Executive Summary

Background

The National Audit of Dementia (NAD) care in general hospitals is commissioned by the Healthcare Quality Improvement Partnership on behalf of NHS England and the Welsh Government, as part of the National Clinical Audit Programme. NAD examines aspects of the care received by people with dementia in general hospitals in England and Wales.

Audit management and governance

The audit is managed by the Royal College of Psychiatrists in partnership with:

- Royal College of Nursing
- Royal College of Physicians
- British Geriatrics Society
- Alzheimer’s Society
- Dementia Action Alliance
- Age UK
- John’s Campaign.

Who should read this report

In line with HQIP Reporting for Impact guidance, this report is designed to provide information for:

- People who receive care or provide care for someone – people with dementia and their families
- People involved in providing care – professional staff, managers and Trust Boards working in general hospitals in England and Wales
- People involved in commissioning care – NHS England, Welsh Government, clinical commissioning groups
- People who regulate care – including the Care Quality Commission, clinical audit and quality improvement professionals.

Data collection and reporting

Data for this round of audit were collected April–November 2016. This report was published 13 July 2017.
Service user and carer participation

Representatives with experience of living with dementia or caring for someone who has dementia sit on the Steering Group which advises on all aspects of the project, together with representatives from the organisations above. Development of the carer questionnaire for this round of audit was informed by the Imperial College Patient & Public Involvement panel. Carers involved in testing the questionnaire returned comment on content and format.

Data collection and anonymity

No patient identifiable data was collected for the audit of casenotes. Staff and carer surveys were distributed with prepaid envelopes for direct return to the Project Team, or completed online. No identifying details were requested.

Carers who completed the questionnaire for this round of audit made frequent comment on the quality of care received by people with dementia (see page 38). The comments provide very useful insight and context and we present a breakdown of comments and show comment excerpts. To protect anonymity, we have not used verbatim comments.

Dementia in general hospitals

Dementia is the term used to describe a range of symptoms caused by diseases which damage the brain, such as Alzheimer’s disease, or a series of strokes. Symptoms vary extensively but may include memory loss and difficulties with thinking, language and problem solving, and changes in mood and behaviour\(^b\).

For a person with dementia, these symptoms are severe enough to cause significant problems in daily life. Dementia is most prevalent in people over the age of 65 and the likelihood of developing dementia increases with age. People are not generally admitted to hospital for dementia. Common reasons reported by the Alzheimer’s Society\(^c\) previously include falls, hip fractures, stroke, urinary tract and respiratory infections. In this audit, 50% of the primary causes for admission were either falls, hip fracture or dislocation, respiratory related or urinary infections.

Admission to hospital is exceptionally difficult for people with dementia. Illness or injury, loss of familiar surroundings and routine, and a busy task centred environment can all worsen dementia symptoms and increase the risk of delirium. The Alzheimer’s Society cites figures obtained from Department of Health stating that people with dementia in hospital account for around 3.2 million bed days a year\(^d\). Governments in both England and Wales have identified dementia care in hospitals as a priority for improvement. NHS England is committed to supporting the implementation of the Prime Minister’s Challenge on Dementia 2020 Implementation Plan and supports the Dementia Friendly Hospitals initiative of the Dementia Action Alliance.

\(^b\) https://www.alzheimers.org.uk/info/20007/types_of_dementia/1/what_is_dementia
Two previous rounds of this audit have taken place, reporting in 2011 and 2013. Round 2 of the audit found that some improvement had taken place in care processes such as assessment and discharge planning, and increased support for dementia in hospital from the introduction of senior clinical leads, dementia champions, and training provision. The second round report recommended collecting feedback from the carers of people with dementia and staff who provide care, to gain a better understanding of important aspects of care such as communication and understanding individual needs.

The third round of NAD collected data between April and November 2016. One hundred and ninety-nine hospitals in England and Wales took part in the audit and were asked to complete four elements:

- A hospital level organisational checklist
- A retrospective casenote audit with a target of a minimum of 50 sets of patient notes
- A survey of carer experience of quality of care
- A staff questionnaire on providing care and support to people with dementia.

Ninety-eight percent (199/203) of hospitals eligible to participate across England and Wales submitted data for all or part of the audit. In total, the audit received 199 organisational checklists, 10047 casenote submissions, 14416 staff questionnaires and 4664 carer questionnaires.

