

PPMI Online Study

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1. Screener Questions

1. Do you live in the US?
 - a. Yes
 - b. No
2. What is your date of birth?
 - a. MM/DD/YYYY [dropdown of month, day, and year]
3. What was your sex at birth?
 - a. Female
 - b. Male
4. Have you been diagnosed with Parkinson's disease?
 - a. Yes
 - b. No

3a. High Interest [Getting Started] (PD)

1. Do any of the following relatives have Parkinson's disease?
Mother, Father, Sister, Brother, and/or Children
 - a. Yes
 - b. No
 - c. I am not sure
 - d. Prefer not to answer

2. Are you of Eastern European (Ashkenazi) Jewish descent?
 - a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

3b. High Interest [Getting Started] (non-PD)

1. Do you have a diagnosis of REM behavior disorder, also known as **RBD**?
 - a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

 2. Have you ever been told, or suspected yourself, that you seem to "act out your dreams" while asleep (for example punching, flailing your arms in the air, making running movements, etc.)?
 - a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

 3. Do you have any problems with your sense of smell?
 - a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

 4. Do any of the following relatives have Parkinson's disease?
Mother, Father, Sister, Brother, and/or Children
 - a. Yes
 - b. No
 - c. I am not sure
 - d. Prefer not to answer
- Skip Logic: If 4=a, show 5.**
5. Are you of Eastern European (Ashkenazi) Jewish descent?
 - a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

4. Parkinson's disease History (PD age)

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

1. At what age were you first diagnosed with Parkinson's Disease (to the best of your memory)? [\[Validation Message: Please enter a number between 1 and 99.\]](#)

5. You and Your Background (Race/Ethnicity)

[QUESTIONS ARE NOT REQUIRED]

1. Do you identify as being Hispanic or Latino (Spanish origin)?
 - a. No
 - b. Yes
 - c. Unknown or prefer not to answer

2. Do you identify as being Ashkenazi Jewish descent?
 - a. No
 - b. Yes
 - c. Unknown or prefer not to answer

3. Do you identify as being of Basque descent?
 - a. No
 - b. Yes
 - c. Unknown or prefer not to answer

4. Do you identify as being of African Berber descent?
 - a. No
 - b. Yes
 - c. Unknown or prefer not to answer

5. Do you identify yourself as being American Indian or Alaska Native?
 - a. No
 - b. Yes
 - c. Unknown or prefer not to answer

6. Do you identify yourself as being Asian?
 - a. No
 - b. Yes
 - c. Unknown or prefer not to answer

7. Do you identify yourself as being Black or African American?
 - a. No
 - b. Yes
 - c. Unknown or prefer not to answer

8. Do you identify yourself as being Native Hawaiian or Other Pacific Islander?
 - a. No
 - b. Yes
 - c. Unknown or prefer not to answer

9. Do you identify yourself as being White?
 - a. No
 - b. Yes
 - c. Unknown or prefer not to answer

6a. Parkinson's disease History Part 2 (Return PD)

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

1. When you enrolled in this study, you told us you had a diagnosis of Parkinson's disease. Do you still have a diagnosis of Parkinson's disease?
 - a. I still have a diagnosis of Parkinson's disease.
 - b. I no longer have a diagnosis of Parkinson's disease.
 - c. I have **never** had a diagnosis of Parkinson's disease.
 - d. Not sure
 - e. Prefer not to answer

Skip Logic: If 1=b, show 2.

2. Has your Parkinson's diagnosis been changed to any of the following conditions? (Please select the best option)
 - a. Essential tremor
 - b. Dementia with Lewy Bodies or DLB
 - c. Progressive supranuclear palsy or PSP
 - d. Multiple system atrophy or MSA
 - e. Corticobasal syndrome ("CBS") or corticobasal degeneration ("CBD")
 - f. Alzheimer's disease (AD)
 - g. Another condition not listed here
 - h. Not sure
 - i. Prefer not to answer

6b. Parkinson's disease History Part 2 (Return non-PD)

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

1. When you enrolled in this study, you told us you did not have a diagnosis of Parkinson's disease. Is this still correct?
 - a. I do **not have** a diagnosis of Parkinson's disease
 - b. I **have** a diagnosis of Parkinson's disease
 - c. Not sure
 - d. Prefer not to answer

Skip Logic: If 1=b, show 2.

2. At what age were you first diagnosed with Parkinson's disease? _____ [Validation Message: Please enter a number between 1 and 99.]

7. Experiences of Daily Living (MDS-UPDRS Part Ib and Part II)

Instructions:

This questionnaire will ask you about your experiences of daily living through part of the Movement Disorder Society Unified Parkinson's Disease Rating Scale (MDS-UPDRS).

There are 20 questions. We are trying to be thorough, and some of these questions may therefore not apply to you now or ever. If you do not have the problem, simply mark 0 for NO.

Please read each one carefully and read all answers before selecting the one that best applies to you.

Use only 0, 1, 2, 3, 4 for answers, nothing else. Do not leave any blanks.

Who is filling out this questionnaire (select the best answer):

- Participant
- Care partner
- Participant and Care partner
- Another person

Part I: Non-Motor Aspects of Experiences of Daily Living (nM-EDL)

SLEEP PROBLEMS

Over the past week, have you had trouble going to sleep at night or staying asleep through the night? Consider how rested you felt after waking up in the morning.

- 0: Normal: No problems.
- 1: Slight: Sleep problems are present but usually do not cause trouble getting a full night of sleep.
- 2: Mild: Sleep problems usually cause some difficulties getting a full night of sleep.
- 3: Moderate: Sleep problems cause a lot of difficulties getting a full night of sleep, but I still usually sleep for more than half the night.
- 4: Severe: I usually do not sleep for most of the night.

DAYTIME SLEEPINESS

Over the past week, have you had trouble staying awake during the daytime?

- 0: Normal: No daytime sleepiness.
- 1: Slight: Daytime sleepiness occurs, but I can resist and I stay awake.
- 2: Mild: Sometimes I fall asleep when alone and relaxing. For example, while reading or watching TV.
- 3: Moderate: I sometimes fall asleep when I should not. For example, while eating or talking with other people.
- 4: Severe: I often fall asleep when I should not. For example, while eating or talking with other people.

PAIN AND OTHER SENSATIONS

Over the past week, have you had uncomfortable feelings in your body like pain, aches, tingling, or cramps?

- 0: Normal: No uncomfortable feelings.
- 1: Slight: I have these feelings. However, I can do things and be with other people without difficulty.
- 2: Mild: These feelings cause some problems when I do things or am with other people.
- 3: Moderate: These feelings cause a lot of problems, but they do not stop me from doing things or being with other people.
- 4: Severe: These feelings stop me from doing things or being with other people.

URINARY PROBLEMS

Over the past week, have you had trouble with urine control? For example, an urgent need to urinate, a need to urinate too often, or urine accidents?

- 0: Normal: No urine control problems.
- 1: Slight: I need to urinate often or urgently. However, these problems do not cause difficulties with my daily activities.
- 2: Mild: Urine problems cause some difficulties with my daily activities. However, I do not have urine accidents.
- 3: Moderate: Urine problems cause a lot of difficulties with my daily activities, including urine accidents.
- 4: Severe: I cannot control my urine and use a protective garment or have a bladder tube.

CONSTIPATION PROBLEMS

Over the past week have you had constipation troubles that cause you difficulty moving your bowels?

- 0: Normal: No constipation.
- 1: Slight: I have been constipated. I use extra effort to move my bowels. However, this problem does not disturb my activities or my being comfortable.
- 2: Mild: Constipation causes me to have some troubles doing things or being comfortable.
- 3: Moderate: Constipation causes me to have a lot of trouble doing things or being comfortable. However, it does not stop me from doing anything.
- 4: Severe: I usually need physical help from someone else to empty my bowels.

LIGHT HEADEDNESS ON STANDING

Over the past week, have you felt faint, dizzy, or foggy when you stand up after sitting or lying down?

- 0: Normal: No dizzy or foggy feelings.
- 1: Slight: Dizzy or foggy feelings occur. However, they do not cause me troubles doing things.
- 2: Mild: Dizzy or foggy feelings cause me to hold on to something, but I do not need to sit or lie back down.
- 3: Moderate: Dizzy or foggy feelings cause me to sit or lie down to avoid fainting or falling.
- 4: Severe: Dizzy or foggy feelings cause me to fall or faint.

FATIGUE

Over the past week, have you usually felt fatigued? This feeling is not part of being sleepy or sad.

- 0: Normal: No fatigue.
- 1: Slight: Fatigue occurs. However it does not cause me troubles doing things or being with people.
- 2: Mild: Fatigue causes me some troubles doing things or being with people.

- 3: Moderate: Fatigue causes me a lot of troubles doing things or being with people. However, it does not stop me from doing anything.
- 4: Severe: Fatigue stops me from doing things or being with people.

Part II: Motor Aspects of Experiences of Daily Living (M-EDL)

SPEECH

Over the past week, have you had problems with your speech?

- 0: Normal: Not at all (no problems).
- 1: Slight: My speech is soft, slurred or uneven, but it does not cause others to ask me to repeat myself.
- 2: Mild: My speech causes people to ask me to occasionally repeat myself, but not every day.
- 3: Moderate: My speech is unclear enough that others ask me to repeat myself every day even though most of my speech is understood.
- 4: Severe: Most or all of my speech cannot be understood.

SALIVA AND DROOLING

Over the past week, have you usually had too much saliva during when you are awake or when you sleep?

- 0: Normal: Not at all (no problems).
- 1: Slight: I have too much saliva, but do not drool.
- 2: Mild: I have some drooling during sleep, but none when I am awake.
- 3: Moderate: I have some drooling when I am awake, but I usually do not need tissues or a handkerchief.
- 4: Severe: I have so much drooling that I regularly need to use tissues or a handkerchief to protect my clothes.

CHEWING AND SWALLOWING

Over the past week, have you usually had problems swallowing pills or eating meals? Do you need your pills cut or crushed or your meals to be made soft, chopped, or blended to avoid choking?

- 0: Normal: No problems.
- 1: Slight: I am aware of slowness in my chewing or increased effort at swallowing, but I do not choke or need to have my food specially prepared.
- 2: Mild: I need to have my pills cut or my food specially prepared because of chewing or swallowing problems, but I have not choked over the past week.
- 3: Moderate: I choked at least once in the past week.
- 4: Severe: Because of chewing and swallowing problems, I need a feeding tube.

EATING TASKS

Over the past week, have you usually had troubles handling your food and using eating utensils? For example, do you have trouble handling finger foods or using forks, knives, spoons, chopsticks?

- 0: Normal: Not at all (no problems).
- 1: Slight: I am slow, but I do not need any help handling my food and have not had food spills while eating.

- 2: Mild: I am slow with my eating and have occasional food spills. I may need help with a few tasks such as cutting meat.
- 3: Moderate: I need help with many eating tasks but can manage some alone.
- 4: Severe: I need help for most or all eating tasks.

DRESSING

Over the past week, have you usually had problems dressing? For example, are you slow or do you need help with buttoning, using zippers, putting on or taking off your clothes or jewelry?

- 0: Normal: Not at all (no problems).
- 1: Slight: I am slow, but I do not need help.
- 2: Mild: I am slow and need help for a few dressing tasks (buttons, bracelets).
- 3: Moderate: I need help for many dressing tasks.
- 4: Severe: I need help for most or all dressing tasks.

HYGIENE

Over the past week, have you usually been slow or do you need help with washing, bathing, shaving, brushing teeth, combing your hair, or with other personal hygiene?

- 0: Normal: Not at all (no problems).
- 1: Slight: I am slow, but I do not need any help.
- 2: Mild: I need someone else to help me with some hygiene tasks.
- 3: Moderate: I need help for many hygiene tasks.
- 4: Severe: I need help for most or all of my hygiene tasks.

HANDWRITING

Over the past week, have people usually had trouble reading your handwriting?

- 0: Normal: Not at all (no problems).
- 1: Slight: My writing is slow, clumsy or uneven, but all words are clear.
- 2: Mild: Some words are unclear and difficult to read.
- 3: Moderate: Many words are unclear and difficult to read.
- 4: Severe: Most or all words cannot be read.

DOING HOBBIES AND OTHER ACTIVITIES

Over the past week, have you usually had trouble doing your hobbies or other things that you like to do?

- 0: Normal: Not at all (no problems).
- 1: Slight: I am a bit slow but do these activities easily.
- 2: Mild: I have some difficulty doing these activities.
- 3: Moderate: I have major problems doing these activities, but still do most.
- 4: Severe: I am unable to do most or all of these activities.

TURNING IN BED

Over the past week, do you usually have trouble turning over in bed?

- 0: Normal: Not at all (no problems).

- 1: Slight: I have a bit of trouble turning, but I do not need any help.
- 2: Mild I have a lot of trouble turning and need occasional help from someone else.
- 3: Moderate: To turn over I often need help from someone else.
- 4: Severe: I am unable to turn over without help from someone else.

TREMOR

Over the past week, have you usually had shaking or tremor?

- 0: Normal: Not at all. I have no shaking or tremor.
- 1: Slight: Shaking or tremor occurs but does not cause problems with any activities.
- 2: Mild: Shaking or tremor causes problems with only a few activities.
- 3: Moderate: Shaking or tremor causes problems with many of my daily activities.
- 4: Severe: Shaking or tremor causes problems with most or all activities.

