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Case-finding for dementia during acute hospital admissions: impacts on patient care after discharge and costs for the health service

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Case-finding for dementia during acute hospital admissions: impacts on patient care after discharge and costs for the health service

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Keywords: Dementia, dementia case-finding, cognitive impairment, service use, cost estimation, older people

Abstract

Objective: Between 2012 and 2017 dementia case-finding was routinely carried out on people aged 75 and over with unplanned admissions to acute hospitals across England. The assumption was that this would lead to better planning of care and treatment for patients with dementia following discharge from hospital. However, little is known about the experiences of patients and carers or the impacts on other health services. This study explored the impact of dementia case-finding on older people and their families and on services.

Design: Thematic content analysis was conducted on qualitative interview data and costs associated with service use were estimated. Measures included the Mini-Mental State Examination (MMSE), the EQ-5D-5L quality of life scale and a modified Client Service Receipt Inventory (CSRI).

Setting: Four counties in the East of England.

Participants: People aged ≥75-years who had been identified by case-finding during an unplanned hospital admission as warranting further investigation of possible dementia and their family carers.

Results: We carried out 28 interviews, including 17 patient-carer(s), 8 patients and 3 family carer interviews. Most patients and carers were unaware that memory assessments had taken place, with many families not being informed or involved in the process. Participants had a variety of views on memory testing in hospital and had concerns about how hospitals carried out assessments and communicated results. Overall, case-finding did not lead to GP follow up after discharge home or lead to referral for further investigation. Few services were initiated because of dementia case-finding in hospital.

Conclusions: This study shows that dementia case-finding may not lead to increased GP follow up or service provision for patients after discharge from hospital. There is a need for a more evidence-based approach to the initiation of mandatory initiatives such as case-finding that inevitably consume stretched human and financial resources.

Strengths and limitations

- Dementia case-finding was introduced across the English National Health Service in the absence of evidence it improved outcomes for patients.
- This is one of the first studies to explore the impact of dementia case-finding on the experiences of patients and on service use.
- Identifying concerns about patients' cognition while in hospital did not necessarily lead to follow up from GPs or lead to referrals for further investigation or lead to new supportive services being put in place.
- Patients and their family carers were often unaware of memory assessments undertaken whilst in hospital and had mixed attitudes towards dementia case-finding in hospitals.
- Study limitations include a small sample size and a reliance on participants self-reporting of service use data.

Introduction

Pre-existing cognitive impairment in hospitalised older people is estimated at between 15% to 42%, much of which may go undetected.[1-5] This has led to concerns about providing adequate care for older people with dementia, and related policy development.[6-9] In the English National Health Service initiatives were introduced to increase awareness and improve the identification of dementia in secondary care.[10-13] In 2012-2013, the Department of Health introduced a mandatory policy requiring that all hospitals across England routinely carry out cognitive assessments with ≥75-year-olds who have had an emergency admission and that those identified as potentially having dementia are appropriately assessed and referred. The rationale being that early identification of cognitive impairment would lead to a timely diagnosis, informed patient care and improved health outcomes for older people.[14 15] This was in the absence of any randomised control trial evidence to know the impact of such an approach.

Although cognitive assessment tests can detect undiagnosed dementia,[16-18] there are concerns over the impacts of screening for dementia.[19 20] Healthcare professionals have been reported as viewing case-finding as a financially and politically driven policy with little or no evaluation of patient outcomes.[21-24] In a previous paper we reported how the variation in approaches to dementia case-finding has meant that information communicated to primary care is inconsistent and has an impact on how well GPs can effectively plan patients' treatment and care once they are home in the community.[24]

Little is known about the wider impacts of dementia case-finding on patient and carer experiences and on their access to dementia-related or other care services. The overall aims of this study were to explore the impacts of dementia case-finding on older people identified by hospital case-finding as warranting further investigation, their family carers and the health service. For example, were they being re-assessed in primary care and, if appropriate, receiving specialist referral, being given a diagnosis or receiving new services?

Methods

This study involved in-depth exploratory interviews with former hospital patients and their family carers. A range of qualitative and quantitative data was collected. This was the second phase of the CASCADE study.[25] Phase 1 results are reported in full elsewhere.[24]

We recruited former patients of two participating hospitals in the East of England. Eligible patients were aged at least 75-years-old, had been acutely admitted 6-12 months previously, had been flagged by dementia case-finding as warranting further investigation about their cognition, and were community dwelling. Family carers of these patients were also recruited for interviews. Invitation letters were sent to eligible participants from the hospital elderly medicine consultant under whose care they had been admitted, together with an information sheet and response form.

Semi-structured interview schedules were developed to gather patient and family carers' experiences and perceptions of dementia case-finding and the impacts of case-finding on their subsequent treatment and care. Demographic data was collected and the MMSE[26] and EQ-5D-5L[27] validated scales were used to characterise participants' cognition and health related quality of life (HRQoL) respectively. For the analysis those with a score below 24 on the MMSE were classified as cognitively impaired and those with a score of 24 and above were categorised as cognitively intact. Proxy versions of these assessments were undertaken with carers to characterise patients who were not present at interview. Carers also completed EQ-5D-5L questionnaires in relation to their own HRQoL. All completed EQ-5D-5L were scored against the published algorithm.[28] Data were collected on patients' self-reported use of inpatient and outpatient services, day activity services since the index hospital admission, community care services, and current medication. Service use was collected using relevant sections of the Client Service Receipt Inventory[29] using 'Visio' timelines[30] to facilitate recall and recording of events such as referrals or the start of new services. Two researchers (A-MB, JF) carried out the interviews in the patients' and family carers' homes across four counties in the East of England (Bedfordshire, Cambridgeshire, Essex and Hertfordshire). Participants gave signed consent before the interview and interviews were taped, transcribed and anonymised.

An initial thematic framework was developed by the research team (A-MB, FB, JF) which was informed by the research questions and coding a selection of transcripts. The codeframe and the anonymised transcripts were transferred into NVivo V.11 and the data analysed using thematic content analysis.[31] This enabled the key features of patients' and carers' experiences to be elicited from the data. Quantitative data was entered into an Excel spreadsheet.

