, etc. or other medical condition and, if needed, connect participants with medical care.

Parkinson's Advisors in Research and Training Pilot: A Patient Advisory Board Model
National Collaborative Virtual Monthly Meeting
Friday, February 28, 2020 1:00 p.m. ET

Agenda
1. Introductions
2. Discussion of Recruitment Flyer Draft
3. Discussion of Toolkit
4. Google Doc for Ideas, Resources and Documents
5. Next Steps

Discussion
1. Introductions
In addition to the National Collaborative members present at the January in-person meeting, Melissa Armstrong, MD, MSc, FAAN University of Florida joined the call, as a new consultant to the project.

2. Discussion of Recruitment Flyer Draft
A draft of the recruitment flyer was shared with the group. The group provided feedback and edits.

3. Discussion of Toolkit
The toolkit and training manual are the key materials for the advisory board members. To make terms and concepts understandable to all involved in the patient advisory boards, it was determined that a glossary of lay definitions would be included.

4. Google Doc for Ideas, Resources and Documents
It was determined that a central hub for documents and resources was needed. It would house the resources shared on diversity and inclusion practices, best practices on cognitive impairment, links to other resources and the list of glossary terms to include in the toolkit.

5. Next Steps
Next steps are:
- edit and make changes to the recruitment flyer
- create a Google Doc for the team to use and store resources
- create a best practices document for working with people with cognitive impairment, and
- gather resources regarding diversity and inclusion trainings.

Parkinson's Advisors in Research and Training Pilot: A Patient Advisory Board Model
National Collaborative Virtual Monthly Meeting
Friday, April 24, 2020 1:00 p.m. ET

Agenda
6. Site Updates
7. PCORI Covid-19 Enhancement Options
8. Discussion of Virtual Model

Discussion
6. Site Updates
Updates were provided to the Collaborative regarding research and care at the institutions where the advisory boards would take place. Most sites don't expect to open to the public beyond treatment before the fall, some even predicting winter or spring. There are concerns with the aging population, especially later in the year as different cities and states re-open. Most sites have halted research for the time being, with a few exceptions.

7. Option to Extend from PCORI
After speaking to representatives from PCORI, the Foundation presented the option to extend the project to the collaborative. Due to Covid-19 and the delays in research and the re-opening of institutions to the public, it was agreed that we should explore a no-cost project extension, looking into developing a virtual model for the training and advisory boards.

8. Discussion of Virtual Model
National Collaborative affirmed the best option to move forward would be to adapt a virtual model for the training and advisory boards. Pros and cons of virtual meetings were brought up. Main pros: can meet during the pandemic and more aging populations are increasingly comfortable with technology. Main cons: telehealth is limited; less representative group of participants than with in-person meetings; device and internet challenges. Folks recommended sharing various "tips and tools" for virtual meetings and IT.

Parkinson's Advisors in Research and Training Pilot: A Patient Advisory Board Model
National Collaborative Virtual Monthly Meeting
Friday, May 22, 2020 1:00 p.m. ET

Agenda
9. Updated Timeline with Built-in Extension
10. Agreement of Virtual Model

Discussion
9. Updated Timeline with Built-in Extension
The collaborative was presented with the updated timeline, using the framework of the three month no-cost extension that the Foundation will apply for. The new timeline is as follows:
- June – July 2020 – develop recruitment plan and materials, work with Foundation to determine training date;
- August – November 2020 – recruit participants;
- December 2020 – make final selections;
- January – March 2021 – Participant trainings virtually held.

10. Agreement of Virtual Model
All members of the collaborative agreed that moving forward using a virtual model was the best method for continuing the project. Materials created, such as the recruitment flyer and training manual, will be edited to reflect this.