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Dementia case-finding in hospitals: a qualitative study exploring the views of healthcare professionals in English primary care and secondary care

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ABSTRACT

Objectives In 2012–2013, the English National Health Service mandated hospitals to conduct systematic case-finding of people with dementia among older people with unplanned admissions. The method was not defined. The aim of this study was to understand current approaches to dementia case-finding in acute hospitals in England and explore the views of healthcare professionals on perceived benefits and challenges.

Design Qualitative study involving interviews, focus groups and thematic content analysis.

Setting Primary care and secondary care across six counties in the East of England.

Participants Hospital staff involved in dementia case-finding and primary care staff in the catchment areas of those hospitals.

Results We recruited 23 hospital staff and 36 primary care staff, including 30 general practitioners (GPs). Analysis resulted in three themes: (1) lack of consistent approaches in case-finding processes, (2) barriers between primary care and secondary care which impact on case-finding outcomes and (3) perceptions of rationale, aims and impacts of case-finding. The study shows that there were variations in how well hospitals recorded and reported outcomes to GPs. Barriers between primary care and secondary care, including GPs' lack of access to hospital investigations and lack of clarity about roles and responsibilities, impacted case-finding outcomes. Staff in secondary care were more positive about the initiative than primary care staff, and there were conflicting priorities for primary care and secondary care regarding case-finding.

Conclusions The study suggests a more evidence-based approach was needed to justify approaches to dementia case-finding. Information communicated to primary care from hospitals needs to be comprehensive, appropriate and consistent before GPs can effectively plan further investigation, treatment or care. Follow-up in primary care further requires access to options for postdiagnostic support. There is a need to evaluate the outcomes for patients and the economic impact on health and care services across settings.

Strengths and limitations of the study

- This is one of the first studies to explore the views of primary and secondary care professionals regarding dementia case-finding in acute hospitals.
- This study makes an important contribution to the debate about the value of dementia case-finding in hospitals.
- The study was conducted in counties across the East of England and may not represent the views and experiences of healthcare professionals in other regions of the UK and other countries.
- The hospital staff who participated in the study were involved in dementia case-finding in their hospital and may have more positive attitudes to case-finding compared with other hospital staff.
- General practitioners who participated may be more likely to have an interest in cognitive disorders or views on case-finding (either positive or negative), leading to a possible bias in reported comments.

BACKGROUND

Large numbers of older people admitted acutely to hospitals have an undiagnosed pre-existing cognitive impairment. Estimates of dementia prevalence in hospital settings range from 15% to 42%.[1–5] The consequent demand for complex care and concerns about care for older people living with dementia[6–10] have prompted a number of policy initiatives in the UK over the last decade including financial incentives to service providers for dementia case-finding in hospitals[11–14] and general practices.[15–17] The rationale for dementia case-finding is that the recognition of cognitive impairment in older patients may lead to a timely diagnosis and enable better planning of appropriate current and future care, maybe delaying progression of cognitive decline and improving health outcomes.[18 19]

Reviews and national screening committee reports have found no evidence to support dementia screening and, to the authors' knowledge, no systematic review has evaluated the impact of dementia case-finding on outcomes for patients or carers.[20–23] Despite this, the Department of Health has

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introduced strong directives to secondary care that stipulate that all people aged ≥75-years with unplanned hospital admissions have been cognitively assessed and that those identified as potentially having dementia have further investigations or are appropriately referred. Dementia case-finding targets for acute hospitals have continued for several years[12–14] alongside the introduction of incentives for general practice to fulfil similar requirements through an enhanced payments scheme[15–17] aiming to embed this approach in ongoing practice. It is notable that this policy was not introduced following research, to inform whether it led to benefits or harms, and the cost of diversion of key staff time for the collection, recording and reporting of information has not been evaluated. These nationwide initiatives did allow local services to fulfil targets using methods devised to fit local settings, leading to a plethora of approaches being adopted.

