



# Report of the National Audit of Dementia Care in General Hospitals 2011







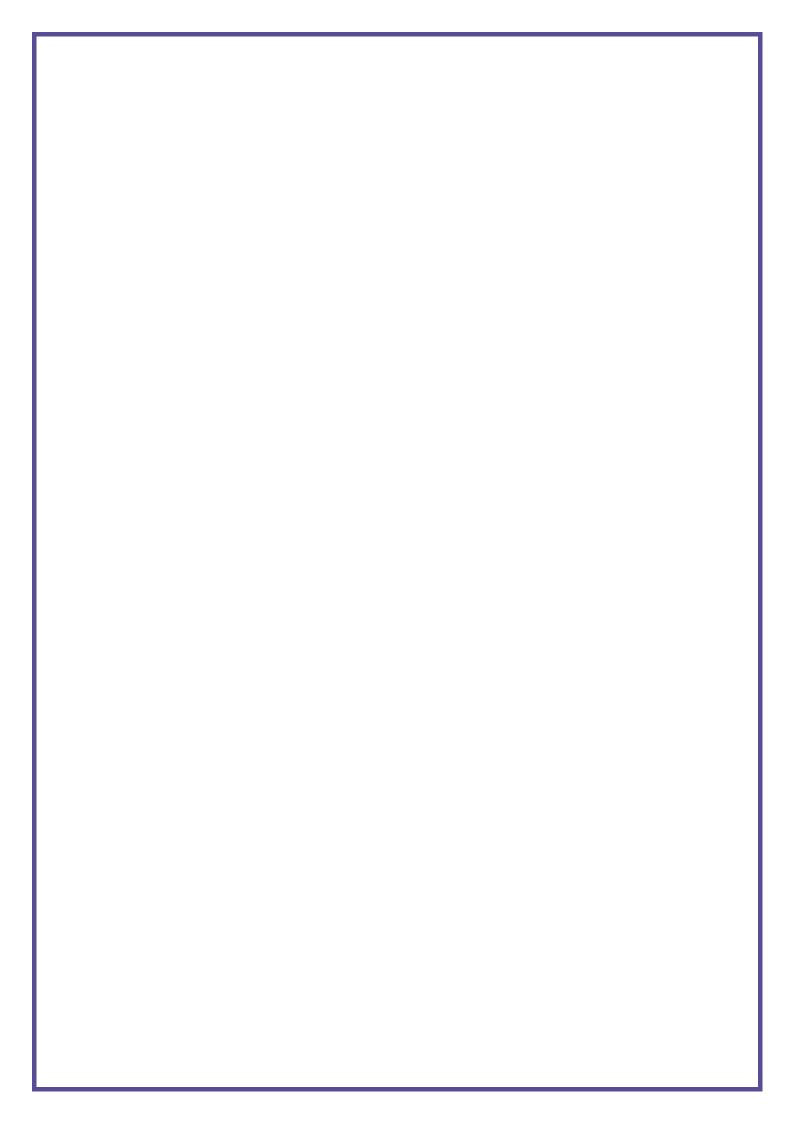












# **Audit governance**

This audit is funded by the Healthcare Quality Improvement Partnership and managed by a project team (see Appendix 3) based at the Royal College of Psychiatrists' Centre for Quality Improvement (CCQI).

The collaborators in this project are the professional bodies for five of the main disciplines involved in providing dementia services, and one of the main voluntary sector providers of supports and services:

- The Royal College of Psychiatrists
- The British Geriatrics Society
- The Royal College of Nursing
- The Royal College of Physicians
- The Royal College of General Practitioners
- The Alzheimer's Society

Representatives from the above organisations and from the Living with Dementia group comprised the Steering Group together with the Project Team.

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Content is advised and approved by all members of the Steering Group. For full details of the Steering Group members and the Project Team please see Appendix 3 on page 209.

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We present in this report the findings of the first National Audit of Dementia (care in general hospitals).

The aim of the audit was to examine the quality of care received by people with dementia in the general hospital. This created the necessity to collect evidence covering the whole hospital stay from admission to discharge. Despite the difficulties of collecting data from casenotes across the admission period, we were delighted with the response from hospitals. 89% of hospitals eligible for audit submitted data, which equals inclusion of 99% of Trusts/Health Boards in England and Wales. The high participation rate shows that care of people with dementia has been recognised by hospitals as a highly important area for quality improvement.

This report includes findings from data collected at both hospital and ward level to achieve a fuller picture of the care experience. Wards audited submitted checklists and questionnaires from staff, and carried out observations of care as it was taking place. This has provided important feedback about the quality of care as experienced by patients and the support available to staff who carry out care. The audit included a specially commissioned observational module (known as Person, Interaction, Environment or PIE), and this has produced detailed analysis of the features of communication and interaction which support the care of people with dementia.

The results of the audit overall suggest that the majority of hospitals have yet to consider and implement measures which would address the impact of the hospital experience on people with dementia, and to assess the impact on the hospital of admitting people with dementia. Presenting the results from hospitals and ward level audit together by theme helps us to see why this is so. For example, although assessment is vital to care delivery, it can never be sufficient to carry out an assessment of nutritional status or mental state, unless staff on the ward are provided with the knowledge, support and time to carry out the necessary care – to support the patient to eat or to alleviate their distress.

The audit findings as a whole echo the statement of the NICE *Dementia Quality Standard*<sup>58</sup>: **An integrated approach to provision of services is fundamental to the delivery of high quality care to people with dementia.** 

The patient journey of a person with dementia can take many routes. Provision of high quality care requires a whole systems approach, in which the entirety of the organisation, from the Board to ancillary services, must undertake to identify and address these needs at every point.

A person-centred approach benefits all patients, as the emphasis is on inclusion in care decisions and on making sure that the care is delivered to each patient in the way which is most suitable to them, which is the underlying principle of essential care. While no approach will avert all possible problems and distress, the approach should

support staff to provide the best care within their ability. The observational module (PIE) did find examples of excellent care and this undoubtedly reflects good practice to be found throughout the NHS. However, the responsibility for providing high quality care should never rest solely on individual staff members, or ward teams.

It is important also to point out that many local, regional and national initiatives are already underway to improve care. Updates on progress made since the point of data collection can be found within the chapters of the main report. The PIE chapter provides detail of the actions most commonly identified by staff as the next step to improving care delivery at ward level.

We hope that the information and recommendations contained in this report provide a benchmark against which progress can be fully measured and described in the next round of audit in 2012.

**Professor Peter Crome** 

Chair of the Steering Group, National Audit of Dementia

Former President of the British Geriatrics Society

# **Executive summary**

# **Background**

The National Audit of Dementia (care in general hospitals) was established in 2008 with funding from the Healthcare Quality Improvement Partnership to examine the quality of care received by people with dementia in the general hospital.

Key questions for the audit were:

- What structures and resources do hospitals have in place to enable them to identify and meet the care needs of people with dementia? (Measuring the ability to care)
- What evidence can be assembled to show that people with dementia in the hospital have received an acceptable standard of care? (Measuring the quality of care)

This led to the development of a two part audit:

- a hospital level, 'core' audit;
- a ward level, 'enhanced' audit.

Key findings from both parts of the audit are presented here.

### **Audit standards**

A literature review identified source documents for the audit. These included:

- national reports and guidelines;
- standards, guidelines and recommendations issued by professional bodies;
- reports and recommendations issued by organisations representing service users and carers.

A secondary review identified key areas of concern for service users (patients) and carers (see 'Patient and carer priorities', page 31). The identified priorities were used in compiling the standards for audit on which data collection tools were based (www.nationalauditofdementia.org.uk).

Appendix 5, on page 214, sets out how standards were classified and used for local reporting.

#### Method

Audit tools producing measurable criteria were produced and piloted in 2009, prior to national roll-out in 2010.

#### Core audit tools

Each hospital was asked to complete:

- i. a hospital organisational checklist to audit the service structures, policies, care processes and key staff that impact on service planning and provision for people with dementia;
- ii. a retrospective casenote audit of the records of 40 patients with a diagnosis or current history of dementia, audited against a checklist of standards that relate to their admission, assessment, care planning/delivery and discharge.

#### **Enhanced audit tools**

Each participating ward was asked to complete:

- i. a ward organisational checklist concerning staffing, support and governance at a ward level;
- a ward environmental checklist to gather information about aspects of the ii. ward physical environment known to impact on people with dementia;
- staff questionnaires to gather feedback from ward staff about awareness of iii. dementia and about support offered to patients with dementia on their ward;
- carer/patient questionnaire that evaluates carers' experience of the support received from ward staff and patients' overall perception of the quality of care on the ward;
- observation of care interactions to evaluate the quality of the hour-to-hour ٧. provision of care to people with dementia.

Data collection was carried out between March 2010 and April 2011. 89% of eligible hospitals representing 99% of Trusts/Health Boards in England and Wales participated in the audit.

For further information about data collection, see page 41.

# **Summary findings**

Chapters in the main body of the report represent findings by theme including data from both hospital and ward level audit where relevant. The key results are summarised and presented in this section with recommendations.

#### Overall compliance with standards by participating hospitals

Analysis of the core audit data showed a national picture of a low level of performance.

Table 1: Standards met in the core audit tools

Standards met	Casenote audit (N = 50)	Organisational checklist (N = 80)
Highest	25 (50%)	69 (86 %)
Lowest	0	19 (24%)
Median	3 (6%)	38 (48%)

The standards were classified by 'type', into type 1 (essential), type 2 (expected) and type 3 (aspirational). None of the hospitals met all standards identified as type 1 the highest number of these standards met in the organisational checklist was 20/21 and in the casenote audit 14/28 (See page 214 in Appendix 5 for more details).

There is wide variation between participating hospitals on key standards. For example, although the data from the total sample of casenotes shows that a nutritional assessment had been undertaken for 70% of patients nationally, the proportion of patients receiving the assessment ranged from 3% to 100% between hospitals.

There is little correlation between the two elements of the core audit, indicating that the presence of a hospital policy or procedure is not a good marker of actual practice. This finding was borne out at the level of individual standards. For example, at hospital level the percentage of casenotes showing that a mental state assessment had been carried out was not significantly different between those hospitals that had a policy specifying the assessment and those that did not. (See in particular the 'Assessment' chapter on page 68 and 'Discharge planning and discharge' chapter on page 145).

# Summary of results by theme

#### 1. Governance

The theme of governance relates to the set up and running of hospitals and whether the systems and resources an organisation has in place can take into account and meet the needs of people with dementia.

This chapter presents findings from the organisational checklist on key policies, guidelines and resources in the hospital, and from the ward organisational checklist on availability of services at ward level.

- 6% of hospitals had a care pathway in place for people with dementia at the time of audit and 44% of hospitals had a care pathway in development.
- Less than a quarter of hospital Boards/Trust Executive Boards regularly look at information about delayed discharges of people with dementia and only 8% review re-admissions of people with dementia.
- The majority of hospitals had access to intermediate care services that would admit people with dementia. Only 50% of hospitals had direct access to intermediate care which would avoid admission to hospital.
- Access at ward level to specialist service input, such as social services, liaison psychiatry and occupational therapy, was generally available in "office hours" -Monday to Friday during the day, with the important exception of specialist continence services. Availability during evenings or weekends was limited for most services.

The evidence collected showed a lack of leadership both at Trust/Health Board level and at hospital level, in terms of identifying champions and leads, and identifying required resources. Trust Boards/Health Boards require better intelligence and information relating to the admission, care, treatment and discharge of people with dementia to make the necessary improvements to processes and overall governance to consistently deliver a good standard of care throughout the hospital.

#### 2. Assessment

People with dementia admitted to hospital should have a comprehensive assessment of their physical and mental health needs, plus assessment relating to their ongoing care, to ensure the best recovery outcomes and safer discharge. Hospital guidelines or procedures often set out the range of assessments that should be expected. The results of the casenote audit showed that important elements of assessment were not routinely carried out.

- Information collected at hospital level around multidisciplinary assessment for people with dementia shows that:
  - 84% of hospital assessment guidelines/procedures included assessment of functioning (this includes basic activities of daily living, instrumental activities of daily living, activity/ exercise status, gait and balance). However, only 26% of casenotes showed that an assessment of functioning had been carried out.
  - 96% of hospital assessment procedures included assessment of nutritional status. However, only 70% of casenotes showed that an assessment of nutritional status had been carried out.
  - 75% of hospital assessment procedures included assessment of mental state. However, only 43% of casenotes showed that a standardised mental status test had been carried out.
  - 96% of hospital assessment procedures included social assessment and 91% reported that assessment includes environmental assessment. However, 72% of casenotes showed a formal care provision assessment, and 65% of casenotes showed a home safety assessment had been carried out.
- 13% of casenotes showed no formal pressure sore risk assessment.
- 19% of casenotes did not show that the patient was asked about any continence needs as part of the assessment.
- 24% of casenotes did not show that the patient was asked about the presence of any pain as part of the assessment.

The findings demonstrate a gap between policy and practice. Adherence to multidisciplinary assessment procedures should be clarified and reinforced.

# 3. Mental health and liaison psychiatry

People with dementia in hospital require access to specialist mental health services, and these should be provided by a liaison team. The team should be able to provide a response to emergency or urgent referrals as well as routine referrals. The audit organisational checklist collected information about the availability and make up of liaison services.

- 90% of hospitals had access to a liaison psychiatry service, and in most cases this service was provided by a team, rather than a single practitioner.
- Around a third of hospitals who have access to a liaison psychiatry service are able to provide an out-of-hours service during evenings or weekends.

Casenote audit data showed that patients with dementia referred to liaison psychiatry were often not seen in a timely manner, with nearly a third of urgent referrals waiting over 4 days to be seen.

On discharge from hospital, people with dementia should have ongoing needs, including mental health needs, reviewed and summarised so that appropriate treatment and care can continue to be provided. The audit of casenotes collected information about mental health needs review at discharge.

- Only 28% of casenotes contained summaries of persistent behavioural and psychological symptoms of dementia at discharge.
- Of the total sample, only 6% of people with dementia had their level of cognitive impairment measured on admission and on discharge. This is lowest of all for people who lived in care homes before admission and returned there afterwards - 3% of the total sample, or 8% of those admitted from care homes.

People with dementia are at heightened risk of developing symptoms such as agitation, distress, or behaviour can become aggressive when in hospital. This can be due to the hospital environment, aspects of care, illness or injury, or a downturn in the dementia condition. These symptoms are often collectively known as "challenging behaviour" or "behaviour that challenges". The NICE guidelines<sup>60</sup> and the *Common* Core Principles<sup>28</sup> clearly set out the approach that should be taken, in which the use of medication should be a last resort or when there is immediate risk of harm. organisational checklist asked about protocols governing the approach to challenging behaviour, agitation and distress and the audit of casenotes collected information about prescription of antipsychotics.

- 34% of hospitals reported having adequate protocols in place for the treatment and management of patients with behavioural and psychological symptoms of dementia leading to challenging behaviour.
- 28% of people with dementia received antipsychotic medication in the hospital. 12% of people with dementia were newly prescribed this medication during this admission to hospital. Reasons for prescription were not recorded in 18% of these cases.
- 30% of people living in care homes and 14% of people living elsewhere were already taking antipsychotics on admission.

Overall the audit shows widespread provision of liaison psychiatry. However, a lack of availability at evenings and weekends is likely to impact on the time taken by services to respond to an emergency or urgent referral. It may also affect ability to carry out assessment or to see patients who require onward referral for diagnosis.

A lack of mental health assessment during admission and at discharge shows that mental health needs are still often overlooked in general hospitals. This needs to be urgently addressed as a clinical governance issue. In particular, hospitals should look at anticipating challenging behaviour and ensure that it is managed with awareness and understanding, ensuring that guidelines and protocols are reviewed and updated and training for staff is in place. Where antipsychotic medication is prescribed, a reason should be clearly recorded and all medication should be reviewed regularly. Equivalent attention should be given to people with dementia living in care homes in review and assessment.

#### **Nutrition** 4.

The importance of improving nutrition in hospital, particularly for older or more vulnerable patients, has been highlighted in many reports. The audit of casenotes found that people with dementia had not always received a nutritional assessment, and that systems in place to aid people with eating and drinking were not always adequately resourced.

- 96% of hospitals have a procedure for multidisciplinary assessment which includes nutritional assessment. However, only 70% of the casenotes in the sample included this assessment, and only 63% of these casenotes had a record of the patient's weight.
- 92% of hospitals have established protected mealtimes, and 97% of wards audited said that this was in place. However, only 74% of wards have a system to ensure staffing levels are sufficient at mealtimes to aid people with dementia to eat and choose food if necessary.
- 93% of wards could provide food between mealtimes, and 66% of staff agreed the ward can provide meals and snacks to patients at any time.
- Nearly all hospitals had access to specialist assessment and advice on helping patients with dementia in their swallowing and eating.

The audit results suggest much could be done at hospital level and ward level to improve nutritional standards, including providing standardised assessment, and recording of weight over time; providing support to assist patients at mealtimes; making food available at other times; and ensuring full implementation of protected mealtimes (i.e. allowing carers or family to assist but not allowing interruption for clinical or care purposes).

#### 5. Information and communication

The theme of information and communication arises throughout the audit. Involvement of carers in this process and the ability of the hospital to use personal information to provide better care were identified as priority topics for patients and The organisational checklist looked at procedures in place to collect and communicate key information and the audit of casenotes looked at information collected. At ward level, wards were asked about information provision and staff were surveyed about the use of personal information and ward contacts for families and carers.

- 40% of hospitals had a clear procedure for information sharing with families and only around half of hospitals were found to have guidelines for the involvement of families for discharge and support arrangements.
- 88% of wards in the enhanced audit had a system for communicating personal information about patients with dementia.
- 43% of the casenotes had a section dedicated to collecting information from a carer, friend or relative, and around 40% of the casenotes were organised so that information about the person's dementia and about care and support needs could be quickly found in a specified place.
- Only 24% of casenotes contained information about factors that might cause distress to the person with dementia.
- 92% of wards could provide information on what to expect in hospital and almost all of the wards made patients and carers aware of the complaints procedure.
- 61% of wards said a responsible healthcare professional was identified to the family as a contact for help and information, but only 45% of staff reported that patients are allocated a named professional as a contact.

There is clearly a lack of guidance in hospitals for the involvement of families in discharge and support arrangements, and this is related to the findings that families are not routinely involved in the care of the patient with dementia and are often not given a named healthcare professional to contact for help.

Although it is reported at ward level that there are systems for recording and communicating some basic personal information about patients with dementia to help them feel more settled in hospital, the collection of this information does not form a systematic part of the patient's assessment. Of particular note is the fact that patients' families or carers are not asked about behaviours that may indicate distress or what strategies may be useful in helping the patient feel safe and calm. If this information was readily available to the clinical team it could reduce the incidence of untoward behaviour disturbance and avoid the need for prescriptions of antipsychotic medication.

More clarity is needed on the purpose and use of personal information. Hospitals need clear guidelines on the information that should be collected, and on supporting staff to share and use information and involve carers appropriately, according to the best interests of the person with dementia.

### 6. Staff training

The ability of staff members to engage with people with dementia, to provide clear information and understand how to deliver care in the way most suited to the person with dementia, can ensure that care is provided consistently and can lead to a qualitatively different experience of care (see chapter 10, page 153). Awareness and understanding of dementia shown by the frontline staff providing daily care was identified as a priority for patients and carers. The organisational checklist audit found that training frameworks and strategies to address essential skills were not generally in place, and staff responses also pointed to deficiencies in training.

- Only 5% of hospitals had mandatory training in awareness of dementia for all staff, and 23% of hospitals had a training and knowledge framework or strategy identifying the necessary skill development in working with and caring for people with dementia.
- 32% of staff said they had sufficient training/learning and development in dementia care, including awareness training and skills based training.
- 26% of hospitals had a training strategy specifying that staff working with people with dementia are trained to anticipate challenging behaviour and are taught how to manage violence, aggression and extreme agitation, including deescalation techniques and methods of physical restraint. Less than half the staff surveyed said they had sufficient learning and development/training in these areas.
- 23% of hospitals had a training strategy specifying that staff of all grades and disciplines have access to communication skills training involving older service users. Half the staff surveyed said they had sufficient learning and development/training in this area.
- Training in person-centred care was felt to be sufficient by 67% of staff, and about one half of staff said training in involving people with dementia and their carers in decisions on care and treatment was sufficient.
- 66% of staff said they had sufficient training/learning and development in introduction to adult protection policy and procedures. However, less than half the staff said they had sufficient training or learning and development in the Mental Capacity Act and in how to assess capacity.
- Most staff from all job roles agreed that further training would be beneficial and would improve the level of care received by people with dementia.

The number of staff agreeing on the need for further training in relation to awareness of dementia was striking. The data and comments on training received in particular aspects of care reveal that further training is needed across all job roles for a range of competencies related to the care of people with dementia.

### 7. Staffing and staff support

The provision of essential care to patients in general hospital wards requires a level of staffing which is determined by an assessment of the general level of care and support need on the ward, combined with information on qualification and skill mix, numbers of staff per occupied bed, unfilled posts and turnover, sickness and absence. The audit collected data about the numbers of staff (whole time equivalent) per 10 beds and about the ratio between registered nurses and healthcare assistants, and also asked ward staff about their experience in terms of whether they felt there was enough staff to provide for the patients in their care.

- Variations across wards in relation to both staffing numbers and skill mix indicate a lack of consistency in the determination of staffing levels.
- 93% of wards have a system to ensure minimum staffing levels are in place. However, less than a third of staff considered staffing was sufficient to meet patient needs.
- 99% of hospitals had a recognised system to record potential risk to patient care due to insufficient staffing numbers. Around half the staff felt that the system deals with reports in a timely way.
- Over 90% of registered nurses and healthcare assistants had access to mentorship and appraisal. Clinical supervision is provided less consistently with 60% of wards offering this to registered nurses, but less than 40% of wards providing this support for healthcare assistants.

It is important that a systematic approach is taken to assessing ward staffing requirements suitable to meet the needs of patients. For wards admitting people with dementia this should include consideration of the time and attention necessary for care. Also key to supporting staff in their caring role is providing leadership via key roles such as Dignity Leads and Dementia Champions, and ensuring access to mentorship, supervision and appraisal.

#### 8. Physical ward environment

An environment which helps people with dementia to orient themselves to their surroundings and guide themselves around the ward can provide reassurance, help maintain independence and avert distress. The environmental checklist audited important aspects of the environment in participating wards relating to the care experience for people with dementia.

- 56% of wards stated that patients with dementia are able to see a clock from their bed area, but only 5% of wards stated patients were able to see a calendar from their bed area which would help improve orientation.
- 56% of wards reported that information (words and pictures) on signs is in clear contrast to the background, and 38% of wards reported that signs/maps are large, bold and distinctive.
- 15% of wards use colour schemes to help patients with dementia find their way around the ward.
- Large toilets and bathrooms allowing for assistance were provided in most wards and there was also a choice of bathing facilities available.
- Space for patients with dementia to walk around was available in 69% of wards. Rooms or designated areas providing a break from the ward environment were only available in 47% of wards.
- 59% of wards reported that personal items were not always situated where the patient could see them at all times.
- Flooring that may cause confusion for people with dementia, such as busy patterns or high gloss surfaces, seems to be avoided in most hospital wards.

In terms of the physical environment, attention to orientation both in the ward (signage, use of colour) and the bed area (positioning of familiar personal items) could improve the experience of people with dementia. Use of space to provide breaks from the ward environment could also contribute, as on busy wards people experiencing confusion may have no opportunity to escape noise and bustle. Evidence from observations of care also suggested that attention to noise and creating a warm, friendly atmosphere are important considerations in the care of people with dementia.

## 9. Discharge planning and discharge

Attention to the discharge process is essential to ensure safe discharge with the appropriate ongoing care and support for people with dementia. The organisational checklist looked at discharge policies and organisation, and the audit of casenotes looked at discharge planning carried out for the sample of patients with dementia.

- 94% of hospitals have a commitment to begin planning for discharge within the first 24 hours of admission, but in about half of the audited casenotes this had not taken place, and it was not possible to specify a reason.
- Around half of the casenotes audited stated a named discharge co-ordinator, with responsibility for managing the process and consulting with all relevant parties, was involved in the discharge process.

- 67% of casenotes contained an up-to-date discharge plan and 58% of casenotes showed evidence that any support needs had been identified in the discharge plan. Only 41% of casenotes stated that a copy of the plan had been passed on to patients or carers.
- 75% of casenotes recorded that an assessment of the carer's current needs had taken place before discharge, and 80% of casenotes showed evidence that the place of discharge and support needs had been discussed with the carer/relative.

It is encouraging that the majority of casenotes show evidence of attention to the carers' needs, and that most showed involvement of the carer when discussing discharge and support. However, it is less encouraging that in half the casenotes discharge planning had not begun at admission, for no stated reason. There was no named co-ordinator of discharge in the same proportion of casenotes. Providing a copy of the discharge plan to the person with dementia or carer is important to ensure that discharge discussions are understood.

Early discharge planning is important to facilitating timely discharge and lessening the time spent by the person with dementia in the acute environment and could also produce savings in cost. The Alzheimer's Society has calculated that savings in excess of £80 million could be produced if the length of stay for people with dementia in hospital was reduced by one week.<sup>6</sup>

# 10. Observations of care - Person, Interaction and **Environment (PIE)**

The review of aspects of care prioritised by older people and carers emphasised the importance of care which is person centred – treats the person with dementia as an individual and takes into account their perspective within a supportive environment. This guided the content of the observational tool. Person, Interaction, Environment represent the elements of knowing and using information about the patient as a person in care, the quality of staff-patient interaction, and the effect of the immediate environment. The observations for this audit were carried out in each case by staff from the hospitals in which participating wards were situated. The overall finding from ward observations is that care and communication is generally reactive and based on an organisationally set, task-driven routine rather than being person-focused, flexible and proactive.

- On most hospital wards there is little evidence of a person-centred ward approach or 'culture', or that the care received by patients is generally personcentred.
- The content of the staff/patient encounter is mainly task related and delivered in a largely impersonal manner.

- There are periods of care-based activity interspersed with inactivity, leading to lack of attention, lack of stimulation and boredom for patients.
- The environment is often impersonal and not dementia friendly, with excess noise at times, and a lack of orienting cues, dementia aids or areas for socialising.
- There is inconsistency in the quality of communication. People with dementia experienced differences in the approach of individual staff members, or between groups of staff (such as pharmacy/housekeeping) or both. In some cases, some elements of care delivery were positive (explanations and information were consistently given to patients) while other elements of care delivery in the same ward were clearly not (staff not knowing the patient as a person, for example, using the name by which the patient preferred to be addressed, or allowing time to communicate).

"Pockets" of positive, person-centred care were found in the practice of individual staff members, or as elements of ward practice. Only a handful of wards (5/105) reported ward practice which was person-centred more often than not.

- No one hospital submitted data where all the participating wards were clearly described as being person-centred. This suggests that there is no evidence that wards which are more person-centred are sharing their approach across the organisation and, conversely, there is no evidence of an effective organisational system for implementing person-centred care in place in any one hospital.
- Ward type was not related to the quality of care delivery observed. Many hospitals had similar findings across all their participating wards while many others observed some key differences (suggesting both hospital and ward leadership factors come into play).
- The observers clearly articulated that all staff and staff groups need to be engaged more positively with patients. However, a whole ward team organisational approach is required – individual staff cannot by themselves provide a person-centred care experience for patients.

It is apparent that there is considerable scope to develop and enhance person-centred care for people with dementia. The aim should be to initiate a progression from the currently dominant culture of task based care to one in which there is an integral focus on the person. Taking a proactive approach and having a timely and attentive response to people with dementia also means that their discharge is likely to be more appropriately facilitated, impacting on costs, as identified by the Alzheimer's Society<sup>6</sup>.

# Recommendations

#### Recommendations for National **Clinical Directors** Dementia and Older People (England)/ Medical Director and **Nurse Director (NHS Wales)**

- The National Clinical Directors for Dementia and for Older People (England) 1. should promote the development of an overall competency framework to ensure that guidance on staff training contained in the Common Core Principles<sup>28</sup> is implemented across all secondary care settings. In addition to providing 100% of staff with basic dementia awareness training and updates, local frameworks should promote and evidence enhanced and specialist levels of knowledge, e.g. that 50% of front line workers should have or be working towards, enhanced knowledge of dementia care, and that 10% of front line workers should have or be working towards specialist knowledge. The Medical Director and Nurse Director for NHS Wales should promote development of a framework along similar lines in secondary care settings to support and enable the pathway/interventions set out in 1000 Lives Plus.
- 2. The National Clinical Directors for Dementia and for Older People (England) should ensure the Common Core Principles<sup>28</sup> and NICE guidance<sup>60</sup> on the use of antipsychotic medication is disseminated to general hospitals and that there is a process that separately audits prescribing in general hospitals. A period of treatment in hospital should be highlighted as an appropriate point for reviewing any use of antipsychotic medication. The Medical Director of NHS Wales should ensure that the review targets for psychotropic medication set out in 1000 Lives Plus are fully addressed in secondary care settings.

# Recommendations for the Department of Health/Welsh Government Department for Health, Social Services and Children, General Medical Council and Nursing and Midwifery Council

- The Department of Health, Welsh Government Department for Health, Social 1. Services and Children, NHS Estates, and NHS Wales Shared Services Partnership, should provide guidance on dementia friendly ward design, to be incorporated as standard into all refurbishments and new builds, including safe walking spaces and the use of colour, lighting, signage, orientation cues and space used to promote social interaction.
- The General Medical Council and Nursing Midwifery Council should develop 2. appropriate curricula for enhanced and specialist skills in dementia care, including requirements in undergraduate & postgraduate medical and nursing curricula.

#### **Recommendations for Professional Bodies**

- 1. The Royal College of Physicians, the Royal College of Psychiatrists and the British Geriatrics Society should recommend brief screening tools for cognitive function and delirium for the assessment of people with dementia and older people in the general hospital.
- 2. The Royal College of Nursing should provide guidance to Trusts/Health Boards on how staffing levels should be determined, including consideration of measures of acuity and dependency sensitive to the care of people with dementia.
- 3. The Royal College of Physicians with the British Geriatrics Society should recommend brief tools for the standardised assessment of functional ability and for the assessment of pain in people with dementia. The Royal College of Physicians and the British Geriatrics Society should liaise with other Royal Colleges about including these assessments in the management of surgical patients and others.
- The Royal College of Psychiatrists, Royal College of Nursing, Royal College of 4. Physicians with the British Geriatrics Society, should provide guidance on any circumstances in which PRN (as required) prescription of antipsychotics is appropriate.

### **Recommendations for Commissioning Boards/Health Boards**

Commissioning Boards/Health Boards should ensure that liaison psychiatry 1. services are in place to provide adequate access over 24 hours for treatment and referral of people with dementia in hospital. This should include the ability to provide an emergency or urgent response<sup>82</sup>. Response times to referral should be a key performance indicator for these services.

#### Recommendations for the Trust **Board/Board** of **Governors/Board of the Health Board**

- 1. The Trust Board/Board of Governors/Board of the Health Board should ensure that review of key policies and procedures include the needs and perspective of people with dementia is undertaken, requiring the following as evidence:
  - Clinical information on admission rates, falls, treatment and discharges, in which people with dementia can be identified;
  - The appointment of a Senior Clinician Lead for Dementia with designated time in their job role to develop, implement and review the dementia pathway;

- Information from a local sample of casenotes of people with dementia tracked through admission, demonstrating adherence to the pathway;
- Measurement of nutritional status (weight and BMI) at admission and discharge for people with dementia;
- Evidence of measures of frequency of assessment for pressure sore risk and pain for people with dementia;
- Measures of cognitive functioning and delirium at admission for people with dementia;
- Evidence from audit of in-hospital prescription of antipsychotics that prescription is in line with guidance.
- 2. Trusts should consider including this information in their Quality Accounts. Health Boards should consider including this information in their Quality and Safety Committee Reports.

#### **Recommendations for the Chief Executive**

- The Chief Executive Officer should ensure that the Trust/Health Board identifies a 1. Senior Clinician in each hospital to take charge of developing, implementing and monitoring the care pathway for dementia.
- 2. The Chief Executive Officer should ensure that it is within the remit of the senior clinician to identify Dementia Champions in each department in the hospital and at ward level.
- 3. The Chief Executive Officer should ensure that key leadership roles and support from specialist staff are in place to ensure delivery of dignified, skilled and compassionate care, for example Dignity Leads, Dementia Champions, Older People's Nurse Consultants.
- 4. The Chief Executive Officer should review policies and procedures in place to ensure that they clearly set out guidance for interventions for challenging behavioural and psychological symptoms of dementia in line with NICE guidance. In-hospital prescription of antipsychotics should be routinely audited for clear indicators that prescription is in line with guidance and this information should be presented to the Trust Board/Board of the Health Board.
- 5. The Chief Executive Officer should ensure that non-reporting of nutritional status, missed meals or other risk to nutrition is considered a safequarding issue for people with dementia and reported in accordance with guidance.

- The Chief Executive Officer should review Trust/Health Board discharge policies 6. with particular reference to the needs of people with dementia/their carers to ensure that they describe the task of discharge co-ordination, and the importance of carer assessments.
- 7. The Chief Executive Officer should ensure that notification of discharge is a routinely collected statistic for reporting to the Governing/Executive Board/Board of the Health Board. This should be presented as the percentage of discharges of people with dementia where less than 24 hours notice has been given/divided by all discharges of cases receiving less than 24 hours notice (unscheduled care).
- 8. The Chief Executive and Trust Board/Health Board should promote the role of public/patient governors and non-executive directors (Independent Board Members in Wales) in reviewing the environment and comfort for people with dementia on the wards. Reviews could make use of a checklist of standards and feedback from patients, carers and visitors and include looking at placement of signs, availability of personal items, and the quality of the food.

# Recommendations for Directors of Nursing and Medical **Directors**

- 1. The Director of Nursing should require Ward Managers to carry out an assessment of staffing levels required to support mealtimes, including assessment of the additional support needs of people with dementia, and Ward Managers should review this on a regular basis.
- 2. The Medical Director, Director of Nursing and Head of Therapy Directorate should ensure the provision of education and training to support the routine use of the MUST tool (or alternative recommended nutritional assessment tool) and monitoring nutritional intake must be provided to all staff, including Healthcare Assistants.
- 3. The Medical Director, Director of Nursing and Head of Therapy Directorate should ensure that all staff responsible for the assessment of older people have had training in the assessment of mental state using standardised measures.
- 4. The Medical Director, Director of Nursing and Head of Therapy Directorate should develop the training and knowledge strategy such that all staff are provided with basic training in dementia awareness and a locally agreed and specified proportion of ward staff receive higher level training.
- 5. The Director of Nursing should make sure that comprehensive systems for quidance, supervision and support are in place for staff on the ward caring for people with dementia, including:

- supervision, mentorship and appraisal for registered nurses and healthcare assistants;
- access to peer support and reflective practice groups.

Ward managers should be supported to ensure that these systems for support are available to all nursing staff.

6. The Director of Nursing should ensure ward managers are given responsibility and support to promote mealtimes as a social activity and provide appropriate equipment and an engaging environment, e.g. music, group tables or seating, use of familiar types of crockery and vessels.

#### Recommendations for the Senior Clinical Lead for Dementia

- 1. The Senior Clinical Lead for Dementia should ensure that the hospital has a care pathway in place for dementia that is adaptable for use within or fitted to existing acute care pathways, with the aim of making sure that the acute care and treatment provided by the hospital takes account of the needs of people with dementia at each stage of admission.
- 2. The Senior Clinical Lead for Dementia should ensure that champions represent the range of job roles working with people with dementia including those staff involved in day-to-day care provision.
- 3. The Senior Clinical Lead for Dementia should ensure that a named healthcare professional acts as a point of contact for people with dementia and their families during the admission to hospital. The named healthcare professional should ensure that the family, next of kin or appointee is involved in the care plan and in decisions about discharge.
- 4. The Senior Clinical Lead for Dementia should put in place procedures for clinical teams to follow to ascertain how the patient's next of kin should be involved in treatment decisions. This should take into consideration mental capacity, stated wishes and best interests decisions (as defined under the Mental Capacity Act)\*, and should be communicated to the ward team and to the family carer.
- The Senior Clinical Lead for Dementia should ensure that a personal information 5. document (e.g. "This is Me"9) is in use throughout the hospital. This should be completed with the help of someone who knows the patient well. The document should include information such as the patient's preferred name; routines and preferences; whether the person needs reminders or support with personal care; recurring factors that may cause or exacerbate distress; support or actions that can calm the person if they are agitated. This document should be held in the

www.bestinterests.org.uk

- patient's notes as well as by the bed so that it is readily accessible to all those involved in the patient's care.
- 6. The Senior Clinical Lead for Dementia should implement systems of good practice to ensure that staff can identify people with dementia on the ward/during care and treatment and can provide an appropriate response to their needs (e.g. "Butterfly Scheme")\*.

#### Recommendations for Ward Managers and Dementia **Champions**

- 1. Ward Managers should highlight to their teams the importance of involving people with dementia and their carers (where applicable) in discussions on care, treatment and discharge.
- 2. Ward Managers should ensure that all those involved in supporting people with dementia at mealtimes, including staff and volunteers, are provided with training or are skilled in recognising swallowing problems, the use of equipment and aids and encouraging nutritional/hydration intake.
- 3. Ward Managers should ensure that nutritional snacks and finger foods are readily available at mealtimes and between mealtimes on wards so that people with dementia are provided with options to enable them to maintain nutritional intake.
- 4. Ward Managers and Dementia Champions should ensure that simple and effective improvements to the environment are promoted in all wards admitting older people, including:
  - appropriate lighting and floor coverings plus aids to support orientation and visual stimulation<sup>5</sup>;
  - personalising bed area;
  - adequate space and resources to support activity and stimulation.

#### **Recommendations for Mental Health Providers**

Mental health providers should self-assess their policies and practice of liaison 1. teams and report to commissioners on equality of access for people with dementia.

www.butterflyscheme.org.uk

# Recommendations for the National Audit of Dementia **Project Team**

- The National Audit of Dementia Project Team should seek to identify key 1. examples of good practice in information provision and sharing with people with dementia and their carers.
- 2. The National Audit of Dementia Project Team should assess whether current provision for staff training is in line with recommendations made in Common Core Principles<sup>28</sup> in the 2012 re-audit.

# **Background**

# Why audit the care of people with dementia general hospitals?

There are currently 750,000 people with dementia in the UK. There will be over a million people with dementia by 2021.

Only 40% of people with dementia currently receive a diagnosis.

At any one time, up to one quarter of acute hospital beds are in use by people with dementia over the age of 65.6

People with dementia in hospital are more likely to belong to older age groups and more likely to have additional mental and physical healthcare needs.

This audit was commissioned following a scoping report for the Healthcare Commission prepared by Professor Martin Orrell and the Royal College of Psychiatrists' Centre for Quality Improvement in 2007. The report was based on a literature review of key documents and consultation with stakeholders and looked at the purpose, range and feasibility of a national audit of dementia services.

The report found that dementia, together with associated care needs, was often overlooked or untreated on admission to hospital. The hospital as a whole, and key frontline staff charged with delivering essential care, may be unaware of a dementia condition in their patients or ill prepared and supported to address the needs arising from it. Admission itself can lead to the worsening of the effects of dementia. This can be due to the disorientation and distress that arise from separation from familiar people, environment and routine, and to increased cognitive impairment due to illness<sup>24</sup>. People with dementia are at increased medical risk when they are ill or injured – delirium is five times more likely to occur in someone with dementia in these cases<sup>79</sup>. It is also known that people with dementia experience longer lengths of stay than people without dementia with the same condition, and that this is not necessarily associated with any need for an extended recovery period<sup>6</sup>. Longer lengths of stay are associated with deterioration in physical and mental health, making admission to a care home more likely, and increasing the risk of antipsychotic prescription<sup>6</sup>.

The report to the Healthcare Commission recommended the development of an audit which would collect data on key aspects of care received by people with dementia in hospital, and examine the ability of hospitals to recognise both the specific needs associated with dementia (in terms of memory, cognition problems and any behavioural and psychological symptoms) and the heightened care needs overall.

#### Context

In 2009 the National Dementia Strategy (England)<sup>27</sup> identified improved care in general hospitals as a key objective:

Objective 8: Improved quality of care for people with dementia in general hospitals. Identifying leadership for dementia in general hospitals, defining the care pathway for dementia there and the commissioning of specialist liaison older people's mental health teams to work in general hospitals.

The further objectives of improved public and professional awareness of dementia, good quality information provision for those with diagnosed dementia, support for carers, and an informed and effective workforce are also key to improved quality of care in the hospital setting, and have been drawn on for the standards and audit tools.

These objectives have also been made priorities for the 1000 Lives Plus campaign in Wales <sup>64</sup>.

For several years, government, health service organisations and organisations representing professionals and service users have worked to identify standards and produce guidance relating to the care in hospital of both people with dementia and frail elderly who may have needs related to cognitive impairment. The topic has long been recognised as one where change and improvement is vital to maintaining the rights and dignity of older people admitted to hospital and to developing a culture and skills base to support truly person-centred care.

A systematic review carried out by the Royal College of Psychiatrists in 2005 concluded that mental disorder in an older person admitted to hospital is an independent predictor of poor outcome: "Furthermore, mental disorder will have an adverse effect on the performance of the general hospital responsible for that older person's care" 79.

In the same year the Care Services Improvement Partnership guideline Everybody's Business highlighted the increased likelihood of transfer to long-term institutional care, increases in hospital-acquired complications, increased likelihood of re-admission and "evidence that mental health problems are poorly detected and managed by general hospital staff" 24.

In 2009 the National Dementia Strategy (England) noted that the impact that admission to hospital has on people with dementia is not widely appreciated by clinicians, managers and commissioners, and the impact of increased costs to hospitals<sup>27</sup>. The National Audit Office estimated the excess cost to be more than £6 million per year in an average general hospital<sup>54</sup>.

Improved care in hospitals for people with dementia, avoiding unnecessary admission and reducing length of stay and unnecessary institutionalisation are priority objectives for the National Dementia Strategy (England)<sup>27</sup> and for the 1000 Lives Plus Campaign for Wales<sup>64</sup>. Understanding the experience of people with dementia and their carers and "mainstreaming" dementia in the commissioning and delivery of services are underpinning principles of the Department of Health Commissioning Framework for Dementia.\*

Specific recommendations for the support care and treatment of people with dementia and their carers were produced by the National Institute for Health and Clinical Excellence in 2006<sup>60</sup> and recently updated. In 2010, NICE published the *Dementia* Quality Standard covering care provided by health and social care staff in direct contact with people with dementia in hospital, community, home-based, group care, residential or specialist care settings. It contains specific, concise quality statements, measures and audience descriptors, providing patients and the public, health and social care professionals, commissioners and service providers with definitions of highquality care.

# **Patient and carer priorities**

A literature review was carried out for the audit in 2009 by Rosemary Woolley, research fellow at Bradford Teaching Hospitals NHS Foundation Trust. The review identified key areas of patient and carer priorities for the care of people with dementia in hospitals. These can be summarised as:

- care planning and support, from admission to discharge, which is both personcentred and recognises the particular needs associated with the dementia (rather than the acute condition alone);
- care of patients with acute confusion;
- maintaining dignity in care;
- maintenance of patient ability;
- communication and collaboration: between staff and patients/carers;
- information exchange;
- end-of-life care<sup>‡</sup>;
- ward environment.

