

Fox Insight Cohort: ALL

Participant facing title: Quality of Life and Symptoms in People with PD after DBS

Thank you for your interest in this survey. This survey is to learn more about quality of life and symptoms after deep brain stimulation (DBS). This information could help doctors understand which patients are more likely to benefit from DBS. Findings may help direct treatment for Parkinson's patients in the future.

This survey is open to both (i) people with Parkinson's who are using DBS and (ii) all caregivers (paid and unpaid) of people with Parkinson's who are using DBS.

Multiple choice, single answer, required

1. Which of the following best describes you (the person who is responding to this survey)?

Note: A care partner is someone who regularly provides support to a person with a health condition so that they can meet their day-to-day care needs, such as through physical, emotional, or social support.

- a. A person with Parkinson's disease who has undergone DBS
- b. A person with Parkinson's disease who has **not** undergone DBS
- c. A care partner (paid or unpaid) for someone who has Parkinson's disease and has undergone DBS
- d. A care partner (paid or unpaid) for someone who has Parkinson's disease and has **not** undergone DBS
- e. None of the above describe me

Skip logic: If (b.), (d.), or (e.) is selected, then skip to End of Survey 2

Branching starts here: if (a.) is selected, pt will complete the PD survey. If (c.) is selected, pt will complete the care partner survey.

PD Survey

Text entry, numbers only, required

2. How many months has it been since you first received DBS treatment? Please round your answer to the nearest month. If you are not sure, please enter your best guess.

Months since first DBS treatment:_____

Multiple choice, single answer, required

3. What region is targeted for your DBS treatment?
- a. Subthalamic Nucleus (STN)
 - b. Globus pallidus internus (GPI)
 - c. Ventral intermediate nucleus of the thalamus (VIM)
 - d. Other region
 - e. Not sure
 - f. Prefer not to answer

Multiple choice, single answer, required

4. Did you receive DBS bilaterally or unilaterally?
- a. I received DBS bilaterally (on both sides of the brain)
 - b. I received DBS unilaterally (on only one side of the brain)
 - c. Not sure
 - d. Prefer not to answer

Multiple choice, single answer, required

5. Did you have your DBS procedure done completely asleep (under general anesthesia)?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Multiple choice, single answer, required

6. How many months has it been since your physician last changed your DBS settings?
If you are not sure, please enter your best guess. Please enter only whole numbers.
- a. Please enter the number of months since your physician last changed your DBS settings in the box just below: _____
 - b. Not sure
 - c. Prefer not to answer

Multiple choice, single answer, required

The next section aims to assess how your cognitive (thinking and memory) functions have changed since you received DBS. **We recognize other factors, such as natural progression of disease, may impact cognition.** You will answer each question using a

scale. Your answers should reflect **how you feel** and not how others perceive your cognitive functions.

Multiple choice, single answer, required

7. Reading

Potential issues include *but are not limited to* the following:

- Not being able to read a book or text displayed on a screen (e.g. television, computer, tablet)

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

8. Time keeping

Potential issues include *but are not limited to* the following:

- Keeping track of time during activities of daily life or work, punctuality in appointments and meeting deadlines

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

9. Counting and using money

Potential issues include *but are not limited to* the following:

- Counting the correct amount of money when making purchases
- Having difficulties completing electronic purchases

- Managing bills

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

10. Following verbal or written instructions

Potential issues include *but are not limited to* the following:

- Following the steps in a sequence of instructions, one at a time
- Remembering medical instructions without having them repeated
- Reading and following complex instructions
- Taking instructions and then remembering them later

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

11. Handling unfamiliar problems

Potential issues include *but are not limited to* the following:

- Dealing with an unfamiliar situation
- Performing tasks for the first time
- Problem solving

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

12. Explaining stepwise procedures

Potential issues include *but are not limited to* the following:

- Explaining how to do something involving several steps to another person
- Being able to identify the individual steps of a complex task

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer
- g.