There is a need to examine whether dementia case-finding processes function as planned to deliver the outcomes intended. While there is evidence that brief screening tests can detect undiagnosed dementia,[24–26] it is less clear where the balance of benefits and harms of screening lies,[1 27 28] and there are concerns about the potential impacts of an unsought diagnosis.[29 30] As case-finding in hospitals takes place during acute admissions, there is also the issue of distinguishing between dementia and delirium or unspecified cognitive impairment which may never lead to a diagnosis.[31] Many cognitive assessments have not been validated with patients with delirium[25 32] and may lead to false-positives. Moreover, in practice the distinction between screening and case-finding is often not clear to either clinicians or the general public, a factor which is also likely to affect the impacts.[33 34]

How hospitals are implementing current policies to encourage case-finding and how these initiatives impact on other services is poorly understood, and there has been a call for more evidence to evaluate such initiatives.[35] The overall aims of this study were to (1) understand the current approaches to dementia case-finding in hospitals, (2) understand how these impact on communication regarding case-finding outcomes from hospitals to general practitioners (GPs) and subsequent follow-up in primary care and (3) explore the experiences and perceptions of hospital staff and GPs involved in case-finding processes.

METHODS

We undertook exploratory qualitative interviews and focus groups with hospital staff and GPs in the East of England. This research is part of a study called CASCADE (CASe finding in hospitals - impacts on CAre for people with DEmentia).[36] We approached 18 hospitals and purposively identified key clinicians who were involved in carrying out case-finding assessments in their hospital (eg, dementia nurse-specialists, liaison psychiatrists, clinical leads for dementia) and invited them by email for a telephone interview. GPs in catchment areas served by hospitals across the Eastern region (Bedfordshire, Cambridgeshire, Essex, Hertfordshire, Norfolk and Suffolk) were invited for a telephone interview or to attend a focus group. They were recruited through regional professional and clinical research networks, Clinical Commissioning Groups and direct contacts.

Procedures

We developed two interview schedules, one tailored to primary care and one to secondary care professionals. The interview schedule for hospital staff (presented in online supplementary file 1) was designed to understand how dementia case-finding processes were developed and implemented at their hospital and to gather their perceptions of case-finding processes and impacts. The interview schedule for primary care (presented in online supplementary file 2) was developed to elicit GPs' perspectives and experiences of receiving reports or recommendations for their patients as a result of case-finding during an acute admission and how this informed their decisions regarding possible further investigations, treatment and care of their patients.

Information sheets outlined the study to health professionals and provided contact details of the research team. Signed consent was obtained prior to interviews and focus groups. Telephone interviews were carried out by two female researchers (A-MB, JF) and focus groups were held at two general practices in the East of England facilitated by one researcher (JF). Both researchers have extensive experience of conducting qualitative research in the area of dementia and health services. Interviews and focus groups lasted about an hour, were audio-recorded, transcribed verbatim and anonymised following protocols for secure data storage. Researchers agreed at which point data saturation had been achieved.

Analysis

We undertook thematic content analysis[37] to elicit the key features of clinicians' experiences from the data. Three researchers (A-MB, FB, JF) independently scrutinised and developed codes from the transcripts and through discussion compared codes and developed an initial coding frame. Emerging themes were discussed with representatives from the Patient and Public Involvement Groups at both participating universities and the study advisory group, and refinements were made to the coding frame. The transcripts and coding framework were entered into NVivo software V.11 to assist management of further qualitative data analysis, and a number of overarching themes were identified.

RESULTS

We recruited 23 hospital staff from 12 of the 18 acute hospitals in Bedfordshire, Cambridgeshire, Essex, Hertfordshire, Norfolk and Suffolk. Through regional professional networks and Clinical Commissioning Groups,

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Table 1 Summary of telephone interviews with hospital staff and GPs

Healthcare professionals	Number	Recruited from	Role of participants
Hospital staff	23	Hospitals in East of England 12	Dementia specialist nurses 12 Non-dementia nurses 3 Consultants 6 (geriatricians 5, gastroenterologist 1) Commissioner 1 Dementia case-finding coordinator (non-clinical) 1
GPs	17	GP practices 15	GP partners 15* Salaried GPs 1 Locum GP 1
Total	40		

