Cannabis Use in PD

Q1 Thank you for your interest in sharing experiences with cannabis (marijuana) use. You are invited to participate if you have taken cannabis since being diagnosed with Parkinson's disease (PD).

Before completing the survey, there are some important things that you need to know. As of January 2020, 33 US states and Guam, Puerto Rico, and U.S. Virgin Islands have passed legislation allowing the use of marijuana-based products for medical purposes. However, the authorized medical conditions, formulations, and patient and physician requirements are different in each state. Due to the nature of this research, this study is covered by a Certificate of Confidentiality, https://grants.nih.gov/policy/humansubjects/coc.htm, from the National Institutes of Health. This means that the researchers cannot release or use information, documents, or samples that may identify you in any action or suit unless you say it is okay. They also cannot provide them as evidence unless you have agreed. This protection includes federal, state, or local civil, criminal, administrative, legislative, or other proceedings.

The Certificate CANNOT BE USED to stop a sponsoring United States federal or state government agency from checking records or evaluating programs. The Certificate also DOES NOT prevent your information from being used for other research if allowed by federal regulations. The Certificate of Confidentiality also DOES NOT prevent you from willingly releasing information about your involvement in this research.

Q2 Acknowledgement of Certificate of Confidentiality (CoC)

○ I agree

○ I do not agree

Skip To: End of Block If Q2 = I do not agree

Q3 Cannabis (marijuana) is made up of many chemicals, but the research team is specifically interested in:
- **Tetrahydrocannabinol (THC)** - makes people feel "high" (euphoria, intoxicated, etc.)
- **Cannabidiol (CBD)** - does **not** make people feel "high."

Cannabis products can be classified according to the relative amounts of THC and CBD in them. We would like to know which type of cannabis product with which you have the most

experience, as well as the benefits and side effects you experienced with this product. If you are taking cannabis, please look at the package or label to decide which type it is.

- **High CBD, low THC** - is usually purchased from a dispensary and is supposed to give you more effects from the CBD than the THC, so that you do not get intoxicated, or "high". This is different from hemp because hemp has less than 0.3% THC. Products in this category also include CBD oil if purchased at a cannabis dispensary. The product label may say "cannabis-infused".
- **High THC, low/no/unknown CBD** - is usually purchased from a dispensary and is supposed to have enough THC to cause you to feel some "high". The product label may say "cannabis-infused".
- **Similar amounts of THC and CBD** - is usually purchased from a dispensary and is supposed to give you more mild effects of THC along with CBD, with less of a "high". The product label may say "cannabis-infused".
- **Hemp** - is from a cannabis plant, is high in CBD and is supposed to have less than 0.3% THC. Because it has such low THC it is sold outside of cannabis dispensaries: online and in a variety of stores. This category includes many CBD oil products. The product may not even have CBD anywhere on the label, but if it is hemp then it is mostly CBD, and the mg of hemp, for the purposes of this survey, is the same as the mg of CBD. The product label may say "CBD-infused" or "hemp-infused.

Usually cannabis products with more than 0.3% THC are bought from a dispensary, but some people grow their own cannabis plants, and some may get cannabis from unsanctioned sources.

We ask you fill out this survey regarding the type of cannabis (marijuana) product you have used THE MOST. Even if you do not know which type you taken, we are still interested in your experience. Participation in this survey is optional; if you wish to exit the survey at any time during completion, you may do so and it will not affect your enrollment in Fox Insight.

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Q4 Who is filling out this survey?

○ Person with PD

○ Caregiver (on behalf of person with PD)

○ Person with PD and caregiver in equal proportion

Q5 Are you filling out this survey about cannabis you are taking now or have taken in the past?

○ Now

○ Not now, but less than 1 year ago

○ More than 1 year ago

Q6 What type of cannabis do/did you use most frequently?

○ High CBD/low THC is usually purchased from a dispensary and is supposed to give you more effects from the CBD than the THC, so that you do not get intoxicated, or "high". This is different from hemp because hemp has <0.3% THC. Products in this category also include CBD oil if purchased at a cannabis dispensary. The product label may say "cannabis-infused".

○ High THC/low/no/unknown CBD is usually purchased from a dispensary and is supposed to have enough THC to cause you to feel some "high". The product label may say "cannabis-infused".

○ Similar amounts of CBD and THC is usually purchased from a dispensary and is supposed to give you more mild effects of THC along with CBD, with less of a "high". The product label may say "cannabis-infused".

○ Hemp is from a cannabis plant, is high in CBD and is supposed to have <0.3% THC. Because it has such low THC it is sold outside of cannabis dispensaries: online and in a variety of stores. This category includes many CBD oil products. The product may not even have CBD anywhere on the label, but if it is hemp then it is mostly CBD, and the mg of hemp, for the purposes of this survey, is the same as the mg of CBD. The product label may say "CBD-infused" or "hemp-infused".

○ Don't know

Q7 If you use/used particular cannabis products, please...

○ List their brand names here:

_____

○ Don't know the brand name

Q8 On the days you take/took **THC** products, how much **THC** do/did you take <u>total per day</u> on average?

○ Up to 5 mg

○ 6 - 50 mg

○ More than 50 mg

○ Don't know

○ None, or not applicable, because I use/used hemp

Q9 On the days you take/took **CBD** products, how much **CBD** do/did you take <u>total per day</u> on average?

