

COMMEND RCT

Participant booklet

9 months

Date of completion

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | | | | |
| d | d | m | m | y | y | y | y |

Method of completion

- ☐ Booklet returned by post
- ☐ Booklet completed with participant by phone
- ☐ Booklet completed with participant by video conference
- ☐ Booklet completed with participant by email
- ☐ Booklet completed with participant at face-to-face visit

Capacity to consent

Has the participant's ongoing capacity to consent been assessed?

☐ Yes

☐ No

Does participant still have the capacity to consent? ☐ Yes ☐ No

Please complete a **Study completion / Discontinuation form**

Reason

Medication changes

Have there been any changes to the participant's medications since last visit?

☐ Yes

☐ No

Please update the
Concomitant medications form

Adverse events

Has the participant developed a new co-morbid psychiatric condition since last visit?

☐ Yes ☐ No

Has the participant experienced an event which significantly affected their psychological health status since last visit? (e.g. bereavement)

☐ Yes ☐ No

Has the participant made a new report of suicidal ideation (with or without active plans / suicidal behaviours) since last visit?

☐ Yes ☐ No

Has the participant reported any physical self harm since last visit? (Note: this constitutes a *serious* adverse event)

☐ Yes ☐ No

Has the participant had any other reportable* adverse or serious adverse events events since last visit? (e.g. unplanned hospital admission)

☐ Yes ☐ No

If any of the above are "Yes", please update the **Adverse events** log and / or **SAE** form(s)

* Please refer to section 8 of the COMMEND protocol for clarification on reportable Adverse and Serious Adverse Events for COMMEND.

Instructions

This questionnaire contains statements that are each followed by two opposite answers.

Numbers extend from one extreme answer to the opposite.

Please circle the number between 0 and 10 which is most true for you.

There are no right or wrong answers.

Completely honest answers will be most helpful.

EXAMPLE:

I am hungry:

| | | | | | | | | | | | | |
|------------|---|---|---|---|---|---|---|---|---|---|----|-----------|
| not at all | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | extremely |
|------------|---|---|---|---|---|---|---|---|---|---|----|-----------|

- If you are not even a little bit hungry, you would circle 0.
- If you are a little hungry (you just finished a meal but still have room for dessert), you might circle a 1, 2, or 3.
- If you are feeling moderately hungry (because mealtime is approaching), you might circle a 4, 5, or 6.
- If you are very hungry (because you haven't eaten all day), you might circle a 7, 8, or 9.
- If you are extremely hungry, you would circle 10.



Please answer for how you have been feeling ***JUST IN THE PAST TWO (2) DAYS***

Part A - Overall Quality of Life

A. Considering all parts of my life (for example, physical, emotional, social, spiritual, and financial) over the past two days (48 hours) the quality of my life was:

| | | | | | | | | | | | | |
|----------|---|---|---|---|---|---|---|---|---|---|----|-----------|
| very bad | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | excellent |
|----------|---|---|---|---|---|---|---|---|---|---|----|-----------|

Continue to Part B

Part B Physical

1. Over the past two days (48 hours) my physical symptoms (such as pain, nausea, tiredness and others) were:*

| | | | | | | | | | | | | |
|---------------|---|---|---|---|---|---|---|---|---|---|----|----------------------|
| not a problem | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | a tremendous problem |
|---------------|---|---|---|---|---|---|---|---|---|---|----|----------------------|

**If, over the past two days, you had no physical symptoms or problems, please circle '0 – not a problem' and go to statement #2.*

Please list the physical symptoms that were a problem (please write clearly).