These areas were used in determining priority when compiling standards for audit.

www.dh.gov.uk/publications

http://www.nice.org.uk/quidance/qualitystandards/dementia/dementiaqualitystandard.jsp

<sup>&</sup>lt;sup>‡</sup> The audit did not include a section on end-of-life care as this topic would require specialised standards, data collection techniques and tools which could not be included within the remit and timeline. The Steering Group considers that end-of-life care and dementia would more suitably become the subject of a separate audit.

The patient and carer priorities map closely with the domains for measuring dignity in care identified in *Measuring Dignity in Care*, a research report for Help the Aged by the Picker Institute $^{50}$ . They also relate to the experiences and concerns of patients and carers presented in reports on hospital care that have been published since the audit commenced:

- The Alzheimer's Society's report, Counting the Cost identified key carer concerns as: nurses not recognising or understanding dementia; a lack of person-centred care; not being helped to eat and drink; a lack of opportunity for social interaction; not as much involvement in decision-making as wished for (for both the person with dementia and carer); and the person with dementia being treated with a lack of dignity and respect <sup>6</sup>.
- The report of the Francis Inquiry into care provided by Mid Staffordshire NHS Foundation Trust commented that "many of the cases in which patients and their families have reported concerns have involved elderly patients [who] will often present with a complex of medical and care problems requiring a skilled and allembracing multi-disciplinary team approach". On care of people with dementia the report stated "some medical staff did not understand this diagnosis and its importance and in some instances treated it as 'bad behaviour' rather than as a valid medical condition" 90.
- Most recently, Care and Compassion?, the report of the Health Service Ombudsman, presented ten investigations into complaints made about the standard of care provided to older people by the NHS, of which 3 related to the care of a person with dementia<sup>40</sup>.
- In Wales, Dignified Care?, the report of the Older People's Commissioner for Wales, presented the findings of an expert panel on evidence presented by staff and members of the public on care experiences of older people in hospital. The report raised concerns about a lack of knowledge of the needs of people with dementia, the levels of training and support available, communications, and standards of care<sup>66</sup>.

## Concerns raised by staff working with people with dementia

Reports on hospital care found that staff working in hospitals often expressed concerns similar to those of people with dementia and their carers and identified a need for more organisational support towards providing informed and sensitive care:

Counting the Cost found that 97% of the nurses in hospitals surveyed work with people with dementia. 54% of nursing staff said that they had not received any pre-registration training in dementia; 33% said they had received some training but not enough and only 12% said they had received enough training. 83% of

- nursing staff felt that learning and development opportunities would help them to improve the care they were able to provide<sup>6</sup>.
- The Francis Inquiry found that a reduction in the availability of skilled and senior nurses, under-staffing and lack of leadership were all contributory factors to the poor quality of care in the hospital. The report highlighted concerns that staff had raised about basic care standards and an environment "neither safe for patients or staff" 90.

#### Current national initiatives

#### **Common Core Principles for Supporting People with Dementia**

In late 2010 the Department of Health commissioned Skills for Care, working jointly with Skills for Health, to develop Common Core Principles for Supporting People with Dementia. The Common Core Principles were published on 9 June 2011 and are statements of the type of care which people with dementia and their carers can expect.

They can be used by all those engaged in developing, commissioning, supporting or delivering care for people with dementia, including non-specialists. They can also be used by providers of education and training to inform the content of curricula and training courses.

#### Common Core Principles for Supporting People with Dementia

- Principle 1 Know the early signs of dementia.
- Principle 2 Early diagnosis of dementia helps people receive information, support and treatment at the earliest possible stage.
- Principle 3 Communicate sensitively to support meaningful interaction.
- Principle 4 Promote independence and encourage activity.
- Principle 5 Recognise the signs of distress resulting from confusion and respond by diffusing a person's anxiety and supporting their understanding of the events they experience.
- Principle 6 Family members and other carers are valued, respected and supported just like those they care for and are helped to gain access to dementia care advice.
- Principle 7 Managers need to take responsibility to ensure members of their team are trained and well supported to meet the needs of people with dementia.
- Principle 8 Work as part of a multi-agency team to support the person with

http://www.dh.gov.uk/prod consum dh/groups/dh digitalassets/documents/digita lasset/dh 127587.pdf

#### 1000 Lives Plus Campaign

In Wales, the 1000 Lives Plus guide to Improving Dementia Care was published in 2010. It focuses on specific areas that were developed alongside and in conjunction with the work on the National Dementia Plan for Wales. The aim of the dementia targets collectively is to improve the quality of life and care for people with dementia and their care givers. Care on general hospital wards is one of the five key areas identified.

#### 1000 Lives plus - interventions to improve care for people with dementia on general hospital wards

- Identify on day of admission if person already has diagnosis of dementia. If so, liaise immediately regarding care needs in relation to dementia (including medication) with family and professional carers, and commence discharge planning.
- Where there is no previous history of dementia, check history with family/other carers or people offering support.
- Assess for delirium and ensure appropriate treatment.
- Seek advice from liaison service for older adults with mental health problems, especially where additional needs identified from risk assessment in relation to challenging behaviour.
- Assess environmental needs e.g. safety, stimulation, need for single room
- Assess needs for assistance and maintaining skills, e.g. with meals, toileting, self care, and build into care plan accordingly.
- Review all psychotropic medication on admission.
- Assess for capacity for major decisions, and where person lacks capacity, follow 'best interests' process.
- Carers to be involved in care-planning for the person in relation to discharge planning.
- If the patient has a diagnosis of dementia when being discharged: all carers offered carers assessment.

http://www.wales.nhs.uk/sitesplus/1011/publications

#### Royal College of Nursing (RCN) Dignity in Dementia project

Over the last 12 months the RCN has been facilitating a national project supported by the Department of Health, to influence and guide the provision of dementia care in acute care settings: Dignity in dementia; improving care in general hospital settings. The RCN launched a 5-step commitment to improving dementia care (called SPACE) on 21 September, together with supporting resources including pocket guides for hospital staff and posters setting out the essential principles for care delivery.

#### Make SPACE for good dementia care:

- Staff who are skilled and have time to care.
- **P**artnership working with carers.
- **A**ssessment and early identification of dementia.
- Care plans which are person-centred and individualised.
- **E**nvironments that are dementia-friendly.

http://www.rcn.org.uk/development/practice/dementia

## **Audit structure**

Key questions for the audit were:

- What structures and resources do hospitals have in place to enable them to identify and meet the care needs of people with dementia? (Measuring the ability to care)
- What evidence can be assembled to show that people with dementia in the hospital have received an acceptable standard of care? (Measuring the quality of care)

This led to the development of a two part audit:

- a hospital level, 'core' audit;
- a ward level, 'enhanced' audit.

#### Core audit

The core audit was open to all general acute hospitals in England and Wales providing acute services on more than one ward and admitting adults over 65. The core audit collected information at hospital level about governance, policy and procedures, and evidence from audited casenotes of assessment, care planning and discharge. Each participating <u>hospital</u> was asked to complete two modules:

**Organisational checklist** – This module looked at the structures, policies, care processes and key staff that impact on service planning and provision for the care of people with dementia within a general hospital. Each participating hospital was expected to submit one checklist.

Casenote audit - In this module, hospitals were asked to identify the records of a minimum of 40 patients with a diagnosis or current history of dementia, audited against a checklist of standards that relate to their admission, assessment, care planning/delivery, and discharge.

## **Enhanced audit**

The enhanced audit was a further optional audit component open to hospitals who registered for the core audit. This part of the audit evaluated the quality of personcentred care provided at ward level and the experience of patients and carers.

Each hospital participating in the enhanced audit was asked to nominate two or three wards from a single site:

- one general medical ward, other medical ward, or "shared care" ward (whose patients include people over the age of 65);
- one surgical or orthopaedic ward (whose patients include people over the age of 65);
- a third optional ward that can be either another medical or surgical ward or care of the elderly which treats acute admissions (i.e. may be an "elderly medical" or a pre-discharge ward, but not long stay or rehabilitation).

Each <u>ward</u> participating in the enhanced audit was asked to complete or help to collect:

Ward organisational audit (one per ward) - concerning staffing, support and governance at a ward level.

Ward environmental audit (one per ward) - covering aspects of the ward physical environment known to impact on people with dementia.

Staff questionnaires (for all staff regularly working on the ward) - collected feedback from ward staff about training and support received, awareness of dementia and about support offered to patients with dementia on their ward.

Carer/patient questionnaires (for patients with dementia, in circumstances where it could be reliably confirmed that they would be happy to receive a questionnaire, or for carers for people with dementia on the ward) - collected feedback from carers' of their experience of the support received from ward staff and from patients of their perception of the quality of care on the ward.

Observation of care interactions (Person, Interaction and Experience - PIE) -Evaluated the delivery of person-centred care from the perspective of people with dementia on the ward. This module was based on a research programme managed by Professor John Young (a consultant geriatrician) and Rosemary Woolley (a research fellow), based in the Academic Unit of Elderly Care and Rehabilitation, which is part of Bradford Teaching Hospitals NHS Foundation Trust and the University of Leeds. Staff carrying out observations in participating wards attended a one day workshop on the use of the tool and observations were conducted by 2 staff for at least 2 periods of 2 hours each. Findings from this module are included as a separate chapter authored by Rosemary Woolley and John Young (see page 153).

## **Recruitment and participation rates**

## **Recruitment of hospital sites**

The National Audit of Dementia was open to all general acute hospitals, or those providing general acute services on more than one ward that admit people over the age of 65. Sites were invited to participate in the audit via letters to Chief Executives and Directors of Nursing. 151 Trusts/Health Boards and 236 hospitals were identified as eligible across England and Wales. Recruitment for the audit was carried out over a 6 month period, with Trusts/Health Boards still registering their hospitals a month before data collection began.

At the time of data collection 100% of Trusts/Health Boards had registered one or more of their eligible hospitals. This gave a total of 218 hospitals participating in the audit (92% of eligible hospitals identified) and 56 of these nominating wards for the enhanced ward level audit (151 wards registered in total).

## Participation in the audit

Once data collection commenced, some hospitals withdrew participation from the audit. Reasons for withdrawal were mainly due to changes within their organisation and lack of resources to participate. Consequently, one Trust did not have any of their hospitals submit data for the audit, meaning that the overall Trust/Health Board participation was 99%. 8 hospitals withdrew from the core audit, reducing the hospital participation rate to 88%. 1 hospital withdrew from the enhanced audit, and 3 hospitals withdrew some wards, leaving 145 wards participating.

Table 2: Participation in the core and enhanced audit

Strategic Health Authorities and Welsh regions	Total eligible sites	Participation in core audit	Percentage of hospitals in core audit	Participation in enhanced audit	Percentage of hospitals in core and enhanced
East Midlands	14	10	71	4	29
East of England	20	18	90	4	20
London	34	32	94	10	29
North East	16	15	94	3	19
North West	35	30	86	7	20
South Central	13	12	92	3	23
South East Coast	18	17	94	3	17
South West	21	19	90	10	48
West Midlands	23	21	91	4	17
Yorkshire and the Humber	25	19	76	5	20
Mid and West Wales	8	8	100	0	0
North Wales	3	3	100	0	0
South East Wales	6	6	100	2	33
Total	236	210	89	55	23

#### Core audit participation

4 hospitals were not able to complete both components of the core audit, and therefore 206 hospitals submitted data for both the organisational checklist and the casenote audit.

#### **Enhanced audit participation**

Wards participating in the enhanced audit were asked to give information on their speciality. Hospitals nominated either 2 or 3 wards to submit data.

Table 3: Ward speciality breakdown

Ward speciality	Number of wards participating
Medical	57
Surgical/orthopaedic	56
Care of the elderly	32
Total	145

All wards registered for the enhanced audit were able to submit a ward organisational checklist and all but one of these wards was able to submit an environmental checklist. The ward that withdrew from this module was unable to complete this checklist due to environmental changes being carried out on the ward at the time of data collection. Staff questionnaires and carer/patient questionnaires were not returned by every ward participating in the enhanced audit.

Table 4: Number of hospitals/wards submitting data for each module

Core audit modules	Number of hospitals (N = 210)	Data received
Organisational checklist	210	210 checklists
Casenote audit	206	7934 casenotes
Enhanced audit modules	Number of wards (N = 145)	Data received
Ward organisational checklist	145	145 checklists
Environmental checklist	144	144 checklists
Staff questionnaires *	142	2211 questionnaires
Carer/patient questionnaires *	85	245 questionnaires
Observational module	118	118 feedback forms

<sup>\*</sup> Wards submitting fewer than 8 staff questionnaires and fewer than 5 carer/patient questionnaires were not given local feedback on the data received. However, all questionnaires have been included in the analysis for the national report.

#### Person, Interaction and Environment (PIE) Observation module participation

6 regional workshops were held in January and February 2011, with 109 delegates from 52 hospitals. 1 hospital had to drop out from further participation due to only 1 delegate attending a workshop (2 observers are required per ward observation). Data collection took place between February 2011 and May 2011 with data for each ward being inputted onto an online survey on the Royal College of Psychiatrists' website. By the end of May, data had been returned from 118 wards in 48 hospitals.

#### Ward characteristics

4 hospitals returned data for 1 ward, 16 hospitals for 2 wards (total = 32) and 23 hospitals for 3 wards (total = 69). 38 wards were general medical, 37 wards were surgical, 22 wards were elderly care and 8 wards were general medical and elderly.

Organisational changes affected 15 wards which submitted data: 5 had moved site, 1 had moved site and also had fewer beds and 1 ward had split, due to the single sex agenda. 2 other wards had changed ward type. 6 wards replaced original wards; 1 was of the same type while 5 were different types (this was largely due to organisational changes in the original wards).

#### Observer characteristics

There were two observers in each ward. Across the 105 ward observations, 84 (85%) observers were external, i.e. did not usually work in that ward as part of the established numbers and 32 (15%) usually worked on that ward.

Table 5: Job role of observers

Job title	Number of observers
Matron	20
Practice Development Lead	20
Ward Manager	15
Ward Sister/Senior Sister	12
Nurse Specialist - Older People	8
Nurse Specialist - Dementia	5
Staff Nurse	5
Charge Nurse	3
Other:	8
Specialist Doctor in Dementia Care	1
Patient Governor	1
Senior Occupational Therapist	1
Nurse Researcher	2
Care Home Liaison Sister	1
Deputy Director of Nursing	1
Senior Nurse – Safeguarding	1
Total	96

## **Data collection**

#### **Data submission**

For all modules except the patient/carer questionnaire, data were submitted via an online survey, accessed with the username and password allocated to each participating hospital, ward, or ward staff.

#### Core audit

#### Organisational checklist

Data collection was carried out between 15 March 2010 and 14 May 2010. Each participating hospital was required to submit 1 organisational checklist.

#### **Casenote audit**

Data collection was carried out between 22 May 2010 and 5 August 2010 (an extension on the original deadline, 16 July, was given). Each participating hospital was required to submit a sample of 40 casenotes. The sample of casenotes was selected using discharge dates falling into the period between 1 September 2009 and 28 February 2010.

Audit was of a single admission, and eligible admissions were of 5 days or longer. Wherever there were insufficient numbers of discharge within the specified period, participants were advised to obtain casenotes with consecutive discharge, first from the preceding two months, and then from the subsequent two months. Hospitals were given the opportunity to check submissions before data analysis was carried out.

## **Enhanced audit**

#### **Environmental checklist**

Data collection was carried out between 1 April 2010 and 11 June 2010. Each participating ward was requested to submit 1 environmental checklist.

#### Ward organisational checklist

Data collection was carried out between 1 April 2010 and 28 May 2010. Each participating ward was requested to submit 1 ward organisational checklist.

#### Staff questionnaire

Data collection was carried out between 1 April 2010 and 16 July 2010. Information sheets for staff were sent to ward leads to be distributed to staff, with information about the audit and how to submit the questionnaire.

#### Carer/patient questionnaire

Data collection was carried out between 1 April 2010 and 13 August 2010. Each participating ward was sent 25 questionnaires with accompanying guidance sheets, information leaflets and posters, and prepaid envelopes so that respondents could return questionnaires directly to the Project Team.

#### Staff were advised:

- to distribute the questionnaires to people with dementia/their carers who had been on the ward for at least 3 days, preferably in the run up to discharge;
- to give the questionnaire to the carer and not directly to the person with dementia unless certain that they were aware of their diagnosis and wanted to receive the questionnaire;
- if the person had no family or carer, they could still be given the questionnaire (if they were happy to receive it);
- the person with dementia could be helped to fill in a questionnaire by a friend or key worker, but not by staff from the ward.

The audit tools listed above are available on the National Audit of Dementia website.\*

#### Person, Interaction and Environment (PIE) - Observation module

Data collection was carried out between January 2011 and April 2011.

Observation times and periods

There were 105 ward observations, each carried out by 2 observers. Only 5 ward observations had to be rescheduled to a different date due to operational issues, indicating general feasibility in planning observations.

- Each ward carried out a minimum of 2 observations to cover a morning and lunch time period. After carrying out an initial practice observation together either on the day of observation or on the previous day, the 2 observers split to observe different patients during each observation period.
- A minimum of 2 hours (on 7 wards) and a maximum of 6 hours observation in each ward were carried out. 85 wards carried out 4 or more hours of observation.

www.nationalauditofdementia.org.uk

- (Excluding practice observation), 100 ward observations were carried out over 2 time periods, and 5 ward observations were split over 3 time periods (one ward observed an additional hour between 17:00 and 18:00).
- The observation times ranged between 07:30 and 18:00. Most morning observations took place between 09:00 and 11:00 and most afternoon observations between 12:00 and 14:00.
- The total number of areas observed in each ward ranged from 1 to 8. The most frequent number (mode) was 2 (67 wards). 9 wards observed one area.
- All observations were carried out in bay areas except for 25 occasions in a single/ side room, once in a corridor, once in a day room and once following a patient.
- The number of patients observed in each ward ranged from 1 to 12. 95 wards observed at least 3 patients. The most frequently observed number (mode) was 6 patients (32 wards).

#### Limitations of the data

#### **Casenote audit**

Sample size

A minority of hospitals were not able to return 40 or more casenotes, and 4 hospitals did not submit any data for this part of the audit.

Table 6: Breakdown of casenotes returned per site

Sample size	Number of hospitals	% hospitals
40 casenotes or more	162	79
30-39 casenotes	29	14
20-29 casenotes	11	5
10-19 casenotes	4	2
Total	206	100

A small minority of hospitals (7%) submitted 29 casenotes or less. These samples are included in the national dataset.

Sample size was also affected by casenotes excluded from this audit. This has occurred where:

auditors have commented to the effect that there is no record of any history or diagnosis of dementia;

the length of stay is less than 5 days (it was decided to include those casenotes where dates appeared to indicate 4 days, as this represented 4 overnight stays and therefore 5 days admission).

#### Inter-rater reliability analyses

Hospitals were asked to re-submit the first five sets of casenotes audited by a different auditor, to establish agreement. 185 hospitals submitted 891 casenotes. These analyses are contained as Appendix A within the full data report on the National Audit of Dementia website.

#### Casenotes excluded from sections of the audit

The audit asked participants to identify those patients who had died during admission, and to identify the final discharge destination. Casenotes of patients who died during admission were excluded from reporting of questions relating to discharge.

Casenotes of patients identified (either from responses or auditor comments) as having self-discharged, transferred to another hospital or transferred on end-of-life care pathway were also excluded from the reporting of these questions.

It has not proved possible to consistently identify from comments, casenotes of those patients who were dying from the point of admission, and the audit did not specifically ask about this. Responses from these casenotes are therefore included throughout.

#### Changes to the data

In a small percentage of responses, it was possible to confidently identify errors in responses from comments returned - i.e. auditors had answered 'No' instead of 'Yes' and vice versa. These responses were marked and the answer changed. Where it was not possible to identify error with complete confidence from the comment, no change was made.

A further small percentage of comments indicated that, although an answer required by the online form had been given, the true answer would have been 'missing' or 'not recorded'. In these cases, responses were deleted. This affects the denominator of responses for these questions, which is therefore lower wherever this occurs.

Data were also deleted for dates of admission and discharge where there was clear error (e.g. negative length of stay).

#### Staff questionnaire

Not all wards taking part in the enhanced audit returned staff questionnaires. In total, we received 2211 questionnaires from 142 out of 145 wards.

Table 7: Staff questionnaires returned per ward (N = 2211)

Number of questionnaires returned	Number of wards
0	3
1 – 9	27
10 – 19	79
20 – 29	33
30 – 45	3

To ensure anonymity of respondents, wards returning fewer than 8 questionnaires received national data only. All questionnaires are included in analysis for this report.

#### Carer/patient questionnaire

The carer/patient questionnaire received the lowest number of responses both nationally and locally (see breakdown by ward below). It was anticipated that this information would be difficult to collect. To avoid causing distress to patients with dementia, guidance was issued which restricted distribution of the questionnaire to those people with dementia with an identified supporting carer or friend, who could ascertain whether the person with dementia would like to receive the questionnaire, and if necessary help them to fill it in or complete it on their behalf.

Table 8: Carer/patient questionnaires returned per ward (N = 245)

Number of questionnaires returned	Number of wards
0	58
1 – 4	74
5 - 10	12
11 – 12	1

Wards with more than 5 questionnaire responses received local results. Other wards received national results only, to ensure anonymity.

Because of the low number of responses overall, the data have not been included in this report as it may not be representative of the national picture. Instead typical comments provided by patients or carers illustrative of the main themes are included.

#### Person, Interaction and Environment (PIE) – Observation module

Each hospital was asked to carry out PIE in the same wards which had participated in the other enhanced audit modules. As there was a time delay in carrying out the observations compared to the other enhanced modules, 12 wards withdrew (and did

not identify replacement wards). On 5 wards, this was because there were no patients perceived to have dementia/memory problems present in the ward on the day of data collection. Other reasons for exclusion were due to organisational changes (such as a ward move or closure), infection control, resource/operational issues or unforeseen circumstances.

Data from 12 wards (all the participating wards from 4 hospitals and 1 ward from another hospital) were excluded as it did not meet the minimum criteria of both observers having attended a PIE workshop. Data from another hospital was also excluded as only one hour observation was carried out. 105 wards from 43 hospitals could therefore be included in further qualitative and quantitative analysis.

Observations were not completed for 6 patients; 2 due to death, 3 due to discharge and 1 due to anxiety or distress at the observer's presence.

## **Audit standards**

## **Identifying standards for audit**

A literature review identified source documents for the audit. These included:

- national reports and guidelines;
- standards, guidelines and recommendations issued by professional bodies;
- reports and recommendations issued by organisations representing service users and carers. A secondary review identified key areas of concern for service users and carers in terms of experience of care received.

From these sources, a comprehensive manual of standards and criteria was produced with 23 identifiable high level standards or topic areas. These were presented with associated criteria and linked to their source documents.

A feasibility study examined which of the criteria identified could be measured within the remit of the audit. From the measurable criteria, audit tools were produced linked to the standards. These were piloted between August 2009 and October 2009. The pilot stage data and feedback from participants led to further amendments to the standards and audit tools, prior to the roll-out of the audit in March 2010. Finally, the Steering Group produced weighting for the standards.

The standards on which the audit tools are based are therefore those identified as measurable at this stage. They should not be read as relating to the totality of care received by people with dementia in every circumstance for which they are admitted to a general hospital. The standards document can be found on the audit's website.

#### "Dementia-specific" standards

Many themes addressed in this audit, for example 'nutrition on the ward', are not specific to people with dementia in terms of their condition. However, they have been included because of the need to present a more comprehensive picture of the care of people with dementia, in terms of whether it offers a framework for person-centred care which can identify individual needs and is responsive to the person as a whole.

For information about classification of standards and use of benchmarked data in local reporting see Appendix 5 on page 214.

## How to read this report

This report is based on the data submitted by participating hospitals for the core audit and enhanced audit modules of the National Audit of Dementia (care in general hospitals). Full national data tables, presenting a breakdown of the responses to each audit question, together with benchmarking data, are available at the project's website.

The report is presented thematically, with each chapter comprising information derived from relevant audit tools. For example, results from the organisational checklist relating to assessment are presented with related results from the casenote audit, for comparison and to give a truer picture of overall achievement in this area.

The report includes combined results from individual tools in the audit. Results are presented as percentages followed by the numerator/denominator (e.g. 25%, 25/100) and the percentages have been rounded to the nearest whole number. The denominator may change throughout the report due to question routing and also 'not applicable' responses in the hospital organisational checklist, casenote audit and ward organisational checklist. If questions within these tools had a 'not applicable' option, these were excluded from the total number of responses for these questions.

A numbered list of documents used for reference throughout the report can be found at Appendix 2. Numbers in text indicate the document referred to.

## Hospital level data (core audit)

#### Organisational checklist data

This includes results from all 210 hospitals that took part in the audit. Results are presented as a percentage of hospitals, e.g. 6% (12/210) of hospitals had a care pathway in place for people with dementia.

#### Casenote audit data

This includes results from 206 hospitals that submitted a total of 7934 casenotes. Results are presented as a percentage of casenotes, e.g. 83% (6583/7934) of <u>casenotes</u> stated that no referral had been made to psychiatric consultation/liaison.

## Ward level data (enhanced audit)

#### Ward organisational checklist

This includes results from 55 hospitals that submitted a total of 145 checklists (1 per participating ward). Results are presented as a percentage of wards, e.g. 86% (125/145) of wards stated that there are vacancies on the ward. Comments from this module are included, where applicable, to illustrate findings from the ward organisational checklist and other tools.

#### **Environmental checklist**

This includes results from 55 hospitals that submitted a total of 144 checklists (1 per participating ward). Results are presented as a percentage of wards, e.g. 48% (69/144) of wards stated that key areas are clearly marked.

#### **Staff questionnaire**

This includes results from 55 hospitals that submitted a total of 2211 questionnaires (142 wards). Results are presented as a percentage of staff, e.g. 39% (851/2211) of staff agreed it was easy to gain access and input from liaison psychiatry.

For questions where staff were asked to give their level of agreement, the response options 'strongly agree' and 'agree' have been amalgamated and presented as 'agree' in this report.

Comments from this module are included, where applicable, to illustrate findings from the staff questionnaire and other tools.

#### **Carer/patient questionnaire**

Due to a low return of questionnaires, overall results from this module are not presented as we cannot determine if they are representative of the national picture.

Comments from this module are included, where applicable, to illustrate findings from other tools.

#### Person, Interaction and Environment (PIE) - Observation module

This includes results from 43 hospitals (105 wards).

As the data were qualitative and hospitals focused on certain areas only, both for reporting and action planning, the quantitative figures given in this chapter are likely to be underestimates. For example, 51 wards identified collecting or using personal knowledge of people with dementia as an issue to address in their ward. However, as only 13 wards identified good practice examples in this area, it is likely that this requires wider attention. A 'few' wards refers to at least 5 (5%), 'many' to 53-79 (50-75%) of wards and 'most' wards to 80-100 (76-95%).

## Reporting carried out to date

The 210 hospitals participating in the core audit received a local report of their results in December 2010.

An interim report presenting key findings from the core audit was published on 16 December 2010. This was a brief summary report, based on key findings from a preliminary analysis of the hospital level data only. Analysis of ward level data and recommendations were not included at this time.

55 hospitals also participating in the enhanced audit received local reports of their results in February 2011 (excluding observation module).

Full national data tables, presenting a breakdown of the responses to each audit question, together with benchmarking data, are available on the National Audit of Dementia website.

## Local work completed and underway

As the majority of data collection was completed in 2010, hospitals were asked to submit action plans with updates in the summer of 2011.

75 updates were received. This feedback is reported in each chapter to show progress since the point of audit, defined as actions completed or due for implementation by the end of 2011.

At action planning events this year, participants shared information on important work already undertaken and ongoing at local and regional level. It is not possible here to report fully on the extent of these initiatives, but we include examples below.

As further information on shared web-based resources becomes available, it will be compiled by the Project Team and publicised via the website.

#### **East of England**

In March 2010 the East of England region arranged for the Alzheimer's Society 'This is Me' leaflet to be distributed free of charge in the region. This initiative has removed barriers to the use of 'This is Me' in acute hospitals, Mental Health Trusts and care homes. It is being used to support personal care planning in acute hospitals when people with dementia are admitted.

#### For further information go to:

http://www.alzheimers.org.uk/site/scripts/download\_info.php?fileID=1009&categoryID=20030

#### London

Healthcare for London published their Dementia Services Guide in 2009 incorporating a general hospital care pathway.

For further information go to:

http://www.londonhp.nhs.uk

#### **North West**

In the North West, hospital leads are focussing on a range of areas including environment, staff awareness and care pathway development.

#### For further information go to:

http://www.northwest.nhs.uk/document\_uploads/MentalHealthNews\_July09/Issue031\_Demen Strat SR.pdf

#### **South Central**

South Central has a joint programme with the Department of Health South East to improve services and outcomes for people with dementia and their carers. The key priorities of the implementation plan are identified as:

- Early intervention diagnosis for all.
- Improved quality of care for people with dementia in general hospitals.
- Living well with dementia in care homes.
- Reducing the use of antipsychotic drugs.
- Improved community personal support services.

#### For further information go to:

http://www.southcentral.nhs.uk/what-we-are-doing/mental-health-and-learning-disabilities/

#### **South West**

In 2011 the region produced the South West Hospital Standards in Dementia care, together with implementation guidance and self assessment tools. The website also contains a dementia competency framework; some examples of new ways of working in dementia; learning material on dementia with a 3 step model; a guide on dementia workforce issues for service commissioners.

#### For further information go to:

http://www.southwestdementiapartnership.org.uk/hospital-care/hospital-standards

#### **West Midlands**

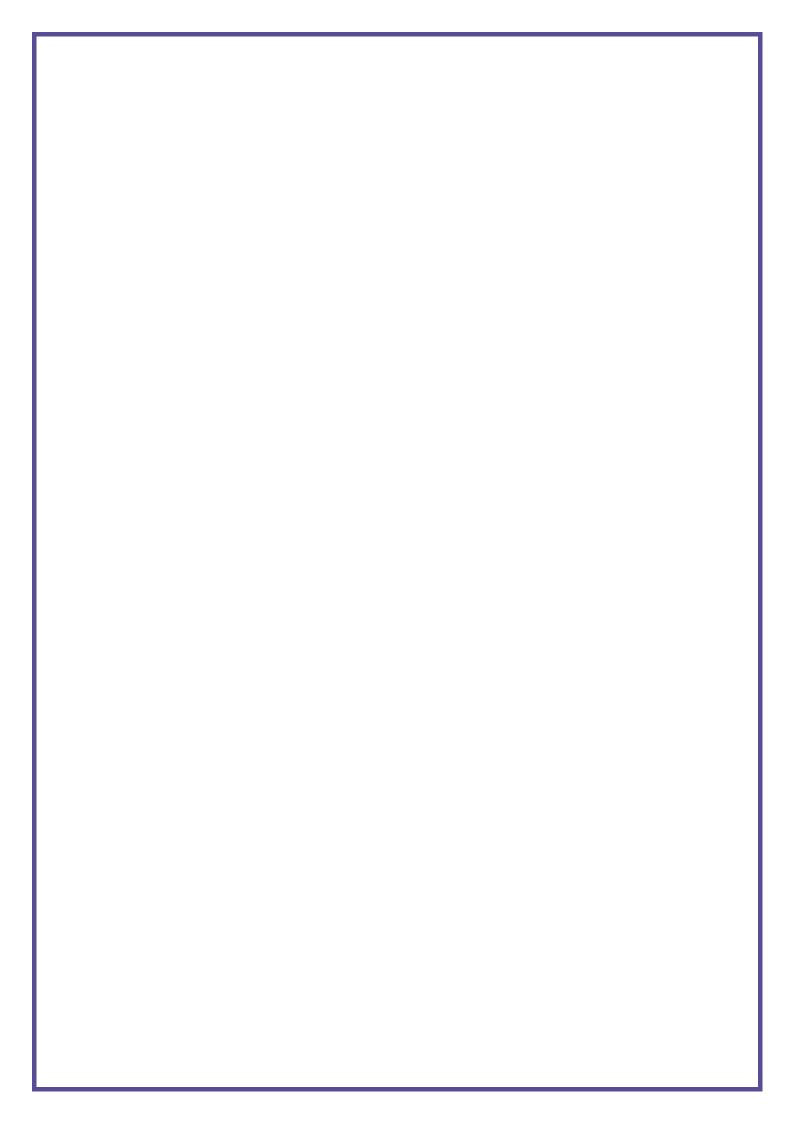
The New Cross Hospital Project, Delivering Excellence in Dementia Care in Acute Care, focuses on a new, specially designed 20 bed ward for people with dementia and physical illness. The project aims for a whole systems approach. Aims include:

- To ensure that anyone with a diagnosis of dementia, receiving treatment at the Royal Wolverhampton Hospitals receives care, which demonstrates best clinical practice, is cost-effective, whilst also providing individuals with respect, dignity and compassion.
- To develop a set of evidence based interventions, a care bundle, which all need to be in place and used/drawn upon by all staff to provide consistent quality of care – a composite approach.

The learning from this project was rolled out across the region at an event in July 2011 and an evaluation report is due out this autumn.

#### For further information go to:

http://nhslocal.nhs.uk/story/new-cross-hospital-pioneers-care-people-dementia-hospital





# Findings of the National Audit of Dementia



### 1. Governance

## **Summary**

- 6% of hospitals had a care pathway in place for people with dementia at the time of audit and 44% of hospitals had a care pathway in development.
- Less than a quarter of Executive Boards regularly review information related to delayed discharge of people with dementia and only 8% review re-admissions of people with dementia.
- 69% of hospitals had access to intermediate care services that would admit people with dementia, however only 50% of hospitals had direct access.
- 61% of hospitals had access to interpreting services and 83% had access to advocacy services which could meet the needs of people with dementia.
- Access at ward level to specialist service input, such as social services, liaison psychiatry and occupational therapy, was generally available Monday to Friday during the day. Availability at evenings or weekends was limited for most services.

## Care pathway for dementia

### How many hospitals had a care pathway for dementia?

Hospital admissions are a time of high risk for people with dementia, who in most cases are admitted to hospital for clinical reasons other than their diagnosis of dementia. People with dementia who are admitted to hospital tend to have worse outcomes and this is reflected in prolonged length of stay, higher mortality rates and deterioration in health, leading to an increase in care and support needs<sup>27,64</sup>. Therefore it is important that the dementia is taken into account throughout the hospital stay and that a care pathway is in place to ensure the needs of the patient are met, both for the dementia and the primary reason for which the person has been admitted. Having a care pathway in place will allow for a more consistent approach to care and for the achievement of better quality in care<sup>27,64</sup>. Very few hospitals had a care pathway in place at the point of audit and a minority were developing their pathway:

- 6% (12/210) of hospitals had a care pathway in place for people with dementia.
- 44% (92/210) of hospitals had a care pathway in development.
- 51% (106/210) of hospitals did not have a care pathway in place or in development.

#### Care pathway and clinical leadership

The National Dementia Strategy in England<sup>27</sup> and the 1000 Lives Plus Campaign in Wales<sup>64</sup>, identified the importance of strong leadership and clinical expertise within the hospital in making effective improvements to the quality of care. The audit asked whether there was a senior clinician responsible for implementation and/or review of a care pathway for dementia:

- 51% (106/210) of hospitals had no care pathway. Of these 93% (99/106) had not identified a senior clinician to take charge of development.
- 41% (85/210) of hospitals had a care pathway in place or in development, and had a senior clinician responsible for implementing/reviewing the care pathway.

Hospitals identified a variety of senior roles as their clinical leads for dementia, summarised in the table below.

Table 9: Hospital leads for dementia by job title (N = 92)

Job title	%
Clinical/Medical Director	9
Consultant Geriatrician/Specialist Physician in Elderly Care	57
Consultant Psychiatrist	5
Consultant Physician	14
Consultant Nurse	5
Lead Nurse Practitioner/Matron	5
Other	4
Total	100

#### Care pathway and palliative care

The National Institute for Health and Clinical Excellence dementia guideline<sup>60</sup> stresses the importance of the palliative care approach in dementia care and specifies the responsibility of health and social care practitioners and commissioners to ensure that people with dementia have equivalent access to palliative care. The audit asked if the hospital dementia care pathway (either in place or in development) interfaced with the end of life or palliative care pathway:

35% (36/104) of hospitals said that the dementia care pathway interfaced with the end of life or palliative care pathway.

It is important that the care pathway for dementia is developed to be fully integrated and compatible with care pathways in the hospital in order to ensure that care and treatment needs are addressed holistically.

## Involvement of the Executive Board

## Do hospital policies and procedures recognise the needs of people with dementia?

Ensuring that people with dementia as a group can be identified within reporting procedures will help hospitals to plan and improve care for a group of patients known to be particularly vulnerable within the hospital environment. Without this, problems in procedures affecting people with dementia and impacting on the hospital overall in terms of quality, efficiency and cost effectiveness, are less likely to be picked up and addressed.

The Alzheimer's Society report Counting the Cost<sup>6</sup> showed that patients with dementia are more likely to stay in hospital for longer, when compared to the total sample of all patients admitted to hospital for the same physical condition. For instance, the report stated that 57% of patients with dementia admitted for a hip replacement (one of the top five reasons for admission) stayed in hospital for two weeks or longer, compared to the median stay of seven days.

The NHS Confederation Report Acute Awareness<sup>63</sup> suggested that the quality of care received by people with dementia could be improved by ensuring patients leave hospital with an appropriate care plan, to help decrease the number of re-admissions. The report also identified length of stay for people with dementia as a key question for Boards and recommended reviewing discharge processes and auditing re-admissions of patients with dementia.

Most hospitals do not identify people with dementia as a group within existing reporting procedures and therefore Executive Boards are not in a position to routinely review information that relates to people with dementia:

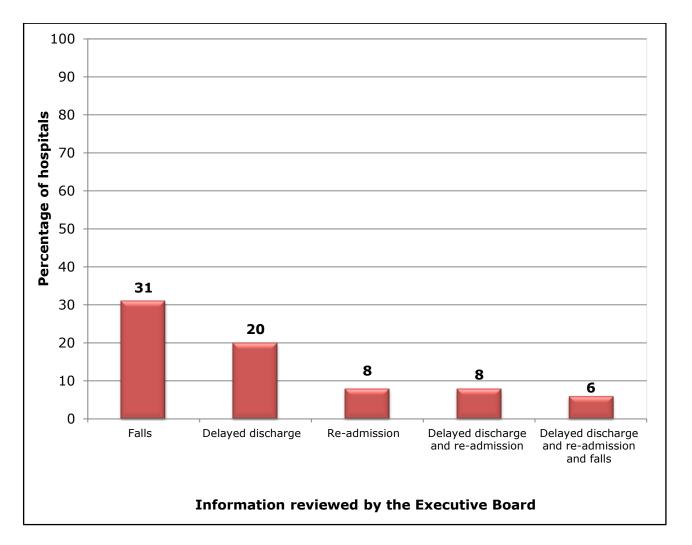
- 20% (41/210) of Boards review information on delayed discharges (transfers) of people with dementia.
- 8% (16/210) of Boards review information on re-admissions of people with dementia.
- 8% (16/210) of Boards review both delayed discharges (transfers) and readmissions of people with dementia.

The audit also asked whether hospitals have involvement from the Executive Board in regularly reviewing hospital discharge policy and procedures, as they relate to people with dementia:

30% (63/210) of Boards review discharge policy and procedures.

The Department of Health<sup>22</sup> recommended that the number of in-hospital falls and their causes should be collected and reviewed by the Executive Board on a regular basis so that any issues arising can be identified and acted upon. The National Audit of Falls and Bone Health in Older People<sup>78</sup> highlighted that dementia is a 'strong risk factor for falls and fractures'. Audit results showed that less than a third (31%, 66/210) of hospitals can identify people with dementia in reported information on inhospital falls and their causes.

Figure 1: Hospital Executive Boards reviewing information (N = 210)



Executive Boards/Health Boards have a range of information sources available to them which can provide valuable intelligence on the quality of care delivered to people with dementia. The audit asked if feedback was received, for review by the Board:

- 48% (100/210) of Boards receive feedback from clinical leads for older people.
- 42% (88/210) of Boards receive feedback on complaints, analysed by age.
- 37% (78/210) of Boards receive feedback from the Patient Advisory Liaison Service, in relation to older people and people with dementia.
- 32% (68/210) of Boards receive feedback from Patient Forums or Local Involvement Networks, in relation to the services for older people and people with dementia.

Only 2% (4/210) of hospitals reported that the Executive Board regularly receives feedback from all of the above. However, 74% (155/210) of hospitals reported that the Executive Board regularly receives feedback from at least one of the above.

#### Can people with dementia use intermediate care services?

Intermediate care services can come into play to avoid unnecessary admission to acute hospitals or to decrease the length of stay. Department of Health guidance<sup>26</sup> specifies that people with dementia or people with mental health needs in hospital should be able to access intermediate care in order to receive the specialist care necessary, to help them recover functioning and get an informed assessment of their future needs. Without this, a stay in hospital can be prolonged, or premature transfer to a care home may take place. The *National Service Framework for Older People in Wales*<sup>94</sup> also states the importance of intermediate care access as part of safe and effective discharge planning for all patients, including older vulnerable patients.

• 69% (145/210) of hospitals had access to intermediate care services that accepted people with dementia.

Of these, about three quarters (74%, 106/144) were able to state that access allowed people with dementia to be admitted directly and avoid hospital admission. This means that for half of the audited hospitals (50%, 104/210) direct access to intermediate care for people with dementia could not be achieved.

The audit did not collect data on the type of intermediate care provision (e.g. transitional care team, dedicated beds) or on overall criteria for access. We are unable to draw assumptions from the data about whether local provision enables all people with dementia, including those in mid and late stages, to access intermediate care.

## Designated support and liaison for people with dementia and their carers

## Do people with dementia get support from a social worker or liaison worker?

The role of the social worker in hospital can be key in providing information and advice to patients and carers. The social worker is often involved in liaising with ward staff and community based teams to ensure that discharge arrangements take account of the care needs of the person with dementia once they have left the hospital<sup>8,77</sup>.

The audit asked about a named person in the hospital (a social worker, liaison worker or other named person) with responsibility in their role for advising and supporting people with dementia and carers with a range of issues (such as getting to and from hospital, residential and nursing care, help at home, or any difficulties affecting the ability of the carer to continue with care).

• 31% (65/210) of hospitals had a named person with this responsibility.

At ward level, nearly all wards surveyed said that they had access to social services 5 days a week (see 'Access to specialist services at ward level' subsection on page 62). Hospitals are likely to have answered about social workers permanently based within the hospital.

## Interpreting services, advocacy and faith specific support

# Can people with dementia in hospital get help from interpreting services, advocacy and support for faith/spiritual needs?

Interpreting services should be available whenever 'language or acquired language impairment is a barrier to accessing or understanding services, treatment and care'  $^{60}$ . The person with dementia and their carers should be able to access this service whenever needed, and health and social care professionals should be able to provide information on how this can be accessed. Data collected from casenotes about the first language spoken by patients showed that English was not the first language of 3% (195/7934) of patients. This may be an underestimate as in another 28% (2182/7934) of casenotes the first language had not been documented. The audit asked whether they had access to an interpreting service:

• 61% (127/210) of hospitals reported that they had access to an interpreting service which could meet the needs of people with dementia (i.e. the service employed interpreters with experience of working with people with dementia).

