

## ATTITUDES AND BELIEFS REGARDING RESEARCH AND GENETIC TESTING FOR PARKINSON'S DISEASE

Thank you for taking part in this survey. Your answers to these questions will help us learn more about what people know and think about research studies, genetic testing, and disease risk.

### **Block 1: Intro**

*Multiple choice, single answer, required*

1. Have you been diagnosed with Parkinson's disease?
  - a. Yes
  - b. No

*Text entry limited to 0-99, single answer, required*

2. At what age were you diagnosed?

Display Logic: If (a) is selected for Q1

### **Block 2: Questions about Parkinson's Disease**

The following statements are about Parkinson's disease. Please read each statement carefully, then select whether or not you agree with the statement.

*Multiple choice, single answer, required*

3. Parkinson's disease is more common in older adults.  
***When answering, please select whether or not you agree with this statement.***
  - a. Agree
  - b. Disagree
  - c. Not sure
  - d. Prefer not to answer

*Multiple choice, single answer, required*

4. In most cases, the cause of Parkinson's disease is unknown.  
***When answering, please select whether or not you agree with this statement.***
  - a. Agree
  - b. Disagree
  - c. Not sure
  - d. Prefer not to answer

*Multiple choice, single answer, required*

5. In most cases, people with Parkinson's disease did not know they were at risk of developing the disease before they were diagnosed.  
***When answering, please select whether or not you agree with this statement.***
  - a. Agree
  - b. Disagree
  - c. Not sure
  - d. Prefer not to answer

*Multiple choice, single answer, required*

6. Medicines can improve the symptoms of Parkinson's disease.

***When answering, please select whether or not you agree with this statement.***

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

7. Exercise can improve the symptoms of Parkinson's disease.

***When answering, please select whether or not you agree with this statement.***

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

8. Diet can improve the symptoms of Parkinson's disease.

***When answering, please select whether or not you agree with this statement.***

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

### **Block 3: Questions About Medical Research**

**The following questions are going to present you with statements about medical research. Please read each statement carefully, then select whether or not you agree with the statement.**

*Multiple choice, single answer, required*

9. Clinical studies test the effects of procedures, drugs, or treatments that no one is yet certain about.

***When answering, please select whether or not you agree with this statement.***

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

10. Research studies can help scientists find new treatments or cures for diseases.

***When answering, please select whether or not you agree with this statement.***

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

11. Anyone who qualifies can take part in medical research studies.

***When answering, please select whether or not you agree with this statement***

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

12. I hear about research opportunities in my community.

**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

13. If I wanted to take part in a research study, I would know where to find a study and sign up.

**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

14. In addition to participating in Fox Insight, do you participate in other Parkinson's disease research studies?

- a. Yes, I am participating in other Parkinson's disease research studies at present
- b. Yes, I have participated in other Parkinson's disease research studies in the past
- c. Yes, I am participating in other Parkinson's disease research studies now and have participated in the past
- d. No
- e. Not sure
- f. Prefer not to answer

*Multiple choice, multiple answer, required*

15. Please indicate the types of Parkinson's disease research activities that you have done.

**Please select all that apply.**

- a. Complete surveys or questionnaires online using a computer or smartphone
- b. Complete surveys or questionnaires by telephone interview
- c. Complete surveys or questionnaires in the clinic
- d. Participate in a medical interview and examination using a computer or smartphone (telemedicine)
- e. Participate in a medical interview and examination in the clinic
- f. Take medicine by mouth
- g. Receive medicine directly into a vein
- h. Receive medicine as a skin patch
- i. Receive medicine as an injection into the muscle
- j. Receive medicine through an inhaler
- k. Receive medicine through a tube into the intestine
- l. Give saliva samples
- m. Give blood samples

- n. Have an outpatient procedure, such as a skin biopsy or lumbar puncture
- o. Exercise, such as walking or running on an exercise machine
- p. Have a brain scan
- q. Have brain surgery
- r. None of the above
- s. Prefer not to answer

