**Baseline questionnaire**

Participant ID: \_\_\_\_\_\_\_\_\_\_\_\_\_

It is normal to let participant’s doctors know that they are taking part in a research trial. Do we have your permission to write to your doctors to let them know? Please circle one of the options below:

1. Yes, it is okay to let my doctors know
2. No, I would prefer you not to tell my doctors

If you indicated ‘yes’ please fill in the details below:

GP surgery or practice name: \_\_\_\_\_\_\_\_\_\_\_\_\_

Address: \_\_\_\_\_\_\_\_\_\_\_\_

Telephone number (if known): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Parkinson’s care team, main contact name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_

Hospital/clinic name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_

Telephone number (if known): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Thank you for agreeing to take part in this study. Please fill in your personal details below:

1. Age: \_\_\_\_\_\_\_\_\_\_ years
2. Gender:

Man

Woman

Non-binary

Other (please specify)\_\_\_\_\_\_\_\_\_

1. Ethnicity:

White British/Irish/Other

Black/African/Caribbean/Black British

Mixed or multiple ethnic groups

Asian/Asian British

Other ethnic group: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. Education:

Up to GCSE or equivalent

Graduate or equivalent

Postgraduate

Other (please specify)\_\_\_\_\_\_

1. Employment:

Full-time employment

Part-time employment

Retired

Retired early due to Parkinson’s

Other (please specify) \_\_\_\_\_\_\_\_\_

1. Do you have a carer? (Circle applicable option)
2. No care needed
3. Care needed full-time
4. Care needed part-time
5. My partner is my care
6. I have outside carer(s)
7. Have you been diagnosed with:
   1. Parkinson’s disease
   2. Parkinsonism
   3. Progressive Supranuclear Palsy
   4. Other \_\_\_\_\_\_
8. When did you receive your diagnosis? If you cannot remember exactly, please give an approximate time

\_\_\_\_\_\_\_\_\_\_\_\_month \_\_\_\_\_\_\_\_\_\_\_\_year

1. What medications are you currently taking for managing your Parkinson’s? \_\_\_\_\_\_\_\_\_\_
   1. Have you been taking these medications for longer than two months? Yes/No
   2. Do you expect to stop taking the medication you are currently prescribed or change the prescribed dose in the next 6 weeks? Yes/No

**Technology use and familiarity:**

1. How often do you use devices like smartphones or tablets?

Everyday, every other day, once in a while, very rarely

1. How comfortable/confident do you feel using technology like smartphone or tablets?

Rating from 1 (not comfortable at all) to 5 (very comfortable)

**The Parkinson’s Disease Activities of Daily Living Scale**

Please tick one of the descriptions that best describes how your Parkinson’s disease has affected your day-to-day activities in the last month.

1. No difficulties with day-to-day activities. ❒

For example: Your Parkinson’s disease at present is not affecting your daily living.

1. Mild difficulties with day-to-day activities. ❒

For example: Slowness with some aspects of housework, gardening or shopping. Able to dress and manage personal hygiene completely independently but rate is slower. You may feel that your medication is not quite effective as it was.

1. Moderate difficulties with day-to-day activities. ❒

For example: Your Parkinson’s disease is interfering with your daily activities. It is increasingly difficult to do simple activities without some help such as rising from a chair, washing, dressing, shopping, housework. You may have some difficulties walking and may require assistance. Difficulties with recreational activities or the ability to drive a car. The medication is now less effective.

1. High levels of difficulties with day-to-day activities. ❒

For example: You now require much more assistance with activities of daily living such as washing, dressing, housework or feeding yourself. You may have greater difficulties with mobility and find you are becoming more dependent for assistance from others or aids and appliances. Your medication appears to be significantly less effective.

1. Extreme difficulties with day-to-day activities. ❒

For example: You require assistance in all daily activities. These may include dressing, washing, feeding yourself or walking unaided. You may now be housebound and obtain little or no benefit from your medication.

