

National Audit of Dementia

Care in General Hospitals 2016-2017

**Service user comments on the findings of
Round 3**



This report was produced by Chloë Snowdon and Chloë Hood from the National Audit of Dementia Project Team. It was published in January 2018.

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Contents

Introduction.....	2
Round 3 of the National Audit of Dementia.....	2
This report.....	3
Background to this report.....	3
The Service User Review Panels.....	4
Format of this report.....	4
Summary of the SURP discussions.....	5
Information and communication.....	5
Access to family and carers.....	6
Staff attitude, training and support.....	7
Nutrition and hydration.....	9
Clinical care.....	10
Environment in the hospital.....	10
Discharge.....	11
Overall thoughts.....	12
Actions for the audit following the SURPs.....	13
Actions identified by the SURP members.....	13
National Audit of Dementia Project Team response and actions.....	13
Appendix A: Form submitted to the SURPs for review prior to the meetings.....	15

Introduction

The National Audit of Dementia (Care in General Hospitals) looks at the care provided by acute general hospitals in England and Wales to people with dementia. All hospitals are reviewed against a set of standards, which are measured through different audit tools.

There have been three rounds of audit so far and another round will take place in 2018/2019. The three rounds have shown that care for people with dementia in hospital is improving. However, there are still aspects of care which need to progress further.

Round 3 of the National Audit of Dementia

In 2016, 199 hospitals (98% of eligible hospitals) in England and Wales participated in Round 3 of the National Audit of Dementia. Hospitals collected four different types of data using four different tools:

- A checklist at an organisational level which asked questions about the procedures and reviews the hospital has in place regarding the care of people with dementia
- A review of patient notes to see what assessments and discharge planning people with dementia received from the hospital
- A staff questionnaire asking staff about how well supported they felt to provide care to people with dementia and their opinions on aspects of care such as access to food and drink
- A carer questionnaire given to people visiting people with dementia in hospital which asked the carer how good or poor they thought the care was.

The National Audit of Dementia Project Team published a report on the findings of Round 3 of the audit in July 2017. In this report, data from all four of the tools were presented alongside each other to allow for comparison. You can view the report on the [audit website](#).

Key messages from Round 3 of the National Audit of Dementia

The Round 3 report highlighted some key messages and corresponding recommendations for hospitals to focus on. The five key messages were:

Delirium recording requires improvement

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

Personal information to support better care must be accessible

A ward spot check carried out during the audit looked for the document with key personal information about care needs and communication that should be completed for people with dementia, and found that only half of these patients had one in place. Forty percent of staff

said that they could not access this information most of the time, and under half of carers said definitely, staff were well informed.

Services must meet the nutritional needs of people with dementia

Catering services in the majority of hospitals should be able to provide for the needs of people with dementia, who may not be able to eat full meals at regular times and need finger food meal alternatives and snacks available at any time to ensure they are nourished. Less than 75% of staff said that they could obtain finger foods or snacks between meals for these patients. Twenty-four percent of staff thought people with dementia had nutritional needs met sometimes, or were not met.

Championing dementia means supporting staff

To support staff to deliver better care, nearly all hospitals have created dementia champions at ward level. Just under 70% of carers gave a high rating to care overall. Staff said they needed more support, especially out of hours when less than a quarter of staff said they could access specialist support for dementia always or most of the time.

Involve the person with dementia in decision making

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

This report

Background to this report

Round 3 of the National Audit of Dementia did not include service user feedback during data collection. This is because the audit has not been able to establish an optimum way of collecting this data on a national scale. A combined patient and carer survey was tested in Round 1 but returned very little data (less than 2 questionnaires per ward). This was generally because the person with dementia was not aware of their diagnosis and so could not be given a questionnaire, the patient had no carer to support them, or the patient was too unwell to complete the survey.

To ensure the opinions of people with dementia on this round of audit were represented, the National Audit of Dementia Project Team applied to speak with Service User Review Panels (SURP) through the Alzheimer's Society. This report details the discussions and resulting actions from the meetings of these SURPs.