GETTING OUT OF BED, A CAR, OR A DEEP CHAIR

Over the past week, have you usually had trouble getting out of bed, a car seat, or a deep chair?

- 0: Normal: Not at all (no problems).
- 1: Slight: I am slow or awkward, but I usually can do it on my first try.
- 2: Mild: I need more than one try to get up or need occasional help.
- 3: Moderate: I sometimes need help to get up, but most times I can still do it on my own.
- 4: Severe: I need help most or all of the time.

WALKING AND BALANCE

Over the past week, have you usually had problems with balance and walking?

- 0: Normal: Not at all (no problems).
- 1: Slight: I am slightly slow or may drag a leg. I never use a walking aid.
- 2: Mild: I occasionally use a walking aid, but I do not need any help from another person.
- 3: Moderate: I usually use a walking aid (cane, walker) to walk safely without falling. However, I do not usually need the support of another person.
- 4: Severe: I usually use the support of another person to walk safely without falling.

FREEZING

Over the past week, on your usual day when walking, do you suddenly stop or freeze as if your feet are stuck to the floor?

- 0: Normal: Not at all (no problems).
- 1: Slight: I briefly freeze, but I can easily start walking again. I do not need help from someone else or a walking aid (cane or walker) because of freezing.
- 2: Mild: I freeze and have trouble starting to walk again, but I do not need someone's help or a walking aid (cane or walker) because of freezing.
- 3: Moderate: When I freeze I have a lot of trouble starting to walk again and, because of freezing, I sometimes need to use a walking aid or need someone else's help.
- 4: Severe: Because of freezing, most or all of the time, I need to use a walking aid or someone's help.

This completes the questionnaire. We may have asked about problems you do not even have, and may have mentioned problems that you may never develop at all. Not all people develop all these problems, but because they can occur, it is important to ask all the questions to every person. Thank you for your time and attention in completing this questionnaire.

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8. Thinking Abilities (PDAQ-15)

[Note: all questions are formatted in a single-row matrix]

[Note: numerical values associated with each response are used for data analysis only, and are not included in the implemented version]

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

Please select the following that best describes YOU.

1. How much DIFFICULTY do you currently have reading the newspaper or magazine?
 - a. None (4)
 - b. A Little (3)
 - c. Somewhat (2)
 - d. A Lot (1)
 - e. Cannot Do (0)

2. How much DIFFICULTY do you currently have keeping track of time (e.g. using a clock)?
 - a. None (4)
 - b. A Little (3)
 - c. Somewhat (2)
 - d. A Lot (1)
 - e. Cannot Do (0)

3. How much DIFFICULTY do you currently have counting the correct amount of money when making purchases?
 - a. None (4)
 - b. A Little (3)
 - c. Somewhat (2)
 - d. A Lot (1)
 - e. Cannot Do (0)

4. How much DIFFICULTY do you currently have reading and following complex instructions (e.g. directions for a new medication)?
 - a. None (4)
 - b. A Little (3)
 - c. Somewhat (2)
 - d. A Lot (1)
 - e. Cannot Do (0)

5. How much DIFFICULTY do you currently have handling an unfamiliar problem (e.g. getting the refrigerator fixed)?
 - a. None (4)

- b. A Little (3)
 - c. Somewhat (2)
 - d. A Lot (1)
 - e. Cannot Do (0)
6. How much DIFFICULTY do you currently have explaining how to do something involving several steps to another person?
- a. None (4)
 - b. A Little (3)
 - c. Somewhat (2)
 - d. A Lot (1)
 - e. Cannot Do (0)
7. How much DIFFICULTY do you currently have remembering a list of 4 or 5 errands without writing it down?
- a. None (4)
 - b. A Little (3)
 - c. Somewhat (2)
 - d. A Lot (1)
 - e. Cannot Do (0)
-
8. How much DIFFICULTY do you currently have using a map to tell where to go?
- a. None (4)
 - b. A Little (3)
 - c. Somewhat (2)
 - d. A Lot (1)
 - e. Cannot Do (0)
9. How much DIFFICULTY do you currently have remembering new information like phone numbers or simple instructions?
- a. None (4)
 - b. A Little (3)
 - c. Somewhat (2)
 - d. A Lot (1)
 - e. Cannot Do (0)
10. How much DIFFICULTY do you currently have doing more than one thing at a time?
- a. None (4)
 - b. A Little (3)
 - c. Somewhat (2)
 - d. A Lot (1)
 - e. Cannot Do (0)
11. How much DIFFICULTY do you currently have learning to use new gadgets or machines around the house?
- a. None (4)
 - b. A Little (3)

- c. Somewhat (2)
- d. A Lot (1)
- e. Cannot Do (0)

12. How much DIFFICULTY do you currently have understanding your personal financial affairs?

- a. None (4)
- b. A Little (3)
- c. Somewhat (2)
- d. A Lot (1)
- e. Cannot Do (0)

13. How much DIFFICULTY do you currently have maintaining or completing a train of thought?

- a. None (4)
- b. A Little (3)
- c. Somewhat (2)
- d. A Lot (1)
- e. Cannot Do (0)

14. How much DIFFICULTY do you currently have discussing a TV show, book, movie, or current events?

- a. None (4)
- b. A Little (3)
- c. Somewhat (2)
- d. A Lot (1)
- e. Cannot Do (0)

15. How much DIFFICULTY do you currently have remembering what day and month it is?

- a. None (4)
- b. A Little (3)
- c. Somewhat (2)
- d. A Lot (1)
- e. Cannot Do (0)

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9. History of Falls (Falls Baseline)

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

1. Thinking about the past 12 months, have you had any falls?
 - a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Skip Logic: If 1=a, show 2.

2. How many falls have you had in the past 12 months? If you are not sure, please make your best guess. _____ [Continuous 4-digit integer. Range = 1-9999; Validation Message: Please enter a number between 1 and 9999.]
-

3. Thinking about the past 12 months, have you had any near-falls? By near-fall, we mean a time when you started to fall, but prevented a fall by grabbing a stable object or a person.
 - a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Skip Logic: If 3=a, show 4.

4. How many near-falls have you had in the past 12 months? If you are not sure, please make your best guess. _____ [Continuous 4-digit integer. Range = 1-9999; Validation Message: Please enter a number between 1 and 9999.]
-

5. Thinking about the past 12 months, on a scale of 1 to 5, how would you rate your fear of falling?
 - a. 1 = I am not at all afraid of falling
 - b. 2 = I am slightly afraid of falling
 - c. 3 = I am moderately afraid of falling
 - d. 4 = I am very afraid of falling
 - e. 5 = I am extremely afraid of falling

10. History of Falls Part 2 (Falls Surveillance)

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

1. Thinking about the time since the last study visit (about the past 3 months), have you had any falls?
 - a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Skip Logic: If 1=a, show 2.

2. How many falls have you had since the last study visit (about the past 3 months)? If you are not sure, please make your best guess. _____ [Continuous 3-digit integer. Range = 1-999; Validation Message: Please enter a number between 1 and 999.]

3. Thinking about the time since the last study visit (about the past 3 months), have you had any near-falls? By near-fall, we mean a time when you started to fall, but prevented a fall by grabbing a stable object or a person.
 - a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Skip Logic: If 3=a, show 4.

4. How many near-falls have you had since the last study visit (about the past 3 months)? If you are not sure, please make your best guess. _____ [Continuous 3-digit integer. Range = 1-999; Validation Message: Please enter a number between 1 and 999.]

5. Thinking about the time since the last study visit (about the past 3 months), on a scale of 1 to 5, how would you rate your fear of falling?
 - a. 1 = I am not at all afraid of falling
 - b. 2 = I am slightly afraid of falling
 - c. 3 = I am moderately afraid of falling
 - d. 4 = I am very afraid of falling
 - e. 5 = I am extremely afraid of falling

MASTER11. Acting Out Dreams (RBD Combined)

Acting Out Dreams

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

Acting Out Dreams

1. Have you ever been told, or suspected yourself, that you seem to "act out your dreams" while asleep (for example punching, flailing your arms in the air, making running movements, etc.)?
 - a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

Postuma *et al.* *Mov Disord.* 2012 June ; 27(7): 913–916

2. Do you know or have you been told that you ever "act out your dreams" while asleep with very active movements of your arms or legs or loud yelling, screaming or other vocalizations?
 - a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer
3. Have you ever injured yourself or your bed partner during sleep?
 - a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer
4. Do you generally sleep with a bed partner?
 - a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

Skip Logic: If 4=a, show 5.

5. Has your bed partner ever told you that you have active movements of your arms or legs or loud yelling, screaming or other vocalizations during sleep?
 - a. Yes
 - b. No

- c. Not Sure
- d. Prefer not to answer

6. Have you ever been told you have sleep apnea?

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

7. Have you ever been told you have narcolepsy?

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

8. Do you walk in your sleep?

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

12. Sleep Habits (PDSS-2)

Parkinson's Disease Sleep Scale (PDSS-2)

PDSS-2 © Ray Chaudhuri, Claudia Trenkwalder 2010, All rights reserved [\[citation needs to be on every survey page\]](#)

Please rate the severity of the following based on your experiences during the past week (7 days). Please select one response. [\[This will appear before each question.\]](#)

1. Overall, did you sleep well during the last week?
 - a. Very often (This means 6 to 7 days a week)
 - b. Often (This means 4 to 5 days a week)
 - c. Sometimes (This means 2 to 3 days a week)
 - d. Occasionally (This means 1 day a week)
 - e. Never

2. Did you have difficulty falling asleep each night?
 - a. Very often (This means 6 to 7 days a week)
 - b. Often (This means 4 to 5 days a week)
 - c. Sometimes (This means 2 to 3 days a week)
 - d. Occasionally (This means 1 day a week)
 - e. Never

3. Did you have difficulty staying asleep?
 - a. Very often (This means 6 to 7 days a week)
 - b. Often (This means 4 to 5 days a week)
 - c. Sometimes (This means 2 to 3 days a week)
 - d. Occasionally (This means 1 day a week)
 - e. Never

4. Did you have restlessness of legs or arms at nights causing disruption of sleep?
 - a. Very often (This means 6 to 7 days a week)
 - b. Often (This means 4 to 5 days a week)
 - c. Sometimes (This means 2 to 3 days a week)
 - d. Occasionally (This means 1 day a week)
 - e. Never

5. Was your sleep disturbed due to an urge to move your legs or arms?
 - a. Very often (This means 6 to 7 days a week)
 - b. Often (This means 4 to 5 days a week)
 - c. Sometimes (This means 2 to 3 days a week)
 - d. Occasionally (This means 1 day a week)

- e. Never
6. Did you suffer from distressing dreams at night?
- a. Very often (This means 6 to 7 days a week)
 - b. Often (This means 4 to 5 days a week)
 - c. Sometimes (This means 2 to 3 days a week)
 - d. Occasionally (This means 1 day a week)
 - e. Never
7. Did you suffer from distressing hallucinations at night (seeing or hearing things that do not exist)?
- a. Very often (This means 6 to 7 days a week)
 - b. Often (This means 4 to 5 days a week)
 - c. Sometimes (This means 2 to 3 days a week)
 - d. Occasionally (This means 1 day a week)
 - e. Never
8. Did you get up at night to urinate?
- a. Very often (This means 6 to 7 days a week)
 - b. Often (This means 4 to 5 days a week)
 - c. Sometimes (This means 2 to 3 days a week)
 - d. Occasionally (This means 1 day a week)
 - e. Never
9. Did you feel uncomfortable at night because you were unable to turn over in bed or move due to immobility?
- a. Very often (This means 6 to 7 days a week)
 - b. Often (This means 4 to 5 days a week)
 - c. Sometimes (This means 2 to 3 days a week)
 - d. Occasionally (This means 1 day a week)
 - e. Never
10. Did you feel pain in your arms or legs which woke you up while you were sleeping during the night?
- a. Very often (This means 6 to 7 days a week)
 - b. Often (This means 4 to 5 days a week)
 - c. Sometimes (This means 2 to 3 days a week)
 - d. Occasionally (This means 1 day a week)
 - e. Never
11. Did you have muscle cramps in your arms or legs which woke you up while you were sleeping during the night?
- a. Very often (This means 6 to 7 days a week)
 - b. Often (This means 4 to 5 days a week)
 - c. Sometimes (This means 2 to 3 days a week)
 - d. Occasionally (This means 1 day a week)
 - e. Never
12. Did you wake up earlier than usual with painful posturing of arms and legs?

- a. Very often (This means 6 to 7 days a week)
- b. Often (This means 4 to 5 days a week)
- c. Sometimes (This means 2 to 3 days a week)
- d. Occasionally (This means 1 day a week)
- e. Never

13. On waking in the morning or during the night, did you experience tremor?

- a. Very often (This means 6 to 7 days a week)
- b. Often (This means 4 to 5 days a week)
- c. Sometimes (This means 2 to 3 days a week)
- d. Occasionally (This means 1 day a week)
- e. Never

14. Did you feel tired and sleepy after waking up in the morning?

- a. Very often (This means 6 to 7 days a week)
- b. Often (This means 4 to 5 days a week)
- c. Sometimes (This means 2 to 3 days a week)
- d. Occasionally (This means 1 day a week)
- e. Never

15. Did you wake up at night due to snoring or difficulties with breathing?

- a. Very often (This means 6 to 7 days a week)
- b. Often (This means 4 to 5 days a week)
- c. Sometimes (This means 2 to 3 days a week)
- d. Occasionally (This means 1 day a week)
- e. Never

For any information on the use of the PDSS-2, please contact Mapi Research Trust, Lyon, France.

