# CSRI

This questionnaire should be completed by the researcher in an interview with the carer of the person with dementia (PwD).

# Section 1: PwD

1. How many people are there in the participant's household?

	Number
Number of adults including study participant	
Number of children under the age of 16 years	

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



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

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



## 5. What type of accommodation did the 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 the participant or a family member pay for this accommodation?' and tick ves if the person reports having naid 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	fai	pant or nily bution Yes	Provide (see note*
Care home								
Nursing								
Other - please describe using 'Name of home' box								

[\*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

## 6. In the <u>last 3 months</u>, has the study participant used any of the services below? [SHOW CARD 1 in the Response Book]

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

Service	No	Yes	No. of home visits	No. clinic or office visits	Average duration of contact (minutes)
GP					
Practice nurse (at GP surgery)					
Community/District Nurse					
Community psychiatric / Community Mental Health Nurse					
Psychiatrist					
Social worker or care manager					
Psychologist					
Physiotherapist					
Occupational therapist					
Dietician					
Counsellor					
Mental health team worker					
Specialist nurse (e.g. Admiral Nurse, palliative care nurse, respiratory nurse) - please describe in box					

## 7. In the <u>last 3 months</u>, has the participant used any of the services below? [SHOW CARD 2 in the Response Book]

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 ves if the person reports having paid all or part of the costs* 

Service	No Ves		Number of home visits	No. of clinic / office	Average duration of contact	Participant or family contribution	
				visits	(minutes)	No	Yes
Home care/home help							
Home care/home help: additional organisation							
Home care/home help: additional organisation							
Cleaner							
Meals on wheels							
Laundry service							
Sitting service (e.g. Crossroads)							
Carer's support worker							
Optician							
Chiropodist							
Dentist							
Other health or social care s	ervices	s:					
1							
2							

## 8. In the last 3 months has the participant used any of the day services below?

**[SHOW CARD 3 in the Response Book]** 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)	or fami	rticipant ly pay or ribute Yes	Provider (see note*)
Day centre								
Lunch club								
Patient education group (e.g. reminiscence) please describe:								
Other health or so	cial ca	are da	y services:					
1								
2								

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

# **Direct Payments**

**9.** Has the participant been in receipt of direct payments, individual budget or personal budget\* **in the last 3 months**? (\* **see Q9 definitions card in the Response Book**)

Direct payments / Personal Budgets	No	Yes	Total weekly value in £
Direct payments			
Individual budget / Personal budget			

# **Hospital services**

# 10. In the last 3 months has the 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 measurem ent	No. of days/ attend	NHS Trust code*
Accident & Emergency Department (A&E)					Attendance		
Inpatient ward admission 1					Inpatient day		
Inpatient ward admission 2					Inpatient day		
Inpatient ward admission 3					Inpatient day		
Inpatient ward admission 4					Inpatient day		
Inpatient ward admissions 5					Inpatient day		
Outpatient Department (OPD) Attendance 1					Appointmen		
OPD Attendance 2					Appointmen		
OPD Attendance 3					Appointmen		
OPD Attendance 4					Appointmen		
OPD Attendance 5					Appointmen		
Day hospital Attendance 1					Day attendance		
Day hospital Attendance 2					Day attendance		

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

# **Equipment and adaptations**



*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'.

		Wł	no/Whic	h organ	isation paid	d for this?
Type of adaptation or equipment	Tick if yes	Council	NHS	Self	Volunt./ charity	Other
Medication reminder dispenser						
Calendar clock						
Falls detector/falls alarm						
Community/personal alarm (inc. pull-cord and pendant alarms)						
Outdoor railing						
Grab rail/Stair rail						
Walking stick						
Walking frame						
Walk-in shower/shower cubicle replacing bath						
Over-bath shower						
Bath seat/shower seat						
Kitchen stool						
Bed lever/rail						
Toilet frame/raised toilet seat						
Commode						
Continence pads						

# **12.** <u>In the last 3 months</u> has the participant had any other adaptations or equipment for his/her condition? Please describe.