*Five of the 15 GP partners also held clinical lead roles, for example, practice lead for teaching and Clinical Commissioning Group leads for mental health, older people, care homes and end-of-life care.
GP, general practitioner.

we recruited 36 primary care staff (including 30 GPs) within the catchment of hospitals in the East of England. Further details of participants are given in tables 1 and 2. All hospital staff took part in individual telephone interviews and had clinical experience ranging between 8 and 41 years (mean 22.8 years). In primary care, 17 GPs took part in individual interviews and 19 staff took part in focus groups. Participants' clinical experience varied in focus groups, ranging from GP trainees to senior partners about to retire, among interviewees ranging from 6 to 30 years (mean 22.5 years).

Three main themes emerged from the data, summarised in table 3: (1) lack of consistent approaches in case-finding processes, (2) barriers between primary care and secondary care which impact case-finding outcomes and (3) perceptions of rationale, aims and impacts of case-finding. Example quotes are referred to in the text and given in full in tables 4, 5 and 6 (quotes=Q).

Table 2 Summary of focus groups with GPs and other primary care staff

Focus groups	Participants	Role of participants
Cambridgeshire	10	GPs 7 (6 GP partners, one salaried GP) Practice nurses 2 Administrator responsible for diagnostic coding 1
Norfolk	9	GPs 6 (4 GP partners, 2 GP registrars) Practice nurses 2 Practice manager 1
Total	19	

GP, general practitioner.

Theme 1: lack of consistent approaches in case-finding processes

Hospitals have their own systems and processes for case-finding. These varied in terms of who was responsible for the assessments, how cognition was assessed and how case-finding was documented and recorded. A diverse range of staff were involved in undertaking case-finding assessments. This included junior doctors during admission in emergency departments, clinical staff on the wards and in some cases hospitals employed staff who were not part of the team caring for the patient to track down patients who had not been assessed, to check documentation and ensure assessments were completed (Q1). The range of staff involved meant that non-compliance was a problem, particularly within specialties which did not prioritise case-finding (Q2), with regional differences in specialist staff availability, and some hospitals experiencing difficulty in recruiting geriatricians or dementia specialist nurses.

There was no standard cognitive assessment tool used across different hospitals or even across departments within some hospitals where specialties had their own preferences for certain assessment tools (Q3). Although most hospitals usually assessed a patient's cognition only once (eg, on admission), some hospitals repeated the assessments before discharge.

There was no standard hospital information technology (IT) system for capturing case-finding data. Individual hospitals had developed their own systems, often inflexible, not fit for purpose or constantly evolving to ensure integration with other systems. This impacted on how case-finding information was documented and recorded, including change across time, resulting in variable and missed information on discharge summaries sent to GPs. Although IT systems were designed to make the collecting of certain data mandatory, problems with system design and functionality meant that fields were not always completed (Q4). Systems were also sometimes inflexible meaning that additional information could not be included. One member of hospital staff said she found the process of case-finding inflexible and not allowing for individual professional judgement (Q5).

Theme 2: barriers between primary care and secondary care which impact on case-finding outcomes

A number of barriers emerged between primary care and secondary care that affected how case-finding outcomes were communicated from hospital to GP and subsequent follow-up of patients in primary care.

Poor communication of case-finding information from secondary care to primary care made it difficult for GPs to make informed judgements about patient care. Many GPs reported that discharge summaries were inconsistent and omitted essential case-finding information, for instance, the type of cognitive assessment used, the patient's assessment score or instructions for follow-up and referral (Q6, Q7). Some GPs had concerns about the reliability of the scores and felt it was important to know who had

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Table 3 Main themes and subthemes

