

Day 000 IQCODE

Record ID _____



UK ISRCTN 98886991
UK IRAS306761
UK CPMS 50913
WHO UTN U1111-1273-9942

Pharyngeal Electrical stimulation for Acute Stroke dysphagia Trial (PhEAST)

Day 000 IQCODE v1.2

Informant Questionnaire on Cognitive Decline in the Elderly

- ▶ Please check consent form obtained.
- ▶ Please check Eligibility form completed.
- ▶ Please check Baseline & Baseline Clinical, EQ-5D, EQ-VAS forms completed.

Section A: Participant details

A1. Centre name:

(Centre)

A2. Participant ID :

(Participant ID)

A3. Participant initials (e.g. ABC or A-C) :

(3 uppercase letters, or 2 separated by a hyphen (-))

Section B: Informant

B1. Assessment start time

(Date DD-MM-YYYY HH:MM)

B2. Has an informant been consented?

Yes No

If "No" is selected, the form does not have to be filled in.

Enter the assessor's details and any comments before completing the CRF.

B3a. Relationship to Participant

- Partner or spouse
 Daughter
 Son
 Sibling
 Other relative
 Friend or neighbour
 Other

B3b. If 'Other', please specify relationship

B4. Informant ID

(Auto calculated (2000 + trial ID))

△ Informant details questions B2-B3 should all be answered.

Section C: Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)

Now we want you to remember what your friend or relative was like 10 years ago and to compare it with what he/she is like now.

Below are situations where this person has to use his/her memory or intelligence and we want you to indicate whether this has improved, stayed the same, or got worse in that situation over the past 10 years.

Note the importance of comparing his/her present performance with 10 years ago. So if 10 years ago this person always forgot where he/she had left things, and he/she still does, then this would be considered "Hasn't changed much". Please indicate the changes you have observed by selecting the appropriate answer.

Average IQCODE score per question [iqcode_avg_000]

1= Much improved - 5= Much worse

Compared with 10 years ago how is this person at:

	1 - Much improved	2 - A bit improved	3 - Not much change	4 - A bit worse	5 - Much worse
C1. Remembering things about family and friends, e.g. occupations, birthdays, addresses	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2. Remembering things that have happened recently	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C3. Recalling conversations a few days later	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C4. Remembering his/her address and telephone number	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C5. Remembering what day and month it is	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

C6. Remembering where things are usually kept	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C7. Remembering where to find things which have been put in a different place from usual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C8. Knowing how to work familiar machines around the house	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C9. Learning to use a new gadget or machine around the house	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C10. Learning new things in general	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C11. Following a story in a book or on TV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C12. Making decisions on everyday matters	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C13. Handling money for shopping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C14. Handling financial matters, e.g. the pension, dealing with the bank	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C15. Handling other everyday arithmetic problems, e.g. knowing how much food to buy, knowing how long between visits from family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C16. Using his/her intelligence to understand what's going on and to reason things through	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

△ IQCODE questions C1-C16 should all be answered.

Section D: The 4A Test - Collateral information (4AT)

Screening instrument for cognitive impairment and delirium

D. 4AT Acute change or fluctuating course

4: Yes 0: No Not done

Has there been a change or fluctuation in the participant's alertness, cognition or other mental functions (e.g. paranoia, hallucinations) over the last 2 weeks that are still evident in the last 24 hours?

△ 4AT question must be answered.

Section E: Neuropsychiatric Inventory, Questionnaire Version (NPI-Q)

Ask the informant to answer the following question based on changes that have occurred since the participant first began to experience memory problems.

Tell the informant to answer 'yes' only if the symptom has been present in the last month. Otherwise answer 'no'.

