Dementia case-finding tool for care workers

Briefing report

Health Innovation Network South London

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Contents

Project team

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Introduction

The Health Innovation Network is the Academic Health Science Network for South London, one of 15 AHSNs across England formed to pioneer new and innovative ways of creating system-wide improvements in patient and population health.

We are a membership organisation, focused on driving lasting improvements in health and wellbeing for our diverse local communities across South London.

We are working with industry partners driving innovation to improve health across our clinical areas – diabetes, dementia, musculoskeletal, alcohol and cancer.

Our cross-cutting themes – patient safety, patient experience, information and technology, wealth creation, and education and training run through all our work programmes.

The aim of this project was to increase identification of possible dementia and subsequent diagnosis rates in residential and nursing homes in South London by co-designing a dementia case-finding tool with, and for care workers.

The Alzheimer's Society estimates that up to 80% of residents in care homes have dementia or severe memory problems (Alzheimer's Society, 2013). The disparity between the number of those who are likely to have dementia and those with an actual diagnosis means that many people are not being given the opportunity to make informed choices, receive care informed by a thorough understanding of their care needs or access appropriate treatments, interventions or services.

A diagnosis will aid the understanding of care workers, family members and friends, leading to better care and support of the person with dementia.

We would like to thank the following care homes for their valuable contribution to this project:

- Whiteoak Court Nursing Home, Chislehurst
- Lynde House, Richmond
- Fairmount Residential Care Home, Mottingham
- Deer Park View Care Centre, Teddington
- Coloma Court Care Home, West Wickham

Executive summary

The Health Innovation Network Dementia Programme team conducted this feasibility study to ensure appropriate diagnosis in residential and nursing homes in South London by co-designing and testing a dementia case-finding tool with care workers, to be used by care workers.

It is well recognised that timely diagnosis can have a positive impact on the quality of life of people with dementia (Prince, Bryce, & Ferri, 2011). A diagnosis will aid the understanding of care workers, family members and friends, leading to better support of the person with dementia. It can lead to more appropriate care and support, it may give the person with dementia the opportunity to plan for the future and depending on the type and stage of dementia specific treatments or interventions may be available (Burns, 2014; Prince et al.,2011).

The case-finding tool was co-designed by creating focus groups with care workers in four care homes. Participants were entry-level or senior care workers. We explored:

- their attitudes towards having a role in identifying people who may have dementia
- their self-perception of relevant knowledge
- their level of experience as a formal care giver and
- their preferences of various possible formats of a case-finding tool.

Care workers then tested the case-finding tool in three care homes over a three-week period and were asked to use the tool with residents who they believed showed signs of possible dementia, but who did not have a diagnosis. Completed case-finding tools were reviewed by a GP or a Specialist Memory Nurse (SMN), so that they could either confirm or rule out a diagnosis or decide on the necessity of further assessment.

Follow-up with care workers showed that the case-finding tool was easy to use and that carers felt confident in using it. Over **87%** (20 out of 23) of the care home residents who were reviewed using the tool were either diagnosed with dementia or referred for further assessment.

"The tool is a positive development because it empowered me to say what I had already suspected." Carer

"The tool is "most helpful", saving time because care workers had identified residents showing possible signs of dementia prior to my arrival at the home." Specialist Memory Nurse

Our work to date suggests that the dementia case-finding tool is effective and efficient in identifying those who may have dementia. Care workers felt 'empowered' because they were given the opportunity to identify those residents who they suspected to have dementia. The case-finding tool helped them to communicate this in a formalised way. Visiting clinicians reported that the case-finding tool helped to provide a more efficient use of their time, whilst importantly incorporating useful observations made by those who care for people on a daily basis. Based on these positive findings, we are now conducting a wider pilot with a greater number of residents.

The importance of receiving a diagnosis of dementia

Over some years debates have taken place on the clinical relevance of diagnosing dementia and a consensus emerged that – apart from a range of ethical considerations, such as the 'right to know' - having a diagnosis can have a positive impact on quality of life (Prince et al., 2011).

A diagnosis will aid the understanding of care workers, family members and friends, leading to better care and support of the person with dementia. It enables people to plan for the future and depending on the type and stage of dementia, specific treatments or interventions may be available.