Theme 1	Theme 2	Theme 3
Lack of consistent approaches in case-finding processes	**Barriers between primary care and secondary care which impact case-finding outcomes**	**Perceptions of rationale, aims and impacts of case-finding**
► Hospitals implemented different strategies for case-finding (how, when, where). ► Wide variety of staff involved, with different priorities. ► Different cognitive assessment tools across and within hospitals. ► No standard IT system impacts on how case-finding information is captured, recorded and communicated.	► Poor communication of case-finding outcomes impacts GP judgements about patient care. ► Lack of access to hospital results leads to duplication of effort. ► Lack of clarity about roles and responsibilities.	► Politically and financially driven policy with no evaluation of outcomes. ► Conflicting priorities for primary care and secondary care regarding case-finding ► Case-finding raised awareness and improved training in secondary care. ► Hospital not appropriate environment for case-finding can lead to mislabelling. ► Impact on families is mixed. ► Lack of buy-in from GPs (feel they know patient; concerns over lack of postdiagnosis support). ► Resources diverted—impact on services.

GP, general practitioner; IT, information technology.

done the assessment; information was not included in discharge summaries or letters. There was variation in type and amount of detail provided from hospitals which was particularly apparent to GPs whose populations attend more than one hospital. In general, different assessment tools were used in secondary care and primary care, meaning that GPs were less familiar with those used in hospitals and had difficulty interpreting scores (Q8). In contrast to some reportedly sparse discharge letters, several GPs said that some hospitals electronically generated discharge summaries which were too long, making it difficult to locate important and relevant information (Q9).

A number of GPs reported that a lack of access to hospital test results led to repeat investigations and duplication of effort. They raised concerns that not only was it not cost-effective to repeat tests already done in hospital (Q10), but also that this can be particularly difficult for older patients. Some GPs suggested that hospitals could carry out a full range of investigations with patients during their hospital stay and that referrals to memory services could be expedited if all test results were automatically transferred from hospitals to GPs and memory services (Q11). Some remembered this as having worked more smoothly years before dementia case-finding or even memory clinics were introduced (Q12). Within secondary care, some shared the view that hospitals were well placed to make direct referral for further assessment through liaison psychiatry teams if available (Q13, Q14, Q15).

There was a lack of clarity about the roles and responsibilities between primary care and secondary care. Some GPs expressed frustration that secondary care identified patients as warranting 'cause for concern about cognition' and then passed the responsibility to primary care without initiating any investigation or treatment plan (Q16). It was not always clear to GPs who should refer patients to memory services and sometimes patient follow-up was missed during the transition from secondary care to primary care (Q17).

Theme 3 perceptions of rationale, aims and impacts of case-finding

Primary and secondary healthcare professionals commented consistently that the drive for case-finding was political and financial, rather than based on clinical rationale or an evidence base. Case-finding had become an indicator of a hospital's performance, and the financial incentives were a key motivator for hospitals to complete case-finding (Q18). In addition, hospital staff were concerned that the outcomes of the policy were unknown as, in general, staff had no way of knowing if patients were followed up by their GP or referred on to memory services postdischarge (Q19). One hospital reported that they followed up patients after discharge through a care of the elderly outpatients' clinic at the hospital (Q20). Several hospital staff were concerned that patients were not being followed up by their GP and suggested that instead hospitals should refer patients directly to memory services.

There were conflicting attitudes between primary and secondary care staff regarding the value of case-finding. Overall, hospital staff thought that case-finding had increased the identification of patients with cognitive impairment. They felt it was an effective way of capturing those people who might not present to general

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Table 4 Quotes illustrating theme 1

Quote	Lack of consistent approaches in case-finding processes
1	…we have a member of staff here who daily goes to the ward and makes sure that the case-finding questions are being asked and the documentation is being completed by the doctors (Hospital staff 03)
2	Erm [sighs] it's very difficult, I mean, I do speak to surgeons and, you know, you get the sort of, I get fed back, "Oh, it's ridiculous, it's a waste of time, it's not important to us" (Hospital staff 07)
3	The OTs [Occupational Therapists] always use the MoCA, the MMSE does get done occasionally, but usually they redo the AMTS (Hospital staff 22)
4	…we'd had a bit of a glitch where we were missing some of the mandatory fields off if they were started before the 72 hours (Hospital staff 11)
5	But I think the trouble with the case-finding…is there is no room really for professional judgement if you like, in a way…it has taken away some of that flexibility (Hospital staff 15)

