SPIRiTT Unique Identification Number: Assessment time-point

Specialist Parkinson's Integrated Rehabilitation Team Trial (SPIRiTT)

Data Collection Form for Person with Parkinson's

We would be grateful if you could provide as much information as possible
All information collected is treated with complete confidentiality

Date: __/___/ 20__ **Time:** __:__ AM PM **Location:** ☐ Home ☐ Other _____

Person completing form: ☐ Carer ☐ Person with Parkinson's ☐ Researcher ☐ Other (please specify): _____

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Favourable ethical opinion has been granted by Surrey Research Ethics Committee

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SELF ASSESSMENT PARKINSON'S SCALE

For each item below, please tick the box which best describes how easy or difficult it is for you to perform that activity. If you are more able at some times than others, indicate how you are IN GENERAL at the times of day you would normally perform these activities. If you use a frame or walking stick or any special aids to help you, please answer according to how well you would manage WITHOUT the aid.

Activity	Able to do alone without difficulty	Able to do alone with a little effort	Able to do alone with a lot of effort or with a little help	Able to do but only with a lot of help	Unable to do at all
1) Get out of bed					
2) Get up from an armchair					
3) Walk around the house/flat					
4) Walk outside such as to the local shops					
5) Travel by public transport					
6) Walk up stairs					
7) Walk down stairs					
8) Wash face and hands					
9) Get into a bath					
10) Get out of a bath					
11) Get dressed					
12) Get undressed					
13) Brush your teeth					
14) Open tins (not using an electric opener)					
15) Pour milk from a bottle or carton					
16) Make a cup of tea or coffee					
17) Hold a cup and saucer					
18) Wash and dry dishes					
19) Cut food with a knife and fork					
20) Pick up an object from the floor					
21) Insert and remove an electric plug					
22) Dial a telephone					
23) Hold and read a newspaper					
24) Write a letter					
25) Turn over in bed					

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EuroQol QUESTIONNAIRE

Please indicate which statement best describes your own health. Please tick only one box in each section.

1) Mobility
- ☐ I have no problems with walking around
- ☐ I have some problems with walking around
- ☐ I am confined to bed

2) Self-care
- ☐ I have no problems with self-care
- ☐ I have some problems with washing or dressing myself
- ☐ I am unable to wash or dress myself

3) Usual activities (e.g. work, study, housework, family or leisure activities)
- ☐ I have no problems with performing my usual activities
- ☐ I have some problems with performing my usual activities
- ☐ I am unable to perform my usual activities

4) Pain/Discomfort
- ☐ I have no pain or discomfort
- ☐ I have moderate pain or discomfort
- ☐ I have extreme pain or discomfort

5) Anxiety/Depression
- ☐ I am not anxious or depressed
- ☐ I am moderately anxious or depressed
- ☐ I am extremely anxious or depressed

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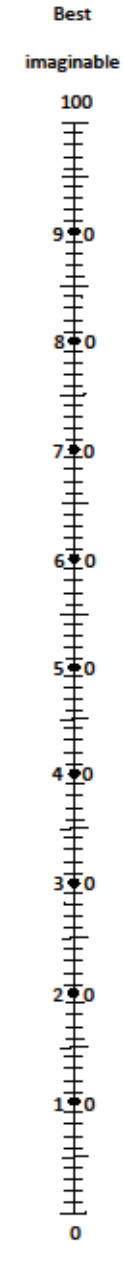
EuroQoL THERMOMETER

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is TODAY, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is TODAY.

Your own health state today



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NON-MOTOR SYMPTOMS QUESTIONNAIRE

From the list below, please tick the box 'Yes' if you have experienced the symptom during the PAST MONTH. You should answer 'No' even if you have had the symptom in the past, but not in the past month.

