

**Fox Insight Cohort:** ALL

**Target launch date:**

**Participant facing title:** Understanding Parkinson's Disease, Neurodevelopment and Autism Spectrum Disorder (ASD)

**Thank you for your interest in completing this survey. The purpose of this survey is to explore and better understand the connection between Parkinson's disease and Autism Spectrum Disorder (ASD). Please note that you do NOT need to have PD or ASD to complete this survey. The information gathered from all participants will be useful in giving investigators a better idea of the relationship between the two disorders.**

*Multiple choice, single answer, required*

**1. Has a doctor diagnosed you with Parkinson's disease?**

- a) Yes
- b) No

*Multiple choice, multiple answer, required*

**2. What is your connection to Parkinson's disease? Please check all that apply.**

- a) I am a PARENT of someone with Parkinson's disease
- b) I am a SIBLING of someone with Parkinson's disease
- c) I am a CHILD of someone with Parkinson's disease
- d) I am a PARTNER or SPOUSE of someone with Parkinson's disease
- e) I am a second degree relative of someone with Parkinson's disease (grandparents, grandchildren, aunts, uncles, nephews, nieces or half-siblings)
- f) I am friends with someone with Parkinson's disease
- g) I am a caregiver of someone with Parkinson's disease
- h) I was previously diagnosed with Parkinson's disease but this has been changed by a healthcare professional
- i) I have a genetic mutation associated with PD but have not been diagnosed with PD
- j) My work relates to Parkinson's disease
- k) I do not know anyone with Parkinson's disease but I want to participate in research
- l) I have no other connection to Parkinson's disease
- m) Other

Display Logic: If (b. No) is selected for "Has a doctor diagnosed you with Parkinson's disease"?

## HOUSEHOLD INFORMATION

**The next set of questions will ask about your household and living situation.**

*Multiple choice, multiple answer, required*

**3. Which best describes your current living situation? Please select all that apply.**

- a) Living alone
- b) Living with spouse/partner/significant other
- c) Living with adult child/children
- d) Living with minor child/children

- e) Living with parents
- f) Living with siblings
- g) Living with other family
- h) Living with paid in-home care provider/aide
- i) Living in a group home or assisted living facility
- j) Living in nursing home
- k) Other

*Multiple choice, single answer, required*

**4. Have you always lived with your parents, siblings, and/or other family as an adult?**

- a) Yes – almost always (e.g., except for brief periods, such as when in college)
- b) Yes – but only intermittently (e.g., due to employment disruptions)
- c) No – currently living with them for reasons due to Parkinson's (e.g., support needs)
- d) No – currently living with them for other reasons not related to Parkinson's

Display Logic: If (e., f., or g. Living with parents/siblings/other family) is selected in "Which best describes your living situation?"

## EMPLOYMENT HISTORY INFORMATION

**The next set of questions will ask about your employment history.**

*Multiple choice, single answer, required*

**5. Have you ever been employed?**

- a) No
- b) Yes, but I am currently unemployed
- c) Yes, but I am currently retired
- d) Yes, currently employed

*Multiple choice, single answer, required*

**6. What is the longest time you have held a job? If you are not sure, please make your best guess.**

- a) less than 6 months
- b) 6-12 months
- c) 1-4 years
- d) 5-9 years
- e) 10 or more years

Display Logic: If (a.) is NOT selected for "Have you ever been employed?"

*Multiple choice, single answer, required*

**7. How many hours on average did you work per week when employed? If not consistent week to week, what is the most usual number of hours you worked per week?**

- a) 1 – 9 hours
- b) 10 – 19 hours
- c) 20 – 34 hours
- d) 35 or more hours

Display Logic: If (a.) is NOT selected for "Have you ever been employed?"