National policy

The Prime Minister's 'Challenge on Dementia' aims to improve dementia care, increase dementia research and improve dementia diagnosis rates (Department of Health, 2012a). The importance of the identification of people with dementia led to a 'Find, Assess, Investigate, Refer' (FAIR) CQUIN programme, which we include in a diagram in appendix 1. In this approach patients over the age of 75, who have been in an acute hospital for longer than 72 hours and who appear to have memory problems, undergo a brief memory test, which may result in referral (usually by the GP and after discharge) for further assessment.

The aim of the project was to conduct a feasibility study to increase diagnosis rates in care and nursing homes using a similar approach to that used in the acute hospital setting.

Outcomes

The project's objectives were to:

1 co-design a dementia case-finding tool by holding focus groups to ascertain care workers':

- knowledge and understanding of dementia
- experience of providing dementia care
- preferences of a selection of brief cognitive tests.

2 test the resulting case-finding tool to establish whether care workers have the skills, knowledge and understanding to use it appropriately and autonomously

3 to determine what proportion of those residents identified were subsequently diagnosed with dementia by a clinician

> "**80%** of residents in a care home have dementia or severe memory problems."
> Alzheimer's Society

Focus Groups

Methodology

Expressions of interest were invited from care homes in South London for their care workers to attend a focus group, led by a facilitator from the Health Innovation Network. The purpose of the focus groups was to gather care workers' views on these themes:

- feelings, knowledge, understanding and experience of dementia
- thoughts and preferences of presented case-finding tools
- thoughts on case-finding in the care home sector and perceived roles.

Participants included care workers and senior care workers, but registered nurses and care home managers were excluded, as we wanted to explore how to empower care workers in identifying residents who they thought might have dementia. We felt these staff might play a vital role, given the fact that they provide the most hands-on care. Each focus group had between three and six participants, all of whom gave consent to the discussions being recorded and transcribed. One-to-one interviews were also conducted with GPs to obtain feedback from clinicians.

APPENDIX 2 shows the topics and themes of discussion.

The findings of the discussions of the focus groups, presented by 'theme' are as follows:

Theme 1: Feelings, knowledge and experience of dementia

Care workers had a good understanding of the signs and symptoms of dementia and unanimously reported that memory problems were the main sign that they were familiar with and often participants would associate this with older age. In addition to memory problems many other signs and symptoms of dementia were identified by the participants, including dyspraxia, problems with eating, swallowing and speech problems.

Care workers were asked to identify some of the common themes of working with people who have dementia. Responses included explaining things multiple times to residents and being patient. Sometimes residents could be aggressive and violent, but care workers did not usually feel upset about this. Personal care could be challenging, because often residents with dementia do not allow the care workers to bathe them or provide personal care, despite care workers explaining that they are trying to help. On the other hand, care workers reported that working with residents who have dementia can be very rewarding, especially when they are able to use their personal relationship and knowledge of the resident to make them content.

> "If you make them feel satisfied then you feel satisfied, and your job is done."
> Care worker

Theme 2: Thoughts and preferences of presented case-finding tools

Care workers were presented with a selection of existing cognitive tests and were asked questions about their preferences for each test.

AMT-10 (Abbreviated Mental Test – 10)

This tool was well liked, because many of the questions were simple and not too 'testing'. However, a small number of care workers for whom English was not their first language, reported difficulties with some of the cultural questions for example, who is the currrent monarch and when did World War One start. Some care workers commented that this could disadvantage residents and may make it difficult for some care workers to use.

AMT-4 (Abbreviated Mental Test – 4)

This tool was similarly well liked and care workers believed that people without significant confusion or memory problems should be able to answer the questions. Furthermore, some care workers highlighted that the AMT-4 did not take long to complete and so would be more suitable for use in the time-constrained care home environment. However, in one care home some care workers felt that those with mild dementia would be able to "fool" the AMT-4, and that they could be more sure of a correct result with a longer, more detailed test.