Estimation of service costs

Service use, reported by means of the modified CSRI, were costed using several sources. For community based health care we obtained cost per hour of staff time from a published source of unit cost data.[32] Estimates of average contact time and the proportion of health care professionals time that would be spent on direct client contact were used to estimate a cost per contact.[33] For some contacts respondents reported frequency rather than numbers of contacts, for example 3 times a week. To convert this to numbers of contacts we required a time period, this was taken as the time difference between the date of discharge and the date of the interview. This duration therefore varied between individuals.

Costs for secondary care were obtained from NHS references costs.[34] For elective inpatient admissions we used a weighted average of either elective short stays or long stays. This gave estimates for the costs of elective stages of £616 for an elective short stay and £3,058 for an elective long stay. For non-elective admissions, again a weighted average was obtained from NHS references costs, this was £3,058 for long stays. For A&E visits a weighted average of £204 was used. A detailed estimate of the cost of memory services was available from the literature.[32] This gave a cost per client of £1,218. However, this was based on a different NHS trust and it is not clear how representative this would be of the service provided to participants in the current study. For memory related drugs a price was obtained from a published source.[35] All costs are in UK pound sterling for the year 2015/16. As the period of analysis was for one year only discounting was not used.

FINDINGS

We conducted a total of 28 interviews involving 48 participants. Of those 25 were former patients who had been identified as having a concern about their memory during an unplanned hospital admission and 23 were family carers. Seventeen interviews were held jointly with the patient and their family carers, either a spouse or adult child. All patients had received a memory assessment during their hospital stay which indicated that there was a cause for concern over their cognition which warranted further investigation.

The median age of former patients was 85 (range 79-94) and just over half (53%) were women. Of the carers nearly three quarters (74%) were women. The median MMSE score was 23.0 (IQR 16.5-26) indicating mild cognitive impairment, but there was considerable variation with scores ranging between 6-30. Patients had considerable levels of physical impairment and difficulty with activities of daily living with half having severe problems with walking and a third having severe problems with washing and dressing.

Individual EQ-5D-5L scores showed that both patients and carers reported poor health when compared with equivalent aged healthy populations (see Table 1). The EQ-5D-5L can provide scores between one and -0.594. On this scale, one is equivalent to full health and death would have a value of zero. There were 25/28 (89%) patients who provided a value for their own health state. There were 4 proxy values provided by carers, for 2 of these we also have a value from the patient, for the remaining two we only had the proxy value. The mean value for these individuals was 0.38. There were 22 carers who provided a valuation of their own health, as well as 3 EQ-5D-5L values provided on their own health by second carers. Carers had better health than patients but were not a healthy population (EQ-5D-5L 0.76).

Table 1 – EQ-5D-5L values

	Score	Lower 95% CI	Upper 95% CI
EQ-5D-5L, participants' valuation of their own health (N=25)	0.38	0.25	0.50
EQ-5D-5L, proxy valuation (N=4)	0.26	-0.04	0.55
EQ-5D-5L, First carers' valuation of their own health (N=22)	0.76	0.67	0.84
EQ-5D-5L, Second carers' valuation of their own health (N=3)	0.90	0.71	1.00

Impacts of dementia case-finding on service use

Nine people had been assessed post discharge either in a memory clinic or by an old age psychiatrist but two of these had already been referred by their GP prior to hospital admission. For the seven people who had been referred to memory services since hospital discharge it was not clear whether these referrals were a result of hospital case-finding or not. Patients referred for investigation since discharge (n=7) generally had lower MMSE scores than those not referred (MMSE of 17 (IQR 15 - 22) versus 25 (IQR 19 - 26)). In the non-referred group, two patients had MMSE scores that indicated severe cognitive impairment and five had scores indicating moderate cognitive impairment. Five patients who were referred since case-finding had been started on dementia medication (e.g. Donepezil, Memantine), but two of these had stopped taking this medication within a fortnight because of side effects.

Estimates of the costs incurred by former patients of dementia case-finding for the period between index stay discharge and interview are given in supplementary file 1. We had available data for 28 participants. Precise costing was not generally possible, so these costs should be taken as indicative. This group, as would be expected, are comparatively high users of health and social care services, with a mean cost of £5,180 in the period following the index stay. There is also considerable uncertainty around these cost estimates as indicated by the confidence intervals. The major drivers of cost were inpatient and outpatient services, district nursing and home care worker. Comparatively few costs were specifically related to cognitive services, apart from memory clinics and some spending on memory related drugs. There was also one GP home visit that was specified as related to memory assessment.

Attitudes and experiences of dementia case-finding

Two main themes emerged from the qualitative analysis (i) Attitudes and experiences of dementia case-finding and (ii) Patients' and carers' follow up experiences. Examples quotes (Q = quotes) are given in Tables 2 and 3.

Patients and carers were often unaware that memory assessments had taken place during their hospital admission and, in many cases, the patient had been assessed alone without a family carer being present or notified (Q1-2). For those carers who were aware of the memory assessment, they lacked information about the purpose or outcome of the test.

Although some patients and carers did not mind having a memory test in hospital, others felt that it was inappropriate to conduct such tests when someone was acutely ill (Q3-6, 9-10). Some patients reported feeling anxious about answering the memory questions incorrectly (Q7, Q8). There were examples of poor practice in terms of the way the test had been administered, such as the test being administered in an insensitive manner (Q11). Even when case-finding had flagged up a concern about a patient's cognition this did not appear to have impacted on discharge planning or the involvement of carers (Q12, Q13). For example, patients were being discharged with altered medication and the hospital did not inform the family carers (Q14, Q15).

