Foreword

Dementia is the number one health concern for people over 50 and is described by the Prime Minister as ‘one of the greatest challenges of our time’. There are already 670,000 people with dementia in England, 550,000 friends and family acting as primary carers for them and the costs across health and social care and wider society are estimated to be £19 billion, higher than the costs of cancer, heart disease or stroke.

As this report demonstrates, a significant proportion of these costs are met by hospital trusts. Patients with dementia stay in hospital for longer than those without and are more likely to be readmitted or suffer from higher rates of mortality.

There are some fundamental issues that underlie our current circumstances; issues such as inconsistencies in the way we identify, refer to and report on people with dementia who use our acute services – we can see this reflected in this report where terms such as ‘senility’ are still in use. This tells us a lot about where we are now and it helps us to see what action we can take to make significant changes.

In response to this, the Prime Minister has called for an all-out concerted effort and commitment, from all of us, to change the way we view this disease and our attitudes to those who are living with dementia; one that cuts across society, and has made dementia the focus of a particular personal challenge.

Charities, businesses and public sector bodies from across England including high street banks, energy companies and retailers are responding to this challenge and are committing to real action to improve the lives of people with dementia. Working closely with people with dementia and carers as partners in these changes; utilising the expert insights they have gained through their direct experience of living with the condition.

Hospital trusts also have a crucial role to play in meeting this challenge. Different hospital trusts are at different stages on the journey to becoming dementia friendly and we want your hospital to be at the forefront of this movement.

This report sets out the economic case for becoming dementia friendly and why it should be core business for every hospital. It also reinforces the need for action by hospital trusts that ties into wider initiatives across health and social care and involves the wider community, to spend money meaningfully to improve the support people affected by dementia have the right to.

We are offering you this report to help you to understand and frame the context in which we are working and invite you to join this society wide movement by committing to a programme of action to become more dementia friendly including joining your Local Dementia Action Alliance to work with local firms and organisations, carers and people with dementia to drive forward improvements (in your local area).
Along with some essential core activities, this programme of action could include working with care homes in their step-down intermediate care capacity to prevent admission and facilitate early discharge, as well as developing end of life care pathways so people with dementia are not admitted to hospital to die.

We hope you find this report food for thought and that it inspires you to investigate further how becoming dementia friendly can improve the running of your hospital trust and the lives of people with dementia who use the services you provide.

To register your commitment and sign up to the Call to Action go to:

http://www.dementiaaction.org.uk/therightcare

Sharon Blackburn, Policy & Communications Director, National Care Forum

Jeremy Hughes, Chief Executive, Alzheimer’s Society

Professor Graham Stokes, Director of Dementia Care, Bupa Care Services UK

Gill Ayling, Deputy Deputy Director, Older People and Dementia, Social Care Local Government Care Partnerships, Department of Health
Introduction

Dementia is a significant challenge for the NHS with an estimated 25% of acute beds occupied by people with dementia, their length of stay is longer than people without dementia and they are often subject to delays on leaving hospital. Whilst work is underway to improve the nature of outcome data, the process measure of dementia risk assessment will set an effective foundation for appropriate management of patients. This will allow significant improvements in the quality of care and substantial savings in terms of shorter lengths of stay.

Dementia affects an estimated 670,000 people in England, and the costs across health and social care and wider society are estimated to be £19 billion – both figures are set to rise with the ageing of the population. This report has found that £212 million of savings may be possible through improvements to care in hospitals.

Currently only around 42% of people with dementia in England have a formal diagnosis despite the fact that timely diagnosis can greatly improve the quality of life of the person with dementia by preventing crises (and thus care home and hospital emergency admission) and offering support to carers (who are invariably under stress).

The NHS Institute for Innovation and Improvement in partnership with the Dementia Action Alliance has launched a Call to Action for the improvement of care for people with dementia in acute hospitals. The goal of this work is that by March 2013 every hospital will commit to becoming a dementia friendly hospital.

Becoming a dementia friendly hospital will require different action in different areas by different people. It is a big commitment which will require time and energy to undertake. An important part of moving forward will be understanding how the hospital currently works.

How many patients are coming through the hospital, what happens to them when they are admitted, where do they get discharged to and what support awaits them are just a few questions.