"Test Your Memory" (TYM) test

This tool was also viewed positively by care workers. They felt reassured by the longer length and how comprehensive it was, so they could be certain that it would identify both those with mild as well as those with more severe dementia. Participants also thought the Test Your Memory test was a good option because it could be presented as an activity. This triggered discussion around ethics, where it was felt that informed consent should be gained before asking the residents to undertake a dementia case-finding test and that it should not be used covertly as an activity. In most focus groups, a long discussion took place as care workers debated the answers to the questions because they themselves were not always sure of the correct response. Some care workers were concerned that residents would not be able to use the test because it was self-administered and they were no longer able to write. Furthermore, care workers felt that residents would become distracted whilst in the process of completing it because it is such a lengthy test.

GP-COG

Although care workers thought the tool was good - as it included an informant questionnaire for them to complete - the GP-COG appears to assume that the participant lives independently, asking whether they administer their own medication and if they need help with transport. These questions are not necessarily applicable to the care home environment.

Theme 3: Thoughts around case-finding in the care home and perceived roles

In all focus groups care workers felt that dementia case-finding should fall within their remit as care workers. They said that the resident's GP should ultimately make a diagnosis. However, since care workers often know the residents better than the GP, they are well placed to raise an initial alert that someone might have dementia.

"To diagnose, the GP is the one. But to notice, those that are close to him, the relatives or the carers (workers) or the nurse."

"Because even I can say the nurse doesn't have as much insight as us. We are the ones who sit with them, do personal care, are with them 24/7."

Care workers stated they would feel confident to complete a case-finding tool with residents although some reported that they might feel apprehensive if the resident didn't want to complete it.

General Practitioners (GPs)

Informal interviews were conducted with four local GPs in South London. They were shown a draft of the case-finding tool and were asked to provide general feedback on the concept, the design of the tool and implementation.

One GP was initially sceptical because she considered that the case-finding tool may add to the paperwork burden on her and her colleagues. However, once the process of the tool had been explained, the GP realised that the case-finding tool could save time because care workers would have already identified those residents with a history of confusion or memory problems. Ultimately, she suggested that GPs could distribute the tool to the care homes they cover to improve dementia identification and diagnosis rates.

All the remaining GPs were very positive about the tool. They suggested that completed case-finding tools could be added to the GP list for review for each care home visit.

Design of case-finding tool

One of the outputs from the focus groups was a set of principles for the design of the tool.

The case-finding tool should be:

- uncomplicated and easy to follow, so it doesn't need intensive training
- accessible to people with English as a second language or those who may not have much knowledge of British history and culture, to cater for care workers and residents from minority ethnic backgrounds
- aesthetically pleasing, to ensure it is recognisable and easy to use
- paper-based, as most care homes use paper notes.

Essential requirements of the tool were:

- there must be an initial case-finding question to prevent indiscriminate screening of residents
- there must be an observation chart as part of the case-finding tool, to provide clinicians with a more complete picture
- the case-finding tool and referral letter should both be in the same document so that clinicians who have not come across the tool will understand why it has been given to them and what it is
- included with the case-finding tool should be an instruction sheet and a 'Frequently Asked Questions' document for care workers.

Final design

In the final design, the AMT-4 cognitive test was chosen, because it was felt by the care workers that this would be the most easily completed in the time-constrained care home environment. Furthermore, it was felt that this would be sensitive and specific enough to identify many residents in care homes with undiagnosed dementia.

In addition to the AMT-4, a short observation chart listing some of the more common signs and symptoms of dementia is included so the care workers can provide a more comprehensive picture of the resident.

Care workers were asked to feedback on a number of iterations of the tool and a considerable number of adjustments were made to ensure a truly co-designed tool had been produced, which could be easily used by care workers in any care home.

APPENDIX 3 shows the completed case-finding tool used in the feasibility test.