**Prompt for memory aids:** e.g. bath overflow and temperature alarms, also: gas and carbon monoxide sensors and smoke alarms <u>that are monitored by a telecare centre</u>

*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'.

	Who/which organisation paid for this?					
Type of adaptation or equipment	Tick if yes	Council	NHS	Self	Volunt./ charity	Other
1						
2						
3						
4						
5						
6						

# Medications

## 13. Has the participant taken any medications for his/her condition over the last 3 months?

Tradename DEMENTIA DRUGS	<b>First day</b> dd/mm/yy	<b>Last day</b> (if applies) dd/mm/yy	Ongoing (if applies)	Dose	Medicat'n Frequency Medication unit code code code*
	_//	_//_			
	_//	_//			
	//	//			
	//	//			
	//	//			
OTHER MENT	AL HEALTH D	RUGS			
	_//	//			
	//	//			
	//	//			
	//	//			
	//	//			

[\*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	MI	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"

# Section 2: Carer

#### 1. Do you live with the study participant (the service user/participant)?

YesGo to Q5No $\bigcirc$  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			$\square \longrightarrow$	Go to Q6
	Retired			$\square \longrightarrow$	
	Unable to work			$\square \longrightarrow$	Go to Q8
	Unemployed and looking for work			$\square \longrightarrow$	
	At home and not looking for work (	e.g. housewife/hu	usband)	$\square \longrightarrow$	
	Doing voluntary work			$\overset{-}{\square} \longrightarrow$	
	Student (full or part-time)			$\longrightarrow$	
	Other (Please describe)			${\Box} \longrightarrow$	
If co	arer is employed:				
-	/hat is your current job(s)/occupatior	n(s)?			
7. N	umber of hours you work per week ir	n all the jobs you	do [		Go to Q10
If co	arer is not in paid employment:				
8. V	/hen were you last employed? (Mont	:h/Year)			
		mm	уу		
9. W	/hat was/were your most recent job(	s)/occupation(s)?			
<b>10.</b> H	ave you given up or cut down on wor	rk in order to prov	vide care for	the study parti	cipant?
	Yes, given up work		Go to Q1	L	
	Yes, cut down		•		
	No		Go to Q13	3	
If co	arer gave up or cut down work:				
<b>11.</b> W	/hen did this happen? (Month/Year)				
		mm	УУ		

#### If carer cut down on work:

**12.** By how much did you cut down on work each week? Hours per week

 1	 -
	 -

## *If the carer lives with the study participant, ask Q13*

#### If the carer does <u>not</u> live with the study participant, ask Q14

**13.** On a typical day, how much time do you spend looking after/providing help for the study participant? (*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:	
L	

**14.** How many hours do you spend each week looking after/providing help to the study participant?

(If the carer does <u>not</u> 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:	

16. Other than yourself, do other friends or relatives regularly help/provide care for the study participant?

Yes	Go to Q17
No	Go to Q19

17. Thinking about an average week, how many such carers help/provide care for the study participant?

**18.** Thinking about an average week, and about <u>all</u> such carers, for how many hours do they help/provide care for the study participant?

Hours per week

	 •	

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



**20.** If yes, can you estimate the <u>total</u> number of days that relatives/friends have taken off work over the last 3 months to help/provide care for the study participant? (*If no, write 0 in boxes*)

Total days	
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## **Travel Costs**

21. <u>In the last 3 months</u>, have you accompanied your relative (the study participant) to any clinic, hospital, or day services <u>for his/her condition</u>?



22. If yes, over the last 3 months, how many times did you accompany your relative (the study participant)?

	Number of times per week	Number of times in last 3 months
Accompanied respondent		

23. 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]
	coucj

#### **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		

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

	Hours	Minutes
Number of		

25. 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		

26. 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		

27. 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)

28. If y	Number of way ou normally travelled	one- d by car, if yo	 ou had	to pay for	<sup>,</sup> parking, ho	w much did	you
		£		pence			
	Expenditure on parking						

pay?