

Medication Deprescribing and Clinical Research Study Participation

Part of this survey, questions 3-25, was adapted for Fox Insight from the “Revised Patients’ Attitudes Towards Deprescribing (rPATD) Questionnaire”.

Citation:

Reeve, Low, L.-F., Shakib, S., & Hilmer, S. N. (2016). Development and Validation of the Revised Patients’ Attitudes Towards Deprescribing (rPATD) Questionnaire: Versions for Older Adults and Caregivers. *Drugs & Aging*, 33(12), 913–928. <https://doi.org/10.1007/s40266-016-0410-1>

MEDICATION DEPRESCRIBING AND CLINICAL RESEARCH STUDY PARTICIPATION

Intro:

Thank you for taking part in this survey. Your participation in this survey will help us understand how you feel about reducing or stopping a medication under a healthcare professional’s oversight, also known as medication deprescribing. Your answers will also help us understand how you feel about clinical research study participation.

As always, your answers are confidential.

Block 1:

Fox Insight Deprescribing Survey (for PD and Non-PD participants):

Q1: Have you been diagnosed with Parkinson’s disease or Parkinsonism?

- a. Yes
- b. No

Q2: Are you currently taking medications for ANY medical conditions?

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

Skip Logic: If (b. No) is selected for Q1: “Have you been diagnosed with Parkinson’s disease or Parkinsonism?” AND (b. No), (c. Not sure) or (d. Prefer not to answer) is selected for Q2: “Are you currently taking medications for ANY medical conditions?”, skip to End of Survey 2.

Instructions: Choose a single answer for each of the following questions. Please base your answer on your thoughts about all of the medications you currently take, no matter what medical condition or symptom you take them for.							
number	Question	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Prefer not to answer
3.	I spend a lot of money on my medicines.						
4.	Taking my medicines every day is very inconvenient.						
5.	I feel that I am taking a large number of medications.						
6.	I feel that my medicines are a burden to me.						
7.	Sometimes I think I take too many medicines.						
8.	I feel that I may be taking one or more medicines that I no longer need.						
9.	I would like to try stopping one of my medicines to see how I feel without it.						

10.	I would like my doctor to reduce the dose of one or more of my medicines.						
11.	I think one or more of my medicines may not be working.						
12.	I believe one or more of my medicines may be currently giving me side effects.						
13.	I would be reluctant to stop a medicine that I had been taking for a long time.						
14.	If one of my medicines was stopped, I would be worried about missing out on future benefits.						
15.	I get stressed whenever changes are made to my medicines.						
16.	If my doctor recommended stopping a medicine, I would feel that he/she was giving up on me.						
17.	I have had a bad experience when stopping a medicine before.						
18.	I have a good understanding of the reasons I was prescribed each of my medicines.						
19.	I know exactly what medicines I am currently taking, and/or I keep an up-to-date list of my medicines.						
20.	I like to know as much as possible about my medicines.						
21.	I would like to be involved in making decisions about my medicines with my doctors.						
22.	I always ask my doctor, pharmacist, or other healthcare professional if there is something I don't understand about my medicines.						
23.	If my doctor said it was possible, I would be willing to stop one or more of my regular medicines.						
24.	Overall, I am satisfied with my current medicines.						
25.	I would be reluctant to stop a medication if someone other than the physician who prescribed it to me told me to do so.						

Display Logic: If (a. Yes) is selected for Q2: "Are you currently taking medication?"

Q27: Do you currently take medications for Parkinson's disease or Parkinsonism?

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

Display Logic: If (a. Yes) is selected for Q1: "Have you been diagnosed with Parkinson's disease or Parkinsonism?"