Table 2: Quotes illustrating theme 1

Quote	Views and experiences of dementia case-finding
1	I think someone did come to see him but they didn't see me. (Carer 16)
2	I don't think that was on his release papers neither 'cos they usually put things that he's had done on his release papers. (Carer 04)
3	Didn't worry me one bit. (Patient 21)
4	…if there's no medication or they're not going to put you on treatment what's the point. That's my view. (Carer 03)
5	I thought it very inappropriate when somebody's in and they're feeling really rough, their breathing is dreadful, full of pneumonia and all the rest of it (Carer 08)
6	at two o'clock in the morning… We'd been in A&E for hours…They decided that Dad should stay because he had an infection, and they gave him the memory test…I remember saying, "You are having a laugh" (Carer 26)
7	you feel as though they're encroaching on your brain to try and make you make a mistake, that's how I felt (Patient 05)
8	[about the test] …he was shattered, and I think he was frightened. (Carer 26)
9	I would have thought that if there were to be any benefit gained it would be once the patient is stable. At admission, everything's frightening, worrying, they don't know what they're there for maybe or they're worried about what they're there for (Carer 23)
10	I explained it, she's more aware at home, I explained how bad she was in hospital to how different she is at home (Carer 02)
11	"…doctor came in and she asked [patient] some questions and of course [patient] just doesn't always understand because it's the comprehension isn't it, cognitive as well, and so [patient] said, "ask my wife", and she said, "I am asking you" [said in an abrupt manner] which made me prickle so I said, "well, [patient]'s dysphasic and you know, he does have difficulty…and I was really cross about that, I thought time and place"(Carer 08)
12	Well I was a little bit confused really over the whole thing, you know, well I think the family were really. (Carer 01)

13	I think they were just telling me that I had to get her to the doctors, to organise the Memory Clinic, I'm sure that's what it was, they were telling me, but it wasn't really clear, like I'm saying, I think she should have been sent home with some paperwork to say right, this is what is needed. (Carer 02)
14	they changed her medication and they stopped that, so there must have been a reason for stopping it...but they didn't tell us, we had no way of knowing until three months later, which I think is frightening. (Carer 23)
15	they were in a rush to get her out because she didn't need any more treatment, albeit she was discharged taking an antibiotic and there was no indication what the antibiotic was for, or anything on the, it wasn't included on the medications list. (Carer 07)

Patients and carers' follow up experiences

There was a consistent pattern for patients and relatives in terms of their follow up experiences. Most reported that they had not had a follow up discussion with their GP about the dementia case-finding outcomes or re-assessment of their cognition post discharge (Q16, Q17). Even though some had seen a GP or practice nurse since leaving hospital, they reported that the issue of dementia case-finding had not been raised (Q18). Some carers contacted their GP about their relative's memory but felt the follow-up was not always adequate (Q19-Q20). One carer could not understand why the hospital did not deal with their relative's memory problem since they had identified it and felt this was another issue for carers to take on board (Q23).

Dementia case-finding did not appear to have impacted on service provision post-discharge. Relatively few new services appeared to have been instigated and others, such as OT assessments and adjustments to the home, were not timely. In addition, in several cases equipment supplied was not suitable for patients needs or it was delivered but never fitted (Q21, Q22). Whilst some families reported satisfaction with social care services, such as respite care, (Q24, Q25) many others felt their needs were not being met. For example, carers coming at inappropriate times and the provision of poor care (Q26-Q28).

Table 3: Quotes illustrating theme 2

Quote	Patients' and carers' follow up experiences
16	Well I mean, I'm a bit surprised that the GP hasn't been to see her (Carer 01)
17	I don't feel the GP's that interested. (Carer 16)
18	I did, I prompted it. So how did you prompt it, what happened? Alright, I… I told the GP that she needs this test (Carer 06)
19	No, that was me … [raised wife's memory after unrelated GP visit] That was a good while ago and he's never mentioned anything since. (Carer 20)
20	I'd asked his GP if he could have a psychiatric assessment and they sent round a CPN and she chatted to him and she said to me "oh yes, he has got dementia", she said "I'm not quite sure what type, I'll discuss it with the team" because the consultant was away at that time "and we'll let you know". Well she never did get back to me. (Carer 16)
21	she came along and so she said "Where do you want to put that frame [name of participant]?" I said "Shove it in the spare bedroom", she put it right up against the window and that's where it's stayed ever since. (Carer 05)
22	we had to take the measurements from the bed to the mattress to the toilet to the armchair, height and the depth and me and me Dad had to measure it all and take it to them, so no-one actually (Carer 03)
23	so why is it not dealt with in the hospital when they're actually there, and they can see there's a problem (Carer 02)
24	We could not have managed without it. We were getting desperate – we could not manage, we couldn't be there for long enough. (Carer 14)
25	I think it works well, like I said, it works well too that I've kind of got a bit of my life back…it definitely helps having carers three times a day. (Carer 02)
26	mum said "He hasn't had his supper yet, you know, why would you put him to bed at five? (Carer 19)
27	It's not care, they just come in, write a bit in her folder and that is it, that is not care, they do not look after my mum (Carer 05)
28	they come at so weird times. I mean, for instance, the other Sunday night they came at twenty past five to put her to bed. Have you ever heard of anything so stupid! (Carer 01)

DISCUSSION

Dementia case-finding in acute hospitals involves the routine cognitive assessment of older people during an unplanned hospital stay and aims to improve the identification of patients with dementia so that they could be flagged to their GP for further investigation and referral. This study aimed to assess whether this was in fact happening. The study was conducted in two acute hospital settings in the East of England where dementia case-finding was implemented with little or no evaluation of its effectiveness in terms of improving patient outcomes. To our knowledge, this is the first study to explore the views and experiences of older patients and their family carers to case-finding and to estimate the economic impact for the health service.