*Multiple choice, single answer, required*

**8. Did you ever seek out professional supports to help you get a job (e.g., access services through the Vocational Rehabilitation agency for your state) or to maintain / keep your job (e.g., use a job coach to provide job training or on-site job support).**

- a) No
- b) Yes

*Simple matrix, single answer, multiple choice, required*

**9. How would you describe your financial state each month after paying all of your bills, including housing, car payments, etc.?**

	Every month	Most months	Some months	Never
I am able to pay for all food and clothing needs				
I am able to pay for extra things like entertainment or shopping for fun				
I am able to put some money into savings				

## BEHAVIORAL AND PSYCHOLOGICAL HISTORY

**The next set of questions will ask you about your birth and any delays you may have experienced in your early development. If you are not sure about this information, please make your best guess.**

*Multiple choice, multiple answer, required*

**10. As an infant, do you know if there was anything out of the ordinary with your delivery/birth?**

**Please select all that apply.**

- a) Premature (born before 39 weeks)
- b) Multiple birth (twins, triplets)
- c) Emergency C-Section
- d) Not breathing when born, needed resuscitation, lost oxygen during delivery
- e) Other
- f) No known issues / concerns – born full term (39+ weeks)
- g) Not sure

**11. In the previous question, you indicated you were born prematurely (born before 39 weeks).**

**Please indicate at what week of gestation you were born. If you are not sure, please make your best guess.**

\_\_\_\_\_ weeks of gestation [1-38]

Display Logic: If (a. Premature) was selected for “As an infant, do you know if there was anything out of the ordinary with your delivery/birth? “

*Multiple choice, multiple answer, required*

- 12.** Did you experience any delayed motor skills in your first year of life such as sitting up, rolling over or crawling?
- a) Yes
  - b) No
  - c) Not sure
  - d) Prefer not to answer

*Multiple choice, multiple answer, required*

- 13.** Which of the following delayed motor skills did you experience in your first year of life. Please select all that apply:
- a) Sitting up
  - b) Rolling over
  - c) Crawling
  - d) None of the above

Display Logic: If 'Yes' is selected for "Did you experience any delayed motor skills in your first year of life such as sitting up, rolling over or crawling?"

*Multiple choice, single answer, required*

- 14.** Did you experience any delays in walking independently?
- a. Yes
  - b. No
  - c. Not sure
  - d. Prefer not to answer

*Multiple choice, single answer, required*

- 15.** Please select when you were able to walk independently.
- a) Never able to walk independently
  - b) BEFORE 2 years of age
  - c) BETWEEN 2-5 years of age
  - d) AFTER 5 years of age
  - e) Not sure

Display Logic: If 'Yes' is selected for "Did you experience any delays in walking independently?"

*Multiple choice, single answer, required*

- 16.** Did you experience any delays in speaking single words?
- a. Yes
  - b. No
  - c. Not sure
  - d. Prefer not to answer

*Multiple choice, single answer, required*

- 17.** Please select when you were able to speak single words:
- a. Never able to speak in SINGLE WORDS
  - b. BEFORE 2 years of age

- c. BETWEEN 2-5 years of age
- d. AFTER 5 years of age
- e. Not sure

Display Logic: If 'Yes' is selected for "Did you experience any delays in speaking single words?"

*Multiple choice, single answer, required*

**18.** Did you experience any delays in speaking in phrases?

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

*Multiple choice, single answer, required*

**19.** Please select when you were able to speak in phrases:

- a) Never able to speak in PHRASES
- b) BEFORE 2 years of age
- c) BETWEEN 2-5 years of age
- d) AFTER 5 years of age
- e) Not sure

Display Logic: If 'Yes' is selected for "Did you experience any delays in speaking in phrases"

*Multiple choice, multiple answer, required*

**20.** Did you receive any learning supports in school? Please select all that apply.

- a) I did not receive any learning supports in school
- b) Individualized Education Program (IEP) or 504 plan
- c) Individual aide
- d) Special Education classroom
- e) Special Education teacher within general ed classroom
- f) Resource Room
- g) Speech therapy
- h) Occupational therapy
- i) Physical therapy
- j) Tutoring
- k) Other

