

iCST: Individual Cognitive Stimulation Therapy for People with Dementia

This booklet of questionnaires should be completed by the researcher in an interview with the carer.

General Instructions to Interviewer

Before commencing the interview, please ensure that the **Participant Identity Number** has been entered in the boxes below.

Subsequent processing of these questionnaires involves photocopying and the use of data scanning equipment.

To ensure the smooth operation of the equipment, it would be appreciated if the following could be observed:

- Please complete the form using a **black** ballpoint pen.
- Please do not fold or crease the form.
- Please complete all the questions.
- Please enter your responses in the boxes/spaces provided, as instructed.
- Please use only a single line to delete mistakes and initial each such correction.

At the end of the interview please complete the remaining boxes below.

Your cooperation is very much appreciated.

To be completed by the interviewer

Participant Identity Number:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Centre Name: _____

Which assessment is this? *Please tick one box only.*

Baseline Assessment

1st Follow-up *(13 weeks after baseline)*

2nd Follow-up *(26 weeks after baseline)*

Completed by (please print name): _____

Signed: _____

Interview date:

		/			/				
--	--	---	--	--	---	--	--	--	--

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Section 1: Participant

1. How many people are there in your relative's (participant's) household?

Number

Number of adults including service user

Number of children under the age of 16

2. What kind of accommodation does your relative (participant) live in at the moment? (tick *one* box)

Council-rented housing

Housing-association rented housing

Private rented housing

Owner-occupied housing

Other housing

Please describe

3. Is your relative's (participant's) accommodation "sheltered" housing (has a warden or scheme manager on-site)?

Yes

No

4. Has your relative (participant) lived anywhere else during the last 3 months? (excluding hospital stays)

Yes → *Go to Q5*

No → *Go to Q6*

5. What type of accommodation did your relative (participant) stay in at that time?

If participant reports a stay in a care/nursing home or other location, complete the questions in that row.

For 'Participant or family contribution', ask: 'Did you or a family member pay for this accommodation?' and tick yes if the person reports having paid all or part of the costs

Service	No	Yes	Reason for using service (e.g. respite)	Name of home (not to be entered into database)	Number of days	Participant or family contribution		Provider (see note*)
						No	Yes	
Care home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nursing home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other - please describe using 'Name of home' box	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*[*Note: Use the "Name of home" information to complete the Provider box, using WHO codes, after the interview]*

WHO codes

1	Local Authority/Social Services/Council
2	NHS
3	Voluntary/charitable organisation
4	Private company or insurance company
5	Self or family members
6	Other
7	Researcher unable to classify response
8	Not completed

Community health and social services

6. In the last 3 months, has your relative (participant) used any of the services below? [SHOW CARD 1]

Note: please tick the 'no' box if participant has not used the service

Service	No	Yes	Number of home visits		Number of clinic or office visits		Average duration of contact (minutes)		
GP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Practice nurse (at GP surgery)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community/District Nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community psychiatric/Community Mental Health Nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychiatrist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social worker or care manager	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Occupational therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dietician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Counsellor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mental health team worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialist nurse (e.g. Admiral Nurse, palliative care nurse, respiratory nurse)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>please describe:</i>									

7. In the **last 3 months**, has your relative (participant) used any of the services below? [SHOW CARD 2]

Note: please tick the 'no' box if participant has not used the service

For 'Participant or family contribution', ask: 'Did you or a family member pay for this service?' and tick yes if the person reports having paid all or part of the costs

Service	No	Yes	Number of home visits	Number of clinic or office visits	Average duration of contact (minutes)	Participant or family contribution	
						No	Yes
Home care/home help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home care/home help - Additional organisation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home care/home help - Additional organisation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cleaner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meals on wheels	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Laundry service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sitting service (e.g. Crossroads)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Carer's support worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Optician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chiropodist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dentist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other health or social care services:							
1.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Day services

8. In the last 3 months, has your relative (participant) used any of the day services below?

[SHOW CARD 3]