**PHQ-9**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | | | | |
| Over the *last 2 weeks*, how often have you been bothered by any of the following problems? | Not at all | Several days | More than half the days | Nearly every day |
| 1. Little interest or pleasure in doing things | 0 | 1 | 2 | 3 |
| 2. Feeling down, depressed, or hopeless | 0 | 1 | 2 | 3 |
| 3. Trouble falling or staying asleep, or sleeping too much | 0 | 1 | 2 | 3 |
| 4. Feeling tired or having little energy | 0 | 1 | 2 | 3 |
| 5. Poor appetite or overeating | 0 | 1 | 2 | 3 |
| 6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down | 0 | 1 | 2 | 3 |
| 7. Trouble concentrating on things, such as reading the newspaper or watching television | 0 | 1 | 2 | 3 |
| 8. Moving or speaking so slowly that other people could have noticed? Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual | 0 | 1 | 2 | 3 |
| 9. Thoughts that you would be better off dead or of hurting yourself in some way | 0 | 1 | 2 | 3 |
| (For office coding: Total Score \_\_\_\_ = \_\_\_\_ + \_\_\_\_ + \_\_\_\_) | | | | |

**GAD-7**

Over the last 2 weeks, how often have you been bothered by the following problems?

1. Feeling nervous, anxious or on edge

0 – Not at all; 1 – several days; 2 – more than half the days; 3 – nearly everyday

1. Not being able to stop or control worrying

0 – Not at all; 1 – several days; 2 – more than half the days; 3 – nearly everyday

1. Worrying too much about different things

0 – Not at all; 1 – several days; 2 – more than half the days; 3 – nearly everyday

1. Trouble relaxing

0 – Not at all; 1 – several days; 2 – more than half the days; 3 – nearly everyday

1. Being so restless that it is hard to sit still

0 – Not at all; 1 – several days; 2 – more than half the days; 3 – nearly everyday

1. Becoming easily annoyed or irritable

0 – Not at all; 1 – several days; 2 – more than half the days; 3 – nearly everyday

1. Feeling afraid as if something awful might happen
2. – Not at all; 1 – several days; 2 – more than half the days; 3 – nearly everyday

**PDQ-8**

Please tick one box for each question

❒ Never ❒ Occasionally ❒ Sometimes ❒ Often ❒ Always or cannot do at all

Due to having Parkinson’s disease, how often during the last month have you…

1. Had difficulty getting around in public?

2. Had difficulty dressing yourself?

3. Felt depressed?

4. Had problems with your close personal relationships?

5. Had problems with your concentration, e.g. when reading or watching TV?

6. Felt unable to communicate with people properly?

7. Had painful muscle cramps or spasms?

8. Felt embarrassed in public due to having Parkinson’s disease?

**ACT variables**

**AAQ-2**

Below you will find a list of statements. Please rate how true each statement is for you by selecting a number next to it.

Scale: 1 – never true; 2 – very seldom true; 3 – seldom true; 4 – sometimes true; 5 – frequently true; 6 – almost always true; 7 – always true

1. My painful experiences and memories make it difficult for me to live a life that I would value
2. I’m afraid of my feelings
3. I worry about not being able to control my worries and feelings
4. My painful memories prevent me from having a fulfilling life
5. Emotions cause problems in my life
6. It seems like most people are handling their lives better than I am
7. Worries get in the way of my success

**Experiences questionnaire – Decentering**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1 | 2 | 3 | 4 | 5 |
| Never | Rarely | Sometimes | Often | All the time |

1. I am better able to accept myself as I am.
2. I can observe unpleasant feelings without being drawn into them.
3. I notice that I don’t take difficulties so personally.
4. I can treat myself kindly.
5. I can separate myself from my thoughts and feelings.
6. I have the sense that I am fully aware of what is going on around me and inside me.
7. I can slow my thinking at times of stress.
8. I am not so easily carried away by my thoughts and feelings.
9. I can actually see that I am not my thoughts.
10. I am consciously aware of a sense of my body as a whole.
11. I am kinder to myself when things go wrong.
12. I can take time to respond to difficulties.
13. I view things from a wider perspective.
14. I remind myself that thoughts aren’t facts.

**Committed Action Questionnaire (CAQ-8)**

Directions: Below you will find a list of statements. Please rate the truth of each statement as it applies to you by circling a number.

Use the following rating scale to make your choices. For instance, if you believe a statement is “Always True”, you would circle the 6 next to that statement.