AMTS, Abbreviated Mental Test Score; MoCA, Montreal Cognitive Assessment; MMSE, Mini–Mental State Examination.

practice. For example, those who have no informal support network to flag up cognitive issues or who were reluctant to seek help (Q21). They felt dementia case-finding helped improve diagnosis rates, enabled patients to be put on an appropriate care pathway and increased the likelihood that appropriate community services could then be put in place (Q22). In contrast, many GPs did not think providing patients with a dementia diagnosis was a priority per se and would discuss the implications of a diagnosis (including perceived and actual negative impacts) with patients and their relatives before deciding whether to refer to memory services (Q23).

Many hospital staff valued case-finding because it has raised awareness about dementia among secondary care staff across different medical specialties. Many hospitals have implemented dementia-friendly initiatives and improved staff training around dementia in an effort to improve care for patients with dementia (Q24). However, there was a clear consensus that training around distinguishing delirium from dementia needed to be improved (Q25).

Most GPs did not think hospitals were appropriate environments for assessing patients' cognition as acute conditions, medication or delirium could lead to low or imprecise assessment scores, and they felt that a community setting was more likely to lead to a true assessment of a patient's cognition. In fact, they reported a high level of false-positives in case-finding reports and said following up false-positives increased their workload (Q26). They felt a tick-box approach to case-finding resulted in patients being flagged as a consequence of delirium at the time of admission assessment (Q27) without further assessment before discharge. GPs in particular had concerns about the risk of mislabelling people with dementia and the resultant unwelcome consequences of diagnosis. Patients with a 'known dementia' are excluded from the dementia case-finding process, but some hospital staff also raised concerns that some patients might be incorrectly labelled as having dementia by junior staff without appropriate expertise (Q28).

Hospital staff reported mixed impacts of case-finding for patients and families. Families can be relieved that someone is taking notice of their relative's memory problems (Q29) but assessments can sometimes be distressing for patients. Both primary and secondary care staff thought that case-finding needs to be communicated sensitively to patients and carers (Q30, Q31). GPs felt that the social stigma associated with dementia meant that discussions about diagnosis needed to be approached sensitively by trained and skilled staff. It was viewed as unhelpful and distressing for patients to see the word 'dementia' in discharge summaries (Q32, Q33). A negative impact on families can be that case-finding can raise expectations of help, only to then find that there is no treatment and availability of services is limited.

Overall GPs were less positive about the benefits of case-finding than clinicians in secondary care. Many thought that case-finding was a tick-box exercise which had little impact on improving diagnosis rates or the subsequent care for people with dementia (Q34). GPs felt that they were better placed to carry out cognitive assessments as they are in regular contact with older patients and can discuss memory referral and dementia diagnosis with the patient and their family. They believed they were usually already aware of a patient's cognitive impairment (Q35, Q36).

Many of the GPs commented that there is very little postdiagnosis support for patients and their families, a key factor influencing their views on the value of a dementia diagnosis (Q37). The shifting patterns of support from services and the voluntary sector makes it difficult for GPs to keep track of what is available, although hospital staff had an expectation that GPs would know. GPs had particular concerns about resources being diverted away from other services for case-finding and were reluctant to raise concerns or expectations with patients and their families when treatment options were so limited (Q38, Q39).

Hospital staff suggested that dementia case-finding was increasing the pressure on memory clinics and mental health services due to the numbers of patients being identified as having potential cognitive problems. In contrast, GPs did not think hospital case-finding has increased referrals to memory clinics or impacted on diagnosis rates from their own service (Q40). Some commented

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Table 5 Quotes illustrating theme 2