We spoke to patients and carers of patients who had been identified as having a concern about their cognition during their hospital admission. MMSE scores of included participants ranged from 6-30 although the median score at interview indicated that most patients had mild cognitive impairment. The findings from this study suggest that there was little follow up from patients' GPs post discharge and few further investigations or referrals or medication instigated due to dementia case-finding outcomes; although in some cases, patients had already been seen by their GP prior to their hospital stay about their cognition. The lack of follow up may not be surprising in light of the fact the outcomes of dementia case-finding are often poorly reported to GPs.[24]

Patients and their families had mixed attitudes towards dementia case-finding but many did not remember the assessment and/or did not appear to have been informed about what this would mean in terms of their subsequent care and treatment. There was also concern that the acute hospital setting might not be the best place in which to assess cognition. Indeed, 10 former patients had MMSE scores which indicated no cognitive impairment despite having been picked up by the case-finding process when in hospital. In a previous paper we reported that dementia case-finding has raised awareness about dementia within hospitals.[24] However, delirium is often undetected in hospitals[36] and can increase the likelihood of reporting false-positives and result in misdiagnosis of dementia.[37]

The results of the costing evaluation showed that participants/patients had average costs of £5,180. The mean length of time over which these costs were incurred was 283 days, excluding the initial stay. Although these individuals had been identified from dementia case-finding the proportion of those costs attributed directly to services related to cognition appear to be small (approximately 6%). This is not surprising as we found that few services had been instigated due to case-finding. Whilst the costs of case-finding did not appear to be high in the community it is likely that case-finding is associated with significant costs within the hospital itself. This suggests that an evaluation of the costs of such a policy, including the opportunity costs within the policy implementations system (Public Health England, NHS England) are warranted.

Limitations

The small sample size and the reliance on participants' self-reporting are limitations of the study. Recruiting in this setting is challenging and only a small proportion of those who have experienced hospital case-finding could be consulted for the study and may not be representative of the patient group even within the single settings. Participants found it difficult to correctly recall services received and the reason for those services. Therefore, it was difficult to judge whether services received were a direct consequence of dementia case-finding. The participants in this study may not be representative of others elsewhere in the UK, although no such study has taken place to our knowledge. Since presentation of our findings to key policy makers the mandatory nature and financial incentives associated with dementia case-finding are no longer in place. The study remains relevant as moves to promote case-finding across health settings affect many countries and it serves as an illustration of the vital need to test policies before implementing them on the large scale.[38 39]

Conclusions

This study highlights that dementia case-finding in hospitals did not necessarily lead to a GP follow up or referrals for further investigation or lead to new supportive services being put in place. Often patients and their family carers were not informed that memory assessments had been carried out whilst in hospital or what the outcomes of the assessment would mean in terms of their future care and treatment. There is a need for a more evidence-based approach to the initiation of mandatory initiatives such as case-finding. This includes evaluation of the costs of such a policy, including the opportunity costs within the policy implementations system.

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Contributors: JF, FB, DAT, CF, CB wrote the protocol. JF and A-MB collected the data. A-MB, JF, DAT, FB analysed the data. A-MB, FB, JF and DAT wrote the first draft of the manuscript. All authors contributed to the writing of the manuscript and approved its content. FB (the manuscript's guarantor) affirms that the manuscript is an honest, accurate and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned have been explained.

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Supplementary File 1

Cost table

Type of service	Mean number	Mean Cost	95% CI
A&E admissions	0.25	197	(-29 to 422)
General ward admissions	0.14	481	(-112 to 1073)
Long stay ward admissions	0.04	22	(-21 to 65)
Total cost of inpatient stays since index		**699**	**(76 to 1322)**
Memory clinic	0.2	261	(72 to 450)
Outpatient psychiatry clinic	0.0	6	(-6 to 18)
Other hospital outpatient clinic	3.3	444	(-383 to 1271)
Outpatient visits at day hospital	0.2	28	(3 to 53)
Other	0.2	28	(-3 to 59)
Total cost of all outpatient contacts		**767**	**(-73 to 1607)**
Local authority day care centre	2.1	70	(-65 to 206)
Voluntary sector day care centre	1	45	(-17 to 107)
Total cost of day service care		**116**	**(-30 to 262)**
GP	1.9	68	(46 to 91)
Practice Nurse	3.3	5	(-2 to 12)
District Nurse	27	913	(-24 to 1851)
Community Psychiatric Nurse	1	3	(-1 to 7)
Alzheimer's society support worker	0	1	(-1 to 3)
Home care worker	199	2382	(594 to 4170)
Consultant psychiatrist	0	6	(-6 to 18)
Social worker	1	2	(-2 to 6)
Occupational Therapist	2	23	(5 to 42)
Physiotherapy	3.5	81	(10 to 151)
Chiropodist	1	38	(12 to 65)
Dental visits	0.3	6	(2 to 10)
Optician visits	1.1	8	(4 to 12)
Other community services	0.1	2	(-1 to 6)
Total costs of community contacts		**3539**	**(1514 to 5563)**
Memory related drug		60	(-13 to 132)
Total for all costs		**5180**	**(2519 to 7842)**

COREQ check list

Domain 1: Research team and reflexivity	
Interviewer/facilitator Credentials Occupation	On cover page
Gender	On p8
Experience/training	Not given in text but the researchers involved (AMB, JF, FB) are experienced at conducting interviews and focus groups
Relationship to participants prior to study commencement?	Not reported in text but there was no prior relationship
Participant knowledge of interviewer	Made clear on information sheet who the researchers were and the purpose of the study
Interviewer characteristics	Gender given. Other characteristics apparent from cover page
Domain 2: Study Design Methodological orientation	
Sampling	Purposive sampling p7 (inclusion criteria also given)
Method of approach	Yes p7
Sample size	Yes - in results and in tables
Non-participation	NA
Setting of data collection	P8
Presence of non-participants	NA
Description of sample	Yes – p9/10
Interview guide	Data collection described p7-8
Repeat interviews	No
Audio/visual recording	Yes p8
Field notes	No
Duration	Yes p8
Data saturation	Not mentioned
Transcripts returned	No not done
Domain 3: Analysis and Findings	

Number of data coders	Yes – p8
Description of the coding tree	No
Derivation of themes	Themes described in text
Software	Use of Nvivo – p9
Participant checking	Yes p8/9
Quotations presented	Yes table 2 and 3
Items 30-32	

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Case-finding for dementia during acute hospital admissions: a mixed methods study exploring the impacts on patient care after discharge and costs for the English National Health Service

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Case-finding for dementia during acute hospital admissions: a mixed methods study exploring the impacts on patient care after discharge and costs for the English National Health Service

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Keywords: Dementia, dementia case-finding, cognitive impairment, service use, cost estimation, older people

Abstract

Objective: Between 2012 and 2017 dementia case-finding was routinely carried out on people aged 75 and over with unplanned admissions to acute hospitals across England. The assumption was that this would lead to better planning of care and treatment for patients with dementia following discharge from hospital. However, little is known about the experiences of patients and carers or the impacts on other health services. This study explored the impact of dementia case-finding on older people and their families and on their use of services.