Display Logic: If (a, b, or c) is selected for Q14

*Multiple choice, single answer, required*

16. I participate in medical research studies unrelated to Parkinson's disease.

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

*Multiple choice, multiple answer, required*

17. Please indicate the types of other medical research activities unrelated to PD that you have done.

**Please select all that apply.**

- a. Complete surveys or questionnaires online using a computer or smartphone
- b. Complete surveys or questionnaires by telephone interview
- c. Complete surveys or questionnaires in the clinic
- d. Participate in a medical interview and examination using a computer or smartphone (telemedicine)
- e. Participate in a medical interview and examination in the clinic
- f. Take medicine by mouth
- g. Receive medicine directly into a vein
- h. Receive medicine as a skin patch
- i. Receive medicine as an injection into the muscle
- j. Receive medicine through an inhaler
- k. Receive medicine through a tube into the intestine
- l. Give saliva samples
- m. Give blood samples
- n. Have an outpatient procedure, such as a skin biopsy or lumbar puncture
- o. Exercise, such as walking or running on an exercise machine
- p. Have an X-ray, MRI, ultrasound or nuclear medicine scan
- q. Have a test such as an electrocardiogram (ECG or EKG)
- r. Have surgery
- s. None of the above
- t. Prefer not to answer

Display Logic: If (a) is selected for Q15

*Multiple choice, single answer, required*

18. I would take part in a research study that might help people with Parkinson's disease, even if it did not benefit me directly.

**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure

- d. Prefer not to answer

*Multiple choice, multiple answer, required*

19. If I had Parkinson's disease, I would not care if others knew.

**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

Display Logic: If (b) is selected for Q1

*Multiple choice, single answer, required*

20. I do not care if others know about my Parkinson's disease.

**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

Display Logic: If (a) is selected for Q1

*Multiple choice, single answer, required*

21. I am a member of a community center or group.

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

22. In general, I spent \_\_\_\_ hours a week outside of my home (not counting time spent at medical visits).

**When answering this question, please think back to a time before COVID-19 pandemic regulations were in effect.**

- a. 0-2 hours
- b. 2-4 hours
- c. 4-8 hours
- d. 8 hours or more
- e. Not sure
- f. Prefer not to answer

*Multiple choice, single answer, required*

23. How often did you take part in community events or activities?

**When answering this question, please think back to a time before COVID-19 pandemic regulations were in effect.**

- a. I did not take part in community events or activities
- b. 1-2 times a month
- c. 3-5 times a month
- d. More than 5 times a month

*Multiple choice, single answer, required*

24. If a trusted member of my community told me about a research study, it would make me more likely to take part.

**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

25. If my doctor told me about a research study, it would make me more likely to take part.  
**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

26. If a research study was linked to an academic institution, it would make me more likely to take part.  
**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

27. If I had a personal connection to the disease being studied in a research study, I would be more likely to take part.  
**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, multiple answer, required*

28. Do you have any concerns about taking part in medical research?  
**Please select all that apply.**

- a. Distance from where I live to the research center
- b. Transportation to and from the research center
- c. Complex instructions or consent forms
- d. Time it takes to do research activities
- e. Overall effort involved in participation
- f. Privacy of my health information
- g. Research participants may be different than me.
- h. Researchers may not speak my preferred language.
- i. Researchers may not understand and respect my religious or cultural beliefs.
- j. Other, please describe:
- k. I do not have any concerns about taking part.
- l. Prefer not to answer

*Multiple choice, single answer, required*

24. If you were taking part in a research study, what research activities would you be willing to do?  
**Please select all that apply.**