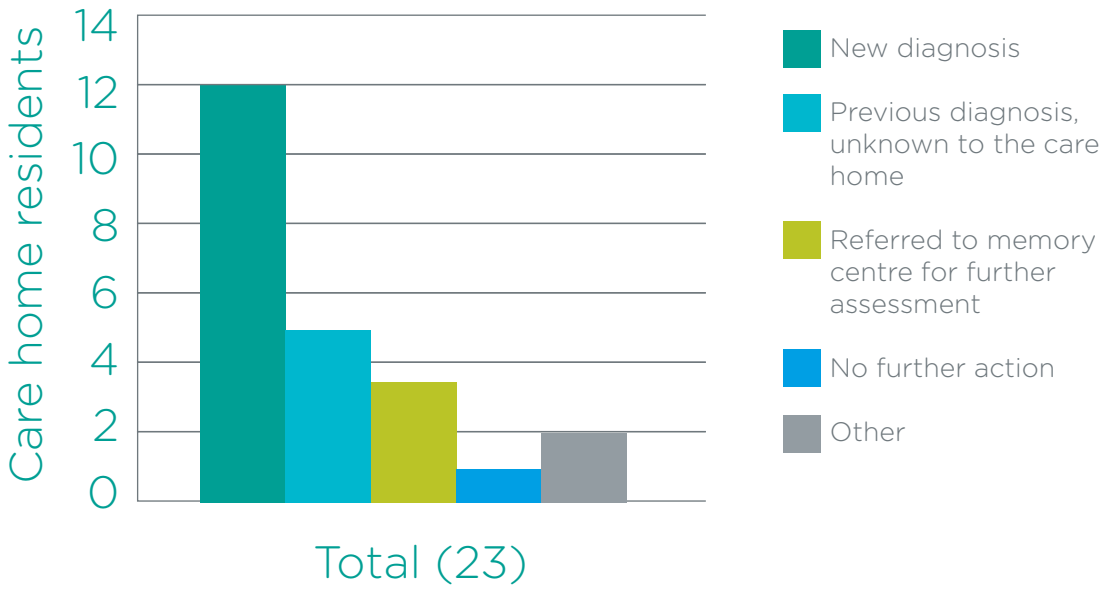
Feasibility testing

The dementia case-finding tool was tested with three care homes over a three-week period.

Between three and five carer workers per home were asked to use the tool with residents who they believed showed possibly signs of dementia, but did not have a diagnosis of dementia. A one hour training session was provided to participating care workers prior to commencement of the test period. Role play was used to demonstrate how consent should be obtained and how to appropriately complete the case-finding tool. Care workers were then given the opportunity to ask any questions.

The guidance included with the case finding tool clearly instructs care workers that they must obtain informed consent before using the case finding tool with a resident. In the event that the resident is unable to provide informed consent, the care worker should complete and submit the observation chart alone.

In two of the care homes a Memory Nurse arranged to visit at the end of the testing period to review the residents who had been identified for further assessment. At the third home a GP reviewed the residents and completed case-finding tools.



Results

Care workers completed 23 case-finding tools during the feasibility study. On review, clinicians diagnosed 12 (52%) residents with unspecified dementia and referred three (13%) to memory services. Furthermore, five (22%) were found by the clinicians already to have a diagnosis which was unknown to the care homes. No further action was taken with one (4%) resident who had a normal cognitive score when assessed by a clinician and two (8%) were not reviewed by the clinicians because they were physically unwell at the time of review.

A follow-up focus group and evaluation forms completed by care workers suggested that the case-finding tool was easy to use and that carers felt confident when using it. One carer commented that she thought the tool was a positive development because it empowered her to say what she had already known: some residents appear to have undiagnosed dementia.

The Specialist Memory Nurse said that the tool was "most helpful" and saved him time because care workers had already identified residents showing signs of dementia prior to his arrival.

Conclusion

The feasibility study showed that after a short training session, care workers in three care homes in South London were able to use the dementia case-finding tool appropriately with residents who they believed to show signs of dementia but did not have a diagnosis of dementia.