Internet: <https://eprovide.mapi-trust.org>

13. Mood (GDS)

Choose the best answer for how you have felt over the **past week**.

1. Are you basically satisfied with your life?
No Yes
2. Have you dropped many of your activities and interests?
No Yes
3. Do you feel that your life is empty?
No Yes
4. Do you often get bored?
No Yes
5. Are you in good spirits most of the time?
No Yes
6. Are you afraid that something bad is going to happen to you?
No Yes
7. Do you feel happy most of the time?
No Yes
8. Do you often feel helpless?
No Yes
9. Do you prefer to stay at home, rather than going out and doing new things?
No Yes
10. Do you feel you have more problems with memory than most?
No Yes
11. Do you think it is wonderful to be alive now?
No Yes
12. Do you feel pretty worthless the way you are now?
No Yes
13. Do you feel full of energy?
No Yes
14. Do you feel that your situation is hopeless?
No Yes
15. Do you think that most people are better off than you are?
No Yes

Sheikh JI, Yesavage JA: Geriatric Depression Scale (GDS): Recent evidence and development of a shorter version. *Clinical Gerontology: A Guide to Assessment and Intervention*. 165-173, NY: The Haworth Press, 1986.

14. Worry and Stress (PAS)

[Persistent anxiety]

In the past **four weeks**, to what extent did you experience the following symptoms?

1. Feeling anxious or nervous

- a. Not at all, or never
- b. Very mild, or rarely
- c. Mild, or sometimes
- d. Moderate, or often
- e. Severe, or (nearly) always

2. Feeling tense or stressed

- a. Not at all, or never
- b. Very mild, or rarely
- c. Mild, or sometimes
- d. Moderate, or often
- e. Severe, or (nearly) always

3. Being unable to relax

- a. Not at all, or never
- b. Very mild, or rarely
- c. Mild, or sometimes
- d. Moderate, or often
- e. Severe, or (nearly) always

4. Excessive worrying about everyday matters

- a. Not at all, or never
- b. Very mild, or rarely
- c. Mild, or sometimes
- d. Moderate, or often
- e. Severe, or (nearly) always

5. Fear of something bad, or even the worst, happening

- a. Not at all, or never
- b. Very mild, or rarely
- c. Mild, or sometimes
- d. Moderate, or often
- e. Severe, or (nearly) always

[Episodic anxiety]

In the past **four weeks**, did you experience episodes of the following symptoms?

6. Panic or intense fear

- a. Never
- b. Rarely
- c. Sometimes
- d. Often
- e. Nearly always

7. Shortness of breath

- a. Never
- b. Rarely
- c. Sometimes
- d. Often
- e. Nearly always

8. Heart palpitations or heart beating fast (not related to physical effort or activity)

- a. Never
- b. Rarely
- c. Sometimes
- d. Often
- e. Nearly always

9. Fear of losing control

- a. Never
- b. Rarely
- c. Sometimes
- d. Often
- e. Nearly always

[Avoidance behavior]

In the past **four weeks**, to what extent did you fear or avoid the following situations?

10. Social situations (where one may be observed, or evaluated by others, such as speaking in public, or talking to unknown people)

- a. Never
- b. Rarely
- c. Sometimes
- d. Often
- e. Nearly always

11. Public settings (situations from which it may be difficult or embarrassing to escape, such as queues or lines, crowds, bridges, or public transportation)

- a. Never
- b. Rarely
- c. Sometimes
- d. Often
- e. Nearly always

12. Specific objects or situations (such as flying, heights, spiders or other animals, needles, or blood)

- a. Never
- b. Rarely
- c. Sometimes
- d. Often
- e. Nearly always

The Parkinson Anxiety Scale (PAS). Copyright of this scale and its translations is held by the authors (Leentjens AFG, Dujardin K, Pontone GM, Starkstein SE, Weintraub D, and Martinez-Martin P; 2014).

15. Thinking Changes (Cognitive Change)

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

1. Have you noticed that you are having more problems with thinking, such as difficulty with memory or concentration, that is a change from your normal abilities?

Some examples of thinking problems might include:

- Memory: such as remembering what someone recently told you, familiar names, or upcoming events
- Concentration: such as reading an article or book, or watching a television show or movie
- Organization: such as paying bills, managing medications, or organizing and completing a shopping list
- Spatial ability: such as driving or finding one's way around an unfamiliar location
- Understanding language: such as making sense of conversations or finding words when talking

- a. No
- b. Yes

16. Sleepiness (ESS)

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

Epworth Sleepiness Scale

How likely are you to doze off or fall asleep in the following situations, in contrast to feeling just tired?

This refers to your usual way of life in recent times.

Even if you haven't done some of these things recently try to work out how they would have affected you.

Use the following scale to choose the **most appropriate number** for each situation:

- 0 = would **never** doze
- 1 = **slight chance** of dozing
- 2 = **moderate chance** of dozing
- 3 = **high chance** of dozing

It is important that you answer each question as best as you can.

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[\[citation needs to on every survey page besides the Thank You page and the More Information page\]](#)

1. How likely are you to doze off or fall asleep in the following situation, in contrast to feeling just tired?
Situation: Sitting and reading
 - a. **0 = would never** doze
 - b. **1 = slight chance** of dozing
 - c. **2 = moderate chance** of dozing
 - d. **3 = high chance** of dozing
2. How likely are you to doze off or fall asleep in the following situation, in contrast to feeling just tired?
Situation: Watching TV
 - a. **0 = would never** doze
 - b. **1 = slight chance** of dozing
 - c. **2 = moderate chance** of dozing
 - d. **3 = high chance** of dozing
3. How likely are you to doze off or fall asleep in the following situation, in contrast to feeling just tired?
Situation: Sitting, inactive in a public place (e.g., a theatre or a meeting)

- a. **0** = would **never** doze
 - b. **1** = **slight chance** of dozing
 - c. **2** = **moderate chance** of dozing
 - d. **3** = **high chance** of dozing
4. How likely are you to doze off or fall asleep in the following situation, in contrast to feeling just tired?
Situation: As a passenger in a car for an hour without a break
- a. **0** = would **never** doze
 - b. **1** = **slight chance** of dozing
 - c. **2** = **moderate chance** of dozing
 - d. **3** = **high chance** of dozing
5. How likely are you to doze off or fall asleep in the following situation, in contrast to feeling just tired?
Situation: Lying down to rest in the afternoon when circumstances permit
- a. **0** = would **never** doze
 - b. **1** = **slight chance** of dozing
 - c. **2** = **moderate chance** of dozing
 - d. **3** = **high chance** of dozing
6. How likely are you to doze off or fall asleep in the following situation, in contrast to feeling just tired?
Situation: Sitting and talking to someone
- a. **0** = would **never** doze
 - b. **1** = **slight chance** of dozing
 - c. **2** = **moderate chance** of dozing
 - d. **3** = **high chance** of dozing
7. How likely are you to doze off or fall asleep in the following situation, in contrast to feeling just tired?
Situation: Sitting quietly after a lunch without alcohol
- a. **0** = would **never** doze
 - b. **1** = **slight chance** of dozing
 - c. **2** = **moderate chance** of dozing
 - d. **3** = **high chance** of dozing
8. How likely are you to doze off or fall asleep in the following situation, in contrast to feeling just tired?
Situation: In a car, while stopped for a few minutes in the traffic
- a. **0** = would **never** doze
 - b. **1** = **slight chance** of dozing
 - c. **2** = **moderate chance** of dozing
 - d. **3** = **high chance** of dozing
-

THANK YOU FOR YOUR COOPERATION

**For any information on the use of the ESS, please contact
Mapi Research Trust, Lyon, France.**

Internet: <https://eprovide.mapi-trust.org>

17. Constipation

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

1. What is your usual number of bowel movements per day?
 - a. Less than once every other day
 - b. Once every other day
 - c. Once per day
 - d. Two per day
 - e. Three per day
 - f. More than three per day
 - g. Unknown
 - h. Prefer not to answer

2. How often do you typically use laxatives to help you move your bowels?
 - a. Never
 - b. Daily
 - c. 2 to 3 times per week
 - d. Weekly
 - e. Once per month
 - f. Every 2 months
 - g. Rarely
 - h. Not Sure
 - i. Prefer not to answer

18. Sense of Smell (Hyposmia)

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

1. Do you have any problems with your sense of smell?
 - a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

19. Movement Changes (Brief Motor Screen)

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

When answering these questions, please think about your **current** abilities.

1. Do you have trouble rising from a chair?
 - a. No
 - b. Yes
 - c. Uncertain

2. Is your handwriting smaller than it once was?
 - a. No
 - b. Yes
 - c. Uncertain

3. Do you have more difficulty than you once did typing, using a computer mouse, or using a touchscreen on a tablet or mobile phone?
 - a. No
 - b. Yes
 - c. Uncertain

4. Do people tell you that your voice is softer than it once was?
 - a. No
 - b. Yes
 - c. Uncertain

5. Is your balance poor?
 - a. No
 - b. Yes
 - c. Uncertain

6. Do your feet ever seem to get stuck to the floor?
 - a. No
 - b. Yes
 - c. Uncertain

7. Do people tell you that your face seems less expressive than it once did?
 - a. No
 - b. Yes

c. Uncertain

8. Do your arms or legs shake?

a. No

b. Yes

c. Uncertain

9. Do you have trouble buttoning buttons?

a. No

b. Yes

c. Uncertain

10. Do you shuffle your feet and/or take tiny steps when you walk?

a. No

b. Yes

c. Uncertain

11. Do you move more slowly than other people your age?

a. No

b. Yes

c. Uncertain

20. Health History (Quarterly)

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

Diabetes

1. Has a healthcare provider ever diagnosed you with **diabetes**?
 - a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Skip Logic: If 1=a, show 2.

2. At what age were you diagnosed with diabetes? If you are not sure, please make your best guess.
_____ [Validation Message: Please enter a number between 1 and 99.]

RBD

3. Has a healthcare provider ever diagnosed you with REM sleep behavior disorder, also known as **RBD**?
 - a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Skip Logic: If 3=a, show 4, 5, and 6.

4. Did you ever have a study in a sleep laboratory (otherwise known as a polysomnogram or PSG) that confirmed this condition?
 - a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer
5. At what age were you diagnosed with RBD? If you are not sure, please make your best guess.
_____ [Validation Message: Please enter a number between 1 and 99.]
6. Do you currently have this problem?
 - a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Depression

7. Has a healthcare provider ever diagnosed you with **depression**?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Skip Logic: If 7=a, show 8, 9, and 10.

8. At what age were you diagnosed with depression? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

9. Have you taken medication for depression?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

10. Is depression currently a problem?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Erectile Dysfunction (ED)

11. Has a healthcare provider ever diagnosed you with **Erectile dysfunction (ED)**?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer
 - e. NOT APPLICABLE

Skip Logic: If 11=a, show 12 and 13.

12. At what age were you diagnosed with ED? If you are not sure, please make your best guess. _____
[Validation Message: Please enter a number between 1 and 99.]

13. Have you taken medication for ED?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

21. Health History Part 2 (Annual)

[Version 2]

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

1. Do you currently have a diagnosis of any of the following conditions from a physician or other healthcare professional? (Select all that apply)
 - a. Essential tremor
 - b. Dementia with Lewy Bodies or DLB
 - c. Progressive supranuclear palsy or PSP
 - d. Multiple system atrophy or MSA
 - e. Corticobasal syndrome ("CBS") or corticobasal degeneration ("CBD")
 - f. Alzheimer's disease (AD)
 - g. None of the conditions above [Validation Message if this box is not selected by itself: You are unable to select "None of the conditions above" with any other response choices. Please confirm your response.]
 - h. Prefer not to answer [Validation Message if this box is not selected by itself: You are unable to select "Prefer not to answer" with any other response choices. Please confirm your response.]

Skip Logic: If 1a OR 1b OR 1c OR 1d OR 1e OR 1f are selected, show relevant 2 questions.

2.
 - a. At what age were you diagnosed with Essential tremor? If you are not sure, please make your best guess. _____
 - b. At what age were you diagnosed with Dementia with Lewy Bodies or DLB? If you are not sure, please make your best guess. _____
 - c. At what age were you diagnosed with Progressive supranuclear palsy or PSP? If you are not sure, please make your best guess. _____
 - d. At what age were you diagnosed with Multiple system atrophy or MSA? If you are not sure, please make your best guess. _____
 - e. At what age were you diagnosed with Corticobasal syndrome ("CBS") or corticobasal degeneration ("CBD")? If you are not sure, please make your best guess. _____
 - f. At what age were you diagnosed with Alzheimer's disease (AD)? If you are not sure, please make your best guess. _____

For 2a through 2f [Validation Message: Please enter a number between 1 and 99.]

Anxiety

3. Has a healthcare provider ever diagnosed you with **anxiety**?
 - a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Skip Logic: If 3=a, show 4, 5, and 6.