The Service User Review Panels

Alzheimer's Society holds Service User Review Panels at a local level to provide people with dementia the opportunity to influence both the way the charity itself is run, and decisions made by other organisations. External organisations can apply to speak with SURPs about a wide variety of topics. The audit Project Team applied to all SURPs in England and Wales to speak with the groups about the results of Round 3 of the audit.

The results of the audit were discussed by four SURPs; three in England and one in Wales. The Project Team attended 3 Service User Review Panels. A further panel was run, and feedback provided to the Project Team, by the group's leader from the Alzheimer's Society.

The groups varied in attendance size with between 2 and 8 service users at each meeting. Whether family or carers attended also varied from group to group. Representation from the Alzheimer's Society differed between meetings as well.

Discussions with the SURPs lasted up to two hours and were focused around three questions relating to the audit which were sent to the groups in advance of the meeting. The three questions were:

- Do you think our 5 key messages are important for hospitals and the public to hear?
- What would matter to you if you were to go into hospital?
- What would you like us to ask hospitals in the next round of audit?

The information sheet sent to SURPs to establish whether they would like the NAD Project Team to attend their next meeting, is attached at Appendix A.

Conversations were not rigid. Members discussed around the three questions, often returning to subjects as new ideas arose.

Format of this report

The discussions from the four Service User Review Panels have been combined and organised by theme. Where possible, the Project Team have identified whether points were raised by carers/family, or by service users. Often, subject areas were mentioned by both service users and carers and this has also been noted.

The themes identified from the discussions are:

- Information and communication
- Access to family and carers
- Staff attitude, training and support
- Nutrition and hydration
- Clinical care
- Environment of the hospital
- Discharge
- Overall thoughts on dementia care in hospital.

Some of these areas were spoken about in relation to the 5 key messages and some arose spontaneously. The origins of the conversations are noted.

The final part of the report lays out how the conversations with the SURPs will influence the National Audit of Dementia in future.

Summary of the SURP discussions

Information and communication

Involving the person with dementia in decisions and conversations about care

All groups agreed on the importance of involving the person with dementia in decision making. Service users agreed that they wanted to be involved in decisions about their care. Carers also noted this was very important.

Both service users and their family members discussed instances when doctors and other clinicians spoke directly to the family member, rather than to the person with dementia. Both service users and their families said that they thought this was wrong and that the person with dementia should be spoken to first – and the carer or family member could help where needed.

“It is annoying when doctors talk over me. I am trying to explain, and they talk over me and talk to my wife instead”.

People with dementia also said that they want the option of having family or carers present when they speak to a doctor about their care and treatment.

Keeping people informed

People with dementia wanted staff to provide them with lots of details about their diagnosis, prognosis and treatment while they were in hospital. Carers wanted to be kept informed of any developments or changes.

One carer wanted hospitals to ask carers whether they would mind being contacted at any time of the day - to keep them informed and to ask questions the hospital may have.

Groups also discussed how hard it can be for people with dementia to remember questions for doctors and nurses when they are put on the spot. A carer thought a way to get around this may be to give people with dementia somewhere to write down questions they have and for doctors to prompt regarding this list when they come to see them.

Communication between staff members

Many service users said they wished staff communicated to each other that they have dementia, so they did not have to explain every time someone new comes on shift:

“Staff don’t share with each other at handover that you have dementia so then I tell them, and they are shocked!”

Personal information documents

Staff making routine use of a personal information document to inform themselves about the person, their preferences and their needs was a key message of the audit. Although not all members of the groups had heard of personal information documents before, once the concept was explained, everyone agreed they were important.

Service users provided examples of information they would include and they thought it a very good idea to have this written down and available to staff. Two of the groups noted that this information would be extremely important for those patients with dementia who could not communicate what they wanted themselves.

Some service users noted problems in staff using personal information documents. These included the documents not following people when they moved around the hospital, being left at the bottom of the bed and not used, or the scheme falling out of use in their local hospitals.