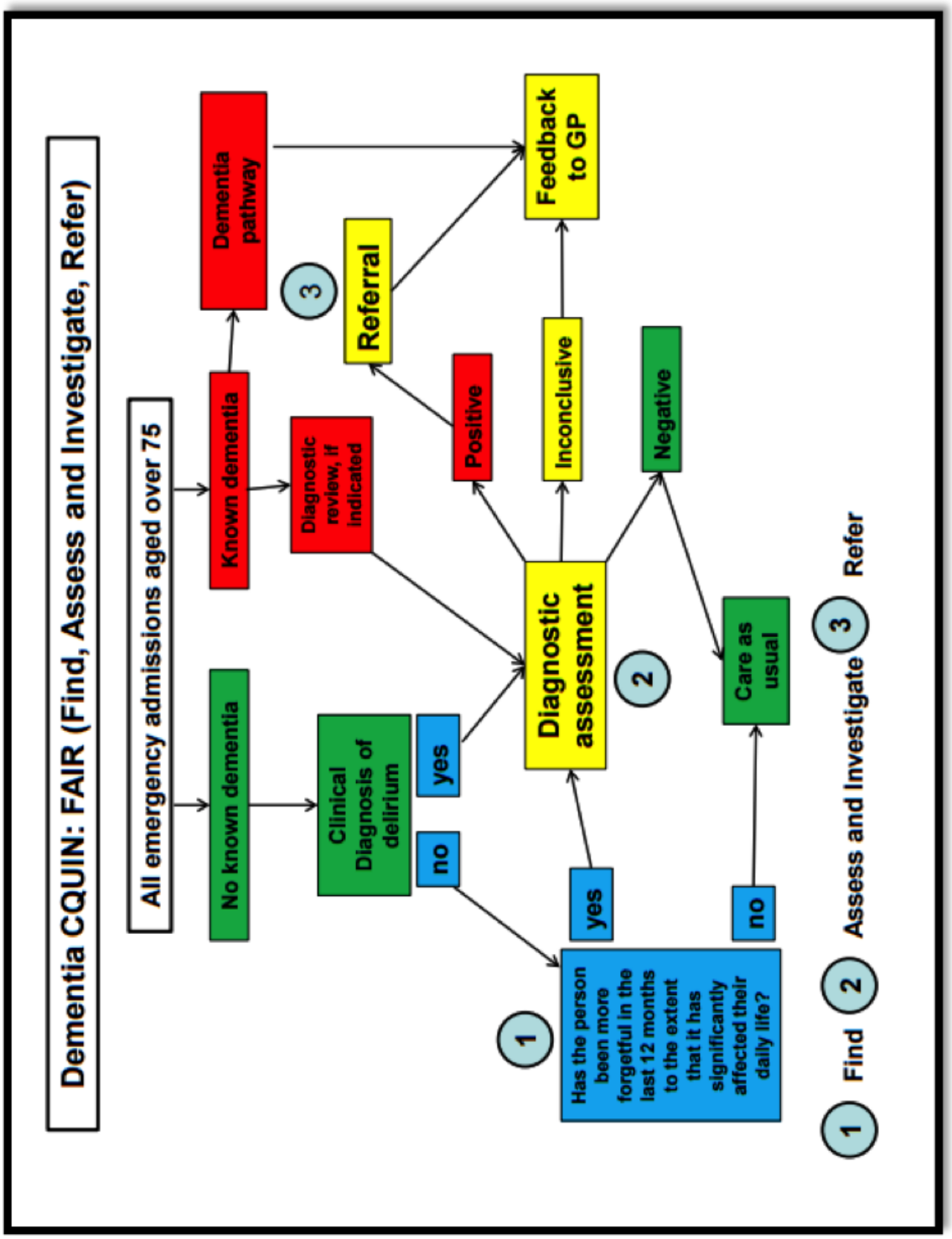
Of the 23 case-finding tools completed by care workers, the vast majority identified residents who were either subsequently diagnosed with dementia or subsequently referred for further assessment or already had a diagnosis of dementia which was not known by the care home.

Feedback regarding the case-finding tool was positive from both clinicians and care workers. Care workers felt empowered by the tool which helped their communication with clinicians and made it more robust.

The dementia case-finding tool is an efficient way to start the process of identifying care home residents who may have dementia. It can be used by care workers confidently and effectively. Furthermore, its use prior to a visit by a clinician is an efficient use of resources because it means clinicians' time is more focused.

We are now doing further work to evaluate the case finding tool with a larger number of care home residents.

Appendix 1



Department of Health, 2012b

Appendix 2

Theme 1: Feelings, knowledge and experience of dementia

1. When you hear the word "dementia", what does it make you think of?

2. As a carer, what are your experiences of working with people with dementia?
   a. What are the good things about working with people with dementia?
   b. What are the challenges of working with people with dementia?

3. What might make you think that a resident had dementia or might be starting to show signs of dementia?
4. If you suspect that a resident is showing signs of dementia, what do you do?