This report attempts to create a picture of care in hospitals and helps to inform how to use the data as a vehicle for improvement and stimulate ideas about where to focus attention. There is national data within this report as well as data for the PCTs within your region. The analysis was commissioned by the NHS Institute for Innovation and Improvement and the report was designed in conjunction with regional dementia leads.
Important

Data sets should be viewed as indicators (data sources and methodology used are detailed in appendix 2). As they stand, they do not give explanations but they do provide a snapshot in time. The power of this information will be in viewing it as a whole rather than taking single indicators to inform how the system is performing.

Frequency of dementia and levels of recording

There are a number of reports showing that people with dementia are a major population in English hospitals and that they tend to use greater resources during their stay. It is also recognised that it is a widely under diagnosed and reported diagnosis.

Table 1, below shows the number of spells in acute hospitals for people without dementia, for people with dementia and for those who have been coded with senility. The spells for patients with dementia is made up from:

- spells of patients occurring in 2010 (or 2011) where no diagnosis of dementia had previously been made but who were subsequently diagnosed with dementia before the end of 2011
- spells of patients occurring in 2010 (or 2011) where diagnosis of dementia had previously been made (or was first made in the current spell).

<table>
<thead>
<tr>
<th></th>
<th>2010</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of spells for non-dementia patients (the patient's record since 2006 did not contain an ICD code of dementia)</td>
<td>8,133,341</td>
<td>8,372,169</td>
</tr>
<tr>
<td>Number of spells for dementia patients</td>
<td>549,454 (6.32% of total spells)</td>
<td>498,408 (5.61% of total spells)</td>
</tr>
<tr>
<td>Number of spells for patients with senility (the patient's record since 2006 did not contain an ICD code of dementia but contains a diagnosis of senility [code R54])</td>
<td>352,458 (4.06% of total spells)</td>
<td>334,141 (3.77% of total spells)</td>
</tr>
</tbody>
</table>
The prevalence ranges from 10-40% but it is recognised that the largest proportion of people sit at around 25%.

**Key questions**

- How do these results compare with hospitals in your region?
- Is senility a frequently used code in your organisations? If so is it being used inappropriately?
- Are admissions for people with dementia monitored?
- Are there processes in place to identify people with dementia attending as elective admissions as well as emergencies?
- Is your hospital under-reporting the patient spells for people with dementia?
Length of stay in patients with dementia compared to patients without dementia

Longer length of stay is a significant issue. The longer people with dementia stay in hospital, the worse the effect the symptoms of dementia have on their physical health. It is more likely that they will be discharged to a care home and by extension an increased likelihood of further prescribing of antipsychotics.

Headlines

27.2%
Excess length of stay for people with dementia in 2010,
Average length of stay for people with dementia was 13.57 compared to 10.67 days for people without dementia*

22.1%
Excess length of stay of people with dementia in 2011
Average length of stay for people with dementia was 13.25 compared to 10.85 days for people without dementia*

*comparisons are made using standards from non-dementia patients

Regional variation

There is significant variation across the country for excess length of stay for people with dementia. The graph (page 7) shows this variation with London PCTs highlighted.
Variation within London

Excess Length of Stay for people with dementia in Acute Hospitals

Above 100% represents higher than expected length of stay. Below 100% represents lower than expected.
Variation within London

Excess Length of Stay for people with dementia in Acute Hospitals In London

Above 100% represents higher than expected length of stay. Below 100% represents lower than expected.
Key questions

It is important to be clear that reducing length of stay in acute trusts is a whole system issue.

What evidence is there that:

- Joint planning occurs with SS / PCT to improve community services?
- Intermediate care services are adequately developed?
- There is a joint and pragmatic approach to delayed discharges occurring?
- The NICE Guidance for delirium been implemented and audited?
- There are health care delays i.e. waiting for a rehabilitation, intermediate, re-ablement bed, panel for funding?
- There are delays with social services providing packages of care or lack of care home beds in the locality?
- There are a number of patients from “out of area” specialist hospitals?
- Mental Health Liaison services require development?
Returning to usual place of residence

The ability for people with dementia to be discharged from hospital to their usual place of residence is an excellent quality standard to strive for as being in a familiar environment is of great benefit to patients and carers alike.

Below we can see the headlines from the data showing patients returning to their usual place of residence following treatment for an acute condition. This is contrasted with the expected proportion based on standard rates of non-dementia patients of similar age and treated for similar conditions.