Quote	Barriers between primary care and secondary care which impact on case-finding outcomes
6	I mean sometimes you don't even get anything [from the hospital], sometimes you get nothing but I mean you usually get something, but sometimes you don't get a discharge summary (GP 01)
7	…it might be helpful to know how far, you know, how badly they fail or they pass the test, which type of test they're doing (GP 15)
8	We get sent the information, it's unsolicited, it's using a tool which we do not use ourselves therefore we don't have an awful lot of experience in…but it's a shame that there isn't a tool used across both sectors that we could compare results with (GP 14)
9	I know a lot of my colleagues often it will be ignored so it's not really followed up, not intentionally or whatever, but it just gets lost in the volume of information that we're given (GP 07)
10	…you see the patient is getting mucked about because they're having to have more tests done and it's really very poor cost effectiveness for the NHS because, you know, tests are being duplicated (GP 01)
11	In our area we are even trying to see if the GPs can request a CT scan as well, so that, you know, by the time the patient has seen the old-age psychiatrist, everything is there, all the old-age psychiatrist has to do is see the patient and diagnose (GP 06)
12	…when I was trained in elderly psychiatrics about ten years ago on an elderly ward it was a dementia diagnosis was done there and then, and then everything was put in place. It's only after the Memory Clinics came on board that it got a bit fragmented. Dementia diagnosis was done at the hospital as well as community at the time and, you know, both by psychogeriatricians but also by the geriatricians (GP 05)
13	…actually you've picked up a problem, get on and do the referral rather than sending them back (GP, Focus group 2)
14	[The letter] will say the psychiatrist thinks they need further treatment…why can't the ward make the referral, 'cos then that would shorten the interval for waiting (GP, Focus group 1)
15	I've had a few doctors recently say to me, they don't quite understand why we have to go through the GP, why don't we just refer straight to the Mental Health Trust directly? And that's a fair point, because it is cutting out yet another layer where it can go wrong, maybe, or delays (Hospital staff 07)
16	"Look, we've identified this, we're now passing the buck to you and we haven't done anything about it" and that's unfortunately what seems to happen a lot (GP 12)
17	…we used to get quite a few calls [from GPs] to say, "What is my responsibility? What are you asking us to do?" (Hospital staff 14)

GP, general practitioner.

that longer waiting times for memory services were due to reduced funding.

DISCUSSION

Dementia case-finding in hospitals aims to improve the recognition of dementia among older patients enabling a 'timely' diagnosis and planning of appropriate treatment and care. This study explored the approaches to dementia case-finding being implemented in acute hospitals in the East of England and explored the views of primary and secondary care staff regarding the benefits and challenges of case-finding for dementia. Our analysis showed that hospitals had developed and implemented different processes in terms of how, where and when they assessed patients' cognition and in how they recorded and reported the results to GPs. The quality and quantity of the data captured from case-finding depended on the priorities of the wide variety of staff involved and on the effectiveness of individual hospital IT systems.

There appeared to be considerable variation between hospitals such that it was unclear what postdischarge pathway there was, if any, for patients who had been identified as a result of case-finding. Instead there was evidence of poor communication of case-finding outcomes from hospital to GP, and a lack of clarity for GPs regarding who was responsible for referral to memory services—hospitals or GPs. Concerns that patient referral could be missed during transitions between primary care and secondary care prompted some healthcare professionals in both primary care and secondary care to suggest hospitals directly refer patients to memory services.

We found that case-finding has raised awareness about dementia within hospitals, but there are still gaps in staff training around the identification of delirium which is often undetected in hospitals[38] and increases the likelihood of reporting false-positives and patient misdiagnosis.[39] Both dementia and delirium are intricately linked and should be considered together when assessing patients' cognition and when developing policy.[32] Guidelines are increasing recognition of delirium[40 41] but there is still a lack of consensus on the assessment and diagnosis of delirium superimposed on dementia.[42] In part but not only due to such difficulties, primary and secondary care staff were polarised in their views about the value of providing patients with a dementia diagnosis.