Design: Thematic content analysis was conducted on qualitative interview data and costs associated with service use were estimated. Measures included the Mini-Mental State Examination (MMSE), the EuroQol (EQ-5D-5L) quality of life scale and a modified Client Service Receipt Inventory (CSRI).

Setting: Four counties in the East of England.

Participants: People aged ≥75-years who had been identified by case-finding during an unplanned hospital admission as warranting further investigation of possible dementia and their family carers.

Results: We carried out 28 interviews, including 19 joint patient-carer(s), 5 patient only and 4 family carer interviews. Most patients and carers were unaware that memory assessments had taken place, with many families not being informed or involved in the process. Participants had a variety of views on memory testing in hospital and had concerns about how hospitals carried out assessments and communicated results. Overall, case-finding did not lead to general practitioner (GP) follow up after discharge home or lead to referral for further investigation. Few services were initiated because of dementia case-finding in hospital.

Conclusions: This study shows that dementia case-finding may not lead to increased GP follow up or service provision for patients after discharge from hospital. There is a need for a more evidence-based approach to the initiation of mandatory initiatives such as case-finding that inevitably consume stretched human and financial resources.

Strengths and limitations

- This is one of the first studies to investigate the impacts of a mandatory policy introduced nationwide without prior piloting, feasibility testing or evidence of effectiveness – case-finding for dementia amongst all hospital patients aged ≥75 whose admission was unplanned.
- Qualitative research methods using topic-guided interviews enabled in-depth exploration of personal experiences of dementia case-finding both during a hospital stay and of health and care services used subsequently.
- As the focus was on those identified by case-finding while in-patients, the study design sought to interview relatives/family carers as well as these former patients themselves.
- Study limitations include a small sample size and a reliance on participants' self-reporting of service use data.
- It was beyond the scope of this study to track actual service use costs so our cost estimation draws on published unit costs data.

Introduction

Pre-existing cognitive impairment in hospitalised older people is estimated at between 15% to 42%.[1-5] Many of these patients may not have had a previous diagnosis of dementia.[3 6] This has led to concerns about providing adequate care for older people with dementia, and policy development to improve the identification of dementia in older people in hospital.[7-10] In the English National Health Service (NHS) initiatives were introduced to increase awareness and improve the identification of dementia in secondary care.[11-14] In 2012-2013, the Department of Health introduced a mandatory policy requiring that all hospitals across England routinely carry out cognitive assessments with ≥75-year-olds who have had an emergency admission and that those identified as potentially having dementia are appropriately assessed and referred. The rationale for case-finding in hospital was that early identification of cognitive impairment would lead to a timely diagnosis, informed patient care and improved health outcomes for older people.[15 16] This was implemented in the absence of any randomised control trial evidence to know the impact of such an approach.

Although cognitive assessment tests can detect undiagnosed dementia,[17-19] dementia does not fit the criteria for screening programmes and there are concerns over the impacts of case-finding as well as screening for dementia.[20 21] Moreover, in practice the distinction between screening and case-finding is often not clear to clinicians and the public.[22 23] Healthcare professionals have been reported as viewing case-finding as a financially and politically driven policy with little or no evaluation of patient outcomes.[24-27] In a previous paper we reported how the variation in approaches to dementia case-finding has meant that information communicated to primary care is inconsistent and has an impact on how well general practitioners (GPs) can effectively plan patients' treatment and care once they are home in the community.[27]

Little is known about the wider impacts of dementia case-finding on patient and carer experiences and on their access to dementia-related or other care services. The overall aims of this study were to explore the impacts of dementia case-finding on older people identified by hospital case-finding as warranting further investigation, their family carers and their use of health service and care services. For example, were they being re-assessed in primary care and, if appropriate, receiving specialist referral, being given a diagnosis or receiving new services?

Methods

This study involved in-depth exploratory interviews with former hospital patients and their family carers. A range of qualitative and quantitative data was collected. This was the second phase of the CASCADE study (CASe finding in hospitals - impacts on CAre for people with DEmentia).[28] Phase 1 results are reported in full elsewhere.[27]

We recruited former patients of two participating hospitals in the East of England. Eligible patients were aged at least 75-years-old, had been acutely admitted 6-12 months previously, had been flagged by dementia case-finding as warranting further investigation about their cognition, and were community dwelling. Family carers of these patients were also recruited for interviews. Invitation letters were sent to eligible participants from the hospital elderly medicine consultant under whose care they had been admitted, together with an information sheet and response form.

Semi-structured interview schedules were developed to gather patient and family carers' experiences and perceptions of dementia case-finding and the impacts of case-finding on their subsequent treatment and care (supplementary file 1). Demographic data was collected and the Mini-Mental State Examination MMSE[29] and EuroQol (EQ-5D-5L)[30] validated scales were used to characterise patients' cognition and health related quality of life (HRQoL) respectively. For the analysis, those with a score below 24 on the MMSE were classified as cognitively impaired and those with a score of 24 and above were categorised as cognitively intact. EuroQol's validated proxy version of the EQ-5D-5L was undertaken with carers to characterise patients in the minority of cases when a carer were interviewed separately from the former patient. Completed EQ-5D-5Ls were scored against the published algorithm and results from the scale's five domains were used to characterise participants' levels of difficulty in each.[31] Data were collected on patients' self-reported use of inpatient and outpatient services, day activity services since the index hospital admission, community care services, and current medication. Service use was collected using relevant sections of the Client Service Receipt Inventory (CSRI)[32] using 'Visio' timelines[33] to facilitate recall and recording of events such as referrals or the start of new services. Two female researchers (A-MB, JF) carried out the interviews in the patients' and family carers' homes across four counties in the East of England (Bedfordshire, Cambridgeshire, Essex and Hertfordshire). Interviews lasted about an hour. Participants gave signed consent before the interview and interviews were tape recorded, transcribed and anonymised.