2. Over the past two days (48 hours) I felt:

| | | | | | | | | | | | | |
|---------------------|---|---|---|---|---|---|---|---|---|---|----|-----------------|
| physically terrible | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | physically well |
|---------------------|---|---|---|---|---|---|---|---|---|---|----|-----------------|

3. Over the past two days (48 hours), being physically unable to do things I wanted was:

| | | | | | | | | | | | | |
|---------------|---|---|---|---|---|---|---|---|---|---|----|----------------------|
| not a problem | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | a tremendous problem |
|---------------|---|---|---|---|---|---|---|---|---|---|----|----------------------|

Continue to Part C

— Part C Feelings and thoughts —

4. Over the past two days (48 hours), I was depressed:

| | | | | | | | | | | | | |
|------------|---|---|---|---|---|---|---|---|---|---|----|-----------|
| not at all | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | extremely |
|------------|---|---|---|---|---|---|---|---|---|---|----|-----------|

5. Over the past two days (48 hours), I was nervous or worried:

| | | | | | | | | | | | | |
|------------|---|---|---|---|---|---|---|---|---|---|----|-----------|
| not at all | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | extremely |
|------------|---|---|---|---|---|---|---|---|---|---|----|-----------|

6. Over the past two days (48 hours), I felt sad:

| | | | | | | | | | | | | |
|-------|---|---|---|---|---|---|---|---|---|---|----|--------|
| never | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | always |
|-------|---|---|---|---|---|---|---|---|---|---|----|--------|

7. Over the past two days (48 hours), when I thought of the future, I was:

| | | | | | | | | | | | | |
|------------|---|---|---|---|---|---|---|---|---|---|----|-----------|
| not afraid | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | terrified |
|------------|---|---|---|---|---|---|---|---|---|---|----|-----------|

8. Over the past two days (48 hours), my life was:

| | | | | | | | | | | | | |
|--|---|---|---|---|---|---|---|---|---|---|----|---|
| utterly meaningless and without purpose | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | very purposeful and meaningful |
|--|---|---|---|---|---|---|---|---|---|---|----|---|

9. When I think about my whole life, I feel that in achieving life goals I have:

| | | | | | | | | | | | | |
|-----------------------------------|---|---|---|---|---|---|---|---|---|---|----|---|
| made no progress whatsoever | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | progressed to complete fulfilment |
|-----------------------------------|---|---|---|---|---|---|---|---|---|---|----|---|

10. Over the past two days (48 hours), I felt that the amount of control I had over my life was:

| | | | | | | | | | | | | |
|---------------|---|---|---|---|---|---|---|---|---|---|----|-------------------------|
| not a problem | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | a tremendous problem |
|---------------|---|---|---|---|---|---|---|---|---|---|----|-------------------------|

11. Over the past two days (48 hours), I felt good about myself as a person

| | | | | | | | | | | | | |
|------------------------|---|---|---|---|---|---|---|---|---|---|----|---------------------|
| completely disagree | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | completely agree |
|------------------------|---|---|---|---|---|---|---|---|---|---|----|---------------------|

Continue to Part D

— **Part D Social** —

12. Over the past two days (48 hours), communication with the people I care about was:

| | | | | | | | | | | | | |
|-----------|---|---|---|---|---|---|---|---|---|---|----|-----------|
| difficult | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | very easy |
|-----------|---|---|---|---|---|---|---|---|---|---|----|-----------|

13. Over the past two days (48 hours), I felt my relationships with the people I care about were:

| | | | | | | | | | | | | |
|--------------------------------------|---|---|---|---|---|---|---|---|---|---|----|------------|
| more distant than I would like | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | very close |
|--------------------------------------|---|---|---|---|---|---|---|---|---|---|----|------------|

14. Over the past two days (48 hours), I felt supported:

| | | | | | | | | | | | | |
|------------|---|---|---|---|---|---|---|---|---|---|----|------------|
| not at all | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | completely |
|------------|---|---|---|---|---|---|---|---|---|---|----|------------|

Tick the box beside the reply that is closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate is best.