Health and social care professionals should be able to provide information to patients with dementia and their carers about advocacy, and its use should be encouraged<sup>60,95</sup>.

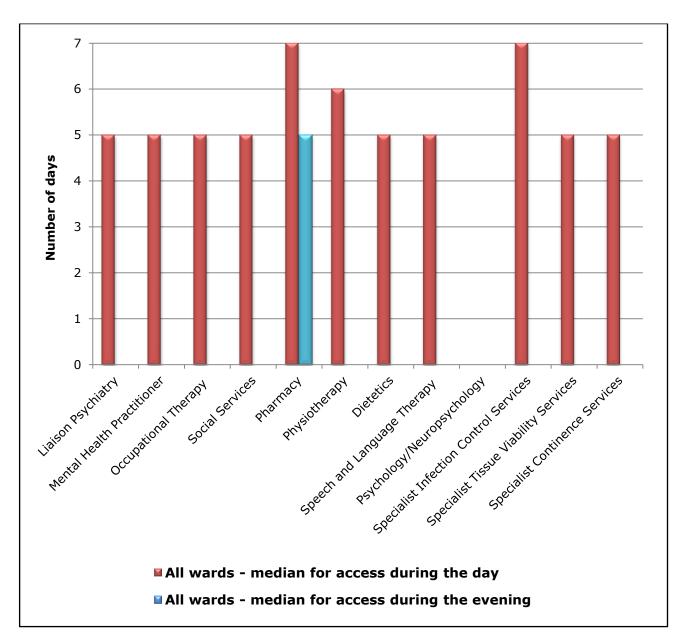
• 83% (174/210) of hospitals had access to advocacy services with experience and training in working with people with dementia.

Knowledge and understanding of individual religious beliefs and spiritual needs can help to identify and allay distress in people with dementia<sup>60</sup>. The audit asked wards about their ability to provide access to relevant faith-specific support from someone with experience of supporting vulnerable adults<sup>81</sup>.

• 79% (115/145) of wards reported that this support was in place.

As part of the enhanced (ward level) audit, participating wards were asked about the range of professionals or services regularly attending the ward to provide care and treatment to patients. Access to these services is necessary to cater for the complex needs of older people admitted to hospital, especially frailer older people and people with dementia. Each ward supplied information about the number of days or evenings they had access to the following services:

Figure 2: Access to services at ward level: median day and evening access reported by wards (N = 145)



The majority of wards reported access to most of the specified services 5 days a week. This is nearly always Monday to Friday. Evening access is the exception for all services except pharmacy.

In addition, staff on the wards were asked in the staff questionnaire about ease of access to four key services - liaison psychiatry, social services and occupational therapy or physiotherapy. Staff did not always agree that it was easy to gain access.

It should also be noted that for some of the services above, there were wards that reported no access. The proportion of wards reporting less than 5 days access or no access at all to each service was generally very low, with the important exception of specialist continence services.

Table 10: Breakdown of access to services by weekday, evening and weekend (N = 145)

Service input at ward level	Available less than 5 days %	Available Monday to Friday %	Available evenings %	Available weekends** %	Not available %
Mental health input *	2	17	66	38	9
Occupational therapy	2	81	2	17	0
Physiotherapy	0	48	17	51	0.7
Social services	2	77	14	21	1
Pharmacy	0	8	51	91	1
Dietetics	1	95	1	4	0
Speech and language therapy	1	94	1	3	3
Specialist infection control	1	47	42	52	0
Specialist tissue viability	4	88	2	4	5
Specialist continence services	1	51	0	0.7	47

<sup>\*</sup> Mental health input includes liaison psychiatry or mental health practitioner or psychology

#### Liaison psychiatry and other mental health input

84% (122/145) of wards said that they had access to liaison psychiatry at least 5 days a week during the day. Access during the evening and weekends is limited. 32% (46/145) of wards said they had access to liaison psychiatry in the evening at least 5 evenings a week, and 34% (49/145) had access at weekends during the day, which reflects the results reported at hospital level via the organisational checklist (see 'Mental health and liaison psychiatry' chapter on page 75).

However, only 39% (851/2211) of staff surveyed agreed it is easy to gain access and input from liaison psychiatry.

A few wards (15%, 21/145) had no access to liaison psychiatry, and of these, 62% (13/21) also had no input from a mental health practitioner or psychology services, meaning 9% (13/145) of wards with no mental health input of any kind.

<sup>\*\*</sup> Weekends = Saturday, Sunday or both

#### Social services

Although the majority of hospitals reported via the organisational checklist that they did not have a named social worker or liaison worker in post, nearly all wards audited (97%, 141/145) had access to social services at least 5 days a week during the day. Few wards reported any access during the evening (14%, 20/145) or at weekends during the day (21%, 30/145).

64% (1415/2211) of staff surveyed agreed it was easy to gain access and input from social services.

#### Occupational therapy

Nearly all wards reported access to occupational therapy (98%, 142/145) at least 5 days a week during the day. Few wards reported any access during the evening (2%, 3/145), or at weekends during the day (17%, 24/145).

#### **Physiotherapy**

Nearly all wards reported access to physiotherapy (99%, 144/145) at least 5 days a week during the day. Few wards reported any access during the evening (17%, 25/145), and about half of the wards reported access at weekends during the day (51%, 74/145).

Most staff surveyed (88%, 1946/2211) agreed it was easy to gain access and input from occupational therapy and physiotherapy.

#### **Pharmacy**

Nearly all wards reported access to pharmacy (99%, 144/145) at least 5 days a week during the day. About half of the wards reported access during the evening (51%, 74/145), and the majority of wards reported access at weekends during the day (91%, 132/145).

#### **Tissue viability services**

The majority of wards reported access to tissue viability services (91%, 132/145) at least 5 days a week during the day. Few wards reported any access during the evening (2%, 3/145), or at weekends during the day (3%, 5/145).

#### **Specialist infection control services**

Nearly all wards reported access to specialist infection control services (99%, 144/145) at least 5 days a week during the day. A minority of wards reported access during the evening (42%, 61/145), and a majority of wards reported access at weekends during the day (59%, 86/145).

Although the median daytime access to specialist continence services is 5 days a week, the percentage of wards without this service was alarmingly high with 47% (68/145) of wards saying they had no access. This could be because continence services are often community based. While such services may be available to see patients in hospital, they may lack the capacity to respond at short notice<sup>31</sup>.

Overall, although the picture of daytime provision is good in most wards surveyed, lack of weekend provision has implications for continuity of care and could delay both urgent referrals and pre-discharge assessments.

#### **Conclusion**

Delivery of high quality care for people with dementia requires whole organisation commitment, and this was not shown by the audit findings. Evidence showed a lack of leadership both at Trust/Health Board level and at hospital level, in terms of identifying champions and leads, and identifying required resources. Trust Boards/Health Boards require better intelligence and information relating to the admission, care, treatment and discharge of people with dementia to make the necessary improvements to processes and overall governance.

#### Recommendations

- 1. The Trust Board/Board of Governors/Board of the Health Board should ensure that review of key policies and procedures to include the needs and perspective of people with dementia is undertaken, requiring the following as evidence:
  - clinical information on admission rates, falls, treatment and discharges, in which people with dementia can be identified;
  - the appointment of a senior clinician lead for dementia with designated time in their job role to develop, implement and review the dementia pathway;
  - information from a local sample of casenotes of people with dementia tracked through admission, demonstrating adherence to the pathway;
  - measurement of nutritional status (weight and BMI) at admission and discharge for people with dementia;
  - evidence of measures of frequency of assessment of pressure sore risk and pain for people with dementia;
  - measures of cognitive functioning and delirium at admission for people with dementia;

- evidence from audit of in-hospital prescription of antipsychotics that prescription is in line with guidance.
- 2. Trusts should consider including this information in their Quality Accounts. Health Boards should consider including this information in their Quality and Safety Committee Reports.
- 3. The Chief Executive Officer should ensure that the Trust/Health Board identifies a senior clinician in each hospital to take charge of developing, implementing and monitoring the care pathway for dementia.
- 4. The Chief Executive Officer should ensure that it is within the remit of the senior clinician to identify Dementia Champions in each department in the hospital and at ward level.
- 5. The Senior Clinical Lead for Dementia should ensure that the hospital has a care pathway in place for dementia that is adaptable for use within or fitted to existing acute care pathways, with the aim of making sure that the acute care and treatment provided by the hospital takes account of the needs of people with dementia at each stage of admission.

## **Updates from hospital action plans**

Area for action	Action identified	Completed or due for implementation by end of 2011
G	36 hospitals identified a total of <b>41 actions</b> on the care pathway. This included:	
Care pathway	<ul> <li>Developing a dementia care pathway (32)</li> <li>Review of existing care pathways to ensure they meet the needs of people with dementia (9)</li> </ul>	28 actions
Care plan	26 hospitals identified a total of <b>39 actions</b> on improving the care plan so it is tailored to meet the needs of people with dementia.	18 actions
	23 hospitals identified a total of <b>57 actions</b> on involving the Executive Board in the following areas:	
Involvement of the Executive Board	<ul> <li>Reviewing information on readmissions of people with dementia (15)</li> <li>Reviewing the number of in-hospitals falls which identify people with dementia (10)</li> <li>Reviewing delayed transfers of people with dementia (9)</li> <li>Receiving feedback on complaints analysed by age (8)</li> <li>Receiving feedback from PALS (8)</li> <li>Receiving feedback from clinical leaders (2)</li> <li>Other (5)</li> </ul>	47 actions
Policies and protocols*	23 hospitals identified a total of <b>29 actions</b> on implementing or reviewing policies and protocols. The main areas identified were regarding end of life, delirium and nutrition.	25 actions
Intermediate care	8 hospitals identified <b>10 actions</b> on improving links to intermediate care services and GPs/primary care.	7 actions
Local audit	27 hospitals identified <b>41 actions</b> around carrying out local audits. The majority of these were audits of documentation and carrying out observations of care.	32 actions

<sup>\*</sup>For updates on the discharge policy see 'Discharge planning and discharge' chapter on page 145, and for updates on challenging behaviour policy see 'Mental health and liaison psychiatry' chapter on page 75.

## 2. Assessment

## **Summary**

- Information collected at hospital level around multidisciplinary assessment shows that:
  - 84% of hospital assessment procedures included assessment of functioning using a standardised instrument. However, only 26% of casenotes showed that an assessment of functioning had been carried out.
  - 96% of hospital assessment procedures included assessment of nutritional status. However, only 70% of casenotes showed that an assessment of nutritional status had been carried out.
  - 75% of hospital assessment procedures included assessment of mental state. However, only 43% of casenotes showed that a standardised mental status test had been carried out.
  - 96% of hospital assessment procedures included social assessment and 91% of procedures included environmental assessment. However, 72% of casenotes showed a formal assessment of care provided, and 65% of casenotes showed a home safety assessment had been carried out.
- 87% of casenotes showed that a formal pressure sore risk assessment had been carried out and score recorded.
- 81% of casenotes showed that the patient had been asked about any continence needs as part of the assessment.
- 24% of casenotes showed that the patient had not been asked about the presence of any pain as part of the assessment.

## Physical assessment

## How comprehensive is the physical health assessment provided to people with dementia?

All older people admitted for emergency care to hospital require a comprehensive assessment that includes maximising their rehabilitation potential so that the most positive outcomes from the admission are achieved. Such positive outcomes include shorter length of stay, reduced mortality and a greater likelihood of continuing to live independently in the community<sup>6,37</sup>. Routine comprehensive assessment is particularly important for people with dementia who will often have difficulty describing their problems accurately. Pre-admission assessments for elective treatments (mainly surgery) should also be comprehensive.

Guidance for standards of care in this audit were taken from the British Geriatrics Society's Comprehensive Assessment for the Older Frail patient in Hospital<sup>13</sup>. This includes several recommended domains of assessment: medical, functional, psychological, social and environmental. The assessments are to be carried out with a standardised reliable approach, with an expectation to assess capacity and respond appropriately where this is lacking, and with the older person being central to the process.

The results of this audit show that although the general medical assessment of people with dementia seems adequate, the assessment of function did not routinely involve a standardised assessment:

84% (176/210) of hospitals reported that multidisciplinary assessment includes assessment of functioning using a standardised instrument. However, only 26% (2051/7932) of casenotes showed that this was included in the assessment.

Moreover, in line with other national reports highlighting concerns over food intake of people with dementia in general hospitals<sup>40 \*</sup>, nutritional status (including weight) was not routinely assessed or monitored. 96% (202/210) of hospitals reported that multidisciplinary assessment includes nutritional status, however, the casenote audit results show that 70% (5536/7934) of casenotes included assessment of nutritional status. Of these, 63% (3337/5338) stated that the assessment of nutritional status included recording of weight.

People with dementia have increased risk of pressure sores, and with poor nutritional status, it is important that pressure sore risk assessment is carried out. This did not occur in over 10% of casenotes audited:

http://www.cgc.org.uk/newsandevents/newsstories.cfm?widCall1=customWidgets.content\_view\_1&cit\_id=37384

- 87% (6863/7934) of casenotes showed that a formal pressure sore risk assessment had been carried out and score recorded.
- 81% (6080/7467) of casenotes showed that the patient had been asked about any continence needs as part of the assessment. However, it should be noted that the audit of wards showed that 47% (68/145) of wards had no access to specialist continence services. This implies a significant variation between hospital wards in their ability to respond to any identified continence needs (see 'Governance' chapter, subsection 'Access to specialist services at ward level' on page 62).

People with more severe dementia often cannot describe pain though may display behavioural consequences of untreated pain. Pain should be recognised and treated appropriately for its underlying cause. Pain should therefore be routinely assessed but almost a quarter of casenotes failed to mention whether this had been done, in relevant cases:

24% (1798/7534) of casenotes showed that the patient had not been asked about presence of any pain as part of the assessment.

Despite the fact the organisational checklist reports multidisciplinary assessment is carried out routinely, there is a major gap between policy and practice. This indicates a lack of adequate governance.

#### Mental assessment

## How comprehensive is the mental assessment provided to people with dementia?

Comprehensive assessment of older people in the acute hospital should include a sufficiently thorough assessment of mental state to detect depression, delirium and dementia. This will therefore include an assessment of appearance and behaviour, emotional tone, psychotic phenomena, cognitive ability and mental capacity.

Without a structured assessment of cognitive functioning, it is very likely that the rates of undiagnosed dementia will be high<sup>79</sup>. Without recognition and assessment of the mental state associated with the dementia, no forward planning or appropriate management can be instigated.

There is accumulating evidence of the costs associated with increased lengths of stay of people with dementia, the often unnecessary nature of this bed occupancy<sup>27,54</sup>, and the morbidity and mortality associated with poor detection of dementia (such as hospital acquired infections or delirium). Despite this, from the organisational audit, it can be seen that hospitals do not have confidence that standard assessments are being carried out routinely, and the casenote audit supports this. Hospitals have not yet taken seriously the need to routinely assess mental state as part of a comprehensive assessment of older people:

- 74% (155/210) of hospitals reported that multidisciplinary assessment includes assessment of mental state.
- 28% (58/210) of hospitals reported that an assessment of mental state is carried out on all patients over the age of 65 admitted to hospital.
- 25% (52/210) of hospitals said that their multidisciplinary assessment includes mental state <u>and</u> that this is carried out for all patients over 65.

Given that the focus of this audit was people with a known diagnosis of dementia, one might have expected to see relatively high levels of mental state assessment. However, in this audit, the expectation of assessment of mental state of older people in general and those with dementia in particular, is poor.

• Only 43% (3422/7934) of casenotes showed that a standardised mental status test had been carried out.

Delirium is associated with a range of medical conditions and is an independent predictor of poor outcomes including increased length of stay and mortality. Delirium is likely to be misdiagnosed as dementia, missing opportunities for the urgent treatment that is required if its poor outcome is to be avoided<sup>59</sup>. However, in this audit, routine screening does not cover delirium which is therefore often likely to be missed. It is likely that prevention strategies are not being used. Hospitals have not yet grasped the delirium agenda:

- 33% (70/210) of hospitals have policies or guidelines in place to ensure that
  patients with dementia or cognitive impairment are screened for delirium, using
  a standardised method.
- Only 9% (676/7934) of casenotes showed that a screen for delirium had been carried out.

Equally poor is the very low use of standardised assessments for the detection of depression, despite its association with many long term conditions, its independent association with poor prognosis and its treatability<sup>57</sup>.

• 2% (190/7934) of casenotes stated that a standard mood (depression) test had been carried out.

There are several brief, psychometrically robust and user-friendly screening tools freely available for dementia, delirium and depression<sup>59,61</sup>.

#### **Social care needs**

#### Is an adequate assessment of social care needs being carried out?

National guidance suggests that effective discharge planning should start on or soon after admission, to facilitate discharge to the most appropriate environment and to avoid unnecessary delays<sup>23</sup>. People with dementia often have unrecognised and unmet needs associated with risk, institutionalisation and re-hospitalisation. Delays in hospital are thus particularly damaging so forward planning is essential.

The responses to the organisational checklist provided by hospitals suggest that hospitals believe that most people with dementia have a full social, financial and environmental safety assessment in hospital:

- 96% (202/210) of hospitals reported that assessment includes social assessment i.e. care input, voluntary agency support, family support, financial support.
- 91% (192/210) of hospitals reported that assessment includes environmental assessment.

However, this is not borne out by casenotes. As people with dementia are at increased likelihood of involving others in their care and wellbeing it is important that there is assessment of formal care provision and home safety for all people with dementia.

- 72% (4171/5792) of casenotes showed a formal assessment of care provided.
- 65% (2821/4324) of casenotes had carried out a home safety assessment.

Healthcare staff often do not ask about financial affairs, 36% (1637/4552) of casenotes contained this assessment, and consider this only of relevance when a review of formal care is required. However, there are a number of benefits available to people with dementia, including attendance allowance, carer's allowance and council tax rebate, which can make a significant difference to the quality of life for people with dementia and their carers. Even if not completed while an in-patient, people requiring more complex financial assessments could be referred as required.

While the social situation of people with dementia will vary widely, and likewise their need for informal and formal care, consideration should always be given to appropriate assessment to ensure a safe and effective discharge process.

#### **Conclusion**

The majority of hospitals reported that they had assessment procedures in place covering key physical, mental and social care assessments. However, by contrast the casenote audit showed that key physical and mental assessments were not routinely carried out. Adherence to multidisciplinary assessment procedures should be clarified and reinforced.

#### Recommendations

- 1. The Royal College of Physicians, the Royal College of Psychiatrists and the British Geriatrics Society should recommend brief screening tools for cognitive function and delirium for the assessment of people with dementia and older people in the general hospital.
- 2. The Royal College of Physicians with the British Geriatrics Society should recommend brief tools for the standardised assessment of functional ability and for the assessment of pain in people with dementia. The Royal College of Physicians and the British Geriatrics Society should liaise with other Royal Colleges about including these assessments in the management of surgical patients and others.
- The Medical Director, Director of Nursing and Head of Therapy Directorate should 3. ensure that all staff responsible for the assessment of older people have had training in the assessment of mental state using standardised measures.

# **Updates from hospital action plans**

Area for action	Action identified	Completed or due for implementation by end of 2011
Assessment	47 hospitals identified a total of <b>74 actions</b> on reviewing and improving the comprehensive assessment for people with dementia. This included:  - Mental state assessment (45)  - Social and environmental assessment (4)  - Risk assessment (4)  - Assessment of pain (2)	44 actions

## 3. Mental health and liaison psychiatry

## Summary

- 90% of hospitals in this audit had access to a liaison psychiatry service, and 91% of these had liaison psychiatry delivered by a team and not a single practitioner.
- Where hospitals had access to a liaison psychiatry service, almost all of the services could provide assessment and treatment of older people and 80% of services were led by a consultant psychiatrist specialising in the care and treatment of older people.
- Around a third of hospitals who have access to a liaison psychiatry service are able to provide an out-of-hours liaison service during evenings or weekends.
- Casenote audit data showed that patients with dementia referred to liaison psychiatry were often not seen in a timely manner, with nearly a third of urgent referrals waiting over 4 days to be seen.
- Less than 10% of hospital discharge summaries included important information about mental health problems present at discharge.
- People with dementia living in care homes appear less likely to receive predischarge assessments and more likely to have an existing prescription for antipsychotics in place when admitted to hospital than people with dementia who live elsewhere.
- 34% of hospitals reported having any adequate protocols in place for the treatment and management of patients with behavioural and psychological symptoms of dementia leading to challenging behaviour.
- 28% of people with dementia received antipsychotic medication in the hospital. 12% of people with dementia were newly prescribed this medication while in the hospital. Reasons for prescription were not recorded in 18% of these cases.

## **Liaison psychiatry**

It has been widely recommended that mental health liaison services meeting the needs of people with dementia and older people with mental health problems should be available in all hospitals<sup>1,2,6,24,27,55,58,60,63,79,80,92</sup>. The NICE Dementia Quality Standard<sup>58</sup> specifies that this should be provided by a service that specialises in the diagnosis of dementia and older people's mental health (Statement 8). The National Dementia Strategy<sup>27</sup> and the National Service Framework for Older People<sup>94</sup> in Wales, state that this should be a commissioned older people's liaison mental health service. Liaison psychiatry services for older people have been shown to improve outcomes<sup>35</sup> and reduce length of stay<sup>88</sup>, healthcare utilisation and cost<sup>49</sup>. An important role of these services is training general hospital staff<sup>79</sup>. However, major gaps in the provision of these services have been highlighted by the Public Accounts Committee<sup>44</sup>.

## Are people with dementia able to access a specialist older people's mental health liaison service in hospital?

Most hospitals in this audit report access to a liaison service of some sort:

- 90% (189/210) of hospitals provide access to a liaison psychiatry service which can provide assessment and treatment to adults throughout the hospital. Of these:
  - 99% (185/187) provide access that includes assessment and treatment of older people.
  - 83% (154/185)provide that includes emergency/urgent access assessment.
  - 91% (172/189) have a specialist mental health team providing liaison psychiatry, rather than an individual practitioner.

The accepted model of care delivery in psychiatry is the multidisciplinary team with practitioners providing the essential core elements of medical, nursing, psychological and social expertise. This is just as relevant to general hospital practice to deliver maximum effectiveness and continuity<sup>2,79</sup>. 81% (172/210) of all participating hospitals reported that liaison psychiatry is provided by a specialist team. However, there are some important caveats, in terms of leadership, specialism and dedicated time.

#### **Consultant leadership and specialism**

About half of the hospitals (45%, 94/210) have a liaison service led by a named consultant with time dedicated within his/her job role, and with a specialism in the care and treatment of older people.

The model older people's liaison team requires a consultant old age psychiatrist with dedicated time for work in the general hospital<sup>2,24,79,80</sup>. When consultant psychiatrists are expected to cover the general hospital, without sessional commitment identified in job plans, they consider it low priority, 'add-on' work that takes second place to their primary commitments<sup>79</sup>. The audit found:

- 75% (142/189) of hospitals with a liaison service have a named psychiatrist for consultation/liaison. Of these hospitals:
  - 82% (117/142) said that the consultant psychiatrist has dedicated time in their job plan to carry out consultation liaison.
  - 80% (113/142) said that the consultant psychiatrist specialises in the care and treatment of older people.
- 56% (117/210) of all hospitals audited have a named psychiatrist for consultation liaison with dedicated time in his/her job plan to carry out consultation liaison.
- 45% (94/210) of all hospitals audited have a named psychiatrist with dedicated time who is also a specialist in care and treatment of older people.

The work of liaison teams for older people inevitably involves complex medical problems and the team will need the medical knowledge that only a psychiatrist with training in old age psychiatry can provide. Their role will include advising on medication for physically ill people taking multiple medications and fulfilment of statutory obligations required by mental health legislation. This role cannot be delegated to unsupervised doctors in training and requires dedicated (allocated) time so that teams are not left uncertain of psychiatric support and input.

However, the picture does suggest a significant improvement from the UK position in 2003 when only 27% of older people's mental health services reported providing a consultation liaison service<sup>43</sup>.

## Referrals to liaison psychiatry

## How long does it take to get an assessment?

Research recently published showing a cross national data comparison over time containing data on referrals, shows rising demand for liaison psychiatry services<sup>10</sup>. In this audit 17% (1345/7928) of casenotes in the sample contained a referral for assessment.

Response time should be an important performance indicator for liaison services. The majority of services are available only during office hours and this will affect ability to provide an emergency (within 1 hour) or urgent (within 24 hours) response. As

shown, 90% (189/210) of hospitals provided access to a liaison service. (153/210) of all hospitals said that liaison services could both provide assessment and treatment for older people and provide emergency and urgent assessment. However a minority of hospitals had availability out-of-hours:

- 100% (189/189) of hospitals with a liaison psychiatry service said that the service is available during the day. Of these hospitals:
  - 35% (66/189) reported liaison psychiatry is available during the evening.
  - 34% (65/189) reported liaison psychiatry is available at weekends.

Of the services able to assess and treat older people and provide emergency or urgent assessment, 56% (86/153) reported liaison psychiatry is available either during the evening or at weekends.

This picture of provision is echoed in the 145 wards surveyed on access to services. 15% (21/145) had no access to liaison psychiatry, and of these, 62% (13/21) also had no input from a mental health practitioner or psychology services, meaning 9% (13/145) of wards have no mental health input of any kind.

The audit of casenotes collected information on liaison services response time to referral.

Table 11: Liaison psychiatry response time to referrals (urgency indicated) recorded in casenotes (N = 633)

	Time between referral and appointment								
			Within 60 minutes	Within 24 hours	Within 24-48 hours	Within 48-72 hours	Within 72–96 hours	Longer than 96 hours	Total
Indicated urgency of ferral (when stated)	Emergency	N	1	14	3	0	2	2	22
		%	5	64	14	0	9	9	100
	Urgent	N	1	50	39	19	10	48	167
		%	1	30	23	11	6	29	100
Indic urgen referral stat	Routine	N	3	70	117	58	42	154	444
		%	1	16	26	13	10	35	100
Total N %		5	134	159	77	54	204	633	
		%	1	21	25	12	9	32	100

The breakdown of response times shown in the table above is drawn from the standards defined by the Psychiatric Liaison Accreditation Network<sup>80</sup>, which is supported by the Royal College of Nursing, the Royal College of Physicians, the Royal College of Psychiatrists and the College of Emergency Medicine. These standards specify response times for emergency, urgent and routine referral.

32% (7/22) of referrals considered an emergency (response required within 1 hour) waited more than 24 hours and 29% (48/167) deemed urgent (response required within 24 hours) waited longer than 4 days.

While most referrals are considered routine (including those where urgency is not stated), delays in response may add unnecessary days to the hospital length of stay. The cost of people with dementia waiting in hospital for assessment once medically fit for discharge has been highlighted by the National Audit Office<sup>24</sup>.

One consequence of delay is that people may not be seen at all - 15% (207/1345) of all those referred were not seen before discharge. If someone is not seen by a liaison service, they will rarely be referred to mental health services after discharge (18%, (22/126), of those where referral had been considered).

## Recognition of mental health needs at discharge

## Is mental health status reviewed and recorded before discharge?

The purpose of the overall summary completed at discharge is to provide a record of the hospital admission, containing the information needed by GPs and other primary care and community based services and the family to continue appropriate treatment and care on return home. Discharge information establishes the recovery or decline that has occurred during a hospital admission and outstanding concerns that may still need to be addressed. For example, recording of delirium and whether symptoms continue has important implications for prognosis and continuing need for psychological support<sup>59</sup>. Completion of a summary at discharge should include a review of mental health needs to ensure the efficacy of discharge arrangements, including the need to continue any antipsychotic drugs prescribed during admission. A full end of admission assessment might be expected to reduce risk of re-admission.

The casenotes reviewed in this audit were those of patients with a known diagnosis or current history of dementia, and the audit asked about information summarised at discharge about both the cause and the level of cognitive impairment.

Few casenotes (17%, 1020/6009) recorded the level of cognitive impairment assessed by standardised testing at the point of discharge, although the majority of casenotes recorded the cause, which is likely to have been known on admission.

The audit of casenotes asked specifically about information collated at discharge relevant to mental health disorders commonly arising amongst older people admitted to hospital and known to impact on outcomes and ongoing treatment<sup>79</sup>. These were delirium, depression, and behavioural and psychological symptoms of dementia (for example, agitation, wandering or challenging behaviour):

Of casenotes containing evidence of symptoms relating to a mental health disorder:

- 27% (693/2552) summarised any symptoms of delirium (where present) for discharge.
- 28% (718/2554) summarised any symptoms of persistent behavioural and psychiatric symptoms of dementia (where present) for discharge.
- 11% (175/1624) summarised any symptoms of depression (where present) for discharge.

The need to include this important information in the summary could perhaps be better signposted to the staff and teams involved. Only 9% (19/210) of hospital discharge summaries contained any dedicated section or prompt to record complicating mental health problems.

## Discharge destination and cognitive impairment assessment

#### Are people living in care homes assessed differently?

22% of medical admissions over the age 70 with dementia have been shown to be admitted from care homes<sup>84</sup>. Indeed, over 90% of people admitted from a care home have dementia (though not necessarily diagnosed)<sup>84</sup>. Older people with co-morbid mental disorder, including dementia, are also more likely to be discharged from hospital to care homes even when admitted from independent living<sup>6,27,79</sup>.

Data from the casenote audit shows that people admitted from and returning to care homes are less likely than others to have their level of cognitive impairment assessed by a simple standardised instrument at discharge. Only 8% (194/2390) of people with dementia, who came from and returned to a care home, had this assessment, compared with 22% (438/1987) of people who were admitted from and returned to their own home.

Hospitals are under such pressure to discharge quickly, that it is possible that people already residing in care homes receive less attention because they will be discharged back to a place of care. There is concern that for these reasons people with dementia are often discharged to care homes, when not yet ready for this level of care<sup>54</sup>.

It appears that general hospitals may currently consider it less important to conduct assessments of cognitive impairments for people living in care homes. This may reflect the fact that people in such settings may be more likely to have a known diagnosis of dementia, or that assessing the extent of impairment is considered irrelevant to discharge planning in these cases. The situation is marginally better when all casenotes of people discharged to care homes are considered, including those who were previously living independently. 14% (531/3774) of those discharged to residential or nursing care had this assessment, compared to 22% (443/2003) of people discharged to their own home.

Recognition of dementia and the level of cognitive impairment is important, regardless of place of residence, for informing discharge and treatment decisions, for example, in the prevention of delirium<sup>59</sup> and for post-operative rehabilitation after hip fracture and return to independent living<sup>46</sup>. The degree of cognitive impairment has implications in assessing a person's capacity to make health and welfare decisions<sup>42</sup> (completed by health and social care professionals).

#### Governance and mental health

## Do hospitals have clear protocols giving guidance on the management of challenging behaviour?

Most people with dementia do not display challenging behaviour in hospital. However, all people with dementia are at increased risk of developing such symptoms when in hospital, which can be due to illness or injury, the environment, or the dementia condition itself.

In mental health settings, wards caring for people with dementia report a higher number of violent incidents<sup>39</sup>. People with dementia and cognitive impairment admitted to a general hospital are between 6 and 11 times more likely to develop delirium, which can be complicated by challenging behaviour<sup>59</sup>. All hospitals should have clear guidelines in place for assessment and management.

The audit asked hospitals about any protocol or policy in place governing the use of interventions for patients displaying behavioural and psychological symptoms of dementia (BPSD). 34% (71/210) of hospitals had such a protocol. However, not all of these were able to report that the protocol was adequate for its purpose, specifying that restraints and sedations should be used only as a final option and in the best interests of the person with dementia, and the necessary precautions and risk assessments, that should be carried out before any such intervention:

• 24% of hospitals (50/210) reported having a protocol in place containing adequate quidance.

The response to challenging behaviour has major implications for patient safety, clinical outcome and organisational risk. Protocols should reflect NICE guidance and specify that both health and social care staff should be trained to anticipate and prevent challenging behaviour, manage violence, aggression and extreme agitation, and that staff administering medication should be trained in the correct use of drugs and understand the risks involved.

Failure to provide guidance and training for hospital staff places them at risk, as well as the people they care for. Clear guidance on the management of challenging behaviour for people with dementia<sup>60</sup> and delirium<sup>59</sup> is available. To date, the majority of hospitals are failing to implement these guidelines.

## **Antipsychotics prescribed**

#### How many people received antipsychotic drugs and why?

The need to reduce antipsychotic drug prescribing to people with dementia is now a national requirement<sup>11</sup>. Some people do benefit from these drugs but many experience potentially serious adverse effects including increased mortality, and these can manifest with relatively short term use. Antipsychotic drugs produce a range of complications that increase the rate of admission (re-admission) to hospital<sup>11</sup>. Appropriate use of these medications is clearly described for people with dementia<sup>60</sup> and delirium<sup>59</sup>.

The audit collected data from casenotes about any antipsychotic drugs given during admission. Casenotes containing evidence of prescription of antipsychotics were subdivided into those where the prescription for antipsychotics was made before the admission to hospital, those where any new ongoing prescription had been made, and those where a PRN (as required) prescription had been put in place and administered. These categories prove to overlap to a certain extent – that is, a minority of patients in the sample received antipsychotics both via an existing prescription and prescription in hospital.

The figure below shows the proportion of all casenotes with any antipsychotic prescription, and the proportion of those where there was any in-hospital prescription, both in-hospital only and in addition to prescription predating admission.

■ Existing prescription of antipsychotics only 16% ■ New prescription/PRN or both administered 7% during admission 5% ■ Existing prescription on admission and new prescription/PRN or both administered during admission 72% ■ No antipsychotics

Figure 3: Prescription of antipsychotics recorded in casenotes (N = 7932)

Other studies also show that, if not initiated in hospital, a significant number of people with dementia will be taking these medications on admission. For example, a recent study in England and Wales found 10% of people with dementia in the community and 30% living in care homes were receiving antipsychotic drugs<sup>85</sup>. Audit data reflects this. The casenote sample showed that 30% (1006/3476) of people admitted from care homes and 14% (635/4456) admitted from other settings were taking these drugs on admission, representing 21% (1641/7932) of the total sample.

There has been concern that a significant proportion of prescriptions are started in hospital<sup>11</sup>. There is a modicum of reassurance from the audit that only 6% (395/6291) of people with dementia who were not taking these drugs on admission received a new, regular prescription (excluding PRN).

However, the data shows that of all patients, 13% (1001/7932) were prescribed antipsychotics in hospital, including those patients already taking them on admission.

In comparison, Counting the Cost<sup>6</sup> found that 12% of carers said that antipsychotics had been prescribed, and 77% of nurses said antipsychotics are used "always or sometimes" in the hospital environment.

The level of prescription will require further scrutiny. We cannot determine whether antipsychotics being taken on admission may have been initiated during any previous admission, and the audit data suggests that one in five people with dementia entering hospital are taking these drugs. We also have no information on the proportion of new drugs continued after discharge (PRN is typically not continued) or if any existing prescriptions are reduced or stopped during admission.

Assuming existing and new prescriptions only continue and PRN (as required prescription) is not continued, then 26% (2036/7932) of people with dementia are leaving hospital on antipsychotic drugs. The lack of recorded information in discharge summaries on cognitive function, behavioural and psychological symptoms and delirium at discharge leaves uncertainty about the proportion of prescriptions that remain indicated at the point of discharge.

Antipsychotic drugs produce a range of complications that increase the rate of admission to hospital<sup>24</sup>. If people with dementia are taking antipsychotic drugs on admission this is an opportunity to review indications for continued use. Review of cognitive impairment, behavioural symptoms and symptoms of delirium at the time of discharge (audit showing this to be infrequent) may result in fewer people being discharged on antipsychotic drugs.

The data shows that PRN prescriptions are frequently administered (69%, 709/1039). We might question whether antipsychotics should be prescribed on this basis (that is, in case indications should arise, and without further assessment).

The audit of casenotes asked for the main or primary recorded reason/indication for antipsychotic prescription, providing a drop-down list of commonly recorded indications, and a comment box for any other recorded indication:

Table 12: Main or primary reason recorded for prescription of antipsychotics (N = 1002)

Main or primary reason recorded	%
Co-morbid psychotic disorder *	5
Immediate risk of harm to self/others *	3
Severe distress, not responsive to other intervention *	3
Need to carry out investigation	0.4
Need to carry out treatment	1
Need to carry out nursing care	0
Agitation/anxiety **	42
Aggression/threatening behaviour **	16
Disturbance through noise	2
Disturbance through wandering, obsessive behaviour, mannerisms, tics	
Not recorded	18
Other	6

<sup>\*</sup> These reasons for prescription are in line with NICE guidance<sup>60</sup>.

<sup>\*\*</sup> The audit did not gather information on whether other interventions were attempted prior to prescription, therefore it is not possible to state whether these prescriptions are in line with NICE guidance.

The overriding consideration in any case where use of antipsychotics may be indicated should be the best interests of the person with dementia. It is a matter of concern that 18% (183/1002) of casenotes recorded no indication for prescription. indicators for use given by the NICE guideline<sup>60</sup> are severe distress or immediate risk of harm. If prescription for co-morbid psychotic disorder is also allowed for, then only 10% (101/1002) seemed to comply with these criteria.

59% (586/1002) of casenotes audited gave the recorded reason as either agitation/anxiety or aggression/threatening behaviour. It may be that in a proportion of these cases, non-pharmacological approaches were tried and failed. As we have no evidence on this it is not possible to state whether these prescriptions meet NICE quidelines<sup>60</sup>.

Of other reasons given for prescription, those relating to a need to carry out treatment or investigation, or to prevent a disturbance of some kind, amount to about 8% (84/1002). Although information is limited, these reasons appear to relate more to the needs of the hospital as an organisation, rather than those of the person with dementia.

#### Conclusion

The results of the audit show more widespread provision of liaison psychiatry than was demonstrated by a 2003 survey of psychiatric services for older people in general hospitals<sup>43</sup>.

However, a lack of availability at evenings and weekends is likely to impact on the time taken by services to respond to an emergency or urgent referral. It may also affect ability to carry out assessment or to see patients who require onward referral Although only casenotes of people with a confirmed diagnosis of dementia were included in this audit, we should note the objective of the National Dementia Strategy for England to improve access to memory services for people with suspected dementia. The large number of people with undiagnosed dementia entering acute hospitals makes this an important population to identify if increased diagnostic rates are to be achieved above the current 30–50%.

A lack of mental health assessment during admission and at discharge shows that mental health needs are still often overlooked in general hospitals. This needs to be urgently addressed as a clinical governance issue. In particular, hospitals should look at anticipating challenging behaviour and ensure that it is managed with awareness and understanding, ensuring that guidelines and protocols are reviewed and updated and training for staff is in place. Where antipsychotic medication is prescribed, a reason should be clearly recorded and all medication should be reviewed regularly. Equivalent attention should be given to people with dementia living in care homes in review and assessment.

#### Recommendations

- Commissioning Boards/Health Boards should ensure that liaison psychiatry 1. services are in place to provide adequate access over 24 hours for treatment and referral of people with dementia in hospital. This should include the ability to provide an emergency or urgent response<sup>82</sup>. Response times to referral should be a key performance indicator for these services.
- 2. The National Clinical Directors for Dementia and for Older People (England) should ensure the Common Core Principles and NICE guidance on the use of antipsychotic medication are disseminated to general hospitals and that there is a process that separately audits prescribing in general hospitals. A period of treatment in hospital should be highlighted as an appropriate point for reviewing any use of antipsychotic medication. The Medical Director of NHS Wales should ensure that the review targets for psychotropic medication set out in 1000 Lives Plus are fully addressed in secondary care settings.
- 3. The Royal College of Psychiatrists, Royal College of Nursing, Royal College of Physicians with the British Geriatrics Society, should provide guidance on any circumstances in which PRN (as required) prescription of antipsychotics is appropriate.
- The Chief Executive Officer should review policies and procedures in place to 4. ensure that they clearly set out guidance for interventions for challenging behavioural and psychological symptoms of dementia in line with NICE guidance. In-hospital prescription of antipsychotics should be routinely audited for clear indicators that prescription is in line with guidance and this information should be presented to the Trust Board/Board of the Health Board.
- 5. Mental health providers should self-assess their policies and practice of liaison teams and report to commissioners on equality of access for people with dementia.

# **Updates from hospital action plans**

Area for action	Action identified	Completed or due for implementation by end of 2011
Prescription of antipsychotics	<ul> <li>17 hospitals identified a total of 24 actions around the prescription of antipsychotics for people with dementia. This included:</li> <li>Reviewing current prescription of antipsychotics for people with dementia (e.g. local audit), with the aim of reducing prescription (21)</li> <li>Providing guidance around antipsychotic</li> </ul>	15 actions
Challenging behaviour policy	prescribing (3)  18 hospitals identified a total of <b>18 actions</b> on implementing or reviewing protocols for governing the use of interventions for patients with behavioural and psychological symptoms of dementia.	12 actions
Liaison teams	<ul> <li>16 hospitals identified a total of 24 actions regarding the liaison psychiatry team. These included:</li> <li>The structure of the team and when it can be accessed (12)</li> <li>The team specialising in the treatment of older people in the hospital, including people with dementia (6)</li> <li>Members of the team having protected time to carry out consultation liaison (4)</li> <li>The liaison team being consultant led (2)</li> </ul>	19 actions

## 4. Nutrition

## **Summary**

- 96% of hospitals have a procedure for multidisciplinary assessment which includes nutritional assessment. However, only 70% of the casenotes in the sample included this assessment, and only 63% of these casenotes had a record of the patient's weight.
- 92% of hospitals have established protected mealtimes, and 97% of wards audited said that this was in place. However, only 74% of wards have a system to ensure staffing levels are sufficient at mealtimes to aid people with dementia to eat and choose food if necessary.
- 93% of wards could provide food between mealtimes, and 66% of staff agreed the ward can provide meals and snacks to patients at any time.
- Nearly all hospitals had access to specialist assessment and advice on helping patients with dementia in their swallowing and eating.

# Are assessments of nutritional status carried out for people with dementia?

The importance of assessing the patient's nutritional status, and the devastating effect particularly for frail older people if this is not done appropriately, has been highlighted in several reports<sup>3,40,66</sup>. The NICE Guideline *Nutrition Support in Adults*<sup>56</sup> recommends that all hospital in-patients should be screened on admission, i.e. weighed, measured and have their Body Mass Index (BMI) calculated. It goes on to recommend that screening should be repeated weekly and a clear process should be established for documents and subsequent actions if a patient is at risk. In the earlier stages of dementia, problems may be associated with inappropriate eating, difficulties with recognition and managing utensils. At later stages, deterioration of swallowing function and loss of interest in food may be an indicator of end-of-life but can cause distress due to choking or spluttering. As dementia can have a significant impact on a person's nutritional status, it is essential that appropriate steps are taken to ensure assessments are carried out to support nutrition and alleviate distress/harm as a result of swallowing problems. Despite recent drives to raise awareness and support staff in nutritional assessment skills, the findings, along with recent CQC Dignity and Nutrition reports\*, would indicate there is still much need for improvement.