4. At what age were you diagnosed with anxiety? If you are not sure, please make your best guess. _____
[Validation Message: Please enter a number between 1 and 99.]
5. Have you taken medication for anxiety?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer
6. Is anxiety still a problem?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Bipolar Disorder

7. Has a healthcare provider ever diagnosed you with **bipolar disorder**?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Skip Logic: If 7=a, show 8, 9, and 10.

8. At what age were you diagnosed with bipolar disorder? If you are not sure, please make your best guess.
_____ [Validation Message: Please enter a number between 1 and 99.]
9. Have you taken medication for bipolar disorder?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer
10. Is bipolar disorder still a problem?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Hypertension or high blood pressure

11. Has a healthcare provider ever diagnosed you with **hypertension or high blood pressure**?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Skip Logic: If 11 =a, show 12, 13, 14.

12. At what age were you diagnosed with hypertension or high blood pressure? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

13. Have you taken medication for **hypertension or high blood pressure**?

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

14. Is **hypertension or high blood pressure** still a problem?

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

Melanoma

15. Has a healthcare provider ever diagnosed you with **melanoma**?

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

Skip Logic: If 15=a, show 16.

16. At what age were you diagnosed with melanoma? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

Seborrheic Dermatitis

17. Has a healthcare provider ever diagnosed you with **seborrheic dermatitis**?

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

Skip Logic: If 17=a, show 18.

18. At what age were you diagnosed with seborrheic dermatitis? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

Gout

19. Has a healthcare provider ever diagnosed you with **gout**?

- a. Yes
- b. No
- c. Not sure

- d. Prefer not to answer

Skip Logic: If 19=a, show 20.

20. At what age were you diagnosed with gout? If you are not sure, please make your best guess. _____
[Validation Message: Please enter a number between 1 and 99.]

Inflammatory Bowel Disease

21. Has a healthcare provider ever diagnosed you with **inflammatory bowel disease** (such as Crohn's disease or ulcerative colitis)?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Skip Logic: If 21=a, show 22 and 23.

22. At what age were you diagnosed with inflammatory bowel disease? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

23. With which type of inflammatory bowel disease were you diagnosed?
- a. Crohn's disease
 - b. Ulcerative colitis
 - c. Not sure
 - d. Prefer not to answer
-

Frozen Shoulder

24. Has a healthcare provider ever diagnosed you with **frozen shoulder** (also known as adhesive capsulitis)?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Skip Logic: If 24=a, show 25.

25. At what age were you diagnosed frozen shoulder? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

Peptic Ulcer Disease

26. Has a healthcare provider ever diagnosed you with **peptic ulcer disease**?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Skip Logic: If 26=a, show 27.

27. At what age were you diagnosed with peptic ulcer disease? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

Hepatitis

28. Has a healthcare provider ever diagnosed you with **hepatitis**?

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

Skip Logic: If 28=a, show 29.

29. At what age were you diagnosed with hepatitis? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

Chronic Fatigue

30. Has a healthcare provider ever diagnosed you with **chronic fatigue**?

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

Skip Logic: If 30=a, show 31.

31. At what age were you diagnosed with chronic fatigue? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

Previous Surgeries and Procedures

32. Have you had your **appendix** removed?

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

Skip Logic: If 32=a, show 33.

33. At what age did you have your appendix removed? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

Previous Surgeries and Procedures

34. Have you previously had a **vagotomy procedure** (a procedure where the vagus nerve is surgically cut)?

- a. Yes
- b. No
- c. Not sure

d. Prefer not to answer

Skip Logic: If 34=a, show 35.

35. At what age did you have a vagotomy procedure? If you are not sure, please make your best guess. _____
[Validation Message: Please enter a number between 1 and 99.]

Previous Surgeries and Procedures

36. Have you previously had one or both **ovaries surgically removed**?

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

Skip Logic: If 36=a, show 37.

37. At what age did you have one or both ovaries surgically removed? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

22. Medications

[Version 2]

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

1. Are you currently taking any medications for Parkinson's disease or parkinsonism symptoms such as tremor, stiffness or slowness?
 - a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Skip Logic: If 1=a, show 2.

2. Are you currently taking any of the following medications? Brand names are mentioned in parentheses. (Please select all that apply)
 - a. Not taking any of the following medications [Validation Message if this box is not selected by itself: You are unable to select "Not taking any of the following medications" with any other response choices. Please confirm your response.]
 - b. Carbidopa / Levodopa Immediate Release (Sinemet, Kinson)
 - c. Carbidopa / Levodopa Controlled Release (Sinemet CR)
 - d. Carbidopa / Levodopa Extended Release Capsules (Rytary or Numient)
 - e. Carbidopa / Levodopa Orally Disintegrating Tablets (Parcopa)
 - f. Carbidopa / Levodopa Inhalation Powder (Inbrija)
 - g. Carbidopa / Levodopa Intestinal Gel (Duopa or Duodopa)
 - h. Carbidopa (Lodosyn)
 - i. Carbidopa / Levodopa and Entacapone (Stalevo)
 - j. Carbidopa / Levodopa and Entacapone Intestinal Gel (Lecigon)
 - k. Entacapone (Comtan)
 - l. Opicapone (Ongentys)
 - m. Tolcapone (Tasmar)
 - n. Levodopa / Benserazide Immediate Release (Madopar, Madopark, co-beneldopa or Prolopa)
 - o. Levodopa / Benserazide Controlled Release (Madopar CR, Madopar HBS, or Prolopa CR)
 - p. Levodopa / Benserazide Dispersible (Madopar Rapid)
 - q. Rasagiline (Azilect)
 - r. Selegiline (Deprenyl, Eldepryl, Zelapar)
 - s. Selegiline Transdermal (Emasm)
 - t. Safinamide (Xadago or Equfina)
 - u. Pramipexole (Mirapex, Labrixile)
 - v. Pramipexole Extended Release or modified release tablets (Mirapex ER or Sifrol ER or Pramipexole XR GP or or Labrixile ER or Pipexus)
 - w. Piribedil (Pronoran, Trivastal, Trivastan)
 - x. Ropinirole (Requip or Adartel)
 - y. Ropinirole Extended Release (Requip XL)

- z. Ropinirole Transdermal Patch (Haruropi Tape or HP-3000)
- aa. Rotigotine Transdermal Patch (Neupro Patch)
- bb. Amantadine (Symmetrel)
- cc. Amantadine Extended Release (Gocovri ER or Osmolex ER)
- dd. Istradefylline (Nourianz or Nourias)
- ee. Trihexyphenidyl (Artane or Apo-Trihex)
- ff. Benztropine (Cogentin)
- gg. Bromocriptine (Parlodel)
- hh. Apomorphine (Apokyn)
- ii. Apomorphine sublingual film (Kynmobi)
- jj. Ethopropazine (Parsitan or Parsidan or Profenamine or Parsidol, or Parkin)
- kk. Mucuna Pruriens
- ll. AtreMorine
- mm. Prefer not to answer [Validation Message if this box is not selected by itself: You are unable to select "Prefer not to answer" with any other response choices. Please confirm your response.]

23. Family History of Parkinson's disease

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

1. Do you have any family history of Parkinson's disease or parkinsonism?

- Yes
- No
- I am not sure
- Prefer not to answer

Skip Logic: If 1=a, show 2.

2. Do any of these family members have Parkinson's disease or parkinsonism? (Please select all that apply)

- Biological Mother
- Biological Father
- Maternal Grandmother
- Maternal Grandfather
- Paternal Grandmother
- Paternal Grandfather
- Full Sister
- Full Brother
- Maternal half siblings
- Paternal half siblings
- Maternal Aunts and Uncles
- Paternal Aunts and Uncles
- Maternal Cousins
- Paternal Cousins
- Children
- None of the above [Validation Message if this box is not selected by itself: You are unable to select "None of the above" with any other response choices. Please confirm your response.]
- Prefer not to answer [Validation Message if this box is not selected by itself: You are unable to select "Prefer not to answer" with any other response choices. Please confirm your response.]

24. COVID-19 Experience

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

1. Have you been diagnosed with **COVID-19** by a medical professional?
 - a. I have been diagnosed with COVID-19
 - b. I have been told I may have COVID-19
 - c. I have not been diagnosed with COVID-19
 - d. I don't know
 - e. Prefer not to answer

Skip Logic: If 1=a or 1=b, show 2 and 3. If 1=c, d, or e, skip to 5.

2. When were you diagnosed or told you may have COVID-19 by a medical professional?
 - a. _____ Month (dropdown of January - December) _____ Year (dropdown of 2020-2025)
3. When you were diagnosed with COVID-19, were you also tested for COVID-19?
 - a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Skip Logic: If 3=a, show 4.

4. What was the COVID-19 test result?
 - a. According to the result, I had coronavirus
 - b. According to the result, I did not have coronavirus
 - c. The test result could not be interpreted by my doctor
 - d. The test results are not available yet
 - e. I don't know the test results
 - f. Prefer not to answer

(continues on next page)

5. Have you received the COVID-19 vaccine?
- a. Yes, one dose
 - b. Yes, two doses
 - c. No
 - d. Not sure
 - e. Prefer not to answer

Skip Logic: If 5=a, show 6 and 7.

Skip Logic: If 5=b, show 6, 7, 8, and 9.

6. When did you receive your **first** COVID-19 vaccine dose?
- a. _____ Month (dropdown of January - December) _____ Year (dropdown of 2020-2025)
7. Which COVID-19 vaccine did you receive for your **first dose**?
- a. Pfizer-BioNTech
 - b. Moderna
 - c. Johnson & Johnson's Janssen
 - d. AstraZeneca/Oxford
 - e. Novavax
 - f. Other
 - g. Not sure
 - h. Prefer not to answer
8. When did you receive your **second** COVID-19 vaccine dose?
- a. _____ Month (dropdown of January - December) _____ Year (dropdown of 2020-2025)
9. Which COVID-19 vaccine did you receive for your **second dose**?
- a. Pfizer-BioNTech
 - b. Moderna
 - c. Johnson & Johnson's Janssen
 - d. AstraZeneca/Oxford
 - e. Novavax
 - f. Other
 - g. Not sure
 - h. Prefer not to answer

25. Smoking History

[Version 2]

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

Section A: Cigarettes

1. In your lifetime, have you smoked 100 or more cigarettes (5 packs)?

- Yes
- No
- Not Sure
- Prefer not to answer

Skip Logic: If 1 ≠ a, go to 7.

2. In your lifetime, have you ever regularly smoked cigarettes, that is, at least one cigarette per day for 6 months or longer?

- Yes
- No
- Not Sure
- Prefer not to answer

Skip Logic: If 2 ≠ a, go to 7.

3. At what age did you first start regularly smoking cigarettes? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

4. Do you currently regularly smoke cigarettes?

- Yes
- No
- Not Sure
- Prefer not to answer

Skip Logic: If 4=a, go to 6.

5. At what age did you last regularly smoke cigarettes? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

6. During the time that you regularly smoked, on average, how many cigarettes per day did you smoke? If you are not sure, please make your best guess. _____

(cigarettes, 1 pack=20 cigarettes)

[Validation Message: Please enter a number between 1 and 200.]

Section B: PIPES AND CIGARS:

The following questions ask about smoking pipes and cigars during your lifetime.

7. Have you ever regularly smoked pipes or cigars, that is, at least once per day for 6 months or longer?
- Yes
 - No
 - Not Sure
 - Prefer not to answer

Skip Logic: If 7 ≠ a, go to 11.

8. At what age did you first start regularly smoking pipes or cigars? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

9. Do you currently smoke pipes or cigars?
- Yes
 - No
 - Not Sure
 - Prefer not to answer

Skip Logic: If 9=a, go to 11.

10. At what age did you last stop regularly smoking pipes or cigars? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

Section C: SMOKELESS TOBACCO:

The following questions ask about your use of smokeless tobacco during your lifetime

11. Have you ever used smokeless tobacco such as chewing tobacco or snuff regularly, that is, at least once per day for 6 months or longer?
- Yes
 - No
 - Not Sure
 - Prefer not to answer

Skip Logic: If 11 ≠ a, go to 15.

12. At what age did you first start regularly using smokeless tobacco? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

13. Do you currently use smokeless tobacco?
- Yes
 - No

- c. Not Sure
- d. Prefer not to answer

Skip Logic: If 13=a, go to 15.

14. At what age did you last stop regularly using smokeless tobacco? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

Section D: eCIGARETTES:

The following questions ask about your use of electronic cigarettes (e-cigarettes, vape pens, and other nondisposable and disposable vaping devices) during your lifetime.

15. Have you ever used electronic cigarettes (e-cigarettes, vape pens, and other nondisposable and disposable vaping devices), that is, at least once per day for 6 months or longer?
- a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

Skip Logic: If 15 ≠ a, go to end.

16. At what age did you first start regularly using electronic cigarettes? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

17. Do you currently use electronic cigarettes?
- a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

Skip Logic: If 17=a, go to end.

18. At what age did you last stop regularly using electronic cigarettes? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

END of Smoking

26. You and Your Background Part 2 (SES)

[QUESTIONS ARE NOT REQUIRED]

1. How many years of education have you completed? If you are not sure, please make your best guess.
_____ [Validation Message: Please enter a number between 0 and 99.]

2. What is your yearly household income?
 - a. Less than \$20,000
 - b. \$20,000 to \$34,999
 - c. \$35,000 to \$49,999
 - d. \$50,000 to \$74,999
 - e. \$75,000 to \$99,999
 - f. More than \$100,000
 - g. Prefer not to answer

27. Head Injury

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

The next questions ask about any head injuries or concussions you may have had during your lifetime. Please answer these questions to the best of your ability. If you are not sure of an answer, please give your best estimate.

