

Introduction/explanation/seeking consent

- Thank you very much for seeing me. My name is [... ...] and I'm a researcher at the [University of ...]. We're speaking to people who were admitted to [...] Hospital about 6 to 12 months ago.
- [Your relative/friend] was sent an information sheet with your hospital doctor's invitation to join the study. I have copies of the information sheet for family and friends for us to go through any questions you maybe have. Do you have any questions you want to ask me before I explain more?
- I can just briefly explain what this study is about. When someone aged 75 or older goes into hospital unexpectedly it is government policy that, amongst the many tests they have done, there should also be an assessment of their memory. This research project is looking at what impacts these assessments may have on patients and the care they receive. For instance we would like to understand how well information about these assessments is passed on to GPs from the hospitals and how GPs use such information. This will help with planning better services for the future.
- Do take your time to look through the information sheet again, and we also have a one-page study summary. If you would like more time to discuss any of this with anyone or to think about it, you don't have to decide right now. Our contact details are on these if you want to get back to us.
- We would be very grateful if you feel able to answer our questions about how things have been since you returned home from hospital, but you don't have to answer any questions or share any personal experiences that you don't want to. We can stop the interview at any point if you want.
- Everything you tell us is confidential and this study does not affect [.....]'s medical care at all.
- We would like to record this interview. That means I won't have to be trying to write down everything you say at the time, and it can be written down later more accurately. Both the recording and the 'transcript' will be kept secure, and in the written version we will change the names of any people or places you mention to make sure this stays anonymous.
- Is there anything you would like to ask me?
- How do you feel about me interviewing you for the study?
- If you are willing to take part we both need to sign this consent form before we begin...

Consent

- Ask the participant to read and sign the consent form (1 copy for study, 1 copy for participant)
- For relatives or friends of potential participants with dementia or apparently marked cognitive impairment, explain the need for assessment of their relative's/friend's capacity to participate in the interview and, if appropriate, the need for a consultee to sign the Consultee Declaration Form.

Background information

First of all can you tell me a bit about [..... your relative/friend] and about you yourself?

... [if friend not family] How long have you known [.....]?

... [if not living at same address] How often do you see [.....]?

... How old is s/he now? Do you mind if I ask your age too?

... How long has s/he lived here?

... [if not local] Where did s/he grow up/go to school/any further training?

... What did s/he used to do for a living?

... Any (other) family/friends? ... nearby? ... how much s/he sees of them?

... etc

Find out socio-demographic information in conversation with relative/friend to later record in the participant characteristics section at the end (questions 1-16):

- Age
- Living situation
 - Have they always lived in current area or from another area?
 - Living alone? If not, who else lives with them?
- Social network
 - Family – married/widowed, children/grandchildren?
 - Family/friends nearby?
 - How often do they see/speak to family and friends?
- Education and employment
 - When did they leave school? Any further education or training?
 - Previous employment

Your relative's / friend's hospital stay

As you know, we are interested in how information is passed from hospitals to GPs, and I gather [.....] was in [...] hospital during this last year. I'd like to ask a few questions about that.

- Can I just check first, was that his/her most recent stay in hospital? (Give admission date if known)
- If not, how many times has s/he been back into hospital since then?

[If more than one admission in the preceding year, get participant to focus on index admission 6-12m ago.]

- Thinking back to that time (*6-12m ago*), can you tell me why s/he went into hospital on that occasion?
- While in hospital were you aware of him/her doing any sort of memory test? Was s/he aware?
- Can you tell me anything about that?

... Where/when (e.g. A&E/ward), Who (doctor/nurse)?

... What were you and/or [..... your relative/friend] told about that (beforehand/afterwards)?

... How did [.....] feel about being asked questions to test his/her memory? How did you feel?

... Did anyone in the hospital discuss with [.....] or with you anything about letting your GP know the results of the memory test?

After your relative/friend left hospital

I'd like to know more about the healthcare s/he has received since coming home after that hospital stay. I've got some calendar pages that may help with working out a 'time line' of what happened when.

[Use the time-line tool to gather data to facilitate recall and recording of events since discharge from hospital after the admission 6 to 12 months ago, such as referrals or the start of new services potentially initiated as a result of concerns about dementia / cognitive impairment. Note dates if possible or at least try to gather approximate dates/frequencies/etc, and which services/medications are still on-going, sufficient to complete the CSRI sections at the end.]

- Thinking back to when [..... your relative/friend] first came home from hospital, did s/he see the GP?
 - If so, was it the GP who asked to see him/her or did s/he, or you, arrange to see his/her GP?
 - What was that for? What happened then?
- Did his/her GP contact him/her about his/her memory at all after s/he came out of hospital?
 - Or has s/he been to see his/her GP so as to mention anything about his/her memory?
 - If so, was that a new concern that only came up since going into hospital?