| | |
|-----------------------------------|--------------------------|
| I feel tense or 'wound up' | |
| Most of the time | <input type="checkbox"/> |
| A lot of the time | <input type="checkbox"/> |
| From time to time, occasionally | <input type="checkbox"/> |
| Not at all | <input type="checkbox"/> |

| | |
|--------------------------------------|--------------------------|
| I feel as if I am slowed down | |
| Nearly all of the time | <input type="checkbox"/> |
| Very often | <input type="checkbox"/> |
| Sometimes | <input type="checkbox"/> |
| Not at all | <input type="checkbox"/> |

| | |
|--|--------------------------|
| I still enjoy the things I used to enjoy: | |
| Definitely as much | <input type="checkbox"/> |
| Not quite so much | <input type="checkbox"/> |
| Only a little | <input type="checkbox"/> |
| Hardly at all | <input type="checkbox"/> |

| | |
|---|--------------------------|
| I get a sort of frightened feeling like 'butterflies' in the stomach | |
| Not at all | <input type="checkbox"/> |
| Occasionally | <input type="checkbox"/> |
| Quite often | <input type="checkbox"/> |
| Very often | <input type="checkbox"/> |

| | |
|--|--------------------------|
| I get a sort of frightened feeling as if something awful is about to happen | |
| Very definitely and quite badly | <input type="checkbox"/> |
| Yes, but not too badly | <input type="checkbox"/> |
| A little, but it doesn't worry me | <input type="checkbox"/> |
| Not at all | <input type="checkbox"/> |

| | |
|--|--------------------------|
| I have lost interest in my appearance | |
| Definitely | <input type="checkbox"/> |
| I don't take as much care as I should | <input type="checkbox"/> |
| I may not take quite as much care | <input type="checkbox"/> |
| I take just as much care as ever | <input type="checkbox"/> |

| | |
|---|--------------------------|
| I can laugh and see the funny side of things | |
| As much as I always could | <input type="checkbox"/> |
| Not quite so much now | <input type="checkbox"/> |
| Definitely not so much now | <input type="checkbox"/> |
| Not at all | <input type="checkbox"/> |

| | |
|---|--------------------------|
| I feel restless as if I have to be on the move | |
| Very much indeed | <input type="checkbox"/> |
| Quite a lot | <input type="checkbox"/> |
| Not very much | <input type="checkbox"/> |
| Not at all | <input type="checkbox"/> |

Tick the box beside the reply that is closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate is best.

| | |
|---|--------------------------|
| Worrying thoughts go through my mind | |
| A great deal of the time | <input type="checkbox"/> |
| A lot of the time | <input type="checkbox"/> |
| From time to time, but not too often | <input type="checkbox"/> |
| Only occasionally | <input type="checkbox"/> |

| | |
|--|--------------------------|
| I look forward with enjoyment to things | |
| As much as I ever did | <input type="checkbox"/> |
| Rather less than I used to | <input type="checkbox"/> |
| Definitely less than I used to | <input type="checkbox"/> |
| Hardly at all | <input type="checkbox"/> |

| | |
|------------------------|--------------------------|
| I feel cheerful | |
| Not at all | <input type="checkbox"/> |
| Not often | <input type="checkbox"/> |
| Sometimes | <input type="checkbox"/> |
| Most of the time | <input type="checkbox"/> |

| | |
|---------------------------------------|--------------------------|
| I get sudden feelings of panic | |
| Very often indeed | <input type="checkbox"/> |
| Quite often | <input type="checkbox"/> |
| Not very often | <input type="checkbox"/> |
| Not at all | <input type="checkbox"/> |

| | |
|---|--------------------------|
| I can sit at ease and feel relaxed | |
| Definitely | <input type="checkbox"/> |
| Usually | <input type="checkbox"/> |
| Not often | <input type="checkbox"/> |
| Not at all | <input type="checkbox"/> |

| | |
|---|--------------------------|
| I can enjoy a good book or radio or TV program | |
| Often | <input type="checkbox"/> |
| Sometimes | <input type="checkbox"/> |
| Not often | <input type="checkbox"/> |
| Very seldom | <input type="checkbox"/> |



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Zigmond, AS; Snaith, RP (1983). "The hospital anxiety and depression scale".
Acta Psychiatrica Scandinavica. 67 (6): 361–370

The following questions refer to how you are currently functioning at home.