Two carers attending one of the groups agreed that ideally GPs should keep a copy of people’s personal information document so that this could be shared with hospitals as and when needed (especially in cases where the carer may be away, or ill themselves). One service user thought it would be a good idea if there was one version of the form produced nationally – instead of many different versions being used by various organisations.

One carer asked the Project Team to make sure hospitals are asked whether they keep copies of their preferred personal information document and make them available to patients, carers and staff to use.

Feedback

One group raised the issue of hospitals collecting feedback from patients with dementia. The group said that hospitals should be collecting this information through face to face interviews. The group wanted the audit Project Team to ask hospitals whether they routinely collect feedback from patients with dementia and if so, what they do with this information.

Access to family and carers

The Project Team asked service users what would be the most important thing to them if they were going into hospital. Most responses were about the importance of family visits:

“Family! Coming to see you!”

“Partners welcome - rather than strict visiting hours!”

Service users and carers alike were quick to say that restricting carer access would be very detrimental to the person with dementia. One service user said he would really struggle without lots of visits from his family and friends and would like to have the option of this throughout the day and night.

Staff attitude, training and support

One of the key messages from Round 3 of the audit was ‘championing dementia means supporting staff’. Of the 5 key messages, this generated the most conversation among attendees at each of the SURPs. Staff training, attitude of staff and support provided to staff to care for people with dementia were all discussed.

Supporting staff

Carers and service users agreed hospitals supporting staff in dementia care was important. Some carers thought specialists in dementia should be more obvious to patients, staff and family alike.

One carer suggested a dementia manual which sets out for staff what they need to know when someone with dementia is admitted to their ward. This could include how to access support from dementia champions, how to order finger foods and where the personal information document is found.

The importance of supporting hospital staff was stressed by all of the groups and many believed that if this was done right, all other aspects of care would improve. One service user said:

“I think that’s the most important. If you get that right, then everything else will click into place – like the nutrition and the delirium screening.”

Staffing practicalities

Linked to support provided to staff, were conversations around the practicalities of staffing. Several service users and some carers noted that staffing levels were a problem, or that staff always seemed to be busy:

“They can’t focus on every patient, they haven’t got the time.”

Two of the groups mentioned volunteers in hospitals, saying they should be better utilised. A carer said hospitals should use volunteers to provide directions to people arriving at the hospital. Another carer said hospitals should have trained volunteers to visit people with dementia, especially if a person does not have family or friends visiting them.

Another staffing practicality which service users raised was being able to read name badges, saying they were often facing the wrong way. A couple of the groups also discussed having the same person caring for you, where possible. One carer suggested a board next to the

bed would be helpful which read 'if you have any questions, ask for [name]' so that people with dementia can read it, ask for their named nurse and not feel so hesitant about asking for help.

Staff training and attitude

Staff training in dementia care was a widely discussed subject among the groups. Many of the service users gave examples of when staff training and level of understanding had affected the care they received:

"I had one time where a nurse came in and put those surgical stockings on the bed and said put them on. I was panicking because they are hard to get on. A nice nurse came in and said, don't worry, I am just going to do this and then I will come and help you. I needed that."

"I have been shouted at before – they say, 'I've already told you that'."

"They look at you like you are from the moon when you say you have early onset dementia."

"'Have you got any questions' is an awful question for people with dementia. I think, 'yes, what day is it?!'"

"Knowing that someone understands me is important."

Service users wanted staff to understand that tasks like finding the toilet in a strange place are difficult and instructions are not good enough – they need to physically show people. Additionally, they said tablets should not just be placed on the table, staff should remind people to take them. Carers wanted staff to understand that they need to be patient with people with dementia and go at the pace of the person - otherwise, that person will become stressed. Another suggestion raised for keeping stress to a minimum was around maintaining people's routines as far as possible and staff being flexible to service user needs.