Most hospitals (96%, 202/210) reported that their multidisciplinary assessment procedure includes nutritional status, and 89% (186/210) of hospitals reported that as part of initial assessment procedures, patients are weighed on admission. However, results from the casenote audit are less encouraging:

- 70% (5536/7934) of casenotes stated that the multidisciplinary assessment included assessment of nutritional status. Of these casenotes:
  - 63% (3337/5338) stated that the assessment of nutritional status included recording of weight.
  - 74% (4110/5535) stated that the assessment of nutritional status included identification of any help needed with eating/drinking.
- 13% of all casenotes showed that weight had been measured on admission and at discharge.

The Malnutrition Universal Screening Tool (MUST) has been recommended as an easy-to-use validated tool and has been widely adopted in hospital and other care settings<sup>12</sup>.

http://www.cqc.org.uk/newsandevents/newsstories.cfm?FaArea1=customwidgets.content\_view\_1&cit\_id=37390

# What do wards have in place to support nutritional needs for people with dementia?

The Royal College of Nursing Nutrition Now Campaign\* highlighted the role of nurses in supporting good nutritional care for all patients but also called for appropriate support with training and the need for a multidisciplinary approach. Safeguarding adults and preventing harm due to malnutrition is also a key responsibility for healthcare practitioners<sup>33</sup> and appropriate steps must be taken to report negligence or abuse due to malnourishment and to prevent this from happening.

Reports and guidelines recommend the use of systems such as protected mealtimes and red trays to support the nutrition of older frail people, including people with dementia $^{3,21}$ . These initiatives have been widely adopted in acute hospitals and the findings indicate that 92% (194/210) of hospitals have protected mealtimes established on all wards admitting frail elderly people, and 97% (140/145) of wards audited operate a protected mealtime system. Additional information was also collected at a ward level about mealtimes on the ward:

- 97% (140/145) of wards have a protected mealtime system which allows for carers to visit and assist during mealtimes.
- 79% (115/145) of wards have a red tray or other visual signal to signal the need for help.
- 68% (99/145) of wards can provide adapted utensils to encourage patients to assist themselves with their meals and eat independently.
- 74% (107/145) of wards have a system to ensure staffing levels are sufficient at mealtimes to aid people with dementia to eat and choose food if necessary.

#### Ward organisational checklist comments:

"With reduced staffing levels we are not always able to provide one to one care at mealtimes for patients who require assistance so we actively encourage relatives/carers who would like to participate"

"All staff assist with giving out meals and feeding patients. Carers are welcome to come in and help with feeding if they wish. We have a 'traffic light' system above each bed to indicate how much help the patient needs at meal times"

<sup>\*</sup> http://www.rcn.org.uk/newsevents/campaigns/nutritionnow

When staff were asked whether there was a system in place to ensure all staff are aware of patients who have difficulties at mealtimes, 83% (1826/2211) of staff reported that this system was in place. 88% (1945/2211) of staff also felt that patients are given food that they have chosen or that meets their dietary needs.

#### Staff comments:

"We often do not have enough staff available to assist all those patients who need help at mealtimes in a timely manner. Protected mealtimes are not always respected by other departments"

"We are introducing protected mealtimes to assist with meeting patients nutrition needs. However, I think that we need more training in how to encourage patients with dementia to eat and therefore, meet their nutritional needs. For example, they [patients] tell us to go away and we need guidance on how to manage this"

"We place a high priority on making sure that patients who require assistance receive help at mealtimes and the domestic staff are very co-operative in this matter, for example they make a point of informing a trained nurse before removing a plate of untouched food"

However it is important to note that fewer wards (72%, 104/145) had protected meal times <u>and</u> had systems to ensure staffing levels are sufficient. The nutritional needs of people with dementia can be particularly complex due to changes in appetite and preference, problems with swallowing/chewing and visual-spatial difficulties. In addition patients may be distressed as a result of poor comprehension and reluctance to accept help. As well as giving attention to additional staffing at mealtimes plus involvement of carers, it is important to ensure that adequate training and support is provided to allow nutritional intake to be assisted or maintained and monitored carefully. This would be further supported by an increase in the availability of nutritious meals and/or snack, finger food between meals. The audit found that:

- 93% (135/145) of wards reported the ward is able to provide food to patients between mealtimes.
- 66% (1466/2211) of staff reported the ward can provide meals and snacks to patients at any time.

#### Ward organisational checklist comments:

"We are able to order snack boxes throughout the day if required and can also order hot meals from the restaurant if a patient will not eat anything that is offered on the menu"

"There is minimal food available for patients between meals, just toast or biscuits"

#### Carer/patient comments:

"Finger food was requested and not often given"

Further attention to the importance of recording missed meals, as recommended by the National Patient Safety Agency, is also important and could be highlighted through safeguarding routes. The Royal College of Nursing and National Patient Safety Agency *Hydration Best Practice Toolkit for Hospitals and Healthcare*<sup>75</sup> also highlights the need to make sure drinking water is readily available at all times and is actively encouraged, especially for people with dementia who are often more at risk of dehydration. Staff were asked whether they were encouraged to report non-consumption of meals and 81% (1781/2211) of staff surveyed agreed this was done.

#### Evidence from the observations of care (PIE):

The PIE observational findings demonstrated that various support mechanisms need to be in place to support the nutrition and hydration needs of people with dementia.

Formal systems in place such as protected mealtimes, provision of red trays and adapted utensils worked well in many wards, but in others they were not being effectively implemented. Problems reported included the interruption of protected mealtimes for other clinical tasks or for staff handover; staff not being available to help; people with dementia sometimes missed, e.g. in drinks rounds. The observational findings confirmed this is an area of care that requires careful qualitative monitoring to ensure patients are receiving adequate one to one support.

#### Feedback from PIE observations:

"Patient trying to drink from a cup holder - not recognising that it was not a cup. Food getting cold and not attractive to patient".

"Protected mealtimes not always observed - Doctors continued to see patients"

"All staff engaged including hostess and housekeeper. Patients who were able were helped out of bed to sit in a chair for their meal"

"Lack of interaction with patients at mealtimes. Staff around nursing station at this time - writing notes, etc"

"Patients unable to complete their menu choice - sometimes are not always given the opportunity for a member of staff to sit & go through the menu & offer them a choice of food"

"Drinks left on tables in front of patients not checked or encouraged to drink"

## **Specialist input**

#### Is specialist assessment and advice available?

Difficulties with eating and swallowing are common problems in dementia, which can result in undernutrition and make it difficult for those caring for people with dementia to provide the help they need to eat. Specialist advice should be available from a speech and language therapist and dietician to support appropriate guidance on how best to manage swallowing problems and maintain adequate nutritional intake<sup>60</sup>. Having specialist input can have a significant impact in the diagnosis and management of these problems. There is evidence, for instance, that the appropriate assessment and management of dysphagia can reduce morbidity, mortality and improve the patient's quality of life<sup>83</sup>. This recommendation is supported in end of life guidance, e.g. *Compromised Swallowing*; a best practice guide for people with dementia<sup>67</sup>. The audit found that:

- 97% (204/210) of hospitals reported there is access to specialist assessment and advice on helping patients with dementia in their swallowing and eating. Of these hospitals:
  - 100% (204/204) reported specialist assessment and advice can be obtained from both speech and language therapists and from dieticians.
  - 47% (96/204) reported specialist assessment and advice can also be obtained from other professional(s).

At ward level, 97% (140/145) of wards had access to speech and language therapists at least 5 days a week (daytime) and 99% (143/145) had access to dietetics at least 5 days a week (daytime).

Whilst it is important that most hospitals had access to specialist assessment and advice on swallowing and eating, it is equally important that this advice is communicated into a clear care plan and that staff are trained and supported in carrying out 'supportive feeding'. As swallowing and eating problems are so common in dementia it would be beneficial to adopt the standard for care of stroke patients, where patients in acute care should have a swallowing assessment within 24 hours<sup>19</sup>. This might be supported by the role of other staff in using 'swallow' screening tools to recognise swallowing difficulties and ensure appropriate referral to a specialist.

A number of swallow/dysphagia screening tools are recommended to reduce the risk of pneumonia or dehydration, e.g. Hind  $et\ al^{41}$  and Massey swallow screen\* (see also Management of Patients with Stroke<sup>86</sup>).

#### **Conclusion**

The audit results suggest much could be done at hospital level and ward level to improve nutritional standards, including providing standardised assessment, and recording of weight over time; providing support to assist patients at mealtimes; making food available at other times; and ensuring full implementation of protected mealtimes (i.e. allowing carers or family to assist but not allowing interruption for clinical or care purposes).

#### **Recommendations**

- 1. The Chief Executive Officer should ensure that non-reporting of nutritional status, missed meals or other risk to nutrition is considered a safeguarding issue for people with dementia and reported in accordance with guidance.
- 2. The Director of Nursing should require ward managers to carry out an assessment of staffing levels required to support mealtimes, including assessment of the additional support needs of people with dementia, and ward managers should review this on a regular basis.
- 3. The Medical Director, Director of Nursing and Head of Therapy Directorate should ensure the provision of education and training to support the routine use of the MUST tool (or alternative recommended nutritional assessment tool) and monitoring nutritional intake must be provided to all staff, including Healthcare Assistants.

http://www.coloradostroke.org/documents/MasseyBedsideSwallowingScreen.pdf

- 4. The Director of Nursing should ensure ward managers are given responsibility and support to promote mealtimes as a social activity and provide appropriate equipment and an engaging environment, e.g. music, group tables or seating, use of familiar types of crockery and vessels.
- 5. Ward managers should ensure that all those involved in supporting people with dementia at mealtimes, including staff and volunteers, are provided with training or are skilled in recognising swallowing problems, the use of equipment and aids and encouraging nutritional/hydration intake.
- 6. Ward managers should ensure that nutritional snacks and finger foods are readily available at mealtimes and between mealtimes on wards so that people with dementia are provided with options to enable them to maintain nutritional intake.

# **Updates from hospital action plans**

Area for action	Action identified	Completed or due for implementation by end of 2011
Protected mealtimes	11 hospitals identified a total of <b>12 actions</b> on protected mealtimes.	8 actions
Nutritional Assessment	27 hospitals identified a total of <b>34 actions</b> on nutritional assessment. This included 11 actions around using Malnutrition Universal Screening Tool.	27 actions
Help at mealtimes	9 hospitals identified a total of <b>11 actions</b> on encouraging/providing help at mealtimes from carers, relatives or volunteers.	10 actions
Food menu review	6 hospitals identified a total of <b>6 actions</b> on reviewing the food and menu that is available for patients.	5 actions
Flagging system at mealtimes	9 hospitals identified a total of <b>10 actions</b> on identifying patients who need help at mealtimes. This included 6 actions around using red trays/jugs.	5 actions

## 5. Information and communication

## Summary

- 40% of hospitals had a clear procedure for information sharing with families and only around half of hospitals were found to have guidelines for the involvement of families for discharge and support arrangements.
- 88% of wards in the enhanced audit had a system for communicating personal information about patients with dementia.
- 43% of the casenotes had a section dedicated to collecting information from a carer, friend or relative, and around 40% of the casenotes were organised so that information about the person's dementia and about care and support needs could be quickly found in a specified place.
- Only 24% of casenotes contained information about factors that might cause distress to the person with dementia.
- 92% of wards could provide information on what to expect in hospital and almost all of the wards made patients and carers aware of the complaints procedure.
- 61% of wards had a responsible healthcare professional identified to the family as a contact for help and information, however only 45% of staff reported that patients are allocated a named professional as a contact.

## **Involvement of family and carers**

## How do hospitals involve families and significant others in the care of patients with dementia?

When patients with dementia are admitted to hospital they are often not in a position to provide a reliable history of their condition. If the patient has a family member who can reliably inform hospital staff about the events that have led up to admission then the assessment of the patient's problems will be more expedient and information about how to meet personal care needs can make the patients stay more pleasant. If the patient has been admitted from a care home, then it will be important to have this information from a member of care home staff.

There can be a lack of clarity about what information about patients with dementia can be shared with family members and staff who provide care on a regular basis, such as care home staff. This often centres around a wish to maintain patient confidentiality, but when a patient has a significant degree of dementia this can act against the patient's best interests. A decision about this needs to be taken on an individual basis, taking into account<sup>65</sup>:

- the capacity of the person with dementia to make decisions about treatment;
- their ability to provide a reliable history;
- the best interests of the patient.

Because this is a complex decision, clear guidelines need to be in place for how this decision is arrived at on admission. The audit found that less than half of hospitals have this in place:

40% (83/210) of hospitals have clear guidelines on making sure the carer knows what information can be shared with them and why.

At ward level, the majority of wards (73%, 105/145) reported that carers and relatives know when information about personal and healthcare information would be shared with carers. Staff were also asked about information sharing with carers:

- 56% (1244/2211) of staff said there was a system in place to ensure that all staff were aware of what information can be shared with the carer.
- 83% (1827/2211) of staff reported there is a system in place to ensure that all staff are aware of how the carer can be contacted.

Family members may want to remain involved in providing personal support to the patient whilst they are in hospital. They can provide a link between home and hospital and may be happy to help at mealtimes and with personal care. Their presence can help settle the person with dementia

Less than half of hospitals (40%, 83/210) have guidelines about asking the carer to what extent they want to be involved with the care and support of the person with dementia whilst in hospital. Staff were also asked about this:

60% (1323/2211) of staff reported there was a system in place to ensure that all staff are aware of the carer's involvement.

Discharge planning needs to actively involve family members so that they can make arrangements for the patient coming home<sup>60</sup>. About one half of hospitals (52%, 110/210) have clear guidelines on asking the carer about their wishes and ability to provide care and support of the person with dementia post-discharge.

Hospitalisation can be very stressful for families of people with dementia. Hospital staff who are sensitive to family distress can make a great deal of difference to how families cope in the longer term. Having the carer's experience as part of formal education and training about dementia can be a very powerful means of helping staff gain an insight into the challenges faced and assist staff to respond appropriately<sup>79</sup>. The audit found that not many hospitals include this in their training:

29% (60/210) of hospitals involve people with dementia and their carers, and the experiences of both, in the training for ward staff.

#### Carer/patient comments:

"Some staff were good at simplifying questions and requests but others were not"

"Nursing staff frequently used medical terms/abbreviations to explain what they were doing"

"Communication was very poor, bordering on non-existent"

"Doctors were brilliant, explained what was happening and treated dad with respect"

"Long delay before procedure. Being told different things by different members of staff (conflicting)"

"Some information giving was variable and depended on staff but we did need to ask questions often to get information"

#### Information collected about the with person dementia

## What information is routinely collected that could help the person with dementia have a better stay in hospital?

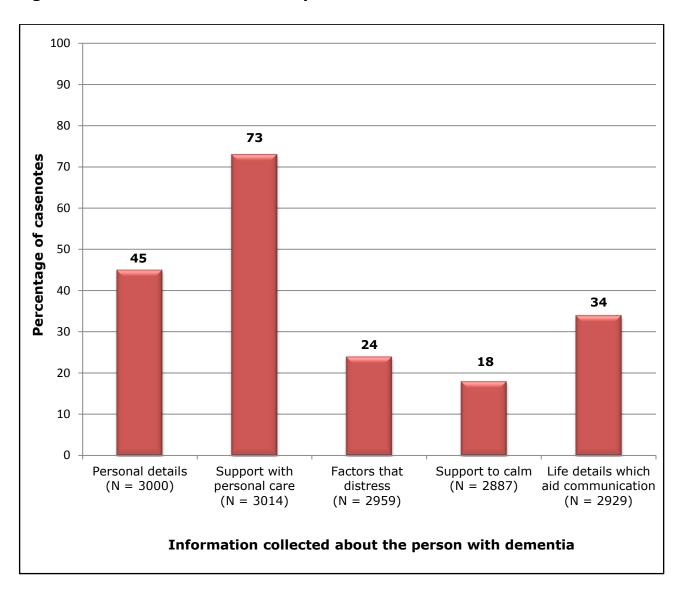
Family members and care home staff can provide important information on how to give personal care for the patient. Patients with dementia will often not be able to communicate this information for themselves. Good quality information provided before or on admission will mean that the patient will not be expected to do things for themselves that they can no longer do, and that skills they still have can be maintained. Information about the patient can also include personal details that will aid communication and help the patient feel more understood.

This will include information such as the patient's preferred name; routines and preferences; whether the person needs reminders or support with personal care; recurring factors that may cause or exacerbate distress; support or actions that can calm the person if they are agitated. Information collected as part of the assessment could also include details about the person's life or details which can aid communication such as their family situation, interests and past or current occupation. For patients with a significant degree of cognitive impairment, this information is regarded as so important to their care whilst in hospital that the formal care assessment documentation should contain this information 60. Under one third of hospitals (30%, 63/210) had a formal system in place to gather information pertinent to caring for a person with dementia. The audit found that:

43% (3094/7185) of the casenotes contained a section dedicated to collecting information from a carer, friend or relative.

The graph below shows what information was collected as part of the assessment.

Figure 4: Information collected as part of the assessment



Collecting information on recurring factors which might cause distress as well as information on support which could help to calm the person with dementia, is very important in trying to avoid patients becoming unduly distressed or agitated, thus risking the prescription of antipsychotic medication.

Systems need to be in place to ensure that information about the patient is well communicated, as a patient with dementia may not be able to provide this information themselves<sup>60</sup>. At ward level, 93% (135/145) of wards record the preferred name of the person with dementia and 88% (128/145) of wards have a system in place to communicate this personal information to all staff involved in care and treatment of the person with dementia.

#### Staff comments:

"When a patient comes onto the ward, the first thing we do after introducing ourselves is to ask them what they like us to call them. The next thing we ask is what is their normal routine like so we can keep it as familiar has possible"

#### The audit found that:

- 88% (128/145) of wards reported there is a system for communicating other personal information (such as routines, preferences and support needed with personal care) to staff involved in the care/treatment of the person with dementia.
- 54% (1189/2211) of staff reported there is a system for communicating other personal information (routines, backgrounds, preferences) that is known by all staff involved in the patient's care, in order to improve the level and type of care they receive.

#### Staff comments:

"The communication between staff is a very high standard, a good team that works well together sharing information for the care patients need on a very demanding ward"

"Staff in our ward are fully informed about the patient with dementia"

"These systems are in place, but due to high numbers of agency staff that are unfamiliar with documentation these systems are not always effective"

"Although staff do communicate with one another I feel there is lacking handover information especially to nursing assistants"

"A minimal handover is given with the most basic of information, due to cutting time. Extra information is ideal but not realistic on this ward"

Around half of the staff surveyed (49%, 1089/2211) said that personal information is routinely collected about people with dementia regarding their usual routines, backgrounds and preferences.

#### Staff comments:

"We speak to family in detail, use 'Getting to know you' sheets if applicable"

"We routinely collect social and healthcare information and are sometimes given copies of carers/care home documents to give an insight into a patients specific needs."

"We now have a booklet on the ward for patients and/or family to fill in to help."

"There would be benefit of a 'questionnaire' for family and carers to complete with staff to highlight patients' usual routines that is completed on admission and put in patients' notes for all health professionals to access in order to minimise patient distress"

"There is NO WAY EVER enough time to collect or even read the personal information for the patient"

Staff who are directly involved in caring for and providing treatment for the person with dementia need to be informed about any effect of the dementia on the person's behaviour and communication, such as their ability to answer queries about health accurately or to follow instructions, or other behavioural/psychological symptoms such as agitation or hallucinations. This needs to be communicated both to ward staff and to staff in other areas of the hospital where the patient may receive treatment<sup>60</sup>. The audit results show that only a few hospitals have a system in place to convey this information:

19% (40/210) of hospitals reported that there is a system in place across the hospital that ensures that all staff in the ward or care area are aware of the person's dementia or condition and how it affects them and that other staff are aware whenever the person accesses other areas.

At ward level, communicating information about the person with dementia seemed more encouraging:

- 82% (119/145) of wards reported to have a system for communicating to ward staff any issues to do with the effect of the dementia on the person's behaviour or communication.
- 67% (97/145) of wards have a system for conveying this information to other departments where the patient may receive treatment.
- 67% (1472/2211) of staff surveyed reported there is a system in place on the ward to ensure that all staff who are in contact with the patient are aware of their dementia.

The patient's notes should be organised in such a way that it is easy to identify any communication or memory problems and related care and support needs. The audit asked hospitals about the organisation of patients' notes and also collected this information in the casenote audit:

- 33% (70/210) of hospitals reported that patient' notes are organised in such a way that it is easy to identify any communication or memory problems. 41% (3279/7923) of casenotes were organised so that information about the person's dementia could be quickly found in a specified place in the file.
- 61% (129/210) of hospitals reported that patients' notes are organised in such a way that it is easy to see the care plan. However, only 39% (3077/7923) of casenotes were organised so that information about care and support needs could be quickly found in a specified place in the file.

#### Evidence from observations of care:

The qualitative PIE observations confirmed just how variable the collection, sharing and use of knowledge about the person with dementia is across wards, as 56 wards (out of 105) identified this as an area for considerable improvement in person-centred care. In addition, the extent to which knowledge about the person with dementia was employed by staff in interactions was revealed to have a direct impact on whether patients were able to participate in their care - and therefore on their potential for recovery back to normal health (see 'Person, interaction and environment' chapter on page 153).

### Information available on the ward

### What information is provided on the ward for people with dementia and their families?

Being admitted to an acute hospital is a confusing experience for many people. For people with dementia and their families it can be very frightening. The provision of clear information on what to expect and who to go to for help can help alleviate anxiety and confusion.

Patients and their families should be provided with information about the ward and hospital routines, such as mealtimes, visiting hours, periods of rest/quiet and the local complaints procedure. The audit found:

92% (133/145) of wards reported that patients and their families received information about ward routines such as mealtimes and visiting hours.

98% (142/145) of wards reported that patients and carers are made aware of the complaints procedure. However, only 60% (1320/2211) of staff surveyed stated that patients are made aware of the complaints procedure.

A carer's assessment is available to those people who are providing a significant amount of care and provides the opportunity to tell social services about the things that could make caring easier. Carers can ask for an assessment of their own needs whenever the person they are caring for is also having an assessment. A hospitalisation counts as an assessment and information about the carer's assessment should be available on wards. However, only about one half of wards (54%, 77/145) reported they provide information about how to get a carer's assessment.

The healthcare professional responsible for co-ordinating the patient's care should be easily identified by the patient and their family<sup>7</sup>. The audit collected information about this at ward level:

- 61% (88/145) of wards reported that a healthcare professional responsible for coordinating care is identified to the person with dementia and carers/relatives as a point of contact.
- 45% (991/2211) of staff reported that patients are allocated a named nurse, or another healthcare professional, as a contact.

#### Staff comments:

"Nurses photos on show on wall - helpful"

"Couldn't tell you who I was talking to, no introductions and no name badges"

### **Conclusion**

There is clearly a lack of guidance in hospitals for the involvement of families in discharge and support arrangements, and this is related to the findings that families are not routinely involved in the care of the patient with dementia and are often not given a named healthcare professional to contact for help.

Although it is reported at ward level that there are systems for recording and communicating some basic personal information about patients with dementia to help them feel more settled in hospital, the collection of this information does not form a systematic part of the patient's assessment. Of particular note is the fact that patients' families or carers are not asked about behaviours that may indicate distress or what strategies may be useful in helping the patient feel safe and calm. If this information was readily available to the clinical team it could reduce the incidence of untoward behaviour disturbance and avoid the need for prescriptions of antipsychotic medication.

More clarity is needed on the purpose and use of personal information. Hospitals need clear guidelines on the information that should be collected, and on supporting staff to share and use information and involve carers appropriately, according to the best interests of the person with dementia.

### Recommendations

- 1. The Senior Clinical Lead for Dementia should ensure that a named healthcare professional acts as a point of contact for people with dementia and their families during the admission to hospital. The named healthcare professional should ensure that the family, next of kin or appointee is involved in the care plan and in decisions about discharge.
- 2. The Senior Clinical Lead for Dementia should put in place procedures for clinical teams to follow to ascertain how the patient's next of kin should be involved in treatment decisions. This should take into consideration mental capacity, stated wishes and best interests decisions (as defined under the Mental Capacity Act)\*, and should be communicated to the ward team and to the family carer.
- 3. The Senior Clinical Lead for Dementia should ensure that a personal information document (e.g. "This is Me"<sup>9</sup>) is in use throughout the hospital. This should be completed with the help of someone who knows the patient well. The document should include information such as the patient's preferred name; routines and preferences; whether the person needs reminders or support with personal care; recurring factors that may cause or exacerbate distress; support or actions that can calm the person if they are agitated. This document should be held in the patient's notes as well as by the bed so that it is readily accessible to all those involved in the patient's care.
- 4. The Senior Clinical Lead for Dementia should implement systems of good practice to ensure that staff can identify people with dementia on the ward/during care and treatment, and provide an appropriate response (e.g. "Butterfly Scheme").
- 5. Ward managers should highlight to their teams the importance of involving people with dementia and their carers (where applicable) in discussions on care, treatment and discharge.
- 6. The National Audit of Dementia Project Team should seek to identify key examples of good practice in information provision and sharing with people with dementia and their carers.

www.bestinterests.org.uk

www.dignifiedrevolution.org.uk

# **Updates from hospital action plans**

Area for action	Action identified	Completed or due for implementation by end of 2011
Gathering information about the person with dementia	46 hospitals identified a total of <b>60 actions</b> on improving how information was gathered about the person with dementia. The majority of these actions were about using the Alzheimer's Society's 'This is Me' document or a similar document.	45 actions
Involvement of carers and people with dementia	18 hospitals identified a total of <b>26 actions</b> on how to involve carers and people with dementia in the care and treatment they receive.	23 actions
Information for carers and people with dementia	12 hospitals identified a total of <b>19 actions</b> on improving the information given to carers and people with dementia.	18 actions
Identifying people with dementia	23 hospitals identified a total of <b>31 actions</b> on the use of flagging systems to identify people with dementia in the hospital. This included the use of the 'butterfly scheme', wrist bands or 'forget me not' symbols.	27 actions
Carer's assessment	11 hospitals identified a total of <b>12 actions</b> to ensure carers are offered/given a carer's assessment.	All actions
Documentation	19 hospitals identified a total of <b>23 actions</b> regarding the documentation relating to the care of the person with dementia. This included how to improve the organisation of patients' notes, flagging any mental health problems and revising handover sheets.	12 actions

# 6. Staff training

# **Summary**

- Most staff from all job roles (92–98%) agreed that further training would be beneficial and would improve the level of care received by people with dementia.
- 23% of hospitals had a training and knowledge framework or strategy that identifies necessary skill development in working with and caring for people with dementia, and only 5% of hospitals had mandatory training in awareness of dementia for all staff.
- 32% of staff said they had sufficient training/learning and development in dementia care, including awareness training and skills-based training.
- 26% of hospitals had a training strategy which specifies that staff working with people with dementia are trained to anticipate challenging behaviour and are taught how to manage violence, aggression and extreme agitation, including deescalation techniques and methods of physical restraint. Less than half of staff said they had sufficient learning and development/training in these areas.
- 23% of hospitals had a training strategy specifying that staff of all grades and disciplines have access to communication skills training involving older service users. One half of staff said they had sufficient learning and development/training in this area.
- Training in person-centred care was felt to be sufficient by 67% of staff, and about one half of staff said training in involving people with dementia and their carers in decisions on care and treatment was sufficient.
- 66% of staff said they had sufficient training/learning and development in introduction to adult protection policy and procedures. However, less than half of staff said they had sufficient learning and development training in the Mental Capacity Act and in how to assess capacity.

# **Dementia care/awareness**

The Alzheimer's Society<sup>6</sup> has identified that 'at any one time up to one quarter of hospitals beds are occupied by people with dementia over 65 years of age'. Casenote data from this audit showed people with dementia occupy beds in wards of many different specialities. Training in dementia care and dementia awareness is required by all staff who provide care or support for this group of patients.

#### Carer/patient comments:

"Some staff seemed more aware of and understanding of her needs than others"

"Nursing staff excellent, however people serving meals do not have sufficient understanding"

"Nursing staff (particularly senior nurses) had a far better understanding of dementia than other relevant ward staff, e.g. physiotherapists, occupational therapists, Doctors - who had a poor understanding and reached inaccurate conclusions as a result"

"It appeared that staff were ill-prepared to cope with this illness. I was informed that none of the staff had training in dementia care"

#### Training strategy and dementia awareness

The National Institute for Clinical Excellence<sup>58,60</sup> recommends that all staff working with older people should receive dementia care training that is consistent with their roles and responsibilities.

The audit found that less than a quarter of hospitals (23%, 49/210) reported having a training and knowledge framework or strategy that identifies necessary skill development in working with and caring for people with dementia. This finding suggests that training is not consistent nationwide, and all Trusts/Health Boards need to address this as a priority.

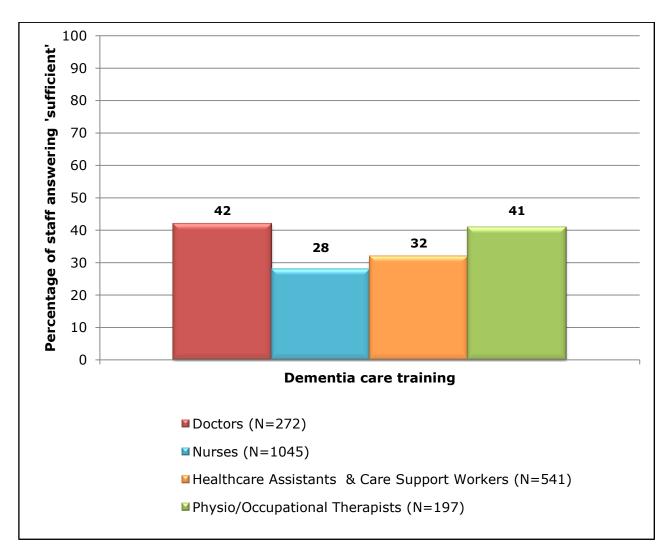
Very few hospitals (5%, 10/210) reported that training in awareness of dementia was mandatory for all staff. Of the hospitals that said training was not mandatory for all staff (95%, 200/210) only a few hospitals reported training was mandatory for some staff:

 4% (7/200) of hospitals reported it was mandatory for doctors, 5% (10/200) of hospitals reported it was mandatory for registered nurses, and 6% (12/200) of hospitals reported it was mandatory for healthcare assistants/clinical support workers. At a ward level the audit found that:

32% (713/2211) of staff surveyed said they had sufficient learning and development in dementia care, including awareness training and skills based training.

Comparisons of responses by job role does not demonstrate a high level of variance, with less than half of the staff in any group stating that dementia care training was sufficient:

Figure 5: Dementia care training, broken down by job role



#### Staff comments:

"I have never had any training related to caring for patients with dementia or Alzheimer's. I feel that more training should be available and made mandatory for nurses working on general wards as we do have patients who suffer from this illness admitted to our wards on a regular basis. As staff have not had training I feel that these patients do not receive the specialised attention that they deserve or understanding and time from staff"

"There clearly needs to be ongoing training of staff at all levels in dealing with patients with dementia who get admitted to a general hospital whose core business is treating other conditions and dementia being only part of it"

"Dementia awareness training is improving significantly and a roll out plan has been launched which includes a dementia resource file, individual patient passport and core care plan. We need more training and awareness classes to aid staff in dealing with dementia patients"

Several recent national reports have identified deficiencies in training and support as a critical issue resulting in poor care standards for people with dementia<sup>40,66</sup>. Most staff from all job roles (92-98%) agreed or strongly agreed that further training would be beneficial and would improve the level of care received by people with dementia.

# **Challenging behaviour**

The Royal College of Nursing<sup>77</sup> suggests that challenging behaviour in people with dementia is often caused by the hospital environment and the people around them. It is important that there is a focus on the prevention of agitation and challenging behaviours, as well as the ability to respond to them. There should be an understanding that challenging behaviour can be a communication of unmet needs, such as undetected pain and discomfort<sup>60</sup>. Training for staff should provide an understanding of the possible causes of challenging behaviour and how they should be approached. However, around a quarter of hospitals (26%, 54/210) reported that the training strategy specifies that staff working with people with dementia are trained to anticipate challenging behaviour and are taught how to manage violence, aggression and extreme agitation, including de-escalation techniques and methods of physical restraint.

The NICE Guideline<sup>60</sup> and the Royal College of Psychiatrists<sup>79</sup> recommend that mental health liaison services should be involved in providing education and training to ward staff, so that they are better prepared to manage behavioural and psychological symptoms of dementia. The audit found that less than 40% of hospitals (39%, 81/210) reported liaison teams from local mental health and learning disability services offer regular training for healthcare professionals who provide care for people with dementia in the hospital. The survey of staff asked about the training provided in this area:

- 46% (1006/2211) of staff surveyed said they had sufficient learning and development in dealing with challenging/aggressive behaviour.
- 33% (729/2211) of staff surveyed said they had sufficient learning and development in when and when not to use restraints/sedations and the risks associated, particularly for older patients.

Pain that goes unrecognised has been identified as a common trigger of challenging behaviour in people with dementia and staff were asked about the training received<sup>60</sup>:

• 44% (965/2211) of staff surveyed said that they had had sufficient learning and development in recognising pain in people with dementia.

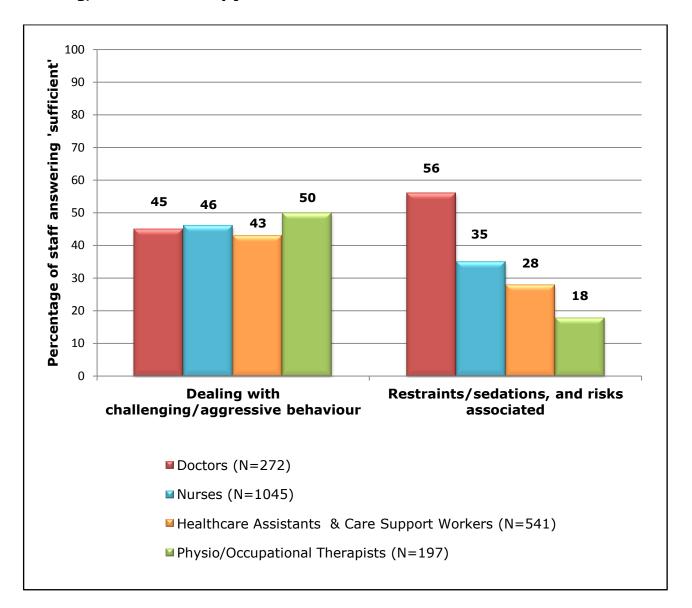
#### Staff comments:

"I feel we should receive more training in the management of clients with 'challenging' behaviour to assist in their care and prevent deterioration of their cognition and function secondary to nurse's actions"

"I believe there is a greater need for further training on dealing with challenging/aggressive behaviour and the appropriate de-escalation of this behaviour, this is a common problem I have discovered on the ward and can often lead to over sedating patients which is not always in their best interest"

Comparisons of responses by job roles for these training areas shows variance between staff groups, with almost 20% difference for doctors and nurses stating that they had sufficient training on the appropriate use of restraint or sedation:

Figure 6: Challenging/aggressive behaviour and use of restraints/sedations training, broken down by job role



# Communication

Communicating with people with dementia can be challenging due to different levels of cognitive impairment, as well as additional difficulties these patients may encounter, such as hearing and visual impairments. The NICE Guidelines<sup>60</sup> emphasise the importance of good communication skills when caring for people with dementia, as well as communication with their carers. It states that particular attention should be paid to 'the pace of communication, non verbal communication and the use of language that is non-discriminatory, positive, and tailored to an individual's ability.'

#### Carer/patient comments:

"Some staff were better than others. There was a noticeable lack of sympathy for people with hearing impairment (and understanding the problems), which obviously affects comprehension"

"Staff were aware, but did not appear to be able to communicate effectively, or show understanding that my husband could not explain things himself"

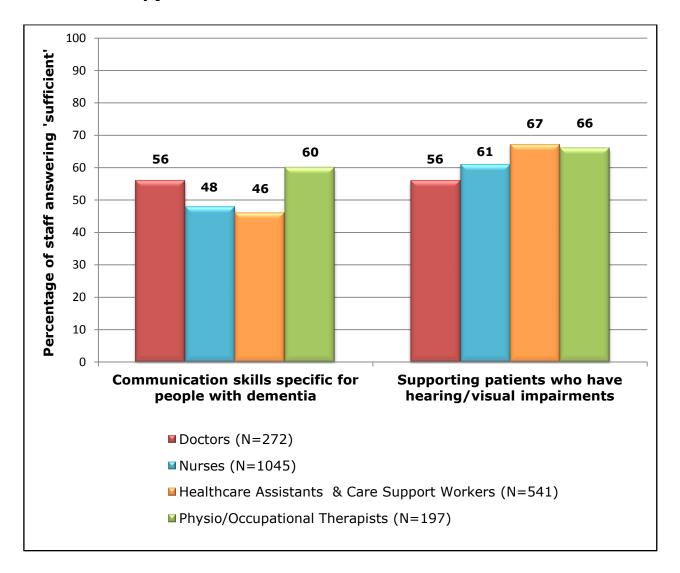
"Carers in wards varied in quality. Some communicated well but I felt that a number of the carers would profit by some training in the best way to deal with dementia sufferers"

#### The audit found:

- 23% (49/210) of hospitals have a training strategy specifying that staff of all grades and disciplines have access to communication skills training involving older services users.
- 50% (1095/2211) of staff surveyed said they had sufficient learning and development in communication skills specific for people with dementia, including non-verbal communication.
- 55% (116/210) of hospitals reported that all staff have an awareness of how to support people with hearing/visual impairments.
- 61% (1355/2211) of staff surveyed said they had sufficient learning and development in supporting patients who have hearing/visual impairments.

Comparison of responses by job role in both training areas also showed some variation in training received.

Figure 7: Communication skills and hearing/visual impairments training, broken down by job role



#### Staff comments:

"Staff should be aware of the needs of dementia patients. The way to speak to them in the proper manner, understand their needs and the stages of dementia for appropriate care needed. Staff learning and development could improve this"

"Staff are not given any additional training on how to treat or communicate with people suffering from dementia, which often leads to dementia patients having decisions made for them, which is depriving them of their rights and liberties"

# Involvement of people with dementia and carers

Person-centred care is a vital principle in caring for people with dementia<sup>6,28,60</sup>. As well as receiving care from staff who understand the dementia and its symptoms, the person needs to be treated as an individual who has their own unique routines and preferences. The audit found:

• 67% (1485/2211) of staff surveyed said they had sufficient learning and development in using the principles of person-centred care.

The Royal College of Psychiatrists<sup>79</sup> suggests that inclusion of experiences of people with dementia and their carers in the training of staff can be a powerful tool for staff learning. The audit found that less than a third of hospitals (29%, 60/210) reported that involvement of people with dementia and carers, and use of their experiences, is included in the training for ward staff.

The involvement of carers and families can be key to providing care that is personcentred, as they can communicate personal information on the person's behalf, such as their likes and dislikes, and play an active role in their care and decision making <sup>6,27,60</sup>. The audit found:

 52% (1143/2211) of staff surveyed said they had sufficient learning and development in involving people with dementia/carers in decisions on care and treatment.

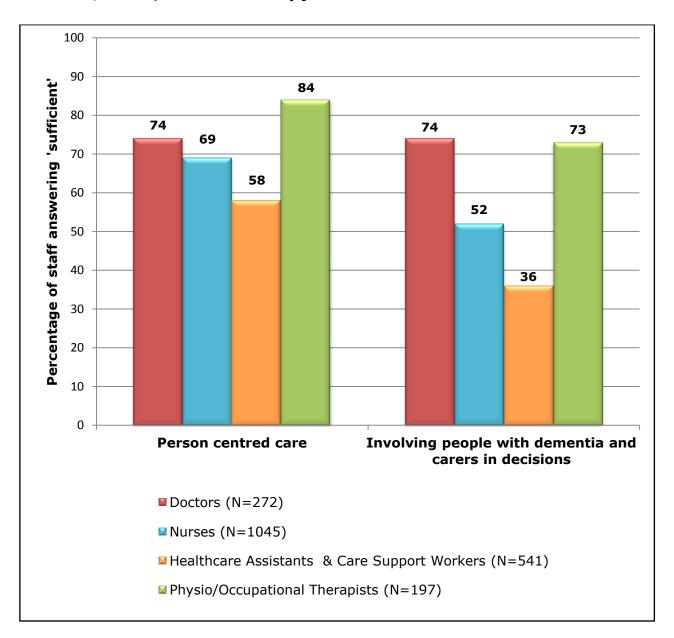
#### Carer/patient comments:

"We were given later on, after mother's admission, a check list setting out mother's preferences etc, which would have helped earlier in the process had it been given. Have to say after we voiced our concerns we have been listened by the nursing staff"

"The main issue relates to my father's inability to communicate anything to us. We therefore relied on nurses passing on what had been said. My father has difficulty understanding and remembering and we were not encouraged to be present when Doctor's rounds happened"

Comparison of staff responses on training in these areas by job role shows that doctors and physio/occupational therapists are more likely to report training is sufficient, when compared to nurses and healthcare assistants/care support workers.

Figure 8: Training in person-centred care and involvement of people with dementia/carers, broken down by job role



#### Staff comments:

"Recently took part in a 2 day study session with the Trust in person-centred care for people with dementia, found this very useful"

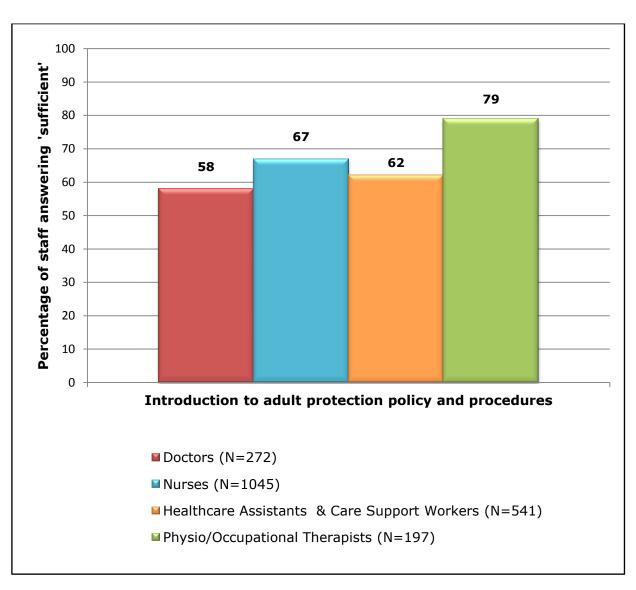
"Feel that it is important that all staff are made aware of patients cognitive impairments as this has an impact on information provided to them and decisions made about surgery. All staff need to be aware of the impact dementia has on patients function and decision making"

Staff working with people with dementia should receive information and training about adult protection, as this group of people are more vulnerable to abuse and  $neglect^{60}$ . The audit found that 84% (177/210) of hospitals reported that all staff working with people with dementia and older adults have training in protection of vulnerable adults. Staff were also asked about the training they had received on this:

 66% (1457/2211) of staff said they had sufficient learning and development in introduction to adult protection policy and procedures, including how to report concerns and who to contact.

Comparison of staff responses by job role shows almost 20% difference between physio/occupational therapists when compared with both healthcare assistants/care support workers and doctors.