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Table 6 Quotes illustrating theme 3

Quote	Perceptions of rationale, aims and impacts of case-finding
18	I think the motivation with a lot of these things it is financial, for example, when one has a CQUIN then there's a big push to do it (Hospital staff 06)
19	That ticks the boxes and we've fulfilled our CQUIN requirement, but there's… no-one seems to be assessing whether what we're doing is appropriate or correct or whether the care plan is written in an appropriate way (Hospital staff 10)
20	…we request that they're brought back to the Care of the Elderly outpatient clinic and we will revisit it then again to see actually has the patient regained their abilities, are they back to their norm, and I think it's quite unique to [Hospital 14] because when I meet with the collaborative CQUIN groups for [Place name 12], not all hospitals offer that facility (Hospital staff 09)
21	I think it is an opportunity for people who would have been missed, who wouldn't have gone to their GP…I think it's great that we get an opportunity to pick people up and it improves that and it can open up other services and help with support for them, so I think that bit's great (Hospital staff 15)
22	I think it's actually something that is still worth doing because, actually, this is about quality care and quality of diagnosis (Hospital staff 07)
23	…we don't always want to give them a dementia label, because it might make a massive impact on their relocation from their home to somewhere else (GP 11)
24	…it has not only increased awareness, but other departments are now making commitments to ensure that… Their patients may have dementia… and therefore they need to ensure that the appropriate steps are taken (Hospital staff 20)
25	There seems to be a little bit of misunderstanding amongst junior doctors of the difference between delirium and dementia (GP 13)
26	…sometimes they send lots of people out saying their memory is a problem and whenever you actually get them in it's not really a problem, but if you have a tick box approach to it that's what can… ends up being the difficulty that takes up a lot of GP time to untangle that (GP 02)
27	When they are ill, they are very often confused, especially if they've got a UTI [Urinary tract infection] or something… I know perfectly well, because I saw the patient the week before they went into hospital, that actually they're functioning perfectly well and don't need further referral (GP 09)
28	I think in A&E somebody should be making those calls to establish which patient is a known dementia patient rather than just assumed, which is what tends to happen… So they now filter through to the wards with dementia, dementia, dementia until we come and say "This patient doesn't have dementia, don't put the yellow flag on this patient, there's no evidence of dementia" (Hospital staff 21)
29	Sometimes they really appreciate it and it'll open the flood gates, as it were, in terms of you've asked that question and suddenly they're like, "Oh yeah, we have been having problems actually, this has happened, yeah, he's getting really confused about his daily activities of living," and things, so it's… sometimes it's really helpful (Hospital staff 09)
30	The impact is quite variable. I think it's a matter of communication, but you can see that patients can become a little upset that they can't remember, and we have to explain why we're doing this, not to embarrass them (Hospital staff 20)
31	…in a good world you will have, actually have an assessment by an old age psychiatrist, someone with real skill in the area (GP 08)
32	The family is saying "Dementia, we were never told he had dementia", so actually it's not… The communication is not there, and then they're very upset with us by having it on their records here (GP, focus group 1)
33	…obviously it raises then worries, sometimes worries for the patient as well 'cos it's a scary thing to be told you might have dementia, it's scary for people (GP 16)
34	We have found that it can sometimes become less meaningful if it's more of an automatic tick box, certainly from one hospital (GP 10)
35	Usually it's been people that we already knew, you know, it's either you know, it's already been flagged up by their family, so we're sort of monitoring it (GP 17)
36	…sometimes… I've already spoken to the patient about it and they don't want to be referred at that stage, or they don't see the point in being referred or they want to wait – (GP 16)
37	I'm not really sure that case-finding dementia is helpful in a world that is the cutting services of people with dementia (GP 03)
38	Large amounts of money have been put into doing all this and I wonder whether it wouldn't be better spent elsewhere (GP 10)
39	It often raises hopes from the family that something exciting is going to happen and someone's going to help dad who lives on his own, and he's usually sent home, I mean most discharges are pretty unsafe to start with (GP, Focus group 1)
40	I wouldn't say that the case-finding coming out of the hospital has made a significant impact on our number of dementia cases at all (GP 12)

A&E, accident and emergency; CQUIN, Commissioning for Quality and Innovation; GP, general practitioner.

Many GPs in our study were opposed to hospital dementia case-finding and this is consistent with other research where clinicians have been reluctant to diagnose dementia because of the risks of misdiagnosis, the negative implications of stigma and impacts on families.[43 44] GPs in our study believed, as others have argued,[35] that they are best placed to assess their patients' cognition since they have knowledge of the patient and their family as well as the skills to make the judgement if a patient will benefit from a diagnosis of dementia.

