

1 **Supplementary File**

2 **Supplementary Table S1**

	Currently taking medication	Took medication in the past	Never taken medication
Total	426	149	305
Caffeine	64	13	19
%	13.1	8.0	5.9
Standardised residual (a)	2.3	-0.7	-2.3
Cannabidiol	120	38	62
%	24.5	23.5	19.1
standardised residual	0.9	0.3	-1.3
Cannabis	76	21	45
%	15.6	13.0	13.9
Standardised residual	0.6	-0.5	-0.3
Cocaine	8	3	3
%	1.6	1.9	0.9
Standardised residual	0.4	0.4	-0.8
Amphetamine	7	2	0
%	1.4	1.2	0.0
Standardised residual	1.2	0.4	-1.7
MDMA	4	2	2
%	0.8	1.2	0.6
Standardised residual	0.0	0.6	-0.4
Ketamine	3	4	0
%	0.6	2.5	0.0
Standardised residual (b)	-0.3	2.6	-1.5
Psychedelics	4	3	3
%	0.8	1.9	0.9
Standardised residual	-0.5	1.0	-0.2

3
4 (a) Chi-square 12.110 (d.f.2) p = 0.002

5 (b) Chi-square 9.348 (d.f. 2) p =0.009

6 **Supplementary Table 1:** Comparison of frequency of legal and illicit substances use group by medication status (current, in
7 the past only, and never). Frequencies were compared with Chi-square and those which were significant have been bolded.

8

9 **Abridged survey with relevant questions**

10 **0 Consent**

11

12 **0.1** Based on the KCL REC information above, please click "agree" or "disagree" below to provide
13 your consent to participate in this survey: [agree, disagree]

14 Welcome to the Patients' perspectives on illness, treatment and self-management in functional
15 neurological disorder: a web-based questionnaire study.

16

17 There are inadequate treatments for the majority of people who suffer with functional
18 neurological disorders (FND). Because of this, there is an incentive for us, as researchers, to
19 learn about your experiences of living with symptoms of FND and how you might have tried to
20 deal with these symptoms.

21

22 The purpose of this survey is to help us better understand people's perceptions and experiences
23 of living with functional neurological disorders (FND), as well as how people with FND manage
24 their symptoms, which might provide clues for future treatment developments. Your responses
25 to this questionnaire could help to steer future research into treatment options for FND.

26

27 The study is being conducted by researchers at the Institute of Psychiatry, Psychology and
28 Neuroscience with the approval of King's College London Research Ethics Committee.

29

30 **1 Demographics**

31

32 This section will ask some basic demographic questions that will help us understand a little more about
33 you, your history and experience with FND.

34

35 **1.1** Please tell us your gender: [male, female, other, prefer not to say]

36 **1.2** What is your country of residence? [dropdown]

37 **1.3** What is the year of your birth? [dropdown]

38

39 **2 Diagnosis and symptoms**

40

41 In this section, we'd like to ask you some specific questions about your condition.

42

43 **2.1** Have you been diagnosed with functional neurological disorder by a medical
44 professional? [yes, no]

45 **2.2** [if yes to above] Who was it who diagnosed your functional neurological disorder?
46 [psychiatrist, neurologist, neuropsychiatrist, another type of doctor]

47 **2.3** What was the approximate year that you experienced your first symptoms of FND?
48 [date text]

49

50 **2.4** What was the approximate year that you were diagnosed with FND? [date text]

51

52 **3 Management**

53 In this section, we would like to know about your experiences with different types of
54 medications, treatments and self-help strategies for your symptoms. Reminder: your answers
55 will remain confidential, please answer to the best of your ability.