Multiple choice, single answer, required

13. Remembering lists

Potential issues include *but are not limited to* the following:

- Remembering a list of 4 or 5 tasks or words without writing it down
- Memorizing a shopping list with a few items

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

14. Orientation

Potential issues include *but are not limited to* the following:

- Using a map to tell where to go (either in paper or electronic form, e.g. Google maps)
- Navigating in an environment using cues and landmarks

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

15. Learning new information

Potential issues include *but are not limited to* the following:

- Remembering new information like phone numbers or simple instructions
- Remembering the names of people when first meeting them
- Remembering things that have happened recently

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

16. Multi-tasking

Potential issues include *but are not limited to* the following:

- Doing more than one thing at a time (e.g. doing housework while talking on the phone)

- Switching from one thought or task to another

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

17. Using new appliances

Potential issues include *but are not limited to* the following:

- Learning to use new gadgets or machines around the house
- Learning how to use new electronic devices
- Being able to use machines in a public space (e.g. ticket vending machines)

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

18. Management of own finances

Potential issues include *but are not limited to* the following:

- Understanding your personal financial affairs
- Keeping important personal papers such as bills, insurance documents and tax forms organized
- Meeting bill payment deadlines

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

19. Maintaining and organizing thoughts

Potential issues include *but are not limited to* the following:

- Maintaining or completing a train of thought
- Staying on topic while talking
- Planning out the steps of a task or what to do during the day
- Organizing what you want to say

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

20. Discussing current events

Potential issues include *but are not limited to* the following:

- Discussing a TV show, book, movie or current events
- Participating in conversations about recent social or political topics

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

21. Time perception

Potential issues include *but are not limited to* the following:

- Remembering what day and month it is
- Planning for and keeping appointments that are not part of your weekly routine

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

The next section aims to assess how your movement and non-movement abilities changed since you received DBS. **We recognize other factors, such as natural progression of disease, may impact these abilities.** You will answer each question using a scale. Your answers should reflect **how you feel** and not how others perceive your movement and non-movement abilities.

Multiple choice, single answer, required

22. Speaking

Potential issues include *but are not limited to* the following:

- Not being able to articulate your words well
- Speaking too quietly to be heard
- Slurring words
- General difficulty with expressing your thoughts and feelings through speech

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now

- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

23. People understanding what I say

Potential issues include *but are not limited to* the following:

- People ask me to repeat myself
- People have difficulty understanding what I say even when I repeat myself
- People cannot understand me at all

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

24. Excessive saliva or drooling

Potential issues include *but are not limited to* the following:

- Excessive saliva that you find uncomfortable or inappropriate
- Drooling while awake
- Drooling while asleep

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

25. Chewing and swallowing food, drinks, or pills

Potential issues include *but are not limited to* the following:

- Chewing with difficulty
- Chewing or swallowing requires concentration
- Needing food to be cut or mashed in order to swallow
- Difficulty swallowing drinks or pills
- Choking

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- Much better now
- Better now
- About the same as before DBS
- Worse now
- Much worse now
- Prefer not to answer

Multiple choice, single answer, required

26. Eating

Potential issues include *but are not limited to* the following:

- Difficulty handling utensils (spoons, forks, knives, etc.)
- Dropping food or having difficulty putting food on your plate
- Eating so slowly that you are frustrated
- Needing help to eat

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- Much better now
- Better now
- About the same as before DBS
- Worse now
- Much worse now
- Prefer not to answer

Multiple choice, single answer, required

27. Dressing and undressing

Potential issues include *but are not limited to* the following:

- Difficulty getting dressed or undressed
- Needing help to get dressed or undressed

- Needing help with certain types of clothing (may involve buttoning, using zippers, tying knots, etc.)