For each item marked "Yes":

a) Rate the SEVERITY of the symptom (how it affects the patient):

- 1 = Mild (noticeable, but not a significant change)
- 2 = Moderate (significant, but not a dramatic change)
- 3 = Severe (very marked or prominent, a dramatic change)

b) Rate the DISTRESS you experience due to that symptom (how it affects you):

- 0 = Not distressing at all
- 1 = Minimal (slightly distressing, not a problem to cope with)
- 2 = Mild (not very distressing, generally easy to cope with)
- 3 = Moderate (fairly distressing, not always easy to cope with)
- 4 = Severe (very distressing, difficult to cope with)
- 5 = Extreme or Very Severe (extremely distressing, unable to cope with)

(NPI-Q) Apathy

E1. Apathy: Yes No Not done

Does the participant seem less interested in his/her usual activities or in the activities and plans of others?

E1a. Apathy: severity (patient) 1: Mild
 2: Moderate
 3: Severe
 Not done
 (Severity: 1-Mild, 2-Moderate, 3-Severe)

E1b. Apathy: distress (affects you) 0: Not distressing
 1: Minimal
 2: Mild
 3: Moderate
 4: Severe
 5: Extreme or Very Severe
 Not done
 (Distress: 0-Not distressing, 1-Minimal, 2-Mild, 3-Moderate, 4-Severe, 5-Extreme & Very severe)

(NPI-Q) Delusions

E2. Delusions: Yes No Not done

Does the participant have false beliefs, such as thinking that others are stealing from him/her or planning to harm him/her in some way?

E2a. Delusions: severity (patient) 1: Mild
 2: Moderate
 3: Severe
 Not done
 (Severity: 1-Mild, 2-Moderate, 3-Severe)

E2b. Delusions: distress (affects you) 0: Not distressing
 1: Minimal
 2: Mild
 3: Moderate
 4: Severe
 5: Extreme or Very Severe
 Not done
 (Distress: 0-Not distressing, 1-Minimal, 2-Mild, 3-Moderate, 4-Severe, 5-Extreme & Very severe)

(NPI-Q) Hallucinations

E3. Hallucinations: Yes No Not done

Does the participant have hallucinations such as false visions or voices? Does he/she seem to hear or see things that are not present?

E3a. Hallucinations: severity (patient) 1: Mild
 2: Moderate
 3: Severe
 Not done
 (Severity: 1-Mild, 2-Moderate, 3-Severe)

E3b. Hallucinations: distress (affects you) 0: Not distressing
 1: Minimal
 2: Mild
 3: Moderate
 4: Severe
 5: Extreme or Very Severe
 Not done
 (Distress: 0-Not distressing, 1-Minimal, 2-Mild, 3-Moderate, 4-Severe, 5-Extreme & Very severe)

(NPI-Q) Agitation/Aggression

E4. Agitation/Aggression: Yes No Not done

Is the participant resistive to help from others at times, or hard to handle?

E4a. Agitation/Aggression: severity (patient) 1: Mild
 2: Moderate
 3: Severe
 Not done
 (Severity: 1-Mild, 2-Moderate, 3-Severe)

E4b. Agitation/Aggression: distress (affects you)

- 0: Not distressing
 1: Minimal
 2: Mild
 3: Moderate
 4: Severe
 5: Extreme or Very Severe
 Not done
 (Distress: 0-Not distressing, 1-Minimal, 2-Mild, 3-Moderate, 4-Severe, 5-Extreme & Very severe)

(NPI-Q) Depression/Dysphoria

E5. Depression/Dysphoria:

- Yes No Not done

Does the participant seem sad or say that he/she is depressed?

E5a. Depression/Dysphoria: severity (patient)

- 1: Mild
 2: Moderate
 3: Severe
 Not done
 (Severity: 1-Mild, 2-Moderate, 3-Severe)

E5b. Depression/Dysphoria: distress (affects you)

- 0: Not distressing
 1: Minimal
 2: Mild
 3: Moderate
 4: Severe
 5: Extreme or Very Severe
 Not done
 (Distress: 0-Not distressing, 1-Minimal, 2-Mild, 3-Moderate, 4-Severe, 5-Extreme & Very severe)

(NPI-Q) Anxiety

E6. Anxiety:

- Yes No Not done

Does the participant become upset when separated from you? Does he/she have any other signs of nervousness such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?