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Many GPs were more concerned with the lack of postdiagnosis support and raising patients' and relatives' expectations about treatment options and that case-finding had diverted resources away from community services. Given that drug treatments for dementia are limited, the benefits of an early diagnosis of dementia are debated.[35 45] The stigma of a dementia diagnosis can cause patients and families to hide their symptoms and negatively affect one's identity,[46] concerns that previous studies have also highlighted from views of patients, carers and the general public as well as professionals.[47 48] This study also shows that healthcare professionals view case-finding as a politically and financially driven initiative with little or no evaluation of the outcomes.[30 33 44] From the limited research to date on the impact of policies aiming to increase dementia diagnosis rates in general practice, there is insufficient evidence of effect[49] and even a suggestion that when referrals from general practice for dementia assessment increased, the proportion among these who were subsequently diagnosed with dementia fell.[50]

Previous research has shown that hospital staff felt underprepared to care for older patients with dementia or delirium,[39] and improving recognition of these often co-existing conditions is one of the considerable challenges faced in acute settings.[32] One of the strongest perceived benefits of dementia case-finding mentioned by hospital staff in our study was the awareness raising of dementia in hospitals. It is unclear to what extent this has been due to case-finding itself or to an overall push on dementia care: for 3 years the Department of Health's national dementia Commissioning for Quality and Innovation included separate targets for staff training and supporting relatives of patients with dementia. This study did not address impacts on inpatient care; hospital staff who were interviewed recognised their experience of dementia case-finding was only in the inpatient setting and that the impacts after discharge were largely unknown to them.

This study provides new insights into current practice and the views of primary and secondary care clinicians. This was a qualitative study conducted in the East of England and some consideration should be given to the transferability of the results to other regions of the UK and other countries. Although the funding structures that have encouraged hospital dementia case-finding here are specific to the UK's health service, moves to promote case-finding across health settings, including in hospitals, affect many other countries.[51 52] The healthcare professionals we spoke to were self-selecting, many of whom had a specific interest in dementia and their views may not reflect those of their colleagues. We purposively recruited hospital staff who were directly involved in case-finding and consequently they may be more positive about the initiative than those not directly involved. There is a possibility that the GPs who volunteered to participate may be more or less dissatisfied with case-finding than non-responders.

This research is part of a wider study[36] which is also exploring the views of older people whose GPs were advised to review their cognition after a recent hospital admission, their relatives' attitudes to hospitals routinely memory testing older patients and reported experiences of follow-up after discharge. IT limitations and information governance restrictions in the UK currently prevent the use of routine data to examine individual trajectories. If available, these data could help to answer some of the questions raised by both primary and secondary care clinicians in our research which are beyond the scope of this small qualitative study. Some GPs' comments on the negative impacts of repeated service re-organisation highlighted the value of institutional memory. Targets for inpatient case-finding have never attracted media attention so hospitals avoided the heated debate on the ethics of a short-lived funding scheme in general practice that paid per dementia diagnosis,[53] but the introduction of any costly initiative without evidence also raises ethical questions. With public and voluntary sector resources so stretched, cost-effectiveness and cost–benefit research is a priority that could address GPs' particular concerns about funding supporting an unproven intervention to increase diagnosis rates while services to support people with a diagnosis are so scarce.

CONCLUSIONS

This study highlights the plethora of approaches to dementia case-finding across hospitals in the East of England and how this impacts on the communication of case-finding outcomes from hospital to GP and subsequent follow-up in primary care. Information communicated to primary care needs to be comprehensive, appropriate and consistent before GPs can effectively plan further investigation, treatment or care, but this intended follow-up in primary care further requires access to options for postdiagnostic support. Above all, there is a need to evaluate the impact on health and well-being outcomes for patients identified by dementia case-finding and health economic outcomes for health and care services across settings so as to inform the evidence base that is currently lacking.

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