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

28. Hygiene

Potential issues include *but are not limited to* the following:

- Difficulty taking showers or baths
- Difficulty with grooming tasks (styling your hair, trimming nails, shaving, etc.)
- Difficulty maintaining dental hygiene
- Difficulty using the restroom
- Inability to maintain good hygiene without help

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

29. Handwriting

Potential issues include *but are not limited to* the following:

- Difficulty reading your own handwriting
- Other people having difficulty reading your handwriting
- Handwriting takes a lot of effort
- Writing neatly is difficult or impossible
- Difficulty writing checks, greeting cards, etc.

Do you regularly perform this activity?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

30. Handwriting

Potential issues include *but are not limited to* the following:

- Difficulty reading your own handwriting
- Other people having difficulty reading your handwriting
- Handwriting takes a lot of effort
- Writing neatly is difficult or impossible
- Difficulty writing checks, greeting cards, etc.

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer
- g.

Display logic: If (a. Yes) is selected for “Handwriting”

Multiple choice, single answer, required

31. Using electronic devices

Potential issues include *but are not limited to* the following:

- Difficulty typing on a computer, tablet, or phone (e.g., opening and writing emails or text messages)
- Difficulty using typical apps such as map, calculator, etc.
- Difficulty answering and making video calls or phone calls
- Difficulty using self-checkout terminals in grocery stores
- Difficulty using credit cards or completing ATM transactions

Do you regularly perform this activity?

- a. Yes
- b. No

- c. Prefer not to answer

Multiple choice, single answer, required

32. Using electronic devices

Potential issues include *but are not limited to* the following:

- Difficulty typing on a computer, tablet, or phone (e.g., opening and writing emails or text messages)
- Difficulty using typical apps such as map, calculator, etc.
- Difficulty answering and making video calls or phone calls
- Difficulty using self-checkout terminals in grocery stores
- Difficulty using credit cards or completing ATM transactions

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Display logic: If (a. Yes) is selected for “Using electronic devices”

Multiple choice, single answer, required

33. Doing hobbies

Potential issues include *but are not limited to* the following:

- Cannot do physical activity associated with a hobby
- Cannot do mental activities associated with a hobby
- Cannot enjoy any hobbies at all

Do you regularly perform this activity?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

34. Doing hobbies

Potential issues include *but are not limited to* the following:

- Cannot do physical activity associated with a hobby

- Cannot do mental activities associated with a hobby
- Cannot enjoy any hobbies at all

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Display logic: If (a. Yes) is selected for “Doing hobbies”

Multiple choice, single answer, required

35. Turning in bed

Potential issues include *but are not limited to* the following:

- Difficulty turning in bed on your own
- Inability to turn in bed without help

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

36. Experiencing tremors

Potential issues include *but are not limited to* the following:

- Tremors prevent you from doing your regular activities
- Tremors make moving difficult
- Tremors greatly bother you

Do you regularly experience tremors?

- a. Yes
- b. No

- c. Prefer not to answer

Multiple choice, single answer, required

37. Experiencing tremors

Potential issues include *but are not limited to* the following:

- Tremors prevent you from doing your regular activities
- Tremors make moving difficult
- Tremors greatly bother you

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Display logic: If (a. Yes) is selected for “Experiencing tremors”

Multiple choice, single answer, required

38. Getting up from the sitting position

Potential issues include *but are not limited to* the following:

- Being slow or experiencing pain when trying to get up
- Needing more than one attempt to get up
- Needing help to get up

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

39. Walking and maintaining balance

Potential issues include *but are not limited to* the following:

- Walking too slowly
- Losing your balance
- Needing a cane or walker
- Being unable to walk at all

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

40. Freezing while moving

Potential issues include *but are not limited to* the following:

- Experiencing frequent freezing episodes
- Difficulty with starting to move again after a freezing episode
- Needing help to start moving again after a freezing episode
- Freezing episodes greatly bother you

Do you regularly experience freezing while moving?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

41. Freezing while moving

Potential issues include *but are not limited to* the following:

- Experiencing frequent freezing episodes
- Difficulty with starting to move again after a freezing episode
- Needing help to start moving again after a freezing episode
- Freezing episodes greatly bother you

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Display logic: If (a. Yes) is selected for “Freezing while moving”

The next section aims to assess how your mental and emotional well-being has changed since you received DBS. **We recognize other factors, such as natural progression of disease, may impact your mental and emotional well-being.** You will answer each question using a scale. Your answers should reflect **how you feel** and not how others perceive your mental and emotional well-being.