E6a. Anxiety: severity (patient)

- 1: Mild
 2: Moderate
 3: Severe
 Not done
 (Severity: 1-Mild, 2-Moderate, 3-Severe)

E6b. Anxiety: distress (affects you)

- 0: Not distressing
 1: Minimal
 2: Mild
 3: Moderate
 4: Severe
 5: Extreme or Very Severe
 Not done
 (Distress: 0-Not distressing, 1-Minimal, 2-Mild, 3-Moderate, 4-Severe, 5-Extreme & Very severe)

(NPI-Q) Elation/Euphoria

E7. Elation/Euphoria: Yes No Not done

Does the participant appear to feel too good or act excessively happy?

E7a. Elation/Euphoria: severity (patient) 1: Mild
 2: Moderate
 3: Severe
 Not done
 (Severity: 1-Mild, 2-Moderate, 3-Severe)

E7b. Elation/Euphoria: distress (affects you) 0: Not distressing
 1: Minimal
 2: Mild
 3: Moderate
 4: Severe
 5: Extreme or Very Severe
 Not done
 (Distress: 0-Not distressing, 1-Minimal, 2-Mild, 3-Moderate, 4-Severe, 5-Extreme & Very severe)

(NPI-Q) Disinhibition

E8. Disinhibition: Yes No Not done

Does the patient seem to act impulsively, for example, talking to strangers as if he/she knows them, or saying things that may hurt people's feelings?

E8a. Disinhibition: severity (patient) 1: Mild
 2: Moderate
 3: Severe
 Not done
 (Severity: 1-Mild, 2-Moderate, 3-Severe)

E8b. Disinhibition: distress (affects you) 0: Not distressing
 1: Minimal
 2: Mild
 3: Moderate
 4: Severe
 5: Extreme or Very Severe
 Not done
 (Distress: 0-Not distressing, 1-Minimal, 2-Mild, 3-Moderate, 4-Severe, 5-Extreme & Very severe)

(NPI-Q) Irritability/Lability

E9. Irritability/Lability: Yes No Not done

Is the participant impatient and cranky? Does he/she have difficulty coping with delays or waiting for planned activities?

E9a. Irritability/Lability: severity (patient) 1: Mild
 2: Moderate
 3: Severe
 Not done
 (Severity: 1-Mild, 2-Moderate, 3-Severe)

E9b. Irritability/Lability: distress (affects you)

- 0: Not distressing
 1: Minimal
 2: Mild
 3: Moderate
 4: Severe
 5: Extreme or Very Severe
 Not done
 (Distress: 0-Not distressing, 1-Minimal, 2-Mild, 3-Moderate, 4-Severe, 5-Extreme & Very severe)

(NPI-Q) Motor disturbance

E10. Motor disturbance:

- Yes No Not done

Does the participant engage in repetitive activities such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly?

E10a. Motor disturbance: severity (patient)

- 1: Mild
 2: Moderate
 3: Severe
 Not done
 (Severity: 1-Mild, 2-Moderate, 3-Severe)

E10b. Motor disturbance: distress (affects you)

- 0: Not distressing
 1: Minimal
 2: Mild
 3: Moderate
 4: Severe
 5: Extreme or Very Severe
 Not done
 (Distress: 0-Not distressing, 1-Minimal, 2-Mild, 3-Moderate, 4-Severe, 5-Extreme & Very severe)

(NPI-Q) Nighttime behaviour

E11. Nighttime behaviour:

- Yes No Not done

Does the participant awaken you during the night, rise too early in the morning, or take excessive naps during the day?

E11a. Nighttime behaviour: severity (patient)

- 1: Mild
 2: Moderate
 3: Severe
 Not done
 (Severity: 1-Mild, 2-Moderate, 3-Severe)

E11b. Nighttime behaviour: distress (affects you)

- 0: Not distressing
 1: Minimal
 2: Mild
 3: Moderate
 4: Severe
 5: Extreme or Very Severe
 Not done
 (Distress: 0-Not distressing, 1-Minimal, 2-Mild, 3-Moderate, 4-Severe, 5-Extreme & Very severe)

(NPI-Q) Appetite/Eating

E12. Appetite/Eating: Yes No Not done

Has the participant lost or gained weight, or had a change in the type of food he/she likes?