Figure 9: Adult protection training, broken down by job role



# **Cognitive ability and the Mental Capacity Act**

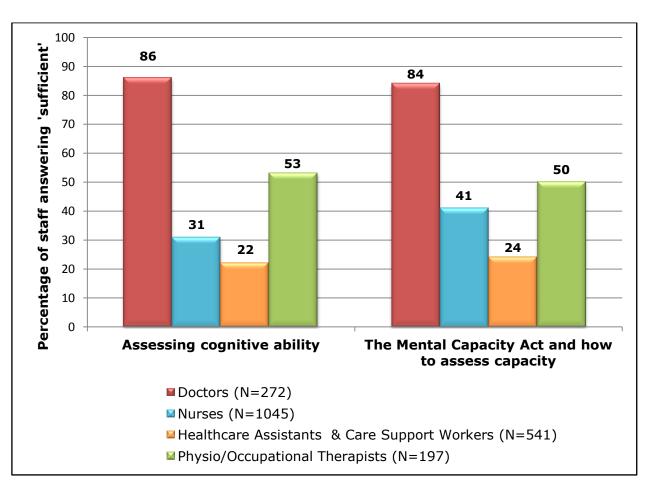
A key principle of the Mental Capacity Act<sup>42</sup> is that it should be assumed that adults have the capacity to make decisions for themselves unless proven otherwise. Training in the principles and application of the Mental Capacity Act will help to ensure that people with dementia are not excluded from discussions and decisions on care and treatment. The audit found that 78% (164/210) of hospitals reported that all staff working with older people receive basic training in how to assess capacity and have an understanding of the Mental Capacity Act.

Staff were also asked about the training they had received on this:

- 42% (922/2211) of staff surveyed said they had sufficient learning and development in the Mental Capacity Act and how to assess capacity.
- 37% (812/2211) of staff surveyed said they had sufficient learning and development in assessing cognitive ability.

Comparisons of staff responses by job role show that doctors are significantly more likely to report that the training they have received in these areas is sufficient.

Figure 10: Assessment of cognitive ability and Mental Capacity Act training, broken down by job role



#### Staff comments:

"Very little [training] appears to be offered, although some [training] encouraged, such as Mental Capacity Act training and assessing cognitive ability"

"I have had Mental Capacity Act training but this did not include how to assess capacity which I feel would be very beneficial in my role [Occupational Therapist]"

### Staff cover

### Are arrangements in place for staff to attend training?

The National Dementia Strategy<sup>27</sup> and 1000 Lives Plus<sup>64</sup> proposed that all health and social care staff involved in the care of people who may have dementia, should have the necessary skills to provide the best quality of care in the roles and settings where they work. This should be achieved by effective basic training and continuous professional and vocational development in dementia. Since the Alzheimer's Society *Counting the Cost* report<sup>6</sup>, which indicated that 52% of nursing staff had not received any work-based education in dementia, it is encouraging to see from the findings that arrangements for staff cover to allow staff to attend training on dementia are in place in the majority of wards (77%, 112/145).

As recent results from the Royal College of Nursing survey<sup>73</sup> of professional and carers suggest, education and training in dementia remains one of the key concerns in improving care. It is essential that continued efforts are made to ensure this takes place.

### Conclusion

The number of staff agreeing on the need for further training in relation to awareness of dementia was striking. The data and comments on training received in particular aspects of care reveal that further training is needed across all job roles for a range of competencies related to the care of people with dementia.

# Recommendations

1. The National Clinical Directors for Dementia and for Older People (England) should promote the development of an overall competency framework to ensure that guidance on staff training contained in the *Common Core Principles*<sup>28</sup> is implemented across all secondary care settings. In addition to providing 100% of staff with basic dementia awareness training and updates, local frameworks should promote and evidence enhanced and specialist levels of knowledge, e.g. that 50% of front line workers should have or be working towards, enhanced

knowledge of dementia care, and that 10% of front line workers should have or be working towards specialist knowledge. The Medical Director and Nurse Director for NHS Wales should promote development of a framework along similar lines in secondary care settings to support and enable the pathway/interventions set out in 1000 Lives Plus.

- 2. The General Medical Council and Nursing Midwifery Council should develop appropriate curricula for enhanced and specialist skills in dementia care, including requirements in undergraduate and postgraduate medical and nursing curricula.
- 3. The Medical Director, Director of Nursing and Head of Therapy Directorate should develop the training and knowledge strategy such that all staff are provided with basic training in dementia awareness and a locally agreed and specified proportion of ward staff receive higher level training.
- 4. The National Audit of Dementia Project Team should assess whether current provision for staff training is in line with recommendations made in *Common Core Principles*<sup>28</sup> in the 2012 re-audit.

# **Updates from hospital action plans**

Area for action	Action identified	Completed or due for implementation by end of 2011
	59 hospitals identified a total of <b>133 actions</b> on training for staff (clinical and non-clinical) who work with people with dementia. Training was identified in the following areas:	
Types of training	<ul> <li>Dementia awareness (79)</li> <li>Delirium/confusion (13)</li> <li>Mental Capacity Act (7)</li> <li>Mental health/mental status assessment (5)</li> <li>End of life/palliative care (4)</li> <li>Protection of vulnerable adults (4)</li> <li>Respect and dignity (4)</li> <li>Communication skills (3)</li> <li>Nutrition (3)</li> <li>Hearing/visual impairments (1)</li> </ul>	97 actions
Involvement of mental health liaison teams in the training of staff	9 hospitals identified a total of <b>9 actions</b> around involving mental health liaison teams in the training of staff.	4 actions
Involvement of carers/people with dementia in the training of staff	7 hospitals identified a total of <b>8 actions</b> on making use of the experiences and feedback from carers and people with dementia in the training of staff.	4 actions
Resources for staff	11 hospitals identified a total of <b>11 actions</b> on having resources available for staff to support them caring for people with dementia. This included information packs/folders and information on the intranet.	10 actions
Review of training	12 hospitals identified a total of <b>12 actions</b> around reviewing the training provided to staff.	All actions
Training strategy	30 hospitals identified a total of <b>39 actions</b> around developing and implementing a training strategy or training programme for staff.	27 actions

# 7. Staffing and staff support

# Summary

- Variations across wards in relation to both staffing numbers and skill mix indicate a lack of consistency in the determination of staffing levels.
- 93% of wards have a system to ensure minimum staffing levels are in place. However, less than a third of staff considered staffing was sufficient to meet patient needs.
- 99% of hospitals had a recognised system to record potential risk to patient care due to insufficient staffing numbers. Around half the staff felt that the system deals with reports in a timely way.
- Over 90% of registered nurses and healthcare assistants had had access to mentorship and appraisal. Clinical supervision is provided less consistently with 60% of wards offering this to registered nurses, but less than 40% of wards providing this support for healthcare assistants.

### Staff numbers and skill mix

### Are staff levels and skill mix reviewed on a daily basis?

Concern about staffing levels and staff support is highlighted both in recent reports and media coverage about shortfalls in the provision of dignified care for older people and those with dementia<sup>40,66,72,89</sup>

The Royal College of Nursing guidance on safe staffing levels<sup>72</sup> provides broad indicators, and a current project aims specifically to address safer staffing in hospital and guidance for nursing older people. However, to date optimum staffing levels for supporting people with dementia in hospital settings have yet to be fully established.

The Royal College of Nursing<sup>76</sup> raised concern about the lack of planning and use of tools which help determine staffing levels to ensure patients care needs are met.

The Royal College of Nursing guidance on staffing levels<sup>72</sup> recommends the following indicators should be monitored by providers, to monitor variations and review staffing against external benchmarks:

- actual staff in post as a proportion of the total establishment;
- proportion of registered nurses out of the total of all nursing staff;
- nursing staff relative to population served;
- nursing staffing relative to patients;
- staff turnover and sickness and absence rates.

Although data was not collected on how ward staffing levels are determined, the findings suggest significant variation across the wards. The numbers of staff per patient range varies from 4 to 16 per 10 beds. In addition the ratios of qualified nurses to healthcare assistants vary significantly from 39:61 to 86:14. Royal College of Nursing guidance on staffing levels<sup>72</sup> recommends a minimum ratio of registered nurses to healthcare assistants of 65:35.

http://www.kcl.ac.uk/schools/nursing/nnru/prog/rn4cast.html

**Table 13: Number of staff per 10 beds** 

	All wards		Medi	Medical wards		Surgical/ orthopaedic wards		Care of the elderly wards	
	Median	Range	Median	Range	Median	Range	Median	Range	
Staff *	10	4 - 16	10	5 - 16	9	5 - 16	10	4 - 15	
Registered Nurses *	6	3 - 12	6	3 - 10	6	4 - 12	5	3 – 8	
Healthcare Assistants *	4	1 - 9	4	1 - 7	4	1 - 7	4	1 - 9	

<sup>\*</sup> Whole time equivalents per 10 beds.

**Table 14: Staff Ratios** 

	All wards		Medical wards		Surgical/ orthopaedic wards		Care of the elderly wards	
	Median %	Range %	Median %	Range %	Median %	Range %	Median %	Range %
Skill mix ratio of staff working per ward * (Registered Nurses: Healthcare Assistants)	59:41	39:61 - 86:14	60-40	40:60 - 79:21	59-41	44:56 - 86:14	57-43	39:61 - 83:17

<sup>\*</sup> Whole time equivalents.

The findings suggest that systems to review and regulate staffing levels are in place on most wards:

- 93% (135/145) of wards had an agreed minimum staffing level across all shifts which is met.
- 93% (135/145) of wards reported that there are systems in place to ensure that all factors that affect nursing staff numbers and skill mix are taken into consideration and staffing levels are reviewed on a daily basis.

#### Ward organisational checklist comments:

"Ward is fully staffed, ward manager completes off duty, matron checks weekly to ensure ward is as safe as possible"

"We do have agreed minimum staffing levels but with staff vacancies and slippage at present levels not met"

However, there is a strong indication that staff feel staffing levels are insufficient to adequately meet the needs of their patients:

- 28% (625/2211) of staff agreed that there are enough staff on the ward at all times to ensure patients are assisted if required.
- 12% (271/2211) of staff reported that staffing is sufficient to provide one-to-one nursing when required.
- 39% (868/2211) of staff reported they have enough time to ensure that patients are comfortable in their environment and to support any patients who are unfamiliar with and/or disorientated by their environment.

#### Staff comments:

"Unfortunately staffing numbers are at a crisis, sometimes below minimum. Working on this ward is very busy at all times and stretches staff when a patient is suffering from dementia, wanders or falls. More staff are required to ensure dementia is supported and the patient receives the care they deserve as a patient/person/client and not as a condition"

"Ward frequently short staffed which impacts on patients as most do have dementia"

"Not enough nursing staff. Patients are continually left in distress for example when needing toileting. A lack of dementia awareness/empathy from some ward staff regarding communicating with patients who have dementia. Not enough therapy staff to provide orientation support (for example) or to complete functional skill/safety assessments such as kitchen tasks"

"Our ward often consists of 5-10 patients with dementia plus other patients most have fallen and broken their hips. They are at risk of falling again but there would never be enough staff to look after them on a one to one basis"

A survey of ward staffing levels<sup>70</sup> indicated that the dependency levels of patients on medical and surgical wards had increased over the last few years, and that there was a higher proportion of unqualified staff on older people's wards. In addition, a review of nursing staff morale<sup>71</sup> and a recent survey of practitioners delivering care to people with dementia<sup>73</sup> both support the view that staff consider the nursing establishment to be insufficient to meet patient needs.

With up to 70% of acute hospital beds occupied by older people, approximately 40% of whom have dementia, it is essential that the care of this group is prioritised<sup>29</sup>. This should include ensuring the tools used to measure need and determine staffing levels reflect the often complex needs of people with dementia. The Nurse Workforce

Planning Tool\*, supported by Skills for Health, aims to assist nursing workforce planning and help make better decisions about cost effective numbers and mixes of nurses.

More recently the development of the Safer Nursing Care Tool NHS<sup>†</sup> offers an evidence-based tool, which uses acuity and dependency to help plan for future workforce requirements. This tool is aimed at acute general hospital care and uses indicators such as infection, falls and pressure sores.

However, these tools rely on quantitative measures to assess frailty and need. Qualitative aspects that would inform the assessment of need for people with dementia such as communication, distress and orientation are unlikely to be picked up. It is therefore considered that systematic approaches to assessing need would be further enhanced with consideration allowed for the additional time, care and attention that is required by people with dementia.

#### Feedback from the Royal College of Nursing survey of carers and people with dementia<sup>74</sup>:

"In an ideal world there would be more nurses on the ward, then each and every patient would be able to have good quality care as you would have the time not only to be able to see to their hygiene needs and assist patients with feeding but have the time to sit and talk with them - wouldn't that be nice"

"It is not necessarily the numbers of staff in the clinical area that is most important but the skill mix. The number of registered nurses who are able to deal with complex communication needs, dietary care, challenging behaviour and physical impairments and who are experienced at care planning and assessment is of greater importance than just increasing staffing levels per se. These patients need intensive care and registered nurse staffing ratios such as those found in other critical care areas like ICU should be mirrored in areas where elderly patients with dementia are being cared for."

http://www.healthcareworkforce.nhs.uk/resource library/latest resources/nursing workforce planning tool.html

http://www.institute.nhs.uk/quality and value/introduction/safer nursing care tool.html

#### Feedback from PIE observations on staffing:

"Protected meal times (are an area for action) - identifying and assisting patients that need help prior to meal time and allocating staff. Staff are mostly supervising and flitting from one patient to another"

"When clinical environments are experiencing high work demands, opportunities for social interaction can be affected. At times patients can be inactive, especially if not able to initiate or sustain activities independently"

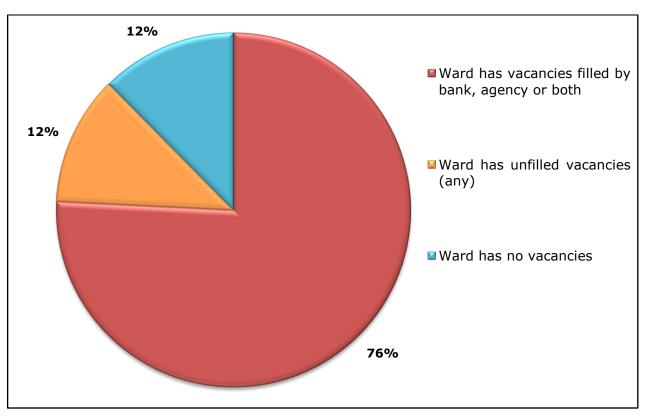
"We felt all was working well on this ward - and provided the staffing levels are not depleted there was no action required"

#### Bank and agency staff

The findings reveal a significant reliance on bank or agency staff to fill vacant posts, which is likely to lead to inconsistencies in the way care is delivered. Bank or agency staff are also less likely to receive any available internal training or education in the needs of people with dementia. All of these factors combined present significant challenges to the delivery of skilled, informed nursing care for people with dementia with complex needs.

The audit collected information on any vacancies on the ward, and the use of bank and agency staff. This data is presented in the pie chart below.





#### Ward organisational checklist comments:

"We often do not get bank shifts filled despite the dependency of the patients"

#### Staff comments:

"Ward is very busy, staffing levels poor, and over reliance on bank staff"

#### Evidence from observations of care:

The qualitative PIE observations revealed the extent to which staff teams are placed under pressure within the clinically oriented environment. The typical ward culture is one where staff teams are narrowly focused on delivering a task within an organisationally set routine, rather than one which is flexible to respond to people with dementia. Very often, the needs of individual patients are simply not seen and there is no staff supervision of people with dementia. Unless there are organisational systems to support care delivery, and opportunity for one-to-one continuous quality interactions with people with dementia, for example at mealtimes, patients' care needs are often not met.

# Reporting risks to patients

# Do staff have a system to record and report risks to patients?

Research evidence demonstrates that there is a direct association between nurse staffing and patient outcomes, with better staffed hospital wards having lower mortality rates<sup>47</sup>. It is essential for the safety and protection of patients that a system is in place whereby potential risk to the provision of safe care is identified should staffing levels be compromised. The Royal College of Nursing<sup>72</sup> offers guidance on safe nurse staffing levels and highlights a number of essential elements for planning and reviewing nurse staffing levels. This includes recommendations that healthcare organisations have up-to-date information on staffing profiles in each area of practice, which is recorded and reviewed regularly. A routine and systematic approach is important to ensure that staffing levels are maintained and that both patient safety and quality of services are upheld.

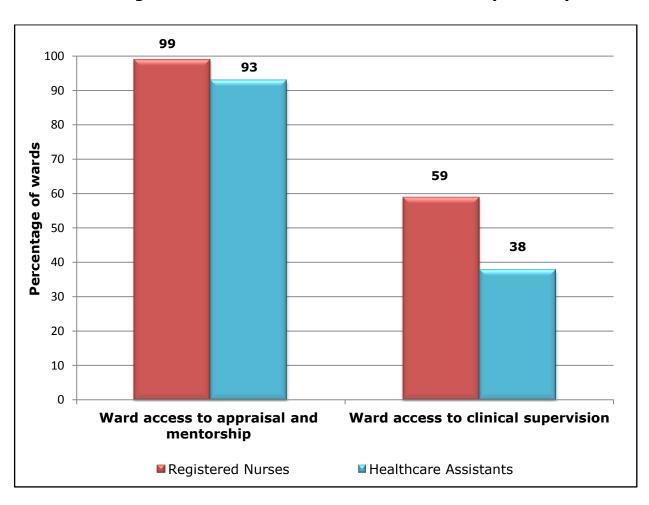
Whilst the majority of hospitals (99%, 207/210) and staff (76%, 1678/2211) in the audit reported having a recognised system in place to record risks to patient care caused by insufficient staffing levels, it is important to note that only one half (51%, 862/1678) of staff felt that the system deals with the reports in a timely way.

# Support for staff

### What systems are in place to support staff?

The Nursing and Midwifery Council (NMC)\* states that 'clinical supervision should be available to registered nurses throughout their careers so they can constantly evaluate and improve their contribution to the care of people'. The NMC also set standards for continuing professional development, which it suggests should be an integral part of regular appraisal and mentorship. Clinical supervision, appraisal and mentorship are all considered an important part of clinical governance. As healthcare assistants are now delivering a great deal of hands-on care, it is considered essential that they are offered training to carry out their roles<sup>69</sup>. It is also important that they have the same access to clinical supervision, mentorship and appraisal. The findings indicate that healthcare assistants do not have the same access to appraisal and mentorship or clinical supervision as registered nurses.

Figure 12: Wards reporting appraisal, mentorship and clinical supervision are available to Registered Nurses and Healthcare Assistants (N = 145)

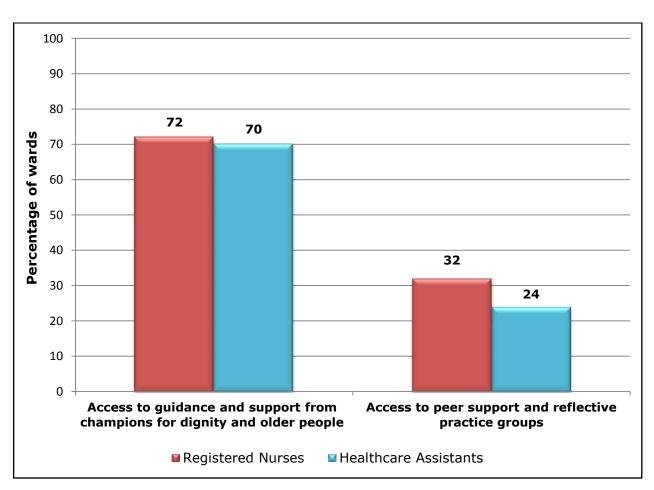


http://www.nmc-uk.org/Nurses-and-midwives/Advice-by-topic/A/Advice/Clinical-supervision-for-registered-nurses/

Clinical supervision is seen as important in increasing understanding of professional issues, developing skills and knowledge, enhancing understanding of practice and ultimately improving standards of care. In addition, caring for people with dementia and supporting their families can be both emotionally distressing and complex due to the loss and change that is experienced. Clinical supervision is important for staff to reflect, learn how to cope and, importantly, to feel supported in their work. It is therefore essential that healthcare assistants involved in the direct delivery of care are offered equal access to clinical supervision to support them in their role. As well as highlighting the difference between the availability of clinical supervision for registered nurses and healthcare assistants, it is also important to consider that only 59% (85/145) of wards provide this support to registered nurses and only 38% (55/145) of wards provide this support for healthcare assistants.

Wards were also asked about other systems of support available to staff. The majority of wards said that staff had access to guidance and support from champions for dignity and older people. However, only a minority said staff had access to groups providing peer support or reflective practice. It is important to note that not all staff agreed or were aware that there was a Dignity Lead available for them to consult (see 'Dignity Lead' subsection on page 132)

Figure 13: Other systems to support staff available to Registered Nurses and Healthcare Assistants (N = 145)



# **Dignity Lead**

# Is there a Dignity Lead in the hospital?

Initiatives from the Department of Health and the Welsh Government including the National Service Frameworks for Older People<sup>19,94</sup>, the follow-up Next Steps<sup>25</sup> document and the *Dignity in Care* Campaign\*, incorporating the Dignity Challenge<sup>†</sup>, have all raised the need to ensure that older people and their carers are treated with respect, dignity and fairness.

Dignity Leads have been identified as key to driving up standards and supporting the delivery of dignified care<sup>87</sup>. Resources are available and a well-established network aims to bring together champions to support dignified care and share best practice. The Healthcare Commission report on the care of older people in hospital<sup>39</sup>, found that whilst policies were in place to support dignified care, these were not being translated into practice effectively. They recommended that older people's leads and Dignity Leads needed to be more visible to ensure dignity issues are being considered in the delivery of care.

These issues seem to be corroborated in the audit findings with feedback from the staff survey suggesting more work needs to be done in some areas to ensure that such roles are visible and available to staff. Although the majority of hospitals (79%, 165/210) reported that there is a named Dignity Lead to provide guidance, advice and consultation to staff; only 40% (892/2211) of staff surveyed reported that there is a Dignity Lead for them to consult concerning advice and support.

# **Administrative support**

# Is administrative support in place?

In order to ensure that nursing staff have time to provide skilled effective assessment and care for people with dementia, it is important that they are supported by effective administration. Initiatives such as the Releasing Time to Care; Productive Ward *Programme*<sup>‡</sup>, part of the QIPP programme encourage an examination of environment and effective use of staff time and are also reliant on effective administrative support/ward clerks. It is encouraging to see the findings indicate most wards have administrative support on the ward (98%, 142/145), although this is less available at weekends (16%, 22/142).

http://www.dignityincare.org.uk/DignityCareCampaign/

 $<sup>^{\</sup>dagger} \ \text{http://www.dignityinc} \underline{\text{are.org.uk/Topics/championresources/ToolkitForAction/ToolkitForActionGeneral/TheDignityChallenge/} \\$ 

http://www.institute.nhs.uk/quality and value/productivity series/productive ward.html

### **Conclusion**

It is important that a systematic approach is taken to assessing ward staffing requirements suitable to meet the needs of patients. For wards admitting people with dementia this should include consideration of the time and attention necessary for care. Also key to supporting staff in their caring role is providing leadership via key roles such as Dignity Leads and Dementia Champions, and ensuring access to mentorship, supervision and appraisal.

### Recommendations

- 1. The Royal College of Nursing should provide guidance to Trusts/Health Boards on how staffing levels should be determined, including consideration of measures of acuity and dependency sensitive to the care of people with dementia.
- 2. The Chief Executive Officer should ensure that key leadership roles and support from specialist staff are in place to ensure delivery of dignified, skilled and compassionate care, for example Dignity Leads, Dementia Champions, Older People's Nurse Consultants.
- 3. The Director of Nursing should make sure that comprehensive systems for guidance, supervision and support are in place for staff on the ward caring for people with dementia, including:
  - supervision, mentorship and appraisal for registered nurses and healthcare assistants;
  - access to peer support and reflective practice groups.

Ward managers should be supported to ensure that these systems for support are available to all nursing staff.

4. The Senior Clinical Lead for Dementia should ensure that champions represent the range of job roles working with people with dementia including those staff involved in day-to-day care provision.

# **Updates from hospital action plans**

Area for action	Action identified	Completed or due for implementation by end of 2011
Support for staff	5 hospitals identified a total of <b>5 actions</b> on providing the following support for staff:  - Supervision (2)  - Reflective practice group (2)  - Appraisal (1)	All actions
Dementia champion	25 hospitals identified a total of <b>30 actions</b> around identifying dementia champions to provide training and/or support for staff. These could be dementia link roles, dementia advisor, dementia Nurses.	26 actions

# 8. Physical ward environment

# Summary

- 56% of wards stated that patients with dementia are able to see a clock from their bed area, but only 5% of wards stated patients were able to see a calendar from their bed area which would help improve orientation.
- 56% of wards reported that information (words and pictures) on signs is in clear contrast to the background, and 38% of wards reported that signs/maps are large, bold and distinctive.
- 15% of wards use colour schemes to help patients with dementia find their way around the ward.
- Large toilets and bathrooms allowing for assistance were provided in most wards and there was also a choice of bathing facilities available.
- Space for patients with dementia to walk around was available in 69% of wards, and rooms/areas providing a break from the ward environment were only available in 47% of wards.
- 59% of wards reported that personal items were not always situated where the patient could see them at all times.
- Floor surfaces that may cause confusion for people with dementia, such as busy patterns or high gloss surfaces, seem to be avoided in most hospital wards.

### **Orientation**

### What orientation cues are in place on wards?

Being in the unknown environment of a hospital ward is a difficult time for most people, but for those with dementia it can lead to worsened confusion and an increase in anxiety caused by a difficulty in understanding where they are and why they are there<sup>45</sup>.

Providing a calm and relaxing environment and using orientation cues can help a person with dementia orientate themselves around the ward and reduce distress caused by their admission<sup>64</sup>. Simple cues, such as visible clocks and calendars around the ward, can contribute to improving orientation for people with dementia<sup>68</sup>. The audit found that about half of the wards audited had clocks but very few had calendars which were visible to patients:

- 56% (80/144) of wards reported that patients with dementia are able to see a clock from their bed area.
- 5% (7/144) of wards reported that patients with dementia are able to see a calendar from their bed area.

### How well are wards signposted?

Signage around the ward and the hospital are important for people with orientation and cognitive problems. Anxiety levels for patients can increase when they are unable to find their way around the ward and hospital. Having adequate signage around the ward and hospital can assist orientation, help support patients to maintain their independence and lessen their confusion. The audit found that less than half of wards (48%, 69/144) reported that key areas are clearly marked.

It is important to consider that too many signs or signs that are complicated, can lead to further confusion. There is sufficient guidance suggesting what signs are appropriate for patients with dementia; the Housing Corporation<sup>45</sup> recommends that 'useful signs are those that display simple essential information with realistic symbols and large clear lettering'. Clear and understandable signs are also highlighted in Essence of Care benchmarks<sup>29</sup> and 1000 Lives Plus<sup>64</sup>. The audit found that not all wards have signs that are appropriate for people with dementia:

- 56% (81/144) of wards reported that information (words and pictures) on signs is in clear contrast to the background.
- 38% (54/144) of wards reported that signs/maps are large, bold and distinctive.

### Do wards use colour schemes to aid orientation?

The use of colour around the ward can also play an important part in orienting people with dementia. Davis et al<sup>17</sup> highlighted that by using colour and contrasts in the ward environment, confusion and agitation can be minimised and confidence and independence can be promoted. This could be painting bays and toilet doors in different colours so patients can find their way around the ward. The audit found that few wards make use of colour schemes:

15% (22/144) of wards use colour schemes to help patients with dementia find their way around the ward.

One of the challenges faced by patients with dementia, when admitted to hospital, is loss of continence. Signage and colour coding around the toilet and bathroom area can be crucial to help maintain 'independence and toileting whenever possible, such as making toilets easy to locate and identify'18. The audit found that the use of signage and colour schemes around the toilet area in the wards was variable:

- 28% (40/144) of wards reported that signs to locate the toilet are visible from the patient's bed area/door of room.
- 90% (130/144) of wards reported that toilet and bathroom doors carry signs.
- 87% (125/144) of wards have toilet and bathroom doors that are a different colour to the walls.
- 84% (121/144) of wards have door handles which are a different colour to the wall so they stand out.
- 38% (55/144) of wards have toilet paper which is a different colour to the wall so that it stands out.

#### Carer/patient comments:

"Toilets could have been signposted better"

"No 'toilet' sign ever seen!"

# Supporting people with dementia on the ward

# Are mobility aids available on wards?

Mobility can be a barrier for many older people including those with dementia, and in order to ensure an adequate ward environment, mobility should be promoted. Parker et al<sup>68</sup> recommend that mobility aids should be available in order for independence to be encouraged and maintained for this group of patients. The audit found:

- 90% (130/144) of wards have hand rails, large handles and a raised toilet seat to support patients.
- 63% (91/144) of wards are adapted to assist people with mobility difficulties.
- 94% (135/144) of wards can readily provide equipment to assist mobility.

#### Carer/patient comments:

"Walking aid supplied but very little help in escorting or encouraging walking"

"The physios provided a walking frame, and encouraged my mother to stand or walk once a day during the week. Unfortunately there were no physios available at weekends"

"She uses a 3 wheeler walker at home but she didn't have one in hospital although the patient in the next bed had one. She was in hospital after a fall and had lost her confidence in walking"

### Is hearing assistance equipment available on wards?

Similarly, hearing impairments are also common amongst this group of patients, and the Department of Health<sup>29</sup> highlights the importance of having hearing aids readily available to patients in order to maintain communication between patients, carers and staff. The audit found that not all wards can provide this:

54% (77/144) of wards can provide hearing aids such as amplifiers/ communicators/hearing loops/batteries for personal aids or other assistive devices.

It is also important that staff working on wards are aware of individual patient needs, to ensure that these aids can be provided if needed. In the staff questionnaire we found that 61% (1355/2211) of staff surveyed reported they had sufficient training in supporting patients with visual and hearing impairments.

### Do toilet and bathing facilities support patients with dementia?

When reviewing existing research on toilet design, Day et al<sup>18</sup> found that staff felt it was difficult to assist patients with toileting when the toilet area was not big enough to allow for assistance. A high percentage of wards in the audit reported to have this in place:

- 82% (118/144) of wards reported that toilets are big enough for assisted toileting.
- 88% (127/144) of wards reported that the bathroom is big enough for assisted bathing.

The audit also asked whether call buttons were visible in the toilets/bathroom, as this is important for when people use these facilities unassisted:

98% (141/144) of wards reported that there are call/alarm buttons visible in the toilet/bathroom.

It is important to highlight, however, that even though call buttons may be in place, staff need to be aware of patients' abilities to use them.

#### Carer/patient comments:

"She also didn't understand how to use 'call button' for assistance so totally reliant on staff for her needs"

Although bathing is part of a person's routine when they are admitted to hospital, many studies have shown that it can be a time of high stress for patients with dementia, often caused by unfamiliar equipment and procedures<sup>18</sup>. Giving patients an option on how they wish to be bathed can help minimise distress. The audit found:

81% (116/144) of wards reported that facilities are available so that patients have choices about bathing or assisted bathing (e.g. at the sink, overhead showering, hand held shower head, full bath).

#### Carer/patient comments:

"No bath/shower only bed baths"

"No bath on ward"

"There was not bath on the ward, just a shower"

### Do wards allow privacy and dignity to be maintained?

National Service Frameworks for Older People for England<sup>19</sup> and Wales<sup>94</sup> identified that 'mixed sex wards can be embarrassing and for some older people culturally insensitive'. The importance of providing single sex washing and toileting facilities was also highlighted in the 'Benchmarks for the Care Environment' 29 and is listed as an indicator for best practice. The audit found that nearly all of the wards in the enhanced audit had single sex bays and toilet/washing facilities:

- 95% (137/144) of wards reported that they had no mixed bays on their wards. However, 5% (7/144) of wards reported that they did have mixed bays, and this ranged between 1 to 5 mixed bays per ward.
- 94% (136/144) of wards reported that single sex toilet/washing facilities are provided for patient use.

# Do wards allow patients with dementia to walk around safely?

The Alzheimer's Society\* states that up to 60% of people with dementia feel the need to walk about which can be referred to as 'wandering behaviour'. The reason why a person with dementia may wander varies from person to person and will require different approaches to deal with this behaviour. Nevertheless, walking can be beneficial to some people, and the hospital environment should take this into account by ensuring that patients can move around safely within the ward, without the risk of wandering off the ward<sup>19</sup>. The audit found:

69% (100/144) of wards reported that there is a space for restless patients with dementia to walk up and down where they are visible to staff and staff are visible to them.

#### Carer/patient comments:

"With her condition the conventional hospital ward is inappropriate when recuperating, lack of opportunity to walk around and inadequate mental stimulation"

"I was not satisfied with being told to just sit in the chair next to my bed all the time when I wanted to walk about"

"I wondered how secure the ward was if someone had a tendency to wander off"

## Is there a room on the ward where patients can go for a break from the environment?

As well as heightening anxiety and confusion, hospital environments can also be stressful because they are not always a calm and reassuring place to stay. The noise and fast pace caused by the number of people in the ward can cause distress for people with dementia<sup>19</sup>, and so a space away from this environment can be beneficial.

http://alzheimers.org.uk/site/scripts/news\_article.php?newsID=239

The audit found that less than half of the wards in the enhanced audit had this available:

47% (67/144) of wards reported that a room/area is available for patients to use for a break from the ward environment.

#### Carer/patient comments:

"The ward was very busy with very few staff, sometimes appeared chaotic and this could be confusing"

"The ward always seemed very busy with lots of people coming and going"

"Patient in 4 bed bay with other dementia patients who were sometimes very noisy"

"It was a busy ward with lots of staff doing different jobs and a fairly high patient turnover"

"Ward always frantic, except night-time"

"Calmer when manager there. Night nurses very loud voices - always shouting down ward to nurses - very disturbing to sleep"

## Do patients have personal items in their bed area?

Familiar objects (e.g. family photographs) and accessible self care items (e.g. glasses) can help people with dementia to feel safer and more comfortable in the hospital environment. It is a benchmark of best practice that the person's environment can be managed or modified to meet their individual needs<sup>29,94</sup>. The audit found that only 59% (85/144) of wards situate messages from relatives and personal objects, including self care items, where the patient can see them at all times.

#### Carer/patient comments:

"Personal items were out of reach unless you were mobile"

# Safety of flooring

## Are the wards a safe place for patients with dementia to walk around?

Floor design is especially important for older people, including those with dementia, who are more likely to be frail, have difficulty walking and be visually impaired<sup>45</sup>.

Minimising glare and increasing visibility of contrasts<sup>18</sup>, marking level changes and slopes, and avoiding busy patterns and shiny surfaces<sup>45</sup> should be considered when making hospital wards safe environments for people with dementia, thus reducing the risk of falls and confusion. Wards were asked about the safety of their flooring:

- 78% (112/144) of wards reported that floor surfaces are non slip.
- 66% (95/144) of wards reported that level changes and contrasts are clearly marked.
- 95% (137/144) of wards reported that floors are plain or subtly patterned, not 'busy'.
- 93% (134/144) of wards reported that floor surfaces are subtly polished rather than high gloss.

#### Evidence from observations of care on the ward environment:

The PIE observations also showed that in some wards, lack of familiar items, excess noise levels, a lack of orientation cues and not having items such as buzzers or drinks in reach negatively affected people with spatial and perceptual problems. There was also much scope to improve activities and resources to provide stimulation for people with dementia, with this being identified as an area for action in 55 out of 105 wards.

#### Feedback from PIE observations:

"The absence of a clock without any exception to all patients was an issue"

"Radio on all day as background but too low to hear properly - gets irritating on top of other ward noises"

(Action plan) "Explore opportunities to improve activities for patients e.g. access to personal audio equipment, collecting resources for a patient activity box, e.g. books, cards, pictures, knitting, magazines etc"

"Signage extremely good. Patients obviously responding to it when going to the toilet. Large clocks visible from every bed. Orientation board at doorway with correct day and date on. Names behind beds support and aid way finding for patients. Environment warm, bright and friendly. Flowers on the dining table - patient points and smiles at them. "

## **Conclusion**

In terms of the physical environment, attention to orientation both in the ward (signage, use of colour) and the bed area (positioning of familiar personal items) could improve the experience of people with dementia. Use of space to provide breaks from the ward environment could also contribute, as on busy wards people experiencing confusion may have no opportunity to escape noise and bustle. Evidence from observations of care also suggested that attention to noise and creating a warm, friendly atmosphere are important considerations in the care of people with dementia.

### Recommendations

- 1. The Department of Health, Welsh Government Department for Health, Social Services and Children, NHS Estates, and NHS Wales Shared Services Partnership, should provide guidance on dementia friendly ward design, to be incorporated as standard into all refurbishments and new builds, including safe walking spaces and the use of colour, lighting, signage, orientation cues and space used to promote social interaction.
- 2. The Chief Executive and Trust Board/Health Board should promote the role of public/patient governors and non-executive directors (Independent Board Members in Wales) in reviewing the environment and comfort for people with dementia on the wards. Reviews could make use of a checklist of standards and feedback from patients, carers and visitors and include looking at placement of signs, availability of personal items and the quality of the food.
- 3. Ward managers and Dementia Champions should ensure that simple and effective improvements to the environment are promoted in all wards admitting older people, including:
  - appropriate lighting and floor coverings plus aids to support orientation and visual stimulation<sup>5</sup>;
  - personalising bed area;
  - adequate space and resources to support activity and stimulation.

# **Updates from hospital action plans**

Area for action	Action identified	Completed or due for implementation by end of 2011
Physical environment	21 hospitals identified a total of <b>36 actions</b> on improving the physical environment for people with dementia. These included:	22 actions
	<ul> <li>Providing orientation cues (9)</li> <li>Improving signage/colour schemes (10)</li> <li>Encouraging stimulation and social interaction for people with dementia (9)</li> </ul>	

# 9. Discharge planning and discharge

# Summary

- 94% of hospitals have a commitment to begin planning for discharge within the first 24 hours of admission, but in about half of the audited casenotes this had not taken place, and it was not possible to specify a reason.
- Around half of the casenotes audited stated a named discharge co-ordinator, with responsibility for managing the process and consulting with all relevant parties, was involved in the discharge process.
- 67% of casenotes contained an up-to-date discharge plan and 58% of casenotes showed evidence that any support needs had been identified in the discharge plan. Only 41% of casenotes stated that a copy of the plan had been passed on to patients or carers.
- 75% of casenotes recorded that an assessment of the carer's current needs had taken place before discharge, and 80% of casenotes showed evidence that the place of discharge and support needs had been discussed with the carer/relative.

# The discharge policy

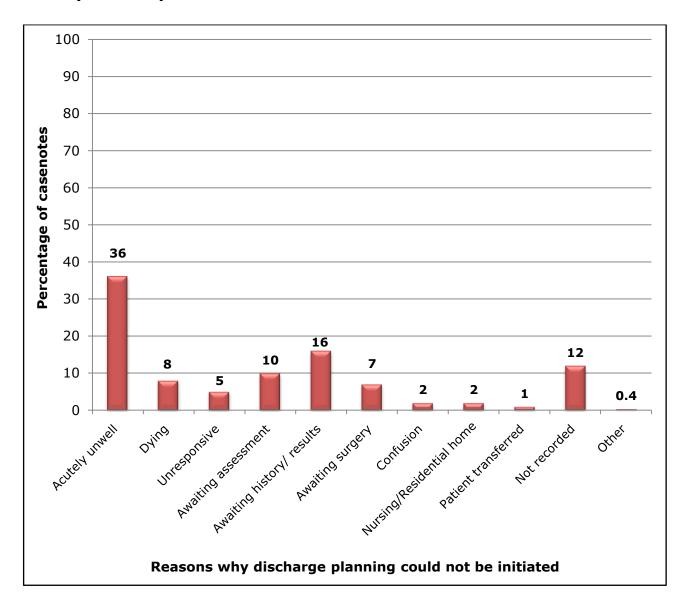
# Do hospitals have a discharge policy in place for people with dementia?

Leaving the hospital can be a time of heightened anxiety and stress for any patient, but particularly so for people with dementia who may find it difficult to understand what is happening, and for their carers who may have concerns over the practical aspects of care at home. Best practice advice emphasises the importance of a clearly laid out hospital discharge policy that specifies that discharge is an actively managed process which begins within 24 hours of admission<sup>20,53,64</sup>. The audit found that:

- 94% (197/210) of hospitals reported that their discharge policy states that discharge is an actively managed process which begins within 24 hours of admission.
- 36% (2828/7934) of casenotes showed evidence that discharge planning had been initiated within 24 hours of admission. 48% (3801/7934) of casenotes stated discharge planning was not initiated within 24 hours of admission without a reason given, and 16% (1305/7934) of casenotes stated this could not be done.

For a minority of patients (16%, 1305/7934), discharge planning could not be initiated within 24 hours. This can be largely explained by clinical factors: nearly 50% (49%, 640/1305) of these patients were too unwell, dying or in coma (unresponsive) for the discharge process to be relevant. A further 30% (431/1305) were awaiting assessments, results or surgery. However, in 12% (157/1305) of cases the reason is not recorded.

Figure 14: Reasons why discharge planning could not be initiated within 24 hours (N = 1305)



# The discharge process

# How is the discharge process organised?

Many different professionals plus family carers may be involved with the discharge process and good practice guidance recommends that there is a named person with overall responsibility for discharge co-ordination<sup>53,79</sup>. Less than half of casenotes (48%, 2727/5697) provided evidence that the discharge plan had been co-ordinated by a named discharge co-ordinator.

In advance of discharge, patient specific information should be compiled into a single, up-to-date, discharge plan. A copy of the discharge plan should be passed on to the patient and/or carer(s). The needs of the carer(s), including the possibility of a separate carer assessment should be identified 53,79.

A majority of casenotes audited did contain an up to date discharge plan. However, a lower percentage of casenotes showed that the plan covered all identified support needs. A copy of the plan had been passed on to patients/carers in a minority of cases:

- 67% (3995/6009) of casenotes contained a single plan for discharge which included updated information.
- 58% (2759/4781) of casenotes showed evidence that any support needs that had been identified were included in the discharge plan or summary.
- 41% (2471/6008) of casenotes stated that the patient and/or carer received a copy of the plan or summary.

# **Discharge co-ordinator**

## How is discharge co-ordination supported?

People with dementia often stay in hospital longer than needed and can be inappropriately discharged from hospital<sup>27</sup>. The role of a discharge co-ordinator is very important. They will liaise with the services involved, the patient and their family to ensure the information is in place for a handover of responsibility for care<sup>63</sup>. Discharging people with dementia from one setting to another requires patience, understanding and good communication skills<sup>31</sup>. Providing leadership for the discharge co-ordination process is also important and helps to ensure that information about care planning and discharge needs and how to assess that someone is safe to discharge, is communicated to staff at ward level.

The audit asked about a named person in the hospital with overall or lead responsibility for discharge co-ordination for people with dementia (this role could include other responsibilities, e.g. all complex discharges):

- 32% (68/210) of hospitals have a named person who takes responsibility for discharge co-ordination for people with dementia. Of these hospitals:
  - 56% (38/68) reported that the person with overall responsibility for discharge co-ordination has training in ongoing needs of people with dementia.
  - 84% (57/68) reported that the person with overall responsibility for discharge planning has experience of working with people with dementia and their carers.
- 18% (37/210) of hospitals have a person with overall responsibility for discharge co-ordination who has had training in ongoing needs of people with dementia and

the person has experience of working with people with dementia and their carers.