Note: please tick the 'no' box if participant has not used the service

For 'Participant or family contribution', ask: 'Did you or a family member pay for this service?' and tick yes if the person reports having paid all or part of the costs

Service	No		Yes		Number of times per week	Number of times in last 3 months	Name of service (not to be entered into database)	Participant or family paid or contributed		Provider (see note*)
	No	Yes	No	Yes				No	Yes	
Day centre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lunch club	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient education group (e.g. reminiscence) <i>please describe:</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other health or social care day services:										
1.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*[*Note: Use the "Name of service" information to complete the Provider box, using WHO codes, after the interview]*

Direct Payments

9. Has your relative (participant) been in receipt of direct payments, individual budget or personal budget* in the last 3 months?

Direct payments/Personal Budgets	No	Yes	Total weekly value in £
Direct payments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Individual budget / Personal budget	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

**see Q9 definitions card*

Use of Hospital services

10. In the last 3 months, has your relative (participant) used any of the following hospital services?

Note: please tick the 'no' box if participant has not used the service

Service	No	Yes	Name of ward, clinic hospital or centre	Reason for using service (condition, specialty)	Unit of measurement	Number of days/ attendances	NHS Trust code*
Accident & Emergency Department (A&E)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	Attendance	<input type="text"/> <input type="text"/>	<input type="text"/>
Inpatient ward admission 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	Inpatient day	<input type="text"/> <input type="text"/>	<input type="text"/>
Inpatient ward admission 2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	Inpatient day	<input type="text"/> <input type="text"/>	<input type="text"/>
Inpatient ward admission 3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	Inpatient day	<input type="text"/> <input type="text"/>	<input type="text"/>
Inpatient ward admission 4	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	Inpatient day	<input type="text"/> <input type="text"/>	<input type="text"/>
Inpatient ward admissions 5	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	Inpatient day	<input type="text"/> <input type="text"/>	<input type="text"/>
Outpatient Department (OPD) Attendance 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	Appointment	<input type="text"/> <input type="text"/>	<input type="text"/>
OPD Attendance 2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	Appointment	<input type="text"/> <input type="text"/>	<input type="text"/>
OPD Attendance 3	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	Appointment	<input type="text"/> <input type="text"/>	<input type="text"/>
OPD Attendance 4	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	Appointment	<input type="text"/> <input type="text"/>	<input type="text"/>
OPD Attendance 5	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	Appointment	<input type="text"/> <input type="text"/>	<input type="text"/>
Day hospital Attendance 1	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	Day attendance	<input type="text"/> <input type="text"/>	<input type="text"/>
Day hospital Attendance 2	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	Day attendance	<input type="text"/> <input type="text"/>	<input type="text"/>

*[*Note: Use 'name of hospital' information to assign NHS Trust code after the interview]*

Equipment and adaptations

11. In the last 3 months, has your relative (participant) had any adaptations or equipment to meet their needs? [SHOW CARD 4]

Yes

No

If yes, tick the box for each type of change or equipment that the participant has had and ask 'who or which organisation paid for these'.

Type of adaptation or equipment	Tick if yes	Who/Which organisation paid for this?				
		Council	NHS	Self	Voluntary /charity	Other
Outdoor railing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Outdoor ramp	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Grab rail/Stair rail	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walk-in shower/shower cubicle replacing bath	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Over-bath shower	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walking stick	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walking frame	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Wheelchair	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hoist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kitchen trolley	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kitchen stool	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Toilet frame/raised seat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Commode	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bed lever/rail	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bath seat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Continence pads	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12. Any other adaptations or equipment in the last 3 months: please describe.

If yes, tick the box for each type of adaptations or equipment that the participant has had and ask 'who or which organisation paid for these'.