**Headlines**

<table>
<thead>
<tr>
<th>% rate of return to usual place of residence for people with dementia for people admitted electively</th>
<th>% rate of return to usual place of residence for people with dementia for people admitted non-electively</th>
</tr>
</thead>
<tbody>
<tr>
<td>97.6%</td>
<td>73.6%</td>
</tr>
</tbody>
</table>

110,273 people with dementia return to their usual place of residence. The expected number is 111,867. This is a deficit of 1594 patients

283,111 people with dementia return to their usual place of residence. The expected number is 305,043. This is a deficit of 21,563 patients

**Key questions**

- How does this result compare with data in your region?
- What support is offered post-discharge to people with dementia?
- What level of information is provided to the patient and carer prior to discharge?
- What proportion of discharges to different residences is for clinical reasons?
Readmission rates for people with dementia

An analysis of readmissions to acute hospitals within 30 days of discharge for the two groups of patients was made. There are limitations to high level data analysis in this area because it is often the case, when trying to interpret readmissions that the number of permutations in patient flows can make the analysis complex. Variables such as route of admission, reason for admission and linkages with previous reasons for admission are generally visible only through a case load audit. However, the high level data will provide a starting point for investigation within your organisations.

Headlines

8.2% Standardised readmission rates for people with dementia following elective procedure
Compared with 3.5% for people without dementia

25% Standardised readmission rates for people with dementia following non-elective spell
Compared with 17% for people without dementia

Key questions

- How does this result compare with hospitals in your region?
- Are readmission rates routinely monitored for people with dementia in your area?
- Where are people with dementia readmitted from?
- Are there patterns of readmissions?
- For example is there a cohort of patients who are readmitted from home because they choose to return home against clinical advice?
- Are patients often readmitted from care homes especially at night?
- Are care home staff adequately supported to care for people with dementia particularly at night?
Falls in hospital for people with dementia

It was considered likely that the number of falls in hospital among patients with dementia might be higher than those in patients without dementia.

Falls usually occasion an increased need for care and additional resources and analysis has allowed us to estimate the scale of such requirements. This shows the observed number of in-hospital falls in patients with dementia and the expected number if they occurred at a similar rate as in non-dementia patients.

**Headlines**

<table>
<thead>
<tr>
<th>Number of excess falls for people with dementia admitted electively</th>
<th>Number of excess falls for people with dementia admitted non-electively</th>
</tr>
</thead>
<tbody>
<tr>
<td>170</td>
<td>6219</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Inpatient falls rate for people with dementia admitted electively</th>
<th>Inpatient falls rate for people with dementia admitted non-electively</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.2%</td>
<td>2.4%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Additional days in hospital for a person with dementia admitted electively who has experienced a fall</th>
<th>Additional days in hospital for a person with dementia admitted non-electively who has experienced a fall</th>
</tr>
</thead>
<tbody>
<tr>
<td>20.4</td>
<td>16.4</td>
</tr>
</tbody>
</table>
Regional variation for falls in hospital for people with dementia

Number of Excess falls in hospital for people with dementia in 2011

Excess Falls vs. Count of Excess Falls
Variation within London

Number of Excess falls in hospital for people with dementia in 2011 in London

- Sutton and Merton PCT
- Bromley PCT
- Greenwich Teaching PCT
- Hillingdon PCT
- Kingston PCT
- Lewisham PCT
- Wandsworth PCT
- Barking PCT
- Enfield PCT
- Hounslow PCT
- Richmond and... PCT
- Croydon PCT
- Redbridge PCT
- Newham PCT
- Ealing PCT
- Waltham Forest PCT
- Havering PCT
- Westminster PCT
- Lambeth PCT
- Southwark PCT
- Brent Teaching PCT
- Harrow PCT
- City and Hackney... PCT
- Camden PCT
- Haringey Teaching PCT
- Kensington and Chelsea PCT
- Islington PCT
Key questions

- How does this relate to length of stay information for your organisations?
- Are the levels too high or too low?
- Are falls for people with dementia routinely monitored?
- Are you over reporting or under reporting?
- How many falls result in harm?
- Have fall assessments, care plans falls and care bundles been implemented and audited?
- What trends are there for falls in your organisation? For example do falls happen at a particular time or place?
- How is enablement to promote independence championed in your organisation?
- How many falls occur despite all reasonable interventions?
Mortality in patients with dementia compared to patients without dementia

There is considerable variation across the country relating to mortality rates in hospitals for people with dementia in hospitals. Again, it is important to view this data as part of the whole set rather than in isolation.