Instructions: Choose a single answer for each of the following questions. Please base your answer on your thoughts about medications for **Parkinson's disease (PD) or Parkinsonism** you currently take.

number	Question	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Prefer not to answer
28.	Sometimes I think I take too many PD medicines.						
29.	I feel that I may be taking one or more PD medicines that I no longer need.						
30.	I would like to try stopping one of my PD medicines to see how I feel without it.						
31.	I would like my doctor to reduce the dose of one or more of my PD medicines.						
32.	I believe one or more of my PD medicines may be currently giving me side effects.						
33.	I would be reluctant to stop a PD medicine that I had been taking for a long time.						
34.	My PD doctor knows the most about which medications might interact with my PD or my PD medications.						
35.	If my PD doctor said that avoiding some types of medications might be good for my PD in the long- term, I would make sure that I did not take those medications.						
36.	Slowing down or preventing a worsening in PD motor symptoms is important to me. Examples of motor symptoms are tremor, stiffness, slowness, trouble walking, shuffling gait, rigidity, loss of dexterity, falls, and cramps.						
37.	Slowing down or preventing a worsening in PD non-motor symptoms is important to me. Examples of non-motor symptoms are anxiety/depression, memory loss/dementia/hallucinations, fainting, troubles with constipation or urinating/reflux, pain, and vision problems.						
38.	Which of the following groups of potential PD symptoms would you most like to <u>prevent</u> from experiencing? Please select THREE. <ul style="list-style-type: none"> ○ Anxiety, panic ○ Depression, sadness ○ Hallucinations, delusions, psychosis ○ Forgetfulness, Memory loss, confusion, dementia ○ Urinary urgency, frequent urinating, loss of bladder control ○ Fainting, sweating ○ Sexual dysfunction ○ Constipation, loss of bowel control ○ Blurry vision, trouble reading, double vision ○ Trouble sleeping, insomnia, acting out dreams/nightmares, daytime sleepiness, sleep apnea ○ Pain, fatigue, weight change, heartburn/reflux 						
39.	If you are prescribed a new medication for urinary problems (frequent urinating, loss of urine, urinary urgency), which of the following potential side effects would you like to <u>avoid</u> the <u>most</u> ? Please select THREE. <ul style="list-style-type: none"> ○ Constipation ○ Dry mouth 						

	<ul style="list-style-type: none"> ○ Blurred vision ○ Urinary retention, trouble urinating ○ Headache ○ Nervousness ○ High blood pressure ○ Urinary tract infection ○ Memory or thinking problems, confusion ○ Insomnia ○ Hallucinations ○ Dizziness ○ Trouble walking, falls 	
40.	<p>If you were prescribed a new medication for mood (anxiousness, sadness, anxiety, depression), which of the following potential side effects would you like to <u>avoid</u> the <u>most</u>? Please select THREE.</p> <ul style="list-style-type: none"> ○ Decreased libido or sexual function, abnormal orgasm ○ Constipation or trouble urinating ○ Nausea ○ Dizziness ○ Trouble sleeping, insomnia ○ New or worse tremor ○ Weight loss, loss of appetite ○ Nervousness ○ Memory or thinking problems, confusion ○ Back pain, muscle pain or headache ○ Trouble walking, falls ○ Hallucinations ○ Dry mouth ○ Drowsiness 	
41.	<p>If you were prescribed a new medication for hallucinations, which of the following potential side effects would you like to <u>avoid</u> the <u>most</u>? Please select THREE.</p> <ul style="list-style-type: none"> ○ Lightheadedness with standing/ orthostatic hypotension/fainting ○ Decreased HDL, increased cholesterol level, increased triglyceride level ○ Weight gain, increased appetite ○ Dry mouth ○ Swelling of the feet or legs ○ Drowsiness, fatigue ○ New or worse PD motor symptoms ○ Headache ○ Constipation ○ Memory or thinking problems, confusion ○ Nausea, heartburn 	

Display Logic: If (a. Yes) is selected for Q3: "Are you currently taking medication for Parkinson's disease or Parkinsonism?"

The next set of questions refers to hypothetical/pretend research studies, not actual studies.

Instructions: Please read each study scenario, and then answer the questions that follow.