Multiple choice, single answer, required

42. Hallucinations

Potential issues include *but are not limited to* the following:

- Perceiving things that other people do not (e.g. hearing a voice, seeing objects or people, smelling or tasting something etc)
- Feeling paranoid

Have you ever experienced this condition at any time since your Parkinson’s diagnosis?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

43. Hallucinations

Potential issues include *but are not limited to* the following:

- Perceiving things that other people do not (e.g. hearing a voice, seeing objects or people, smelling or tasting something etc)
- Feeling paranoid

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Display logic: If (a. Yes) is selected for “Hallucinations”

Multiple choice, single answer, required

44. Depression

Potential issues include *but are not limited to* the following:

- Persistent sadness, pessimism, loss of interest in hobbies, helplessness.
- Difficulty carrying out daily activities due to your low mood.
- Difficulty being with people.

Have you experienced this condition at any time since your Parkinson’s diagnosis?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

45. Depression

Potential issues include *but are not limited to* the following:

- Persistent sadness, pessimism, loss of interest in hobbies, helplessness.
- Difficulty carrying out daily activities due to your low mood.
- Difficulty being with people.

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now

- e. Much worse now
- f. Prefer not to answer

Display logic: If (a. Yes) is selected for “Depression”

Multiple choice, single answer, required

46. Anxiety

Potential issues include *but are not limited to* the following:

- Feeling nervous, tense, unable to relax
- Difficulty carrying out daily activities due to your anxiety
- Difficulty being with people
- Irritability

Have you experienced this condition at any time since your Parkinson’s diagnosis?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

47. Anxiety

Potential issues include *but are not limited to* the following:

- Feeling nervous, tense, unable to relax
- Difficulty carrying out daily activities due to your anxiety
- Difficulty being with people
- Irritability

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Display logic: If (a. Yes) is selected for “Anxiety”

Multiple choice, single answer, required

48. Apathy

Potential issues include *but are not limited to* the following:

- Lack of interest in doing activities or being with people
- Difficulty carrying out daily activities due to lack of motivation

Have you experienced this condition at any time since your Parkinson's diagnosis?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

49. Apathy

Potential issues include *but are not limited to* the following:

- Lack of interest in doing activities or being with people
- Difficulty carrying out daily activities due to lack of motivation

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Display logic: If (a. Yes) is selected for "Apathy"

Multiple choice, single answer, required

50. Unusually strong urges

Potential issues include *but are not limited to* the following:

- Urges that are hard to control or hard to stop (examples: overspending when shopping, obsessing about food or sex, gambling, repetitive and obsessive behavior)

Have you experienced this condition at any time since your Parkinson's diagnosis?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

51. Unusually strong urges

Potential issues include *but are not limited to* the following:

- Urges that are hard to control or hard to stop
(examples: overspending when shopping, obsessing about food or sex, gambling, repetitive and obsessive behavior)

How do you feel this aspect changed since you received DBS? The answers should reflect **your own feelings** and not how others might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Display logic: If (a. Yes) is selected for “Unusually strong urges”

End of Survey Thank You

Thank you for your participation in this survey. The information you provided is very important to help doctors understand which patients are more likely to benefit from DBS.

Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.