An initial thematic framework was developed by the research team (A-MB, FB, JF) which was informed by the research questions and coding a selection of transcripts. The codeframe and the anonymised transcripts were transferred into NVivo V.11 and the data analysed using thematic content analysis.[34] This enabled the key features of patients' and carers' experiences to be elicited from the data. Quantitative data was entered into an Excel spreadsheet. Ethical approval was obtained from South Central – Oxford C Research Ethics Committee (reference: 15/SC/0728).

Estimation of service costs

Service use, reported by means of the modified CSRI, were costed using several sources. For community based health care we obtained cost per hour of staff time from a published source of unit cost data.[35] Estimates of average contact time and the proportion of health care professionals time that would be spent on direct client contact were used to estimate a cost per contact.[36] For some contacts respondents reported frequency rather than numbers of contacts, for example 3 times a week. To convert this to numbers of contacts we required a time period, this was taken as the time difference between the date of discharge and the date of the interview. This duration therefore varied between individuals.

Costs for secondary care were obtained from NHS references costs.[37] For elective inpatient admissions we used a weighted average of either elective short stays or long stays. This gave estimates for the costs of elective stages of £616 for an elective short stay and £3,058 for an elective long stay. For non-elective admissions, again a weighted average was obtained from NHS references costs, this was £3,058 for long stays. For accident and emergency (A&E) visits a weighted average of £204 was used. A detailed estimate of the cost of memory services was available from the literature.[35] This gave a cost per client of £1,218. However, this was based on a different NHS trust and it is not clear how representative this would be of the service provided to participants in the current study. For memory related drugs a price was obtained from a published source.[38] All costs are in UK pound sterling for the year 2015/16. As the period of analysis was for one year only discounting was not used.

Patient and public involvement

Two well-established patient and public involvement groups were involved in the study; the University of Hertfordshire Patient Involvement in Research Group, and the University of Cambridge's Public Involvement in Research into Ageing and Dementia Group. Four members of these groups acted as a User Reference Group for the study. They provided feedback on the aims of the study, study documents such as patient information sheets, and commented on preliminary findings from the qualitative analysis.

FINDINGS

We conducted a total of 28 interviews involving 49 participants. Of those, 24 were former patients who had been identified as having a concern about their memory during an unplanned hospital admission and 25 were carers. Nineteen interviews were held jointly with the patient and their family carer(s). All patients had received a memory assessment during their hospital stay which indicated that there was a cause for concern over their cognition which warranted further investigation.

Table 1 summarises descriptive characteristics of the former patients in our study. Both their median and mean age was 85 (range 79-94) and just over half (53%) were women. The median MMSE score was 23.0 (IQR 16.5-26) indicating mild cognitive impairment, but there was considerable variation with scores ranging between 6-30. Patients had considerable levels of physical impairment and difficulty with activities of daily living, for example nearly half and over a third had severe problems and were unable to walk or wash and dress themselves. The EQ-5D-5L scoring system[31] can provide scores between one and -0.594. This range has anchor points where 1 is considered to be full health and 0 is considered to be equivalent of dead. The scoring algorithm allows some scores to be lower than zero, i.e., worse than dead. Twenty-four former patients provided a value for their own health state and the mean value for these individuals was 0.39 (95%CI: 0.25-0.52). There were 25 carers who provided a valuation of their own health with a mean value 0.78 (95% CI: 0.69 – 0.86). For comparison, population norms are available for those aged over 75 for the EQ-5D-3L[39] which give values of 0.75 and 0.71 for males and females respectively. The value obtained here for former patients is considerably below these values.

Table 1: Characteristics of the former patient sample

Full sample		n=28
Age	Mean and median	85, 85
	(Range)	(79-94)
% Female		53%
MMSE	Median (IQR)	23 (16.5-26)
	Mean (SD)	20.8 (6.8)
Sample with EQ-5D-5L		n=24
Severe problems walking / unable to walk		44%
Severe problems washing and dressing self / unable to wash & dress self		37%
Severe problems doing usual activities / unable to do usual activities		52%
Severe / extreme pain or discomfort		4%
Severely / extremely anxious or depressed		15%
EQ-5D-5L valuation (95%CI)		0.39 (0.25 - 0.52)

Impacts of dementia case-finding on service use

Nine people had been assessed post discharge either in a memory clinic or by an old age psychiatrist but two of these had already been referred by their GP prior to hospital admission. For the seven people who had been referred to memory services since hospital discharge it was not clear whether these referrals were a result of hospital case-finding or not. Patients referred for investigation since discharge (n=7) generally had lower MMSE scores than those not referred (MMSE of 17 (IQR 15 - 22) versus 25 (IQR 19 - 26)). In the non-referred group, two patients had MMSE scores that indicated severe cognitive impairment and five had scores indicating moderate cognitive impairment. Five patients who were referred since case-finding had been started on dementia medication (e.g. Donepezil, Memantine), but two of these had stopped taking this medication within a fortnight because of side effects.

Estimates of the costs incurred by former patients of dementia case-finding for the period between index stay discharge and interview are given in Table 2. We had available data for 28 former patients, 24 where the patient was present at interview and 4 where only a carer was present. Precise costing was not generally possible, so these costs should be taken as indicative. This group have a mean estimated cost of £5,180 (95% CI: £2394 to £7967) in the period following the index stay. There is also considerable uncertainty around these cost estimates as indicated by the confidence intervals. The major drivers of cost were inpatient and outpatient services, district nursing and home care worker. Comparatively few costs were specifically related to cognitive services, apart from memory clinics and some spending on memory related drugs. There was also one GP home visit that was specified as related to memory assessment.

Table 2: Estimated service use cost since discharge from hospital

Service Category	Mean cost	95% CI
Inpatient Stays	£699	£47 to £1351
Outpatient Visits	£767	-£113 to £1646
Day Service Use	£116	-£37 to £269
Community Care Contacts	£3,539	£1419 to £5658
Cost of Memory related drug	£60	-£16 to £136
Total	£5,180	£2394 to £7967

Attitudes and experiences of dementia case-finding

Two main themes emerged from the qualitative analysis (i) Attitudes and experiences of dementia case-finding and (ii) Patients’ and carers’ follow up experiences. Examples quotes (Q = quotes) are given in Tables 3 and 4.