Have you experienced any of the following in the LAST MONTH?	Yes	No
1) Dribbling of saliva during the daytime		
2) Loss or change in your ability to taste or smell		
3) Difficulty swallowing food or drink or problems with choking		
4) Vomiting or feelings of sickness (nausea)		
5) Constipation (less than three bowel movements a week) or having to strain to pass a stool		
6) Bowel (faecal) incontinence		
7) Feeling that your bowel emptying is incomplete after having been to the toilet		
8) A sense of urgency to pass urine makes you rush to the toilet		
9) Getting up regularly at night to pass urine		
10) Unexplained pains (not due to known conditions such as arthritis)		
11) Unexplained change in weight (not due to change in diet)		
12) Problems remembering things that have happened recently or forgetting to do things		
13) Loss of interest in what is happening around you or in doing things		
14) Seeing or hearing things that you know or are told are not there		
15) Difficulty concentrating or staying focused		
16) Feeling sad, 'low' or 'blue'		
17) Feeling anxious, frightened or panicky		
18) Feeling less interested in sex or more interested in sex		
19) Finding it difficult to have sex when you try		
20) Feeling light-headed, dizzy or weak standing from sitting or lying		
21) Falling		
22) Finding it difficult to stay awake during activities such as working, driving or eating		
23) Difficulty getting to sleep at night or staying asleep at night		
24) Intense, vivid or frightening dreams		
25) Talking or moving about in your sleep, as if you are 'acting out' a dream		
26) Unpleasant sensations in your legs at night or while resting, and a feeling that you need to move		
27) Swelling of the legs		
28) Excessive sweating		
29) Double vision		
30) Believing things are happening to you that other people say are not		

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Please tick √ only one box for each question below.

Due to having Parkinson's, how often during the LAST MONTH have you	Never	Occasionally	Sometimes	Often	Always
1) had difficulty getting around in public?					
2) had difficulty dressing yourself?					
3) felt depressed?					
4) felt embarrassed in public due to having Parkinson's?					
5) had problems with your close personal relationships?					
6) had problems with your concentration such as when reading or watching TV?					
7) felt unable to communicate with people properly?					
8) had painful muscle cramps or spasms?					

FRENCHAY ACTIVITIES INDEX

Please answer the following questions by placing a checkmark/tick in one of the boxes.

SPIRiTT Unique Identification Number: **Assessment time-point**

In the LAST 3 MONTHS, how often have you undertaken:	Never	Less than once a week	1 to 2 times a week	Most days
1) preparing main meals? *(not just making snacks or reheating prepared food)*				
2) washing up? *(not just rinsing or an occasional item)*				

In the LAST 3 MONTHS, how often have you undertaken:	Never	1 to 2 times in 3 months	3 to 12 times in 3 months	At least weekly
3) washing clothes?				
4) light housework? *(such as dusting, polishing, ironing)*				
5) heavy housework? *(such as changing beds, cleaning floors, vacuuming, moving chairs, gardening)*				
6) local shopping?				
7) social outings? *(can include social activities at home such as visits from friends, not for the purpose of providing care)*				
8) walking outside more than 15 minutes? *(includes shopping)*				
9) actively pursuing a hobby *(includes reading)*?				
10) driving a car/going on a bus? *(must travel independently)*				

PAIN VISUAL ANALOGUE SCALE

Please mark, using a 'X' on the visual analogue scales below, what your pain levels have been like, on average, in the LAST 2 WEEKS. 0 represents 'no pain at all' and 10 represents 'worst imaginable pain possible'

1) During your 'on' state:

no pain at all 0 _____ 10 *worst imaginable pain possible*

2) During your 'off' state:

no pain at all 0 _____ 10 *worst imaginable pain possible*

SPIRiTT Unique Identification Number: **Assessment time-point**

SPEECH SELF REPORT QUESTIONNAIRE

Here are 11 statements about speaking. You may feel that some of them are a characteristic of your speech. Read each one carefully and indicate by ticking √ the appropriate box how often they apply to you.

Statements	Never	Rarely	Occasionally	Often	Very often	Always
1) My voice is weak and I have difficulty in raising it to make it louder						
2) I find it difficult to keep speaking at the same speed such that my speech gets faster and faster						
3) My face becomes stiff and this makes speaking difficult						
4) My speech sounds flat and monotonous with little variation in pitch or quality						
5) I have difficulty coordinating my breathing with my speech so that I become "out of breath" in a long conversation						
6) People complain of my voice being too quiet						
7) I find it difficult to start speaking so that I can sound hesitant						
8) My voice sounds husky						
9) My speech does not sound as clear as it used to						
10) Sometimes I cannot remember the name of something						
11) I find food/drink escapes from my lips when eating/drinking						

SPIRiTT Unique Identification Number: **Assessment time-point**

Here are 15 situations. Please indicate by ticking √ the appropriate box, how often you may AVOID these situations because of your communication.