Please read each item carefully and base your answers on your functioning today compared to the time before you had any symptoms of MND.

Please choose the answer that best fits your functional status today.

Place an "x" in the box next to your answer.

Compared to the time before you had symptoms of MND:

1. Have you noticed any changes in your **speech**?

- ☐ **no change**
- ☐ **noticeable speech differences**
- ☐ speech has changed; **asked often to repeat words or phrases**
- ☐ speech has changed; sometimes need the use of **alternative communication methods** (i.e. computer, writing pad, letter board or eye chart)
- ☐ **unable** to communicate verbally

2. Have you noticed any changes (increases) in the amount of **saliva** in your mouth (regardless of any medication use)?

- ☐ **no change**
- ☐ slight but definite excess of saliva with or without **night time drooling**
- ☐ moderate amounts of excessive saliva with or without **minimal day time drooling**
- ☐ marked amounts of excessive saliva with **some day time drooling**
- ☐ marked excessive saliva with **marked drooling** requiring a constant tissue or handkerchief

3. Have there been any changes in your ability to **swallow**?

- ☐ **no changes** (all foods and liquids)
- ☐ some changes in swallowing or **occasional choking episodes** (including coughing during swallowing)
- ☐ unable to eat all consistencies of food and have **modified the consistency of foods** eaten
- ☐ use a **feeding tube (PEG) to supplement** what is eaten by mouth
- ☐ **do not eat anything by mouth** and receive all nutrition through a feeding tube (PEG)

Compared to the time before you had symptoms of MND:

4. Has your **handwriting** changed? Please choose the answer that describes your handwriting with your **dominant (usual)** hand without a cuff or brace.

- ☐ **no changes**
- ☐ slower and/or sloppier but all the words are **legible**
- ☐ **not all words are legible**
- ☐ able to **hold a pen** but **unable to write**
- ☐ **unable to hold a pen**

The following question refers to your ability to **cut foods and handle utensils** (feed yourself) compared to before you had symptoms of MND.

If most of your nutrition is through a feeding tube (PEG), skip to **part b** of this question. If you eat most of your meals by mouth answer **part a**.

5a. Cutting food and handling utensils:

- ☐ **no change**
 - ☐ **somewhat slow and clumsy** (or different than before) but no assistance or adaptive equipment
 - ☐ **sometimes need help** with cutting more difficult foods
 - ☐ **food must be cut by someone else** but can feed slowly without assistance
 - ☐ **need to be fed**
-

5b. Using a feeding tube (PEG)

- ☐ use PEG **without assistance or difficulty**
- ☐ use PEG without assistance however may be **slow and/or clumsy**
- ☐ **require assistance with closures and fasteners**
- ☐ **provide minimal assistance to caregiver**
- ☐ **unable to perform** any of the manipulations

Compared to the time before you had symptoms of MND:

6. Has your ability to **dress and perform self-care activities** (i.e. bathing, teeth brushing, shaving, combing your hair, other hygienic activities) changed?
- ☐ **no change**
- ☐ perform self-care activities without assistance but **with increased effort or decreased efficiency**
- ☐ require **intermittent assistance or use different methods** (i.e. sit down to get dressed, fasten buttons with a fastener or your non-dominant hand)
- ☐ **require daily assistance**
- ☐ do not perform self-care activities and **completely dependent** on caregiver
-
7. Has your ability to **turn in bed and adjust the bedclothes** (i.e. cover yourself with a sheet or blanket) changed?
- ☐ **no change**
- ☐ can turn in bed and adjust the bed clothes **without assistance** but it is **slower or more clumsy**
- ☐ can turn in bed **or** adjust the bedclothes **without assistance but with great difficulty**
- ☐ can **initiate** turning in bed or adjusting the bed clothes but **require assistance** to complete the task
- ☐ **helpless** in bed
-
8. Has your ability to **walk** changed?
- ☐ **no change**
- ☐ **walking has changed** but **do not require any assistance or devices** (i.e. foot brace, cane, walker)
- ☐ **require assistance** to walk (i.e. cane, walker, foot brace or hand held assistance)
- ☐ **can move legs or stand up** but **unable to walk** from room to room
- ☐ **cannot walk** or move my legs
-
9. Has your ability to **climb stairs** changed?
- ☐ **no change**
- ☐ **slower**
- ☐ **unsteady** and/or more **fatigued**
- ☐ **require assistance** (i.e. using the handrail, cane or person)
- ☐ **cannot** climb stairs