5. What do you think the benefits of a dementia diagnosis are?

Theme 2: Thoughts and preferences of presented case-finding tools

1. What are your initial thoughts around the tools I've shown you?

2. Regarding number 1 (case-finding question);
   a. What do you like about it?
   b. What do you not like about it?

3. Regarding number 2 (AMT-10);
   a. What do you like about it?
   b. What do you not like about it?

4. Regarding number 3 (AMT-4);
   a. What do you like about it?
   b. What do you not like about it?

5. Regarding number 4 (Test Your Memory);
   a. What do you like about it?
   b. What do you not like about it?

6. Regarding number 5 (GP-COG);
   a. What do you like about it?
   b. What do you not like about it?

7. Out of the tools I've shown to you, which do you prefer?
   a. And why?

Theme 3: Thoughts around case-finding in the care home and perceived roles

1. Do you think there are any barriers or challenges to using dementia case-finding tools like these in care homes?

2. Whose job do you think it is to use these sorts of tools?
   a. Do you think it is part of your role?
   b. Would you feel confident using one?
   c. Would you feel confident reporting the results of one?
   d. What factors might make you use a tool?

3. How might the tools be adapted to make them more likely to be used by carers?

Draw to a close: Do you have any other comments which we haven't talked about yet which you think are important?

Appendix 3 Case-finding tool used in feasibility testing

Health Innovation Network South London

Date:

Dear Doctor / Specialist Memory Nurse

Re: Patient name:_____ Date of birth: ____/____/_____

Care Home: _____ Phone: _____

The South London Health Innovation Network is carrying out a feasibility study to explore how to assist primary care practitioners to identify residents with possible dementia in the care home sector.

We have designed a simple case finding tool (overleaf) which care home workers are trained and encouraged to use, if they are concerned a resident may have dementia.

We stress this is not a screening tool: staff are instructed only to use it with those residents who display signs or symptoms raising concern. Furthermore, identification by using this case finding tool does not confirm a diagnosis and is not a diagnostic exercise.

Staff at the above care home have been concerned about the above patient and have used the case finding tool, the results of which can be seen overleaf.

We encourage staff to collect further information if at all possible, and – if available – this information is documented overleaf on the observation behavior chart.

We thank you for reviewing the results and considering further action, as appropriate.

Dr Hugo de Waal
Consultant Old Age Psychiatrist
Clinical Director for Dementia
South London Health Innovation Network

Enquiries regarding this project should be directed to Laurence Cowderoy, Darzi Fellow by emailing laurence.cowderoy@nhs.net.

Health Innovation Network South London

Dementia case-finding tool V0.6

Residents must give verbal consent to having their memory assessed in this way

Name: _____ DOB: ____ / ____ / _____

Care Home: _____ Care-worker: _____

For more information, see the FAQs.

Once completed, store this form in the agreed place for investigation by the GP or specialist Nurse when they attend.

1 Must be answered "YES" to continue to section 2 and 3:

Does this resident show signs of confusion or memory problems?

YES / NO

2 Observed in last 3 months:	Often	Sometimes	Rarely	Never
Forgetting things				
Repeating themselves				
Disorientated				
Restless				
Wandering				
Needs prompting with basic tasks (dressing, hygiene)				
Speech and language problems				
Withdrawn				

Other (specify)

Please note here if the resident does not appear to have capacity. Do not proceed to section 3.

3 Abbreviated Mental Test-4 (AMT-4)

Question	Answer
How old are you?	
What is your date of birth?	
Where are we now?	
What is the year?	
Score Less than 4 is abnormal	/4

Appendix 4

	Residents	Tools complete	New diagnoses	Previous diagnosis	Referred to memory centre	No further action	Other (see notes)
Care home A (memory nurse)	27	10	9	0	0	0	1
Care home B (GP)	76	6	1	0	3	1	1
Care home C (memory nurse)	38	7	2	5	0	0	0
Total	141	23	12	5	3	1	2

Care home A completed 10 forms
- Specialist Memory Nurse (SMN) diagnosed nine with unspecified dementia (90%).
- One resident had died (10%).

Care home B completed 6 forms
- GP diagnosed one with unspecified dementia
- GP referred three to the memory service
- One no further action (normal AMTS score)
- One was at the end of life so not assessed.

Care home C completed 7 forms
- SMN diagnosed two with unspecified dementia
- SMN found five of those identified already had a diagnosis, unknown to carehome.

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