A person with overall responsibility for discharge would not have direct involvement in all individual discharges of people with dementia (or complex needs). However, in each case, it is important that there is a named person who takes responsibility and can liaise with the healthcare professionals who have carried out care and provided assessment. In about half of the audited casenotes involvement of a co-ordinator was not recorded:

48% (2727/5697) of casenotes stated that the discharge plan had been coordinated by a named discharge co-ordinator.

# Support for carers and family on discharge

Close family members and friends play a key role in the care of people with dementia. It is important that an assessment of their own needs and ability to continue to provide care is assessed, and discussed with social and healthcare staff <sup>29,93</sup>. The assessment of psychological distress, which carers may experience, should be an ongoing process. Assessments should also look at the provision of practical support such as transport or short-break (respite) services<sup>60</sup>.

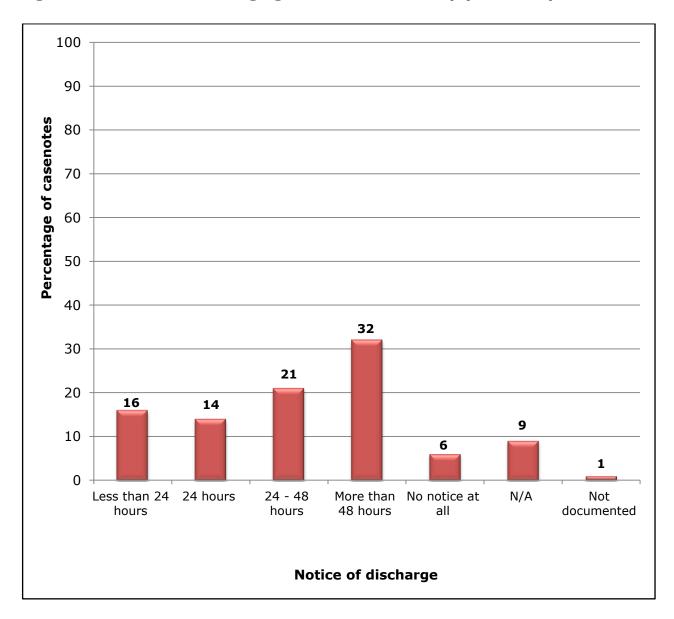
The Department of Health<sup>31</sup> and the Welsh Government<sup>93</sup> highlight the importance of consulting carers and relatives about their willingness and ability to provide care to the person with dementia post-discharge. It should not be assumed that the carer/relative is able or willing to continue providing care after admission, as the carer's needs may also change through this process and need to be considered. The audit found that:

- 57% (120/210) of hospitals reported that there is a system in place to ensure that carers are advised about obtaining carer's assessment and support.
- 52% (110/210) of hospitals reported having guidelines about asking the carer about their wishes and ability to provide care and support of the person with dementia after discharge.
- 75% (2281/3060) of casenotes recorded that an assessment of the carer's current needs had taken place (where this was relevant).

Research carried out by the National Audit Office<sup>53</sup> suggests that 'very few patients and carers have been actively involved in decisions about post-discharge arrangements'. However, data from this audit is more encouraging as most casenotes (80%, 4336/5421) showed evidence that the place of discharge and future support needs had been discussed with the person's carer/relative.

Insufficient notice of discharge from hospital can create anxiety and distress for people with dementia and carers, who may not have had care arrangements confirmed. It also creates risk if the person with dementia returns home without the ongoing support they need. The figure below shows that notice of discharge varied in the casenotes audited, with less than one third of the sample (32%, 1935/6009) stating that more than 48 hours notice had been given.

Figure 15: Notice of discharge given to carers/family (N = 6009)



#### Carer/patient comments:

"We did ask when she was ready to go back to the home she is staying at. And they let us know in plenty of time"

"The discharge process is a sore point as it was not mentioned until the day it was decided that mum was fit for discharge, and then I was being rushed into arranging it. I had a very unhappy experience with a discharge facilitator who was extremely rude and actually raised her voice to me, saying she was discharging mum home today in her best interests, despite the fact it was a Friday on a bank holiday weekend 3.30pm and she asked me nothing about mum situation at home at all"

"Very displeased with the way my relative was discharged. Told she would be discharged between 1-5pm and she was not discharged until 9.30pm, an 88 year old left in a chair for about 12 hours"

### Conclusion

It is encouraging that the majority of casenotes show evidence of attention to the carers' needs, and that most showed involvement of the care when discussing discharge and support. However, it is less encouraging that in half the casenotes discharge planning had not begun at admission, for no stated reason. There was no named co-ordinator of discharge in the same proportion of casenotes. Providing a copy of the discharge plan to the person with dementia or carer is important to ensure that discharge discussions are understood.

Early discharge planning is important to facilitating timely discharge and lessening the time spent by the person with dementia in the acute environment and could also produce savings in cost. The Alzheimer's Society has calculated that savings in excess of £80 million could be produced if the length of stay for people with dementia in hospital was reduced by one week.<sup>6</sup>

# Recommendations

- 1. The Chief Executive Officer should review Trust/Health Board discharge policies with particular reference to the needs of people with dementia/their carers to ensure that they describe the task of discharge co-ordination, and the importance of carer assessments.
- 2. The Chief Executive Officer should ensure that notification of discharge is a routinely collected statistic for reporting to the Governing/Executive Board/Board of the Health Board. This should be presented as the percentage of discharges of people with dementia where less than 24 hours notice has been given/divided by all discharges of cases receiving less than 24 hours notice (unscheduled care).

# **Updates from hospital action plans**

Area for action	Action identified	Completed or due for implementation by end of 2011
Discharge Co-ordinator	4 hospitals identified a total of <b>6 actions</b> around identifying a person in the hospital to coordinate discharge.	5 actions
Discharge plan	5 hospitals identified a total of <b>5 actions</b> around making improvements on their discharge forms. All 5 of the actions specified that there should be a section for recording mental health information, including dementia and delirium.	2 actions
Discharge policy	10 hospitals identified a total of <b>16 actions</b> on reviewing and developing the discharge policy.	8 actions

# 10. Person, Interaction and Environment (PIE) **Observational findings**

## Summary

## What are the experiences of people with dementia in acute care?

The overall finding from ward observations is that care and communication is generally reactive and based on an organisationally set, task-driven routine rather than being person-focused, flexible and proactive.

- On most hospital wards there is little evidence of a person-centred ward approach or 'culture' or of an overall person-centred experience for patients.
- The content of the staff/patient encounter is task related and delivered in a largely impersonal manner.
- There are periods of care-based activity interspersed with inactivity, leading to lack of attention, lack of stimulation and boredom for patients.
- The environment is often non-dementia friendly and impersonal, with excess noise at times, and a lack of orienting cues, dementia aids or areas for socialisation.
- There is inconsistency in the quality of communication. For example, people with dementia experienced differences in the approach of individual staff members, or between groups of staff (such as pharmacy/housekeeping) or both. Or, some elements of care delivery were positive (such as explanations consistently given to patients) while other elements of care delivery in the same ward were clearly not (not knowing the patient as a person).

"Pockets" of positive, person-centred care were found in the practice of individual staff members, or as elements of ward practice. Only a handful of wards (5/105) reported ward practice which was person-centred more often than not.

- No one hospital submitted data where <u>all</u> the participating wards were clearly described as being person-centred. This suggests that there is no evidence that wards which are more person-centred are sharing their approach across the organisation and, conversely, there is no evidence of an effective organisational system for implementing person-centred care in place in any one hospital.
- Ward type was not related to the quality of care delivery observed. Many hospitals had similar findings across all their participating wards while many others observed some key differences (suggesting both hospital and ward

leadership factors come into play).

The observers clearly articulated that all staff and staff groups need to be engaged more positively with patients. However, a whole ward team organisational approach is required - individual staff cannot by themselves provide a person-centred care experience for patients.

## **Introduction**

This chapter presents the qualitative findings from observations of the experiences of people who may have, or are known to have, dementia in general hospital wards. The purpose of the observational audit was to find out what happens during care interactions for people who have conditions affecting their memory or communication at the interface of direct care delivery and to help inform how NHS Trusts/Health Boards can improve ward practice so that it becomes more person-centred.

## Why focus on person-centred care?

The literature and the national audit findings clearly show that people who have an acute illness superimposed on a dementia require a tailored and specific dementiasensitive approach, if even basic standards in relation to meeting their care needs are to be met. Current systems and processes inadequately cater for this vulnerable group who, if their needs in relation to the dementia go unaddressed, are highly susceptible to further deterioration in behavioural and psychological symptoms, adverse effects on their general physical health unrelated to the medical condition and unintended adverse events such as delirium and falls. As a result, there is greater mortality and loss of independence, with the resource consequences of increased length of hospital stay and new care home admissions<sup>6,79</sup>.

For people with dementia, good quality acute care should therefore be personcentred. According to a review of current knowledge, the aim of person-centred care is to acknowledge the personhood of people with dementia in all aspects of their care. This generally includes the recognition that the personality of the person with dementia is increasingly concealed rather than lost; personalisation of the person's care and their environment; offering shared-decision-making; interpretation of behaviour from the viewpoint of the person; and prioritising the relationship as much as the care tasks<sup>36</sup>.

## Method

# Why develop a new observational tool for the audit?

Although good quality acute care for people with dementia is person-centred, there is no consensus on its definition and a lack of tools to measure person-centred care in clinical settings<sup>36</sup>. Neither is there sufficient guidance for implementation. For example, the drive to provide dignity in care as part of the National Service Framework for Older People (England)<sup>19</sup> addresses a broader agenda and does not focus on the specific experiences of people with dementia in relation to personcentred care.

Observation is particularly helpful for capturing the experiences of people with dementia and for informing person-centred practice development or audit cycles<sup>15</sup>. Although an initial literature review identified several potential candidate tools, none were readily applicable for the audit because they were not dementia-specific, not tailored for use in the acute setting, or were overly complex or resource-intensive 16. A Dementia Care Mapping derivative, the Short Observational Framework for Inspection (SOFI 2)\*, is currently used by the Care Quality Commission in acute hospital settings to evaluate the experience of care from the perspective of the person with dementia (mood, engagement and quality of staff interactions). However, it is not available for wider use by ward teams. The Person, Interactions and Environment (PIE) observational method for hospital audit of dementia was therefore designed to be context-specific to acute care.

An understanding of how person-centred care might be understood and achieved in concrete terms in the acute situation is essential if it is to have any chance of being embedded in routine ward practice and improving the experiences of people with dementia.

#### What is PIE?

The Person, Interactions and Environment (PIE) observational method for hospital audit of dementia was designed following a literature review of the acute care experiences of people with dementia and their families and in consultation with hospital staff and older people. It was piloted in 7 NHS Trusts (18 wards) and refined prior to use in the national audit.

PIE is a qualitative observational method capable of describing the care experience of patients with dementia and identifying specific changes required in staff practices and systems so that they become more person-centred.

PIE is designed to be feasible for staff to use after a one day workshop. It is presented in the form of a work-book manual and involves identifying and gaining informal consent to observe the care of up to 6 patients who have memory or communication problems in a ward area. Real-time observations are conducted by 2 hospital staff (including 1 practice development nurse independent to the ward) who pair up to observe different patients for at least 2 periods of 2 hours each (1 morning, 1 over lunch time, with flexibility to do more). Data collection involves exploring the extent to which staff are considering what is known about the individual patient as a Person to personalise their care; the quality of Interactions with staff and the impact of the immediate *modifiable* physical <u>Environment</u> or organisation of care. Following reflection and feedback with the ward team, each ward identifies an area of good practice and an area which requires considerable improvements in person-centred care, together with easily achievable short-term and longer-term actions they plan to undertake across the directorate and Trust/Health Board.

http://www.brad.ac.uk/health/dementia/dementiacaremapping/sofi/

## What findings are presented here?

Qualitative data from 105 wards (43 hospitals) were analysed (for further information about hospital participation see page 40, and for the method of analysis see page 219). This chapter focuses on the findings in relation to communication and interactions with people with dementia, as this was found to underpin care quality across discrete areas such as nutrition, hydration, personal care and rehabilitation. 'Interaction' refers to the content of what happens between staff and patients (e.g. the task of giving medication) and the process of delivering the content (the relational quality e.g. how medication is delivered). 'Communication' refers to the level or quality of interactions achieved.

Although no ward provided a completely person-centred care experience for patients, a few wards (N = 5) clearly are (more often than not) providing components of care which are person-centred for people with dementia, demonstrating that it is possible to work within such a framework. The analysis of patient experiences observed in these wards together with positive and negative patient experience reported across wards, has enabled us to 1) identify the key distinguishing characteristics of a personfocused approach to communication in acute care and 2) to describe the quality of communication typically experienced by people with dementia. This framework can inform wards and NHS Trusts/Health Boards in making changes to practice at the level of micro-interactions which are easy to implement and have an observable and immediate effect on patients. Key recommendations are also made by wards at directorate/Trust or Health Board level for longer-term action.

As the data were qualitative and hospitals focused on certain areas only for reporting and action planning, the quantitative figures given in this chapter are likely to be underestimates, for example, 51 wards identified collecting or using personal knowledge of people with dementia as an issue to address in their ward. However, as only 13 wards identified good practice examples in this area, it is likely that this requires wider attention. A 'few' wards refers to at least 5 wards (5%), 'many' to 53-79 (50–75%) of wards and 'most' wards to 80–100 (76–95%).

#### **Interactions between** patients and staff distinguishes person-focused communication?

Person-focused communication was found to comprise of connecting with each individual who may have dementia in a personally meaningful way, in order to:

address their social and emotional needs (such as to help people feel significant, included, comfortable, reassured and safe etc in an unfamiliar environment); and at the same time;

help facilitate their acute care and recovery (such as encouraging them to participate in personal care, consultations, rehabilitative activities such as walking, and eating and drinking).

On those wards which were very clearly person-centred, the following 3 components of communication were all identified as being in place and proactively applied. Thus, person-focused communication is facilitated by:

- A whole-ward ethos in which there is an openness to engage with people who 1. have (or may have) dementia, including sensitivity to cues given by patients, enabling their needs to be anticipated and responded to in a timely way.
- 2. The use of systems to support a meaningful connection between staff and the individual with dementia which are:
  - knowledge of the patient as a person and
  - allowing communication to take place flexibly on the person's terms.
- 3. Employing specific features of good practice in interactions or 'propellers' (such as simply and clearly providing information) to support the reassurance, understanding and participation of the person who has dementia.

Crucially, all of the above necessitated:

- a focus on the person with dementia, and not just the practical task in hand, to initiate and guide the interaction;
- consistent or unvarying use by most staff;
- predictable or regular use across time.

There was a timely, organised and thoughtful way of working with people who may have dementia (not just ad hoc pockets of positive practice presently evident in wards).

On the typical ward, communication appeared to be primarily shaped by an organisationally driven, set routine focused around care activities being delivered from a staff perspective. The guiding focus or priority in interactions on the immediate care activity rather than the person often meant that:

Staff simply did not see and engage with people with dementia, illustrated by the very common observation of people being left for long periods or passed over quickly in interactions.

- The content of interactions was confined to instances of practical care; on occasion there was little or no engagement with the patient as the task was being carried out.
- There was little evidence of using knowledge of the individual person with dementia to guide interactions.
- There was a general lack of awareness within and across the staff teams of the necessity to engage with or support people who may have dementia in a way which is specific to the individual because of the very problems they experience with their memory, cognition or spatial awareness i.e. differently to other patients.

The quality of support offered to people with dementia in the course of delivering care was therefore variable across and within wards and the likelihood of adequately addressing their needs lessened (or became "hit and miss") because all the components for person-focused communication were not consistently in place.

There was thus a qualitative distinction between wards which were primarily "personfocused" in their approach and supportive of people with dementia and those which were not. There was otherwise a continuum of care quality with some wards having more pockets of person-focused practice than others, and a few clearly having detrimental practices.

Across wards, there were clear examples given of the way in which the content and quality of staff interaction with patients, or missed opportunities for interactions, had a direct positive or negative impact on patients. Care processes were observed to be self-reinforcing as the quality of communications observed had an impact on the person (patients), staff and ward atmosphere which then shaped further interactions (and the positivity or negativity of how those are experienced). For example, staff being open to engage with patients at every opportunity meant that in turn patients felt more comfortable to initiate contact or to engage with them, creating a warm, friendly atmosphere on the ward.

The following 3 sections outline the key distinguishing features of a ward approach in which communication is person-focused, directly compared to the more typical approach. The typical ward approach did not mean that the experience was always a negative one for patients (it may have some positive components with basic care being provided and kind and courteous interactions). However, when communication is not person-focused, there is clear evidence from the data that for some patients neither is 'essential care' being received (e.g. drinks or meals).

This model should help to guide action planning processes so that wards can take specific steps towards improving communication and facilitating the recovery of people with dementia in a more structured and consistent way. Encouragingly, the data suggests that every step taken by a ward to become more person-focused is likely to have an immediate positive effect and enhance the experiences of patients

and staff. The aim should be to gradually move from the position where the care is mostly organisationally driven and task-focused, with a few person-centred episodes, to the reverse.

# Section 1: Ward ethos in regard to engaging with people who may have dementia

Is there a ward ethos in which there is an openness to interact with people who may have dementia at any time?

Does this include sensitivity to cues given by patients and an anticipatory response to address their needs?

#### What does this mean?

This is about the general ward approach, specifically the degree to which there are opportunities for people who are cognitively impaired to engage in communication/ interaction with the staff teams. It involves all or most of the ward staff (and other members of staff such as housekeeping/catering/porters and medical/therapy/ phlebotomy/pharmacy/other clinical staff/etc) using all available opportunities to connect with patients such as when passing by or giving care. It involves paying attention to all patients in the area, including those who are quiet and less able to communicate i.e. a proactive approach.

#### Why is this important?

If staff are not seeing or interacting with the patient, then there is simply no opportunity to provide for their care. As well as providing a social function by acknowledging and respecting patients, being observant and responsive to verbal and non-verbal cues given by people with dementia creates the opportunity for staff to address emotional or physical needs quickly before they escalate. This helps prevent distress or discomfort and means that patients are not struggling to communicate their needs to staff.

#### **Main findings**

On at least half of wards, there was no or little engagement with patients by some staff carrying out tasks. There were differences in approach between ward based care staff and non-ward based staff such as medical or housekeeping (N = 51 wards), or between individual staff within and across teams (N = at least 34 wards). This first principle of proactively engaging with people who may have dementia was therefore not evident in practice.

#### Table 15: Ward ethos – Is there openness to interact at every opportunity?

The first column in Table 15 identifies the elements of establishing interaction with people with dementia were in place consistently and constantly (as most staff took this approach most or all of the time) on the most person-centred wards in the PIE dataset. The second column reflects the continuum of observations commonly made in wards. Illustrative examples from the data are given in each column.

Ward approach	Person-focused	Non person-focused (typical)	
	FREQUENCY OF INTERACTION		
acknowledge and interact with patients?  during direct care delivery and when carrying out specific tasks around patients, when passing by, entering the room or sometimes just to be 'social'	There is frequent patient-staff interaction including during direct care delivery and when carrying out other specific tasks around patients, when passing by, entering or leaving the room or sometimes just to be 'social'. All	Interaction occurs only some of the time and is restricted to instances of direct care delivery. There are missed opportunities for interaction, and periods when patients are not frequently checked on.	
When or through what types of	available general/ social opportunities are taken to interact with patients.	(Ward 35) 'The heavy workload of the ward meant that whilst staff were always busy and active, communication	
activity?	(Ward 30) 'They (all staff) would engage in conversation for a minute before passing by patients.'	with patients was restricted to instances of care deliver Such instances were often perfunctory and determin	
	(Ward 62) 'Lots of chatting between patients and staff. Staff utilise all opportunities to interact and chat with	by the need to complete actions rather than by a need to engage patients.'	
	patients'.  (Ward 64) 'Staff wave and smile to patients as they pass or carry out other tasks'.	(Ward 99) 'Task orientated routines, little or sometimes no interaction with patient.'	
		(Ward 112) 'No interaction outside of tasks.'	
	There is often a staff presence with all individual patients being regularly checked on.	It may be commonplace for staff to carry out tasks around patients without acknowledging their presence. There are missed opportunities to engage socially. If there is an interaction for the sake of being social – even if it is just a quick greeting – this is judged to be enriching for the patients.	
		(Ward 10) 'A nursing assistant (working on the bank)	

came into the bay from the area she was working in to collect equipment. Made eye contact with patients en route stopped and smiled and said hello. Actually acknowledged her presence (something that others hadn't done), patients smiled and waved hello back.

There may be general acknowledgement of the patient's presence but no real opportunity for them to engage.

(Ward 55) 'Although Doctors introduce themselves and addressed patients by name there was a tendency to then talk about the person without including them.'

In the worst instances, there may be no interaction at all with patients when doing something to them.

(Ward 33) 'A porter came to take a patient for an investigation. A HCSW [healthcare support worker] was helping to push the bed. The patient only had a sheet over her. Neither the porter nor the HCSW told her what was happening or where they were taking her. The porter looked at her and said 'is she alright?' the HCSW said 'she's the same as normal'. They talked over her as if she didn't exist."

#### INITIATION OF INTERACTION

Who initiates interaction?

Can patients call for help when there are no staff in the area?

Both staff and patients initiate interaction patients are encouraged and feel at ease to converse with staff at any time or vice versa. Staff are visible to patients or can be easily called for assistance, with buzzers in reach.

(Ward 30) 'Patients encouraged to converse with staff'.

Interactions are largely initiated by staff, especially when there is a task to be completed with the patient. Patients may be struggling to ask for assistance when staff are not in the area or visible. Buzzers may be out of reach or curtains drawn around a patient, isolating them.

(Ward 48) 'Buzzers were left out of patients reach for 2 out of the 5 patients. 1 was picked up by the phlebotomist however the other patient went all morning

without a buzzer. Drs left curtains drawn, causing 1 patient potentially to feel isolated...'

#### CONSISTENCY IN APPROACH ACROSS STAFF

Do all staff engage with patients at every opportunity?

The majority of the ward team and/or different groups of staff frequently interact with patients.

(Ward 30) 'The care of the patient and interaction with all of them was fantastic. The whole ward team were constantly speaking to patients.'

(Ward 74) 'All staff including hostess, cleaner, Nurses, Doctors visiting health professional etc spoke to the patients, when in the bay area, whilst completing their tasks.'

There is evidence of an organisational or team approach to interacting with patients on a frequent basis e.g. staff carrying out tasks in the area or checking on patients.

Tasks are carried out by some staff or groups of staff around patients without acknowledging their **presence**. This was a very common occurrence in ward teams and especially across staff groups.

(Ward 42) 'Non-effective communication from other Healthcare Professionals i.e. pharmacist, doctors, physios when entering patient areas they didn't communicate with the patients, just picked up paperwork then walked away.'

(Ward 77) 'A different domestic was cleaning around and moving beds out etc without telling the patients what she was doing, no eye contact or even a smile. The patient looked afraid and vulnerable.'

(Ward 102) 'Housekeepers often did not communicate verbally or non-verbally with people with dementia they were cleaning closely around... lack of awareness about their impact on the person with dementia i.e. ignoring, coming into close personal space to clean but no talking, eve contact. One cleaner made a really loud banging noise while cleaning the bed area, startling the patient but housekeeper unaware.'

(Ward 103) 'Lack of interaction between qualified Nurses and patients with dementia.'

There may be inconsistency in the staff team in terms of checking on patients and poor visibility of patients to staff.

#### **INCLUSIVITY OF PEOPLE WITH DEMENTIA**

How inclusive are we of everyone including people who may have memory or communication problems, or who are 'quiet'?

Are some individuals treated differently to others?

All patients are communicated with, acknowledged or included by staff, regardless of how they present, not just those who are able to verbalise, mobilise, or who are 'social' or 'challenging' or 'compliant' or based on any other criteria.

(Ward 30) 'One patient who was walking around was never walked past or ignored by any member of the staff...'

(Ward 62) 'All staff were extremely patient when individuals were becoming repetitive in speech and behaviour'.

(Ward 64) 'Nursing staff address everyone in the area no-one is excluded'.

Staff may be attentive only to the person they are seeing and not acknowledging other patients in the same area.

(Ward 57) 'When persons enter room attention given to one patient and no acknowledgement to others.'

(Ward 59) 'Medical staff only speaking to the patient they have come to review instead of saying good morning to everyone'.

People with dementia or communication problems are not always approached to the same extent as **other patients.** They may be overlooked or appear to be invisible to staff (e.g. not offered a drink) and thus discriminated against.

(Ward 88) 'On several occasions patients with dementia were not fully engaged, although conversations would happen with patients who had health conditions not related to dementia.'

(Ward 29) 'Caterer took the red tray to patient and put down on table - no interaction with patient. Patient who is compos mentis gets asked full menu and there is interaction.'

(Ward 48) 'After the washes had been done Nurses did walk in twice however did not check on the patients who struggled with communication. They tended to come in and speak to the more able bodied patients... The staff spoke to patients who were more coherent rather than checking on all the patients in the bay.'

(Ward 119) 'Quiet patients had a tendency to be ignored unless a 'task' needed to be performed for them.'

Table 16: Ward ethos – Is there sensitivity to patient cues and an anticipatory response to needs?

Ward approach	Person-focused	Non person-focused (typical)
	RESPONDING TO PATIEN	T CUES
How attentive and sensitive are we to verbal and	Staff are extremely aware of and responsive to non-verbal and verbal cues given by patients, anticipate their needs and act on these	Staff may respond appropriately to individuals who ask for help, but this is reactive rather than proactive.
non-verbal cues given by individual	<b>immediately</b> to pre-empt/ prevent discomfort, agitation or distress. This means patients are not struggling to communicate their needs (e.g. few buzzers are used).	(Ward 48) 'Once a need was highlighted they dealt with the situation accordingly and in a respectful manner'.
patients?	(Ward 62) 'Staff anticipate patient needs and respond to non-verbal communication very well Cadet comes from behind curtain to check one lady is ok as she can	Verbal and non-verbal cues indicating the patient has a concern or wishes to interact may go unnoticed/ be ignored.
How quickly are these acted on?	hear her moving in bed. Walks over to another lady who is coughing slightly, rubs her back gently and asks "did it go down the wrong way?" This level of response meant that patients did not become distressed or agitated due to unmet needs or struggle to communicate these needs.'	(Ward 48) 'A patient who did not have access to a buzzer started to call out for help. Unfortunately no one came to the patient for at least 20 minutes despite members of staff walking into the bay The staff were notified that the patient was distressed eventually by the other patients in the bay.'
Are patients ignored at all?	(Ward 64) 'Staff are quick to respond to patients needs even when not vocalised. Quick to anticipate needs so call buzzers rarely heard.'	(Ward 106) 'Housekeeping staff did not interact with patients, despite the patients asking them questions, etc.'
What are the consequences?	(Ward 65) 'HCA saw one patient crying and upset and rubbing his tummy and mouth. She comforted him and walked him gently off to the bathroom. On return this gentleman was laughing and smiling, had obviously had a wash and his teeth cleaned. He was settled, relaxed and smiling at the HCA and other patients in the bay. Started laughing at times too. HCA continued to check on him throughout the morning, smiling and winking at	(Ward 97) 'On two separate occasions staff entered the bay and undertook activities without speaking to the patients. One patient sat forwards and was looking and tapping her fingers on the table when she saw someone come into the bay but then sat back and said 'oh dear' when they left without speaking to anyone.'  (Ward 18) 'Pharmacy check of drug charts, went around
	him each time she entered the bay. By picking up on this gentleman's non verbal communication, the HCA was	all beds picking up charts at end – all patients aware, often looking expectantly at person but no

able to meet needs which he could not verbally communicate.'

(Ward 68) 'Non-verbal and behaviour clues from the patient triggered prompt action by member of team to successfully address concern.'

This is likely to mean patients become better known to staff and cues can be acted on quickly to address a need (i.e. it is cyclical). For example:

(Ward 52) 'Staff are responsive to non verbal communication aware of puzzled look on patient face obviously has looked after her a few times and is aware of the problem and reacts to reassure patient.'

acknowledgments of patient presence, no smile or explanation.'

Thus, people may be struggling to communicate their needs and are not attended to. In the worst instances of patients being deliberately ignored, there were obvious immediate negative consequences on their physical and/ or mental health.

(Ward 106) 'Phlebotomist came to do blood test, did not speak to patient and continued to ignore him when he said that the blood test was hurting him.'

(Ward 76) 'Member of nursing staff walked straight past a patient who asked for help, she looked at her and ignored her. This lady was then incontinent and had to be changed.'

(Ward 76) 'Gentleman stood at Nurses' station whilst 2 staff and 1 Doctor were there. They ignored him - he became frustrated and 'acted out' due to his frustration.'

# Section 2: Systems to support connecting with the individual in a personally meaningful way

**During staff-patient interactions...** 

Do staff know and use information about the person to engage socially and emotionally with them?

Do staff flexibly work with the person's perspective, to help them participate in care activity?

#### What does this mean?

This is about all staff focusing on the individual person with dementia during an interaction and finding the means to engage in a way that makes sense to them (trying to take their perspective or 'enter their world'). This is the opposite of treating everyone in the same way and requires seeking to understand ways of relating to that person on their own terms. The person-focused approach starts with an openness to see the person and to engage with people who are vulnerable, in the recognition that the staff team then has to do more work to create an interaction in keeping with their life-world perspective.

#### Why is this important?

People with dementia have difficulties with their memory, cognition or spatial/ perceptual awareness that act as potential barriers to their understanding of, and participation in, what is going on. Systems to support connecting with the individual in a personally meaningful way are particularly important to enable staff to:

- i) address their social and emotional needs (such as to help people feel significant, included, comfortable, reassured and safe etc in an unfamiliar environment); and at the same time;
- ii) help facilitate their acute care and recovery (such as encouraging them to participate in personal care, consultations, rehabilitative activities such as walking, eating and drinking).

Engaging in a person-centred way is not simply about being kind, courteous or respectful to people with dementia which were highlighted as positive features of communication in many wards that participated in PIE. Neither is it about providing for a person's individual essential care needs such as hygiene or continence, unless this is in a way which engages them socially, maximises their usual abilities (e.g. to wash or walk to the toilet themselves) and which fits their preferred routine (e.g. choosing a bath or shower and use of products). This is important for enabling the

person to make a full recovery from the acute episode to their usual level of independence.

Because it is about focusing on the individual person with dementia and finding the key to specifically engage with them, knowing and using information about the person's history, responses or usual routine, likes and dislikes is especially important, as is having the skills to work sensitively and to be flexible or find creative ways of helping the person understand and participate. This requires communicating with each individual in a way which works with their perceptions at any moment in time and allowing this to direct the interaction (working WITH rather than doing FOR the person). A simple example may be recognising that a person with dementia needs prompting to eat a meal or cannot see a drink placed in front of them, then working with them at their pace and with ongoing encouragement to help them to complete this action. Knowing or finding out their preferences may help them to both participate in and enjoy their meal or drink.

#### Main findings

On the person-focused wards (N = 5), both knowing and using information about the person and working with the person's perspective to help them participate in care activity were in evidence.

On many wards, however, there was limited evidence of staff collecting, sharing or using information about the person with dementia to help guide interactions. 51 wards identified this as an area for action. Only 13 wards indicated good practice in this area. Also typically, the priority being given to completing tasks within a set routine meant that there was limited evidence of staff flexibly working with the person's perspective to help them participate in care. Care was often perceived to be a mechanistic way. There were 'pockets of person-focused communication' in many wards delivered by individual members of staff but these appeared to be the exception to the norm. Some wards provided no such examples. Ironically, focusing on completing a task from the staff perspective and not following this through with the patient meant that their care needs were not always met (therefore, the task was not completed).

### Table 17: Connecting with the individual in a personally meaningful way - Do staff know and use information about the person to engage socially and emotionally?

Table 17 identifies what differentiated meaningful engagement with individuals with dementia from the more typical commonly observed encounter. The first column provides examples of person-focused communication from across wards compared to non person-focused examples in the second column.

Ward approach	Person-focused	Non person-focused (typical)		
	KNOWING THE PATIENT AS A PERSON			
Do staff appear to have personal knowledge of the patient?  How much is this evident across the staff team?  Is this information used to address patients' social and emotional needs?	Patients preferred names are known and used by staff. Knowledge of patients' personal history, background, likes and dislikes is evident in activity or conversation with them or in their surroundings. Examples from the person-focused wards where this approach was taken by all/most staff were:  (Ward 30) 'C/N [charge nurse] has bought a newspaper for one patient. Staff all knew personal history of pts. Pictures from family were on wall besides beds all staff knew personal details about the patients with dementia, who grandchildren were and small extra details.'  (Ward 64) 'Lots of personal interactions – relevant and with an obvious knowledge of the patients and their histories staff call patients by their preferred names. Never have to ask a patient their name, even when only recently admitted.'  (Ward 67) 'Addressing using patients preferred name Interactions during care, sharing the conversation, talking about things known to the patient.'  Examples of pockets of person-focused practice in other wards were:	There is limited (little, if any) evidence of personalised knowledge of patients' personal history, background, likes and dislikes in activity, engagement or conversation with them or in their surroundings.  (Ward 10) 'Communication not collecting/using/valuing personal life history.'  Their preferred name may not seem to be obvious to or used by staff. Some staff may seem to have far more knowledge of the person than others.  (Ward 20) 'The Registered Nurse in charge of the bay knew all of his patients. He addressed them by an agreed name and chatted to them throughout the observation A HCA approached the dementia patient in the bay. She stood in front of him, took handover sheet from her pocket, read it, then addressed him. It was clear that she did not know the patients that she was looking after.'  (Ward 96) 'Due to the high turnover of patients it was evident that some staff were not familiar with individuals likes and dislikes (others were very		

(Ward 55) 'Staff member bought a soft toy for a patient familiar).' who was anxious and distressed saying that her own one had been removed for washing, another staff member wrapped it in a towel and the person cuddled it and looked more settled.'

(Ward 85) 'The positive attitude of staff - staff were kind, attentive and professional to individual patients whilst delivering care. In particular both the qualified Nurses and Healthcare Assistants had detailed knowledge relating to each patient around important aspects of each patient's life. In particular a Healthcare be talking with or to the patient solely about the task. Assistant came in to the bay and asked a lady if her son who lives in America had made his usual phone call to her at the weekend. The lady, who had previously been very quiet during the observation period, beamed a broad smile and started to tell the Healthcare Assistant all her news. This recognition of the patient as an individual and the genuine interest expressed by the Healthcare Assistant had a positive effect on the patient.'

(Ward 112) 'Whilst helping with a patient's personal hygiene, HCA asked the patient about her family which gave her valuable in-depth information about the person and cheered the patient up, as she obviously liked talking about her family.'

(Ward 48) 'It is evident that staff use washes as an opportunity to communicate with the patients. This can range from encouraging them to be aware of how they are getting better, 'your legs look much better today' to just to see how they feel. The Nurses often engage with the patient during this time discussing grand children and their own family.'

On occasion, staff may refer to patients using a label rather than their name. This occurred on a ward in which otherwise there was evidence of a consistent personalised approach:

(Ward 30) 'One staff nurse came in and said, 'bed 24 needs tramadol' we felt that not using the name and also announcing it in the bay was not person-centred.'

There may be little social conversation. Staff may

(Ward 60) 'Although staff talk to patients it is very task orientated, there was no conversation... Staff chatted to the patients whilst they were caring for them about what they needed them to do but there was no conversation about the individual, the weather, previous jobs etc.'

In the least person-focused instances, staff may be having a conversation between themselves about care or an unrelated topic which excludes the patient.

(Ward 47) 'Generalised discussion about social things in front of patients was a continuing theme which was evident when doing tasks such as making a bed.'

being the hostess who serves the food, patient should

be given a choice and time allowed for them to do this.

Table 18: Connecting with the individual in a personally meaningful way - Do staff flexibly work with the person's perspective, to help them participate in care activity?

Ward approach	Person-focused	Non person-focused (typical)	
HELPING THE PERSON TO PARTICIPATE IN THEIR CARE			
Is an attempt being made to enter the patient's world and work with them and their reality?	Whatever the focus of the specific interaction is for staff (e.g. personal, clinical, medical care or other) a clear attempt is made to work with the patient's perspective of the situation to help them to engage in the care activity. They are approached and encouraged to participate in a way which considers their feelings and meets their social/emotional and acute (e.g.	The focus is more on completing the task from the staff perspective. There may be little time/attention paid to helping the patient understand that there is an activity to complete (e.g. placing a drink next to them then moving away). Care may be delivered in a mechanistic way, with little evidence of flexibly engaging the patient to meet their needs or	
Does this help	clinical/physical/nutritional) care needs.	preferences. Their social/emotional and/or acute care needs might not be met.	
them to understand and participate in a 1:1 interaction or to complete an action?  Are staff flexible and creative in	(Ward 30) 'Lunch with pt1. Pt1 was very restless and refusing to eat and drink. He sat at a desk and was trying to ring his daughter. C/N [charge nurse] caring for him took a drink over and sat with him asking if he would like to try it. When pt agreed, he held the phone for him while he drank and then waited before bringing his food bit by bit to the desk. He chatted, sat at level and gave lots of positive reinforcement and managed to get him to eat all meal. This took nearly one hour.'	(Ward 92) 'The phlebotomist appeared to approaching her job as a very task orientated role. routine was to speak to each patient and tell them needed to take a blood sample whilst checking blood forms and the patient identity in a mechan manner. Although it was clear that she was a competent to perform the technical aspects of the technical communications with patients to put them at ease	
their approach? Is there permission to take this approach?	(Ward 71) 'Physio approaches patient, calls her by her preferred name and asks how she is feeling then talks to her about the benefits of walking. Explains what she would like to do and seeks the ladies permission to go ahead in a sensitive encouraging way. The lady	lacking. Had the patients been in a confusional state of disorientated this would have had quite a detrimental effect on the patients in terms of them understanding what needed to take place and them co-operating with the procedure.'	
	responds well and is happy to walk up and down the bay with the support worker and the physio.'	(Ward 70) 'Not all members of the multidisciplinary team give patient centred care; some of them give	
	This may involve having prior knowledge about	ritualistic care and treat them all the same. An example	

the person.

(Ward 74) 'Had bottle of coke on her table which she could reach and take lid off independently when wanted she preferred the bottle.'

(Ward 83) 'Staff knew that patient had been a boxer and encouraged him to eat and participate in physio by talking about getting to training.'

(Ward 93) 'One patient was due to be discharged later in the day. The patient was aware that her discharge was planned as she was ready and dressed and was gathering personal belongings together from her locker putting them onto her bed ready to put into a bag. A nurse came into the bay to check the patients understanding of what arrangements had been agreed the day before regarding transport home and who was going to be at home to greet her etc. During the conversation the nurse crouched down to the level of the patient touched her gently on the arm and called her by name. She also spoke about the patient's family network by name which clearly indicated that she knew the patients family background well.'

#### It may involve creative thinking from staff to meet all the patients' needs.

(Ward 83) 'German patient was asked to assist in communicating with another patient - made her feel valued and ensured the other patient got breakfast.'

(Ward 88) 'Staff showed good ingenuity to address needs of patient who said they were bored, by linking in with another patient who required close observations, enabling them to talk to each other.'

If they are not sure what might work for the person with dementia, then they are willing to try to find out.

However time is not allowed for the patients to ponder and as they have to serve all the patients on the ward.' a drink - had been offered to have it poured in glass but 12-55 HSW goes to each patient in turn and goes though the menu asked ML what do you want but did not wait for a reply.'

> (Ward 92) 'Not everyone coming into the area spoke to the patients as individuals and adopted either a totally task orientated approach to the job they were doing or didn't wait for patients to respond to their question and continued on with the iob they were doing.'

> In the worst instances, there may be little consideration paid to the person's wishes with staff being unwilling or feeling unable to step outside the task they set out to do/their perceived role.

> (Ward 77) 'One lady asked for the toilet. The OT [occupational therapist] walked past and told her it was not her job, 'press your buzzer'. The OT did not go to tell nursing staff that the lady wanted the toilet, just left her there having told her to press the buzzer, she didn't know what the buzzer was.'

> (Ward 31) 'A Staff Nurse walked in and went to pt's bed. Moved a drip stand from a mobile onto a bed pole. She had to lean across the patient to do this and never spoke to the patient. When she left, the patient's table was out of reach. Patient asked what the name of the patient opposite was and the nurse answered, 'I'm not allowed' and walked out.'

> (Ward 72) A male patient asked a staff nurse if he could stretch his legs the staff nurse said 'not now' and walked off.'

(Ward 37) 'Doctors breaking off to get carer involvement.'

(Ward 102) 'This lady also wanted to keep the curtains open while using commode and the toilet door open while using the toilet. Nursing staff helped find solutions. They realised she was afraid in confined spaces and took her to a larger shower room to use the toilet to reduce her fears.'

(Ward 72) 'The nurse encouraged the patient to drink trying three different types of drink to see if any would tempt the lady. The lady was very reluctant to drink but the nurse was very patient, and left the least disliked drink in easy reach with the top off the beaker and kept popping back with encouragement. The lady did indeed begin to give herself a drink.'

#### Section 3: Propellers - Specific features of the interaction person-focused to support communication

Is there evidence of staff employing specific features of interactions to support the reassurance, understanding and participation of the person who has dementia?

#### What does this mean?

This is about staff employing mechanisms (specific features of interactions termed 'propellers', such as simply and clearly providing information) to achieve particular facets of person-focused communication with a person who may have dementia.

#### Why is this important?

Each of the propellers outlined below was identified by wards as important for helping an individual to experience less confusion and have a greater understanding of, and familiarity with, what is happening, and to have a say in directing the interaction. In other words, the propellers help to support a person's social and emotional needs and/or facilitate their understanding and participation in the acute care process and recovery. Helping people with memory loss or impaired cognition to feel reassured was identified as being particularly important in the unfamiliar acute ward environment.

#### **Main findings**

Encouragingly, 102 out of 105 wards identified positive aspects of communication or interactions with patients as an area for celebration. Most wards fell short of having a comprehensive and consistent approach demonstrating a whole ward ethos of being open to engaging with people with dementia, or the majority of staff connecting with the individual in a personally meaningful way.

Rather, they described how some ward staff had certain attributes such as being kind and courteous, or wards employed certain positive features of interactions such as greeting patients, providing privacy, explaining care or presenting choices to patients.

Examples presented demonstrated individual staff in wards or the staff team using one or more specific features of interactions which are positive (e.g. explaining to patients what is happening) are identified below. However, without employing all these features of interactions, or without a whole ward approach involving the majority of staff, it was clear that the use of one or more interaction features does not by itself constitute person-centred care. A positive interaction is a necessary but not in itself a sufficient condition for person-focused communication. For example, orienting a person to what is happening might involve greeting someone by their

name. This will not be effective unless their hearing aid is in. Knowing this entails knowing the person. The ward cannot support orientation unless all staff on all occasions acknowledge the patient and know their name and personal circumstances This is before beginning to give further explanation about what is happening during a care activity.

Very often, therefore, several features will occur in one interaction and these need to be tailored to the person to be 'person-focused'. The majority of wards recognised this and reported that although they observed positive aspects of communication, other aspects required improvement – 92 out of 105 wards identified aspects of interactions or communication as an area for action. 90 out of 105 wards identified that different aspects of communication were deserving of both celebration and action.