Compared to the time before you had symptoms of MND:

10. Do you experience **shortness of breath** or have **difficulty breathing**?

- ☐ **no change**
 - ☐ shortness of breath only **with walking**
 - ☐ shortness of breath with **minimal exertion** (i.e. talking, eating, bathing or dressing)
 - ☐ shortness of breath **at rest** while either sitting or lying down
 - ☐ **significant shortness of breath** (all of the time) and considering using mechanical ventilation
-

11. Do you experience shortness of breath or have difficulty breathing while lying down on your back?

- ☐ **no change**
 - ☐ occasional shortness of breath while lying on back but **don't routinely use more than two (2) pillows** to sleep
 - ☐ shortness of breath while lying on back and **require more than two pillows** (or an equivalent) **to sleep**
 - ☐ **can only sleep sitting up** due to shortness of breath
 - ☐ **require the use of respiratory (breathing) support** (BiPAP® or invasive ventilation via tracheostomy) to sleep and **do not sleep without it**
-

12. Do you require **respiratory (breathing) support**?

- ☐ **no respiratory support**
- ☐ **intermittent use of BiPAP®**
- ☐ continuous use of **BiPAP® at night**
- ☐ continuous use of **BiPAP® at night and during the day** (nearly 24 hours per day)
- ☐ **mechanical ventilation** by intubation or tracheostomy

(BiPAP® is commonly used to describe non-invasive positive pressure ventilation and its use here in no way endorses or promotes a particular product)

Under each heading, please tick the ONE box that best describes your health TODAY

MOBILITY

- I have no problems in walking about ☐
- I have slight problems in walking about ☐
- I have moderate problems in walking about ☐
- I have severe problems in walking about ☐
- I am unable to walk about ☐

SELF-CARE

- I have no problems washing or dressing myself ☐
- I have slight problems washing or dressing myself ☐
- I have moderate problems washing or dressing myself ☐
- I have severe problems washing or dressing myself ☐
- I am unable to wash or dress myself ☐

USUAL ACTIVITIES (*e.g. work, study, housework, family or leisure activities*)

- I have no problems doing my usual activities ☐
- I have slight problems doing my usual activities ☐
- I have moderate problems doing my usual activities ☐
- I have severe problems doing my usual activities ☐
- I am unable to do my usual activities ☐

PAIN / DISCOMFORT

- I have no pain or discomfort ☐
- I have slight pain or discomfort ☐
- I have moderate pain or discomfort ☐
- I have severe pain or discomfort ☐
- I have extreme pain or discomfort ☐

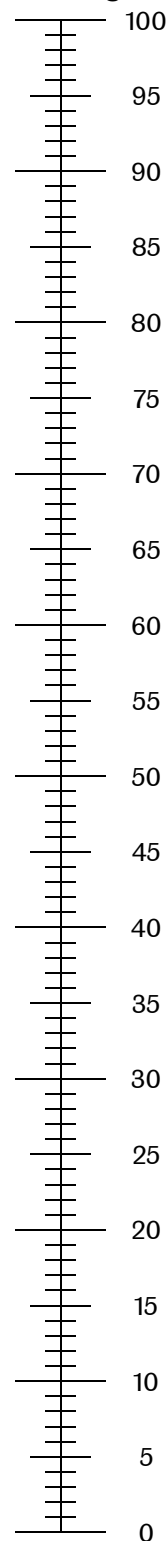
ANXIETY / DEPRESSION

- I am not anxious or depressed ☐
- I am slightly anxious or depressed ☐
- I am moderately anxious or depressed ☐
- I am severely anxious or depressed ☐
- I am extremely anxious or depressed ☐

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100
- 100 means the best health you can imagine.
0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

The best health
you can imagine



The worst health
you can imagine

Below you will find a list of statements.