- a. Complete surveys or questionnaires online using a computer or smartphone
- b. Complete surveys or questionnaires by telephone interview
- c. Complete surveys or questionnaires in the clinic
- d. Participate in a medical interview and examination using a computer or smartphone (telemedicine)
- e. Participate in a medical interview and examination in the clinic
- f. Take medicine by mouth
- g. Receive medicine directly into a vein
- h. Receive medicine as a skin patch
- i. Receive medicine as an injection into the muscle
- j. Receive medicine through an inhaler
- k. Receive medicine through a tube into the intestine
- l. Give saliva samples
- m. Give blood samples
- n. Have an outpatient procedure, such as a skin biopsy or lumbar puncture
- o. Exercise, such as walking or running on an exercise machine
- p. Have a brain scan (MRI, ultrasound or nuclear medicine)
- q. Have an X-ray, MRI, ultrasound or nuclear medicine scan of another area (not the brain)
- r. Have brain surgery
- s. None of the above
- t. Prefer not to answer

**Please read the following information about social distancing before proceeding:**

**Social distancing**, also known as “physical distancing”, is defined by the Centers for Disease Control as keeping space between yourself and other people outside of your home. Many people are practicing **social distancing behaviors** such as remaining 6 feet from anyone not in their household, only leaving the house for essential reasons, not gathering in groups, etc.

*Multiple choice, single answer, required*

29. I have practiced some form of social distancing behaviors since the COVID-19 pandemic began (December 31, 2019) or since local guidelines were implemented in my area.

***When answering, please select whether or not you agree with this statement.***

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

30. Once social distancing guidelines due to the COVID-19 pandemic are lifted, I will be:

- a. More likely to participate in medical research
- b. Less likely to participate in medical research
- c. Equally likely to participate in medical research
- d. Not sure
- e. Prefer not to answer

*Multiple choice, single answer, required*

31. Once social distancing guidelines due to the COVID-19 pandemic are lifted, I would participate in a medical study if it were:

***Please select all that apply.***

- a. Conducted online
- b. Conducted in my home
- c. Conducted in the clinic
- d. None of the above
- e. Not sure
- f. Prefer not to answer

#### **Block 4: Questions about Genetic Testing**

**The following questions are going to present you with statements about genetic testing. Please read each statement carefully, then select whether or not you agree with the statement.**

**Please read the following information about genes and genetic testing before proceeding:**

- **Genes** are passed down from parents to children and play a big part in determining who we are, the way we look, and even our health. For example, genes determine whether you have blue or brown eyes and curly or straight hair.
- **Genetic testing** is done by testing small samples of blood, saliva, or other body samples. They can show doctors any missing or changed genes.

*Multiple choice, single answer, required*

32. Changes in genes can lead to a higher chance of getting certain diseases.

***When answering, please select whether or not you agree with this statement.***

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

33. Genetic testing can tell me if I am more likely to get certain diseases.

***When answering, please select whether or not you agree with this statement.***

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

34. Researchers have found genes that are linked to Parkinson's disease.

***When answering, please select whether or not you agree with this statement.***

- a. Agree
- b. Disagree
- c. Not sure

- d. Prefer not to answer

*Multiple choice, single answer, required*

35. Parkinson's disease can be passed down in the family through genes.

***When answering, please select whether or not you agree with this statement.***

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

36. A genetic test to determine whether or not one has a genetic form of Parkinson's disease is available right now.

***When answering, please select whether or not you agree with this statement.***

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

37. Genetic testing could help scientists' efforts to find cures and treatments for Parkinson's disease.

***When answering, please select whether or not you agree with this statement.***

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

38. If a blood test accurately showed if I had inherited a Parkinson's disease gene, I would want to have that test.

***When answering, please select whether or not you agree with this statement.***

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

39. A test showing that I had a gene for Parkinson's disease would make me more likely to look into new therapies and treatments for Parkinson's disease.

***When answering, please select whether or not you agree with this statement.***

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

40. Genetic testing would help my doctor better manage Parkinson's disease.

**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

41. I would be concerned about my family's reaction to my genetic test results.

**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, multiple answer, required*

42. I would share my genetic test results with:

**Please select all that apply.**

- a. My spouse or partner
- b. My children
- c. My siblings
- d. My grandchildren
- e. Distant relatives
- f. My close friends
- g. My physician or another healthcare provider
- h. Other
- i. No one
- j. Prefer not to answer

*Multiple choice, single answer, required*

43. If I preferred not knowing my results, I would delegate a trusted person to know these results and make decisions for me.