**The next set of questions will ask about other diagnoses. Please read each question carefully to distinguish if the question is asking about an official medical diagnosis or if it is asking about your own or other people's thoughts.**

*Multiple choice, multiple answer, required*

**21.** Have you ever received any of the following diagnoses? Please select all that apply.

- a) I have never received any of the diagnoses below
- b) Autism Spectrum Disorder
- c) Autistic Disorder
- d) Asperger's Syndrome
- e) Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)
- f) Social Communication Disorder

- g) Nonverbal Learning Disorder
- h) Sensory Processing Disorder

*Dependent matrix, single answer, required*

Display Logic: If (a. I have never received any of the diagnoses below) is NOT selected for “Have you ever received any of the following diagnoses?”

22. Do you recall the approximate age you received this diagnosis? If you are not sure at what age you were diagnosed, please make your best guess.

	Before 5 years old (before kindergarten)	5-18 years old (K- 12)	18-29 years old (young adulthood)	30 or more years old (adulthood)
Autism Spectrum Disorder				
Autistic Disorder				
Asperger’s Syndrome				
Pervasive Developmental Disorder Not Otherwise Specified (PDD- NOS)				
Social Communication Disorder				
Nonverbal Learning Disorder				
Sensory Processing Disorder				

Display Logic: For any diagnoses selected for “Have you ever received any of the following diagnoses?” corresponding item will be displayed in this matrix.

*Multiple choice, single answer, required*

**23. Have you ever thought you may fit the description for any of the following diagnoses?**

- **Autism Spectrum Disorder**
- **Autistic Disorder**
- **Asperger’s Syndrome**
- **Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)**
- **Social Communication Disorder**
- **Nonverbal Learning Disorder**
- **Sensory Processing Disorder**

- ☐ Yes
- ☐ No

- ☐ Not sure
- ☐ Prefer not to answer

Display Logic: If (a. I have never received any of the diagnoses below) is selected under “Have you ever received any of the diagnoses below”

*Multiple choice, single answer, required*

**24. Has anyone else ever suggested that you may fit the description for, or were you ever tested for any of the following diagnoses?**

- **Autism Spectrum Disorder**
  - **Autistic Disorder**
  - **Asperger’s Syndrome**
  - **Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)**
  - **Social Communication Disorder**
  - **Nonverbal Learning Disorder**
  - **Sensory Processing Disorder**
- 
- ☐ Yes
  - ☐ No
  - ☐ Not sure
  - ☐ Prefer not to answer

Display Logic: If (a. I have never received any of the diagnoses below) is selected under “Have you ever received any of the diagnoses below”

*Multiple choice, single answer, required*

**25. To your knowledge, do any biological family members or relatives have one of the following diagnoses?**

- **Autism Spectrum Disorder**
  - **Autistic Disorder**
  - **Asperger’s Syndrome**
  - **Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)**
  - **Social Communication Disorder**
  - **Nonverbal Learning Disorder**
  - **Sensory Processing Disorder**
- 
- ☐ Yes
  - ☐ No
  - ☐ Not sure
  - ☐ Prefer not to answer

*Simple matrix, multiple choice, single answer, required*

**26. Which of your biological family members or relatives have any of the following diagnoses?**

- **Autism Spectrum Disorder**
- **Autistic Disorder**
- **Asperger’s Syndrome**
- **Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)**
- **Social Communication Disorder**
- **Nonverbal Learning Disorder**

- **Sensory Processing Disorder**

	Not diagnosed	Suspected / Not sure	Diagnosed
Grandparents			
Uncles/Aunts			
Cousins			
Parents			
Siblings			
Spouse			
Children			

Display Logic: If 'Yes' is selected for "To your knowledge, do any biological family members or relatives have one of the following diagnoses?"