Situations	Never	Rarely	Occasionally	Often	Very often	Always
1) Making telephone calls						
2) Answering the telephone						
3) Speaking in shops (empty)						
4) Speaking in shops (full)						
5) Buying a train/bus ticket						
6) Speaking to strangers						
7) Asking the way						
8) Speaking to young children						
9) Speaking to friends						
10) Speaking to a group of people						
11) Ordering in a café/restaurant/bar						
12) Introducing myself						
13) Introducing one person to another						
14) Participating in a meeting						
15) Phoning to make an appointment/arrange details						

SPIRiTT Unique Identification Number: **Assessment time-point**

SELF EFFICACY SCALE – 6

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to how confident you are that you can do the tasks regularly at the present time.

How confident are you that you can:	Please tick the box which best represents your confidence level
1) keep the fatigue caused by your condition from interfering with the things you want to do?	*Not at all confident* ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ *totally confident* 1 2 3 4 5 6 7 8 9 10
2) keep the physical discomfort or pain of your condition from interfering with the things you want to do?	*Not at all confident* ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ *totally confident* 1 2 3 4 5 6 7 8 9 10
3) keep the emotional distress caused by your condition from interfering with the things you want to do?	*Not at all confident* ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ *totally confident* 1 2 3 4 5 6 7 8 9 10
4) keep any other symptoms or health problems you have from interfering with the things you want to do?	*Not at all confident* ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ *totally confident* 1 2 3 4 5 6 7 8 9 10
5) do the difficult tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?	*Not at all confident* ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ *totally confident* 1 2 3 4 5 6 7 8 9 10
6) do things other than just taking medication to reduce how much your condition affects your everyday life?	*Not at all confident* ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ *totally confident* 1 2 3 4 5 6 7 8 9 10

SPIRiTT Unique Identification Number: **Assessment time-point**

WELLBEING QUESTIONNAIRE (Hospital Anxiety and Depression Scale)

Without thinking too much, please place a checkmark/tick √ in the box that applies to you. Please choose only one box for each question.

1) I feel tense or 'wound up'

☐ Not at all ☐ From time to time, occasionally ☐ A lot of the time ☐ Most of the time

2) I still enjoy the things I used to enjoy

☐ Hardly at all ☐ Only a little ☐ Not quite so much ☐ Definitely as much

3) I get a sort of frightened feeling as if something awful is about to happen

☐ Not at all ☐ A little, but it does not worry me ☐ Yes, but not too badly ☐ Very definitely and quite badly

4) I can laugh and see the funny side of things

☐ Not at all ☐ Definitely not so much now ☐ Not quite so much now ☐ As much as I always could

5) Worrying thoughts go through my mind

☐ Only occasionally ☐ From time to time, but not too often ☐ A lot of the time ☐ A great deal of the time

6) I feel cheerful

☐ Not at all ☐ Not often ☐ Sometimes ☐ Most of the time

7) I can sit at ease and feel relaxed

☐ Not at all ☐ Not often ☐ Usually ☐ Definitely

8) I feel as if I am slowed down

☐ Not at all ☐ Sometimes ☐ Very often ☐ Nearly all the time

9) I get a sort of frightened feeling like 'butterflies' in the stomach

☐ Not at all ☐ Occasionally ☐ Quite often ☐ Very often

10) I have lost interest in my appearance

☐ Definitely ☐ I do not take as much care as I should ☐ I may not take quite as much care ☐ I take just as much care as ever

SPIRiTT Unique Identification Number: Assessment time-point

11) I feel restless as if I have to be on the move

☐ Not at all ☐ Not very much ☐ Quite a lot ☐ Very much indeed

12) I look forward with enjoyment to things

☐ Hardly at all ☐ Definitely less than I used to ☐ Rather less than I used to ☐ As much as I ever did

13) I get sudden feelings of panic

☐ Not at all ☐ Not very often ☐ Quite often ☐ Very often indeed

14) I can enjoy a good book or radio or TV programme

☐ Very seldom ☐ Not often ☐ Sometimes ☐ Often

SPIRiTT Unique Identification Number: **Assessment time-point**

SHORT FORM 36 HEALTH SURVEY

Please respond to the questions below, by placing a checkmark/tick √ in the appropriate box.

1) In general, would you say your health is:

☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor

2) Compared to one year ago, how would you rate your health in general NOW?