Although many observers also identified interactions that were positive because they upheld the privacy, confidentiality or dignity of patients (such as pulling curtains across when giving care, ensuring people are covered appropriately or maintaining confidentially during conversations), these are not outlined here. This is because, although this is self-evidently important, such issues are currently well-recognised and addressed within the dignity agenda informing hospital care for older people. The intention here is to focus on specific aspects of communication and how these might be improved for people with dementia rather than the broader issue of dignity.

# Table 19: Propellers - Specific features of the interaction to support person-focused communication

Table 19 identifies which specific characteristics of one-to-one interactions were perceived as person-focussed, and able to support people with dementia (first column) compared to those which did not (second column).

Staff action	Example of propeller for person-focused communication	Example of propeller for less person-focused communication	
	FORM OF ADDRESS		
Use of patient's preferred name	(Ward 79) 'Patients preferred names are present on the notice board above their beds, this encourages staff members to call them by their preferred names rather than their given names.'	(Ward 36) 'A number of staff used depersonalising terms, including sweetie, sweetheart, love, duck and little dot.'	
	ORIENTATION		
Telling a patient your name	(Ward 11) 'Everyone addressed by their names. Staff always introduced themselves prior to undertaking any intervention.'	(Ward 36) 'No member of staff told a patient their own name. This meant familiarity with the patient but not with the staff.'	
Continual orientation to time of day, routine, and place	(Ward 36) 'A patient required orientation to time and place. This was undertaken by multiple members of staff, many times and with patience.'  (Ward 62) 'Staff continually orientate patients to time of day and routine – 'we'll be having our breakfast soon'. Lots of commentary going on so that everyone within the bay knows what is happening – patients appear extremely reassured by this'.  (Ward 113) 'Whilst being taken to the toilet by an HCA [healthcare assistant], a patient became agitated about where he was and why he was in hospital. The nurse calmly explained that he was in hospital and why. This	(Ward 65) 'Conversations between staff gathered at the staff base, or on the corridors, could be heard within the bays. There is serious potential for these to be misinterpreted by patients with cognitive impairment/confusional states, which could lead to excessive distress due to the nature of some of these conversations Staff do not always communicate with patients on entering a bay. This could potentially distress someone who is disorientated and looking to staff and the environment for cues and clues about their situation.'  (Ward 47) 'Patient was taken for a test off the ward.	

	would allay the patient's fears and orientate him.'	Staff did not engage with patient clearly to explain where they were going. Patient's bed was being moved by porter and nurse and patient seemed startled at bed being moved.'	
	INFORMATION PRESENTATION		
Simple and clear presentation of information	(Ward 99) 'Nurse approached patient to assist them choose their meals for the following day. They spoke clearly and slowly, allowing time for the patient to understand what was being said and make their choice. Where necessary they changed the way they asked the question to help the patient to understand.'	(Ward 37) 'Different caregivers would give the same dish different names, patient known to be aphasic, so words would have further confused the patient. Food should be shown, not just type of dish.'	
		(Ward 120) 'Staff nurse asked the patient about pain relief in a very complicated way. Patient didn't hear and didn't understand but the staff nurse repeated what she said without moving closer to her.'	
Use of various and appropriate verbal and non-verbal communication techniques	(Ward 35) 'A therapy assistant gave information to one patient using varied communication techniques. This involved good body positioning, clear speech but also utilised visual information, demonstration and feedback. As a result the patient was more engaged than at any other time during the observation.'	(Ward 119) 'Registered nurse gave hardly any eye-contact, didn't smile, didn't call the patient by their name. Didn't remind the patient who they were. Showed little insight into the needs of a cognitively impaired patient who needs information reinforced in a positive way at very regular intervals.'	
	EXPLANATION		
Step-by-step explanation during care activity in terms that the person can understand	(Ward 89) 'A student nurse interacted well with patients while carrying out observations. Explaining clearly the process involved. She also used the Care Round Tool to ask specific questions of patients. Are you comfortable, are you in any pain? Do you want a drink. Then took appropriate action when a patient wanted pain-killers. The rapport was such that when offered help from another nurse the patient said they would wait for the student to come back from her	(Ward 99) 'Blood samples being taken immediately following meal. Very little interaction with patient to explain procedure, minimal restraint required which resulted in patient being unsettled and unhappy.'	

	break as she said that she would help her then with a wash.'	
Checking back with the patient that they understand	(Ward 94) 'Whilst administering medication there was a query made by the patient about her treatment. Staff responded to the query in a knowledgeable manner and checked back with the patient that she had understood the explanation. This led onto further questions about what was likely to happen before the patient could go home. Again staff discussed what needed to happen which appeared to reassure the patient and lessen her anxiety.'	
	(Ward 81) 'Patient with confusion was given nurse call buzzer by nurse, nurse asked the patient to demonstrate to her that she could use the buzzer before she left the patient.'	
	NEGOTIATION	
Negotiation / agreement with the person	(Ward 64) 'Staff negotiate care with patients. HCA [healthcare assistant] gently woke patient and asked would he like a bath or a wash. Said he would like a bath and both agreed what time. HCA [healthcare assistant] kept popping back in to let patient know what was happening and that she hadn't forgotten him. He thanks her and says 'I know you won't forget.'	(Ward 78) 'Listened to care being given to a patient, orders were 'barked' at the patients, there was no conversation with that patient other than instructions. One patient being toileted whilst two members of staff talked over her in first language.'
	Even though it is almost lunchtime when this gent goes to the bathroom, he's had a settled, relaxed and restful morning. Lunch is kept hot for him and when he returns from the bathroom he's obviously relaxed and happy and enjoys his lunch.'	(Ward 35) 'Patients in one bay were approached, their curtains drawn and told that the staff were there to turn them. In this case the patients had no choice as to how, when or whether the activity took place.'
	(Ward 100) 'Member of staff required bloods for testing. Full explanation of the procedure given to patient and attempted to gain patients understanding and consent. Continued to explain intervention	(Ward 16) 'Toileting. Patients who can walk not being offered option to go out to bathroom rather than commode behind curtains.'

throughout procedure which resulted in the patient remaining calm and co-operative throughout. Dignity and respect shown to patient. Patient was able to communicate non-verbally and showed she felt comfortable by smiling and nodding at the member of staff.'

(Ward 54) 'Good examples of staff listening to the person i.e. complaint of pain which was managed.'

#### Knowing or facilitating personal choice

(Ward 54) 'Choice of "favourite" pudding showed the staff member knew the person quite well.'

(Ward 62) '82 year old lady was left with 2 cups of tea with her breakfast as staff knew that she liked this.'

(Ward 85) 'Person-centred care was delivered. Awareness was shown of the individual preferences of the patients. In particular a Healthcare Assistant asked a lady if she would like a bath. Whilst conversing with the patient it was evident the Healthcare Assistant had detailed awareness of the patients preferred hygiene choices, the fact that she really enjoyed a bath and would love to have her hair washed. This recognition of the patient as an individual and the sensitive manner of the Healthcare Assistant had a positive effect on the patient who engaged verbally and non-verbally, with a lovely smile, whilst having her hair done.'

(Ward 82) 'One patient in particular had particular preferences to his drinks (like and dislikes), staff ensured he had his favourites at hand (this was important as his oral intake needed encouragement).'

(Ward 35) 'A lady was given headphones to wear. This appeared personalised as the patient settled. However, there was no choice in the music played. This was popular music which was so loud the observer was able to hear it.'

(Ward 82) 'Not all staff were aware of personal preferences in terms of patient care/choices e.g. likes and dislikes in diet and drinks. One patient reported they liked their water warm, staff brought a glass of cold water, the patient said they liked warm water and the water was cold and couldn't take their medicine. It was the nutrition assistant that noticed the patient's distress and took action. Other patient asked for a drink of coffee, coffee was cold, staff member noticed this and told the patient they would fetch another cup of tea, brought tea, patient said he wanted coffee but "never mind I'll drink it"

(Ward 90) 'Housekeeper did not offer a patient an alternative when she refused a cup of tea.'

#### POSITIVE REINFORCEMENT TO COMPLETE AN ACTION

Encouragement/

(Ward 60) 'Lots of encouragement and praise from (Ward 90) 'Once the dinners had been given, the staff

#### prompts

therapy staff to go a little further than they had previously managed post op and praising them when they had achieved this."

(Ward 62) 'Staff continually give prompts, instructions and praise.'

(Ward 64) (at meals) 'HCA's constantly checking that patients can manage.'

(Ward 70) '08-30 M.L is being washed when audit commenced, comments from inside the curtain form the HCA, can you comb your hair, here we are here is the brush. ML No you do it, oh come on have a go for me. Oh alright I will do it. There you look lovely. E (enriching)'

(Ward 88) 'Staff were encouraging patients with drawing a picture, the more encouragement the staff gave the patient, the more animated and interested the patient became.'

went to other areas, therefore for patients who needed encouragement/prompting to eat, this was a missed opportunity.'

(Ward 99) 'Throughout morning patient was reminded that he had a cup of tea but it was left on his bedside table. No attempt made to give any physical prompts or interaction to ensure that patient was aware of his cup of tea. Tea was left untouched for one and a half hours. Patient was obviously very thirsty by lunch-time and drank five cups of water.'

(Ward 98) 'A patient was taken to the bathroom to wash and was gone for 30 minutes before someone went to check on her. The patient was sitting patiently waiting to be collected but ? if she had washed herself.'

#### PACE OF CONVERSATION OR ACTIVITY

#### Time given to the patient

(Ward 76) 'Staff talked to the patients taking their time with them i.e. patients hearing aid was not in position correctly, the nurse took 30 minutes talking to the patient reassuring her and getting her hearing aid in place correctly.'

(Ward 102) 'Patient with dementia was shouting requests to staff to use toilet, have a drink. Requests would also be repetitive e.g. asking to go to the toilet after just been. She appeared agitated. All requests were met by ward staff. They always took the time to deal with each request.'

(Ward 97) 'One patient was observed to be hurried along with his wash in the morning, politely and in a friendly manner but this did not allow the patient to do as much for himself as he may have been able to.'

# Effect on patients and staff of working in a personfocused way

The examples given in the tables illustrate how, when person-focused communication was taking place, patients were made to feel visible to, valued and reassured by staff and were encouraged to socially engage and to participate in their care.

Crucially, interacting with individuals in a way that was personally meaningful, facilitated participation in care processes essential to their acute recovery and return to their usual state of health, e.g. in supporting eating, drinking, walking or continence.

There was a positive attitude and higher staff morale observed on the person-focused wards or in wards in which there were evidently pockets of person-focused practice. For example:

'Positive attitude of staff was clearly visible. Patients clearly felt safe and secure. Staff constantly came round and checked if patients were all okay.'

Staff clearly gave of themselves in person-focused interactions, not just in placing the needs of the person above the pressures of the clinically oriented routine – which was identified to be challenging in many wards – but in being compassionate and engaging on a reciprocal level, for example discussing their own families or activities. Patient feedback directly received during PIE on one of the person-focused wards illustrated the positive feelings this engendered:

'82 year old lady [with dementia] tells observer that she had to be moved to another ward for a couple of days, but when she returned to this ward, all of the staff welcomed her back. "It was like coming home. If they could turn this into a residential home I'd come flying".'

'One lady says "at my age you're just not used to men doing things for you... but X [male healthcare assistant] is lovely. I don't mind asking him for anything".'

It was observed that although there were incidences where some staff did not interact with patients; 'no patients appeared distressed by these occurrences during the observation, as they obviously felt secure due to the positive relationships between other staff and themselves' (i.e. there is a degree of compensation).

# Action planning: What are the key steps to facilitate person-focused communication?

# What are the common actions being taken?

All participating wards identified short-term actions to take which were intended to be realistic and achievable for the ward team within the next month. Across wards, shortterm and long-term actions mirrored the need for and covered the spectrum of embedding the three main elements of person-focused communication (openness to engage, meaningful connection, use of supportive features of interaction). Often, strategies were discussed which the person-focused wards already had in place and which have been identified in the model presented above.

The main areas identified for action in relation to communication (with typical examples from across wards) were:

# Action 1: Encourage staff to interact with people with dementia at every opportunity

This was a common area for action.

Examples from ward action plans on encouraging interaction:

- Encourage all staff members to use each patient contact as an opportunity to enhance the patient experience and communicate effectively, even if it is a wave or a good morning etc.
- Speak to all members of staff about the need to interact with all patients and to explain what they are doing instead of walking in and out of a room.
- Advise all staff on using commentary while delivering care to all patients in a bay - encourage this as normal practice.
- Remind staff that quiet/sleeping patients may be in need of interaction and encourage them to do this.

# Action 2: Raise staff awareness of the immediate impact of positive and negative interactions on patients

It was also extremely common to suggest sharing practice examples of what is working well and what is not working well with the ward team and all staff groups, so that they are aware of the impact of their interactions and of missed opportunities for interaction on patients.

Examples from ward action plans on raising staff awareness:

- Talk to the domestic staff about the importance of leaving all patients a drink, not just those who are awake or able to talk. If there is a drink by their bed, staff are more likely to give it to them than if they have to go and make drink for the patient.
- Celebrating good practice reinforcing how well these positives impact on patient's wellbeing.
- Ensure feedback (from observations) is given to all staff and the message of the good work they are doing gets across to them. Ask some ward staff to sit and observe for 30 minutes, they will see for themselves some of the (less positive) things discussed.

# Action 3: Organise ward activity to enable frequent patient-staff interaction

Examples from ward action plans on enabling frequent interaction:

This was sometimes linked to other ongoing initiatives, with some wards introducing hourly rounding:

Encourage all staff visiting the ward to communicate more with patients, including equipment store staff, pharmacist, library volunteers etc. This is part of the approach of the Care Round Checklist, to ensure that all staff take responsibility for responding to patients needs.

Careful thought was given to how barriers in establishing communication might be overcome by shifting the locus of ward activity, especially administrative tasks or by having a patient allocation system to spread activity and ensure ongoing contact and stimulation between patients and staff. Also to ensure the visibility of patients to staff and vice versa for example, curtains being pulled back after care, or people who have dementia being located near to the nursing station. Having smaller bays in wards was also identified to be helpful.

- As far as possible patients with dementia are nursed together near to the nurse's station.
- Encourage staff to be present in the bays when writing up notes (all notes trolleys are now on wheels with a flat top for writing).
- For a member of staff to be based within bays to spend time with the patients.

Having busy then quiet periods was very common across wards so some suggested changing the times of ward routines to increase staff presence.

Develop person-centred handover further. Patients included in bedside handover consider extending this further to include quiet times.

### Action 4: Ensure people with dementia can reach their call buzzers

As incorporating frequent checks on patients at times of high clinical demand was identified to be challenging in some wards, this was another simple strategy.

Examples from ward action plans on reaching call buzzers:

Ensure that all buzzers are within reach and that patients are given repeated reassurance that it is ok to use it if they need help.

This included reinforcing to all staff groups the importance of placing buzzers back in reach after patients receive care e.g. Doctors' rounds.

Staff to ensure that tables are always returned to a position within reach of the patient and that the call bell is visible and within reach (to include Doctors).

### Action 5: Collect, use and share information about the patient as a person

This was viewed as important for implementation in individual wards and across Trusts/Health Boards. Many wards planned to use or better use a standardised document. Also suggested, was making information about the person easily accessible near their bed space, e.g. cards above beds with preferred names or photographs/ resources to stimulate conversation/activity. On the person-focused wards such information was quickly obtained (on admission) and disseminated to all staff members.

Examples from ward action plans on collecting and sharing information:

- Work with the dementia specialist nurse to introduce more information about the patient as a person e.g. 'This is Me' leaflet<sup>9</sup>.
- To encourage staff to interact more with dementia patients, to learn something about them that may make conversation and interaction easier.
- Ward manager to consider developing a 'food preference' questionnaire for families to complete for those patients who are unable to communicate effectively.
- The directorate are planning to implement the 'This is Me'9 documentation from the Alzheimer's Society.
- Encourage relatives to bring in reading material, photo albums, playing cards etc to stimulate patients/reduce boredom factor or patient's money to buy daily paper.
- Likes and dislikes document available to all staff in the care plan folder will include a visual prompt in terms of nutrition (food and drink) but also in terms of personal care e.g. prefers a shower, likes pyjamas instead of a nightie.
- Place 'This is Me'9 leaflet onto clipboard or end of bed to make it more accessible.

# Action 6: Negotiate with and provide care to the person to fit their routine and preferences rather than the ward routine

This was in recognition that the ward routine or a mechanistic way of working often took priority over the individual. Thus, greater flexibility was required.

Examples from ward action plans on providing care according to routine and preferences:

- Encourage patient focussed/ individualised care. Try to formulate a care pathway around the patient's normal activities rather than care which is focussed around ward routine.
- Patients to be offered choice regarding washing and toileting, not where staff want to do it. Staff to work more as a team in bays, negotiating between themselves after handover so that if two people are needed for a task they can prioritise their other work as needed so as to be available together, especially important with morning routine.
- Encourage staff to offer choice before care activities are undertaken.

# Action 7: Recognise the attributes of exceptionally skilled members of staff and use them as role models or dementia champions within the team

Also identified were clear ward leadership and access to specialist dementia Nurses. On one of the person-focused wards, there was clear senior support for front-line staff e.g. suggestions by Healthcare Assistants for dementia aids at meal times following dementia awareness training.

Examples from ward action plans on use of role models and champions:

- Team leader to provide better direction and focus on individualised patient care.
- Identify which ward staff could be dementia champions and what resources they would need.
- The C/N (charge nurse) who showed such skill has agreed to become a facilitator and will now train Healthcare Assistants in caring for patients with dementia.
- Registered Nurses to provide clear expectations of the standard of care they expect to be delivered. This could be made explicit at the beginning of a shift using "Key expectations" i.e. "During this shift I expect you to greet and speak to patients using their preferred name and give clear explanations of the care you are delivering". Ensure that all agency and Healthcare Assistants get to work alongside good role models.
- Encourage junior staff to job shadow more skilled staff on the ward.

# Action 8: All staff (ward staff and other staff groups) to attend dementia awareness and communication training

This was the most common action identified for implementation across the directorate or Trust/Health Board. It was clear that on the person-focused wards on-going dementia training and action initiatives were taking effect.

Examples from ward action plans on training:

- Ongoing dementia awareness training for all staff who come into contact with patients with dementia in the Trust.
- Staff to attend the fundamentals of dementia care which are run in this organisation.
- Staff to have a better insight in dementia by attending appropriate study days or courses.
- Cascade the benefits of improved access to dementia awareness between all staff, ensuring that non clinical staff benefit from staff experience and expertise.

# Action 9: Work with all staff managers and teams to raise awareness and to develop an agreed and consistent approach

This was identified to be crucial to help embed all the above.

Examples from ward action plans on working across teams:

- Medical staff to be informed of what has been observed and its impact on the patients.
- Talk to some of the other teams catering, domestic and portering to improve interactions with patients with dementia.
- Identify key staff to become 'Dementia Champions' in each area (not just clinical), e.g. housekeeping. Investigate training available to housekeepers and implement if required.
- There are a lot of changes going on in the Trust at present with senior management being restructured... Housekeeping staff are now under the ward managers control so it will be easier to ensure that their practice is monitored and managed as required.

# What support is being provided at Trust/Health Board level?

101 wards identified areas for longer-term action at directorate level (2 additional wards identified organisational barriers to implementation and 2 wards did not identify actions at this level). 102 wards identified areas for longer-term action at Trust/ Health Board/strategic level (2 additional wards identified organisational barriers to implementation and 1 ward did not identify actions at this level). It was encouraging

therefore that most Trusts/Health Boards indicated they planned to implement longerterm actions.

The actions intended at directorate and Trust/Health Board level involved:

- Sharing and rolling out elements of good practice identified in individual wards.
- Implementing and embedding Trust/Health Board-wide changes to current systems through:
  - Trust/Board wide dementia steering groups and action plans.
  - to and involvement of other senior management committees/groups and patient advocate or volunteer groups.

Reference was made to existing Trust/Health Board-wide initiatives such as 'protected mealtimes', introducing a 'patient passport' across Trusts, early introduction of 'hourly rounding', introducing the 'Butterfly scheme' and attendance at dementia awareness study or staff training days. For example:

The Trust is currently developing a local dementia strategy that will include: self assessment, audit results and action plans. 'This is Me' has been piloted and will be rolled out across the organisation.

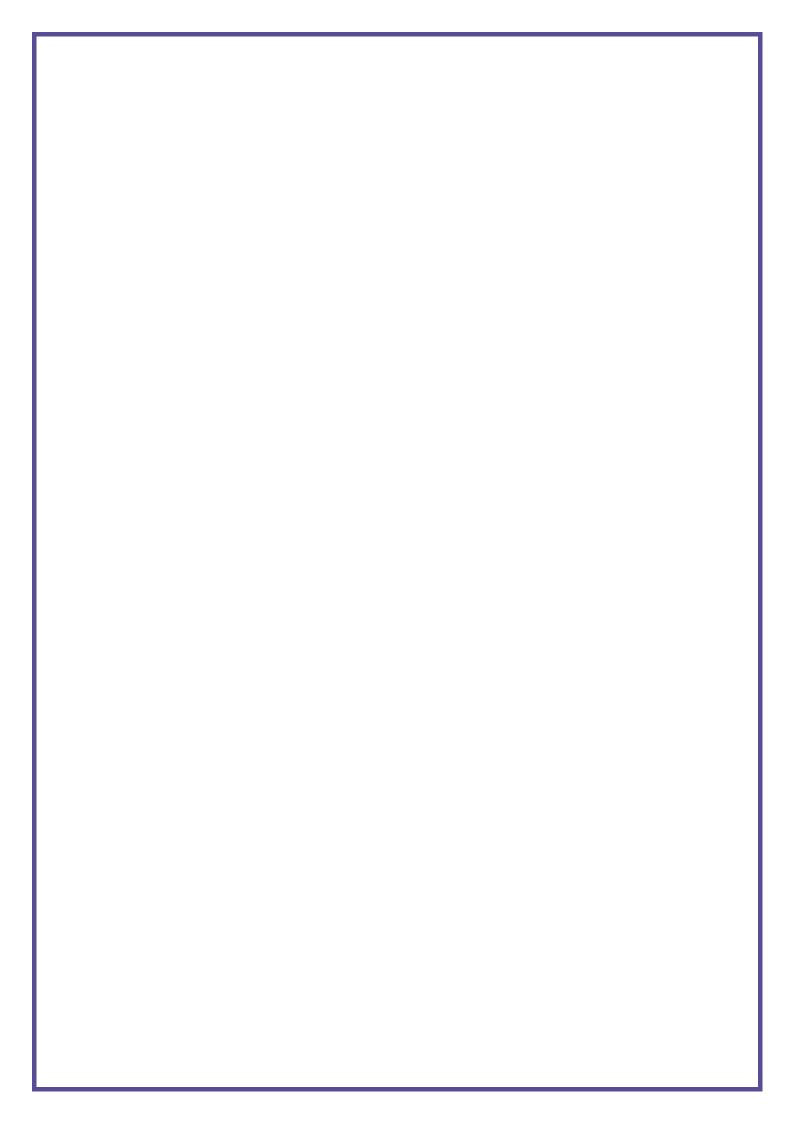
Meeting with and gaining the support of senior colleagues and management was identified as the key mechanism for raising awareness and initiating directorate or Trust/Health Board wide actions. For example:

- Head of porter/ housekeepers needs to provide training for their staff. We are presenting the finding to the matron's meeting and the nursing and midwifery advisory group.
- Pass this (information) on to other wards through Sisters meetings and clinical governance.
- Feedback and celebration of good practice within the Department of Medicine for Older People and across the organisation, using Departmental Management Meetings and the Organisational plans for 'Nurses Day' Celebrations of good practice.
- Use real cases to give feedback to the Executive Board.
- Findings to be discussed at the Dementia Operations Committee (Trust-wide). Consideration needs to be given to identifying how clinical staff from all areas can be given the opportunity to undertake PIE observation for themselves. The systems and process to support these actions are already in place.
- Trust has started Dementia Strategic Development group to facilitate staff training and care pathways.

# **Conclusion**

The function of communication in acute care has to be one which consistently focuses on, and provides for, the particular needs of people with dementia in order to successfully facilitate their participation and recovery. The results of the PIE audit shows this is achievable but rarely fully delivered. It is apparent that there is considerable scope to develop and enhance person-centred care for people with dementia. The aim should be to initiate a progression from the currently dominant culture of task based care to one in which there is an integral focus on the person. Taking a proactive approach and having a timely and attentive response to people with dementia also means that their discharge is likely to be more appropriately facilitated, impacting on costs, as identified by the Alzheimer's Society<sup>6</sup>.

Using the PIE observational tool was reported to be a valuable exercise for raising staff awareness and for identifying easily implementable actions to improve care. Therefore, wards could consider observations of practice as a key method for data collection and for monitoring progress over time. The participating staff also reported positively on the opportunity to network - to discuss, share and disseminate ideas or strategies for person-centred practice for people with dementia across Trusts/Health Boards. The next helpful step would be to investigate how or whether greater staff awareness and action planning arising from PIE actually effects change.





# **Appendices**



# **Appendix 1: Glossary**

**Acute illness:** A disease with an abrupt onset and short course.

**Advocacy services:** A service that can speak on behalf of a patient or a group of patients to help them make their wishes known.

**Agency staff:** Staff who have a contract of service/employment with an external agency and not with the hospital.

**Ancillary services:** Services that provide support to patients in the hospital; such as physical therapy, pharmacy, dentistry.

**Antipsychotics:** A group of medications used to treat people with mental health conditions.

**Appraisal:** Evaluates an individual staff member's contribution to the organisation and discusses learning or development objectives.

**Attendance allowance:** A tax-free benefit for people aged 65 or over who need help with personal care because they are physically or mentally disabled.

**Audit:** Quality improvement process that seeks to improve patient care and outcomes through systematic review of care against explicit criteria and the implementation of change.

**Bank staff:** Pool of clinical, allied healthcare and administrative staff who cover maternity leave and temporary vacancies.

**Behavioural and psychological symptoms of dementia (BPSD):** A term used to describe the behavioural and psychiatric disturbances often seen in later stages of dementia. Symptoms commonly include depression, apathy, agitation, disinhibition, psychosis (delusions and hallucinations), wandering, aggression, incontinence and altered eating habits.

**Benchmark:** A measure or standard that can be used to compare an activity, performance, service or result.

**Body Mass Index (BMI):** The individual's body weight divided by the square of his or her height.

**Boards:** Body of elected or appointed members who jointly oversee the activities of the Trust/Health Board.

**Butterfly scheme:** A system that offers discreet identification of people with memory impairment, backed up by a five-point plan for all staff to follow when they see the butterfly symbol.

**Capacity:** The ability to understand and take in information, weigh up the relative pros and cons and reach a sensible decision about an issue.

**Care pathway:** Sequence of practices, procedures and treatments that should be used for people with a particular condition. The aim is to improve the quality of care.

**Care plan:** Strategies designed to guide healthcare professionals involved with patient care. Such plans are patient-specific and are meant to address the total status of the patient.

**Care support worker:** See 'healthcare assistant' in glossary.

Carer's allowance: A benefit to help people who look after someone who is disabled.

**Carers:** Someone (commonly the patient's spouse, a close relative or a friend) who provides ongoing, unpaid support and personal care at home.

**Casenote:** A written account of a patient's examination and treatment that includes the patient's medical history and complaints, the results of diagnostic tests and procedures, medications and therapeutic procedures.

Challenging behaviour: Verbally or physically aggressive behaviour.

**Champions:** A member of staff who lead good dementia care in different areas of the hospital.

**Chief Executive:** Appointed heads of bodies such as NHS Trusts responsible for leadership and management.

**Clinician:** A health professional whose practice is based on direct observation and treatment of a patient.

**Cognitive functioning:** Intellectual process by which one becomes aware of, perceives or comprehends ideas. It involves all aspects of perception, thinking, reasoning and remembering.

**Commissioning:** The process used by health services and local authorities to identify the need for local services; assess this need against the services and resources available from public, private and voluntary organisations; decide priorities; and set up contracts and service agreements to buy services. As part of the commissioning process, services are regularly evaluated.

**Co-morbid:** Co-existence of more than one disease or an additional disease (other than that being studied or treated) in an individual.

**Comprehensive assessment (for frail older people):** A multidimensional and usually interdisciplinary diagnostic process, designed to determine a frail older person's medical conditions, mental health, functional capacity and social circumstances.

**Consultant psychiatrist:** A specialist medical doctor, fully trained in psychiatry and on the General Medical Council's Specialist Register.

**Council tax rebate:** A council tax benefit for those who pay council tax with an income and capital (savings and investments) below a certain level.

**Cross-observing:** Observing on a ward different to one's own.

**De-escalation techniques:** Techniques used to avoid escalating a situation and to bring about the possibility of resolution through communication, not force.

**Delirium:** A medical diagnosis when a person cannot concentrate or think clearly, and are unaware of what is going on around them. People with delirium can often see or hear things that are not actually there (hallucinations), but which seem very real to them. It develops very quickly and is usually temporary.

**Dementia Care Mapping:** An observation tool designed to examine quality of care from the perspective of the person with dementia. It is part of a process of bringing about improvements to dementia care and is designed to be used only in formal care settings

**Dementia:** A condition in which there is a gradual loss of brain function. The main symptoms are usually loss of memory, confusion, problems with speech and understanding, changes in personality and behaviour, and an increased reliance on others for activities of daily living. There are a number of types of dementia. Alzheimer's disease is the most well known.

**Dementia-sensitive approach:** Being aware of and attending to the specialist needs of people with dementia.

**Descriptive statistics:** Description of the main features of a collection of data. Descriptive statistics aim to summarise a dataset, e.g. mean and median.

**Director of Nursing:** A director of nursing is in charge of the performance of nursing staff in a hospital or any other healthcare facility. He or she is primarily responsible for directing and motivating others, and developing and implementing patient care services.

**Directorate:** A board of directors.

**Discharge plan:** A plan to facilitate a patient's movement from one healthcare setting to another, or to home.

**Discharge summary:** A clinical report prepared by a physician or other health professional at the conclusion of a hospital stay or series of treatments. It outlines the patient's main complaint, the diagnostic findings, the therapy administered and the patient's response to it, and recommendations on discharge.

**Dysphagia:** Difficulty in swallowing.

**Elective treatment:** Care provided at a planned or pre-arranged time rather than in response to an emergency.

**Evidence-based interventions:** Involves making decisions about the care of individual patients, based upon the best available research evidence, rather than on personal opinion or common practice (which may not always be evidence-based).

**Executive board:** See 'Boards' in glossary.

**Faith-specific support:** Access to support from a practitioner of the same faith as one's own.

**Feasibility study:** A process that defines what a project is and what strategic issues need to be considered to assess its feasibility, or likelihood of succeeding.

**Flagging systems:** A system which "flags" a person with dementia to identify and raise awareness of their specific needs, as they move through the hospital and come into contact with different members of staff.

**Framework:** Long term strategies for improving specific areas of care or training. They set measurable goals within set time frames.

**Functioning:** Social, occupational and psychological functioning of adults, e.g. how well to one is meeting, or adapting to, various problems in living.

**Governance:** The system through which NHS organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care.

**Handover:** A communication that occurs between two shifts of nurses with the specific purpose of communicating information about the patients under their care. This can be written or verbal information.

**Head of therapy directorate:** The person responsible for the operational and strategic management, and professional and clinical leadership of the Trust's therapy service.

**Health boards (Wales):** Local Health Boards (LHBs) were created in 2003 to replace Health Authorities in Wales. A Welsh NHS Trust will typically administer all hospitals in a region, as well as all community care and mental health functions.

**Healthcare assistant:** Also known as a support worker, nursing assistant, or nursing auxiliary. They help healthcare professionals with the day-to-day care of patients, such as helping patients to wash and eat.

**Healthcare utilisation:** The extent to which a given group uses a particular service in a specified period.

**Holistically:** When all aspects of a person's needs are taken into account and seen as a whole, i.e. psychological, physical and social.

**Home safety assessment/environmental assessment:** Identifies potential risks and hazards in the normal home environment and offers information, advice and practical assistance to overcome these.

**Hourly rounding:** Carrying out intentional checks on high risk patients on an hourly basis, combined with asking about any needs, such as comfort, pain, thirst, need to use toilet, ensuring bell within reach and specific offer of help with any further needs.

**In-patient:** A patient who is admitted to a hospital for treatment that requires at least one overnight stay.

**Institutionalisation:** To place a person in the care of an institution, such as care homes or nursing homes.

**Inter-rater reliability:** The degree of agreement among auditors. It gives a score of how much consensus there is in the responses given by different auditors.

**Intermediate care services:** A range of integrated services to promote faster recovery from illness, prevent unnecessary acute hospital admission, support timely discharge and maximise independent living.

**Interpreting services:** Services that help with communications between professionals (doctors, nurses and other health professionals) and patients, families and carers who are unable to communicate using English.

**Interquartile range (IQR):** A statistical term that represents the distance between the 75<sup>th</sup> percentile and the 25<sup>th</sup> percentile. It is essentially the range of the middle 50% of the data.

**Job plans:** A consultant job plan is a prospective agreement that sets out a consultant's duties, responsibilities and objectives for the coming year.

**Legislation:** A proposed or enacted law or group of laws.

**Length of stay:** The total number of days a person stays in hospital.

**Liaison psychiatry:** A psychiatric liaison team working in a general hospital, for example in accident & emergency or in-patient wards. They can provide psychiatric assessment and treatment to those patients who may be experiencing distress whilst in hospital and provide a valuable interface between mental and physical health.

**Life-world perspective:** How the person with dementia understands or tries to make sense of their experiences.

**Literature review:** Collecting, reading and assessing the quality of published (and unpublished) articles on a given topic.

**Local and regional level:** Data at a local level is data collected from an individual hospital site. Data at a regional level is data compiled from all hospital sites in a region.

**Local involvement networks (LINks):** LINks are made up of individuals and community groups, such as faith groups and residents' associations, working together to improve health and social care services.

**Matron:** An experienced senior nurse on a ward.

**Median:** The median is the middle point of a dataset; half of the values are below this point, and half are above.

**Medical Director:** A Physician in a hospital who serves in a medical and administrative capacity as head of an organised medical staff, and who also may serve as liaison for the medical staff with the administration and governing board.

**Mental assessment:** Gives an overall picture of how well a person feels emotionally and how well they are able to think, reason and remember.

**Mental Capacity Act:** Provides a framework to empower and protect people who may lack capacity to make some decisions for themselves.

**Mental health disorders:** Disorders that affect the way a person thinks, feels or behaves. They can significantly affect a person's relationships, work and quality of life.

Mental health liaison services: See 'Liaison psychiatry' in glossary.

**Misdiagnosis:** An inaccurate assessment of a patient's condition.

**Mode:** A mathematical term to describe the number which appears most often in a set of numbers.

**Morbidity:** A diseased condition or state.

**Multidisciplinary assessment:** Comprehensive assessment of needs by a range of health and social care professionals, e.g. consultant physicians, occupational therapists, social workers.

**NICE (National Institute for Health and Clinical Excellence):** An independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health. NICE provide guidance on three areas of health: public health, health technologies and clinical practice.

**Non-pharmacological approaches:** Healthcare treatments that do not involve the use of drugs.

**Non-verbal:** A process of communicating by sending and receiving messages without the use of verbal language. This process is usually visual and can be expressed through gestures, body language, facial expressions and eye contact.

**Nutritional status:** State of the body in relation to the consumption and utilisation of nutrients.

**Orientation:** The ability to locate oneself in one's environment with reference to time, place and people.

**Out-of-hours:** Services available during evenings and weekends.

**Outcomes:** The condition of the patient at the end of their admission/treatment, in terms of their degree of wellness and the potential need for continuing care, medication or support.

**Palliative care:** The active holistic care of patients with advanced progressive illness.

Pasw v17 (Predictive Analytics Software version 17): A statistical programme used to analyse data.

**Patient Advisory Liaison Service (PALS):** A service within the hospital, available to patients and relatives, to talk about their concerns.

**Patient forums:** Every NHS Trust has a patient forum. Their functions include monitoring the quality of services and seeking the views of patients and carers about those services.

**Patient passport:** A simple communication tool that articulates the normal everyday needs of a person. It helps mainstream services deliver person-centred care and understand the person's individual needs.

**Performance indicator:** A statistic or marker that has been chosen to monitor health or service activity. For example, an indicator might be the number of patients with dementia who have been screened for delirium.

**Person-centred:** A broad term used to describe an approach to care in which the person with dementia is valued, treated as an individual, their perspective is taken into account and a positive social environment experienced.

**Person-focussed:** When the priorities of the person receiving care are a fundamental principle to guide care interactions.

**Pilot:** A small scale preliminary study conducted before the main research, in order to check the feasibility or to improve the design of the research.

**Practice development nurse:** The role of a practice development nurse is to ensure professional and practice development of all team members by developing training packages or facilitating training and development of the team using various delivery methods. This role is also responsible for developing and evaluating training packages to ensure they are up-to-date and relevant for organisational and national requirements.

**Practitioner:** Healthcare professional, e.g. physicians, nurses.

**Pre-registration training:** To work in the NHS, nurses must hold a degree or diploma in nursing (a "pre-registration" programme), which leads to registration with the Nursing and Midwifery Council (NMC), enabling them to practice as a nurse.

**Pressure sore/ulcer:** Pressure ulcers, also known as bedsores or pressure sores, are a type of injury that affects areas of the skin and underlying tissue. They are caused when the affected area of skin is placed under too much pressure.

**Primary care:** Healthcare delivered to patients outside hospitals. Primary care covers a range of services provided by general practitioners, nurses and other healthcare professionals, dentists, pharmacists and opticians.

**PRN (pro re nata):** A medical phase meaning 'as required'.

**Professional bodies:** Usually non-profit organisations seeking to further a particular profession, the interests of individuals engaged in that profession and the public interest.

**Prognosis:** A probable course or outcome of a disease.

**Protected mealtimes:** Protected mealtimes are periods when all ward-based activities (where appropriate) stop to enable nurses, ward based teams, catering staff and carers to serve food and give assistance and support to patients.

**Protocol:** A plan or set of steps that defines how something will be done.

**Psychometric:** Theory and technique of psychological measurement, relates to the construction and validation of measurement instruments such as questionnaires, tests and personality assessments.

**Psychotic disorder:** A condition in which a person is not in contact with reality. This can include sensing things that are not really there (hallucinations); having beliefs that are not based on reality (delusions); problems in thinking clearly; and not realising that there is anything wrong with themselves (called 'lack of insight').

**Qualitative:** Qualitative research explores people's beliefs, experiences, attitudes, behaviour and interactions. It asks questions about how and why.

**Quality accounts:** Quality accounts aim to enhance accountability to the public and engage the leaders of an organisation in their quality improvement agenda.

**Quality and safety committee (Wales):** The purpose of the quality and safety committee is to provide advice to the Board to ensure the quality and safety of healthcare.

**Quantitative:** Research that generates numerical data or data that can be converted into numbers.

**Question routing:** Some of the questions in the audit tools are 'routed' so there are specific conditions for when that question should be asked or omitted.

**Range:** Range is the difference between the highest and the lowest values in a dataset, when in numerical order.

**Re-admissions:** A hospital admission that occurs within a specified time frame after discharge from the first or index admission.

**Real-time observations:** Observations conducted in real-time, i.e. alongside patients.

**Referral:** Directing a patient to another service, such as liaison psychiatry.

**Reflective practice group:** A process of continuous learning where staff meet to discuss and reflect on their own professional experiences.

**Registered nurse:** A graduate nurse who has been legally authorized (registered) to practice after examination by a state board of nurse examiners or similar regulatory authority, and who is legally entitled to use the designation RN.

**Residential care:** A care home which is registered to provide personal care and will offer support, ensuring that basic personal needs, such as meals, bathing, going to the toilet and medication, are taken care of.

**Respite:** Short-term care used as a temporary alternative to a person's usual care arrangements.

**Risk assessment:** The process of evaluating a potential hazard, likelihood of suffering, or any adverse effects.

**Safeguarding adults:** Also known as the Protection of Vulnerable Adults (POVA), are systems and processes which are in place to protect vulnerable adults from abuse, harm or exploitation.

**Scoping report:** A report that sets out what a piece of work will and will not cover.

**Screen/screening:** The examination of a group of individuals with no apparent symptoms to detect those with a high probability of having or developing a given disease or condition.

**Self assessment tools:** A tool to be completed by services, staff and carers/patients themselves, to review the quality and provision of a service.

**Service users:** People who receive, have received or are eligible for health and social care services, particularly on a longer term basis.

Short Observational Framework (Short Observational Framework for Inspection, SOFI): A derivative of Dementia Care Mapping (see 'Dementia Care Mapping' in glossary) that aims to capture similar information about engagement, mood and quality of staff interactions. It is designed to capture a snapshot of care and observations, and usually takes place over a 2-hour period, including a mealtime, in communal areas.

Site variation: Differences in results between individual hospital sites.

**Skill mix:** The balance between trained and untrained staff, qualified and unqualified staff, and supervisory and operative staff within a service area as well as between staff groups.

**Social assessment:** The assessment of social circumstances such as informal support available from family or friends, visitors or daytime activities and the eligibility for being offered care resources.

**Social care professional:** A professional who focuses on social, emotional and practical issues, e.g. social workers, support workers, care assistants.

**Specialist continence services:** A service that provides advice, assessment, treatment and management of bladder and bowel problems.

**Specialist infection control services:** A service that provides advice about the prevention and management of infection within the hospital. It aims to reduce the risk of healthcare associated infection to visitors, patients and staff.

**Stakeholder (for consultation):** Those with an interest in dementia, including service users and carers, NHS organisations, professional bodies and voluntary organisations.

**Standardised assessment/instrument:** An empirically developed examination with established reliability and validity which are determined by repeated evaluation of the method and results.

**Standards:** Standards are a means of describing the level of quality healthcare organisations are expected to meet or to aspire to. The performance of organisations can be assessed against this level of quality.

**Steering Group:** A group of professionals with different expertise who meet on a regular basis and discuss the progress of the audit.

**Strategic Health Authority (SHA):** Manage the local NHS on behalf of the secretary of state. These bodies will be abolished under current plans to reform the NHS.

**Systematic review:** Research that summarises the evidence on a clearly formulated question according to a pre-defined protocol using systematic and explicit methods to identify, select and appraise relevant studies, and to extract, collate and report their findings.

**Tissue viability services:** A service that provides specialist advice and support on chronic wounds, such as pressure ulcers or surgical wounds.

**Trusts:** In the context of the UK's National Health Service (NHS), Trusts are organisational units, e.g. hospital Trusts.

**Wandering behaviour:** Rhythmic, repetitive action of walking; can be caused by restlessness, disorientation, agitation or boredom.