○ None

○ Up to 5 mg

○ 6 - 50 mg

○ 51 - 200 mg

○ 201 - 600 mg

○ More than 600 mg

○ Don't know

- -

Q10 How do you know how much CBD and THC is in the cannabis product that you take/took? (Select all that apply)

☐ I have the package and the amounts are on the label

☐ A dispensary worker told me the product had more or less of CBD compared to THC

☐ I don't know how much I took

☐ Other: _____

Q11 How do/did you usually take this cannabis product? (Select all that apply)

☐   Smoke/combustion (cigarette, pipe)

☐   Vape (vaporizer/vape pen)

☐   Swallow: food (edible: gummy, chocolate bar, etc.)

☐   Swallow: drink (beverage)

☐   Swallow: oil

☐   Sublingual/tincture

☐   Apply to skin (oil, lotion, cream)

☐   Patch

☐   Suppository

Q12 How <u>often</u> do/did you take this type of cannabis?

    ◯ Less than once a month

    ◯ Less than 1 time a week, but at least once/month

    ◯ Not daily, but more than 1 time/week

    ◯ 1 time a day

    ◯ 2-3 times a day

    ◯ More than 3 times a day

Q13 How <u>long</u> have you taken or did you take this type of cannabis, total?

    ◯ Less than 1 month

    ◯ 1 - 6 months

    ◯ 7 months – 1 year

    ◯ More than 1 year

Q14 Please check the effect that this type of cannabis has/had on:

	I have **NOT HAD** this symptom	This symptom **STARTED WITH** cannabis	Had symptom; cannabis made it **MARKEDLY WORSE**	Had symptom; cannabis made it **MILDLY WORSE**	Had symptom; cannabis had **NO EFFECT** on this symptom	Had symptom; cannabis made it **MILDLY BETTER**	Had symptom; cannabis made it **MARKEDLY BETTER**
Tremor	○	○	○	○	○	○	○
Slow movement in general	○	○	○	○	○	○	○
Stiffness	○	○	○	○	○	○	○
Balance problems	○	○	○	○	○	○	○
Dyskinesia (extra movement from levodopa)	○	○	○	○	○	○	○
Dystonia (sustained muscle contraction of foot/leg or hand/arm)	○	○	○	○	○	○	○
Muscle cramps	○	○	○	○	○	○	○
Freezing (your foot or feet won't move, usually occurs when you start to walk or when turning)	○	○	○	○	○	○	○

Thinking or memory problem	○	○	○	○	○	○	○
Hallucinations	○	○	○	○	○	○	○
Depression	○	○	○	○	○	○	○
Anxiety	○	○	○	○	○	○	○
Agitation	○	○	○	○	○	○	○
Apathy (lack of interest or motivation)	○	○	○	○	○	○	○
Fatigue	○	○	○	○	○	○	○
Sleep problems at night	○	○	○	○	○	○	○
Acting out dreams	○	○	○	○	○	○	○
Daytime sleepiness	○	○	○	○	○	○	○
Spine pain, low back or neck	○	○	○	○	○	○	○
Muscle or arthritis pain (other than spine pain)	○	○	○	○	○	○	○
Any other pain	○	○	○	○	○	○	○
Headache	○	○	○	○	○	○	○
Bladder problems	○	○	○	○	○	○	○

Sexual dysfunction	○	○	○	○	○	○	○
Constipation	○	○	○	○	○	○	○
Diarrhea	○	○	○	○	○	○	○
Nausea	○	○	○	○	○	○	○
Dizziness	○	○	○	○	○	○	○
Decreased appetite or weight	○	○	○	○	○	○	○
Increased appetite or weight	○	○	○	○	○	○	○
Liver problems	○	○	○	○	○	○	○
Dry mouth	○	○	○	○	○	○	○
Drooling	○	○	○	○	○	○	○
Increased heart rate	○	○	○	○	○	○	○

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Q15 Please check the effect that this type of cannabis has/had on:

	Cannabis made it **MARKEDLY WORSE**	Cannabis made it **MILDLY WORSE**	Cannabis had **NO EFFECT**	Cannabis made it **MILDLY BETTER**	Cannabis made it **MARKEDLY BETTER**
Ability to perform complicated daily activities (such as managing medications, paying bills, etc.)	○	○	○	○	○
Ability to perform basic daily activities (such as dressing, bathing, etc.)	○	○	○	○	○

Q16 Have you taken a different type of cannabis in the past and stopped it due to negative side effects?

○ Yes

○ No

Q17 Have you discussed the use of cannabis with any of your physicians?

○ Yes

○ No

Q18 What would you consider to be the primary purpose of your cannabis use?

○ Medicinal

○ Recreational

○ Both

⤨

Q19 Do you feel that using cannabis has caused you to change how much <u>prescription</u> medication you take for the below conditions?

	No change	Increased	Decreased	Stopped	Not applicable (not taking any prescription medication for this)
Tremor, slowness, stiffness	○	○	○	○	○
Sleep	○	○	○	○	○
Pain	○	○	○	○	○
Depression	○	○	○	○	○
Anxiety	○	○	○	○	○
Hallucinations	○	○	○	○	○

Q20 MJFF is collaborating with the Parkinson's Foundation to explore related research questions in this area. Have you recently completed a survey on cannabis use and Parkinson's, distributed by the Parkinson's Foundation (or PF representative)?

○ Yes

○ No

Q21. This is the last page of the survey. If you want to review or change any of your answers please click the back arrow below. If you are satisfied with all your answers click the forward arrow below and you will have submitted your answers.

End of Block: Survey