Patients and carers were often unaware that memory assessments had taken place during their hospital admission and, in many cases, the patient had been assessed alone without a family carer being present or notified (Q1-2). For those carers who were aware of the memory assessment, they lacked information about the purpose or outcome of the test.

Although some patients and carers did not mind having a memory test in hospital (Q3), others felt that it was inappropriate to conduct such tests when someone was acutely ill (Q4-6, 9-10). Some patients reported feeling anxious about answering the memory questions incorrectly (Q7, Q8). There were examples of poor practice in terms of the way the test had been administered, such as the test being administered in an insensitive manner (Q11). Even when case-finding had flagged up a concern about a patient’s cognition this did not appear to have impacted on discharge planning or the involvement of carers (Q12, Q13). For example, patients were being discharged with altered medication and the hospital did not inform the family carers (Q14, Q15).

Table 3: Quotes illustrating theme 1

Quote	Views and experiences of dementia case-finding
1	I think someone did come to see him but they didn’t see me. (Carer 16)
2	I don't think that was on his release papers neither 'cos they usually put things that he's had done on his release papers. (Carer 04)
3	Didn’t worry me one bit. (Patient 21)
4	…if there’s no medication or they’re not going to put you on treatment what’s the point. That’s my view. (Carer 03)
5	I thought it very inappropriate when somebody’s in and they’re feeling really rough, their breathing is dreadful, full of pneumonia and all the rest of it (Carer 08)

6	at two o'clock in the morning… We'd been in A&E for hours…They decided that Dad should stay because he had an infection, and they gave him the memory test…I remember saying, "You are having a laugh" (Carer 26)
7	you feel as though they're encroaching on your brain to try and make you make a mistake, that's how I felt (Patient 05)
8	[about the test] …he was shattered, and I think he was frightened. (Carer 26)
9	I would have thought that if there were to be any benefit gained it would be once the patient is stable. At admission, everything's frightening, worrying, they don't know what they're there for maybe or they're worried about what they're there for (Carer 23)
10	I explained it, she's more aware at home, I explained how bad she was in hospital to how different she is at home (Carer 02)
11	"…doctor came in and she asked [patient] some questions and of course [patient] just doesn't always understand because it's the comprehension isn't it, cognitive as well, and so [patient] said, "ask my wife", and she said, "I am asking you" [said in an abrupt manner] which made me prickle so I said, "well, [patient]'s dysphasic and you know, he does have difficulty…and I was really cross about that, I thought time and place"(Carer 08)
12	Well I was a little bit confused really over the whole thing, you know, well I think the family were really. (Carer 01)
13	I think they were just telling me that I had to get her to the doctors, to organise the Memory Clinic, I'm sure that's what it was, they were telling me, but it wasn't really clear, like I'm saying, I think she should have been sent home with some paperwork to say right, this is what is needed. (Carer 02)
14	they changed her medication and they stopped that, so there must have been a reason for stopping it...but they didn't tell us, we had no way of knowing until three months later, which I think is frightening. (Carer 23)
15	they were in a rush to get her out because she didn't need any more treatment, albeit she was discharged taking an antibiotic and there was no indication what the antibiotic was for, or anything on the, it wasn't included on the medications list. (Carer 07)

Patients and carers' follow up experiences

There was a consistent pattern for patients and relatives in terms of their follow up experiences. Most reported that they had not had a follow up discussion with their GP about the dementia case-finding outcomes or re-assessment of their cognition post discharge (Q16, Q17). Even though some had seen a GP or practice nurse since leaving hospital, they reported that the issue of dementia case-finding had not been raised (Q18). Some carers contacted their GP about their relative's memory but felt the follow-up was not always adequate (Q19-Q20). One carer could not understand why the hospital did not deal with their relative's memory problem since they had identified it and felt this was another issue for carers to take on board (Q21).

Dementia case-finding did not appear to have impacted on service provision post-discharge. Relatively few new services appeared to have been instigated and others, such as OT assessments and adjustments to the home, were not timely. Whilst some families reported satisfaction with social care services, such as respite care (Q22), many others felt their needs were not being met. For example, carers coming at inappropriate times and the provision of poor care (Q23-Q25).

Table 4: Quotes illustrating theme 2

Quote	Patients' and carers' follow up experiences
16	Well I mean, I'm a bit surprised that the GP hasn't been to see her (Carer 01)
17	I don't feel the GP's that interested. (Carer 16)
18	I did, I prompted it. So how did you prompt it, what happened? Alright, I… I told the GP that she needs this test (Carer 06)
19	No, that was me … [raised wife's memory after unrelated GP visit] That was a good while ago and he's never mentioned anything since. (Carer 20)
20	I'd asked his GP if he could have a psychiatric assessment and they sent round a CPN and she chatted to him and she said to me "oh yes, he has got dementia", she said "I'm not quite sure what type, I'll discuss it with the team" because the consultant was away at that time "and we'll let you know". Well she never did get back to me. (Carer 16)
21	so why is it not dealt with in the hospital when they're actually there, and they can see there's a problem (Carer 02)
22	I think it works well, like I said, it works well too that I've kind of got a bit of my life back…it definitely helps having carers three times a day. (Carer 02)
23	We could not have managed without it. We were getting desperate – we could not manage, we couldn't be there for long enough. (Carer 14)

24	It’s not care, they just come in, write a bit in her folder and that is it, that is not care, they do not look after my mum (Carer 05)
25	they come at so weird times. I mean, for instance, the other Sunday night they came at twenty past five to put her to bed. Have you ever heard of anything so stupid! (Carer 01)

DISCUSSION

Dementia case-finding in acute hospitals involves the routine cognitive assessment of older people during an unplanned hospital stay and aims to improve the identification of patients with dementia in hospitals so that they could be flagged to their GP for further investigation and referral. This study aimed to explore patients’ and their families’ experiences of how this worked in practice. It was conducted in two acute hospital settings in the East of England where dementia case-finding was implemented with little or no evaluation of its effectiveness in terms of improving patient outcomes. To our knowledge, this is the first study to explore the views and experiences of older patients and their family carers to case-finding and to estimate the economic impact for the health service.