Many service users and carers were keen to know what sort of training staff in hospitals currently receive and whether it was basic or more advanced. Some expressed concerns that the momentum behind training in dementia care may be fading out. One group wanted the audit to ask hospitals how many of their staff have received training in dementia care.

Some of the groups spoke about training they delivered in their local areas. Service users from one group went to the local university to give lectures to trainee nurses and they said the sessions were always well received. Members of another group took part in a scheme where undergraduate health professionals came to spend time with them in their houses to understand how dementia affects their day to day life. The groups expressed hope that this training would help future generations of healthcare staff to provide good quality dementia care.

“Linked to staff training is staff attitude – they say to you ‘why didn’t you tell me xyz’ or say to your partner ‘why didn’t she tell me’ – I can’t remember if I have told people or not.”

A lot of the conversations around the training of hospital staff in dementia care flowed into discussions about staff attitude. The general theme of the conversations around staff attitude and behaviour was that a little thought makes a big difference:

“What a difference it makes when people bringing the tea and coffee talk to you!”

“The best people seem to be the porters - they talk to you like you are a normal person.”

Many of the service users said they wanted to be respected by staff and they wanted to feel reassured. They said staff should treat them as they wish to be treated. Other words used in these discussions included empathy and understanding. Again, the service users gave examples of their experiences:

“The staff don’t talk to you – you get ignored and it’s isolating.”

“One time, there was another patient with dementia who was quite vocal, and the nurses used to moan about it and that really upset me because I thought, that could be me they are talking about.”

Carers also spoke about this subject and said that staff need to understand that a person with dementia’s confidence is probably lower than it was before their diagnosis (of dementia).

Nutrition and hydration

Conversations about nutrition and hydration were prompted mainly by discussion of the key message stating hospitals must do more to meet the nutritional needs of people with dementia. All groups thought that providing food suitable to people’s wants and needs was essential, as good food aids recovery.

Ideas which were raised by the service users to help improve nutrition when in hospital included:

- Allowing people to eat at times which suited them (not necessarily at set mealtimes)
- Picture menus
- Presenting the food in an appealing way
- Allowing people to eat with their family or carer
- Having a variety of foods available and not the same foods over and over again.

Groups gave examples when they, or people they knew, had not had their nutritional needs met e.g. not being able to have finger foods or a simple sandwich instead of a main meal.

One of the groups asked the Project Team to ask hospitals whether they ensure the catering companies they hire, train their staff in dementia awareness. The group thought this was important to ensure the staff understood the needs of people with dementia, would greet them when serving, and would recognise when someone needed help.

Clinical care

When asked what was most important when going into hospital, some service users' first response was quite simply:

"Make me better."

People were keen to know that they would be given the best possible care and treatment and that they would receive a correct diagnosis – there was concern that because some people with dementia might not be able to explain what was wrong with them, some symptoms may be missed.

One service user said they would prefer to be treated at home whenever possible. Another raised the issue of medication rounds, saying that they vary which end of the ward they start from - this means that sometimes, they don't get to you with your medications until 11pm.

One carer raised concern about the use of anti-psychotic medications:

"To be quite honest I dread the thought of [name] going into hospital - the stories I have heard are that drugs are given to make patients almost comatose so they don't cause any problems during their stay."

Delirium

The audit key message on the importance of screening for delirium and recording the outcome prompted discussions around delirium screening, assessment and treatment. All groups agreed it was very important and one group said many people with dementia going into hospital have a UTI or a respiratory infection, which increase the risk of delirium.

One carer spoke about a frightening situation when their partner experienced hallucinations (as a result of medication) and said that if delirium could cause similar symptoms, it was very important it be addressed straight away.

Environment in the hospital

Conversations around this topic arose when the Project Team asked service users what would be important when going into hospital. People had different preferences about being in a side room or in a bay, and it was generally agreed that if possible, people should be given a choice.