**Overview of results**

The National Audit of Dementia (care in general hospitals) measures the performance of general hospitals against criteria relating to care delivery which are known to impact upon people with dementia while in hospital. These criteria have been derived from national and professional guidance, including NICE Quality Standards and guidance, the Dementia Friendly Hospitals charter, and reports from the Alzheimer’s Society, Age Concern and Royal Colleges. These have been compiled as a set of standards, which can be found on the audit website, together with their sources and the questions used for measurement in this audit.

This report contains results from data sets made up of the combined data submitted by all hospitals in England and Wales taking part in the third round of audit. Results from all four of the tools in this round are presented together.
Audit themes
Audit standards are measured across each of the tools. Therefore, data submitted are presented thematically, with data from each tool presented together.

The themes are:

1. **Assessment**
   Data from the casenote audit. This looks at whether people with dementia admitted to hospital have received a comprehensive assessment, and how well each element of assessment is carried out.

2. **Information and communication**
   Data from the organisational checklist, casenote audit, staff and carer questionnaires. This looks at communication systems in use in the hospital, evidence of their use in casenotes, and presents feedback from carers and from staff about the quality of communication.

3. **Staffing and training**
   Data from the organisational checklist, staff questionnaire and carer questionnaire. This looks at staffing provision, the extent of training delivery in hospitals and presents feedback from staff on training quality.

4. **Nutrition**
   Data from the organisational checklist and staff questionnaire. This looks at whether hospitals have services that provide for the needs of people with dementia and presents feedback from staff on service quality.

5. **Discharge and hospital transfer**
   Data from the organisational checklist and casenote audit. This looks at the extent of planning for discharge from hospital for people with dementia and whether they and their carers are adequately informed.

6. **Governance**
   Data from the organisational checklist and staff questionnaire. This looks at the involvement of hospital leads and the Executive Board in leading, planning and monitoring care, review of the environment and carer engagement.

In this round, we find that hospitals have begun to implement many of the improvements needed to support the care of people with dementia, notably in training provision, ward level leadership, and the use of services which accommodate complex needs. However, feedback from carers and from staff shows that progress in many areas is yet to take place, or is inconsistent. There is still some way to go before changes are embedded.
Scoring in Round 3 of audit
For the first time, we present hospital level scores. The scoring system allows easy comparison between hospitals on the different themes of the audit and a table of all scores per hospital can be found in Appendix A. There are seven scores, each relating to an audit key theme, plus the carer overall rating of care. The range of scores nationally is presented within each results chapter, where relevant.

Scores are derived from separate data sources and should be viewed independently. For example, a hospital’s score for Assessment should be compared to other Assessment scores, rather than the other scores for that hospital. This is because a hospital’s highest score may not reflect its area of greatest achievement, if it is a theme in which all hospitals have scored highly. The full method for the scoring is shown in Appendix B.

Not every hospital has received a complete set of scores. To receive a full set, hospitals were required to provide one complete organisational checklist, more than 19 casenotes, 20 or more staff questionnaires and 10 or more carer questionnaires. Hospitals with fewer than the required number, have not received a score for that theme.

National mean averages for each score are presented on page 22.

Key findings

Delirium recording requires improvement
In more than half of casenotes of people with dementia, there was no recording of an initial screen or check for symptoms of delirium. Inconsistency in what is recorded and communicated may affect clinical care and thereby increase a person with dementia’s risk to developing delirium.

Personal information to support better care must be accessible
A ward spot check carried out during the audit looked for the document with key personal information about care needs and communication that should be completed for people with dementia, and found that only half of these patients had one in place. Forty percent of staff said that they could not access this information most of the time, and under half of carers said definitely, staff were well informed.

Services must meet the nutritional needs of people with dementia
Catering services in hospitals should be able to provide for the needs of people with dementia, who may not be able to eat full meals at regular times and need finger food meal alternatives and snacks available at any time to ensure they are nourished. Less than 75% of staff said that they could obtain finger foods or snacks between meals for these patients. Twenty-four percent of staff thought people with dementia had nutritional needs met only sometimes, or were not met.
Championing dementia means supporting staff
To support staff to deliver better care, nearly all hospitals have created dementia champions at ward level. Just under 70% of carers gave a high rating to care overall. Staff said they needed more support, especially out of hours when less than a quarter of staff said they could access specialist support for dementia always or most of the time.