**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, multiple answer, required*

44. Please indicate who you would delegate:

**Please select all that apply.**

- a. My spouse or partner
- b. My children
- c. My siblings
- d. My grandchildren
- e. Distant relatives
- f. My close friends
- g. My physician or another healthcare provider
- h. Other
- i. Prefer not to answer

Display Logic: If (a) is selected for Q43

*Multiple choice, single answer, required*

45. I have concerns about genetic testing.

**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, multiple answer, required*

46. I have the following concerns about genetic testing:

**Please select all that apply.**

- a. I don't know much about it.
- b. I would not know where to go get it.
- c. Cost
- d. It goes against my personal or cultural beliefs.
- e. I know, or have heard, that there are negative things that can come from it.
- f. I am worried that my results would put me at risk of losing insurance.
- g. I am worried that my results will not remain private.
- h. I am worried that my results would prevent me from keeping or finding a job.
- i. Other, please describe: \_\_\_\_\_
- j. Prefer not to answer.

Display Logic: If (a) is selected for Q45

### **Block 5: Questions about Disease Risk**

**The following questions are going to present you with statements about disease risk. Please read each statement carefully, then select whether or not you agree with the statement.**

*Multiple choice, single answer, required*

47. Researchers have found that certain chemical exposures or lifestyle behaviors can predict a higher chance of getting Parkinson's disease.

**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

48. Researchers have found that certain symptoms can occur years before typical Parkinson's disease symptoms develop.

**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

49. Studying these exposures, behaviors, or symptoms could help scientists' efforts to find cures and treatments for Parkinson's disease.

**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

50. If I had an exposure, behavior, or symptom that was linked to developing Parkinson's disease, I would want to know.

**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

51. If I had an exposure, behavior, or symptom that was linked to developing Parkinson's disease, I would be worried about my family's reaction.

**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, multiple answer, required*

52. If I knew I had an exposure, behavior, or symptom that was linked to Parkinson's, I would share this information with:

**Please select all that apply.**

- a. My spouse or partner
- b. My children
- c. My siblings
- d. My grandchildren
- e. Distant relatives
- f. My close friends
- g. My physician or another healthcare provider
- h. Other
- i. No one
- j. Prefer not to answer

*Multiple choice, single answer, required*

53. I would prefer not knowing I had an exposure, behavior, or symptom that was linked to Parkinson's disease, but a trusted person could know and make decisions for me.

**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, multiple answer, required*

54. The trusted person who could know and make decisions for me would be:

**Please select all that apply.**

- a. My spouse or partner
- b. My children
- c. My siblings
- d. My grandchildren
- e. Distant relatives
- f. My physician or another healthcare provider
- g. Other
- h. Prefer not to answer

Display Logic: If (a) is selected for Q53

*Multiple choice, single answer, required*

55. I have concerns about participating in a research study on exposures, behaviors, or symptoms that may be linked to Parkinson's disease.

***When answering, please select whether or not you agree with this statement.***

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, multiple answer, required*

56. I have the following concerns about participating in a research study on exposures, behaviors, or symptoms that may be linked to Parkinson's disease:

***Please select all that apply.***

- a. I do not know much about this type of study.
- b. I am worried about cost associated with participation.
- c. I would prefer not to know what exposures, behaviors, or symptoms may be linked to developing Parkinson's disease.
- d. It goes against my personal or cultural beliefs.
- e. I know, or have heard, that there are negative things that can come from this type of study.
- f. I am worried about losing insurance.
- g. I am worried that my health information will not remain private.
- h. I am worried that my health information would prevent me from keeping or finding a job.
- i. Other, please describe: \_\_\_\_\_
- j. Prefer not to answer

Display Logic: If (a) is selected for Q55

### **Block 6: Questions about You**

**The following questions are going to present you with statements about yourself. Please read each statement carefully, then select whether or not you agree with the statement.**

*Multiple choice, single answer, required*

57. I tend to seek out new opportunities for my health, such as learning about new programs, treatments, remedies, or exercises.