Noise often factored in discussions about the environment. Some service users said they found background noise to be the biggest inhibitor to their ability to hear and understand what doctors are saying to them. One of the carers wanted the audit to ask staff whether they make an effort to remove distracting noises when they are explaining something to patients with dementia.

Noise created by other patients' visitors was raised as a concern by one service user. Other members spoke about staff being too noisy, particularly at night:

"Nurses are noisy!"

"They put you opposite the nurses' station. But that's where they congregate and talk". Another member said, "I don't mind that, I like people watching". To which the first replied "not when I'm sleeping! If I don't sleep, I'm irritable. Our brain function is better if we have slept."

Conversations about noise were often linked to the need to keep stress to a minimum. One carer said that a quiet space was necessary – another room away from the busyness of the ward. Service users gave examples of distress caused by the environment of the hospital:

"Wards are very busy – I spent a night in a corridor once and then was moved to a side ward and when [my wife] came to visit, they couldn't find my name on the list."

The availability of activities on the wards was raised by two of the groups. Carers in particular were concerned about a lack of stimulation for people with dementia when in hospital. One of the carers wanted the audit to make sure it asks hospitals whether they provide any activities for people with dementia.

One group discussed call bells and that you could not tell whether they were working. They suggested the bell flashed in the room when you press it so that you know it is definitely working, and someone is on their way.

Another issue raised about the environment in the hospital was finding your way around - and generally how "dementia friendly" the entire hospital was. One service user said the names of departments on the signs should be the same as the names given on letters for outpatient appointments. One of the groups said that they found different colour coded lines on the floor/walls helpful when finding the department you need. A carer suggested the audit should ask hospitals whether they had reviewed the whole hospital to understand if it is "dementia friendly" or not.

Discharge

Two of the groups briefly mentioned the discharge process.

"It is annoying when your discharge is delayed because you have to wait for the ward round, or to see the doctor."

"I want to be kept informed of exactly when I can go home."

One of the groups also expressed concern about news stories of people being discharged without the right social care in place. They wanted to be sure all the right support was organised and in place for when one goes home.

Overall thoughts

A couple of the groups provided some of their overall thoughts about the care of people with dementia in hospital. Some expressed concern:

"I cannot imagine that dementia comes anywhere high on the list of priorities for any hospital. I do hope I find out it is different to this."

One service user summarised the thoughts of many of the SURP members saying:

"If you get it right for dementia, you get it right for everyone – at least you are half way there to getting it. [Hospitals] don't realise this. Dementia affects sight and hearing – and people with dementia suffer from all those things people without dementia suffer from – so hospitals should get it right for people with dementia, to get it right for everyone."

The key messages of the audit are geared towards improvements and the discussions at the SURPs were largely around these issues, and other improvements the SURP members would like to see. However, many of the service users and carers also wanted to acknowledge the hard work healthcare staff do, particularly in an increasingly difficult NHS climate.

Actions for the audit following the SURPs

Actions identified by the SURP members

During the discussions, members of the groups raised items that they wanted the audit Project Team to ask hospitals regarding the care they provide for patients with dementia:

- Whether they routinely collect feedback from patients with dementia and if so, what they do with this information
- Whether they ensure the companies they hire to provide catering, train their staff in dementia awareness
- Whether they keep copies of their preferred personal information document and make them available to patients, carers and staff to use
- How many of their staff have received training in dementia care
- Whether staff make an effort to remove distracting noises when they are speaking to patients with dementia
- Whether they have reviewed the environment of the whole hospital to understand how easy it is for people with dementia to navigate and use
- Whether they provide any activities for people with dementia.

National Audit of Dementia Project Team response and actions

Some of the questions identified by the SURPs are already asked about/covered in some way by the audit. These are:

- Whether they keep copies of their preferred personal information document and make them available to patients, carers and staff to use
- How many of their staff have received training in dementia care
- Whether they have reviewed the environment of the whole hospital to understand how easy it is for people with dementia to navigate and use
- Whether they provide any activities for people with dementia.