Involve the person with dementia in decision making
Where a change in residence after discharge (e.g. from their own home to a care home) was proposed, just over one third of patients did not have their consent to begin this process recorded, or evidence that a best interests decision making process had taken place, in the case that they lacked capacity.

Key recommendations
Below we present the key recommendations for this report, relating to the key findings above. The full list of recommendations can be found on page 87. Each theme also contains the associated recommendations.

Delirium
Medical and Nursing Directors should:
• Ensure that hospitals have robust mechanisms in place for assessing delirium in people with dementia including:
  – At admission, a full clinical delirium assessment, whenever indicators of delirium are identified.
  – Cognitive tests administered on admission and again before discharge.
  – Delirium screening and assessment fully documented in the patients notes (regardless of the outcome).
  – Care offered in concordance with the delirium evidence-base recommendations when the assessment indicates symptoms of delirium.
  – Results recorded on the electronic discharge summary.
• Ensure staff receive training in delirium and its relationship to dementia, manifestations of pain, and behavioural and psychological symptoms of dementia.

Personal information use
• National Commissioners (Welsh Government, NHS England) should propose a nationally backed monitoring programme aimed at embedding the collection, sharing and use of person centred information. This should include a clear expectation that once gathered, this information will follow the patient between providers, and this will be monitored.
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<th>Executive Summary</th>
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<tr>
<td>• Ward Managers should audit implementation/use of personal information collected to improve care for patients (e.g. <em>This is Me</em> or other locally developed document). The result of the audit should be fed back to the dementia champions/dementia lead and ward staff.</td>
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<td><strong>Nutrition</strong></td>
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<td>• Clinical Commissioning Groups and Health Board commissioning services should ensure that tenders let by Trusts for new catering contracts always specify provision of finger foods for main meals and access to a range of snacks 24 hours a day.</td>
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<td>• Medical and Nursing Directors should promote the attendance of key carers to support care, but ensure that this is complementary to, and not instead of, care delivered by staff. The level of input by carers, and how carers feel about the level of input they have been asked to deliver should be monitored through carer feedback, complaints and PALS enquiries. Carer satisfaction should be seen as a marker of good care. Ward managers should be supported to ensure carers supporting patients should not be asked to leave at mealtimes/stopped from helping with meals (this excludes emergency and urgent care and treatment).</td>
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<td><strong>Dementia Champions</strong></td>
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<td>• The Chief Executive Officer should ensure that there is a dementia champion available to support staff 24 hours per day, 7 days per week. This could be achieved through ensuring that people in roles such as Site Nurse Practitioners and Bed Managers have expertise in dementia care.</td>
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<td><strong>Decision making</strong></td>
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<td>• The Safeguarding Lead should ensure that staff are trained in the Mental Capacity Act, including consent, appropriate use of best interests decision making, the use of Lasting Power of Attorney and Advance Decision Making. Training should cover supportive communication with family members/carers on these topics.</td>
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<td><strong>Future rounds of audit</strong></td>
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<td>It is expected at the time of writing that the audit detailed in this report will be repeated in 2018, reporting in 2019.</td>
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<td><strong>Audit activity in 2017-2018</strong></td>
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<td><strong>Clinical Outcomes Programme Publication (COP)</strong></td>
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<td>The audit will be submitting data from key measures derived from the casenote audit and carer and staff questionnaires for publication as part of the COP. This programme brings together and publishes quality measures from a range of audits and helps support their inclusion via accessible platforms such as NHS Choices.</td>
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Optional casenote audit
The casenote audit tool is open until the end of July 2017, to allow hospitals who wish to build a year on year record of performance to submit further cases.

Spotlight audit on psychotropic medication
This module will look at medication which may be prescribed for behavioural and psychological symptoms of dementia, received by patients with dementia admitted to hospital in April 2017. The module will be rolled out in August, with a closing date in October. The full report will be completed in February 2018.

Quality Improvement Workshops
Following publication of the national and local reports, audit leads can attend one of eight quality improvement workshops taking place around England and Wales in September and October 2017.

The workshops will be led by Maureen McGeorge, who has many years’ experience in the development and use of improvement programmes in healthcare. Workshops will help leads to devise practical applications to address shortfalls identified by audit.
Average Hospital Scores across England and Wales

The scores represented are averages from 7 scoring themes in this report based on data submitted by 199 hospitals in England and Wales. See Appendix A for all hospital scores.