Type of adaptation or equipment	Tick if yes	Who/which organisation paid for this?				
		Council	NHS	Self	Voluntary	Other
1. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Medications

13. Has your relative (participant) taken any medications for his/her condition over the last 3 months?

Tradename	First day dd/mm/yy	Last day (if applicable) dd/mm/yy	Ongoing (if applicable)	Dose	Medication unit code	Frequency code	Medication code*
DEMENTIA DRUGS	dd/mm/yy	dd/mm/yy					
	_/ _/ _	_/ _/ _	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
	_/ _/ _	_/ _/ _	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
	_/ _/ _	_/ _/ _	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
	_/ _/ _	_/ _/ _	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
	_/ _/ _	_/ _/ _	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
OTHER MENTAL HEALTH DRUGS							
	_/ _/ _	_/ _/ _	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
	_/ _/ _	_/ _/ _	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
	_/ _/ _	_/ _/ _	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
	_/ _/ _	_/ _/ _	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
	_/ _/ _	_/ _/ _	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>

[*Note: Use 'Tradename' information to assign medication code after the interview]

Tick if participant does not take any medications for his/her condition

Medication unit codes

1	mg	7	Drops
2	microgram	8	Sprays (spray)
3	gram	9	Bottles
4	ml	10	Packs
5	Tubs/tubes	11	IU (injections)
6	Puffs (inhalers)	99	Other - give details

Medication frequency codes

1	Once daily	7	Once a week
2	Twice daily	8	Once every two weeks
3	Three times daily	9	Once every three weeks
4	Four times daily	10	Once every four weeks
5	Three times a week	11	Once every five weeks
6	Twice a week	88	As required / "PRN"

Benefits

14. Over the past 3 months has your relative (participant) received any of the following state benefits? (include payments made jointly to others in household) [SHOW CARD 5]

	Service User (participant) (tick as many as apply)	Other member of household (1.Spouse/partner 2. Child 3. Other)	How long has service user (participant) received this benefit (in weeks, over the last 3 months)
State Retirement (old age) Pension	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
Widow's or War Widow's Pension	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
Pension Credit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
War Disablement Pension	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
Winter fuel payment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
Income Support/Minimum Income Guarantee (MIG)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
Severe Disablement Allowance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
Disability Living Allowance Care Component	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
Disability Living Allowance Care Component rate: 1. high 2. medium 3. low	<input type="checkbox"/>		
Disability Living Allowance, Mobility Component	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
Disability Living Allowance Mobility Component rate: 1. high 2. low	<input type="checkbox"/>		
Attendance Allowance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
Housing Benefit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
Council Tax Benefit (discount)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
Incapacity Benefit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
Any other state benefit not listed (please state)_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
Any other state benefit not listed (please state)_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
Any other state benefit not listed (please state)_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
Tick if participant does not receive any state benefits	<input type="checkbox"/>		

Section 2: Carer

1. Do you live with your relative (the service user/participant)?

Yes → *Go to Q5*

No → *Go to Q2*

2. How many people are there in your household?

Number

Number of adults (including responder)

Number of children under the age of 16

3. What kind of accommodation do you live in at the moment? (tick *one* box)

Council-rented housing

Housing-association rented housing

Private rented housing

Owner-occupied housing

Other housing

Please describe

4. Is your accommodation “sheltered” housing (has a warden or scheme manager on-site)?

Yes

No

Employment

5. Which of the following best describes your current employment situation?

(Tick the one box that applies best to carer's situation)

In paid employment



GO TO Q6

Retired



Go to Q8

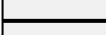
Unable to work



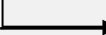
Unemployed and looking for work



At home and not looking for work (e.g. housewife/husband)



Doing voluntary work



Student (full or part-time)



Other *(Please describe)*

If carer is employed:

6. What is your current job(s)/occupation(s)?

7. Number of hours you work per week in all the jobs you do

If carer is unemployed/unable to work/at home/retired:

8. When were you last employed? (Month/Year)

mm

yy

9. What was/were your most recent job(s)/occupation(s)?

10. Have you given up or cut down on work in order to provide care for your relative?

Yes, given up work



Go to Q11

Yes, cut down



No



Go to Q13

If carer gave up or cut down work:

11. When did this happen? (Month/Year)

mm

yy

12. **If carer cut down on work:**

By how much did you cut down on work each week?