E12a. Appetite/Eating: severity (patient) 1: Mild
 2: Moderate
 3: Severe
 Not done
 (Severity: 1-Mild, 2-Moderate, 3-Severe)

E12b. Appetite/Eating: distress (affects you) 0: Not distressing
 1: Minimal
 2: Mild
 3: Moderate
 4: Severe
 5: Extreme or Very Severe
 Not done
 (Distress: 0-Not distressing, 1-Minimal, 2-Mild, 3-Moderate, 4-Severe, 5-Extreme & Very severe)

△ NPI-Q questions E1-E12 should all be answered.

Section F: Lawton Activities of Daily Living (ADL)**LAWTON - BRODY****INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (I.A.D.L.)**

* ♀♂ **In the late 1960s, Lawton and Brody used the scale to assess all eight domains of function for women but only five for men (food preparation, housekeeping, and laundry were excluded).**

A summary score ranges from 0 (low function, dependent) to 8 (high function, independent) for women and 0 through 5 for men to avoid potential gender bias.

F1a. Ability to use telephone

- 1 - Operates telephone on own initiative; looks up and dials numbers, etc.
 1 - Dials a few well-known numbers
 1 - Answers telephone but does not dial
 0 - Does not use telephone at all

F1b. Shopping

- 1 - Takes care of all shopping needs independently
 0 - Shops independently for small purchases
 0 - Needs to be accompanied on any shopping trip
 0 - Completely unable to shop

F1c. ♀ Food preparation *

- 1 - Plans, prepares and serves adequate meals independently
- 0 - Prepares adequate meals if supplied with ingredients
- 0 - Heats, serves and prepares meals or prepares meals but does not maintain adequate diet
- 0 - Needs to have meals prepared and served

F1d. ♀ Housekeeping *

- 1 - Maintains house alone or with occasional assistance
- 1 - Performs light daily tasks such as dishwashing bed making
- 1 - Performs light daily tasks but cannot maintain acceptable level of cleanliness
- 1 - Needs help with all home maintenance tasks
- 0 - Does not participate in any housekeeping tasks

F1e. ♀ Laundry *

- 1 - Does personal laundry completely
- 1 - Launders small items, rinses stockings, etc
- 0 - All laundry must be done by others

F1f. Mode of transportation

- 1 - Travels independently on public transport or drives own car
- 1 - Arranges own travel via taxi, but does not otherwise use public transport
- 1 - Travels on public transport when accompanied
- 0 - Travel limited to taxi or automobile with assistance of another
- 0 - Does not travel at all

F1g. Responsibility for own medications

- 1 - Is responsible for taking medication in correct dosages at correct time
- 0 - Takes responsibility if medication is prepared in advance in separate dosage
- 0 - Is not capable of dispensing own medication

F1h. Ability to handle finances

- 1 - Manages financial matters independently, collects and keeps track of income
- 1 - Manages day-to-day purchases, but needs help with banking, major purchases, etc
- 0 - Incapable of handling money

△ I.A.D.L. questions F1a-F1h should all be answered.

Section G: Assessor information

G1. Please enter the name of the person who collected the information

G2a. What is his/her professional role?

- Doctor
 - Research coordinator
 - Nurse, clinical
 - Research nurse
 - Physiotherapist
 - Occupation therapist
 - Speech & Language therapist
 - Other
- (Choose one answer)

G2b. If "Other", please specify role

G3. Does his/her role involve working on stroke wards?

Yes No

G4. Please enter your name if you did not collect the information

G5. Please sign the form

(✍️ Signature)

Assessment completed

G6. Date & time assessment completed? Enter date and time the assessment was completed. This will be used to monitor the time required to complete the test.

Comments and full explanation for missing data

Are any values missing due to tests not done (or measures not taken), or because data are unknown and every effort has been made to find the data - i.e. 'Not done' / 'Not known'?

Yes
 No

If any values are missing, please provide a full explanation ☐☐ Comments