Please rate how true each statement is for you by circling a number next to it.

Use the scale below to make your choice.

| | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | | | | |
|----|--|------------|------------------|-------------|----------------|-----------------|--------------------|-------------|----------------|-----------------|--------------------|-------------|
| | | never true | very seldom true | seldom true | sometimes true | frequently true | almost always true | always true | | | | |
| | | | | | | Never true | Very seldom true | Seldom true | Sometimes true | Frequently true | Almost always true | Always true |
| 1. | My painful experiences and memories make it difficult for me to live a life that I would value | | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2. | I'm afraid of my feelings | | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3. | I worry about not being able to control my worries and feelings | | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 4. | My painful memories prevent me from having a fulfilling life | | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 5. | Emotions cause problems in my life | | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 6. | It seems like most people are handling their lives better than I am | | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 7. | Worries get in the way of my success | | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

COMMEND RCT

Adapted CSRI

P /

9 months

Primary & community services

Have you used any of the following in the last 3 months?

☐ Yes ☐ No
↓

| (✓) | Service (please tick all that apply) | Number of visits | Average duration | Additional information (if any) |
|---|---|---|--|------------------------------------|
| For example, if you saw your GP three (3) times in the last 3 months and most visits were about 10 minutes long, complete as follows: | | | | |
| <input checked="" type="checkbox"/> | GP | 03 | 10 mins | |
| <input type="checkbox"/> | GP | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | Physiotherapist | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | Occupational therapist | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | Speech & Language therapist | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | Dietician | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | Nutrition nurse | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | Social worker | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | MNDA advisor | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | MNDA volunteer visitor | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | Psychologist / psychotherapist | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | Community mental health team | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | Home help (household tasks) | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | Home help (personal care) | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | Palliative care nurse | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | MND nurse specialist | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | Respiratory nurse specialist | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | District nurse | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | Sitting service (charity provision) | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | Counselling | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | Alternative therapist (e.g. homeopath) | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | Other, please specify: <input type="text"/> | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | Other, please specify: <input type="text"/> | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |
| <input type="checkbox"/> | Other, please specify: <input type="text"/> | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> mins | |

COMMEND RCT

Adapted CSRI

P /

9 months

— Hospital, nursing home, or hospice inpatient services —

Have you used any of the following in the last 3 months?

☐ Yes ☐ No
↓

| (✓) | Service (please tick all that apply) | Number of visits | Total nights | Additional information (if any) |
|---|---|---|---|------------------------------------|
| <i>For example, if you used a hospice for respite two (2) times in the last 3 months and you stayed for 2 nights for the first time and 3 for the second, complete as follows</i> | | | | |
| <input checked="" type="checkbox"/> | Hospice (including for respite care) | <input type="text"/> 0 <input type="text"/> 2 | <input type="text"/> 0 <input type="text"/> 5 | <input type="text"/> |
| <input type="checkbox"/> | Nursing or residential home | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> | <input type="text"/> |
| <input type="checkbox"/> | Hospice (including for respite care) | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> | <input type="text"/> |
| <input type="checkbox"/> | Neurology inpatient ward | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> | <input type="text"/> |
| <input type="checkbox"/> | Intensive care unit | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> | <input type="text"/> |
| <input type="checkbox"/> | Admission for gastrostomy tube insertion / management | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> | <input type="text"/> |
| <input type="checkbox"/> | Admission for NIV / IV assessment / management | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> | <input type="text"/> |
| <input type="checkbox"/> | Other inpatient ward, specify type of ward: <input type="text"/> | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> | <input type="text"/> |
| <input type="checkbox"/> | Other inpatient ward, specify type: <input type="text"/> | <input type="text"/> <input type="text"/> | <input type="text"/> <input type="text"/> | <input type="text"/> |

— Outpatient and day care services —

Have you attended any of the following in the last 3 months?