Hours per week

***If the carer lives with the service user/participant, ask Q13
If the carer does not live with the service user/participant, ask Q14***

13. On a typical day, how much time do you spend looking after/providing help for your relative? (*Tick if yes*)

- Provides no help in a typical day
 - Less than 1 hour
 - More than 1 hour and up to 2 hours
 - More than 2 hours and up to 3 hours
 - More than 3 hours and up to 5 hours
 - More than 5 hours and up to 10 hours
 - More than 10 hours, but not overnight
 - More than 10 hours *and/including* overnight
 - Other, describe:
-

14. How many hours do you spend each week looking after/providing help to your relative? (*If the carer does not live with the service user*)

Hours per week

15. On a typical day, what tasks do you usually help your relative with? (*Tick as many as apply*)

- Personal care
 - Helping with finances
 - Practical help
 - Taking the person to appointments
 - Medications
 - Keeping the person company
 - Making sure the person is safe (supervision)
 - Other, describe:
-

Other carers

16. Other than yourself, do other friends or relatives regularly help/provide care for your relative?

Yes

No

17. If yes, thinking about an average week, and about all such carers, for how many hours do they help/provide care for your relative? (If no, write 0 in boxes and go to next question)

Hours per week

18. Have any **friends and relatives** taken time off paid work over the last 3 months to help/provide care for your relative?

Yes

No

19. If yes, can you estimate the total number of days relatives/friends have taken off work over the last 3 months to help/provide care for your relative? (If no, write 0 in boxes and go to next question)

Total days

TRAVEL COSTS

20. In the last 3 months, have you accompanied your relative to any clinic, hospital, or day services for his/her condition?

Yes → **Go to Q21**

No → **Go to Q28**

21. If yes, over the last 3 months, how many times did you accompany your relative?

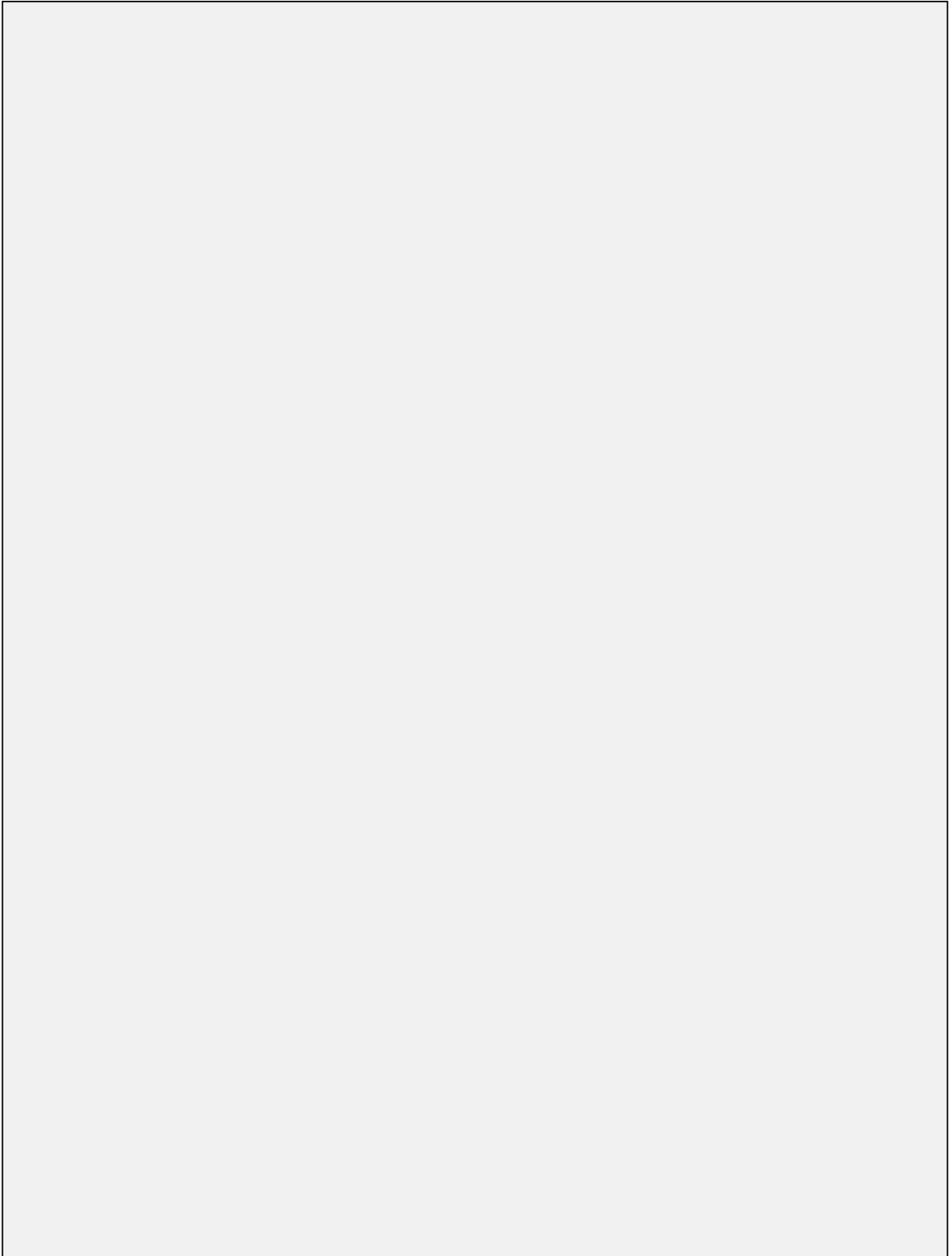
	Number of times per week	Number of times in last 3 months
Accompanied respondent	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>