- **Has his/her GP, or anybody else, organised anything new since s/he was in hospital?**

... for example

- **Has a GP arranged for him/her to see any specialists since s/he came out of hospital?**
- **Have s/he been referred to any clinics since s/he has been discharged from hospital?**
- **Have s/he been referred to any other services since coming home from hospital?**
- **Has anyone (apart from family/friends/neighbours) visited him/her at home since hospital?**
- **Has a GP or anyone else changed his/her medication since s/he went into hospital?**

Reminder list of potentially relevant services:

Emergency care – A&E dept. observation ward / clinical decision unit (overnight)

In-patient – acute general hospital ward / acute psychiatric ward / rehabilitation / long-stay / other

Out-patient – memory clinic / psychiatric outpatient / other hospital outpatients / day hospital / other

Day services – day care/activity centre (local authority social services / voluntary sector / community MH) / social club / other

Primary and community services – practice nurse / district nurse / community matron /

CPN / OPMH team / Admiral nurse / Alzheimer's Society support worker / home care worker
psychiatrist / psychologist / individual/group counselling or therapy / support group /
social worker / OT / physio / other

– or have you been going back to see the GP since you first came home?

Medication – Memantine (Ebixa) / Donepezil (Aricept) / Rivastigmine (Exelon) / Galantamine (Reminyl)

Perceptions of health/care services since index hospital admission

- **What has been good about the care [..... your relative/friend] has received since leaving hospital?**
- **What do you think has not been good about the care s/he has received?**
- **Are there any healthcare services, social services or others that you think would be helpful?**

More about your relative/friend

Health and other things can affect how people manage day-to-day, so I'd like to ask a bit more about [..... your relative/friend].

EQ-5D-5L – proxy version

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By placing a tick in one box in each group below, please indicate which statements **the person you care for** would choose to describe his/her health state TODAY if he/she could tell us.

MOBILITY

No problems in walking about ☐

Slight problems in walking about ☐

Moderate problems in walking about ☐

Severe problems in walking about ☐

Unable to walk about ☐

SELF-CARE

No problems washing or dressing him/herself ☐

Slight problems washing or dressing him/herself ☐

Moderate problems washing or dressing him/herself ☐

Severe problems washing or dressing him/herself ☐

Unable to wash or dress him/herself ☐

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

No problems doing his/her usual activities ☐

Slight problems doing his/her usual activities ☐

Moderate problems doing his/her usual activities ☐

Severe problems doing his/her usual activities ☐

Unable to do his/her usual activities ☐

PAIN / DISCOMFORT

No pain or discomfort ☐

Slight pain or discomfort ☐

Moderate pain or discomfort ☐

Severe pain or discomfort ☐

Extreme pain or discomfort ☐

ANXIETY / DEPRESSION

Not anxious or depressed ☐

Slightly anxious or depressed ☐

Moderately anxious or depressed ☐

Severely anxious or depressed ☐

Extremely anxious or depressed ☐

More about you

And finally I'd also like to ask you the same five questions that you just answered about [..... your relative/friend].

EQ-5D-5L

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Under each heading, please tick 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 ☐

[...cont./ Under each heading, please tick **ONE** box that best describes your health **TODAY**.]

PAIN / DISCOMFORT

- | | |
|------------------------------------|--------------------------|
| I have no pain or discomfort | <input type="checkbox"/> |
| I have slight pain or discomfort | <input type="checkbox"/> |
| I have moderate pain or discomfort | <input type="checkbox"/> |
| I have severe pain or discomfort | <input type="checkbox"/> |
| I have extreme pain or discomfort | <input type="checkbox"/> |

ANXIETY / DEPRESSION

- | | |
|--------------------------------------|--------------------------|
| I am not anxious or depressed | <input type="checkbox"/> |
| I am slightly anxious or depressed | <input type="checkbox"/> |
| I am moderately anxious or depressed | <input type="checkbox"/> |
| I am severely anxious or depressed | <input type="checkbox"/> |
| I am extremely anxious or depressed | <input type="checkbox"/> |

Help the participant to make the transition from research context back into their day-to-day context

Thank you very much for your time.

Do you have any questions?

To be completed following the interview with data gathered using topic-guided questioning.