☐ Yes ☐ No
↓

| (✓) | Service (please tick all that apply) | Number of attendances | Average duration | Additional information (if any) |
|--------------------------|---|--|---|---------------------------------------|
| <input type="checkbox"/> | Neurology outpatient ward | <input type="text"/> <input type="text"/> in last 3 months | <input type="text"/> <input type="text"/> <input type="text"/> mins | <input type="text"/> |
| <input type="checkbox"/> | Other hospital outpatient visit, specify: <input type="text"/> | <input type="text"/> <input type="text"/> in last 3 months | <input type="text"/> <input type="text"/> <input type="text"/> mins | <input type="text"/> |
| <input type="checkbox"/> | Day care centre (nursing home) | <input type="text"/> <input type="text"/> in last 3 months | <input type="text"/> <input type="text"/> <input type="text"/> mins | <input type="text"/> |
| <input type="checkbox"/> | Day care centre (hospice) | <input type="text"/> <input type="text"/> in last 3 months | <input type="text"/> <input type="text"/> <input type="text"/> mins | <input type="text"/> |
| <input type="checkbox"/> | A&E visit (without admission) | <input type="text"/> <input type="text"/> in last 3 months | <input type="text"/> <input type="text"/> <input type="text"/> mins | <input type="text"/> |

9 months

Equipment

Have you obtained (bought, been supplied with, or been loaned) any of the following equipment in the last **3** months because of your ALS / PMA / PLS?

☐ Yes ☐ No
↓

| (✓) Service (please tick all that apply) | Provider (if more than one provider, please tick all that apply) | | | | | |
|---|---|-----------------------------|----------------------------------|-------------------------------|---------------------------------|----------------------|
| <input type="checkbox"/> Ankle / foot orthotic | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Walking aid – cane | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Walking aid – zimmer / rollator | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Wheelchair - manual | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Wheelchair - electric | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Adapted car with wheelchair access | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Mobile arm support | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Lightwriter | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Speech amplifier | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Stairlift | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Specialist cutlery / cups / plates | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Riser recliner chair | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Specialist bed | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Mattress elevator | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Hoist – bedroom / mobile | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Wash and dry toilet | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Bath hoist | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Neck support | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Specialist computer equipment | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Environmental controls / switch | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Feeding pump (gastrostomy) | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Breathing equipment (NIV) | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |
| <input type="checkbox"/> Other, please specify: <input type="text"/> | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: | <input type="text"/> |

9 months

Home adaptations

Have any of the following adaptations been made to your home in the last **3** months because of your ALS / PMA / PLS?

☐ Yes ☐ No



| (✓) | Service (please tick all that apply) | Provider (if more than one provider, please tick all that apply) | | | | |
|--------------------------|--|---|-----------------------------|----------------------------------|-------------------------------|--|
| <input type="checkbox"/> | Extension built | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: <input type="text"/> |
| <input type="checkbox"/> | Downstairs toilet installed | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: <input type="text"/> |
| <input type="checkbox"/> | Downstairs shower installed | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: <input type="text"/> |
| <input type="checkbox"/> | Wheelchair ramps installed | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: <input type="text"/> |
| <input type="checkbox"/> | Doors widened | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: <input type="text"/> |
| <input type="checkbox"/> | Bathroom adapted | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: <input type="text"/> |
| <input type="checkbox"/> | Through floor lift / elevator | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: <input type="text"/> |
| <input type="checkbox"/> | Hand rails installed | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: <input type="text"/> |
| <input type="checkbox"/> | Other, please specify: <input type="text"/> | <input type="checkbox"/> NHS | <input type="checkbox"/> LA | <input type="checkbox"/> Charity | <input type="checkbox"/> Self | <input type="checkbox"/> Other: <input type="text"/> |

Continued on the next page

— Psychological therapies

Have you accessed any of the following psychological therapies from external sources (i.e. not as part of the trial) in the last 3 months?