End of Survey Thank You 2

Thank you for participating in Fox Insight. This survey is currently only collecting responses from People with PD who have undergone DBS and their Care Partners. **Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.**

Care Partner Survey

Multiple choice, single answer, required

52. What is your relationship to the person with Parkinson’s disease (PwPD)?

- a. Family member

- b. Friend
- c. Professional caregiver (paid or volunteer)
- d. Other

Multiple choice, single answer, required

53. Were you the PwPD's care partner even before he or she received Deep Brain Stimulation (DBS)?

- e. Yes
- f. No

Skip logic: If (b. No) is selected, skip to End of Survey Thank You 2

Text entry, numbers only, required

54. For how many months have you been the PwPD's care partner?

Number of months: ____

Matrix, text entry, required

55. How many hours do you usually take care of the PwPD? If you do not take care of the PwPD on certain days, please type 0 for that day. If the hours vary week by week, please provide your best estimate.

Days	Hours (number)
Monday	
Tuesday	
Wednesday	
Thursday	
Friday	
Saturday	
Sunday	

The next section aims to assess how the cognitive (thinking and memory) functions of the PwPD you care for have changed since she or he received DBS. **We recognize other factors, such as natural progression of disease, may impact cognition.** You will answer each question using a scale. Your answers should reflect **your judgment** and not how the PwPD tells you he or she is feeling about each aspect.

Multiple choice, single answer, required

56. Reading

Potential issues the PwPD may face include *but are not limited to* the following:

- Not being able to read a book or text displayed on a screen (e.g. television, computer, tablet)

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect your own feeling and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

57. Time keeping

Potential issues the PwPD may face include *but are not limited to* the following:

- Keeping track of time during activities of daily life or work
- Punctuality in appointments and meeting deadlines.

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect your own feeling and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

58. Counting and using money

Potential issues the care recipient may face include *but are not limited to* the following:

- Counting the correct amount of money when making purchases
- Having difficulties completing electronic purchases
- Managing bills

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect your own feeling and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

59. Following verbal or written instructions

Potential issues the PwPD may face include *but are not limited to* the following:

- Following the steps in a sequence of instructions one at a time
- Keeping medical instructions straight without having them repeated
- Reading and following complex instructions
- Taking instructions and then remembering them later

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect your own feeling and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

b.

Multiple choice, single answer, required

60. Handling unfamiliar problems

Potential issues the PwPD may face include *but are not limited to* the following:

- Dealing with an unfamiliar situation
- Performing tasks for the first time
- Problem solving

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect your own feeling and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now

- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

61. Explaining stepwise procedures

Potential issues the PwPD may face include *but are not limited to* the following:

- Explaining how to do something involving several steps to another person
- Being able to identify the individual steps of a complex task

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect your own feeling and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

62. Remembering lists

Potential issues the PwPD may face include *but are not limited to* the following:

- Remembering a list of 4 or 5 tasks or words without writing it down
- Memorizing a shopping list with a few items

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect your own feeling and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

63. Orientation

Potential issues the PwPD may face include *but are not limited to* the following:

- Using a map to tell where to go (either in paper or electronic form, e.g. Google maps)

- Navigating in an environment using cues and landmarks

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect your own feeling and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

64. Learning new information

Potential issues the PwPD may face include *but are not limited to* the following:

- Remembering new information like phone numbers or simple instructions
- Remembering the names of people when first meeting them
- Remembering things that have happened recently

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect your own feeling and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

b.

Multiple choice, single answer, required

65. Multi-tasking

Potential issues the PwPD may face include *but are not limited to* the following:

- Doing more than one thing at a time (e.g. doing housework while talking on the phone)
- Switching from one thought or task to another

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect your own feeling and not how the PwPD might perceive.

- a. Much better now

- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

66. Using new appliances

Potential issues the PwPD may face include *but are not limited to* the following:

- Learning to use new gadgets or machines around the house
- Learning how to use new electronic devices
- Being able to use machines in public spaces (e.g. ticket vending machines)

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect your own feeling and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

67. Management of own finances

Potential issues the PwPD may face include *but are not limited to* the following:

- Understanding his/her personal financial affairs
- Keeping important personal papers such as bills, insurance documents and tax forms organized
- Meeting bill payment deadlines

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect your own feeling and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