**The following question will ask about behavioral and psychological diagnoses. Please choose the appropriate response for each diagnosis or make your best guess if you are not sure.**

*Simple matrix, multiple choice, single answer, required*

**27. Do you have any of the following behavioral or psychological diagnoses?**

Diagnoses	NO, I never received this diagnosis	YES, I received this diagnosis when younger but not currently experiencing symptoms or receiving treatment	YES and I believe this diagnosis is still relevant to me	Not diagnosed but suspected (i.e., experience some symptoms consistent with these diagnosis)
Depressive Disorders (includes Major Depression, Persistent Depressive Disorder, Unspecified Depressive Disorder, etc.).				
Anxiety (includes Generalized Anxiety, Social Anxiety, Panic Disorder, Specific phobia etc.).				
Obsessive-Compulsive Disorder (OCD)				
Bipolar disorders (includes Bipolar I, Bipolar II, etc.)				
Personality Disorder (includes Borderline Personality Disorder, etc.).				
Eating disorder				
Schizophrenia				
Attention-Deficit/Hyperactivity Disorder (ADHD)				
Speech or Language Disorder (e.g., apraxia, stuttering)				



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Intellectual Disability OR Learning Disability (e.g., Dyscalculia, Dyslexia, etc)				
Other				

<RAADS – 24 modified – age 18>

28. Simple matrix, multiple choice, single answer, required

<b>Instructions</b> Please respond with the answer that most accurately describes how each of the statements below applies to you. For the purposes of this test:  "True now and when I was younger than 18" is used to report any behavior that is present <b>NOW and also</b> was present when you were a child or adolescent (i.e., before you were 18 years old).  "True only now" is used to report behaviors that are present <b>NOW</b> (but were <b>NOT</b> true when you were young)  "True Only when I was younger than 18" is used to report any behavior that was only present when you were a child or adolescent (i.e., only true before you were 18 years old)				
	True NOW and when I was younger than 18	True only NOW	True ONLY when I was younger than 18	NEVER true
1. It is difficult for me to understand how other people are feeling when we are talking.				
2. Some ordinary textures that do not bother others feel very offensive when they touch my skin.				
3. It is very difficult for me to work and function in groups.				
4. It is difficult to figure out what other people expect of me.				
5. I often don't know how to act in social situations.				
6. I can chat and make small talk with people.				
7. When I feel overwhelmed by my senses, I have to isolate myself to shut them down.				
8. How to make friends and socialize is a mystery to me.				
9. When talking to someone, I have a hard time telling when it is my turn to talk or to listen.				
10. Sometimes I have to cover my ears to block out painful noises (like vacuum cleaners or people talking too much or too loudly).				
11. It can be very hard to read someone's face, hand, and body movements when we are talking.				
12. I focus on details rather than the overall idea.				
13. I take things too literally, so I often miss what people are trying to say				

14. I get extremely upset when the way I like to do things is suddenly changed.				
15. I have been told that I have an unusual voice (for example flat, monotone, childish or high pitched)				
16. I do certain things with my hands over and over again (like flapping, twirling sticks or strings, waving things by my eyes)				
17. It calms me to spin around or to rock in a chair when I am feeling stressed				
18. I like things to be exactly the same day after day and even small changes in my routines upset me				
19. when I go somewhere I have to follow a familiar routine or I can get very confused or upset				
20. I only like to talk to people who share my special interests.				
21. I keep lists of things that interest me, even when they have no practical use (for example sports statistics, train schedules, calendar dates, historical facts and dates)				
22. I have never been interested in what most of the people I know consider interesting.				
23. I like to copy the way certain people speak and act. it helps me appear more normal.				
24. I have been told that people can not tell how I am feeling by my facial expressions or gestures.				

**End of survey thank you:**

Thank you for taking part in this survey. Your answers will help us learn more about Parkinson's disease, neurodevelopment and autism spectrum disorder. **Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.**