TRIAL SCENARIO A	
<p>A national research trial will test whether a new medication for Parkinson's disease is safe and effective. The previous studies of this medication have been done in the lab. Scientists do not know if the drug is safe or works in humans. If it works, it will slow down the progression of Parkinson's disease.</p> <p>TYPE OF STUDY: Treatment/drug intervention.</p> <p>Potential risks: We do not know if the drug is safe or works in humans. It has been tested in the lab and looks safe and effective in other animals.</p> <p>Potential benefits: It may slow down or stop Parkinson's disease. It will not reverse it.</p>	
<p>Based on the information above, how likely would you be to participate in the trial? Answer based on your current level of interest, symptoms, and functional ability.</p>	<p>1 Extremely unlikely to enroll 2 Unlikely to enroll 3 Neutral 4 Likely to enroll 5 Extremely likely to enroll</p>
Now rate whether each of the following study design factors would make you more or less likely to participate in this trial. Please check one answer for each option.	
<p>You would be required to undergo DNA or genetic testing. Genetic testing is performed by swabbing the inside of your mouth with a cotton swab. The results will be stored in a research database so we can learn more about genes that might cause PD. The genetic information will be kept anonymous. Please rate whether genetic testing would make you more or less likely to participate in this trial.</p>	<p>1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll</p>
<p>You would be required to have regular blood tests, mostly to make sure you are not having an adverse reaction to the study drug. This involves piercing the skin with a needle and collecting blood in a small tube. Please rate whether regular blood tests would make you more or less likely to participate in this trial.</p>	<p>1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll</p>
<p>You would be required to complete cognitive tests throughout the trial. This involves answering questions, working on puzzles, and doing mental tasks for at least one hour. The test is designed to identify problems with thinking or memory. Please rate whether cognitive tests would make you more or less likely to participate in this trial.</p>	<p>1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll</p>
<p>You would be required to have an MRI scan. This involves receiving an injection of contrast dye in your veins and then lying still and flat on your back in an MRI scanner for up to an hour while pictures of your brain are taken. An MRI scanner leaves about one foot of space above your face. The MRI may show brain disease other than Parkinson's disease. Please rate whether an MRI scan would make you more or less likely to participate in this trial.</p>	<p>1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll</p>
<p>You would be required to have a DaTscan. A DaTscan is a type of brain scan that measures the amount of dopamine that your brain is producing. You will receive a small amount of a radioactive drug, or tracer, and then lie</p>	<p>1 Much less likely to enroll 2 Less likely to enroll</p>

<p>on your back for about an hour while a specialized camera takes pictures of your brain. A research team may use this test to see if the results differ from person to person, or, to see if this test changes over time. Please rate whether a DaTscan would make you more or less likely to participate in this trial.</p>	<p>3 Neutral 4 More likely to enroll 5 Much more likely to enroll</p>
<p>You would be required to undergo at least one lumbar puncture, also known as a spinal tap. During a lumbar puncture, a needle is inserted into your lower back, and a sample of spinal fluid is removed. The procedure takes 45 minutes, and you may have back pain or headache afterwards. Please rate whether a lumbar puncture would make you more or less likely to participate in this trial.</p>	<p>1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll</p>
<p>The trial has study visits that last more than 3 hours each time. Please rate whether 3-hour long study visits would make you more or less likely to participate in this trial.</p>	<p>1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll</p>
<p>The trial has in-person study visits that occur every four to six weeks for at least one year. Please rate whether these in-person study visits would make you more or less likely to participate in this trial.</p>	<p>1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll</p>
<p>You would have a 25% chance of getting the fake/placebo treatment. Please rate whether the chances of getting a fake/placebo treatment would make you more or less likely to participate in this trial.</p>	<p>1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll</p>
<p>You would have a 50% chance of getting the fake/placebo treatment. Please rate whether the chances of getting a fake/placebo treatment would make you more or less likely to participate in this trial.</p>	<p>1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll</p>
<p>You would receive financial compensation for all study visits, imaging and procedures. Please rate whether financial compensation would make you more or less likely to participate in this trial.</p>	<p>1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll</p>
<p>You are required to have a care partner, friend or family member come with you to every study visit. Please rate whether this requirement would make you more or less likely to participate in this trial.</p>	<p>1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll</p>