68. Maintaining and organizing thoughts

Potential issues the PwPD may face include *but are not limited to* the following:

- Maintaining or completing a train of thought
- Staying on topic while talking
- Planning out the steps of a task or what to do in the day
- Organizing what he/she wants to say

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect your own feeling and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

69. Discussing current events

Potential issues the PwPD may face include *but are not limited to* the following:

- Discussing a TV show, book, movie or current events
- Participating in conversations about recent social or political topics

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect your own feeling and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

70. Time perception

Potential issues the PwPD may face include *but are not limited to* the following:

- Remembering what day and month it is

- Planning for and keeping appointments that are not part of his/her weekly routine

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect your own feeling and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

The next section aims to assess how the movement and non-movement abilities of the PwPD you care for have changed since she or he received DBS. **We recognize other factors, such as natural progression of disease, may impact these abilities.** You will answer each question using a scale. Your answers should reflect **your judgment** and not how the PwPD tells you he or she is feeling about each aspect.

Multiple choice, single answer, required

71. Speaking

Potential issues the PwPD may face include *but are not limited to* the following:

- Not being able to articulate words well
- Speaking too quietly to be heard
- Slurring words
- General difficulty with expressing thoughts and feelings through speech

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect **your own feeling** and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

72. People understanding what the PwPD says

Potential issues the PwPD may face include *but are not limited to* the following:

- People ask the PwPD to repeat himself/herself.
- People have difficulty understanding what the PwPD says even when he/she repeats it.
- People cannot understand the PwPD's speech at all.

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect **how you and others understand** his or her speech.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

73. Excessive saliva or drooling

Potential issues the PwPD may face include *but are not limited to* the following:

- The PwPD is bothered by excessive saliva
- Drooling while awake
- Drooling while asleep

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect **your own feeling** and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

74. Chewing and swallowing food, drinks, or pills

Potential issues the PwPD may face include *but are not limited to* the following:

- Chewing with difficulty
- Chewing or swallowing requires concentration
- Needing food to be cut or mashed in order to swallow
- Difficulty swallowing drinks or pills

- Choking

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect **your own feeling** and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

75. Eating

Potential issues the PwPD may face include *but are not limited to* the following:

- Difficulty handling utensils (spoons, forks, knives, etc.)
- Dropping food or having difficulty putting food on a plate
- The PwPD gets frustrated because he/she eats too slowly
- The PwPD needs help to eat

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect **your own feeling** and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

76. Dressing and undressing

Potential issues the PwPD may face include *but are not limited to* the following:

- Difficulty getting dressed or undressed
- Needing help to get dressed or undressed
- Needing help with certain types of clothing (may involve buttoning, using zippers, tying knots, etc.)

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect **your own feeling** and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

77. Hygiene

Potential issues the PwPD may face include *but are not limited to* the following:

- Difficulty taking showers or baths
- Difficulty with grooming tasks (styling your hair, trimming nails, shaving, etc.)
- Difficulty maintaining dental hygiene
- Difficulty using the restroom
- Inability to maintain good hygiene without help

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect **your own feeling** and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

78. Handwriting

Potential issues the PwPD may face include *but are not limited to* the following:

- You or other people have difficulty reading the PwPD's handwriting
- Handwriting takes a lot of effort
- Writing neatly is difficult or impossible
- Writing checks, letters, greeting cards, etc. is difficult or impossible

Does the PwPD regularly perform this activity?

