



Feedback regarding the research conducted by The Parkinson Alliance

The Parkinson Alliance regularly pursues feedback regarding the research that we conduct. We request feedback about each survey in hopes to ensure that we are meeting the needs of our “community.” We recently conducted phone interviews with participants of our research endeavors to pursue feedback about past surveys and the future direction of research conducted by The Parkinson Alliance.

METHODS

Twenty-four participants who had participated in previous research projects were randomly selected from a secure database. Participants included 13 individuals with Parkinson’s disease with Deep Brain Stimulation (8 male and 5 female), and 11 individuals with Parkinson’s disease without Deep Brain Stimulation (6 male and 5 female). These individuals were contacted via telephone, and they were asked the following questions:

1. Have you enjoyed the recent topics that we have researched, such as the topics related to coping, sleep, anxiety, and depression?
 - a. What did you like about them?
 - b. How could we have improved them?
2. What would you like to see in our future surveys?
 - a. Are there any particular topics related to symptoms of PD that you would like us to include in a report?
 - b. Out of the list below, what topic would you like us to research? (The list included: speech disturbance, the experience of pain, exercise, and emotional well-being).

FEEDBACK FROM THE PARTICIPANTS

- In general, the feedback from the participants was positive.
 - The participants found the reports very informative, useful, and easy to understand. One of the participants mentioned that even though it contains technical information, it is still easy for a lay person to understand. This feedback is very important to The Parkinson Alliance, as we strive to describe the “experiences” of individuals with PD in an understandable way and through use of everyday language.

- Some individuals reported that they pass along the results of the surveys to their support groups. For example, it was noted that some reports are disseminated as a whole, while one participant indicated that he enlarges the charts within the survey and takes them to his support group for discussion.
- Constructive criticism was also relayed.
 - A couple of participants requested that they would like to see the reports in the format of a newsletter, with headlines providing pertinent information. They requested a “Reader’s Digest” version.
- Topics regarding future projects were also mentioned.
 - With regard to the future topics requested, some individuals who have undergone DBS requested research on “speech” and “pain”. Other individuals who have not undergone DBS requested research on “emotional well-being” and “exercise”.
 - Other topics were also presented to us. As you will see in the points below, there were requests for a variety of subjects.

Requests from Participants who have undergone DBS

- Speech
- Pain
- Gait Disturbance (problems with walking)
- Freezing
- Relationship between drinking coffee and having tremors
- Psychiatric Issues
- DBS and impulsiveness
- Ups and downs of DBS
- Social interaction
- Survey on Young Onset PD
- Programming
- Stimulator Hardware Issues: Broken leads/battery problems
- The impact of DBS as it relates to unilateral versus bilateral stimulation and its impact on unilateral symptoms.
- Medications for PD
- Duration of the benefit of DBS (comparing those who have had DBS longer to those who have received DBS therapy more recently)

Requests from Participants who have not undergone DBS

- Studies on cognitive deficit PD and cognitive issues and DBS
- Social interaction
- Emotional well being
- Exercise
- Long term effects of PD on digestive system –GERD
- More info on sleep and PD
- How to talk to doctors and make sure they listen
- Shock Therapy and tremors

DISCUSSION

- We appreciate the feedback provided to our research team. It appears that the surveys are proving to be of interest and of value to those who participate in the research.
- There are several different ways individuals are using the research, which include for personal enlightenment and also to share with others (e.g., in PD support groups).
- There was a request for a “Reader’s Digest” version of the reports. For example, a couple individuals thought it would be helpful to incorporate a short summary of the report in a newsletter. Providing a short summary in a newsletter is a nice suggestion. The Parkinson Alliance staff will certainly consider this idea in the future.
- Several topics for future research were presented.
 - When considering research topics, the logistics and feasibility of the topic has to be taken into account. Research that uses a survey-based approach is very informative and provides a good glimpse into participants’ perception of the questions asked of them.
 - Topics that are easily assessed in this format include, but are not limited to, speech, sleep disruption, emotional well-being, coping strategies, pain, assessment of the participants perceived experience of motor and other non-motor symptoms, social interaction, exercise, etc. There are several sound instruments to collect data using this survey method.
 - There are, however, research topics that are better investigated through the use of more rigorous methods (e.g., requiring face-to-face assessment). Some of these research topics include cognitive changes, medications, battery function, hardware or software issues, programming, unilateral vs. bilateral stimulation and its impact on specific symptoms, etc.
- We appreciate all of the feedback provided. We could not conduct the research we do and be a “voice” for the PD community without your help. The research provided by our participants is very valuable in reaching the people with Parkinson’s disease, the carers for the PWP, and researchers and clinicians who attempt to help this PD community.
- We also hope that we can count on your continued participation in future projects. You will be receiving a new survey within the next couple of months.
- Should you have any questions or comments about the feedback or our research projects, please feel free to contact us at 1-800-579-8440. We would be delighted to discuss this with you.

ACKNOWLEDGEMENTS

I want to express my gratitude for Ms. Valentina Trepatschko, a staff member of The Parkinson Alliance, who assisted in making this feedback possible. She made the phone calls and collected the information to assist in improving our research and reaching out to our community.

I am very grateful to the people who took time to speak with Ms. Trepatschko. Thank you.

Margaret Tuchman
President
The Parkinson Alliance