Headlines

- 8.6% Crude mortality rate in hospitals for people with dementia
- 7.5% Excess mortality in patients with dementia in hospitals (when compared with expected number of deaths in this group)
Regional variation

Excess in-hospital mortality for people with dementia 2011

Above 100% represents higher than expected mortality rates. Below 100% represents lower than expected.
Variation in London

Above 100% represents higher than expected mortality rates. Below 100% represents lower than expected.

Excess in-hospital mortality for people with dementia 2011 in London

Above 100% represents higher than expected mortality rates. Below 100% represents lower than expected.
Key questions

- How do these findings relate to the other data in this report?
- Is there an explanation for the variation across the region?
- How does this relate to the admission source?
- Is there a trend?
**Appendix one**

**List of ICD 10 codes included in definition of dementia**

F000, Dementia in Alzheimer's disease with early onset  
F001, Dementia in Alzheimer's disease with late onset  
F002, Dementia in Alzheimer's disease atypical or mixed type  
F009, Dementia in Alzheimer's disease unspecified  
F010, Vascular dementia of acute onset  
F011, Multi-infarct dementia  
F012, Subcortical vascular dementia  
F013, Mixed cortical and subcortical vascular dementia  
F018, Other vascular dementia  
F019, Vascular dementia unspecified  
F020, Dementia in Pick's disease  
F021, Dementia in Creutzfeldt-Jakob disease  
F022, Dementia in Huntington's disease  
F023, Dementia in Parkinson's disease  
F024, Dementia in human immunodef virus [HIV] disease  
F028, Dementia in other specified diseases classified elsewhere  
F03X, Unspecified dementia  
F050, Delirium not superimposed on dementia so described  
F051, Delirium superimposed on dementia  
G300, Alzheimer's disease with early onset  
G301, Alzheimer's disease with late onset  
G308, Other Alzheimer's disease  
G309, Alzheimer's disease unspecified  
G20X, Parkinson's disease  
G22X, Parkinsonism in diseases classified elsewhere
Appendix two

Methods

The Health Episodes Statistics (HES) data files used in these analyses cover all hospital admitted spells for patients aged over 45, in calendar years (CY) 2010 and 2011. Only admissions to acute general hospitals have been included; those to specialist hospitals are not included.

These spells (occurring in 2010 and 2011) have been linked at individual patient level to all other spells for that patient from the start of the 2006/7 financial year (FY) and a range of variables derived to specify patients with differences in the diagnosis and/or coding of dementia. The data have been separated into:

(i) spells of patients without dementia (defined as patients whose hospital records from start of 2006/7 FY to end of 2011 CY contain no diagnoses codes of dementia)
[Note: the list of diagnoses codes of dementia is included in the appendix one]

(ii) spells of patients occurring in 2010 (or 2011) where no diagnosis of dementia had previously been made, but who were subsequently diagnosed with dementia before the end of 2011 CY

(iii) spells of patients occurring in 2010 (or 2011) where diagnosis of dementia had previously been made (or was first made in the current spell).

This latter group was further divided to identify where the HES record of the current spell recognises the dementia of the patient and those records where it remains uncoded. These uncoded spells provide some estimate of the possible scale of unrecognised dementia in patients in hospital being treated for an acute condition.

We have also separated out (from (i) to (iii) above) patients who have a senility diagnosis (ICD10 code R54, which is actually a ‘Sign and symptom’) but without a record of any other dementia diagnosis. We have been advised by coding experts that this group of patients should differ substantially from group (iii) above, as dementia should be coded separately where it occurs. These patients have not been considered in the following analysis, except in Table 1 (page 4), which shows that this group contains a sizeable number of such spells.

In most of the comparative analyses that follow, data records of patients with dementia were compared to those of non-dementia patients. Since this latter group was likely to contain a very different mix of patients, the analyses used data standardised to take out any differences between the two groups in respect of clinical condition (defined by 249 CCS groups), type of admission (elective/non-elective) and age band.

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1 CCS – Clinical Classifications Software (CCS) is a tool for clustering patient diagnoses and procedures into a manageable number of clinically meaningful categories. It was developed in the United States of America by the Agency for Healthcare Research and Quality. CCS offers researchers and planners the ability to group conditions and procedures without having to sort through thousands of codes.