☐ Much better now than one year ago ☐ Somewhat better now than one year ago ☐ About the same as one year ago ☐ Somewhat worse than one year ago ☐ Much worse than one year ago

With reference to the activities listed below that you may do during a typical day, does your health NOW limit you in these activities? If so, how much?	**No, not limited at all**	**Yes, limited a little**	**Yes, limited a lot**
3) Vigorous activities such as running, lifting heavy objects, participating in strenuous sports			
4) Moderate activities such as moving a table, pushing a vacuum cleaner, bowling or playing golf			
5) Lifting or carrying groceries			
6) Climbing several flights of stairs			
7) Climbing one flight of stairs			
8) Bending, kneeling or stooping			
9) Walking more than a mile			
10) Walking half a mile			
11) Walking one hundred yards			
12) Bathing or dressing yourself			

During the PAST 4 WEEKS, have you had any of the following problems with your work or other regular daily activities as a result of your PHYSICAL health?	**Yes**	**No**
13) Cut down on the amount of time you spent on work or other activities		
14) Accomplished less than you would like		
15) Were limited in the kind of work or other activities		
16) Had difficulty performing the work or other activities (for example, it took extra effort)		

During the PAST 4 WEEKS, have you had any of the following problems with your work or other regular daily activities as a result of any EMOTIONAL problems (such as feeling depressed or anxious)?	**Yes**	**No**
17) Cut down on the amount of time you spent on work or other activities		
18) Accomplished less than you would like		
19) Did not do work or other activities as carefully as usual		

SPIRiTT Unique Identification Number: Assessment time-point

20) During the PAST 4 WEEKS, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?

☐ Not at all ☐ Slightly ☐ Moderately ☐ Quite a bit ☐ Extremely

21) How much bodily pain have you had during the PAST 4 WEEKS?

☐ None ☐ Very mild ☐ Mild ☐ Moderate ☐ Severe ☐ Very severe

22) During the PAST 4 WEEKS, how much did pain interfere with your normal work (including both work outside the home and housework)?

☐ Not at all ☐ A little bit ☐ Moderately ☐ Quite a bit ☐ Extremely

23) During the PAST 4 WEEKS, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives etc)?

☐ All of the time ☐ Most of the time ☐ Some of the time ☐ A little of the time ☐ None of the time

How much of the time during the PAST 4 WEEKS:	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
24) Did you feel full of life?						
25) Have you been a very nervous person?						
26) Have you felt so down in the dumps that nothing could cheer you up?						
27) Have you felt calm and peaceful?						
28) Did you have a lot of energy?						
29) Have you felt downhearted and low?						
30) Did you feel worn out?						
31) Have you been a happy person?						
32) Did you feel tired?						

SPIRiTT Unique Identification Number: **Assessment time-point**

How TRUE or FALSE is each of the following statements to you?	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
33) I seem to get ill more easily than other people					
34) I am as healthy as anybody I know					
35) I expect my health to get worse					
36) My health is excellent					

SPIRiTT Unique Identification Number: **Assessment time-point**

ACTIVITIES OF DAILY LIVING QUESTIONNAIRE (BARTHEL)

Please select the statement which best describes your situation. Please tick only one box in each section.

1) Mobility around house

☐ Immobile ☐ Wheelchair independent around corners etc ☐ Walks with verbal or physical help of 1 person ☐ Independent *(but can use walking aid such as a stick)*

2) Stairs

☐ Unable ☐ Needs verbal or physical help *(carrying aid)* ☐ Independent up and down

3) Transfer from bed to chair and back

☐ Unable ☐ Needs major help (1 or 2 people, physical help) ☐ Needs minor verbal or physical help ☐ Independent

4) Bathing

☐ Dependent ☐ Independent

5) Grooming (personal hygiene such as brushing teeth and hair, shaving, washing face)

☐ Needs help ☐ Independent

6) Dressing

☐ Dependent ☐ Needs help but can do half unaided ☐ Independent

7) Feeding (able to eat normal food, not just soft food)

☐ Unable ☐ Needs help cutting, spreading butter etc ☐ Independent

8) Toilet use

☐ Dependent ☐ Needs some help but can do something ☐ Independent

9) Bladder

☐ Incontinent or catheterised and unable to manage ☐ Occasional accident (maximum 1 time in a day) ☐ Continent over 7 days

10) Bowels

☐ Incontinent ☐ Occasional accident (1 per week) ☐ Continent

THANK YOU for taking the time to complete this questionnaire.

Please check through to ensure that you have answered all the questions.

Your input is extremely valued and very much appreciated.