**Ward ethos:** The "way of doing things" or the value base and culture in the ward.

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# Appendix 3: Steering Group and Project Team members

# **Steering Group**

Professor Peter Crome, Professor of Geriatric Medicine, Keele; Consultant Geriatrician, North Staffordshire Combined Healthcare NHS Trust (Chair)

Dr Dave Anderson, former Chair of the Faculty for Old Age Psychiatry, Royal College of Psychiatrists; Consultant Old Age Psychiatrist and Medical Director, Mersey Care NHS Trust

Dr Andy Barker, Consultant in Old Age Psychiatry; Vice Chair, Royal College of Psychiatrists Faculty of Old Age Psychiatry

Professor Dawn Brooker, Director, University of Worcester Association for Dementia

Janet Husk, Programme Manager, Healthcare of Older People, Clinical Effectiveness and Evaluation Unit (CEEU), Royal College of Physicians

Kevin Stewart, Clinical Director, Clinical Effectiveness and Evaluation Unit (CEEU), Royal College of Physicians (from 2011)

Louise Lakey, Policy Manager, Alzheimer's Society

Dr Kim Manley, Learning & Development Manager: Resources for Learning and Improving, Royal College of Nursing (2008 – 2010)

Professor Martin Orrell, Professor of Ageing and Mental Health, University College London, Associate Medical Director, North East London Foundation Trust

Dr Jonathan Potter, Clinical Director, Clinical Effectiveness and Evaluation Unit (CEEU), Royal College of Physicians (2008 – 2011)

Dr Imran Rafi, Medical Director, Royal College of General Practitioners, Clinical Innovation and Research Centre (CIRC)

Rachel Thompson, Dementia Project Lead, Royal College of Nursing (from 2011)

Dr Daphne Wallace, Living With Dementia Group

Rosemary Woolley, Research Fellow, Bradford Institute for Health Research

Professor John Young, Head, Academic Unit of Elderly Care and Rehabilitation, Leeds University and Bradford Teaching Hospitals NHS Trust

# **The National Audit of Dementia Project Team**

Dr Paul Lelliott, Director of the College Centre for Quality Improvement (to September 2011)

Professor Mike Crawford, Director of the College Centre for Quality Improvement (from 2011)

Maureen McGeorge, Implementation Team Manager

Lucy Palmer, Senior Programme Manager

Chloe Hood, Programme Manager

Aarti Gandesha, Project Worker

Renata Souza, Project Worker

Stacey Dicks, Project Worker

# **Appendix 4: Demographic information**

# Characteristics of the people with dementia whose notes were audited (N = 7934)

# Age range and site (hospital) average

	Age (years)
Maximum age	110
Minimum age	34
Average age	83
Lowest average age per site	78
Highest average age per site	88

# Age range as percentage of sample

Age range	Number of casenotes	Percentage of casenotes
0 - 59	91	1
60 - 69	243	3
70 – 79	1540	19
80 - 89	4401	55
90 – 99	1635	21
100 +	24	0.3

#### Gender

Gender	Number of casenotes	Percentage of casenotes
Male	2851	36
Female	5083	64

## **Ethnicity**

Ethnicity	Number of casenotes	Percentage of casenotes
White British	5974	75
Not documented	1483	19
Other *	476	6

<sup>\* 6</sup> other ethnicities, largest group being 'Other White/European background' accounting for 2% (144 casenotes) of the entire sample.

#### Language

First language	Number of casenotes	Percentage of casenotes
English	5557	70
Not documented	2182	28
Other *	195	3

<sup>\* 32</sup> other languages, largest group being 'Welsh' accounting for 0.4% (34 casenotes) of the entire sample.

#### **Ward specialty**

Participants were asked to indicate the speciality of the ward in which the patient had spent the greatest part of their admission

Ward specialty	Number of casenotes	Percentage of casenotes
Cardiac	137	2
Care of the elderly	3467	44
Critical care	17	0.2
General medicine	2583	33
Nephrology	29	0.4
Obstetrics/gynaecology	22	0.3
Oncology	12	0.2
Orthopaedics	840	11
Surgery	352	4
Other *	475	6

<sup>\* 18</sup> other ward specialities, largest being 'Stroke ward' accounting for 2% (120 casenotes) of the entire sample.

#### **Length of stay overall**

Patient's length of stay was documented in the casenotes (N = 7835)

Length of stay	Number of days	
Range	4 - 407	
Median	15	

#### Length of stay as percentage of the sample

The length of stay of all casenotes has been displayed as a percentage in 10% interval spacing, for clarity; for example 10% of patients from the national sample were still in hospital on the 50<sup>th</sup> day.

Percentage of patients from casenote sample	Number of days
100	4
90	6
80	7
70	9
60	12
50	15
40	19
30	25
20	34
10	50

# Characteristics of the people with dementia whose care was observed in PIE (N = 608)

#### Age range

	Age (years)
Maximum age	103
Minimum age	27
Average age	81

#### Age range of observation sample

Age range	Number of observed patients *	Percentage of observed patients *
0 - 59	20	4
60 - 69	32	5
70 – 79	124	21
80 – 89	293	49
90 – 99	124	21
100 +	4	0.7

<sup>\*</sup> The age of 11 patients observed was not documented.

#### **Gender of observation sample**

Gender	Number of observed patients *	Percentage of observed patients *	
Male	235	39	
Female	364	61	

<sup>\*</sup> The gender of 9 patients observed was not documented.

#### Length of stay at point of observation

Length of stay at point of observation	Number of days *
Range	0 - 194
Median	17

<sup>\*</sup> The length of stay of 7 patients was not documented.

# **Appendix 5: Audit standards**

# Classification of standards and use of benchmarked data in local reporting

The classification of the standards is in accordance with the following broad principles:

- **Type 1** failure to meet these standards would result in a significant threat to patient safety, rights or dignity and/or would breach the law.
- **Type 2** standards that an organisation/ward would be expected to meet in normal practice.
- **Type 3** standards that an organisation/ward should meet to achieve excellent practice.

Classification of the standards in this way was used to add context to the detail of local reports, in order to aid hospitals with prioritisation.

As the overall level of performance against standards of all types is low, detail of standard type has not been included in the main body of the report.

# Measuring standards in the core audit

# **Organisational checklist**

Most questions in the organisational checklist relate to a standard, although some were subsidiary questions for informational purposes, e.g. make up of liaison psychiatry teams. A hospital met a standard if the organisational checklist submitted confirmed that they had a particular policy/procedure in place. A total of 81 standards were measured in this tool.

#### Number of standards met in the organisational checklist (site level)

Type of standard	Total number of standards	Median number of standards met	Range of standards met
Type 1 standards	21	12	3 – 20
Type 2 standards	53	25	9 – 45
Type 3 standards	7	2	0 – 7
All standards	81	38	19 – 69

#### **Casenote audit**

Most questions in the casenote audit relate to a standard, although some were included for informational purposes, e.g. length of stay. A hospital met a standard if it had been evidenced in 100% of the casenotes they submitted. For example, the audit asked whether a nutritional assessment had been recorded in each casenote in the sample. If 40 out of 40 casenotes submitted recorded a nutritional assessment, then this standard was met. A total of 50 standards were measured in this tool.

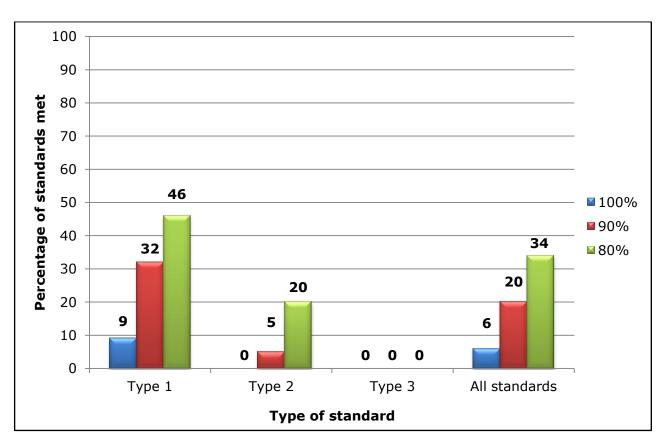
#### Number of standards met in the casenote audit (site level)

Type of standard	Total number of standards	Median number of standards met	Range of standards met
Type 1 standards	28	2.5	0 - 14
Type 2 standards	20	0	0 - 10
Type 3 standards	2	0	0 – 2
All standards	50	3	0 – 25

#### Varying the requirement for standards met in the casenote audit

In order to further test the finding of overall low performance by hospitals completing the casenote audit, we carried out a further breakdown of results, varying the requirement for meeting an individual standard.

# Median percentage of standards met in the casenote audit when requirement is set at 100%, 90% and 80%



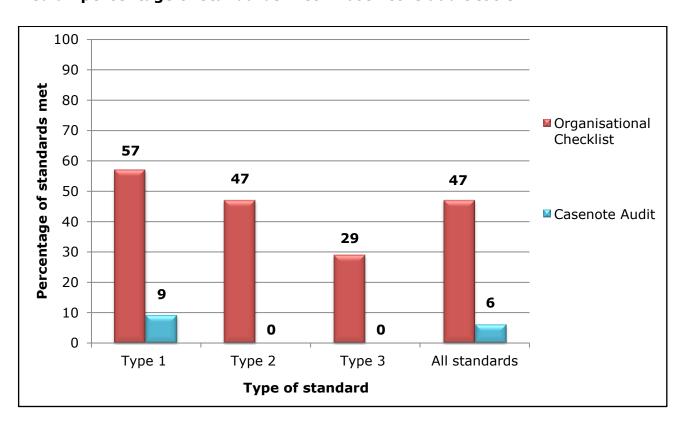
The graph shows the impact on the median percentage of standards met by hospitals, if the benchmark for meeting a standard is varied. Using the benchmark of 100%, the median percentage of type 1 standards met is 9% (2.5/28). Lowering the benchmark to 80% causes the median to increase to 46% (13/28). For type 2 standards, lowering the benchmark to 80% of casenotes per site sample causes the median to increase from 0% (0/20) to 20% (4/20).

However, the overall picture remains one of low performance, as the median percentage of standards met by all hospitals is 34% of all standards (17/50), even if the benchmark is set at 80% of the casenote site sample.

#### Comparing standards between core audit tools

A higher percentage of standards were achieved in the organisational checklist than in the casenote audit.

#### Median percentage of standards met in both core audit tools



#### Site variation in the core audit

Standards were said to be met in the core audit if they could be evidenced in 100% of the local casenote sample. The range and interquartile range (IQR) of the site level data response for each question in the casenote audit is presented in the full data tables on the project website<sup>1</sup>. An example is shown below:

<sup>&</sup>lt;sup>1</sup> www.nationalauditofdementia.org.uk

				National data Benchmarking inform		rmation		
Std	Type		Q	N	%	Range	IQR	Median
1.9	1	2e	The medical assessment includes assessment of nutritional status (Y/N)	5536/7934	69.8	2.6 - 100	57.5 - 87.5	74.4

The overall percentage of casenotes which include assessment of nutritional status is 70%, as shown. This is close to the median of 74%. However, the benchmarking information shows a wide variance between sites of 3% to 100% of casenotes containing this information.

Achievement of a standard in the organisational checklist did not equate to meeting related standards in the casenote audit. This means that even though hospitals report having policies and procedures in place, this is not reflected in the record of care received by patients with dementia as evidenced in casenotes.

A further breakdown of casenote data, including only those hospitals stating that particular policies or procedures were in place, showed the existence of a policy at hospital level did not produce noticeable differences to recorded practice.

In the table below, casenote evidence of mental state assessment carried out, has been drawn from 3 samples of data:

- 1. from <u>all</u> hospitals who submitted casenotes (N = 206, 100% of hospitals);
- 2. from hospitals where this assessment <u>is</u> included in the guideline or protocol for multidisciplinary assessment (N = 155, 75% of hospitals);
- 3. from hospitals where this assessment is not included in the guideline or protocol for multidisciplinary assessment (N = 51, 25% of hospitals).

Percentage of casenotes (per hospital) recording mental state assessment					
	All hospitals (N = 206)	Hospitals with assessment in guideline (N = 155)	Hospitals with assessment not included (N = 51)		
Median	42.5	41.5	43.6		
Range	6 - 100	10 - 100	5.7 - 80.5		
Interquartile range (IQR)	28 - 57	30 - 57	22.5 - 58		

As there is no demonstrable difference between hospitals incorporating or excluding assessments in their local policy or procedure, differences between local casenote samples are not discussed in the main body of this report.

# Measuring standards in the enhanced audit

#### **Environmental checklist**

Most questions in the environmental checklist relate to a standard, although some were included for informational purposes, e.g. number of beds. A ward met a standard if they gave a positive response to the question. A total of 29 standards were measured in this tool.

#### Number of standards met in the environmental checklist

Type of standard	Total number of standards	Median number of standards met	Range of standards met
Type 1 standards	7	6	3 – 7
Type 2 standards	16	10	4 – 15
Type 3 standards	6	3	0 – 6
All standards	29	19	9 – 27

### Ward organisational checklist

Most questions in the ward organisational checklist relate to a standard, although some were included for informational purposes, e.g. staffing ratios. A ward met a standard if they gave a positive response to the question. A total of 26 standards were measured in this tool.

#### Number of standards met in the ward organisational checklist

Type of standard	Total number of standards	Median number of standards met	Range of standards met
Type 1 standards	11	9	3 – 11
Type 2 standards	13	10	4 - 13
Type 3 standards	2	1	0 – 2
All standards *	26	20	9 – 26

<sup>\*</sup> This total excludes the questions on access to services as the standard did not specify the amount access a ward should have to each of the services.

# Staff and carer/patient questionnaires

The results from these questionnaires cannot be used to determine the meeting of standards, as they are mostly attitudinal and relate to individual experiences.

# Appendix 6: Analysis of qualitative data and descriptive findings from the PIE module

Descriptive statistics were computed on Excel or on PASW v17. The qualitative data was read through for the purpose of familiarisation with the dataset.

There was great variation in the level of detail provided for each data entry with some observers providing a lot more insight than others. The most descriptive cases of 5 wards (from 3 hospitals) which were most clearly person-centred (and provided 'practice exemplars') were initially explored to identify the key components of their approach to working with people who have dementia and what processes appeared to be shaping this exemplary care on these specific wards. What was unique about these wards was that they identified multiple areas of practice in which they judged care to be person-centred with systems in place to support team-working. The detailed data from some of the mixed quality wards was also explored to tease out the dimensions and what appeared to be shaping the more person-centred and less person-centred aspects of care experienced by patients.

The findings were analysed firstly in relation to the quality of communication/ interactions between people with dementia and staff, as aspects of these were reported on in every ward and clearly seen as being central to shaping patients' experiences.

The emerging themes (e.g. whether staff have knowledge about the person with dementia which helps them to address needs) were then tested in relation to the rest of the dataset, with the findings from different wards compared and contrasted for similarities and differences. Some of the data was counted, for example, to establish how many hospitals identified lack of stimulation or a lack of personalised knowledge of patients as an area for action. The dataset as a whole was of sufficient quality and quantity for a robust analysis, as there was sufficient diversity yet evidence of striking similarities in the findings between hospitals and of common emerging patterns. The data in relation to interactions between patients and staff was explored to saturation point so that distinctions could be made with confidence in the emerging conceptual model for a person-focussed communication approach. This provides the focus for the PIE observation findings (page 153).

Other key areas for action frequently reported by hospitals were lack of stimulation for people with dementia for long periods (cognitive or environmental), aspects of the physical ward environment (e.g. lack of orientation cues and noise levels), and care delivery at mealtimes or with drinks. These areas were therefore also qualitatively analysed, by comparing and contrasting the data across wards to identify the range of experiences of people with dementia, and what was identified to be working well or not well. Most of the emerging themes fitted the findings in relation to communication e.g. lack of prompting some patients affecting their nutritional intake. As other themes, such as to do with features of the physical ward environment, supported the findings from the rest of the enhanced audit, these findings are referred to in the particular relevant chapters.

# Appendix 7: Participating Trusts/Health Boards, hospitals and wards

Participation in the core and enhanced audit modules (excluding observational module)

		Core	audit		Enhanced audit			
Trust/Health Board	Hospital	Organisational checklist	Casenote audit	Participating wards	Ward organisational checklist	Environmental checklist	Staff questionnaire	Carer/patient questionnaire
Abertawe Bro Morgannwg University Health Board	Morriston Hospital	✓	✓					
Abertawe Bro Morgannwg University Health Board	Neath Port Talbot Hospital	✓	✓					
Abertawe Bro Morgannwg University Health Board	Princess of Wales Hospital	✓	✓					
Abertawe Bro Morgannwg University Health Board	Singleton Hospital	✓	✓					
Aintree University Hospitals NHS Foundation Trust	University Hospital Aintree	✓	✓					
Airedale NHS Trust	Airedale Teaching Hospital	<b>✓</b>	✓	Ward 2 Ward 10 Ward 6	✓ ✓ ✓	✓ ✓ ✓	✓ ✓ ✓	✓ ✓ X
Aneurin Bevan Health Board	Nevill Hall Hospital	✓	✓	4/1 Monnow Ward 1/2 Gilwern Ward	<b>√</b>	<b>√</b>	X ✓	<b>√</b>
Aneurin Bevan Health Board	Royal Gwent Hospital	✓	✓					
Ashford & St Peter's Hospitals NHS Trust	St Peter's Hospital	<b>~</b>	✓	Maple Ward Elm Ward Holly Ward	✓ ✓	√ √ √	✓ ✓ ✓	✓ ✓ X
Barking, Havering & Redbridge Hospitals NHS Trust	King George Hospital	✓	✓					
Barking, Havering & Redbridge Hospitals NHS Trust	Queen's Hospital	✓	✓	Ocean B Ward Sky A Ward	<b>√</b>	√ √	√ √	✓ X
Barnet & Chase Farm Hospitals NHS Trust	Barnet General Hospital	✓	✓					

		Core a	audit		Enhanced audit			
Trust/Health Board	Hospital	Organisational checklist	Casenote audit	Participating wards	Ward organisational checklist	Environmental checklist	Staff questionnaire	Carer/patient questionnaire
Calderdale & Huddersfield NHS Foundation Trust	Calderdale Royal Hospital	✓	✓					
Calderdale & Huddersfield NHS Foundation Trust	Huddersfield Royal Infirmary	✓	✓					
Cambridge University Hospitals NHS Foundation Trust	Addenbrooke's Hospital	✓	✓	Ward C5 Ward D8 Ward G4	✓ ✓ ✓	√ √ √	✓ ✓ ✓	X X ✓
Cardiff & Vale NHS Trust	Llandough Hospital	✓	✓					
Cardiff & Vale NHS Trust	University Hospital of Wales	✓	✓	Ward A4	✓	✓	✓	✓
Central Manchester University Hospitals NHS Foundation Trust	Manchester Royal Infirmary	✓	<b>✓</b>					
Chelsea & Westminster Hospital NHS Foundation Trust	Chelsea & Westminster Hospital	✓	✓					
Chesterfield Royal Hospital NHS Foundation Trust	Chesterfield Royal Hospital	✓	✓					
City Hospitals Sunderland NHS Foundation Trust	Sunderland Royal Hospital	✓	✓					
Colchester Hospital University NHS Foundation Trust	Colchester General Hospital	✓	✓					
Countess of Chester Hospital NHS Foundation Trust	Countess of Chester Hospital	✓	✓					
County Durham & Darlington NHS Foundation Trust	Darlington Memorial Hospital	✓	✓					
County Durham & Darlington NHS Foundation Trust	University Hospital North Durham	✓	✓	Ward 5 Ward 12 Ward 1	✓ ✓ ✓	✓ ✓ ✓	✓ ✓ ✓	X ✓
Cwm Taf Local Health Board	Prince Charles Hospital	✓	✓					
Cwm Taf Local Health Board	Royal Glamorgan Hospital	✓	✓					
Dartford & Gravesham NHS Trust	Darent Valley Hospital	✓	✓	Spruce Ward Maple Ward Oak Ward	√ √ √	√ √ √	√ √ √	✓ ✓ X
Derby Hospitals NHS Foundation Trust	Royal Derby Hospital	✓	✓	Ward 304 Ward 204 Ward 409	√ √ √	√ √ √	✓ ✓ ✓	X X

	Core audit					Enhanced audit				
Trust/Health Board	Hospital	Organisational checklist	Casenote audit	Participating wards	Ward organisational checklist	Environmental checklist	Staff questionnaire	Carer/patient questionnaire		
Doncaster & Bassetlaw Hospitals NHS Foundation Trust	Doncaster Royal Infirmary	<b>✓</b>	<b>√</b>							
Dorset County Hospital NHS Foundation Trust	Dorset County Hospital	✓	✓							
Dudley Group of Hospitals NHS Trust	Russells Hall Hospital	✓	✓							
Ealing Hospital NHS Trust	Ealing Hospital	✓	✓							
East & North Hertfordshire NHS Trust	Lister Hospital	✓	✓							
East & North Hertfordshire NHS Trust	Queen Elizabeth II Hospital	✓	✓							
East Cheshire NHS Trust	Macclesfield District General Hospital	✓	✓	Ward 3 Ward 5	<b>√</b> <b>√</b>	<b>√</b>	<b>√</b>	×		
East Kent Hospitals Foundation Trust	Kent & Canterbury Hospital	✓	✓							
East Kent Hospitals Foundation Trust	Queen Elizabeth the Queen Mother Hospital, Margate	✓	✓							
East Kent Hospitals Foundation Trust	William Harvey Hospital, Ashford	✓	✓							
East Lancashire Hospitals NHS Trust	Royal Blackburn Hospital	✓	✓							
East Sussex Hospitals NHS Trust	Conquest Hospital	✓	✓							
East Sussex Hospitals NHS Trust	Eastbourne District General Hospital	✓	✓							
Epsom & St Helier University Hospitals NHS Trust	Epsom General Hospital	✓	✓	Croft Ward Elizabeth/ Chuter Ward	√ √	<b>√</b>	✓ ✓	<b>√</b> ✓		
Epsom & St Helier University Hospitals NHS Trust	St Helier Hospital	✓	✓							
Frimley Park Hospital NHS Foundation Trust	Frimley Park Hospital	<b>√</b>	✓	Ward F2 Ward F4 Ward G2/G3	√ √ √	✓ ✓ ✓	✓ ✓ ✓	X X X		

		Core	audit			Enhanc	ed audit	
Trust/Health Board	Hospital	Organisational checklist	Casenote audit	Participating wards	Ward organisational checklist	Environmental checklist	Staff questionnaire	Carer/patient questionnaire
Gateshead Health NHS Foundation Trust	Queen Elizabeth Hospital	✓	✓	Ward 5 Ward 21	<b>✓</b>	<b>√</b>	√ √	<b>√</b>
George Eliot Hospital NHS Trust	George Eliot Hospital	✓	<b>√</b>	Elizabeth Ward Alexandra Ward Adam Bede Ward	✓ ✓ ✓	✓ ✓ ✓	✓ ✓ ✓	✓ ✓ ✓
Gloucestershire Hospitals NHS Foundation Trust	Cheltenham General Hospital	✓	✓					
Gloucestershire Hospitals NHS Foundation Trust	Gloucester Royal Hospital	✓	✓	Rehab Ward 1 Ward 3A	<b>√</b> ✓	<b>√</b>	<b>√</b> ✓	X ✓
Great Western Hospitals NHS Foundation Trust	Great Western Hospital	✓	<b>√</b>	Jupiter Ward Kingfisher Ward Ampney Ward	✓ ✓	✓ ✓ ✓	✓ ✓ ✓	✓ ✓ X
Guy's & St Thomas' NHS Foundation Trust	St Thomas' Hospital	✓	✓					
Harrogate & District NHS Foundation Trust	Harrogate District Hospital	✓	✓					
Heart of England NHS Foundation Trust	Birmingham Heartlands Hospital	✓	✓					
Heart of England NHS Foundation Trust	Good Hope Hospital	✓	✓					
Heart of England NHS Foundation Trust	Solihull Hospital	✓	✓					
Heatherwood & Wexham Park Hospitals NHS Foundation Trust	Wexham Park Hospital	✓	<b>√</b>	Ward 9 Ward 1	<b>√</b>	<b>√</b>	<b>√</b>	×
Hereford Hospitals NHS Trust	County Hospital	✓	✓					
Hinchingbrooke Health Care NHS Trust	Hinchingbrooke Hospital	✓	✓					
Homerton University Hospital NHS Foundation Trust	Homerton University Hospital	✓	✓	Lamb Ward Halley Ward Aske Ward	√ √ √	√ √ √	✓ ✓ ✓	X X X

		Core	audit		Enhanced audit			
Trust/Health Board	Hospital	Organisational checklist	Casenote audit	Participating Wards	Ward organisational checklist	Environmental checklist	Staff questionnaire	Carer/patient questionnaire
Hull & East Yorkshire Hospitals NHS Trust	Hull Royal Infirmary	✓	✓					
Hywel Dda Local Health Board	Bronglais General Hospital	✓	✓					
Hywel Dda Local Health Board	Prince Philip Hospital	✓	✓					
Hywel Dda Local Health Board	West Wales General Hospital	✓	✓					
Hywel Dda Local Health Board	Withybush Hospital	✓	✓					
Imperial College Healthcare NHS Trust	Charing Cross Hospital	✓	✓					
Imperial College Healthcare NHS Trust	Hammersmith Hospital	✓	✓					
Imperial College Healthcare NHS Trust	St Mary's Hospital	✓	✓					
Ipswich Hospital NHS Trust	Ipswich Hospital	✓	✓					
Isle of Wight NHS Primary Care Trust	St Mary's Hospital	✓	✓					
James Paget University Hospitals NHS Foundation Trust	James Paget Hospital	✓	✓	Ward 15 Ward 7 Ward 4	✓ ✓ ✓	✓ ✓ ✓	✓ ✓ ✓	X ✓ X
Kettering General Hospital NHS Foundation Trust	Kettering General Hospital	✓	✓	Pretty A Barnwell C Naseby A	✓ ✓ ✓	✓ ✓ ✓	✓ ✓ ✓	X X ✓
King's College Hospital NHS Foundation Trust	Kings College Hospital	✓	Х					
Kingston Hospital NHS Trust	Kingston Hospital	✓	✓					
Lancashire Teaching Hospitals NHS Foundation Trust	Chorley & South Ribble Hospital	✓	✓					
Lancashire Teaching Hospitals NHS Foundation Trust	Royal Preston Hospital	✓	✓					

		Core	audit			Enhanc	anced audit		
Trust/Health Board	Hospital	Organisational checklist	Casenote audit	Participating Wards	Ward organisational checklist	Environmental checklist	Staff questionnaire	Carer/patient questionnaire	
Leeds Teaching Hospitals NHS Trust	Leeds General Infirmary	✓	✓	Ward 60 Ward 15	<b>√</b> <b>√</b>	<b>√</b> <b>√</b>	X ✓	✓ X	
Leeds Teaching Hospitals NHS Trust	St James' University Hospital	✓	X						
Lewisham Hospital NHS Trust	University Hospital Lewisham	<b>√</b>	✓	Cherry Ward Cedar Ward Ash Ward	✓ ✓ ✓	√ √ √	✓ ✓ ✓	X ✓	
Luton & Dunstable Hospital NHS Foundation Trust	Luton & Dunstable Hospital	✓	✓						
Maidstone & Tunbridge Wells NHS Trust	Kent & Sussex Hospital	✓	✓						
Maidstone & Tunbridge Wells NHS Trust	Maidstone Hospital	✓	✓						
Mayday Healthcare NHS Trust	Mayday University Hospital	✓	✓						
Mid Essex Hospital Services NHS Trust	Broomfield Hospital	✓	✓	Ward B5 Ward B23	<b>√</b>	<b>✓</b>	<b>√</b>	X X	
Mid Staffordshire NHS Foundation Trust	Staffordshire General Hospital	✓	✓						
Mid Yorkshire Hospitals NHS Trust	Dewsbury & District Hospital	✓	✓						
Mid Yorkshire Hospitals NHS Trust	Pontefract General Infirmary	✓	✓						
Milton Keynes Hospital NHS Foundation Trust	Milton Keynes Hospital	✓	Х						
Newham University Hospital NHS Trust	Newham University Hospital	<b>~</b>	<b>√</b>	Beckton Ward Silvertown Ward West Ham Ward	<b>√</b> <b>√</b>	✓ ✓ ✓	<b>√</b> <b>√</b>	X X X	
Norfolk & Norwich University Hospital NHS Foundation Trust	Norfolk & Norwich University Hospital	✓	✓						
North Bristol NHS Trust	Frenchay Hospital	✓	✓	Ward 206 Ward 202 Ward 107	✓ ✓ ✓	√ √ √	✓ ✓ ✓	√ √ √	

✓

✓

Nottingham City Hospital

**Nottingham University** 

**Hospitals NHS Trust** 

		Core	audit		Enhanced audit			
Trust/Health Board	Hospital	Organisational checklist	Casenote audit	Participating wards	Ward organisational checklist	Environmental checklist	Staff questionnaire	Carer/patient questionnaire
Nottingham University Hospitals NHS Trust	Queen's Medical Centre	✓	✓	Ward B48 Ward C4 Ward C53	✓ ✓ ✓	√ √	✓ ✓ ✓	✓ ✓ ✓
Oxford Radcliffe Hospitals NHS Trust	Horton Hospital	✓	✓					
Oxford Radcliffe Hospitals NHS Trust	John Radcliffe Hospital	✓	✓					
Pennine Acute Hospitals NHS Trust	Fairfield General Hospital	✓	✓					
Pennine Acute Hospitals NHS Trust	North Manchester General Hospital	✓	✓					
Pennine Acute Hospitals NHS Trust	Rochdale Infirmary	✓	✓					
Pennine Acute Hospitals NHS Trust	Royal Oldham Hospital	✓	✓					
Peterborough & Stamford Hospitals NHS Foundation Trust	Edith Cavell Hospital	<b>√</b>	✓					
Peterborough & Stamford Hospitals NHS Foundation Trust	Peterborough District Hospital	✓	✓					
Plymouth Hospitals NHS Trust	Derriford Hospital	✓	✓					
Poole Hospital NHS Foundation Trust	Poole Hospital	✓	✓					
Portsmouth Hospitals NHS Trust	Queen Alexandra Hospital	<b>√</b>	✓	Ward C5 Ward D2 Ward G3	<b>√</b> <b>√</b>	✓ ✓ ✓	<b>√</b> <b>√</b>	X ✓ ✓
Royal Berkshire NHS Foundation Trust	Royal Berkshire Hospital	✓	✓					
Royal Bournemouth & Christchurch Hospitals NHS Foundation Trust	Royal Bournemouth Hospital	<b>√</b>	✓	Ward 3 Ward 15 4/5 Unit	✓ ✓ ✓	√ √ √	✓ ✓ ✓	X X ✓
Royal Cornwall Hospitals NHS Trust	Royal Cornwall Hospital	✓	✓	Grenville Ward Wheal Jane Ward	<b>√</b> ✓	<b>√</b>	<b>√</b>	<b>√</b>

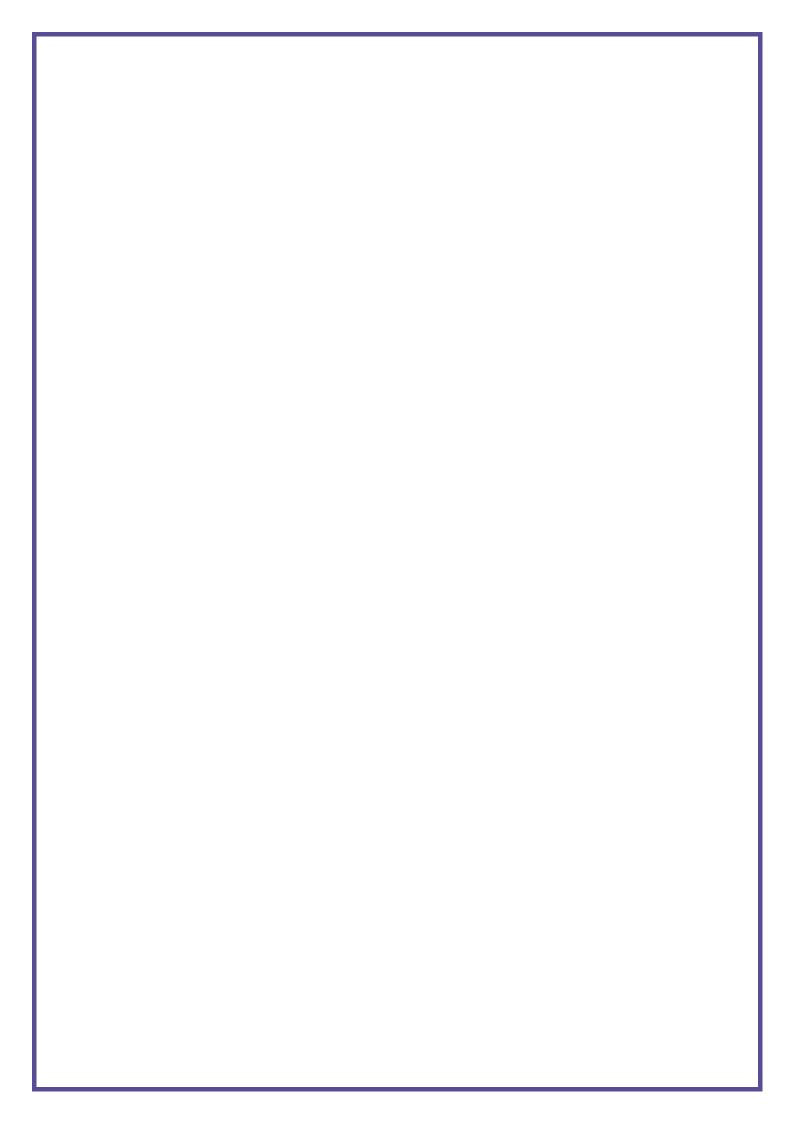
		Core	audit			ed audit	udit	
Trust/Health Board	Hospital	Organisational checklist	Casenote audit	Participating wards	Ward organisational checklist	Environmental checklist	Staff questionnaire	Carer/patient questionnaire
Royal Devon & Exeter NHS Foundation Trust	Royal Devon & Exeter Hospital (Wonford)	<b>~</b>	✓	Harbourne Ward Durbin Ward Bolham Ward	✓ ✓ ✓	✓ ✓	✓ ✓ ✓	X ✓ X
Royal Free Hampstead NHS Trust	Royal Free Hospital	✓	✓	7 North Ward 9 North B Ward	√ √	<b>√</b>	<b>√</b> ✓	X X
Royal Liverpool & Broadgreen University Hospitals NHS Trust	Broadgreen Site	✓	✓					
Royal Liverpool & Broadgreen University Hospitals NHS Trust	Royal Liverpool Site	<b>√</b>	✓	Ward 6X Ward 4A Ward 2X	√ √ √	√ √ √	✓ ✓ X	X ✓
Royal Surrey County Hospital NHS Trust	Royal Surrey County Hospital	✓	✓					
Royal United Hospital Bath NHS Trust	Royal United Hospital	<b>√</b>	✓	Respiratory Ward Pierce/ Forrester Brown Ward Combe Ward	✓ ✓ ✓	✓ ✓ ✓	√ √ √	X ✓
Royal Wolverhampton Hospitals NHS Trust	New Cross Hospital	<b>√</b>	✓	Ward D19 Ward D5 Ward D7	✓ ✓	✓ ✓	√ √	✓ ✓ ✓
Salford Royal NHS Foundation Trust	Salford Royal Hospital	✓	✓					
Salisbury NHS Foundation Trust	Salisbury District Hospital	✓	✓					
Sandwell & West Birmingham Hospitals NHS Trust	City Hospital	✓	✓					
Sandwell & West Birmingham Hospitals NHS Trust	Sandwell General Hospital	✓	✓					
Scarborough & North East Yorkshire Healthcare NHS Trust	Scarborough Hospital	<b>√</b>	✓					
Sheffield Teaching Hospitals NHS Foundation Trust	Northern General Hospital	✓	✓	Hadfield 5 Ward Huntsman 6 Ward Brearley 7 Ward	√ √ √	✓ ✓ ✓	<b>* * *</b>	<b>* * *</b>

				Enhanc	ed audit			
Trust/Health Board	Hospital	Organisational checklist	Casenote audit	Participating wards	Ward organisational checklist	Environmental checklist	Staff questionnaire	Carer/patient questionnaire
Sheffield Teaching Hospitals NHS Foundation Trust	Royal Hallamshire Hospital	✓	✓					
Sherwood Forest Hospitals NHS Foundation Trust	Kings Mill Hospital	✓	✓					
Shrewsbury & Telford Hospital NHS Trust	Princess Royal Hospital	✓	✓					
Shrewsbury & Telford Hospital NHS Trust	Royal Shrewsbury Hospital	✓	✓					
South Devon Healthcare NHS Foundation Trust	Torbay District General Hospital	✓	✓	Dunlop Ward Ainslie Ward	<b>√</b>	<b>√</b>	<b>√</b>	X ✓
South London Healthcare NHS Trust	Princess Royal University Hospital	✓	✓	Ward M4 Ward S3 Ward S1	✓ ✓ ✓	✓ ✓ ✓	✓ ✓	✓ ✓ ✓
South London Healthcare NHS Trust	Queen Elizabeth Hospital	✓	✓					
South London Healthcare NHS Trust	Queen Mary's Hospital	✓	✓					
South Tees Hospitals NHS Trust	Friarage Hospital	✓	✓					
South Tees Hospitals NHS Trust	James Cook University Hospital	✓	✓					
South Tyneside NHS Foundation Trust	South Tyneside District Hospital	✓	✓					
South Warwickshire General Hospitals NHS Trust	Warwick Hospital	✓	✓					
Southampton University Hospitals NHS Trust	Southampton General Hospital	✓	✓					
Southend University Hospital NHS Foundation Trust	Southend Hospital	✓	✓	Stambridge Ward	✓	✓	✓	✓
Southport & Ormskirk Hospital NHS Trust	Southport & Formby District General Hospital	✓	✓					
St George's Healthcare NHS Trust	St George's Hospital	✓	✓					

# Participation in Person, Interaction and Environment (PIE) – Observation module

Trust/Health Board	Hospital		Participating wards	
Airedale NHS Trust	Airedale Teaching Hospital	Ward 2	Ward 10	Ward 6
Ashford & St Peter's Hospitals NHS Trust	St Peter's Hospital	Mable Ward	Elm Ward	Holly Ward
Barking, Havering & Redbridge Hospitals NHS Trust	Queen's Hospital	Foxglove Ward (King George Hospital)	Sky A Ward	-
Bradford Teaching Hospitals NHS Foundation Trust	Bradford Royal Infirmary	Ward 30	Ward 23	-
Cambridge University Hospitals NHS Foundation Trust	Addenbrooke's Hospital	Ward D8	G6	-
Cardiff & Vale University Health Board	University Hospital of Wales	Ward A4	-	-
County Durham & Darlington NHS Foundation Trust	University Hospital of North Durham	Ward 5	Ward 12	Ward 1
Dartford & Gravesham NHS Trust	Darent Valley Hospital	Spruce Ward	Maple Ward	Oak Ward
Derby Hospitals NHS Foundation Trust	Royal Derby Hospital	Ward 304	Ward 205	Ward 409
East Cheshire NHS Trust	Macclesfield District General Hospital	Ward 3	Ward 5	-
Epsom & St Helier University Hospitals NHS Trust	Epsom General Hospital	Croft Ward	Elizabeth/Chuter Ward	-
Frimley Park Hospital NHS Foundation Trust	Frimley Park Hospital	Ward F2	Ward F4	Ward G2/G3
Gateshead Health NHS Foundation Trust	Queen Elizabeth Hospital	Ward 5	Ward 21	-
George Eliot Hospital NHS Trust	George Eliot Hospital	Elizabeth Ward	Alexandra Ward	Adam Bebe Ward
Gloucestershire Hospitals NHS Foundation Trust	Gloucester Royal Hospital	Rehab Ward 1	Ryeworth Ward	-
Great Western Hospitals NHS Foundation Trust	Great Western Hospital	Jupiter Ward	Kingfisher Ward	Ampney Ward
Heatherwood & Wexham Park Hospitals NHS Foundation Trust	Wexham Park Hospital	Ward 9	Ward 1	-
Homerton University Hospital NHS Foundation Trust	Homerton Hospital	Lamb Ward	Halley Ward	Aske Ward
James Paget University Hospitals NHS Foundation Trust	James Paget Hospital	Ward 12	Ward 3	Ward 4
Kettering General Hospital NHS Foundation Trust	Kettering General Hospital	Barnwell C Ward	Naseby A Ward	-
Leeds Teaching Hospitals NHS Trust	Leeds General Infirmary	Ward 60	-	-
Mid Essex Hospital Services NHS Trust	Broomfield Hospital	Ward B5	Ward B23	=
Newham University Hospital NHS Trust	Newham University Hospital	West Ham Ward	-	-
North Bristol NHS Trust	Frenchay Hospital	Ward 206	Ward 202	Ward 205
North Middlesex University Hospital NHS Trust	North Middlesex University Hospital	Ward T7	Eleanor East Ward	Michael Bates Ward

Trust/Health Board	Hospital		Participating wards	
North West London Hospitals NHS Trust	Northwick Park Hospital	Dryden Ward	Evelyn Ward	Flecher Ward
North West London Hospitals NHS Trust	Central Middlesex Hospital	Gladstone 2 Ward	Abbey Ward	-
Nottingham University Hospitals NHS Trust	Queen's Medical Centre	B48/47	Ward C4	C53
Portsmouth Hospitals NHS Trust	Queen Alexandra Hospital	Ward C5	Ward D2	Ward G3
Royal Bournemouth & Christchurch Hospitals NHS Foundation Trust	Royal Bournemouth Hospital	Ward 3	Ward 4	4/5 Unit
Royal Devon & Exeter NHS Foundation Trust	Royal Devon & Exeter Hospital	Harbourne Ward	Durbin Ward	Bolham Ward
Royal Free Hampstead NHS Trust	Royal Free Hospital	7 North Ward	9 North B Ward	-
Royal United Hospital Bath NHS Trust	Royal United Hospital	Combe Ward	-	-
Royal Wolverhampton Hospitals NHS Trust	New Cross Hospital	Ward D19	Ward D5	Ward D22
Sheffield Teaching Hospitals NHS Foundation Trust	Northern General Hospital	Hadfield 5 Ward	Huntsman 6 Ward	Brearley 7 Ward
South Devon Healthcare NHS Foundation Trust	Torbay General Hospital	Dunlop Ward	Ainslie Ward	-
St Helens & Knowsley Hospitals NHS Trust	Whiston Hospital	Ward 2D	3 Alpha Ward	Ward 5A
Stockport NHS Foundation Trust	Stepping Hill Hospital	E3 Ward/Brabyns Ward	Ward D1	-
Taunton & Somerset NHS Foundation Trust	Musgrove Park Hospital	Mendip Ward	Portman Ward	Sedgemoor Ward
The Newcastle Upon Tyne Hospitals NHS Foundation Trust	Freeman Hospital	Ward 16	Ward 9	
The Rotherham NHS Foundation Trust	Rotherham District General Hospital	Ward A2	Ward B3	Fitzwilliam Ward
United Lincolnshire Hospitals NHS Trust	Pilgrim Hospital	Ward 3B	Ward 6B	-
University Hospital Birmingham NHS Foundation Trust	Queen Elizabeth Hospital Birmingham	Ward 515	Ward 410	Ward 518
University Hospitals Bristol NHS Foundation Trust	Bristol Royal Infirmary	Ward 27	Ward 2	Ward 24
University Hospitals Coventry & Warwickshire NHS Trust	University Hospital (Coventry)	Ward 1	Ward 31	Ward 40
University Hospitals of Morecambe Bay NHS Trust	Royal Lancaster Infirmary	Ward 2	Ward 20	-
Warrington & Halton Hospitals NHS Foundation Trust	Warrington General Hospital	Ward B12	Ward A9	-
Winchester & Eastleigh Healthcare NHS Trust	Royal Hampshire County Hospital	Shawford Ward	Bartlett Ward	Taunton Ward



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