Views and **I**nsigh**T**s **A**bout **L**umbar Punctures in **P**arkinson's **D**isease (VITAL-PD)

Please answer the following questions about lumbar punctures (also known as spinal taps). A lumbar puncture is a medical test. A clinician numbs the skin on the lower back and inserts a needle into the lower back to collect cerebrospinal fluid (CSF), the fluid that bathes the brain and spinal cord. CSF can be tested to confirm the diagnosis of Parkinson's Disease (PD) or another health condition. Clinicians may also deliver medication into the CSF via a lumbar puncture.

There are many types of clinicians who perform lumbar punctures: neurologists, anesthesiologists, radiologists, nurse practitioners, physician assistants, students. The procedure typically takes place in a clinic room, not in the operating room, and often takes less than an hour to complete. Patients either lay on their side or lean forward while sitting. Compared to a needle used to draw blood, the needle used for lumbar punctures is skinnier, but longer in order to reach the CSF space. The four most common side effects related to a lumbar puncture are back pain, headache, bruising at the insertion site, and infection at the insertion site.

Your participation in this survey will help us understand how people with PD experience and understand lumbar punctures. There are no right or wrong answers. **You can complete this survey even if you have never had a lumbar puncture.** We will use this information to improve education about lumbar punctures for people with PD.

Section 1: Your Experience in Research

Multiple choice, multiple answer, required

1. Please indicate the types of scientific research activities that you have participated in. Please select all that apply.

a. An in-person observational research study (A study without a drug, surgery, or device intervention.)

b. A research study involving a medication taken by mouth, infused by vein, or injected into the skin

c. A research study involving surgery

d. A research study involving a wearable or external device such as a smartwatch or Fitbit

e. A research study involving online surveys

f. I have not participated in any research

g. Prefer not to answer

Dependent matrix, single answer, required

2. For each of the following research activities you selected, did you undergo a lumbar puncture?

	No	Yes, one lumbar puncture	Yes, more than one lumbar puncture
An in-person observational research study	☐	☐	☐
A research study involving a medication taken by mouth, infused by vein, or injected into the skin	☐	☐	☐
A research study involving surgery	☐	☐	☐

Display logic: If (a., b., or c.) is selected from "Please indicate the types of scientific research activities …" *For answer choices selected from a., b., or c. in the previous question, corresponding item will be displayed in this matrix.*

Section 2: Your Knowledge and Understanding of Lumbar Punctures

Multiple choice, single answer, required

3. How familiar are you with the procedure known as a "lumbar puncture"?

    a. Not at all familiar/Never heard of it

    b. Slightly familiar

    c. Moderately familiar

    d. Very familiar

    e. Prefer not to answer

Multiple choice, multiple answer, required

4. How did you learn about lumbar punctures? Please select all that apply.

a. Clinician

b. Research team

c. Internet

d. Friends/family

e. Personal experience

f. Seen them done

g. I have never been informed about lumbar punctures before

h. Other, please describe: _____ *[100 character limit]*

i. Prefer not to answer

Multiple choice, single answer, required

5. A large study of patients with PD was conducted involving lumbar punctures. In this study, what do you estimate was the percentage of people who experienced **any side effects** as a direct result of the lumbar puncture? Please select your best guess.

    a. Less than 20%

    b. 21-40%

    c. 41-60%

    d. 61-80 %

    e. Greater than 80%

    f. Prefer not to answer

Multiple choice, single answer, required

6. A large study of patients with PD was conducted involving lumbar punctures. In this study, what do you estimate was the percentage of people who experienced a **headache** as a direct result of the lumbar puncture? Please select your best guess.

    a. Less than 20%

    b. 21-40%

    c. 41-60%

    d. 61-80 %

    e. Greater than 80%

    f. Prefer not to answer

Section 3: Your Attitudes and Perceptions of Lumbar Punctures

Multiple choice, single answer, required

7. How would you describe your overall attitude toward lumbar punctures?

    a. Very negative

    b. Somewhat negative

    c. Neutral

    d. Somewhat positive

    e. Very positive

    f. Prefer not to answer

Multiple choice, multiple answer, required

8. Regardless of whether you've had a lumbar puncture before, what aspects of the procedure are **most** concerning to you? Please select all that apply.

a. Fear of needles

b. Fear of clinician not being experienced enough

c. Pain/discomfort

d. Fear of temporary side effects

e. Fear of permanent damage or paralysis

f. Lack of information

g. Anxiety about results

h. I am not sure why I need it/I feel like it is not necessary

i. Other, please describe: _____ *[100 character limit]*

j. Prefer not to answer

Multiple choice, multiple answer, required

9. PD is diagnosed by listening to patients and performing a detailed neurological examination. In some cases, we need a test to support the diagnosis of PD. All the tests below may be used to help detect PD.

   If you needed a test to confirm your diagnosis of PD today and insurance/cost was not a factor, which of the following confirmatory tests would you consider undergoing? Please select all that apply.

   a. **Lumbar puncture:** The CSF is tested for a misfolded protein called alpha-synuclein, one of the main markers of problems in the brain in PD.

   b. **DaT Scan (dopamine transporter scan):** A low dose of a radioactive tracer is injected into the vein. After about four hours of waiting in the hospital, a special camera is used to detect levels of dopamine use in the brain. Reduced dopamine activity is an indicator of PD.

   c. **Skin biopsy:** After numbing the skin, three small samples (not requiring stiches) are taken from the lower thigh, upper leg, and shoulder. Nerve fibers in the skin are tested

for the presence of alpha-synuclein, one of the main markers of problems in the brain in PD.