We spoke to patients and carers of patients who had been identified as having a concern about their cognition during their hospital admission. Although the median MMSE score of included participants at interview indicated that most patients had mild cognitive impairment, MMSE scores ranged from 6-30. The findings from this study suggest that there was little follow up from patients’ GPs post discharge and few further investigations or referrals or medication instigated due to dementia case-finding outcomes; although in some cases, patients had already been seen by their GP prior to their hospital stay about their cognition. The lack of follow up may not be surprising in light of the fact the outcomes of dementia case-finding are often poorly reported to GPs.[27]

Patients and their families had mixed attitudes towards dementia case-finding but many did not remember the assessment and/or did not appear to have been informed about what this would mean in terms of their subsequent care and treatment. There was also concern that the acute hospital setting might not be the best place in which to assess cognition. Indeed, 10 former patients had MMSE scores which indicated no cognitive impairment despite having been picked up by the case-finding process when in hospital. In a previous paper we reported that dementia case-finding has raised awareness about dementia within hospitals.[27] However, delirium is often undetected in hospitals[40] and can increase the likelihood of reporting false-positives and result in misdiagnosis of dementia.[41]

The results of the costing evaluation showed that participants/patients had average costs of £5,180. The mean length of time over which these costs were incurred was 283 days, excluding the initial stay. Although these individuals had been identified from dementia case-finding the proportion of those costs attributed directly to services related to cognition appear to be small (approximately 6%). This is not surprising as we found that few services had been instigated due to case-finding. Whilst the costs of services initiated in the community following case-finding did not appear to be high, from health professionals' reports of how case-finding has been implemented in the previous phase of the Cascade study[27] it is likely that case-finding is associated with significant costs within the hospital itself, though to our knowledge no research to date has quantified these yet. This suggests that an evaluation of the costs of such a policy, including the opportunity costs within the policy implementations system (Public Health England, NHS England) are warranted.

Limitations

The small sample size and the reliance on participants' self-reporting are limitations of the study. Recruiting in this setting is challenging and only a small proportion of those who have experienced hospital case-finding could be consulted for the study and may not be representative of the patient group even within the single settings. Patients found it difficult to correctly recall services received and the reason for those services. Therefore, it was difficult to judge whether services received were a direct consequence of dementia case-finding. Carers were responsible for coordinating their relative's care and consequently carers were able to provide more information than patients. The participants in this study may not be representative of others elsewhere in the UK, although no other such study has taken place to our knowledge. Since presentation of our findings to key policy makers the mandatory nature and financial incentives associated with dementia case-finding are no longer in place. The study remains relevant as moves to promote case-finding across health settings affect many countries and it serves as an illustration of the vital need to test policies before implementing them on the large scale.[42 43]

Conclusions

This study highlights that dementia case-finding in hospitals did not necessarily lead to a GP follow up or referrals for further investigation or lead to new supportive services being put in place. Often patients and their family carers were not informed that memory assessments had been carried out whilst in hospital or what the outcomes of the assessment would mean in terms of their future care and treatment. There is a need for a more evidence-based approach to the initiation of mandatory initiatives such as case-finding. This includes evaluation of the costs of such a policy, including the opportunity costs within the policy implementations system.

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Contributors: JF, FB, DAT, CF, CB wrote the protocol. AM commented on the protocol, assisted with recruitment and commented on the paper. JF and A-MB collected the data. A-MB, JF, DAT, FB analysed the data. A-MB, FB, JF and DAT wrote the first draft of the manuscript. All authors contributed to the writing of the manuscript and approved its content. FB (the manuscript's guarantor) affirms that the manuscript is an honest, accurate and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned have been explained.

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Cascade - Topic Guide for Family and Friends

Interview number……………. Date……………………….

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

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 ☐

[**EQ-5D-5L – proxy version** ...cont.]

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

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 ☐

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 ☐

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)	

		Circle, delete or fill in as applicable	*Coding*
8	**Any grandchildren?**	No	*0*
		Yes	*1*
8a, 8b	**If yes, how many?** ………..grown up grandchildren ………..grandchildren still small		

Contact with family

9	**Any family in the area?** *(same village/town or in easy reach)*	No, none	*0*
		Yes	*1*
	If yes, how many?		
9a, 9b		………..son(s) ………..daughter(s)	
9c, 9d	How many? ………..grown up grandchildren ………..grandchildren 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)			

CSRI (cont.)

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?	*or* 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?	*or* Since before in hospital?

COREQ check list

Domain 1: Research team and reflexivity	
Interviewer/facilitator Credentials Occupation	On cover page
Gender	On p8
Experience/training	Not given in text but the researchers involved (AMB, JF, FB) are experienced at conducting interviews and focus groups
Relationship to participants prior to study commencement?	Not reported in text but there was no prior relationship
Participant knowledge of interviewer	Made clear on information sheet who the researchers were and the purpose of the study
Interviewer characteristics	Gender given. Other characteristics apparent from cover page
Domain 2: Study Design Methodological orientation	
Sampling	Purposive sampling p7 (inclusion criteria also given)
Method of approach	Yes p7
Sample size	Yes - in results and in tables
Non-participation	NA
Setting of data collection	P8
Presence of non-participants	NA
Description of sample	Yes – p9/10
Interview guide	Data collection described p7-8
Repeat interviews	No
Audio/visual recording	Yes p8
Field notes	No
Duration	Yes p8
Data saturation	Not mentioned
Transcripts returned	No not done
Domain 3: Analysis and Findings	

Number of data coders	Yes – p8
Description of the coding tree	No
Derivation of themes	Themes described in text
Software	Use of Nvivo – p9
Participant checking	Yes p8/9
Quotations presented	Yes table 2 and 3
Items 30-32	