[\[New page\]](#)

We are interested in knowing if you may have had a head injury or concussion. These may have occurred during sporting activities from falls, violence, car accidents, or other accidents. Include injuries from both childhood and adulthood. Some people have the misconception that concussions only happen when you black out after a hit to the head or when the symptoms last for a while. But, in reality, a concussion has occurred anytime you have had a blow to the head that caused you to have symptoms for any amount of time. These include: blurred or double vision, seeing stars, sensitivity to light or noise, headache, dizziness or balance problems, nausea, vomiting, trouble sleeping, fatigue, confusion, difficulty remembering, difficulty concentrating, or loss of consciousness. Whenever anyone gets a “ding” or their “bell rung,” that too is a concussion.

1. Have you ever had a head injury or concussion during your life?
 - a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

Skip Logic: If 1 ≠ a, skip to end of the survey.

2. In your lifetime, how many head injuries or concussions in total have you had? If you are not sure, please make your best guess. _____ [\[Validation Message: Please enter a number between 1 and 50.\]](#)
3. At what age did you experience your **first** head injury or concussion? If you are not sure, please make your best guess. _____ [\[Validation Message: Please enter a number between 1 and 99.\]](#)
4. At what age did you experience your **most recent** head injury or concussion? If you are not sure, please make your best guess. _____ [\[Validation Message: Please enter a number between 1 and 99.\]](#)
5. At what age did you experience your **most severe** head injury or concussion? If you are not sure, please make your best guess. _____ [\[Validation Message: Please enter a number between 1 and 99.\]](#)
6. Thinking about your **most severe** head injury or concussion:
Did you lose consciousness from this injury?
 - a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

Skip Logic: If 6=a, show 7.

7. How long were you unconscious?

- a. Less than 5 minutes
- b. 5-59 minutes
- c. 1-24 hours
- d. Longer than 1 day
- e. Not Sure
- f. Prefer not to answer

8. Thinking about your **most severe** head injury or concussion:

Did you have a skull fracture from this injury?

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

9. Thinking about your **most severe** head injury or concussion:

Did you have a seizure from this injury?

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

10. Thinking about your **most severe** head injury or concussion:

Did you have memory loss, amnesia, or trouble thinking from this injury?

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

11. Thinking about your **most severe** head injury or concussion:

Were you hospitalized for this injury?

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

[Required footer at the end of survey:](#) Questions 1-3 were adapted from the BU Head Impact Exposure Assessment and used with permission from BU CTE Center Investigators

28. Caffeine Use

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

Section A: Caffeinated Coffee

Section B: Caffeinated Black Tea

Section C: Caffeinated Green Tea

Section D: Caffeinated Soda

Section E: Caffeinated Diet Soda

Section F: Caffeinated Energy Drinks or products

Section A: Caffeinated Coffee

1. In your lifetime, have you ever regularly drunk caffeinated coffee, that is, at least once per WEEK for 6 months or longer?
 - a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

Skip Logic: If 1 ≠ a, go to 6.

2. At what age did you first start regularly drinking caffeinated coffee? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]
3. Do you currently regularly drink caffeinated coffee?
 - a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

Skip Logic: If 3=a, go to 5.

4. At what age did you last regularly drink caffeinated coffee? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]
5. During the time that you regularly drank caffeinated coffee, on average, how many cups per week did you drink? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 100.]

Section B: Caffeinated Black Tea

6. In your lifetime, have you ever regularly drunk hot or iced caffeinated black tea, that is, at least once per WEEK for 6 months or longer? (Black team includes most types of non-herbal tea, such as Lipton, Earl Grey and others.)
- Yes
 - No
 - Not Sure
 - Prefer not to answer

Skip Logic: If 6 ≠ a, go to 11.

7. At what age did you first start regularly drinking caffeinated black tea? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]
8. Do you currently regularly drink caffeinated black tea?
- Yes
 - No
 - Not Sure
 - Prefer not to answer

Skip Logic: If 8=a, go to 10.

9. At what age did you last regularly drink caffeinated black tea? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]
10. During the time that you regularly drank caffeinated black tea, on average, how many cups per week did you drink? If you are not sure, please make your best guess. _____
[Validation Message: Please enter a number between 1 and 100.]

Section C: Caffeinated Green Tea

11. In your lifetime, have you ever regularly drunk caffeinated green tea, that is, at least once per WEEK for 6 months or longer?
- Yes
 - No
 - Not Sure
 - Prefer not to answer

Skip Logic: If 11 ≠ a, go to 16.

12. At what age did you first start regularly drinking caffeinated green tea? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

13. Do you currently regularly drink caffeinated green tea?
- Yes
 - No
 - Not Sure
 - Prefer not to answer

Skip Logic: If 13=a, go to 15.

14. At what age did you last regularly drink caffeinated green tea? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

15. During the time that you regularly drank caffeinated green tea, on average, how many cups per week did you drink? If you are not sure, please make your best guess. _____
[Validation Message: Please enter a number between 1 and 100.]

Section D: Caffeinated Regular Soda

16. In your lifetime, have you ever regularly drunk caffeinated, regular soda, that is, at least once per WEEK for 6 months or longer?
- Yes
 - No
 - Not Sure
 - Prefer not to answer

Skip Logic: If 16 ≠ a, go to 21.

17. At what age did you first start regularly drinking caffeinated, regular soda? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

18. Do you currently regularly drink caffeinated regular soda?
- Yes
 - No
 - Not Sure
 - Prefer not to answer

Skip Logic: If 18=a, go to 20.

19. At what age did you last regularly drink caffeinated regular soda? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

20. During the time that you regularly drank caffeinated regular soda, on average, how many cans or 12 oz/375ml servings per week did you drink? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 100.]

Section E: Caffeinated Diet Soda

21. In your lifetime, have you ever regularly drunk caffeinated diet soda, that is, at least once per WEEK for 6 months or longer?
- Yes
 - No
 - Not Sure
 - Prefer not to answer

Skip Logic: If 21 ≠ a, go to 26.

22. At what age did you first start regularly drinking caffeinated diet soda? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

23. Do you currently regularly drink caffeinated diet soda?
- Yes
 - No
 - Not Sure
 - Prefer not to answer

Skip Logic: If 23=a, go to 25.

24. At what age did you last regularly drink caffeinated diet soda? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

25. During the time that you regularly drank caffeinated diet soda, on average, how many cans or 12 oz/375ml servings per week did you drink? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 100.]

Section F: Caffeinated Energy Drinks or products

26. In your lifetime, have you ever regularly consumed caffeinated energy drinks or products, that is, at least once per WEEK for 6 months or longer? Some common energy drinks and products include Redbull, Monster, or electrolyte tablets containing caffeine including Nuun, Gu etc.

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

Skip Logic: If 26 ≠ a, go to end.

27. At what age did you first start regularly consuming caffeinated energy drinks or products? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

28. Do you currently regularly consume caffeinated energy drinks or products?

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

Skip Logic: If 28=a, go to 30.

29. At what age did you last regularly consume caffeinated energy drinks or products? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

30. During the time that you regularly consumed caffeinated energy drinks or products, on average, how many cans or 12 oz/375ml servings per week did you drink? If you are not sure, please make your best guess.

_____ [Validation Message: Please enter a number between 1 and 100.]

End Caffeine

29. Pesticide Use at Work

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

The next questions ask about pesticides you may have used at work during different periods of your life. Please answer these questions to the best of your ability. If you are not sure of an answer, please give your best estimate.

1. Over your lifetime, have you ever had a **JOB** in which you mixed, applied, or were exposed in some other way to any type of pesticide, including herbicides (kill weeds), fungicides (kill fungus/mold), insecticides (kill insects), or fumigants (gas used to kill fungus/mold or insects)?
 - a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

Skip Logic: If 1 ≠ a, skip to end

2. How old were you when you had a JOB in which you used pesticides? Please select all age periods that apply.
 - Age 18-29 [Displayed section if this is selected]
 - Age 30-39 [Displayed section if this is selected]
 - Age 40-49 [Displayed section if this is selected]
 - Age 50-59 [Displayed section if this is selected]
 - Age 60-64 [Displayed section if this is selected]
 - Age 65-69 [Displayed section if this is selected]
 - Age 70-74 [Displayed section if this is selected]
 - Age 75-79 [Displayed section if this is selected]
 - Age 80 or over [Displayed section if this is selected]

Age 18-29

3. From age 18-29, what type of job(s) or industry were you working in when you mixed, applied, or were exposed in some other way to pesticides? Please select all that apply.
 - a. Farming or Ranching
 - b. Forestry
 - c. Landscaping / Gardening / Groundskeeping
 - d. Nursery / Greenhouse
 - e. Pest control / Exterminator
 - f. Building maintenance / Janitorial
 - g. Other
 - h. Not sure
 - h. Prefer not to answer
4. From age 18-29, how many total years did you have jobs where you mixed, applied or were exposed in some other way to pesticides? If you are not sure, please make your best guess. _____ (Total Years)
[Validation Message: Please enter a number between 1 and 12]

5. From age 18-29, what types of pesticides did you mix, apply, or get exposed to in some other way at work during these years? Please select all that apply.
- Herbicides (kill weeds)
 - Fungicides (kill fungus/mold)
 - Insecticides (kill insects)
 - Fumigants (gas used to kill fungus/mold or insects)
 - Not Sure
 - Prefer not to answer
6. From age 18-29, did you mix, apply, or were exposed in some other way to any of the following pesticides? Consider all brand name products that may have contained the pesticides below. Please select all that apply.
- 2,4-D
 - Alachlor or Acetochlor
 - Aldrin
 - Atrazine or Cyanazine
 - Benomyl
 - Chlordane
 - Chlorothalonil
 - Chlorpyrifos
 - Copper compounds
 - Cyhalothrin
 - DDT
 - Dieldrin
 - Diquat
 - Fipronil
 - Glyphosate
 - Heptachlor
 - Hexachlorobenzene
 - Lindane (hexachlorohexane)
 - Malathion
 - Maneb or Mancozeb
 - Metolachlor
 - Parathion or parathion methyl
 - Paraquat
 - Phorate (Thimate)
 - Permethrin or similar pyrethroids (cypermethrin, deltamethrin)
 - Rotenone
 - Terbufos
 - Trifluralin
 - Ziram or Zineb
 - Other
 - Not sure
 - Prefer not to answer
7. From age 18-29, when you personally mixed or applied pesticides at work, did you wear some type of protective equipment more than half the time such as gloves, mask/respirators, goggles?
- Yes
 - No
 - Not Sure
 - Prefer not to answer
8. From age 18-29, did you ever get concentrated pesticide on your skin?

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

Skip Logic: If 8=a, show 9.

9. From age 18-29, when you got concentrated pesticide on your skin, did you usually stop what you were doing and wash it off?
- a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

Age 30-39

10. From age 30-39, what type of job(s) or industry were you working in when you mixed, applied, or were exposed in some other way to pesticides? Please select all that apply.
- a. Farming or Ranching
 - b. Forestry
 - c. Landscaping / Gardening / Groundskeeping
 - d. Nursery / Greenhouse
 - e. Pest control / Exterminator
 - f. Building maintenance / Janitorial
 - g. Other
 - h. Not sure
 - i. Prefer not to answer
11. From age 30-39, how many total years did you have jobs where you mixed, applied or were exposed in some other way to pesticides? If you are not sure, please make your best guess. _____ (Total Years)
[Validation Message: Please enter a number between 1 and 10]
12. From age 30-39, what types of pesticides did you mix, apply, or get exposed to in some other way at work during these years? Please select all that apply.
- a. Herbicides (kill weeds)
 - b. Fungicides (kill fungus/mold)
 - c. Insecticides (kill insects)
 - d. Fumigants (gas used to kill fungus/mold or insects)
 - e. Not Sure
 - f. Prefer not to answer
13. From age 30-39, did you mix, apply, or were exposed in some other way to any of the following pesticides? Consider all brand name products that may have contained the pesticides below. Please select all that apply.
- 2,4-D
 - Alachlor or Acetochlor
 - Aldrin
 - Atrazine or Cyanazine
 - Benomyl
 - Chlordane
 - Chlorothalonil
 - Chlorpyrifos

- Copper compounds
- Cyhalothrin
- DDT
- Dieldrin
- Diquat
- Fipronil
- Glyphosate
- Heptachlor
- Hexachlorobenzene
- Lindane (hexachlorohexane)
- Malathion
- Maneb or Mancozeb
- Metolachlor
- Parathion or parathion methyl
- Paraquat
- Phorate (Thimate)
- Permethrin or similar pyrethroids (cypermethrin, deltamethrin)
- Rotenone
- Terbufos
- Trifluralin
- Ziram or Zineb
- Other
- Not sure
- Prefer not to answer

14. From age 30-39, when you personally mixed or applied pesticides at work, did you wear some type of protective equipment more than half the time such as gloves, mask/respirators, goggles?
- a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

15. From age 30-39, did you ever get concentrated pesticide on your skin?
- a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

Skip Logic: If 15=a, show 16.