[Code any missing responses: Not asked = 7, Not answered/Don't know = 8, Not applicable = 9]

Circle, delete or fill in
as applicable

Coding

Demographics

- 1 Age (years)
- 2 Date of birth (DD) (MM) (YYYY)
- 3 Sex
- | | |
|-------|---|
| Man | 1 |
| Woman | 2 |

Living situation

- 4 Local or not?
- | | |
|--|---|
| Always lived in this area | 0 |
| Moved to this area while young / working age | 1 |
| Moved to this area after retirement age | 2 |
- 5 Living alone or who with?
- | | |
|---|---|
| Alone | 0 |
| With husband / wife | 1 |
| With son / daughter | 2 |
| With another relative (relationship to participant) | 3 |
| With a friend / partner / other (relationship to participant) | 4 |
- 6 Marital status
- | | |
|----------------------------|---|
| Married / with a partner | 1 |
| Widowed / partner has died | 2 |
| Divorced / separated | 3 |
| Single | 4 |

Family

- 7 Any children?
- | | |
|----------------------|---|
| No | 0 |
| Yes | 1 |
| Yes, but none living | 2 |

7a, 7b If yes, how many?son(s)daughter(s)

8 Any grandchildren?	No	0
	Yes	1

8a, 8b **If yes, how many?**grown up grandchildrengrandchildren still small

Contact with family

9 Any family in the area? <i>(same village/town or in easy reach)</i>	No, none	0
	Yes	1

If yes, how many?

9a, 9b son(s)daughter(s)

9c, 9d **How many?**grown up grandchildrengrandchildren still small

9e **How many?**other relatives (relationship to participant)

10 How often do you get to see or speak to any of your family?

Never	sees / speaks to	0
Less than once a month	sees / speaks to	1
At least monthly	sees / speaks to	2
At least weekly	sees / speaks to	3
2-3 times a week	sees / speaks to	4
Daily	sees / speaks to	5

11 Of all your relatives, with which one do you have the most contact?

Daughter	1
Son	2
Daughter-in-law	3
Son-in-law	4
Sister	5
Brother	6
Other female relative	7
Other male relative	8

[Code any missing responses: Not asked = 7, Not answered/Don't know = 8, Not applicable = 9]

Circle, delete or fill in
as applicable Coding

Contact with friends

12 Any friends in the area? *(same village/town or in easy reach)*

No, none 0

Yes 1

13 How often do you get to see or speak to any of your friends?

Never sees / speaks to 0

Less than once a month sees / speaks to 1

At least monthly sees / speaks to 2

At least weekly sees / speaks to 3

2-3 times a week sees / speaks to 4

Daily sees / speaks to 5

Education and employment

14 How old were you when you left school?

..... (years)

15 How many years did you spend after school in further education/training?

..... (years)

16 What was your main job? / (if never worked and married) ... your husband's main job?

Specify:

.....

.....

(e.g. self-employed +/- employees, employed +/- managing others, qualifications...)

Client Service Receipt Inventory

To be completed following the interview with data gathered using the time line tool and topic-guided questioning. Enter '0' if service has not been used. See CSRI manual for definitions.

Inpatient admissions since index hospital admission

Service	Name of facility	Number of admissions	Total number of inpatient days
A&E dept. observation ward / clinical decision unit (o/n)			
Acute general hospital ward			
Acute psychiatric ward			
Rehabilitation ward			
Long-stay ward			
Other (describe)			

Outpatient services since index hospital admission

Service	Name of facility	Unit of measurement	Number of units received
Memory clinic			
Psychiatric outpatient clinic			
Other hospital outpatient clinic (including A&E)			
Day hospital (excluding day care centre)			
Other (describe)			

Day activity services since index hospital admission

Service	Name of facility	Number of attendances	Average duration
Local authority social services department day care (activity) centre			
Voluntary sector day care (activity) centre			
Community mental health centre			
Social club			
Other (describe)			

CSRI (cont.)**Community care services** since index hospital admission

Service	Provider sector*	Total number of contacts
General practitioner		
Practice nurse		
District nurse / other community nurse		
Older persons community team member		
Community psychiatric nurse / older people's mental health team member		
Admiral nurse		
Alzheimer's Society support worker		
Home care worker		
Consultant in psychiatry:		
Senior registrar in psychiatry:		
Psychologist		
Individual counselling / therapy		
Group counselling / therapy / support group		
Social worker		
Occupational therapist		
Physiotherapist		
Chiropodist		
Dentist		
Optician		
Other (describe)		

* 1=NHS, 2=social services department, 3=voluntary organisation, 4=private

CSRI (cont.)**Current medication**

Please list below use of any drugs taken over the last month.

Name of drug	Dosage (if known)	Dosage frequency	When started?	<i>or</i> Since before in hospital?

Medication used since index hospital admission – any other not listed in ‘Current medication’ above

Name of drug	Dosage (if known)	Dosage frequency	When started?	<i>or</i> Since before in hospital?