- a. Yes
- b. No
- c. Prefer not to answer

79. Handwriting

Potential issues the PwPD may face include *but are not limited to* the following:

- You or other people have difficulty reading the PwPD's handwriting
- Handwriting takes a lot of effort
- Writing neatly is difficult or impossible
- Writing checks, letters, greeting cards, etc. is difficult or impossible

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect **your own feeling** and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Display logic: If (a. Yes) is selected for “Handwriting”

Multiple choice, single answer, required

80. Using electronic devices

Potential issues the PwPD may face include *but are not limited to* the following:

- Difficulty typing on a computer, tablet, or phone (e.g., opening and writing emails or text messages)
- Difficulty using typical apps such as map, calculator, etc.
- Difficulty answering and making video calls or phone calls
- Difficulty using self-checkout terminals in grocery stores
- Difficulty using credit cards or completing ATM transactions

Does the PwPD regularly perform this activity?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

81. Using electronic devices

Potential issues the PwPD may face include *but are not limited to* the following:

- Difficulty typing on a computer, tablet, or phone (e.g., opening and writing emails or text messages)
- Difficulty using typical apps such as map, calculator, etc.
- Difficulty answering and making video calls or phone calls
- Difficulty using self-checkout terminals in grocery stores
- Difficulty using credit cards or completing ATM transactions

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect **your own feeling** and not how the PwPD might perceive.

- Much better now
- Better now
- About the same as before DBS
- Worse now
- Much worse now
- Prefer not to answer

Display logic: If (a. Yes) is selected for “Using electronic devices”

Multiple choice, single answer, required

82. Doing hobbies

Potential issues the PwPD may face include *but are not limited to* the following:

- Cannot do physical activity associated with a hobby
- Cannot do mental activities associated with a hobby
- Cannot enjoy any hobbies at all

Does the PwPD regularly perform this activity?

- Yes
- No
- Prefer not to answer

Multiple choice, single answer, required

83. Doing hobbies

Potential issues the PwPD may face include *but are not limited to* the following:

- Cannot do physical activity associated with a hobby
- Cannot do mental activities associated with a hobby
- Cannot enjoy any hobbies at all

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect **your own feeling** and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Display logic: If (a. Yes) is selected for “Doing hobbies”

Multiple choice, single answer, required

84. Turning in bed

Potential issues the PwPD may face include *but are not limited to* the following:

- Difficulty turning in bed alone
- Inability to turn in bed without help

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect **your own feeling** and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Not sure
- g. Prefer not to answer

Multiple choice, single answer, required

85. Experiencing tremors

Potential issues the PwPD may face include *but are not limited to* the following:

- Tremors prevent the PwPD from doing regular activities
- Tremors make moving difficult

Does the PwPD regularly experience tremors?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

86. Experiencing tremors

Potential issues the PwPD may face include *but are not limited to* the following:

- Tremors prevent the PwPD from doing regular activities
- Tremors make moving difficult

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect **your own feeling** and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Display logic: If (a. Yes) is selected for “Experiencing tremors”

Multiple choice, single answer, required

87. Getting up from the sitting position

Potential issues the PwPD may face include *but are not limited to* the following:

- Being slow or experiencing pain when trying to get up
- Needing more than one attempt to get up
- Needing help to get up

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect **your own feeling** and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

88. Walking and maintaining balance

Potential issues the PwPD may face include *but are not limited to* the following:

- Walking too slowly
- Losing balance
- Needing a cane or walker

- Being unable to walk at all

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect **your own feeling** and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Multiple choice, single answer, required

89. Freezing while moving

Potential issues the PwPD may face include *but are not limited to* the following:

- Experiencing frequent freezing episodes
- Difficulty with starting to move again after a freezing episode
- Needing help to start moving again after a freezing episode

Does the PwPD regularly experience freezing while moving?

- d. Yes
- e. No
- f. Prefer not to answer

Multiple choice, single answer, required

90. Freezing while moving

Potential issues the PwPD may face include *but are not limited to* the following:

- Experiencing frequent freezing episodes
- Difficulty with starting to move again after a freezing episode
- Needing help to start moving again after a freezing episode

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect **your own feeling** and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Display logic: If (a. Yes) is selected for “Freezing while moving”

The next section aims to assess how the mental and emotional well-being of the PwPD you care for has changed since she or he received DBS. **We recognize other factors, such as natural progression of disease, may impact mental and emotional well-being.** You will answer each question using a scale. Your answers should reflect **your judgment** and not how the PwPD tells you he or she is feeling about each aspect.