	5 Much more likely to enroll
The trial provides door-to-door transportation to and from all study visits. Please rate whether provided transportation would make you more or less likely to participate in this trial.	1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll
Only two of the study visits have to be done in person. The rest can be done in your home at a time and day of the week you choose, including weekends or evenings. Please rate whether these study visits would make you more or less likely to participate in this trial.	1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll
The study medication may cause a stroke in up to 10 out of every 100 people who take it. Please rate whether the study medication would make you more or less likely to participate in this trial.	1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll
The study medication may cause earlier death in up to 10 out of every 100 people who take it. Please rate whether the study medication would make you more or less likely to participate in this trial.	1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll
The study medication may cause pain or numbness in the feet in up to 10 out of every 100 people who take it. Please rate whether the study medication would make you more or less likely to participate in this trial.	1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll
The study medication may slow the progression of your Parkinson's disease by 6 months. Please rate whether the study medication would make you more or less likely to participate in this trial.	1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll
The study medication may slow the progression of your Parkinson's disease by 1 year. Please rate whether the study medication would make you more or less likely to participate in this trial.	1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll
The study medication may slow the progression of your Parkinson's disease by 3 years.	1 Much less likely to enroll

Please rate whether the study medication would make you more or less likely to participate in this trial.	2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll
The study medication is a pill that you will take once a day. Please rate whether the study medication would make you more or less likely to participate in this trial.	1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll
The study medication is an intravenous infusion (medicine given in the vein). You would have to go to a hospital or doctor's office to get it once a month. Please rate whether study medication would make you more or less likely to participate in this trial.	1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll

Display Logic: If (a. Yes) is selected for Q1: "Have you been diagnosed with Parkinson's disease or Parkinsonism?"

The next set of questions refer to another hypothetical/pretend research study, not an actual study.

Instructions: Please read the study scenario, and then answer the questions that follow.

<p>TRIAL SCENARIO B</p> <p>A national research trial will test whether a new care model for Parkinson disease is safe and effective. There are no extra treatments or study drugs involved in this study. Instead, the primary intervention would be for you to avoid taking certain medications.</p> <p>The medications that you would be asked to avoid are ones that scientists think may worsen thinking and memory over time in people with Parkinson disease. These medications are not usually used to treat motor symptoms in PD, but they are sometimes used to treat other medical conditions. Every medication that you will be asked to avoid has an alternative treatment option, so you are not being asked to give up treatment entirely for any symptom or condition.</p> <p>TYPE OF STUDY: Intervention</p> <p>POTENTIAL RISKS: We do not know if this intervention is safe or works in persons living with PD. This care model has been tested in other adults with other medical conditions, and it has been helpful in some of them but not in others. You may get tired of or annoyed by study tests (surveys, blood draws, brain scans, etc.). You may also find out you are very likely to develop memory or thinking problems in the future, even though you feel fine now.</p> <p>POTENTIAL BENEFITS: The intervention may reduce or delay your chances of developing thinking difficulties, memory loss, dementia, or hallucinations.</p>	
Based on the information above, how likely would you be to participate in the trial? Answer based on your current level of interest, symptoms, and functional ability.	1 Extremely unlikely to enroll 2 Unlikely to enroll 3 Neutral 4 Likely to enroll 5 Extremely likely to enroll