56

57 **3.1** Have you ever undertaken any of the following to help with your FND symptoms?
58 [yes currently, yes in the past, no]

59

- Standard exercise (walking/swimming/running/gym/cycling etc)

- 60 • Alternative exercise (e.g. yoga, Tai Chi, Pilates etc)
- 61 • Managing pain (e.g. non-prescription painkillers, local heat application, TENS)
- 62 • Nutritional supplements (e.g. Vitamin D, CoQ10, B Vitamins, Omega3, Whey
- 63 Protein, Magnesium)
- 64 • Sleep (e.g., sleeping more or less than usual)
- 65 • Relaxation (breath awareness meditation, 3-2-1 Sleep meditation, self-massage)
- 66 • Avoidance (e.g., trying not to see people, go out or avoiding specific
- 67 situations/stressors)
- 68 • Other [free text]

69

70 **3.2** Have you ever used other legal substances to help with your FND symptoms? [yes, no, don't
71 know]

72 **3.3** [if yes to 4.4] If yes, what have you tried? [energy drinks/caffeine, alcohol, tobacco
73 (including snuff/dip), e-cigarettes/nicotine, liquorice roots, Kudzu, CBD, poppers (amyl
74 nitrate), solvents (glue), other [free text]

75 **3.4** [in relation to answers from 4.5] How effective have you found each substance in the
76 management of FND? [Unsure, completely ineffective, minimally effective, somewhat
77 effective, very effective, completely effective]

78 **3.5** Have you ever tried any surgical operations or invasive procedures to help with your FND
79 symptoms? [yes, no, don't know]

80 **3.6** [if yes to 4.7] If yes, what was this? [Botulinum Toxin Injection, Nerve block, micro-
81 vascular decompression], Other [free text]

82 **3.7** Have you ever tried using wearable technology (e.g. smart watches, activity trackers)
83 to help monitor or manage your FND symptoms? [yes, no, don't know]

84

85 **3.8** Have you ever used prescription medication obtained without a prescription from a
86 doctor to manage your FND symptoms? [yes, no, don't know]

87 **3.9** Have you ever considered using illegal (street) drugs or unregulated substances to
88 treat FND symptoms but have not done so due to illegality/concerns about safety? [yes, no,
89 don't know]

90 **3.10** Have you ever actually used any illegal (street) drugs or unregulated substances to
91 help manage your FND symptoms? (reminder: your answers will remain confidential, please
92 answer to the best of your ability) [yes, no, don't know]

93 **3.11** [if yes to 4.12] What illegal (street) substances have you tried?

94

95 Marijuana/cannabis, spice, cocaine (as well as crack), amphetamines ('speed' or 'crystal
96 meth'), MDMA (ecstasy), khat, nitrous oxide, mephedrone (MCAT), PCP ('angel dust'),
97 GBL/GHB ('liquid ecstasy'), ketamine, 'psychedelics' (also known as hallucinogenics):
98 Psilocybin (AKA Magic Mushrooms), LSD, bromo-LSD(BOL), LSA (seeds, MG, HBW, RC),
99 dimethyltryptamine (DMT, Ayahuasca), mescaline/peyote

100

101 **3.12** [in relation to answers from 4.13] How effective have you found each substance in
102 the management of FND? [Unsure, completely ineffective, minimally effective, somewhat
103 effective, very effective, completely effective]

104 **3.13** [in relation to answers from 4.13] Did you experience any significant and/or long-
105 lasting adverse psychological or emotional effects from these substances? [None, minimal
106 complications, some complications, severe complications]

107 **3.14** [in relation to answers from 4.13] Did you experience any physical or medical
108 complications from these substances? [None, minimal complications, some complications,
109 severe complications]

110

111 **4 Views on alternative treatments**

112 In this section we will ask you for your views on alternative treatments for FND symptoms.

113

114 **4.1** I would be willing to consider using psychedelic substances (e.g. psilocybin (magic
115 mushrooms) or LSD) in a medically controlled setting if they were shown to be safe and
116 effective treatments for FND symptoms: [Very unlikely, unlikely, somewhat unlikely,
117 undecided, somewhat likely, likely, very likely]

118 **4.2** I would be willing to try wearable technology if it was shown to be safe and effective
119 treatments for FND symptoms? [Very unlikely, unlikely, somewhat unlikely, undecided,
120 somewhat likely, likely, very likely]

121

122 **5 Follow up**

123 **5.1** May we contact you in order to follow up on your responses? We will only ask for a
124 valid email address [free text box]