Multiple choice, single answer, required

91. Hallucinations

Potential issues the PwPD may face include *but are not limited to* the following:

- Perceiving things that other people do not (e.g. hearing a voice, seeing objects or people, smelling or tasting something etc)
- Paranoid behavior

Has the PwPD experienced this condition at any time since his/her Parkinson’s diagnosis?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

92. Hallucinations

Potential issues the PwPD may face include *but are not limited to* the following:

- Perceiving things that other people do not (e.g. hearing a voice, seeing objects or people, smelling or tasting something etc)
- Paranoid behavior

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect **your own feeling** and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS

- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Display logic: If (a. Yes) is selected for “Hallucinations”

Multiple choice, single answer, required

93. Depression

Potential issues the PwPD may face include *but are not limited to* the following:

- Persistent sadness, pessimism, loss of interest in hobbies, helplessness.
- Difficulty carrying out daily activities due to the low mood.
- Difficulty being with people.

Has the PwPD experienced this condition at any time since his/her Parkinson’s diagnosis?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

94. Depression

Potential issues the PwPD may face include *but are not limited to* the following:

- Persistent sadness, pessimism, loss of interest in hobbies, helplessness.
- Difficulty carrying out daily activities due to the low mood.
- Difficulty being with people.

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect **your own feeling** and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Display logic: If (a. Yes) is selected for “Depression”

Multiple choice, single answer, required

95. Anxiety

Potential issues the PwPD may face include *but are not limited to* the following:

- Feeling nervous, tense, unable to relax
- Difficulty carrying out daily activities due to the anxious mood
- Difficulty being with people
- Irritability

Has the PwPD experienced this condition at any time since his/her Parkinson's diagnosis?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

96. Anxiety

Potential issues the PwPD may face include *but are not limited to* the following:

- Feeling nervous, tense, unable to relax
- Difficulty carrying out daily activities due to the anxious mood
- Difficulty being with people
- Irritability

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect **your own feeling** and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Display logic: If (a. Yes) is selected for "Anxiety"

Multiple choice, single answer, required

97. Apathy

Potential issues the PwPD may face include *but are not limited to* the following:

- Lack of interest in doing activities or being with people
- Difficulty carrying out daily activities due to lack of motivation

Has the PwPD experienced this condition at any time since his/her Parkinson's diagnosis?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

98. Apathy

Potential issues the PwPD may face include *but are not limited to* the following:

- Lack of interest in doing activities or being with people
- Difficulty carrying out daily activities due to lack of motivation

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect **your own feeling** and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Display logic: If (a. Yes) is selected for "Apathy"

Multiple choice, single answer, required

99. Unusually strong urges

Potential issues the PwPD may face include *but are not limited to* the following:

- Urges that are hard to control or hard to stop (examples: overspending when shopping, obsessing about food or sex, gambling, repetitive and obsessive behavior)

Has the PwPD experienced this condition at any time since his/her Parkinson's diagnosis?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

100. Unusually strong urges

Potential issues the PwPD may face include *but are not limited to* the following:

- Urges that are hard to control or hard to stop (examples: overspending when shopping, obsessing about food or sex, gambling, repetitive and obsessive behavior)

How do you feel this aspect changed since the PwPD received DBS? The answer should reflect **your own feeling** and not how the PwPD might perceive.

- a. Much better now
- b. Better now
- c. About the same as before DBS
- d. Worse now
- e. Much worse now
- f. Prefer not to answer

Display logic: If (a. Yes) is selected for “Unusually strong urges”

End of Survey Thank You

Thank you for your participation in this survey. The information you provided is very important to help doctors understand which patients are more likely to benefit from DBS.

Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.

End of Survey Thank You 2

Thank you for participating in Fox Insight. This survey is currently only collecting responses from People with PD who have undergone DBS and Care Partners who have been helping people with PD before and after their DBS. **Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.**