***When answering, please select whether or not you agree with this statement.***

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

58. I tend to only visit the doctor when I am in pain or if I am feeling sick.

**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

59. I prefer alternative or traditional medicine to Western medicine.

**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

60. I try to avoid taking medicines as much as I can.

**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

*Multiple choice, single answer, required*

61. I worry a lot about side effects when it comes to taking medication.

**When answering, please select whether or not you agree with this statement.**

- a. Agree
- b. Disagree
- c. Not sure
- d. Prefer not to answer

**Please read the following information about exercise before proceeding:**

**Exercise** is defined by the Centers for Disease Control as a type of physical activity that involves planned, structured, and repetitive bodily movement done to maintain or improve one or more components of physical fitness.

*Multiple choice, single answer, required*

62. How often did you exercise?

**When answering this question, please think back to a time before COVID-19 pandemic regulations were in effect.**

- a. Everyday
- b. A few times per week
- d. A few times per month
- e. Less than once a month
- f. Never

*Multiple choice, multiple answer, required*

63. What did you do to exercise?

**When answering this question, please think back to a time before COVID-19 pandemic regulations were in effect.**

**Please select all that apply.**

- a. Engaged in light activities, such as walking, household chores, or other similar activities
- b. Engaged in moderate activities, such as playing recreational sports, dancing, or other similar activities
- c. Engaged in strenuous activities, such as jogging, swimming, playing competitive sports, or other similar activities
- d. Engaged in exercises to increase muscle strength and endurance, such as lifting weights, pushups, or other similar activities
- e. Other
- f. Prefer not to answer

Display Logic: If (a), (b), (c), (d) or (e) is selected for Q58

*Multiple choice, multiple answer, required*

64. Which of the following circumstances affects your participation in exercise activities?

**When answering this question, please think back to a time before COVID-19 pandemic regulations were in effect.**

**Please select all that apply.**

- a. I had a physical condition that limited my activities.
- b. I was not sure about the benefits of exercising.
- c. I was not interested in exercising.
- d. I did not have access to a gym or exercise equipment.
- e. I did not have the time.
- f. I did not enjoy exercising.
- g. It went against my personal or cultural beliefs.
- h. I did not feel safe exercising in my neighborhood.
- i. Other
- j. None of the above
- k. I prefer not to answer

*Multiple choice, single answer, required*

65. Does anyone in your family have Parkinson's disease?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

*Multiple choice, multiple answer, required*

66. Who in your family has Parkinson's disease?

**Please select all that apply.**

- a. Father
- b. Mother
- c. Full brother or sister
- d. Half brother or sister
- e. Aunt or uncle
- f. Grandparent
- g. Cousin
- h. Other
- i. Prefer not to answer

Display Logic: If (a) is selected for Q65

*Multiple choice, single answer, required*

67. Does anyone in your family have Alzheimer's disease?
- a. Yes
  - b. No
  - c. Not sure
  - d. Prefer not to answer

*Multiple choice, multiple answer, required*

68. Who in your family has Alzheimer's disease?

**Please select all that apply.**

- a. Father
- b. Mother
- c. Full brother or sister
- d. Half brother or sister
- e. Aunt or uncle
- f. Grandparent
- g. Cousin
- h. Other
- i. Prefer not to answer

Display Logic: If (a) is selected for Q67

*Multiple choice, single answer, required*

69. Does anyone in your family have other types of dementia?
- a. Yes
  - b. No
  - c. Not sure
  - d. Prefer not to answer

*Multiple choice, multiple answer, required*

70. Who in your family has other types of dementia?

**Please select all that apply.**

- a. Father
- b. Mother
- c. Full brother or sister
- d. Half brother or sister
- e. Aunt or uncle
- f. Grandparent
- g. Cousin
- h. Other
- i. Prefer not to answer

Display Logic: If (a) is selected for Q69

Thank you for taking part in this survey. Your answers will help us learn more about what people know and think about research and genetic testing. **Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.**