d. None of the above

e. Prefer not to answer

Matrix, multiple answer, required

10. Please indicate your level of agreement with the following statements about lumbar punctures:

	Strongly disagree	**Slightly disagree**	**Neutral**	**Slightly agree**	**Strongly agree**	**Prefer not to answer**
I believe lumbar punctures are safe.						
I am concerned about pain during the procedure.						
I am concerned about possible side effects.						
I am concerned that I will have to take days off following the lumbar punctures.						
I trust a qualified clinician to perform the procedure safely.						
I would be willing to undergo a						

lumbar puncture if recommended by my clinician.						
I would be willing to undergo one lumbar puncture if needed for a research study.						
I would be willing to undergo multiple lumbar punctures if needed for a research study.						
I would be willing to undergo a lumbar puncture if needed to help diagnose PD.						
I would be willing to undergo a lumbar puncture if needed to administer a study drug.						
I feel adequately informed about the risks and benefits of lumbar puncture.						

Section 4: Your Experience with Lumbar Punctures

Multiple choice, single answer, required

11. Have you ever had a lumbar puncture for any reason?

    a. Yes, one

    b. Yes, multiple

    c. No

    d. Not sure

    e. Prefer not to answer

Skip logic: If (a. Yes or b. Yes, multiple) is NOT selected for "Have you ever had a lumbar puncture for any reason?", skip to "Have you been asked to have a lumbar puncture and chosen not to?"

For questions 12-18, the following will appear at the top of the page: If you've had multiple lumbar punctures, please consider your first/earliest lumbar puncture when answering this question.

Multiple choice, single answer, required

12. Who conducted the procedure?

    a. Neurologist

    b. Anesthesiologist

    c. Radiologist

    d. Nurse practitioner

    e. Physician assistant

f. Resident or fellow

g. Medical student

h. Other clinician

i. Not sure

j. Prefer not to answer

Multiple choice, single answer, required

13. How did you feel about the lumbar puncture **prior** to the procedure?

a. Very negative

b. Somewhat negative

c. Neutral

d. Somewhat positive

e. Very positive

f. Prefer not to answer

Multiple choice, multiple answer, required

14. What were your worries about the lumbar puncture prior to the procedure? (Select all that apply)

a. Pain

b. Discomfort

c. Long procedure

d. Side effects

e. Clinician would not explain it well

f. Clinician would not perform it well

g. I was not worried

h. Other, please describe: _____ *[100 character limit]*

i. Prefer not to answer

Multiple choice, single answer, required

15. How did the experience with the lumbar puncture compare to your expectations?

a. Worse

b. Somewhat worse

c. Neutral

d. Somewhat better

e. Better

f. Prefer not to answer

Multiple choice, multiple answer, required

16. Why was your experience with the lumbar puncture worse or somewhat worse compared to your expectations? Please select all that apply.

a. More pain than expected

b. More discomfort than expected

c. Longer procedure than expected

d. Side effects were more severe than expected

e. Side effects persisted longer than expected

f. Clinician did not explain it well

g. Clinician did not perform it well

h. Other, please describe: _____ *[100 character limit]*

i. Prefer not to answer

Display logic: if (a. Worse or b. Somewhat worse) is selected for "How did the experience with the lumbar puncture compare to your expectations?"

Multiple choice, multiple answer, required

17. Why was your experience with the lumbar puncture better or somewhat better compared to your expectations? Please select all that apply.

a. Less pain than expected

b. Less discomfort than expected

c. Quicker procedure than expected

d. No side effects experienced

e. Side effects were milder than expected

f. Side effects went away quicker than expected

g. Clinician explained it well

h. Clinician performed it well

i. Other: _____ *[100 character limit]*

j. Prefer not to answer

Display logic: if (d. somewhat better or e. better) is selected for "How did the experience with the lumbar puncture compare to your expectations?"

Multiple choice, multiple answer, required

18. What could have improved your experience? Please select all that apply.

    a. More information beforehand from sources such as pamphlets, the internet or friends

    b. Clinician explained it better beforehand

    c. Clinician performed the procedure better

    d. Clinician reviewed my records about my overall condition and health prior to the procedure

    e. Clinician evaluated my PD and health prior to the procedure

    f. Better pain management

    g. Emotional support

    h. Shorter wait time

    i. Shorter procedure time

    j. Better relationship with the clinician performing the procedure

    k. Other, please specify: _____ *[100 character limit]*

    l. Prefer not to answer

Multiple choice, single answer, required

19. Have you been asked to have a lumbar puncture and chosen not to?

    a. Yes

    b. No

    c. Not sure

    d. Prefer not to answer

Multiple choice, multiple answer, required

20. When deciding whether to have a lumbar puncture, which of the following would be helpful in improving your understanding and reducing your anxiety about the procedure? Please select all that apply.

    a. Pamphlet or flyer

    b. Instructional video

    c. People sharing their experience

    d. Detailed explanation from the clinician performing the lumbar puncture

    e. Other, please specify: _____ *[100 character limit]*

    f. Prefer not to answer

Section 5: Open-Ended

Shown at the top of each question page: **For this question, please do not provide any information that may contain personal identifying information in your answers. This includes names of people or places (e.g. the name of a clinic, hospital, or business), any part of an address, phone numbers, or specific dates.**

Open text, not required

21. Do you have any remaining concerns or questions about lumbar punctures you haven't already shared? If so, please specify. *[500 character limit]*

Open text, not required

22. Is there anything else you would like to share about your thoughts or experiences with lumbar punctures you haven't already shared? If so, please specify. *[500 character limit]*

<u>End of survey thank you:</u>

Thank you for taking part in this survey. Your answers will help us learn more about attitudes and experiences of lumbar punctures in people with PD. **Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.**