16. From age 30-39, when you got concentrated pesticide on your skin, did you usually stop what you were doing and wash it off?
- a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

Age 40-49

17. From age 40-49, what type of job(s) or industry were you working in when you mixed, applied, or were exposed in some other way to pesticides? Please select all that apply.
- a. Farming or Ranching
 - b. Forestry
 - c. Landscaping / Gardening / Groundskeeping
 - d. Nursery / Greenhouse

- e. Pest control / Exterminator
- f. Building maintenance / Janitorial
- g. Other
- h. Not sure
- i. Prefer not to answer

18. From age 40-49, how many total years did you have jobs where you mixed, applied or were exposed in some other way to pesticides? If you are not sure, please make your best guess. _____ (Total Years)
[Validation Message: Please enter a number between 1 and 10]

19. From age 40-49, what types of pesticides did you mix, apply, or get exposed to in some other way at work during these years? Please select all that apply.

- a. Herbicides (kill weeds)
- b. Fungicides (kill fungus/mold)
- c. Insecticides (kill insects)
- d. Fumigants (gas used to kill fungus/mold or insects)
- g. Not Sure
- h. Prefer not to answer

20. From age 40-49, did you mix, apply, or were exposed in some other way to any of the following pesticides? Consider all brand name products that may have contained the pesticides below. Please select all that apply.

- 2,4-D
- Alachlor or Acetochlor
- Aldrin
- Atrazine or Cyanazine
- Benomyl
- Chlordane
- Chlorothalonil
- Chlorpyrifos
- Copper compounds
- Cyhalothrin
- DDT
- Dieldrin
- Diquat
- Fipronil
- Glyphosate
- Heptachlor
- Hexachlorobenzene
- Lindane (hexachlorohexane)
- Malathion
- Maneb or Mancozeb
- Metolachlor
- Parathion or parathion methyl
- Paraquat
- Phorate (Thimate)
- Permethrin or similar pyrethroids (cypermethrin, deltamethrin)
- Rotenone
- Terbufos
- Trifluralin
- Ziram or Zineb
- Other
- Not sure

- Prefer not to answer
21. From age 40-49, when you personally mixed or applied pesticides at work, did you wear some type of protective equipment more than half the time such as gloves, mask/respirators, goggles?
- a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer
22. From age 40-49, did you ever get concentrated pesticide on your skin?
- a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

Skip Logic: If 22=a, show 23.

23. From age 40-49, when you got concentrated pesticide on your skin, did you usually stop what you were doing and wash it off?
- a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

Age 50-59

24. From age 50-59, what type of job(s) or industry were you working in when you mixed, applied, or were exposed in some other way to pesticides? Please select all that apply.
- a. Farming or Ranching
 - b. Forestry
 - c. Landscaping / Gardening / Groundskeeping
 - d. Nursery / Greenhouse
 - e. Pest control / Exterminator
 - f. Building maintenance / Janitorial
 - g. Other
 - h. Not sure
 - i. Prefer not to answer
25. From age 50-59, how many total years did you have jobs where you mixed, applied or were exposed in some other way to pesticides? If you are not sure, please make your best guess. _____ (Total Years)
 [Validation Message: Please enter a number between 1 and 10]
26. From age 50-59, what types of pesticides did you mix, apply, or get exposed to in some other way at work during these years? Please select all that apply.
- a. Herbicides (kill weeds)
 - b. Fungicides (kill fungus/mold)
 - c. Insecticides (kill insects)
 - d. Fumigants (gas used to kill fungus/mold or insects)
 - e. Not Sure
 - f. Prefer not to answer
27. From age 50-59, did you mix, apply, or were exposed in some other way to any of the following pesticides? Consider all brand name products that may have contained the pesticides below. Please

select all that apply.

- 2,4-D
- Alachlor or Acetochlor
- Aldrin
- Atrazine or Cyanazine
- Benomyl
- Chlordane
- Chlorothalonil
- Chlorpyrifos
- Copper compounds
- Cyhalothrin
- DDT
- Dieldrin
- Diquat
- Fipronil
- Glyphosate
- Heptachlor
- Hexachlorobenzene
- Lindane (hexachlorohexane)
- Malathion
- Maneb or Mancozeb
- Metolachlor
- Parathion or parathion methyl
- Paraquat
- Phorate (Thimate)
- Permethrin or similar pyrethroids (cypermethrin, deltamethrin)
- Rotenone
- Terbufos
- Trifluralin
- Ziram or Zineb
- Other
- Not sure
- Prefer not to answer

28. From age 50-59, when you personally mixed or applied pesticides at work, did you wear some type of protective equipment more than half the time such as gloves, mask/respirators, goggles?

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

29. From age 50-59, did you ever get concentrated pesticide on your skin?

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

Skip Logic: If 29=a, show 30.

30. From age 50-59, when you got concentrated pesticide on your skin, did you usually stop what you were doing and wash it off?

- a. Yes
- b. No
- c. Not Sure

- d. Prefer not to answer

Age 60-64

31. From age 60-64, what type of job(s) or industry were you working in when you mixed, applied, or were exposed in some other way to pesticides? Please select all that apply.
- a. Farming or Ranching
 - b. Forestry
 - c. Landscaping / Gardening / Groundskeeping
 - d. Nursery / Greenhouse
 - e. Pest control / Exterminator
 - f. Building maintenance / Janitorial
 - g. Other
 - h. Not sure
 - h. Prefer not to answer
32. From age 60-64, how many total years did you have jobs where you mixed, applied or were exposed in some other way to pesticides? If you are not sure, please make your best guess. _____ (Total Years)
[Validation Message: Please enter a number between 1 and 5]
33. From age 60-64, what types of pesticides did you mix, apply, or get exposed to in some other way at work during these years? Please select all that apply.
- a. Herbicides (kill weeds)
 - b. Fungicides (kill fungus/mold)
 - c. Insecticides (kill insects)
 - d. Fumigants (gas used to kill fungus/mold or insects)
 - e. Not Sure
 - f. Prefer not to answer
34. From age 60-64, did you mix, apply, or were exposed in some other way to any of the following pesticides? Consider all brand name products that may have contained the pesticides below. Please select all that apply.
- 2,4-D
 - Alachlor or Acetochlor
 - Aldrin
 - Atrazine or Cyanazine
 - Benomyl
 - Chlordane
 - Chlorothalonil
 - Chlorpyrifos
 - Copper compounds
 - Cyhalothrin
 - DDT
 - Dieldrin
 - Diquat
 - Fipronil
 - Glyphosate
 - Heptachlor
 - Hexachlorobenzene
 - Lindane (hexachlorohexane)
 - Malathion
 - Maneb or Mancozeb
 - Metolachlor
 - Parathion or parathion methyl

- Paraquat
- Phorate (Thimate)
- Permethrin or similar pyrethroids (cypermethrin, deltamethrin)
- Rotenone
- Terbufos
- Trifluralin
- Ziram or Zineb
- Other
- Not sure
- Prefer not to answer

35. From age 60-64, when you personally mixed or applied pesticides at work, did you wear some type of protective equipment more than half the time such as gloves, mask/respirators, goggles?

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

36. From age 60-64, did you ever get concentrated pesticide on your skin?

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

Skip Logic: If 36=a, show 37.

37. From age 60-64, when you got concentrated pesticide on your skin, did you usually stop what you were doing and wash it off?

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

Age 65-69

38. From age 65-69, what type of job(s) or industry were you working in when you mixed, applied, or were exposed in some other way to pesticides? Please select all that apply.

- a. Farming or Ranching
- b. Forestry
- c. Landscaping / Gardening / Groundskeeping
- d. Nursery / Greenhouse
- e. Pest control / Exterminator
- f. Building maintenance / Janitorial
- g. Other
- h. Not sure
- i. Prefer not to answer

39. From age 65-69, how many total years did you have jobs where you mixed, applied or were exposed in some other way to pesticides? If you are not sure, please make your best guess. _____ (Total Years)
[\[Validation Message: Please enter a number between 1 and 5\]](#)

40. From age 65-69, what types of pesticides did you mix, apply, or get exposed to in some other way at work during these years? Please select all that apply.

- a. Herbicides (kill weeds)
- b. Fungicides (kill fungus/mold)
- c. Insecticides (kill insects)
- d. Fumigants (gas used to kill fungus/mold or insects)
- e. Not Sure
- f. Prefer not to answer

41. From age 65-69, did you mix, apply, or were exposed in some other way to any of the following pesticides? Consider all brand name products that may have contained the pesticides below. Please select all that apply.

- 2,4-D
- Alachlor or Acetochlor
- Aldrin
- Atrazine or Cyanazine
- Benomyl
- Chlordane
- Chlorothalonil
- Chlorpyrifos
- Copper compounds
- Cyhalothrin
- DDT
- Dieldrin
- Diquat
- Fipronil
- Glyphosate
- Heptachlor
- Hexachlorobenzene
- Lindane (hexachlorohexane)
- Malathion
- Maneb or Mancozeb
- Metolachlor
- Parathion or parathion methyl
- Paraquat
- Phorate (Thimate)
- Permethrin or similar pyrethroids (cypermethrin, deltamethrin)
- Rotenone
- Terbufos
- Trifluralin
- Ziram or Zineb
- Other
- Not sure
- Prefer not to answer

42. From age 65-69, when you personally mixed or applied pesticides at work, did you wear some type of protective equipment more than half the time such as gloves, mask/respirators, goggles?

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

43. From age 65-69, did you ever get concentrated pesticide on your skin?

- a. Yes
- b. No
- c. Not Sure

- d. Prefer not to answer

Skip Logic: If 43=a, show 44.

44. From age 65-69, when you got concentrated pesticide on your skin, did you usually stop what you were doing and wash it off?
- a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

Age 70-74

45. From age 70-74, what type of job(s) or industry were you working in when you mixed, applied, or were exposed in some other way to pesticides? Please select all that apply.
- a. Farming or Ranching
 - b. Forestry
 - c. Landscaping / Gardening / Groundskeeping
 - d. Nursery / Greenhouse
 - e. Pest control / Exterminator
 - f. Building maintenance / Janitorial
 - g. Other
 - h. Not sure
 - i. Prefer not to answer
46. From age 70-74, how many total years did you have jobs where you mixed, applied or were exposed in some other way to pesticides? If you are not sure, please make your best guess. _____ (Total Years)
[Validation Message: Please enter a number between 1 and 5]
47. From age 70-74, what types of pesticides did you mix, apply, or get exposed to in some other way at work during these years? Please select all that apply.
- a. Herbicides (kill weeds)
 - b. Fungicides (kill fungus/mold)
 - c. Insecticides (kill insects)
 - d. Fumigants (gas used to kill fungus/mold or insects)
 - e. Not Sure
 - f. Prefer not to answer
48. From age 70-74, did you mix, apply, or were exposed in some other way to any of the following pesticides? Consider all brand name products that may have contained the pesticides below. Please select all that apply.
- 2,4-D
 - Alachlor or Acetochlor
 - Aldrin
 - Atrazine or Cyanazine
 - Benomyl
 - Chlordane
 - Chlorothalonil
 - Chlorpyrifos
 - Copper compounds
 - Cyhalothrin
 - DDT
 - Dieldrin

- Diquat
- Fipronil
- Glyphosate
- Heptachlor
- Hexachlorobenzene
- Lindane (hexachlorohexane)
- Malathion
- Maneb or Mancozeb
- Metolachlor
- Parathion or parathion methyl
- Paraquat
- Phorate (Thimate)
- Permethrin or similar pyrethroids (cypermethrin, deltamethrin)
- Rotenone
- Terbufos
- Trifluralin
- Ziram or Zineb
- Other
- Not sure
- Prefer not to answer

49. From age 70-74, when you personally mixed or applied pesticides at work, did you wear some type of protective equipment more than half the time such as gloves, mask/respirators, goggles?

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

50. From age 70-74, did you ever get concentrated pesticide on your skin?

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

Skip Logic: If 50=a, show 51.

51. From age 70-74, when you got concentrated pesticide on your skin, did you usually stop what you were doing and wash it off?

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

Age 75-79

52. From age 75-79, what type of job(s) or industry were you working in when you mixed, applied, or were exposed in some other way to pesticides? Please select all that apply.

- a. Farming or Ranching
- b. Forestry
- c. Landscaping / Gardening / Groundskeeping
- d. Nursery / Greenhouse
- e. Pest control / Exterminator
- f. Building maintenance / Janitorial
- g. Other
- h. Not sure

- j. Prefer not to answer
53. From age 75-79, how many total years did you have jobs where you mixed, applied or were exposed in some other way to pesticides? If you are not sure, please make your best guess. _____ (Total Years)
[Validation Message: Please enter a number between 1 and 5]
54. From age 75-79, what types of pesticides did you mix, apply, or get exposed to in some other way at work during these years? Please select all that apply.
- a. Herbicides (kill weeds)
 - b. Fungicides (kill fungus/mold)
 - c. Insecticides (kill insects)
 - d. Fumigants (gas used to kill fungus/mold or insects)
 - e. Not Sure
 - f. Prefer not to answer
55. From age 75-79, did you mix, apply, or were exposed in some other way to any of the following pesticides? Consider all brand name products that may have contained the pesticides below. Please select all that apply.
- 2,4-D
 - Alachlor or Acetochlor
 - Aldrin
 - Atrazine or Cyanazine
 - Benomyl
 - Chlordane
 - Chlorothalonil
 - Chlorpyrifos
 - Copper compounds
 - Cyhalothrin
 - DDT
 - Dieldrin
 - Diquat
 - Fipronil
 - Glyphosate
 - Heptachlor
 - Hexachlorobenzene
 - Lindane (hexachlorohexane)
 - Malathion
 - Maneb or Mancozeb
 - Metolachlor
 - Parathion or parathion methyl
 - Paraquat
 - Phorate (Thimate)
 - Permethrin or similar pyrethroids (cypermethrin, deltamethrin)
 - Rotenone
 - Terbufos
 - Trifluralin
 - Ziram or Zineb
 - Other
 - Not sure
 - Prefer not to answer
56. From age 75-79, when you personally mixed or applied pesticides at work, did you wear some type of protective equipment more than half the time such as gloves, mask/respirators, goggles?
- a. Yes

- b. No
- c. Not Sure
- d. Prefer not to answer

57. From age 75-79, did you ever get concentrated pesticide on your skin?

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

Skip Logic: If 57=a, show 58.