22. How did you normally travel to get to the services your relative used (e.g. to go to your GP surgery or hospital)? If you used more than one form of transport please say how you travelled for the main/longest part of your journey.

[use TRANSPORT code]

TRANSPORT codes

1	Walked	7	Took hospital transport
2	Cycled	8	Went by ambulance
3	Took the bus	9	Other
4	Took the train		
5	Took a taxi		
6	Drove the car		



23. How long did it normally take to travel there from home?

	Hours	Minutes
Number of	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>

24. If you normally travelled by public transport, what was the cost of the fare in one direction (cost of a one-way ticket)?

	£	pence
Cost of one-way fare	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>

25. If you normally travelled by taxi, what was the cost of the fare in one direction (cost of a one-way journey)?

	£	pence
Cost of one-way fare	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>

26. If you normally travelled by car, how many miles/kilometres did you travel to get there (one-way journey)? (*write in underlined space whether using miles or kilometres*)

Number of <u> </u> one-way	<input type="text"/> <input type="text"/> <input type="text"/>
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27. If you normally travelled by car, if you had to pay for parking, how much did you pay?

	£	pence
Expenditure on parking	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>

Benefits

28. Over the past 3 months have you received any of the following state benefits? (include payments made jointly to others in household) [SHOW CARD 6]

	Carer (tick as many as apply)	Other member of carer's household (1. Spouse/partner 2. Child 3. Other)	How long has carer received this benefit (in weeks, over last 3 months)	
State Retirement (old age) Pension	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Widow's or War Widow's Pension	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pension Credit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
War Disablement Pension	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Winter fuel payment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Income Support/Minimum Income Guarantee (MIG)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Severe Disablement Allowance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Direct Payments from Social Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Disability Living Allowance Care Component	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Disability Living Allowance Care Component rate: 1. high 2. medium 3. low	<input type="checkbox"/>			
Disability Living Allowance Mobility Component	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Disability Living Allowance Mobility Component rate: 1. high 2. low	<input type="checkbox"/>			
Attendance Allowance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Carer's Allowance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Housing Benefit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Council Tax Benefit (discount)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Incapacity Benefit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Job Seeker's Allowance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Child Benefit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Working Tax Credit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any other state benefit not listed (please state)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any other state benefit not listed (please state)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Tick if carer does not receive any state benefits