0 – Never true; 1-very rarely true; 2-seldom true; 3-sometimes true; 4-often true; 5-almost always true; 6-always true

1. I can remain committed to my goals even when there are times that I fail to reach them
2. When a goal is difficult to reach, I am able to take small steps to reach it
3. I prefer to change how I approach a goal rather than quit
4. I am able to follow my long terms plans including times when progress is slow
5. I find it difficult to carry on with an activity unless I experience that it is successful
6. If I feel distressed or discouraged, I let my commitments slide
7. I get so wrapped up in what I am thinking or feeling that I cannot do the things that matter to me
8. If I cannot do something my way, I will not do it at all

**Client service receipt inventory (CSRI)**

**We are asking you the following questions because we would like to know the cost of your illness both to you, those looking after you and to society in general.**

**1.** Please list below use of any medications taken over the last month.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Medication  name | Dose | Freq. | How long did / have you taken this for? | | Indication |
| (trade or generic)  - Include homeopathic medications | (mg) | (how often) | For continuing medications give an approximate start date | If stopped, approximately how long was this drug taken for?  (weeks) | (What are you taking it for?) |
|  |  |  |  |  |  |
|  |  |  |  |  |  |

**2.** In the last month, what face-to-face consultations have you had with these practitioners?

(*Note: only record one-to-one contacts here; see next questions for inpatient care and investigations)*

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Care provider | Have you  used this  service? | | Number of contacts in last month | | Average duration of contact |
|  | (Please circle one) | | **PD related** | **Other reasons** |  |
| **A. General practitioner (GP)** | **No** | **Yes** |  |  |  |
| **B. Neurologist** | **No** | **Yes** |  |  |  |
| **C. Psychiatrist** | **No** | **Yes** |  |  |  |
| **D. Other doctor 1 - state what type *(e.g. cardiologist)***  **\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_** | **No** | **Yes** |  |  |  |
| **E. Other doctor 2 - state what type *(e.g. dentist)*** | **No** | **Yes** |  |  |  |
| **F. PD nurse** | **No** | **Yes** |  |  |  |
| **G. Pharmacist (for advice)** | **No** | **Yes** |  |  |  |
| **H. Psychologist / therapist** | **No** | **Yes** |  |  |  |

**3.** In the last month have you spent time as a hospital inpatient? **Yes/No**

**If yes:**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Admission | Hospital name, plus department or type of ward  (e.g. King's, neurology) | Reason for admission | Dates | | Total  days |
|  |  |  | **Admission** | **Discharge** |  |
| **1st admission** |  |  |  |  |  |
| **2nd admission** |  |  |  |  |  |
| **3rd admission** |  |  |  |  |  |

a) How many times have you been admitted to hospital and discharged in the same day? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**4.** In the last month how many times have you attended A & E? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

a) What was the reason?

**5.** In the last month, have you had any of the following investigations or diagnostic tests?

|  |  |  |  |
| --- | --- | --- | --- |
| Type of test | Have you had this test?  (Please circle one) | | *Number of investigations / tests in the last month* |
| **A. Magnetic Resonance Image (MRI)** | **No** | **Yes** |  |
| **B. CT / CAT scan** | **No** | **Yes** |  |
| **C. Ultrasound** | **No** | **Yes** |  |
| **D. X-ray** | **No** | **Yes** |  |
| **E. Electroencephalogram (EEG)** | **No** | **Yes** |  |
| **F. Blood test** | **No** | **Yes** |  |
| **G. Other (please describe)** | **No** | **Yes** |  |

**6.** In the last month, have you received help from friends or relativeson any of the following tasks as a consequence of your PD?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Type of help** | (Please circle one) | | **Average number of hours help per week** | **Who provides this care?** | **Do they live in your house?** |
| **Child Care**  (circle ‘No’ if you have no children) | **No** | **Yes** |  |  |  |
| **Personal care**  (E.g. washing, dressing etc.) | **No** | **Yes** |  |  |  |
| **Help in / around the house**  (E.g. cooking, cleaning etc.) | **No** | **Yes** |  |  |  |
| **Help outside the home**  (E.g. shopping, transport etc.) | **No** | **Yes** |  |  |  |
| **Other**  **\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_** | **No** | **Yes** |  |  |  |
| **Total hours** | | |  | | |

7. In the last month, have you used any self-help support (e.g. websites, apps, booklets) for psychological support? **Yes/No**

If yes, how often have you used this kind of support? \_\_\_\_\_\_\_\_\_\_ (how many times per week)

What was the name of the support you used? (e.g. app name or organization’s website) \_\_\_\_\_\_\_\_\_\_\_\_

8. In the last month, have you received any psychotherapy or participated in any other research involving a psychological intervention? **Yes/No**

If yes, please elaborate (what kind of psychological support and how often) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_