58. From age 75-79, when you got concentrated pesticide on your skin, did you usually stop what you were doing and wash it off?

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

Age 80 or over

59. From age 80 or over, what type of job(s) or industry were you working in when you mixed, applied, or were exposed in some other way to pesticides? Please select all that apply.

- a. Farming or Ranching
- b. Forestry
- c. Landscaping / Gardening / Groundskeeping
- d. Nursery / Greenhouse
- e. Pest control / Exterminator
- f. Building maintenance / Janitorial
- g. Other
- h. Not sure
- k. Prefer not to answer

60. From age 80 or over, how many total years did you have jobs where you mixed, applied or were exposed in some other way to pesticides? If you are not sure, please make your best guess. _____
(Total Years) [[Validation Message: Please enter a number between 1 and 20](#)]

61. From age 80 or over, what types of pesticides did you mix, apply, or get exposed to in some other way at work during these years? Please select all that apply.

- a. Herbicides (kill weeds)
- b. Fungicides (kill fungus/mold)
- c. Insecticides (kill insects)
- d. Fumigants (gas used to kill fungus/mold or insects)
- e. Not Sure
- f. Prefer not to answer

62. From age 80 or over, did you mix, apply, or were exposed in some other way to any of the following pesticides? Consider all brand name products that may have contained the pesticides below. Please select all that apply.

- 2,4-D
- Alachlor or Acetochlor
- Aldrin
- Atrazine or Cyanazine
- Benomyl
- Chlordane
- Chlorothalonil

- Chlorpyrifos
- Copper compounds
- Cyhalothrin
- DDT
- Dieldrin
- Diquat
- Fipronil
- Glyphosate
- Heptachlor
- Hexachlorobenzene
- Lindane (hexachlorohexane)
- Malathion
- Maneb or Mancozeb
- Metolachlor
- Parathion or parathion methyl
- Paraquat
- Phorate (Thimate)
- Permethrin or similar pyrethroids (cypermethrin, deltamethrin)
- Rotenone
- Terbufos
- Trifluralin
- Ziram or Zineb
- Other
- Not sure
- Prefer not to answer

63. From age 80 or over, when you personally mixed or applied pesticides at work, did you wear some type of protective equipment more than half the time such as gloves, mask/respirators, goggles?

- e. Yes
- f. No
- g. Not Sure
- h. Prefer not to answer

64. From age 80 or over, did you ever get concentrated pesticide on your skin?

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

Skip Logic: If 64=a, show 65.

65. From age 80 or over, when you got concentrated pesticide on your skin, did you usually stop what you were doing and wash it off?

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

Medical care

Display Logic: If 1=a, show 66

66. Did you ever seek medical care because of an exposure to pesticides at work?

- a. Yes
- b. No

- c. Not Sure
- d. Prefer not to answer

Skip Logic: If 66=a, show 67-69

67. How many times in total did you seek medical care due to an exposure to pesticides at work? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 50.]
68. At what age did you **FIRST** seek medical care due to an exposure to pesticides at work? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]
69. At what age did you **LAST** seek medical care due to an exposure to pesticides at work? If you are not sure, please make your best guess. _____ [Validation Message: Please enter a number between 1 and 99.]

END of Pesticide questionnaire

30. Chemical Exposure at Work

The next questions ask about chemical and other exposures you may have had at work during different periods of your life. Please answer these questions to the best of your ability. If you are not sure of an answer, please give your best estimate.

Solvents and degreasers

1. In your lifetime, have you used any of the following solvents or degreasers 100 or more days at work?

Please select all that apply.

- a. Did not use solvents or degreasers
- b. Avgas, jet fuel
- c. Carbon tetrachloride
- d. Kerosene
- e. Methylene chloride
- f. Methyl ethyl ketone (MEK)
- g. Mineral spirits, naphtha, paint thinner
- h. n-Hexane
- i. PERC (perchloroethylene)
- j. Stoddard solvent
- k. toluene
- l. Trichloroethylene (TCE)
- m. xylene
- n. Other solvents or degreaser not listed here
- o. Not Sure
- p. Prefer not to answer

Skip Logic: If 1= any a-n, show 2

2. How old were you when you used solvents or degreasers? Please select all age periods that apply.

- Age 18-29
- Age 30-39
- Age 40-49
- Age 50-59
- Age 60-64
- Age 65-69
- Age 70-74
- Age 75-79
- Age 80 or over

Welding

3. In your lifetime, have you welded metal 100 or more days at work?

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

Skip Logic: If 3=a, show 4.

4. How old were you when you welded metal? Please select all age periods that apply.

- Age 18-29
- Age 30-39
- Age 40-49
- Age 50-59
- Age 60-64
- Age 65-69
- Age 70-74
- Age 75-79
- Age 80 or over

31. Physical Activity

Who is completing this questionnaire?

- Participant
- Care partner
- Participant and Care partner
- Another person

The following questions will ask you about the time you spent doing different types of physical activity and how long you slept. Please answer all questions even if you do not consider yourself to be a physically active person.

When answering these questions consider "vigorous activity" to be activities that produce a large increase in breathing and heart rate and "moderate activity" to be activities that produce a moderate increase in breathing and heart rate.

While answering these questions, please consider physical activity at your work, such as lifting boxes; at your home, such as vacuuming or gardening; and in your hobbies or recreational activities.

1. Please select your current age group:

- Age 18-29 [[Display section 1](#)]
- Age 30-39 [[Display sections 1, 2](#)]
- Age 40-49 [[Display sections 1, 2, 3](#)]
- Age 50-59 [[Display sections 1, 2, 3, 4](#)]
- Age 60-64 [[Display sections 1, 2, 3, 4, 5](#)]
- Age 65-69 [[Display sections 1, 2, 3, 4, 5, 6](#)]
- Age 70-74 [[Display sections 1, 2, 3, 4, 5, 6, 7](#)]
- Age 75-79 [[Display sections 1, 2, 3, 4, 5, 6, 7, 8](#)]
- Age 80 or over [[Display sections 1, 2, 3, 4, 5, 6, 7, 8, 9](#)]

SECTION 1

From age 18 through age 29, in a typical week, how many hours of:

1a. vigorous physical activity did you engage in?

- a. Not at all
- b. Less than 1 hour
- c. 1-4 hours
- d. 5-10 hours
- e. More than 10 hours/week

1b. moderate physical activity did you engage in?

- a. Not at all
- b. Less than 1 hour
- c. 1-4 hours
- d. 5-10 hours
- e. More than 10 hours/week

1c. sleep did you get on an average night?

- a. Less than 5 hours

Last update 12/15/2022

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- b. 5-6 hours
- c. 6-7 hours
- d. 7-8 hours
- e. More than 8 hours
- f. Not sure
- g. Prefer not to answer

SECTION 2

From age 30 through age 39, in a typical week, how many hours of:

2a. vigorous physical activity did you engage in?

- a. Not at all
- b. Less than 1 hour
- c. 1-4 hours
- d. 5-10 hours
- e. More than 10 hours/week

2b. moderate physical activity did you engage in?

- a. Not at all
- b. Less than 1 hour
- c. 1-4 hours
- d. 5-10 hours
- e. More than 10 hours/week

2c. sleep did you get on an average night?

- a. Less than 5 hours
- b. 5-6 hours
- c. 6-7 hours
- d. 7-8 hours
- e. More than 8 hours
- f. Not sure
- g. Prefer not to answer

SECTION 3

From age 40 through age 49, in a typical week, how many hours of:

3a. vigorous physical activity did you engage in?

- a. Not at all
- b. Less than 1 hour
- c. 1-4 hours
- d. 5-10 hours
- e. More than 10 hours/week

3b. moderate physical activity did you engage in?

- a. Not at all
- b. Less than 1 hour
- c. 1-4 hours
- d. 5-10 hours
- e. More than 10 hours/week

3c. sleep did you get on an average night?

- a. Less than 5 hours
- b. 5-6 hours
- c. 6-7 hours

- d. 7-8 hours
- e. More than 8 hours
- f. Not sure
- g. Prefer not to answer

SECTION 4

From age 50 through age 59, in a typical week, how many hours of:

4a. vigorous physical activity did you engage in?

- a. Not at all
- b. Less than 1 hour
- c. 1-4 hours
- d. 5-10 hours
- e. More than 10 hours/week

4b. moderate physical activity did you engage in?

- a. Not at all
- b. Less than 1 hour
- c. 1-4 hours
- d. 5-10 hours
- e. More than 10 hours/week

4c. sleep did you get on an average night?

- h. Less than 5 hours
- a. 5-6 hours
- b. 6-7 hours
- c. 7-8 hours
- d. More than 8 hours
- e. Not sure
- f. Prefer not to answer

SECTION 5

From age 60 through age 64, in a typical week, how many hours of:

5a. vigorous physical activity did you engage in?

- a. Not at all
- b. Less than 1 hour
- c. 1-4 hours
- d. 5-10 hours
- e. More than 10 hours/week

5b. moderate physical activity did you engage in?

- a. Not at all
- b. Less than 1 hour
- c. 1-4 hours
- d. 5-10 hours
- e. More than 10 hours/week

5c. sleep did you get on an average night?

- a. Less than 5 hours
- b. 5-6 hours
- c. 6-7 hours
- d. 7-8 hours

- e. More than 8 hours
- f. Not sure
- g. Prefer not to answer

SECTION 6

From age 65 through age 69, in a typical week, how many hours of:

6a. vigorous physical activity did you engage in?

- a. Not at all
- b. Less than 1 hour
- c. 1-4 hours
- d. 5-10 hours
- e. More than 10 hours/week

6b. moderate physical activity did you engage in?

- a. Not at all
- b. Less than 1 hour
- c. 1-4 hours
- d. 5-10 hours
- e. More than 10 hours/week

7c. sleep did you get on an average night?

- a. Less than 5 hours
- b. 5-6 hours
- c. 6-7 hours
- d. 7-8 hours
- e. More than 8 hours
- f. Not sure
- g. Prefer not to answer

SECTION 7

From age 70 through age 74, in a typical week, how many hours of:

7a. vigorous physical activity did you engage in?

- a. Not at all
- b. Less than 1 hour
- c. 1-4 hours
- d. 5-10 hours
- e. More than 10 hours/week

7b. moderate physical activity did you engage in?

- a. Not at all
- b. Less than 1 hour
- c. 1-4 hours
- d. 5-10 hours
- e. More than 10 hours/week

7c. sleep did you get on an average night?

- a. Less than 5 hours
- b. 5-6 hours
- c. 6-7 hours
- d. 7-8 hours
- e. More than 8 hours
- f. Not sure

- g. Prefer not to answer

SECTION 8

From age 75 through age 79, in a typical week, how many hours of:

8a. vigorous physical activity did you engage in?

- a. Not at all
- b. Less than 1 hour
- c. 1-4 hours
- d. 5-10 hours
- e. More than 10 hours/week

8b. moderate physical activity did you engage in?

- a. Not at all
- b. Less than 1 hour
- c. 1-4 hours
- d. 5-10 hours
- e. More than 10 hours/week

8c. sleep did you get on an average night?

- a. Less than 5 hours
- b. 5-6 hours
- c. 6-7 hours
- d. 7-8 hours
- e. More than 8 hours
- f. Not sure
- g. Prefer not to answer

SECTION 9

From age 80 or over, in a typical week, how many hours of:

9a. vigorous physical activity did you engage in?

- a. Not at all
- b. Less than 1 hour
- c. 1-4 hours
- d. 5-10 hours
- e. More than 10 hours/week

9b. moderate physical activity did you engage in?

- a. Not at all
- b. Less than 1 hour
- c. 1-4 hours
- d. 5-10 hours
- e. More than 10 hours/week

9c. sleep did you get on an average night?

- a. Less than 5 hours
- b. 5-6 hours
- c. 6-7 hours
- d. 7-8 hours
- e. More than 8 hours
- f. Not sure
- g. Prefer not to answer

32. How You Heard about PPMI

1. How did you hear about PPMI? (Please select all that apply)

- a. Michael J. Fox Foundation
- b. A doctor or other medical professional
- c. An advocacy and/or PD organization
- d. A PD support group
- e. A family member or friend
- f. Another PPMI participant
- g. A web-based clinical trials directory
- h. Print Materials, Radio, or TV
- i. Web-based search
- j. An in-person PD event
- k. Online Ad
- l. Online Article
- m. Social Media
- n. Other
- o. Not Sure
- p. Prefer not to answer

Follow-up display questions to 1:

Question – IF ANSWERED MICHAEL J. FOX FOUNDATION

Through what Michael J. Fox Foundation platform did you learn about PPMI?