Now rate whether each of the following study design factors would make you more or less likely to participate in this trial. Please check one answer for each option.	
<p>You would be required to undergo DNA or genetic testing. Genetic testing is performed by swabbing the inside of your mouth with a cotton swab. The results will be stored in a research database so we can learn more about genes that might cause PD. The genetic information will be kept anonymous.</p> <p>Please rate whether genetic testing would make you more or less likely to participate in this trial.</p>	<p>1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll</p>
<p>You would be required to have regular blood tests, mostly to make sure you are not having an adverse reaction to the study drug. This involves piercing the skin with a needle and collecting blood in a small tube.</p> <p>Please rate whether regular blood tests would make you more or less likely to participate in this trial.</p>	<p>1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll</p>
<p>You would be required to complete cognitive tests throughout the trial. This involves answering questions, working on puzzles, and doing mental tasks for at least one hour. The test is designed to identify problems with thinking or memory.</p> <p>Please rate whether cognitive tests would make you more or less likely to participate in this trial.</p>	<p>1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll</p>
<p>You would be required to have an MRI scan. This involves receiving an injection of contrast dye in your veins and then lying still and flat on your back in an MRI scanner for up to an hour while pictures of your brain are taken. An MRI scanner leaves about one foot of space above your face. The MRI may show brain disease other than Parkinson's disease.</p> <p>Please rate whether an MRI scan would make you more or less likely to participate in this trial.</p>	<p>1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll</p>
<p>You would be required to have a DaTscan. A DaTscan is a type of brain scan that measures the amount of dopamine that your brain is producing. You will receive a small amount of a radioactive drug, or tracer, and then lie on your back for about an hour while a specialized camera takes pictures of your brain. A research team may use this test to see if the results differ from person to person, or, to see if this test changes over time.</p> <p>Please rate whether a DaTscan would make you more or less likely to participate in this trial.</p>	<p>1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll</p>
<p>You would be required to undergo at least one lumbar puncture, also known as a spinal tap. During a lumbar puncture, a needle is inserted into your lower back, and a sample of spinal fluid is removed. The procedure takes 45 minutes, and you may have back pain or headache afterwards.</p> <p>Please rate whether a lumbar puncture would make you more or less likely to participate in this trial.</p>	<p>1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll</p>
<p>The trial has study visits that last more than 3 hours each time.</p> <p>Please rate whether 3-hour long study visits would make you more or less likely to participate in this trial.</p>	<p>1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll</p>

	5 Much more likely to enroll
The trial has in-person study visits that occur every four to six weeks, for at least one year. Please rate whether these in-person study visits would make you more or less likely to participate in this trial.	1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll
You would receive financial compensation for all study visits, imaging and procedures. Please rate whether financial compensation would make you more or less likely to participate in this trial.	1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll
You are required to have a care partner, friend or family member come with you to every study visit. Please rate whether this requirement would make you more or less likely to participate in this trial.	1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll
The trial provides door-to-door transportation to and from all study visits. Please rate whether provided transportation would make you more or less likely to participate in this trial.	1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll
Only two of the study visits have to be done in person. The rest can be done in your home at a time and day of the week you choose, including weekends or evenings. Please rate whether these study visits would make you more or less likely to participate in this trial.	1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll
As part of your participation in the intervention, PD and medication specialists will review all of your medications. If your other doctors have prescribed you a medication that may not be good for your PD in the long term, the specialists will contact your other doctors to let them know, and they will work together to identify an alternative for you to take. Please rate whether this medication review would make you more or less likely to participate in this trial.	1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll
As part of the intervention, you will be required to tell each of your doctors if a medication they have prescribed or want to prescribe you may not be good for your PD in the long term. You will show them the list of alternatives and ask to be prescribed one of the alternatives instead. Please rate whether this required communication make you more or less likely to participate in this trial.	1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll
The intervention may slow the progression of thinking or memory problems or delay the onset of dementia by <u>6 months</u> .	1 Much less likely to enroll

Please rate whether the intervention would make you more or less likely to participate in this trial.	2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll
The intervention may slow the progression of thinking or memory problems or delay the onset of dementia by <u>1 year</u> . Please rate whether the intervention would make you more or less likely to participate in this trial.	1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll
The intervention may slow the progression of thinking or memory problems or delay the onset of dementia by <u>3 years</u> . Please rate whether the intervention would make you more or less likely to participate in this trial.	1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll
Because of your participation in the study, you may have to change 25% of the medications you currently take for non-motor PD symptoms or other medical conditions. These could include medications that you currently take for sleep problems, anxiety, depression, frequent urination or bladder leakage, constipation, diarrhea, seasonal allergies/hay fever, or vertigo. Please rate whether medication changes would make you more or less likely to participate in this trial.	1 Much less likely to enroll 2 Less likely to enroll 3 Neutral 4 More likely to enroll 5 Much more likely to enroll

Display Logic: If (a. Yes) is selected for Q1: “Have you been diagnosed with Parkinson’s disease?”

End of Survey 1:

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

End of Survey 2:

Thank you for participating in Fox Insight. This survey is currently only collecting responses from people who are currently taking medication or have been diagnosed with Parkinson’s disease. We appreciate your interest in sharing your experiences. **Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.**