Yes No

↓

| (✓) | Therapy (please tick all that apply) | Number of attendances | Average duration | Provider | |
|--------------------------|---|--------------------------|--|------------------------------|----------------------------------|
| <input type="checkbox"/> | CBT (Cognitive Behavioural Therapy) (A talking therapy with an emphasis on changing thoughts by looking at the evidence for and against them, and an emphasis on changing behaviours.) | <div></div> <div></div> | <div></div> <div></div> <div></div> mins | <input type="checkbox"/> NHS | <input type="checkbox"/> Private |
| <input type="checkbox"/> | Relaxation therapy (A talking therapy with an emphasis on learning deep breathing or muscle relaxation skills.) | <div></div> <div></div> | <div></div> <div></div> <div></div> mins | <input type="checkbox"/> NHS | <input type="checkbox"/> Private |
| <input type="checkbox"/> | Mindfulness-Based Cognitive Therapy or Mindfulness-based Stress Reduction (A talking therapy with an emphasis on observing thoughts and feelings and allowing them to be rather than trying to change them.) | <div></div> <div></div> | <div></div> <div></div> <div></div> mins | <input type="checkbox"/> NHS | <input type="checkbox"/> Private |
| <input type="checkbox"/> | Counselling (A talking therapy with a focus on the client doing most of the talking, with little skills practice in session and at home.) | <div></div> <div></div> | <div></div> <div></div> <div></div> mins | <input type="checkbox"/> NHS | <input type="checkbox"/> Private |
| <input type="checkbox"/> | Psychodynamic therapy (A talking therapy focussed on the past, on the subconscious, and on repeating patterns in relationships.) | <div></div> <div></div> | <div></div> <div></div> <div></div> mins | <input type="checkbox"/> NHS | <input type="checkbox"/> Private |
| <input type="checkbox"/> | Behavioural activation (A talking therapy aimed at helping to increase activities that give a sense of pleasure or mastery / achievement in one's life.) | <div></div> <div></div> | <div></div> <div></div> <div></div> mins | <input type="checkbox"/> NHS | <input type="checkbox"/> Private |
| <input type="checkbox"/> | Systemic therapy (A talking therapy aimed at helping families or couples to explore difficulties they are experiencing.) | <div></div> <div></div> | <div></div> <div></div> <div></div> mins | <input type="checkbox"/> NHS | <input type="checkbox"/> Private |
| <input type="checkbox"/> | Not sure of therapy type (Received a form of talking therapy but not sure what type.) | <div></div> <div></div> | <div></div> <div></div> <div></div> mins | <input type="checkbox"/> NHS | <input type="checkbox"/> Private |
| <input type="checkbox"/> | Other, please state / describe <div></div> | <div></div> <div></div> | <div></div> <div></div> <div></div> mins | <input type="checkbox"/> NHS | <input type="checkbox"/> Private |

Treatment allocation

What treatment arm do you think the participant has been allocated to?

☐ ACT with usual care

☐ Usual care alone

How certain are you of the participant's allocation?

☐ 0 – not at all sure

☐ 1

☐ 2

☐ 3

☐ 4 – very sure

Has the participant been given an honorarium of £20 voucher at this follow-up point?

NOTE: Participants should be offered a voucher at each follow-up point, even if they have not completed the follow-up visit.

☐ Yes

☐ No

☐ Declined

☐ Other, specify:

Has the participant / participant's representative signed the payment form(s) to confirm receipt of the voucher(s)?

☐ Yes

☐ No

reason