- a. Michael J. Fox Foundation Website
- b. A Michael J. Fox Foundation email
- c. A Michael J. Fox webinar
- d. A Michael J. Fox podcast
- e. A Michael J. Fox publication (i.e., Year in Research, Newsletter, etc)
- q. Other
- r. Not Sure
- s. Prefer not to answer

Question - IF ANSWERED DOCTOR OR OTHER MEDICAL PROFESSIONAL

What type of medical professional told you about PPMI?

- a. Primary care provider
- b. A general neurologist
- c. A neurologist specializing in movement disorders (i.e., a Parkinson's disease specialist)
- d. Another type of physician or healthcare professional
- e. Not Sure
- f. Prefer not to answer

Question – IF ANSWERED ADVOCACY OR PD ORGANIZATION

Through what advocacy or PD organization did you learn about PPMI?

- a. The Michael J. Fox Foundation
- b. Other
- c. Not Sure
- d. Prefer not to answer

Question – IF ANSWERED WEB-BASED CLINICAL TRIALS DIRECTORY

Through what web-based clinical trials directory did you learn about PPMI?

- a. Fox Trial Finder
- b. ClinicalTrials.gov
- c. PDTrials.org
- d. Other

- e. Not Sure
- f. Prefer not to answer

Question – **IF ANSWERED PRINT MATERIALS**

Through what type of print source did you learn about PPMI?

- a. A print newspaper ad
- b. A print newspaper article
- c. A print newsletter ad
- d. A print newsletter article
- e. A print magazine ad
- f. A print magazine article
- g. Other (poster, postcard, etc.)
- h. Not Sure
- i. Prefer not to answer

Question – **IF ANSWERED ONLINE AD and/or ARTICLE**

Where online did you learn about PPMI?

- a. The PPMI website
- b. The Michael J. Fox Foundation website
- c. An internet search (i.e., Google or Bing)
- d. The 23andMe website
- e. TV/Streaming Service
- f. TV/Broadcast
- g. YouTube
- h. Other
- i. Not Sure
- j. Prefer not to answer

Question – **IF ANSWERED SOCIAL MEDIA**

On which social media platform did you learn about PPMI?

- a. Facebook
- b. Instagram
- c. Twitter
- d. Linked In
- e. Reddit
- f. Not Sure
- g. Prefer not to answer

Question – **IF ANSWERED IN-PERSON PD EVENT**

At what kind of PD event did you hear about PPMI?

- a. A Michael J. Fox Foundation event
- t. Other
- u. Not Sure
- v. Prefer not to answer

2. Do you have a connection to Parkinson's disease? (Please select all that apply)

- a. I am a first degree relative of someone with Parkinson's disease (parent, sibling, or child).
- b. I am a second degree relative of someone with Parkinson's disease (grandparents, grandchildren, aunts, uncles, nephews, nieces or half-siblings).
- c. My spouse or partner has Parkinson's disease.
- d. I am friends with someone with Parkinson's disease.
- e. I am a caregiver or care partner of someone with Parkinson's disease.
- f. I was previously diagnosed with Parkinson's disease, but this has been changed by a healthcare professional.

- g. I have a genetic mutation associated with PD but have not been diagnosed with PD.
- h. My work relates to Parkinson's disease.
- i. I do not know anyone with Parkinson's disease, but I want to participate in research.
- j. I have no other connection to Parkinson's disease
- k. Other
- l. Not Sure
- m. Prefer not to answer

33. PPMI Experience (PPMI Non-Complete Survey Questions)

1. What was your motivation for wanting to participate in PPMI?
 - a. Being able to make a positive impact
 - b. Contributing to science
 - c. Gaining education in PD
 - d. Having access to newest treatments and information
 - e. Other
2. Where did you first hear about PPMI?
 - a. Michael J. Fox Foundation (CONDITIONAL - IF 'A' SELECTED, DISPLAY QUESTION i BELOW):
 - i. If from Michael J. Fox Foundation, please choose one of the following:
 1. Michael J. Fox Foundation Website
 2. A Michael J. Fox Foundation email
 3. A Michael J. Fox Webinar
 4. A Michael J. Fox Podcast
 5. A Michael J. Fox Publication
 6. Other
 - b. A doctor or other medical professional
 - c. An advocacy and/or PD organization
 - d. A PD support group
 - e. A family member or friend
 - f. Another PPMI participant
 - g. A web-based clinical trials directory
 - h. A print newspaper, newsletter or magazine I would say to adjust to "Printed Material" (I.e. Newspaper, newsletter, magazine)
 - i. Radio or TV
 - j. Web-based search
 - k. An in-person PD event
 - l. Online Ad
 - m. Online Article
 - n. Social Media
 - o. Other
3. What prevented you from participating/completing questionnaires in the study? (Select all that apply)
 - a. Lack of time/poor timing
 - b. Data privacy concerns
 - c. Health concerns
 - d. Lack of reminders / I forgot
 - e. Previous experience with research study
 - f. Lack of incentive
 - g. Technical issues
 - i. [CONDITIONAL QUESTION – this appears only if they answer "G" above] If technical issues, please provide additional details (select all that apply)
 1. I am using a tablet
 2. I am using a mobile phone
 3. I am using a desktop
 4. I am using a Mac
 5. I am using a PC
 6. I am using Google Chrome
 7. I am using Safari
 - h. Other

4. What would make it easier for you to participate/complete questionnaires? (Select all that apply)
 - a. Knowing how much time would need to be invested
 - b. Understanding how my data is used and shared
 - c. Offering an incentive
 - d. An easier way to sign up
 - e. An easier way to complete surveys
 - f. Other

5. What is your connection to Parkinson's Disease?
 - a. I have been diagnosed with Parkinson's disease.
 - b. I am a first degree relative of someone with Parkinson's disease (parent, sibling, or child).
 - c. I am a second degree relative of someone with Parkinson's disease (grandparents, grandchildren, aunts, uncles, nephews, nieces or half-siblings).
 - d. My spouse or partner has Parkinson's disease.
 - e. I am friends with someone with Parkinson's disease.
 - f. I am a caregiver or care partner of someone with Parkinson's disease.
 - g. I was previously diagnosed with Parkinson's disease but this has been changed by a healthcare professional.
 - h. I have a genetic mutation associated with PD but have not been diagnosed with PD.
 - i. My work relates to Parkinson's disease.
 - j. I do not know anyone with Parkinson's disease but I want to participate in research.
 - k. I have no other connection to Parkinson's disease
 - l. Other

6. Are you willing to be contacted to share more thoughts on PPMI?
 - a. Yes
 - b. No

34. Occupation and Military Service

1. What is your current employment status? **Please select one**
 - a. Employed, working 40 or more hours per week
 - b. Employed, working 1-39 hours per week
 - c. Not employed, looking for work
 - d. Not employed, NOT looking for work
 - e. Retired
 - f. Disabled, not able to work
 - g. None of the above
 - h. Prefer not to answer

2. Which category **best** describes your longest held occupation? **Please select one**
 - a. Management
 - b. Business and Financial Operations
 - c. Computer and Mathematical
 - d. Architecture and Engineering
 - e. Life, Physical, and Social Science
 - f. Community and Social Service
 - g. Legal
 - h. Educational Instruction and Library
 - i. Arts, Design, Entertainment, Sports, and Media
 - j. Healthcare Practitioners and Technical
 - k. Healthcare Support
 - l. Protective Service
 - m. Food Preparation and Serving Related
 - n. Building and Grounds Cleaning and Maintenance Occupations
 - o. Personal Care and Service Occupations
 - p. Sales and Related Occupations
 - q. Office and Administrative Support Occupations
 - r. Farming, Fishing, and Forestry Occupations
 - s. Construction and Extraction Occupations
 - t. Installation, Maintenance, and Repair Occupations
 - u. Production Occupations
 - v. Transportation and Material Moving Occupations
 - w. Military
 - x. None of the above
 - y. Prefer not to answer

3. Have you **ever** served in the Armed Forces, Reserves, National Guard or other uniformed services?
 - a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

Skip Logic: If 3 ≠ a, go to end of survey thank you

Service branch 1:

4. At what age were you when you **first** served in the Armed Forces, Reserves, National Guard or other uniformed services? If you are not sure, please make your best guess.
_____ [Validation Message: Please enter a number between 1 and 99.]

5. What was your first service branch? **Please select one**

- a. US Air Force
- b. US Air Force Reserve
- c. US Air National Guard
- d. US Army
- e. US Army Reserve
- f. US Army National Guard
- g. US Coast Guard
- h. US Coast Guard Reserve
- i. US Marine Corps
- j. US Marine Corps Reserve
- k. US Navy
- l. Navy Reserve
- m. US Space Force
- n. Royal Canadian Navy
- o. Canadian Army
- p. Royal Canadian Air Force
- q. Other
- r. Prefer not to answer

6. Do you currently serve in that branch?
- a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

Skip Logic: If 6 = a, go to 19 (deployment).

7. At what age were you when you stopped serving in that branch? If you are not sure, please make your best guess.

_____ [Validation Message: Please enter a number between 1 and 99.]

8. Did you serve in additional branches of the Armed Forces, Reserves, National Guard or other uniformed services?
- a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

Skip Logic: If 8 ≠ a, skip to 19 (deployment).

Service branch 2:

9. At what age were you when you **next** served in the Armed Forces, Reserves, National Guard or other uniformed services? If you are not sure, please make your best guess.

_____ [Validation Message: Please enter a number between 1 and 99.]

10. What was your service branch? **Please select one**
- a. US Air Force
 - b. US Air Force Reserve

- c. US Air National Guard
- d. US Army
- e. US Army Reserve
- f. US Army National Guard
- g. US Coast Guard
- h. US Coast Guard Reserve
- i. US Marine Corps
- j. US Marine Corps Reserve
- k. US Navy
- l. Navy Reserve
- m. US Space Force
- n. Royal Canadian Navy
- o. Canadian Army
- p. Royal Canadian Air Force
- q. Other
- r. Prefer not to answer

11. Do you currently serve in that branch?

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

Skip Logic: If 11 = a, go to 19 (deployment).

12. At what age were you when you stopped serving in that branch? If you are not sure, please make your best guess.

_____ [Validation Message: Please enter a number between 1 and 99.]

13. Did you serve in additional branches of the Armed Forces, Reserves, National Guard or other uniformed services?

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

Skip Logic: If 13 ≠ a, skip to 19 (deployment).

Service branch 3:

14. At what age were you when you **next** served in the Armed Forces, Reserves, National Guard or other uniformed services? If you are not sure, please make your best guess.

_____ [Validation Message: Please enter a number between 1 and 99.]

15. What was your service branch? **Please select one**

- a. US Air Force
- b. US Air Force Reserve
- c. US Air National Guard
- d. US Army

- e. US Army Reserve
- f. US Army National Guard
- g. US Coast Guard
- h. US Coast Guard Reserve
- i. US Marine Corps
- j. US Marine Corps Reserve
- k. US Navy
- l. Navy Reserve
- m. US Space Force
- n. Royal Canadian Navy
- o. Canadian Army
- p. Royal Canadian Air Force
- q. Other
- r. Prefer not to answer

16. Do you currently serve in that branch of the Armed Forces, Reserves, National Guard or other uniformed services?
- a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

Skip Logic: If 16 = a, go to 19 (deployment).

17. At what age were you when you stopped serving in that branch? If you are not sure, please make your best guess.
_____ [Validation Message: Please enter a number between 1 and 99.]

18. Did you serve in additional branches of the Armed Forces, Reserves, National Guard or other uniformed services?
- a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

Deployment

19. Were you ever deployed at any time during your service?
- a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

End of Survey thank you: Thank you for sharing with PPMI. Please click on SUBMIT to complete this question set.

35. Genetic Testing history

1. Have you previously undergone genetic testing for mutations or variants related to Parkinson's disease? Examples include testing in the LRRK2, GBA (also associated with Gaucher disease), Parkin, Pink1, and/or alpha-synuclein (SNCA) genes.
 - a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

Skip Logic: If 1≠a, go to end of survey thank you.

2. Were you found to have a positive mutation or variant in a gene related to Parkinson's disease?
 - a. Yes
 - b. No
 - c. Not Sure
 - d. Prefer not to answer

3. How did you receive genetic testing? Please select all that apply.
 - a. My doctor ordered genetic testing as part of my clinical care
 - b. I participated in a research study and a copy of the results were returned to me
 - c. I used direct-to-consumer testing that included information on my Parkinson's disease risk (Ex: Ancestry, EasyDNA, 23andMe, etc)
 - d. None of the above
 - e. Prefer not to answer

End of Survey thank you: Thank you for sharing with PPMI. Please click on SUBMIT to complete this question set.

36. Residential location

1. What are the **first 3 numbers/letters** of your zip code or postal code?

[Text Box] [3-CHARACTER. Validation Message: Please enter 3 NUMBERS/LETTERS.]

2. Please describe the area/region you live in. (If you are not sure, please make your best guess.)

- a. City or large metropolitan area
- b. Town or village
- c. Rural
- d. Other
- e. Not sure
- f. Prefer not to answer

End of Survey thank you: Thank you for sharing with PPMI. Please click on SUBMIT to complete this question set.