The remaining questions are being considered for inclusion in Round 4 of the audit which is taking place in 2018. Inclusion will be discussed by the expert Steering Group which provides guidance to the audit before a final decision is made. The initial thoughts of the Project Team are set out below.

Do hospitals ensure the companies they hire to provide catering, train their staff in dementia awareness?

This seems a straightforward question which could be included in the organisational checklist (hospital survey on resources and governance). The Project Team think it could perhaps be expanded to include other companies providing services through the hospital: Do hospitals ensure that external companies providing services to patients train staff in dementia awareness?

Do staff make an effort to remove distracting noises when they are explaining something to patients with dementia?

This question is more difficult to include. It is not immediately obvious what would be considered a distracting noise, as this could vary at a personal level. This would make it difficult for staff to answer. The current staff questionnaire was not developed to investigate the practice of individual staff but to look at how the hospital helps them to provide care. This item is something to consider for inclusion in a future list of questions for people with dementia (not yet developed). The Project Team could also ask hospitals what they do to combat excessive noise, as part of their ongoing review of the environment.

Do hospitals routinely collect feedback from patients with dementia? What is done with the information?

The Project Team has already begun to look into this since the SURP meetings. The audit would like in the future to include some patient feedback from people with dementia while they are in hospital (or as they are being discharged).

We would like to gather feedback from hospitals on the ways in which they collect feedback from patients with dementia at the moment. The aim would be to compare the various methods to establish the best (i.e. which method consistently obtains feedback that can be compared between hospitals). To do this, we may ask hospitals whether they collect data from patients with dementia currently, and if so, how they do this. We may also ask for some information about their response rates.

The next Steering Group where these items will be considered is in February 2018. Changes to the tools for Round 4 of the audit will then be made, and data collection will run from April until September 2018. Reporting for Round 4 will take place in 2019.

Appendix A: Form submitted to the SURPs for review prior to the meetings

Would you be interested in helping the National Audit of Dementia, by telling us what would be most important to you if you were in hospital?

Reason for the request:

We work with 200 hospitals in England and Wales, collecting information which can help to improve care for people with dementia. We would like to gain the opinions of people living with dementia on what the most important aspects of care in hospital are.

We have identified 5 key messages for hospitals and the public. They were produced from information from patient notes, hospital staff and families/carers of people with dementia. The key messages are:

1. **Delirium recording requires improvement:** Delirium is a state of mental confusion that can happen if you become medically unwell. It can be frightening. Delirium is more common in older people and people with dementia. We found that some people with dementia are not being assessed for delirium when they go into hospital.
2. **Personal information documents (like This is Me) must be accessible:** In a spot check, only half of patients had a personal information document (e.g. This is Me).
3. **Hospitals must meet the nutritional needs of people with dementia:** Some staff thought nutritional needs of people with dementia were not met. Some staff thought snacks were not easily accessible for patients with dementia. This can be important because hospital meals might not be served at a time when a person is ready to eat.
4. **Hospital staff need more support from people who are specially trained in dementia:** Staff said they needed more support from dementia specialist staff.
5. **Involve the person with dementia in decision making:** Information in patient notes showed people with dementia were not always involved when decisions about a change in housing needs were made.

We would like you to tell us if these are important messages for hospitals and the public to hear. We would also like you to tell us what else is important for people with dementia when they are in hospital.

We have a number of questions we would like to ask you:

1. Do you think our 5 key messages are important for hospitals and the public to hear?
2. What would matter to you if you were to go into hospital?
3. What would you like us to ask hospitals in the next round of audit?

How the information will be used and what it will influence:

We will give you immediate feedback on the meeting and how we will be using the information via your Alzheimer's Society representative.

A report will be published on the National Audit of Dementia website based on the discussion and feedback from this meeting. The report will be published on the NAD website in early 2018. We will send all those who take part a copy of the report via email (or post if preferred) when it is published.

The feedback we receive from you will also be used to shape the next round of audit. The report will state how the feedback received will influence the next round of the National Audit of Dementia.

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